Those Who Suffer Much Know Much

about

Low Dose Naltrexone (LDN) Why weren't you told?

an old drug
a controversial treatment
benefiting immune system diseases
thousands achieving health success
hundreds of recorded patient testimonies

WHY haven't you heard of it?
WHY won't you be offered it?

In keeping with the altruism of contributors
Case Health continues to offer this book to you FREE
without charge or expectation

You can 'share it forward' or host it on a website
under the same philosophy
without modification and free of charge

in this fifth revision
51 Health Case Studies
19 health professional interviews & perspectives
low dose naltrexone (LDN) in the beneficial treatment of immune system diseases

Supporting evidence for the value of patient testimony
to e-health systems worldwide

Cris Kerr, Case Health
55 Webb Street, Brisbane, Queensland, Australia 4053
Advocating the value of patient testimony since May 2001
© Case Health 2006, revised July 2007, July 2008, July 2009, July 2010
(Original Websites: casehealth.com.au & casehealth.com May 2001 to May 2009)

The case studies in this book feature

Low Dose Naltrexone (LDN)

an old drug
a controversial treatment
benefiting immune system diseases
thousands achieving health success
hundreds of recorded patient testimonies

WHY haven't you heard of it?
WHY won't you be offered it?

of those conditions LDN has benefited
the following are featured in this book

Multiple Sclerosis

HIV

Hepatitis B & C

Primary Lateral Sclerosis

Cancer, Lymphoedema

Fibromyalgia

Crohn's Disease

Arthritis

Parkinson's Disease

Relapsing Polychondritis (RPC)

and diseases of immune system dysfunction

Supporting data for this book has been assembled from untested patient testimony of health success.

© Case Health Pty Ltd

dedicated to Dr Bernard Bihari *and* all Patient Champions

who through their own suffering have grown to understand

not only the need to raise their voice

but to record and share their health journeys in detail

with altruistic intent, to benefit another.

To all those whose generous contributions made this book possible …

THANK YOU

with my sincere apology for the English language limitation of this book

Dr Bernard Bihari

Sadly, Dr Bernard Bihari passed away on Sunday, 16 May 2010 after a prolonged period of illness. He was 78. The flow-on effect of Dr Bihari's use of LDN in clinical practice did not just deliver hope to his own patients but to patients around the world, and his pioneering work resulted in real relief from real suffering, and real improvement in quality of life for tens of thousands, and we hope in the years to come... hundreds of thousands.

Words cannot express how deeply his passing was felt by the thousands he has touched... whose quality of life was dramatically turned around due to his compassion for patients, and his pioneering work in their collective best interests, against all odds.

We are forever in his debt.

To Linda

A very special note of appreciation goes across the waves to Linda Elsegood of LDN Research Trust in the UK. Thank you Linda, for your valued friendship and assistance with the following patient testimonies:

Out of wheelchair under a week - Scott
MS & Me – Jackie
LDN gave me Hope for the future - Annmarie
LDN has given me hope - Audrey
Crohn's and Me - Peter B
Most wonderful thing in my life - Jonathan
Cancer, back from the brink - Eileen
LDN kept me out of hospital - Zillah
My 2 Little Pills are called LDN - Kristie

© Case Health Pty Ltd

Content

		Page
Dedications		3
Why You Weren't Told About LDN		
	'Those who suffer much, know much' by Cris Kerr	9
Dr David Gluck USA, Linda Elsegood UK		33
CASE STUDIES grouped by condition		
	Multiple Sclerosis	
1	My pre & post LDN MS story - LDN since **Dec 2003 – Jim, USA**	35
2	Until there's a cure there's LDN - LDN since **Sept 2002 – Carol, USA**	44
3	Out of wheelchair under a week – LDN since **July 2004 – Scott, USA**	49
4	MS, but walking & driving my car again – LDN since **July 2005 - Bill, USA**	53
5	Improvement was gradual and subtle – LDN since **August 2005 – Julia, UK**	57
6	LDN allowed me to work with MS – LDN since **May 2004 – Neil, Aust**	61
7	Paul's MS & LDN story began in 2004 – LDN since **July 2005 – Aletha, USA**	65
8	LDN 4 me – LDN since **August 2007 – Maurey, USA**	69
9	LDN, MS & Me – LDN since **April 2004 – Jackie, UK**	72
10	MS & LDN since May 2002 – LDN since **May 2002 – Joyce, USA**	76
11	Thanks to LDN I can enjoy Life – LDN since **August 2007 – Vickie, USA**	82
12	LDN has been a miracle for me – LDN since **March 2005 – Art, USA**	86
13	My MS & TM Story – LDN since **September 2005 - Crystal, USA**	89
14	I have PPMS but doing well – LDN since **April 2006 - Emily, USA**	95
15	LDN giving me my best friend back – LDN since **September 2006 - Nancy, USA**	98
16	Linda Elsegood's MS Story, UK – LDN since **December 2003 – Linda E, UK**	104
	plus… **About the LDN Research Trust**	109
17	My MS with LDN journey – LDN since **October 2005 - Gigi, USA**	110
18	LDN gave me Hope for the future – LDN since **October 2007 - Annmarie, UK**	117
19	LDN has given me hope – LDN since **March 2007 - Audrey, UK**	122
20	Mary finds proof of Santa for Noel – LDN since **Sept 2002 - Noel & Mary, USA**	128
21	LDN kept me out of hospital – LDN since **November 2006 - Zillah, UK**	134
22	Most wonderful thing in my life – LDN since **January 2007 - Jonathan, UK**	138
23	SPMS Improved, but with hiccups – LDN since **January 2008 - Dianne, Aust**	141
24	My Two Little Pills are called LDN – LDN since **March 2008 - Kristie, USA**	145
25	Incremental Improvement for MS – LDN since **January 2009 - Ellen, USA**	148
26	MS Symptom Improvement a Bonus – LDN since **January 2009 – Silvia, UK**	153

© Case Health Pty Ltd

27	LDN, Trust & Patience has worked for me – LDN since **Dec 2007 – Sal, Aust**	157
28	LDN-Back to my old self – LDN since **January 2008 – Laura, Ireland**	162
29	MS plus Crohn's plus LDN equals JOY – LDN since **March 2009 – Pat, USA**	165
48	Specialists frown on it, but works for me – LDN since **May 2007 – Kelli, Aust**	168
49	LDN – I started in July 2003 – LDN since July 2003 – **Brenda, USA**	170
	HIV	
30	HIV viral load and T-cell Tracking – LDN since **Dec 2004 - Matt, USA**	174
	Graphs – Test Results – CD4, Viral Load	180
31	HIV-blood & liver enzymes now normal – LDN since **Jan 2006 - Noreen, USA**	181
	Hepatitis B Case Study	
32	LDN benefiting daughter's HepB – LDN since **July 2007 – Joyce C, USA**	187
	Graphs – Test Results – Liver Enzymes, Viral Load	194
	Hepatitis C Case Study	
50	LDN and ALA Benefiting HepC – LDN since **April 2009 - Chris, USA**	195
	Primary Lateral Sclerosis	
33	Antioxidants & LDN stabilized my PLS - LDN since **Feb 2004 - Gary, Aust**	198
	Cancer	
34	LDN was working-Metastatic IVB Cancer - LDN since Feb 2007 **Dee, Hong Kong – Sadly, Dee passed away on 22 April 2010**	202
35	Every condition has improved – LDN since **November 2007 - Celia, Scotland**	211
36	Five years breast cancer free – LDN since **April 2004 - Lola, USA**	216
37	Cancer, back from the brink – LDN since **December 2007 - Eileen, UK**	218
	Crohn's Disease	
38	Crohn's and Me – LDN since **October 2007 – Peter, UK**	222
39	Crohn's best it's ever been – LDN since **Feb07 or Nov08 – Claudia, USA**	227
40	LDN benefited son's Crohn's – LDN since **January 2008 - Paul B, PA-C, USA**	232
41	The Story of My Current Life – LDN since **July 2008 - Rachel, USA**	236
	Fibromyalgia	
42	My LDN & Fibromyalgia story – LDN since **January 2009 – Janis, Aust**	238
43	LDN Dramatically reduced Fibro Pain – LDN since **January 2009 - Judy, USA**	242
44	'LDN benefiting arthritis & fibro – Edward, USA', LDN since March 2005. CASE STUDY Number 44 was featured on page 194 of the 2009 edition but has been removed due to data oversight, though of note is that Edward continued to report benefiting from LDN.	246
	Rheumatoid Arthritis	
45	LDN & My Peculiar Circumstance – LDN since **April 2009 - Margaret, France**	247
	Parkinson's Disease	
51	Bentley's Parkinson's benefited from LDN & HBO - LDN since **Oct 2004** - **Destiny on behalf of Bentley, USA**	256

	Multiple Conditions – Multiple Benefits **Fibromyalgia, Lyme Disease, Crohn's Disease, Multiple Sclerosis, Peripheral Neuropathy, Hashimoto's Thyroiditis, Microscopic Colitis (MC), Relapsing Polychondritis Post Polio Syndrome, Psoriasis, Microscopic Colitis (MC), Goiter**	
46	Fibromyalgia and more – LDN since **July 2007 - Bill W, USA**	262
47	Autoimmune Disease vs LDN – LDN since **July 2008 - Nettie, New Zealand**	266
52	LDN helping Relapsing Polychondritis – LDN since **July 2009 - Nancy, Australia**	272
	Interviews & Perspectives - Health Professionals	
	Dr Bernard Bihari, USA	279
	Dr David Gluck, USA	289
	Dr Tom Gilhooly, Scotland	294
	Dr Jaquelyn McCandless, USA	296
	Dr Skip Lenz, Pharmacist, USA – Updated February 2010	303
	Skip's Pharmacy: Results of LDN Patient Survey 2008	308
	Dr Bob Lawrence, United Kingdom	312
	Dr Burton M Berkson, USA	318
	Prof Jill Smith, USA	326
	Dr Phil Boyle, Ireland	330
	Antony Condina, Compounding Pharmacist, Australia	335
	Larry Frieders, Compounding Pharmacist, USA	337
	Dr Pat Crowley, Ireland	342
	Dr Terry Grossman, USA	345
	Dr Ian S Zagon, USA	348
	Dr Edmond O'Flaherty, Ireland	353
	Maira Gironi, MD, PhD, Italy	355
	Dr Julian Whitaker, USA	359
	Professor George Jelinek, Australia	365
	Paul Battle, PA-C (Physician Assistant), USA	366
	Related Health Articles	
	USA MS Sufferer, Malcolm West, Ponders 'WHY you won't hear about LDN'	369
	'Shared Vision for Health' by Cris Kerr	372
	'Bad things Happen When Good People do Nothing' by Cris Kerr	376
	Meet the People – News, Conferences, Videos	
	Media – LDN in the News – Tv, Tabloid, Online - plus Political Proceedings	382
	USA Conferences – Video Testimonies	387
	European Conference – Video Presentations	392
	European Conference – Video Testimonies	393

Bihari Documentary, Celebrity Medico Dr Chris Steele advocates LDN	393
LDN Advocates	
Blog Talk Radio, Paul Battle's Presentation, Websites & discussion groups	395
Other Books featuring LDN	397
LDN Treatment Information	
LDN Research Trust UK Fact Sheet 2010	400
LDN Pilot Trials & Studies	
LDN Pilot Trials & Studies	
A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis	405
Pilot trial of low dose naltrexone and quality of life in MS	406
Fibromyalgia symptoms are reduced by low-dose naltrexone: a pilot study	407
Low dose naltrexone therapy improves active Crohn's disease	408
Clinical Trials Awaiting Publication	409
Featured LDN Papers & Research	
'Revisiting the ALA/N (α-Lipoic Acid/Low-Dose Naltrexone) Protocol for People With Metastatic and Nonmetastatic Pancreatic Cancer: A Report of 3 New Cases'	410
'Opioid growth factor suppresses expression of experimental autoimmune encephalomyelitis'	411
'Endogenous opioids regulate expression of experimental autoimmune encephalomyelitis: a new paradigm for the treatment of multiple sclerosis'	412
Related Research/Trials	
'A study of 24-hour profiles of plasma met-enkephalin in man'	413
'Circadian rhythm of beta-endorphin in the plasma of clinically healthy subjects and in patients with adrenocortical disorders'	414
'Circadian Pattern of Serum Leptin and B-Endorphin Levels in Obese and Non Obese Women'	415
'Association between circadian rhythms of endogenous hypothalamic opioid peptides and of natural killer cell activity'	416
'Methionine enkephalin-like, substance P-like, and B-endorphin-like immunoreactivity in human parotid saliva'	416
'An about 50,000-dalton protein in adrenal medulla: a common precursor of [Met]- and [Leu]enkephalin'	417
'Processing of proenkephalin is tissue-specific'	417
'Beta-endorphin and dynorphin mimic the circadian immunoenhancing and anti-stress effects of melatonin'	418
'Circadian variation in the expression of cell-cycle proteins in human oral epithelium'	419
Glucocorticoids Play a Key Role in Circadian Cell Cycle Rhythms	419
Beta-endorphin: stimulation of growth hormone release in vivo	420
'Circadian cancer therapy'	420
Trial: 'Comparison of Toxicity Associated with Early Morning Versus Late Afternoon Radiotherapy in Patients with Head-and-Neck Cancer'	421
More LDN References	423

Why weren't you told?

© Case Health Pty Ltd

Those Who Suffer Much Know Much

Why weren't you told?

by ***Cris Kerr***
Case Health – Health Success Stories
Advocate for the value of patient testimony
to health frameworks & ehealth systems worldwide
October 2005, rev July 2007, 2008, 2009, 2010

In 2001 Cris Kerr created the 'Case Health – Health Success Stories' website to collect and share health success case studies attributed to any successful health intervention, and build evidence of the value of patient testimony to improving health outcomes. Though based in Brisbane, Australia, the website held stories from all over the world, accessible through a searchable database.

The Case Health website was provided as a community service for eight years, closing in May 2009, but the primary mission of achieving long overdue recognition of the value of patient testimony and its potential to enhance health systems and improve health outcomes continues in this 2010 revision of the 'proof of concept' book, 'Those Who Suffer Much, Know Much', now in its fifth edition.

Health Injustice on our Doorstep

I first became aware of an obscure treatment that can halt or slow progression of Multiple Sclerosis (MS) and enhance quality of life for sufferers after receiving a health success story submission almost seven years ago, in 2003.

Since then it's become clear this obscure treatment can benefit a wide range of immune system diseases, a handful of which are featured in the accompanying case study collection.

The treatment employs low doses of an old, off-patent drug with a good safety profile. That drug is naltrexone, and a growing body of compelling patient testimony, research, studies and clinical trials, says this obscure treatment works, and works well - BUT, sufferers either won't be told about it or can't get their doctor to prescribe it.

The low dose naltrexone (LDN) treatment isn't a cure, and it doesn't work for everyone, but it does work – and it should be readily available as a treatment option for anyone who might benefit.

If your life has ever been turned upside down by ill health, or you've watched helplessly as a loved one suffered, you too will want to know how it can be that a promising treatment such as this can remain buried for over 20 years, along with its potential for 'what could have been'.

© Case Health Pty Ltd

This low dose naltrexone story is compelling and should be freely shared forward

Dr Bernard Bihari's groundbreaking clinical work with low doses of naltrexone (LDN) commenced over twenty years ago in the late 1980s, but it was not until the birth of the internet that a small, but growing number of physicians learned of and began prescribing low doses of naltrexone (LDN) to minimize progression and symptoms of immune system diseases for their patients.

Bihari first successfully treated HIV patients, then Multiple Sclerosis (MS) and Cancer patients with low doses of between 3mg and 4.5mg of naltrexone. In the ensuing years LDN has been cited as beneficial across a broader spectrum of known or suspected immune system diseases, such as; Crohn's Disease, Fibromyalgia, Hepatitis B and C, Arthritis, Chronic Fatigue, Parkinson's Disease and a still growing list of others.

If you're wondering how all these diseases are linked, look no further than an errant immune system.

Whilst commercial interests continue to differentiate disease states, with each year seeing an increase in the number of apparently disparate diagnoses (based on different lists of symptoms), the breadth of favourable responses to LDN is teaching us something very different, something very important; that the range of diseases and conditions responding to LDN is indicating they have much more in common than not.

Early Adopter Advocates

Recognizing the potential of this treatment, a handful of professionals have adopted it to benefit their patients: In Ireland, Dr Pat Crowley has been prescribing LDN successfully for years, as has Dr Edmond O'Flaherty. Dr Bob Lawrence in England, himself an MS sufferer, and Dr Tom Gilhooly in Scotland have long been prescribing LDN, with success, to treat their MS patients.

In the USA, Dr Jaquelyn McCandless discovered LDN could benefit Autism, which prompted Dr Tyrus Smith of Coastal Compounding to develop the first LDN topical formulation - a cream comprising emu oil and naltrexone that's applied to the fine skin on the inside wrist, to bypass digestive issues. Dr Tyrus Smith has since shared his LDN topical formulation with other compounding pharmacists around the world, in the best interest of helping sufferers worldwide.

Dr McCandless has also generously donated her time, expertise, and money. In 2006 she travelled to Mali, Africa with her husband Jack Zimmerman to initiate a (soon to be published) LDN trial for HIV that was also generously supported by a band of LDN advocates.

© Case Health Pty Ltd

In New Mexico, Dr Burton Berkson has been combining LDN with IV Alpha Lipoic Acid to successfully treat Pancreatic Cancer patients, and Dr Phil Boyle of Ireland has been successfully prescribing LDN to reverse infertility.

In Italy, the results of Dr Maira Gironi's pilot trial of low-dose naltrexone in primary progressive multiple sclerosis (PPMS) indicated, among other benefits, that LDN was safe and well-tolerated in patients with PPMS; and in the USA, Prof Jill Smith of Pennsylvania State University has found LDN beneficial in the treatment of Crohn's disease. More recently Drs Mackay and Younger of Stanford University have found LDN benefits Fibromyalgia.

Other early adopter advocates of this treatment include Dr Terry Grossman, Dr Joseph McWhirter, and others. All of these professionals have championed patient needs and hence, have contributed to positive progress for this controversial treatment option.

The number of doctors familiar with and prescribing LDN is still small but growing internationally. In the UK, to the credit of Linda Elsegood and Trust directors Bob Lawrence and Tom Gilhooly; the number of GPs prescribing, and Neurologists consenting to GPs prescribing, continues to grow.

Sufferers like Crystal[13], whose MS disease progression has been alleviated by LDN, are passionate advocates, and many have formed websites and discussion groups dedicated to spreading the word, so you too might hear of this treatment option. Vicky Finlayson of California, another MS sufferer, undertook a sponsored walk to Capitol Hill in the hope of gaining an audience with the Governor and prime media interest in how LDN had benefited her. Not discouraged by her first attempt, Vicky planned a second sponsored walk to Capitol Hill in 2010.

The first combined patient/clinician conference dedicated to increasing awareness of the clinical benefits of LDN was held in New York in 2005. Since then, conferences have been held annually in the USA, with patient advocates like Susie O'Malley volunteering their time and organizational skills to make them happen.

In April 2009, the first European LDN conference was held in Glasgow and the USA conference of that year was supported for the first time by an International LDN Awareness Week (ILDNAW), spearheaded by Linda Elsegood of LDN Research Trust, UK and supported internationally by LDN advocates too numerous to mention by name here. In the lead-up, LDN Research Trust released an inaugural free ILDNAW book; '100 Reasons Why You Should Know About LDN', which contained 100 patient testimonies, and this year will release '201 Reasons Why… '.

LDN advocates have been striving to help fellow sufferers via information-sharing, emotional support, and fund-raising for clinical trials; the first of which began in 2007 at the University of California, San Francisco (UCSF), initiated and funded by a dedicated support group led by Vicky Finlayson, co-ordinated

© Case Health Pty Ltd

through SammyJo's LDNers.org, assisted by AcceleratedCure.org and supported by LDN advocates.

Two advocates have published books: The first was 'Up the Creek with a Paddle' by Mary Boyle-Bradley[20], and the second, 'The Promise of Low Dose Naltrexone' by Elaine Moore and Samantha Wilkinson.

All of these activities have contributed to increased awareness, however; with increased awareness comes increased risk. The upside of the proliferation of LDN information over the internet is that it enhances awareness of this treatment option - the downside is that it increases the risk of misinformation and infiltration by competing and conflicting interests.

Why the focus on Clinical Trials?

Clinical trials seek to answer the 'who, what, why, where, how, and when' questions that establish patient profile, efficacy, safety, optimum dose and time. Clinical trials are supposed to establish evidence of successful, safe outcomes or unsuccessful, unsafe outcomes.

Clinical trial data is submitted to federal drug regulators for evaluation prior to a drug being 'approved' to treat an identified disease or condition. Doctors therefore, quite rightly, base treatment decisions on approved drugs that have been clinically trialed, because at present, this is still the safest system to follow.

Due to the absence of randomized clinical trial and public health system data on the Low Dose Naltrexone (LDN) Treatment Protocol, it has not achieved mainstream scientific acceptance as a treatment option for MS or many of the other diseases it has been benefiting. To-date, naltrexone remains recognized only as a treatment for drug addiction.

Opioid drugs are prescribed legally to relieve pain but they're also taken illegally for recreation/pleasure. Both avenues can lead to addiction. Naltrexone is approved as a treatment for drug and alcohol dependence because of its capacity to block opioid receptors, and for that application it's usually prescribed in 50mg doses several times a day (around 150mg per day): Thirty times the low dose range of 3mg to 4.5mg.

The length of time opioid receptors are blocked depends on variable factors like size of dose and speed of individual metabolisation, however; while receptors remain blocked, opioid drugs cannot attach to their target opioid receptors and the body is therefore, unable to assimilate the opioid drug's effects - hence, no pleasure gained from taking the opioid drug.

The only known naltrexone safety issues relate to a study on naltrexone administered in doses of 300mg per day, which showed adverse effects on the

liver. Another risk, associated with drug dependency treatment, is that those in 'recovery' might return to 'dependence'.

Whilst a growing number of doctors are prescribing LDN 'off label', as doctors do with many other drugs that have never been 'approved' for the conditions they're treating, most will still not prescribe LDN… which is particularly puzzling given that naltrexone is an old drug that has been clinically trialed and 'approved', and has in all the years since, maintained a good safety profile at the standard 50mg dose.

In many jurisdictions doctors are free to prescribe this drug 'off label', particularly where there is no 'approved' treatment for a particular disease or condition, or for compassionate use when all other treatments have failed (which unfortunately, may be too late). Doctors in many jurisdictions can also prescribe a drug 'off label' as an adjunct to complement an 'approved' treatment - though this increases the risk of medication conflict for the patient.

Different Approaches to Treatment

Disease modifying drugs are often prescribed for the many conditions LDN's been benefiting, yet certain types of disease-modifying drugs suppress immune system responses in order to suppress/alleviate symptoms. Suppression of an immune system response can relieve symptoms, but can also introduce a degree of vulnerability to an immune system where over-suppression of the immune system response can weaken the body's natural defenses against bacterial and viral invasion.

Certainly, the human body has its own natural, inbuilt capacity to suppress immune system responses, if the need arises: During a healthy, full-term pregnancy, the body's pregnancy hormones are rallied. Their role is to ensure the growing foetus is protected and nurtured, and just as critically, ensure the growing foetus is not perceived as a foreign, viral or bacterial invader that needs to be addressed: This is one of the best examples of the body's innate, natural capacity to adapt and temporarily change immune system responses in a beneficial way - for both mother and baby.

Naltrexone works differently. After naltrexone has effected a blockade of opioid receptors the body's circulating sentinels perceive the blockade as a shortfall in endogenous endorphins. When the blockade lifts, the body responds by not only dramatically increasing endogenous endorphin production (opioid peptides such as beta-endorphin and met-enkephalin, amongst others), but also the number of opioid receptors (capacity to assimilate an increase in endorphins).

In layperson's terms… the body is 'tricked' into thinking it's deficient in endorphins and as result, dramatically boosts its own natural production of endorphins as well as its capacity to employ more endorphins. Endorphins are key regulators of immune system health through intricate links with all immune

system functions and responses – the full degree of which scientists still struggle to understand.

The increase in endorphin production effected by LDN orchestrates other beneficial immune system responses that appear to collectively help moderate immune system functions, regardless of whether functions and responses have been over-active or under-active; thereby orchestrating up-regulation or down-regulation of adverse fluctuations in immune system functions and responses that manifest as disease symptoms and progression. In other words, LDN works toward normalizing immune system function.

Research clearly indicates the duration of opioid receptor blockade is an important factor, and yet another example of where 'more' is not necessarily 'better'. Low doses of naltrexone result in a short-term blockade of opioid receptors and beneficial immune system responses whilst higher doses of naltrexone result in blockades of a longer duration that illicit different responses and outcomes.

Dr Bihari researched the available data on beta-endorphins and found research indicating beta-endorphin production followed a circadian rhythm that peaked in the morning. He theorized that blocking endorphin receptors just prior to peak morning production would best take advantage of a window of opportunity with potential for optimum gain. This is why Bihari trialed night dosing of LDN, later measuring increases of around 200% in endorphin production. It is also why patients have until recent years, religiously followed his recommended night-dosing protocol.

In the recent years, Dr Zagon has turned his research attention to one particular endogenous opioid peptide that's beneficially influenced by LDN, met-enkephalin. My understanding of Dr Zagon's research direction is that he focussed on Opioid Growth Factor (OGF) because he believed this factor held the most promise as a cancer treatment beyond LDN.

News of research is often circulated and discussed amongst LDN chat groups. Sometimes it is misinterpreted, other times misrepresented. Unfortunately, research released on Met-enkephalin and its precursors resulted in protracted conflicts around the best time to take LDN, with subsequent claims that Bihari's night-dosing protocol was not grounded in 'science'.

There is ample scientific research to confirm a circadian rhythm to beta-endorphin circulation, with additional observation that circulating levels do indeed peak in the morning as Bihari claimed (and some of that research is now included in this book). But again unfortunately, there's no research to confirm higher levels of endorphin production when LDN is administered at night.

Most evidence available to-date regarding optimal dosing time for LDN continues to come from patients who take LDN, doctors who prescribe LDN for their patients, and pharmacists who compound LDN and who are in constant

contact with patients; and the majority of those collective voices of experience remain in favour of night-time dosing, with some exceptions – particularly for those few who for unknown reasons continue to experience interrupted sleep.

Certainly for most advocates of LDN, there is no question in their mind about whether it is better to boost endorphin production or suppress immune system responses. To quote the oft-used phrase of passionate LDN advocates, Bren[5] and Art[5]; "Taking an immune system suppressant while taking LDN is like driving with one foot on the brake and one foot on the accelerator at the same time."

Commercialized Health Regulatory Systems

Most health systems don't support the clinical innovation that is LDN, and their drug approval systems are based on expensive clinical trial data.

Due to their expense, clinical trials are typically initiated and sponsored by pharmaceutical companies expecting to patent a new drug or new drug application, with intent to recoup costs by commercializing and profiting from the successful results.

That's business and that's how it should be. If an organisation is prepared to fund the very high cost of research, development, and clinical trials they're entitled to view that cost as an investment that will turn a profit.

But naltrexone is an old drug, well past its patent protection period. A clinical trial of an old 'out-of-patent drug' doesn't present an attractive commercial proposition for those sponsoring organisations that traditionally initiate clinical trials because they can't gain an exclusive patent and subsequent profits from any successful outcomes.

One way around this is to re-engineer an older drug – change a molecule here and there, apply for a new drug patent, and market a new drug at a newer, higher price. Whether that new drug proves to be more effective than what is presently being used, or not, is not considered during the drug approval process. Comparative effectiveness is not trialled or measured, and does not need to be presented before a new drug is approved.

Another pathway is to apply for an Orphan Drug Status patent, or in other words, apply for a patent on a new therapeutic application for an old drug.

Dr Jill Smith has reported that, in the interest of patients gaining easier access to LDN treatment for Crohn's disease; Drs Moshe Rogosnitzky, Ian Zagon, and Jill Smith formed a company almost three years ago so they could apply for a patent on the use of naltrexone for Crohn's disease. And Dr Smith's application to the FDA for Orphan Drug Status for the use of naltrexone in children with Crohn's disease was recently approved.

After their patent is approved/awarded, their company will gain exclusive rights to manufacture naltrexone in low doses to treat the 'new therapeutic application' specified in their application. The group will then need to contract/licence an accredited drug manufacturer to pursue their next step, FDA approval of their manufactured drug product.

After a company has been licensed to manufacture naltrexone in low doses, it will become illegal for compounding pharmacies to compound low doses of naltrexone for the specified condition, Crohn's disease, and instead, compounding pharmacies will only be able to sell the licensed version of the manufactured drug.

Exactly how this will achieve easier access to LDN for Crohn's patients, or increase the overall number of patients able to benefit from LDN for other conditions remains unclear.

Prolonged ill health is clearly not in the best interests of patients or national economies, yet it does support a multi-billion dollar health industry. Whilst there is no single bad guy out there plotting our collective ruin, health regulatory systems are clearly purpose-designed to meet commercial interests, not patient need.

Patient Testimony has added weight to the Evidence
just not 'officially'

This LDN story began with Ian Zagon and Patricia McLaughlin's research and Bernard Bihari's groundbreaking clinical work - yet no-one else heard of LDN.

The professionalism, dedication, and support of professionals such as Dr David Gluck and Dr Skip Lenz of Skip's Pharmacy followed, and; with the help of tireless voluntary LDN advocates, more began to hear of LDN, followed by a subsequent increase in patient testimonies crediting LDN for improved health.

Interestingly, as LDN's profile increased on the back of patient testimony, so did further research and trials.

Yet how can this be when scientists tell us patient testimony has no scientific value?

Patient testimonies from MS and other disease sufferers who've slowed or halted progression of their disease and had symptom improvement with LDN should be credited for helping build a compelling case for LDN. The increasing volume of their collective voices has been heard through the increasing volume of their heartfelt testimonies.

While scientists of nearly every health discipline continue to reiterate that patient testimony bears no scientific value and can never achieve any scientific value, heightened awareness, research, and studies prove patient testimony

has been perceived as a form of evidence that has added weight to the promise, and therefore, has been recognized as having 'volume value'.

Patient Testimony would add value to our Health Systems

It's true that testimonies represent only one facet of 'health outcome evidence'. It's also true that at present, LDN health success stories and case studies, along with a good safety profile, are still not sufficient to alleviate fear of litigation for those doctors who may want to offer LDN as a treatment option for their patients.

A collection of patient case studies can, however; build to provide sufficient evidence to challenge the status quo, and could be used to advocate for governments to initiate and fund clinical trials or pilot clinical network studies in the best interests of public health.

Patient testimony incorporated into our public health systems would add value:

(1) If patient testimony was incorporated into well-structured, centralized health systems free of conflicting interests that threaten data integrity, it would validate and complement other qualitative and quantitative evidence of health outcomes, as well as provide new and valuable insights that aid prioritization of public and private health research, and clinical network studies.

(2) And, if patient testimony was recorded in greater numbers as case studies, it would build into statistically significant volumes of qualitative and quantitative evidence in its own right. Through the sheer power of numbers, case studies could achieve their own 'volume value'.

Who's in the best position to validate whether a health treatment is effective or not? **Arguably, *it's the patient*.**

Both the above pathways would complement core public health system data by aiding the validation of treatments and outcomes, providing insights into public health improvement opportunities and risks, and providing data that justifies research and clinical study priorities.

Certainly, if such a system were already in place, the 20-year promise of naltrexone would have been honored long ago.

The 20-year promise of Naltrexone

In New York, USA in the 1980s, Dr Bernard Bihari was focused on improving outcomes for his patients. His research led him to consult with Dr Ian S Zagon, whose little known lab research with naltrexone in mice with cancer was generating promising results. Consequently, in the late 80s Bihari began

© Case Health Pty Ltd

clinically trialling low doses of naltrexone, which led to his successful treatment of HIV, then later MS and Cancer.

In the USA Dr David Gluck, a childhood friend of Dr Bihari and LDN advocate, helped Bihari set up the website lowdosenaltrexone.org and it's sub-site ldninfo.org with the aid of his son, Joel. The website features key information on LDN and the Foundation for Immunologic Research (FFIR), founded in 1989 by Bernard Bihari, MD and two colleagues in an attempt to raise trial funds for the broader range of LDN's promising applications.

If not for Bihari's clinical successes, the website Dr Gluck manages, patient testimonials, and an army of LDN advocates, Zagon and McLaughlin's important lab research may never have received the attention it deserved and might have remained as obscure as other promising research. Conversely, if not for Zagon and McLaughlin's lab research, we may never have learned of LDN's potential to benefit human immune system diseases.

Linda Elsegood is an MS sufferer whose life was turned around by LDN. Linda founded the LDN Research Trust in the UK in May 2004, and now produces not only a monthly newsletter, but also manages an International LDN Awareness Week whilst answering hundreds of calls and email enquiries about LDN.

Linda's been an active LDN advocate for many years and is fully supported by her trust directors Dr Bob Lawrence, Dr Tom Gilhooly, and a band of Trust volunteers who, like Linda, volunteer their time in the interest of raising awareness of LDN so others might benefit. The good doctors are not just Trust directors, they have successfully treated patients with LDN and have contributed significantly to enhancing awareness of LDN across Europe, with UK television personality, Dr Chris Steele of IT 'This Morning' learning first-hand of LDN from Dr Tom Gilhooly.

LDN Now, formed in 2009 by Jayne Crocker and Andrew Barnett, is an advocacy group focused on petitioning governments to review LDN as a treatment option. To-date the group has submitted petitions and leveraged the videotaped support of Dr Chris Steele. Of particular note is a videotaped Scottish parliamentary committee meeting in 2009 during which discussion about their LDN petition was led by Scottish LDN advocates, Bob, Celia, and Margaret (you'll find this video link within 'Advocate' pages).

The 'LDN story' is an international phenomenon; a worldwide advocate movement of all those who know of LDN and all those patients who've benefited from LDN. Everyone is doing everything they can to raise awareness and promote further research and clinical trials… the hard way.

You can't help but be impressed when you see sufferers of a range of diseases raising funds and volunteering their time in support groups, in spite of their own daily health challenges - all in the interest of helping other sufferers learn of and benefit from LDN as they have.

© Case Health Pty Ltd

And this collective advocacy effort has achieved outstanding progress: A 2009 advocate survey of known compounding pharmacies worldwide prompted Mary Boyle Bradley (angel of the LDN airwaves) to announce at the 2009 USA conference that an estimated 100,000 patients are now taking LDN internationally.

Skip Lenz of Skip's Pharmacy (Florida, USA) is now compounding tens of thousands of 3-month LDN prescriptions every month. Further, Skip's desire to contribute to the evidence base for LDN efficacy prompted him years ago to initiate his first MS patient population survey, and his latest results continue to confirm a consistently high favourable response rate:

At the 2009 USA Conference, Skip Lenz of Skips Pharmacy in Florida reported 83% of his pharmacy's LDN/MS patient population had not had a relapse in over 3 years.

Clearly, if LDN was a new, patented, high cost, profit-generating drug or vaccine, it would have won it's early discoverers or clinical adopter the Nobel Prize long ago.

Please pause to fully absorb what you've read so far and what all this means:

Even though those numbers seem high and are growing, they represent but a small fraction of sufferers worldwide who could benefit… those numbers represent only those lucky enough to have heard of and tried LDN.

Even though clinical benefits were first discovered over twenty years ago, well before any drug was approved specifically to treat HIV or MS, LDN is still not readily available to you or your loved ones as a treatment option. To my knowledge, this is one of the most compelling examples of the downside of elevating commercialized health systems whilst neglecting gaping holes in public health systems, and why 'balance' must be restored and monitored.

If this can happen with LDN, then it dramatically increases the probability we've also been denied other effective treatments, or been subjected to ineffective treatments, and undeniably… we've lost 20 years of potential international research into how LDN benefits, which surely would have advanced our collective scientific knowledge of immune system diseases.

Those that could be helped are not being helped

And so we're left to grimly reflect on all those who exhausted all their treatment options without success, who might have been helped by LDN, but did not hear of LDN.

And today, whilst there's ample evidence from patient testimony that LDN improves health outcomes, and is an effective and economic treatment option with a good safety profile, people are still not hearing about LDN and the

© Case Health Pty Ltd

majority of practitioners are still not prescribing LDN. The cycle of this health injustice continues.

What's Disturbing about this Picture of Health?

When you read LDN success stories; the first thing you notice is a consistent thread of optimism running through this ever-growing body of evidence:

' … I have been on LDN for a little over 7 months now and it has given me a lot of my life back. For the first time in many years, the progression of disability has stopped. …'

' … I have had NO new symptoms and NO further progression since starting LDN six years ago. I still drive and do all my own shopping, cleaning, etc. I feel certain, had I not been on LDN, I would not be as active as I am, nor as mobile. I wish every MSer had the chance to try LDN to see if they are one of the ones who would benefit. … '

The second thing you'll notice is the extraordinary difficulty sufferers experience after first learning of, then seeking to try this treatment option. MS is a debilitating condition with multiple adverse symptoms. People with MS are already suffering. You can't help becoming indignant at this injustice:

' … I phoned the neuro … to see if she would give me the Low Dose Naltrexone (LDN) treatment. She had never heard about it … she was so excited about this … she had to clear it with the legal dept … A week later she phoned to tell me the lawyers said no! … My health was being decided by a group of lawyers!! … September 4, 2005: I am happy to report a small but significant improvement. Last night for the first time in years I was able to lift my left foot and take a couple of heal to toe steps... instead of dragging my foot or walking toe to heal. … '

Patients Abandoned

Dr Bernard Bihari's patients had professional support when they first commenced LDN treatment. This meant, even though his patients had never heard of LDN, they were told what to expect and were prepared, monitored, and supported by a professional. If an MS patient experienced an exacerbation (with accompanying apprehension) in the first three to six months of treatment, they were likely comforted by; 'this can happen, but experience has shown it does pass'.

Few doctors have knowledge of naltrexone and its safety profile, and even fewer know of LDN as a treatment option. As a result, patients have been abandoned after their specialists or general practitioners learned they were taking LDN - a patient abandoned by her Oncologist, and MS patients abandoned by their Neurologists and GPs. Patients returning to their doctors after improvement have been told their initial diagnoses may have been incorrect, or their MRIs may have been misinterpreted.

Even more astonishingly, patients who've experienced improvement have been advised to 'keep doing whatever it is you're doing', without any enquiry as to what that may be – not what you'd expect from an enquiring, scientific mind focussed on achieving successful health outcomes for their patients.

Over-worked and over-stretched doctors rarely record successful health outcomes, or unsuccessful health outcomes in detail.

At present, the primary motivation to devote that time is the chance of;
a) publication in a prestigious scientific journal, or;
b) an invitation to present at a commercially-sponsored scientific conference.

In both instances there's little incentive for doctors to record successful outcomes from out-of-patent drugs that won't enhance sales of patented, profitable drugs, or open pathways to new commercial markets within the multi-billion dollar health industry.

Patient Research, Expectations, and Preparation

Patients without professional support have had to back-fill the knowledge gap and support themselves, and this absence of professional support has had mixed results:

On the downside of this spectrum, patients influenced by over-zealous stories of 'miracle cures' have embarked on their LDN journey with unrealistic expectations, and without any prior research, knowledge or preparation. High expectations, little or no knowledge of what to expect, and no professional support has led to unnecessary angst and disappointment. Subsequently, some who may have benefited from LDN have not.

Others, to their good fortune, researched extensively, and planned and prepared for their journey, beginning with Dr Gluck's ldninfo.org. They also utilized pioneering doctors, the volunteered knowledge and support of volunteer patient champions within the Yahoo 'lowdosenaltrexone' and related discussion groups, and Linda Elsegood of LDN Research Trust… and were supported and guided to success.

Dr David Gluck's ldninfo.org website contains a wealth of information to aid research and preparation, yet there are still those who begin LDN without ever reviewing this website, who begin in haste, who commence LDN concurrently with other conflicting medications, supplements, and treatments, or who defer complementary lifestyle changes such as improving their diet or alcohol intake, or supplementing nutritional or dietary deficiencies.

I've been recording health success stories since 2001, and LDN stories since November 2003, as well as observing communication exchanges within the Yahoo 'lowdosenaltrexone' group since August 2005. It's been a valuable learning curve and provided many insights: Those who patiently research and prepare prior to starting LDN and who take ownership of their own health future, are those most likely to succeed: Performing their own research often results in patients initiating lifestyle improvements that complement and enhance their likelihood of success – and this positive turning point to overall

improved health has resulted in additional symptom improvement beyond LDN's benefit.

The downside of patients performing their own research is that it exposes them to misinformation and competitive marketing strategies: Desperate to find something that works, patients often try numerous new treatments and therapies simultaneously, depending on the latest marketing trend or 'chatroom buzz'. This increases the risk of treatment conflict and failure, and could even interfere with or negate the effects of LDN.

LDN is not a high impact treatment. It's true that many with MS notice benefits within weeks, but depending on the degree of progression and other variable factors, it can take others six or sometimes even twelve months to benefit. Testimony of long-term outcomes is also varied - from halted disease progression with reversal of symptoms, to slowed progression with minor symptom improvement, such as improved bladder control.

This is where patient testimony reveals some of its value, because it provides insights into variable factors other than LDN that contribute to improved outcomes, or alternatively factors that contribute to limited or unsuccessful outcomes. Insights gained from patient testimony and case studies have already contributed value to the LDN knowledge base.

Health case studies deliver unequalled opportunity to look deeper into factors contributing to success or failure, and hence, provide insights and contribute value to an evolving knowledge base that can enhance the likelihood of success and minimize risk for others who follow. I have great respect and admiration for those rare patient champions who not only contribute their stories and case studies, but also commit to updating them to continue to add value to that knowledge base in our collective best interest.

Where's the official body that acts on behalf of patients?

Research, drug development, and clinical trials are typically initiated by commercial sponsors developing new products. There's no recognized impartial public health body that can officially step up to the plate to speak and act on behalf of (advocate for) patients affected by this health injustice. I know this because I've tried, without success, to find any authority that's sanctioned to do so in my country and others.

Drug regulatory authorities and national health and research bodies are not chartered to act on this information. National bodies monitoring public health quality and complaints are not chartered to act on this information. It is as though Public health in the national interest is an orphan.

Organisations that should be acting on behalf of patients; officially recognized 'disease specialist' societies, other 'non-profit' health organisations, and even

© Case Health Pty Ltd

some patient groups can be unduly influenced by stakeholders who are personally, commercially, or politically motivated.

In fact, the deeper you look into 'the LDN story', the more you find 'conflict of interest' tentacles, reaching into every possible nook and cranny of our public and private health systems and supporting frameworks. Many of the organisations that should or could be doing something about this often respond as if they have a personal patch to protect, not a charter to help patients.

LDN advocates have been abused many times over the years for posting information about LDN on 'specialist' society and other non-profit health organisation websites, or for mentioning LDN in their support groups whether at a hall or online, which in turn raises questions around exactly who it is those groups are supporting, if not patients.

Broad Tentacles & Conflicting Priorities

Consider this chain of events…
(1) New health research leads to new discoveries.
(2) New discoveries lead to new patents (ownership of the discovery).
(3) New patents lead to new products and new profit streams.

So who's funding all the health research that leads to new products? Is the commercial health industry bearing the burden of this cost alone?

Our government research bodies, institutes, and public universities fund a high proportion of new health research. Non-profit specialist health organisations and societies, collectively, also fund a high proportion of new health research.

Our government research bodies, institutes, and public universities are **publicly funded by our tax dollars**, and specialist non-profits are **funded by our donations**. This means a significant percentage of all new health research is funded by consumers, not industry.

And what about the directions and outcomes of all those health research dollars?

Australia's National Health and Medical Research Council spent $24 million (tax dollars) on Multiple Sclerosis research between 2000 and 2009, yet not surprisingly, none $1 of that went to LDN research. Imagine what the worldwide figure of dollars spent on MS research in the past 20 years worldwide could be? So what was it all spent on?

In LDN advocate Malcolm West's article (reproduced later in this book), he writes ' … the NMSS and NIH in the USA are presently working together on a $19 million dollar study announced in July 2009: The study combines two established MS treatments Avonex (Biogen, Inc.) and Copaxone (Teva

Pharmaceuticals, Inc.). Both Avonex and Copaxone cost about $2500 a month for a prescription and have been rising in cost at 20% a year. … '

Exactly how do government, 'disease specialist' and other research bodies prioritize where and how they direct research funding? How do they evaluate and justify which research is worthy of funding and which is not? What hierarchical structure is applied to establish public health priorities in need of research?

Wouldn't a public health system that included patient testimony aid that process, by providing evidence that informs and justifies where taxpayer funded research dollars are spent?

With such deep and profitable pockets, those that feed well from this industry can readily afford to protect and even enhance the flow of milk from this huge cash cow.

But times are changing. In this economic climate, governments can ill afford to continue turning a blind eye to 'conflicts of interest' within the health industry; where strategic drug marketing has long overtaken other forms of ongoing medical and pharmaceutical education, where expert 'scientific' opinion has been unduly influenced, where scientific data has been skewed, and where political lobbying and other profit-protective and profit-generating strategies have not only been detrimental to patients, but also to national health, productivity, and economies.

Ponder This

Government research bodies do not patent and sell new health products developed from health research and discoveries funded by your tax dollars.

'Disease specialist' societies and other non-profits also do not patent and sell new health products developed from health research and discoveries funded by your donations.

Who does?

Whilst the primary driving force for Public Health Research is the potential for profit, nothing will change.

Other organisations, individuals, and even some religious groups who've traditionally stood up for and protected our moral, civil and human rights, are either already overwhelmed and under-resourced, shackled by 'expert advisor' scientific opinion, or dare not risk loss of sponsorships, funding or tax concessions by testing their moral, civil or human rights charters within the

political and regulatory environments of our governing systems and frameworks.

It seems there is either too much at risk or too few resources for most to advocate the degree of health reform desperately needed, or to recognize and investigate the extended benefits of a generic, unprofitable drug on behalf of patients, or to champion the value of patient testimony to our health systems. There is either too much competing or conflicting influence, or too much at stake.

And from my own personal experience, raising the profile of this health injustice has attracted its own set of challenges.

The commercial health industry is worth billions of dollars. Change any facet of a market-driven, market-influenced health system and it will impact the profits and livelihoods of those who work in it and trade in it – positively or negatively.

Historically, this has fuelled a strong commercial argument for deferring deep reform, but with most governments facing an insurmountable economic burden due to aging and ailing populations and runaway health inflation, this argument is no longer defensible. More of the same government policies will result in more of the same failings and will not resolve this problem, will not improve health outcomes, and will not reduce the projected economic burden of public health or slow health inflation.

Governments cannot rely on a private market-based health system to step up to meet the needs of public health in the best interests of patients and economies. In the real world, private enterprise only ever steps up to meet demand in it's own best interests, where it can profit by doing so. Why? Because the private sector has no moral obligation to, or responsibility for, public health. They're obliged to shareholders, not patients.

There's no blockbuster profit to be made from trialling an off-patent drug like naltrexone for every disease it may benefit – so regardless of the promise naltrexone holds to alleviate suffering, improve productivity, and deliver economic public health benefits, nothing will happen – as nothing has happened the last 20 years. Whilst the primary driving force for Public Health Research is the potential for profit, nothing will change.

A symptom of a Much Larger Disease

Believe it or not this LDN story, as powerful as it is, represents only one, small, single example of how our health systems have been failing us.

In this respect, the LDN story is only a single symptom of a much larger disease.

When people learn of LDN, logically, they also want to know WHY THEY'VE NEVER HEARD OF LDN, hence; this article rightly shares a small part of the history and background of competing influences that have contributed, and continue to contribute to this injustice. When you look into any corner of the LDN story, you'll find yet another competing influence.

In an effort to contain rising public health costs, many governments have adopted multiple short-term strategies to contain rising costs, by quietly shifting more of the economic burden of public health to the private sector each passing year.

Over the past decade or so, depending on where you reside, government policies have actively orchestrated this quiet evolution of benefit to industry, not patients - public health to private health - via ever-increasing levels of political and financial support for private sector involvement, whilst simultaneously releasing the public health reins more with each passing year - and industry, not surprisingly, has been actively supporting that evolution in front of and behind the scenes.

Unsuspecting consumers have been subjected to repeated public health propaganda 'scare' campaigns, cajoled by health subsidies and concessions, and lulled into a false sense of security under an orchestrated 'conditioning' process that's resulted in consumers readily accepting ever-increasing private sector involvement *as the only possible public health resolution.* We've been falsely led to believe the private health sector will always pick up the reins and do a better job than our public health systems for the same or better price. This is propaganda, and a fallacy of the highest order.

Consequently, core government responsibility for public healthcare has progressively devolved into one of casual oversight of increasing private, market-based healthcare and private health insurance, right under our very noses, below our public health media radars, and with little to no objection from us, as consumers.

Public health is a government responsibility, full stop!

Desperate measures by governments to contain rising public health costs via this shifting of responsibility have done nothing to improve public health outcomes, national productivity, or slow health inflation. In fact, the shifting of public health responsibility and cost burden from government to industry and subsequently, (full circle) back to us consumers, has fuelled the health inflation and low productivity economies struggle with today.

The private sector is concerned with profit, not public health, full stop. It is not responsible for public health, and not therefore; a fit caretaker of public health.

Private health insurance companies are today employing various strategies, including lobbying, to gain even bigger slices of the pie. But, they cannot profit

from the sick, so they either long ago abandoned or are presently lobbying to abandon the core underpinning equity principle of health insurance; 'community rating'. It is this principle that ensures everyone is treated equally. Without this guiding principle, everyone can legally be treated unequally.

'Community rating' is a safeguard that guarantees your insurability, regardless of your risk profile today, or if it changes tragically tomorrow - as it often does. In the absence of legislation protecting the 'community rating' principle, a private health insurer is free to assess your individual health risk profile and charge you accordingly, or; elect not to insure you at all.

Youth and good health are fleeting. They won't insulate you against this inequity. Accidents happen. What's here today is gone tomorrow, and every single person is, or will eventually be disadvantaged where this guiding principle is removed.

The Private Sector is not responsible for Public Health

If half as much political attention had been afforded public health over past decades, we'd already be well on the path to improved health outcomes for all, would already be using an effective public health data system and would already be achieving higher levels of quality and productivity from the same limited resources.

Consequently, governments would already be reaping economic benefits from improved 'economies of scale'.

Over recent years consensus on the potential of public ehealth systems to improve health outcomes has grown, albeit begrudgingly from many corners, but this has not quelled strong resistance and lobbying from widespread competing interests.

Why else would we be witnessing influential support for disparate, commercially operated ehealth silos over the adoption of one core, secure, and 'fit-for-purpose' public health platform that ensures meaningful data with integrity, to gain maximum benefit from improvement opportunities?

Same horse, more patches

Many governments have come under recent pressure to legislate in favour of re-patenting of (re-profiting from) older drugs. Such an enticement to re-profit might spur clinical trials of LDN for a couple or even a handful of the diseases it can benefit… but what of the fate of those suffering the 200+ diseases presently linked to immune system dysfunction that might benefit from LDN? And, where would that leave the potential of other promising but non-patentable or non-profitable treatments?

© Case Health Pty Ltd

Such legislation may serve the 'wants' of industry, but adding more patches to already over-patched health regulatory systems will contribute nothing to desperately needed public health reform. More patches on this dud horse will never transform it into a race winner.

When public health systems are sick, nations and economies are sick

Governments often perpetuate the practice of piece-meal health policies as knee-jerk reactions to the latest health system hype or failure to hit news headlines. Short-term health policies are announced on the run to win votes, but do us all long-term disservice. They draw attention to a single fractured piece of the health jigsaw and distract us from the fractured nature of the whole puzzle.

Health system reporting is also preoccupied with bits and pieces – recording numbers of patients, incidents, and hospital beds. Recording and reacting to numbers alone does nothing to improve health outcomes and keep people out of hospitals. A health system prioritising numbers and reductions in operating costs over quality outcomes (prioritising quantitative over qualitative systems and measures) is a sick and fractured system.

The primary purpose of a public health system framework is to minimize public health risk, and support quality and improvement in health outcomes for patients, which in turn facilitates increases in the number of successful outcomes and reduces the risk of unsuccessful outcomes.

This can only happen when everyone shares the same goals and works as a team to improve health outcomes – transparently contributing data together in a purposeful and meaningful way – to be shared/merged for the present and future benefit of all. Add ethical oversight and audit analysis to guard against 'conflict of interest' creep that could render data worthless, and data integrity could be maintained and grow more valuable with each passing year.

Further, patient testimony incorporated into health systems, again with integrity safeguards and in a structured and meaningful way, would complement and validate heath outcomes data, and would in ensuing years, build into insightful evidence in its own right through achieving 'volume value'.

We need governments to look up and out to the horizon, then stand up and step forward - beyond the next populist crack on the concrete path, beyond the next election, beyond commercial and competitive interests and influences - to exercise visionary policies that are pro-active, not reactive, and that secure what is fair and right for all our long-term health futures.

Public health systems must be purpose-designed so each piece of the jigsaw connects seamlessly toward improving health outcomes. Proposed health

© Case Health Pty Ltd

reforms that cannot pass this basic 'fit for purpose' measure should be rejected outright.

Patient testimony can achieve 'volume value'

Patient testimony of success with LDN is scattered across the internet and while it remains scattered, it can be more readily dismissed by the scientific community as random patient anecdote. Scattered, it doesn't register on the public health radar. Scattered, it can't be validated or measured. Scattered, it's not considered a facet of evidence and can't build a compelling case for a promising treatment in its own right.

But patient testimony can build into a compelling body of evidence that can't be ignored. The collective is stronger than the single, and though this LDN story is already an excellent example of the power of numbers, it is still in need of greater patient support.

It's my hope the scientific community, through LDN, will officially recognize the potential value of patient testimony to public health systems, and its potential to achieve 'volume value' in its own right.

Who should be primary caretaker of our public health data?

Valuable public health information (data), including data on treatments that work or don't work, is isolated and spread far and wide in unproductive 'silos' of public and commercial health systems. As with patient testimony, when public health data is spread far and wide it has less value and less potential to improve outcomes than it would if it were brought together.

Clearly, incorporating all public health data, including patient testimony, centrally into health systems has immense potential to improve health outcomes, reduce the economic and community burden of health, improve national productivity, and slow health inflation.

How could any government implementing ehealth systems justify support for disparate, commercial health data and IT systems - where data remains isolated in 'silos', and where operating systems (hardware, software, frameworks and processes) are incompatible and therefore, incapable of meaningfully merging data with other systems to extend our collective health knowledge?

With such potential to contribute to improving national health outcomes, how could any government justify a public ehealth path forward that perpetuates 'silos' of health data or isolates patient testimony?

And, how could any government remain comfortable delegating yet another slice of the public health pie to the commercial for-profit sector and its vested

interests, thereby sentencing the future potential of ehealth to certain death by 'conflict of interest' implosion.

Has the commercial sector proven itself a fit advisor or primary caretaker of valuable public health data? Have they proven themselves capable of protecting privacy or sharing information freely in the national interest of public health and patients? Have they proven they can prioritize quality health outcomes over profit at every opportunity? Have they proven themselves to be effective self-regulators?

Exposing an injustice

Many of our health economies and systems are sick and unjust. They're costly and inequitable. They don't place sufficient value on health success and improving health outcomes. They don't place sufficient value on advocating for the patient. They don't place sufficient value on the need for public health research and clinical network studies in the public's best interest. If they did, there'd already be a body sanctioned to speak and act on this compelling body of testimonials.

How many stories similar to the LDN story are out there? We don't know, because they haven't all been collected, stored, and shared centrally.

That makes me feel uneasy and it should make you feel uneasy. This LDN story is just the tip of the iceberg, and until now, we've been blinded to the injustice that lies beneath.

Governments first need to acknowledge the value of patient testimony

This LDN story, it's history and background, is a valid, powerful and compelling example of why 'public health' and the systems that support it need extensive reform to rebalance public health system scales in favour of patients, and attribute more weight and credibility to patient testimony of health outcomes, and the patient health journey.

Reactive health policy patching and short-term 'work-around' health system fixes are no longer credible or viable options for economies under increasing pressure from mounting public health costs. They are no longer defensible.

Implementation of proactive, ethical reform that results in robust, meaningful public health system frameworks that improve outcomes offers the only viable path forward for governments committed to long-term, proactive public health solutions.

It's my hope governments worldwide presently reviewing or implementing longer-term public health visions, will welcome, accommodate, and integrate patient testimony as a valued, protected, and integral part of public health IT

systems that are purpose-designed to improve patient outcomes, with complete integrity, and will create official bodies chartered to oversee and act in the best interests of public health - impartially, and without prejudice or conflict of interest.

I am but an individual, without sufficient resources to lobby for action on this international human rights injustice, this orphaned public health cause that's desperately in need of more champions - hence this free book in the hope of building international awareness and support.

He who suffers much will know much

Greek proverb

Dear Journalists,
Case study contributors who've consented to interviews by prime media are colour-coded within this book. Interview requests can be emailed to Cris Kerr casehealth@optusnet.com.au

The views expressed in this article are those of the author.

Supporting data for this article came from untested patient testimony, references, resources, and articles included or listed within this book.

###

(1) **Bernard Bihari, MD**, was the discoverer of the major clinical effects of low dose naltrexone. A private practitioner in Manhattan, Dr. Bihari was a Board-certified specialist in Psychiatry and Neurology, with a practice located at 139 East 33rd Street, #10K, New York, NY 10016. Tel (212) 929-4196. Sadly, Dr Bernard Bihari passed away on Sunday, 16 May 2010 after a prolonged period of illness. He was 78. The flow-on effect of Dr Bihari's use of LDN in clinical practice did not just deliver hope to his own patients but to patients around the world, and his pioneering work resulted in real relief from real suffering, and real improvement in quality of life for tens of thousands, and we hope in the years to come... hundreds of thousands. Words cannot express how deeply his passing was felt by the thousands he has touched... whose quality of life was dramatically turned around due to his compassion for patients, and his pioneering work in their collective best interests, against all odds. We are forever in his debt.

(2) **David Gluck, MD** (NY Lic. #083512), is the editor of ldninfo.org and its mirror site lowdosenaltrexone.org. He is a Board-certified specialist in both Internal Medicine and Preventive Medicine. Dr. Gluck has served as medical director for JCPenney and MetLife, and is now semi-retired, living and working in New York City.

(3) **Ian S. Zagon, PhD**, discovered the potential of low doses of naltrexone and has spent over two decades doing basic research concerning endorphins. He is Professor of Neural and Behavioral Sciences, Pennsylvania State University, Dept. of Neural and Behavioral Sciences, H-109, Hershey Medical Center, Hershey, PA 17033, USA; office phone: (717) 531-6409; email: isz1@psu.edu
Website http://www.fred.psu.edu/ds/retrieve/fred/investigator/isz1

(4) **Patricia McLaughlin, D.Ed**., is credited as co-discoverer of the potential of low doses of naltrexone. Patricia is the Director of the Graduate Program in Anatomy at the College of Medicine, and a Professor of Neural and Behavioral Sciences, Dept. of Neural and Behavioral Sciences, Pennsylvania State University, H-109, Hershey Medical Center, Hershey, PA 17033, US; office phone 717 531 6414; email: pxm9@psu.edu

(5) The **http://www.ldninfo.org** and mirror website **lowdosenaltrexone.org** are edited by Dr David Gluck with the help of his son, Joel Gluck. The sites are sponsored by Advocates For Therapeutic Immunology. The purpose of the websites is to provide information to patients and physicians about important therapeutic breakthroughs in advanced medical immunology. The authors of the sites do not profit from the sale of low-dose naltrexone or from website traffic, and are in no way associated with any pharmaceutical manufacturer or pharmacy. The sponsors also created the **Yahoo 'lowdosenaltrexone' discussion group**. A comprehensive overview of LDN is on ldninfo.org, including Q & As.

(6) **Bren** and **Art**'s case studies are included in this book.

FURTHER READING:

(1) Books authored/co-authored by **Ray Moynihan**
Too Much Medicine? (1998), Selling Sickness (2005), Ten Questions you must Ask your Doctor (2008), Sex, Lies & Pharmaceuticals (Sept 2010)**:** Ray has won the Human Rights Media Award, was a co-winner of the 1995 Peter Grieve Award for medical journalism, 1996 Michael Daley Award for excellence in science journalism, and his series on the ties between physicians and pharmaceutical companies won the British Medical Journalists' Association Award
(2) Books authored/co-authored by **Melissa Sweet**
Ten Questions you must Ask your Doctor (2008), Inside Madness (2006), Smart Health Choices; Making Sense of Health Advice (2008), The Big Fat Conspiracy; How to Protect Your Family's Health
(3) Hooked: Ethics, the Medical Profession, and the Pharmaceutical Industry, by Howard Brody, Rowman and Littlefield Publishers, 2007
(4) The Truth about the Drug Companies: How They Deceive Us and What to Do About It by Dr Marcia Angell, Random House, 2004
(5) On the Take: How Medicine's Complicity with Big Business Can Endanger Your Health, by Jerome Kassirer, Oxford University Press, 2005
(6) Side Effects: A Prosecutor, a Whistleblower and a Bestselling Antidepressant on Trial, Algonquin, 2008
(7) Listening to Profits, by Dr Nicholas Z. Rosenlicht, 12 May 2010, Inside Story - Essays and Reportage online: http://inside.org.au/listening-to-profits/

PERMISSION TO REPRODUCE
© Cris Kerr of Case Health grants permission to reproduce the 2010 revised version of the article 'Those Who Suffer Much, Know Much', written by Cris Kerr as lead article in the book 'Those Who Suffer Much, Know Much: Cris Kerr of Case Health grants unreserved rights to reproduce the entire article **without any omissions, in the interest of building awareness, and on the provision this permission advice is included.** If you reproduce the article, please send a courtesy advice to Cris Kerr at casehealth@optusnet.com.au. This article has been previously published in earlier versions with different titles: (a) 2005 abridged version published on News-Medical.Net, 1 December, 2005; 'Drug stops multiple sclerosis - but sufferers can't get it!' Cris Kerr highlights Naltrexone in her latest issue of 'Case Health - Health Success Stories' http://www.news-medical.net/?id=14749. (b) 2006 version entitled 'Anecdotal evidence points to relief for MS sufferers' was published on ONLINEopinion Australia's e-journal of social and political debate, 3rd January, 2006 http://www.onlineopinion.com.au/view.asp?article=3905. (c) Drug stops multiple sclerosis - but sufferers can't get it! was published in the Case Health LDN Booklets 2006, 2007 (d) 'Those Who Suffer Much, Know Much' article, book of same title 2008 edition (e) 'Those Who Suffer Much, Know Much' article, book of same title 2009 edition.

"Those suffering from a chronic disease have the right to be fully informed of all their treatment options … even the unprofitable ones." Nov '07

"LDN is not a cure, nor is it 100% effective … but it is effective. If it's possible a patient could benefit from LDN, what valid reason remains not to consider LDN as a treatment option?" Nov '07

"Over-emphasis on commercialization, profit, and competing interests, places a basic human right at risk." Nov '07

"… when health success stories are recorded in greater detail and numbers as case studies, they can build into statistically significant volumes of evidence through the sheer power of numbers, achieve 'volume value' in their own right, and facilitate insights into public health priorities and improvement opportunities."
Aug '08

"When public health systems are sick, nations and economies are sick." Aug '09

Cris Kerr
Advocate for the value of patient testimony
to health & ehealth system frameworks worldwide

USA LDN CONFERENCE 2010 – none planned

Dr David Gluck, Editor, LDNinfo.org

"The use of low doses of naltrexone for multiple sclerosis (MS) enjoys a worldwide following amongst MS patients. There is overwhelming anecdotal evidence, that in low doses naltrexone not only prevents relapses in MS but also reduces the progression of the disease."

International LDN Awareness Week **1**8-24 OCT 2010
http://www.ldnresearchtrust.org

Birmingham LDN Aware Conference 23rd October 2010
http://birmingham2010.ldnresearchtrust.org/

Linda Elsegood, LDN Research Trust UK
http://www.ldnresearchtrust.org

Free Book: '201 Reasons Why *You Should Know About LDN'*
201 LDN patient testimonies
http://www.ldnresearchtrustfiles.co.uk/docs/ebook.pdf

Linda & Leo 2010

"I work towards the day when everyone's able to access LDN easily, wherever they live in the world… and that day is getting closer." July 2009

Please support THE INTERNATIONAL LDN PETITION – RESESARCH INTO LDN FOR MS
www.thepetitionsite.com/1/sign-support-the-campaign-for-research-trials-in-low-dose-naltrexone-for-multiple-sclerosis

Case

Studies

© Case Health Pty Ltd

1 My pre & post LDN MS story – Jim

LDN since December 2003
- story submitted Dec 2005
- story updated Dec 2005
- story updated Aug 2006
- story updated July 2007
- story updated July 2008
- story updated Jun 2009
- story updated April/June 2010 (over 6yrs on LDN)

SPECIFICS

DIAGNOSED
- Jan 2002 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)
- Feb 2002 to Nov 2003 - Beta-Seron

MEDICATION (post LDN)
- Dec 2003 to Jan 2004 - 3mg Low Dose Naltrexone (LDN)
- Jan 2004 to present – 4.5mg Low Dose Naltrexone (LDN)
- Nov 2009 to present – Vitamin D3 12000 units daily (4000units x 3 times daily) – as a participant in a 5 year Vitamin D study by 'D Action' (www.grassrootshealth.net)

TESTS
- Nov 2009 - Vitamin D 19ng per liter
- Jun 2010 - Vitamin D 65ng per liter

LDN DOSE & TYPE
a) Dose – 3mg for 1 month, then increased to 4.5mg Low Dose Naltrexone (LDN)
b) Time – nightly, as close to 11pm as possible.
c) Type - Compounded capsules with pure Naltrexone powder and Avicel filler.

SUPPLEMENTS
- May 2008 to Nov 2009 – one each as follows:
Mornings, as follows:
Primal Defense (Probiotic)
Alpha - Lipoic Acid x 300mg
L-Carnitine (CarniPure) x 500mg
Super "B" Complex
Noon, as follows:
Primal Defense (Probiotic)
Alpha - Lipoic Acid x 300mg
Turmeric Extract (95% Curcumin)
Selenium x 50mcg
Resveratrol x 75mg (Japanese Knotweed)
Evenings, as follows:
Primal Defense (Probiotic)
Alpha - Lipoic Acid x 300mg
Oregano Extract x 450mg
Zinc x 50mg
Ginkgo Neuro-Mind x 50mg
Bedtime (around 11pm):
Cal-Mag (Chelated) x 250mg
Cat's Claw x 300mg
Move Free (Glucosamine 1500mg Chondroitin 1200mg Hyaluronic Acid 3.3mg)
Vitamin C x 1000mg (unless feeling 'puny' then I up it to 5000mg for a couple days)
- Nov 2009 to Feb 2010 (stopped). Recommenced June 2010 to present – as follows:
Mornings, as follows:
Primal Defense (Probiotic) x 2
Alpha - Lipoic Acid x 300mg
L-Carnitine (CarniPure) x 500mg
Super 'B' Complex
Noon, as follows:
Primal Defense (Probiotic) x 2
Alpha - Lipoic Acid x 300mg
Turmeric Extract (95% Curcumin)
Selenium x 50mcg
Resveratrol x 75mg (Japanese Knotweed)

Evenings, as follows:
Primal Defense (Probiotic) x 2
Alpha - Lipoic Acid x 300mg
Oregano Extract x 450mg
Zinc x 50mg
Ginkgo Neuro-Mind x 50mg
Iodine x 1 tablet
Bedtime (around 11pm):
Cal-Mag (Chelated) x 250mg
Cat's Claw x 300mg
Move Free (Glucosamine 1500mg Chondroitin 1200mg Hyaluronic Acid 3.3mg)
Vitamin C x 1000mg (unless feeling 'puny' then I up it to 5000mg for a couple days)

DIET
- 2007 Joined weight watchers and lost 55 pounds - 70 lbs more to go. Attempting to quit smoking (talk about stress) haha.
- 2008 – My diet has improved since I made time to regroup and reorganize my thoughts on my eating patterns. I've adopted the advice of my Kinesiologist: I drink more water, I do the 'juicing' (which has become a favorite), I eat more green vegetables and fruit, I stay away from dairy as much as possible, and I eat very little red meat (sigh). Weight loss is still an issue but slowly improving too. All in all, I've improved my eating habits and my diet is much 'healthier' than it was previously.
- 2009 – Diet still improved.

EXERCISE OR INTERESTS
- 2007 - Tai-Chi & martial arts, learning to relax, as well as more walking.
- 2008 – my strength is a little better since I've started doing some more exercise. I spend less time in front of the TV, and more time up and about, looking for things to do that will occupy my time as the energy permits – and I stay away from stress if at all possible. I've 'finally' learned to calm down, and not be such an "A" type of person. For me, it was really stressful. Now, I'm 'laid back' and enjoying life more, doing some woodwork, and camping/RVing.
- 2009 – Strength and stamina is improved when I maintain regular exercise.

MY STORY *Before LDN*

So, here is my story *BEFORE* beginning Low Dose Naltrexone (LDN). The period represents 2 years.

I would like anyone who reads this to please understand, this is how "I" felt. It's not a biography. I'm going to try to relate to you the effects of the disease on me personally. This was how "I" felt, pre-LDN and I'm going into detail so you can experience what I experienced.

Let's take a little walk as I try to use the correct words to express it to you. I may jump around some, nature of the disease. Cognitive issues are much better now with this stupid little wonderful pill (Naltrexone), but even though, still wish they were better. Everything below may sound terrible, but I'm writing it with a smile, not a frown. Attitude is key!

There are a lot of "symptoms" associated with this disease, and for some reason, I was "blessed" with a lot of them. I'm going to run you through a week of exercise and pain. We're only going to make it last for five days. Most people would be horrified to learn that it's all the time, and I'll get to that meaning after awhile.

Day one and two; we're going to experience the bone-dragging weakness that comes from too much of a good thing...You're going to be a weightlifter!!! Oh joy. 48 hours ... you get to lift weights, as heavy as you think you can, and you're going to do it for the ENTIRE 48 hours, with NO breaks. Get started ... ya done yet? <grin> keep going, just a little more. ...

Hey guess what, it's now day 3, and you get to go on a cross-country run!!! We are on the West coast, you get to run to the east coast...You've got 2 days, better hurry ... nope, no sleep ... keep moving, this whole week is going to be without sleep, and you don't get no-doze either. sorry.

Second day on the run...where are you at now??? better hurry, faster, looks like you're just going to make it ... pant pant pant ... sigh.

Here it is ... Day 5 ... now the fun begins. :-) the first four days were just to let you know about the lack of strength after all that gruelling work, and the fatigue that goes along with it (lack of sleep). Day 5 is here, and

the pool is waiting ... you get to go into the water now. Only it's not water ... it's Jell-O, and the Jell-O has set up, strange, even though it's set up, it's still warm? hmmm.

Well, the pool is only about 5 to 6 feet wide, and it's a mile long. You have to wade from this end to the other as quickly as you can. Added treat, the pool is slanted at a downward angle, and once in awhile, it might be slanted upwards quickly. As you start off, remember to keep your balance as every so often, the pool is going to tip to the right, or the left rather quickly.

Another point to remember is NOT to turn your head very fast, for if you do ... the entire pool will SPIN around in a circle at about a million miles an hour and come screeching to a halt, leaving you holding on by your eye teeth, and wondering what in the blue blazes just happened. This is normal. As you go along your merry way, it seems you're walking in an arc. Me, I walked from the right, slowly to the left, like everything sloped that way.

What was I thinking...the fun, oh yeah! Have to add in all the little props that will make this a memorable little journey for you. :-)

We're going to attach weights (100lbs each) to your arms, and your legs. Probably around the wrists and ankles so you'll get the full effect. Ahhh, forgot, the 100 pound sack of flour or rice, (your choice) that goes on top of your head ... that way you'll understand how the neck feels trying to hold your head up!!! We'll probably tie a big line around your middle and attach it to a diesel locomotive for you to drag through the pool with you. Don't worry; this is done by others on a daily basis.

Now it's going to get really interesting ...

Thumbscrews of a type that are large enough to fit over the top of your head and go into your temples. Nice touch. ... If you feel like you've got a splitting headache, it's because of the axe that's embedded in your skull.

Now the eyeballs...we'll just take them out, and rub them down with some heavy grit sandpaper and put them back in. Good effect there.

Vision...woo hoo, let's make you wear glasses, and we'll put wax paper over one side, and rub the other side with Vaseline. (This lasted a week for me, before it went away.)

Now the cognitive issues ... as they say, no brain, no pain. Well, maybe that part about the pain ain't true. But you sure feel like your melon is quite empty. Wife and I were having a discussion at the table ... I held my hand up for her to stop...all the words seemed to be in a foreign language - huh???

A major portion of the time, if she asked me to do something, I forgot as soon as she said it. No ladies, this wasn't to get out of anything. Just a case of missing grey matter. Seemed like it at the time. No focus, no memory. 2 plus 2 could be five, I don't know. Guess what??? I'm married!!! Don't remember getting married, sure it ain't a mistake?? 33 years now??? Wow, and your name is??? <grin> Quite embarrassing when you don't remember people you've know and associated with all your life.

OOPS!!! Forgot all the fun things ... fun fun fun. ... At any given moment, you'll have a pain. It can be a minor one, or...a major one. It can be very brief, it can come and go, it can last ALL DAY! How bout a nice ice pick into the back of your arms, or thighs. Cramps, how did you know? They don't call me chucky for nothing ... here's another Charlie horse for you. How bout a nice migraine huh, I had one that went on for two and half years. Everyday! Sometimes the pain was literally blinding. Every seen a grown man cry, want to??? Hold up there, don't go running off ... we are not through here ... more to come.

Ever burn yourself?? Scald yourself?? Imagine that's what has just happened to your body, different places, and different intensities ... know what a raccoon is, right? Imagine you have a mask just like it ... only it's a burning sensation like hot coals dropped on you. Guess what, sometimes, it moves ... my right side was like that, only my right foot felt like it was in a bucket of ice?? Go figure. Hmm. Now, we will hook up the electrodes, and know the old saying about how a frog's leg will "jump" in a hot fryin' pan?? That's what's going to happen to you.

You get to be your very own sideshow. Just a twitchin' and a' jumpin' - legs and arms. How bout the head, let's do something with it as well. Make it shake a bit, just enough to bother you when you're trying to watch TV. Nice. Maybe bounce without control. What fun.

Balance, we've pretty well covered that, but when you walk down the hallway, you'll need to hold onto the walls or no telling what will happen.

Just about finished for now, a couple more things and we'll call it a day.

I apologize in advance, but if you truly want to know what it's like, you'll forgive me.

Onward ...

Bladder and Bowel control ... hmmmm ... not the best of topics but certainly one of the most pressing on a daily basis. You take a drink of water, and you get to spend the next 2 to 3 hours getting rid of it, an ounce or dribble at a time. Don't be surprised if some winds up on the inside of your unmentionables ... it happens - a lot. Wet spots are proof we have no control.

Bowel function, gaaah ... it's one or the other. If you feel the slightest bit of an urge, the very smallest sensation ... RUN or you get to wear it. Yuck!!! Sigh, there's always Depends ... sigh.

Lastly ... we're going to take all of the above, compress it down into one day, one 24 hour period ... had a lady from church ask me after I relayed pretty much all of the above, (she did want to know) and her words were, Oh Jim, how awful ... how often does this happen ... hamata I smiled and said, "From the time I wake up in the morning, until the time I either fall asleep or pass out!"

I've had problems in the past sleeping. Both ways.

1st example...I got off work on a Friday at 4pm. Was home in about 5-10 minutes and sitting in my easy chair. Around 4:30pm I dozed off. Didn't wake up until 10pm Saturday night and was up for about an hour and went back to sleep. After falling asleep again, I finally woke at 6 am Monday morning - just in time to get up, and get ready to go to work. Effectively lost the whole weekend.

2nd example...after being retarded ... err ... ahem ... uhh ... retired. Ok, now that we have that straight, I'm retired now. Well, a year ago, and it was on a Tuesday night, I couldn't go to sleep. Was awake for what seemed like forever. The mind just wouldn't shut off and let me sleep. It was right around noon the following Friday (more than 3 days later) that I was finally able to drop off and get some rest, or crash and burn as some say.

Most people will say something to the effect, "Well why didn't you take a sleeping pill or something?" ---------- Didn't I mention to you, my brain doesn't work? ... We don't think of things like that. It's all a new day, new things to learn then promptly forget. Simple tasks are not so simple for some of us when we are like this. WE are simple. Imagine trying to hold down a job under these circumstances.

I'm sure there is more to all this, and probably some things I've left out. As I've said, my brain isn't quite there like it used to be. Some things are gone for good. Some (memories) make a brief re-appearance and then vanish, poof - cloud of smoke and it’s gone. I have regained some, and hoping to regain more. Only time will tell.

Some people, good intentioned, make the mistake of asking me "how are you doing?" I'm doing lousy thank you, and you? And one of the things I absolutely HATE now is, 'Oh, but you look so good!' (Thinking it will help me feel better if I’m told I don’t look how I feel – if they only knew.) Next time I hear that, I'm going to poke someone in the nose. Oh oh oh...here's a good one from some of the --holes out there (giggle) "You don't look like there's anything wrong with you to ME?" Gimme a hammer, or a shovel...ARrrrrgh!

Some people (good intentions again) have tried to ‘help’ me when I lose my balance, and try to ‘grab’ me. That's nice but, only if I'm actually falling - which of course you'll need to guess within a fraction of a second. You see, my weak muscles are desperately trying to compensate for the swaying and will more than likely prop me back up and I'll regain my balance, but if you've "grabbed" me, I'll loose what balance I have and overcorrect and fall. It's happened. But, that's just me.

And that brings me to the last for the day ... depression. ... The pain was so intense at times I'd sit outside under our covered breezeway, and just sit, and cry. Sometimes for an hour, sometimes FOR hours. I stayed there until I could go back in without sniffling in front of the wife. Didn't do her any good, and she couldn't help anyway.

Anyone here think all this wouldn't cause depression? Didn't think so.

You don't want to be a part of it, just take sharp instruments and/or weapons away from us, hide them when we're like this and we'll eventually get over it.

I used to take one of the CRAB Drugs ... during the last six and a half to seven months on it I suffered site reactions - redness that swelled up, then turned black and blue, then really painful, the flu-like symptoms from the drug never went away, the depression was worse than ever before. Sick, (stomach) chills, shakes, fever, hot flashes, pain, all after taking my injections that the doctors say, are well tolerated ... (bull-soup). Let them suckers stick themselves with this poison for the rest of their lives. ...

In the mornings, after I'd been through my bathroom routine, getting ready for the day, I'd go into our closet to get clean clothes, and walk past a shiny piece of metal, that fit in the palm of my hand, blued barrel, .357 calibre, and stare at it, and think to myself, how easy it would be to just "check out!" That's how I felt every day for that last 6-7 months - not once in awhile, but EVERY DAY.

This has been a 'tad' longer than I'd anticipated, but I believe it will give you something to think about. All of these symptoms are not experienced by everyone, some have very mild symptoms. But, when you've got them ... man o' man do you have them.

All the above was Pre-LDN which is what I'm taking now for my MS.

Now here's the bit you've been waiting for …

MY STORY *After LDN*

My Story *AFTER* beginning Low Dose Naltrexone (LDN) – in December 2003: Personally, I believe it has halted the progression of my disease and it has given me back some of the abilities I thought were gone for good. No....this is NOT a solicitation, this is not some sort of scam, this is MY Story ... MINE ... you want to find out more, check out remedyfind.com and then go to ldninfo.org and you may, just may, have an inkling of why I've now got hope back in my life.

My neurologist says it's a placebo effect, and I said, okay ... you'll write the prescription for the sugar pills ... okay?? She did - then we parted company. She didn't like the fact I'm better, and I'm no longer on the poisons she wanted me to take. (My opinion of the CRABS, and mine only.)

I have my balance pretty much back, vision has improved to where it was before my diagnosis (dx), bladder is now under control. I can think once again, although once in awhile things do cloud up upstairs. Most of the pain went away initially, but some of it has returned but is mild enough I can easily ignore it.

I don't stagger when I walk, don't rely on a cane for balance, don't use a wheelchair for the distances anymore. No longer do I slur my words, don't shake, spasm, tremor or any of that. The never-ending migraine ... gone. ... Now if I get a headache, it's usually due to sinuses, and a sinus tab or couple of Excedrin take care of it. Am I cured??? Not by any stretch of the imagination, and sadly, most people don't receive the almost full reversal of symptoms that I've had the joy of receiving. Most all do say they experience better bladder control.

If you've made it this far, and maybe checked out the LDN website - go back and re-read it - then read it again a couple more times before you jump up and down and think THIS IS IT!!!! Read ... 'it's intended' or I should say, 'it's believed' that it halts/stops the "PROGRESSION" of the disease.

Anything else like symptom improvement is a happy side effect and not a guarantee. Just icing on the cake ... something to be hoped for, not expected – but a bonus. Starting to sound like a #%$@ ad for the drug ... I'll end here. May the Lord Bless you and watch over you, and remember - this is just my version of how "I" felt, not anyone else. Some people actually feel much worse.

UPDATE December 2005

Been a while since I checked in with the discussion group, and today is my 2-year anniversary on LDN. Started Dec 11th 2003 at 3mg, was on that for a month, then upped it to 4.5mg and have been there ever since. Like Reg, I'm another Happy Camper on LDN who has a lot to be thankful for. I still tend to 'lurk' in the

shadows of the group, and will probably continue to do so, but thought I'd throw my 2 cents in for what it's worth. So, now that I'm out of my "Cave" I'll re-gale you with a short version of Thanks....

Thanks to the 'old-timers' for your encouragement a-ways back, when I was at my ropes end just looking for something that would halt/stop the onward progression of this MonSter. All I wanted, hoped for, was something, anything, that would stop me from getting any worse. Received more than I was hoping for.

As it turns out, I 'realised' an "almost" complete turnaround of symptoms. Not remission. I did try Dr. Bob Lawrence's 'two days off' system but couldn't walk at the end of the two days so have learned, for me, it 'appears' to work better without having scheduled breaks and missing doses. Again, thanks to all who helped me in the beginning. To try to name all of you would be next to impossible and if you remember me, then you've probably helped me at one time or another. Thank you! Cured??? Not hardly, but I will say again, my 'worst' day taking LDN is by far and away much, much better than my 'Best' day on the injections.

Just my personal observation as it relates to me. I still have the ups and downs, but seem to bounce back pretty well. I have good days, and 'better' days. Any day I can get up, out of bed, make it to the 'throne'-room (blush) without falling down, having an 'accident' along the way, and make it there by myself, without a cane, or the wheelchair, is a good day.

The better days are when I have the energy to last all day without falling asleep in the middle of the day, actually get projects complete around here. Being able to (half-way) think once again, having a 'memory' once again, balance, bladder control, no more shakes/tremors, a general 'lessening' of most symptoms to the point that most of them are easily tolerated or ignored altogether, is absolutely wonderful and more than I ever expected. It's nice to be able to stand for more than a couple of minutes without having to sit down, because the legs are starting to wobble, or tingle and going numb. And if they go numb, I fall.

I have pushed myself too hard on occasion, and have paid for it, but not like in the past. No more knives in the backs of the thighs, arms, back, or elsewhere. No more electric type shock sensation, no more Intense burning over half the body – very mild now. If only ... if only I had been guided to the LDN website earlier, had been given LDN information and the option to try LDN medication in the beginning, probably would not have (maybe?/maybe not?) ANY lingering symptoms as I have now.

I'll happily settle for what I've regained as opposed to what 'could have been' because I was lucky. I found LDN and had the courage to try LDN before I got even worse. What if I hadn't? I know many have given coffee away, but I still drink maybe 4-6 cups of coffee in the morning. Two years, no ... I repeat … NO relapses, no flu, no colds, no pneumonia, no more migraines, no more 'Sorry honey, I"VE got a headache' <grin> and I really believe, NO progression. To ALL the newbies joining the group, and people I haven't had the chance to meet yet in the group … Welcome, and hang in there. Listen to the 'old-timers' as they've been around a little while, and just want to help you if they possibly can, plus from what I've been reading, some of the newbies are pretty sharp themselves and have done some homework.

There is a wealth of information to be harvested here, and information to share that is available to all of us. Sharing is important – when you've been helped, it's your turn to help others. All we have to do is 'post' a question and someone who has information, answers ... hmmm duhh ... if I can do this, anyone can. <grin> Lot of sharp people there, and they want to help.

To anyone out there still sitting on the fence as I once was ... read all you can about LDN, both the pros and the cons on it. One thing I did that you might try ... ask if you can e-mail a couple of people off the message board (private), get their story, ask if you can call them up, or ask if they can call you. Talk to them "in person" so you get up front and personal. For me, it changed the whole way I thought about it. Figured it couldn't hurt, so why not, take a leap of faith, and maybe, just maybe, it might help. For me, it did. Hopefully for you, it will also.

Hope this makes sense to 'someone' out there, hmmm, guess I'm sicker than I thought, as it's starting to make sense to me. Hahaha Time to go before this becomes another book, so off to my "Cave!" Take care, have a Great Day!

UPDATE January 2006

Preamble: My story is lengthy because it's important for readers to understand what MS patient's experience, and why we need LDN clinical trials.

The bigger picture - the health system - has many limitations. If it didn't, my first two years after diagnosis may have been very different for me and my family. Did I suffer unnecessarily? I don't know - but I do know it's important for those who are in positions where they can actually DO SOMETHING to IMPROVE the system to understand what sufferers experience and why the system needs to be improved.

UPDATE August, 2007

Just checking in to say life is pretty decent once again. :-) June 11th was 3 1/2 years on LDN. Life changed literally overnight. From the pit of despair, having to use a wheelchair, cane, or the walls to remain upright, to being able to walk again without needing any of the aforementioned as aides.

I count myself among the blessed that have received an 'almost' complete turn-around of symptoms. Three real challenges remain - extreme fatigue, weakness, and heat intolerance. I still have my 'moments' when things aren't quite right. Some of the symptoms raise their ugly heads and make a brief re-appearance to let me know they have not gone away completely...just laying in wait...no biggee...been here before and now know they are only temporary. Thing is NOT to freak out...just to RIDE it out and all quiets down again.

I find that if I stay up and moving, keeping the mind active and the hands busy, I can ward off the fatigue most of the time, and some exercise and lifting weights just to keep 'toned up' help with the strength. So far, the only thing that really combats the heat is remaining indoors under the air-conditioning unit - sigh.

It does help to wear a neckerchief with the 'crystals?' that absorb water and puff up, after it's been in the refrigerator to chill. Using a bottle 'mister' that you pump up and spray, plus a small hand held portable fan. They all help 'some' but as with anything, they do have their limits. Keeping stress out of my life (much as possible) has been a help. I do remain optimistic that I 'may' improve some more...just have to keep working at the lifestyle changes.

We (wife and I) are planning on attending the next LDN conference in Nashville, TN, and hope to meet some of the people we've been in contact with via the LDN discussion group and phone calls. I don't post much anymore as there are now a lot of people to help the newbies but I still help behind the scenes. All we can do is tell our story and let those who are thinking about trying LDN get all the information they can, and make up their own minds about it.

I still try to talk to at least one person a day about LDN. Good news is; after 3 1/2 years there are now 4 doctors in town that will prescribe LDN, another two are located 10 miles south and an hour north of us. 20 people I know personally are taking it here and they've told others who are now taking LDN. This has taken on a life of it's own!!!

We are anxiously awaiting the results of the UCLA LDN clinical trials, and as soon as we hear anything I'm taking plenty of copies of the information to my doctor so he can pass it out to other doctors he's knows.

UPDATE July, 2008

My My...time really does fly. Here it is, almost 4 1/2 years later, after starting on a 'new' (old) therapy for MS. For me, one that has worked very well and not like the 'traditional' therapies that did not work me.

Unlike the 'traditional' therapies, there are no flu-like symptoms, no nausea, no aches and pains, no cold chills, no night sweats, no headaches, no sick feeling every other day. Basically, no side effects for me, at all.

Still Hangin' in there. No progression noted. Symptom reversal still remains pretty much the same, but I still have the ups & downs but that is to be expected. I still suffer from extreme fatigue at times, weakness, and severe heat intolerance, but, I am working to improve these 'challenges' a little at a time and finding ways to overcome them to some degree. Better than before, but not great, sigh.

What I have to give thanks for are the appearance of, 'reversal' of symptoms. Strength is a little better since I've started doing some more exercise, and diet, now that I've taken the time to regroup, reorganize my thoughts on my eating patterns, is improving. Weight loss is still an issue but one that is 'my cross to bear' at this time but slowly improving too.

I take my vitamins throughout the day. Now I do the 'juicing' which has become a favorite. I eat fruits & vegetables and stay away from the dairy as much as possible. All in all, I eat much 'healthier' than previously, spend less time in front of the TV, and more time up and about, looking for things to do that will

occupy my time as the energy permits – and I stay away from stress if at all possible. I've 'finally' learned to calm down, and not be such an "A" type of person. For me, it was really stressful. Now, I'm 'laid back' and enjoying life more.

General overall Health: Pretty decent. At times, or brief periods, I can "almost" forget I have MS. "Almost."

For Zil: It all goes back to what a friend said..."Never Give Up!" "Never Surrender!"

Sooo, with that in mind, I start my day.

For you, and anyone who may read this...Have a Great Day!

UPDATE June 11, 2009 (5.5 years on LDN)

June 11th of 2009. 5½ years on LDN. No further progression that we've noted. Still bothered by the extreme fatigue and the weakness that accompanies it. Have learned that exercise is key. Keeps you going The only other thing that really bothers me is the heat. When home and not out RVing somewhere, we/I keep the house temperature (air-conditioning) set between 74-76 degrees. Imagine the electric bill. Sigh.

All in all, I'm still doing pretty well. Got out of the exercise mode for a little while and noticed that it is a little harder to get started again. Point seems to be.... NOT to get out of the exercise mode. Stick with it and it sticks with me. Yeah, I'm hard-headed, but learning? Guess that means I'm still 'teachable.' (I hope.) Grin.

I still maintain that 'I' believe LDN has stopped my progression. For me, this is my drug/medication of choice, and I will NOT take anything else until they come up with something better, with little or no side effects the same as this. A cure sure would be nice, but until then...there's LDN!

UPDATE April/June 2010 (over 6years on LDN)

Most of January was spent in Arizona with my wife's parents...then home in February… a very bad month...our son died on February 6 and we've been dealing with all of the issues as they come up. He left behind a wife, and two darling girls...sigh...we're all slowly picking up the pieces and we're trying to move forward. Time...just need to give it time...

I don't have a computer at the moment, so I'll check back at a later date. With all this stress, I've been expecting a major exacerbation, but none...Thank God for LDN!

I haven't taken my usual vitamins since February, but will be starting them again soon.

I joined a 5-year Vitamin D study over 6 months ago and I have my blood tested every six months: www.grassrootshealth.net 'D* Action is the name of it.

I supplement with 2000units of Vitamin D3, 3 times a day and I've upped my pro-biotic to 2 capsules, 3 times a day. I also take an Iodine tablet once a day. A 150-pound person needs 6000 units of Vitamin D3. There's a formula on the site for your weight or how to find out how much you need.

I've raised my Vitamin D levels from 19 to 65. According to the 'D* Action group, I'm supposed to be between 40-60ng per liter. According to my Kinesiologist the target for me is 80-100, which he believes would be better for me. 200ng per liter is considered toxic.

Vitamin D deficiency is linked with being a contributor to cancer and autoimmune challenges. Also, the very 'BEST' time to synthesize the vitamin from the sun is between the hours of 10am and 2pm depending on the time of year.

Basically it's when the sun is directly overhead and you cast a very small shadow. Only 20 to 30 minutes is all that's needed if memory serves me correctly. Your skin being the largest organ of the body, you should try to get as much skin exposed as possible for that short period of time.

Sun block is a 'no-no'. You don't need it. There's even some writings that it may promote cancer. Go figure?

Yes this flies in the face of convention as most say the sun is bad. Bull soup, that's a fallacy and scare tactic. Then again, it depends on 'what' you're reading and whom you choose to believe. So far, it's working very

good for me. WE (MS'ers) NEED to exercise more, watch what we eat, and be more involved in our own health, not leave it all up to the doctors. We are the ones with the 'vested' interest. Read, learn, read more even when we don't feel like it. Talking to the choir I know, but too many whole heartedly trust their doctors.

I trust them only so much. Seeing a neurologist every 6 months or a year... why? Have they come up with a cure? Or, do they just want to try a 'different' medication on us?

(Cap'n Caveman & Wo-man)
Jim, USA

MY RECOMMENDED READING:
To any and all who don't know there are a few books you might be interested in checking out...

1) '20 Years And STILL Coping and Prevailing' (with MS) by Thomas Bayuk
2) 'The Things We Don't Talk About...OR....You Better Smile Through The Tears' (also) by Thomas Bayuk
3) 'Up the Creek with a Paddle' by Mary Anne Boyle Bradley

MY RECOMMENDED SITES:
ldninfo.org & lowdosenaltrexone.org
remedyfind.com

Jim, USA

"Cured??? Not hardly, but I will say again, my 'worst' day taking LDN is by far and away much, much better than my 'best' day on the injections." Dec '05

"5½ years on LDN. No further progression that we've noted. Still bothered by the extreme fatigue and the weakness that accompanies it. Have learned that exercise is key. … I will NOT take anything else until they come up with something better, with little or no side effects the same as this." Jun '09

2 Until there's a cure there's LDN – Carol

LDN since Sept 2002
- story submitted July 2006
- updated August 2007
- updated July 2008
- unable to obtain a 2009 update
- updated May 2010 (over 7.5yrs on LDN)

SPECIFICS

DIAGNOSED
- Jun 1999 – Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)
- 1999 to Sept 2002 - Avonex, then Copaxone, then Beta-Seron; Prednisone; 10mg Baclofen x twice per day
- 1999 to Sept 2002 – Topamax 100mg
(NB I started on Topamax after I had 3 seizures, 2 of which were in a Walmart Store in Florida in 2003. My Neuro felt it was due to my MS and the store lighting.)

MEDICATION (post LDN)
- Sept 2002 to May 2006 - Topamax 100mg
(NB I stopped taking Topamax in May 2006 because after a few years on LDN I felt so much better and hadn't had a seizure in years. I'm prepared to go back on Topamax, if necessary, but am hoping that won't be the case.)
- Sept 2002 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone between 10pm and 2am each day
c) Type – Compounded capsules with pure Naltrexone powder and Avicel filler.

SUPPLEMENTS
- July 2007 - I take the following:
Multi Vitamin x 1 daily
Fish Oil tablet x 1 daily
- May 2008 to present - I take the following:
Vitamin D x 1 daily
Multi Vitamin x 1 daily
Fish Oil x 1 daily

DIET
– July 2007 - Always been careful - fresh vegetables, fruits, chicken, fresh fish, whole grains - rarely eat red meat, and limit my dairy, white flour, refined sugar intake - occasional sweets.
- May 2008 to present - I have the same eating habits as I've always had. Fresh vegetables and fruits, very little red meat, a lot of chicken and fish, whole grains, occasional sweets, but I do limit my dairy, sugar and white flour intake.

EXERCISE & INTERESTS
- LDN has helped me get more exercise. I take slow walks.

MY STORY

My name is Carol. I am 49 years of age, and I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in June of 1999. When I received the results of my final test (spinal tap) and was told of the ABC's (an acronym for the first initials of MS drugs, also known as CRABS) I had to chose from (none of which sounded good to me) I told my Neurologist from the very beginning … "I Will find something better".

I was immediately prescribed Avonex and remained on it for 2 yrs, along with a handful of pills each day to help with fatigue, loss of sleep, and spasms. The stress alone of having to inject myself with an intramuscular shot once a week was a horror. Dealing with the side effects was just as bad. But I did have hopes the Avonex would help me.

I found myself going into extremely bad relapses (every 3-4 months), which kept me from walking for sometimes up to 6 weeks at a time. Along with each relapse came the steroid IV treatments, followed by 13 days of weening off with Prednisone pills. This DID NOT make me happy, nor did it make me any better.

My Neurologist, finally, decided to try me on Copaxone. Injecting myself every day led to more stress and I found myself having extremely bad side effects. After two months of extreme side effects, I realized I was allergic to it and again changed my therapy.

I moved on to Beta-Seron - every other day injections - still hoping I would find some relief and start slowing the progression but around this time I started using a cane to get around and found my health and life was changing dramatically - for the worse - as time passed.

The relapses didn't stop although they weren't hitting me quite as often, but my symptoms were definitely worsening and my health deteriorating. I was 'In search of' something better, something that was actually going to HELP or STOP my MS before the rest of my body was destroyed.

That's when I heard about Dr. Bihari and Low Dose Naltrexone (LDN) from a friend who also has MS.

I immediately made a call to Dr. Bihari's office and set my appointment with him for a month later. During that time I stopped all my medications, injections included, to rid my body of all other chemicals. I wanted to start the LDN with nothing else in my system so I would know EXACTLY what, if anything, it was doing for me.

I did however, let my Neurologist know what my intentions were and showed him all the printed information I had on LDN. I told him I respected his opinions but that it was MY body, and as I was the one with MS I should be able to make MY own decision on how to treat it. He was not impressed because LDN is not yet FDA approved for MS, but I stood my ground.

On September 9th, 2002 I met with Dr. Bihari in NY. I lived in Florida at the time but I would have travelled from anywhere. Dr Bihari prescribed LDN and I started my first dose of 4.5 mg Naltrexone capsules the same night.

On the second day after starting LDN I woke up without spasms. I was convinced it was too soon to be the LDN and was thinking it was 'just a coincidence'. By the third day I was feeling strong enough to walk along the beach - something I had NOT been able to do in the three years since my MS diagnosis, and certainly not with any of the previous drugs I'd been prescribed. I walked a good 3 blocks in the sand ... I couldn't believe it!! I was elated and by now convinced LDN was already having an effect.

Nothing happened quickly, but as time progressed I noticed small incremental improvements – gradually increasing body strength, more clarity, less spasms, less numbness and tingling, fewer headaches - and my sleep pattern was getting better.

I have been on the LDN for almost 4 yrs now, and will NEVER stop taking it.

My life has Quality again now - something I feared I'd lost forever. I won't sit here and say I don't have some down days - I still have MS after all! But, my days are mine again. They belong to me now, not the MS - and I'm feeling stronger than I have in years. I no longer use my cane unless it's for extremely long distances and this pleases me immensely.

I haven't had one relapse since starting LDN. LDN has STOPPED my MS progression - not just SLOWED it down like the other therapies I've used. I don't have to worry about side effects either – another reason I wasn't worried about trying LDN.

I'm a true believer in LDN and here's why: After starting on LDN I had an MRI (in 2003). It showed that my (4) "lesions are healing themselves". Those words came from my Neuro when he showed me the films and I couldn't see the lesions any longer. Yes, they were Prominent, and now only one small spot is visible.

I asked my Neurologist if he was still questioning the benefits of LDN after seeing the wonderful improvement: His cautious reply was … "Don't stop doing what you're doing" … yet he still will not write a prescription for LDN. My last words to him were, "Shame on you for not sharing this with the rest of your patients".

After moving back to NY I made an appointment with a new Neuro - and that's a whole other story!! Let's just say 'she was shocked' by my MRI results. In the past 4 years (since starting LDN) there has been no progression.

There she was - telling me my lesions HAD to be multiplying - and that IF my results showed more lesions, she wanted me to consider going back on the injections – and she added that if I didn't go back she wouldn't take me on as a patient! Needless to say I left her office with a copy of my MRI report and told her I'm doing what is BEST for MY body and I now had to decide whether or not I wanted HER as my Neuro!

I was diagnosed with Lobular Breast Cancer in February 2006. It was my first Mammogram (wrong on my part to have waited so long). It turned out to be Pre-Cancerous but I still had to have the tumor removed. In my heart I honestly believe this could have resulted in a very different outcome - a horror story. I believe taking the LDN has kept it at bay, kept it from growing. I turned down the hormone therapies (which I found out can cause Cervical or Uterine Cancer) and am sticking to my LDN.

I hope all doctors will take notice of this wonderful treatment option - that the major media will finally acknowledge LDN - that LDN clinical trials for MS and other diseases will happen and will prove LDN to be an effective and economical treatment - and that the FDA will approve it - so everyone suffering from this and other Auto Immune System Diseases will be able to benefit from it.

UPDATE July 2007

I'm happy to say.... LDN has NOT stopped working for me! I'm still quite content with how I've been doing since this time last year. June was my 8th anniversary of being diagnosed and this September will be 5 yrs on LDN. I truly haven't experienced too many changes, other than slowing down a bit more. (I did just turn 50!!)

My legs get a little more worn out than they did a year ago, and I've had a few minor flare-ups - but no relapses, and nothing major like before LDN. I have an appointment with a new Neuro this month. I'm sure that will be interesting! I plan on taking all my info on LDN with me, along with my MRI films for the past 8 yrs (those of which have no changes in them) and see how that goes. I love knowing that I can help others in some way when it comes to my experiences with LDN.

I AM a BELIEVER

UPDATE: September 2007

Imagine this ... I don't know how many of you remember my experience with a Neuro 2 years ago who told me she "couldn't take me on as a patient" because I didn't follow the "Normal Protocol" for MS. Back then, after comparing my new MRI with the one from 2 years prior, she was "amazed" at the fact that it hadn't changed - but - still didn't believe it had anything to do with LDN.

I told her "I couldn't take HER on as my Neuro". I waited another 2 years, found another Neuro (in the hopes of him believing in LDN) and requested another MRI ... just to satisfy my own curiosity again.

Well I went for my MRI's - he did 3 - brain, upper and lower spine. He also did extensive blood work to test me for Lyme Disease, etc. They all came back negative and the MRI revealed ... NO CHANGE!

This doctor couldn't believe that I have MS, telling me that I "MAY HAVE HAD MS". I almost fell off my chair! "COULD HAVE HAD??" I wasn't aware MS could just "GO AWAY!" Now, this doctor has 5 years of my past records which clearly state that I was diagnosed with RRMS in 1999 by a spinal tap and also that I, for 3 years, was going into relapses every 4 months and using a cane to get around.

He is fully aware that I still have MS Symptoms that I have been dealing with for the past 8 years and is also aware that I have not relapsed since starting LDN 5 years ago.

He REFUSES to believe in LDN, even after I told him that "I am PROOF" that it has definitely STOPPED my progression. He brushed the comment off, telling me he wanted to do another Spinal because he believes I was "mis-diagnosed" - because I am NOT progressing and he thinks what I have is Clinically Isolated Syndrome! Isolated: meaning ONE RELAPSE and being diagnosed too quickly after that (again, 'he has my records').

CIS can "turn into MS later on," he said. I think I am 'beyond' that point! Needless to say, I left his office extremely frustrated. It amazes me that doctors refuse to acknowledge the good LDN is doing for so

many MSers. I left, telling him how sad it is to me that he can't see 'Outside-the-Box', and, that I believe HE should look further into LDN for the sake of his patients.

I also told him that I WILL NOT go for another Spinal just to prove to him that I wasn't mis-diagnosed and that I didn't go to him seeking a diagnosis to begin with.

One day, things will change. I have high hopes for that. Doctors will one day become knowledgeable in the benefits of LDN, and more people with MS will be given the choice and opportunity to start a medication with such Positive Results. I suppose in another 2 years I'll find yet another Neuro to have another MRI done to satisfy my curiosity.

I won't stop looking for a Neuro who'll believe in LDN. I figure it's like this … if I keep finding Neuro's who don't believe in it, I'm at least introducing it to them. And I KNOW that when I leave their offices...leaving a folder behind with ALL the information on LDN, they are left with the evidence if they choose to explore it! Just thought I'd share this with all of you!

UPDATE July 2008 – almost 6 years on LDN

I am still benefiting from LDN. I can't imagine a day without it! And, may I add, that I am extremely pleased to have been asked again to have 'My Story' added to this year's book. I can only hope that someone finds it helpful in their fight against MS.

UPDATE 2009

NB Unable to obtain an update in time for publication, August 2009.

UPDATE: May 2010 – over 7.5yrs on LDN

I missed last year's update due to a LOT going on. Things are just now starting to settle down.

I'm doing okay, though feeling a bit more tired than usual (might be stress!).

As for the MS, everything is pretty much the same as my last update (not sure if you still need it or not!). I'm still on my 4.5mg LDN, Fish Oil, Vitamin D, and a daily Multi Vitamin as well.

I continue to eat a well balanced diet and walk daily. I have noticed that my flair up's have shown up a bit more often. During those times my legs get weaker, and my walking distance shortens due to pain. But, I continue on!

April 20th was 11 yrs. since my diagnosis, and personally, I think I'm doing Pretty Good!!!

I still don't have a Neurologist, so I'm basically taking care of myself. I've been extremely discouraged for the past 5 years and since moving back to New York. Trying to find a local doctor that is open-minded enough to see past the textbook is extremely difficult!

I got tired of hearing nothing but negative responses about LDN. I was actually told at my last doctor visit that I'm not "Medicating myself" (well, not in the way they want).

I've even had a Neurologist go as far as telling me he didn't think I had MS and wanted to "Re-do" my Spinal Tap. UNBELIEVABLE! So, I pretty much keep to myself with my MS and continue doing what I chose to do, and that's My LDN!

I'm healthy, I'm walking, and I'm happy! What more could I ask for??

"Until There's A Cure...There's LDN" is my quote… and I Live by it!

God Bless
Carol

Carol, USA

"I love knowing that I can help others in some way when it comes to my experiences with LDN.

Until there's a cure, there's LDN." Carol Jul '06

3 Out of wheelchair under a week – Scott

LDN since July 2004
- story submitted May 2005
- story updated Jan 2006
- story updated May 2006
- story updated July 2007
- story updated July 2008
- story updated July 2009
- story updated Jan 2010 (5.5yrs on LDN)

SPECIFICS

DIAGNOSED
- Oct 2001 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)
- Jan 2002 to Apr 2004 - Avonex
- Apr 2004 to July 2004 - Rebif

MEDICATION (post LDN)
- Jul 2004 to Aug 2004 – 3mg Low Dose Naltrexone (LDN)
- Aug 2004 to present – 4.5mg Low Dose Naltrexone (LDN)

DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone at 11pm each day
c) Type - My Naltrexone capsules contain pure Naltrexone powder with Avicel filler.

DIET
- Jan 2004 to present - Swank diet (stopped for 1 month during 2008-2009 with noticeable adverse changes, so recommenced immediately after)

SUPPLEMENTS
- July 2008 to July 2009 – Tried but stopped Valerian Root
- July 2008 to present - This is my complete current list:
B-12 sublingual Multi-Vitamin
Vitamin A
Vitamin B complex
Vitamin C
Vitamin E
Folic Acid
Ginkgo Biloba
Vitamin D
Calcium
Fish Oil
Magnesium

EXERCISE & PHYSICAL THERAPY
- 2007 - aqua therapy at the YMCA three times a week plus exercising at home three days a week
- Jun 2008 - aqua therapy, exercising at home, physical therapy instead of YMCA
- Jul 2009 - Everything is fine. There have just been a few changes (nothing bad). I no longer take the Valerian Root, attend YMCA swim classes, or do physical therapy. Instead, I do several exercises at home (including mowing my grass with a self-propelled mower.
- Jan 2010 – I'm still doing several exercises at home and mowing my grass with a self-propelled mower. I got some leg weights for Christmas 2009, so I've been walking with them 3 days a week as well.

MY STORY

My Quest for LDN - May 2005

Hi, I'm in my early thirties and was diagnosed in October 2001 with Relapsing Remitting MS. I had slurred speech that went away before the diagnosis. I felt all right in 2002 and then in mid 2003 I began to have problems.

In January of 2004 I was laid off from my job because of poor balance, bladder problems, deteriorating vision, and poor handwriting. In March of 2004 I began to use a wheelchair due to leg weakness.

I began to read everything I could on what helped others with MS. I found Remedyfind.com. I read about Low Dose Naltrexone (LDN). What was this? The more I read the more I liked the idea.

I asked my doctor about it and without batting an eyelash she said "NO! It's horrible stuff." Why was I told 'no' so quickly without a discussion? Many people were on this medication and it was working well for them. I thought I deserved more than a simple "no".

I found another doctor who would prescribe it and began LDN on 23 July 2004. Within two weeks my muscle spasms went. My bladder urgency was the same but I could deal with that, as my other symptoms were getting better. Within a few days I was out of my wheelchair (I was in it for five months) although I was using the walls to aid my walking.

Ten months later, I mow my own grass. I still have balance problems and muscle spasms but they are not as bad as they were. My 'brain fog' has gone completely. The problems I have with my vision have lessened and I plan on seeing an ophthalmologist. My eyes are stopping me from driving. I use a pedometer to track how much walking I do each day. I tend to walk about 2 to 2.5 miles a day, I also exercise 3 times a week to help keep up my strength. LDN has given me my life back.

UPDATE January 2006

First I'll relate a little more history to help you understand why I was happy to try LDN and why I continue to take LDN. I'm in my early thirties and was diagnosed with Relapsing-Remitting MS in October of 2001. I was on Avonex and Rebif (two of the CRAB drugs) for over two years. I quickly deteriorated, particularly toward the end of that time - winding up in a wheelchair for 5 months, and 'legally blind' for 18 months.

Three months into my wheel chair nightmare (around May 2004) I was surfing the internet (which was frustratingly difficult with my now severely deteriorated vision) and stumbled across information on a drug called Naltrexone. It appeared other MS sufferers were having success with the drug. As my condition had deteriorated on the CRAB drugs, I was tempted to try Naltrexone but concerned it wasn't a mainstream treatment. It's wise to be cautious so I read everything I could find. It took me two months to decide and to find a doctor who would prescribe Naltrexone.

In July 2004 I stopped taking the CRABS completely and started taking low doses of Naltrexone (LDN). In less than a week I was out of the wheelchair yet still using the walls to walk and balance myself. Being determined, I began to exercise at home. I was soon able to stand-up whilst showering. You can imagine how elevated I felt after noticing improvement so soon after starting on LDN.

In January 2004 I had started on the Swank diet, supplemented by a strict vitamin regimen. I kept up this regimen after starting on LDN and I still use this regimen because I've noticed I just feel better all-round. I am writing this in January 2006 after 18 months on LDN. I mow my own grass with a self-propelled mower and my vision impairment has improved enough that I have just been approved to drive during daylight hours! I attend aqua therapy at the YMCA three times a week while exercising at home another three days during the week. I live alone and perform my own housework. I anticipate that in mid-summer I will start physical therapy.

Overall, I do very well managing the symptoms with the LDN. I can still have a bad day but my worst day now is much better than my best day pre-LDN. During this entire time since my diagnosis, I have maintained the attitude that I would rather try and fail 1,000 times than never try at all. I am so thankful that I got off the CRABS and started LDN.

To any and all people that are still researching LDN for their condition, I urge you to go ahead and start it now while continuing your research because I've noticed the majority of individuals who post to the LDN forum (with MS or other conditions) regret not starting on LDN sooner.

UPDATE May 2006

I added Magnesium to my supplement regimen in April 2006. Within 5 or 6 days it made my legs feel very heavy, like walking thru knee-deep mud, and I was doing the wall walking thing again. At first I wasn't sure

what had caused the change. I had been taking 800 mgs Magnesium at the time, so I tried reducing it to 400 mgs. The improvement was almost immediate and I felt a lot better. Having said that, I continue taking 400 mgs Magnesium because I think it has helped with my muscle spasms. I haven't changed anything else - LDN treatment, Swank diet, exercise, and supplements remain the same.

For the past 2.5 years (that's right I said years) I had not been able to drive. However, my eyes have improved gradually and I got the BMV's approval - so I am driving again! I am soooo happy because I'd been relying on others to drive me places. I only went to the grocery store once a month because that was the only time someone could take me – it was too far to walk safely and manage grocery bags. I used to sit alone in my house a lot.

I tell ya ... now that I have a car and drive myself places (and even though I'm restricted to daytime driving only) no one will be able to wipe this smile off my face. My eyes had improved gradually with time - until the point I suspected I'd be able to pass the test so I went to see a doctor the BMV recommended.

What do I attribute this particular improvement to? I honestly don't know. It could be due to one thing or a progressive improvement due to my complete regimen. Because I can't attribute my improvement to any one thing, I don't want to raise any false hopes.

UPDATE July 2007

Now a year later it is time for my 3-year update. There have not been many changes in the last year. I did, however, miss two weeks of LDN (due to 2 surgeries). Also, because of the surgeries I had to miss approximately 2 months of aqua therapy. Due to these 2 factors my health declined slightly. I now have poor balance and use a cane more than I did before.

Aside from that I don't have anything negative to say. I can say the lack of exacerbation is still a positive. I'm still driving (though not a lot and always nervously) and still living alone keeping my independence. I've tried several times to get my neurologist to write a prescription for LDN, but his only compromise was that he'd write a prescription for LDN if and only if I would take Copaxone as well. Needless to say I said 'no thanks'.

I did show him the LDN conference DVD. I also asked how he could explain me getting better on LDN. His response was; "That's just MS". I'm going to be looking for a new doctor (doctor number 5) very soon. I believe all of my improvements are directly a result of using LDN religiously. I will continue to use it until someone finds a cure for MS. As another has said; "until there is a cure there is LDN." Period.

UPDATE July 2008

No change to report. I still take LDN and it's still working for me. I still go to the YMCA for aqua therapy however, for the summer session I will not be going as I will be focusing on mowing my grass. That may not sound much, but it takes about a week to mow it (when I first bought this house 10 years ago it took an hour). I cannot do both the aqua therapy and mowing the grass. I think it will be good because I will get more exercise done.

UPDATE July 2009 – 5yrs on LDN

Everything is fine. There have just been a few changes (nothing bad). I no longer take the Valerian Root, attend YMCA swim classes, or do physical therapy. Instead, I do several exercises at home (including mowing my grass with a self-propelled mower.

I still take my LDN every night, and I've proven, at least to myself, that my diet is as important as my LDN. During the past year I stopped following the Dr Swank diet for a month and my health started to slide noticeably downhill (others noticed it as well). After I returned to the Swank Diet the following month I regained my losses, thank goodness. My sleep pattern is still good. I sleep approximately 8-9 hours a night.

UPDATE - January 2010

Not much has changed.

I still take 4.5mg LDN nightly.

I also still take all the vitamins and am on the Dr Swank diet.

I got some leg weights for Christmas and I've been walking with them 3 days a week.

Scott, USA

Scott, USA

"I asked my doctor about it and without batting an eyelash she said, "NO! It's horrible stuff." Why was I told 'no' so quickly without a discussion?" May '05

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

4 MS, but walking & driving my car again – Bill

LDN since July 2005
- story submitted March 2006
- story updated - August 2006
- story updated – July 2007
- story updated – July 2008
- story updated – July 2009
- story updated – Feb 2010
- story updated – August 2010 (5yrs on LDN)

SPECIFICS:

DIAGNOSED
- 1998 - Relapsing Remitting Multiple Sclerosis (RRMS)
- 2002 - Secondary Progressive Multiple Sclerosis (SPMS)

MEDICATION (pre LDN)
- Feb 1998 to Aug 2001 - Avonex
- Feb 1999 to Feb 2000 - Copaxone AND Avonex taken together
- Mar 2002 to June 2005 - Rebif
- Sept,2001 to Feb 2002 – Cytoxan (chemotherapy)
- Aug 2001 plasma exchange for eleven days (first infusion was in June, 1998)
- 2001 to 2005 - multiple infusions of Solumedrol IV steroids (at least four infusions a year before LDN)
- Gabapentin (Neurontin) x 3 per day 300mg
- Clonazepam (Klonopin) x 1 at bedtime 1mg
- Effexor XR x 1 twice per day 37.5mg
- Aricept x 1 a day 10mg
- Provigil x 1 a day 100mg
- Flomax x 1 a day 0.4mg
- Singulair x 1 a day 10mg
- Baclofen x 3 per day 10mg
- Potassium CL 10 MEQ CAP x 1 a day 10 MEQ CAP
- Furosemide (Lasix) x 1 a day 40mg

MEDICATION (post LDN)
- Jul 2005 to present – 3mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose – July 2005 - 1.5mg for 1 week, then 3mg thereafter. I stopped taking Rebif at the same time.
b) Time - I take the Naltrexone between 10pm and 2am each day
c) Type – Compounded capsules with pure naltrexone powder and Avicel filler.

MEDICATION OTHER (post LDN)
- Jul 2005 to present - 10mg of baclofen, twice a day

SUPPLEMENTS
PAST
- to Jul 2005 Multi-Vitamin x 1 per day
- to Jul 2005 Vitamin B-1 x 1 per day
- Dec 2008 to May 2009 – 1000iu x D3 per day
- May 2009 to Feb 2010 – 2000iu x D3 per day

PRESENT
- Jul 2008 to present - one multiple vitamin x 1 per day
- Sep 2009 to present- Alpha Lipoic Acid - 200mg daily

DIET
– March 2006 to 2009 - average, no particular diet
- July 2009 to present - I have been 'taste-testing' peas, beans, squash, okra, tomatoes, eggplant, cucumbers, cabbage, collards, and corn, and drinking GALLONS of water.

EXERCISE & INTERESTS
- 2006 to 2009 - walking, lifting light weights, and abdominal exercises, landscaping, President of Local Beautification Council, Member of Local Tree Commission
- July 2009 to present - I am spending a great deal of time working and sweating in the community garden. :-) I have also lost about twenty-five pounds in that garden. I want to lose about twenty more by summer's end.

MY STORY

I am in my mid fifties. I was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in 1998, and upgraded to Secondary Progressive (SPMS) in 2002. My chief symptoms are (were) extreme mixed sleep apnoea, chronic obstructive pulmonary disease (COPD), inability to walk, total deafness in my left ear, and inability to concentrate for any period of time.

I have been treated with Avonex, Copaxone, and Rebif of the ABCR drugs, chemotherapy (Cytoxan, plasma exchange, as well as many, many sessions of IV steroids (Solumedrol).

As of June, 2005, I was on oxygen 24/7, wheelchair bound, having a flair of my MS on an average of once a month, and doctors had told me that my breathing difficulties, caused by the MS, would ultimately result in my demise.

I had also ballooned in weight to 289 pounds. Two of the top neurologists in Birmingham consulted and agreed that, while continuing on Rebif, I should begin taking a week of IV steroids every three months, regardless of my condition.

I did not feel that the steroids were offering enough positive results any longer, and I did not want to take any more. I asked if they would mind my getting an alternate opinion from another neurologist. They agreed.

My new neuro re-ran all of the standard MS tests, including magnetic resonance images (MRIs). After studying the results, she suggested I stay on the Rebif and see what the next two months showed with regard to flares or episodes, then to probably go back on chemotherapy. I asked her, at that time, if she would prescribe a drug therapy I'd read of - Naltrexone - in low doses (LDN). I had read a great deal about LDN and talked to a number of MS sufferers who had improved with the use of LDN. She said she had never prescribed it but had also read a lot about it. She agreed to prescribe it.

I began around the first of July 2005 with 1.5 mg of Naltrexone taken in one dose per day for the first week. I then increased to one 3.0 mg dose per day. I stopped taking the Rebif at the same time.

While I did not notice any symptom improvement for the first three months, I also had NO flares either. But, after around three months I began to notice small improvements - my breathing was improving - I could take time off from the oxygen for extended periods of time - the strength in my legs and arms was improving - I began to be able to take short walks with a walker - then was able to take longer walks - then upgraded from my wheelchair to a cane - then actually walked to the bathroom without assistance! My sleep began to improve as well.

My improvement continued incrementally. When I went for my six-month check-up with my neuro, I did not even take my cane, and I blew away my neuro by ace-ing all the tests. I couldn't drive a car for four years. I am now driving again and I'm walking without any aid or assistance. My weight has dropped to 232 pounds. I hope to get back to my target weight of 195 pounds by year's end.

I attribute my miraculous improvement to LDN, attitude, faith, and my new neurologist's willingness to prescribe LDN for me.

The only real dietary change I have made is to make water my primary liquid of choice.

I recently had surgery for an unrelated problem. I was half expecting to get an MS flare up but am very pleased to say I didn't and recovery is on schedule. After my check-up next week, I'm planning to begin an exercise schedule involving walking, lifting light weights, and abdominal exercises, and I might even get started on some long overdue yard work! I wish to acknowledge and thank Dr Bernard Bihari for his groundbreaking work. Clearly I was on a downhill slide before I learned of his Low Dose Naltrexone (LDN) drug therapy.

I realize that money and profits are the motivation for initiating studies to have LDN approved for treatment of MS, as well as ALS, Alzheimer's, Parkinson's, HIV, AIDS, Cancer, etc. With that in mind, and knowing that the standard treatment for MS, the ABCR drugs, all cost insurance companies and/or patients in excess of $1000.00 per month, I do not understand why insurance companies are not initiating these studies themselves.

© Case Health Pty Ltd

I also do not understand why, if the "Mission Statement" of the National MS Society is to "find a cure for MS," THEY are not funding these studies.

UPDATE July 2007

I continue to do very well on LDN. I cannot know how long my good fortunes in health will continue, so I am trying to make the most of it while I can. I am doing landscape consultation for our city, finishing a backyard landscape project of my own that I began last summer, and I'm doing some landscape design work for a local contractor.

I still talk to people from all over the country about LDN and do volunteer work here, too. By the way, last summer, while working on my backyard, my ladder tipped over, and I badly dislocated my left ring finger. It was in a cast for a couple of months. I built the fence, the pergola, and planted all the shrubs! Though it has taken me much longer than it once would have, I never thought I would be able to undertake such again. I'm planning on attending the conference in Tennessee this October (2007).

UPDATE July 2008

I continue to do well on 3mg of LDN daily. It has been three years since my last exacerbation (before LDN). I still find it hard to believe how much my quality of life has improved because of LDN.

UPDATE July 2009 – 4 years on LDN

I continue to do well on LDN after almost four years. I've added 2000ius of D3 per day. Our community has started a three and a half acre community garden to help those who need food. I have the pleasure of heading up the project and work in the garden an average of five hours per day. To date, we have distributed almost five hundred pounds of fresh vegetables.

I began taking D3 before the first of the year after reading up on it. I began with 1000 IUs and increased to 2000 IUs in May. None of this was based on doctor recommendations...just going with what I feel. As far as high fiber diet, I pretty much eat what I want to. I am spending a great deal of time in the garden, sweating, working, and 'taste-testing' peas, beans, squash, okra, tomatoes, eggplant, cucumbers, cabbage, collards, and corn, and GALLONS of water. :-) I have also lost about twenty-five pounds in that garden. I want to lose about twenty more by summer's end.

While LDN is NOT a cure for MS, it has afforded me the opportunities to do things that I never thought I would be able to do again. One of those opportunities has been to spearhead the community garden here in my home town. Even with the improvements I have experienced through the use of LDN, I was not sure I could endure the rigors involved in working this three and a half acre vegetable garden.

I do have to be careful, take lots of breaks, drink LOTS of water, and 'delegate authority', but I am very proud of what we have accomplished thus far. I owe a large part of my own personal success in the garden to LDN. As of June 29, 2009, we had given away over 600 pounds of vegetables and sold over 250 pounds at a very reduced rate. We expect to double that production by season's end. We are planning to add another acre and a half for next year, PLUS add up to 75 six-by-ten-foot raised garden beds to lease to individuals for their own garden plots. They will lease for $5.00 per year, including drip irrigation and on-site assistance.

This is by no means all 'my' project. The success of this garden has come from the hours and days of hard work by many whose only desire is to help others. LDN has allowed me to join in, too. :-)

UPDATE: February 2010

I am having some numbness and tingling in my legs, and fatigue issues; but I continue to be able to walk without assistance and carry on a relatively busy volunteer program. I'm also President of the local Beautification Council, Tree Commission, and Leadership training program, and Head gardener for our local 3 and 1/2 (soon to be 5!) acre Community Garden.

After hearing of the risks associated with D supplementation, I'm going to stop taking the 2000iu of D-3 for a while to see if it could have been a catalyst for recent adverse health changes.

UPDATE – August 2010 – 5 years on LDN

I'm feeling fine, though it is VERY hot (100+) and humid at present.

The community garden is taking lots of my time and ALL of my energy. We increased the size from three acres to five, added a second building for storage, a greenhouse, and rain collection containers (two x 1000 gallon containers and one x 500 gallon container).

We've built 26 raised bed gardens for individuals to grow their own veggies and are working with county and city school systems to incorporate vegetable gardening into the curriculum. We've had five full-time young people helping, as well as youth groups from three different states. I'm worn out but feel VERY blessed and gratified for the opportunities that LDN has afforded me.

I did stop taking my D3 supplement in February, and though I do still have some tingling and numbness, the degree of tingling, etc. is less. The fatigue part… well, I'm over 60 and I'm out in the VERY hot sun for as much as eight hours a day. I think I'm Supposed to be fatigued.

Still, I'm pretty careful out there: I drink LOTS of water and take cooling breaks as well as midday naps.

Nothing is hurting or causing weakness in my limbs. I just live with it. Also, I do listen to this old body, and that's why I nap for an hour or so at midday, which seems to help a lot. I look at every day as a gift and an opportunity to make a difference for others. The garden is one of those wonderful opportunities.

Bill, USA

Bill, USA

"I was on oxygen 24/7, wheelchair bound, having a flair of my MS on an average of once a month, and doctors had told me that my breathing difficulties, caused by the MS, would ultimately result in my demise." Mar '06

Bill's
Community Garden
Fresh Food Project

"This is what I'm able to do now." Jul '09

5 Improvement was gradual and subtle – Julia

LDN since August 2005
- story submitted November 2005
- story updated August 2007
- story updated July 2008
- story updated March 2009
- story updated July 2010 (5yrs on LDN)

SPECIFICS

DIAGNOSED
- Apr 2005 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)
- none

MEDICATION (post LDN)
- Aug 2005 to Jun 2006 – 3.5mg Low Dose Naltrexone (LDN)

(NB I suffered a relapse between March and June 2006. Initially, I felt the LDN wasn't as effective as it had been and changed to the liquid version. However; the relapse occurred during a particularly stressful period for me (relationship, money, moving house) so that may have been the catalyst.
- Jun 2006 to Nov 2007 – 2.5ml to 3ml (varied) Pre-prepared liquid Low Dose Naltrexone (LDN) from Glasgow
- Nov 2007 to present – 3mg Low Dose Naltrexone (LDN)
- Mar 2009 to Apr 2009 - Gabapentin x 100mg x 3 capsules daily (for neuropathic pain as needed)

MEDICATION (post LDN) - CURRENT
- late 2008 to present – Domperidone x 10mg (anti-nausea med taken as needed for nausea or dizziness caused by vision problems)
- March 2009 to present - Dantrolene 25mg (in place of Baclofen, for spasms and stiffness)
- Nov 2009 to present - Citalopram x 10mg daily (for mood swings)

DOSE & TYPE
a) Dose – 3mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone at bedtime (not earlier than 9pm)
c) Type – capsules compounded with avicel filler from Dicksons

SUPPLEMENTS
- 1 x multivitamin (multibionta or Pharmaton from Supermarket)
- July 2010 – Thinking about starting Vit D before Sept 2010 (will update on this later)

DIET
- nothing special, everything in moderation

EXERCISE
- Nov 2005 to March 2010 - work, everyday activities
- March 2010 to present – not working since March 10 but try to keep mobile as much as possible. Walking the dogs, light gardening and 4 grandchildren keep me busy.

My Story – November 2005

I used to have a great sense of humour, always had my finger in many pies and generally lived life and was rarely still for 10 minutes. Then I got multiple sclerosis. I didn't want to go out, meet people, or do anything. If problems arose, I would hide from them and rather let someone else sort it.....not like me at all. I had to have someone with me everywhere I went. I was afraid of falling, getting lost or confused and several times forgot entirely what I went out for in the beginning. It got so bad I didn't go out for nearly a year.

As my Mum has Relapsing Remitting MS, my diagnosis was expected, so I had a chance to read up on the offered disease modifying drugs (dmd's); Interferon alpha and beta, Copaxone, Avonex, and Rebif; and frankly none appealed to me because of the side effects. Whilst doing some digging, I came across something in the Lancet medical journal which says the dmd's on offer aren't working as expected, etc.

I discussed this with my neurologist when he gave me my diagnosis in April 05 and said I qualified for

Interferon. Although he was surprised I knew about the article in the Lancet, he did discuss it honestly and said taking the Interferon was catch 22 as yes, they knew the dmd's on offer weren't working as was hoped in stopping relapses and further progression of MS. He admitted the success rates weren't as expected when they were first introduced as an option to treat MS.

I said there was no way I was going on Interferon and would look for something myself. I wanted to feel better, not worse. He agreed and I was given 3 months to go away and look for an alternative before going back to see him again.

My search led me to a treatment involving 'low doses of Naltrexone' (LDN). It's a tablet taken at bedtime which works with your own body's natural endorphins. As at 1 November '05, I've been taking LDN for three months.

I've never felt so well. In fact I feel like the old me! I can't begin to describe the difference after nearly 4 years of feeling unwell and a list of over 86 symptoms. Initially, the improvement was gradual and subtle - you were aware something was better but couldn't quite say what or why. Then you think back three months and remember how you were. That's when you realise how much of a difference LDN has made.

Some GP's will prescribe LDN on the NHS in the UK. As for me, my GP and Neuro said a flat 'no', so I just looked 'em in the eye and said I would buy it myself and take it anyway. My neurologist said it was my body and whilst he couldn't agree or disagree with my decision, it was my body and I had to do what I thought was best.

Thank God I ignored the drugs they were trying to get me to take, made my own decision, and went on LDN!! Once I'd made my mind up, I had the tablets within 4 days and noticed an improvement from day one. The only side effects I experienced were a slight worsening of existing symptoms i.e. more leg spasms and restless legs at night, a couple of vivid dreams and constipation for the first week.

My symptoms got worse for about 3 weeks but I was well aware that might happen - I stuck with it - then suddenly the worsening eased off and my symptoms got better. After feeling rough, achy and stiff every morning (almost like I was coming down with the flu), I noticed a change at weeks 3-4. I suddenly felt really good in the afternoon and have stayed pretty much the same since.

I saw the neurologist a month after starting LDN and he asked me if I was the same woman. He was sufficiently impressed to say he would prescribe it on the NHS in future and send my GP a letter telling him he can see its benefits, so the GP should be able to prescribe it. My friends and family have seen the difference too.

I have no horrible mood swings - I am alert, not confused - better humour - better memory - better concentration - better sleep - far less fatigue - from 5 trips to the loo down to none or one - legs are better and they don't ache or twitch so much - shakes in the morning have gone - better appetite - taste has returned. I feel better all round, ready to face the day and not hide. Yes, I still get blips when I've overdone it but I guess I hate wasting all this new found energy - so I only have myself to blame and frankly, I feel its a small price to pay for something that has given me so much back.

UPDATE: August, 2006

I've been taking LDN for one year now. My only update is that I am now on the liquid LDN from Glasgow (month 2) at 2.5ml and have no reason to up that dose, as I'm doing very well on it (I was previously on 3.5mg capsules from Martindales). I changed to liquid because Martindales was taking too long to deliver and was more expensive for the NHS. £93 per 60 tablets compared with around £45 for 3 months from Dicksons in Glasgow.

The last couple of batches of tablets didn't seem to have the same effect but the jury is out on whether it was something to do with the filler. I will probably never know for sure. I find the liquid easier and the 2.5ml suits me well. I vary between 2.5ml - 3ml. It also gets delivered to my door, so no trips back and forth to the chemists, I can just get a repeat over the phone now and have it delivered to my home.

After suffering a relapse from March to early June, I saw the neuro in June 06. The relapse was put down to overdoing things after splitting with a partner, moving house and money worries. The neuro will see me in 6 months then if all is the same (as I was back to the usual me again) I will go onto yearly appointments. I felt

at times that the LDN was trying to pull my system back in line. Some days I felt okay and the next I was awful but gradually I've felt well again and had no problems since. I didn't need to take steroids.

I now have a part-time job, 16 hours per week and am managing that okay. The only downside I can see is that LDN doesn't help with persistent neuropathic pains but overall, I'm very pleased and will continue taking LDN, for the rest of my life if necessary.

If LDN's claim to fame is to stop progression and relapses, then the side benefits are indeed an extra bonus. I would urge anyone to try this drug and give their honest opinion, as honesty is what it's all about. Information on LDN spreads by word of mouth and I would recommend it to anyone.

UPDATE: July, 2007

My LDN carries on being a success. I changed GP's and am at present waiting for the paperwork to catch up from the old surgery, which has the letter from my Neuro saying he is happy for my GP to prescribe it on the NHS. As my new GP hasn't ever prescribed LDN, she feels this is neccessary. Unfortunately for me, my timing was not on the ball and I found myself without LDN for 2 and a half weeks.

The brain fog, fatigue and bowel problems came back, along with a loss of appetite and general off colour feeling. I managed to get an emergency bottle from Dicksons and within 2 days of restarting it, I was back to how I was before. LDN is not a cure all. It helps me in certain areas, mainly bladder (don't have to go every 5 minutes), bowel (keeps me regular and stops diarrhoea), and brain fog (I can think clearly and complete tasks and remember things). I feel up to doing many things with the added energy I believe LDN provides - things I just wouldn't attempt otherwise, such as trips to town and walking the dog.

This year (2007) has been very stressful from the start. I still believe LDN plays a major part in keeping me on an even keel. The two weeks without it, certainly showed me what things would be like if I wasnt taking it. I still have "blips" but remembering what I was like without the LDN certainly makes me wonder what those "blips" would have been like if I'd never started LDN. I would say I'm very happy to be on LDN since Sept 2005 and if I had to pay for it instead of getting it on the NHS, then I would still take LDN without hesitation.

UPDATE: July, 2008

I moved house again in January and my partner moved in with me in May. Lots of work on the house and garden in progress and I had a car accident that wrote the car off in late May.

I've also been trying to set up a new business as a courier, so I have lots going on. Apart from periods of stiffness and fatigue, everything else is great and (fingers crossed) no relapse since 2007. I'm back on the 3mg capsules from Dicksons as it's easier to transport around and my GP is still happy to prescribe it on the NHS.

UPDATE: March, 2009

Well, it's been pretty stressful, what with moving house, partner moving in, losing 5 cats out of the original 10 I had (either going missing or getting poisoned or run over).

I also started a courier business with my partner, mainly to stay home and sort the paperwork side out. If I'd known just how much paperwork, I think I may have thought twice!

Still, it's been up and running for about 4 months now and going well. When I get ahead on the paperwork side (and my daughters are helping me), then I think I may calm down a bit.

In myself health-wise, fatigue is a major problem. I've not got the time to stop and rest like I did before and if I don't I think the fatigue just builds up and then starts causing other problems with symptoms.

On the whole, I've stayed pretty much the same. Mobility is a tad worse, in that I walk slower and not as far. Right side is affected a little more but I'm hoping that when I get the rest I need, that will calm down as well.

I still take one 3mg capsule of LDN per day, and 1 multivitamin per day, but I now have Gabapentin for neuropathic pains at 100mg x 3 capsules per day, but only for a month at a time. That way, when I stop I can see where the pain is at and continue to use if necessary - but not be on it long enough to have to up the dose (as you would have to on long term use). Sometimes I don't need it for months.

I also have a supply of Domperidone 10mg (anti nausea) which I take if and when I feel sick (or for dizzy spells). The nausea is usually eyesight related – if I can't focus or have vision wobbles.

The GP has just started me on Dantrolene 25mg, working up the dose until it's effective (in place of Baclofen, for spasms and stiffness) so can' t really report on that as yet.

I have to say at the moment I'm feeling a tad rubbish which is why I'm on so many tablets.

Hopefully in a month or two I shall be back just on the LDN and multivitamins.

I've always said less is more, so if I don't need them, I wont take them.

I've not had a cold in the last year, even when all the others had the rounds twice. I get a sore throat for a few days then it magically disappears.

To be honest, without the LDN, I firmly believe that there's no way I would be coping with all I have to cope with at the moment, and have had to deal with for the past 8 months.

UPDATE: July 2010 (5yrs on LDN)

I am still taking LDN.

I still notice after forgetting to get my repeat prescription in and not taking it for a week. There's a noticeable decline, more stiffness, brain fog and running to the loo.

Since my last update I've been to a new Neuro. He wasn't as lenient with me taking LDN as my old one was – and without my knowledge or consent, he wrote to my GP "suggesting" she stop prescribing LDN for me. I was outraged!

I told my GP she could stop prescribing LDN if she wanted, but that I would carry on taking it by buying it privately. The next thing I knew I had a new referral to see a different Neuro arrive through the post, so I'm thinking my GP wasn't too impressed with the Neuro's actions either!

Apart from that, I'm trying to stay busy and looking forward to moving house shortly and just getting on with things in general.

I was experiencing mood swings so I was prescribed 10mg Citalopram daily about 8 months ago.

I haven't been working since 10th March, but I still try to keep mobile as much as possible. Walking the dogs, light gardening and caring for 4 grandchildren keeps me busy.

I'm interested in the CCSVI and Vitamin D debates and I'm thinking of starting on Vit D before Autumn. All the rest is still the same.

Julia, UK

Julia, UK

"Initially, the improvement was gradual and subtle – you were aware something was better but couldn't quite say what or why. Then you think back three months and remember how you were. That's when you realise how much of a difference LDN has made." Nov '05

6 LDN allowed me to work with MS – Neil

LDN since May 2004
- story submitted October 2005
- story updated September 2006
- story updated August 2007
- story updated July 2008
- story updated July 2009
- story updated May 2010 (6yrs on LDN)

SPECIFICS

DIAGNOSIS:
- 1989 - Multiple Sclerosis

MEDICATION (pre LDN)
- 1997 - Interferons: I was on them back in 1997 and all they did for me was to make me 10 times worse. Pre-interferons I was a 14 handicapper at golf … post-interferons I was in a wheelchair.

MEDICATION (post LDN)
- May 2004 to present - 4.0 ml Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose – 4ml Low Dose Naltrexone (LDN) liquid preparation
b) Time - nightly, between 10pm and 2am
c) Type - I make up a batch of liquid LDN using 50ml sterile cool water and one 50mg naltrexone tablet. I keep it in the fridge. I shake the bottle well and use a syringe to draw up a 4ml dose once a day.

SUPPLEMENTS
- Jul 2008 - Yoghurt-based probiotic drinks to aid digestion

DIET
- average, nothing strict.
- Jul 2008 - My diet has improved. I've been buying quality meats and vegetables

EXERCISE or INTERESTS
- I was working four days on, four days off (May 1999-May 2007), the rest of the time working at home on the computer = seven days on, so no time for hobbies or interests.

MY STORY – October 2005

This is my story on low-dose naltrexone, I am not the best typist in the world, and I am using a program called Dragon NaturallySpeaking, which is a voice recognition program so I hope everything is okay and please feel free to make any changes.

I read about low-dose naltrexone on the Internet, pre-May 2004. What got my interests up was an article written by an undergraduate, called the unprofitable cure and hating drug companies and doctors, I chose to read it and pay attention to its content. That made me start to look into it with more depth, and I discovered there was no information on it in Australia which made me look even further.

It was by chance that I stumbled onto Dr George O'Neil, the local heroin doctor in Perth, and he distributes naltrexone to the addicts. I was doing a double up in a taxi, with his best friend, and things snowballed from there after I explained LDN to them.

After a meeting with George O'Neill, I decided to start taking LDN as there are no harmful side-effects, and I could see it doing nothing but good for me. After the first dosage I noticed I had greater mobility, less fatigue, better speech, and overall I felt better. The people at work, noticed the immediate change in my abilities to be able to maintain my composure and dexterity better and to do the job with more confidence.

I am classed as an emergency worker in my position, because I control the operations of the Perth tunnel, so my ability to be able to handle pressure is paramount to my ability to be able to do my job. For that reason alone it was worth the gamble to take low-dose naltrexone and see if it helped in any way, which it did.

I was told by a neurologist that I could only work 12 hours a week, which is for me a load of garbage because

I need to continue to work to keep my brain active and my self-esteem. A working week for me encompasses four 12 hours shifts - two days 10 a.m. to 10 p.m., two nights 10 p.m. to 10 a.m. with no breaks - and I have been doing this since day one, 5 1/2 years ago.

I sit at eight computers for 12 hours straight staring at $1 million worth of monitors and watch 90,000 cars per day travel through the 1.6 km of tube. If there is a crash or a disturbance down below, it is up to me to organise what needs to be done, eg; tow trucks, police, ambulance, fire department, RAC or a simple phone call for a motorist; so as you can see low-dose naltrexone, kept me working. I have got to have my wits about me to pick up any discrepancies in the flow of traffic so my brain needs to be in gear and low-dose naltrexone does it for me.

I've been on interferons. I was on them back in 1997 and all they did for me was to make me 10 times worse. Pre-interferons I was a 14 handicapper at golf … post-interferons I was in a wheelchair … thus my hatred of drug companies and my distrust of the medical fraternity.

I saw a neurologist six months ago - the first one I had seen for three years. He had an open-mind to LDN and is looking forward to seeing what improvements LDN has done for me. My original neurologist was so stupid that he once said, "The only problem Neil has is showering so take him out in the back yard and spray him down with a hose.". If I could have walked over to him, I would have broken his jaw. How insensitive can one person be?

I was a very athletic person at 6 foot 2 inches and 14 stone. I've played regular sport all of my life so to get a disease like MS gutted me. Pre-MS I worked in the music industry for 10 years as a roadie. I am now a shell of the man I once was and for me that alone was very hard to stomach, but to have the so-called experts belittle me as well really got my goat up.

According to everyone I know I haven't changed a bit but according to me, I've changed a lot and that was the hardest aspect to get used to. I still haven't come to terms with it but that's probably been fortunate in a way: I didn't 'resign' myself to MS. I rose to the challenge, researched, and found out about LDN.

One of the best things about low-dose naltrexone is the price. At six dollars Australian per tablet (which lasts approximately 2 1/2 weeks) you can afford to continue medication whether it's on the pharmaceutical benefits scheme (PBS) or not. So far as I know I'm the only person here in Perth that uses this medication. If there is anyone else here in Perth using LDN I would love to know and swap notes with them.

The local MS society over here does bugger all to check these things out so I do not even worry about speaking to them about it. It appears too difficult for them to look on the Internet to check it out so I don't trust them at all. While on the price of drugs, it costs approximately $1000 Australian per month (Oct 05) for someone to be on interferons for which they get the luxury of sticking a needle in themselves once every two days. I'm no expert, but doing the math it makes sense to me to go with the cheaper and better option!

If anybody out there has any reservations about low-dose naltrexone and its side-effects I can say there are none that I have experienced, whilst I experienced multiple side-effects whilst on crab drugs. $12 Australian compared to $1000 Australian per month makes sense to me. Politicians don't seem to be prioritising what's right for the patient and the economy, otherwise, the system would not be commercially driven.

As I stated at the beginning of this story I'm using a program called Dragon NaturallySpeaking version 8 and I've typed this entire letter at 160 words per minute without touching a keyboard or a mouse! This program makes using a computer very simple and I cannot recommend it highly enough. It took me five minutes of talking for the program to store my vocal patterns on its database.!!!!!!!

STORY UPDATE: 18 September, 2006

I now work seven days a week with four days off in-between at the tunnel. Recent changes to industrial relations laws in Australia added unnecessary stress to my workload. I'm the main breadwinner, supporting one wife and two children in private school.

My employer can now sack without having to build a case so I have had to be especially careful and protect myself as best I can. I wasn't in a union but joined recently because I thought I might need that support. My employer then sent me a warning letter without reason. So life has been pretty tough this year looking over my shoulder all the time and working seven days a week - a bad year stress-wise.

I'm still on the low-dose naltrexone and I dare say if I wasn't I would be in hospital. I don't know if it is doing anything as I seem to have plateau-ed for the last six months (no further symptom improvement) but the amount of stress I've been under would have something to do with that. I'm trying not to dwell on what could lie ahead, but with employers these days more concerned with profit than people, it's hard not to.

STORY UPDATE: 7 August, 2007

Things have changed just a little bit. I no longer have a very stressful work situation. Compliments of Australia's new industrial relations laws, my employer sacked me with no warning for going to the toilet on Easter Sunday!

I'm still taking the low-dose naltrexone but because my life has got even more stressful I think it is plateauing a little bit.

What has changed is that they pulled an occupational health and safety issue on me for using the scooter at work, so I had to move to an automatic wheelchair. The only movement you use is your two fingers on your right hand and that has had a detrimental effect to my quality of life and health - so even though the hospital thought they were helping me out, this change has actually been detrimental.

I hate to be the bearer of bad tidings, but things aren't getting any better for me, getting the sack will probably cost me my house, any chance of a job and my family, because I don't think my wife and children will hang around.

To give you a full indication of what happened:
(1) I was terminated because I broke a procedure! I rang my wife who was half an hour way instead of ringing my boss who was two hours away, broken procedure? Common sense I would have called it.
(2) Sitting next to me in the meeting was the union and there was absolutely nothing they could do, so basically I have no rights whatsoever.

LDN would still allow me to work with MS, but my concern now is getting another job.

STORY UPDATE: July, 2008 – 4+ years on LDN

Things here have changed a little bit. As you know I lost my job, and as I said earlier, everything that could happen did.

My wife left me. She took the children and I saw them for the first time in six months two weeks ago.

I've been dragged through the legal system for the last six months by the wife for settlement of the property, which has been now been sold.

Stress has been incredible during this period and if it was not for low-dose naltrexone, I think I would be in hospital. So as you can see things have not been the best, I started to take the pill form of a low-dose naltrexone, but that did not seem to work as well as the liquid form so I reverted back to the liquid.

The only problem I have now is my bowels due to the fact that I got terminated for going to the toilet and psychologically, that has had a major impact on my system, but I am slowly getting over it and getting back to a regular routine. In about six weeks, the property settlement will be over and I will be able to buy a unit and modify it to suit my needs which will make life a lot easier because at the moment I am in a totally disabled, unfriendly accommodation environment where I have to shower in a 1 foot by 1 foot area and have been doing so for four months.

The disability services commission have been fantastic in getting me accommodation and care but according to the combined application process, I am not disabled enough to require carers? My body does not work at all any more and the only movable part is my right hand so you tell me!

I don't like to whinge about things so I am doing what I normally do, just getting on with life.

There seem to be a few people in Western Australia using low dose naltrexone but I don't know who they are and I have made no contact with them, but the practitioner at the heroin clinic rang me and asked me where I was able to get compound pills.

Since I have moved out from the wife and kids I must say that my stress level has decreased and I am now in a more relaxed frame of mind - as the doctors, lawyers and anyone that gets in my way has found out; you don't mess with a person that has a brain, because they will snap back and I have been enjoying it because I enjoy a good argument and challenge, and most people think that people with multiple sclerosis can't argue, but they are grossly wrong. I hope this is of some value to you and please do not hesitate to use any of this in any way you can.

UPDATE - July 2009

Well, everything is starting to settle down a little bit. The divorce is proceeding and I have finally bought myself a new unit. I haven't seen my children since Good Friday, but I speak to them on the phone a few times a week.

I'm still taking low-dose naltrexone in liquid form, but it does not seem to be doing too much, although it is keeping me plateaued. I now have carers from the M.S. society coming in twice a day to get me out, get me ready, and prepare breakfast, They come back to get me dinner and put me to bed.

A friend of mine has also moved in and is good company, and he acts as my son's stand in grandfather.

My health seems to be okay, although nothing moves anymore except my hand and talking is getting a bit difficult, and with the economic climate at the moment, work is a non-event. Apart from that, everything is okay.

Update May 2010

Sorry for the delay in update but I have been having major dramas with my computer system, and it seems to shut down when it wants to and irritates me no end.

I am still taking low-dose naltrexone every night, but I am convinced that it has now plateaued. Both my legs and my left arm have given up and do not work at all.

My separation from my family is smoother now, and I am now used to living alone. The only problem I have now is not being able to work, which is very boring, but I keep my mind active as much as possible. I still believe that if I didn't take low-dose naltrexone, I would be much worse.

Neil, Australia

Neil, Australia

"I'm still on the low-dose naltrexone and I dare say if I wasn't I would be in hospital." Sept '06

7 Paul's MS & LDN story began in 2004 – Aletha

LDN since December 2004
- story submitted May 2007
- story updated August 2007
- story updated July 2008
- story updated March 2009
- story updated April 2010 (over 5yrs on LDN)

SPECIFICS

DIAGNOSIS
- 2004 - Multiple Sclerosis

MEDICATION (pre LDN)
- no standard MS medication

MEDICATION (post LDN)
- Dec 2004 to May 2008 - 3mg Low Dose Naltrexone (LDN)
- May 2008 to present - 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - Paul takes his Naltrexone between 9pm and 3am each day
c) Type - Compounded capsules with pure Naltrexone powder and Avicel filler.

DIET
- May 2007 - Paul changed his diet. He lowered his fat intake (minimal red meat). No dairy. No wheat products.
- May 2008 - Paul is eliminating salt/sodium from his diet in response to recent high blood pressure.

SUPPLEMENTS
- Oct 2004 to present - as follows:
Q-10 75mg
B-12 500mg
Lecithin 1200mg
Alpha Lipoic Acid 600mg
Coral Calcium with vitamin D and Magnesium
Curcumin Complex (Swanson brand with Bioperine)
Evening Primrose Oil 1000mg
Flaxseed Oil 1000mg
Echinacea-Goldenseal
Either Fish oil, Salmon oil or Cod Liver oil
Benfotiamine-V at 150mg (a non-toxic form of Vitamin B1)
- Jan 2005 - the following was added:
DL-Phenylalanine (DLPA) - 1 x 500mg morning, 1 x 500mg afternoon (empty stomach, half hour before eating)
- Feb 2007 - the following were added or changed:
B complex
Niacin 500mg
Zinc 50mg
1 x 500mg DL-Phenylalanine (DLPA) per day, morning, half hour before eating (After a while Paul found one morning pill was sufficient.)
- May 2008 - the following was changed;
1 x 500mg DL-Phenylalanine (DLPA) - scaled back to only once a week.

ACTIVITIES OR EXERCISE
- May 2007 - regular sports.
- May 2008 - Paul surfs about 4 days a week and he plays tennis, kayaks, and works out the other days.

HOBBIES & INTERESTS
- Regular sport

OUR STORY - May 2007

When nearing the end of my husbands 48th year we had decided to purchase a rental property in a rapidly growing community in Florida. We worked for months doing research and finding a good property manager. Then there was the hard work of finding the right property and securing a loan. The most difficult part of our

venture was doing this all from California and not being able to see the home in person. Things began to fall into place in a way that seemed almost orchestrated.

We came to find out that a friend of ours was in the process of moving and had taken a job as a mortgage lender near the area that we were looking in and she was happy to scout at houses for us with the realtor. Within a few weeks she found a house that met our criteria and she had the loan papers underway. Once we felt things were going very well we booked a vacation for the family and flew to Cancun. From the resort we checked our e-mail and the house had closed escrow one morning. The next morning the internet reported that Hurricane Charlie had hit the coast of Florida.

When back home in California, my husband worried for the entire month of September while the Sunshine State was ravaged by four consecutive hurricanes. He worked at a weather center where the days were filled with the topic of the hurricanes. Then he would come home and check the internet and spend the evening watching CNN. At the end of the month our new house was fine, but my husband was not.

Paul went to his doctor complaining of neck pain and, within a few weeks of extensive testing and a series of different specialists, we were told he had what appeared to be Multiple Sclerosis. The news was completely devastating to my husband as he pictured his life in a wheelchair and being unable to surf, play basketball, and play tennis.

Paul's symptoms began appearing in rapid succession. He experienced a strong depression and lacked the feeling of well being; he found that he could not coordinate a cordless screw driver to put up our new curtains; he had bladder frequency and could not stray far from restrooms; and one day he came home in tears because he could no longer shoot and make a basket.

Paul's depression grew despite going to a psychologist, learning to meditate, going through hypnosis and trying a selection of antidepressants. Every morning I would sit with him in bed and give him a pep talk. I would point out all of the people that do just fine with MS and how it can be very slow in progressing for some people.

Although he would try everything suggested to him to get beyond the empty spiral of extreme depression he was not getting out. The worst of Paul's symptoms was extreme fatigue. Everyday for two and a half months Paul would go to work for half a day and come home after lunch break. He was too tired to stay at work and too depressed to concentrate on getting anything done while he was there. Paul began thinking of how to end it all.

After going through a series of neurologists, our family doctor got us an appointment with a young neurologist in the area. She was very kind and caring. She took the time to explain everything to us. We felt like we were finally getting somewhere. She explained the four C.R.A.B. drugs to us and told us that Paul had a little time before deciding which one would be best for him. That evening I went on a quest to find out everything I could about these four drugs. Most of the sites that I found were from the drug companies themselves and from other organizations that advocated using them. (NB The term CRAB is often used as an acronym for the four main MS drugs - Copaxone, Rebif, Avonex, and Betaseron.)

Over the next few days I spent countless hours trying to find out what people who were actually using these drugs had experienced. I finally happened upon a site called Remedyfind.com, which lists many ailments and their treatments. People themselves rate the drugs they have tried and they are able to write a paragraph about their experiences.

The news was pretty bad for all of the CRAB pharmaceuticals. They required taking shots, having a lot of nasty side effects, were very costly ($800 to $1400 per month) and did not appear to help very many people. When I looked at the overall rating of these drugs I was stunned to find them at the bottom of the list with a rating of 4 to 5.5 on a scale of 10.

I looked up to see what was in the number one place and it was a drug I had not heard of. It was called LDN and it was rating at 9.1. I quickly read that this drug was taken in a pill form and it had very minor side effects that typically disappear within the first month - and the drug only cost approximately $20/month. The most amazing thing however was the stories of how people were getting their lives back. An added bonus was that a majority of people were experiencing a lack of progression. Their MRI's were coming back with no new lesions and their symptoms were disappearing. I spent the better part of an evening crying as I read through more than 60 stories from LDN users.

I printed out all of the stories so that I could give them to our new neurologist. I was sure this was a no-brainer and she would write Paul a prescription and we would be on our way. But she did not seem interested in looking them over or doing further research on this miracle medicine. I could not understand because it was FDA approved at a much higher dosage of 50mg, while you only took 3 to 4.5mg for MS. Certainly there was no danger in trying it.

While I concede that I am not a scientist, I cannot understand how this many people could be wrong. I decided we needed to take my husbands health into our own hands. The following week I made an appointment with the doctor in New York that originally thought through the idea of administering this drug in a low dosage for people with auto-immune disorders. Dr Bihari said that most neurologists are concerned about giving LDN a try because it up-regulates the patients autoimmune systems which they are concerned might then aid the immune system in further hurting and attacking the body.

Three out of the four CRAB drugs are immune suppressants (Copaxone being the only one that does not suppress the immune system). But as it turns out once the immune system is up-regulated it actually goes into gear and remembers how to behave. The day after my husband took his first dosage he went to work and did not come home until 5pm. His feeling of well-being returned and within a week his bladder frequency was gone. Within a month Paul could use the cordless screwdriver and he was back to 2 sports a day in the next few months.

It's now two and a half years since starting LDN, and my husband has never come home due to fatigue and his MRI's show no new progression. The only symptom that Paul has is minor numbness and tingling in his hands.

Incidentally, Paul's neuro worried him by saying that his follow-up MRI had a suspicious new area and that he should get on one of the Crab meds. She did not know Paul had started LDN a few months earlier and she did not even notice the huge differences in his symptoms. Later, Dr Bihari got a copy of the same MRI's and called Paul to congratulate him because the original lesion was no longer enhancing (the other doctor did not say a thing about that).

When Paul asked about the suspicious new area, Dr. Bihari told him to read the written report that accompanied the MRI because it said the suspicious new area was just a glitch in the slide. Paul read it, and low and behold that is exactly what it said!

What I have learned from being on the Yahoo LDN chat site (groups.yahoo.com /group/lowdosenaltrexone) is that about 85% of people with various auto-immune diseases have lack of progression and/or some form of symptom relief. Not everyone reacts as quickly as my husband and not everyone has miraculous recoveries. But once in a while I hear of people that get out of wheel chairs, get their vision restored, gain their cognitive skills back or feel like they no longer have the dreaded Monster.

I believe that neurologists that truly care about the health and well-being of their MS patients should first try LDN and move onto the CRAB drugs only if LDN is not effective for them.

UPDATE: August, 2007

Paul continues to do exceptionally well. He has not had any re-occurrence of symptoms and he continues to do one to two sports per day. This year we plan on going on a trip to France for two weeks, a trip to Hawaii for a week and most importantly to the LDN conference in Tennessee. We know in our hearts that it would not be possible for Paul to be doing all of this if it were not for LDN. We are eternally grateful to all of the wonderful doctors, pharmacists and the most wonderful group of helpful and giving people I have ever met from the LDN Yahoo chat site. They have all made it possible for my husband to have his life back, and me to have my husband back. Bless them all.

UPDATE: July, 2008

Paul continues to do well with LDN. He no longer needs the DLPA every day and has scaled this back to once a week. There have been no significant changes in Paul's MS since last year. His only symptom is areas of numbness and tingling in his palms.

Paul recently found out he has high blood pressure, so Paul is working on changing his diet to eliminate salt and sodium intake.

UPDATE: March 2009

Paul continues to do great on LDN with no returning symptoms. This year we were able to travel through Norway and Denmark effortlessly and we have been enjoying our first year of being grandparents. We are so grateful to have LDN which keeps Paul healthy and able to enjoy life.

UPDATE: April 2010 – over 5yrs on LDN

The day after my husband took his first dosage he went to work and did not come home until 5pm. His feeling of well being returned and within a week his bladder frequency was gone. Within a month Paul could use the cordless screwdriver and he was back to 2 sports a day in the next few months.

Paul commenced LDN in December 2004, nearly 5 and half years ago now. My husband has never come home due to fatigue and his MRI's show no new progression. The only symptom that Paul has is minor numbness and tingling in his hands.

Aletha, USA

Aletha, USA

"I believe that neurologists that truly care about the health and well-being of their MS patients should first try LDN and move onto the CRAB drugs only if LDN is not effective for them." May '07

8 LDN 4 me – Maurey

LDN since August 2007
- story submitted April 2008
- story updated July 2008
- story updated 16 July 2009
- story updated 5 February 2010 (2.5 years on LDN)

SPECIFICS

DIAGNOSIS
- May 2007 – Optic Neuritis
- July 2007- Multiple Sclerosis
- January 2008 - Neurologist report says 'may turn out to be benign MS'
- March 2009 - diagnosed with Lyme, Babesia and high mercury levels by an alternative doctor.

MEDICATION (PRE LDN)
- May 2007- 5 days 250mg oral Prednisone for optic neuritis

TESTS:
- July 2007 – Neurologist ordered MRIs of brain, cervical, thoracic, and lumbar regions - pages of blood work - lumbar puncture - Visual Evoked Potential - Chest x ray - Sensory evoked potential – Neuro-ophthalmology Eye Exam – test for Lyme disease
- Mar 2009 - FCT testing (ordered by alternative Dr)
- Aug 2009 - Repeat MRI shows no new lesions

MEDICATION (POST LDN)
- Aug 2007 to Sept 2007 - 3mg Low Dose Naltrexone (LDN) nightly
- Sept 2007 to Dec 2008 - 4.5mg Low Dose Naltrexone (LDN) nightly
- Dec 2008 to present – 3mg Low Dose Naltrexone (LDN) nightly
- July 2008 to present - Clonazipam for restless legs and insomnia

LDN - DOSE & TYPE
a) Dose – 3mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone around 10 pm each night.
c) Type - my 1.5mg capsules are compounded by Skip's Pharmacy with pure Naltrexone powder and avicel filler.

OTHER THERAPIES:
- Feb 2010 to present - Field Control Therapy (FCT), which involves bio-resonance testing and a prescribed 'therapy' that employs dropper bottles of water infused with 'frequencies'. The therapy was introduced by Dr Yukovsky: http://www.yurkovsky.com

DIET
- Since July 2007 as follows: No dairy, very little wheat or sugar. Little saturated fats. Breakfast - Smoothie with banana, berries, apple, whey protein, rice milk
- late 2008 to present – Added one cup of Kefir nightly with supplements (solves constipation)

SUPPLEMENTS
- July 2007 to late 2008:
Fish oil capsules
Multiple vitamin
B Complex
Calcium/Magnesium/D
Vitamin E
Grapeseed Extract and Bromelaine when I feel inflammatory or "MS ey"
UltraInflamx powder "Medical Food" by Metagenics in Rice Milk or Almond Milk at night with my vitamins and LDN.
- Late 2008 to present as follows:
Fish oil capsules
Multiple vitamin
Calcium/Magnesium/D
Vitamin E
Curcumin
Alpha Lipoic Acid
- December 2009 to present – added to above list:
Natural CALM magnesium supplement for restless legs. Helps to reduce the need for Clonazepam to sleep.

ACTIVITIES & EXERCISE
- April 2008 to late 2008:
I raise Welsh Ponies so most of my exercise is practical; stacking hay, cleaning the paddock, and training ponies. Running is a challenge, but I work to lengthen my stride and increase the distance by running with ponies. Lots of stretching. I have an exercise ball chair at home and at work. The chairs come with stretching exercises. Yoga is new to me. I use the Rodney Ye PM yoga DVD to aid sleep and help with balance.

- late 2008 to present:
I'm still raising Welsh Ponies; stacking hay, cleaning the paddock, and training ponies. Running is still a challenge, but I still work to lengthen my stride and increase the distance by running with ponies. Still lots of stretching, and I still have and use an exercise ball chair at home and at work. Exercising is challenging, but I feel better the next day if I stretch my limits.
- February 2010 to present:
Same strategies as previous. Stretching is very important. Leg strength is improving.

MY STORY – April 2008

I was diagnosed with MS in July '07. Looking back before my major episode, I had strong symptoms that I denied for 5 years or so. In July 2007 I couldn't climb steps, I dragged my legs to get around, had no central vision in one eye, cried for no reason, had slurred speech and couldn't find the words for my thoughts, and I was so dizzy I walked into walls.

I started LDN in August '07, right after receiving my diagnosis. The first month I took 3mg, and I've been taking 4.5mg ever since. The greatest improvement in my symptoms occurred in the first 30 days. Improvement is slower now, so I keep a diary and check in with myself every 3 months. I haven't been disappointed yet. Once in a while if my legs feel stiff I drop back to 3 mg for a day.

I follow most diet and supplement recommendations related to my condition. I also have high cholesterol but my new diet has reduced my bad cholesterol by 20 points and increased my good by 7 – a nice side benefit.

I have 80% of my leg function back, no more dizzy spells, and no more speech problems. I have some loss of color vision in one eye, but I can see. My MS taps me on the shoulder every now and then, but I no longer think about it 24x7. I continue to work on my balance and leg strength with various activities.

At my 6-month check up with the same neurologist, he gave me a lecture on LDN not being FDA approved and strongly recommended Rebif to slow the progression. I asked him how he could possibly recommend expensive painful injections when I'm doing so well on LDN.

My LDN was prescribed by my GP who said "Why not? It makes perfect sense, won't hurt you, and the CRAB drugs are limited in their effectiveness."

My Neuro report came in the mail. He must have done some thinking after our visit. It reads, "The patient has done quite well since I saw her in July. She has had no attacks of multiple sclerosis. She takes low dose Naltrexone. She gets that medication through her primary care provider. She is aware that there is no evidence that this is helpful in multiple sclerosis. She is not interested in going on Interferon medication at this time and I do not think that it is necessary at this point either. It may turn out that she has benign multiple sclerosis."

I say, that if it is benign, it's only because of LDN, diet and exercise. I do believe attitude plays a big role. I'm putting a son through college and have 5 horses that must be fed and cared for. I cannot be disabled and will find the way. That's my story and I'm sticking to it.

UPDATE: July, 2008 – 1 Year on LDN

Certainly! I've read through the specifics section, and all remains the same. Still doing very well on LDN - no further progression or attacks, no medical information to report. Still following the same routine, LDN, supplements and exercise. No episodes, no progression, slow but steady improvement in leg strength and balance. Tolerating the heat of summer much better than last year.

UPDATE: July 2009 – 2yrs on LDN

Still firmly committed to LDN. No exacerbations - one very tired day after extreme exercise in high heat. In general, I'm able to handle heat much better than a year ago. Frustrated by a plateau in improvement, I've been seeing an acupuncturist/Chinese herbalist who is doing FCT testing and therapy for Lyme, Babesia and mercury poisoning. I believe it has sparked some improvement.

I'll see my neurologist on July 31 for my first repeat MRI.

UPDATE: February 2010 - 2.5 yrs on LDN

I had my first repeat MRI in July. It showed all the same lesions as before, possibly one more in the brain, but the neurologist said that it was probably there before, just showed up in this 'slice'. No active lesions and no other new lesions.

No exacerbations since starting LDN - I would not go a day without it.

I wanted my diagnosis changed from MS to Lyme disease. The neurologist said, "That will never happen. You will always have the diagnosis of MS.".

My alternative Dr. says that the Lyme disease and heavy metal poisoning are no longer an issue, but are what caused my symptoms in the first place. He is now working on regenerating nerve impulse via a therapy called 'Field Control Therapy' (FCT). He uses bio-resonance testing and prescribes 'therapies' that involve dropper bottles of water infused with 'frequencies'. It is very cost effective. The therapy was introduced by Dr Yurkovsky.

It's working. I am skiing and horseback riding.

My remaining symptoms are leg weakness, loss of color vision and acuity in one eye and occasional, but manageable fatigue.

Maurey, USA

Maurey, USA

"My Neuro report came in the mail. " … It may turn out that she has benign multiple sclerosis." I say, that if it is benign, it's only because of LDN, diet and exercise." Apr '08

Why I contributed my case study

I contributed my case study because I found so much help and encouragement from other people diagnosed with MS using LDN on the yahoo group. I went for my first visit to the neurologist knowing from research what the result was going to be, but very optimistic that I'd get the best of the best from the experts. I left that visit discouraged, then fired up to get the word out that no one should feel hopeless and take shots that do far less than inexpensive healthy alternatives. I'm grateful that you are willing to take your time to help spread these stories. I have learned and benefited so much from others willing to share.

9 LDN, MS & me – Jackie

LDN since April 2004
- story submitted October 2005
- story updated Jul 2008
- story updated July 2009
- story updated April 2010 (6yrs on LDN)

SPECIFICS

DIAGNOSED
- Apr 1980 - Relapsing Remitting Multiple Sclerosis (RRMS)
- 1995 - Secondary Progressive Multiple Sclerosis (PPMS)

MEDICATION (pre LDN)
- 1993 to Aug 2004 - detrusitol LA
- 2003 (approx 9 mths) - beta interferon
- 2003 (approx 1 mth) - baclofen (horrible stuff, I'd rather deal with the spasticity)

MEDICATION (post LDN)
- Apr 2004 to May 2004 - 3mg Low Dose Naltrexone (LDN)
- May 2004 to present - 4.5 mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - bedtime, between 10.00pm and 11.30pm
c) Type - 4.5 mg capsules compounded by Dickson's Pharmacy, Glasgow, Scotland (not sure about the filler)

SUPPLEMENTS
- May 2008 to present (see further below for supplement content:
Dr Tom Gilhooly's Baseline AM x 1 daily
Dr Tom Gilhooly's Baseline PM x 1 daily
Dr Gilhooly's Ideal Omega 3 Fish Oil x 1 daily
Revinol x 1 x twice daily

Dr Tom Gilhooly's Baseline AM - Each Capsule Contains:
Vitamin D 50µg (1000% of RDA*)
Calcium 200g (25% of RDA*)
Magnesium 100mg
Zinc 20mg (133% of RDA*)
Selenium 50µg
Chromium 400µg
Co-Enzyme Q10 30mg
Pine Bark Extract 100mg
Maganese 0.5mg

*RDA = Recommended Daily Allowance

Product Description: Baseline AM (60 Vegetarian Capsules): One capsule contains naturally sourced anti-oxidants, and some of the most important essential vitamins and minerals. These help maintain a healthy immune system, support optimal nerve function and blood circulation. BaselineAM provides a selection of key minerals, chromium, magnesium, maganese, selenium and zinc. Manufacturer - Glasgow Health Solutions

Notation: If BaselineAM and BaselinePM are taken within 2 hours of each other, the effectiveness of the antioxidant minerals zinc and copper are reduced due to competition for absorption. The two-hour gap allows for the first mineral to be completely absorbed prior to the next one arriving in the intestine.

Dr Tom Gilhooly's Baseline PM - Each Capsule Contains:
Vitamin A 75µg (9% of RDA*)
Vitamin C 200mg (333% of RDA*)
Thiamin 5mg (357% of RDA*)
Riboflavin 2.5mg (156% of RDA*)
Niacin 5mg NE# (28% of RDA*)
Vitamin B6 5mg (125% of RDA*)
Folic Acid 400µg (200% of RDA*)
Vitamin E 12mg (18iu) (120% of RDA*)
Vitamin B12 5µg (500% of RDA*)
Biotin 150µg (100% of RDA*)
Pantothenic Acid 25mg (417% of RDA*)
Calcium 100mg (12.5% of RDA*)
Manganese 0.5mg

Copper 2500µg
Betacarotene 2.5mg

*RDA = Recommended Daily Allowance
+RE = Retinaol equivalents
NE# = Niacin equivalents

Ingredients:
Calcium Carbonate Preparation (Calcium Carbonate, Acacia, Maltodextrin), Vitamin C (as Ascorbic Acid), Vegetable capsule shell (hydroxypropyl Methylcellulose), Bulking Agent (Microcrystalline Celulose), Beta Carotene, Pantothenic Acid (as D-Calcium Pantothenate), Copper Gluconate, Natural Source Vitamin E (as di-alpha tocopherol succinate), Anti-Caking Agents (Magnesium Stearate, Silicon Dioxide), Vitamin B6 (as Pyroxide Hydrochloride), Vitamin B1 (as Thiamine Hydrochloride), Vitamin B12 (Cyanocobalamin) Preparation (Mannitol), Vitamin B12, Niacin (as Nicotinamide), Vitamin B2 (as Riboflavin), Manganese Amino Acide Chelate, Vitamin A Preparation (Starch, Arabic Gum, Vitamin A, Sucrose), Folic Acid, Biotin.

Product Description: BaselinePM is the first product to be designed to specifically address the nutritional balance required to support omega effectiveness. BaselinePM contains the most important co factors in optimum amounts that support the conversion of fatty acids into the most active form of omegas. When taken with BaselineAM, BaselinePM form the ultimate broad spectrum multi-nutrients combination. Manufacturer - Glasgow Health Solutions

Caution: These products should be avoided during pregnancy and breastfeeding unless advised by a medical practitioner. Food supplements must not replace a varied and balanced diet or healthy lifestyle.

Notation: If BaselineAM and BaselinePM are taken within 2 hours of each other, the effectiveness of the antioxidant minerals zinc and copper are reduced due to competition for absorption. The two-hour gap allows for the first mineral to be completely absorbed prior to the next one arriving in the intestine.

Ideal Omega3 Fish Oil 1200mg Contains EPA, DHA, & DPA Omega-3 fatty acids:
EPA (Eicosapentaenoic acid) = 700mg
DHA (Docosahexaenoic acid) = 200mg
DPA (Docosapentaenoic acid) = 20mg
Vitamin E = <0.02mg
Manufacturer - Glasgow Health Solutions

Revinol contains:
Vitamin C (as Calcium Ascorbate, equiv. to 53.3mg), Vitamin C and 6.5mg Calcium), Curcumin, White Pine Bark, Grape Seed Extract, Vitamin A (as beta carotene) equiv. to 5700 IU, Vitamin A (as dL-alpha Tocopheryl Acetate, equiv. to 8 IU), Ginkgo Biloba, Maritime Pine Bark. TOTAL ACTIVES 199.93mg (Caution: Contains Soya extracts)
Recommended dose: Take two tablets twice daily for three days to start, then take one tablet twice daily to maintain.

DIET
- May 2008 - I eat a generally healthy diet, lots of fruit and veg, fish, not much red meat, no dairy except a very small amount of skimmed milk, limited caffeinated drinks - 1 or 2 cups of tea a day, 2 cups of coffee a week. A fair amount of wine, mainly red - no other alcoholic drinks. No fizzy drinks at all, no sugar, no cakes biscuits etc.

EXERCISE OR INTERESTS
- art and creative software

MY STORY – October 2005

When I first started taking LDN I also began a daily journal to record my symptoms and any changes I observed.

Looking back over it prior to starting this piece, I was impressed by how quickly things seemed to change for me. Taking LDN has definitely made a significant difference to my quality of life. Some of its effects have taken rather longer to become apparent than others but the two most immediate results, there before my eyes and still evident, were a significant increase in stamina and a welcome improvement in my sleep pattern.

Since the mid 1990s when my MS became progressive, this has been the first winter I have survived without deterioration in my condition.

My bladder has improved so much in the past year that I no longer take any medication for it. Spasticity has also decreased and I am a little more mobile. I have maintained a standard over a timed walk for the past seven months, having gradually improved to that level after starting LDN.

I am hopeful that my condition has stabilized. My outlook has certainly improved and I am working hard in my studio. I only regret that I did not discover LDN sooner, but am thankful to have at last found something that seems to work for me.

UPDATE: July, 2008 - 4 years on LDN

Prior to beginning this up-date I re-read my previous, 2005, piece on my experience of taking LDN (low dose naltrexone) for progressive M.S.

What struck me most strongly was the positive tone of the article and the sense that the drug had given me hope for the future despite a rather gloomy prognosis. I felt then that LDN had improved a number of my symptoms and was hopeful that that improvement would be sustained; and by and large, it has been.

I am still taking LDN - four years now and counting, during which time I would say that my M.S. has stabilised. It would be wrong to assume that the disease has not progressed at all - I have an increase in spasticity in my right hand and arm for instance; but that increase has been very gradual and is fairly slight.

The important thing is that I am still on my feet - despite a badly fractured ankle a couple of years ago, and continue to enjoy life.

I am still working as an artist. See http://homepage.mac.com/jackie.smith/PhotoAlbum2.html for images and information from my last exhibition and am currently teaching myself how to use Adobe Illustrator. A thankless task!

I now walk with the aid of an FES stimulator (see http://www.salisburyfes.com), which has helped enormously with my characteristic M.S. dropped foot. I still drive with the addition of hand controls to my car and remain optimistic for the future.

It is impossible to quantify what effect LDN has had in maintaining my condition, perhaps when trials at last take place on this therapy we might better understand its potential to assist in M.S. management. My belief is that it has been of considerable benefit and I intend to continue taking it - at least until the cure comes along!

Jackie, written whilst in a cast with yet another broken leg.

UPDATE – July 2009

It is now Summer 2009 and I am still taking LDN plus Dr Gilhooly's supplements. My condition is reasonably stable although my right hand is now very weak. Still making art, still driving and still getting around although I now use a powered wheelchair when I get tired.

Recent hot weather has affected me badly, I think my temperature control has deteriorated of late. I try to remain optimistic - who knows what's around the corner? Wireless FES for one!

UPDATE – April 2010

Yes, I am still taking LDN but having said that, I am not sure of its continued efficacy: I have not had a good year with a marked decline in my condition, BUT I have been under quite a bit of stress so that could be to blame.

I have had a string of infections, mainly the dreaded UTI's, but also two colds, which is unusual for me because I usually don't catch colds. This string of health issues severely affected my energy levels and I am only now beginning to regain some momentum in my life and get back to making some artwork.

Basically, I think I have been suffering from depression brought on by external factors, which has affected my MS. My mobility has suffered and my right hand and arm have become stiffer and more prone to spasticity. I have also been suffering from severe muscle spasms, especially at night, which my GP reckons were brought on by the infections, so none too bright really.

I continue to take Dr Tom's MS supplements and have been doing so since he introduced them. I take one of each per day. Prior to the arrival of these supplements I took Revinol plus the fish oil, which I have been taking since the year dot.

When things return to normal, I hope for improvement. Watch this space!

Jackie, UK
Jackie is an artist who lives in Perthshire with her partner and their dog.

Jackie, UK
"I am still taking LDN – four years now and counting, during which time I would say that my M.S. has stabilised. It would be wrong to assume that the disease has not progressed at all – I have an increase in spasticity in my right hand and arm for instance; but that increase has been very gradual and is fairly slight." Jul '08

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

10 MS & LDN since May 2002 – Joyce

LDN since May 2002
- story submitted 19 November 2003
- story updated August 2006
- story updated August 2007
- story updated July 2008
- story updated April 2009
- story updated August 2009
- story updated April 2010
- story updated July 2010 (over 8yrs on LDN)

SPECIFICS

DIAGNOSED
- 1984 - On reflection, first sign was Optic Neuritis
- 1989 - Multiple Sclerosis

MEDICATION (pre LDN)
– nothing to May 2002

MEDICATION (post LDN) - PAST
- May 2002 to 1 Apr 2010 – 4.5mg Low Dose Naltrexone (LDN)
- 1 Apr 2010 to 1 Jul 2010 - 3 month break from LDN
- 20 Jul 2010 to 20 Aug 2010 – Prokarin patch x 2 patches (first tried 1, then 1 ½ patches without benefit)

MEDICATION (post LDN) - PRESENT
- 1 Jul 2010 to present - 4.5mg Low Dose Naltrexone (LDN)

DOSE & TYPE
a) Dose – 4.5mg low dose naltrexone (LDN)
b) Time – At bedtime, between 10 pm and 2 am
c) Type – Compounded Capsule - fast release

SUPPLEMENTS
- August 2006 – I was taking the following:
Methlycobalamin 1mg. once a day sublingualy
CoQ10 100 capsule once a day
Cranberry capsule x 1680mg twice a day
Super booster softgel x 1 x once a day (life extension supplement)
Digestive enzymes x 2 x twice a day with meals
Spirulina 1000 mg x 3 times a day
Super EPA/DHA with Sesame Lignans and Olive Fruit Extract (life extension supplement)
Vitamin C x 1000 mg x twice a day
Mitochondrial Energy Booster capsules x 4 in the morning. (This contains Alpha Lipoic Acid 300mg, Acetyl L-Carnitine 1000 mg, Benfotiamine150mg, along with several B vitamins, D3 and chromium)
Gamma E Tocopherol capsule x 1 x once a day
MSM & glucosamine x 1 x once a day
Coral Calcium 1000 mg x 1 x once a day
Chlorella 1000 mg x 3 times a day
Life Extension Mix Caps x 6 x twice a day
DL Phenylalanine 500 mg x once a day
Fuco-Thin x 3 capsules x 3 times a day (Fucoxanthin)
Evening Primrose Oil 1300 mg x 1 x once a day
Apple cider vinegar with juice x 1 Tblsp (as needed)
- Jun 2007 - the following was added:
Natural Cellular Defense (zeolite drops) to remove heavy metal
Green tea drops into my morning cup of tea
- Aug 2007 - the following was added:
Mynax x 3 tablets x 3 times a day (Calcium EAP product from Koeler, as recommended by a naturopath)
Aloe Vera freeze dried x ½ tsp x once a day (As recommended by a naturopath)
1 teaspoon of Homozon nightly for colon health
oxygen drops in water
- Sept 2007 - the following was added:
electrical impulse unit – under pillow on retiring at night
- May 2008 – the following is a complete and current list:
Cranberry capsule x 1680mg twice a day
Super booster softgel x 1 x once a day (life extension supplement)
Digestive enzymes x 2 x twice a day with meals
Super EPA/DHA with Sesame Lignans and Olive Fruit Extract (life extension supplement)
Vitamin C x 1000 mg x 3 times per day
Mitochondrial Energy Booster capsules x 4 in the morning. (This contains Alpha Lipoic Acid 300mg, Acetyl L-Carnitine

1000 mg, Benfotiamine150mg, along with several B vitamins, D3 and chromium)
Gamma E Tocopherol capsule x 1 x once a day
MSM & glucosamine x 1 x once a day
Chlorella 1000mg x 3 times a day
Life Extension Mix Caps x 6 x twice a day
DL Phenylalanine 500 mg x once a day
Fuco-Thin x 3 capsules x 3 times a day (Fucoxanthin)
Evening Primrose Oil 1300 mg x 1 x once a day
Apple cider vinegar with juice x 1 Tblsp (as needed)
Natural Cellular Defense (zeolite drops) to remove heavy metal
Green tea drops into my morning cup of tea
Mynax x 3 tablets x 3 times a day (Calcium EAP product from Koeler, as recommended by a naturopath)
Aloe Vera freeze dried x ½ tsp x once a day (As recommended by a naturopath)
Homozon x 1 tsp x once per day (nightly for colon health)
Oxygen drops for water
Selenium x 200 mcg x once a day
Lithium aspartate 5mg x once a day
Silica 500mg x 1 x once a day
Boku Superfood green powder x 1 scoop in a smoothie with 1 tablespoon of coconut oil once a day
Colosan x 1 capsule x once per day
(NB I no longer use the electrical impulse unit)
- Aug 2009 – the following is a complete and current list:
ON HOLD:
Calcium AEP x 1 per day (Byron Richards Wellness Resources – Calcium from Calcium 2-Amino Ethanol Phosphate-Cal2-AEP x 200mg, Amino Ethanol Phosphate 1800mg)
Metabolic enzymes x 3 x twice per day (not with meals)
NGF-Neuron Growth Factor x 1 per day (Acetyl L – Carnitine DiHCI x 320mg, Acetyl L – Carnitine HCI x 300mg, Gotu Kola x 300mg, Ginkgo Biloba x 60mg, Uridine x 50mg)
Zeolite drops x 5 drops in water daily
Stemgevity x 3 capsules per day (to promote stem cell activity)
CURRENT:
Methlycobalamin 5mg once a day sublingually (Life Extension Foundation)
Healthy Aging x 1 per day (Pure Country Naturals – per tablet - Vit D x 500iu, B6-pyridoxal-5-phosphate x 25mg, Magnesium-Magnesium aspartae x 200mg, Vanadium-vanadyl sulfate x 2.5mg, Rhodiola Rosea 5% extract-root-standardized to 5% rosavins x 25mg, L-Carnosine x 125mg, Acetyl-L-Carnitine HCL x 250mg, Alpha Lipoic Acid x 100mg, Green Tea 95% Extract-standardized to provide 95% polyphenols 40% EGCG 25% catechins x 150mg, Grape Seed 95% Extract-from fruit standardized to provide 95% proanthocyanidins x 50mg)
Dl-Phenylalanine x 500mg x 1 per day (to upregulation of endorphins from LDN)
Silica (Horsetail Extract) x 500mg x 1 per day (Alta)
Quercetin x 650mg x 1 per day (Byron Richards Wellness Resources)
Vitamin D3 x 1000iu x 1 per day (includes 3000iu of naturally occurring fish liver oil)
Mintchewburst (Body Ecology – Vit E, A, D3, Omega 3's DPA, EPA, DHA)
Thyroid Helper (Byron Richards Wellness Resources – Selenium from L-Selenomethione x 75mcg, Manganese from picolinate x 1mg, L-Tyrosine x 200mg, Ashwagandha-Withania somnifera-standardized for 1.7% withanaloids x 300mg, Gugulipid-Commiphora mukul-2.5% guggulstrerones x 300mg)
Co-Q10 plus x 100mg x 1 per day
Vit C x 1000mg x 1 per day (Byron Richards Wellness Resources – also contains calcium x 61mg, magnesium x 39mg)
Lithium-as Lithium aspartate x 5mg x 1 per day (NSI brand)
Evening Primrose Oil x 1300mg x 1 per day (NSI brand – GLA x 117mg)
Mega EFA x 1 or 2 per day (NSI brand – purified fish oil-molecularly distilled x 2,200mg, EPA x 800mg, DHA x 400mg)
Chlorella x 1000mg x 3 times per day
Cranberry x 400mg x twice per day
Multi-Vit x 2 capsules x twice per day (Byron Richards Wellness Resources – per capsule – Vit A-as a natural carotene complex from 7.5% dunaliella salinas x 3,333iu, Vit C-from calcium & potassium ascorbate x 84mg, Vit D-3 x133iu, Vit E-as d-alpha tocopheryl succinate, plus beta, gamma, and delta tocopheryls x 66iu, Vit B-1-from coenzyme thiamin diphosphate x 8mg, Vit B-2-from coenzyme riboflavin 5'-phosphate x 8mg, Vit B-3-Niacin-from inositol hexonicotinate x 25mg, Vit B-6-from coenzyme pyridoxal 5'phosphate x 8mg, Folate-from coenzyme calcium folinate x 266mcg, Vit B-12-as 50% coenzyme adenosylcobalamin & 50% coenzyme methylcobalamin x 266mcg, Biotin-pure crystalline x 100 mcg, Vit B-5-33% mg coenzyme Pantethine and 67% mg d-calcium pantothenate x 25mg, calcium-from coral minerals, fumerate, malate, succinate, alpha-ketoglutarate, aspartate & ascorbate x 34mg, Magnesium-from coral minerals & malate x 34mg, Zinc x 7mg, Selenium-L-selenomethionine x 17mg, Copper-sebacate & aspartate x 500mcg, Manganese-glycinate x 1.5mg, Chromium-Nichrom III GTF x 66mcg, Molybdenum-fumerate, malate, succinate, alpha-ketoglutarate & aspartate x 50mcg, Potassium-fumerate, malate, succinate, alpha-ketoglutarate, aspartate & ascorbate x 33mg, Choline-bitarate x 25mg, Inositol-crystalline, dextrose free & inositol hexonicotinate x 50mg, Boron-glycinate & ascorbate x 1mg, Vanadium-fumerate, malate, succinate, alpha-ketoglutarate & aspartate x 34mcg, Malic Acid-from mineral malates x 166mcg, Aspartic acid-from mineral aspartates x 44mg, Succinic acid-from mineral succinates x 17mg, Alpha-ketoglutaric acid-from mineral alpha-ketoglutarates x 17mg, Fumaric Acid-from mineral fumerates x 1.5mg, Octacosanol-spinach extract x 166mcg)
Colosan x 1 capsule x 1 per day OR Homozon-0xygenating x 1 tsp x 1 per night (alternated for bowel health)
NGF-Neuron Growth Factor (Acetyl L – Carnitine DiHCI x 320mg, Acetyl L – Carnitine HCI x 300mg, Gotu Kola x 300mg, Ginkgo Biloba x 60mg, Uridine x 50mg)
Apple Cider Vinegar x tblsp with water and honey (occasionally as needed)
Iosol Iodine x 1 drop in water daily

Aloe Vera freeze dried powder x half tsp in Smoothie x once per day
Living Fuel whole food powder mixed with water or juice & banana or strawberries x once or twice a week (as a meal replacement)
Liquid Probiotic (Body Ecology brand)
Green tea drops (Body Ecology brand)
Cat's Claw 1.5gm x 3 capsules twice per day
Selenium x 200mcg x 1 per day
Prevagen (to promote healthy memory)
Moxxor (fish oil supplement)
Udo's Oil x once per day
Vit D3 drops (to be taken for 3 mths)
Lauricidin (to treat viruses)
- April 2010 – the following is a complete and current list:
Prevagen (apoaequorin calcium binding protein) - 1 capsule daily
Iosol Iodine 1 or 2 drops daily (Byron Richards Wellnessresource.com)
Micelized Vitamin D3 (one drop is 1000mg) x 10 drops per day (Aug 2010 - increased from 6 to 10 drops)
MethylCobalamin - Life Extension Foundation 5mg x 1 per day
Horse Chestnut (Timed Release) 200mg x 1 in the morning, 1 in the evening
Lithium 5mg x 1 daily (NSI)
Selenium 200mcg x 1 capsule daily (NSI)
Silica 500mg x 1 daily (Alta Health Products)
Curcumin 500mg & Black Pepper 50mg x 2 daily (Bioactive Nutrients)
Co-Q10 100mg x 1 per day (Life Extension Foundation)
Cranberry 400mg x 2 daily (NSI)
Broccoli Sprouts x 1 daily (Seagate company)
Krill Oil 1000mg x 3 daily (Mercola)
Borage Oil 1300mg x 1 daily (NSI)
Cat's Claw 1.5gram x 3 daily
Cayenne 450mg x 2 daily
Lion's Mane mushroom extract x 30 drops daily
Magnesium (Magna Calm) x 1 scoop daily
Probiotic x 2 daily (Dr. Ohira's)

DIET
- My diet is very low saturated fat and coincides with the Swank MS diet, but I use olive oil as much as I can and take in other good fats via supplements.

EXERCISE
- regularly

MY STORY – as at May 2002

My story starts quite a few years ago when I had an episode of Optic Neuritis. I've had several such attacks that led to a diagnosis of MS. I could never quite understand why I was doing so well with it, for example...very few attacks and almost no permanent physical impairments... this went on for about 10 years or so.

I would have the typical bouts of numbness here and there. I started to go downhill with my balance and walking a few years ago and knew that it was time to research a medication for my MS as I always said that I would when that time came.

There are several clinically tested medications on the market these days for MS but regrettably they are all injectable and come with some potentially bad side effects. I've heard it said that they could possibly help about 30% of the people about 30% of the time. I thought...wow...I don't like those odds, so I searched further and thank God I did because I was able to find the good work of Dr. Bernard Bihari in New York City.

He has been working with LDN or Low Dose Naltrexone for many years with HIV patients on the theory that a lack of endorphins rather then an overactive immune system is the cause of all autoimmune diseases. You see, LDN, when taken once daily causes your body to create 200% to 300% more endorphins, which in turn regulates the immune system back to normal. Hence, no further progression of the MS.

I have been on it for about 18 months now. It is November of 2003 and I started with it in May of 2002. My endorphins have increased again, and I haven't looked back. So far so good.

There is a website dedicated to information about it with regards to MS and a wealth of other diseases like Lupus and Fibromyalgia, ALS and Parkinson's ..... www.lowdosenaltrexone.org. .....

Virtually all autoimmune disorders should respond to this therapy. I only have experience with it and my MS. Dr. Bihari has been doing work with it and cancer for years. Treating people with MS came after he helped a friend's daughter who suffered with MS.

Naltrexone is an FDA approved drug, but one that has been in existence at a much higher dose of 50 mg for almost 19 years now (as at Nov 03). Therefore, an orphan drug? There is no money to be made by these huge pharmaceutical companies who are the ones that do clinical testing. Any doctor can prescribe it but one must have it compounded down from the original 50mg tablet to a 4.5mg dose.

Several compounders are doing just that and some of them are listed on the website. One such compounder has statistics of many MSers being helped by it and he claims that it is the one medication that he would take if he had MS. One of the things that convinced me to look into this whole thing further was the knowledge that no one is making huge amounts of money from it.

There is some work in finding a doctor to prescribe it for you and then in finding a compounder to make it up for you in a dose of 4.5mg. It must be formulated into a fast release version as well.

Good luck to all who have come here to read my story .... God bless .... Now back to my story.... you see this all makes good sense to me because I never really did start going downhill until I slacked off from my very vigorous aerobic exercise routine a few years back. You see, that is what was producing all those endorphins and I never knew of the connection till now.

Us MSers are always being told that exercise seems to help but I'm certain that most don't know the true reason behind it.

UPDATE August 2006

As far as an update. I'm sure that I could but there's not much to tell. People are always asking for an update but I think hmmmmmm how many ways are there to state that there are no MS issues?..lol.

I must admit that I no longer think that the LDN will halt the MS but rather it should slow it down considerably. The reason I say that is that **my legs aren't as good as they were**. My legs would get a little rubbery towards the end of the day. Now my legs get that way soon after waking. My balance seems to be just a tad worse as well so that spells progression to me.

Other than that, as I stated, no real MS issues and as far as I'm concerned, that's great. I lead a pretty normal life here. I have the usual MS issues about making sure that there will not be a lot of walking involved with any activities and such and an occasional day with some vertigo but other than that, nothing different than any others.

Having said that, no one would even know I have MS and indeed, my co-workers still do not know.

It is now just over 4 years on the LDN and I love not having to see any sort of doctors other then the internist that prescribes the LDN for me. I also think it's important that one uses a compounder that is well-versed on how the LDN must be compounded in order for it to work. It must contain fast-release filler because of the mechanism by which it works.

I think that the time has come for the world to be aware of this remarkable therapy. Then, Godspeed to a cure! Until that day comes, I am happy to take my little LDN capsule once a day.

UPDATE August 2007

There is really not a whole lot to update. The only change is that I have been tending to just keep getting a bit worse as each year goes on. Nothing major and no attacks really but I know how I was walking and how my balance was just a year or so ago and it just seems to mysteriously get worse. It's hard to explain that really.

The only thing that comes to mind is that I am experimenting with a few things such as taking oxygen products like drops for the water and taking a teaspoon of Homozon nightly for colon cleansing. I take many supplements and have just gotten information about something called Mynax from a California naturopath. It is a calcium EAP product. I've been taking it for just over a week so too soon to tell whether that will help.

I've also been advised by a Canadian naturopath to take Aloe Vera internally. I've been taking a half teaspoon of a free dried aloe vera product for a few weeks now, so we'll see how that goes. One has to wonder if any of these things affect the outcome of the LDN in any way. I do know that I will continue to take the LDN because I do believe it is the best thing out there for MS and many other immune system based disorders.

UPDATE July 2008

Since I noticed some minor progression, I've been experimenting with various supplements to try to interrupt it. I'll keep you posted on the outcomes.

UPDATE April 2009

I have adjusted my supplement dose by deleting a few things and adding others. My exercise is a bit more erratic as my walking and balance has deteriorated a bit more. I feel that there is some sort of internal inflammation happening that I am trying to pinpoint. I feel that the LDN is still working by holding off any major exacerbations. My diet is very low saturated fat and coincides with the Swank MS diet.

UPDATE August 2009

I've been trying different things to see if they help. **I tried varying how I take my LDN dose - taking my LDN every other night, as theorized by Dr Zagon,** and at the same time I stopped taking the Colosan oxygen-type capsule, a powerful bowel cleanser and antioxidant, on the nights that I took LDN. I used to take it every night after LDN, so I'm avoiding it just in case it was interfering with metabolisation. In fact, I've eliminated any sort of anti-oxidant thing around the time I take my LDN at night.

I do try to get in some good fats...and I bought another bottle of Udo's Oil. I use olive oil whenever I can, and I take a good fish oil called Moxxor (made from green lipped mussels in New Zealand).

At present, I've put some supplements 'on hold' and **I'm back to taking the LDN nightly**, and am being particular not to risk LDN metabolisation by taking any other supplements or anything else around the same time I take it.

I'm still trying to get to the bottom of what is going on with me, so I'm having all my mercury fillings replaced, and to that end, have made an appointment to start mid September 2009. I'm also going to have IV Vitamin C therapy after each treatment.

I had a consult with a natural health doc that has a machine that checks your meridians for blockage and he said I have issues with heavy metals, herbicides/pesticides, allergies and a virus. He recommended products to chelate the heavy metals and something for the virus called Lauricidin.

I'm already chelating to some degree, with something called Total Chelate and with chlorella and Cilantro. He also gave me some vitamin D3 drops to take for at least a month or two.

UPDATE April 2010

As far as the LDN, I'm currently on a break from it. I decided to call Elaine DeLack, the nurse who created Prokarin Histamine patch and had a very interesting conversation with her. When I mentioned that the LDN was working for me for the first 5 or 6 years and then suddenly things started to change, she said something very interesting to me. She said that it was very possible that I had burned out my adrenals.

She seemed to think that the LDN could have done that. She suggested that I take some adrenal re-builder, which I plan to order. I thought that I might just stop the LDN for a short time and then see what happens. I may even give the Prokarin a try as one of the compounders offers the first month free... no reason not to at least see if it would help me.

I have also been following all the buzz surrounding CCSVI – sure is amazing. I would love to be tested to see if the vein thing is an issue for me so I am following it to see how I may do that locally.

I finally got a few moments to sit down and make up my most recent supplement list, which is good timing because I have an appointment to visit a new doc tomorrow and I do like to take something like that with me. I'll probably get some advice to do other things… we'll see. I have not ordered any of the adrenal support

product yet as I wanted to wait for this visit to see what the new doc will say. He seems to be very forward thinking, gets a lot of his info from Germany, with many of the therapies they do there being cutting edge.

Anyway, I'm not sure how to update this other then to say that **I am on a short break from LDN** and am considering all this information and associated options, as well as looking into systemic enzymes to see how they might help me. When I decide what I'm going to do and act on it, I'll update again.

UPDATE 1 July 2010

I had a bad week this past week... just felt nauseous... not sure if this is a symptom of MS but my walking is worse yet again so who knows.

I have started taking the LDN again. Was taking some systemic enzymes too but not sure they helped any. I've recently gotten very interested in learning about energy medicine and will see someone on Monday to get more familiar with how it all works and find ways to do it on myself.

I still think that I will find an answer for myself but have not found it yet. I recently bought a re-bounder and try to get on it for a bit every day. I am still following news about the CCSVI thing too.

UPDATE 28 July, 10 August 2010

Well the jury is still out on the Prokarin patch. I did call up the compounder and he said that I can certainly try adjusting the dose by simply wearing 1 1/2 patches and then 2 if need be; so I think I will try to do two tomorrow. I have tried 1 1/2 for a few days and I have not noticed much of anything. I don't think it is going to help me really.

I started back on the LDN about 3 or 4 weeks ago. I don't seem to ever notice anything from anything I do lately. I never stopped with the supplements.

I bought one of Donna Eden's books and the energy medicine thing is utterly fascinating to me. I went to see a woman that actually studied with Donna Eden and she helped answer some of my questions. It has to do with the fact that we have all those electrical meridians running through us and sometimes they get screwed up.

She showed me some things that I can do and that is the beauty of all this stuff. We all have the ability to do certain things to help ourselves. I have just researched that whole grounding/earthing stuff. Something else I recommend everyone look into. It's all about how we are disconnected from the earths impulses simply because we don't walk on the earth barefoot anymore. A great book 'Earthing'… I highly recommend.

I stopped the Vit D temporarily after talking with Elaine DeLack who said it would interfere with the Prokarin working. I don't think I'll be ordering any more Prokarin, however, since it's been about 2 weeks now and I don't think it's working for me anyway. I was taking 6 drops (6000units) of Micelized Vit D3, so when the Prokarin is done in about a week, I'll start back on that but at a higher dose of 10 drops (10,000units) as advised by a doc.

Joyce F, USA

Joyce F, USA

"I never really did start going downhill until I slacked off from my very vigorous aerobic exercise routine a few years back. You see, that is what was producing all those endorphins and I never knew of the connection till now." May '02

11 Thanks to LDN I can enjoy life – Vickie

LDN since August 2007
- story submitted 13 January 2008
- story updated July 2008 (2yrs on LDN)
- story updated July 2009 (3yrs on LDN)
- story updated January 2010 (3.5yrs on LDN)

SPECIFICS

DIAGNOSIS
- April 26 2006 to Dec 2006 – Sudden onset of frightening symptoms, eg; girdling referred to as MS hug - this resulted in a frustrating series of doctor visits and tests, including MRI, and the following diagnoses – a syrinx (a cyst in the spinal cord) - neurologist, and transverse myelitis - neurosurgeon.
- Dec 2006 – Multiple Sclerosis - Symptom progression resulted in a Lumbar Puncture, diagnosis of MS, and prescription for Rebif.

MEDICATIONS (pre LDN):
- Sept 2006 to Aug 2007 - 200 mg Lyrica 2 or 3 times a day
- Jan 1 2007 to Jul 2007 – Rebif
- Aug 2007 to Aug 2007 - Prokarin
- Jun 2007 to Aug 2007 - 10 mg Baclofen 3 or 4 times a day

MEDICATIONS (post LDN):
History:
- Aug 2007 to Aug 2007 – 3ml LIQUID Low Dose Naltrexone (LDN)
- Sep 2007 to Sep 2007 – 4.5ml LIQUID Low Dose Naltrexone (LDN) – BRIEF DOSE INCREASE ONLY
- Sept 2007 to Dec 2007 – 3ml LIQUID Low Dose Naltrexone (LDN)
- Dec 2007 to June 2008 – 4.5 ml LIQUID Low Doses of Naltrexone (LDN)
- Aug 2007 to Dec 2007 - 10 mg Baclofen 3 or 4 times a day
- Dec 2007 to Mar 2009 – 5mg Baclofen 3 or 4 times a day (reduced dosage)
- Mar 2009 - discontinued Baclofen
- Aug 2007 to Dec 2007 - 200 mg Lyrica 2 or 3 times a day
- Dec 2007 to Jan 2008 – 100mg Lyrica 2 or 3 times a day (reduced dosage)
- Mar 2009 - stopped taking Ambien
- Mar 2009 to Jan 2010 - 50mg Lyrica 2-3 times a day, 100mg once a day
- Jun 2008 to 16 Oct 2009 – 4.5mg compounded Low Dose Naltrexone (LDN) – stopped due to shoulder surgery

Present:
- 1 Jan 2010 to present - 4.5mg compounded Low Dose Naltrexone (LDN) – resumed after shoulder surgery
- Jan 2010 to present – 100mg Lyrica 2 times per day, 50mg once a day if needed
- Jan 2010 to present – Losartan (losartan potassium) x 100mg x once daily for High Blood Pressure
- Jan 2010 to present – D3 x five 10,000mg compounded capsules x twice a week
- Jan 2010 to present – B12 shot x twice a week
- Jan 2010 to present – Bi-est 2mg (DHEA 10mg, Testos 1mg) in cream form (bioidentical hormones) x once daily
- Jan 2010 to present – Progesterone 50mg in cream form x once daily
- Jan 2010 to present – Citalopram Hydrobromide 20mg (for sleep) x once daily

MEDICATION (LDN) - Notations
I started on 3ml, but soon after increasing to 4.5ml I experienced some anger issues and increased spasticity so I dropped back down to 3ml for another two months before again increasing to 4.5ml and staying there. Initially, I bought 50mg tablets and dissolved one 50mg tablet into 50ml cooled, sterilized water to make the liquid myself. I'd shake the bottle and use a needle-less syringe to draw up the exact dose and squirt it into my mouth. In June 2008 I started taking the compounded capsules instead.

SURGERY
- 16 Oct 2009 – shoulder surgery.

LDN – DOSE & TYPE
a) Dose – 4.5 mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone around 10:00pm each night
c) Type – 4.5mg compounded capsules

DIET:
Modified in response to allergy testing and guidance. No wheat, beans, dairy, eggs, cheese, walnuts, chocolate, or tuna. No nightshade vegetables. Nothing made with yeast. Limited caffeine, alcohol, sugars

SUPPLEMENTS:
Jan 2008 - I supplement with the following:
D3 - 9000 IUs daily – specially compounded
B12 injections – 3 times per week - self-administered

Enzymes - 2 capsules - three times per day
Probiotics – 2 per day - two different types taken on alternate days
Cytozyme-AD - 80 mg - twice per day
MSM – 30mcg - twice a day
Multivitamin – 1 per day
Chlorophyll tablets – 8 tablets - three times per day
Acetyl L carnitine – 1 per day
Evening primrose oil – 1 capsule - twice per day
CoQ10 - 300 mg - twice per day
B complex – 1 per day
Inf-Zyme Forte –1 per day - with a meal
Mar 2009 to Jan 2010 - I supplemented with the following:
D3 - 9000 IUs – twice per week – specially compounded
B12 injections – 2 times per week - self-administered
Enzymes - 2 capsules - three times per day
Probiotics – 2 per day - two different types taken on alternate days
Chlorophyll tablets – 8 tablets - three times per day
Acetyl L carnitine – 1 per day
Evening primrose oil – 1 capsule - twice per day
CoQ10 - 300 mg - twice per day
B complex – 1 per day
Calcium – 1500mg per day
Krill Oil
DHEA
Bio-identical hormones
Jan 2010 – This is my current list of supplements:
Chlorophyll tablets x 12 per day
CoQ10 300mg x twice per day
Calcium 1500mg x 1 per day
Krill Oil

ACTIVITIES & EXERCISE:
Jan 2008 - My lifestyle had become increasingly limited and restricted by extreme fatigue. I'm more productive. I can go out with friends, stay up late like a grown up! I can shop. I can walk my puppies.
July 2009 - I'm riding my bike again. I bought it shortly before I developed symptoms. It sat in the garage for two years!
January 2010 – I'm using Wii for exercise and walk my dogs at least once a day.

MY STORY – January 2008

I had a sudden onset of symptoms beginning April 26, 2006. Most notably was the girdling or MS hug. I was misdiagnosed by a GP but eventually referred to a neurologist. I had test after test, including MRIs, and was originally told I had a syrinx. This didn't feel right to me. I took my MRIs to a neurosurgeon who told me I had transverse myelitis.

My symptoms continued to progress so I had a lumbar puncture and in December 2006 I was told I had MS. In January 2007 I started on Rebif.

Over the course of the next seven months my physical condition deteriorated. I had to take naps, sometimes on the floor of my office. I didn't think I was going to be able to continue working.

I felt as though I had a large boulder on my shoulders. My lifestyle had become increasingly limited and restricted by extreme fatigue. I shuffled along slowly. I used a cane if I had to walk any distance. On the rare occasions I went to the grocery store I had to use the carts, so I had begun 'shopping' for an electric cart because I couldn't walk.

This was a very difficult time for me. I'd spent twenty years in the military and was very fit mentally and physically. During all those years I was always the person others had a hard time keeping up with when walking, but I'd reached a point where I didn't feel like doing much of anything. I'd go to work, come home, sit for a little while, then sleep.

I wasn't getting anywhere, and my first neurologist didn't listen and didn't seem to care. Once I made up my mind to discontinue the CRAB medication, I cut my ties with the intent of going it alone.

In July 2007 I stopped taking the Rebif. I just couldn't bear the thought of another shot. As each day passed I felt stronger and stronger.

Then, during my travels over the Internet I came across the low-dose naltrexone treatment (LDN). I was intrigued. I had a good doctor but he appeared to be influenced by the Rebif people – and he certainly wasn't open to alternative medicine.

I took a leap of faith on 1st August 2007 and started LDN. I'd read a lot about LDN. I was hopeful it'd halt progression of my MS and I also hoped to benefit from symptom improvement.

During the same period I also tried Prokarin for a very short time, but I found it too difficult to work with and stopped taking it.

I now go to the Veterans Administration for my MRIs and medications. I have not discussed my taking LDN with the VA. I'll raise it after I see the results of the MRI at the end of the year.

My condition has improved greatly. If nothing else LDN has increased my energy level. I think it also helps me sleep. I've been able to cut my use of Baclofen and Lyrica in half.

I had MRIs of brain, cervical and thoracic spine in December 2007. The neurologist told me that the lesion over T8 was inactive, no change when the contrast was introduced – and there were no new lesions in my brain.

I've also found an ecological internist. She's started me on high doses of D3, shots of B12 and a box full of supplements. I was tested for allergies and have been working hard on cleaning up my diet.

I'm not 100% yet but I work all day with no problems. In fact I feel like I'm more productive. I can go out with friends. I can stay up late, like a grown up! I can go shopping. I can walk my puppy.

Now I feel like I've got my life back I want to tell everyone who might benefit about LDN. Some people are very receptive, others not so much. But I figure if you plant the seed, when they're ready they'll remember. Low-dose Naltrexone has given me my life back so I'm sharing my story in the hope it'll inspire and benefit others.

UPDATE: July 2008 – 2 years on LDN

Changed from liquid LDN preparation to compounded capsules. Also switched doctors. The new doctor is an M.D. who runs a clinic offering infrared sauna, acupuncture and other services. I am starting chelation therapy in a week to reduce my heavy metals load. I'm still benefiting from LDN and will continue to take it.

UPDATE: July 2009 – 3 years on LDN

I'm still taking my LDN, and I've also done 18 chelation therapy treatments.

I went back to Hippocrates in W. Palm Beach Florida in March 2009, and spent three weeks doing wheat grass, juices, raw food diet, mineral pool, infra-red sauna. I did great.

When I came home I purchased a portable infrared sauna and a dehydrator. I'm juicing daily. I also started seeing a true osteopath in town. I believe he is helping me a great deal. I'm doing manual medicine treatments and also attending a healing circle two or three times a month.

I'm being very proactive about my health, and it's paying off.

Update - January 2010 – 3.5 years on LDN

I have completed twenty chelation treatments to deal with the heavy metals in my system. I now try to go once a month for chelation. From October 16 2009 to January 1 2010 I was unable to take LDN due to a shoulder surgery and subsequent use of pain medications. During my recovery period I did Manual Medicine Therapy as well as Physical Therapy.

I added Dr. Keith Barbour, an Osteopathic Medicine doctor, to my 'arsenal'. I do aqua therapy and regular manual medicine treatments. My orthopaedic surgeon was actually surprised at how well I was doing at my three-month check up.

I still try to watch what I eat although I sometimes struggle. I have cut my coffee consumption greatly. I still juice and buy sunflower sprouts at least once a week to add to the juice. I recently attended level 1 of an Esoteric Healing class so that I can understand energy work and use it to help myself.

I no longer use Baclofen and the spasticity is not a problem. Neither is the fatigue. I take 100mg of Lyrica twice a day and on a long day I may take a 50mg between. I am using Wii for exercise and walk my dogs at least once a day.

My only real complaint is the neuropathy in my legs and feet, but this doesn't stop me from walking or working full-time. I am grateful that I found LDN and alternative medicine treatments.

Vickie, USA

Vickie, USA

"I'm not 100% yet but I work all day with no problems. In fact I feel like I'm more productive. I can go out with friends. I can stay up late, like a grown up! I can go shopping. I can walk my puppy." Jan '08

Why I contributed my case study…

I started my journey with M.S. on Rebif because the doctors told me that it was my only hope. Every time I gave myself the injection I felt it coursing through my body and I became more physically disabled. Until I found LDN my future looked bleak. I didn't think I'd be able to continue working. I had to use a cane and I couldn't shop without using the electric carts. Whenever I meet someone facing a serious illness I try to tell them about LDN and how it can help them. It's sometimes difficult to convince people that something as inexpensive as LDN can work better than the $1600 a month of conventional medicines. With Rebif I had side effects that required four or five other medications. With LDN I take only one other medication. LDN gave me my life back.

12 LDN has been a miracle for me – Art

LDN since March 2005
- story submitted Dec 2007
- story updated July 2008
- story updated January 2009 (almost 4 yrs on LDN)
- story updated January 2010 (almost 5yrs on LDN)

SPECIFICS

DIAGNOSIS
- 1988 - Relapsing Remitting Multiple Sclerosis (RRMS)
- 2002 – Secondary Progressive Multiple Sclerosis (SPMS)

MEDICATIONS (pre LDN)
- 1992 to Mar 2005 – Medicinal Marijuana – occasionally on weekends – helps relax stiff muscles, aid sleep
- 1994 to 1994 - IV Solumedrol, oral Prednisone
- 1997 to 2001 - Avonex
- 2001 to June 2005 - Copaxone, plus five treatments of Novantrone, plus numerous IV Solumedrol/Prednisone taper-offs

MEDICATION (post LDN)
- 1992 to present – Medicinal Marijuana – occasionally on weekends – helps relax stiff muscles, aid sleep
- Mar 2005 to Apr 2005 – 3mg Low Dose Naltrexone (LDN) NB I continued with Copaxone at the same time but only for 2-3 months.
- Apr 2005 to present – 4.5mg Low Dose Naltrexone (LDN)
- July 2008 - Prokarin patch for pain - 1 x 1.65mg in the morning, lasts 16 hours
- July 2008 - 4-aminopyridine (4-AP) 5mg x 8 times a day
- early 2010 – steroid injections to control inflammation and pain from 2 herniated discs in my spine

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN) NB Started at 3.0mg, then went to 4.5mg after one month.
b) Time - I take my Naltrexone at 10.45pm every night
c) Type - My naltrexone is compounded into capsules with Avicel filler.

SUPPLEMENTS
- Jan 2010 – During the last 12mths, I've taken the following daily & occasionally:
Multivitamin without iron
4-AP
Probiotics
Citrucel Fiber Tablets
Montmorency Tart Cherry Juice
Magnesium
Omega-3 Fish Oil Capsules
CoQ-10
Vitamin D3
Ester C
B-Complex 100
B-12 (Methylcobalamin)
Benfotiamine
Turmeric Extract
- Jan 2010 – I commenced these new supplements in Jan 2010:
Epicor
Fucoidan

DIET
- Dec 2007 - I restrict my diet: I don't eat dairy, sugar, soy, legumes, eggs, red meat, or gluten (found in wheat, barley, rye, and oats). The foods I do eat are fresh fish, organic chicken, and fresh raw organic fruits and vegetables. I drink only bottled distilled water, and believe highly in the benefits of Coconut Oil (3 tablespoons a day) and Stevia (which is an excellent sugar substitute and has replaced my desire for sugar), and I use coconut oil in place of butter and cooking oil.
- Jan 2010 - I still try to avoid eating foods containing gluten, casein, sugar, corn, soy, legumes, eggs, red meat. The foods I try to eat are fresh wild fish, organic chicken, brown rice, and fresh raw organic fruits and vegetables. I believe highly in the benefits of Coconut Oil and Stevia.

ACTIVITIES & EXERCISE
- Dec 2007 - light stretching and casual walking
- Jan 2010 - I try to walk as much as possible, light stretching, ride my exercise bike, deep breathing and lift moderate weights.

HOBBIES & INTERESTS
- Dec 2007 - reading, music, my girlfriend

MY STORY – December 2007

In April 1988 I had a neurological attack that sent me to the hospital for over one month and out of work for many months. The MRI showed I had lesions on my brain stem / pons area of the brain. After ruling out Lyme disease, encephalitis, stroke, cancer and other things the neurologist diagnosed me with Multiple Sclerosis. It was very upsetting. I was still a young man and my passion was playing sports that I could see myself doing until the day I died. That dream was over forever.

I was very messed up for two years after the initial attack. Couldn't see or walk straight. Was actually blind for a few weeks. Never thought I would recover and become independent again. I briefly considered suicide because I was very depressed.

I gradually pulled out of the attack with the help of IV Solumedrol and oral Prednisone, which was all the doctors had to offer back then. CRAB meds were unheard of. At first, the IV Solumedrol was like a miracle, always pulling me out of an exacerbation. I think I probably got more relief from the IV solumedrol and oral prednisone than anything else, but over time even these drugs became less and less effective.

I made a full recovery and was symptom free until around 1994. It was like I never had MS. At the time I wasn't under the care of a neurologist, which, in hindsight, was a mistake.

1996 was a very rough winter here in New York. We had a major blizzard and snowfall after snowfall. I work as a maintenance supervisor for a real estate company and part of my job is to see that the snow is removed from their properties. It was a very stressful winter for me both mentally and physically.

MS returned with a vengeance that year so I ended up seeing a Neurologist who put me on Avonex. I don't recall the Avonex doing anything very positive for me, in fact, it made me very ill. I had flu-like symptoms and became depressed, and the injections were very painful.

Even so, there was nothing else recommended so I took the Avonex for over three years until it stopped working for me. What I mean by 'stopped working' is that I was told I'd developed antibodies against interferon medications, so the Neurologist changed my prescription to Copaxone. I took that for over three years.

Did I notice any change with Copaxone? No, nothing - zero, zilch – but the injections were a pleasure compared to the Avonex. My Neurologist also prescribed five treatments of Novantrone.

I had many, many IV Solumedrol/Prednisone taper-offs in between all of this, but I'd reached the point where nothing was holding the MS off - nothing - so the Neurologist then suggested Betaseron.

I was incredulous. I asked him why he suggested Betaseron when he'd led me to believe I was immune to interferon meds. He responded; "well, we have to try something".

He also thought about putting me on Tysabri - just before it started killing people and was pulled from the market. It was then I realized he was only experimenting on me and really didn't have any definite answers.

I am 6'7" and weigh 240lbs but I broke down and cried in his office. His nurse saw me and suggested I look into LDN even though the neurologist was against it. She is my special angel. So, I researched LDN.

Shortly after, Tysabri was pulled from the market. My neurologist already knew I didn't want to use Betaseron (hard to argue with someone my size), so he agreed to give me the script for LDN.

I've been on LDN since March 2005 and I shudder to think where I'd be without it.

It was VERY scary deciding to go on LDN. I felt like I was taking a big risk - like a victim of a shipwreck dumped into the sea without a life preserver. It was either swim or sink.

Thankfully my fears didn't last long. I noticed positive improvements within days of starting LDN - better bladder control, less blurry eyesight and a bit less fatigue, those being the main ones. Like a miracle!

I know everyone doesn't experience symptom improvement, so I feel very lucky. I had improved my diet before starting LDN so maybe that made the difference for me.

I was originally diagnosed with Relapsing/Remitting type MS but my Neurologist upgraded it to the next level around 2002. I think it's called Secondary Progressive Multiple Sclerosis (SPMS).

Yes, I'm a BIG advocate for LDN and wish I could sue someone's ass off for the years I used the dangerous, expensive, ineffective CRAB/Novantrone meds. They only made me worse.

LDN has been a miracle for me.

UPDATE: July 2008 – 3 years on LDN

No change in health.

UPDATE: January 2009

I've been using coconut oil for about three years now in place of butter and cooking oil. It is delicious and I feel it is helping me control/reduce a candida yeast problem.

One of the tell tale signs has been a severe toe fungus problem I have been struggling with for a long time, without using any prescription drugs. Since starting coconut oil, it has just about vanished. It takes a long time, but worth the effort.

I am on a diet free of gluten, casein, sugar, soy, tap water, and red meat. I take up to six capsules a day of acidophilus and I am about to start something called Threelac for candida yeast control.

If you want to be as healthy as possible you've got to go all the way, half way doesn't cut it. Sacrifice and willpower is the ticket.

UPDATE: January 2010

I am still taking 4.5mg LDN every night. I get my capsules via mail order from a compounding pharmacy in Florida. The cost is approx $25.00 a month.

I have experimented with doses, dosing times, and skipping doses, but find personally, I am better off with my usual every night dosing schedule, taking my LDN exactly at 10pm now instead of 10.45pm.

My multiple sclerosis has not progressed as far as I can tell. My eyesight is less blurry, fatigue level improved, little numbness in my face, bladder control is okay, although I have an occasional accident in bed while sleeping as I don't always empty my bladder before bed. Thinking is sharp and so is memory.

I do have problems with two herniated discs in my spine and will be going for steroid injections soon. The discs cause me more problems than does the MS. LDN has solved that problem. I work full-time as a maintenance supervisor for a real estate company. It is very stressful.

I still follow a restrictive diet free of sugar, gluten, casein, red meat, eggs, corn and legumes to the best of my ability. When I was first diagnosed with MS back in 1988 I thought my life was over. LDN has given it back to me.

It is a crime LDN is not more widely accepted. So many people who could benefit from it are being denied it's healing powers and I think the biggest reason is greed and money.

Art, USA

Art, USA

"At first, the IV Solumedrol was like a miracle, always pulling me out of an exacerbation. I think I probably got more relief from the IV Solumedrol and oral prednisone than anything else, but over time even these drugs became less and less effective." Dec '07

© Case Health Pty Ltd

13 My MS & TM Story – Crystal

LDN since 3rd September 2005
- story submitted July 2008
- story updated May 2009
- story updated April 2010
- story updated April & July 2010 (over 4.5yrs on LDN)

SPECIFICS

DIAGNOSIS
- Childhood - Heart murmur discovered at birth - no treatment
- late 1960s - Viral Meningitis
- late 1960s to late 1970s – seizures requiring hospitalisation
- 1997 - Endometriosis
- 1998-1999 – pressure in head led to doctor prescribing blood pressure medication that resulted in emergency trip to hospital
- Nov 2004 – Secondary Progressive Multiple Sclerosis (SPMS) and Transverse Myelitis (TM) – based on MRIs plus clinical assessment.
- Jun 2005 to Aug 2005 – bad case of Cellulitis at injection site, then progressive decline over next 8 mths - walker, to a wheelchair to a Hoveround power chair.
- Oct 2008 – Ovarian Cysts and Fallopian Tubes were blocked and wrapped around colon - fallopian tubes and ovaries removed.
- Apr 2010 - Gallstones

TESTS

- 15 Nov 2004 – MRI of Thoracic Spine
- 23 Nov 2004 - X-ray, lumbar puncture
- 23 Nov 2004 - MRI of Thoracic Spine with Contrast:
Clinical History – Abnormal spinal cord lesion identified on MRI 15th Nov 2004. Evaluate for transverse myelitis, intrinsic spinal cord tumor, or a demyelinating lesion.
Findings – **Comparison is made with a noncontast MRI of the thoracic spine of 15th Nov 2004. Again demonstrated is abnormal T2 hyperintense signal centered within the spinal cord extending from the mid T4 through the mid T5 vertebral body. The largest portion of the lesion is located at the T4-5 disc space level.** There is no cord expansion of cord atrophy. The abnormal signal is not limited to the H-shaped region expected of isolated grey matter involvement only. There is the suggestion of minimal low corresponding T1 weighted signal intensity at the superior end plate of T5 level demonstrated on axial precontrast T1 weighted sequence #11. Following gadolinium administration, there is minimal enhancement of the lesion best demonstrated on sagittal T2 weighted image #6 and postcontrast axial image #10 and #11. As stated above, the lesion is centrally locally and does not preferentially involve the dorsal or posterolateral aspects of the cord as is often found in multiple sclerosis. There is no corresponding very low T1 weighted signal alteration to this lesion to support a finding of syrinx.
Impression: **Abnormal intramedullary cord lesion from the mid T4 through the mid T5 vertebral body levels.** The abnormal signal is centered within the thoracic spinal cord, contains minimal contrast enhancement, and is not correlated with spinal cord expansion or atrophy. This finding is entirely non-specific. **Differential diagnosis includes a demyelinating process such as multiple sclerosis, although not typical. Other etiologies to consider include transverse myelitis** less likely lupus or sarcoidosis. Primary/metastatic disease cannot be entirely excluded. Please correlate clinically. A follow-up enhanced MRI of the thoracic spine in 8 weeks time is recommended to evaluate for interval change or stability unless clinical symptomatology dictates a follow-up examination at an earlier date.
- 23 Nov 2004 – MRI of the Brain without and with contrast:
Clinical History - Multiple Sclerosis
Findings – The ventricles are normal in size and within the midline. There is no evidence of extra-axial fluid collections, mass, mass effect or intraparenchymal hemorrhage. **There are minor scattered foci of increased FLAIR signal intensity within the subcortical white matter. These foci measures 3mm or less.** There are no periventricular lesions or abnormal foci of increased T2/falir signal intensity involving the structures of the posterior fossa. Normal intracranial vascular flow-voids are present in the major vessels of the Circle of Willis and dural venous sinuses. There are no gross abnormalities related to the sella turcica or pituitary gland. The optic chiasm is not compressed. There is no cerebellar tonsillar ectopia. There are no significant inflammatory changes of the paranasal sinuses or mastoid air cells. There is no abnormal contrast enhancement throughout the brain parenchyma or meninges.
Impression – **Nonspecific, minimal foci of increased FLAIR signal intensity in the subcortical white matter.** All foci measure 3mm of less, are not associated with mass effect or abnormal contrast enhancement. These small foci may be found in asymptomatic individuals. Clinical correlation is necessary.
- Mar 2006 – MRI of the Brain
- 7 Dec 2006 – MRI of Thoracic Spine without and with contrast:
Indication for Study – Numbness in back question MS
Scan Findings – There is normal vertebral body height and alignment. **An intramedullary lesion at T4-5 is identified located fairly centrally within the cord.** It does not enhance with Gadolinium administration. There is normal vertebral body height and alignment. No pathologic abnormalities of marrow signal are seen. No large disk herniations are identified. **When comparison is made to the outside study dated 15th Nov 2004, the intramedullary lesion which likely reflects a demyelinating plaque is either unchanged or is slightly smaller. No other intramedullary lesions are seen.**

Impression – **Non enhancing intramedullary lesion at T4-5 which may reflect a demyelinating plaque without significant change from the study of 2004.**
- 7 Dec 2006 – MRI of Brain Cmplx without and with contrast:
Indication for Study – Numbness in back, question Multiple Sclerosis
Scan Findings – Examination demonstrates several scattered foci of high T2 signal in the periventricular white matter which are indeterminate *but may reflect demyelinating plaques*. They are not hypointense on 11 weighting and while noted on the FLAIR images are scarcely noted on the 12-weighted sequences. They are not identified on the diffusion weighted images nor do they enhance with Gadolinium administration. No extraaxial fluid collections are seen. The craniocervical junction appears normal.
Impression – *Scattered white matter lesions which may reflect demyelinating plaques*.
- 18 July 2007 - Blood Tests: Result - all within normal range.
Complete Blood Count (CBC) with Differential/Platelet
Complete Metabolic Panel (CMP) - (14)
Thyroxine (T4) Free, Direct S
Folate (Folic Acid), Serum
TSH
Vitamin B12.
- 12 Aug 2007 – MRI Brain without and with contrast:
Clinical History - Previous diagnosis of Multiple Sclerosis
Findings – The ventricular system is normal in size and configuration. On T2-weighted images there are multiple very small areas of increased signal noted in the centrum semiovale and corona radiata. There are no definite pericallosal or periventricular lesions noted. This is non-specific. The area of the pineal and pituitary is normal. The area of the sinuses, nasopharynx and upper cervical cord is normal. After the administration of contrast there is no abnormal enhancement noted.
Impression – Abnormal MRI of the brain because of non-specific white matter disease as noted above. This was not particularly specific for multiple sclerosis but that cannot be ruled out. There are no significant pericallosal or periventricular lesions that would be typical for multiple sclerosis.
- 3 July 2008 – Neurological Annual Check-up:
Problem List – (1) History of demyelinating disease – previously diagnosed with transverse myelitis and MS (2) History of transverse myelitis in the T-spine in 2004. (3) Viral Meningitis at birth (4) Heart murmur since birth (5) Hysterectomy (6) History of C-section.
Medications – Klonopin 0.5 bid, naltrexone 4.5mg qd, Darvocet N 100 one-half tablet bid, (discontinued muscle relaxers).
History of Present Illness – Crystal has come back in today for a six-month follow-up. She is doing great. She has had no exacerbations and no problems. She is staying at home. The summer heat has been giving her a bit of trouble and she sometimes has some weakness in her right arm when she gets hot, but otherwise she has not had any kind of problems. She has continued to take her regular medications except for her muscle relaxers. She stopped taking them because they really didn't seem to be helping. She says sometimes she just has cramping and burning pains in her muscles and her arms and legs will begin to draw up. She also describes a new problem which is restlessness of the legs. They have a difficult to describe sensation in them. They crawl, they burn, and they pull at night. She has to move her legs continuously, has trouble sitting at the computer for very long, and it is hard for her to watch a whole movie. This seems to be getting a little worse over the past three or four months. Family, social and personal history, and review of systems are up to date and in the chart. She has had a problem with a flare up of a ruptured ovarian cyst back in June, but is over that now.
Physical Examination – W 122. BP 120/76. P 54. R 16. General – Crystal is pleasant. She is alert and oriented. She is neatly kept and looks great. Cranial nerves II through XII are intact. She has sharp disk margins. EOMs are normal. No nuchal rigidity. Negative Lhermitte's. She has 5+ strength in the upper and lower extremities. She has normal sensation. DTRs are 3. She stands and walks with a steady gait and has good balance.
Assessment – (1) History of demyelinating disease – previously diagnosed with transverse myelitis and MS. She has no recent activity of disease. She has been doing very well and has not had any exacerbations. She is due for her annual check-ups. (2) Probable restless legs syndrome – by her history given, it sounds that this could be a problem. We will let her try a different medication for it.
Plan – (1) Given refills on her current prescriptions. (2) Given a prescription for Zanaflex 4mg. She can use it two three times a day if needed for the muscle cramping and spasms – hopefully she will be able to take the Zanaflex and be able to wean herself off of the Darvocet which is the goal. (3) Given a Requip starter pack for restless legs syndrome along with two booklets on RLS. Questions were answered. She will call and let me know how that works out. (4) Blood tests ordered – CBC, CMP, TSH, free T4, B12, folic acid. (5) MRI brain with and without contrast for her annual study. (6) We will see her back in six months.

HOSPITALIZATION, SURGERY, TREATMENT
- July 1992 - Caesarean
- late 1960s to late 1970s – seizures requiring hospitalisation
- 1997 – Endometriosis – resulted in partial Hysterectomy (Cervix and Uterus) and fallopian tubes being cut and tied
- Aug 2005 – Cellulitis - surgery to drain fluid
- Oct 2008 – Hysterectomy - Fallopian tubes and ovaries removed due to Ovarian cysts, and tubes blocked and wrapped around my colon
- April 2010 – Surgery to remove gallbladder

MEDICATIONS (pre LDN)
- late 1960s to late 1970s - Phenobarbital for seizures
- 1998-1999 - unidentified blood pressure medication taken for 2 weeks
- Nov 2004 - 3 days of IV steroids in hospital, oral steroids at home
- Nov 2004 to Jul 2005 - Betaseron injections

- 2004 to Sept 2005 - Klonopin
- 2004 to Sept 2005 - Methocarbamol
- 2004 to Sept 2005 - Parafon Forte

MEDICATION (post LDN) - HISTORY
- Sept 2005 to Feb 2009 – Methocarbamol (replaced by Flexeril)
- July 2008 to July 2008 - Zanaflex 4mg (trialled as replacement for Methocarbamol, unsuccessfully)
- 3 Sept 2005 to Feb 2006 – Started on 3mg Low Dose Naltrexone (LDN), increased to 4.5mg by Feb 2006
- Feb 2009 to ? - Flexeril - occasionally at night - muscle relaxant and aids drowsiness (instead of Methocarbamol)

MEDICATION (post LDN) - CURRENT
- Sept 2005 to present – Klonopin 5mg x twice per day
- Sept 2005 to present – Darvocet (taken in place of Parafon Forte)
- Feb 2006 to present – 4.5mg Low Dose Naltrexone (LDN)
- Feb 2009 to present – Estradiol 2mg x once per day (Hormone replacement following hysterectomy)
- Sept 2005 to present – Darvocet-N 100 x 650mg x twice per day as needed (initially to replace Parafon Forte)
- Apr 2010 to present - Parafon Forte 500mg x twice per day
- Apr 2010 to present - Prilosec 20mg x once per day
- Apr 2010 to present - Valium 2mg x once per day at night (taken in place of Flexeril)
- Apr 2010 to present - Imitrex 50mg x once or twice per day (as needed for Migraines)

LDN – DOSE & TYPE:
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone between 9pm and 10pm each night
c) Type – my naltrexone capsules are compounded from pure naltrexone powder and Avicel filler by Skips Pharmacy, Florida, USA.

DIET
- average, no restrictions

SUPPLEMENTS
- none

ACTIVITIES & EXERCISE
- Some walking and whatever I can do when I can do it

MY STORY - July 2008 – almost 3 yrs on LDN

My name is Crystal and I am a 40+ mother of 3 teenagers (a son and beautiful twin daughters). On November of 2004 I was diagnosed with Secondary Progressive Multiple Sclerosis (SPMS) and Transverse Myelitis (TM).

I'm pretty sure it started when I was very little. After I was born I was diagnosed with Viral Meningitis and I had seizures and was on Phenobarbital up till I was 12-13 years old, then I out-grew it. I had been in and out of the hospital over the years throughout my childhood because of the seizures. I remember my mom telling me she would say things to me to try to get my attention but it would take her a while. She also said that sometimes I would not remember things that she and others would tell me.

While I was growing up I had gone to see many doctors regarding different symptoms and they would always tell me something different was wrong or that nothing was wrong with me. Around 1998-1999 I started having symptoms that I couldn't explain but all the Dr's I went to kept telling me nothing was wrong with me, it was all in my head or I was having panic/anxiety attacks. One time I was having a lot of pressure in my head that I knew was not normal so my first husband took me to this Dr and he gave me these pills and said to take them and it would take the pressure away. So I took the pills for 2 weeks until I woke up one morning feeling really strange; like I was drifting away. I called my mother and she told me to lay on the couch and I'd be ok.

At that time I was getting no support from anyone in my family because they believed all the Dr's that said it was all in my head. Anyway I just didn't feel right and felt like I was dying so I called 911 and lucky I did or I would be dead right now. They came and my blood pressure and heart rate was so low they had to give me something in the ambulance to bring them back up and I spent 2 days in the hospital. Well I found out that the Dr gave me blood pressure medication for the pressure in my head.

One morning I managed to get out of bed and made it to the living room and collapsed because my legs were totally numb. So my husband took me up to the little hospital in town and they left me lying on a hospital

bed for a few hours not doing any tests and then just sent me home. They did nothing and said nothing was wrong with me. I wasn't even able to drive, but yet there was nothing wrong with me.

Eventually, I started feeling better, driving and went back to work as a CNA in a Nursing Home for 2 years. Later I got a job at a small family-owned office supply store. Things were going really bad with my marriage and it was affecting my health so I got the courage up and told my husband I wanted a divorce and he tried to force me to stay but I said no. A week later he came home, had my mother take my kids out of the house without me knowing and kicked me out of the house with nothing. My ex dragged the divorce on for 2 years while telling my kids it was all me. Talk about stress...

After my divorce I was in 2 car accidents that were not my fault. I moved back in with my mother and stepfather for a year, then I met a guy from Florida and ended up moving down to Florida. On March 20th, 2004, a year after moving to Florida, we got married. Eight months later I was diagnosed with SPMS and TM. At the time I had been working for a brochure company driving a van to hotels and other places putting in brochures in the racks to keep them full. I was with them for almost a year before my diagnosis. My first symptom was feeling extremely tired all the time. When I got home from work I would have to lie down and take a nap, which was unusual for me. Later I read that tiredness is one of the first signs of MS. I then started having a lot of back and neck pain and then went numb from my feet up to my chest and could barely walk. I ended up working for a week driving a van and delivering brochures in this condition.

I visited our family doctor and after explaining to him what was wrong he only asked for an x-ray and checked my lower back and of course he found nothing. So he quickly dismissed my symptoms as stress and too much physical activity. After months of this constant numbness and pain, I decided to go to a Chiropractor because I thought it was a pinched nerve. So I went and he did some x-rays and an MRI.

The next day that doctor asked me to come in right away. The 10 minute drive to his office was the longest drive, filled with fear and anxiety, I'd ever felt. When I arrived for my results he told me he could not examine my back or carry out any procedures on my back because there was a mass in my spinal cord from the lumber region to my shoulder blades but he could not tell me if it was a tumor or just a mass. He said he'd made an appointment for me with a Neurologist the next day. The hours before the appointment with the Neurologist were the longest that me and my family had to endure at home wondering what was in store for me and us.

The next morning at the Neurologist, I explained the symptoms I was having. He did some more tests in his office, and asked for another MRI with and without contrast (important to diagnose MS) and admitted me to the hospital to do a Lumbar Puncture. He ordered three days of Steroids through IV in the hospital and another week at home. A week later my Neurologist explained that after reviewing the symptoms I had complained about and reviewing my medical records he determined that I had Transverse Myelitis. Also, he said he knew I had Multiple Sclerosis before he got the results of the Lumbar puncture, and that he believed MS had been present at other points in my life. He just needed the Lumbar puncture results to confirm.

When he told me I felt like I was in a bad dream. It felt like I hit a brick wall. My mind was numb and I didn't want to believe what I was hearing. I was so devastated and all I thought about was that I would end up being a cripple the rest of my life and would have to depend on others to take care of me. I was scared to death!!!

My husband and I sat my kids down and explained that I was sick. We tried to explain it in a way that they could understand for their age. They seemed to understand and didn't say much but I know they were worried. We also told them that I wouldn't be able to do a lot of stuff I was able to do before and they said they understood.

My Neurologist started my treatment right away, which is essential in treating MS. He prescribed Betaseron injections, a medication for MS which is supposed to help slow down the progression of MS. What the doctors don't tell you is that it's only supposed to help Relapsing Remitting MS (the 1st stage). I was on Betaseron for the first 8 months after my diagnoses, but it wasn't helping me at all and just made me feel worse.

I ended up getting a bad case of Cellulitis, a bad infection, in my right upper thigh from the injections. I was bedridden for 3 months during the summer of 2005. I ended up having to have surgery to drain all the fluid. It was the most painful thing I have ever felt in my whole life. My husband had to help me up to the bathroom because I couldn't walk by myself and I cried all the way there and all the way back because of the pain.

In the next 8 months I went from using a walker, to a wheelchair to a Hoveround power chair.

While I was bedridden with the infection I did a lot of research online and found out about another medication that some MS people were using and it was helping them a lot. I started e-mailing with them and got all the information I could. The medication is called Low Dose Naltrexone (LDN) and it is compounded into a capsule you take every night between 9pm and 3am. I went to my Neurologist and asked him about it but he had never heard of it because it had not been approved to treat MS or TM.

I had printed a bunch of information about it and gave it to him and he said he would read through it and get back to me on it. A couple of days later he called me and said it looked good and we could give it a try if I still wanted to. I said yes and he called it in. I started taking 3mg on September 3rd, 2005. My understanding was it could take up to a few months to get the full effect from LDN but I started feeling beneficial effects from it the very first night. I didn't have any side effects until around five months later when I increased the dose to 4.5mg. I had a hard time sleeping and had really vivid, weird dreams for about 2 weeks, then they went away and I've been fine since.

LDN took away my 'MS Hug', and helped me walk without a walker, wheelchair, or Hoveround power chair. It also helped with some of my back pain, muscle spasms, most of the numbness or tingling in my legs, and my swallowing problems. Another benefit was that I was no longer fatigued most of the time. LDN gave me back the ability to do a lot of things I never thought I'd be able to do again.

It's difficult for people that don't have MS or Transverse Myelitis to understand what you are going through. These are Neurological disorders, and some of the symptoms can't be seen on the surface, so those who don't understand these diseases may think there is nothing wrong with you.

After I was diagnosed with MS and TM I recalled different things that had happened to me over the years and I could link them to symptoms of these diseases. I was always misdiagnosed with something else or the doctors would tell me it was all in my head. Believe me, I wish it had all been in my head.

After I was diagnosed with SPMS and TM we went looking online to find information. We had to go through tons of different websites and I thought, 'this is crazy'. So, I decided instead of sitting there and pitying myself, and not doing anything that I would start my own website.

I started Crystal's MS, TM and LDN website in 2005 and on it I published a list of all the websites I found about MS and TM, plus other information that would make it easier for people learn more. I also started an LDN_Users Support Group for people that need support and information about LDN for autoimmune diseases, and I started Crystal's LDN Gift Shop. I now send out a monthly newsletter about things that have to do with MS, TM and LDN.

UPDATE May 2009

As of May 2009 and being on LDN for 3 years and 8 months for Secondary Progressive MS and Transverse Myelitis, I am still doing good and no relapses at all. If it wasn't for finding LDN in 2005 I would still be in a powerchair but because of LDN I have most of my life back. I still have good and bad days but not near as bad as before LDN. I've been to the beach 3 times in the last couple of months and stayed 4-5 hours each time and if not for LDN I wouldn't have been able to stay for maybe an hour.

UPDATE – 13 April 2010

I moved to be closer to my mum, but I'm missing my children.

I have had a lot going on. I thought things were settling down but now I have to have surgery to have my Gallbladder out due to gallstones. I go tomorrow morning, 14 April, for a surgery consult to find out when they are going to do the surgery. I'll keep you posted...

I am still on 4.5mg LDN. This year on Sept 3rd will be 5 years on LDN. Yes, it is still benefiting me for my SPMS and TM.

All I can say is Thank God for LDN and Until There Is A Cure - There Is LDN!!!

May there be a miracle in YOUR life today and may you have the EYES to see it.

UPDATE - 10 May 2010

I'm doing okay since my gallbladder surgery in April, but have had some complications from the surgery that I'm getting checked out. I had some tests done and I have a Urinary Tract Infection (UTI). I also have to go for an MRI tomorrow on my left leg because since the surgery it's felt really weird when I lay on it, and it went numb from my left hip to upper thigh. It wasn't like that before, so I've been resting and trying to get my strength back.

UPDATE – 24 May 2010

I'm getting better slowly. After surgery I had a Urinary Tract Infection, and I then had to go for an MRI because my left hip and upper thigh started going numb and felt weird when I lay on it. They chipped one of my front teeth while they had the tube down my throat during surgery, so they're having that fixed this Friday.

I've always had sinus headaches but I think they've turned into migraines, and I had one this past weekend so wasn't feeling real good.

I'm still trying to adjust to living by myself, which is very hard most times. My girls are graduating high school June 3rd and I was going to go down to Florida for it but the tickets are way too expensive for me to afford to go. They're Streaming Live this year for the first time so I'll at least see it online and get to save it, I hope.

UPDATE – July 2010

I'm finally feeling better since surgery to remove my gall bladder, but I don't like where I'm living because I can't get out very much and I'm missing my girls who graduated last June.

From My Heart to Yours
Love, Hugs & Blessings,
Crystal, USA
www.crystalsmstmldn.org
"We either make ourselves miserable, or we make ourselves strong. The amount of work is the same."

Crystal, USA

"LDN took away my 'MS Hug', and helped me walk without a walker, wheelchair, or Hoveround power chair. … LDN gave me back the ability to do a lot of things I never thought I'd be able to do again." Jul '08

www.crystalsmstmldn.org

'Crystal Speaks' 2007 – video

http://crystalangel6267.webs.com/videosonmsldn.htm

1. Crystal's MS,TM and LDN website: freewebs.com/crystalangel6267/index.htm
2. LDN_Users Support Group: health.groups.yahoo.com/group/LDN_Users
3. Crystal's LDN Gift Shop: cafepress.com/crystalldngifts

14 I have PPMS but doing well – Emily

Low Dose Naltrexone (LDN) since April, 2006
- story submitted February 2008
- story updated July 2008
- story updated July 2009
- NO RESPONSE TO 2010 UPDATE REQUEST

SPECIFICS

DIAGNOSIS
- Aug 1991 - Diagnosed with Multiple Sclerosis
- 2004 - Stage 4 Breast Cancer
- May 2005 – Diagnosed with Primary Progressive Multiple Sclerosis (PPMS)
- Apr 2009 – Breast Cancer free for 5 years

MEDICATION/TREATMENT (pre LDN)
- 1961 to 1990 - 1 x .50mg Synthroid daily
- 1990 to 2008 – 1 x 1.25mg Synthroid daily
- 2000 to 2003 - Baclofen 10mg - 3 times daily
- 2003 to 2005 - Baclofen 20mg - 3 times daily
- 2005 to Apr 2006 - Baclofen 10mg - 3 times daily
- 2004 - Mastectomy, chemotherapy, radiation therapy
- 2004 to Apr 2006 - Amantadine 100mg – 2 times daily
- 2004 to Apr 2006 - Lexapro – once daily in the evening (after improving on LDN I stopped taking Lexapro)
- 2004 to Apr 2006 - Arimidex - 1mg - once daily (for estrogen positive cancer for 5 years)

MEDICATION (post LDN) - HISTORY
- Apr 2006 to Feb 2008 - Lexapro – once daily in the evening (after improving on LDN I stopped taking Lexapro)
- Apr 2006 to Apr 2009 - Arimidex - 1mg - once daily (for estrogen positive cancer for 5 years)
- Apr 2006 to Jan 2008 – 3.0mg Low Dose Naltrexone (LDN) nightly (began at 3mg, increased to 4mg Jan 2008)

MEDICATION (post LDN) - CURRENT
- Apr 2006 to present - Amantadine 100mg x twice daily
- Apr 2006 to present - Baclofen 10mg x 3 times daily
- Feb 2008 to present - Synthroid .75mg x once daily
- Jan 2008 to present - 4.0mg Low Dose Naltrexone x once nightly

TESTS
- 2005 – Mammogram – no evidence of cancer
- 2006 - Mammogram – no evidence of cancer
- 2007 - Mammogram – no evidence of cancer
- 2008 - Mammogram – no evidence of cancer
- 2009 - Mammogram – no evidence of cancer

LDN DOSE & TYPE
a) Dose - 4.0 mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone around 9:00pm each night. I get up at 5:00am every morning so I go to bed early.
c) Type - my 4.0mg capsules are compounded by Skips Pharmacy with pure Naltrexone powder and avicel filler.

DIET & SUPPLEMENTS
- as at July 2008
- 2008 to present - Multivitamin x 3 times daily
- 2008 to present - Calcium 1000mg + Vitamin D x 3 times daily
- 2008 to present - Magnesium 500mg x once daily

ACTIVITIES & EXERCISE
- I walk for at least 45 minutes each day

MY STORY – February 2008

I was first diagnosed with Multiple Sclerosis in August 1991.

In 2004 I was diagnosed with Stage 4 Breast Cancer that had metastasised to the lymph nodes. My treatment consisted of a mastectomy, chemotherapy and radiation therapy.

Then in May 2005, after almost 14 years of slow MS progression, my diagnosis was changed to Primary Progressive Multiple Sclerosis (PPMS).

I had to use a cane to walk and was so exhausted I could only shop for around 30 to 45 minutes at a time. This meant I only shopped for a few things at a time. Walking was terribly painful due to osteoarthritis and osteopenia, the first stage of osteoporosis. I could not stand up long enough to cook supper or even to clean my house in an afternoon. Life for me was slowly closing in and I felt as if I could not put my family through this pain.

In 2006 I heard about Low Dose Naltrexone (LDN) as a treatment for my MS. I joined the Yahoo LDN chat group to learn more, and in April 2006 I began taking 3mg every night. It's been almost 2 years now and I can tell you my physician is thrilled with the results.

I started taking 3.0mg Naltrexone in Apr 2006, but in January 2008 after nearly 2 years, I increased my dosage to 4.0mg. I cannot tell you how wonderful it has been to know I'm responding to this drug, especially as I'm well over 50 years old.

After commencing LDN my MS symptoms did not increase. If anything, some of them decreased. It was not an overnight miracle either. As the months, at least 4 or 5, went by I really did not notice any marked decrease in my symptom. it was so subtle I adjusted without noticing - but my family did.

I began to stand for longer periods. I was not using the cane nearly as much. I planted flowers and worked at weeding the garden. My husband brought it to my attention that my housecleaning seemed to be improving. (I hate housework so I schedule it on Saturdays and if I can't do it on Saturday it just does not get done.)

My shopping trips went from minutes to hours. I'd began to shop for longer periods, without carts, at the department store and I'd begun doing more of the types of activities I used to do without thinking before I had MS, but was constantly challenged by after I developed MS.

The improvement was so very gradual I reached a point where I forgot about my MS limitations and pushed myself a bit more into doing things. As I exercised more I got stronger. *This could be the key to those folks who may expect LDN to right their symptoms. I pushed because I wanted my abilities back. I would walk farther and not let feeling sorry for myself get the better of me, and LDN (gradually) allowed me to do that.*

There have been other benefits as well. Before LDN I was taking 1.25mg thyroid medication (Synthroid), but within 3 months of commencing LDN my doctor noticed my levels were too high. I began reducing the dose and as at February 2008, the dose had reduced 40%, down to .75mg Synthroid daily.

I also gave all the LDN information to my Oncologist who is one of the top men in his field and he too is interested in the effects of LDN.

So far I am cancer free and my MS is at bay. LDN is not a cure. I still have my good days and my bad days but I do feel that my bad days are less since I have been on LDN. I am ambulatory and I no longer need my cane.

Here's a hint for those of you thinking of going to your family doctor: Take all of the information from the LDN website which describes LDN, and ask him/her to read it. The rule of thumb is - 'he who speaks first loses' - so if he reads it in front of you don't say anything until he's finished. If he states he will read it later then tell him you will set up an appointment to go over the information with him. (They get too busy and it ends up in the round file.)

When I took the LDN information to my family doctor he was intrigued, then after a long silence he said, "Let's do this" – and he is amazed at the results. I wish everyone could have the kind of doctors I do. My family doctor is fresh out of Medical school and is willing to listen to patients.

My Oncologist is tops in the field and even he is looking more closely at LDN. Same scenario, I gave him the literature and asked him to review it. He is a very busy man but on my next appointment 4 months later he was so amazed with how I was doing he said he was going to go back and revisit the information for some of his other patients.

I'm still taking 10mg Baclofen three times a day to relax my muscles. I continue to take Arimidex (for estrogen positive cancer as it has to be taken for 5 years, and I take Amantadine to counter extreme drowsiness. Also,

my oncologist has me on a cancer regime of eating more fruits and vegetables (minimum 5-6 servings a day).

Thanks to the LDN website and Yahoo group I'm on a lower Synthroid dosage and I have lost almost 40lbs since improving my diet. My symptoms haven't increased - some have decreased, and I hope yours will too.

UPDATE July 2008

I still take LDN and am still benefiting in the same way from LDN. No changes to report.

UPDATE July 2009

I am doing well. I have a lot more stress in my life these days but still on two feet.

We lost a house in the Flood in Iowa. We were not in the 'Flood Zone', so no flood insurance. It was totalled. My daughter was living there and she is still homeless, and we are still trying to get a settlement since we are not entitled to Fema help.

We are now in line for a buyout but they are telling us a minimum of 18 months before they begin. Meanwhile we have to mow weekly and shovel the snow when it snows. We live 50 miles away and it is just a pain - let alone we had to clean the place out and check on it weekly because of squatters.

But enough of that. I am seeing a little progression of the MS, but if I take time to rest it seems to abate. I'm working full time and doing well at that. There's nothing else to report. I am still taking all medications and the 4mg of LDN. Oh, and no cancer has returned. Now 5 years free. Will let you know of anything else new.

Emily, USA

NB As at August 2010, no response to 2010 email update requests. Reason unknown.

Emily, USA

"After commencing LDN my MS symptoms did not increase. If anything, some of them decreased. It was not an overnight miracle either. As the months, at least 4 or 5, went by I really did not notice any marked decrease in my symptom. it was so subtle I adjusted without noticing - but my family did." Feb'08

15 LDN giving me my best friend back – Nancy

LDN since September 2006
- story submitted January 2007
- story updated July 2008
- story updated July 2010 (4yrs since starting on LDN – cumulatively, nearly 2 years off)

SPECIFICS

DIAGNOSIS
- 1994 – diagnosed with Chronic Progressive Multiple Sclerosis (CPMS)
- 1996 to 2005 – As a result of chronic progression Mark was in a wheelchair, had either constant diarrhoea or constipation, had constant bladder pressure (never felt empty), had frequent urinary tract infections (UTIs), had consistent brain fog and confusion and speech difficulties. Mark's progression had led to no feeling or reflexes in his legs, no movement of his legs, no feeling in his arms, and subsequently, no capacity to feel pain. He had phlegm on his lungs, loss of both short and long-term memory, physical exhaustion and constant sleep, he had no bladder control, a cataract in one eye, and an inability to speak at all. He became diabetic, had more frequent and more severe seizures, and even had episodes where his speech was backwards.

MEDICATION, TREATMENT (pre LDN)
- 1994 to 2005 - Betaseron, Avonex and Copaxone
- 2002 to Sept 2006 - digoxin, amiodarone 200mg x 2 day (for heart)
- 2002 to 2005 - Mark was hospitalised, on average, 2 to 3 times a year.
- May 2005 - Mark had a seizure (which just like every other time) put him into the hospital, ventilated and using a feeding tube. That admission was the start of the end according to doctors.
- 2006 – Another hospital admission, ventilator, feeding tube, another poor prognosis - we were told again 'he's not gonna get better only worse', and were asked about his 'Do Not Resuscitate' (DNR) instructions.

MEDICATION (post LDN) - CEASED
- Sept 2006 to May 2007 - digoxin, amiodarone 200mg x 2 day (for heart) - ceased, no longer needed
- June 2008 to June 2010 - Metoclopram for stomach
- June 2008 to June 2010 - Pancrease for digestion
- Sept 2006 to June 2010 - 3mg to 4mg compounded Low Dose Naltrexone (LDN)

NB Due to poor quality compounding and periods of illness and hospitalisation, Mark has had multiple periods of being off and on LDN. Dates were not recorded, but cumulatively, it's believed to be approx 2 years between 2006 & 2010.

MEDICATION (post LDN) - CURRENT
- June 2010 to present – 4mg compounded Low Dose Naltrexone (LDN)
- June 2008 to present - Keppra 1/2 tsp x twice daily (for seizures)
- June 2008 to present - Adavan x 1/2 ml x 3 times daily (but we only give as needed – if he's anxious or not resting much or if I see signs of seizure)
- June 2008 to present - heartburn pill occasionally
- June 2008 to present - Benadryl (if he's been restless or needs to rest), not every day, usually 1 dose but on a bad day he may get 3 over a 24 hr period.

LDN - DOSE & TYPE
a) Dose - 4mg Low Dose Naltrexone daily
b) Time – one dose between 11pm and 2am (we usually try to give it to him as close to 2am as possible)
c) Type – pure naltrexone powder compounded by Skips Pharmacy. (We dissolve his 4.5mg LDN in cooled, sterilized water before giving it to him.).

SUPPLEMENTS
- 2007 to present – Mark was taking the following:
Vitamin D3
Magnesium 250mg
Super B-complex
B-1 (Thiamine)
Flax seed 1000mg
Fish oil 1000 mg
Vitamin E 1200iu
MSM 500mg
Garlic 1000mg
Lecithin 1000mg
Potassium 100mg
Glucosamine 500mg
Co-Q 10 200mg
Fresh blueberries
Calcium 500mg
Vitamin C 500mg

Cranberry Concentrate Juice 1oz daily
Pomegranate concentrate Juice 1 oz daily
We'll be reviewing these again soon.

DIET
- 2006 – overweight – around 228lbs
- 2008 – normal weight was 135lbs, he was 5' 5" (before he shrank) - weight is down to around 118 lbs now
- 2010 – He presently weighs 120lb and needs to put on a bit of weight, so we plan on getting on a blended diet and using the feeding tube.

EXERCISE & INTERESTS:
- 2008 – planning physical therapy and speech therapy

MY STORY – January 2007

Okay. Here goes. Now I'm not good at typing so please excuse me if I make any mistakes, okay?

My brother's name is Mark. He's 55. He was diagnosed with multiple sclerosis (MS) about 12 years ago (in 1994). Soon after diagnosis his health declined quickly.

He was in a wheelchair by the end of year 2 (1996). He had all the same problems, and then some – similar to most who suffer with chronic progressive MS. He went thru all the typical symptoms like spasms, leaded feet, dropping things, slurred speech, imbalance, loose bowels without any notice, falling down, eye twitching, sensitivity to light, depth misconception (like he would go to put a glass on a table and it would end up on floor).

The four years 2002-2006 were the hardest for him. He tried Betaseron, Avonex and Copaxone. None seemed to help and only hurt his condition. He was hospitalised, on average, 2 to 3 times a year. In May 2005 he had a seizure which (just like every other time) put him into the hospital. But that hospital admission was the start of the end - according to doctors.

They kept telling me there was no hope. They told me he was getting worse – that is body was failing – and that I had to face it that MS is a debilitating, progressive, and yes, fatal, illness. They said he would not die from MS but from the cumulative damage MS had caused his body.

Well, our family wasn't prepared to sit by and accept a death sentence for Mark. We fought the doctors and were determined not to put him in a nursing facility where he would wither away and die.

2005 was a big, worrying, draining year for our family. Long story short – he was in and out of hospital all year and needed the aid of a respirator to breath during two very harrowing periods. In January 2006 he was in and out of hospital again and additional complications ended up keeping him there until April 2006.

On one occasion the hospital had released him but he had to go back into hospital 2 weeks later due to an infection. The next time the hospital wanted to release him I made sure he did not leave until all signs of infection were gone.

In 2006 Mark was on the ventilator for a second time, and using a feeding tube for a second time, then sent home with a poor prognosis. We were told again, "He's not gonna get better, only worse. It's just a matter of time". We fought hard to get him the care he's had because doctors saw no reason to put him through anything else. We were asked many times about his 'Do Not Resuscitate' (DNR) instructions. My response has always been, "You do whatever you need to do to help him. I'll worry about his quality of life." If we're being frank here, Mark was sent home to die a long time ago.

On April 8th 2006 when he was finally able to come home, he had a feeding tube and didn't talk much. He was having trouble with muscles that help project the voice.

The family searched for some way to help him. We found out about LDN and early in Sept 2006 we put him on 3 mg LDN, along with a vitamin regime we'd developed.

Sometimes improvement can be very slow and gradual, but when you're so far down the track, little things become big things.

He had no feeling in his legs. He now has feeling in his legs. He could not move his legs. He can now move his legs. He had no feeling or reflexes in his arms. His arms now hurt and ache (good and bad huh?)

He was overweight but he's lost weight. He was on heart medication – now he's off it. His lungs had phlegm but they're now clear. He had brain fog and confusion but now his concentration and thinking have both improved, and his memory has also improved a little.

He was constantly exhausted and slept most of the day and night but he stays awake for longer periods now. He had a bedsore that should have caused a major problem but it healed very well.

Now this is a big one for me, because before LDN his bladder leaked all day and night - but now his muscles are working better his bladder is working better. He has a catheter but his bag is not constantly filling. It will often contain the same amount of waste as it did say 5 hours before.

He has a cataract in one eye which looks like its clearing up - if that's possible. He even has less depth of wrinkles then he did a couple of yrs ago. His wrinkle folds have filled out a bit so he looks healthier and younger. He says (as best as he can) that he feels great inside.

All of these improvements have been happening since he left hospital and since we started him on LDN and have been caring for him. This man, my brother, has not been able to even move his big toe for 6 yrs or more. MOST IMPORTANTLY – he now has some movement of legs and even extremities - his toes.

He had no feeling at all when he came home - not even pain. Now he's very sensitive to touch. I can run my fingers along his leg and he jerks. I can touch his feet and he gets very annoyed because it tickles.

One more thing before I go. Mark's seizures never stopped on their own. They would always last for hours necessitating hospitalisation. After his last 2 seizures he was sent back home from the emergency room without being admitted because he now has seizures that are not as severe. He can answer questions while having a seizure where before he could not - nor could he understand what you were saying.

Before, his seizures affected him more mentally – like no-one was home. Now they don't. It's like the seizures are only superficial and not coming from the brain. Does that make any sense to anyone? All I know is between his alternative therapy of vitamins and the LDN I am getting my best friend back!!!!

UPDATE: July 2008 – almost 2 years on LDN

Between September 2006 and a ktichen fire in May 2007, Mark was on LDN uninterrupted and had not one problem, not one Emergency Room visit.

Mark was doing well before the kitchen fire, but because his room is close to the kitchen he took in a lot of smoke. He seemed okay after we put him up in a motel for 11 days while a cleaning crew did their work, except for a fall while Mark was in the motel. His hoyer didn't fit under bed and it fell. There were two of us but we couldn't stop the fall. He broke his nose and got a forehead cut above his left eye that needed stitches, as well as 2 black eyes. He looked like hell but within a week - no black eyes and no real visual signs of the fall, just a scar above his eye that was barely noticeable - now that's healing power!!!!

After he got home he got sick – had a seizure, developed pneumonia, and then a urinary tract infection (UTI). He was hospitalised again and he went from the emergency room (ER) to the ICU due to the pneumonia. He was told he had it for at least 10 days, so that was a shock.

The next day he was out of the ICU and ready to go home!!!! I can't recall days but I remember he went in, I think late night on a Wednesday, was admitted and sent upstairs about 2am. By midday when I saw him, I was told how serious he was. I made him give me a strong cough, suctioned him, and retrieved a lot of mucus. He's always congested due to being bedridden.

Being in an ICU, I felt comfortable going home for the night. The next day he was out of the ICU and doctors said he was ready to be released the following morning!!! I'm pretty sure what his cough brought up was the pneumonia. Either the doctors misdiagnosed him or the cough he was able to bring up cleared his lungs well enough to send him home on antibiotics.

In June 2007 we had to take care of a Methicillin Resistant Staph (MRSA) infection he'd picked up during his hospital stay. Then on thanksgiving night he had another seizure and another trip to the ER. This was also a

short stay of about 8 hours. Through all this Mark was feeling fine - no discomfort, no pain, and when I searched his eyes I could see he was gonna be fine.

The year ended reasonably well, considering everything he'd been through. For several months there were no real problems, then everything started again – fever, seizure, UTI, pneumonia, bacterial pneumonia, signs of liver damage, blocked bowel ducts, kidney stones, gallstones, you name it them dang doctors threw it at me.

Unfortunately, every time Mark went into hospital he'd be off the LDN and we'd have to start it again when he returned home.

In March and April 2008 he had 3 hospital stays, but he now seems to be improving. I think the fact that we had so many setbacks these past 12 months is cause we had him off his program of LDN and vitamins. We put him back on LDN and vitamins, then another trip to the ER resulted in only a few hours stay. I often wonder if he would've responded faster or better to hospital treatment if he'd continued on LDN during his hospital stays.

After they did kidney drainage and laser treatment (lithotripsy) for an hour to bust up the stone, his bowel unblocked itself, and other stones were not stones after all because the liver tested fine and so did the gallbladder!!!!

He had a staghorn stone so big it almost completely blocked and filled up his kidney!! They said it would have been growing for about 5 yrs to get that big, then added the same ole things, he's getting worse and we have to accept that.

After all this they sent him home early, a few days too soon, and because of that the next week he was back in due to bacterial pneumonia, but that stay was only 4 days, not 2 weeks like before - but he did need oxygen to return home with.

Now, after 6 weeks back home on LDN we are seeing good things again.

I figured out his seizures were the result of panic attacks. He panics if he gets too congested, or has a swallowing problem, and the brain takes over and a seizure follows.

A couple of weeks ago I fell asleep for 4 hours, then awoke to him having a seizure. I forced suction on him, got him to cough, and gave him 2 Adavan – and followed that with watchful waiting. He relaxed, and the seizure stopped!!!! This was the first seizure ever when I did not have to call 911.

We're in the process of finding him a new alternative doctor. We're going to get his saliva, stool and urine completely analysed. He's still on 3 mg LDN but we're going to increase the dose to 4mg this week. We're going to do that by taking 4 x 3mg capsules (12mg) and dissolving them into cooled, sterilized water, then we'll divide that into 3 equal doses of 4ml each.

So far he's off almost all drugs. He's on Keppra for seizures, Metoclopram for stomach, Pancrease for digestion, an occasional heartburn pill if he gets acid reflux (though he says he does not get it). Everything else he takes is alternative or over counter!!!

For a while back in 2005 he was even diabetic (when he was eating a little by mouth such as certain meds and food, he was testing as diabetic). He's not diabetic at all now and I don't even check his sugar. His seizures were getting more frequent and more severe (now we can control them and they are not as often or severe). He even had episodes where his speech was backwards - that's right his words made no sense until we realized he was talking backwards (he hasn't done that in 2 yrs).

So, let's see what LDN has done for us. His ability to heal is a great example: His skin, bedsores, and collapsed blood veins heal faster. Though he's had several cases of pneumonia, his capacity to overcome it has improved. He now feels pain, which also means he can now feel it when we touch him. He can concentrate and hold his thoughts and his comprehension. He understands everything we say.

We aren't aware of any new lesions. His swallowing has improved. He sleeps more peacefully. He's told us his dreams are more vivid. He can remember dreaming, but he isn't able to describe dreams to me because he doesn't have the strength to speak.

His eyes have also improved. A cataract has dramatically improved with only a slight film left over his pupil that most wouldn't notice (you have to look hard to see it). He's had major weight loss and this has improved his breathing, blood pressure and heart issues.

When he's awake he's more alert and demanding – always a good sign, LOL!

His skin is beautiful and looks very healthy, though sometimes a little dry. He has healthy strong, fungus-free nails (unlike me), and he has some arm and leg movement. His cough strength has also improved. For example, he was coughing yesterday and by the time I got to him he'd already managed to cough up and spit out phlegm that was so thick it was gummy. I was so proud of him. Don't get me wrong Mark always has mucus. It's just that now he can help extract it by coughing. I still suction him daily as needed, and it is needed.

I have even had one doctor, a Neuro, say that the MRIs he's seen don't show any reason why Mark can't walk, so he does not believe Mark's inability to walk is from MS. Like me, he believes one day we could get him walking again.

Our next goal is to get him on 4mg LDN, then get tests run on stool, saliva and urine, do a body cleanse, remove other infected mercury filled teeth, get him some physical therapy to build his strength so he can use his arms more, speech therapy to help him talk, and I pray all of this will one day help him to eat unaided. Then we'll work on his walking. For now he still has no muscle tone, and his arms and legs are weak from muscle atrophy.

I don't really understand exactly what LDN does, so I try and notice everything and hope it's from the LDN. One thing I really like is that he's able to relax his shoulders and actually lay back with no discomfort. He is also able to lay on either side comfortably for several hours: These are two things that only a few short years ago were impossible without breathing distress and discomfort and pain.

Oh yes, and one more thing. When he's shaved and we're out and about, I'm always mistaken for his MOTHER. He really does look younger. My old computer had pictures so you could see the change. I'm still trying to get it back from the repairman so I can retrieve those pictures.

We're still working on his bowel constipation, but his bladder is working perfectly. That's about it for now.

I believe a person has to have a strong will and desire to get better or nothing will help, and I know Mark has that desire.

NB Unable to obtain a 2009 update.

UPDATE – July 2010 – almost 4 years on LDN

Every time Mark restarts LDN (quality compounded) he shows great progress.

When his prescription expired, I got his Primary Care Physician to call in another script, but he made a mistake and prescribed 50mg tablets. When I asked him to correct the prescription, he then decided not to renew the script. Mark being bed-bound, we could not get him to another doctor willing to write a new script.

During Mark's time off LDN, he stopped moving his right arm, though he did still have feelings in it. Thankfully, there were no signs of a stroke.

He also battled through several other adverse health events and hospital stays, but I don't believe any were related to LDN, or the lack of it. Most were related to medical mishap, malpractice, and neglect.

Mark is now back on LDN but after his last hospital stay we had to start on a low dose and build up slowly. We are back up to 4.0mg, and though mark now has a trachea we plan on weaning him off it.

He's also had several mercury-filled teeth removed and still has a couple more to go.

Our experience is that it does make a difference who compounds the LDN, where the LDN comes from... because we were at a stand-still for almost a year when we were getting the LDN compounded locally, but after switching to Skip's Pharmacy, observed a noticeable difference.

Since getting a new primary care doctor who does home visits, we're seeing some improvement but there's still a way to go due to Mark taking several steps backwards this past year.

On the plus side, Mark has progressed to being off the ventilator, and his body functions have improved.

He still has no diabetes, nor high blood pressure, hearing problems, kidney, liver, or gall bladder problems. He also has no digestive problems.

The only meds apart from LDN that he's taking are a reduced dose of Keppra for seizures, and Adavan as needed. Everything else is alternative, that is; supplements and vitamins.

His healing ability is amazing.

He still has a trachea fitted because the hospital took too long to wean him off the ventilator and had to trachea him, using the excuse that he had too much mucus for them to risk taking the trachea out, but after 60 days the insurance payments had been tested to their limits, and it was time for me to either send Mark to a nursing facility or bring him home. I choose home.

Mark still has problems with his memory each day, yet he has dreams and can recall those dreams, and this makes us happy. His skin is remarkable and he still looks like a 35 yr old man not a 58 yr old.

Mark's desire to get well is still strong and I believe the LDN helps with that... being able to feel his legs and feel the sensation of touch gives him hope, and we all need hope.

He presently weighs 120lb and needs to put on a bit of weight, so we plan on getting on a blended diet and using the feeding tube.

All in all I can say he's had less sickness while on LDN than when he's off it, and our biggest hope is that we'll be able to maintain greater consistency with his LDN dosing.

For anyone interested, Mark is still here, still hanging in there, and still has hope.

Nancy, sister and carer of beloved brother, Mark.

Nancy, USA

Nancy, USA

"One thing I really like is that he's able to relax his shoulders and actually lay back with no discomfort. He is also able to lay on either side comfortably for several hours: These are two things that only a few short years ago were impossible without breathing distress and discomfort and pain." Jul '08

16 Linda Elsegood's MS Story

LDN since December 2003
- story submitted March 2006
- story updated July 2008
- story update July 2009
- story updated April 2010 (6+ years on LDN)

SPECIFICS

DIAGNOSED
- partially deaf at birth
- 1963 to 1977 - repeated tonsillitis
- 1969 - Epstein-Barr virus
- 1973 – regular urinary tract infections
- 1973 – First developed gastroesophageal reflux (GERD)
- 1988 – diagnosed with cervical cancer - I do feel confident the LDN will help me with this.
- 1988 – early MS symptoms? Strange leg weakness that only lasted a matter of weeks and disappeared, a trapped nerve in my neck that sent electric shocks down my arms to my finger tips (L'Hermittes).
- Dec 1999 to April 2000 – Extreme fatigue, tooth abscess (antibiotics), tooth removed. Pins, needles, numbness diagnosed as slipped disc (had acupuncture). Also had flu and gastroenteritis.
- April 2000 - MS symptoms first emerge - tongue numbness, pins & needles left side of face, soon followed by extreme fatigue, frequent urination, numbness spread down left side, and bed most of the day sleeping
- Nov 2000 – Optic Neuritis
- Oct 2000 – Relapsing Remitting Multiple Sclerosis (RRMS)
- Oct 2003 – Secondary Progressive (SPMS)
- Feb 2004 - Relapsing Remitting Multiple Sclerosis (RRMS) – 'in remission'
- 2005 – Diabetes Type 2
- Dec 2008 – Diabetes Type 2, but changed from diet-controlled to medication-controlled with Glucophage

SURGERY/HOSPITALIZATION/PROCEDURES
- 1964 – operation to restore hearing, adenoids removed at the same time
- 1974 – Dilatation & Curettage (D&C)
- 1977 – tonsils removed
- 1988 - Initial Loop Diathermy excision to remove cancerous cells, then 4 more exploratory ops on lumps, the last being Oct 2000 when I had fibroids removed, followed by D&C and check on other abnormalities.
- 12 Jul 2010 - Hysteroscopy (inspection of uterine cavity by endoscopy as an outpatient)
- 3 Aug 2010 - Hysteroscopy (inspection of uterine cavity by endoscopy as an outpatient)
- 3 Aug 2010 - Polypectomy - Dilatation and & Curettage (D&C)

TESTS (pre LDN)
- 1998 – endoscopy (camera) of urinary tract
- Aug 2000 - MRI scan, lumbar puncture and twenty-eight blood tests.
- Feb 2003 – Expanded Disability Status Scale (EDSS) Score 2.5
- Oct 2003 – Expanded Disability Status Scale (EDSS) Score 6
- Mar 2003 to Dec 2003 - Liver Function - initially over acceptable level but climbed higher with each subsequent test

TESTS (post LDN)
- Dec 2003 - Liver Function returned to 'normal'
- Feb 2004 - Expanded Disability Status Scale (EDSS) Score 0
- Mar 2005 to Jun 2008 – Every year since starting LDN - Expanded Disability Status Scale (EDSS) Score 0
- Dec 2008 – blood test for Diabetes indicated change and need for medication
- 12 Jul 2010 - blood tests, biopsies to check for cervical cancer (plus Hysteroscopy as an outpatient)

MEDICATION (pre LDN)
- 1963 to 1977 – repeated doses of antibiotics for tonsillitis
- 1967 to 1976 – steroids and hormone pills to manage menstrual problems
- 1976 to 1978– contraceptive pill
- Aug 2000 - 3-day course of IV steroids
- Oct 2000 - 3-day course of IV steroids
- May 2002 - 3-day course of IV steroids
- Mar 2003 to Nov 2003 – Rebif (interferon)
- 2000 to Nov 2003 - Provigil

MEDICATION (post LDN)
- 2000 to present – Omeprazole for reflux (also known as Omeprazone)
- Mar 2000 to Mar 2007 – Atorvastin (for cholesterol)
- Mar 2007 to present – Simvastatin (this reduced my cholesterol to just under 5)
- 3 Dec 2003 to 3 Jan 2004 – 3mg Low Dose Naltrexone (LDN) capsule, calcium carbonate filler

© Case Health Pty Ltd

- 3 Jan 2004 to Jul 2005 – 4.5ml Liquid LDN from Dicksons
- Jul 2005 to present – 4.5mg compounded capsule, avicel filler
- Dec 2008 to present – 500mg Glucophage (slow release metformin) daily

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time – I take my Naltrexone at 10pm each night
c) Type - 4.5mg compounded capsules with pure Naltrexone powder and Avicel filler

SUPPLEMENTS
- July 2008 to present
4 MorEPA Omega 3 capsules
Dr Tom Gilhooly's Baseline AM & PM daily
- Jan 2010 to Jan 2010 – D-Mannose x 2 teaspoons of powder every 3 hours for 4 days, then twice a day for a week.

DIET
- Nov 2003 to June 2004 - wheat, gluten, dairy, red meat, citrus fruit, caffine free diet.
- Jun 2004 to present - I'm now trying to eat a healthy low fat diet, with fresh foods and little processed foods. I don't follow any particular diet.
- Dec 2008 – Modified due to developing diabetes, had to halve my meals - lost 40lbs.

EXERCISE OR INTERESTS
- LDN Research Trust

MY STORY – 4.5 years on LDN

1999 started off being a good year....

My husband Marcus had been made redundant after 18 years working for Anglia TV but was managing well in the freelance "sound" world.

My elder daughter Sara was happy living away from home.

My younger, Laura, was 14 and had asked to go to boarding school to take her GCSEs to cut down on travelling, she wanted to spend the extra time studying.

As for me, I had the job I wanted working for the Virgin One Account (banking). The family were happy and well and life was good.

Until ... I came home from work the Monday before Christmas, my friend was already there cutting Marcus's hair and she was telling me to get my coat off and my hair washed as she was almost ready to cut mine.

Then something happened that had never happened before, my father called me, he doesn't hear well and hates talking on the phone. He said "Your Mum's had a heart attack and they are now taking her to hospital."

That statement was to change all our lives forever!

I'm an only child so had no siblings to share this difficult time with. I arrived at the hospital about 8.30 pm, mum was in ICU. I was too scared and frightened to sleep for two nights, I thought if I slept mum would slip away. I was very tired, stressed and worried, I also had the added worry of my father who is wheelchair-bound. Little did I know what the trauma would do to me.

Mum survived, even though a third of her heart died and they both had to come live with me for a while. Mum's heart attack was due to hereditary high cholesterol; this was when I found out my cholesterol level was 9.7, which resulted in me having to take pills daily.

I carried on working, feeling so very tired; the 60-90 minute drive to work every day was killing me. On my days off I was cleaning, doing food shopping, and other housework. My life was work, cooking, cleaning and spending as much time as I could in bed.

Between Christmas 1999 and Easter 2000, I had a tooth abscess that resulted in having the tooth removed, a slipped disc, flu and gastroenteritis. I had never felt so ill in all my life; I felt I couldn't cope anymore. I said to Marcus I wanted to go away on holiday and come back a new woman. He said he was unable to take any time off, so Laura and I went to Portugal for a week.

© Case Health Pty Ltd

The day before we left I took Laura shopping for shorts and T Shirts. I had an odd feeling on the left hand side of my tongue, it felt like I had eaten food that was too hot and had burnt my tongue. I spent some time trying to remember what I had eaten that might have caused this, but gave up and carried on.

Portugal was very wet, cold and windy. We had the choice of sitting in the apartment or making the most of being there-going out and getting wet. I thought it very strange that the cold and the wind were making the left side of my face numb with pins and needles.

When we got home, I returned to work and made an appointment to see my doctor. After a week away I was feeling even worse than when I left. I was giving work 100% but was collapsing in bed as soon as I got home, and I stayed there until I had to have a shower and go back to work.

My GP thought I should see a Neurologist as he was unsure what was wrong with me. I also had to rethink working, as I simply couldn't manage the hours. It was agreed that I could work part-time and have 3 days off a week. I managed to do this for a few weeks until I developed double vision, at which point I had to listen to my body, stop work and rest.

All I wanted to do was sleep; I thought it was best to let my body heal; not knowing that short-term would turn out to be about a year.

I now had the problem of not working, hence not getting paid. We had Laura's school fees to pay on one salary. Marcus worked out we could afford for me to have 2 months off work. It was fortunate that at the time we didn't know I was never to return.

I was sleeping more and more, going to the toilet more often. The numbness was spreading from my face and down my left side. The hearing went in my left ear, muscles were twitching, and my thighs were burning as if sun burnt. Balance was a thing of the past, fainting and vertigo was becoming the norm. Trying to get to sleep at night my legs would thrash about and when I tried to get out of bed they felt as if they were made of rubber, I would bob up and down and more often than not I would fall over. I became a master of falling asleep either while talking myself or while other people were talking to me.

Marcus at this point of our married life hadn't learnt to cook, clean or use the washing machine, and the iron was a mystery to him. He had a crash-course and had to learn quickly. Life wasn't easy for him either, when he works he's away and he couldn't afford to stay at home looking after me.

Each day something else in my body didn't work properly, I was having really bad problems with "exploding" bowels. I was unable to put a cup to my lips, I was walking holding on to furniture but was unable to go through my front door without help, let alone shower.

My parents would come over on Saturdays to visit me, mum would sit on the bed and talk to me and I would alternate between sleeping and awake. Sometimes she would try and help me get up and sit in the lounge but it took so much out of me that she would have to help me back into bed. I was sleeping 20 hours out of 24, but it was a blessing as I felt nothing while asleep. I wasn't living I was surviving.

At this point it was killing me to see the sorrow in people's eyes when they looked at me. I knew they all wanted to help me and felt inadequate, as did my doctor.

The pains I was experiencing in my head slowly got worse and unbearable. There was a trade off, I could either suffer the pain or take strong painkillers and feel very nauseous.

I finally saw a Neurologist who thought I had either, had a mild stroke, a tropical disease, brain tumour or MS. I didn't like any of these choices to be honest but had to wait for the results of a lumber puncture, MRI, evoked-potential tests and 28 blood tests.

While I waited for the results I was given a 3 days course of IV steroids. Six weeks later my condition deteriorated to the extent the Neurologist was concerned that I would loose my sight and hearing completely and recommended another 3-day course of IV steroids, even though the first course did nothing. I then developed optic neuritis. It was after this Relapsing and Remitting MS was diagnosed.

Marcus was away working, Laura was at school, my next-door neighbour was keeping an eye on me and the doctor came out to see me. He let himself in, brought me some more painkillers and fetched me a glass of

water. I asked him when he thought I would start to feel better, and he replied; "If you were going to, you would have by now" and then he left. I felt so ill, I couldn't do anything let alone achieve anything and I was in a lot of pain. I couldn't bear what all this was doing to my family, and our friends had stopped visiting.

I looked at the painkillers and thought if I were to end it all, it would be a shock to everyone, but I felt they would understand and eventually life would carry on for them. I then had to think it through, things like, who would be the person to find me? It would have been Laura, how could I do this to a 15 year old. The answer was simple. I couldn't do it. It was then that I decided I would show my doctor he was wrong and that I would beat this MS if it killed me!!!

The biggest problem I had was cognitive problems, suddenly I couldn't retrieve my vocabulary or if I did it was very slow and often I said totally the wrong thing and thought I had said it correctly. I feared I was losing my mind. I spoke slowly and it was often rubbish!

I was having a relapse every 6 months, and it was taking about 4 months to start to recover from a relapse only to have another start. I went for an assessment at the interferon clinic and started on Rebif. This was something I didn't want to do but my family thought it was the only thing available to help me. My liver-function tests hit the roof on Rebif, but even so, my Neurologist wanted me to stay on it. He said it would settle down, but it never did.

It was during this period Sara brought home Darren, her future husband. We didn't know they were coming and I managed to drag myself out of bed but couldn't manage to get dressed. He must have wondered what kind of family she came from.

I was spending a lot of time at the hospital seeing a variety of consultants, for my bowels, stomach, and bladder. I had cervical cancer when I was 32, around the time of the first MS symptoms, had a series of follow-up operations and was told I needed another but they couldn't operate again until I had been free of steroids for 6 months. This was extra stress I didn't need. I then became type 2 diabetic, diet controlled.

I went for a medical assessment with my company doctor, who after examining me announced that I was "unemployable for the foreseeable future". For a workaholic it was devastating news, the thought of going back to work one day had been keeping me going.

Sara and Darren planned to get married September 2003, I managed to get showered and dressed and then needed to go back to bed and sleep. I told Marcus I couldn't go to the wedding but for him my staying at home was not an option. We went and I only managed due to the fact I used my electric scooter. As soon as the speeches were over we left, which was upsetting for all involved.

Though my last relapse was back in May 2002, my MS had been progressing to the extent the strength in my left leg went, and it was at that point I was told by my Neurologist that I was Secondary Progressive and there was nothing more that could be done for me. So, no plan B: We would see about that.

When I needed the toilet I would struggle to get to the PC and I would then sit for a short time, squinting with one eye and try to find out what other people were taking for MS. I eventually, after a few weeks, found LDN and people already taking it with great results.

I printed everything and took it to my new doctor, the original one had retired. I now have a great young lady that could have been a school friend of Sara's! I asked her to read the documents and tell me what she thought and could she prescribe it. I went back two weeks later and she said the partners in the practice wouldn't allow her to prescribe LDN for me, but she said if I got it privately she would be more than happy to monitor me so that is what we did.

I contacted Dr Bob Lawrence who suggested that I change my diet, take supplements and start LDN. I started LDN 3rd December 2003. After just three weeks things were improving and I started to feel like the old me again. This continued for about two years and then I stabilised.

Before starting Rebif in March 2003 I had a 2.5 score on the EDSS scale. Three months after starting LDN in December 2003 it went to 0, where it still is today.

Ok, I know I have MS but life is good. I can set targets and achieve them; I once again have goals and aims for the future. I'm not troubled by my old symptoms apart from fatigue and hot weather.

© Case Health Pty Ltd

After my success with LDN I wanted everyone to know about it. I formed the LDN Research Trust in May 2004 and I spent all my time trying to help other people who are in the same place I used to be in, whilst trying to raise funds for LDN clinical trials.

My biggest blessing is having my grandson Leo; I can be the grandmother to him that my mum was to my girls, something that wouldn't have been possible before LDN.

Life isn't the same as 1999 for any of us, things have changed but then nothing stays the same in life for anyone. I now am not afraid of what the future holds....

Update – July 2009

The only thing that has changed is that I was very ill with diabetes at Christmas. I have Type 2 Diabetes and I was no longer able to control it with diet. I had to start taking a slow release metformin. I also had to loose weight so I halved my meals and have lost 40 lbs since Christmas!

MS wise, I had flu just before Christmas, which was the cause of my diabetes playing up and my MS symptoms starting to return (in the form of chronic fatigue and leg weakness). Once everything settled down, so did the MS symptoms and I'm the same now as I was this time last year :)

Update – April 2010 – (6.5yrs on LDN)

Yes, I'm still taking LDN and it is still benefiting me.

Everything MS-wise remains the same.

I should add that last winter from October 2009 to January 2010 I was sick: I had laryngitis 4 times, an unrelenting chest infection, and a UTI resulting in 5 courses of antibiotics - without response. The infections finally cleared after a very high dose of D-Mannose (2 teaspoons of powder every 3 hours for 4 days and then twice a day for a week). Although I felt very ill during that time, my MS behaved itself and I put this down to the LDN.

In consideration of the workload associated with the first International LDN Awareness Week, I think it was to be expected to some degree. I'm being more careful in the lead-up to the 2010 Awareness Week, trying to pace myself and spread the workload evenly, and plan on taking a short break at the end of May.

Linda Elsegood, LDN Research Trust, UK
ldnresearchtrust.org

Linda, UK

"Before starting Rebif in March 2003 I had a 2.5 score on the EDSS scale. Three months after starting LDN in December 2003 it went to 0, where it still is today. … Ok, I know I have MS but life is good. I can set targets and achieve them; I once again have goals and aims for the future. I'm not troubled by my old symptoms apart from fatigue and hot weather." Jul '08

About the LDN Research Trust in the UK

6th August 2009

The LDN Research trust is very proud that over the last 4 years we've helped people learn of, and access LDN - not just in the UK, but around the world. We now have a database of 5,000 people, and the number grows daily - even from outside the internet. We've been able to help every person who wanted to try LDN, regardless of where they live.

When we started the Trust, Dr Bob Lawrence was the main prescriber and medical advisor to the Trust. We contacted over 400 private GPs, sending them the facts on LDN and asked them if they would do their own research and if they were happy with their finding, if they would become an LDN prescriber. It was at this stage we found Dr Tom Gilhooly who agreed to become our second medical adviser. 17 private GPs have joined us in prescribing.

Initially it was mainly people with MS contacting us, these days it is still mostly MS followed by Crohn's, MS/CFS, Cancer, HIV and many of the other conditions suggested by Dr Bernard Bihari, whom we all owe so much.

When people contact us, we send out an *LDN Fact Sheet and ask them to take it to their own GP, who may or may not prescribe LDN on the NHS (if they are in the UK).

We are delighted that over time more people are getting LDN on the NHS and we know of 13 Neurologists who are willing to write to their patients' GPs saying they can prescribe LDN with their consent. This is a major breakthrough. Many GPs are prescribing LDN as they can see it isn't going to be harmful, even if they are unsure it will help. We are always actively looking for private GPs to join us.

Our second, new and improved LDN MS survey is now ready: We'd like people to take part every 6 months so we can track progress. You have to register with the LDN Research Trust to participate. As with Case Health, all data is held securely and never passed on to a 3rd party without your consent - for any reason whatsoever.
Link http://www.ldnresearchtrust.org/survey.asp

The Trust has so far raised £22,000 toward funding needed for clinical trials of LDN. We were only able to do this with the help of our members, who've raised funds and made personal donations. We'd like to say a big 'thank you' to them for all their support. No one involved with the Trust ever gets paid. We are still awaiting the outcome of the CSO's grant application for the trial of 'LDN on Bladder Dysfunction in MS' by Dr Tom Gilhooly, the principle investigator, along with Consultant Neurologist Dr Jonathan O'Riordan. The trial will hopefully start in 2010.

For our newsletter we're always looking for personal experience with LDN for any condition. If you'd like to share your story with us, we'd love to hear from you.
Please email contact@ldnresearchtrust.org.

These are the countries of our members: Argentina, Australia, Belgium, Brazil, Bulgaria, Canada, Chile, CzechRepublic, Egypt, Finland, France, Germany, Greece, Hawaii, Holland, Hong Kong, Hungary, India, Ireland, Isle of Islay, Isle of man, Isle of Wight, Italy, Jersey, Luxemboug, New Zealand, Norway, Orkney, Pakistan, Poland, Portugal, Romania, Serbia, Shetland, Singapore, Slovenia, South Africa, Spain, Sweden, Thailand, Turkey, United Kingdom, Ukraine, United State of America, Vienne. West Indies.

© Case Health Pty Ltd

17 My MS with LDN journey – Gigi

LDN since October 2005
- story submitted July 2008
- story updated Oct 2008
- story updated Jan 2009 (3+ yrs on LDN)
- story updated May 2010
- story updated August 2010 (almost 5yrs on LDN)

SPECIFICS

DIAGNOSIS
- 1959 - Right hip slipped capital femural epiphysis
- 1960 - Left hip slipped capital femural epiphysis
- 1982 - allergies - mold, and seasonal allergies
- 1987 - arthritis
- 1988 - asthma
- 1994 - narcolepsy sleep disorder
- 1995 - high blood pressure
- 1997 - chronic obstructive pulmonary disease (COPD)
- 2000 – Osteoarthritis/degenerative disc and joint disease
- 2004 – Early signs of Rheumatoid Arthritis
- Jun 2005 - Multiple Sclerosis (MS)
- Sep 2006 - Colitis
- 2006 - CT scan - lung nodule detected
- 2006 - Hiatal hernia
- 2007 - PET scan – lung nodule, minimum activity
- Nov 2007 - pulmonary embolism
- Jan 2008 - PET scan - lung nodule now lobular and retracting a portion of my lung, but minimum activity, so 'wait and see'
- Jul 2008 - PET scan determined nodule was active. The thoracic surgeon believes there is a 90% chance it is a cancerous tumor not a granuloma.
- Oct 2008 – Nodule Biopsy – no cancer cells
- 2008 – right popliteal blood clot (right leg)
- Dec 2008 - Septic (suppurative) Pneumonia (nodules were abscesses)

TESTS
- Oct 2004 - MRI of brain - multiple brain lesions possible for MS
- 2005 - Functional tests (coordination, balance, reflex, strength, sensation and balance. Evoked potential testing (BAEP, VEP and SEP)
- 2006 - CT scan - lung nodule detected
- 2007 - PET scan - lung nodule minimum activity
- 2007 - MRI and CT scan follow ups of back and legs, surgery recommended for total left replacement
- Jan 2008 - PET scan - lung nodule now lobular and retracting a portion of my lung, but minimum activity, so 'wait and see'
- 21 Jul 2008 - PET scan determined nodule was active. The thoracic surgeon believes there is a 90% chance it is a cancerous tumor not a granuloma.
- Oct 2008 – Nodule Biopsy – no cancer cells
- 2008 – right popliteal blood clot (right leg)
- Dec 2008 - Septic (suppurative) Pneumonia (nodules were abscesses)
(NB I've had numerous tests for diagnosis or rule-out throughout the years in addition to the above, including x-rays, multiple MRI's, full body CT scans, PET scans, arteriogram, GI function tests, breathing and stress tests, CEA blood test to reveal tumor markers, colonoscopy, plus others I'm sure but unable to recall.)
- Jan 2010 – X-ray - clear lungs with no nodules
- May 2010 - Doppler on my right leg - check for a possible returning blood clot - just a baker's cyst because of chronic knee problems

SURGERY/HOSPITALIZATION
- 1954 - Tonsil and adenoidectomy
- 1959 and 1960 - Spica casts for each occurrence of slipped capital femural epiphysis
- 1969 - Surgical removal of benign cyst, (L) breast
- 1982 - Dilatation & Curettage (D&C) following miscarriage
- 1994 - laparoscopic cholecystectomy and biopsy of cyst (R) breast - benign
- Nov 2006 - Arthroscopic surgery (L) knee
- 27 May 2007 - total replacement of left hip- Jul 2007 – Hip Replacement (admission extended from 2 weeks to more than 1 month following MRSA infection (Methicillin-resistant Staphylococcus aureus)
- Nov 2007 - pulmonary embolism
- Dec 2008 – Septic (suppurative) Pneumonia – over 3 weeks in hospital, 10 of those days on life support due to MRSA infection (Methicillin-resistant Staphylococcus aureus)

MEDICATIONS/TREATMENTS (pre LDN)
- 1995 to Oct 2005 - Provigil x 400mg every morning - trialed 'Modafinil', which later came to be called Provigil after the FDA approved it (effectively treating Narcolepsy, but also helped with pain management)
- 1995 to 2007 - Numerous Blood Pressure medications, including monopril, which resulted in anaphylactic reaction and angio-edema.
- 2002 to 2004 - regular steroid cocktail (never full strength steroid alone) injections for joint pain, (hips, knees, shoulders)

MEDICATION (post LDN)
PAST
- Oct 2005 to 2007 - 3ml Low Dose Naltexone – (Liquid made with 1x50mg Revia tablet dissolved in distilled H2O)
- 2007 to 2007 - 3mg compounded LDN capsules (after receiving prescription for LDN)
- 2007 to Nov 2008 - 4.5mg compounded LDN capsules (increased from 3mg to 4.5mg during 2007)
- 2007 to 2008 - Numerous Blood Pressure medications, including monopril, which resulted in anaphylactic reaction and angio-edema.
- early 2008 - atacand 32mg every morning
- 2008 to July 2009 - Lasix x 20mg every morning (changed to HCTZ)
- Dec 2008 to April 2009 - Warfarin
- Jul 2009 to July 2010 - Hydrochlorothiazide (HCTZ) (changed back to Lasix)

CURRENT
- Dec 2008 to present - 4.5mg compounded LDN capsules (temporary break Dec 2008 due to hospitalisation)
- 1995 to present - Provigil x 400mg every morning
- 2007 to present - Albuterol Rescue Inhaler – PRN (100 dose metered inhalers which I use as needed).
- 2008 to present - Spiriva inhaler every morning for asthma
- 2008 to present - aspirin for pain as needed
- early 2008 to present - Atacand x 32mg (blood pressure med) every morning
- early 2009 to present - Diltiazem CD 240mg (blood pressure med) every morning
- July 2009 to present - Propafenone HCL (generic rhythmol) 150mg tab x 3 times daily
- Jul 2010 to present - Lasix x 40mg every morning

LDN - DOSE & TYPE
a) Dose - 4.5mg compounded LDN capsules
b) Time - I take my Naltrexone at bedtime (between 9pm and 2am each night)
c) Type - Initially I dissolved one 50mg Revia tablet in 50ml distilled water (H2O) to make liquid naltrexone. I would keep it in the fridge, shake well, then use a needle-less syringe to draw up the 3ml dose. In 2007 I switched to naltrexone capsules compounded using pure naltrexone with avicel filler from Skips Pharmacy.

DIET
- Fewer sweets, more fish, salad, and fresh fruits. Seeking most effective diet to combat cancer in conjunction with LDN treatment.

SUPPLEMENTS
July 2008 to present:
- B complex x 1 every morning
- potassium gluconate 595mg x 1 every morning
- folic acid 400mcg x 1 every morning
- vitamin D 400IU x 1 every morning
- Omega-3 x 1 every morning
- Calcium, Magnesium, and Zinc x twice per day
- Vit C crystals - several times per day

In July 2010 I added the following:
- Biotin 1000mg x 1 every morning

ACTIVITIES & EXERCISE
- Swimming has been very helpful for painless exercise. Exercises by physical therapist following hip replacement were very helpful. Have been able to better tolerate routine housework, cooking, etc. and able to resume some additional activities, i.e.; some gardening and water sports.

HOBBIES & INTERESTS
- Writing short stories and poetry suffered during my brain fog but am again able to put thoughts into words. Mask making as well as other craft making has been restored with improved coordination and concentration. Cooking is once again a joy instead of a risk since I am now spasm free and no longer fear dropping things.

MY STORY - July 2008

Without a doubt LDN has given me a new chance at life! Having had slipped capital femural epiphysis as a young child as predicted developed arthritis. Fortunately, and I am so thankful, I was treated by an 'old-fashioned' doctor who opted to Spica cast rather than the traditional cutting and pinning method. I had many years of relatively normal ambulating ability with the exception of an odd gait when tired.

Every mobility-related symptom after that was attributed to arthritis, and later degenerative disc and joint disease therefore ignoring the possibility of any other problems. In 1995 I trialed and began taking Provigil for narcolepsy which had a side effect that helped with pain management and enabled me to continue working until 2001 when falling became a safety issue and pain meds just made me sleepy. For the sake of my patients I quit working until I could 'get better'. But I continued to get worse and my doctors referred to many of my symptoms as 'an enigma' and simply treated for pain, depression, and symptoms obvious to them. By October of 2004 my GP sent me for a brain MRI after having reported waking up blind, which resolved within 10 to 30 minutes on three occasions. The report stated, multiple brain lesions possible for MS. I began researching my symptoms and found they were linked to MS.

By the time I was diagnosed in June of 2005 I had lost my voice for nearly three months, had terrible brain fog, frequent falls, dropped things often, had slurred speech, b & b problems, awoke several times through the night with pain and spasms and bladder issues, choked on food and drink, could not stand to cook or wash dishes for more than 15 minutes from pain and MS hug discomfort, suffered extreme fatigue, frequent pneumonia, relied on a cane to walk, and was in constant pain.

I was a mess but refused the lumbar puncture (LP) my neuro had suggested 'to determine the level of CRAB meds' I should start on. I had no intention of using standard MS drugs.

I discovered LDN via some wonderful people on the internet who referred me to the LDN sites. I knew all these people couldn't be wrong so it was certainly worth a try. My neuro refused to prescribe LDN, so I began my LDN journey the last week of October 2005 with naltrexone tablets and mixed my own liquid. Later another neuro I was seeing said it was 'apparently helping' me, and she wrote a prescription that was sent for compounding.

Two years, eight and a half months later the only MS symptoms that remain mostly when I get tired, are some brain fog, a little pain, and some 'hug' when I've been too busy. All other symptoms are gone and no new lesions, no pneumonia, only one cold, which lasted just three days. Although I have other unrelated health issues I believe LDN has already worked on some of them - fewer allergies, COPD has improved - and LDN may with continued use resolve others.

Unfortunately many of the blood pressure (BP) meds I take warn side effects may produce 'dry cough' as well as a host of other side effects. The doctor has tried numerous BP meds, which end up not working well for me. When I was hospitalised in November 2007 with the pulmonary embolism the 'hospital-ist' changed my BP med (atacand) to metoprolol, plus a heart med and warfarin to keep my blood thin.

Not only did the new BP med fail to do the job right, but I felt awful and developed bruises all over from too much warfarin, and my hair began falling out like rain...yikes! The warfarin level was adjusted and by March I quit taking all of it. The hair loss has slowed down but unfortunately not stopped, horrors!

Early this spring I went to my PC who did blood work and tried two more BP meds with more adverse effects. So, I asked to be put back on the Atacand which, while it does not keep my BP as low as they'd like (hence the diuretic), it seems to have the least adverse obvious effects. My blood work came back OK with the exception of some elevated cholesterol levels, which I'm trying to modify with diet, and kidney function is fine. The LDN has stopped my five trips per night to the loo, but I still have plenty of output.

I believe in LDN that strongly and will continue to advocate for its use and trials for all autoimmune disorders. I can see no argument against, only accolades for a medication with temporary little or no side effects that regulates our immune system into working as intended. It must be made readily available for all who seek a preferable alternative to the harsh medications that end up creating more health problems.

Yes LDN has given me my life back, I am grateful and feel truly blessed with better health and a fantastic group of supportive people. The main problem I'm focused on now is some recent, unexpected news that my lung nodule has not disappeared as I'd hoped but in fact become lobular and is retracting a portion of my lung, and even my second opinion pulmonary specialist recommends surgery ASAP after further tests next week. Not sure what to do since I don't feel good about more surgery.

I know there are complimentary LDN/cancer diets but they seem to be somewhat cost prohibitive from what I've read. I checked out the Budwig diet, which includes fish oil, quark, nuts and fresh berries and juice among other things, all of which can certainly add up when on a fixed income. Unfortunately when one is on SS Disability, has State supplemented insurance and is not an illegal alien, one is at the mercy of whatever

treatment is offered locally. It's too bad really since I was about to interview for a part-time caregiver job, which would have supplemented my urgently needed income.

Sugar is hard to give up especially in my tea or coffee but I'll work on it as it is a small price to pay if it works. Will also increase vitamin C crystals, I'm sure Linus Pauling was right about the effectiveness of vitamin C.

I've been scheduled for a breathing test, new PET scan, and consultation with a new thoracic surgeon on Monday, July 21st and I'll be asking him about RFA, (radio frequency ablation), and VATS (visually assisted thoracic surgery), but I'd really rather not have any surgery at all since I will never give up on LDN's role in this.

UPDATE – 5 October 2008

I finally caught up once again with the Interventional Radiologist and we spoke at length. Since he has only one day clear for the next several weeks I agreed to it, better sooner than later since I've waited perhaps too long already. On Wednesday, October 8th I'm going for a biopsy under general anesthesia, (in case of pneumothorax), and if cancer cells are found they will immediately perform Radio Frequency Ablation on the primary nodule as well as the satellite nodule(s).

I'll probably only have to stay overnight barring any complications. The biopsy is basically to 'type' the cancer. Yes, I'm nervous about this, especially since I have gone into A-fib with the last two administrations of general anesthesia but I know I have to get the ball rolling I'm not getting any better and have an increasingly annoying ache in my back. And, I'm thankful my back is the route they will take for this procedure and not under the arm and through the rib cage as the thoracic surgeon who recommended removal of the lobe and lymph nodes said.

I've been taking the supplements recommended by Dr. Berkson even though he does not treat lung cancer patients. I sent for the information from the Burzynski Clinic in Houston, which is where Dr. Berkson refers lung CA patients. It looks like a wonderful place but the cost is way out of my financial ability and they don't take my insurance, but at least I have the info and can pass it on to others who might be able to afford it.

It's in God's hands no matter what the course of action and I feel RFA is the best and least invasive way to go for now. If it doesn't work I can always get the lobe and lymph nodes out but not the other way around. While I understand there is potential for it to spread in the interim from procedure to check up I have to believe in something so I'm hoping this is the best option available to me. There are just a few days before the procedure and lots of preparation to do. I could sure use a Prayer please.

UPDATE - 14 January 2009

I've been meaning to post on the LDN site but I'm still having some cognitive issues and I wanted to get the post right before throwing it out there.

The biopsy I had last October revealed no cancer cells in the lung mass. This told me what it wasn't, but not what it was. I was told it would be about a week before the cytology results would be available. Perhaps the three release forms I signed became coasters as my doctor still does not have the final biopsy results. Why OH why do they make it so difficult for us to access our own health information?

It turned out the supposed cancer that four doctors were trying to get me to have removed from my lung was, in fact, pneumonia nodules - which then went septic. I was hospitalised most of December. I spent 10 days on life-support while they fought the infection but it didn't respond until I was given some fresh blood.

Had I known earlier that it was pneumonia nodules, it could have been treated before becoming so critical. Well what's past is past, and I'll have to keep a much closer check on all my medical information. Around the same time a right popliteal blood clot (right leg) was discovered and the doctors, reluctantly, (because of some intestinal bleeding), administered blood thinner injections followed by a warfarin prescription to take at home until further notice.

I signed myself out of hospital just before Christmas to be with my children and grandchildren. Not the smartest thing to do, but I was worried it might be the last one so I wanted to make sure I got to spend it with them.

They must have given me some powerful meds, my arms and legs still don't work properly but I'm getting physical therapy at home. I'm still dizzy, fuzzy-brained, on oxygen, in a wheel chair, and taking way too many meds. While hospitalised for three plus weeks, and off LDN nearly a whole month, I had a bad MS exacerbation. A few days after starting back on LDN much of the pain and many of the symptoms subsided.

The great thing is I left the hospital with no nicotine in my system, six weeks cigarette-free now ... Oh, if I can only keep this up! I have a few doctor appointments coming up, I'll be expecting some intelligent answers regarding my current condition and prognosis. I'll keep you informed. And that's what has been going on with me....

Hope we all have a healthy, happy, and productive 2009!

UPDATE – 28 May 2010

Hope all is well with you. Sorry I've pretty much dropped off the radar.

I felt no news is better than the grumbling saga of constant sorrow.

Thank God LDN is still working for my MS, wish it could fix deep depression, degenerative joint and disc, heart problems, the extra half a person I'm carrying around, losing part of my health insurance, employment, purpose, and possibility of foreclosure but it can't.

When I quit smoking I gained 60lbs in 14 months... yikes!

Eating properly can be expensive, the cheaper version caused a fat explosion... ugh!

I had a Doppler done on my right leg to check for a possible returning blood clot. Luckily it is just a baker's cyst because of chronic knee problems. The orthopaedist said I need a double knee replacement. Without full insurance coverage that's not going to happen but I am trying my best to shed the tonnage to reduce the strain on my knees.

I don't know where I left off but a lot has happened between early 2009 and now.

My computer was fixed to death a few months ago so I lost most of my files.

Luckily my daughter-in-law had a spare she used when she was working so I'll update again soon.

UPDATE – 1 August 2010

I've been having problems, both physical and situational. I've been trying to save my home with a mortgage modification and it has taken up much of my real time, as well as my emotional time and energy. As it turns out there really isn't a lot different. I've been smoke free for 20 months now, that's the good news. The bad news is I gained a whole half a person worth of weight and am having difficulty losing it.

Several months ago I had a doppler on my right leg behind my knee. They discovered a Baker's cyst. That was good since I thought it might have been another blood clot. This lead to going to an orthopedist who said I need both knees replaced. I knew there were problems since my knees have been hurting more but so has my right hip and both shoulders.

I also have begun to develop Rheumatoid nodules on the knuckles of two fingers. Having lost the part of my health insurance that covers co-pays, in home therepy, etc; I will not be able to get the knee surgery.

The Rheumatoid Arthritis was discovered before my MS diagnosis and while I was trying to figure out what was wrong with me. The orthopaedist I'd been going to for pain shots (a steroid cocktail) in my hips said that in addition to Osteoarthritis, he saw the beginning of Rheumatoid (RA) as well. That was in early 2004 if memory serves. I forgot to mention earlier about the RA being discovered.

I stopped taking Warfarin last year because first, I no longer had blood clots and second, my hair was falling out in clumps. (This revelation is in retrospect because first I had to track down the source of the problem and that took time. On researching this I discovered one of Warfarin's side effects was hair loss – and as I had no blood clots, I figured I didn't need the warfarin anymore.)

My hair began to recover after stopping the Warfarin, but after about four months of taking HCTZ the recovery stopped. I had been on Lasix for fluid retention but switched to HCTZ about one year ago because I complained to my GP that Lasix kept me in my house several hours after taking it, and my sleep was disturbed no less than 3 to 4 times nightly. It worked for a few months, then less and less.

Unfortunately I didn't link the HCTZ with my hair at the time and have only recently made the link… since I started researching why my hair has become brittle and fine (when once it had been strong and thick). I also wondered if what was effecting my hair could also be effecting my fingernails and my cartilage.

I discovered that HCTZ has been known to cause brittle hair. So out with HCTZ and instead, I recently restarted Lasix for the fluid retention. It keeps me running to 'you know where', and it requires a potassium supplement, but it does not carry that damaging side effect.

There have been so many things going on: Two months ago a nodule (painful hard place) came up on the second knuckle of the middle finger on my left hand. A few days later a smaller one arose on the knuckle near the tip of the same finger. A week later another small nodule came up on the knuckle at the tip of the pinky finger on my right hand.

Oh, and I forgot something else. About a year ago I went on a heart monitor for several weeks because I had been having dizziness and palpitations from my Atrial Fibrillation problems. The cardiologist gave two options, medications or a stint. I opted for Rhythmol 3 times a day.

I have recently been for a check-up with the cardiologist. Nothing new, and no good advice when I told him I'm short of breath. A couple of months ago I had a breathing evaluation by the pulmonologist. He also had nothing much to say about my shortness of breath except that so many years of having smoked was perhaps the cause. Well... why then do I now breath worse than before I quit smoking? No comment. I've given up on getting straight answers from these doctors.

My GP wanted to give me even more meds for my depression but I opted out since I take way too much already. If I can lose some weight it would take pressure off my knees and alleviate some pain; and, if I get the mortgage modification I'm hoping for, that would alleviate lots of worry. Meds can't do that for me, but doctors just want to throw pills at everything.

There's been no recurrence of the abscesses (nodules) they found back in December 2008 when I had Septic Pneumonia. My last x-ray was taken around January 2010 and it indicated clear lungs with no nodules. Luckily I did not let the pressure of four doctors screaming lung cancer dissect me for nothing.

The tops of both shins have become increasingly discolored over the past six or so years. My GP said it is just age related. Well, now there are tiny weaping spots developing. I am inclined to think it is related to the Rheumatoid Arthritis.

Since losing part of my insurance I have had to pay out numerous co-pays for just the normal follow up doctor visits, tests, bloodwork, etc. So I have not been able as yet to make appointments with regard to these other problems.

Of course, I am still taking LDN.

And still on the positive side, I have begun going to a chiropractor, which is covered by my insurance, in the hope he can help with the increasing pain in my lower back. So far so good.

So this seems less like one long WHINE, I'd like to add how thankful I am that LDN is continuing to work so well.

Of all the health problems I have those which are most affected by a weakened immune system have become stable or improved by taking LDN. This includes colds, flu, etc. I've not had a cold lasting more than a couple of days in years.

The pneumonia nodules and subsequent hospitalisation in December of 2008 was inevitable because I had had so many years of respiratory problems that scar tissue in my lungs was harboring pneumonia nodules that eventually had to surface. Having said that, I believe my hospital stay would have been much shorter had I not been infected while in hospital with MRSA, (Methicillin-resistant Staphylococcus aureus), which is rampant in many hospitals here.

I came very close to not making it in Dec 08. The doctor told my oldest son the systemic infection was not responding to the antibiotics and there was little more they could do for me except to try replacing some blood; but that too held potential dangers. Thank God my son said to try it and deal with the 'potential' problems if they come up.

Without MRSA I'm sure the time on life support would have been significantly reduced, I would not have needed ten days of the damaging and hallucination producing drugs to keep me 'asleep'. The infection would have remained localized, and extensive rehabilitation would not have been necessary. To this day, my strength and mobility remains compromised.

MRSA was also introduced in my hip wound when I had the hip replacement in May of 2007, hence a two-week hospital stay became more than a month.

We (nurses) are trained to know nosocomial infections can be prevented or at least reduced with hygienic procedures and clean equipment. When the staff in ICU don't use masks and gowns and stethoscope travel around the neck from room to room it's a wonder anyone survives!

I forgot to mention that I had an annual visit with my neurologist this May and she was pleased that I have had not had any exacerbations. She gave me a prescription (RX) for 12 months of LDN refills and mentioned she is now recommending LDN as an alternative medication to others with MS.

Gigi, USA

Gigi, USA

"Although I have other unrelated health issues I believe LDN has already worked on some of them - fewer allergies, COPD has improved - and LDN may with continued use resolve others." Jul '08

18 LDN gave me Hope for the future – Annmarie

LDN since October 2007
- story submitted July 2008
- story updated 5 Oct 2008
- story updated 25 Mar 2009
- NO RESPONSE TO 2010 UPDATE REQUEST

SPECIFICS

DIAGNOSIS
- 1972 – Multiple Sclerosis (MS) benign
- 1983 - IBS & Diverticular Disease diagnosed
- 1993 - Whiplash - head-on car crash (totally fault of other driver)
- 1993-1996 - Stressful period. Fell and cut back of head. Stitches.

The following symptoms increased during this period:
Progressively losing strength below waist; Difficulty getting up from stooping or kneeling; Extreme fatigue - regularly having to go back to bed and rest; Broken sleep; Poor memory; Eye problems; Left side - pins & needles and pain; Permanently cold; Very cold extremities - hands and especially feet - real pain if knocked or anything dropped on them, however small!
- 1996 - Neurological scar tissue - MRI scan confirmed but was unable to confirm whether it was old or new scar tissue (same as 1972 or recent) as there was no earlier scan to compare it to.
- 1997 - Concussion and Whiplash due to freak car accident - my car hit oil on the road
- 1998 – Flu - stressful period - 2 weeks in bed after bad attack of flu
- 2003-2005 - Stressful period
- Nov 2005 - Major MS exacerbation and relapse

TESTS
- 1972 – MRI & Lumbar Puncture resulting in diagnosis of Multiple Sclerosis (MS) benign
- 1996 - MRI scan – neurological scar tissue

MEDICATIONS (pre LDN)
- 1972 - A course of cortisone injections after diagnosis - type and number unknown

SURGERY
- 1981 - Appendix removed
- Sept 2007 – shoulder surgery

MEDICATIONS (post LDN)
- Oct 2007 to Nov 2007 - 3mg Low Dose Naltrexone (LDN) - for 1 month
- Nov 2007 to Jan 2008 - 3.7mg Low Dose Naltrexone (LDN) - for 2 months
- Jan 2008 to Feb 2009 - 4.5mg capsules Low Dose Naltrexone (LDN) – pure naltrexone with Avicel filler
- Feb 2009 to present – 4.5ml liquid Low Dose Naltrexone (LDN)

LDN - DOSE & TYPE
a) Dose – 4.5 ml Low Dose Naltrexone (LDN)
b) Time – I take my Naltrexone at bedtime, usually between 10pm and 1am each night
c) Type – Low Dose Naltrexone (LDN) as liquid preparation

DIET
- I've always tried to eat well - vegetables, fruits, fish and white meat, whilst minimizing animal fats and sugars, but, I am no saint ... and when I was younger I had an extremely sweet tooth!! I suppose I've been reasonably well-behaved over the last ten years!!

SUPPLEMENTS
- Oct 2007 to present - Advised by Dr Bob Lawrence, I have gradually introduced the following vitamins and minerals. Some days I don't take them all, others I don't take any - my delicate tum is the deciding factor. This is my daily goal:
Fish Oil x 6,000mg
Zinc Gluconate x 100mg (with a monthly zinc taste test)
Calcium Ascorbate x 1000mg (straight vitamin C upsets my tum)
Vitamin B complex
Vitamin D x 1000iu
Vitamin E x 400iu
Beta Carotene x 15mg
Selenium x 200mcg
M.S.M. x 1000mg
Copper x 2mg (to complement zinc gluconate)
Malic Acid (neuralgia pain) x 1500mg
Calcium Magnesium x 1200mg/600mg
Psyllium Husks (tum!) x 1400 mg
GABA x up to 1 teaspoon

THERAPIES
- 1972 to Sept 2007 - Numerous complementary therapies - homoeopathy, reflexology, magnet therapy, allergy testing, naturopathy, McTimoney Chiropractic, mineral/vitamin supplements, crystal healing, dowsing the house, shiatsu healing, cranial sacral therapy, hands on healing, replacing mercury fillings, physio.
- Sept 2007 to Dec 2008 - 2-hour Hypnotherapy Session (Ted Heath) who re-patterned my walking, gave me various triggers for different problems and gave me exercises to strengthen my muscles. Regular physiotherapy, often weekly.
- Dec 2008 to present – Reduction in frequency of physiotherapy sessions to less than one per month.

ACTIVITIES & EXERCISE
Since taking LDN, and meeting my present physiotherapist, I have had marked improvement in balance, standing and walking.
- Sept 2007 - Physio, originally for shoulder, subsequently for lower back and legs to help with my walking
- Apr 2008 - Walking new puppy, Syd - with increased confidence, now able to take him for walks by myself.
- Jun 2008 - T'ai Chi - to improve posture, strength etc. Closely monitored by my teacher.
- Mar 2009 – Due to a change from LDN capsules to liquid Feb 2009 I've been getting to sleep faster and the restfulness of my sleep has also improved, which in turn has resulted in improved energy on waking. My walking has improved so I'm walking more often than before over further distances, such as occasionally walking my dog to the park instead of driving.

HOBBIES & INTERESTS
- Jul 2008 - My passion is playing the piano. Over the last 4 years, I have felt too unwell to do much. Since the end of last year, I have had the energy to practise and the end result has given me and my family a great deal of pleasure. I would also like to resume playing the saxophone in the future. I've always loved cooking although it became a bit of a chore before starting LDN because by the end of my time in the kitchen, I would be doubled over - unable to hold my body upright! Happily, this happens very rarely now. I would also like to go back to Salsa Dancing when I'm a bit more sure-footed. Can't see any reason why not!

MY STORY – July 2008

In 1969, I had a TB vaccination. I was only in my teens, but from that time, my health became erratic.

I continually felt 'wrong'. In my first year sixth, I was absent from school for weeks at a time and whilst I managed to take my 'A' level examinations, my results were disappointing. Everyone, including myself, believed that it was stress-related.

I went to college but once again seemed to be making regular visits to the doctors. Eventually, I was given tranquillisers - as once again stress was diagnosed. I managed to finish my first year but only a couple of days into the summer vacation, symptoms flooded in fast and furiously. My handwriting was practically illegible: I couldn't hit the right notes on the piano; I couldn't walk in a straight line, drink from a cup; parts of my body were numb or had 'pins & needles' - and I was talking with a slur.

At the end of the summer (1972), I had a lumbar puncture and was diagnosed with MS. I was given a course of cortisone injections and no other treatment. At the time I had a few minor symptoms, but nothing that stopped me from working - including running my own business and having 2 children - a time I felt really well. For many years, I was never fully convinced that my diagnosis was correct.

I went back to full-time work when my son was 8 months old, in March 1988. I'd been working long hours and didn't realise I was pregnant for a 2nd time, until I had a miscarriage. I really wanted to spend more quality time with my 3 year old son, so I semi-retired from work in 1990. Not long after, my mother-in-law was diagnosed with bowel cancer, and passed away in December 1992 (within a year of the birth of our daughter).

In 1993, I had a car accident and suffered whiplash. I had problems with legs from that time, increased fatigue, broken sleep etc. In 1996, I had an MRI scan which confirmed lesions, but we did not know if they were from the original attack in 1972 or were more recent.

In 1997 I had another car accident: My car hit an oil patch and careered off the road hitting a fence. Unfortunately, a concrete post was behind the fence. My car ricocheted back over the road and landed in a garden. I was concussed and suffered whiplash again!

The period between 2003 and 2004 was a particularly bad time. My mum had a major stroke. Visiting and caring for her involved travelling to Birmingham every weekend for a year. She passed away in June 2004

and my dad passed away 5 months later, from a broken heart. Then a very good family friend passed away 5 months after that from prostrate cancer, and our dog was run over in May 2005.

I was very run down and tired, and I couldn't seem to improve and get well. In November 2005 I had my 2nd ever relapse - with symptoms that were worse than when I was first diagnosed!! I was unable to walk for a time and had real problems with my left leg especially. I attended an MS Clinic in Cardiff and was assigned an 'MS nurse', but was discharged by June 2006, with no follow-on treatment - but I wouldn't have accepted any anyway!!!

At the time I had brain fog and very bad balance, was unable to walk more than a few steps without help, had extreme fatigue, and after standing for a time found that I was doubling over unable to hold myself upright, etc, etc. I know that I wasn't as poorly as others I saw at the MS clinic but I did feel that I was being sent away until I was!!

All my nurse offered was a blue badge (which I accepted) and a walking stick (which I did not!!). Seemed to me, she had a shopping list and was just ticking it off as I deteriorated. I could do that myself!! I felt I was being left to get worse.

Over the following year or two I was extremely depressed, frightened, and felt very alone. I continued deteriorating and felt there was no hope, and that I would soon be in a wheelchair.

I had a shoulder operation in September 2007. While I was recovering I began checking out MS on the internet and I fell upon LDN. When I found the link to Dr Bob Lawrence, I rang him, had a long chat, and the following week my husband took me to Swansea. I spent 2 to 3 hours with him talking about anything and everything concerning LDN, MS etc. There was no downside as far as my husband and I were concerned, and I started taking LDN at the beginning of October 2007.

My local doctor won't prescribe LDN, but she's watching me very closely. As I continue to improve, I can't see how she can hold out indefinitely. I also take the vitamins, minerals and other supplements Dr Bob suggests. I found a brilliant physio (originally for my shoulder) who is now helping me to re-pattern my brain to walk better and I've recently joined a T'ai Chi class. I eat healthily - but misbehave quite often.

I can honestly say that from the first LDN tablet I took, my problems and symptoms started to alleviate. I know this doesn't happen for everyone, but it's been 7 months and I'm feeling fantastic - a different person from the sad, depressed being who visited Dr Bob all those months ago!! Perhaps it's because wasn't taking anything else before I started on LDN, or because of Dr Bob's supplements, or maybe both.

I have to sing praise to both Dr Bob and Joyce, his right-hand woman!! I've emailed them most days and always had a same-day response - it's easier than ringing and getting the engaged tone. Dr Bob and Joyce are there to help and advise whenever, whatever - even when it's not connected to LDN!!! It really helps knowing Dr Bob takes LDN because he too has MS ... he is somewhere to hang your hat!! In fact, if I lived closer I'd gladly be going there every day to look after them whilst they look after all of us!!

The effect of LDN has been extremely subtle over the time I've been taking it. Just this last week, I've realised that the pains in my left leg are subsiding, slowly but surely. I've even worn shoes with a heel the last couple of days - haven't done that for over 5 years!!

I haven't gone back to bed during the day these last 3 months - in fact, we've just acquired a puppy, so I've been getting up between 6 and 6.30am every day!! I'm not doubled-over anymore after I've been standing. My walking improves with each day, and I am now confident enough to take Syd (the puppy) for a walk without someone to hold on to.

LDN has changed my life - it's stopped me from being frightened and has given me hope for the future - and I know it will continue to. I intend to run again and I haven't done that for 15 years!!! Everyone with an auto-immune disease should know about LDN!! Not every day is good!!! I reckon that in any one month, I have a 'wrong' week but it's nothing in the grand scheme of things. I think of it as a time of transition - my body readjusting and realigning to the subtle changes brought about by LDN.

Update - 25 September, 2008

At the end of July, I had a fantastic hypnotherapy session with Ted Heath who, to-date, has worked with over 300 people with MS. What a fabulous couple of hours! What a positive experience! What a lovely man! I

was convinced that counting back from 100 was no problem. I managed 97!! He re-patterned my walking, gave me various triggers for different problems and gave me exercises to strengthen my muscles - all that and took delivery of a parcel whilst keeping Syd (our dog) amused!!

Well, in August we went to Rome for 5 days and I organized four 3-hour walking tours for the family - giving me an enormous mountain to climb if I did them, but knowing that I didn't have to if I felt unwell. Before I relate the outcome, I have to admit that I went well-armed!!

I completed all 4 tours - one of the Coliseum and Forum, a walk along a section of the Apian Way and around the Catacombs, a city tour and a tour of the Vatican and Sistine Chapel!! Admittedly, I had some funny moments, but then I either took a breather or hung on to hubby, son or daughter - whoever was nearest! But, importantly, I didn't slow the group down, so was I pleased with myself, LDN and especially Ted!!

About 2 weeks ago, I had another of my funny weeks when things just didn't seem right, but then up another notch I went. A couple of days ago, I walked around 2 supermarkets without the trolley that over the last 4 years I've needed to hang on to as I couldn't propel myself forward. More often than not, my daughter has had to pull me along on any necessary shopping trips whilst guiding me so that I don't bump into anyone - she's in her teens and an absolute treasure!!

I was out visiting our son who is now renting a house and in his 2nd year at uni. I asked if he thought my walking and balance had improved. He had, but didn't want to jinx me by saying anything!!!

Also, this week I was out walking Syd with my husband, and we both noticed that I no longer have to hang on to his arm. I can walk again unaided.

I've just taken Syd on a walk by myself. I didn't stop once - pretending to admire a flower, tree etc whilst waiting for my legs to start moving again. I walked there and back just like everyone else does. I'm ecstatic!!!!!!

So, my balance and walking have improved amazingly in the 3 months since writing 'my story' and my sleeping is phenomenal - rarely waking in the night to toilet trot and asleep as soon as my head hits the pillow - and it's a restful sleep. In fact, my husband describes me as 'dead to the world' in seconds.

To sum up, it's now been 4 years since I had my second ever exacerbation, which left me bedridden for a time. I spent the next 3 years getting more and more depressed and convinced that I would soon be in a wheelchair.

In September 2007, a sorry figure visited Dr Bob and Joycie and after a good few hours talking decided there was no down side to taking LDN.

One year later with the help of LDN, GABA, other supplements, a reasonable diet, Dr Bob's good counsel with trusty Joycie and not forgetting the amazing Ted, I now have a life to look forward to.

The best decision ever!!!!

I'd love to keep you posted and if there's ever anything I can help with, please let me know.

Update - 25 March 2009

I can't believe it's been 6 months since my last update - which means 18 months have gone by since I started taking LDN.

The one major change in my regimen is that I began taking LDN 4.5ml liquid instead of tablets in February 2009, when new legislation meant I could no longer get my tablets from Dr Bob Lawrence. This has surprisingly been a positive move - I've found both falling asleep and having sleep that is even more restful has been the outcome!! My only problem with the liquid has been practical - using the syringe supplied with the liquid - much too fiddly, with most of the liquid that should be in the syringe dribbling down my fingers. But, that is easily solved - I now use a teaspoon!!

I've also been a little remiss and not taken my minerals and vitamins religiously - it always happens in the dark dreary days of winter when everything seems such an effort. But, now the sun is shining and the days are getting brighter and longer, I should have the impetus to behave again!!

I continue to hiccup along the way - it happened again a couple of weeks ago - lots of pain in my left arm, side and leg, even interrupting my sleep. I've found that I can lessen the pain if I'm well wrapped and snug, and then I sleep through – a simple solution that is working. Over-the-knee socks are worth the investment too!!!

The left side 'stuff' has been around since I was first diagnosed in 1972 but the emphasis has changed over the years. In 1972, I had pins/needles/electric shocks in my left arm - often lying on it so that I could get to sleep but nothing in my leg.

Since the mid 90's I've had niggly pains/shocks around my left hip sometimes cascading into the front of my upper leg.

About six years ago (during a stressful period in 2003), it all started to become more pronounced and travelled through my left arm, around my left hip and then into the front of my left leg all the way down to the top of my foot.

My left leg always feels extremely cold - I always think of a slab of wet cold fresh fish!!

Dr Bob Lawrence suggested taking Malic Acid about a year ago, which does help enormously with the pain. Now its intermittent - if I try to hurry, it becomes more pronounced so I just don't hurry :-)

I've always felt my body, especially waist down, belongs to two different people - normal sensation in my right side, stuff and nonsense in my left!!

My test for years as I don't have a fish slab, is to lean my legs against the outside of the toilet, obviously in succession!!! - it's cold, smooth and almost feels wet!!!! Right side fine, left side goes haywire, like an electrical storm. Am I barmy!!!!!! One day, there'll be no storm.....

Having said that, my walking continues to improve, albeit small steps only - but I do have to be mindful otherwise I trip where there's nothing to trip over!!

I've had a couple of massages that have really helped and also invested in a set of pedals - not a bike with a seat, just pedals, and I sit on an upright chair - quite a contraption but it works!! At the moment I'm not using any resistance but intend to introduce it gradually. I've had maybe 2 sessions of physio since Christmas, compared with before Christmas when it was practically once a week. Sometimes, I even walk Syd, my dog, from the house to the local park rather than driving there.

So, once again, my update is positive and I'm still enthralled with LDN!! I'm also really looking forward to the 1st LDN European Conference in Glasgow at the end of April. I'll be there waving my flag!!!

Annmarie, UK

NB As at August 2010, no response to 2010 email update requests. Reason unknown.

Annmarie, UK

"I reckon that in any one month, I have a 'wrong' week but it's nothing in the grand scheme of things. I think of it as a time of transition - my body readjusting and realigning to the subtle changes brought about by LDN."
Jul '08

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

19 LDN has given me hope – Audrey

LDN since June 2007
- story submitted July 2008
- story updated Jan 2009
- story updated July 2009
- story updated November 2009
- story updated February 2010 (over 2.5yrs on LDN)

SPECIFICS

DIAGNOSED
- 1981 – diplopia, earliest symptoms of MS
- 1989 - suspected MS
- 28 July 1997 - diagnosed with MS

TESTS (pre LDN)
- 1989 - lumbar puncture and MRI - suspected MS
- 1997 - MRI (when compared to earlier MRI) - resulted in diagnosis of MS

SURGERY
- none

MEDICATION (pre LDN)
- 1981 to Jun 2007 – no medications

MEDICATION (post LDN)
- Jun 2007 to Aug 2007 – 3mg Low Dose Naltrexone (LDN)
- Aug 2007 to present - 4.5mg Low Dose Naltrexone (LDN)

TESTS (post LDN)
- none

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I was taking my naltrexone at bedtime, usually 11.30pm each night, but was experiencing nightmares - so I now take it at 10pm and no longer experience nightmares.
c) Type - Compounded capsules with pure Naltrexone powder from Dicksons, Glasgow.

SUPPLEMENTS
- 1989 to Jul 2008 - I tried the following supplements and some helped ...
Flaxseeds
Vitamin C
potassium and magnesium
flaxseed oil
multi vitamin
- July 2008 - I now take only the following three supplements ...
Baseline AM x 1 per day containing: Calcium 200mg, Magnesium 70mg, Zinc 20mg, Selenium 50mcg, Vitamin D 2000iu, Chromium Polynicotinate 400mcg, Coenzyme Q10 30mg, Pine Bark Extract 100mg, Manganese 0.5mg
Baseline PM x 1 per day containing: Vitamin A 250iu, Beta Carotene 2.5mg, Thiamine 5mg, Vitamin B12 5mcg, Vitamin B2 2.5mg, Vitamin B3 5mg, Vitamin B5 25mg, Vitamin B6 5mg, Biotin 150mcg, Vitamin C 200mg, Vitamin E 12mg, Folic Acid 400mcg, Copper 2.5mg, Manganese 0.5mg, Calcium 100mg.
MorEPA (Smart Fats) x 1000mg x 4 per day containing: EPA 580mg, DHA 88mg.
- Feb 2010 to present – The only thing I take is a couple of tablespoons of Flaxseed oil each day, usually on food.

OTHER/THERAPIES
- Feb 2010 - - 9 Feb 2010 to 23 Feb 2010 – 14 day Detox Diet Therapy using Nutrigold Detox Formula (6 per day), Nutrigold Colon Support Formula (2 per day), Bentonite Clay (28g per day), and a restricted five-food diet. Allowed foods include brown rice (which I sprout first) carrots, apples, lentils, onions and garlic. The detox plan involves AM body brushing, hot and cold showers, hot water and lemon. Breakfast and lunch are from allowed foods, plus 2 capsules of Nutrigold's Colon Support Formula and 2 capsules of Nutrigold's Detox Support Formula. Snacks are fresh juice carrot or apple (or combination) mixed with 28g Bentonite Clay with 2 Detox Support Formula. Dinner consists of allowed foods plus 2 Detox Support Formula. (When complete I plan to start Dr Gray's colon cleanse which could be interpreted as a continuation of the detox. I would like to do the colon cleanse for up to 5 months. I'll have to wait and see how I go.)

DIET
- 1989 to Jun 2007 - I would say I was at my most healthy when I was following a simple, gentle diet of short grain rice, fruit and vegetables, nuts and seeds with lots of juicing. I avoided all salt, never ate processed foods and drank reverse osmosis water. I used to do a lot of yoga and worked out in the gym.
- from Jun 2007 to Aug 2008 – My diet was more relaxed.

- Jan 2009 – I’ve been benefiting from the Best Bet Diet (BBD) and it’s helped me overcome my constipation. Also, after an Elissa test revealed I had a problem with most proteins, I only eat hemp seeds and quinoa for protein at home now.
- July 2009 - I didn't continue with the BBD. I now eat everything; gluten, dairy and the odd glass of wine.
- Feb 2010 – I now follow a vegan diet. I eat ANY unprocessed unrefined food, except foods that contain something derived from an animal.

EXERCISE OR INTERESTS
- Energy, balance, and all symptoms have improved sufficiently to enable me to again fully participate in just about everything life has to offer, even joining a gym.
- July 2009 – I didn’t end up going to the gym.
- Feb 2010 – I have been feeling so good I was able to run a 5 kilometre race.

MY STORY – July 2008

There's not much to my story really. I am in my late thirties now, but I've had MS since I was young (when I had diplopia for a few weeks). I also had burning sensations in my legs. In my early 20s I had a lumbar puncture and MRI. As it was during the late 1980s, the doctors thought it better not to tell me, even though they wrote in my medical notes that they 'suspected' MS.

Throughout my twenties I had relapses, but I wasn't diagnosed until I ended up in tears in front of a compassionate GP. He sent me for another MRI, and then the two MRI's were compared. MS was confirmed.

Throughout my thirties my relapses got progressively worse and despite following a healthy diet I got to the point where I couldn't see, couldn't stand up, and was falling over - mainly because of balance problems. I had fatigue that prevented me walking very far. I couldn't even peel a carrot, and was generally feeling suicidal and hopeless. During this time, I never tried any other drug.

I seemed to be on a steep decline. I had five relapses with no intermission and no short breather. The last went on for six months. I wasn’t sure what was happening but my MS was really progressing.

If I went for a walk it was like the plug was pulled out after a short distance. My energy was zapped. I could barely walk. Very, very little energy to do anything or go anywhere. I would awaken as if I had done a marathon the day before. My right hand would keep me awake at night from nerve damage - it had been numb for six years.

One of my relapses just six months prior to LDN left me unable to drive, with difficulty walking, talking, eating and preparing food. I had terrible fatigue. No energy and no ability to make something to eat - with no one to help, including my husband. I found it difficult to go to the toilet to empty my bladder. I dropped whatever I touched literally.

My balance became bad and I would constantly fall over. I would go into remission, only to have another relapse straight away. I had double vision and needed an eye patch. I sprained my ankle 5 times because I couldn't see. I had problems with cognition, no clarity of thought – often called ‘brain fog’ by others with MS. Then I had a bladder infection and I had to take antibiotics and both my legs went numb and stiff with spasticity.

Then I found out about LDN. My neuro and two local GPs would not prescribe LDN, but fortunately, a Harley Street GP came through for me. At the time of starting LDN, I had spasticity in my legs and general fatigue. Within a matter of days I felt like a new woman. It was as though I had been given my life back. The spasticity left, and the fatigue lifted.

I noticed a difference within a few days. I began three days before I had an appointment with my MS nurse. I actually walked to the hospital - something I definitely couldn't have achieved before starting. It must have been 1 mile at least. My mood was much happier and I noticed a difference from the word go. I found myself dancing to the radio and realised my fatigue had disappeared.

I saw my GP and he noticed my walking was much better. The previous time I saw him I was walking with a stick. Today my right hand (which suffered from nerve damage and numbness) feels markedly better.

This is one of my diary notes: 'I have been taking LDN for a month and already I have virtually no symptoms including previous bladder retention. My energy is amazing. I am sleeping the whole night through. Yesterday I got up in the morning, walked the dog, and went for a 1km swim. I went for a strenuous bike ride, walked the dog, made lunch, tidied the house, walked the dog again, went shopping, picked up my husband from the station, walked the dog yet again, and still had enough energy to make something to eat. I find if I plan, I can still spend the day somewhere like St Albans or Windsor and still find energy to drive home, walk the dog and socialize. The most noticeable difference is the reduction in numbness, pins and needles, bladder retention, sleeping the night through, energy levels and probably more. All in the first month.'

Taking LDN has helped me get back on my feet and build up my strength sufficiently to stop my rapid decline.

On the way to my second appointment with the GP who originally prescribed my LDN, I got off the train at Marlebone and ran all the way to Harley Street. I remember running down the platform at the station and beating everyone to the barriers. I thought that was pretty good considering I'd spent six months incapable of much at all not that long ago.

I originally paid for the LDN myself, but later went to my own GP and asked if she would prescribe LDN. She said; "Wow you look fantastic', and prescribed it for me. Two male GP's at the same local practice had previously turned me down.

I've now been on LDN since March 2007, 16 months. Despite a short exacerbation, which wasn't as severe as previous relapses, I'm still active and full of life.

I have a border collie who is extremely active and keeps me busy.

More than anything LDN has given me hope.

Update – January 2009

I've had diplopia for as long as I can remember. When I look to the far left, right, up or down. If I do exercise it gets a bit worse. I saw my optician recently and he thinks I had it as a child, just didn't notice. I haven't had a relapse and it's been like this the whole time I've been on LDN.

I am trying to be careful with diet and lifestyle but Christmas is a difficult time of year. I've just had a birthday celebration and I was as good as gold. I ate pigeon and venison. I had an Elissa test and it revealed I had a problem with most proteins. The only proteins I eat at home are hemp seeds and quinoa.

The constipation problem disappeared soon after starting on the Best Bet Diet (BBD), and I got rid of my nightmare problem by taking my LDN a bit earlier at 10.00pm instead of 11.30pm.

I have just joined a gym for three months so I hope to make the most of it. I don't think my border collie is going to be too pleased!!

Update – July 2009

To update my case I never did go to the gym and I didn't continue with the BBD. My Elissa test told me to exclude everything I was eating but to give up so many foods would be impossible. I now eat everything, gluten, dairy and the odd glass of wine.

My health has been good and I didn't have a cold all winter until May. I don't feel like I have MS. I am even attempting to have a baby, something I never thought I'd hear myself say. I'm closer to the end than the beginning of my child bearing years so it's a bit late, but I am putting my trust in the LDN.

Update – November 2009

Following my lumbar puncture and prior to starting LDN, I'd had over 35 relapses. Since LDN, I've been keeping well with fewer and milder relapses. My last relapse was in Sept 2008, over twelve months ago, and it was milder than all previous relapses. Since then, NOT ONE RELAPSE. Good news for LDN.

I have spent a lot of my time gardening this year especially because we had a cool summer. I have a large garden with lots of trees and this autumn, I've had the energy to rake up the leaves at least once a week. Three years ago I had no energy for gardening, but I'm happy being busy in the garden now.

My use of supplements is still haphazard and I don't take them regularly. In fact, I forget to take them most of the time, but I am eating a healthy, mostly organic diet, enjoying all foods with no detrimental effect. I have been eating some of the wrong foods, but not to excess, and haven't had to exclude anything in particular from my diet.

I have been on LDN for almost 3 years now, and I am so grateful for LDN. When I think back to how I was and compare with how I am now, the difference is just amazing. I was having at least one major relapse a year before LDN, but no longer.

Coincidence? I'm becoming more convinced it's not.

Update - February 2010

I ran a 5 kilometre race in December 2009 for the first time in my life. They are organised locally every weekend. It took me 31 minutes. Amazing, considering how I was pre LDN. It's my goal to go for ten kilometres this year.

I will have had MS for 29 years in June and because I am 99% symptom free my neuro says I am a benign case because I haven't progressed to the point where I need to use a wheelchair after all these years. Prior to starting LDN I felt I was moving into secondary progressive stage after 17 yrs of being remission/relapse stage. As a teenager I only had burning sensations so I probably was benign…pre-teens I had diplopia.

I have not been taking any supplements regularly now for months, except flaxseed oil on cooled baked potato or rice.

I went back to my vegan diet just before Xmas. I eat ANY non-refined or unprocessed food except foods that contain something derived from an animal. There are several reasons for this:

1. I hate all the animal slaughter in the world and I would be adding to it if I ate meat.
2. After my Elissa test, all the foods I was intolerant to were the animal derived foods (uncanny!).
3. I read 'the China Study' recently. It stated a high protein, high fat diet is the cause of all the major diseases in the world today.
4. Whenever I have had an MS exacerbation, it has been after bingeing on cheese, milk chocolate or ice-cream, which I admit I have done to excess at times.

For three months last year from October I started drinking wine again after not drinking it since my twenties. A small glass every single night slowly led to two glasses and then more. I stopped this apres dinner activity outright when I nearly didn't manage to walk to my bed one night because I was so drunk. I now no longer partake in my husbands apres work relaxation technique. Alcohol in moderation doesn't affect my MS.

I am 99% symptom-free when I follow a strict vegan diet, but I'm still heat intolerant if I have a long hot bath, so I avoid hot baths. I felt the detoxification I was doing may have caused me to wake up in the morning a few days ago with some numbness in my leg but this disappeared as soon as I got up and has not happened since.

I do agree with the bit from the BBD that says not to have dairy and soy but I do eat other legumes, which they don't recommend. I don't eat the meat that they can eat.

For most of my twenties and the first half of my thirties I was strictly vegan. I only started eating animal products about six years ago. I found it difficult to give them up, however, reading 'The China Study' has really helped me to mentally commit.

I've been on LDN now for three years. My MS was at its worst 3-3.5+ years ago, but has improved so much in the last three years.

I rarely ever eat processed foods, if possible. I try not to eat sugary cereals, cakes and biscuits because of hidden animal fats. I drink mostly water or freshly prepared juices and avoid foods that contain palm oil. I drink Rooibos tea and the very occasional coffee.

With the news of the research into CCSVI I have felt in the past that having hot and cold showers has always helped me, which would make sense if I had CCSVI. The hot and cold water would force the flow of blood through the veins. This is my theory.

As at February 2010, I'm only taking Flaxseed oil, no other supplements apart from my detox therapy supplements. On 9 February I commenced a 14-day Detox using Nutrigold Detox supplement, plus a five-food diet - allowed foods include brown rice (which I sprout first), carrots, apples, lentils, onions and garlic. I also have a bit of seaweed.

The detox plan involves AM body brushing, hot water and lemon. Hot and cold shower. Breakfast and lunch are from allowed foods, plus 2 capsules of Nutrigold's Colon Support Formula and 2 capsules of Nutrigold's Detox Support Formula. Snacks are fresh juice carrot or apple (or combination) mixed with 28g Bentonite Clay with 2 Detox Support Formula. Dinner consists of allowed foods plus 2 Detox Support Formula.

I am on day 8 of my 14-day detox but when complete I plan to start Dr Gray's Colon Cleanse which could be interpreted as a continuation of the detox. I would like to do the colon cleanse for up to 5 months. I'll have to wait and see how I go.

I credit my present state of well-being to LDN and returning to a strict vegan diet just before Xmas 2009.

Audrey, UK

Audrey, UK

"My health has been good and I didn't have a cold all winter until May. I don't feel like I have MS. I am even attempting to have a baby, something I never thought I'd hear myself say. I'm closer to the end than the beginning of my child bearing years so it's a bit late, but I am putting my trust in the LDN." Jul '09

Why I contributed my case study…

Doing this case study has helped me keep a record of my MS and the ebb and flow of symptoms/relapses. I've had MS for 29 years now and if I hadn't kept a record I'd have forgotten most of the hard times I've been through and the improvement I've had. Doing this means I can help someone else decide if they might benefit from starting LDN. Hopefully It can help someone not to give up on LDN after a short period of time taking it if they feel it's not working.

THIS IS MY SYMPTOM HISTORY

PRIOR TO LDN

1981

BEFORE LUMBAR PUNCTURE & MRI

- Impaired Vision - Double Vision/Diplopia
- Burning sensation - burning sensation in upper legs
- Numbness - numbness around ribs, stomach, and waist (front and back), R. leg, Back very numb, couldn't feel fingers in right hand at all.
- Tingling with Pins and Needles - pins and needles in both hands, both feet, top half of both legs, also over ribs, stomach, waist and around back.
- Tingling - tingling sensation over ribs, stomach and waist.
- Itching - itchy sensation around waist and ribs.

AFTER LUMBAR PUNCTURE & MRI

Relapse became worse after the lumbar puncture and M.R.I.

- Burning sensation - burning down left leg
- Numbness - woke up with numbness all over my body - complete numbness around front and back of torso, also down both legs, couldn't feel my fingers on either hand and could not draw.

1981 to 1989
Symptoms over the following five years were a self-discovery of what caused the symptoms - numbness, optic neuritis, fatigue, etc. Because I was not diagnosed I had to listen to my body. I may not have had full-blown relapses, but definitely had exacerbations that would last from 3 weeks to 3 months.

1989 to 1997
It was a very stressful period for me from 1993 onwards with increasingly frequent relapses, more severe symptoms, and longer duration. Relapses lasted from 4 weeks to 6 months.
Symptoms:
- Impaired Vision – Severe Optic Neuritis, with blindness in right eye after taking amphetamine in 1995. Painful eye movements. Pulsating, pumping sensations in left eye. Pumping feels like flickering heartbeat inside eye. Lasts a few seconds, then goes and comes back again.
- Burning sensation - burning sensation in upper legs and back
- Numbness - numbness would come on gradually and spread to torso - ribs, stomach, waist (front and back), both legs spreading into feet. Legs feel heavy and clumsy. Numbness spreading higher in back past ribs. Numbness in arm and right hand which started in the thumb.
- Tingling with Pins and Needles - pins and needles in both hands, both feet, top half of both legs, also over ribs, stomach, waist and around back.
- Tingling - tingling sensation over ribs, stomach and waist.
- Itching - itchy sensation around waist and ribs.
- Fatigue – fatigue, which led to being sacked from a stressful job and told my work had slipped. I felt I was being psychologically bullied.
- Pain and Cramping - Quick, stabbing, crippling pain and cramps in different parts of feet, other parts of body and head became more frequent and would last longer.
- Skin Sensitivity - Prickly sore sensations in skin on patches of back.
- Mobility - Difficulty walking. Couldn't run at all.
- Vertigo - Lack of balance, dizziness, vertigo upon rising with accompanying nausea.

(During this period I saw a consultant neurologist, Dr T. At the time, I was blind in one eye. You can imagine just how frightening that was. I was scared, and I wanted a diagnosis so I knew what I was up against. His response to my being blind and afraid was cold and detached; "Do you really want the NHS to spend £500 so YOU can have another MRI?". I was devastated by this response. I felt abandoned by the very person whose job it was to heal me or help me, so I set out to help myself.)

1997 to 2007
In 1997 I had a relapse that lasted for 6 months. My second MRI was compared with my first. There were many more lesions and Multiple Sclerosis was confirmed. During 2000 I had five relapses over ten months. In 2001 I was blind in my left eye after I had a mercury filling removed. Relapses became increasingly frequent and lasted longer, and symptoms became more severe.

Worse, after a major relapse in 2003 I was left with residual symptoms that never left.

I tried to listen to my body more to see if I could detect triggers, eg; in 2004 symptoms of pins and needles returned in legs during a stressful period when I was eating a lot of chocolate, and symptoms of numbness and burning would occur around waist and legs after eating cheese, and I noticed poor cognition after gloss paint was used in my house. I soon realised I couldn't eat anything unhealthy without it immediately giving me symptoms of MS or a relapse. I used to get away with eating more 'bad' foods but couldn't any longer. In 2005 I had another seven mercury fillings removed by a specialist dentist, but this time I was really careful because I didn't want to go blind again, and I didn't, but still, **by Feb 2006 I knew my MS was really progressing**.

Relapse Symptoms:
All previous symptoms, plus… Diplopia, blindness in left eye after mercury filling removed, Nystagmus in R. eye, couldn't prepare meals, dropped everything often, extreme fatigue, could not walk more than 15 minutes, prickly and sore sensations now in neck as well, spasticity, new cognitive problems, brain fog, forgetfulness, Inability to focus or concentrate, difficulty putting thoughts and words together, unable to read or listen with comprehension, no clarity of thought, difficulty talking, difficulty eating and swallowing and drinking, choking (including choking on my own saliva), difficulty differentiating temperature changes, difficult emptying bladder resulting in bladder/kidney infection (antibiotics). When talking, felt like I was deaf in my left ear – strange feeling.
What Helped (prior to LDN):
- I have never taken any drugs and managed my MS by healthy diet and stress reduction.
- Numbness from chest down was relieved slightly by lymphatic drainage.
- Found some relief from walking barefoot on grass.
- Hot and cold showers, including the head.

Began LDN June 2007 to Feb 2010
- Last relapse was in Sept 2008 but it was milder than all previous relapses. Since then, NO RELAPSE.

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

20 Mary Finds Proof of Santa for Noel – Mary

LDN since September 2002
- story submitted August 2005
- story updated July 2008
- story updated July 2009
- story updated May 2010 (over 7.5yrs on LDN)

SPECIFICS:

DIAGNOSED
- Oct 1998 – Primary Progressive Multiple Sclerosis (PPMS)

MEDICATION (pre LDN)
- 1999 to 2002 - Avonex

MEDICATION (post LDN)
- Sept 2002 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose – 4.5mg LDN
b) Time – Noel takes his LDN between 9pm and 11pm each night
c) Type - Compounded capsules with pure Naltrexone powder and lactose filler from Irmats Pharmacy

MEDICATION OTHER (post LDN)
- none

TESTS
- Feb 2007 - cholesterol, liver enzymes tested – normal range

SUPPLEMENTS
- Aug 2005 to 2009:
Cranberry
Calcium
- 2009 to present:
Cranberry x 1 daily
Calcium x 1 daily
Fish Oil 1000mg x 1 daily

DIET
- low meat, lots of fruit and veg, chicken and fish, preservative free-ish type diet ... that includes the odd beer or glass of wine or Margarita. That's the best we can realistically do.

EXERCISE & INTERESTS
- Riding a three-wheeler with the kids

MY STORY – August 2005

I was the final speaker at the New York LDN Conference (ldninfo.org) and this was my talk ... more or less ... I improvised a bit ...

I am delighted to be here today and would like to thank Dr Gluck and his son Joel for organizing this event. I hope that this will be the first of many LDN conferences worldwide.

It is wonderful to be able to match our faces to our screen names, and I am thrilled to be joined by my husband Noel, because I can now prove to him that I don't really have imaginary friends ... you guys are real.

So what do I know about LDN? I certainly don't know as much as all of the doctors present here. I don't know the exact medical mechanics by any means, but I know enough to know that Dr Bihari has discovered something wonderful that has the potential to improve millions of lives. That is why I wrote a book about it. I want Dr Bihari to receive a Nobel Prize ... I am not kidding ... I really do.

To be honest, I needed to write the book ... for me more than anyone ... because it is difficult to rest easy when you know there is something so simple that people with disturbed immune systems need ... but don't

know about, because the system works against getting a cheap drug into a clinical trial and medically recognized.

It is just so wrong ... it should be considered criminal ... but that is the system we have been trying to seduce for the last few years.

However ... I have absolutely no doubt that a trial will happen because the people involved in that pursuit are relentless and dedicated ... even obsessed, and for good reason ... because LDN has changed lives. I will share how it has changed my life.

Picture this ... A young mom living in NJ, she is Irish, lets make her a size 6 for a pleasant visual, she has three kids aged 3, 2 and 1 and a dashing husband who loves her very much and she him. Dashing husband has primary progressive MS (PPMS) and as the term implies he is progressing rapidly. The handsome couple are Noel and Mary.

Noels Neurologist attends all of the MS conferences and assures us that he knows everything there is to know about MS and suggests taking Noel off the Avonex and onto Copaxone.

But ... Mary befriends complete strangers on the internet who convince her that a doctor by the name of Dr Bihari in NYC can stop her husbands PPMS from progressing.

IMAGINE!! I don't know about you guys but I completely relate to people who want to beat me up when I first tell them about LDN ... I mean we are all too old to believe in Santa Claus. But ... I was desperate ... my back was against the wall so I phoned Dr Bihari and he spoke to me for about 45 minutes and assured me that LDN would stabilize my husband.

Mary tells Noel. Dashing husband naturally deems she is demented and insists she accept his rapid decline gracefully and make the most of everyday. Mary tells him all about her virtual friends in cyberspace and the success they have had with LDN.

The duo approach the Neurologist who, after recommending intensive therapy for dismal damsel, writes a script for Noel for LDN convinced that it would not work.

He wrote the script on the basis that it would do him no harm and is therefore in line with the first guiding principle of medicine ... first do no harm.

What a wonderful concept ... that should be our starting point ladies and gentlemen ... when you look at everything else we have ... I ask you, does it even come close ????

Noel started LDN and his condition stabilized as Dr Bihari predicted. Much time has passed - three years in September - and he remains stable despite massive stress at times ... Noel has not experienced any brand new symptom since September 2002, when he started taking LDN.

To be honest, part of me is still in shock at how well LDN is working for Noel. Noel uses a wheelchair when we are out and about so people may think that he is not a great poster child for LDN ... but in my mind Noel is the perfect poster child because the onslaught stopped in the nick of time whereby he can still live a full, functional, independent and very happy married life.

As a result of that knowledge (that nobody can dispute) ... I couldn't just forget about it. I told everyone I knew about it.

I kicked off the LDN campaign in Ireland. I tried posting on MS Ireland but was constantly blocked ... and that annoyed me ... I still cannot post there actually ... but way back then I emailed each member of MS Ireland individually as their email was listed ... and I phoned each MS branch personally.

A friend of mine, Robert Joyce in Galway, the west of Ireland, then tried LDN. It arrested both his MS and sarcoidosis. He had the ultimate life changing experience and I so wish he was here today because he tells the most compelling story in such a laid back manner that he puts every Irish story teller to shame …

Robert's Neurologist is now scripting his LDN in Ireland and the western health board ... i.e. ... the Government ... pays for it ... and a local pharmacist in Galway, Brendan Quinn distributes it.

You see ... of course the Irish and European governments have interest ... they are the ones forking out for the expensive approved meds ... the health care in Ireland and England is different to here in the USA ... There the Government pays for it. ... You would think they would jump at the chance to investigate LDN ... but I have learned and written that it is not that straight forward.

However, the LDN snowball did get bigger, Ireland joined forces with England, Scotland and Wales. Dr Bihari went on Irish radio and really got the momentum going on the other side of the Atlantic. I presented the Irish government with a trial proposal on behalf of Dr Bihari and they still have it.

Meanwhile I have contacted many celebrities and other governments and tried to entice them to investigate but to no avail. So what did I do? I wrote a book about it because I needed to write it down ... because it is a story that has to get out there and lets face it … it was great therapy. How could anyone keep a story like that to themselves ... It is just too, too big.

I believe that my book ... Up the Creek with a Paddle ... subtitle Beat MS and Many Autoimmune Disorders will help take the LDN movement forward, and I predict that it is the first book of many on the topic. I know that. It is funny how things happen in life.

The book is actually a collection of emails to my kids kindergarten teacher. I met a lady named Rosemary Konde in September 2003 and I instantly loved conversing with her. She is about 55 and a lot of fun.

But, I accidentally included her in an email to a group of LDN contacts a couple of years ago and because of that email she told me that her 26 year old daughter at the time had an autoimmune illness, Samters, and she was hopeful that LDN could help her.

Her daughter met Dr Bihari and started LDN and thank God, it does seem to be helping her. How crazy is that?? If you believe in coincidence it was a classic.

I am glad that our connection grew because it turned out that the only way I could get my story onto paper was by telling Rosemary the whole thing from the very beginning ... from the first day I met Noel ... in a series of emails.

When I was done getting the story off my chest ... (the teachers in Bergen county are very patient - it took about 6 weeks) … I compiled the emails into a manuscript and the first publishing house that received it, loved it and just ran with it.

That is why I dedicated the book to Rosemary and that is why when people read it, they tell me that it is as if I am just sitting there telling them a story ... because that is what I did.

It is the best story ever ... you see Santa Claus himself even comes second.

The book is an easy read and I am shameless in plugging it ... I just want the world to hear it ... the whole story ... I hide nothing ... and I want Pierce Brosnan to play Noel in the movie by the way.

I bought 50 books and intend to send one to a list of key targets in the hope that one of them will shine the spotlight on it. I have not given up on Oprah by any means.

This is the bottom line ... My husband has not experienced any brand new symptom despite having PPMS because he started taking LDN in September 2002. There is nothing better ... there is nothing better than the release from the onslaught of a progressive degenerative illness. .

I feel for everyone in our boat pre LDN ... I do .. I cant help it ... and I want them to change their future like we did .. and believe me, I have thought about the 'what if Noel found LDN earlier' ... let's not go there.

We need a large scale clinical trial of MS and LDN to blow the socks off the status quo ... such a trial would shed much light on the mechanics of the immune system and hopefully redirect research to help the children of today, like my own ... who are at risk of developing a disturbed immune system illness tomorrow.

The neurologist has assured me I have nothing to worry about ... but I am worried.

Beyond all else ... my children are my incentive… so if I do have the gift of the gab then it is my privilege to use it to get the LDN word out to all those who need it.

To conclude I will end with a relevant quote:

'Many persons have a wrong idea of what constitutes true happiness.
It is not attained through self-gratification but through fidelity to a worthy purpose.'
Helen Keller US blind & deaf educator (1880 - 1968)

UPDATE July 2008

I am delighted to report that Noel has not experienced any new MS symptoms since he started LDN in September 2002, almost six years ago. He is in fact, healthier than most people I know. His cholesterol, liver enzymes and all of his blood tests are perfect. His doctor even told him that apart from the fact he has MS, he is in perfect shape.

I have no doubt that stress contributes to MS exacerbations because I have seen the correlation too many times, and it is fair to say that during the years post LDN, life has thrown us our fair share of stress. As a result of such hits, the pre-existing symptoms in Noels legs are a little worse.

For example, he now needs two canes to get around. He has also lost some muscle tone because he uses his legs less and walks in such a way that the muscles he needs have weakened from lack of use. *All of this is in keeping with the initial promise made to us by Dr. Bihari. He said that we will never experience a day post LDN, worse than our worst day pre LDN*. Pre LDN, our worst days involved Noel's MS spreading up his body. His hands were starting to show symptoms, as were other areas of his body.

To be quite honest, I now feel like we are living with an injury of old, as opposed to a progressive degenerative disease. Today, Noel's MS remains confined to his legs and bladder - and some days both are better than others. Exercise and physical therapy definitely help, as does a healthy diet. I am only talking about a common-sense healthy diet; low in meat, high in fresh fish, fruit and vegetables. We have definitely noticed that if Noel eats well and exercises, he walks better, but that is hardly rocket science or remotely ground-breaking.

Noel is still the primary breadwinner of our family. He is still totally independent in every way and he is still able to live a fully functional married life. We found LDN in the nick of time and continue to encourage everybody with an autoimmune disease to try it. Noel is now as much of an advocate as I am!

My book '*Up the Creek'* has helped many people make that difficult decision to go against their Neurologist in his suit, and listen to strangers on the Internet who know better because they have lived the same nightmare and want more than anything for needless nightmares to be erased … because they can be. I am very proud of the impact '*Up the Creek'* has had on people. It is a personal story that was absolutely worth sharing.

My uncle with Parkinsons Disease (PD) also started 4.5mg LDN in September 2002. Without question, his PD has progressed. He has experienced many brand new symptoms, but we are still hoping that LDN is slowing the progression. It is certainly not doing him any harm so he will continue to take it. I spoke with Dr. Bihari about this and he told me that his other PD patients also progressed and concluded that LDN does not work for PD because although the etiology of PD remains unknown, it seems it is not autoimmune. If I had PD, I would still take LDN. I take LDN myself and continue to take it in the hope that I will stay healthy.

My mother with breast cancer died on August 6th 2007. She also started 4.5mf LDN in September 2002. She started LDN after a mastectomy and months of the standard recommended chemotherapy and radiation. Despite LDN, her cancer spread to her bones and then to her brain. Last summer, I went back to Ireland to care for her during her final months. I scoured the Internet to try to find something that would save her. I mean, against all odds we beat PPMS ... surely there is something out there universally beating cancer. And I believe I found the answer, too late for Mom but in the nick of time for others.

I am about to publish the whole story. It's called *'Going Nowhere? Mom's final lesson: How to beat cancer.'* We tried everything on the Internet and I learned first hand why many theories out there are controversial, but I also learned that there is one theory that is not on the internet yet because once again it is based on an already approved generic drug that nobody will profit from.

The doctor who came up with this cancer theory reminds me a lot of Dr. Bihari. His name was Dr Jurkovic from Slovakia, and here is the kicker …to make his theory even better he was exhausting methods of boosting the immune system. Nothing boosts the immune system like LDN. LDN was the missing piece to his

puzzle. By combining the Bihari and Jurkovic theories and protocols, I'm certain we've struck gold. Time will tell for sure.

My mother's story details her final year, her faith and all the graces she was granted in her final months through the power of prayer. She died exactly right. No medicine, not even LDN, will keep anybody alive forever, so when my time comes to pass, I am grateful that my mother taught me how to die right. There is no finer lesson in life.

UPDATE July 2009

Noel has not experienced one brand new MS symptom since he started LDN in September 2002. It remains confined to his legs and bladder. It really feels like we are living with an injury of old as opposed to a progressive degenerative disease. I don't even worry about my kids getting MS or any autoimmune disease anymore. I know that LDN works.

Such knowledge comes with a price. I have a confession to make. I hoped that my book, "Up the Creek with a Paddle", would allow me to forget about LDN and move on with my life. Part of me desperately wants to forget that Noel ever had MS. I am incredibly proud that my book has helped educate thousands of people and even convince many to use LDN as a first line of defence against a host of autoimmune conditions. It has saved lives and highlights the tragedy that everybody with an autoimmune disorder is not offered LDN. I cannot reach the majority of people who need to hear about LDN.

Furthermore, it is the most depressing reflection of humanity that society accepts that potential financial profit determines whether or not potential uses for drugs should be investigated. We should be ashamed of ourselves for letting profit hungry industries monopolize our healthcare system.

The more I try to forget about LDN the more determined I seem to become to get it to the masses. The bottom line is: nobody in the LDN community can forget about LDN. How can anybody forget about a simple miracle that should be granted to everyone? No matter how I look at it, it is plain and simply our duty to get LDN to the masses.

I started my online LDN radio show to figure out how best to achieve that goal. I put my name on the show because I believe in it. I knew that the LDN harvest was ready to reap and that the world had to hear our united voices and passion. The show is much more popular than I imagined. It is a true honor for me to bring the LDN community to life on air.

There seems to be a couple of ways forward. People have spoken about changing the patent laws so that pharmaceutical companies would profit should they find a new use for an old drug. At first I liked that idea but having thought about it, I don't like it anymore. I hate the idea. I have learned that there are many wonderful therapies out there that pharmaceutical companies ignore, but none of them have the passionate patient advocacy that LDN has behind them.

Therefore, it is the duty of the LDN community to somehow set a precedent for future therapies and quite frankly, to heck with the pharmaceutical companies and their greed for profit. I don't want to play their game. If we change the patent laws, it is like we are saying that it is OK to make a huge profit from sick people. It is not OK. The LDN community has learned that the hard way.

I refuse to feed an already deeply flawed health system. There is no bad guy in all of this, by the way. There is nobody I can call up and yell at. The wrongness is intricately woven throughout the fabric of our system so much so that when a pharmaceutical company refuses to investigate new uses for drugs such as Naltrexone, they cannot be considered bad guys. They are in fact very smart business men. Naltrexone will not make them money so why bother? To heck with them.

I would like to bypass the pharmaceutical companies altogether and rely on good old fashioned democracy. People power. To quote Margaret Mead .. 'Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has.'

If I am totally honest, I believe that some governments are in bed with the pharmaceutical companies but not all. Good guys still exist. I am certain of that.

We are a small, dedicated, passionate, patient-driven community with an abundance of varied talents. We will not be able to privately fund the research we need no matter how many fundraisers we have. We need

our elected Governments to help us. It is their duty to listen to us. Our evidence as to the efficacy and safety of LDN far exceeds anecdotal. We need to intelligently present a state of the art business proposal to our governments with the knowledge that the bottom line, despite the lives at stake, has to be how much money they will save.

We have not presented everything we have intelligently and objectively yet to a reputable government body. We need to do this. As far as I can see, that is our best way forward. The first step has to be educating people. We need a great deal of help to spread the LDN word. Once we have enough people on board, the government will have to listen. I think my radio show will help on that front but we need more!

On a happy note, Noel is still the primary bread-winner in our family. He is the picture of health! This year we are going to drive to Florida in August to vacation for two weeks and next year, 2010, we are planning a five week trip to Ireland during the summer. Our kids are growing up beautifully and life could not be any better thanks to LDN. We appreciate every day together more than most, and wish more than anything that everyone who needs to hear about LDN .. will do so, sooner rather than later.

UPDATE – May 2010

It is now May 2010 and I have learned that even with LDN, life with MS can be tough at times. I am also more certain than ever, that emotional stress is detrimental to MS. I am happy to report that Noel has not experienced one brand new symptom since he started taking LDN in September 2002. That was always the bottom line of Dr Bihari's promise eight years ago.

That said, Noel's legs continue to weaken. When Noel relapses now, it is not like before. Before LDN, during a relapse, his MS would spread all over his body. That no longer happens. It is almost like we are living with an injury as opposed to a progressive degenerative disease, but the damage caused by his MS pre LDN flares like heck now and then, and over time such flare ups ... seem to permanently weaken his legs.

Noel tried taking a break from LDN as Dr Zagon has suggested, but just as Dr Bihari predicted... it did him more harm than good. He still takes the same supplements; calcium, cranberry, and fish oil, and still follows the same diet. The most important thing is, he has no new symptoms, and that is the bottom line.

Noel now uses 2 canes all the time, and we invested in walk aides. His upper body is very strong and his overall health is better than most people his age, His blood work is perfect and he looks the picture of health. I wish we found LDN sooner but I continue to thank God that we found it in the nick of time. Noel still works and is the primary breadwinner. His spirits, attitude and outlook continue to inspire me daily.

My uncle with PD is progressing despite LDN. That said, we continue to hope that he is progressing at a much slower rate than he would without LDN. He cannot tolerate any of the PD meds... and he tried them all! He continues to take LDN and notices a definite difference without it. I would recommend LDN to everyone with PD.

Mary, USA

Mary, USA

"He wrote the script on the basis that it would do him no harm and is therefore in line with the first guiding principle of medicine ... first do no harm." Aug '05
"All of this is in keeping with the initial promise made to us by Dr. Bihari. He said that we will never experience a day post LDN, worse than our worst day pre LDN." Jul '08

Mary Boyle Bradley Speaks – 2007 LDN Conference

Mary Boyle Bradley, Author, 'Up the Creek with a Paddle'
http://www.youtube.com/watch?v=WCTwLbRX2Ys

Mary Bradley Books

'Up the Creek with a Paddle' by Mary Boyle Bradley
http://www.marybradleybooks.com
http://outskirtspress.com/webpage.php?ISBN=3D9781432711504

Mary Boyle Bradley Radio Show - Interviews on Blog Talk Radio

LDN Interviews by Mary Boyle Bradley
http://www.blogtalkradio.com/mary-boyle-bradley

21 LDN kept me out of hospital - Zillah

LDN since November 2006
- story submitted July 2008
- story updated August 2009
- story updated July 2010 (3.5yrs on LDN)

SPECIFICS

DIAGNOSED
- Mar 1994 - Relapsing Remitting Multiple Sclerosis (RRMS)

TESTS
- Mar 1994 - Magnetic Resonance Image (MRI) in Manchester

SURGERY/HOSPITALISATION
- Mar 1994 - hospitalised for 2 weeks
- May 1994 - hospitalised for 1 week
- May 1998 - IV steroids, as an outpatient, for 1 week

MEDICATION/TREATMENT (pre LDN)
- Mar 1994 to Mar 1994 - IV steroids for 2 Weeks
- May 1994 - IV steroids for 1 week
- May 1998 - IV steroids for 1 week
- 2005 - IV steroids, while an outpatient, for 1 week
- Jun 2006 to Nov 2006 - High Dose Oxygen Therapy (HDOT)
- Nov 2006 to Dec 2006 - High Dose Oxygen Therapy (HDOT). (Break taken due to the bereavement and family issues.

MEDICATION/TREATMENT (post LDN)
- Nov 2006 to Dec 2006 - 3mg Low Dose Naltrexone (LDN) x 4 weeks
- Dec 2006 to present - 4.5mg Low Dose Naltrexone (LDN)
- Dec 2008 to present - 2 x 150mg Tramadol slow release capsules (morning & night) for pain relief & urgency
- Dec 2008 to present - 1 x 4mg Detusitol capsules

DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my LDN at or after 9.00pm each day
c) Type - My Naltrexone capsules contain pure Naltrexone powder. I'm unsure of the filler. I obtain them from Dickson's Pharmacy in Glasgow.

THERAPY
- Nov 2006 to present - Physical therapy

DIET
- I began a special MS diet. I was happy to see that the fact that I was Vegetarian was the only dietary change that would be advantageous and I was already vegetarian since birth.

SUPPLEMENTS
- Jul 2008 - I'm taking the following supplements ...
Glucosamine - 1000mg a day
Ginkgo Biloba - 120mg per day
Flax seed oil - 1000mg per day
Devil's Claw - 150mg per day

EXERCISE
- Jul 2008 - After my mobility improved I was able to walk unaided without the crutches and the urgency improved. I managed to sleep through the night more often.

MY STORY - July 2008

I was diagnosed with MS in March 1994. I was told that stress was probably the trigger and working six days a week for about 10 hours a day didn't help.

I was not ready for this news and after a course of steroids helped me to fully recover from my episode I felt sure that I could carry on working the same 10 hours a day.

I was wrong! Approximately two months later I relapsed yet again and was quickly taken back to the hospital. I learned I had Relapsing Remitting Multiple Sclerosis (RRMS), and was provided with a wheelchair from Scope and told to expect to be using it much more within a year. This was also very unwelcome news.

After my recovery the second time, I decided that using the wheelchair sooner rather than later was not going to happen and I started to learn to manage the situation.

The symptoms I experienced were numbness and weakness in my legs, and some tingling in my arms. Providing I didn't overdo it and rested if I got fatigued, I seemed to do fine.

On the whole, I feel I managed the MS well over the years, although there were times when I felt despair because I was so young when it first presented, just out of my teens, and I felt it was so unfair this had happened to me. I've had MS now for 14 years. I've had some relapses during this time - some more frequent than others - and various symptoms.

I've had relapses and they've typically occurred around major events in my life; such as moving house, redundancy, and preparing for my wedding. This taught me stress and anxiety play a major role in the occurrence of relapses, however; on my actual wedding day, my health was very good (probably the good adrenaline!).

A couple of years ago I had a relapse. The steroids didn't help recovery anywhere near as much as they used to when I relapsed, so I decided to see if there was more that could be done - rather than dosing up on steroids, which no longer helped me.

I asked around, and a friend told me he had heard about something called High Dose Oxygen Therapy (HDOT). I did lots research, made some enquiries and found The West of England MS Therapy Centre in Nailsea, near Bristol was offering the therapy.

I was very surprised to learn the centre was established way back in 1985, to provide support, advice and therapies for people with MS - also that they were one of many such centres around the country! Why aren't all patients with MS informed of this?

I went to the centre every day for three weeks. This is the recommended 'saturation period', and it also helps practitioners determine the best treatment level for each patient. I started noticing some lessening of fatigue after the first week, but my balance and mobility were still a problem. After the second week, urgency to go to the toilet considerably improved, and my mobility also began to improve.

For the first time in as long as I can remember, I began to sleep through the night without needing to use the toilet. I felt the oxygen was definitely helping. I began attending the centre regularly, for one or two sessions a week, and was very surprised by how many visitors used its facilities.

While attending the MS Therapy Centre I chatted to others with similar problems. Most were using the HDOT, but some were also having other therapies the centre offered, such as physiotherapy, counselling, reflexology and aromatherapy. The centre offered all their therapies at low 'donation prices', and I thought, if they helped MS sufferers, it was definitely worth it.

I also learned of another medicine that was said to help MS - an alternative to Beta Interferon which, I'd been told, was not justified for my level of symptoms and progression. I found out that, although not readily available in this country LDN had been used in the US for many years to help MS sufferers.

Other people at the centre were taking Low Dose Naltrexone (LDN) with good results. I'd never heard of this before, so I researched further. I discovered plenty of information about the medicine from the internet, particularly from the LDN Research Trust website. I must say, I owe a big debt of gratitude to Linda Elsegood who owns the site, and Dr Bob Lawrence, because both helped me learn more about LDN. I found a doctor who was familiar with LDN, and gained a prescription. I was monitored carefully by him throughout my first few months.

I started taking 3mg and continued that for the first month, then moved up to the optimum higher dose of 4.5mg and have been on that dose since. I've been taking LDN ever since.

Although at the start I noticed some minor re-occurrences of old symptoms, such as tingling in one leg, I'd been forewarned this could happen and so wasn't worried. I just waited patiently for it to pass. I felt the LDN

was definitely helping to stop me from slipping back. In fact, my health continued to improve and the initial recurrence of symptoms dissipated soon after.

In terms of improvement, in a reasonably short period of time I no longer had an urgent need to go to the toilet, my energy and mobility greatly improved, and although I still had some difficulty with balance from time to time, even that was slowly improving. Fatigue was no longer a big issue, as long as I was realistic and sensible. For me, the combination of LDN and Oxygen Therapy was the key to my feeling so much better, on more fronts than I had in years.

Over recent years, my life has undergone some fundamental life-changing events.

The first was on Boxing Day 2006 when my stepson complained about discomfort in the hip and his mobility was affected. My husband ended up spending a couple of hours with him in casualty. He was scheduled for a follow-up hospital appointment in early January 2007, but none of us suspected how serious his condition was, not even the hospital staff.

After his tests, and quite suddenly, everything changed. He was suffering from a very virulent form of Cancer of the ligament, which is extremely rare. An oncologist was called in.

Both his mother and my husband took it in turns to be at his bedside - my husband usually there all night. I visited as much as I could, but the shock hadn't done much for my health. In fact, both sides of the family were regular visitors to his bedside. The way he dealt with this final illness, at only 14 years of age, was truly inspirational, but sadly, it claimed his life only 4 short months after being diagnosed. You can imagine our feelings at his loss.

My husband was devastated, and although I tried my best to support him he was unable either to share his grief with me nor witness evidence of my own personal grief. Unfortunately he became more and more distant, spending more and more time away from home. We eventually parted, without acrimony, just before Christmas 2007 when I finally made the move to live geographically closer to my family because my health was now suffering considerably. I spent a short while living with my mother until I felt able to move into my new home.

Even though I experienced 3 major stressful events over an extended period of time - bereavement, a marriage break-up, and moving house (twice) - I did not end up in hospital. I'm convinced, if not for LDN, I would have been in hospital and on steroids. These 3 events, so close together, did cause a relapse, but nothing as bad as one would expect under these circumstances.

I've recently been working on building myself back up again; and on the positive side, I'm now able to work four days a week (2 in the office and 2 from home). I've been seeing a physio and it's helped with mobility, but unfortunately I can't take additional time off to go for oxygen therapy. I'm more tired and getting aches and pains, and in particular, the pins and needles have become more pronounced, so I plan to go back to Nailsea and resume the oxygen therapy. I feel the LDN and oxygen therapy combined may work better for me while I'm trying to rebuild myself.

It is now 14 years since I was told that I would be in a wheelchair within the year. Although I use a scooter to walk the dog (he's a collie and needs a lot of exercise), and I occasionally use the wheelchair when shopping (e.g. for clothes), on the whole I'm still using my own two feet; even though I sometimes use crutches.

My experience has also helped others. A friend and colleague's wife was recently diagnosed with MS and immediately came to see me for some advice, because they felt I was doing quite well. I wish I'd heard about LDN earlier. There isn't a cure for MS yet, but I'm convinced that LDN is a great help in minimizing its impact.

Update - August 2009

I don't really have any additional information or events since the last update. I am still taking the LDN, and it is still helping. Not a lot has changed since the last update, I am still working 4 days a week and living in my own house.

UPDATE – July 2010

I have been busy and a little ill also, so I can only really give you this short update as things haven't changed immensely for the better.

I think LDN is preventing me from going right down, but the M.S. seems to have taken hold of me a bit right now… though I am working on getting myself back up.

I have had a short time off work because I've been travelling to London on a fairly regular basis to discuss a trial called 'AIMSPRO' with the London Free Hospital in Hampstead.

I've now been told that if I undertake the trial I can continue taking my LDN, which is of great comfort to me as I'm reluctant to give it up: When I was off LDN for about two weeks due to the importation issue, I experienced a noticeable a drop in my ability and energy… so I don't want to be without LDN again if I can help it.

Although I've had time off work but I'm now back to working 5 days a week thanks to my employer being very amenable to my working from home about 95% of the time.

Video and conference calling is a fantastic innovation: My company calls this way of working 'SMART Working' and I tend to agree with them. If I wasn't able to work from home as much, as I am now, I feel I would get very disheartened. Due to my being able to 'SMART Work' like this, I benefit and the company gets a more consistent level of performance from me – a win, win situation.

I now go into the office very rarely; about once or twice a month: I'm lucky because the work I'm doing now is usually something I need to work on in a quiet environment where I can concentrate.

I still believe LDN is helping me, though I've had to go back to using a wheelchair some of the time. Looking forward, with Physiotherapy and the help of family and a good friend, I'm hoping I'll soon be able to leave the wheelchair sitting in the corner again.

There is not a lot more I can say for this update, except Keep Smiling! :-)

Zillah, UK

Zillah, UK

"I wish I'd heard about LDN earlier. There isn't a cure for MS yet, but I'm convinced that LDN is a great help in minimizing its impact." Jul '08

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

22 Most wonderful thing in my life - Jonathan

LDN since 4 January 2007
- story submitted July 2008
- story updated Jan 2009
- story updated May 2010 (over 3 yrs on LDN)

SPECIFICS:

DIAGNOSED
- mid to late 1990s - early symptoms
- Sept-Nov 1999 - tingling on my right side, several unexplained falls, one of them on flat Tarmac
- Jan 2000 – diagnosed with Syringomyelia (cyst on the spinal cord) (NB Syringomyelia (SM) is a disorder in which a cyst forms within the spinal cord. Left undiscovered and/or untreated, this cyst, called a syrinx, can expand and elongate over time and destroy the centre of the cord.)
- Dec 2000 - Multiple Sclerosis

HOSPITALISATION/SURGERY
- Jan 2000 - admitted for 1 week to Neurology Ward, University of Wales Hospital, Cardiff – range of tests – resulted in diagnosis of Syringomyelia
- Feb 2000 – Foramen Magnum Decompression operation (to address Syringomyelia)
- Sept 2000 – hospitalised, lots of tests performed (resulted in diagnosis of Multiple Sclerosis in Dec 2000)

TESTS (pre LDN)
- Sept 2000 – MRI scan, lumbar puncture, urine retention, and a test of my visual fields and reactions, plus more

MEDICATION (pre LDN)
- 1996 - Seroxat discarded after only a few days

TESTS (post LDN)
- none

MEDICATION (post LDN)
- 4 Jan 2007 to present – 4.5mg Low Dose Naltrexone (LDN) nightly

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time – I take my Naltrexone at bedtime each night, usually around PM?
c) Type – my naltrexone is compounded into capsules with pure Naltrexone powder and Avicel filler.

SUPPLEMENTS/THERAPIES
- 2007 to present - I drink Valerian tea (when I feel rough in particular), no set pattern, it helps reduces my MS/neurological symptoms when I am having a bad day. I also use essential oils such as lavender, orange, bergamot, basil and occasional others for arm/leg massage, or in a bath. These are analgesic and anti-spasmodic.

DIET
- 2007 to present - average, no changes

EXERCISE OR INTERESTS
- 2007 to present - My change in mobility resulted in no longer needing two walking sticks and being able to go for long walks unaided. And there was another bonus in the return of sexual function.

MY STORY – July 2008

From the mid nineties onwards there seemed to be something wrong. Being a sheep farmer, we suspected organophosphate poisoning as we knew of several cases in our area. I was without any rational explanation, was running out of energy with periods of very low spirits, and was from time to time suicidal.

I lost my father in 1996 and just didn't seem to pick up from that point on. There were various visits to the doctor, none of which did much good, but I do thank God that I binned the Seroxat after a few days.

It finally came to a head in the Autumn of 1999, a strange tingling on my right side and several unexplained falls, one of them on flat Tarmac. I went to the Doctor and demanded to see a specialist and was referred to a Neurologist.

I paid to go private and saw him around the 6-10th December 1999. He said, after a lengthy pause, there was definitely something wrong but he could not say what. In mid January 2000 I was admitted to the Neurology ward at The University of Wales Hospital, Cardiff. After around a week of tests, I was diagnosed with Syringomyelia and was introduced to a Neurosurgeon, Dr Vafidis, who sent me home wanting to operate as soon as possible with instructions to ring in if anything changed.

After a very hectic weekend with my children running us ragged, by the Sunday evening I found I was unable to speak. On the Monday Morning I phoned his secretary. I was admitted by 4pm and underwent a Foramen Magnum Decompression operation in February 2000. My symptoms improved greatly for a couple of months but then started to get worse again.

By August/Sept 2000 I was in a state of collapse and was carried into the University of Wales Hospital in Sept 2000. The usual range of tests ensued, such as; MRI scan, Lumbar puncture, urine retention, and one I don't remember the name of which tested my visual fields and reactions, and there were probably more that I have forgotten.

There was the customary delay in informing me that I had MS (I was told in December 2000), and then the Neuro sent me away to get on with it. Beyond this my memory fades, a lot of water has passed under the bridge since 2000.

From the outset I was astonished by the attitude of the Neurologists who just seemed to want me to go away and get on with it. I had already had acupuncture and used essential oils for healing, I knew there were options out there to help with the MS so I went about finding things that helped me feel better and slowly made progress against the MS.

I won't detail all of the things that helped and instead will jump to December 2006 when somebody (Andy) phoned me up out of the blue, told me all about Low Dose Naltrexone (LDN) and how it had worked for him. Determined to try it, I noticed Dr Bob Lawrence's name on the internet and as he was close-by, I got in touch.

I started LDN on the 4th January 2007.

For a couple of days I was a little groggy, but almost immediately after I found my head began to clear, and hence, the brain fog of jumbled thoughts began to ease.

I didn't notice much more for a few weeks but then found my legs, which had been very wooden, were coming back to life and all of a sudden, sexual function returned.

In Easter 2007 I led some French friends on a country walk in to the waterfalls country. It’s quite a long walk and something I thought I would never do again. I had gone from struggling round town on two walking sticks to boldly striding out across country.

I remain fit although the MS does give kick now and again, especially if I forget to take LDN as occasionally happens, or if I overdo it. I still seem to have a problem with hot weather, so I still hide indoors when it’s hot.

This description did not work out as brief as I'd hoped, but I do hope it goes a fair way to describe the most wonderful thing in my life - Low Dose Naltrexone.

Update – January 2009

I’m still doing well on LDN. I received a letter today from my GP declining to prescribe LDN on the National Health Service - so I will be buying it on a private basis now.

Update – May 2010

You bet I'm still taking LDN.

My health is good, the occasional bad day and I suffered some 'winter blues', which as usual was treated with acupuncture.

I find myself now only remembering LDN every few days, even getting careless about it.

Jon, UK

Jon, UK

"I didn't notice much more for a few weeks but then found my legs, which had been very wooden, were coming back to life and all of a sudden, sexual function returned." Jul '08

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

23 SPMS Improved, but with hiccups - Dianne

LDN since January, 2008
- story submitted 2 June 2008
- story updated July 2008
- story updated Sept 2008
- story updated Oct 2008
- story updated Jan 2009 (1yr on LDN)
- story updated Jan 2010 (2yrs on LDN)

SPECIFICS

DIAGNOSIS
- Oct 1986 – Relapsing Remitting MS (RRMS)
- 2003 - Secondary Progressive MS (SPMS)

TESTS
- 1992 - MRI - Showing several lesions on brain
- Mar 2003 - MRI – additional lesions noted

MEDICATION (pre LDN)
- 1987 to 2005 - Two or three courses of oral steroids
- Sept 2005 - IV steroids over 3 days
- Apr 2006 - IV steroids over 3 days
- Nov 2006 to present - 100mg Zoloft daily
- Mar 2006 to Jan 2008 - 10mg baclofen x 3 times daily
- Apr to Jan 2008 - 50 mg Zoloft daily

MEDICATION/TREATMENT (OTHER)
- 2005 - After reading George Jelinik's Book 'Taking Control Of Multiple Sclerosis' began Swank Diet and started taking supplements
- Oct 2005 - Attended live-in workshop at Ian Gawler's Facility Yarra Valley (George Jelinik in attendance).

MEDICATION (post LDN)
- Jan 2008 to present - 10mg baclofen x 3 times daily
- Jan 2008 to present - 100mg Zoloft daily
- May 2008 - occasional Stilnox sleeping tablet
- Jan 2008 to Feb 2008 - 1.5mg LDN (one month) - incontinence issues resolved
- Feb 2008 to Mar 2008 - 3mg LDN (one month) - stopped taking anti-depressants
- Mar 2008 to Mar 2008 - 4.5mg LDN (2 weeks)
- Mar 2008 to Apr 2008 - 3.5mg LDN (reduced for 1 month)
- Apr 2008 to May 2008 - 4mg LDN (1 month)
- May 2008 to Sept 2008 – tried 4.5mg, backed down to 3mg, then settled at 4.5mg LDN
- Sept 2008 to present - 4.5mg LDN
- Oct 2008 to Oct 2008 – Antibiotics for Urinary Tract Infection (UTI)

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - at bedtime, between 10.00pm and 11.30pm
c) Type - 4.5mg capsules compounded by Raju's Pharmacy, Gisborne, Victoria with pure naltrexone powder and Avicel filler

DIET
- Jan 2009 - Low Saturated Fat diet (Swank). I take 20ml flaxseed oil daily and I know it's important to keep it fresh, so I buy one in a dark bottle from the local health food shop (Melrose) and keep it refrigerated. If I do have any fatty fish (e.g. salmon), I will not take flaxseed oil that day to make sure that recommended fats and oils aren't exceeded.
- Jan 2010 - Low saturated fat diet. I aim for under 10mg saturated fat per day. Concentrate on 'good oils' in food. No red meat, no dairy, lots of fruit and veg, nuts and seeds. Chicken breast (no skin) and fish for protein, soy milk, soy yoghurt and occasional soy ice-cream. I also limit my sugar intake. I use Olive oil only - for dressings and for cooking when needed. I follow George Jelinik's recommendations re diet and lifestyle.

SUPPLEMENTS
- May 2008 - every morning as follows:
20ml flaxseed oil
1 x multivitamin tablet
1 x sublingual B 12 tablet
4 x 500mg Vit C Tablets
- May 2008 - every evening as follows:
4 x 1000IU capsules Vit D
4 x 500mg Vit C Tablets
1 x 600mg Calcium Tablet

- Oct 2008 – Minor change: I now take the following:
20ml flaxseed oil (night)
1 x sublingual B 12 tablet (morning)
4 x 500mg Vit C Tablets (morning)
4 x 1000IU capsules Vit D (evening)
4 x 500mg Vit C Tablets (evening)
- Jan 2009 – I now take the following:
1 x B complex (morning)
1 x sublingual B12 tablet (morning)
5 x 1000iu capsules Vit D (evenings Mon-Fri)
10 x 1000iu Vit D (evenings – Sat, Sun - weekend only)
4 x 500mg Vit C Tablets (morning)
4 x 500mg Vit C Tablets (evening)
1 x cranberry capsule (morning)
1 x probiotic – Inner Health Plus (morning)
- Jan 2010 – I now take the following:
Multi B Vitamin x 1 (morning)
Sublingual B12 x 1 (morning)
Cranberry Capsule 10,000mg x 1 (morning)
5000iu Vitamin D capsule x 1 per day - Mon – Fri (evening)
5000iu Vitamin D capsule x 2 per day - Sat & Sun (evening)
Flaxseed oil 20ml x 1 per day - when I have not had oily fish that day (evening)
Probiotic capsule (Inner Health Plus) x 1 per day (evening)

ACTIVITIES & EXERCISE
- May 2008 - Now doing all my own housework, shopping, gardening, weights, stretching and step-ups at home, going for walks.
- Jan 2010 - Treadmill - walking at least 1km per day. Gym (strength training weekly), plus some weights at home. Gardening. Still do most housework although have help with heavier chores (floors) fortnightly.

MY STORY – 2 June 2008

I have Secondary Progressive MS and began taking LDN in January, 2008. I found out about LDN on the Swank Diet website, got a script from my GP and my pharmacist made it up.

I started on 1.5 mg, then went to 3mg, then 4.5mg. I wasn't coping well with some of the side effects when I went up to 4.5mg, so I adjusted my dose down for a little while, then back up until I felt comfortable.

Neither my doctor or chemist had ever heard of LDN but since I have started, and spread the word, more locals are starting LDN, which is very pleasing.

LDN has made a huge difference to my quality of life.

I have no more incontinence, more energy, less fatigue, improved cognitive function, less spasticity and I am walking better than I have in years. I am referring as many as I can to www.lowdosenaltrexone.org.

It is truly a 'miracle drug' in the treatment of MS.

Update - July 2008

Unfortunately I have had a bit of a set-back.

About 6 weeks ago, I slipped back into severe depression. Don't know if it was because I had given away anti depressants about 2 months prior (under directions from my chemist) or if it may have been the result of the 4.5mg dose of LDN. (Only recently had upped the dose). I was also experiencing some bladder difficulties - incomplete emptying.

So I started back on antidepressants (100mg Zoloft daily) and cut the dosage of LDN back to 3mg.

After about 2 weeks on 3mg, I increased it back to 4.5mg and then had major incontinence problems.

So at the moment, I am trying to fine-tune the dose - will probably stick to 3mg for a while.

I won't be going to the LDN conference in October due to family commitments. Will be interested in reading about it though.

I am rather disappointed as I was feeling so well when I started LDN and now some doubts have crept in. I have recommended it to quite a few people but no-one has experienced any improvements yet.

Update - September 2008

I had stopped my anti depressants under the direction of my chemist – a slow withdrawal process over many weeks. I don't consider that a slow cessation of antidepressants should have caused my problems.

At the time I lapsed back into severe depression (June 2008), it was just after I went back up to 4.5mg LDN, so I cut back to 3mg LDN daily. But on reflection I believe that the return of some of my old symptoms (sensory as listed) was the result of the depression, which caused lots of stress, poor diet and lack of sleep rather than the larger dose of LDN.

They were not new symptoms, rather old ones that re-appeared. I don't think that I listed these symptoms earlier.

I have since re-commenced taking the antidepressants and will stay on them long-term at this stage.

I have also increased to 4.5mg LDN again, and so far so good.

Bladder function is normal at present, and all my sensory symptoms have disappeared (numbness, tingling, buzzing and twitching skin).

My main symptom is problems with my right leg (limp with fatigue and heaviness). I believe that this is because of permanent damage caused a while ago and don't expect any improvement there.

I am also trying to increase my exercise (walking), as I believe this also helps.

So I seem to be back on track and hope that it will continue.

Update – October 2008

I've changed my supplements a little, mainly because of George Jelinik's recent recommendations in a recent newsletter. His new website is www.takingcontrolofmultiplesclerosis.org if you aren't aware and I believe that anyone can request copies of his newsletters.

As a result, I no longer take a multivitamin in the morning, or calcium at night.

Again, a bit of a setback recently. Got a Urinary Tract Infection (UTI) recently and am currently being treated with antibiotics - and unfortunately my old symptoms have returned as a result - urinary and sensory. I believe I might also have candida, which I've heard can hinder the effectiveness of LDN, so as soon as I finish these antibiotics I'll treat myself with diet and pro-biotics to try to resolve the problem.

Update – January 2009

I am really good. Got myself back on track after the UTI and suspected candida.

I haven't any new symptoms so that is a major positive. When I get tired or have done too much, some of the old stuff may appear but not usually for very long.

I have been taking LDN for 12 months now (4.5mg) and am trying to get the word out as much as possible. Two locals with MS are also on it now and have had wonderful results. If only more people could be made aware of it's possible benefits.

My supplements have changed again - now take a B complex am as well as sublingual B12 am. Also have upped my Vitamin D dosage. I emailed George Jelinek as my levels were only 102nmol despite taking 4000iu per day. He believes that they should be up over 150nmol so he suggested I take a 1 off dose of 50,000iu and then take 5000iu daily except on weekends when I should take 10,000iu each Sat and Sunday. I get the supplements from the U.S., which is a much cheaper way of getting them.

I have ordered a new book 'The Promise of Low Dose Naltrexone Therapy' (Potential Benefits in Cancer, Autoimmune, Neurological and Infectious Disorders) written by Elaine A. Moore and Samantha Wilkinson with a foreward by Yash Pal Agrawal, M.D. Ph.D. I am really looking forward to reading it but it will be a few weeks before I receive it.

Update January 2010

I have been taking LDN 4.5mg for two years now with no further progression of my SPMS. I still have some problems with my right Leg when walking. I limp and need to use a scooter for long distances. However, many symptoms (sensory) have improved or disappeared, bladder function is now normal and my quality of life has significantly improved.

I plan to take LDN indefinitely.

I will continue to spread the word about LDN as far and as wide as is possible so that others with immune system problems are made aware of this wonderful treatment.

I now only have to see my neurologist annually although he will not admit that my current good state of health may be attributed to LDN. He will not prescribe LDN and does not recommend it to his patients. He continues to maintain that this is because LDN has not undergone the usual trials required.

Dianne, Australia

Dianne, Australia

"Two locals with MS are also on it now and have had wonderful results." Jul '09

Why I contributed my case study…

Apart from making others aware of LDN, I believe that follow-ups are important on case studies to encourage others to submit their stories. These would add even more anecdotal proof to support the importance of such evidence in health outcomes.

Naturally, patients are following the advice of their doctors, who in turn give drugs promoted by drug companies. However, these remedies may not necessarily be the best treatment for the condition concerned.

This is why I believe that anecdotal evidence is so important and the documenting of it (and follow up) is necessary to highlight its relevance as a diagnostic tool in our health system.

24 My Two little pills are called LDN - Kristie

- LDN since March 2008
- story submitted March 2009
- story updated April 2010 (2yrs on LDN)

SPECIFICS

DIAGNOSED
- Feb 2002 – Multiple Sclerosis

TESTS
- Feb 2002 - MRI - multiple lesions
- Mar 2002 - spinal (spinal wasn't really needed since I had so many lesions)
- Feb 2002 to Mar 2008 - I had 4 more MRI's showing progression, and multiple new brain and spinal lesions.

SURGERY/HOSPITALISATION
- Jun 2007 – large colon polyp removed
- Nov 2009 - large colon polyp removed

IN HOME MEDICAL CARE
- Mar 2002 to Mar 2007 - Intravenous (IV) Solumedrol every 4 months
- Jul 2007 to Jan 2008 – Intravenous (IV) Solumedrol every 2 months

MEDICATION/TREATMENT (pre LDN)
- Mar 2002 to Feb 2003 - Copaxone injections
- Mar 2004 to Jan 2005 - Rebif injections (I also took part in studies for antibodies to Rebif and my MS doctor said I tested highest of anyone tested and switched me to Betaseron)
- Feb 2005 to Jan 2008 - Betaseron injections
- Mar 2005 to March 2008 - 20mg Citalapram x 1 per day (antidepressant)
- Feb 2008 to March 2008 – 5mg Crestor x 1 per day (cholesterol)

MEDICATION/TREATMENT (post LDN)
- Mar 2008 to present - 20mg.Citalapram x 1 per day (antidepressant)
- Mar 2008 to present – 5mg Crestor x 1 per day (cholesterol)
- Mar 2008 to present - 3mg low dose naltrexone (LDN)

DOSE & TYPE
a) Dose - 3mg Low Dose Naltrexone (LDN) – (Taken as two x 1.5mg capsules)
b) Time - I take my LDN between 9pm and 2am each day
c) Type - My Naltrexone capsules contain pure Naltrexone powder with avicel filler.

DIET
- Mar 2009 - My diet is not restricted

SUPPLEMENTS
- 2006 to present:
Calcium x 800 mg x 1 per day
Once a Day vitamin x 1 per day

EXERCISE
- Mar 2009 - Since Naltrexone I've been able to help a friend gut a whole house, with me in the attic shovelling insulation out and knocking ceiling and walls down. I've spent spring and summer months at a beach on the ocean with the heat not affecting me. I've lifted and moved furniture with no difficulty. I do people's taxes. I clean BIG houses. I jump and play with little kids. There seems to be nothing I am unable to do now.

MY STORY – March 2009

Imagine being the sick child in the family, with tonsils removed at age 6 and having to take liquid nerve medicine because of tummy aches. Imagine always getting a virus! Imagine as a teen not eating pizza because of stomach pains, and being told all other pains are called growing pains even though you only grew to 4ft 11 ½ inches tall. Then as an adult hurting with muscle spasms, and after trying to find out why you want to sleep so much, hearing the doctors say, "You did too much", or "Maybe you're depressed".

I've been through Gall Bladder removal, cystitis, hysterectomy and always having 'Inner Ear Infections', and losing balance for weeks. My eyeball hurts so bad at times I wished I could just take it out for a while. My vision would come and go and the docs would say it's low blood sugar.

I'd wonder why my Mom and Grandma had so much energy and I didn't!

Then in my forties my feet decided to go to sleep! The next day my leg would go to sleep and hurt so bad I couldn't sit, stand, or lie down. I'd have to keep moving to make the pain tolerable, only I'd stumble and couldn't regain my balance again!

So I'd go to my doctor, almost convinced by now that he was right and that it was just in my head, or thinking 'This is a fine time for my inner ear problem to act up!'. And again, the doctor would dismiss my concerns with, "You probably pulled something in your back or hit your leg. If it doesn't leave in 6 weeks come back", forcing you to beg him for at least some pain medicine so you can sleep!

You go home to sleep some and then awaken to a major decision. 'I'm getting another doctor!!!'

And you call a doctor who a friend recommends in the next county and they work you right in. That doctor is very concerned and pats you and says, "Honey we're gonna fix your problem. It's not in your head!"

A week and a half later you've had tests that confirm Multiple Sclerosis (which was the easiest diagnosis the neuro had ever made due to so many lesions showing on my MRI). The spinal really wasn't needed but it was done also.

I was so thankful to hear it was M.S. That may sound odd, but the truth is, of all it could have been, I was thankful it was MS and not something worse. Plus, I was NOT crazy after all! I suddenly knew why I couldn't think of things I was trying to say sometimes, and why I had all the other problems in my past.

I agreed to start on Copaxone injections, then later switched to Rebif, then to Betaseron shots. I was tested again, because for some reason my MS was progressing faster than expected. I had Solumedrol I.V. every 4 months for exacerbations. (Since I have so many medicine allergies, new meds are really scary for me and for my doctors.) When Tysabri and the other new meds were mentioned I said, "No", because I was not ready to take the risks involved in taking them long term.

Then I discovered a treatment called Low Dose Naltrexone (LDN). I found it when searching on the internet. As I worked in a cardiac unit years ago I understood to be very wary of internet claims for medicines, but this intrigued me and made sense.

After studying it for 2 months I asked my Neurologist to check it out and see what she thought. She wanted to make sure it was safe for me and she studied it too. After 4 months she said she was ready to try the LDN for me, if I still wanted to try it. "YES!" After all, by this stage, I thought what can it hurt?

I was her first patient on it. The second was a nurse from another county who works for a cancer doctor. That doctor was so impressed he put a Pancreatic Cancer patient on it and her blood levels dropped dramatically!!! Now my doctor calls LDN 'Kristie's Medicine', and says she is getting known as the LDN Doctor here in my home state. She gets calls almost daily for new patients who want to try it.

I've been on it a year now and I have not had a single exacerbation, nor balance problems! My cane and walker have been put away! Everyone - my family, my friends, my doctors, my pharmacists, and me - are amazed at how well I'm doing! LDN should never be hidden from patients. I talk about it anywhere and everywhere I can to anyone who'll listen!

Later this year I will have my first MRI since starting Naltrexone.

Guess what I did recently … I played teeter-totter and ran with my grandchildren! It sure feels good to feel young and healthy!

UPDATE April 2010

I'm sorry I haven't updated before this but I've been enjoying life so much!!! I'm still on my LDN at 3.0mg. I have not had another MRI since I started on it because so far I have not had another exacerbation! Heat and cold does not bother me at all. I have great balance. I do not sleep like I did before LDN.

I went to my first Nascar race last weekend with my Grandson and his Mom. (I did the driving which was 6 hours getting to it and 11 hours coming home because of the heavy traffic.) I got sunburnt because of the

heat there... I came back home to decorate a wedding chapel and reception for a friend's daughter's wedding the next Saturday. It was beautiful. Today I watched 3 girls (age 1 1/2, 3 and 4 yrs old) and they wanted me to jump on their new Trampoline with them! I was concerned I'd get dizzy but I didn't! I jumped and bounced with them and loved it!

My Neuro says some have come off their LDN, but she says no-one seems to do as well as me! Meaning that I amaze her...LOL. My Neuro still prefers to give the Crab Medicines first then LDN as a second option. I hope that she will soon change and encourage her patients to try LDN first! I don't see her often now because I am doing so well.. I call her occasionally to tell her things I have done. (The last call I made to her office is to let her know I installed my new Kitchen Cabinets all by myself.)

So you see I am doing GREAT on LDN and telling everyone I come across how great it is! Most are amazed that I have MS when they are told I have it.

I am still taking calcium tabs and multivitamins. One amazing thing I still find is I have no need for pain meds for my MS! I don't even notice spasms in my back that used to leave me in bed crying! I do still take meds for cholesterol and my depression med still. That's all I take.

I had a large colon polyp removed in 2007, and last November 2009 I had another large polyp removed. The doctor said they are the type that turn into cancer, and they were very large. I forgot to stop the LDN before surgery so I was on it when I had the surgery under anaesthetic. I had no problems at all and hardly any bleeding, so had no need for strong pain meds. I was offered Tylenol (paracetamol) but I didn't even need to take it. (I will have to remember about LDN if I need surgery in the future.)

I almost forgot...I was around a lot of sick kids this year who had the flu, strep, bronchitis and pneumonia that was going around, but I never got sick like they did… I only had a sinus infection and a cough. So I figure my immune system must be in tiptop shape!

I will never stop my LDN!!!

Prayers and Love to all of you who let me know of LDN,
Kristie, USA

Kristie, USA
"Guess what I did recently … I played teeter-totter and ran with my grandchildren! It sure feels good to feel young and healthy!" Mar '09

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

25 Incremental Improvement for MS - Ellen

- LDN since 19 Jan 2009
- story submitted & updated May 2009
- story updated Jan 2010 (12 months on LDN)

SPECIFICS

HISTORY & DIAGNOSIS
- 25 Dec 1989 - birth of son
- 8 Jan 1990 - earliest signs - legs felt very heavy, slow getting around, body didn't feel right, requested MRI
- June 1990 - MRI ordered by GP - 5 lesions
- 4 July 1990 - major exacerbation felt like a stroke
- August 1990 - Neurologist first appointment - possible multiple sclerosis
- mid 1990 to 1992 - somewhat stable
- 1992 - walking became a problem - made an appointment with Nicholas J Gonzalez MD New York, NY.
- May 18 1994 - MRI reviewed - diagnosed Multiple Sclerosis and prescribed first MS medication
- April 2001 - a period of excessive stress
- 2004 to 2009 - Developed to needing a cane to aid walking

TESTS
- June 1990 - MRI ordered by GP - 5 lesions
- April 1994 - MRI - Diagnosed Multiple Sclerosis
- 2006 - bone scan
- Mar 2009 - bone scan (improved since 3 years ago)
- Apr 2009 – MRI - everything is unchanged since last MRI - no active demyelination - stable

HOSPITALIZATION
- mid July 1994 - 5 days - Hospitalised for weakness with difficulty walking. I received 1 gram daily IV of Solu-Medrol.

MEDICATIONS (pre LDN - July 1994 to 19 Jan 2009)
- July 1994 to 8 Feb 2009 - Copaxone injections x 1 per day - primary treatment over this 15 year period, however; I also briefly tried other MS treatments; Betaseron, Rebif, Avonex. I also tried plasmapheresis in 1999 - all without success, and my symptoms continued to deteriorate.
- July 1994 to 19 Jan 2009 - 1gm IV Solumedrol every month - aided symptoms but raised other risks, such as bone loss
- 1995 to 19 Jan 2009 - 400mg x Advil (Ibuprofen) per night
- 1996 to 19 Jan 2009 - Fosamax x 70mg once per week
- 2004 to 19 Jan 2009 - Bio-identical Hormones - BIEST 50:50 + PROGESTERONE 0.05+40mg/cc (Estriol 0.025mg/cc + Estradiol0.025mg/cc + progesterone 40mg) - Apply 1cc to inner forearm daily

MEDICATIONS (post LDN - from 19 Jan 2009)
- 19 Jan 2009 to 22 May 2009 - 5mg Ambien (sleep sedative), as needed for insomnia
- 19 Jan 2009 to 18 May 2009 – 500mg IV Solumedrol every 6 weeks – followed plan to cease this by July 2009 and titrated the dose down from one gram to one half gram every 6 weeks.
- 18 May 2009 to 20 July 2009 – 250mg IV Solumedrol every 6 weeks (I continued to titrate down slowly and ceased IV Solumedrol altogether in July 2009.)
- 19 Jan 2009 to 23 Nov 2009 - Fosamax x 70mg once per week – I discontinued Fosamax while at the same dose, and didn't titrate down.
- 19 Jan 2009 to 24 Nov 2009 - 4.5mg Low Dose Naltrexone (LDN) – lowered dose due to headaches following cessation of Fosamax on 23 Nov 2009.
- 24 Nov 2009 to 6 Jan 2010 - 3mg Low Dose Naltrexone (LDN) – took lower dose for approx 1.5mths, then increased dose back up to 4.5mg.
- 19 April 2009 to present – plan to discontinue Ambien, only occasionally needed since body began to adjust to LDN
- 6 Jan 2010 to present - 4.5mg Low Dose Naltrexone (LDN)
- 19 Jan 2009 to present - Bio-identical Hormones - BIEST 50:50 + PROGESTERONE 0.05+40mg/cc (Estriol 0.025mg/cc + Estradiol0.025mg/cc + progesterone 40mg) - Apply 1cc to inner forearm daily
- 19 Jan 2009 to present - 500mg x DL Phenylalanine on an empty stomach every morning

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time – nightly, at 11pm
c) Type - compounded capsules with pure Naltrexone powder and Avicel filler

OTHER TREATMENTS/THERAPIES
- July 1994 to present - acupuncture treatments as needed
- July 1994 to present - chiropractic treatments as needed - 3 times a week since
- early 2008 to present - physical therapy - very helpful

DIET
- 1980s - vegetarian diet
- 1992 to 1994 - diet of organic meat, root vegetables, grains, daily carrot juicing, and twice a day organic coffee enemas to detox the body.
- 2009 – experimenting with 'the zone diet'

SUPPLEMENTS
- 1992 to 1994 - 70 daily supplements, enzymes, plus other modalities.
- 1994 to present, the following is an up-to-date list of supplements:
Vitamin C x 1000mg per day
Vitamin D x 8000mg per day
DHA 800mg capsules x 4 capsules x 3 times per day
vitamin E 400mg x 2 times per day
Cayenne capsules 600mg x 2 times per day
Calcium 500mg plus Magnesium 1000mg x 3 per day
Neuro Plus formula x 3 capsules per day
Vit B-100 complex x 1 per day
Complete Probiotics x 1 per day
ALA 300mg x 2 per day
Multivitamin x 1 per day
Krill Oil with Evening Primrose Oil 500mg capsules x 3 capsules per day (all in the morning) – NB Each capsule contains: EPO 500mg, EPA 150mg, DHA 50mg, GLA 45mg
Dr Sears Zone Omega Rx (Zone Labs brand) 1000mg capsules x 4 capsules daily (2 with lunch, 2 with dinner) – NB This is an Omega 3 concentrate & each capsule contains 1000 mg of Fish Oil which delivers 400mg of EPA and 200 mg of DHA. (I'm planning on changing this. Will advise later.)
May 2009 – Fish Oil - Planning to increase my intake – will advise later.
- As at Jan 2010, the following is an up-to-date list of supplements:
Vitamin C x 1000mg per day
Vitamin D x 8000mg per day
DHA 800mg capsules x 4 capsules x 3 times per day
vitamin E 400mg x 2 times per day
Cayenne capsules 600mg x 2 times per day
Calcium 500mg plus Magnesium 1000mg x 3 per day
Neuro Plus formula x 3 capsules per day
Vit B-100 complex x 1 per day
Complete Probiotics x 1 per day
ALA 300mg x 2 per day
Multivitamin x 1 per day
Krill Oil with Evening Primrose Oil 500mg capsules x 3 capsules per day (all in the morning) – NB Each capsule contains: EPO 500mg, EPA 150mg, DHA 50mg, GLA 45mg

EXERCISE & INTERESTS
- early 2007 to present - yoga, guided by Rodney Yee DVD - daily
- early 2007 to present - I swim laps in the summer months
- Jan 2010 to present – I now lift weights to build strength and improve balance

MY STORY – May 2009

My story begins Christmas Day 1989 with the birth of my third son.

It was a normal pregnancy as I went jogging into my fifth month. I actually remember running with my tape headset playing, Christopher Cross song, 'Ride Like the Wind', feeling like I could run faster listening to the music.

I felt great nearing 40. My family was healthy and I was working part-time as a Registered Nurse with the plan of taking a few months off before heading back to a job with more responsibilities. I had decided this would be the last day of running until after the baby arrived. Little did I know I would never run again. My son arrived in a very easy birth. No pain! How strange when he was 8.5 pounds. Years later I understood why.

After a couple of weeks, I noticed my legs felt very heavy and I was slow getting around. My body didn't feel right. I went to my doctor and requested an MRI of my brain.

Lo and behold, on July 4th, 1990, it was very hot and humid. My husband and my two older children, 10 years and under, were walking in the village parade and I was pushing the baby in the stroller. I thought of collapsing on the cement. Maybe I was having a stroke!

My doctor had called the night before warning me of possible problems with hot weather after reviewing my initial MRI finding 5 lesions on my brain. My husband ran home to get the car. I could not walk any further. Whatever it was, my plan was to stay in denial. I was a psychiatric nurse at a hospital and talked often about denial with family members on the young adult unit, and now this is what I wanted. Total denial of any physical body problem!

August 1990 was my first appointment with a Neurologist. He told me a possible diagnosis was multiple sclerosis. I asked myself, what is that? Despite twenty years of nursing, I had never taken care of anyone with multiple sclerosis!

The doctor had no information for me. I could probably find something at the library. My husband and I left his office stunned and vowed never to return. I stayed busy at home with family and my body appeared somewhat stable so I didn't investigate until walking became a problem.

1992: My first adventure to solve the problem: An appointment with my M.D. Diagnosis was made with Hair Analysis. His clientele was 90% cancer patients, though he did accept other illnesses. He put me on a specific diet all according to my hair samples. I was fascinated with his unconventional program. He told me right away I would be on organic meat, root vegetables, grains, daily carrot juicing and yes, twice a day coffee enemas. Organic coffee, of course! Coffee enemas were essential for detoxification of the body.

The program also consisted of about 70 daily supplements, enzymes and other modalities that kept me focused. It was good for me and kept me grounded. I did this program for about two years. I had been a vegetarian for long periods of time in my twenties but this diet gave me more strength and balance.

I had returned to my nursing job with a new title as the head nurse of the young adult, unit with around 30 beds. My life was busy. I had a promotion at work and was determined to stick with it knowing all about stress. That job lasted nine months and I stepped down to part-time.

I had taken six-month leaves several times through my nursing years after my diagnosis, so I could regroup and stay healthy. I was lucky to have my job as long as I did.

My career came to a screeching halt in 2001 when my unit dissolved and I was asked to work at the city jail. I did not need more stress. I retired from my nursing career as I was getting weaker and knew it was unhealthy for me.

My husband and I are trained massage therapists. Naturally, it is a joy to give and receive massages. It has been several years now that I cannot participate in exchanging a deep massage. It is not easy to continually let go of your power. I was a follower of transcendental meditation since the 70's, although I wasn't dedicated to a daily practice. It has now been more important for me to stay committed everyday to meditation.

In mid July 1994, I was hospitalised for weakness and had difficulty walking. It was a five-day inpatient hospital stay, with 1 gram daily IV of Solu-Medrol. I then started on daily shots of Copaxone for ten years. I tried all the CRAB drugs at some point, but mostly used Copaxone.

Western medicine had entered my life and I decided to try anything to keep these symptoms at bay. I truly believed I could cure myself. I questioned my doctor many times about the effectiveness of Copaxone as my symptoms continued to get worse. I was upset when my penmanship was almost unreadable. This was not good.

I continued to walk, but now with a cane. Steroids were my only hope, because I always had some relief with my symptoms. I continued once a month with IV Solu-Medrol, but at the same time this was unhealthy for my bones. I had tried plasmapheresis in 1999 with little improvement. I bought a wheelchair, but fought that concept kicking and screaming. Just ask my husband. He has been my partner, always patient and loving through this challenge we share together.

This past year I had accepted defeat, because fatigue had set in and I was so tired of the fight. I love my family, but I was leaning towards depression thinking negative thoughts.

In January of 2009, my dear friend and old boss informed me of a drug called LDN. I thought, 'what the heck', investigate the medication. After research and calls to Dr. Bihari's office in NYC, I decided to start LDN at 4.5mg on January 19, 2009.

I discussed using IV Solu-Medrol with Dr. Bihari's assistant on the phone. I was on 1gm, IV Solu-Medrol, once a month and wanted to get off of this drug. He advised me to start the LDN and slowly titrate down the steroid. This is the plan!

I have decreased my steroid to one half gram every 6 weeks. The only side effect for me on the LDN is insomnia. I have taken Ambien, a sleep sedative and plan on discontinuing it soon, although it's been very helpful for my insomnia.

Feb 8, 2009, I stopped daily injections of Copaxone.

Feb 24, 2009, I stopped nightly Ibuprofen 400 mg. I believed it helped me with inflammation over the years but now take DL Phenylalanine. As of right now, I'm not sure how this works for me.

Since my diagnosis I have had multiple acupuncture treatments and have always found this experience a healing.

I see the chiropractor 3x a week for adjustments. I have done physical therapy this past year and that has been very helpful in understanding body mechanics and the importance of walking correctly. I feel like I'm starting over.

It has been 19 years of learning about disability and how to continually honor the experience. I forgot to tell you that I'm still walking and my cane has become a real need. I am fortunate to drive my car so I'm grateful for things we all take for granted.

My husband has noticed my improved mood and positive energy change immediately since the start of LDN. I am back to my upbeat self. I feel good and I'm noticing little changes, all positive, while on the LDN.

My penmanship has improved 90%. I'm devoted now to optimism and my new regimen. I know my positive attitude will help me with the on-going challenge.

The past two years I have incorporated yoga, (Rodney Yee DVD) into my daily workout and feel that it keeps me centered and aware of my body alignment. I also swim laps in the summer months.

I continue with the supplements: multivitamin, vitamin C, D, E, fish oils, Probiotics, DL Phenylalanine, Calcium with Enzymes. I have also taken Bio-identicals for the past 4 yrs. I can't forget Fosamax with all those years of steroids. I did get a bone scan last month that indicated my bones had improved since 3 years ago. That was good news.

If you are thinking of trying LDN, journaling is a valuable tool to recall past events. All of us make significant decisions for our health and our body/mind needs time to adjust. Journaling has helped me capture those moments of time.

I'm a little frustrated right now with some recent setbacks, probably due to the weather being so cold and so highly changeable. I was going to end steroids in July, but I'm now considering a longer and gentler path because I've been on them for so long. I'm getting professional advice and trusting my instincts on the best approach and timing.

I have been on LDN for two months and look forward to everyday with the hope of continual improvements with my health. Thank you for this opportunity to share my thoughts with you.

UPDATE - 19 May 2009

I went to see my neurologist today and had my 250mg IV steroid, titrating down, probably finishing in 2 months, July 2009 as planned. Everything else is ok. My doctor actually said good things about LDN and said it looks hopeful as a new treatment!!

I received my news of my MRI taken in April. Everything is unchanged since last MRI. No Active demyelination. Stable. I'll take that and continue with my plan. I went to a MS dinner last week and met a engineer that feels vitamin D does not get into your system unless it’s a gel-cap. Tablets don't digest. He also said liquid fish oil is the best. I'm off to the vitamin store to research and will update later.

UPDATE: 27 January 2010

I titrated my IV Solu-Medrol down very slowly. I had no problems during that period, and I'm pleased to report that I've been free of IV Solu-Medrol since July 20, 2009.

I also stopped taking Fosamax completely on Nov 23 2009, but I suspect cessation of the Fosamax may have caused the headaches that followed. I lowered my dose of LDN from 4.5mg to 3mg to see if that might help, and it did. Since Jan 6, 2010 I've been back on 4.5mg, with no headaches and no problems.

I also stopped taking Dr Sears fish oil. I didn't need it. It was too much. Live and learn.

I have been doing quite well and continue with my Yoga program. I recently added lifting weights to build strength, and since then have noticed improved balance. Oh yeah… I went to China, Vietnam and Thailand for the Christmas holidays, and it was a great experience. I did not take LDN for two weeks while I was travelling, but no problems... Yippee!

Ellen, USA

Why I contributed my case study…

It has been very important for me to tell my story about MS and LDN because it provides proof that I am truly improving physically, mentally and emotionally. It's extremely important to share our stories with others so more MS'ers who suffer can visualize that they too can reach out, share with others, and get the proper treatment they deserve. This LDN book was so enlightening for me and brought excitement to my life while I read all the personal stories. It is a valuable book and I'm truly grateful that I could find this important information. My life is so much improved, and I believe it will continue to be in 2010.

Ellen, USA

"I have been on LDN for two months and look forward to everyday with the hope of continual improvements with my health. Thank you for this opportunity to share my thoughts with you." May '09

26 MS symptom improvement a bonus - Silvia

LDN since 8 January 2009
- story submitted July 2009 (6 months on LDN)
- story updated February 2010 (1 year on LDN)

SPECIFICS

DIAGNOSED
- Nov 2008 – diagnosed Primary Progressive Multiple Sclerosis (PPMS)

KNOWN FAMILY MEDICAL HISTORY
- July 2009 - There are no known and diagnosed autoimmune diseases in my family history, though there have been some instances of cancer in the family. I've also become aware of my sisters' problems, which might suggest autoimmune issues. One of them had been told she had fibromyalgia over 30 years ago, something that was just ignored after that as it wasn't a proper 'illness' then, and my other sister constantly battles with her intestines. Does she have undiagnosed IBS? And does that all mean that there are autoimmune issues running in my family?

HOSPITALISATION
- none

TESTS
- Nov 2008 - MRI – showed at least 2, possibly more lesions.

MEDICATION (pre LDN)
- none

MEDICATION (post LDN)
- Jan 8 2009 to Jan 23 2009 – 3mg Low Dose Naltrexone (LDN)
- Jan 23 2009 to Feb 2010 – 4.5mg Low Dose Naltrexone (LDN). NB I sometimes lower to approx 4mg or 4.2mg when I feel very stiff legs. Does it improve my stiffness, or is it just in my mind? I don't yet know, still testing it.
- Feb 2010 to present – 4mg to 4.5mg Low Dose Naltrexone (LDN). NB Around 4mg seems to suit me. My legs are not too tight and my bladder is well at around this dose, so I tend to take anything between 4mg and 4.5mg, not fussing about an exact dose within this range.)

DOSE & TYPE
a) Dose – 4mg to 4.5mg Low Dose Naltrexone (LDN) – NB Accurately measured within this range.
b) Time - I take the Naltrexone at bedtime (not earlier than 9pm, not later than 2pm)
c) Type – liquid – It allows easy adjustment of dosage, and is supplied by Dickson's chemist in Glasgow.

SUPPLEMENTS
– Jul 2009 - fish oil, multivitamin, and zinc (sporadic, not reliably regular)
- October 2009 to October 2009 - Alpha lipoic acid each day for 5 days only. NB It made me feel awful. I experienced weird heat surges and dizzy spells, also diarrhoea. Within days of stopping I felt better again.

DIET
- Jul 2009 – I minimize my intake of lactose, gluten, and wheat-based food, mainly because there are consequences when I eat too much of it. I do eat yoghurt and ice cream occasionally, and a daily sandwich. I seem to cope.
- Feb 2010 – No change since July 2009.

EXERCISE
- Jul 2009 - One hour MS physio class and 30 minutes swimming per week. I only walk around my house and garden and very short distances from carpark to shops.

MY STORY – July 2009

I'd been having problems with my legs and all sorts of things on my left side for ages. So, when the pain became too much, I finally went to see my GP.

She looked at my legs, realised that one of them was thinner than the other, and wanted me to do some exercises to strengthen those muscles. Not being able to lift my left foot off the ground for more than 8 inches, she concluded that I needed to see a neurologist.

For the last few years I'd been telling myself that I was a hypochondriac and that in my mind there was

constantly something wrong. Well, I was lucky to have private insurance at that time, and I got to have my MRI within a few weeks.

Two days later, in November 2008, I was told that I had PPMS and sorry, there's nothing traditional medicine can do for PPMS. Great! So I went home, felt despondent and very sad, and scoured the internet - mainly wanting to find people who were experiencing the same as me.

I read and read and read, but in the end it was a very lucky question that got me to where I am now. Somebody had asked; "What exactly is LDN?" I had no idea, but fortunately, I was curious enough to find and read the answers.

I read the name Linda Elsegood. I read ldnresearchtrust.org, and I came across the book "Those who suffer much, know much". The fact that there was information out there that didn't seem to profit anybody in particular but that was freely given by people who cared about their fellow people was convincing. I asked my partner to find all the negatives he could, and he didn't actually find anything.

I read the book online. I joined the ldnresearchtrust.org, and I got great information about how and when to start (like immediately!). My GP was hesitant to prescribe something she had never heard of and asked for more time. I said that I didn't feel that I had time, as I wanted to halt progression now, not in a few weeks or months.

I managed to get myself a prescription over the internet (e-med) and sent this off to Dickson's chemist in Glasgow. My doctor totally agreed with that approach and since then she has been giving me all further prescriptions, as she can see that LDN is good for me. To start with, I think she realised that it would do no harm and that seemed good enough for her.

I started taking 3mg naltrexone on 8 January 2009, and stayed at that dose for two weeks, then upped my dose to 4.5mg, and have stayed at that dose since, though with occasional minor adjustments down.

In the first weeks of taking LDN, I felt quite tired, to the point of fatigue, but over the initial weeks, my fatigue improved fairly quickly.

I also experienced increased heartbeats and some pounding during the first week, and if I woke during the night, I seemed to be wide-awake. After one week on LDN I had a strikingly vivid dream of killing two rats with my long handled shoehorn. (Doesn't everybody?).

The first really noticeable improvement was the fact that I wasn't getting leg cramps anymore. I had gotten used to refraining from stretching, as that inevitably ended in a leg cramp. So, when I forgot one morning and stretched, I found that my leg didn't cramp, and I was delighted. This was my first realisation that LDN had changed something in me.

The first month on LDN I had been charting my urine in-and-output for my MS nurse. Urinary frequency was high at 9-15 times daily to the loo, with interrupted sleep from getting up once or twice every night. This interrupted sleep and night symptom had been happening for several years prior to my diagnosis.

Six (6) weeks after commencing LDN I took stock of that symptom, because one day I suddenly realised that I'd been sleeping through for several nights. Daytime loo visits had gone down to 6-8, and I'd begun to sleep through most nights without having to get up and go to the loo. My sleep had improved, so I felt more refreshed when I woke.

My cramps have not come back, and my bladder is excellent, even better than it was about 8 years ago. I still have MS, I tire very quickly, I limp, and I quite happily take a nap during the day. I still sway and nearly lose my balance, but I started taking LDN because I wanted the progression to stop, or at least slow down. I didn't expect symptom improvement and relief, but feel very lucky that I got that as well.

I wish people didn't hesitate so long about LDN. With a no-harm-done drug, wouldn't it be a safer bet to give it a go than to wait until more damage has been done?

Update, February 2010

I had many thoughts during these last 13 months on LDN. Like most people, I started worrying at the first glitch, asking whether I might be kidding myself about the efficacy of LDN. Thank goodness I was advised to

keep a diary, an advice I now also give to everyone who's starting LDN. I found the reassurance this gave me the most valuable part. Every time I felt down and was getting doubtful I just needed to read old entries and I knew LDN was working.

What's been happening with me since I last wrote?

In August 2009 I had a 'doubting period' and needed to read my diary to feel reassurance that I was a lot better. My fatigue lifted and the energy level was increasing. I didn't even need daytime naps anymore. I reduced my gluten and milk intake. Breakfast changed from toast to muesli, the wheat free variety (gluten free is not to my taste), to which I add a tablespoon of linseed and I mix it up with apple juice, not milk (very tasty!). My digestion is much better for it and constipation is rare. If I do experience it, I can always identify the reason, such as eating pasta or something in breadcrumbs, or following Sunday breakfast that still comes with toast. But I can cope with this level of constipation.

Occasionally I have felt my old queasy feeling (which I experienced for 16 years whenever I tilted my head and looked up at the ceiling) stronger, increased and sometimes it came upon moving my head or even just my glance.

In September 2009 I felt my first real surge of improvement. Yes, things had gotten better all the time but at the end of August, beginning of September, i.e. about 8 months after starting LDN, I was feeling stronger than I had done for a long time.

In October I had a funny symptom, was it MS or just something? It was a 'crawling insect' feeling on top of my head across an area the size of a golf ball. It lasted a few seconds in the morning and overall for a few weeks. By November it was gone again.

This is what I actually wrote in my diary just over a year ago, on 28th November 2008: *' ... Well, is this the end? The beginning of the end at least, or is it the beginning of a new era, my life with disability? I must say, I think, I'd find it easier to look into my own death's face than to look into becoming disabled, dependent, a vegetable. I went to see my doctor neurologist today. She is very lovely and has handled it all very well, but it still doesn't stop her from having to tell me that she is 98% certain that my symptoms and scan pictures indicate Primary Progressive MS. Great. OK, it doesn't shock me completely as I have been expecting some bad news. I've had the feeling that something was wrong for quite a while. I suppose, the consolation is, that even had I gone to the doctor earlier, nothing could have been different. It's not that the disease could have been prevented or caught early on. It's just that I would have lived with the knowledge of doom longer, instead of living with the uncertainty of bad news. Both ways pretty bad. Oh well, what is the future going to bring? At the moment I have lots of thoughts, all negative of course, that's just the negative person I am, I guess. ... '*

And this is my diary entry of 28th of November 2009*: ' ... I was so lucky to feel as depressed as I did then, to search the internet, to more or less stop what I was doing until then and read. I was so lucky to stumble across these three letters LDN. My life is totally different to what I pictured it to be last year. I am more active than I was for many years, I am not depressed, I have hope and I am physically stronger, too. I am not deteriorating, if anything, I am somewhat improving. Maybe that's physio and swimming doing its job, but no doubt that's all being helped by a healthy immune system thanks to LDN. The points of sadness I experience most days are the messages I read of people who have lost all hope or who say, if only they had known about LDN when they could still walk, as they would still be walking now. This is the totally unfair bit. LDN is here, it's harmless, it improves lives, it stops deterioration, but unless you are as lucky as I was you won't be told about it and won't actually find it easily. This must change, and this must change soon. ... '*

Today in February 2010, I am feeling well, upbeat, and better than for quite a while before and since diagnosis. I walk steadier and stronger than a year ago, I now manage to swim 21 lengths and don't need a sleep after that, whereas last Spring I barely managed 6 lengths and was totally exhausted and asleep in the afternoon after a swim. I am managing to cook and bake again, occasionally having to pace myself and sit down for a few minutes after standing for a long-ish while, but the perch stool which I needed last Spring has long gone into the cupboard again.

I have dabbled with my LDN dosage. From 4.5mg, I reduced to 4mg, then to 3.5mg, with little steps in-between. The day I got down to 3.5mg I experienced bladder urgency. This might have been a coincidence, but it scared me so I upped the dose again. It looks now that 4mg seems to suit me. My legs are not too tight and my bladder is well at around this dose, so I tend to take anything between 4mg and 4.5mg, not fussing

about an exact dose within this range. My mother who is making her own takes a teaspoon of her LDN solution, which is about 3mg. No fuss about it and it's working great for her.

The vitamins and zinc I have been taking I tend to forget to take. In October for 5 days only I tried Alpha lipoic acid, which made me feel awful. I experienced weird heat surges and dizzy spells, also diarrhoea. I stopped ALA and within days I felt better again. Maybe it's to do with my amalgams in my mouth, or just coincidence?

I baked a cake, muffins and Christmas biscuits, things I feared a year before that I would never be able to do again. Occasionally when I get tired (and I still can do that), I sit on the worktop to rest for a moment.

LDN has brought lots of improvements for me. Has it improved my mobility? No, I don't think so. But it has lifted my fatigue, which gave me more energy to do more physically. I walk the stairs more often than I did. I exercise more. I swim for half an hour a week. Those initiatives are what has improved my mobility. I don't believe it was the LDN, but my taking advantage of the opportunity LDN gave me to do all the other things. LDN was the start of a chain reaction. I know I still have MS. I can still lose balance, for example, and I still have foot drop; but I am stronger and more confident, mentally and physically.

Life is amazingly better.

Silvia, UK

Silvia, UK

"I wish people didn't hesitate so long about LDN. With a no-harm-done drug, wouldn't it be a safer bet to give it a go than to wait until more damage has been done." Jul '09

German LDN website – General Info - Silvia - www.ldnhilft.org

27 LDN, Trust & Patience has worked for me - Sal

LDN since 5 December 2007
- story submitted July 2009
- story updated April 2010 (over 2yrs on LDN)

SPECIFICS:

DIAGNOSIS
- date - asthma
- 1980s – Multiple Sclerosis - first symptoms developed following a bad boating accident
- 2000 – high cholesterol
- Nov 2000 – First major flare of MS symptoms, following surgery
- Date - Menniers Disease
- 2000 to 2003 – Saw various neurologists resulting in definitive diagnosis of Multiple Sclerosis in 2002
- 2008 – irregular heartbeat – due to eating dark chocolate and reacting to the theobromine content

MEDICATIONS (pre LDN)
- unknown to 2000 - statins (high cholesterol) – well-tolerated before major MS flare, but not after and ceased
– to 2009 - various periods of antibiotics from time to time due to chest infections associated with my asthma, and once due to a possum bite
- 2000 to 2003 – steroids, tablet form

MEDICATION (post LDN)
- Jan 2008 to present – Maxolon (as needed for ear problem – Menniers disease)
- Dec 5 2007 to Jan 2008 – 1.5mg low dose naltrexone (LDN)
- Jan 2008 to Mar 2008 – Zoton for Gastric Reflux
- Jan 2008 to Mar 2009 – 3mg low dose naltrexone (LDN)
- Mar 2009 to Mar 2009 – gradual increase in dose from 3mg to 4.5mg – 4.5mg every third night at first, then every second night during a period of approx 2-3 weeks
- Mar 2009 to present – 4.5mg low dose naltrexone (LDN)

TESTS
- 2002 – MRI - definitive MS diagnosis

HOSPITALISATION/SURGERY
- Nov 2000 – gall bladder surgery
- 2008 – 2 trips to hospital due to irregular heartbeat

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone at 10pm every night
c) Type - My naltrexone is compounded into capsules with Acidophilus filler from Green's Pharmacy, Adelaide

SUPPLEMENTS
- 2003 to present – 5ml high grade fish oil, plus other supplements occasionally, eg; probiotics
- April 2010 to present – probiotics now taken daily

DIET
- 2000 to present - I follow a low fat diet and eat very little meat, simply because I'm not keen on meat, prefer fish. I also eat yoghurt for the probiotic content.

OTHER THERAPIES
- 2003 to present – I've been treated by a great Chiropractor, and an Acupuncturist, and both have helped some during past flares.

ACTIVITIES & EXERCISE
- 2003 to present – I've always been as active as I can be with MS, and as a wildlife carer, am always doing something and very active.

MY STORY – July 2009

I've had MS for over 20 years now, and for most of that, my GP would treat symptoms as they arose.

This was because I'd refused to have a Lumbar Puncture (LP) due to past problems with an epidural. As a result, my neuro said he couldn't provide a definitive diagnosis or prescribe the CRAB drugs (which I told him

I wouldn’t take anyway). I couldn’t have an LP or epidural because I was told NOT TO, unless I was in a life-threatening situation, because of past problems.

My regular neurologist, and 2 other neurologists, all said I needed to have a LP to officially confirm an MS diagnosis - even though they all said they were 100% sure I had MS. Then one finally diagnosed me with MS around 2004.

I’d done a lot of research because I guess I have always been a rebel and don't take what the first doctor tells me as being true.

All I can say is that when you do your own research you will find that even the 'experts' can't agree on causes and treatments of MS. The 'experts' all stick to their little book with the MS protocol. Fact is there is no real treatment for progressive MS. None of the CRAB drugs (Avonex, Rebif etc) are for progressive MS. They state that the earlier these drugs are started for MS the better. Once you have progressed they don't work.

I did a lot of research for many years and simply figured that the odds of MAYBE being one of the 30% and getting a 33% improvement was not good enough considering the nasty side affects of those drugs. Then Tysabri came on the market, was withdrawn from the market, then went back on the market. That told me that this drug was also not good enough.

You will find many theories on MS - chicken pox caused it, a virus, a higher prevalence in cold climates. Many areas around the world like northern Europe, Scotland, the southern states in Australia, etc have cold climates and have the highest rates of MS – but now many other people in hotter climates also get MS.

One Italian research team (there have been others too) came up with the theory that MS is a metabolic issue, lack of nutrients such as zinc, copper, vitamin B's, etc. My personal thoughts are that the chemicals in our food have a lot to do with it - maybe these chemicals stop our body from ingesting the normal vitamins and minerals we need.

When you have MS the 'experts' tell you your immune system is over-active and needs to be suppressed, but LDN does not suppress our immune systems, it boosts it.

I found out about a treatment called low dose naltrexone (LDN) when I was researching on the net about 3 or 4 years ago, but I had problems getting a doctor to allow me to try it. Around the middle of 2007 I came across it again. I knew it wasn’t a mainstream approved treatment, but it sounded promising and I wanted to try it.

I had stopped seeing neurologists, etc because it was a waste of time and lots of money. I’d refused the CRAB drugs they offered and instead, tried to find my own way through improved nutrition and supplementation, and I’d been seeing a brilliant chiropractor and acupuncturist whose treatments had helped some.

My cardio doc had recommended taking CoQ10, and a good quality fish oil for high cholesterol problems (because I couldn’t take drugs like Zocor that make my muscle problems much worse), and I’d also done some research on magnesium and other supplements.

When I asked my GP what brands to buy (good ones), his reply was 'I'm a medical doctor and don't have the time to look at alternative medicine', so when I decided to approach him about LDN, I went prepared.

I’d found the 'How to ask your doctor for LDN' guidelines, but after printing all the info and approaching both my GP and Neurologist, neither would prescribe it for me. They wouldn’t even think about it.

I was even prepared to sign a waiver but it was still a no go with my GP. His answer was that if LDN was any good for anything Australia would know about it, bah humbug!!! My GP refused to read the info I took because he had no time. Most of the medical centres near me would not take on new patients, which was another problem. So I dug my heels in and refused to go back to the neuro, and cancelled my future appointment with him.

I needed to find a good doctor. My adult daughter also suffered, from Fibromyalgia.

Well, I finally found a doctor to prescribe the LDN and I started in December 2007, thanks to Crystal of the Yahoo lowdosenaltrexone group.

I started on 1.5mg, and did have some minor sleep disturbances, which happened again when I increased the dose to 3mg. On 3mg I also had increased spasticity and muscle spasms, but I rode it out and they eventually abated, and I stayed on 3mg for 15 months (Dec 2007 to March 2009).

My first improvement on 1.5mg was less fatigue, but nothing else. Once I went to 3mg other things started to improve VERY slowly.

The first thing real improvement I noted was improved bladder control, but around the same time I developed some digestive issues. It felt like food was sitting in my stomach forever. I also had chest pain, bloating, burping, etc. I posted about this to the Yahoo LDN group and some suggested a change of filler, but I didn't think that would help.

It took around 6 months, and by June 2008 I was doing really well.

I'm a wildlife carer, and even though we'd recently moved house around that time, I don't think I'd have coped as well if I hadn't been on LDN.

It was a nightmare move, and the house we were moving to wasn't finished and so had workmen there for over a week after we moved in – and it rained heavily during the move. Moving 6 people and 20 birds and 4 possums under those conditions was not easy! The wildlife had a tough time, and I single-handedly cleaned the house we were leaving. It took me a week but I did it.

Meanwhile, my daughter, who had just moved back from the USA, had tried LDN without success and had been prescribed weekly B12 shots by her new doc here for her Fibromyalgia. (They'd checked her B12 before she left the USA and said it was fine.) The new doc also wanted to run a test on her for heavy metal poisoning.

My daughter's health improved a little after she was off all the awful meds the USA docs had her on. She was on heaps of meds including methadone for Fibromyalgia. I really don't think she had that at all. I think her problems were from a total hysterectomy she had, ovaries included. She is a manager now in a retail store.

Unfortunately, nothing has really worked for her and I firmly believe she did not take LDN long enough. She only had 1 bottle of 1.5mg to begin with, and I sometimes wonder if its not MS - following in my footsteps. I also believe the powerful drugs they had her on worked against her. She was on around 6 or 7 heavy prescription drugs. Since going off all the drugs she has improved but still has a lot of muscle inflammation. B12 seemed to make no difference to her.

I have high cholesterol and used to take statins up until 2000, but after my first major MS flare, my body would no longer tolerate them, so I couldn't take statins anymore. I haven't had a cholesterol test since I started LDN, but I think I'll get a test done eventually because I'm interested to see what the levels are now that I am on LDN and not eating the tiniest bit of chocolate. Just don't have the time to do it right now.

In November 2008 I had been on LDN for 11 months when I had to go without it for 2 weeks due to financial difficulties. I didn't expect it to make such a huge difference, but it did. I noticed a change within 2 or 3 days, though not as bad as pre LDN. I was greatly fatigued, and my bladder issues increased, etc. Slowly after going back on LDN those symptoms went away again. So if you go off LDN and then your symptoms worsen I would say it shows LDN was working.

I had to give up full-time work a few years ago due to my MS, but now I'm doing fine and I'm much better than when I started LDN 18 months ago. I'm positive it's the LDN that's working.

Now I'm doing wildlife rescue and care. I actually started an official wildlife rescue group. We formed the group early this year and recently had our incorporation come through. The official launch of our group was earlier this year and we had a federal politician help us launch, as well as a state member and local councillors, etc. We've also had heaps of support from local and international clubs.

A lot of hard work went into getting that up and running. We had an official launch of the group jointly with a fundraiser. It was a HUGE day with politicians and VIP'S. My day started at 6am, feeding 'babies' in my care, loading the car with gear needed for the day, going to the hall and setting up at 9am so the function could start by 11am. ALL day I was on my feet because it was my job to make sure each area was functioning ok. I had to greet VIP's, do speeches etc, etc. The function wound up at 5pm and then came the cleanup. By 6pm

we were cleaned up and packed up. I then went home and unpacked some stuff but left the rest for the next day.

My hubby then took me out for dinner because I was totally stuffed, major sore feet. I had also not eaten much through the day, no chance to. Was home again by 9pm and fell into bed. The next day I took it VERY easy but was soon fine again. I could NOT have done all that before LDN.

Of course I'm not cured but I am performing way better. I have way more energy, some of the symptoms have vanished, and I've had no progression. Of course I still have to be careful, make sure I get enough sleep etc. When I do have a very hectic day I have to take it easy the following day. Before starting LDN nearly every day was a bad day.

When I started LDN I was lucky that besides the LDN stopping progression I did get some symptom improvement. It wasn't an overnight improvement, more gradual. All of a sudden you think, 'Gee, I haven't had this or that, or that seems a lot better'.

Since starting LDN last December 2007, I've followed Dr Bihari's guidelines, taking 3mg LDN because of muscle spasms and spasticity, but I always intended getting to 4.5mg eventually.

Also the effects of different strengths of medications can vary in people. One person can take an antibiotic at 500mg and they're fine. I take the same and feel like throwing up. My doctor advises me to cut the pill in half and I go to 250mg, and then I'm fine.

Some with MS can't take 4.5mg straight away because it can increase muscle spasms and spasticity and that's what happened to me. I had to take 3mg for 2 or 3 days then one 4.5mg then back to 3mg. That went on for a about two weeks because adjusting to 4.5mg initially gave me muscle spasms. I'm now fine on 4.5mg, no spasticity and muscle spasms have eased greatly.

For me and my MS, 3mg seemed to be the best initial dose BUT after settling in comfortably with that dose, I finally increased to 4.5mg after 15 months, and I'm fine now - though I did have to keep varying between 3mg and 4.5mg for a couple of weeks before the muscle spasms settled for me. I was determined to get to 4.5mg because it is the optimum dose, if you can tolerate it. Some people have taken 3 or 4 attempts to get to 4.5mg.

Some people get a worsening of symptoms for a while when they start LDN, then things get better. Makes sense to me that worsening symptoms do not occur if nothing is happening, so it must be doing something. For me, that just means the LDN is working!!!!!!

I also take a high-grade fish oil, occasional probiotic, and sometimes other vitamins. I follow a low fat diet and eat very little meat, simply because I'm not keen on meat and prefer fish.

I would never tell people they have to do what I do – it's an individual choice, but it's right for me and seems to be working for me. I have not had any steroids for many years now, have much less fatigue, far more energy, and can do much more now than this time last year. I do find I need a good nights sleep and can't have 2 late nights in a row, but that's a small price to pay. I do believe that stress is a big factor with MS.

Thankfully, my local GP has now come on board (after I encouraged him to go to the websites while I was sitting there in his surgery). I showed him the LDN web site where it states therapeutic value is between 1.75mg and 4.5mg, the best dose being 4.5mg. He looked at the web sites, and after I told him I had been on 3mg for over a year, he said it couldn't hurt. He commented that as long as I didn't need more and more it was ok. He has now given me a script for 12 months, and I no longer need to travel over a 100 kilometres to see the other doc.

I had one problem last year (2008) where I had a very irregular heartbeat, and ended up being taken to hospital twice by ambulance. The cardio docs wanted me to go back to a neuro. I told them to forget it, that I had fired the lot of them.

I stuck to my guns and refused a lot of what they wanted to do. They could not figure out what had caused the irregular beats. After I got out of hospital I went to see my wonderful local GP, who at first thought maybe it was the LDN, but I told him, "No way" it was the LDN.

During the conversation he mentioned chocolate being one of the things that could cause weird heartbeats,

with dark chocolate being the worst. My response was, “Oh hell!” because I’d recently changed to the dark chocolate (because it was being promoted as healthy). Seems that my body does not like the theobromine in chocolate. Needless to say, I’ve since stayed away from ALL chocolate. I still get ectopics but have always had them.

I only use De-Gas (Simethicone) now for my gastric reflux but I believe the LDN has helped more. When I had to go without my LDN last December I noticed the reflux came back. After going back on the LDN, within 6 weeks the gastric reflux had gone back to minor problems occasionally. Also, thinking of the Menniers, the LDN has reduced the attacks. I did have a major attack March 2009 where I had to get a Maxolon shot but have had less minor attacks than in the last 4 years prior to LDN.

You have nothing to lose by trying LDN but give it a fair chance because some people have taken almost a year before they see the real benefits. Do I still get fatigue? Only when I have an extremely hectic long day then the next day I have to take it easy.

Just remember that the facts are there that it’s working. Yes, some people get a placebo affect from meds. Give them sugar pills in a clinical trial and they swear the pills are working – for a while – but not this long.

LDN is not a magic drug that is going to cure your MS, but it works. One day maybe there will be a cure BUT in the meantime, you will see improvements with LDN if you’re patient.

My bladder and bowel issues have greatly improved greatly and I have much less fatigue and far more energy – and I have not had any blurred vision for a year.

My family are amazed at just how much I can do now.

Update April 2010

Yes still on LDN and still doing fine. No changes. It’s still hectic caring for wildlife here.

Sal, Australia

Sal, Australia

“You have nothing to lose by trying LDN but give it a fair chance because some people have taken almost a year before they see the real benefits.” Jul ‘09

28 Back to my old self - Laura

- LDN since January 2008
- story submitted July 2009
- **story updated February 2010 (2yrs on LDN)**

SPECIFICS

DIAGNOSIS
- 2006 – Neurologist – diagnosed Relapsing Remitting Multiple Sclerosis (RRMS)

TESTS
- 2006 – Blood tests - normal
- 2006 – Lumbar Puncture - normal
- 2006 – MRI - not normal

MEDICATIONS (pre LDN)
- 2006 to 2006 – Interferon injections (6 months only)

HOSPITALIZATION
- 2006 – hospitalised due to leg numbness

MEDICATIONS (post LDN)
- Jan 2008 to present – 4.5mg Low Dose Naltrexone (LDN)
- Jan 2008 to present – no other medications

LDN - DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time – I take my Naltrexone at bedtime, usually between 9pm and 11pm each night
c) Type – My naltrexone capsules are compounded using pure Naltrexone powder with calcium carbonate ulm poa filler

DIET
- early 2007 to present – Swank Diet
- 2009 – removed beef, lamb, and pork from my diet.

SUPPLEMENTS
As at July 2009 I was taking the following supplements – all in the morning:
Acidophilus with 100mg pectin x 1
Selenium 200 x 1
B2 50mg x 1
B1 50mg x 1
B6 50mg x 1
B3 50mg x 1
B12 50 x 1
Vitamin C 1000mg x 1
Zinc 22mg x 1
Iron 5mg x 1

THERAPIES
- none

ACTIVITIES & EXERCISE
- Jan 2008 to present - Since taking LDN I can now play again for hours with my little boys without being exhausted. I also regularly swim and walk every day.

MY STORY – July 2009

When I was 18 years old I fell in love with a man, and we had our first child when I was 19. We then went on to have a second child when I was 20. We were married that same year and started to plan our future and all of our plans started falling into place.

Then one evening I realised my legs felt numb. It was funny at first, I was laughing and saying pinch me I can't feel it. I genuinely thought it was maybe a trapped nerve in my back as I had been working out pretty hard trying to get back to my pre baby body.

As a week or so went by and the numbness was still there, my family became concerned (I was never one to worry about anything) so for their sanity I went to the doctor. I was pretty shocked when they said I'd have to

stay in for testing and I (against doctors advice) left the hospital. I mean I didn't have time for all that. It definitely wasn't anything serious and the stupid doctors were over reacting, right?

After some stern words from my husband I went back that same night and agreed to have some tests done. So, bloods normal, and lumbar puncture normal. Okay, MRI time - not normal. I was later sent to meet a neurologist. To be honest I didn't even know what that was or what they did. I was 21 years old with my whole life ahead of me, and I had 2 very young children. I mean, my life was just starting.

He said we think you have Relapsing Remitting Multiple Sclerosis (RRMS). "Okay", I said, not knowing what that was and without any idea of its seriousness. I was alone in the office and I think he must have seen that I had no clue how serious what he had just said was. He gave me some information and told me it was very important for me to start treatment immediately. 'MS, what the hell is that?' I thought on my way home. I got home and goggled it. Oh shi*t! So that's what I've got. So I had to decide how I was going to deal with this: I could curl up in my bed and feel sorry for myself and let my family fall apart, or I could fight. I chose to fight it.

So, for the first year I did a lot of research. I had one more episode but thankfully, like the first, it went away by itself. I decided that I would try Interferon, only because it was the treatment with the least injections (and I hate needles). That, for me, was the worst time in my life that I have ever experienced. Reality hit home. This was serious, and it needed serious treatment. I stopped Interferon after 6months as I just couldn't continue with it.

I then discovered Dr. Swank and started that diet at the start of 2007. I made myself very physically fit as I believe that the stronger I am, the better I'm able to fight against this thing. After several months of the diet I was feeling much better - not so much fatigue and my hands were less numb, but I still felt that I could be doing more to fight against.

I again started researching treatments. One day while browsing on the Dr. Swank website, I came across one man's story about how he had found a fantastic new medicine that had taken him from being stuck in a wheelchair to walking again. LDN it was called. I immediately started researching it and found lots of great information, all good. Wow! How can I get this, I thought.

I knew I would be wasting my time going back to my neurologist as he is a 'strictly by the book' kind of doctor, and as LDN isn't approved for Relapsing Remitting Multiple Sclerosis. I knew he wouldn't give it to me. I went back to the Dr. Swank website and asked if anyone knew where I could get it in Ireland. I was told to contact my local MS society. I called them and they gave me a number.

Turned out to be the wrong number. Amazingly, when I said, 'May I speak to Dr O' Flaherty', the man on the other end of the phone said sorry you've got the wrong number, but I see a doctor by that name and I could give you his number if you like. The man on the phone was a patient of the doctor I was looking for, and he also had MS, was on the same diet as me, and was taking LDN - and he lived about 10 minutes from my house (oh my god!).

He had only good things to say about LDN. I called the doctor and went to see him that same week, he gave me 4.5mg of LDN and I started that night. I had a little difficulty sleeping for the first few nights but that passed, and it was the one and only side effect – nothing when compared to Interferon.

After a week or so I noticed my mood improving. I had been suffering with ever-changing moods, that is; I could be depressed one minute, happy the next, and then back to depressed. I was also very easily aggravated. Finally, I was getting back to my old self! No more fatigue, and to my delight, I could play again for hours with my little boys without being exhausted afterwards – and the numbness in my hands was completely gone.

I'm now in my early 20s, and I've been taking LDN for 18 months without any complications. I've recommended it to many people and I hope and pray that one day it will be available to all MS patients. I truly believe this is the best treatment for all new MS patients.

UPDATE February 2010

It's now February 2010 and I've been taking 4.5mg LDN for two years.

It's funny how time flies by. Looking back now on my story I realise just how MS used to be a huge part of my life. Nowadays it seems I hardly ever think or even talk about MS anymore.

My first year of taking LDN went by without any problems, but towards the end of the second year I had a sensory relapse, that is; numbness returned in my legs, along with a tightness around my waist and a shouting type sensation along my spine when I put my head down. It passed by itself after a week or so.

Since the last week of January this year I've had numbness in my feet and lower legs. Nothing that needs treatment and I expect it will pass. Despite the two sensory relapses, I've had NO FURTHER PROGRESSION of MS symptoms. These are symptoms I've had before, and I've had no new symptoms!!

I know what sets the old symptoms off - and stress is a huge factor for me when managing my MS. If I don't keep myself as stress free as possible, I usually will have some kind of MS sensation. Then there's my diet and supplement regimen: I try to keep my diet as low in saturated fat as possible (Dr. Swank Diet) and take my vitamins regularly. I think all of these are important factors in keeping my MS under control. Typically, an old symptom will act up slightly when I let one of these things slide.

Another factor could be my taking LDN too early in the evening. I sometimes take my LDN earlier than recommended (taking it between 7.30pm and 8pm, for one reason or another). This could be another factor in my sensory relapses.

For me LDN still comes out on top when compared to other licensed treatments for MS: Interferon has a reduction in relapses of only 18-38%, Copaxone 29%, and Tysabri's been implicated in death more than once. Then there's the long list of sometimes intolerable side effects like cold and flu symptoms, depression, suicidal thoughts, and liver problems... oh, and lets not forget the injections either daily or weekly!

It's hard for anyone to believe that this small once-a-day pill can actually make a difference. I think it's especially difficult to believe LDN works because other MS treatments that can cause serious side effects keep getting prescribed even after doctors have found out about LDN as an effective option.

To those with MS who read this; I urge you to try this medicine. It won't do any damage and its definitely worth a try. I urge everyone in the medical community to pass this story and others like it on to your communities, this medicine needs to be available to all MS patients yesterday!

As for me... it's been 4 years since my diagnosis, and two full years since starting on LDN. I've had no further progression, no new symptoms, no side effects, and I'm healthier than most of my friends and family.
I hope to write again in two years thanking all involved in the making of these stories for helping to get LDN licensed for MS.

Laura, Ireland

Laura, Ireland

"I'm now in my early 20s, and I've been taking LDN for 18 months without any complications." Jul '09

Why I contributed my case study…

I wrote my story to try to spread the word that LDN really does work, and I hope it helps others!!

29 MS plus Crohn's plus LDN equals JOY - Pat

- LDN since 3 March 2009
- story submitted July 2009
- story updated April 2010 (1yr on LDN)

SPECIFICS

DIAGNOSIS
- Feb 1995 – diagnosed with Multiple Sclerosis
- Sep 2003 – Crohn's Disease

TESTS
- Feb 1995 – spinal tap (as in-patient) - result confirmed MS diagnosis
- Sep 2003 – colonoscopy – result confirmed Crohn's Disease

MEDICATIONS (pre LDN)
- Feb 1995 – IV solumedrol (as in-patient)
- 1995 to 3 Mar 2009 - Avonex
- 1995 to 3 Mar 2009 - Amantadine
- Sep 2003 to Jan 2004 - 6MP (unable to tolerate)
- Feb 2004 to Feb 2004 – IV Remicade (2 infusions) – unable to tolerate, potentiated my MS symptoms
- Feb 2004 to May 2004 – Prednisone (little benefit)
- May 2004 to Mar 2009 – (intermittent) Budesonide (helped)
- May 2004 to 3 Mar 2009 – Methotrexate (maintenance dose)

HOSPITALIZATION
- Feb 1995 – emergency dept - numbness extending from my feet to my chest
- Feb 1995 – hospitalised as in-patient with unrelenting numbness extending from my feet to my chest – treated with IV solumedrol
- Sep 2003 to Jun 2004 – hospitalised 3 times over 9 months due to Crohn's, malnourished and anemic
- Jul 2004 – hospitalised due to head injury

MEDICATIONS (post LDN)
- 3 Mar 2009 to early May 2009 – 6mg Budesonide
- early May 2009 to early May 2009 – 3mg Budesonide (began tapering)
- early May 2009 to Jul 2009 – 6mg Budesonide (4 weeks)
- Jul 2009 to 1st September – 3mg OR 6mg Budesonide alternated daily, gradually tapering to 3mg daily, then 3mg every other day, then 0mg daily (Achieved 1st September 2009!)
- 3 Mar 2009 to Mar 2009 – 1.5mg low dose naltrexone (LDN) – for 3 weeks
- Mar 2009 to Apr 2009 – 3mg low dose naltrexone (LDN) – for 2 weeks
- Apr 2009 to 27 Jul 2009 – 4.5mg low dose naltrexone (LDN)
- 27 Jul 2009 to present – low dose naltrexone (LDN) – 1 x 1.5mg morning, 1 x 4.5mg evening

LDN - DOSE & TYPE
a) Dose – – 4.5mg low dose naltrexone (LDN) in the evening
b) Time – I take my Naltrexone in the evening, usually between 10pm and 12pm each night. On 27 Jul 2009, my doctor prescribed an additional 1.5mg in the a.m. to try to settle Crohn's. I found no additional benefit from the extra dose in the morning, so after 3 months, continued only with 4.5mg in the evenings.
c) Type – capsules compounded with pure Naltrexone powder & Avicel filler from Skip's Pharmacy

DIET
- After my MS diagnosis, I altered my diet to a low saturated fat diet, following Dr Swank's advice in his MS Diet Book. I have no way of telling whether or not it has helped, but it is regarded as a healthy diet for anyone and I wanted to give my body every chance at keeping the dreaded MS beast at bay. After my Crohn's diagnosis in Mar 2003, I didn't significantly alter my diet, other than reducing most dairy products except for yoghurt.
- Apr 2010 – I've added a reduced gluten diet, and it seems to help my Crohn's.

SUPPLEMENTS
<u>As at July 2009</u>:
iron x 20mg
choleast x 600mg twice daily
calcium/magnesium x 500mg twice daily
vitamin D3 x 1000iu daily
vitamin B6 x 200mg daily
DHEA x 20mg daily
<u>As at April 2010</u>:
fish oil x 400mg twice daily
methylguard x 600mg twice daily
choleast x 600mg twice daily
calcium/magnesium x 500mg twice daily
vitamin D3 x 1000iu twice daily

© Case Health Pty Ltd

vitamin B6 x 200mg daily
DHEA x 10mg twice daily
bi-est and progesterone bio-identical creams once daily

ACTIVITIES & EXERCISE
- March 2009 to present - I try to go to the gym 3-4 times a week for cardio and strength workouts. In addition, my dog encourages me to go for a walk every day.

MY STORY – July 2009

In mid-February, 1995, over the course of 4 or 5 days, my body progressively went numb from my feet to my chest. My feet felt like they were in ice buckets and I couldn't tell when my socks bunched in my shoes.

I went to the emergency room, thinking this was related to back surgery I had several years prior. Unable to find anything, they sent me home. When the numbness continued to progress, I returned to the emergency room and was admitted. A spinal tap confirmed my MS diagnosis. I was given Solumedrol infusions and sent home with instructions to see a neurologist. Avonex and Amantadine were prescribed. From 1995 until 2009, I had only two small exacerbations. The tops of my feet are still numb, but thankfully that is my only neurological deficit.

In the fall of 2003, I began to experience bloody stools. After a colonoscopy, I was given the diagnosis of Crohn's Disease. I was hospitalised three times in 9 months, becoming malnourished and anemic with each bout. 6MP was prescribed but I was found to be part of the population that is unable to tolerate it. Prednisone was then prescribed, which had marginal benefits compared to the side effects. I had two infusions of Remicade but it potentiated my MS symptoms.

The next attempt was Budesonide, which was better tolerated than Prednisone and helped calm flares. I was put on a maintenance dose of Methotrexate. A week after being dismissed from the hospital the third time in 2003 for Crohn's, I fell off a horse while on vacation in a semi remote area of the mountains. I was airlifted by helicopter to a nearby city and in the hospital for three weeks recovering from a head injury. 2003 was a year from hell!

In the spring of 2005, I read an article in a wellness magazine about LDN and its success with MS. I had reached a level of stability with my Crohn's and head injury and wasn't ready to 'rock the boat' medicinally, but mentally filed the information away. In 2006, my sister was diagnosed with PPMS and my other sister was having suspicious events, causing her to wonder as well.

In November 2008, my daughter, in her late 20s, was diagnosed with MS. I then spent days on the internet reading everything I could about LDN. She did not want to take any of the CRAB drugs after reading about their side effects, and wanted to try LDN. Her neurologist was not in favor of her taking LDN. She sent her records to a physician out of state and had a phone consult. He prescribed LDN and the prescription arrived from Skip's in just a few days. I also sent my records to the doctor, had a phone consult and received an Rx for LDN. I stopped taking Amantadine, Avonex, and Methotrexate and began taking LDN on March 3, 2009.

After my MS diagnosis, I altered my diet to a low saturated fat diet, following Dr Swank's advice in his MS Diet Book. I have no way of telling whether or not it has helped over the years, but it is regarded as a healthy diet for anyone and I wanted to give my body every chance at keeping the dreaded MS beast at bay.

After my Crohn's diagnosis, I didn't significantly alter my diet, other than reducing most dairy products except for yoghurt.

I also introduced supplements to my regimen, and I take the following daily: Iron 20mg, choleast 600mg twice daily, calcium/magnesium 500mg twice daily, vitamin D3 1000iu daily, vitamin B6 200mg daily, DHEA 20mg daily.

When I began taking LDN capsules with avicel filler, I started on a 1.5mg dose for three weeks, stepped up to 3.0mg for two weeks and then 4.5mg. I take it in the evening between 10.00 and 12.00pm. Prior to starting LDN, I had been on a downhill slide with Crohn's for a couple of months. Two weeks after stopping Methotrexate, I had a flare.

After talking to Dr Skip of Skip's Pharmacy about whether or not I could take LDN and Budesonide (which I knew my gastro would prescribe) at the same time, he said that Dr Jill Smith did not require her patients be off steroids while taking LDN during her Penn State trials.

I went armed with LDN info to my appointment with my gastro. At least he was willing to listen and read the info and not usher me out the door! So I took Budesonide along with LDN for a time, and the two seemed to work together to keep me out of the hospital.

I titrated the Budesonide dose down to 3mg in early May, but again found myself dealing with bloody stools. Following my gastroenterologist's instructions, I went back up to 6mg for four weeks and am currently alternating between 3mg and 6mg, with the intent of tapering down to 3mg daily during the next week and then hopefully, zero, a few weeks after that!

During my telephone consult with my LDN physician on July 27, 2009, he prescribed not only a refill for the 4.5mg evening dose of LDN, but suggested I also take 1.5mg in the morning. Every body responds differently, he said.

It is now 27 July 2009. I've been off immunosuppressant drugs since 3 March 2009, and my only prescription meds are LDN and the temporary Budesonide! Hurray!

I try to go to the gym 3-4 times a week for cardio and strength workouts. In addition, my dog encourages me to go for a walk every day.

A delightful, and unexpected result of being off immunosuppressant drugs is that I have 'me' back. I now enjoy playing the piano, I have 'happy' thoughts, and I have rediscovered my creative side. I'm happy even though there are still struggles in life. I care about living again. It's been a long 14 years without feeling joy.

UPDATE April 2010

On the dietary front, in October 2009 I began to reduce gluten in my diet, and it does seem to help my Crohn's. I also altered the supplements I take and now take the following daily: fish oil 400mg twice daily, choleast 600mg twice daily, calcium/magnesium 500mg twice daily, vitamin D3 1000iu twice daily, vitamin B6 200mg daily, DHEA 20mg daily, methylguard 600mg twice daily, and bio-identical creams bi-est and progesterone.

Between July and September 2009 I focussed on gradually titrating my Budesonide dose, alternating daily between 6mg and 3mg at first, then tapering to 3mg daily, then zero. By 1 September 2009 I was successful, no longer needed steroids daily, and have been fine since.

During my telephone consult with my LDN physician on July 27, 2009, he prescribed not only a refill for the 4.5mg evening dose of LDN, but also suggested I take 1.5mg in the morning as well. "Everybody responds differently", he said. I found it made no difference to my Crohn's and went back to a singular 4.5mg evening dose three months later, in October 2009.

I still try to go to the gym 3-4 times a week for cardio and strength workouts, and my dog still encourages me to go for a walk every day.

Back in 2006, one of my sisters was diagnosed with PPMS and was prescribed Rebif, a CRAB drug. In March 2010, my sister stopped Rebif and began LDN. The good news is spreading!

It is now 1 April 2010. I've been off immunosuppressant drugs since 3 March 2009, and steroids since September 2009, and my only prescription med is LDN! Hurray! My health is better, my quality of life is better, and I love feeling like the old 'me' again.

Pat, USA

Pat, USA

"A delightful, and unexpected result of being off immunosuppressant drugs is that I have 'me' back. I now enjoy playing the piano, I have 'happy' thoughts, and I have rediscovered my creative side. I'm happy even though there are still struggles in life. I care about living again. It's been a long 14 years without feeling joy." Jul09

48 Specialists frown on it, but works for me – Kelli

LDN since May 2007
- story submitted November 2009
- story updated May 2010 (3yrs on LDN)

SPECIFICS:

DIAGNOSED
- 18 Sept 2006 - Relapsing Remitting Multiple Sclerosis (RRMS)

MEDICATION (pre LDN)
- Oct 2006 to Dec 2006 - Betaferon

MEDICATION (post LDN)
- 16 May 2007 to 16 Jun 2007 - 3mg Low Dose Naltrexone (LDN) for one month
- 16 Jun 2007 to Jun 2007 – 4.5mg Low Dose Naltrexone (LDN)
- Jun 2007 to present - 3mg Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose – 3mg Low Dose Naltrexone (LDN)
b) Time – nightly, usually between 9pm and 11pm
c) Type - Compounded capsules with pure Naltrexone powder and Acidophilous filler.

SUPPLEMENTS
- Cod Liver Oil capsule 1000mg x 1 daily (most days)
- Magnesium Oxide 500mg x 1 daily (most days)

DIET
- 2007 to present – I have gradually cut out wheat products wherever I can, and I have over time, reduced my alcohol intake to keep it limited.

EXERCISE OR INTERESTS
- 2007 to present – After diagnosis I made a conscious decision not to stress the everyday, small stuff, and it does help.

MY STORY

I was diagnosed on 18th Sept 2006, after 2 confirmed 'attacks' that took place 2 years apart... I then had a 3rd attack about 6 months after diagnosis, around March 2007.

On the recommendation of my Neurologist, soon after diagnosis in October 2006 I began ImmunoTherapy, specifically; Betaferon, which wasn't as bad or 'painful' as I'd expected but was extremely uncomfortable. I didn't stay on it long though.

I had booked a trip to Thailand for December of 2006. I was aware that it was quite safe to travel with my medication, providing I had a letter from my neurologist and my medication was stored below the correct temperature at all times. But I honestly could not be bothered with the hassle of arranging another Neurologist appointment (how hard are they to organise quickly, right !!?). Then I would have had to ensure the medication was always stored correctly in Thailand - not exactly the coolest place. Then there was the prospect of explaining it all to my travelling partner - who did not know of my diagnosis.

I will deal with it on my return, I thought... At the time I also began to think there must be something better than this. I felt as if I'd been delivered this blow and then told, "You only have a handful of under-performing treatments to choose from, none of which will really do you much good, but we have to be seen to be doing something for you"… HA!

My natural curiosity and investigative streak saw me doing my own research online, and I very quickly came across Low Dose Naltrexone...

I don't remember how, but I began talking to several people about it and those who were taking it from around the globe. The more I discovered about LDN, the more I could not believe that it was being kept a 'secret' or frowned upon by medical specialists - the very people that are meant to be helping me to get better, NOT keeping me sick. Then it dawned on me… if I was 'sick', my neurologist would keep me as a patient… but if I was 'well', that would be one less patient for her and no 'kick-backs' from the Immuno-treatment I wasn't taking!!

I found a wholistic doctor near to me that prescribes and believes 100% in LDN, and so my LDN journey began on 16 May 2007. I started out on 3mg for one month, then increased to 4.5mg, but I felt a bit 'uneasy' on that dose (can't really explain it, just didn't feel right), so I dropped back down to 3mg and stayed there as it works well for me, and I take my LDN between 9pm and 11pm each night.

My capsules are compounded with pure Naltrexone powder with acidophilous filler. I tried Lactose but didn't tolerate it well. My pharmacist first used crushed tablets (for the first 3 month script) until I asked him to order in Pure Powder. I just felt there was less room for error with Pure Powder.

In terms of side-effects, I had very vivid dreams to begin with and to a certain extent, they are still vivid, but I've found that to be a pleasant side-effect...! Other than that, no side-effects.

When I remember, I take Magnesium tablets because they do seem to help with very slight muscle twitching in my legs, and I also take one Cod Liver Oil capsule.

There's not much to tell since then, as I've been (touch wood), great… no further 'attacks' and generally feel healthy.

I have made a few simple lifestyle changes - which everyone should ultimately do anyhow - changing my diet ever so slightly to cut out wheat products wherever I can, limiting my alcohol intake (a struggle but I got there !!), and the most important - NOT sweating the small stuff.

I have experienced a few instances (and I must stress these are less than minor) where I felt a slight tingling, almost a prelude to an attack (as like my 2nd - numbness of left side of nose) for a few minutes and then it disappeared. I am convinced that is the LDN 'kicking in' and doing it's job at stopping the attack.

So, to conclude my story so far... I have never missed a nightly dose of my LDN and my compounding pharmacist now knows me by voice and sight every time I collect my prescription... What better friend to have!!!

UPDATE – May 2010

I am definitely still taking 3mg LDN and to this day have not skipped a night (if only I could be so diligent in other things!!!!).

Touch wood, I remain 'attack' free' since starting on LDN on 16 May 2007, which is 3 years now.

I stopped taking any supplements a while ago now - just simply would forget to take them and as there's no adverse affect when I don't take them, I don't think about it.

I have not seen my neurologist since starting on LDN. I feel that as long as I am well and feel good, there is no need to waste hard earned money on a specialist appointment to find out what I already know is working....!!!

So, once again not much to report because I feel lucky to be one of the ones that does NOT have much to report. ALL good on this front !!!!

Kelli, Australia

Kelli, Australia

"The more I discovered about LDN, the more I could not believe that it was being kept a 'secret' or frowned upon by medical specialists - the very people that are meant to be helping me to get better, NOT keeping me sick."

49 LDN-I started in July 2003 - Brenda

LDN since 11 July 2003
- story submitted December 2005
- story updated August 2007
- story updated July 2008 (5yrs on LDN)
- story updated January 2010 (5.5yrs on LDN)

SPECIFICS

DIAGNOSED
- pre1989 - Cat scratch fever
- 1989 - Chronic Progressive Multiple Sclerosis (CPMS)
- Mar 2003 to Apr 2003 - viral pneumonia sent my MS symptoms to rock bottom.

MEDICATION (pre LDN)
- 1989 to 1990 – no standard MS treatments
- 1990 – Intravenous (IV) steroids during first major attack
- 1990 to 1994 – multiple IV steroids, during severe period ACTH every 4 months
- 1994 to 2003 – tried Provigil
- 2003 – considered Copaxone, more IV Steroids, Botox injections, morphine pump.

MEDICATION (post LDN)
– 11 July 2003 to present - Low Dose Naltrexone (LDN)

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone in the evening between 10pm and 2am.
c) Type – compounded capsules with pure Naltrexone powder and lactose filler.

DIET
- Low-Carb Diet keeps my energy level up. I don't drink alcohol nor have I ever smoked or done illegal drugs in my 40 odd years of life.

SUPPLEMENTS
- 1997 - I started taking numerous supplements. My ophthalmologist gave me trigger point injections into my stomach, ribs, back & neck muscles & my scalp & temples using Procaine & Sodium Bicarbonate. A temporary fix for pain but not fatigue.
- July 2008 – I take some supplements that seem to help.

EXERCISE, INTERESTS, THERAPIES
- 1997 to 2005 - cool water and slightly warm water pool therapy off & on - warm water in an Olympic size pool need not be over 87 degrees F(30.5 C) in winter in an indoor pool facility if pool is an Olympic size - cooler water is needed in a smaller pool.
– pre July 2003 - pool exercises as and when able.
- post July 2003 to present - increased pool therapy to 6 days a week, no less than two hours each session for 1 year, then tapered to a consistent and manageable weekly program, my mom massages me.

MY STORY – December 2005

LDN has given me a better quality of life than I ever thought possible, so I'm telling my story in two sections - before I started LDN & after I started LDN – and when you read my story you'll see why.

I was one of the lucky people to have symptom improvement with LDN. Not everyone will see symptom improvement but hopefully you'll see a halt in progression with LDN.

My MS story BEFORE LDN:

I've had progressive MS since 1989. It is suspected that I had MS as early as age 9 years. I had the symptoms but they were thought to be growing pains.

I'm skipping the years MS should have been a considered diagnosis for me ... ages 9 through 25. I had the symptoms for 16 years and progressed to paralysis before I got a diagnosis.

Dec. 1989, age 26. I was in horrible pain in my muscles & some of the pain felt like it was inside my bones. I had enduring and debilitating fatigue, double & blurry vision, excruciating migraines, petit-mal seizures (periods of confusion), repeated and disturbing forgetfulness. Both feet felt like they had stone bruises. The doctors were not finding anything wrong.

An absence of diagnosis meant no knowledge of what was happening to my body - meant an absence of treatment options. All this left me feeling isolated, hopeless and helpless. I'm good at coping, but coping was becoming increasingly difficult and physically draining. I wanted to fix this problem and get on with my life.

I decided one December day to soak in a warm tub of water to relieve my pain. I had 3 days off work so I thought I'd really get this pain to go away during my days off. I soaked that night in a warm tub of water and went to bed.

I awoke paralysed on my entire left side. That landed me in the hospital, and then my MS diagnosis came. WHAT A RELIEF!! There was a name for what I had and I wasn't going crazy after all. My type of MS attack is extremely rare. Explanation below.

Reproduced from a book that explained my form of MS attack: ' … Cerebral Attack (Falling in a 3 Percent incidence rate of ever occurring): This occurrence comes with a very rare MS attack known as the Cerebral Attack. The symptoms come on like those of a stroke and include memory loss, seizures known as 'absence seizures, which are short confusional seizures', also known as 'petit-mal' seizures. One-sided visual field loss, paralysis of the face, arm and leg on one side, Lassitude fatigue, loss of speech expression or comprehension (aphasia) … '

I managed to regain the use of my left side again but was left with significant weakness on the left side. The doctors told me to file for disability immediately, that I would not be able to continue to work, that my MS would only get worse as time passed. I was diagnosed Severe MS.

I refused to file for disability and returned to work in January 1990. In February 1990 I had an Optic Neuritis attack of the left eye. Had to be away from work. I recovered with a major visual loss in the left eye, 20/180. I returned to work.

I had another attack on my right side in March 1990 involving my right arm, head and neck. I couldn't hold my head up on my own. I had to lay it against something...went through IV steroids for many months and I got to where I could hold my head up on my own again. I can still feel the weakness and fatigue in my neck muscles even today.

I had to quit my job April 1990 and moved home with my parents. 1993 or 94 I went through years of intravenous steroids, ACTH every 4 months, I had had paralysis of my torso and couldn't hold myself up so needed a mobility scooter with a lumbar support seat that tilted backwards slightly.

Spasticity has steadily increased over the years. I was born spastic in all 4 extremities and spasticity has only increased as years passed. Fatigue has been horrendous. My muscles from the so-called MS Hug (I call it the MS Torture Chamber) were so knotted & drawn that when felt by the human hand it felt like bone, not muscle.

My vision slightly improved in my left eye to 20/160 on steroids. I've had migraines so bad that I've had to be knocked out in the ER. I've had to use a cane, a wheelchair and then a scooter. I refused Betaseron when it became available. By the time Betaseron came around I needed symptom relief more than I did anything else. The side effects of Beta didn't sound too good either. I tried Provigil and it was a flop for me. I did consider taking Copaxone about a year ago but changed my mind due to its cost.

About 8 years ago I started taking numerous supplements. My ophthalmologist is also an alternative medicine doctor. He gave me trigger point injections into my stomach, ribs, back & neck muscles & my scalp & temples using Procaine & Sodium Bicarbonate. A temporary fix of pain but not fatigue. I've done cool water and slightly warm water pool therapy off & on during the past 8 years. Warm water need not be over 87 degrees in winter in an indoor pool facility. My mom massages me.

Oh, MS has left me 100% deaf in my right ear. It has actually done eardrum damage. It has left me moderately deaf in my left ear. I have mild to moderate lymphedema (lymph channel blockage resulting in swelling) everywhere I've had paralysis and that is in approximately 90% of my body.

In 2003 I had viral pneumonia for the entire month of March and 3 weeks into April. It put my MS symptoms at rock bottom. I was considering Copaxone, IV Steroids and Botox injections into my muscles and the possibility of a morphine pump. I had heard of LDN for at least 3 years prior to my trying it. I had been too sceptical. It sounded too good to be true. I was finally to the point of no return with this knock down I'd just been given.

I knew that none of the ABCR & N drugs would make me feel better. It's well known that these drugs do nothing for symptom relief and that's what I desperately needed. I was experiencing a fatigue & pain that had me couch and bedridden. I needed Superman!!

July 2003 I decided I was going to try LDN before the Botox injections or steroids. I hoped LDN would be my Superman. My alternative medicine doc said he suspected my MS, which was moderate before 1989, was triggered by my severe bout of cat scratch fever, causing the existing undiagnosed MS to become chronic progressive. I remembered my symptoms did get much worse and I also rapidly developed new symptoms after my cat scratch fever incident.

I started taking low doses of Naltrexone (LDN) in July 2003. To my surprise, several symptoms eased overnight after my first dose of 4.5mg LDN with lactose filler. The first symptom to be noticeably reduced was the horrendous MS hug. I also had reduction in frequency of trips to the toilet at night and I noticed my fatigue had eased slightly.

Here's my MS story AFTER LDN:

Fourteen continuous years of progressive MS has been halted dead in its tracks – because I decided to take a chance on LDN.

It is December 2005, Christmas is here, and I have been taking LDN for 2 and a half years now (since July 11 2003).

I have continued on the same dosage of LDN for the whole period - 4.5mg with lactose filler. I obtain my LDN from Cantrell Drug Co in Little Rock, Arkansas ... they use pure naltrexone powder, which I believe is very important.

I haven't needed my mobility scooter in 2 years but LDN did not do this by itself, I had to do my part too (see my NOTE* below).

I never took the CRAB drugs or Novantrone (also known as chemo) and I believe these decisions have played a huge role in my success on LDN. By the time I was diagnosed at age 26, I was diagnosed chronic progressive. I'm in my 40s now and a May baby.

What has LDN done for me? Well, soon after starting LDN my MS hug pain reduced by a good 60% and my bladder control improved. I noticed less fatigue and would say it reduced by about 25%.

After 6 months my vision slightly improved, my migraines halted, and LDN corrected my many years of suffering insomnia. I've also noticed the tremors in my hands improved slightly.

Here's that NOTE* I mentioned earlier: It's very important for readers of my story to understand LDN won't do it all for them.

I had to do my part too to stay ambulatory (mobile) once I got out of that scooter - like exercise my behind off in the pool. I was doing pool therapy before LDN but after I started LDN I took full advantage of the reduced fatigue and reduced pain that LDN gave me, and I went GUNG_HO on the pool exercising...6 days a week in the pool for no less than two hours each session for 1 year.

I've reduced that time lately because the YMCA is a 50 mile drive one way and fuel prices have risen so high - but I still do pool therapy as often as I can.

LDN is not a cure. It could not help my slurred speech nor my hearing loss or the muscle damage from past paralysis, BUT, based on everything I've read and everyone I've spoken to face-to-face or in forums – LDN appears to be the best available treatment for MS at this time.

Having said that, LDN doesn't alleviate symptoms for everyone who tries it. It may be because they give up too soon. It may be because they don't adhere to the recommended regimen. It may be because their pharmacy doesn't use the pure powder or the right filler. It may be because they've been incorrectly diagnosed. It may be because of their genetic makeup. Regardless, I do believe it helps stop progression in many, not all.

We don't yet know the answers to all the questions, and that's why LDN supporters and users promote the need for a clinical trial.

In terms of my diet - I do a Low-Carb Diet to keep my energy level up. I don't have high blood pressure (never have had), or high cholesterol. I don't drink alcohol nor have I ever smoked or done illegal drugs in my 40 odd years of life.

If you decide to try LDN I hope, like me, you're one of the lucky ones. But please remember luck is only part of the equation. You have to do your bit - like improving your diet - like getting the Naltrexone made correctly by a good compounding pharmacy, by experimenting until you can find the dose that best fits your body and particular illness, by using the right fillers, by making sure your Naltrexone is fast release - and by taking advantage of any improvement LDN gives you and increasing your exercise to strengthen your muscles, keeping them as mobile as possible.

LDN might do something for you straight away or it may take a few weeks or 6 to 9 months for LDN to start halting your disease progression. At first, adjusting to the dosage may be trial and error and I know that's difficult to cope with when you're not well. All I can say is, don't give up on LDN too soon. Try your best to give LDN at least 9 months to halt your disease progression.

UPDATE August 2007

All I can add is that I've had no progression since starting LDN 4 years ago. I still follow a Low-Carb Diet and still do pool therapy to complement my treatment.

UPDATE July 2008

No progression since starting LDN 5 years ago. I still follow a Low-Carb Diet and still do pool therapy to complement my treatment.

UPDATE January 2010

I'm still in remission but still have permanent damage MS caused before I started LDN. I'm extending the length of my home at present, replacing ceilings, putting in new hardwood flooring, etc. I could not even have contemplated that before LDN.

My pre and post LDN journey is recorded on my site here: http://www.ldn.proboards3.com/index.cgi

Brenda, USA

Brenda, USA

LDN might do something for you straight away or it may take a few weeks or 6 to 9 months for LDN to start halting your disease progression. At first, adjusting to the dosage may be trial and error and I know that's difficult to cope with when you're not well. All I can say is, don't give up on LDN too soon. Try your best to give LDN at least 9 months to halt your disease progression.

30 HIV viral load and T-cell Tracking - Matt

LDN since December 2004
- story submitted December 2005
- story updated Mar, Jun, Oct 2006
- story updated May 2007
- story updated July 2008
- story updated Feb, Jul, Aug, Oct 2009
- story updated Mar 2010
- story updated July 2010 (5.5 yrs on LDN)

SPECIFICS

DIAGNOSIS
- Aug 2002 - HIV positive. My infection was diagnosed early during the seroconversion period (the antibody development period which occurs in the first 1 to 6 months of infection).

MEDICATION (pre LDN)
- Sept 2002 to Sept 2003 – 5 HAART medications twice daily for one year

MEDICATION (post LDN)
- Dec 2004 to present - 4.5mg Low Dose Naltrexone (LDN)
- 15 Mar 2010 to present – 400mg x Truvada x once daily with evening meal, usually 8-9pm
- 15 Mar 2010 to present – 800mg x Prezista (darunavir) x once daily with evening meal, usually 8-9pm
- 15 Mar 2010 to present – 100mg x Norvir x once daily with evening meal, usually 8-9pm

TESTS (post LDN)
- 2004 – viral load above 5000
- Feb 2005 - T-cells increased by 50%, Viral Load went down to below 5000
- 6 Dec 2005 - CD4 500, Viral load 2079
- 8 Mar 2006 - CD4 444, Viral Load 4260
- 14 Jun 2006 - CD4 434, Viral Load 5810
- 27 Sep 2006 - CD4 640, Viral Load 9520
- 3 Jan 2007 - CD4 576, Viral Load 18200
- 11 Apr 2007 - CD4 544, Viral Load 35400*
- 11 Jul 2007 - CD4 414, Viral Load test result delayed, still unknown
- 10 Oct 2007 - CD4 544, Viral Load 9210
- 4 Nov 2007 - CD4 544, Viral Load 35400
- 9 Jan 2008 - CD4 544, Viral Load 13600
- 4 Apr 2008 - CD4 740, Viral Load 6880
- 23 Jul 2008 CD4 551, Viral Load 7000
- 21 Jan 2009 – CD4 544, Viral Load 66000*
- 23 Apr 2009 – CD4 700, Viral Load 34000
- 12 Aug 2009 – CD4 554, Viral Load 63,100
- 8 Feb 2010 – CD4 540, Viral Load 134,000*
- 15 Jun 2010 – CD4 480, Viral Load 76
- 29 Sept 2010 - Next scheduled appointment/test

*Note:
(1) In Feb 2010 a significant rise in VL dictated anti-retroviral medication. There was no explanation for the disparity in the VL and CD4 numbers.
(2) At the April 2007 appointment I had a bad cold, and at the Jan 2009 appt I had a severe cold. (The doctor explained that these fluctuations are normal. As you can see, the CD4 count is holding steady in the 550 range. In late 2005, the numbers were just about the same. The doctor did not have the numbers prior to June 2006, as I was on a study back then.)

LDN DOSE & TYPE
a) Dose – 4.5mg LDN
b) Time – 10pm nightly (always between 9pm and 11pm)
c) Type – Compounded capsules with pure Naltrexone powder and lactose filler.

SUPPLEMENTS - HISTORY
- late 2006 to late 2007 - Olive Leaf Extract, taken in the evening with the LDN
- 30 Mar 2007 to late 2007 - 200 micrograms of selenium each day, taken in the evening with the LDN
- late 2007 to Sept 2009 as follows:
Vitamin C 500 mg x once daily taken in the evening with the LDN
Zinc 200mg x once daily taken in the evening with the LDN
Multivitamin x once daily taken in the evening with the LDN
- Sept 2009 to February 2010 - B Complex x one daily, taken in the morning

SUPPLEMENTS - PRESENT
- Sept 2009 to present:
Vitamin C 500mg x one daily, taken at night
Vit E 200iu x one daily, taken at night
Vit A (Retinol Palmitate) 8000iux once daily, taken at night
Zinc 200mg x once daily, taken at night
Multivitamin x once daily, taken in the morning
Olive Leaf Extract (as per bottle instruction) - once daily, taken in the morning

DIET
- no change - average, meat, vegetables, fruit
- Mar 2010 – improved lifestyle for several months now – less alcohol, more exercise, and less junk food (chips, etc).

ACTIVITIES & EXERCISE
- I have always exercised regularly - at least 4 times a week.

HOBBIES & INTERESTS
- none at present

MY STORY - December 2005

I was diagnosed HIV positive in August 2002.

My infection was diagnosed early during the seroconversion period (the antibody development period which occurs in the first 1 to 6 months of infection).

Due to early detection I was enrolled in a clinical trial at the University of Colorado, Denver, USA in September 2002. The basis of the study was to treat the HIV with a cocktail of 5 medicines for one year to see if the treatment could boost the body's capacity to control the virus by itself. I was on 5 HAART (highly active anti-retroviral therapy) medications taken every 12 hours (twice daily). I went through the year on the HAART.

It was a tough year because the medications made me feel consistently unwell.

I went off this treatment regime in September 2003. My body was able to control the virus for about a year, but then the viral load started to climb so I went in search of information.

In December 2004, I learned about a treatment involving low doses of Naltrexone (LDN) for autoimmune diseases. I learned about LDN on the lowdosenaltrexone.org website.

I made an appt. with my general practitioner doctor and asked him if he would prescribe the LDN, and he did. I began taking 4.5mg capsules at bedtime, which is generally between 9:00 and 10:00 pm each night.

Within 2 months of starting on LDN, my viral load went down to below 5000, and my T-cells increased by 50%.

I have been taking the LDN for one year now. My last doctor appointment related to the Denver study was on December 6th 2005. I was informed by the HAART study doctor that I was the only participant in the study NATIONWIDE to do so well and I did not have to go back on HAART.

The only thing I did that was different to others in the study was start taking LDN twelve months before the doctor's appointment so I am justified in believing it is the LDN that made the difference.

If you look at it … my numbers (viral load) were going back up before I started LDN. After starting LDN they went down. The doctor in Denver was sceptical of the LDN but now hesitantly admits that it may have something to do with the fact that I'm doing as well as I am.

The downside of taking HAART medications was they made me feel awful. I have not experienced any side effects since starting LDN and I feel GREAT.

Since starting on LDN twelve months ago I have not taken any other medications or nutritional supplements and I have not made changes to my diet or exercise regime - which I'd say is fairly average.

When I got into work today I had an email from Denver:

Results: CD4 (T-cells) = 500, and my Viral load = 2079 (results from tests on Dec. 6th).

My doctor's goal is to keep my viral load below 5000, and t-cells above 400.

I've been on LDN exactly one year now. I have not taken any other HIV meds now for 2 years, 3 1/2 months. I'm very happy with the results.

My infectious disease doctor in Denver is somewhat dumbfounded. I keep telling him it's the LDN. At least he doesn't say it's a hoax anymore. Thank goodness my general practitioner is open-minded and will prescribe it for me.

Happy Holidays!

UPDATE March 2006

As you'd recall my doctor's goals are to keep my Viral Load below 5000, and my T-cells above 400.

Following my doctor appointment on 8 March 2006, I'm pleased to report my test results were as follows:

Results: CD4 (T-cells) = 444, Viral Load = 4260.

All is going well, and I feel great.

I firmly believe that the LDN has kept me from having to go back on HAART for so long. The study I was on in Denver (ACTG 371) is over. My appointment on March 8th was on my own ticket.

I decided to keep the study doctor in Denver as my infectious disease doctor. As a research doctor they're on the "cutting edge" so to speak and I'm going to keep going to Denver for my peace-of-mind. The doctor again told me on March 8th (as they did in December '05) that I was the only patient on that particular HAART study (ACTG 371) in Denver that did not have to go on a second round of HAART during the study. (This was based on the researcher's communications with and knowledge of other clinical trial centers.)

During my appointment I told the doctor again about taking LDN. There was no response - positive or negative – only a request for the website address followed by a promise to look it up.

Regardless, I'm going to keep taking the LDN. The Denver research doctor told me I'd need to go back on the HAART drugs if my CD4 count dropped below 350. I'm hopeful that will be a very long time from now.

I wish I could attend the LDN conference early in April 2006. Hopefully, I'll be able to attend another year. I enjoyed listening to the audio feeds from last year's conference.

UPDATE June 2006

Cris, I wanted to update you of my most recent check-up at Univ. of Colorado - Denver. My appointment was on June 14, 2006: Results were CD4 count = 434, Viral Load = 5810.

My doctor seemed to feel that these were really good results since they hardly changed from 3 months ago.

September 2006 will be 3 years off HAART. My doctor stated she would not put me back on HAART unless my CD4s fell to 350 or less.

UPDATE 17 October 2006

Here is an update from my Sept. 27th, 2006 appointment in Denver:

Results: CD4 count = 640 (up from 434 in June!!), Viral Load = 9,520.

My new goal is to keep the CD4's above 350. If I go below 350, then I go back on HAART. I'm hopeful that this won't happen. My next appt. is in January 2007.

UPDATE February 2007

Here is an update from my January 3, 2007 appointment in Denver:

Results: CD4 count = 576, Viral Load = 18,200.

UPDATE May 2007

I still take LDN every night, and I've been taking olive leaf extract since late in 2006 because I read positive information regarding olive leaf as an antioxidant to help suppress HIV infection. It's a potent anti-oxidant so I take it at a different time to everything else, just in case it could interfere.

I started taking 200 micrograms of selenium each day on March 30, 2007 after reading some interesting research on selenium and HIV. It even says on the bottle that it may be helpful for cancer.

My last appointment was in Denver, Colorado on April 11, 2007 and here are the results:

Results: My CD4 count was still good - CD4 = 544. My V-Load was 35,400.

My viral load was not good news, but since I had a slight cold, the doctor thinks that may have elevated it.

UPDATE August 2007

Results from appointment on July 11th, 2007 were as follows:

Results: CD4 = 414. The Viral Load test results were delayed.

UPDATE November 2007

Results from appointment on October 10th, 2007 were as follows:

Results were CD4 = 544, Viral Load = 9210.

UPDATE December 2007

Results from appointment on November 4th, 2007 were as follows: Results were CD4 = 544, Viral Load = 35400

UPDATE January 2008

I stopped taking Olive Leaf Extract and Selenium late last year, and started taking a multi-vitamin, Vitamin C, and Zinc daily. Just got the test results from January 9th, 2008 appointment as follows: Results were CD4 = 544, Viral Load = 13600.

That means things are stable and no need to go on HAART drugs at this time. BTW.... As of this month, I've been on LDN for 3 years.

UPDATE June 2008

I am still on LDN. I have excellent news to report ... I had my last appt in Denver on April 4th, 2008: Results were CD4 = 740, Viral Load = 6880.

These are the best numbers I've had in 2 years. No other supplements at this time except for multi-vitamin, Vitamin C, and Zinc. I hope to be able to continue to report good news.

UPDATE July 2008 – 3.5 years on LDN

Results from appointment on July 23rd, 2008 were as follows:

Results: CD4 = 551, Viral Load = 66000.

UPDATE February 2009

I e-mailed my Dr about the Viral Load last July 2008 and it was 66,000 so you can add that now.

My supplements, diet and exercise remain the same.

My last appt was January 21st 2009. Results: CD4 = 544, Viral Load = 66000. My doctor said in an e-mail response that the high v-load from January 2009 was obviously due to my having a severe cold. I had a really terrible cold at the time.

UPDATE July 2009

Here are the results of my April 23 appointment: Viral load - 34,000, and CD4 – 700.

The numbers have improved. I have been feeling well physically, but the stress level has been high lately.

It was interesting to me that my numbers had indeed improved. Just prior to my April appointment, I had gone through a period of great stress with my job. I was expecting that the numbers would worsen because of this stress. But to my surprise... (???).

My next appointment is on August 12 and I'll update you when I get the results. I hope the August numbers are just as good or better.

UPDATE August 2009 – over 4.5 years on LDN

I just got the results from my August 12th appointment: CD4 – 554, and Viral load 63,100. The doc seems to think that it is just a matter of time before I have to go on retroviral therapy.

But... the CD4 count has remained fairly stable for 7 years now. She indicated that she thought the CD4 would be lower.

UPDATE October 2009 – nearly 5yrs on LDN

I added some supplements, such as Vit B complex to help manage stress and anxiety, and it seems to be helping. I also added Vit E - 200iu once daily, and have recommenced taking Olive Leaf Extract - once daily (I started taking this again since it is available at Wal Mart).

UPDATE March 2010 – over 5yrs on LDN, started HIV Antiretrovirals on 15 March 2010

I had my appointment in Denver in February, and the results were: CD4 = 540, and Viral Load = 134,000.

The doc did not have an explanation for the disparity in the VL and CD4 numbers. I think the LDN had something to do with that, but I will never know for sure.

I have not felt different, and my health habits (eating, drinking, exercising) have actually improved in the last several months.

Because of the dramatic rise in Viral Load, the doctor said it was time to go on anti-retroviral meds, and I agreed. The only reason I didn't start straight away was that the doctor had to wait on genotype blood test results.

On 15 March 2010 I started on anti-retrovirals matched to my genotype; 400mg Truvada, 800mg Prezista, and 100mg Norvir; all taken once daily. I have, of course, kept taking LDN.

I have been on the antiretroviral meds for one week now, and I'm feeling fine. I had mild stomach upset for the first few days of taking the meds. That has since subsided. No other changes.

UPDATE July 2010 – 5.5yrs on LDN, 4 months on HIV Antiretrovirals

My March appointment resulted in me starting on antiviral meds and I've been taking a Prezista (darunavir) 600mg, Norvir 100mg, Truvada 400mg mix once daily since 15 March 2010. At present, this antiretroviral mix costs me $195.00 every 3 months.

My last labs were done in mid June, and they indicated my Viral Load (VL) to be 76 and my CD4 to be 480.

The doctor said the VL should be non-detectable after 3 months on the ARVs, so they should be non-detectable by now.

I'm still taking the LDN nightly along with the above and my doctor is happy for me to do that. I'm still taking the same supplements. There have been no changes or tests other than that. My next appt is Sept 29 in Denver.

I feel okay other than I don't have as much energy as before starting the meds (That might have something to do with getting older also!).

I also cannot stand the heat as well as I used to. Other than that, all is well.

Matt, USA

Matt, USA

Dec '05: "I was informed by the HAART study doctor that I was the only participant in the study NATIONWIDE to do so well and I did not have to go back on HAART"

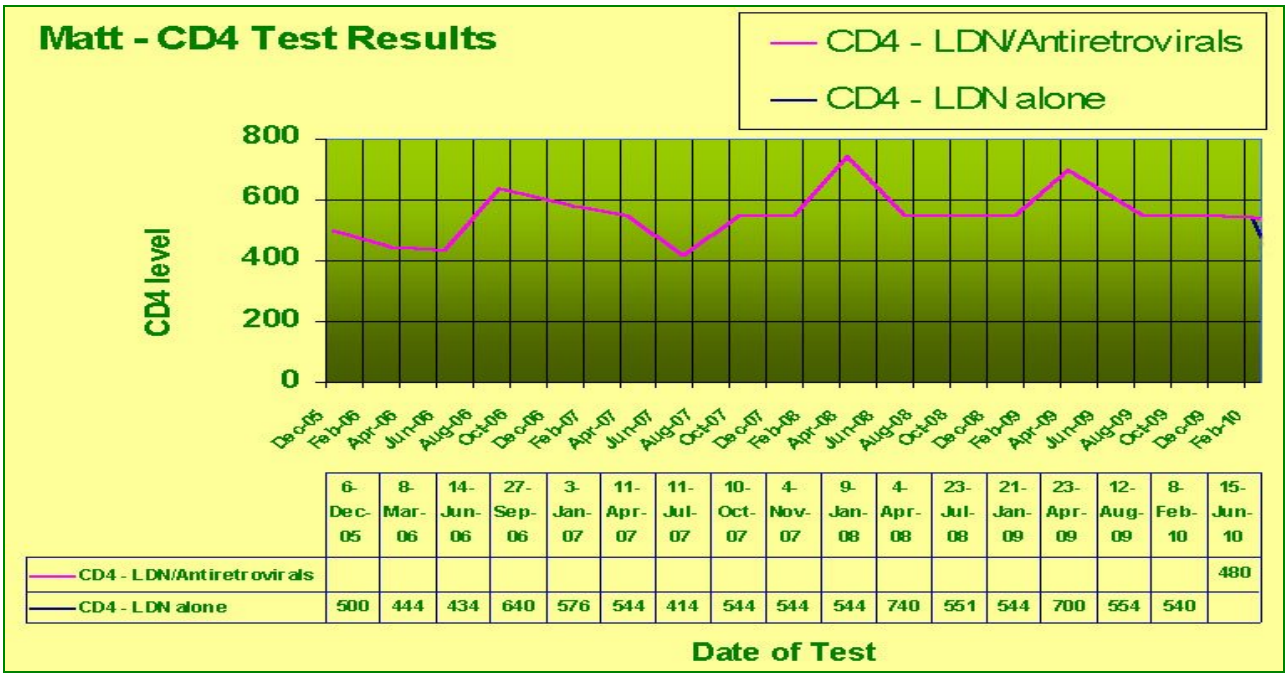
Mar '10: "Because of the dramatic rise in Viral Load, the doctor said it was time to go on anti-retroviral meds, and I agreed. The doc did not have an explanation for the disparity in the VL and CD4 numbers. I think the LDN had something to do with that, but I will never know for sure. On 15 March 2010 I started on anti-retrovirals matched to my genotype; 400mg Truvada, 800mg Prezista, and 100mg Norvir; all taken once daily. I have, of course, kept taking LDN."

Quote, Jaquelyn McCandless, 16 May 2007

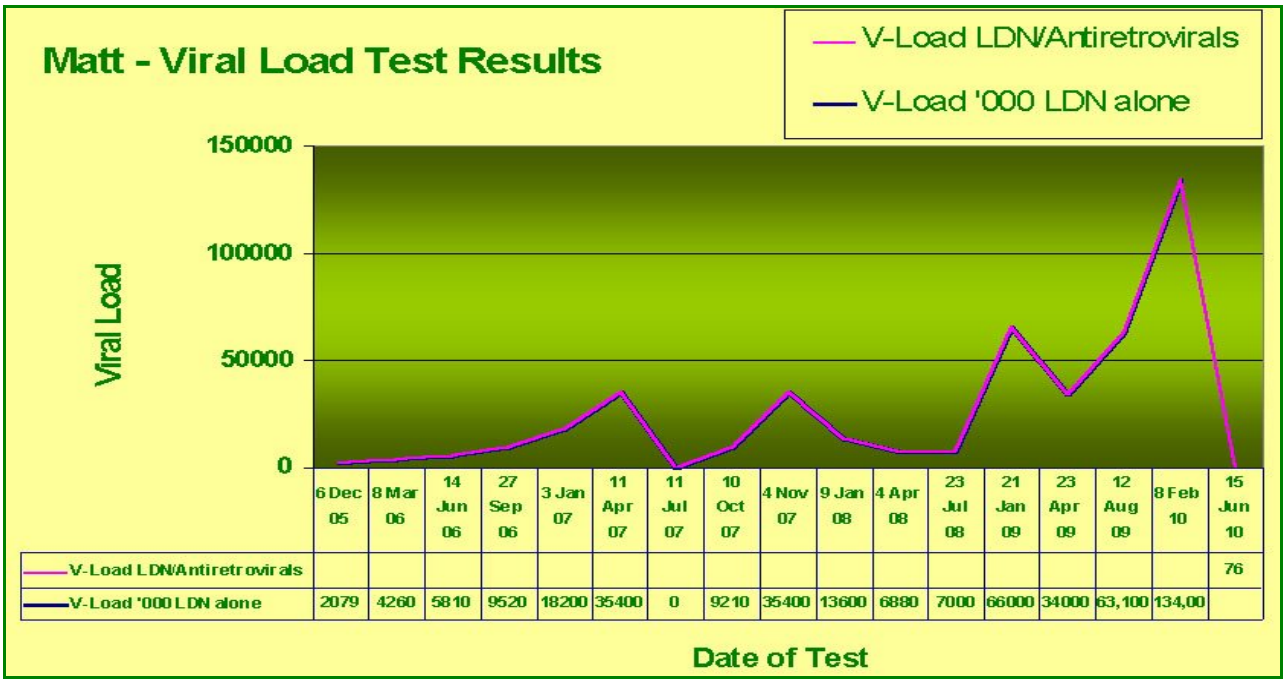
' ... The safety as well as potential efficacy of LDN in preventing AIDS was discovered by Bernard Bihari, M.D., a Harvard-trained New York physician, in 1985. Following, Dr. Bihari treated more than 350 patients, 94% of whom have remained HIV positive without progression into AIDS for up to 18 or more years so far. Many of these individuals received only LDN and some used LDN as an auxiliary to the evolving HAART medications. Of special note, LDN used alone or in conjunction with HAART drugs has been reported by Dr. Bihari to prevent the devastating side effect of the HAART drugs for causing lipodystrophy/lipoatrophy. However, to this date no carefully designed controlled study has been done to prove the efficacy of LDN in HIV positive individuals as a preventative to developing AIDS. ... '

Jaquelyn McCandless, MD, Certified by the American Board of Psychiatry & Neurology, Autism Specialist and Physician Trainer, Author, 'Children with Starving Brains, a Medical Treatment Guide for Autism Spectrum Disorder' and 'Flesh & Spirit, the Mystery of Intimate Relationship' both by Bramble Books.

As at July 2010, Drs Jaquelyn McCandless and Jack Zimmerman (Ojai Foundation Africa Project) have been commuting to Mali, Africa for over 2 years conducting a clinical trial into the effectiveness of LDN for HIV+ in conjunction with investigators at the University Hospital in Bamako.



	6-Dec-05	8-Mar-06	14-Jun-06	27-Sep-06	3-Jan-07	11-Apr-07	11-Jul-07	10-Oct-07	4-Nov-07	9-Jan-08	4-Apr-08	23-Jul-08	21-Jan-09	23-Apr-09	12-Aug-09	8-Feb-10	15-Jun-10
CD4 - LDN/Antiretrovirals																	480
CD4 - LDN alone	500	444	434	640	576	544	414	544	544	544	740	551	544	700	554	540	



	6 Dec 05	8 Mar 06	14 Jun 06	27 Sep 06	3 Jan 07	11 Apr 07	11 Jul 07	10 Oct 07	4 Nov 07	9 Jan 08	4 Apr 08	23 Jul 08	21 Jan 09	23 Apr 09	12 Aug 09	8 Feb 10	15 Jun 10
V-Load LDN/Antiretrovirals																	76
V-Load '000 LDN alone	2079	4260	5810	9520	18200	35400	0	9210	35400	13600	6880	7000	66000	34000	63,100	134,00	

31 HIV-blood & liver enzymes now normal – Noreen

LDN since January 2006
- story submitted 26 October 2007
- story updated July 2008
- story updated March 2009
- story updated April 2010 (over 4yrs on LDN)

SPECIFICS

HEALTH TIMELINE

- mid 70s – I believe I had undiagnosed FM (Fibromyalgia)
- 1975 – Hepatitis (type unknown)
- Dec 1979 - Cancer - abnormal pap smear. Underwent retroperitoneal surgery to biopsy six each lymph nodes. Subsequently had 22 external radiation treatments followed by 2 each radium implants. Cystitis developed due to radiation treatments. Cancer went into remission and has stayed in remission.
- Apr 2002 – left ear buzzing – impaired hearing for one month – prescribed Cipro – immediate allergic reaction – full body rash – ceased Cipro began Keflex for 2 weeks.
- Jul 2002 - initial diarrhea problems. Nurse practitioner attributes this to former radiation treatments. No special tests were run. Treated for herniated disc and pinched nerve in the pain clinic. Underwent one nerve block.
- Dec 2002 - complained to primary care physician of short-term memory loss but no tests were ordered.
- Mar 2003 - developed welts from mosquito bites, heightened emotional state, anxiety, thinning hair - prescribed Prozac and Lorazepam.
- Jul 2003 - short-term memory loss was becoming worse. I also developed GERD (heartburn/reflux) so I was taken off Fossimax, which was attributed to the cause. I had chronic fatigue and started experiencing night sweats.
- Sept/Oct 2003 - nausea, vomiting and diarrhea, which led to accidents. Lack of coordination/concentration, weight-loss, anemia - prescribed iron supplements. Had recurrent cold sores plus treated for vertigo and dizziness with Meclazine.
- Nov 2003 - diagnosed with Epstein Barr Virus, low platelets and other blood abnormalities, advised to see an oncologist as soon as possible.
- Nov 2003 – Due to delay in getting an appt to see the VA Oncologist at the Veterans Administration Hospital (VA), I saw a private Oncologist who recommended a bone biopsy but it was too expensive.
- Nov 2003 - rushed to emergency room because I couldn't breath – breathing was noisy and laboured. Given oxygen, had blood tests, and CAT Scan. Diagnosed with extreme bilateral auxiliary lymphadenopathy.
- Nov 2003 – late November I finally saw the VA Oncologist - I underwent 2 each bone biopsies, which showed severe immune depression. Oncologist also ordered MRI for failing memory and sent me home.
- Dec 2003 – My primary care VA doctor began to take my health more seriously and ordered HIV tests on 3 Dec - two arterial blood gas tests, complete blood count tests and EKG were performed - Tachycardia, high cholesterol, abnormal blood labs. Promethazine prescribed for nausea.
- Dec 2003 – **test results received 18 Dec were positive for HIV** - CD4's at 78, Viral Load over 100K - referred to Infectious Disease Specialist. By now, I had Thrush in my mouth and was placed on Nystatin.
- Dec 2003/January 2004 - Saw alternative doctor - was treated with chelation therapy (Intravenous minerals and hydrogen peroxide) as well as supplements - treatment relieved fatigue somewhat. Experienced heavy labored breathing.
- Jan 2004 – Eight weeks to the day after last doctor visit, saw VA infectious disease specialist on Jan 28 - co-incidentally happened to have MRI same day. Doctors went upstairs and found that I had Progressive Multifocal Leukencephalopathy (PML) or possible HIV Encephalitis. Spinal tap performed this day.
- Jan 2004 – Based on diagnosis of HIV Encephalitis, Infectious Disease Doctor prescribed 3 antiretrovirals and Dapsone. I was given a flu and a pneumonia shot and had an immediate reaction to this and developed cellulitis - so I was placed on a second antibiotic, Keflex. This happened again in Sept 2004 with the same shots. This time the cellulitis lasted for almost a year. Numerous reactions to various drugs was now commonplace.
- Jan 2004 – VA Pharmacist reviewed medications and recommended cessation of Promethazine, suspected of causing my unsteady gait and stumbling - symptom disappeared soon after cessation.
- Feb 2004 - MRI showed two subcentimeter hypodensities within the liver, common bile duct dilated and fatty replaced liver.
- Sept 2007 - Fibromyalgia
- Oct 2007 – Removal of dental fillings and chelation therapy.
- late 2007 to late 2009 – severe back pain and hip bursitis
- Feb 2009 – diagnosed with ADHD

TESTS - HIV
- Jan 2004 – CD4 – 78, Viral Load greater than 100,000
- Oct 2007 – CD4 – mid 80s – Viral Load greater than 100,000
- Dec 2008 - CD4 - 111, Viral Load - 3 million (next test scheduled for 15 Apr 2009)
- Mar 2009 - CD4 – 111, Viral Load - over 3 million
- Mar 2010 – CD4 – 560, Viral Load - 70 (a Lab in Nevada, not my usual lab)

TESTS - OTHER

- Dec 2003 to Jul 2006 - Blood and liver enzymes were tested every 3 months following HIV diagnosis. In July 2006, approximately 6 months after commencing LDN, my blood-work and liver enzymes reverted to normal.

MEDICATION (pre LDN)
- Dec 2003 to Jan 2006 as follows:
Antiretroviral medications, (Efavirenz {non-nucleoside reverse transcriptase inhibitor - NNRTI}, Lamivudine, Tenofovir Disoproxil Fumarate). I later had three more sets of antiretroviral medications, plus Cipro, Dapsone, Keflex, Prozac, Acetaminophen, Loratadine, Omeprazol, Valacyclovir Hydrochloride, Rabeprazole, Metoclopramide, Salsalate, Meclizine, Lorazepam, Oxybutynin Chloride, Tolterodine Tartrate, Nystatin, Hydrocodone 5, Promethazine, Tylenol, Voltaren, Protonix, Nexium, Alendronate, Ranitidine, Tramadol, Flunisolide (corticosteroid), Raloxifene and Chlorpheniramine Maleate.

SUPPLEMENTS (pre LDN)
- Dec 2003 to Jan 2006 as follows:
After being diagnosed HIV+, numerous patient-researched patient-prescribed supplements were taken including; colloidal silver, aloe vera, cat's claw, cayenne, elderberry, lemon balm, milk thistle, neem extract, Pau D'Arco extract, turmeric, olive leaf, shark cartilage, antler velvet, omega 3-6-9, IP6 and Inositol, coconut oil, cod liver oil, acidophilus, rPriflavone, transfactor, DHEA, lecithin, grape seed extract, pycnogenol, alpha lipoic acid, ellagic acid, chlorella, lycopene, beta-glucans, coenzyme Q10, bee products, thymus supplements, colloidal minerals, B complex vitamins, calcium, magnesium, Vitamin C, Vitamin E, zinc, selenium, amino acids, digestive enzymes, Essiac, oil of oregano, N-Acetyl Cysteine (Nac), enzyme Superoxide Dismutase (SOD), Dimethylglycine amino acid (DMG), noni juice, Immune-Assist 247, Agaricus Blazei mushroom (AbM) Extract, Revivo herbal tea, and Greens First (phytochemicals/antioxidant).

MEDICATION (post LDN) - PAST
- late 2007 to early 2008 – steroid injections, approx every 4 months administered by an anaesthesiologist (for back pain).
- late 2008 to late 2009 – Prednisone 20mg initially, then tapered down gradually to 5mg before ceasing (prescribed by Osteopath).
- early 2008 to early 2008 – steroid injections (for bursitis in right hip).
- Feb 2009 to Feb 2010 - Adderal (Amphetamine/dextroaphet)

MEDICATION (post LDN) - CURRENT
- Jan 2006 to present 4.5mg Low Dose Naltrexone (LDN)
- Oct 2009 to present - Atripla 1100mg x 1 per day {a combo med containing: 600mg efavirenz (Sustiva), 200mg emtricitabine (Emtriva), and 300mg tenofovir (Viread).}
- 24 Feb 2010 to present - Biestrogen Vanicream 1mg/gm (Bio-identical estrogen) x 1 pump full per day
- 24 Feb 2010 to present - progesterine x 2 pea size amounts per day

LDN DOSE & TYPE
a) Dose – 4.5mg compounded capsules (commenced and stayed on 4.5mg)
b) Time - At bedtime (usually between 10 pm and 2 am)
c) Capsule Filler - avicel (non-time-release formula from Skip's Pharmacy)

DIET
- low fat, low sugar, no junk food

SUPPLEMENTS (post LDN)
- Oct 2007 – I was taking the following:
multiple vitamin
liquid minerals
omega 3
anti-oxidants
Vitamin D x 3,000 units
selenium plus 10 brazil nuts (equiv 1000 units selenium)
3000mg x Vit C
Vit E x 265 mg (400iu) - taken once per day
- May 2008 – I added the following:
Liquid Life (multi vit, min, anti-oxidant prep) x 30ml - as per label
- March 2009 – This is my new complete list of supplements:
Liquid Life (multi vit, min, anti-oxidant prep) x 30ml - as per label
direction
Flaxseed oil x 1000mg capsule - taken once per day
Selenium - trace mineral - taken as 10 Brazil nuts
(NB Brazil nuts contain 544 micrograms of selenium per ounce = approx 6-8 nuts)
Vit C x 3000mg (taken as 1000mg x 3 times per day)
Vit E x 265 mg (400iu) - taken once per day
(NB Liquid Life contains Vit C x 500mg, Vit E x 60 iu, per serving)
- 24 Feb 2010 – the following was added:
Digestive enzymes

EXERCISE
– walking

MY STORY – October 2007

In 1975, I had hepatitis (type unknown, but I suspect Hep B) due to working in the dental field at a time when protective measures were not in place. I was in hospital under observation for a week and convalesced for another 3 weeks. I was diagnosed with cancer and had cancer treatment in December of 1979. Cystitis developed due to the radiation treatments.

Around April 2002, my left ear was buzzing and I could not hear much in that ear for one month. I was placed on the antibiotic Cipro and had an immediate reaction to it. It looked like I had the measles from head to toe, so this was changed to Keflex for two weeks.

In July 2002 I was diagnosed with a herniated disc and pinched nerves. This story relates to a period of deteriorating health, which went downhill fast, beginning in March 2003.

2003 started off as an unusually warm spring. I was enjoying life and by the end of March, I had a beautiful tan from working outdoors in my garden.

Around this time, I noticed unusually large welts, the size of a silver dollar from mosquito bites. I also began to notice that my hair was thinning for no apparent reason and I began to have short emotional outbursts. I had sought help earlier for this, so my dosage of Prozac was increased and I was also prescribed anti-anxiety medication.

By mid-summer (around July of 2003), I was experiencing worse, short-term memory loss. My long-term memory was fine. I could remember something from twenty years ago but couldn't remember something from 2 weeks ago. I'd make a mental list of groceries I needed but when it was time to go to the store, I couldn't remember anything on the list. At that time, I did not know that I had HIV Encephalitis, which would have explained my short-term memory loss.

My increasingly unreliable memory gave me rare insight and appreciation for what Alzheimer's sufferers must experience. I also started to experience (GERD). I experienced all of the above symptoms every day, as well as chronic fatigue - which I didn't think too much of at the time because I couldn't remember a time when I wasn't extremely fatigued.

By September 2003 however, things took a turn for the worse. I started to have nausea, vomiting, diarrhea and accidents in the house and in public. I lost ten pounds and I spent most of the day on the couch. I didn't have any energy nor did I feel like doing much. My health continued to deteriorate. I was worn out and wanted desperately to improve my health so I saw over ten doctors and every one of those ten doctors sent me for further blood tests. I was diagnosed with anemia and was given iron pills but I continued to go downhill.

In November 2003 my current doctor ran more tests for antibodies to Hep C, diagnosed Epstein Barr Virus, and prescribed Promethazine for my nausea, but nothing improved my health and my blood work was still really abnormal. I was told to see an oncologist as soon as possible.

Later that month the VA oncologist gave me a bone biopsy test. For those who are not familiar with this painful procedure, I'll explain: The patient is placed on one's back and is given an anaesthetic at the biopsy site. Next, a very long tool is literally screwed through the skin into actual bone.

The biopsy specimen was inadequate so the oncologist asked if I wanted to come back for another test. I said no way, to go ahead and get it over with. So he proceeded to take another sample in a different location. Being a cancer survivor, I've had many tests, procedures, surgery and radiation treatments but this particular procedure was the worst that I've ever experienced. The biopsy showed severe immune depression. Finally, the doctor gave me an HIV Antibody Test, which came back positive on 18 Dec 2003.

At this point in time, I was relieved because I just wanted to know what was wrong with me and why I was dying.

To add insult to injury, the oncologist who diagnosed my HIV sent me home with only a referral to the Infectious Disease Specialist. I wasn't given any information or told of any treatment options and I couldn't get in to see the referred specialist for 2 months. I'd just been diagnosed HIV positive and actually had full-

blown AIDS. For two months I had no doctor, no treatment options, and no support from mainstream medicine. I'd developed a new symptom – unsteady gait – and I was alone and felt abandoned by the system.

However, having beaten one incurable disease, I was determined to beat another so I searched deep down for some inner strength and resolved to do something positive and constructive. I made inquiries at my local health store. The owner recommended that I see an alternative doctor and I did. The alternative doctor gave me some supplements and treated me with 8 consecutive intravenous chelation treatments (minerals and hydrogen peroxide). These treatments helped my quality of life tremendously. On therapy day, I could actually get off the couch and move around a bit.

By the time I reached the infectious disease specialist in January 2004, I was half-dead with CD4's at 78 and viral load greater than 100,000. The doctors were considering PML or HIV Encephalitis. (PML can be fatal within a short period of time as one gets better or dies.) The radiologist at VA Hospital stated that it favored this, however HIV encephalitis could show similar results. They really didn't know what I had but that I had abnormal grey matter in my brain. Doctors determined I had Progressive Multifocal Leukencephalopathy (PML). A spinal tap was performed the same day.

I was immediately placed on antiretroviral medications and Dapsone. I was given flu and pneumonia vaccinations and had immediate adverse reactions. I developed cellulitis and was placed on a second antibiotic, Keflex for 2 weeks.

Around this time the pharmacist from the infectious disease visit reviewed my meds and unbeknown to me, the drug promethazine (prescribed Dec 2003 for nausea) had been causing my unsteady gait and stumbling. I stopped this medication and the problem resolved. (The V.A. is a training facility and I had the head doctor, a resident and a pharmacist as my infectious disease team.)

Frustratingly, the medications caused many of the symptoms I'd had in the first place such as, anemia, abnormal blood work and diarrhea. Because these medicines are linked to heart, liver, kidney failure, neuropathy and disfigurement, I was very concerned.

During all of this, I continued to research, read and learn. I wanted to understand what was happening to me and I wanted to learn as much as I could about my treatment options.

In early 2005, I stumbled upon information about an obscure treatment called Low Dose Naltrexone (LDN). There's so much information about treatment options on the Internet - so this too sounded too good to be true. I always believed in natural treatment methods and had an open mind to new treatment methods, so I researched more and read as much as I could find before taking my info with me to discuss with my infectious disease doctors.

My two infectious disease doctors and my local pharmacist were not familiar with this drug. I usually bombarded them with information about supplements and treatment methods from the Internet. However, they were not familiar with this drug and weren't interested at all. So I pressed on.

Around a year later and after having forgotten about LDN, I saw an environmental physician and in the course of the medical history, he stated that he thought I should go on LDN. Wow, was I surprised and happy!

He prescribed LDN at the end of January 2006 and I immediately ordered it from Skip's Pharmacy. After reading about LDN on the lowdosenaltrexone.org website and learning about the great successes with this drug, on 1 Mar 2006 I stepped out in faith and stopped all other medicines and was only taking the LDN, much to the dismay of my doctors and my husband.

After much reading and soul-searching, I decided that this was my life and I had to do what I felt was the right thing to do, no matter who supported me or not. I did so well on the LDN that my husband has since changed his mind and my infectious disease doctors still follow me in amazement.

Finally, in September 2007, I was diagnosed with fibromyalgia, although I feel I'd had it since the 1970's.

It is now October 2007 and I have been on LDN for a total of 21 months. My blood and liver enzymes have been tested every 3 months since being diagnosed with AIDS. Approximately 6 months after being on LDN, my blood-work and liver enzymes reverted to normal and have been so ever since. I am no longer anemic -

something too that never occurred while on the antiretroviral medications. I still have heavy metals, mercury and lead in my body so my dental fillings are being replaced and chelation therapy is underway and being supervised by my environmental physician.

Although my viral load is greater than 100,000 and CD4s stay in the mid eighties, I haven't had one opportunistic infection (OI) or even a cold while on LDN. OI is what kills AIDS patients due to the weakened immune system. The LDN is definitely helping to keep the opportunistic infections at bay and maintaining my health along with good health habits. My quality of life is so much better now. I was couch-bound, sick and dying and now I can reach for the stars!

When I reflect on my sickest days, two occasions stand out: On one particular day I knew I couldn't get any sicker and I was certain I was going to die yet, I wasn't scared and it was the most peaceful day of my life. The other occasion was on a trip to the lab at the VA. I was extremely weak, exhausted mentally and physically. There was always a line outside the blood drawing room yet few seats, so I slumped on the floor and waited my turn.

After all I'd been through, I no longer feared death and saw it merely as a natural, peaceful progression. The best way to describe it as I did in my book, is it was like the Sago coal miners who left notes when they knew they were going to die: When they realized death was imminent there was no fear, only acceptance and peace.

So much, I have placed behind me, all of the sicknesses, terrible health and lack of proper medical care. After researching my records, I also learned that I had been anemic for three consecutive years and I was not told about this. I think my health deteriorated because things that were obvious were not looked into or treated. I now only think of the future and how lucky I am to be alive!

The VA doctors know that I'm doing great and I believe they're really curious about how I'm doing this. I tell them it's the LDN, you see; my blood reports and liver enzymes are now normal and I'm no longer anemic, something that never occurred while on their toxic medications.

And here's something else that's interesting: … In 2002 I was negative for hepatitis (test done by primary care physician at the VA). Then I was told in Dec 2003 that I had antibodies to Hep C, then later didn't have it, and finally my primary care doctor said I did. I was retested in 2005 and again told I had antibodies to Hep C. In October 2007 I was tested for antibodies to Hep B and Hep C (non VA facility) and guess what, it did not show antibodies to either. I've lost all faith in these medical tests.

For me, LDN has been a miracle drug and I know that it is also working for others and saving so many lives! My sincere thanks go to Dr. Zagon and Dr. Bihari and of course to all those who continue to spread the word because they've brought this miracle drug to us.

UPDATE: July 2008

LDN is truly a miracle drug, which has been my lifesaver. Because of LDN, I do not have to take the antiretroviral medications that have so many nasty, side effects. LDN's time has come and now it is getting the proper recognition that it deserves. One who says that it cannot be done should not stand in the way of one who is doing it!

UPDATE: March 2009

Things are about the same with me except my CD4's are 111 and my viral load is over 3 million. Not good by the mainstream's standards but I do not listen to them and continue on with LDN!

UPDATE: April 2010 (over 4yrs on LDN)

I've had back problems for the past 8 years or so; herniated disc, pinched nerve, stenosis, osteoporosis, and curved spine. Due to back problems, in late 2007 and in 2008, I had numerous steroid injections where the anaesthesiologist weaved long needles into my back approximately every 4 months. I also had several shot type injections (steroids) for bursitis in right hip in 2008. During this period, the arthritis doctor had me on prednisone in varying doses from 5mg to 20mg, but then I was slowly weaned off the steroids.

In 2008, I received a formal diagnosis of ADHD and was prescribed the generic of Adderal, which seemed to help. I have since stopped the med (in the fall of last year) due to other health issues, however; have found

since starting Atripla in late 2009 that I don't seem to need it. My philosophy has always been, if it works then use it!

Then in late 2008 and all of most of 2009, my fibromyalgia and chronic fatigue symptoms came back. My arthritis doctor placed me on steroids, various amounts, which helped with both diseases. I felt great but did gain over 20 pounds.

Nevertheless, steroids are not a viable, long-term solution, so I was slowly weaned off them. However, all my painful symptoms returned and I found myself back on the couch and unable to function in life.

During this time, late fall of 2009, I developed new symptoms in my right leg and foot. They were reddish purple, swollen, and very painful. This lasted 4 months and I saw numerous physicians, who were clueless. My infectious doctor finally admitted me to the hospital and numerous tests were undertaken. It was finally determined that I had lymphedema, which was probably related to past damage from radiation treatments and to the loss of lymph nodes for biopsy on that side of my body.

During all of this, I was extremely tired and again my doctor prescribed an antiretroviral: HIV drugs are collectively called 'Highly Active Antiretroviral Therapy (HAART)', and there are numerous drugs within that category. I was prescribed a combination drug called Atripla. Within a very short time, all my symptoms from chronic fatigue and fibromyalgia ceased. I was perplexed to say the least, but it was working for me, and currently; I am symptom free from chronic fatigue and fibromyalgia.

I could not take normal estrogens, so I was prescribed Biestrogen on 24 Feb 2010, and it works great, and I was prescribed Progesterine at the same time.

I've done a lot of research over the years, and read of a connection between AIDS and the HHV6 virus, so I tested for it and was negative for it. I also read about an enzyme in the body called RNase-L and research indicated that when this enzyme is depleted (has half the proper molecular weight), that the body is more susceptible to developing viral illnesses.

Following on from that, I read that a new retrovirus had been identified in Chronic Fatigue patients, XMRV, and that this recently identified retrovirus was believed to be associated with numerous immune system diseases such as Fibromyalgia. The treatment for retroviruses is antiretrovirals so it makes sense to me why my chronic fatigue and fibromyalgia symptoms go away when I go back on the HAART medications.

So now I am in the process of being tested for XMRV, RNase-L Dysfunction, and for mycoplasma by a lab in Reno, Nevada. I will have to come off my medications for 3 weeks but to me it is certainly worth it to maybe, finally, get some answers to a life-time of immune problems, so on 8 April I stopped taking Atripla, estrogen, progesterine, and LDN and will recommence in 3 weeks on 29 April 2010.

I'm seeing a chiropractor for my back issues and that's helping tremendously, thus avoiding long-term use of medicines such as Advil and also the steroid injections way up in my back by the anaesthesiologist.

I would like to add that LDN has kept other immune diseases away from me and it would be highly unlikely that it can cure everything. Nevertheless, I would never stop taking it. I have seen what it has done in my life, my family, and for others! In my opinion, Dr. Zagon should be nominated for a Nobel Prize!

For me, at present, life is great! I continue taking LDN, as I believe that it is keeping opportunistic problems away!

Noreen, USA

Noreen, USA

"I'd just been diagnosed HIV positive and actually had full-blown AIDS. For two months I had no doctor, no treatment options, and no support from mainstream medicine. I'd developed a new symptom – unsteady gait – and I was alone and felt abandoned by the system." Oct '07

'Noreen Martin Speaks'

Noreen Martin, Author, 'Surviving Aids & Cancer'

http://www.youtube.com/watch?v=_Nh-t3LA6e4

32 LDN benefiting daughter's HepB – Joyce C

- LDN since July 2007
- story submitted February 2008
- story updated July 2008
- story updated June 2009
- story updated May 2010 (almost 3yrs on LDN)

SPECIFICS

DIAGNOSIS
- 2001 - Hepatitis B (My daughter was adopted from China. It is presumed her mother had Hepatitis B and passed it to my daughter during birth.)
- 2001 - Food Allergies, Eczema - Severe
- 2005 - Food Allergies, Eczema - Mild (Food allergies and eczema improved considerably after starting Antioxidants, Liquid Vitamins/Minerals, Probiotics, and Herbal treatments.)
- 2007 - Food Allergies, Eczema, Hepatitis - continue to improve
- Jul 2008 - Eczema - totally healed
- Jul 2008 - Food Allergies - able to eat almost all food that she was previously allergic too
- Jul 2008 - Hepatitis B - Sero-converted the 'e' Antigen (HBeAG) and gained the 'e' Antibody (HBeAB).

MEDICATION/TREATMENT (OTHER)
- Aug 2006 to May 2009 - rotations of Milk Thistle, and traditional Chinese Medicines (Schizandra, Liquorice Root, Cordyceps, or Astragalus)

MEDICATION (LDN)
- Jul 2007 - Nov 2007 - 1mg Low Dose Naltrexone (LDN) nightly, at bedtime
- Nov 2007 to Jul 16 2008 - 1.5mg Low Dose Naltrexone (LDN) nightly, at bedtime
- Jul 17 2008 to present - 3.0 mg Low Dose Naltrexone (LDN) nightly, at bedtime
- May 2010 to present – 4.5mg Low Dose Naltrexone (LDN) nightly, at bedtime

LDN - DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone – from May 2010
b) Time - I give my daughter her LDN at bedtime each night, around 9 pm.
(LDN should be taken right before going to sleep to enhance its effectiveness.)
c) Type - Capsules are compounded with pure Naltrexone powder and Avicel filler (compounded by Skip's Pharmacy, Boca Raton, Florida, USA).

MEDICAL TESTS & LAB RESULTS TIMELINE

Oct 1, 2004
- ALT/AST 34/39
- HBV DNA, BLD, QL, PCR - 317,000,000/mL (Ref Range<100)*
- Virus DNA, SER, QN - 1,503,400,000 (Ref Range <160)*
- HBeAG - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBeAB (Antibody) -Non Reactive
- HBsAB - Negative

Sept 15, 2005
- ALT/AST 53/51
- HBV DNA (PCR) - not taken

(*Note: My daughter started Liquid Vitamins/Minerals, Essential Fatty Acids, and Probiotics in Summer 2005 to help food allergies and eczema. We added more Antioxidants and Traditional Chinese Medicine/Herbs to our daughter's supplements in Summer 2006. See above schedule of supplements. Adding these supplements may have boosted my daughter's immune system in order to move from the 'Immune Tolerant' stage to the 'Immune Clearance' Stage where her body started to fight the virus. This is normally evidenced by the increasing ALT/AST liver tests, which happened between 15th Sept 2005 and 11th May 2007.)

Dec 21, 2006
- ALT/AST 136/103*
- HBV DNA, BLD, QL, PCR - 26,500,000 (26.5 Million) (Ref Range <100)*
- Virus DNA, SER, QN - 104,700,000 (Ref Range <160)

Feb 7, 2007
- ALT/AST 124/89*
- HBV DNA, BLD, QL, PCR - 59,200,000 (59.2 Million) (Ref Range <100)*
- Virus DNA, SER, QN - 248,100,000 (Ref Range <160)

© Case Health Pty Ltd

April 23, 2007
- Liver Biopsy (Prior to initiating LDN treatment)
The Grade/Scale is based on 0-4 (0 being none and 4 being worst)
- Scarring: 2
- Inflammation: 2

May 11, 2007
- ALT/AST 196/203*
- HBV DNA (PCR) - not taken

NB July 2007: Low Dose Naltrexone Treatment began mid-July 2007 at 1.0 mg per day.

Aug 10, 2007
- ALT/AST 26/38
- HBV DNA (PCR) - not taken
*Note: After introducing supplementation my daughter's ALT/AST levels started to increase in 2006 (which indicated she'd entered the 'Immune Clearance' stage, or in other words, my daughter's own immune system had begun to recognize the virus and her body had responded by trying to fight the virus). After adding the Low Dose Naltrexone to further help her immune system fight the virus, we saw a dramatic decrease in her liver enzymes and viral load. The doctor's couldn't believe how good the results were, and ordered more tests. Her liver enzymes had returned to the normal range and were the lowest ALT/AST results we'd seen since her diagnosis in 2001.

Aug 17, 2007
- ALT/AST 29/39
- HBV DNA, BLD, QL, PCR - 53,300 (Ref Range <100)*
- Virus DNA, SER, QN - 133,225 (Ref Range <160)*
(*Note: over 99.9% decrease in viral load compared to Feb 2007.)

Sept 21, 2007
- ALT/AST 25/36
- HBV DNA, BLD, QL, PCR - 29,000 (Ref Range <100)*
- Virus DNA, SER, QN - 69,307 (Ref Range <160)*
- HBeAG - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBeAB (Antibody) -Non Reactive
- HBsAB - Negative

Nov 15, 2007
- ALT/AST 22/31
- HBV DNA, BLD, QL, PCR - 170,000 (Ref Range <100)*
- Virus DNA, SER, QN - 462,842 (Ref Range <160)*
- HBeAG - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBeAB (Antibody) -Non Reactive
- HBsAB - Negative
*Note: Between Sept 21, 2007 and Nov 15, 2007 lab results we stopped some of the Antioxidants we were previously using for food allergies and eczema (since those conditions had improved significantly). Because we felt this change may have accounted for the slight increase in Viral Load in Nov 2007 we resumed all supplements and increased the dosage of LDN to 1.5mg nightly.

Feb 8, 2008
- ALT/AST 20/29
- HBV DNA, BLD, QL, PCR - 000,000 Undetectable <100 (Ref Range <100)
- Virus DNA, SER, QN - 000,000 Undetectable <160 (Ref Range <160)
- HBeAG - Negative (Non-Reactive)*
- HBeAB (Antibody) - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBsAB - Negative
*Note: The above protocol of LDN, antioxidants, and various rotations of Traditional Chinese Medicines proved successful in my daughter's 8th Feb 2008 sero-conversion from HBeAG (e Antigen positive) to HBeAG (e Antigen negative). She also gained the HBeAB (e Antibody positive). These same treatment outcome results only happen in approximately 30% of children on Interferon treatments, so the above treatment may possibly compete with Interferon!

July 11, 2008
- ALT/AST 21/31
- HBV DNA, BLD, QL, PCR - 000,551 (Ref Range <100)*
- Virus DNA, SER, QN - 000,983 (Ref Range <160)*
- HBeAG - Negative (Non-Reactive) **Sero-conversion Maintained!!**
- HBeAB (Antibody) - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBsAB - Negative
*Note: Viral Load has very slightly increased from the undetectable range on 2/8/2008. to 551 on 7/11/2008. While

my daughter has done extremely well on the dosage of 1.5 mg at night-time, we are going to increase to the dosage to 3.0 mg a night effective 17 Jul 2008. The 3.0 mg dosage is believed to be the optimal dosage for children. (Note the optimal dosage for adults is 4.5 mg/night).

**Note: We will continue with the above same protocol hoping to also obtain the HBsAG (surface Antigen sero-conversion to HBsAB). While it is very rare (approximately only 5% of Hepatitis B carriers sero-convert to HBsAB), I believe that it can happen. It may take a few years to get there, but I believe in miracles!

8th May 2009
- ALT/AST 34/38
- HBV DNA, BLD, QL, PCR - 000,000 (Ref Range <100)* - Unit Not Reported
- Virus DNA, SER, QN - 000,000 (Ref Range <160)* - Unit Not Reported
- HBeAG - Negative (Non-Reactive) **Seroconversion Maintained!!**
- HBeAB (Antibody) - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBsAB - Negative
- Vitamin D - Hydroxy 25 - 20 ng/ml (20 ng is below the optimal range of approximately 50-80 ng per the Vitamin D Council (vitamindcouncil.org). We will begin to supplement with Vitamin D to reach the optimal range.
- ALPHA 1 FETOPROTEIN - 1.66 (normal range)

*Viral Load has again gone into the undetectable range.

**We will continue with the above same protocol hoping to also obtain the HbsAG (surface Antigen seroconversion to HBsAB). While it is very rare (approximately only 5% of Hepatitis B carriers seroconvert to HBsAB), I believe that it can happen. It may take a few years to get there, but I believe in miracles!*

6th May 2010
- ALT/AST 22/29
- HBV DNA, BLD, QL, PCR - 000,061 (Ref Range <100)
- Virus DNA, SER, QN - 000,355
- HBeAG - Negative (Non-Reactive) ****Seroconversion Maintained!!****
- HBeAB (Antibody) - Positive (Reactive)
- HBsAG - Positive (Reactive)
- HBsAB - Negative

Vitamin D - Hydroxy 25 -- 44 ng/ml (20 ng is below the optimal range of approximately 50-80 ng per the Vitamin D Council (vitamindcouncil.org). We will continue to supplement with Vitamin D to reach the optimal range.)
ALPHA 1 FETOPROTEIN - 1.01 (normal range)

SUPPLEMENTS - PAST
- Aug 2006 to Aug 2008 - L-Glutamine (precursor to Glutathione)
- Jul 2005 to May 2009 - Hemp or Fish Oil (Essential Fatty acids (EFAs) - Omega 3,6,9)
- Jul 2005 to May 2009 - Probiotics
- Aug 2006 to May 2009 - B12
- Aug 2006 to May 2009 - Alpha Lipoic Acid
- Aug 2006 to May 2009 - N-acetyl-cysteine (NAC) (precursor to Glutathione)
- Aug 2006 to May 2009 - Selenium
- Aug 2006 to May 2009 - rotations of Milk Thistle, and traditional Chinese Medicines (Schizandra, Liquorice Root, Cordyceps, or Astragalus)

NB: Apart from a short two-month break between Sept 21 and Nov 15, 2007, we consistently supplemented with most of the above daily during those periods.

SUPPLEMENTS - PRESENT
- Jul 2005 to present - NSI Synergy Once Daily Multi-Vitamin Version 3 (liquid Vitamins/Minerals - includes Vitamin A, B, C, D, & E, Zinc, Selenium, Alpha Lipoic Acid, and other antioxidants)
- May 2009 to present - Vitamin D3 x 2,000iu per day on average (supplement Fall, Winter, Spring). Summer time my daughter wears no sunscreen and gets Vitamin D via sunshine.

DIET
- to Jul 2008 - very restricted due to food allergies to diary, corn, soy, nuts, egg, wheat, and other fruits and vegetables
- from Jul 2008 - Daughter's food allergies have improved dramatically. She can now eat most of the foods she used to be allergic to.

ACTIVITIES & EXERCISE
- n/a

MY STORY - July 2008

I'd been waiting for years to become a mother. When I learned that within a few months I'd be flying on a plane to Asia and would finally be united with my new, wonderful 11 month old daughter, I lay awake at 3 o'clock in the morning excited about what the future held, and thinking about how to decorate my future daughter's bedroom. I wanted her to be surrounded with a special room in her new home-to-be, constantly

reminded that she is loved and a precious gift from God. I remembered a picture I had just purchased with 3 Angels dancing and rejoicing with the inscription 'The Angels Danced the Day You were Born'.

That message became the inspiration for her bedroom. I wanted to write those powerful words into the wet paint on the walls of her room - symbolic of drawing those meaningful words into the fresh canvas of her heart and life. However, I had never tried cursive writing in wet paint before and did not know if it would succeed. But what did I have to lose, and it could actually work - so why not at least try it and see the results? Well, I tried it and it worked beautifully! My experience with hand painting my daughter's room is something similar to my experience with Low Dose Naltrexone (LDN), as I will share in our story of great 'Grace & Hope'.

After arriving home, my daughter Grace (not her 'real' name), underwent normal adoption blood work to check for HIV/AIDS, Hepatitis, parasites, etc. The doctor called back a few days later and asked me to sit down because she had some news to share on Grace's lab results. She had tested positive for Hepatitis B (Chronic Active). How could that be, I wondered? She had been tested for Hepatitis in the orphanage and had a clean health record. After the initial shock, I realized that she was truly a gift and we would face this disease with hope and prayers for a healing miracle.

While Grace's Hepatitis B had very little impact initially in our lives (besides routine lab results), Grace's food allergies and eczema continued to spiral downwards. From 2002 onwards, she'd developed a new food allergy every few months - and feeding her became very challenging. She became allergic to all diary, corn, soy, nuts, egg, wheat, and other fruits and vegetables. Additionally, her eczema was so severe that her skin was constantly raw and red. In 2005, I became desperate.

The conventional treatments offered by her Pediatrician, Allergist, and Dermatologist had not delivered improvement, so I started to investigate and use Complimentary and Alternative Medicine (CAM) protocols to see if we could heal the underlying causes of the food allergies and eczema. Based on my research and additional consultations with a Functional Medicine practitioner, we concurred with adding Antioxidants, Probiotics, Essential Fatty Acids (EFA's), and liquid vitamins/minerals to her diet. (Note: Functional Medicine uses both Conventional & CAM approaches to holistically treat patients - (www.functionalmedicine.org).

These combined efforts finally started to improve my daughter's food allergies and eczema, but we also saw another benefit. Her immune system started to recognize and fight the Hepatitis B virus.

In children, due to their immature immune system, the body is often not able to mount a successful attack to totally eliminate the Hepatitis B virus. When the body's own immune system starts to fight the virus, very often the liver enzyme levels (the ALT and AST particularly) begin to rise. This is known as the 'Immune Clearance' Stage because the body's immune system is trying to 'clear' the virus.

If the liver enzymes are raised for an ongoing period of time, it can damage the liver with inflammation and scarring. It's a paradox that the good the body is doing while fighting the virus is also damaging the liver.

My daughter's liver enzymes and viral load started going up in 2006, and her liver biopsy result in Spring 2007 rated both her 'Inflammation' and 'Scarring' scores at 2 (mid-range in the scale 0-4). Her Gastroenterologist wanted to begin either Interferon treatments, or enrol her in a Pediatric Anti-Viral drug trial for a new drug, Entecavir, that was commencing within 6 months. Her doctor contacted Johns Hopkins (Baltimore, Maryland, USA) and together we determined my daughter would be a good candidate for the upcoming Entecavir Pediatric drug trial that was starting in the near future.

While waiting for the Entecavir drug trial to start I went back to the medical professional who had helped us so much over the past two years with Grace's food allergies and eczema (the Functional Medicine practitioner). She was excited about my daughter getting into the Entecavir drug trial, but when I asked her if she could think of anything that might help boost Grace's immune system prior to the trial, she mentioned 'Low Dose Naltrexone' (LDN). She'd recommended LDN for other medical conditions where the immune system needed further stimulation, with success, so she proposed LDN as a possible solution. She said I should research LDN at http://www.ldninfo.org, to see if it was something we wanted to try, and left the decision to me.

For approximately 2-3 weeks, I poured over the ldninfo.org website, which had a wealth of information. LDN had been used by many patients with various conditions; Cancers, Autoimmune Diseases, and HIV/AIDS. All the info indicated it helped the immune system function properly (which is exactly what I was looking for to combat the Hepatitis B virus).

The website briefly mentioned that LDN had been successfully used in Hepatitis C patients. I also reviewed other medical research, including the National Institutes of Health (NIH) PubMed website, into the growing area of research into how opioids and opioid antagonists can positively or negatively affect the immune system (depending upon how they are used and dosage levels). I've included some of those NIH/PubMed studies at the bottom of this story as a reference, particularly those relating to the liver and Naltrexone.

One concern I had was the 'black box liver warning' for Naltrexone. I did further research into the liver warning and found the warning was based on very high doses of Naltrexone, at 300mg per day, where some liver anomalies had occurred in obese patients.

Dr Jaquelyn McCandless and other doctors had been safely administering minuscule doses of between 1mg and 3mg per day (a tiny fraction of the maximum safe dosage) to treat children with Autism. We rationalized that since LDN had been so helpful for other immune related illnesses, and the side affects were minimal (transitory sleep disturbance when starting LDN being the main side affect), and it was so inexpensive (less than a $1 per day), that we'd like to try it. I grew eager to start LDN before the Entecavir study (to see if maybe the two together would help her).

What did we have to lose in comparison to what we might gain? But, before we started LDN, I wanted to ensure being on LDN would not preclude Grace from getting into the Entecavir Study at Johns Hopkins (because back then, we had no idea how good LDN would actually prove to be).

I spoke with our Pediatric Gastroenterologist in June 2007 to check he was okay with us trying LDN (especially as he was not the prescribing LDN doctor) and to make sure he was aware of our attempt to prime my daughter's immune system with LDN before the trial. While he didn't know if LDN would do any good, he didn't think it could do any harm, since he had other liver patients on a higher dose of Naltrexone for pruritus (severe itching caused by other liver conditions). To maintain eligibility for the trial, we agreed we'd stop the LDN once the Entecavir study actually began. I also consulted my daughter's Pediatrician to ensure she was also aware of our plans. Both doctors concurred with us trying LDN.

In July 2007 we started my daughter on a very minimal dose of 1mg Low Dose Naltrexone (LDN). Within one month of starting LDN, in August 2007, we had liver laboratory tests completed to see if LDN was having a positive result, and it was. The doctors couldn't believe how good the results were, and ordered more tests to confirm. We were all amazed at the dramatic improvement in her liver since starting LDN in July 2007. We saw a remarkable decrease in liver enzymes, from ALT 196/AST 203 in May 2007 to the normal range of ALT 26/AST 38 in August 2007. Her liver enzymes were the lowest ALT/AST results we'd seen since her diagnosis in 2001.

Additionally, we saw a significant viral load reduction from 59.2 million in February 2007, to 53.3 thousand in August 2007. At that point we no longer even qualified for the Entecavir study - yippee! The Advanced Practice Pediatric Nurse who prescribed the LDN was ecstatic with the results. Incidentally, I called my daughter's Pediatric Gastroenterologist when we got her lab results in mid-August 07. I said to the doctor, "Isn't this good news"... He responded..."No ... this is GREAT news!" We discussed that LDN appears to be resulting in similar responses as can be achieved with other anti-viral drugs.

The doctor said he had one teenager on Entecavir and this patient also saw dramatic results within the first month (similar to my daughter's impressive viral load decrease). However, the advantage of LDN was that since it wasn't an anti-viral Hepatitis B drug, but instead helped her own immune system to fight the virus, we didn't have to worry about the anti-viral resistance that can be a problem with other anti-viral drugs.

Also, if at any point the LDN stopped working in the future, we always had the option of starting anti-viral drugs (without the worry of her already building up Anti-viral drug resistance). The Gastro doctor was not the prescribing doctor of the LDN, but he said to keep on doing what we were doing because it appeared to be working!

Between the Sept 21, 2007 and Nov 15, 2007 lab results we'd stopped giving Grace some of the antioxidants we were previously using for food allergies and eczema (since those conditions had improved significantly). Because we felt this change may have accounted for the slight increase in Viral Load in Nov 2007, we resumed all supplements, and increased the LDN dose to 1.5 mg nightly.

In February 2008, 7 months into our LDN/Antioxidant protocol, Grace had Sero-converted, going from HBeAG (e Antigen positive) to HBeAG (e Antigen negative), and she'd gained the HBeAB (e Antibody

positive). This was an outstanding result! These same treatment outcome results only happen in approximately 30% of children on Interferon treatments, so the above treatment may possibly compete with Interferon!

It is now July 2008. Grace's liver enzymes are still in the great range. She has maintained her HBeAG (e Antigen) seroconversion to HBeAB (e Antibody). Her Viral Load has very slightly increased from the undetectable range on 8 Feb 2008 to 551 (but this is still very, very low compared to the 59.2 Million in Feb 2007). Over the past year (since beginning LDN in 2007), we've achieved excellent results below the max 3mg dosage level (at 1mg and then 1.5 mg nightly). While my daughter has done extremely well, we're going to increase the dose to 3mg a night, effective 17 July 2008, as she's grown considerably over the past year. The 3.0 mg dosage is believed to be the optimal dosage for children. (Note: For adults the optimal dosage target is 4.5 mg nightly to obtain the maximum benefit to the immune system.)

Besides our blessing of healing for Grace's Hepatitis, we have also seen fantastic results in her eczema and food allergies due to the multi-pronged approach of LDN with the Antioxidants, Probiotics, and Herbs we commenced in 2005. Grace has no more eczema - her skin is now like silk for the first time in her life. Additionally, her digestive tract has been healed, thus eliminating the extreme responses she had to various foods. She is now able to eat every food (in moderation) with no more allergic reaction. That is a real miracle, and as her body is better equipped to absorb nutrition from what she eats, this bonus has contributed to her improved health.

It appears that my daughter's body may have entered into the 'Immune Clearance' stage with the Antioxidants, Probiotics, Herbs, etc. we began in 2005. When LDN was added in 2007, it helped further stimulate her immune system to dramatically fight the virus. In clinical studies, Naltrexone demonstrated an increase in the body's Natural Kill Cells (which fight viruses). Therefore, I believe that LDN might also help jump start the immune system and take a child from the 'Immune Tolerant' stage to the 'Immune Clearance' stage in a safe and effective way!

The LDN website (ldninfo.org) is full of information that you can print out and give to your doctor. Also, the website has a link to the main LDN Yahoo Group where you can learn about other people's success with LDN, and find out about other 'splinter LDN groups' like mine that focus on specific diseases that LDN has benefited.

Clinical trials of LDN for other diseases (Multiple Sclerosis, Crohn's, HIV/AIDS, Fibromyalgia, etc.) have been completed (or are currently being completed) that indicate the immune modulating effects of LDN. At this point, controlled clinical trials need be undertaken by the medical community in order to prove the efficacy, safety, and dosage recommendations for children and adults. Only when clinical trials are undertaken, will we be able to 'prove' scientifically that LDN really helps to boost the immune system in fighting the Hepatitis virus. However, we need to ask the National Institutes of Health (NIH), FDA, and others in the Medical Community to fund clinical trials for LDN and Hepatitis.

This is one of the end goals of the Yahoo Group that I recently established, 'Hepatitis Children and CAM Alternatives'. Our focus will be on informing other group members, but also documenting our treatment stories in enough detail that we can give it to medical researchers. Our group welcomes both adults and parents of children with any form of Hepatitis (B, C, Autoimmune, etc.) to join us in our journey of healing. Additionally, we have sent our Case Study to National Institutes of Health, Johns Hopkins, and Pennsylvania State University/Hershey Medical Center in order to further spur interest in LDN and Hepatitis research.

We are truly grateful, appreciative, and awestruck by this miracle and have been blessed by God's mercy in this welcome healing! I personally believe LDN may be a safe, viable alternative to the current limited drugs that are available for children (as well as adults) with Hepatitis and other immune related diseases.

Every day my daughter is reminded when she enters her room (with the hand painted walls) that she is a precious gift and 'The Angels Danced the Day You Were Born'. I'm glad that I was willing to try something different - her room turned out beautifully. Maybe you could say I 'saw the handwriting on the wall', and chose to try something different (LDN) to help her immune system. LDN's results have also turned out beautifully!

Update: June 2009

We have continued our success on LDN with my daughter's Hepatitis B – her sero-conversion of the 'HBeAG' ('e' Antigen) and gaining the "HBeAB" (e Antibody) has been maintained over the past 18 months. Additionally, her viral load is undetectable, and her liver enzymes are in the normal range.

On the Hepatitis_Children_and_CAM_Alternatives Yahoo Group, we now have 121 members. Of these, 10 Members with Hepatitis C, 2 Members with Hepatitis B, and 1 Member with Auto-immune Hepatitis have started using LDN. Thus far, every person who has tried LDN has seen improvement in their condition once lab results have been taken after starting LDN (either by reducing liver enzymes and/or viral load). We are excited with the possibilities that LDN offers to the Hepatitis community…

I will continue to advocate for funding for LDN and Hepatitis...it offers a great possibility as an alternative, affordable treatment in our fight to slay the dragon!

I went to the Hepatitis B Foundation Patient 'B Informed' Conference on 26-27 June 2009, shared this Hepatitis B case study among patients and doctors, and promoted the need for LDN trials. Additionally, I shared the LDN success of two other members of the Hepatitis_Children_and_CAM_Alternatives Yahoo Group who have seen dramatic results in the liver lab results for their Hepatitis C.

UPDATE May 2010

The Hepatitis Children & CAM Alternatives Yahoo Group now has approximately 200 members. Over 25 members are using LDN for various liver conditions, including AutoImmune Hepatitis, Hepatitis B, Hepatitis C, Primary Sclerosing Cholangitis (PSC), etc. Most members are seeing positive results. We continue to ask members to track their before / after lab results of LDN. This helps members of the Yahoo Group compare treatment success using LDN. We also send the LDN before / after results to the medical researchers to assist with obtaining funding for a LDN / Hepatitis clinical trial. I'm so grateful for Nola Chris... she's been a real Godsend to me and the Group. She has really been the main contributor since I've been focusing on family and relationships over the past year.

I'm now working more of a full time schedule, as well as trying to build in much more exercise into my life so by the time I get home I don't have much time to write. My daughter is still doing well and is still on LDN, but also because she's been well, we haven't had to have lab tests done for a year, but we just recently got lab work drawn.

Three Cheers for Answered Prayers & LDN! ~~ Joyce
Joyce, USA
Yahoo LDN Group: Hepatitis_Children_and_CAM_Alternatives

Joyce C, USA

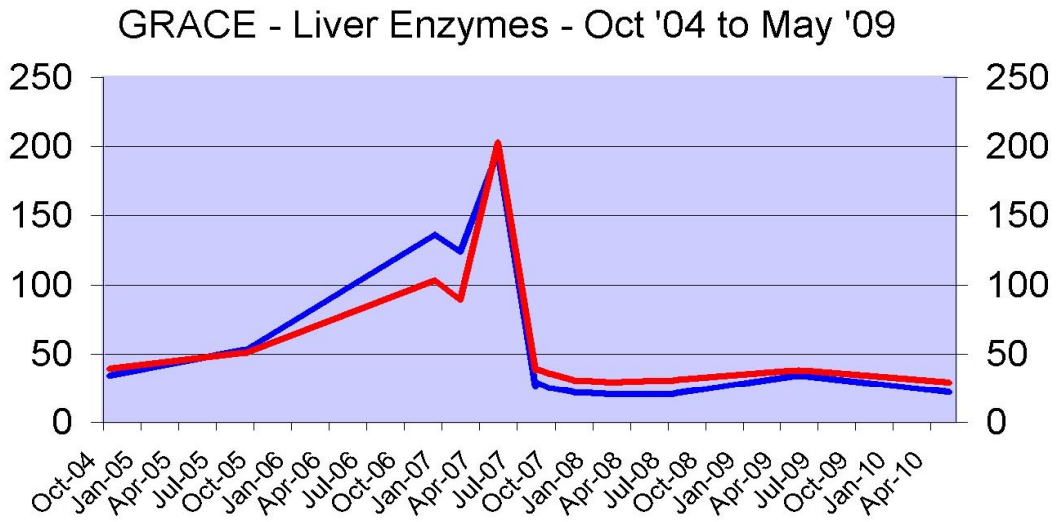
"Within one month her liver enzymes had returned to normal (from a high of 200 down to 22/31 range) and her viral load had gone down from 59.2 Million to 170,000 (a huge decrease)." Feb '08

"I went to the Hepatitis B Foundation Conference of 27-29 June 2009, generously shared this case study among delegates, and promoted the need for LDN trials." Jul'09

References:
NIH/PUBMed Studies - Naltrexone Benefits the Liver:
The National Institutes of Health, National Library of Medicine, Pub Med Website include many clinical studies and articles about how opioids and the opioid antagonist (Naltrexone) help both liver conditions and the immune system. The following are nine Clinical Studies (with the corresponding PUBMed ID number) which demonstrate the safety and very beneficial effects of Naltrexone to the liver for dosages below 300mg a day. While the below are not specific to Low Dose Naltrexone (which is taken in much smaller doses of up to 4.5 mg a day), the below studies demonstrate the beneficial affect that Naltrexone has on liver disease:

National Institutes of Health, National Library of Medicine, Pub Med Website
http://www.ncbi.nlm.nih.gov/sites/entrez?db=3Dpubmed)

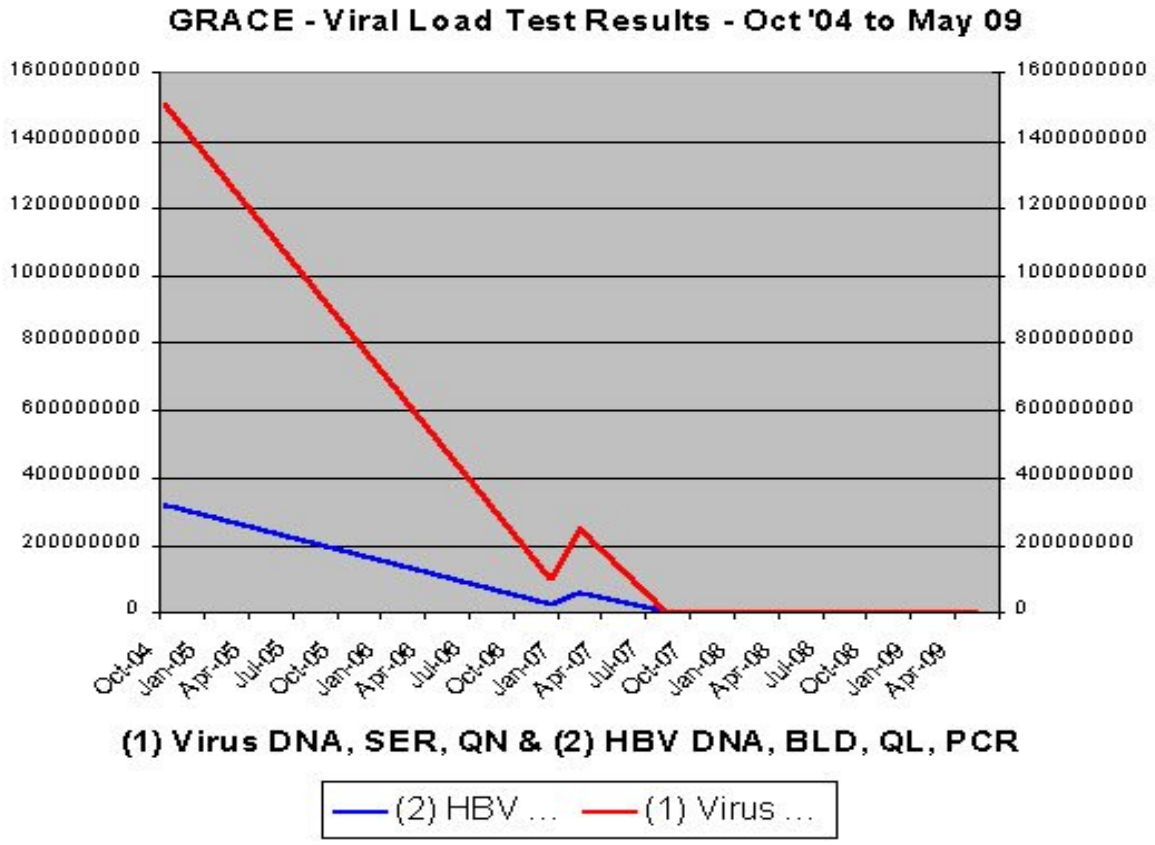
1. Reducing Liver Enzymes Levels, including Hepatitis (PMID: 16839858 & PMID: 9411543)
2. Reducing Liver Damage in Hepatitis (PMID: 15389866)
3. Reducing Liver Injury in Cholestasis (PMID: 17295775)
4. Reducing Liver Enzymes in Cholestasis (PMID: 12570015)
5. Reducing Liver Fibrosis (PMID: 16543289)
6. Anti-inflammatory effects & improving hepatic dysfunction (PMID: 15917999)
7. Benefits in Cholestatic Pruritus (PMID: 9322521 & PMID: 15517116)



	1-Oct-04	15-Sep-05	21-Dec-06	7-Feb-07	11-May-07	10-Aug-07	17-Aug-07	21-Sep-07	15-Nov-07	8-Feb-08	11-Jul-08	8-May-09	6-May-10
ALT	34	53	136	124	196	26	29	25	22	20	21	34	22
AST	39	51	103	89	203	38	39	36	31	29	31	38	29

ALT/AST Test Results

LDN benefiting daughter's HepB-Joyce C



© Case Health Pty Ltd

50 LDN and ALA Benefiting HepC – Chris

LDN since April 2009
- story submitted June 2010

SPECIFICS

DIAGNOSIS
- Oct 2002 – Hepatitis C, Fatty Liver
- 2002 – Staphylococcus Infection
- 2006 – Chemical Sensitivities
- 2006 - Fibromyalgia
- 2006 - Sjogren's syndrome
- 2006 – IBD symptoms without diagnosis

TESTS
- 2007 – Liver Enzymes – slight decrease following adoption of Dr Berkson's recommended supplements.
- July 2009 - Liver Enzymes – within normal range, Viral Load – less than 50,000 (from over a million)
- Sep 2009 - Liver Enzymes – within normal range, Viral Load - 18,729
- Jan 2010 - Liver Enzymes – within normal range, Viral Load - 38,000
- May 2010 - Liver Enzymes – within normal range, Viral Load - 11,300

SURGERY/HOSPITALISATION
- none

MEDICATIONS/TREATMENTS (pre LDN)
- 2002 to Apr 2009 - none (none of the western medicine recommended Hep C treatments)

MEDICATION (post LDN)
- April 2009 to 5 Jun 2010 – 3mg Low Dose Naltrexone (LDN) – Tried 3.5mg for a short time only
- 6 Jun 2010 to present – 3.5mg Low Dose Naltrexone (LDN)
- Alpha Lipoic Acid (ALA)

LDN - DOSE & TYPE
a) Dose – 3.5mg compounded low dose naltrexone (LDN) capsules
b) Time –naltrexone taken at bedtime (no earlier than 9pm and no later than 2am)
c) Type – compounded capsules with avicel filler from Skips Pharmacy

OTHER TREATMENTS/THERAPIES:
-

DIET
- 2007 – I changed my diet: I cut out wheat, and I was amazed at how much better I felt. I was later tested for food allergy and intolerance and found to be sensitive to wheat, cow's milk and yeast and after cutting out those food groups from my diet, noticed further improvement.

SUPPLEMENTS
- 1995 - Starting taking milk thistle as I heard that it helped protect the liver from alcohol
- 2002 – After being diagnosed with Hepatitis C I quit drinking alcohol, increased my milk thistle dosage, and started eating mostly organic foods
- 2003 to 2007 – I began taking a variety of supplements, as follows, and they did help for a while: Milk Thistle, Amino Acids, daily Multi-vitamin, Vitamin C, Vitamin E
- <u>2007 to present – I began taking the supplements Dr Berkson recommends and continue to take them</u>:

Alpha-Lipoic-Acid 300mg x twice per day (morning and afternoon)
B-Complex 100mg x 3 per day - morning/midday/afternoon (taken at the same time as the two doses of ALA), and along with other B vitamins; B12 and Biotin (as follows):
B12 1000mg x once per day
Biotin 300mcg x once per day
Selenium 400mcg x once per day
Amino Acids Lysine 2000mg x once per day
Taurine 500mg x twice per day
NAC 500mg x 2 or 3 times per day
SAMe - 200mg x 2 per day
Vitamin D3 1000-5,000mg once per day
Vitamin C x twice per day
Vitamin E x twice per day
IP6 1000mg x 2 per day
Multivitamin w/out iron x 1 per day
Whey Protein fruit shake x 1 per day
Omega-3 x 4 per day

Cordyceps 800mg x once per day
Olive Leaf Extract 500mg x 2 per day
Grapefruit Seed Extract 400mg x once per day, taken with Artemisia (as follows):
Artemisia 400mg x once per day

ACTIVITIES & EXERCISE
- 2007 to present - I feel good most of the time and am able to exercise daily as well as take care of an online book selling business. I walk several miles at a time and sometimes am up to jogging part of the way. It is important to get up and move and to increase blood flow and get the red blood cells going as the LDN and supplements seem to do a better job. Exercise will also help rid the body of any toxins that can accumulate.

OTHER INTERESTS
- 2007 to present – I've been able to get involved again in volunteer cat rescue.

MY STORY – March 2010

In October 2002, I was devastated to find out that I tested positive for the Hepatitis C virus. I had been feeling tired but had attributed it to working full time, caring for my cats, along with my work in local cat rescue here in New Orleans. I also had a bad skin infection that would not go away despite taking a course of antibiotics. The skin infection was later diagnosed as MRSA (staph) on top of the initial ringworm that I had gotten from a newly rescued cat, that I credit with leading me to my eventual HCV diagnosis.

My initial tests showed elevated liver enzymes and a high viral load. An abdominal ultrasound showed 'fatty liver', and a follow-up biopsy thankfully showed only minimal liver damage. Still, the virus and the Staph infection left me exhausted... some days I was unable to get out of the bed, except to care for my cats. I had severe abdominal upset; IBD and bouts of diarrhea that made it impossible to leave the house. I was afraid and worried about what would happen to my cats. I was newly divorced and my cats were like children to me.

I soon learned as much as I could about the Hepatitis C virus. I was not impressed with the 30-40% success statistics of the combo treatment on my genotype, or my strain of Hep C; so I chose not to do the current therapy of Interferon with Ribavirin… despite being pushed to do so by my doctors. I also read about and met many people who had many bad experiences during the gruelling 48-week regimen of weekly shots and daily pills.

Over time I changed my diet and began taking a variety of supplements. I soon felt well enough to exercise again and was able to walk several miles at a time. My viral load and liver enzymes really did not change that much but my other test results got better. I was able to work part-time but I still got very tired.

Hurricane Katrina and the ensuing levee breaches had a big impact on my health (and everything else as well). My car broke down and I couldn't take my cats, so I stayed behind with them. We survived by climbing up into a high closet to get out of the floodwaters caused by the nearby levee breaches. I had to swim out to my roof in the end to be rescued - and miraculously, the 8 cats all survived too! We lived out of state for 6 months before returning to a new apartment in the Mid-City area of New Orleans in early 2006.

The ordeal took a toll on my health and I soon developed severe chemical sensitivities, then Fibromyalgia, Sjogren's syndrome, and terrible IBD symptoms. I had an attack of shingles and seemed to be in constant pain. It also became increasingly difficult to even leave the apartment, because I'd grown sensitive to many of the everyday things encountered in daily life.

Even going to the grocery store became a chore and I had to hold my breath going down the detergent or bug spray aisles. It was during this time that I finally qualified for disability.

Then in 2007 I started seeing an integrative doctor who told me about Dr. Burton Berkson and his work with ALA (alpha-lipoic-acid) in liver disease. I began to use the supplements that Dr. Berkson uses on his own patients and noted a slight decrease in my liver enzymes.

My own doctor also told me to cut down or completely avoid wheat, which she said many people had sensitivities to. I cut out wheat, and I was amazed at how much better I felt. I was later tested for food allergy and intolerance and found to be sensitive to wheat, cow's milk and yeast. Eliminating those foods alone improved my symptoms a great deal as well.

For my Hepatitis C, I was able to go to Las Cruces, New Mexico to see Dr. Berkson in early 2009. He

prescribed 3mg of Low Dose Naltrexone, or LDN as it is commonly known, to be taken at night-time. Aside from initial sleep disturbance, I had no discomfort or other side effects when I began using it.

My first lab work done after being on LDN for 3 months was amazing! My liver enzymes had dropped down to normal, and my viral load had dropped from over a million to less than 50,000!

My integrative doctor was very impressed with the results, but my gastroenterologist was less than supportive. I faxed him my liver enzyme test results and requested that his office run a Hepatitis C Viral Load test, and he flatly refused. He said the LDN was not supposed to affect one's viral load, and he would not order the test. I have since faxed him my viral load test results and have never heard back from him.

Follow-up lab work done in September 2009 showed an even greater drop in the viral load test to 18,729, and my liver enzymes were still in the normal range as well.

It is now June 2010, and my most recent labs (May 2010) also had very good results - normal liver enzymes and a very low viral load at 11,300. My integrative doctor is very willing to order these tests and has since prescribed LDN to many of her patients.

I feel good most of the time and am able to exercise daily as well as take care of an online bookselling business. I'm also able to return to helping with the ongoing cat rescue throughout my community. My Fibromyalgia has improved, and I'm less bothered by chemical sensitivities.

The stomach upset and IBD have completely disappeared, and my Sjogren's levels have decreased, as have the symptoms.

I joined an online support group called Hepatitis Children and Cam Alternatives, and many members with various forms of liver disease are also using LDN with remarkable results. We are maintaining a Database with 'before' and 'after' LDN lab work in an attempt to interest researchers in conducting a clinical trial for Hepatitis.

I'm also documenting my use of LDN and my own health journey in my blog:
(http://nolahepper.blogspot.com/)

I recommend LDN for Hepatitis and also for the multitude of diseases thousands of people around the world are successfully treating with LDN.

Chris M, USA

33 Antioxidants & LDN stabilized my PLS – Gary

LDN since February 2004
- story submitted July 2008
- story updated November 2008
- story updated July 2009
- story updated April & June 2010 (over 6yrs on LDN)

SPECIFICS

DIAGNOSIS
- 1993 - Primary Lateral Sclerosis (PLS) based on MRI and clinical symptoms

TESTS
- 1993 - MRI
- 1995 - MRI
- Nov 2008 - serum 25-hydroxy vitamin D - result Vitamin D3 deficiency (about a quarter of normal range)

MEDICATION/TREATMENT (OTHER)
- prior to 2005 - small doses of Valium, then antidepressant Prothieden

MEDICATION (LDN)
- Feb 2004 to Feb 2004 - 3 mg Low Dose Naltrexone (LDN)
- Mar 2004 to present – 4.5mg Low Dose Naltrexone (LDN)

LDN - DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone anytime between 9pm and 4am, usually around 3am each night.
c) Type – 4.5mg capsules are compounded by Greens Pharmacy, Adelaide with pure Naltrexone powder and acidophilus filler.

DIET
- 1994 to 1994 - I tried gluten free diet – very restrictive and didn't seem to help.
- 1995 to present - Since then I've tried to eat healthier and a good portion of my diet is organic, however, I do have periods where I tend to eat mainly crap and I know when I do because I get pimples on my face.
- Feb 2010 – addition - commenced taking 1 teaspoon of coconut oil, most days.

SUPPLEMENTS:
- 1998 to present: These are the antioxidants I began taking daily:
NAC (n-acetyl-cysteine) 1 x 500mg
alpha lipoic acid 1 x 100mg
CoQ10 1 x 30mg
Vit E (mixed tocopherol - apparently better than just d-alpha formula) 1 x 1000 IU
Vit C & E with grape seed extract x 1 (manufacturer discontinued making them)
multi-Vit B tablet (supermarket brands)
Fish oil/EPA 2 x 1000mg
Selenium x 200mcg every second day – bought directly from my doctor – when they've all been used, I'm often without for a couple of months between appointments
- 2005 to present - I added the following to my supplement regimen daily:
Benfotiamine 1 x 150mg
synthetic thiamine (Vit B1) - meant to be good for energy, reduce fatigue
DLPA (DL-phenylalanine) 1 x 500mg – was taken to enhance LDN endorphin effect (but it cannot be taken by people with high blood pressure so I only take this occasionally and will soon check my blood pressure)
St Mary's thistle x 4 tablets - as a liver cleanser as some things I read implicated the liver in PLS/ALS - figured it can't hurt to take it and the more I read the more I think it is valuable. (Liv Pro brand discontinued.)
- Jul 2008 – ceased taking DLPA due to elevated blood pressure
- 5 Dec 2008 – added - Vitamin D3 (as cholecalciferol)
1 x 5000IU Vitamin D3 (as cholecalciferol) taken daily with a high fibre meal containing fat, and as I love Brie and Camembert, it's usually accompanied by one of those (Life Extensions brand)

ACTIVITIES, EXERCISE, INTERESTS
- Exercise - none apart from normal walking around (100m at a time would be my absolute limit). Spend half my life on the computer on emails and a car site for people with similar cars to me (I'm an avid petrol head!!).

MY STORY - July 2008

I was diagnosed with Primary Lateral Sclerosis (PLS) when I was in my late thirties, after, in retrospect, about a year of symptoms. By then I was feeling very stiff but attributed that to a change of career to computer programmer about 5 years earlier and spending most of my time sitting.

A few months before diagnosis and thinking my symptoms were all due to lack of exercise I tried to start jogging, but the first time I tried I only took a half dozen strides before my legs got confused about what to do. Eventually I built up to the stage where I could manage about 3km down quite a steep hill, along a flat, pot-holed section and back up to home again. (At that stage we were on a 10-acre property out in hilly country.)

However, in other respects I was getting worse so went to see my doctor who decided there was a problem (possible MS or brain tumour) so sent me to see a neurologist who was also an oncologist! My diagnosis was done on the basis of clinical examinations and an MRI. Interestingly PLS and ALS typically don't show on MRIs (expect possibly the very newest ones -- MRS I believe). My MRI showed some abnormal signalling in the corticospinal tracts leading me to be diagnosed with PLS. In retrospect it was a very brave call given some people take many years to be diagnosed, although mine did progress pretty rapidly.

There is nothing I have read in over 10 years of communication with other PLSers that has ever caused me to question the diagnosis. I had a follow up MRI in 1995, which was similar, possibly a little more abnormal signalling, but nothing since. I get very claustrophobic and no way they're getting me in one again unless it will lead to a cure!!

For the first 5 years after diagnosis I progressed relatively quickly for PLS, to the point of needing a walker to get around and having very poor speech. I did take various antioxidants (mainly vitamins C and E) at times during those 5 years, but never rigorously or consistently.

I then found a great website as the source of much of my info on antioxidants (http://home.goulburn.net.au/~shack/) and based on what I read there I decided to start taking a wide range of antioxidants consistently and rigorously. Steve Shackel, the guy whose site it is has Amyotrophic Lateral Sclerosis (ALS). He had actually improved after starting on all his antioxidants (before I did). The info on his site is oriented towards ALS, but also applies to things like MS and PLS. I worked up my list of antioxidants based primarily on what I found there. There is an almost overwhelming volume of info there now - 10 years ago there was far less.

Within 6 months of starting rigorously on a wide range of various antioxidants my progression stopped and for the subsequent 10 years now has been virtually non-existent, except for my speech which very, very slowly continued to decline, though I feel that is more due to lack of use (because only my family could understand it even 10 years ago anyway). It can be extremely frustrating trying to make myself understood so I probably now only try to say maybe a dozen things per day, hence my speech muscles get little exercise and no practice.

I just wish I had found all the info on antioxidants earlier!! If I could stand beside myself 10 years ago then I would no doubt notice some decline but it has been so slow as to be virtually non-existent from my perspective.

Over 4 years ago I started on LDN after someone on PLS-FRIENDS said how much it was helping her. Within a week or two I was walking a little better (not miraculously better, but noticeably - feet were picking up better) and after about 9 months my urinary urgency (a scourge of PLS for many) dramatically improved. Again, I'd say that in the last four years I have held my slightly improved ground but it's hard to know for sure.

If there has been any deterioration I haven't noticed it. I still drive and until mid 2006 was still working full time. The only reason I am not working now is that my company lost the contract for the work we were doing and most of my group were made redundant.

I attribute the relative stability of my PLS to the antioxidants I started taking about 6 months before my progression basically stopped and the LDN is now the icing on the cake! Based on my own minor improvements with LDN, plus the results I've seen for some others with Motor Neurone Disease (MND), ALS and PLS, I believe 100% in the ability of LDN to help the body and there is no way I'd stop taking it. It's just that four years down the track I don't know how much of my lack of progression is due to the antioxidants, the LDN, or the combination.

In consideration of the six years before LDN, I have to say that most of it is possibly due to the antioxidants and that the LDN is an extra weapon in my arsenal now. From what I've seen, it's possible I could have achieved a similar result with LDN alone but I'll never know for sure because while I'm stable, I'm not prepared to risk what I've gained to test the theory.

Ten years after beginning on antioxidants and later LDN, I still can't take a step without my walking frame and maybe the distance I could manage is somewhat reduced, but basically I still feel my walking ability is much the same, whereas I feel sure if I hadn't started on the antioxidants I would have been permanently in a wheelchair many years ago. In consideration of the speed at which my PLS was initially progressing, I'd say I was very lucky to find Steve's website, then later LDN, and I wouldn't change either.

One thing I consider very important to point out. I got the impression from things I read long ago now that it was far better to take a wide variety of daily quantities of antioxidants rather than mega doses of just one or two and my results compared to a few people I've known who went the mega dose route would seem to bear that out.

My understanding is that using a wide variety is better; (a) because some work synergistically together so that the effect is greater than the sum of the individual parts, and; (b) and because using a variety allows you to take advantage of the different individual actions of each rather than relying on just one or two ways of working (not putting all your eggs in one or two baskets).

UPDATE – November 2008

I used to always get heavy head colds at least once or twice per year, followed by cold-sore(s) on my lips. In the almost 5 years I've been on LDN I've had one (about 2 yrs ago) which lasted about half as long as usual and the resultant cold sore didn't even get as far as blistering. From group discussions I've learned most people have similar results.

UPDATE – July 2009

Basically no change except for feeling stronger and walking more freely at times, probably due to combination of Vit D3 supplementation and fortnightly massage commenced Dec 2008, around six months ago.

UPDATE – April 2010 (6yrs on LDN)

Yes, I'm still taking LDN and there's been no change since my last update (which is a bloody good thing given my first five years!!).

I'm holding steady, and the only difference to my regimen is that I started taking one teaspoon of coconut oil most days since early February. 'Something' yesterday may me feel better in walking than I had for a while, but I don't know if it was the coconut oil or just a 'normal' variation for me, which also happens from time to time. I really can't decide! I seem to be having more good days on average, but I'm not sure whether it's the coconut oil, or its combination with Vit D, or…..???

Incidentally, a recent post made me realise LDN also seems to be helping maintain my eyesight! I can still easily manage with prescription reading glasses I had for a year or more before starting on LDN six years ago.

UPDATE – June 2010 (over 6yrs on LDN)

We recently returned from our 'once in a lifetime' trip to Europe for 5 weeks (have never been before and unless we win Lotto will never go again). We had an absolutely awesome time - enjoyed it more than I'd dared hope!! We had 5 days in Paris then hired a car and my wife drove us (on the 'wrong' side of the road for we Aussies) through France, Switzerland, northern Italy (as far south as Pisa), southern Germany and Austria.

I have LDN to thank for making the trip far more pleasant than it otherwise would have been!! One of the issues around half of us with PLS face (PLS is a form of motor neurone disease and little brother to ALS/Lou Gehrig's disease) is urinary urgency, and before I started on LDN over 6 years ago I was one. I remember times before LDN, being on a car trip, and in less than an hour I'd be absolutely desperate to pee (even when

I'd had nothing to drink for hours). When we found a quiet spot to pull over for me, the volume said I wasn't imagining the need to go...

It was only after about 9 months on LDN that I realised my urinary urgency was improving, and over time it seems to have continued to improve to the point where I now consider myself almost 'normal' in that respect. At times whilst working on my PC now, I can think to myself I need to go soon yet can continue working away for at least another hour, sometimes two, without a problem. If I leave it too long then as those with urinary urgency issues may know, as soon as I stand up the need becomes more desperate.

On our trip we did one long day of travel in the car (over 6 hours) and I didn't need to go until we got to our destination. On another day in Vienna we were on one of those hop-on, hop-off bus tours with different routes. It had been about 2 hours since we left the hotel when the first urge to go came, yet we completed almost another 2 hours on the bus on 2 different tours before being dropped off at the Donauturm (Danube Tower). We then went up the tower, took lots of photos, then came down, and then finally went to the toilet in the café at the base of the tower, and even then, I still wasn't uncomfortable or desperate! No way I could have done that without LDN - I would have ended up embarrassing myself within maybe half an hour of the first urge. Hail LDN!!

Gary C, Australia

Gary C, Australia

"Based on my own minor improvements with LDN, plus the results I've seen for some others with Motor Neurone Disease (MND), ALS and PLS, I believe 100% in the ability of LDN to help the body and there is no way I'd stop taking it. It's just that four years down the track I don't know how much of my lack of progression is due to the antioxidants, the LDN, or the combination." Jul '08

34 LDN was working-Metastatic IVB Cancer – Dee

LDN since 12 February 2007
- story submitted 4 March 2007
- story updated 13 March 2007
- story updated 12 April 2007
- story updated 22 April 2007
- story updated 12 May 2007
- story updated 7 June 2007
- story updated 16 June 2007
- story updated 15 July 2007
- story updated 2 August 2007
- story updated July 2008
- story updated July 2009
- story updated April 2010 (over 3yrs on LDN)
- Sadly, Dee passed away Thursday 22nd April 2010.

SPECIFICS

PRE-LDN TIMELINE – DIAGNOSIS, MEDICATION, TREATMENT, TESTS, SIDE-EFFECTS, OUTCOME

- 26 Oct 2005
Cervical biopsy - Initial results Moderately differentiated (grade 2) invasive squamous cell carcinoma of cervix. I was diagnosed with **Cervical Cancer (Adenosquamous Carcinomas), the rarest form**, which has features of both squamous cell carcinomas and adenocarcinomas.

- 4 Nov 2005
Surgery - Wertheims total hysterectomy and right salpingo-oophorectomy (removal of right fallopian tube and ovary).

- 7 Nov 2005
Pathology Report - Poorly differentiated Adenosquamous Cell Carcinoma, at least 4 cm in maximum extent with prominent lymphatic permeation, 3 positive Lymph nodes - Comment pT2N1Mx (*TNM System Cancer Assessment).

- 8 Nov 2005
PET SCAN - Status CA cervix with hysterectomy done. No abnormal FDG uptake at the pelvic surgical site or at the vaginal vault to suggest residual tumor. No evidence of distant metastasis to the brain, lungs, liver, adrenal glands, and bone is found.

- 1 Dec 2005 to 9 Jan 2006
Began concomitant External Beam Radiotherapy (RT) with Cisplatin chemotherapy treatment. This involved 29 RT treatments over a period of 5 weeks, 5 cycles of Cisplatin (one each week for 5 weeks). Blood counts as well as renal and hepatic function tests were performed during treatment. The file located online here details the treatment I received from my Oncologist. I completed the treatment on 9 January 2006. During treatment I experienced the following side effects: fatigue, severe cystitis, severe pain on bowel movements.
(1) Treatment:
http://www.ldn4cancer.com/files/da-RTChemo-treatment-2006.pdf

- 14 Sept 2006
A follow-up PET Scan approx 8 months later detected a mildly hypermetabolic nodule in latter part of anterior segment of left upper lobe (LUL), worrisome of a pulmonary metastasis but could be granulomatous nodule, in right lung also 3 eumetabolic subpleural nodules which can be in range of inactive granulomatous nodules but difficult to exclude early small metastases.

- 29 Jan 2007
Follow-up PET scan (2) identified nodules in my lungs suspected as metastatic cervical cancer, and confirmed as metastases with at least 13 nodules, the largest nodule (3) being 1.3 cm. Reclassified cancer to Metastatic Stage IVB (based on TNM System Cancer Assessment).
(2) Pet Scan: http://www.ldn4cancer.com/files/da-070129-PET-scan.pdf

- 3 Feb 2007
CT Scan further confirms metastases of at least 13 nodules, largest one being 1.3cm with a calculated 'doubling time' of 33 days. My oncologist said the 'gold standard' of treatment for my cancer type, Taxol/Carboplatin, would not be responsive. He offered palliative chemotherapy and gave me 4-9 months survival, which I refused. Advised to get affairs in order.
(3) CT Scan: http://www.ldn4cancer.com/files/da-070203-CT-scan-thorax.pdf
(4) Doubling Time: http://www.chestx-ray.com/SPN/DoublingTime.html

POST-LDN TIMELINE – MEDICATION, TREATMENT, TESTS, SIDE-EFFECTS, OUTCOME

- 12 Feb 2007
I started taking 4.5mg Naltrexone (LDN) nightly, between 10pm and 11pm. The capsules are compounded with avicel

filler. I took no other medications. After starting on LDN I experienced the following side effects: In the first month I had some difficulty with sleeping. I also experienced intermittent but high levels of anxiety which would last all day.

- 13 Jun 2007
My follow-up CT scan showed a slowing of the largest nodule growth, now 2 cm in size and no further metastases, extending the growth rate to 70 days. After only 4 months, the LDN had prevented further metastases and slowed the 'doubling time' (growth) of the existing nodules.
(5) CT scan:
http://www.ldn4cancer.com/files/da-070611-CT-scan-thorax--lowdose.pdf

- 1 Aug 2007
CT Scan revealed no significant growth for any of the metastatic nodules, the largest nodule now 2.0cm x 2.1cm. LDN appears to have halted the growth of the largest nodule and continued to stop further metastases. Calculated growth rate since previous scan has extended to 232 days.
(6) CT scan: http://www.ldn4cancer.com/files/da-070801-CT-scan-thorax.jpg

- Jan 2008
My tissues in my pelvic region were badly damaged by the radiation 'treatments' I underwent in Dec 2006 (after the cervical tumor was removed). In January of 2008, a fistula developed in my bladder and doctors tried to correct this by stitching it together.

- Feb 2008
My bowels were constricted causing severe stomach pains. I had an operation to remove part of my colon that had been damaged by the radiation treatments, and had a colostomy inserted.

- 15 May 2008
CT SCAN shows the nodules still growing slowly which gives me time to try other treatments which will target the largest nodule directly.
(7) CT scan:
http://www.ldn4cancer.com/files/da-080515-CT-scan-thorax-lowdose.pdf

- 13 Jun 2008
I underwent Radio Frequency Ablation (RFA) to destroy the largest nodule in my left lobe. I've now reset the 'clock' on the largest tumor growth, expecting that the LDN will continue to hold down the growth of the other existing nodules, and extending my high quality of life. Apart from early on, LDN has had no side effects for me, and anyone seeing me would never believe I have cancer since I feel and appear healthy.
(8) RFA: http://www.cancernews.com/data/Article/612.asp
(9) RFA report:
http://www.ldn4cancer.com/images/RFA_report_LT_lungtumor_080613.pdf

- 21 Jul 2008
Low dose CT thorax scan, post RFA (Radio Frequency Ablation)
Result: Successful treatment with RFA to one of the larger tumors in Left upper lobe. Multiple metastatic nodules are shown but some are showing calcifications.

- Feb/Mar 2009
Surgery to correct pelvic radiation damage caused by the External Beam Radiotherapy (RT) in Dec 2005/Jan 2006. Doctors had tried to solve the bladder fistula that arose in January 2008 by stitching it up, but the stitches didn't take because the bladder tissue was too fragile from the radiation damage, so by March 2009, I was on an almost permanent catheter.

- 22 Aug 2009
(8) CT scan of Thorax without contrast (one AP scout. 5mm thick slices obtained at 5mm intervals through the thorax)
Findings: **Comparison is made with previous CT dated 10 Jan 2009**. There are numerous pulmonary nodules in both lungs, consistent with pulmonary metastases. **Some of the nodules show intralesional amorphous calcifications**. There is interval increase in number and size of the pulmonary metastases. The largest lesion in the right lung located in right lower lobe measures 4.3 x 3.1 cm versus 3.2 x 2.6 cm previously. The largest lesion in left lung located in left lower lobe measures 3.2 x 3.6cm versus 2.9 x 2.3 cm previously. The previously noted right paratracheal lymph node is slightly enlarged, measuring about 1.2 x 1 cm versus 1cm previously. **Intralesional calcifications are present**. There is interval development of two mediastinal lymph nodes adjacent to aortic arch, measuring up to 0.9 cm. Findings may represent metastatic lymph nodes. Interval development of small amorphous calcification around diaphragm between the heart and left lobe of liver, may represent metastatic lymph node. No pleural effusion or pericardial effusion is noted. Left lobe of thyroid is enlarged with heterogeneous density and specks of calcification. **No significant interval change is seen.**
Impression**:** (1) Interval increase in number and size of bilateral pulmonary metastases. (2) Slight interval enlargement of right paratracheal lymph node. Interval development of two mediastinal lymph nodes adjacent to aortic arch, suspicious of metastatic lymph nodes. (3) Interval development of small amorphous calcification around the diaphragm, may represent metastatic lymph node.

- Jan 2010
I fell down and opened up a second and 3rd fistula between my lower intestine and bladder. I now have three catheters and my doctor has tried many things to repair the fistulas but due to the extent of damage to tissues,

surgery isn't an option, and instead, all 3 fistulas are temporarily 'plugged' with catheter balloons to route all discharges to the catheter bags instead of the rectum.

- Feb 2010
Pelvic exploratory via CT guided catheter to determine the cause of severe nerve pain in my right leg. Found an enlarged lymph node pressing on the nerve in my leg. Lymph node was aspirated by needle and 10ml of liquid was removed, which is a substantial amount for a lymph node. Doctor was sure it was cancerous but lab tests came back as negative (thanks I'm sure to LDN). The ureter tube was almost closed, causing severe back pain and almost collapsing my right kidney. Doctors went in and inserted a stent into the ureter to resolve the kidney problem.

- Mar 2010
Hospitalized due to severe pain in legs, chest, back. Irregular heart beat detected and treated with medication.

- 22 April 2010
Dee passed away from a suspected heart attack.

LDN DOSE & TYPE
a) Dose - 4.5mg
b) Time - I take my Naltrexone between 10pm and 11pm each night
c) Type - my naltrexone capsules are compounded from pure naltrexone powder and Avicel filler by Skips Pharmacy.

DIET
- March 2007 to Feb 2010 - Normal diet - fresh vegetables and fruits - Japanese.
- Feb 2010 - low residue diet, 'Ensure' complete liquid nutrition by Abbott Labs

SUPPLEMENTS
- none

EXERCISE, INTERESTS
- I work, travel, and use a gym. I'm an advocate for LDN and administer my own website at ldn4cancer.com.

MY STORY – 4 March 2007

In December 2005 I had External Beam Radiotherapy (RT) and Chemotherapy with Cisplatin, completing that regimen on January 9, 2006. The PET Scan after that treatment was clear.

Just over twelve months later, on 29 January 2007, I had a follow-up CT scan and my Oncologist confirmed metastatic cancer with 13 nodes in the lungs, Stage 4B. There is virtually no hope of long-term survival using a conventional regimen involving Carboplatin/Taxol chemotherapy. My Oncologist had nothing else to offer and his prognosis was dire.

On 7 February 2007 I was notifying my friends of my hopeless situation when a close friend living in Florida, suggested I contact a Dr Bernard Bihari who'd developed a treatment using a drug called naltrexone.

I phoned Dr. Bernard Bihari in New York and had a phone consultation. He agreed that Low Dose Naltrexone would be helpful because he had discovered benefits of LDN for MS and cancer patients, and had experienced some success in applying LDN to ovarian cancer patients.

It gave me hope that my rare form of cervical cancer (adenosquamous), which had metastasised to my lungs, might also be responsive. I was lucky to be in a position to start this controversial treatment straight away because I wasn't experiencing any serious effects from the lung nodules, and was therefore not taking any strong medications for pain or inflammation. I also wasn't taking any immunosuppressants.

Dr Bihari faxed a prescription for a 90-day supply of 4.5mg LDN capsules to Skip's Pharmacy in Boca Raton that same day, and my friend in Florida picked up the LDN and had it couriered to me. I started taking the LDN on 12 Feb 2007, taking one 4.5 mg LDN capsule between 10pm and 11 pm each night.

As at 4 March 2007, I've been on the regimen 21 days and will wait for at least another month before having another CT scan to see if the regimen has had any effect on my lung nodules.

UPDATE 13 March 2007

Today is the 28th day since I started taking LDN. I'm still feeling good and going regularly to the gym and doing vigorous workouts on a cross-trainer.

I had some trouble sleeping, but no trouble sleeping now and my appetite is good. I'm keeping my original lifestyle, which involved regular dinners out and drinking wines (red & white) and champagne. My LDN prescribing Doctor, Dr Bernard Bihari, said no need to curtail normal life activity.

My Oncologist had expected my medical situation to have taken a turn for the worse by now, and that I'd be beginning chemotherapy as a last effort to slow down the growth of the metastatic cancer.

Chemotherapy has no track record of success in treating cervical cancer metastatic to the lungs, so going that route is an admission of defeat. I've chosen to use LDN exclusively for the moment, because chemotherapy will not work and will destroy my existing immune system while doing nothing against the existing cancer.

I'll be posting again in 2 weeks, when I'll have been on LDN for 6 weeks, and getting closer to the time when I will begin to find out whether LDN is working because if it isn't, symptoms of the metastasis will become noticeable.

UPDATE: April 12th, 2007 - Month 2 Status

This is now the second month that I've been on LDN. By this time, my oncologist was certain that I would be experiencing serious effects from the rapidly growing cervical cancer metastasis to my lungs. PET scans taken prior to beginning LDN showed a doubling in size of the lung nodules about every 4 weeks. I'm delaying a follow-up scan until I've been on LDN for at least 3 months, since reality is that if LDN isn't working, there are no alternatives anyway. The 2nd line protocol would be Taxol/Carboplatin, which has zero record of success for my cancer cell type.

My previous LDN prescribing doctor, Dr. Bernard Bihari (discoverer of the clinical benefits of low doses of naltrexone), retired from his medical practice and I moved on to one of his referrals, Dr Martin Ehrlich in New York. I had a telephone consultation with him on March 30th when he accepted me as his patient. I've now gotten the first prescription from him for my next 6-month supply.

UPDATE: April 22nd, 2007 - Spreading the word

I spent the Easter holiday in Hawaii with my father and his wife. He's 82 and his wife, Mary, is 75. She's had Rheumatoid Arthritis for many years now, and rarely gets through the night without pain and stiffness.

On April 4th, I suggested she try LDN for her RA and gave her a 4.5mg tablet from my prescription. She continued taking it nightly for the next 7 nights. The 2nd day after starting LDN, she did not experience the usual arthritic pain she was accustomed to, and some other minor ailments she had also disappeared.

She returned to her home in Arizona on April 11th with an 8-day supply from my prescription, and went to her GP for her own prescription on the 17th. He was reluctant to give one, but she persisted and he wrote the prescription on the 18th. An order was placed with Skips Pharmacy in Boca Raton, Florida. It was shipped out and arrived in Arizona on the 21st.

Before her own prescription arrived, the 8-day supply I gave her on the 11th ran out and for 2 days she was without LDN. By the 2nd day, the pain and stiffness from her arthritis had returned, so she was glad to get back on LDN on the 21st. The return of the arthritis after only a short time off LDN was proof positive to her that LDN works.

Now she's convinced of the benefits of LDN for arthritis. She's living in a retirement community with a large population of seniors and she's become an advocate for LDN and is now 'Spreading the Word'.

UPDATE: May 12th, 2007 - Month 3 Status

It's now the 3rd month since I've been on LDN exclusively for my metastatic lung cancer. I have experienced no changes to my overall well-being and have not been curtailing any of my usual life activities (fine dining, fine wines, travel). I will wait one more month before scheduling a CT scan to measure the changes in the lung nodules that were identified in my last CT scan on February 6th.

UPDATE: June 7th, 2007 - Scheduling next scan

I've been trying to contact my Oncologist for an updated scan and he finally replied questioning "Which region do you want scanned?" I have metastasis to my lungs duh??? I requested in my email a CT scan but he thinks since I have had no treatment in 4 months the cancer must be all over the place.

Now I am not "counting my chickens" here but just goes to show that Oncologists don't care about alternative medicine even though I have sent him all the LDN literature and published paper by "his peers". They only want to give chemo knowing it won't do any good. I will see today if he responds back with my request for a "thorax CT scan" and get on with it. Will be posting the results shortly thereafter, but in the meantime, I am feeling good.

UPDATE: June 16th, 2007 - Month 4 Update

Received the results of my CT scan taken June 13, 2007 and the results, though still ambiguous, gave me hope. The largest nodule had increased from 13mm to 20mm (compared to the previous scan taken on Feb 3, 2007, around 4mths ago).

The largest nodule was still growing, however; the growth rate appeared to have slowed. The 'doubling rate' evidenced in previous scans was 33 days, but the growth rate (no longer doubling) of the largest nodule has slowed to 65 days. (The 'doubling rate' was based on the growth of a nodule between two scan dates.)

Looking for more silver lining, there were NO NEW metastases found. When compared to previous scans, my last PET Scan (Jan 29, 2007) showed the largest nodule was doubling in size every 33 days. Based on that projection the largest nodule should have grown to 30mm in size (and I assume would have, had I not taken this course of intervention). Instead, it measured 20mm. I started taking LDN on Feb 12th, 9 days after my last CT scan.

Dr. Bihari's clinical studies show that LDN needs around 6 months to begin seriously impacting the growth of many cancers so I think the fact that the largest nodule was only 20 mm instead of the expected 30 mm over the 4 months, represents around 50% reduction in the expected growth rate (from 33 days to 65 days).

So if LDN started slowing the growth, then it would be a gradual effect as we're dealing with human tissue and immune systems not poisons, so it won't happen overnight. Taking this reality into account and assuming that any reduction will be gradual, I have created a model to track the projected and actual growth rate based on pre and post-LDN scans. Based on this model and focussing on the beginning and end points of nodule growth, the largest nodule appears to have either slowed or stopped.

Before I go on summer holiday, I'm curious to know if my assumption of slowed growth is real. I'll be having a follow-up scan in Aug 2007, a couple of months away. If the nodule growth increases only marginally, say by only 1 mm, this will mean the rate of growth has slowed down to greater than 240 days (based on my model). I'm not expecting a reduction in the tumor size, but if that occurs, all the better.

UPDATE: July 15th, 2007 - Alkaline, pH, and cancer

My new GP asked me at my last visit (my oncologist dropped me) if I was alkaline? Well I knew a bit about this topic but not nearly enough. So I have been researching diet, pH and cancer relationship. Many alternative cancer treatments (DMSO, coral calcium, etc.) are essentially based on raising the alkalinity of the body because cancer cells cannot survive long in an alkaline environment.

I thought there must be some safe and easy methods to do this without the expense and complications of those alternative treatments. First I bought pH test strips at the local pharmacy to check my urine pH balance. Cost about US$10 dollars for 5.5 meters (18 feet) of tape, which will last a long time. I tested myself and was happy with the results – 'in the green' - so pH was over 7 and approaching 8.

From my other readings I thought of baking soda as a way to raise the body's alkalinity safely and found on the internet that many are drinking a small amount of baking soda dissolved in a glass of water twice a day. They claim it works wonders. One doctor in Italy, Dr Tullio Simoncini (specialist in oncology) has even used a cancer treatment regimen based on administering bicarbonate salts orally, through aerosol, and intravenously. There is one case he describes where he treated a man for lung cancer using bicarbonate salts.

He says the man survived for over 20 years. Since keeping the body's pH balance is fundamental to overall health, making it more alkaline is not that unusual and if it does prevent many of the things that ails the body, that would seem to be a complementary approach to the LDN that I'm taking now.

LDN boosts the immune system, while making a more alkaline body makes an inhospitable environment for the cancer cells to survive for long. Makes sense to me and I'll add this to my lifestyle.

UPDATE: August 2nd, 2007 - Its Official - LDN is working

Had a CT scan on August 1st and received the results today. Wonderful news as the results showed stability with no significant increase in tumor sizes or any new metastases. LDN has apparently almost stopped the largest tumor growth plus all the smaller ones that were noted in the previous scan on June 11th.

My last scan was June 13. At that time the growth rate had slowed to 140 days. My scan on August 1 was 51 days later.

Recalculating the growth rate of the largest tumor since previous scan has now resulted in a growth rate of 242 days versus 140 days from the previous scan on June 11th, and the scary 33 day 'doubling rate' before I started LDN on February 12th.

Since Dr. Bihari found in his studies that 6 months is the point where LDN has been known to show positive benefits, I'm glad that I fit the typical profile. It means that there's hope the next scan in November will continue following Dr. Bihari's experience - which is that the nodules begin to decrease in size after around 6 months.

Now that would be a great Thanksgiving that I'll be looking forward to.

UPDATE 15 May 2008

CT SCAN shows nodules still growing slowly which gives me time to try other treatments that will target the largest nodule directly.

Unfortunately I'm also dealing with issues caused by the radiation 'treatments' I underwent in Dec 2005/Jan2006 (after the cervical tumor was removed). My tissues in my pelvic region were badly damaged by the radiation, and in January of 2008, a fistula developed in my bladder, then in February of 2008 my bowels constricted, causing severe stomach pains, so I had an operation to remove part of my colon (damaged by radiation treatment) and had a colostomy inserted.

UPDATE 13 Jun 2008

I underwent Radio Frequency Ablation (RFA) to destroy the largest nodule in my left lobe. I've now reset the 'clock' on the largest tumor growth, expecting that the LDN will continue to hold down the growth of the other existing nodules, and extending my high quality of life. Apart from early on, LDN has had no side effects for me, and anyone seeing me would never believe I have cancer since I feel and appear healthy.

UPDATE July 2008

In January 2008 I developed a fistula in my bladder and it was stitched back together via corrective surgery. Then in February of 2008 my bowels were constricted, causing severe stomach pains so I had an operation to remove part of my colon, resulting in the need for a colostomy. Both problems were due to damage caused by radiation treatment in Dec 2005/Jan 2006.

On 13th June I underwent successful treatment with Radio Frequency Ablation (RFA) to one of the larger tumors in my Left upper lung lobe. Multiple metastatic nodules were evident, but some of them were showing calcifications. It wasn't reported on the scans. My oncologist noticed the calcifications when he viewed the scans during our appointment.

It's now been 16 months since diagnoses with metastatic lung cancer, and well beyond the 10 months my oncologist had given me, even with chemotherapy. LDN has been successful in controlling the cancer growth with no side effects, a success beyond anything I'd hoped for, or that conventional medicine has been able to offer or achieve for my cancer type.

I'll continue with my current LDN protocol and have another follow up in coming months.

UPDATE July 2009

I was in hospital in Feb/March 2009 having surgery to correct ongoing problems caused by pelvic radiation damage from External Beam Radiotherapy (RT) treatment in Dec2005/Jan 2006.

I had developed a fistula in my bladder back in January 2008. It had been corrected by surgery (stitched together), but all the tissue in my pelvic region was and still is so badly damaged from radiation that it is too fragile and won't hold stitches. The stitches failed and I had to have further surgery to correct it, resulting in an almost permanent catheter. Also early in 2008, I had an operation to remove part of my colon (again from radiation treatment damage), resulting in the need for a colostomy.

I was able to cope with all that and went on a cruise over Christmas 2009, but while in Bangkok my weakened right leg tripped me up and I fell down and opened up a second and 3rd fistula between my lower intestine and bladder. My doctor has tried many things to repair the fistulas but due to the extent of damage to tissues, surgery isn't an option, and instead, all 3 fistulas are now temporarily 'plugged' with catheter balloons to route all discharges to the catheter bags instead of the rectum.

So I now have three catheters, and I've been healing from that surgery these past 4-5 months. Needless to say, I haven't gone in for any scans and don't have any news on the cancer/LDN front.

I plan to have updated scans done in August this year, when I return from my next trip. I have just been keeping quiet and healing from the radiation damage corrective surgery, and that takes a long, long time to recover from.

I have nothing else to report except that I feel good on the cancer front with LDN. I've been on LDN almost 2.5 years now, and am still here - 18 months past the anticipated 10 months.

UPDATE April 2010 – over 3 years on LDN

I haven't been doing so well after all the operations, beginning with the fistula repair back in January 2008, and corrective surgery since then (see earlier entries). In all this time, I've only stopped taking LDN when I needed strong pain medication due to very painful medical procedures. I would go off LDN for a few days so the pain meds would work, then back on after I eased off the pain meds.

The most recent development was in January. I developed severe nerve pain in my right leg. A Pelvic exploratory via CT guided catheter determined an enlarged lymph node was pressing on the nerve in my leg. The lymph node was aspirated by needle and 10ml of liquid was removed, which is a substantial amount for a lymph node. The doctor was sure it was cancerous but lab tests came back as negative (thanks I'm sure to LDN).

An added complication was that my ureter tube almost closed, causing severe back pain and almost collapsing my right kidney. Doctors went in and inserted a stent into the ureter to resolve the kidney problem.

So things have been difficult, but I'm still taking LDN nightly. I'm hoping to hang in there as the body replaces its tissues and maybe sometime in the future, a workable treatment for fistula repair will be found. In the interim I'm considering my options.

This is an article http://www.jfponline.com/Pages.asp?AID=4165 on possible experimental procedures for fistulas such as mine, so I might next try pig tissue patch porcine small intestine submucosa (I guess a form of transplant) which is applied to the fistula and hopefully allows new tissue to grow over the patch to seal the fistula. I haven't gone this route yet as my doctor needs to research the procedure and find sources for the patch material.

The only procedures my doctor will do are those that can be done without resorting to surgery because my tissue will not heal from another surgical procedure.

I don't think direct tissue transplants would work for me because most doctors don't want to do anything (because I'm stage 4). My current doctor, however; will try anything and so far has been trying experimental things with so far only temporary success as he expects the 3 catheter balloon fistula seals to soon work free.

So I'm on a low residue diet and 'Ensure', a complete liquid nutrition by Abbott Labs, to try and limit the discharges. I've also had trouble swallowing solid foods and my taste buds are very finicky.

I hope I find a treatment eventually that will get me on some path towards normalcy.

I had my last CT scan of the Thorax on 22 August 2009. The Oncologist said the radiologist's report was 'heartening' because for the first time the report mentions ' ... some of the nodules show intralesional amorphous calcifications …' and ' … intralesional calcifications are present … '.

The Oncologist said that intralesional calcifications are an indication that a tumor is dying from the inside (indicated by the calcifications) and according to the report there are numerous such calcifications throughout the lung. So even though there was some growth in nodules and number (consistent with what LDN has done which is reduce growth to about 1 mm per month), the numerous calcifications indicate a positive outcome if the tumors are not healthy, and the report adds 'no significant interval change is seen'.

My rationale is that if a tumor isn't able to grow at the rapid rate it requires, then many of the rapidly growing cells must die off before the new cancer cells take root. LDN is holding down the growth rate so the cancer doesn't grow at the rate required to overwhelm my lungs. The oncologist was happy after that result as he sees it as having the cancer under control.

SO… all my current difficulties are directly related to the radiation treatment damage done in 2005/2006, and if I were to give any advice to someone in a similar situation to me, it would be to do the surgery and don't do the radiation (since it didn't work anyway), and go on LDN.

I'm still surviving 2 years longer than my original oncologist predicted I would "if I didn't do his 2nd line chemo regimen".

So from an LDN point of view, it's been doing what it's supposed to do.

Dee, HK
MY PERSONAL WEBSITE: http://www.ldn4cancer.com

Update April 24 2010 – ***Sadly, Dee passed away Thursday 22nd April 2010***

Very sad news.

Dee passed away Thursday 22nd April, 2010.

Dee did not die from cancer, but from a suspected heart attack.

Due to 3 irreparable fistulas in her bladder and intestines, Dee had lost a lot of weight in her last 3 months, her body unable to metabolise the nutrients she so desperately needed.

Coupled with that, Dee had been experiencing severe pain throughout the last few weeks of her life; in her legs, chest, and back, and when in hospital, doctors also detected an irregular heart beat for which she was taking medication.

Dee continued to believe in LDN, and continued to take it up until her last night; but unfortunately Dee's body continued to suffer the after-effects of radiation treatment undertaken between Dec 2005 and Jan 2006, which had taken a heavy, irrecoverable toll on her body.

From the moment we met Dee we were impressed by her courage, her patience, her kindness, and a generosity of spirit that shone its light on everyone. When faced with a life-threatening illness, Dee chose not to be introspective but instead to share her story and her challenge with the world... all in the hope her journey would help others... all of whom she didn't know, and would never meet.

We held Dee in the highest esteem, admired her fortitude, and most especially... her altruism in sharing her journey in the hope it would help others, continuing to do so even when suffering and in great pain.

All of us who've read, benefited, or will benefit from her shared journey, and all those who will suffer less thanks to Dee, are forever in her debt.

We'll miss Dee, and we're so very sad she suffered much in her final months... but also know such a beautiful spirit, now released from pain, will be free to soar across the heavens... and her brilliant light and warmth will instead be reflected on all of us from above.

Dee was incredibly special to all of us.

We'll miss you Dee,
Cris

Dee, Hong Kong

Dee's website: LDN4Cancer
http://www.ldn4cancer.com

Dee, at the LDN 2008 Conference, USC Health Sciences Campus
: http://www.youtube.com/watch?v=dvl9OmxnJM8

Dee passed away on 22 April 2010.

NB *The TNM System is a cancer assessment system that classifies stage of disease according to its anatomical extent. Three factors are assessed; the primary tumor T, the nodule N, and the extent of metastasis M; based on a combination of pathological (pTNM) and clinical (cTNM) tests.
Ref: http://www.upmccancercenters.com/cancer/headneck/staging.html

35 Every condition has improved – Celia

LDN since November 2007
- story submitted June 2008
- story updated July 2008
- story updated Dec 08 & Jan 09
- story updated July 2009
- story updated March 2010
- story updated 9 July 2010 (just over 2.5yrs on LDN)

SPECIFICS

DIAGNOSIS
BEFORE STARTING LDN
- late 1960s to 1972 – hyperthyroid (resulted in partial thyroidectomy in 1971)
- 1990 – osteoarthritis
- 1994 - chronic fatigue
- 2003 – high cholesterol
- 2003 – T4 test re fatigue, hyperthyroid (went back on Levothyroxine thyroid med)
- 2004 - IBS with rectal bleeding (so bad sometimes I did not dare go out)
- 2004 - intestinal diverticula
- 2005 - high blood pressure
- 2005 - mild Systemic Lupus Erythematosus (SLE)
- Jan 2006 - **abdominal aortic aneurism, size 3.5cm**
- 2006 – chronic obstructive pulmonary disease (COPD)
- 15 May 2006 - Lung cancer (no tumour found, just metastases to the chest), prognosis with palliative chemo 6-12 months to live. **Palliative care treatment of chemo and radiation resulted in 'No Evidence of Disease' (NED for lung cancer), but told the cancer "would come back", with "less than one per cent chance it wouldn't".**
- Jun 2007 - hiatus hernia and gastric ulcer - no sign of cancer in stomach
- approx July 2006 – **abdominal aortic aneurism had grown to 3.8cm**
- Sept 2006 – 'No evidence of disease' (NED for lung cancer)
- Jan 2007 – COPD flared after chemo & chest radiation - chest x-ray showed inflammation due to infection but clear of cancer
- 14 Mar 2007 – X-ray re back pain found thinning of thoracic spine due to radiation and steroids - thus started Adcal D and Alendronic Acid to build bone.
- 3 May 2007 – NED for lung cancer
- Sept 2007 - **enlarged lymph node in chest, 1cm diameter**
- 1 Oct 2007 – NED for lung cancer, **abdominal aorta aneurism had grown to 4.5cm**
AFTER STARTING LDN
- Dec 2007 – blood pressure lowered (after commencing LDN)
- 17 Dec 2007 - NED for lung cancer, **abdominal aorta aneurism had grown to 4.8cm**
- Jan 2008 - Temporal mandibular joint (Tmj)
- May 2008 – NED for lung cancer, **abdominal aortic aneurism had ceased growing**
- Aug 2008 – **Abdominal aortic aneurism has not grown any further and remains at 4.8cm, NED for lung cancer, enlarged lymph node in chest still 1cm diameter**
- Sept 2008 – Chest Infection
- Dec 11 2008 – Oncologist – weight gain - **no evidence of the enlarged lymph nodes and he could not palpate any of these at all** - full body bone scan ordered for 8 Jan 2009 re painful upper back
- 8 Jan 2009 – physical examination – **no evidence of enlarged lymph node in chest**
- Jan 15 2009 – NED for lung cancer
- Jun 2009 – **abdominal aortic aneurism has decreased in size from 4.8cm to 4.5cm**
- 23 Jul 2009 – physical examination by Oncologist – **no suspect lumps or bumps detected by palpation**
- 23 Mar 2010 - NED for lung cancer
- 9 Jul 2010 – Severe headaches - Head/Brain scanned - No evidence of Disease (NED)
- July 2010 – Severe headaches - attributed to TMJ - additional medications prescribed.

TESTS (pre LDN)
- late 60s – thyroid problems
- 1990 - osteoarthritis
- 2003 – T4 test re fatigue, hyperothyroid
- 2004 – colonoscopy - IBS
- 2005 - positive ANA test detected mild Systemic Lupus Erythematosus (SLE)
- Jan 2006 – ultrasound detected **abdominal aortic aneurism, size 3.5cm**
- May 2006 – Mediastinoscopy detected **enlarged lymph nodes in chest (Lung cancer)**
- approx July 2006 – ultrasound - **abdominal aortic aneurism had grown to 3.8cm**
- **Sept 2006** – CT scan for Lung cancer revealed **'No evidence of disease' (NED for lung cancer)** following palliative chemo & radiation
- Jan 2007 – chest x-ray showed inflammation due to infection – NED for lung cancer
- 14 Mar 2007 – X-ray re back pain found thinning of thoracic spine due to radiation and steroids
- 3 May 2007 - CT scan - 'No evidence of disease' (NED for lung cancer)

- Jun 2007 – Gastroscopy revealed hiatus hernia & gastric ulcer, no sign of cancer in stomach
- 5 Jul 2007 – X-ray – hip - re future hip surgery
- Aug 2007 - Spirometry re breathing and to assess for surgery - I think the result was a FEV I of 42%.
- Sept 2007 - CT scan (prior to hip surgery) - **enlarged lymph node in chest 1cm diameter**
- 1 Oct 2007 - CT scan of chest prior to hip replacement - NED, **abdominal aorta aneurism had grown to 4.5cm**

TESTS (post LDN)
- Dec 2007 – blood pressure lowered (after commencing LDN)
- 17 Dec 2007 - CT scan – NED for lung cancer, but **abdominal aorta aneurism had grown to 4.8cm**
- May 2008 – X-ray – chest - NED for lung cancer
- May 2008 – ultrasound - **abdominal aortic aneurism has not grown any further and remains at 4.8cm**
- Aug 2008 – ultrasound - **abdominal aortic aneurism has not grown any further and remains at 4.8cm**
- 15 Aug 2008 – X-ray – chest - NED for lung cancer
- 16 Aug 2008 - CT scan - NED for lung cancer, **enlarged lymph node in chest still 1cm diameter**
- 8 Jan 2009 – physical examination – **no evidence of enlarged lymph node in chest**
- 15 Jan 2009 – CT scan result (from 8 Jan) full body bone scan – no evidence of disease (NED for lung cancer)
- Jun 2009 - ultrasound - **abdominal aortic aneurism had decreased in size from 4.8cm to 4.5cm**
- 23 Jul 2009 – X-ray – chest - No evidence of disease (NED for lung cancer)
- 23 Mar 2010 - bronchoscopy – No evidence of disease (NED for lung cancer)
- 9 Jul 2010 – Head/Brain Scan - No evidence of Disease (NED)

HOSPITALIZATION/SURGERY
- 1971 - partial Thyroidectomy
- 10 Oct 2007 - total left hip replacement
- Aug 2008 - Hospitalised due to coughing blood on 2 occasions – diagnosed with chest infection

MEDICATION/TREATMENT (pre LDN)
- 1971 to 1972 – 1 x 100mcg daily x Levothyroxine, following partial Thyroidectomy (ceased '72 as I felt well)
- 2003 to Nov 2007 – 1 x 100mcg daily x Levothyroxine (thyroid med)
- 2004 to Nov 2007 – 2mg x Loperamide (for IBS - ceased after improvement on LDN)
- 2004 to Nov 2007 - 135mg x Mebeverine (for IBS - ceased after improvement on LDN)
- 2005 to Nov 2007 – Plaquenil (for SLE)
- 2005 to Nov 2007 – Rampiril (blood pressure)
- 2005 to Nov 2007 – 1 x 20mg Lipitor (statin)
- 2006 to Nov 2007 – Atrovent 500mcs per 2ml in nebuliser daily (for COPD)
- 2006 to Nov 2007 – Salamol Inhaler as needed (for COPD)
- 2006 to Nov 2007 – 1 x Mucodyne capsule 2 or 3 times per day (for COPD)
- May 2006 to Nov 2007 – 10mg to 20mg daily of Temazepam (after cancer diagnosis)
- Jun 2006 to Nov 2007 – 2mg x Valium as needed (after cancer diagnosis)
- Jun 2006 to Aug 2006 – palliative chemo - 8 doses x chemotherapy (Cisplatin & Carboplatin) over 2 months
- Aug 2006 to Sept 2006 – palliative chemo - 12 doses x radiation over a period of 2.5 weeks
- Jan 2007 - I had a very bad exacerbation of COPD, which landed me in the hospital. I came out on oxygen. I continued to use Atrovent 500mcs per 2ml in nebuliser. Was also prescribed steroids (Prednisolone tablets), and Flixotide inhaler (which also contains prednisolone)
- Jan 2007 to Nov 2007 - 10mg Amitriptlyline (for pain in Temporal mandibular joint)
- Feb 2007 - steroid injection in left hip for pain
- Mar 2007 to Nov 2007 - Adcal D3 daily (to build bone due to loss following chemo/radiation)
- Mar 2007 to Nov 2007 - 70mg x Alendronic Acid x once weekly (to build bone due to loss following chemo/radiation)
- Apr 2007 to Nov 2007 – Iscador (series 2) daily – a derivative of Mistletoe - homeopathic hospital referral
- Jun 2007 to Nov 2007 – 20mg to 40mg x Ozmeporazole (for Hiatus hernia and Gastric ulcer)

MEDICATION/TREATMENT (post LDN) - CEASED
- Nov 2007 to Jan 2008 – 2mg x Loperamide (for IBS - ceased after improvement on LDN)
- Nov 2007 to Jan 2008 - 135mg x Mebeverine (for IBS - ceased after improvement on LDN)
- Nov 2007 to Jan 2008 – Plaquenil (for SLE)
- Nov 2007 to Jan 2008 – Rampiril (blood pressure improved 2 mths after starting LDN so I ceased taking)
- Jan 2007 to July 2008 - Flixotide in nebuliser (prednisolone)
- Nov 2007 to approx 2009 – 1 x 20mg Lipitor (statin) – (Update Jul 2008 - when I remember to take them)
- Nov 2007 to approx Aug 2009 – Atrovent in nebuliser daily (for COPD), (From Jul 2008, rarely used)

MEDICATION/TREATMENT (post LDN) - CURRENT
- Nov 2007 to present - 1 x 100mcg daily Levothyroxine
- Nov 2007 to present – Salamol Inhaler as needed (for COPD)
- Nov 2007 to present – 1 x Mucodyne capsule 2 or 3 times per day (for COPD)
- Nov 2007 to present – 10mg to 20mg daily of Temazepam (since cancer diagnosis)
- Nov 2007 to present – 2mg x Valium as needed (since cancer diagnosis)
- Nov 2007 to present - Adcal D3 daily (since radiation thinned thoracic spine)
- Nov 2007 to present – 70mg x Alendronic Acid x once weekly (since radiation thinned thoracic spine)
- Nov 2007 to present - 10mg Amitriptlyline (for pain in Temporal mandibular joint)
- Nov 2007 to present – 20mg to 40mg x Ozmeporazole (for Hiatus hernia and Gastric ulcer)
- Nov 2007 to present – Iscador (series 2) daily – a derivative of Mistletoe - homeopathic hospital referral

© Case Health Pty Ltd

- Nov 2007 to present - 4.5mg Low Dose Naltrexone (LDN)
- Jul 2008 to present – Spiriva in inhaler (replaced Flixotide) x once daily
- Dec 2008 to present – occasional NSAID for back pain
- July 2010 to present - Naproxen x 250mg x twice per day (morning & night)
- July 2010 to present - Amitriptyline x 20mg x once per day (night)

LDN - DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my Naltrexone at bedtime, usually around 9.30pm.
c) Type – 4.5mg capsules were initially compounded with pure Naltrexone powder and calcium carbonate filler, but filler was changed to lactose soon after starting (after I learned calcium carbonate can slow the release).

DIET
- May 2006 to early 2009 – I read about vitamin B17 and I started taking this almost every day in kernel form, but I discontinued taking this in early 2009.
- May 2006 to present – I changed my diet but not radically. I now eat mainly eggs and fish, vegetables and fruit, no red meat. It was easy to give up red meat because after having chemotherapy I could no longer stand the taste of it. I remain careful about my sugar intake because cancer loves sugar. I have discovered a penchant for the darkest chocolate I can find, at least 85 to 86% cocoa.

SUPPLEMENTS - CEASED
- late 2006 to early 2009 - B17 (in the form of 20 Apricot kernels daily - 3-4 at a time during the day, with a day off once or twice a week as per Phillip Day's guidelines)
- July 2008 to 2009 - L. Acetyl Cysteine

SUPPLEMENTS - CURRENT
late 2006 to present - Vitamin C
late 2006 to present - Vitamin E
late 2006 to present - Vitamin B
late 2006 to present - Magnesium
July 2008 to present - Selenium
July 2008 to present - Alpha lipoic acid
July 2008 to present - Milk thistle

ACTIVITIES, EXERCISE, INTERESTS
- Since improvement I'm able to get around a bit more and am walking more now. Feel much more alert.

MY STORY – June 2008

My name is Celia and I live in Scotland… not exactly a spring chicken, but hey, I'm working on it!!

May of 2006 gave me shocking news: I had a chest full of cancerous lymph nodes. Tears and grief overwhelmed me, grief for the life I would never have, and for those I would leave behind. The primary tumour was never found, but I was treated as 'lung' and thus received palliative care only with eight doses of chemo, followed by 12 doses of radiation. It was expected I had 6 to 12 months of living left to do.

I also had the following conditions: mild lupus, IBS (so bad sometimes I did not dare go out), intestinal diverticula, COPD, thyroid problems (had a partial thyroidectomy years ago), osteoarthritis, high blood pressure, high cholesterol, and chronic fatigue.

After my conventional treatment, the oncologist was amazed when I went into remission, but he assured me this would not last, and that I had "less than 1% chance" of making it. Far be it from me to accept that! No further treatment was implemented after that initial work. It was a case of watch and wait, but I was unwilling to do either. Instead, I went in search of anything that might help me.

Of course I went on the usual supplements (but knew this was not enough), changed my diet (but not radically), and now eat mainly eggs and fish, vegetables and fruit, and no red meat. I have also discovered a penchant for the darkest chocolate I can find, at least 85 to 86% cocoa. I read about vitamin B17 and I started taking this almost every day in kernel form.

In January of 2007, I had a very bad exacerbation of COPD, which landed me in the hospital. I came out on oxygen and steroids. I then learned about Iscador, a derivative of Mistletoe, and fortunately, as there is a homeopathic hospital not too far from me, I got a referral and now use Iscador (Series Two), on a regular basis. Still, I searched the Internet, and, lo and behold, came across Low Dose Naltrexone (LDN). I had

never heard of it before, but it seemed like a miracle drug. I had to have it. I fought for it, got it on the NHS, and so it costs me nothing.

I got my first bottle but did not dare take it, as I was on steroids regularly for my chest, and had to have my hip replaced and was thus also on painkillers. Steroids and painkillers should not be taken concurrently with LDN. Each night, I looked at the bottle, and each night I thought, 'Shall it be now?' As soon as my hip pain began to diminish, and I could come off the steroids (it was day ten), I took my first dose of LDN. I don't know why, but I was frightened of it!

My first feelings on LDN were as though I was on a bit of a high. Although I felt great, I had some disturbed nights, but not too many strange dreams (which happens with some people). I have now determined when it is best for me to take it. This is usually about 9:30 pm, and, as I take sleep aids an hour later, this seems to be working for me. Very soon after starting the LDN, I found I did not need the oxygen for my COPD; I only need to nebulise now maybe once a day, if that; and today I walked the furthest I have been able to for what seems like ages. It was a miracle, and I still can't believe I did it! One thing I also noticed early on was that I was not spending half my life in the loo. I had been referred for another sigmoidoscopy late in 2007 after my hip operation, but I cancelled it.

To this day, I haven't had the bowel problem like I did before LDN. All my bowel problems went away, as did 'dire rear' and rectal bleeding, so I cancelled the sigmoidoscopy as I was sick of being poked about and was asymptomatic which was, and is wonderful!! My energy began to return. I had had chronic fatigue for many years, but slowly am getting more energetic. I was fit enough to have a hip replacement about six months ago. Oh, the relief!!

My last x-ray showed no signs of the cancer which was supposed to have killed me over a year ago, and my last CT scan revealed that my abdominal aortic aneurism had ceased growing. My blood pressure is now normal (after being too high for a few years), and I have come off my BP medications. My lupus does not bother me at all. I have a good appetite and am gaining weight.

UPDATE July/August 2008 – 8-9 months on LDN

At the time of this writing, I have been on LDN for about seven months. I feel quite good, all things considered, and I recommend LDN to everyone! The chronic fatigue is much, much better, I have more energy, and there is no sign of lupus. Although I was already in remission from the cancer, the LDN stopped my horrific bowel problem. That's now history!! Don't know if the LDN lowered my BP but something did! My COPD, which was made worse by chest radiation, is also much better than it was. On July 25 I stopped using the nebuliser and instead use Spiriva once daily through my inhaler. Multiple adverse health problems, including cancer, have all been helped by LDN.

A brief update from my early August 2008 appointment with my Oncologist follows: When I saw my Oncologist, he was surprised at how well I looked. He said he thought there should have been 'something' showing up by now. I told him I will not die from this blasted disease … well I will die, but not from that! He said the way I'm going on he wouldn't be surprised!!! As far as he was concerned, I need no further testing at this time. I'm asymptomatic and there is no sign whatsoever of the earlier enlarged lymph nodes - he said - amazingly - absolutely nothing!!!! I said maybe it's the Iscador and LDN, and he conceded. I don't have to see him again for four months. All of the nurses commented on how well I looked. Maybe LDN is also the elixir of youth - ha ha, gimme more of that!!!!

My Onco thinks my GP is being very good to me supplying the LDN and Iscador. I told him right off … if they stop giving it to me, I'll go ordering on the net ..... I will not stop taking LDN for anyone .... So, it seems I am doing good so far, and that's what I wish for us all ..... If this story helps even one person, then it has been well worth the effort.

UPDATE – December 2008 – over 12 months on LDN

I have lung cancer and also a 'growth' on my adrenal gland. The doctors don't know whether the growth is cancerous or not, as it's done nothing but sit there unchanged since my diagnosis in 2006.

A few months ago (August 2008), I was admitted to hospital for a couple of days as I had, on two occasions, been coughing up blood. As a precaution the attending physician ordered a scan. There were no changes on this re my cancer from the one I had had before my hip surgery a year ago! Diagnosis - a chest infection....

December 11th 2008, saw my oncologist, he was surprised that I had put on weight. I have been having some upper back pain so he has ordered a full body bone scan for 8th January 2009. He saw no reason to do a CT as I am still asymptomatic. He says I am doing amazingly well!!:-))

I have been on Iscador for about 18 months now, and LDN for just over a year - to heck with it all - I went for it and as far as I know am OK.

UPDATE – January 2009

December 11th 2008, saw my oncologist, he was surprised that I had put on weight. As I have been having some upper back pain he has ordered a full body bone scan for 8th January 2009. He saw no reason to do a CT as I am still asymptomatic, he says I am doing amazingly well!!:-))

8th January 2009, full body bone scan re back pain, result obtained on the 15th January - NED. The oncologist remains amazed that I am still apparently in remission. There was no evidence of the enlarged lymph nodes, he could not palpate any of these at all, he seems bemused! It is now nearly three years since I was given 6 - 12 months.....

UPDATE - July 2009 –– over 18 months on LDN

I'm up to the proverbial eyeballs right now!!

In May of 2006 I was given 6-12 months. That was just over 3 years ago now. I'm still here, 2 years past the most optimistic of that time frame. Health-wise, as far as I know, I remain little different!!!

In June, my ultrasound for the aneurism came back that it had actually decreased in size from 4.8cm to 4.5cm.

I saw my Oncologist on 23rd July, and there were no obvious lumps or bumps to be felt, and they were quite pleased with my progress – and the results of an X-ray done on the same day came back with 'No Evidence of Disease' (NED) !!!!!!!!!!!!!!!

UPDATE - March 2010 & July 2010 – Over 2.5yrs on LDN

In May of 2006 I was given 6-12 months. That was just over 4 years ago now. I had a bronchoscopy on 23rd March 2010, and the result was NED (no evidence of disease). Whew !!! I'm still here, 3 years after they said I wouldn't be.

I had been getting awful headaches of late - unbearable really - so the Doctor said that, given my history, we would get a head/brain scan, which I did on 9 July 2010. It came back clear. There was 'No evidence of Disease (NED)', so now they are treating my Temporal Mandibular Joint (TMJ) problem, apparently a bad one because jaw crackles beautifully.

So I'm now on anti-inflammatories (Naproxen) and a muscle relaxant (Amitriptyline). As there is bruxism as well, I'm buying a splint. It was pain like never before and I for sure know about pain. I received other treatment from my homeopathic doctor and am rubbing arnica cream into my jaw. I reckon I must break the record with things wrong!!!:-)))

I am also getting acupuncture for the TMJ. I started last week. No recent check on the Abdominal Aortic Aneurism but my last scan showed some growth and it's now about 5mm. Yikes, I will have to be careful.....

Celia, Scotland

Celia, Scotland

"8th January 2009, full body bone scan re back pain, result obtained on the 15th January - NED. The oncologist remains amazed that I am still apparently in remission. There was no evidence of the enlarged lymph nodes, he could not palpate any of these at all, he seems bemused! It is now nearly three years since I was given 6 - 12 months....." Jan '09

March 2010: "I had a bronchoscopy on 23rd March 2010, and the result was NED (no evidence of disease). Whew !!! I'm still here, 3 years after they said I wouldn't be."

36 Five years breast cancer free – Lola

LDN since 21 April 2004
- story submitted July 2008
- story updated June 2009
- story updated April 2010 (6yrs on LDN)

SPECIFICS

DIAGNOSED
- 21 Apr 2004 - Breast Cancer Stage IIA
Recommended Treatment Plan – Not Undertaken
Chemotherapy: 5-FU--Intravenously every 3wks along with
Adriamycin-Intravenously every 3wks along with
Cytoxin--Intravenously every 3wks
for six treatments
Then
Radiation Therapy for approx 6 weeks daily x 5 days, Monday through Friday
(No Anti-hormonal (anti-estrogen) therapy possible)

TESTS (pre LDN)
Copied from the Medical Report, April 2004:
Size of tumor 2.8cm, location 12 O'Clock.
Type Grade III, Poorly Differentiated, Infiltrating (Invasive) Duct Cell Adenocarcinoma
Hormone receptors Estrogen-Negative, Progesterone-Negative
HER-2-NEU Oncogene Negative Over-expression
Flow Cytometry (strands of DNA) Diploid-two
Rate of Growth (percentage of cells dividing) S-Phase Of-13.6% (High-Fast)
Sentinel Node Axillary Lymph Nodes, none of two were positive
Staging Negative for Metastases, Stage IIA (T2 NO MO)
Percentage chance of relapse: 33% over 5-10 years with no further therapy
- 21 to 29 Apr 2004 - No biopsies were done prior to or during surgery

MEDICATION (pre LDN)
- prior to Apr 2004 – none, apart from birth control pill

MEDICATION (post LDN)
- 21 Apr 2004 to present – 4.5mg Low Dose Naltrexone (LDN)

SURGERY (post LDN)
- 29 Apr 2004 - Surgery - Right Partial Lumpectomy

TREATMENT (post LDN)
- May 2004 to Jun 2004 - Radiation Therapy for 6 weeks, daily x 5 days per week, Monday through Friday

TESTS (post LDN)
- July 2008 – To-date bone scans, blood work, mammograms, and CT scan have all come back negative for cancer
- May 4 2009 – Blood Test – no cancer markers

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - at 10pm every night
c) Type - compounded capsules using pure naltrexone powder and lactose filler

SUPPLEMENTS
- prior to Apr 2004 - none
- Apr 2004 to present, as follows:
DL-Phenylalanine 500mg x 2 capsules per day
Tart Cherry Juice – one glass daily
Vitamin D3 15mcg (600 IU) x 1 daily
Fish Oil capsule 1000mg x 2 daily

COMPLEMENTARY THERAPIES
- none

DIET
- 1973 to 1990s – Low Carbohydrate diet
- 1990s to 2002 – off and on Low-Carb diet
- 2008 – Commenced Suzanne Somers diet

© Case Health Pty Ltd

EXERCISE OR INTERESTS
- Apr 2004 to present – normal, no particular restrictions

MY STORY – July 2008 – over 4 years on LDN

I was in my mid 60s when diagnosed with Breast Cancer in April 2004.

Before the diagnosis, I'd only ever been admitted to the hospital once in my lifetime, and that was to give birth to my wonderful daughter in 1963.

I've always been healthy - never had blood pressure problems, nor cholesterol problems. I've never been on any medications except for many years of birth control pills. I seldom even took aspirin. I did smoke, but only until my mid thirties, then I quit for good. I'm 5ft 1in tall and have always weighed around 110lb.

At the time of diagnosis my daughter was taking Low Dose Naltrexone (LDN) for her Multiple Sclerosis (MS), and was doing really well, so she immediately put me on 4.5mg of LDN the night of 21 April, 2004.

I decided to go ahead with the recommended surgery, a Right Partial Lumpectomy, on 29th April, then have the radiation therapy, but I also wanted my daughter to schedule a consultation with Dr Bernard Bihari, to give me a second opinion on the chemotherapy.

On June 9th 2004, during the time I was undergoing radiation therapy, I had a phone consultation with Dr Bihari, after I'd faxed all my medical reports in advance.

After consulting with Dr Bihari I decided not to undertake chemotherapy, but instead continue taking the 4.5mg of LDN each night.

Dr Bihari told me that, as I was taking LDN before the lumpectomy, any cancer cells that may have escaped during surgery would have been destroyed like pac-men by the immune system.

At Dr Bihari's suggestion, I've also been taking two 500mg DL-Phenylalanine capsules, Solaray brand, every day on an empty stomach - to keep my endorphins up throughout the day. (NB This is not for everyone. There are cautions on the label. For example, if you have high blood pressure or PKU, you cannot safely take this supplement.)

It is now July 2008, and ALL of my bone scans, blood work, mammograms and other scans have come back negative for cancer.

I continue to take 4.5mg LDN at 10pm every night, adhering to Bihari's LDN treatment protocol.

I have now been cancer free for 4 years.

Update: June 2009

On May 4th, 2009 I had a blood test to check for cancer markers, and there were no signs of cancer. My doctor said my blood-work couldn't be more perfect. I can now move to less frequent, annual checks. I've been Breast Cancer free now for 5 years. I'm keeping candida yeast overgrowth to a minimum so I can get the maximum benefit from the LDN.

Update: April 2010

I'm still taking LDN, and I'm still cancer free. No changes to anything.

Lola, USA

Reference: ' ... As a fat-soluble vitamin, vitamin D requires some dietary fat in the gut for absorption. ... Very few foods in nature contain vitamin D. The flesh of fish (such as salmon, tuna, and mackerel) and fish liver oils are among the best sources ... ' http://ods.od.nih.gov/factsheets/vitamind.asp

Lola, USA

"I've been Breast Cancer free now for 5 years. I'm keeping candida yeast overgrowth to a minimum so I can get the maximum benefit from the LDN." Jun '09

37 Cancer, back from the brink - Eileen

LDN since December 2007
- story submitted 22 July 2008
- story updated March & April 2009 (over 1 year on LDN)

SPECIFICS

DIAGNOSED
- 2006 – Irritable Bowel Syndrome (IBS)
- June 2007 - tumours of the ovary - very likely cancerous
- June 2007 – Ovarian cancer, Stage 3
- June 2007 – Leak between bowel & bladder - after surgery to remove tumours
- July 2007 – Weeks to live - following failure of correctional surgery
- Sept 2007 – bladder leak healed
- Mar 5 2008 – doctor visit re results of test Feb 4 2008 - no evidence of tumours
- Mar 2009 – Ovarian Cancer detected in 2 very small spots, chemotherapy recommended

TESTS
- Jun 2007 – CAT scan in hospital – detected ovarian tumours
- June 2007 – CAT scan – confirmed Ovarian cancer, which had metastasised to my Omentum and Gallbladder
- June 2007 - CA-125 blood test - 1700
- Sept 2007 – CAT scan, and kidney function test prior to chemotherapy
- Jan 2008 - CA-125 blood test - 400
- Apr 2008 - CA-125 blood test - 35
- Jul 2008 - CA-125 blood test - 7 (up to 35 is normal)
- Feb 4 2008 – CAT scan – no evidence of tumours
- Oct 2008 - CA-125 blood test - 9
- Feb 2009 - CA-125 blood test – 45 (increase)
- Mar 16 2009 – CAT scan – Ovarian Cancer detected in 2 very small spots

SURGERY/HOSPITALISATION
- June 2007 – Emergency trip to hospital with suspected blocked bowel. Two doctors told me the scan showed I had tumours of the ovary, which they thought very likely were cancerous.
- June 2007 – surgery to remove tumours completely was unsuccessful due to where they were situated, and I ended up with a leak between my bowel and bladder that caused food to pass in my urine.
- July 2007 – surgery to correct bowel/bladder leak resulted in a colostomy, then one week later I had faecal matter coming through the wound because the stitches had burst. When I saw the consultant for a prognosis he said I had 'a few weeks to live' because my insides were in such a mess they could not operate again.

MEDICATION/TREATMENT (pre LDN)
- Oct 2007 to Dec 2007 – Paclitaxel & Carboplatin (low dose chemotherapy) every week for 10 weeks as follows:

Sept 12, 2007 - week 1
Paclitaxel 270mg
Carboplatin 370mg

Oct 12, 2007 – week 2
Paclitaxel 123mg
Carboplatin 145mg

Oct 19, 2007 - week 3
Paclitaxel 123mg
Carboplatin 145mg

Oct 26, 2007 - week 4
Paclitaxel 123mg
Carboplatin 145mg

Nov 2, 2007 - week 5
Paclitaxel 123mg
Carboplatin 145mg

Nov 9, 2007 - week 6
Paclitaxel 123mg
Carboplatin 185mg

Nov 16, 2007 - week 7
Paclitaxel 282mg
Carboplatin 470mg

Dec 7, 2007 - week 8
Paclitaxel 282mg
Carboplatin 470mg

Dec 31, 2007 - week 9
Paclitaxel 282mg
Carboplatin 470mg

Jan 25, 2008 – week 10
Paclitaxel 282mg
Carboplatin 470mg

Apr 7, 2009 – week 1
TYPE, DOSE, DURATION UNKNOWN AT TIME OF PUBLICATION

MEDICATION/TREATMENT (post LDN)
- Dec 2007 to Jan 2008 – final weeks of Chemotherapy treatment detailed above.
- Dec 2007 to January 2008 – Sutherlandia 2 x 350 mg daily for 8 weeks
- Dec 2007 to present – 3mg Low Dose Naltrexone (LDN)

DOSE & TYPE
a) Dose – 3mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone around 9pm, just before bed which is usually before 10.30pm
c) Type - My Naltrexone capsules contain pure Naltrexone powder. I don't know what filler is used. I obtain them from Dickson's in Glasgow.

DIET
- Dec 2007 to present - After reading the cancer battle plan, I modified my diet and was not eating meat or milk products, sugar, chocolate, tea, coffee, or alcohol. I eat a little chicken and fish each week, and 10 portions of fruit and vegetables each day.

SUPPLEMENTS
– Dec 2007 to present – I've been taking the following:
Vitamin C – 5000mg x 3 times per day (15000 mg total powdered vitamin C per day)
Kyolic Garlic capsules – 1000mg x 1 per day
Vitamin A – 8000 iu x 1 per day
Vitamin B
Compleate immune - 1 level scoop per day

EXERCISE
- Jul 2008 – I now go to the gym three times per week as well as doing aerobic exercise and maintaining a positive frame of mind.

MY STORY – October 2008

I had been feeling ill for over a year and had been diagnosed with irritable bowel syndrome. However, in the middle of June 2007 I was so ill I had to be taken to the doctor and was sent as an emergency to hospital, with a suspected blocked bowel. I was seen and sent for a scan. Later that evening as I was sitting talking to my eldest daughter, two doctors approached my bed. They told me I had ***tumours of the ovary*** and that they thought it very likely they were cancerous.

This was confirmed by further scans, which found the cancer had also spread to my Omentum (the layer of fatty, protective tissue that covers the abdominal organs), and to my gallbladder. I spoke with the surgeon who said it was stage 3. He said I needed an operation to remove as much tumour as possible and that then I would have chemotherapy.

I said to him that I intended to fight the cancer.

My operation was not as successful as they wanted, as apparently my insides were very stuck together with tumour. The surgeon was still hopeful and made an appointment for me to be seen by an oncologist from the University College Hospital London.

I went home to recuperate.

The appointment was set for 10 days after I left hospital.

However 5 days later I found that when I went to the toilet I had food coming out with my urine. We sent for the GP and I was diagnosed with a leak from the bowel into the bladder.

It was now the beginning of July. I went to the appointment with the oncologist feeling very, very ill and sick. I had been unable to eat or drink much for months and had lost 2 stone. I eventually lost 5.5 stone in total by the end August.

I explained that I had developed a leak and she immediately sent for another oncologist. I was now in another local hospital as that was where she did the appointments for my area. The other specialist arrived and said I would need a second operation to try to repair the problem .It was explained I could not have chemotherapy until my bladder was repaired as the kidney function had to be good before chemotherapy could happen.

I was beginning to wonder what else could go wrong.

I had my second operation about the middle of July and was still feeling very optimistic although scared. I was told they may have to do a colostomy/ileostomy which I did not want. However when I woke up from anaesthetic it was with a colostomy. Okay, I thought, now we can get on with preparing for chemo. However, after about a week the stitches burst and I found that I had faecal matter coming through the wound.

I asked to see the consultant and asked him what my prognosis was. He said I had a few weeks to live and that they could not operate again as my insides were in such a mess.

I asked to go home, as I wanted to be with my family for my last few weeks. I got home to a new house as we had been in the middle of moving. My daughters had done everything for us as my husband had been at my bedside for most of everyday. My eldest daughter moved in to help and my other daughter came around every day with my granddaughter and my new grandson whose birth I had witnessed before my diagnosis.

I was brave at times but very desperate at others. My family and friends were wonderful. One of my daughter's friends put me in touch with the cancer clinic in Bristol and I ordered some diet books and the cancer battle plan.

Another young friend brought me an article on exercise and cancer, so I got the family to get me some dumbbells and tried pushing weights. I was trying to eat but finding it difficult. Nurses were in twice a day to change my dressings. Drugs were moved in to help me through what we thought were my last days. My husband never gave up and bought me a motorised chair so I could get out and go around the shops.

One day in September when I was feeling like a change, we went to have lunch out. The leak form my bladder had healed and my husband decided to ring the oncology nurse at the hospital and tell her I was out and about. She went to the consultant from UCH who was the one who could say ‘yes’ or ‘no’ to chemo. I was given an appointment with her the next week. She said I could have chemo with the hope it might prolong my life and give me a better quality of life.

I was to start the chemo two weeks later, after kidney function tests and a scan. I was to be seen every week for small doses as she felt I was too weak to cope with normal doses. It was a harsh regime and I was seen on the Wednesday by the consultant to check I was strong enough to go to London for Chemo on the Friday.

The chemo went well and I was less sick with it than I had been before and was able to eat more and began to put on weight.

Just before Christmas I was told about LDN and began to explore the internet to find out more. I went to London and got my first prescription just before Christmas.

At the same time I was also changing my lifestyle radically. After reading the cancer battle plan, I’d modified my diet and was not eating meat or milk products, sugar, chocolate, tea, coffee, or alcohol. I was taking vast amounts of vitamin C, garlic capsules, vitamin A, vitamin B. I did all this in consultation with a nutritionist.

I was also taking an African cancer drug called Sutherlandia, which I paid for myself and a powder recommended by the nutritionist and developed by a German Oncologist. All this was designed to boost my immune system.

At the beginning of my diagnosis my CA count was 1700, by January it was 400 and by the end of chemotherapy 35.

I was feeling so well we decided to go to our house in Turkey for 3 weeks. I was able to do a lot of walking and also have a lot of peace. I came back for my next scan and my appointment with the chemo consultant. When I saw her she was delighted she told me my CA count was down to 7 and that my tumours had gone. I was to live a long time and get on with my life.

PHEW!

When my CA count went down to 7, the consultant called me Lazarus. I celebrated by going to Turkey for another holiday.

I do not know what has helped me, the love of family and friends, dedicated doctors and nurses, Chemotherapy (this definitely helped), LDN, my new diet regime, Sutherlandia … or my stubbornness (my old boss said I never do what I am told). It may be a combination of all these things.

My consultant has said to continue whatever it is I am doing as it works. I do not know what the future holds, but I intend to enjoy every day and live life to the full. I feel very lucky.

I have been having regular CAT scans, and I continue to take the same amount of LDN each night. My latest CA count was 9, which is normal - indeed, up to 35 is normal. I go to the gym 3 times a week as well now as exercise (aerobic) is recommended by many Oncologists. I also maintain a very positive frame of mind.

UPDATE: March 2009

Everything is the same but my bloods have gone up to 45 which is outside the normal range. I have a scan on Monday 16th march and results on the 25th march. Fingers crossed it has not come back but I will keep you posted.

UPDATE: April 2009

The ovarian cancer has returned in 2 very small spots. I start chemo on Tuesday, April 7, 2009. I have been offered a trial, which I am going to take up.

Eileen, UK

Eileen, UK

"He said I had a few weeks to live and that they could not operate again as my insides were in such a mess. … I do not know what has helped me, the love of family and friends, dedicated doctors and nurses, Chemotherapy (this definitely helped), LDN, my new diet regime, Sutherlandia … or my stubbornness (my old boss said I never do what I am told). It may be a combination of all these things." Oct '08

"The ovarian cancer has returned in 2 very small spots . I start chemo on Tuesday, Apr 7, 2009."Apr '09

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

© Case Health Pty Ltd

38 Crohn's and Me - Peter

LDN since October 2007
- story submitted July 2008
- story updated August 2009
- story updated February 2010
- story updated April 2010 (stopped taking LDN)

SPECIFICS

DIAGNOSED
- 1996 to 2003 - health deteriorated steadily, many emergency trips to hospital, but no diagnosis. I began to lose weight quite quickly, and during this period I was rushed to hospital 11 times by ambulance and one by car. I was at my wits end. The last time I was picked up in an ambulance I insisted to be taken to the Carlisle hospital instead of Dumfries hospital.
- 2003 - admitted to Carlisle hospital and diagnosed with Crohn's Disease

MEDICATION (pre LDN)
- 1996 to 2003 – no medication
- 2003 to 2003 – during a few weeks in Carlisle hospital - IV morphine & IV steroids
- 2003 to 2006 - Prednisolone (steroids) x 40mg (stopped taking them 2 years ago)
- 2006 to Apr 2008 – no medication

TESTS (pre LDN)
- 1996 to 2003 – approx 12 endoscopies, colonoscopies and barium follow-throughs

SURGERY/HOSPITAL TREATMENT
- 2003 - a section of my intestine, and part of my small bowel was removed

MEDICATION (post LDN)
- Oct 2007 to Oct 2007 - 4.5ml LDN (stomach problems led to reduced dose)
- Oct 2007 to Dec 2007 - 1.5ml LDN
- Dec 2007 to Jan 2008 - 2.5ml LDN
- Jan 2008 to Feb 2008 - 3.5ml LDN
- Feb 2008 to present - 4.5 ml LDN

TESTS (post LDN)
- none

LDN DOSE & TYPE
a) Dose - 4.5ml Liquid LDN
b) Time - I take my LDN at bedtime each night, usually between 10pm and 12pm
c) Type – Liquid (the label says '135 naltrexone')

SUPPLEMENTS
- 1996 to 2008 – I tried lots of herbal supplements.
- Mar 2008 to present - Aloe Vera oil every 3 days and
- May 2008 to present - I now start each day with a chamomile, marigold, primrose tea blend. (I use the actual leaves and buds, soak them in hot water for ten mins, then strain and drink - from a health food shop. It tastes like crap, but seems to set me up for the day and makes me feel good.)
- June 2009 to present – Turmeric supplement daily

THERAPIES
- 2003 – 2008 - Acupuncture - I'd recommend acupuncture highly to anyone suffering from Crohn's. It had no real effect the first time I went, but by hell it did every other time.

DIET
- 1996 to 2008 – very restricted
- 2008 to present: No spices, eggs, or bread. Fruit was off the menu but I now find I can eat it in moderation without adverse consequences. Believe it or not, lucozade was bad news, and red bull a killer. I used to start with black tea but it'd give me a bad gut. Thankfully, my diet is a little less restricted these days: I can have the odd drink of alcohol, very occasionally. If I have an alcoholic drink, then it has to be vodka. Long ago, I used to drink jack daniels but it's a gut rot, as is whisky. All ales and larger make me feel bloated and ill.
- Feb 2010 – I've been using Turmeric in all my cooking. I don't drink anymore, though I did have a pint of lager 2 weeks ago at a party without ill effect. I will continue with not drinking as I think it would knock me back if I did it regularly. I smoke about 6 cigs a day. I eat very well - food that agrees with me. I love cooking and do all my own so I know what's going into each meal and have found to be in very good health since adopting this lifestyle.

EXERCISE OR INTERESTS
- 2008 – I'm getting more exercise and can go for a walk without wondering where the next bathroom is.

© Case Health Pty Ltd

- Feb 2010 **-** I exercise at a local gym when I can, not too much, 15 minutes walking, 15 cycling, 15 on the rowing machine, and then a bit of a swim for 15 minutes. Then I hit the steam room, and it has made quite a difference.

MY STORY - June 2008

I've had Crohn's Disease for some 12 years now. Soon after diagnosis, I had a section of my intestine and a part of my small bowel removed. They then put me on steroids that seemed to ease the pain and make life a little more bearable, but the problem was still there.

I was first ill in 1996 when rushed to hospital on Boxing Day with chest pains. I was worried it was a heart attack, but I was a fit person who was playing 2, sometimes 3 games of football a week. I was checked and they determined it wasn't a heart attack. They had no idea what it was but kept me in for 5 days and kept an eye on me. I was put on an IV drip and given morphine injections to help with the pain. I have to admit I was fine after that for a few weeks, then it happened again and the same process was carried out at the hospital.

I began to lose weight quite quickly, and during this period I was rushed to hospital 11 times by ambulance and one by car. I was at my wits end. The last time I was picked up in an ambulance I insisted to be taken to the Carlisle hospital instead of Dumfries hospital. At Carlisle's I was dealt with in a professional way and had endoscopies and colonoscopies. I was introduced to a gentleman called Mr Palmer who was a cancer specialist. He quickly discovered what the problem was - and a good job too as I had dropped from 12 1/2 stone to 7 stone in a month.

My family never said it, but they all thought I had cancer and were ready to call my brother in from Australia because they were worried I wasn't going to make it. I'd had endoscopies, barium follow-throughs, and colonoscopies by the load before this, but Dr Palmer was the first one that managed to see what the problem was.

Not long after being diagnosed I had surgery - within a matter of days. I have a nice zipper scar that goes down my belly past my belly button. At least he managed to cut out 2 sections that were badly diseased.

I was then put on prednisolone steroids, 40mg, and was on this dosage for at least 3 years (1997-2000), before being told I should have reduced it years before. I steadily reduced the dose and began to feel a bit better, but my whole life changed from the day I first fell ill.

As you know there is no cure for this Crohn's Disease and it is the most intrusive disease known. It affects your whole way of life, no more going out and relaxing, having a drink or going to a restaurant and eating what you want. It's a case of let's plan every trip based on; "are there toilets nearby?", or "sorry, we can't attend that restaurant as they do not serve suitable food". There is also the embarrassing side of the illness that all of us with digestive disorders know about, but I won't touch on it in this story.

I could not go out for meals and drinks when I wanted. I found going anywhere a potential disaster, as I found myself needing the toilet and would be in it for ages so it put a stop to doing things I used to do. I had to change my diet completely. I found foods I usually ate would make me ill and it got to a stage where I was frightened to eat anything because I knew it could result in a day of being ill and camped in the toilet.

Yes there have been times when I felt better – usually those times when I stopped taking the steroids completely as I knew they were not helping but only masking the pain and causing me more illness.

I don't understand why doctors can just so easily say 'take a steroid and go home' - to what I think is a death sentence. Taking steroids did help the spasms in the gut and ease the pain, but do we really know what the drugs are doing to our bodies? We put on weight in a rapid style, and no matter what we do it's hard to get the weight back off. People cannot live that way as the steroids have so many side effects that the public do not know about, such as; mood swings, depression, temper tantrums, brittle bones, kidney damage, and the list goes on … yet, I was given them like they were smarties.

I took steroids for years, and any time I was ill the doctors put me into hospital, stuck me on a drip, starved me of food and water, and pumped me full of steroids and morphine. That's no way to live, but it was the only way I could get relief.

The last straw for me was 2 years ago when I sneezed and cracked 2 ribs. Don't get me wrong, it wasn't a huge sneeze, it was just a normal, every day, run of the mill one. Why had this happened? Steroids, I'm sure, played a part - so I decided there and then to bin them for good.

I tried other herbal things and even acupuncture, which incidentally, I'd recommend highly to anyone suffering from Crohn's. It had no real effect the first time I went, but by hell it did every other time. In the end I took nothing for the illness, had acupuncture, but just lived with the bad gut and pain and put up with it … that is, until October 2007.

I was first introduced to LDN by a friend who suffers from MS and read all about the tests that have been done, and the outcomes of Crohn's patients being on the drug. Tests showed that the scarring and blisters go away, the redness of the intestine walls were a thing of the past and the lining returned to pink. To others who read this story, this will make little sense, but to the worst-hit cases of Crohn's, this is like having 6 numbers in the lottery.

A close friend, Steven, who is fundraiser for LDN, has MS - and he called me to say he had something that would help me. He gave me a number to call so I could speak with a lovely lady called Linda Elsegood.

I called Linda, and within 5 mins she'd convinced me LDN was worth trying. I ordered it online. It was easy to do and I got a bottle of red medicine that didn't taste too good, but hey, if you drink Guinness you'll know what I mean. So anyway, I tried the medicine. I didn't want to get my hopes up, but I have to admit I was surprised at how I felt.

Since starting LDN I've noticed a vast improvement in my well-being. I have more energy and drive in the morning. I've also started to eat much better, and I'm finding I can eat fruit again without having to run to the bathroom. I've rediscovered the freedom of walking again without the worry of my stomach playing up. My moods are much better and I feel friendlier towards people: I've even been out to a bar and had a couple of drinks.

Don't get me wrong. It's early days yet, but so far, I'm being positive. There are a few side effects when starting to take the new medicine. I started taking 4.5mg LDN but had stomach problems, so I dropped the dose down to 1.5mg for 1 month, then took 3mg for 1 month, then took the optimum dose of 4.5mg.

You have to build up slowly with the dosage, because if you start at the maximum 4.5mg, you'll find yourself with a bad stomach and you'll feel like rubbish (I found that out the hard way) - so start at a low dose and build it up slowly. Like every drug it takes time to notice improvement, especially as this is such a low dose. It took a few days for me to notice the first beneficial changes, but there were changes, and so far they've been sustained.

I always take my LDN when I am just getting into bed. I go to the fridge where it's kept, take the liquid, then straight into bed and read for a short while before I am off to sleep. I never used to be able to sleep very well, but since I've started taking LDN I find I can get the rest my body needs.

I don't hide my illness. I make sure people at work and my family are aware of what the illness is … it's nothing to be embarrassed about. Talking to people helps them understand your feelings. They're not mind readers and they don't know what you're going through unless you talk to them and help them see they can help.

I have work friends that know there are days that everything is not great with me and they accept that there may be times I will be in the toilet a while. My family always makes plans if we are going on journeys. We make regular stops without me having to plan the route myself and worry if I'm going to need the toilet. It's nice to hear them say 'ok let's stop here for a sandwich', or any other excuse they can find without making me feel like I need to ask them to stop. It makes a big difference.

On family birthdays, when we all go out for a big meal, they always chose somewhere that they know will have ordinary food that will agree with me rather than booking an Indian meal where everything on the menu will kill me.

I've had emails from people all over the world asking me for advice, and I can say it's been a pleasure to help people. I like knowing I'm helping them move on to something less damaging to their bodies than steroids.

I walk out the front of my house along the sea front knowing that if I was to feel ill, I can always go back home, but at least it's a start - and it comes with a renewed sense of freedom I haven't felt a long time. I recommend others do the same. Don't push it, but try to get some exercise - slowly but surely - and take up a hobby to relax yourself. I find fishing very therapeutic, and when I'm fishing, my body just seems to automatically relax.

Last year, I went on holiday to South Africa to see my mother and father-in-law. They're aware of my illness and were really considerate to my needs - and I'll tell you what … the 2 weeks I was away was the best relief I've felt in years … until now, with LDN.

UPDATE August 2009

I'm still fine and my health is good.

I've started using turmeric as a supplement, and I feel great. I'm going out to dinner tonight, then onto a show. I was fishing for 5 hours in the wind and rain last month and not one gut pain!

Let's just say I'm the cat that got the cream, and the rest of the dairy farm.

UPDATE February 2010

I no longer take LDN and have just been using Turmeric in all my cooking. I exercise at a local gym when I can, not too much, 15 minutes walking, 15 cycling, 15 on the rowing machine, and then a bit of a swim for 15 minutes. Then I hit the steam room, and it has made quite a difference.

I don't drink anymore, though I did have a pint of lager 2 weeks ago at a party without ill effect. I will continue with not drinking as I think it would knock me back if I did it regularly. I smoke about 6 cigs a day. I eat very well - food that agrees with me. I love cooking and do all my own so I know what's going into each meal and have found to be in very good health since adopting this lifestyle.

I've been feeling that good I've been making plans for days out in the car and I don't worry about where the nearest toilet is.

I have a flight in March to South Africa where I'm going on safari and this will be my biggest test yet but one I'm looking forward to.

Life is looking that much happier now.

UPDATE April 2010

I have stopped taking LDN all together now as I no longer need it.

I am only taking Tumeric powder. I am now eating a lot of meat, all good cooked on a barbeque or roasted in the oven (no fried food). I feel really well, and I'm on top of the world.

I'm now looking forward to a more comfortable life and hope that this story will help others realise steroids aren't a long term solution to their health problems.

UPDATE August 2009

I'm still fine and my health is good.

I've started using turmeric as a supplement, and I feel great. I'm going out to dinner tonight, then onto a show. I was fishing for 5 hours in the wind and rain last month and not one gut pain!

Let's just say I'm the cat that got the cream, and the rest of the dairy farm.

Cheers,
Peter, UK

Peter B, UK
"I'm now looking forward to a more comfortable life and hope that this story will help others realise steroids aren't a long term solution to their health problems." Jul '08

Sincere thanks to Linda Elsegood, LDN Research Trust, UK (ldnresearchtrust.org) for freely sharing this story with Case Health.

39 Crohn's best it's ever been – Claudia

LDN since November 2007 or February 2008 (Unknown if LDN was started Nov 2007 or in Feb 2008.)
- story submitted July 2008
- story updated July 2009
- story updated April 2010 (LDN stopped in Nov 2009 - 2yrs on LDN)

SPECIFICS

DIAGNOSIS
- Jun 2004 - Crohn's Disease

MEDICATION/TREATMENT (pre LDN)
- Jun 2004 to Jul 2004 - Cipro, Flagyl, Prednisone
- Jun 2004 to Nov 2004 - Bentyl, Colazol
- Nov 2004 to Feb 2005 - Asacol, Bentyl
- Feb 2005 to Oct 2005 - No medication due to pregnancy (doctor approved)
- Oct 2005 - Mar 2006 - Asacol
- Mar 2006 to Feb 2007 - No medication
- 16 Feb 2007 - phenergan and vicodin for abdominal pain - Hospital Emergency Room (ER)
- Feb 2007 to May 2007 – Asacol, Chromagen (iron)
- May 2007 to May 2007 - Pentasa (not tolerated)
- May 2007 to Aug 2007 - 6 mercaptopurine, Asacol (continued until April 2008)
- Aug 2007 to Apr 2008 - Asacol
- May 2007 to May 2007 – 6-mp, Asacol, Prednisone x 40 mg taper dose for 6 weeks (post hospital admission)

MEDICATION/TREATMENT (post LDN)
- Feb 2008 to Apr 2008 - Asacol
- Apr 17 2009 to Apr 17 2009 - IV antibiotics Flagyl and Cipro – inpatient
- Apr 18 2009 to Apr 18 2009 - IV Flagyl and Cipro, plus IV Solumedrol – inpatient
- Apr 19 2009 to Apr 19 2009 - IV Flagyl and Cipro, diet changed from clear liquids to full liquids – inpatient
- Apr 20 2009 - Increase to solid food and abdominal X-ray – inpatient
- May 2009 to Jun 2009 - 40 mg taper dose of prednisone
- Jun to Jun 2009 - Prescribed Imuran which was not tolerated
- Nov 2007 or Feb 2008 to Nov 2009 – 4.5mg low dose naltrexone (LDN) – Penn State Clinical Trial (NB Unknown at this time whether LDN was started in November 2007 or in February 2008.) Stopped due to need for pain medication following Small Bowel Resection in November 2009.
- Jul 2009 to present - 6mg Entocort daily

HOSPITALIZATION
- Apr 17 2009 - Admitted to hospital via local emergency room following a 'concerning' IV Contrast CAT Scan. Indications of appendicitis and/or abscess. Put on IV antibiotics Flagyl and Cipro.
- April 18 2009 - Repeat IV contrast CAT scan. Surgical consult ruled out appendicitis and abscess. Diagnosis of partial bowel obstruction. Continue IV antibiotics plus IV Solumedrol.
- Apr 19 2009 - Continue IV antibiotics, increase diet from clear liquids to full liquids and monitor patient.
- Apr 20 2009 - Increase to solid food and abdominal X-ray
- Nov 2009 – Small bowel resection

TESTS & PROCEDURES
- Jun 2004 - CT Scan with barium contrast diagnosed Crohn's Disease (in local hospital ER), followed by colonoscopy w/biopsies by a GI to confirm diagnosis (2 days later, still hospitalized)
- Jun 2004 – Colonoscopy Results: Colonoscopy revealed a 'normal looking colon with what appeared to be a fissure or possible Crohn's disease involving the anal canal.' No biopsy from this area was taken. 'The rest of the colon was unremarkable until one got to the cecum. At the cecum, a stenotic ileocecal valve could be seen with some ulcerations surrounding it. The scope was able to be manipulated through this somewhat stenotic area into the terminal ileum. The terminal ileum contained the findings characteristic for Crohn's disease. There was marked fissuring ulceration, induration, cobble-stoning, erythema and edema. Biopsies and photography were obtained.'
- Sept 2004 - CT Scan of abdomen - CT Scan Results: Terminal ileum at the ileocecal valve extending proximally for several cm is abnormal. The call appears thickened. There is inflammatory change in the adjacent fat. A few small soft tissue nodular densities adjacent to the abnormal terminal ileum likely represent lymph nodes. This appearance is most compatible with an exacerbation of her Crohn's disease.
- 4 Dec 2006 - Blood work: Iron 33 MCG/DL, %SAT 10.7
- 1 Feb 2007 – Colonoscopy Results: Internal non-bleeding, mild hemorrhoids were found. One nodular area was found at 22cm proximal to the anus. This looks like a site of previous fistula with scarring. No active inflammation or ulceration. An area of congested mucosa with polypoid-appearing tissue (likely granulomatous tissue) was found at the ileocecal valve. Narrowing of the IC valve was noted. A diffuse area of mucosa in the terminal ileum was moderately erythermatous, nodular and edematous. Tissue was very friable. Unable to advance beyond 5 cm proximal to the IC valve due to luminal narrowing. Biopsy results: Non-specific chronic active ileitis. Chronic inflammation with focal active cryptitis.
- 15 Feb 2007 - Upper GI/Small Bowel Follow-through Results: Showed disease at the terminal ileum but no signs of fistulas or strictures.

© Case Health Pty Ltd

- 4 Apr 2007 - Blood Work: Iron 61 MCG/DL, %SAT 18.5
- 16 Apr 2007 - Capsule Endoscopy: 'There is patchy segmental inflammatory segments throughout the small bowel suggestive of active Crohn's disease. The distal portion of small bowel was obscured by stool. It appears that the capsule time elapsed while still in the small bowel. A possible avm was incidentally noted in the proximal small bowel.'
- 11 May 2007 - CT Scan and later admission into hospital with lower-right quadrant pain. CT Scan Report Results: 'A long segment of abnormal terminal ileum with marked thickening of the wall and narrowing lumen. It also showed that there was mild to distal portion of the appendix which had enlarged up to 9 millimeters in size with some inflammatory changes at the tip of the appendix. Further surgical consultation was advised particularly considering that the appendix had changed in caliber.'
- 11 May 2007 - Had low white blood cell count - apparently due to 6-mp.
- May 2007 - Received surgical consult: Non surgical at this time
- May 2007 - Gastro consult advised resection, which Family Physician and Surgeon did not advise.
- 27 Sept 2007 - Blood work: SED Rate 31 MM/HR
- 13 Nov 2007 – Colonoscopy w/biopsy: Polyp removed from ileocecal valve during procedure.

Colonoscopy Results:
Ileum: Erythema present, vascular pattern absent, erosions present, granularity present, bleeding present, ulcers present, edema present, deep ulcers present.
Sigmoid Colon: Vascular pattern absent. Pseudo polyps present, Granularity present, bleeding absent, ulcers absent, Stenosis, non-ulcerated. Fistula with suspected opening.

Biopsy results:
Ileum: Active chronic inflammation
Right Colon: No pathologic diagnosis
Transverse Colon: No pathologic diagnosis
Left Colon: Active chronic inflammation, severe
Rectum: No pathologic diagnosis
Polyp ileocecal valve: Submucosal lipoma, lymphoid hyperplasia

'The biopsies from the ileum show small intestinal mucosa with villous atrophy, increased lamina propria chronic inflammation and active inflammation involving the surface epithelium and immediately subjacent crypts. The biopsies from the right colon and transverse colon are unremarkable. The biopsies from the left colon contain three unremarkable mucosal fragments and a fourth fragment with marked active chronic inflammation. The rectal biopsies are unremarkable.'

- 15 Feb 2008 – Colonoscopy Results: Ileum: Erythema, granularity, bleeding, ulcers, edema and stenosis present. Activity level severe, Deep ulcers present. 30 cm fistula - Ileum to sigmoid.
- 13 May 2008 – Colonoscopy Results: Ileum: Erythema, erosions, pseudo polyps, granularity, bleeding, ulcers, edema present. Fistula healed.

- Apr 17 2009 - IV Contrast CAT Scan - indications of appendicitis and/or abscess - admitted to hospital via local emergency room.
- April 18 2009 - repeat IV contrast CAT scan - partial bowel obstruction
- Apr 20 2009 - abdominal X-ray

- 10 June 2009 - Blood work: B-12= 269, C-Reactive Protein = 33.9

LDN - DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take my LDN at bedtime, usually around 10pm.
c) Type - capsules compounded with pure Naltrexone and unknown filler

DIET
- 1998 to present - Vegetarian
- Jun 2004 - Jan 2005 - low residue diet
- 2008 to present - Currently no dietary restrictions, but I do not tolerate artichokes or corn

SUPPLEMENTS
- Feb 2005 to Jun 2007 - Iron

ACTIVITIES, EXERCISE, INTERESTS
- Yoga, some Pilates, and I play the Wii :-). Keeping up with my almost 3 year old takes a lot of exercise! I enjoy spending time with my family, shopping, reading and helping in my community.

MY STORY – July 2008

I lived in Florida for the first 25 years of my life. I had been experiencing 'stomach problems' since my late teens, but thought nothing of it. I moved to West Virginia in 2003 and began working at a domestic violence shelter shortly after I moved.

In June of 2004 I began experiencing debilitating abdominal pain after each meal. I still went to work and tried to ignore the pain. Luckily one of my co-workers was formerly a nurse. She saw me doubled over in my office and asked what was wrong. When I pointed to my lower right abdomen as the location of the pain, she insisted that I leave and see the doctor immediately. After arguing with her briefly, the pain became overwhelming and I drove myself to a local clinic. I did not have health insurance and was trying to avoid a hospital bill. The doctor at the clinic pushed on my lower right abdomen and my vision went black.

He immediately sent me to the Emergency Room. I drove myself there. I called the girls at work on my drive to the ER and one of my co-workers met me there shortly after I was seen. They gave me pain meds which made me incoherent. They ran blood tests and had me drink barium for a contrast CT Scan. After several hours of waiting, the results came back and an Emergency Room doctor asked if I knew I had Crohn's disease.

Not only did I not know I had it, I had never heard of it and was not 'with it; enough to understand what he was telling me. I was handed a print-out from the Internet to explain what this diagnosis meant. I was also told that I was going to be admitted to the hospital for further testing. I was given pain medication for the next day and not allowed to eat until I had a colonoscopy which was scheduled for Monday (I was admitted on a Thursday). I felt miserable, weak, drugged, tired and confused. All this and without health insurance.

I had the scope Monday and my blood pressure dropped to 60/40 afterwards. About an hour after the procedure was done, the representative from the local Department of Health and Human Resources came by to gather my financial information to see if I would qualify for help from the state to cover the medical bills - still groggy from sedation, I gave him information and I was denied for help. I was given antibiotics and steroids, as well as Bentyl and Colazol to treat the Crohn's and was released on Wednesday.

The medications were extremely expensive. My fiancé and I decided to move up our wedding date so that I could access his health insurance. We were married in August of 2004 in Las Vegas. I saw the gastro that performed my scope. I was extremely unhappy with him and so was thrilled when I switched to a provider in my insurance network. The new provider took me off the Colazol and informed me that it was only treating the colon, which was not the part of my intestines with the disease.

I had been spending 500 dollars a month on a medication that wasn't even treating the diseased area! This gastro put me on Asacol to better treat the affected area. I saw him a few times over the next year. He advised me that it would be fine to go off the Crohn's medication (Bentyl and Asacol) while I was pregnant (Feb 2005 - October 2005).

While pregnant, I worked full-time until June 2005, but then had to make a trip to the Emergency Room due to severe dehydration. I received IV fluids and phenergan.

In July 2005 I went to the hospital, again while pregnant, and had an ultrasound to rule out kidney stones. The final conclusion was 'round ligament pain'. After I delivered a happy and healthy little boy in October of 2005, I had a monstrous flare, but did not go to the doctor for it - rather I just went back on the medications.

I was working full time again between November 2005 and July 2006, then found part-time work, due in no small part to the Crohn's disease. During the same period I changed gastroenterologists, then became anaemic and was put on Chromagen to help with the iron deficiency.

In January 2007 I enrolled in graduate school to obtain a Master's Degree in Special Education. (I'll graduate in May 2009, after I complete a 12-week internship.)

In February of 2007 I decided to switch gastros again because the one I had did virtually nothing to help me and took very little time with me. My new gastro came very highly recommended and lived up to their reputation. Before I was even seen in the office, I was scheduled for a colonoscopy (as I had not had one since 2004 and was experiencing a lot of bleeding and pain).

We tried Pentasa to better treat the ileum, but I did not tolerate it well. I was placed on 6-mp and a week later was hospitalized again with what they believed was appendicitis. While in the hospital, I received a surgical consult, saw my family doctor and got a consult from a gastro ... the one I left in 2006. He insisted that my ileum needed to be resectioned, but the other two doctors disagreed. I was given steroids, put back on the 6-mp and discharged after 2 days in the hospital.

During my time on the 6-mp, I was more miserable than I had ever been. I had constant headaches and developed gout in my hands from a build up of the uric acid from the medication. The steroids had their typical side effects and I put on weight as well.

I called my gastro and informed her that I was going to take myself off the 6-mp, as I'd rather deal with the disease than feel as awful as I had been feeling. There were days that I couldn't even get off the couch to take care of my son. I missed out on playing with him, cuddling with him and being a mom to him for 3 months because of the medication. That's when I knew there had to be something else out there.

My gastro wanted me to consider Remicade or Humira. I did my own research and found an article by Prof Jill Smith about low-dose naltrexone (LDN) and the clinical trial she had completed regarding its use in Crohn's patients.

I took the literature to my gastro who stated that she didn't know enough about it to prescribe it, but that I was the second person that month to ask her about it. I showed her a list of doctors that prescribe it, but she could not be persuaded. I called doctors on the list, but none prescribed for Crohn's. So, I called Penn State and arranged to meet with Prof Jill Smith about the study and to see if I would qualify.

In November 2007, I drove 4.5 hours to Penn State in Hershey, PA where I filled out paperwork, had a physical, got lab work and scheduled a colonoscopy. I qualified for the trial. For the next 6 months, I drove to Hershey EVERY month, 4.5 hours each way, for a 1 hour appointment. The exception was the three scopes I received when I would go down the night before with a friend and prep for the scope in a hotel room and ride home after the procedure.

The trial changed my life. The medication changed my life. Without the compassion, education and determination of Prof Jill Smith and her nurse, Sandy Bingaman, I would likely be dealing with an active and oppressive disease, and taking toxic medication with horrid side effects.

Instead, I take one pill before bed and experience only odd dreams - which really are quite entertaining. My intestines are not healed and naltrexone is by no means a miracle cure for Crohn's. However, it healed the 30cm fistula I had, and has significantly reduced the bleeding and pain I experienced on a daily basis.

On a side note, I've dropped 20 lbs in the last 4 months while on LDN. This is a positive aspect for me, as I put on a significant amount of weight from the other medications I had taken.

It's now July 2008 and I feel better than I have in years. I'm still on the LDN under the care of Dr. Smith, even though my part in the trial is over. I definitely don't miss that drive every month, but I truly miss the staff at Penn State, who went out of their way to make sure I was comfortable and cared for.

I have a prescription for Bentyl to take ‘as needed’, which is rarely. I hope more people afflicted with Crohn's have the opportunity to at least try LDN. It's helped many people already and will hopefully be widely available to patients who want a medication whose benefits FAR outweigh the risks.

UPDATE – July 2009

I know what sent me spiralling into a flare up and I knew it would happen. I had to teach full time in order to complete my Masters Degree.

I was doing that, taking 9 graduate level credit hours, teaching parenting classes once a week, and raising my 3 year old with autism. I knew it was too much but had been feeling so well that I overestimated what stress I could put on my body. I graduated with my Master's Degree in May, three weeks after I got out of the hospital.

I saw Dr Smith at the end of May. She advised me to stay on the prednisone, which she called in via phone 2 weeks prior, taper off, then switch to Entocort, which I am currently on.

After reviewing my scans and x- rays from my hospital stay, Dr Smith felt I should stay on the naltrexone and add Imuran. I attempted taking the Imuran but was nauseas, had headaches and experienced increased arthritis pain in my hands.

Since Dr Smith began her sabbatical on July 1, and Penn State is nearly a 5 hour drive for me, I have decided to go to Cleveland Clinic which is just under 3 hours away. Dr Smith felt that the LDN has done well for me but that it was time to add a stronger medication.

At this time I am taking Entocort and LDN for the Crohn's while waiting to go to Cleveland on August 7th. In the meantime, my son and I will be spending 2 weeks in Florida visiting family. LDN gave me a solid year and a half of remission which I doubt I would have had otherwise. I am still hopeful about the future of LDN in the treatment of Crohn's and am grateful for the many months of remission!

I think the fatigue is my biggest detriment right now.

Update: April 2010

I had a small bowel resection in November 2009 and after, needed strong pain medication, so went off LDN with intention to return to LDN after coming off the pain medication.

I commenced tapering down the pain medication in the hope of returning to LDN in February 2010, but I'm sad to say it wasn't as easy as I'd thought it would be and I'm having one hell of a problem getting in touch with my Gastroenterologist at Cleveland Clinic, so I've had no LDN since my surgery in November.

I've had some correspondence with Dr. Jill Smith and I'm confident she'll give me a new prescription for LDN, but she and my doc at Cleveland Clinic agree that I need to be on something in addition to that, such as Pentasa. I'm still waiting for my doc at CC to call me back!

Overall I've been feeling pretty well considering I'm med-free, but based on advice from Dr. Smith, I plan to return to LDN with an additional medication such as Pentasa as soon as I can get an appointment.

Claudia, USA

Claudia, USA

"I hope more people afflicted with Crohn's have the opportunity to at least try LDN. It's helped many people already and will hopefully be widely available to patients who want a medication whose benefits FAR outweigh the risks." Jul '08

40 LDN benefited son's Crohn's - Paul B, PA-C

- LDN since January 2008
- story submitted July 2009
- story updated February 2010 (2yrs on LDN)

SPECIFICS

DIAGNOSES
- Oct 2003 – Pediatrician – investigation of severe fatigue, no weight gain in two years.
- Jan 2004 – Crohns' Disease
- Jan 2004 – Abdominal distention, incapacity to eat
- Feb 2004 – Surgeon – diagnosed small bowel obstruction needed surgery
- Nov 2007 **-** extreme exacerbation of Crohn's Disease, resulting in Hypovolemic shock
- Nov 2007 - active Crohn's - from stomach to lower bowel, with abscesses in stomach and throughout the whole intestinal tract, and granulomas.
- Jan 2008 – Dr Grossman prescribed low dose naltrexone (LDN)
- May 2008 - BMX biking accident resulted in ruptured spleen.

TESTS
- Oct 2003 - Hgb - 9.7
- Oct 2003 - albumin - 3.0 (normal range is 3.7-5.1)
- Oct 2003 - Iron - 11.0 (normal range is 40-190)
- Oct 2003 - ESR – 9, monotest positive
- Oct 2003 - TGG - slightly high, suggestive of possible celiac disease
- Nov to Dec 2009 - upper and lower endoscopies
- Apr 2004 – HgB improved to 11.8
- Nov 2007 – Repeat CT scans - active Crohn's - from stomach to lower bowel
- Nov 2007 – upper & lower endoscopies - abscesses in stomach and throughout the whole intestinal tract, and granulomas.
- Nov 2007 – Cultures - bacteria, viruses, and fungus - negative
- Nov 2007 – CRP (inflammatory marker) - 20
- Dec 2007 - Hgb - 12.2
- Jul 2008 – Hgb - 15.5 (higher than it had ever been)
- Jul 2008 - CRP (inflammatory marker) - less than .5
- Jul 2008 – Spectra-cell blood test - glutamine & magnesium low, B12 slightly low
- Jun 2009 - CRP - 1.1 (less than .8 is considered normal)
- Jun 2009 - Hgb - 14.1 (normal range 13.4-18.0)
- Jun 2009 - ferritin - 26 (normal range 20-380)
- Jun 2009 - Iron - 37 (normal range 40-225)
- Jun 2009 - Vit D - 29

HOSPITALISATION
- Feb 2004 – surgery – to address small bowel obstruction - detected 'near perforation', resulting in removal of 60 cm of small bowel, and resection
- Nov 2007 - extreme exacerbation of Crohn's Disease, resulting in Hypovolemic shock - treated with Azacol, Flagyl, and IV calories.

MEDICATION (pre LDN)
- Jan 2004 to Jan 2004 – Prednisone
- Feb 2004 to Apr 2004 - Prednisone (6 weeks)
- Feb 2004 to Feb 2008 – Imuran x 150 mg per day
- Nov 2007 to Nov 2007 – Azacol & Flagyl (during hospitalisation)

MEDICATION (post LDN)
- Jan 2008 to Jan 2008 – 1.5mg Low Dose Naltrexone (LDN) nightly (for 3 weeks)
- Jan 2008 to Feb 2008 – 3mg Low Dose Naltrexone (LDN) nightly (for 3 weeks)
- Feb 2008 to present – 4.5mg Low Dose Naltrexone (LDN) nightly

DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - He takes the Naltrexone every night around 10pm
c) Type – capsules compounded with proprietary filler from Belmar Pharmacy

SUPPLEMENTS
PAST
- May 2004 to Nov 2007 - 300mg fish oil per day
- Nov 2007 to Jul 2009 - 600mg fish oil per day
- May 2008 to 2008 - multivitamin with 18mg Iron x 1 per day (ceased due to nausea)
- Jun 2009 to Jun 2009 - D3 x 50,000iu – once every 2 weeks

- May 2008 to October 2009 - 5 grams Glutamine x 1 per day (dose reduced to 2 grams)
PRESENT
- May 2008 to present - 300mg of magnesium x 1 per day
- Jun 2009 to present - B12
- Jun 2009 to present - B6/Folate
- May 2008 to present – probiotic (Prothera/Klaire) x 1 per day
- Jun 2009 to present - teen multivitamin with 9mg Iron x 1 per day
- Jul 2009 to present - D3 x 50,000iu – once every 10 days
- Jul 2009 to present - 900mg fish oil per day
- Jul 2009 to present – Sacchromyces probiotic x 1 per day
- October 2009 to present - 2 grams Glutamine x 1 per day (dose reduction from 5 grams)

OTHER THERAPIES/TREATMENTS
- none

DIET
- Jan 2004 to present – Restricted diet – no sugar or milk products, limited bread intake (about once a month gets a cramp from eating a poor diet).
- Feb 2010 - He has continued with no milk in his diet, but does eat cheese. He eats some sugar candy, but very little and only very occasionally.

EXERCISE
- May 2008 - He was active enough to return to BMX biking.
- Feb 2010 - He is playing hockey regularly, no exacerbations other than when he had a lot of bread-rolls on a cruise ship and got bad cramps for several hours.

MY STORY

My son developed the first symptoms of Crohn's in 2003 at 9 years of age, and it proved to be severe, resulting in a 60 cm small bowel resection at the young age of 10.

After being on Imuran for almost 4 years, he had a flare from his gastric mucosa to his descending colon, and developed hypovolemic shock. None of the drugs he was prescribed helped him, nor did the surgery. When he got out of the hospital he was still not normal.

When I learned of low dose naltrexone as a treatment option, I researched it further and decided it was worth trying.

I started him on low dose naltrexone (LDN) in January 2008, and within 2 weeks his color had returned and his energy was back to normal. At his follow up examination 5 months later, his lab results were the best they'd been since diagnosis.

He's had NO flare ups since. He still has symptoms of cramping, but only when he does not follow his diet, and it's been 18 months now.

This is how our story started:

In October 2003, I took my ten year old son to the Pediatrician to investigate severe fatigue, and why he'd gained no weight in two years.

I have been a Physician Assistant (PA) for 27 years, so I strongly encouraged the Pediatrician to run some basic blood tests. Due to the blood tests revealing extremely low levels of iron, the Pediatrician recommended iron supplements.

We tried 6 different iron preparations, and my son vomited with each one, so we again consulted the Pediatrician. I suggested finding out why he was anemic, and to perform tests to rule out Celiac disease. The doctor agreed, and his TGG test was slightly high, suggestive of possible celiac.

In November 2003 we saw a Pediatric Gastroenterologist. He scheduled my son for upper and lower endoscopies performed over the following two months, resulting in a diagnosis of Crohn's disease in January 2004, and a prescription for Prednisone at the same appointment.

The same month we had to consult a surgeon due to my son developing an abdominal distention, and incapacity to eat. The surgeon recommended surgery to address my son's obstruction.

During surgery in February 2004, 60 cm of his small bowel was involved with the disease as opposed to the predicted 10 cm on the CT scan. Therefore that segment was resected. The pathology report showed it was nearly perforated.

He was prescribed Prednisone for 6 weeks, and Imuran permanently. My son began to recover and gain weight. Blood tests revealed his Hgb went up to 11.8.

In May 2004 we started supplementing his diet with 300mg of fish oil per day.

Between May 2004 and November 2007, he did well on 150mg Imuran per day, but on 29th October 2007 he developed tremendous diarrhea and lost 19 pounds, with his weight slipping from 116lbs to 97lbs in 5 days.

Hypovolemic shock followed, and we nearly lost our son.

Repeat CT scans were taken, and upper and lower endoscopies performed. They revealed active Crohn's from my son's stomach to his lower bowel, with abscesses in his stomach and throughout his whole intestinal tract, as well as granulomas.

He was treated with antibiotics, Azacol, and Flagyl, fed IV nutrition. He was still not doing well but was discharged. The Children's Hospital staff couldn't find a cause. Cultures for bacteria, viruses, and fungus were negative. His CRP was 20. He was discharged to go home. All medications, with the exception of Imuran, were discontinued. He seemed to stabilize but was still not doing great.

We increased his Fish oil from 300mg daily to 600mg per day after he was discharged.

In December 2007, his Hgb was still only 12.2. It had hovered around that level since he was 10, and since he'd begun taking Imuran medication nearly 4 years earlier.

In January 2008 we heard of a treatment called low dose naltrexone (LDN), and we consulted with Dr Grossman about the possibility of our son taking LDN.

In January 2008, our son started on 1.5mg naltrexone for 3 weeks, then 3.0mg for 3 weeks, then took 4.5mg every night thereafter.

Within 2 weeks of starting the 1.5mg and tapering down the Imuran, our son's color looked better, he became more active, and was off the Imuran completely by the time he was taking 4.5mg naltrexone.

In May 2008, he was active enough to return to BMX biking, but also due to that activity, ruptured his spleen.

The blood test taken for his Gastroenterologist follow-up was promising. His Hgb was up to 15.5, higher than it had ever been since he grew sick – and his CRP (inflammatory marker) was less than 0.5. When he'd been hospitalisation, his CRP had been 20.

His glutamine and magnesium were low on a spectra-cell blood test, and his B12 was slightly low also. We started him on 5 grams of Glutamine, 300mg of magnesium, and a multivitamin with Iron each day. We also started him on probiotics.

By June 2009 he hadn't had any flare ups since commencing LDN in January 2008, 17 months earlier. He was 15 years old, and had grown to 5'9" and 142 pounds. He looked healthy and was continuing to have normal bowel movements.

He still gets cramps if he doesn't maintain his dietary restrictions.

He does not eat sugar or milk products, and his bread intake is limited.

In June 2009, his CRP was 1.1 (less than .8 is considered normal), so it is up a little. Hgb was 14.1 (normal range 13.4-18.0). His ferritin was 26 (normal range 20-380), and his Iron was 37 (normal range 40-225).

I had started but stopped giving him a daily multivitamin with 18mg Iron per day due to him experiencing nausea in 2008, so I am now going to start him on a multivitamin with a lower iron component at 9mg. I'm also putting him on B12, and a combined B6/ Folate supplement.

I also have him on Vit D3 50,000iu once every 2 weeks because his Vitamin D test result was 29. Our goal is to get it into the 60-70 range.

We are increasing his D3 to 50,000iu every 10 days, and his fish oil to 900mg per day.

The fish oil was originally started for a different reason back in 2004, because he had symptoms of ADD. A Purdue University study had shown kids with mental disorders often had low Omega 3 Fatty Acids (FA), so I started him on it for that reason.

We're continuing the probiotics, and have added Sacchromyces, which might help minimize yeast, and has reduced his flatus substantially. The probiotics are from Prothera/Klaire as suggested my Dr Jaquelyn McCandless who has treated many autistic children with LDN and probiotics.

The time he takes his naltrexone varies with his teenage lifestyle, but in general he takes it at about 10 pm each night. I asked Belmar pharmacy what filler they use in his capsules, but the pharmacy will not tell me. They said it is proprietary. I think I will have to challenge them on that.

I also have a friend with MS who started on LDN, and 4 months later had more energy than they'd had in the previous 5 years - and they were able to go off Rebif.

UPDATE February 2010

The update on my son is he is doing well.

We just had the Crohn's researcher call us for an update so the summary is; he is now 5' 10" tall and 156 pounds, so he's gained about 60 pounds since his hospitalisation in November 2007.

He has normal bowel movements, color and consistency, and no cramps unless he overeats on junk food.

He has no milk in his diet, but does eat cheese. He eats some sugar candy, but very little and only very occasionally.

He continues to take a Saccharomyces Probiotic, fish oil, glutamine 2 grams per day when he does not take his glutamine his rash breaks out on his arms, Magnesium 250 mg per day, LDN 4.5mg per day, daily teen vitamin with 9mg of iron, vitamin D 50,000iu every 10 days to 12 days.

He is playing hockey regularly, no exacerbations other than when he had a lot of bread-rolls on a cruise ship and got bad cramps for several hours.

Paul, PA-C
Physician Assistant
Broomfield, Colorado, USA

Paul, PA-C

"His Hgb was up to 15.5, higher than it had ever been since he grew sick - and his CRP (inflammatory marker) was less than .5. When he'd been hospitalised, his CRP had been 20. … By June 2009 he hadn't had any flare-ups since commencing LDN in January 2008, 17 months earlier." Jul '09

41 The Story of My Current Life - Rachel

LDN since July 2008
- story submitted August 2009
- story updated May 2010 (almost 2yrs on LDN)

SPECIFICS:

DIAGNOSED
- Sept 2003 – Primary Care physician (PC) treated symptoms, no diagnosis
- 2003 – Cyst lanced (from ingrown hair)
- Jun 2004 – Ulcerative Colitis
- Jun 2004 – PC diagnosed Type 2 diabetes
- May 2005 – Drug-induced hepatitis caused by 6mp
- May 2005 - Clostridium difficile (C-diff) infection
- Mar 2008 - Indeterminate Crohn's Disease/Ulcerative Colitis

MEDICATION (pre LDN)
- Sep 2003 to Jan 2005 - 40mg to 60mg prednisone prednizone for unexplained hives, ended Jan. 2005
- 2003 to 2003 – Doxicycline – short course to treat cyst infection
- Jun 2004 to Jul 2005 - Asacol
- Jul 2004 to May 2005 - 6mp (dose was titrated up until drug-induced Hepatitis in May 2005)
- July 2005 to Jul 2009 - Colasal
- May 2005 to Dec 2007 – Remicade (ceased after allergic reaction during infusion Dec 2007)
- 31 Dec 2007 to Feb 2008 - Humira (change of insurance, denied Humira for UC, forced med change and further investigation)
- Mar 2008 to Mar 2008 - Humira (Went back on Humira but it never worked for me again.)

HOSPITALISATION/SURGERY
- May 2005 – Hospitalised with Drug-induced hepatitis caused by 6mp (acquired Clostridium difficile infection whilst in hospital
- Aug 2008 – Hernia surgery as out-patient (naltrexone ceased for 9 days)

MEDICATION (post LDN)
- May 2005 to present – Imodium as needed
- May 2005 to present – Lomotil as needed
- May 2005 to present - Gas-X
- May 2005 to present - Pepcid complete
- May 2005 to present - Nulev
- Jul 2008 to present - Balsalazide Disodium (Colazal) 3 x 750mg capsules x 3 times per day
- Jul 2008 to present – 4.5 mg low dose naltrexone (LDN) (with 9-day break during Aug08 hospitalisation)
- Jul 2008 to present - 50mg Zoloft (with LDN so that I don't wake at 3:30 am)
- Mar 2010 to present - Apriso 0.375gm x 4 daily in the morning.

TESTS
- Mar 2008 – Scope – diagnosis of indeterminate Crohn's Disease/Ulcerative Colitis

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone each day at around 11pm
c) Type – Compounded capsules with pure Naltrexone powder and Avicel filler from Skip's Pharmacy.

SUPPLEMENTS
As at August 2009 I take the following supplements. (NB If I flare, with bleeding, I stop all supplements because they come out whole):
Multivitamin
Vitamin D x 6000mg
Calcium with Vit D
Magnesium
Biotin x 5000mg
Fish oil/omega 3
Vitamin C
Probiotic (L. acidophilus DDS-1, B. longum & FOS)

DIET
- Aug 2009 - I have not found any particular diet that helps. I just take it day by day, which is difficult due to diabetes.

EXERCISE & INTERESTS
- Aug 2009 - I enjoy walking, as long as there is a restroom nearby.

MY STORY

In mid 2003 I noticed a bit of liquid stools in the morning, I attributed it to drinking to much alcohol the night before. I ignored it and carried Imodium for when it was needed. I had no idea that this was not normal. I also developed unexplained hives. My PC, dermatologist and allergy docs all prescribed 40mg of evil prednisone. They DID NOT consult each other.

I developed a cyst (from an ingrown hair) and saw a new nurse practitioner who lanced the cyst and put me on Doxicycline. I had never taken this type of medication before and didn't know what to expect. I started eating Activia and taking probiotics, but the diarrhea came on and didn't stop after I stopped the antibiotics.

Then the blood showed up in my stools and I lost 35lbs in 5 weeks. By now it was time for my youngest child to graduate from High school and my parents were here to visit and attend the graduation (read: STRESS). I saw my first Gastroenterologist (GI) in June 2004 and was told that I had Ulcerative Colitis. I was put on Asacol and 60mg of prednisone. I had now been on 40 to 60mg of prednisone for about 10 months.

The prednisone attacked my pancreas and I developed Type 2 diabetes. My hair fell out (I'm a hair dresser, licensed for 30 years) and I knew that it was because of the evil prednisone and the disease. The GI put me on 6mp, but that eventually shut down my liver and landed me in the hospital for 6 days. And, of course, I picked up C-Diff. I tried Remicade and it kicked in within 48 hours, but I eventually became allergic to it. I tried Humira in various doses and it did not work. I am afraid to try any other biologics.

My uncle (dad's youngest brother) had Ulcerative Colitis, leukemia and other issues, and passed from complications. His son (my cousin) was recently diagnosed with ALS and UC. He was very near death while on Humira. He had his colon removed and Is now slowly regaining some strength. His girlfriend got him LDN from Skip's, but I don't think he has started it yet.

I have now been on LDN for almost a year. I am not in remission, but I am able to work part time. My son was married late in 2008 and my daughter got married in June of this year. I KNOW that if it weren't for LDN I would have ended up in the hospital. I did go into a flare after my daughter's wedding, but I only bled one day, and I haven't had an 'accident' in months!

I am having a lot of pain and bloating in my upper abdomen, so my new GI is sending me to the University of Florida in Gainesville for a 3rd opinion from the top specialist in Irritable Bowel Diseases (IBD). Since I won't take the evil prednisone or biologics, everyone says I am a 'complicated case'. I still think that the only reason that I'm not in the hospital is LDN. I'm presently taking Balsalazide Disodium (Colazal) 3 750mg capsules 3 x per day. I've taken the evil prednisone, Asacol, 6mp, Remicade and Humira – one after the other, all before I started LDN. (I didn't take them all at once.)

The prednisone attacked my pancreas and I am now diabetic. The 6mp shut down my liver and gave me drug-induced hepatitis. After 6 days in the hospital and getting rid of the nasty drugs (May '05) I am only taking Colazal and LDN and Imodium and Lomotil (as needed) for my CD/UC. I use Gas-X and Pepcid complete and Nulev, too.

UPDATE – May 2010

Yes, I'm still taking 4.5 mg LDN and the benefits that I have seen have more to do with my overall health, rather than my Crohn's. I do feel that my immune system is stronger now. I started taking Apriso 2 months ago for IBD and that has also helped. On good days, I have formed stools. Stress is a major factor and I have not been eating as well as I should. I hope to improve this over the summer.

Rachel, USA

Rachel, USA

"I am having a lot of pain and bloating in my upper abdomen, so my new GI is sending me to the University of Florida in Gainesville for a 3rd opinion from the top specialist in Irritable Bowel Diseases (IBD). Since I won't take the evil prednisone or biologics, everyone says I am a 'complicated case'. I still think that the only reason that I'm not in the hospital is LDN." Aug '09

42 My LDN & Fibromyalgia story-Janis

- LDN 28 January 2009 to September 2009 (LDN FOR 9 MONTHS)
- story submitted July 2009
- story updated April 2010 (CEASED LDN IN SEPT 2009)

SPECIFICS

MEDICAL HISTORY – FAMILY MEMBERS
- Mental illness - depression (grandmother, uncle, cousin)
- High blood pressure (mother, father)
- Heart disease (mother)
- Asthma (mother)
- Cancer - prostate (both father and brother, cousin)
- Lupus (Aunt)
- Breast cancer (cousin)

MEDICAL HISTORY – PERSONAL
- Mental illness - depression
- High blood pressure
- History of migraine
- Thyroid issues – goitres
- Osteoporosis
- Osteoarthritis

DIAGNOSES
- late 1960's - migraines
- 1985 - diagnosed - wear and tear arthritis; following onset of sudden lower back pain which has continued to occur to date (2009) in varying degrees of severity and increasing with any applied pressure to that area
- 1993- diagnosed - High Blood Pressure
- 1994 - two episodes visual disturbances no specific diagnosis, but possible variation to migraine
- 1995 to 1998 – diagnosis – severe depression (Post traumatic stress disorder), claustrophobia, anxiety and social phobia; due to constant body aches and pains, very low energy levels, insomnia, brain fog, and anxiety
- 2000 - diagnosed - umbilical hernia; following stomach pain
- 2000 - an examination two months later revealed large uterine fibroids as well
- 2001 – diagnosed - arthritis; due to neck and upper back pain (breast reduction followed)
- 2002 - diagnosed - severe morbid obesity; due to ongoing inability to lose weight despite healthy eating regime and moderate exercise. I decided on gastric stapling.
- 2004 - diagnosed - stenosis of and fibrosis at lower end of gastroplasty due to gastric stapling - 50 kg weight loss, but difficulty eating almost anything without vomiting. Doctor recommended reversal of gastric stapling, but I opted for dilation of trouble spot to allow more food to go down.
- 2004- diagnosed - Breast lump - benign
- 2005 – suggested irritable bowel syndrome; following Colonoscopy due to continuing bouts of diarrhoea. Tests negative, no problem indicated.
- 2005- diagnosed - no signs of degenerative or erosive arthritis; following investigation into hip and pelvic pain (once again)
- 2005 – diagnosed - possible osteoporosis; following x-rays of thoracolumbar spine
- 2005 - bone density test - revealed above average for my age.
- 2006 - diagnosed - marked gastro-oesophageal reflux probably due to gastric stapling; following Barium Swallow and Meal; due to continued and severe indigestion
- 2006 – diagnosed – normal; following cardiac perfusion study due to chest and neck pain
- 2007 - Impression: Advanced spondylotic changes in cervical spine. Shoulder advanced degenerative changes of AC joint with inferior spurring of the acromion (x-rays of cervical spine & right shoulder)
- 2007 – precautionary investigation of migraines (via CT scan to head)
- 2007- diagnosed - old tear of tendon fibres. Subdeltoid bursitis. (ultrasound of right shoulder)
- 2007 – diagnosed - C5/6 bilateral severe foraminal stenoses (CT of neck & cervical spine to investigate neck pain)
- 2007 – diagnosed - multinodular goitre (noted on CT scan of thyroid)
- 2007 – diagnosis confirmed - multinodular goitre (ultrasound of thyroid)
- 2007 – diagnosed – negative for thyroid condition. Blood test result; TSH 0.9 mU/L (0.40 - 4.00)
- 2007 – diagnosed – carpal tunnel syndrome; following electrodiagnostic tests performed due to numbness, pins and needles in both hands
- 2008 - Change of doctor
- 2008 – diagnosed - Thyroid Hormone Metabolic Disorder (resistance at a cellular level) - suggests possible need for a boost in T4 hormone Thyroxine
- 2008 - Thyroxine medication attributed to the cessation of migraines (after suffering from them most of my life)
- 2008 – diagnosed - Fibromyalgia – due to medical history and symptoms described earlier (no other tests carried out).
- 2009 – Change of doctor
- 2009 - mercury & lead overload in the body, severe adrenal fatigue, heavy yeast infection
- 2010 - Change of doctor
- Jan 2010 – Initial Phase Diet

TESTS
- 1985 - x-rays of lower back
- 2005 – colonoscopy
- 2005 - investigation into hip and pelvic pain (once again)
- 2005 – x-rays of thoracolumbar spine
- 2005 - bone density test
- 2006 - x-ray following barium meal swallow
- 2006 - cardiac perfusion study; due to chest and neck pain
- 2007 - x-rays - cervical spine & right shoulder
- 2007 – CT scan to head (migraine)
- 2007 – CT scan to neck (neck pain) and cervical spine (back pain)
- 2007 - ultrasound of right shoulder
- 2007 - CT scan of thyroid
- 2007 – ultrasound of uterus
- 2007 – ultrasound of thyroid
- 2007 - Blood test – full blood examination
- 2007 - electrodiagnostic tests

HOSPITALISATION
- 1973 - Childbirth
- 1993 - Kidney stones - resolved on their own
- 2000 - Umbilical hernia repair
- 2000 - severe post operative infection (due to hernia repair)
- 2000 - Abdominal Hysterectomy
- 2001 - Reduction Mammoplasty (to relieve neck pain, but unsuccessful)
- 2002 - Gastric stapling
- 2004 - Severe migraine
- 2004 - Dilation Gastroesophageal Junction
- 2005 - Colonoscopy
- 2007 - Carpal tunnel surgery left hand
- 2008 - Carpal tunnel surgery right hand
- Sept 2009 – Kidney stone, resulting in urethral stent for 5 months (Sept09 to Feb10)

MEDICATION (pre LDN)
- 1980s to 2008 - Panadeine Forte (for pain)
- 1993 to 2000 – blood pressure medication – can't recall type
- 1998 to Jan 2009 - Valium 5mg (for anxiety)
- 1998 to 2003 - Prozac (for depression)
- 2000 to 2004 – Avapro - blood pressure medication
- 2003 to Aug 2008 - Zoloft (for depression)
- 2004 to 2005 – Propranolol – blood pressure medication (and for migraine control)
- 2005 to Jan 2009 - Karvezide (blood pressure medication)
- Jan 2008 to Jan 2009 - Thyroxine 100mcm x 1 per day (low dose, for thyroid)
- Jan 2008 to Jan 2009 - Ibuprofen (Advil) when needed for pain and inflammation
- Aug 2008 to Oct 2008 - St. John's Wort (for depression)
- Oct 2008 to Jan 2009 - Moclobemide 150 mg x 1 twice a day for muscle spasms, fibromyalgia and depression
- Oct 2008 to Jan 2009 - Dothiepin 25 mg x 1 per day for muscle spasms, fibromyalgia and depression

MEDICATION (post LDN)
- Jan 2009 to Sept 2009 - Low Dose Naltrexone (LDN) 4.5mg x 1 every night (CEASED)
- May 2009 to May 2009 - short course of Nilstat for Candida
- Jan 2009 to Jan 2010 – Moclobemide 150 mg x 1 twice a day for muscle spasms, fibromyalgia and depression
- Jan 2009 to Jan 2010 - Dothiepin 25 mg x 1 per day for muscle spasms, fibromyalgia and depression
- Jan 2009 to Jan 2010 - Valium 5mg (for anxiety and muscle spasms)
- Jan 2009 to Jan 2010 - Ibuprofen (Advil) - when needed for pain and inflammation
- Jan 2009 to present - Karvezide 150/12.5 x 1 each day (blood pressure medication)
- Jan 2009 to present - Thyroxine 100mcm x 1 per day (for thyroid)

DOSE & TYPE OF LDN TAKEN JULY 2009 TO SEPT 2009
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone every night after 9pm
c) Type – 4.5mg capsules compounded with acidophilus

SUPPLEMENTS
- 2008 to Jan 2010 - Digestive Enzymes x 2 per day (discontinued Jan 2010)
- 2008 to present - Omega 3 Krill oil 600mg x 2 per day
- 2008 to present - Tresos B Pluse with Selenium (antioxidants & multivitamins) x 1 per day
- 2007 to present - Probiotics (Inner Health Plus) x 1 capsule x once per day
- 2008 to present - Magnesium x 2.5mg to 5mg powder (in water or vegetable juice) x twice per day
- Jan 2009 to present- Vitamin D 2000iu x 1 x twice per day
- Jan 2009 to present – Iodine x 2 drops x once per day
- Jan 2010 to present - Shark Cartilage 750mg x 2 x twice per day
- Jan 2010 to present- Olive Leaf Extract, recommended dose x 2 x twice per day

© Case Health Pty Ltd

- Jan 2010 to present- Slippery Elm Bark Powder x 1 teaspoon in vegetable juice x once day
- Jan 2010 to present - Colloidal minerals x 10ml x once per day
- March 2010 to present- Chlorella capsules x 3 x twice per day
- March 2010 to present - ZeoActiv8 drops x 10 drops x once per day
- March 2010 to present - Maca Powder capsules x 3 x once per day
- March 2010 to present - Kyolic capsules x 3 x once per day

OTHER THERAPIES/TREATMENTS
- 2007 to present - Chiropractic treatments every two weeks
- 2007 to present - Massage every one to two weeks

DIET
- 2009 to present - dramatically reduced intake of gluten
- 2009 to present - maintain a healthy well balanced diet of all food groups
- Jan 2010 to present – Initial Phase Diet (has improved irritable bowel). Phase 1 consists of limiting intake to these foods; grass fed beef, chicken, fish, eggs, nuts, except pistachios and peanuts, vegetables (but no corn, potatoes or mushrooms), carrot juices w/other veggies, water, herbal teas, green apples, berries, grapefruit, lemon, lime, avocados, plain yoghurt, and real butter. In April 2010 I advanced to Phase 2 of the diet which allows reintroduction of some restricted foods, such as; sweet potato, some ancient grains like buckwheat, quinoa, etc, peas, and beans.

EXERCISE
- 2005 to 2007 - sporadic attendance to a gym - discontinued due to pain and fatigue
- 2008 to present - maintained a 15 to 20 minute walk each morning unless pain and stiffness is extreme

MY STORY

The recent diagnosis of Fibromyalgia was unsatisfactory to say the least because it was no diagnosis at all. In a vain effort to find out for myself why I was in pain most of the time, had no energy and was depressed, I researched and made a suggestion to the doctor, “Do I have Fibromyalgia?”. “Yes, you probably do have Fibromyalgia”, he mumbled, and that was my diagnosis.

To be fair he did do one blood test to rule out Lupus and Rheumatoid Arthritis. If there are any other tests that can rule out or determine something I haven’t had them. After having a colonoscopy to try and determine the cause of my constant diarrhoea I was only told that I had the cleanest colon the doctor had ever seen.

So I diagnosed myself with Irritable Bowel Syndrome and to a large extent Fibromyalgia as well. What else was I to do when Doctors have kept saying all my life there was nothing wrong with me, and to go see a psychiatrist.

Twenty- five years ago when I was 29 I had lower back pain which struck suddenly and incapacitated me for a couple of weeks. Moving was slow and painful. I’d had backaches before but nothing like this where walking was sheer hell. The spasms settled but I was left with severe pain when sitting or getting up from a chair.

I used to have to grab the kitchen table to haul myself up. That too faded with time but then I would have episodes where I would have trouble with my balance and I would walk into things and always to the left. Once again that would come and go. No tests were done and I was told there was nothing wrong with me. Some wear and tear arthritis showed up on x-rays but nothing else.

In the 1990’s I had two episodes of brief eye disturbances, which were put down to migraine. I’ve had migraines nearly all my life and due to the pain, my death wishes were very real. These visual disturbances never came with any head pain, just an inability to see anything centrally. End of story with the visual problems. I haven’t had them since.

By 1998 I was living in constant pain and with very low energy levels and teaching at a high school. I could not keep up the pace and was diagnosed with depression and told to leave teaching behind. I’d been fighting brain fog for such a long time and it only got worse after the diagnosis of depression and anxiety.

I’ve been on a few different antidepressants such as Prozac, Zoloft and a few others whose names have gone into the fog. Valium for the anxiety and Panadeine Forte for the pain just made the fog worse. It wasn’t until 2008 that I changed doctors and he agreed with me that it was possible that I had thyroid hormone resistance at a cellular level and so started me on a low dose of Thyroxine. My previous doctor told me there

was nothing wrong with me despite having developed a goitre. Since starting the thyroid hormone treatment over 18 months ago I have had only 1 migraine.

I call that miraculous but then came along information via Dr Mercola's Newsletter about something called Low Dose Naltrexone (LDN). There was nothing about Fibromyalgia in the article but I knew I had symptoms that mimicked some autoimmune diseases so I googled and found that indeed trials had begun to see if LDN could help Fibromyalgia. To say I was excited was understatement. I read all the sites I could find pertaining to LDN and made my decision to find a doctor who would prescribe it. Ironically it was my psychiatrist (the only one who doesn't think my pain is all in my head) who prescribed it for me and wished me luck.

I have now been on LDN for 5 months and I'm happy to report I have more good days than bad now in terms of the clearing of brain fog. I am still on two different antidepressants to help with the muscle spasms and of course the depression but only small doses, not like I was on before.

I go to the chiropractor every two weeks and have a massage each week and the pressure points are still has painful as ever and I find it excruciating to be touch around my lower back. I am hopeful that over time LDN will ease the pain in my lower back. I am patient because I know for some people it takes time for the Low Dose Naltrexone to work. I will give it at least a year and continue to monitor my progress.

If the lifting of the incessant brain fog is all that I get from LDN then I'm happier than I was. My irritable bowel is less irritable possibly due to the LDN and a severe reduction in gluten. I am currently taking 4.5 mg LDN and may decrease the dose down to 3 mg because each morning I still feel like I've been hit by a truck, the pain and stiffness remains and some days it is worse than before taking LDN.

All in all I am happy with my decision to start taking LDN and I do believe it is early days yet and will continue to keep track of my progress. Just a few short months ago it would have been too overwhelming for me to sit at the computer and write this because of the brain fog.

Update April 2010

In September 2009 I stopped taking LDN after ending up in hospital for 3 days with a kidney stone attack.

I had a stent placed in my ureter to help with the pain of the stone until it had dissolved. I had the stent in for 5 months and as yet have not considered going back on LDN. Since coming off LDN neither my arthritis nor fibromyalgia have become worse but my new doctor found more things wrong with me such as mercury and lead overload in the body, severe adrenal fatigue and a heavy yeast infection.

After extensive reading on the subject of LDN, the one common thread that seems to stand out is the fact that LDN is not a standalone treatment. Since finding a holistic doctor who understands mind, body and soul I have decided to go down the path of changing my diet dramatically. Since starting the Initial Phase diet three months ago I no longer have an irritable bowel and after twenty years I find this remarkable. The diet first restricts, then reintroduces whole foods in phases, and having completed Phase 1, I've commenced Phase 2.

I feel this is the direction I need to take right now but I haven't ruled out LDN in the future if diet alone doesn't improve my fibromyalgia. I am now off most medications except ones for blood pressure and thyroid. I'm now on natural supplements, which I'm very happy with. The most important thing I've learned over the past year is to find a doctor who will give an accurate diagnosis. I now feel satisfied that I'm on the right track. If things don't improve then I will approach my new doctor about LDN.

Janis, Australia

Janis, Australia

"Just a few short months ago it would have been too overwhelming for me to sit at the computer and write this … "Jul '09

In September 2009 I stopped taking LDN after ending up in hospital for 3 days with a kidney stone attack … decided to go down the path of changing my diet dramatically … I am now off most medications except ones for blood pressure and thyroid … now on natural supplements … Apr '10

43 LDN dramatically reduced Fibro pain - Judy

- LDN since 21 January 2009
- story submitted 29 June 2009
- story updated April 2010 (over 1yr on LDN)

SPECIFICS

DIAGNOSED
- childhood - Diphtheria
- teen years - early signs of Endometriosis and PCOS
- child-bearing years - pancreatitis resulting in gall bladder removal
- child-bearing years - Hypothyroid
- child-bearing years - high blood pressure
- Oct 1995 - Fibromyalgia
- 1997 - Restless Legs Syndrome
- 2002 - Spinal Stenosis
- 2002 - Endometriosis, Poly Cystic Ovary Syndrome (PCOS)
- 2007 - Double Pneumonia
- 2008 - Periodic Limb Movement Disorder
- 2008 - Spondelolisthesis

MEDICATION (pre LDN)
- child-bearing years - Synthroid
- child-bearing years - high blood pressure medication
- 1995-2008 - Many drugs for Fibromyalgia that produced unpleasant side effects
- 1997 to 2008- Mirapex 1mg at 3-4pm, plus 1mg at bedtime (for Restless Legs Syndrome)
- May to Aug 2008 - Tramadol (Ultram) .5 mg am and pm

HOSPITALISATION
- 1986 - gall bladder removal
- 2000 - gastric bypass surgery
- 2002 - surgery on my back for spinal stenosis
- 2002 - tonsils removed due to constant fever and sore throats.
- 2002 - Cystic Ovary with endometriosis removed
- Dec 4 2008 - Surgery on my back to correct Spondelolisthesis

MEDICATION (post LDN)
- Jan 2009 to Feb 2009 - Mirapex 1mg at 3-4pm, plus 1mg at bedtime (for Restless Legs Syndrome)
- Feb 2009 to Mar 2009 - Mirapex .5mg in late afternoon, 1mg at bedtime (Restless Legs Syndrome)
- Mar 2009 to Apr 2009 - Mirapex 0mg in afternoon, .75 mg at bedtime only (Restless Legs Syndrome)
- Apr 2009 to present - Mirapex .5mg at bedtime only (Restless Legs Syndrome)
- Jan 2009 to present - Low Dose Naltrexone (LDN) 4.5mg at bedtime
- Jan 2009 to present - Armour Thyroid 60mg am, 60mg pm (Hypothyroid)
- Jan 2009 to present - Benicar 20mg am (High Blood Pressure)

LDN DOSE & TYPE
a) Dose - 4.5mg Low Dose Naltrexone (LDN)
b) Time - I take the Naltrexone at bedtime each night
c) Type - Compounded capsules with pure Naltrexone powder and Lactose filler. (Compounded by local pharmacy)

SUPPLEMENTS
- 2007 to June 2009 - Phytonutrients
- As at June 2009 I am taking the following:
Phytonutrients
Multi vitamin-mineral
Calcium, Magnesium, Zinc, Copper, Manganese, Vitamin D – combination supplement
Flax seed oil with Alpha Lipoic Acid and coenzyme Q10 – combination supplement
Blue-Green Algae
Olive leaf extract
Probiotics

DIET
- 2008 - Cut out gluten and sugar.
- June 2009 - Today my diet is simple. I eat vegetables (mostly raw) fruits, nuts and seeds. I try to limit my meat to once a day and gluten-free grains to once or twice a week.

EXERCISE & INTERESTS
- I try to walk as much as possible.
- I make handcrafted wire-wrapped jewellery and I like to sew and paint with oils and pastels

© Case Health Pty Ltd

MY STORY

I was diagnosed with Fibromyalgia in the fall of 1995. I woke up one morning and was in so much pain I couldn't move. I was very lucky however, because my physician was familiar with Fibromyalgia and diagnosed me right away. Unfortunately, all the medications he put me on either gave me bad side effects or didn't help at all.

I think I may have been predisposed to have Fibromyalgia because of genetics, but I know the stresses of life and various illnesses may have contributed also. My mother was a type 1 diabetic when she got pregnant with me. She had been diagnosed when she was 18 and was 24 when I was born. That meant that I weighed 9 lbs 10 oz and was born insulin dependent. Memories of my childhood include many times when mom would pass out because of difficulties with keeping her blood sugars level. Later a doctor actually asked her if he could tell her story at a medical conference because of the type of diabetes she had. He explained that sometimes her body would produce insulin and sometimes it wouldn't.

Even with all her health problems, mom tried to be a good mother. And my father, a minister, tried to be a good father. Unfortunately, I was still sexually abused by a friend's grandfather when I was five. I remember my parents being shocked when I told them, but nothing was ever said or done about it again. I felt as though I had embarrassed them by saying anything, so the second time I was sexually abused, this time by a cousin when I was eight, I didn't tell anyone. It was also around this time that I caught diphtheria and nearly died. The doctor gave me penicillin, but I had an allergic reaction to it. Somehow, however, my fever broke and I recovered.

When I was a teenager and began having my period, I would have terrible pain with it. I was also very irregular and would have them only once every two to three months. Later I found out this is a sign of endometriosis and Poly Cystic Ovary Syndrome. I've had a fighting battle with my weight all my life, but by heavy dieting and exercise I was able to get pregnant with my five children. Unfortunately, that caused a lot of yo-yo dieting which gradually made my health worse. I eventually had pancreatitis and had to have my gall bladder removed. Then I was diagnosed as hypothyroid and put on Synthroid. I also had high blood pressure and was treated for that.

About a year after I was diagnosed with Fibromyalgia, I was diagnosed with Restless Legs Syndrome. I started taking Mirapex, which did help a little. Later a sleep study would show that I also have Periodic Limb Movement Disorder. However, the constant pain all over, numbness in feet and hands, twitching of muscles and total exhaustion of my fibromyalgia, made it nearly impossible for me to do anything. So in 1997 I applied for disability. I was turned down. I appealed. Again I was turned down. I asked for a hearing before a judge. He ordered a psychiatric examination, which I must have failed because I finally got my disability.

By the year 2000, I had gained another 100 pounds, putting my weight at over 300 pounds. I hated it and decided to have gastric bypass surgery. I did lose about 100 pounds, but the weight loss didn't help the pain from the Fibromyalgia. The extra weight had already done its damage though, and I had to have surgery on my back for spinal stenosis. Also, because of constant fever and sore throats, my tonsils were removed. Later that year, I had the endometriosis and Cystic Ovary removed.

Every time a new drug would come out for Fibromyalgia, my doctor would try it on me. It seemed, however, that the side effects always outweighed any benefits. And I had to constantly alternate pain medications because of stomach upset or other problems. Somehow I kept going, though, mostly by taking a lot of Tylenol. Unfortunately, it never did more than barely take the edge off the pain. I think I probably also had Multiple Chemical Sensitivities, but my doctor never confirmed it. And then, because I couldn't be very active, I started to regain much of the weight I had lost from the bypass surgery. Even though it seemed as though my health continued to deteriorate, I didn't give up. But I did decide I would just have to learn to live with my life the way it was.

In 2007, I nearly died from double pneumonia. It really scared me. I determined I had to do something more about my health. I went on the internet and tried to learn everything I could about the new advances in Fibromyalgia and healthy living. About this time I heard about phytonutrients and began to take a supplement that contained them. I started to feel a little better. Next I started the Atkins diet program and totally changed my diet, cutting out gluten and sugar. I finally began losing some of my excess weight. I even began to feel better as the devastating pain wasn't quite as bad and I seemed to have slightly more energy.

Unfortunately, by this time my spine had started to deteriorate. I had two disks that slid out of place and pinched my spinal cord (Spondelolisthesis). The pain became so severe that I was put on Tramadol (Ultram). Unfortunately, I had a severe allergic reaction to it. I started sleeping 18 + hours a day, and I was so out of it when I was awake, I didn't know what was going on around me. Then my eyes and face started to swell. I tried to go cold turkey, but thought I was going to die.

My doctor's office said I would have to wean myself off Tramadol because it was an opioid drug.

Again I went on the internet, and in the process of learning how to come off Tramadol, I came across a drug called Low Dose Naltrexone.

When I discovered that Stanford University was doing a trial of LDN in Fibromyalgia patients, I printed out a stack of information about it and took it to my doctor. While he had never heard about Naltrexone being used for Fibromyalgia, he did agree to read about it. Since I was seeing him at the time for my back problem, he said he wanted me to have my back surgery first.

I had my surgery December 4, 2008 and was finally able to walk again. When I went to see my primary physician in mid January, 2009, he agreed to write a prescription for LDN. **He said he couldn't discover anything about it that would harm me.** I thus started a dose of 4.5 mg LDN at bedtime on January 21, 2009. I was hopeful that this time I had found something that would help, but I'd been disappointed so many times in the past, I was determined not to get too excited about it.

The first night I did fine. No dreaming, but then I couldn't remember dreaming for a long time. I did wake up a couple of times, which isn't that unusual with my Fibromyalgia pain, but I went right back to sleep. I didn't notice anything different when I got up the next morning. Second night, again woke up a couple of times, but this time it took about an hour each time to get back to sleep. Was having a lot of pain in my pressure points. I messaged them until they eased up, then fell back to sleep. Again didn't notice anything different during the day.

Third night, I woke up sweating profusely at around 3am and threw off the covers. I started to chill again after about fifteen minutes, so I pulled up the covers and went back to sleep. I wasn't sure if it was a hot flash or from the LDN. Later that afternoon, I did notice that I seemed to have more energy during the day.

On day four, I again woke up sweating around 3am, but it wasn't as severe as the previous night. When I got up in the morning I realized I didn't have as much stiffness as I usually do. Also, I realized that while I did still have some pain, especially in my pressure points, it wasn't as sharp.

The fifth through seventh days I didn't feel too bad during the day, but by evening I was totally exhausted and I started sleeping 11 to 12 hours at night. I didn't wake up in pain as many times during the night, but I did realize that I was dreaming. I didn't really remember what the dreams were about, but just remembered that I had actually had a dream.

Around the tenth day I realized that my morning stiffness wasn't as bad as before. And I definitely had more energy and less pain. I never expected to notice any changes so quickly.

On the 18th day I woke up between 2-3 am and realized I had been dreaming. And this time I actually remembered the dream. I did stay awake a couple of hours afterward, but finally went back to sleep. When I woke up I felt so good, I ended up overdoing it. I actually straightened the living room and vacuumed the floor. I haven't been able to vacuum for I don't know how long. I've always had to ask my husband to do it for me. He still moved the furniture around, but I actually did the vacuuming. Of course, later I started to notice a lot of pain and exhaustion. It continued through the night and I woke up every time I turned over. However, when I woke up the next morning, I again felt pretty good. If I had tried that before, I would have been in bed for a couple of days at least.

At one month, I couldn't believe how much my life had changed. I had so much more energy and I felt so much better. I still had some pain but had been able to cut back on pain meds, taking them just when I needed to instead of around the clock. I still had days where I felt exhausted and awful, and some nights where I felt like I hardly slept at all. And then there were other days where I woke up feeling like I had the best sleep of my life. Some days I didn't think the LDN was working, and then other days I was so excited because it actually felt like it was.

I could get up and not have to hold onto the wall for support. My morning stiffness and pain were at least 50% better.

One thing I didn't expect was with my restless legs. That started to get better also. I had been taking 1 mg Mirapex at about 3-4pm and then another at bedtime. Gradually, I started to forget to take it until later and later in the afternoon. So I cut that dose in half. Then I didn't need to take any in the afternoon. Then I cut the evening dose to .75 mg and finally .5 mg.

That is something I never expected to ever happen. And I think I'm even more excited about that then how I felt about my fibromyalgia getting better. The Mirapex has some very undesirable side effects, but the relief from symptoms did outweigh the problems.

Another thing I noticed was that my mind seemed clearer. I didn't have as much fibro-fog as before. And most of all, I actually felt like doing things again. In fact I had to watch that I didn't overdo, because I'd start something like cleaning out a kitchen cupboard and forget to take a break.

There was an incident that happened around the beginning of the second month that made me really realize how LDN works.

I caught a very nasty bug of some kind. When I was at my sickest, I woke up two hours after I went to bed and it would feel as though my body's immune system had completely closed down. I felt horrible. I'd stay awake for a couple of hours and then finally drop off to sleep. When I woke up I felt so much better, like my body was fighting off the infection and I was mostly just tired. Then, gradually through the day, I would start to feel worse again. This happened for about 4 days in a row.

My husband kept telling me I should go the doctor, but every day I kept saying I didn't really feel that I needed to. Usually, I would have to get antibiotics when I had something like this, but this time I didn't need to. Amazing. Of course I loaded myself up with vitamins and drank lots of fresh juice, too.

As I write this, I've been on LDN for almost six months. I have come from having daily pain levels of 5-7 to 2-4. I still have to pace myself, but I have so much more energy. In the last 2 months I haven't had to use my walker once. I usually sleep through the night, waking normally after about 8 hours. I had fasting labs drawn that said my liver, kidney and thyroid function are normal. I rarely need to take any pain medication. I would have to say that I feel 70-80% better overall.

For me, I can't say anything bad about the LDN. I think everyone with Fibromyalgia should definitely give LDN a try. What do you have to lose?

UPDATE April 2010

Yes I'm still taking LDN, and yes, I am still feeling the benefits.

After one year on LDN I have 80% improvement in all my Fibromyalgia symptoms. My pain levels have dropped significantly from a daily average of 6-8 to 0-2. When I began LDN I was taking 4 other medications. I've been able to eliminate two of those drugs, and of the remaining two, I've reduced my dose to one half and one quarter respectively.

I call LDN my life-saver,
Judy, USA

Judy, USA

"As I write this, I've been on LDN for almost six months. I have come from having daily pain levels of 5-7 to 2-4. I still have to pace myself, but I have so much more energy. In the last 2 months I haven't had to use my walker once. I usually sleep through the night, waking normally after about 8 hours. I had fasting labs drawn that said my liver, kidney and thyroid function are normal. I rarely need to take any pain medication. I would have to say that I feel 70-80% better overall.?" Jun '09

LDN Fibromyalgia Group
To better health through knowledge
http://health.groups.yahoo.com/group/LDNforFibro

44 LDN benefiting arthritis & fibro – Edward

CASE STUDY DOCUMENT CONTROL NOTATION:

CASE STUDY Number 44 – 'LDN benefiting arthritis & fibro – Edward, USA', LDN since March 2005 was featured on page 194 of the 2009 edition.

It has been removed from this edition due to data oversight, though of note is that Edward continued to report benefiting from LDN.

45 LDN and My Peculiar Circumstance - Margaret

LDN since 22 April 2009
- story submitted July 2009
- story updated 19 August 2009
- story updated 9 September 2009
- **story updated 25 Jan 2010 (9mths on LDN)**

SPECIFICS

DIAGNOSED
- 2002 - Osteo-arthritis in my neck
- 2002 to 2004 – Cataracts in both eyes
- 2004 - Age-related macular degeneration (druse - a cluster of small crystals) on the retina)
- Dec 2008 – Rheumatoid Arthritis (informal recognition of physical signs by GP)
- early Apr 2009 to Jul 2009 – chronic diarrhoea, cause undetermined, unabating
- Apr 2009 – Rheumatoid Arthritis (confirmed via x-ray showing moderate joint damage in hands and feet)
- 12 July 2009 - inflamed colon
- 17 Jul 2009 – candida infection
- 17 Jul 2009 – excessive thyroid hormones
- 4 Aug 2009 – Gastroenterologist – small, chronic ulcer detected in colon
- Aug 2009 - small carcinoid tumour
- Jan 2010 – NED no trace of carcinoid tumour anywhere

MEDICATION (pre LDN)
- 2002 to 22 Apr 2009 - 160 mg aspirin/day for blood disorder (replaced Hydrea) NB Had previously been treated with Busulphan (banned in France)
- unknown to Mar 2009 - Ibuprofen when needed
- 2002 to 22 Apr 2009 - Piascledine 300 (for osteo-arthritis)
- 2004 to 22 Apr 2009 - Nutrof and Ocufen eye drops (for AMD)
- Dec 2008 to Dec 2008 - prednisone for 10 days - 1st 5 days 60 mg/day, 2nd 5 days 40 mg/day
- Jan 2009 to Jan 2009 - prednisone for 10 days: 1st 5 days 60 mg/day, 2nd 5 days 40 mg/day
- mid-Feb 2009 to mid-March 2009 - prednisone (to treat RA) - 30 days: 5 days 60mg/day; 5 days 40mg/day and so on)

MEDICATION - CEASED (post LDN)
- 22 April 2009 to 24 Apr 2009 - 1.5 ml low dose naltrexone (LDN)
- 24 Apr 2009 to May 2009 - 3ml low dose naltrexone (LDN) for 3 weeks
- 15 May 2009 to 23 Jul 2009 - 4.5ml low dose naltrexone (LDN)
- 12 Jul 2009 to 19 Jul 2009 - antibiotics (to treat inflamed colon) for one week
- 23 Jul 2009 to 30 Jul 2009 – 3ml low dose naltrexone (LDN) – lowered dose in response to 11kg weight loss (60 to 51 kg), then stopped for 4 days due to hospitalisation
- 22 Jul 2009 to 24 Jul 2009 – Levothyron 50mg per day (for thyroid) – ceased due to escalation of diarrhoea
- 22 Jul 2009 to 29 Jul 2009 - Triflucan 50mg for the candida for one week
- 24 Jul 2009 to 25 Jul 2009 – Imodium for 2 days - 2mg x 2 first day, 2mg x 2 second day
- 22 Jul 2009 to 30 Jul 2009 – SMECTA or Montmorillon Clay x 1 sachet (for inflamed colon)
- 24 Jul 2009 to 30 Jul 2009 - Jatropha curcas, homeopathic treatment for diarrhoea, Strength 5 CH x 5 granules twice a day - approx 10 am & 11 pm (2 hours after taking ldn)
- 4 Aug to 12 Aug 2009 - Pentasa (mesalazine) granules 2 mg in morning, 2mg at night
- 16 Aug to 15 Sept 2009 - Pentasa (mesalazine) granules 2 mg in morning, 2mg at night (following short 4-day break - trialled stopping this for 4 days but needed to recommence and stay on till mid Sept)
- 4 Aug 2009 to August 2009 – 4.5ml low dose naltrexone (LDN)
- 22 Apr 2009 to Sept 2009 - 160 mg aspirin/day for blood disorder (replaced Hydrea)
- 22 Apr 2009 to Jan 2010 - Piascledine 300 (for osteo-arthritis)
- 22 Apr 2009 to Jan 2010 - Nutrof (for AMD)
- 22 Apr 2009 to Jan 2010 - Ocufen eye drops (for AMD)
- Aug 2009 to Jan 2010 - mesalazine 2mg granules x twice a day, morning and night
- Aug 2009 to Jan 2010 - Imodium 2mg x 2-3 each day
- 4 Sept to Jan 2010 - DIFFU-K (potassium) 2 x 600mg three times per day (blood tests to monitor)

TESTS
- Apr 2009 - x-ray showed moderate joint damage in hands and feet
- Apr 2009 – blood tests - negative for antibodies
- 17 Jul 2009 – stool analysis - candida
- 17 Jul 2009 – blood test - TSH – abnormally high at 7.27 (normal range is 0.35 to 4.97)

<u>The following tests were done while an in-patient in hospital 30 Jul 2009 to 5 Aug 2009</u>:
- 30 Jul 2009 - echograph to check condition of thyroid - thyroid 'small', no nodules
- 30 Jul 2009 - echograph of upper intestinal area, stomach and sides - nothing abnormal

- 30 Jul 2009 - x-ray of intestines - normal
- 30 Jul 2009 - urine analysed twice, second sample taken in sterile conditions
- 30 Jul 2009 - several blood samples taken
- 31 Jul 2009 - red dye swallowed to check transit time
- 4 Aug 2009 - colonoscopy - clear of cancer, but ulcer detected
- 5 Aug 2009 - additional blood tests taken. I had to wait for results before I was allowed home.
- Aug 2009 – low Potassium
- 1 Sept to 21 Sept 2009 – Potassium levels checked twice weekly over 3 weeks.
- 21 Sept to 14 Oct 2009 – Potassium levels checked once weekly over 3 weeks.
- 24 & 25 Nov 2009 – 2 x octreoscans – No trace of Carcinoid Tumour anywhere

HOSPITALISATION/SURGICAL PROCEDURES
- 2002 – Cataract surgically removed
- 2004 – Cataract surgically removed
- 30 Jul 2009 to 5 Aug 2009 – Hospitalised due to weight loss (allowed home over weekend on strict no fibre diet)

Medications/treatments while in hospital:
- 2 x 250 ml saline drips – missed LDN & Nutrof medications this first day, as the hospital only had Piascledine and 160 mg aspirin
- 31 July 2009 - 4.5ml LDN at 9 pm, plus the usual medication
- 1 Aug 2009 – no LDN prior to anaesthetic
- 3 Aug 2009 - purge to 'wash' the colon clear - effective after 1.5 litres
- 4 Aug 2009 - glucose drip just before and during colonoscopy, low blood sugar noted, lactose (I think it was - not sure) given after
- 4 Aug 2009 - unknown medication
- 4 Aug 2009 - Pentasa granules 2 mg in morning, 2mg at night with meals
- 4 Aug 2009 - started LDN again at 9 pm
- 21 Aug to 31 Aug 2009 – Hospitalised for 10 days

MEDICATION - CURRENT (post LDN)
- August 2009 to present - 3ml low dose naltrexone (LDN)

LDN DOSE & TYPE
a) Dose – 3ml low dose naltrexone (LDN)
b) Time – I take my naltrexone around 9pm each evening
c) Type – liquid (made using one 50mg Naltrexone tablet, dissolved and diluted in 50ml distilled water). I tip the bottle gently a few times to disperse the content, and use a needle-less syringe to draw up 3ml of the liquid.

Update Jan 2010 – LDN: I used to tip the bottle gently a few times to disperse the content, then someone said the Naltrexone dissolves like sugar and doesn't sink so there's no need to shake the bottle. So now after the initial shaking to dissolve the tablet, I let it settle, then pour off the dilution and throw away the deposit. I put the dilution back in the bottle and don't shake it again. Not ingesting the iron oxide filler may also be contributing to my improvement.

SUPPLEMENTS
- Apr 2009 to Aug 2009 - Probiotic with milk derivatives (Acidophilus Three Billion)
- Apr 2009 to Aug 2009 - Vitamin C x 1000mg
- Apr 2009 to Aug 2009 - Vitamin E 400mg x approx 2 to 3 per day
- Apr 2009 to Aug 2009 - Omega 3 epa/dha x approx 2 to 3 per day (average 900mg epa/day)

Jan 2010: I'm presently taking the following supplements:-
Advanced 40+ acidophilus x 1 per day
Fish oil capsules x 1 or 2 per day (containing EPA 650mg, DHA 450mg)
Vit D3 x 2,000 IU per day
Vit C x 1000 mg per day
Vit E x 400IU per day
Biotin x 5,000 mcg per day
'Eye Factors' x 2 per day (to replace the Nutrof eye drops for AMD)
DIET
-2009 – I have a restricted diet: no gluten or casein, no read meat, no eggs (have tried eggs again but don't think it's a good idea). I've reduced smoking and smoke as few roll-ups (French Gauloises tobacco) a day as possible. I still have a glass or two of red wine with lunch and dinner. I've never been a finicky eater and fussing about food goes against the grain. I've always eaten fresh food, preferably organic (home grown vegetables when available) cooked in the home or restaurants, I've never liked junk food, don't have sweet tooth. Stopped drinking milk years ago. Now I eat sheep and goat cheese and discovering gluten-free recipes.
- Aug 2009 - The dietician gave me a low fibre, low residue diet to follow which isn't too bad at all.
- 18 Jan 2010 – Began the SCD diet. Colitis improved after first day and after 5 days, symptoms of Colitis were gone and bowel habits were back to 'normal'. I'm probably luckier than some - I don't have a sweet tooth, am used to doing my own basic cooking from fresh, local
ingredients, preferably organic, and the almond flour 'bread' instead of ordinary bread and potatoes suits me fine. There are plenty of recipes available on the web thanks to generous SCDers. In fact, I'm enjoying the SCD and don't understand why it has such a difficult reputation.

INTERESTS
- local and English medieval history, gardening

MY STORY

I was married for 10 years, but it ended by 2005. My husband (French) turned out to have mental problems and drank. In the late 1990s he began to be stalked by a deranged local woman who claimed he belonged to her and was the father of her son. She stalked me and my house, telephone, and letterbox too.

As a result he lost his job and would filch my money. He had two spells in psychiatric hospital, angina, smashed elbow and hip, and hospital emergencies after her physical violence. Even though our marriage was over, he stayed with here for a couple more years, when I at last got him into social housing. A friend reckons this was when my autoimmune disease showed itself due to years of inescapable stress. I've lived in rural France since the early 90s. What family I have are all in the UK.

I had no idea what was happening when in autumn 2008 I started getting pains - first in my right wrist, then my left - shooting up to the knuckles. I was told it was 'rheumatics' which to me meant that aged in my mid sixties; old age was coming down on me fast. Loss of strength had already been depressing me and reducing my quality of life for two or three years. Without thinking about it too hard, I just accepted loss of strength, aches and pains were a normal part of getting old. Not accepting this was somehow a bit silly. Now I know better.

Osteo-arthritis in my neck had been identified in 2002 and I was prescribed Piascledine 300. It worked well. My GP at the time (since retired) said he didn't know how it worked but that everyone who was taking it found it helped a lot.

Around the same time I had two cataracts replaced, the first in 2002 and the next in 2004. During a post-operative check, the ophthalmologist found I had druse (a cluster of small crystals) on both retinas and diagnosed age-related macular degeneration. That was in 2004 but I still had excellent sight until 2008 when it began to distort at the same time as the pains started in my hands. The distortions became steadily more numerous and pointed.

I now realise that the leaden-like exhaustion was one of the first symptoms of my autoimmune disease. In about 2006 I realised I was facing physical work, even movement, with dread and despair. I heat my house with wood and used to order 1 metre logs that I'd chainsaw in two before stacking. Now I had to order the more expensive pre-sawn 50cm logs.

I couldn't start the lawnmower any more, so had to pay someone else to do it. It was clear I ought to think seriously about moving into a more convenient home, but just couldn't get my head around the idea of all that upheaval and stress. I felt I was about to collapse most of the time, and found myself using chairs and tables for support, as I moved from one part of the room to the other. It wasn't till the evening that I could even think about making the bed and washing up.

After a couple of minutes vacuuming I had to stop and rest. Dusting was the same. Every movement hurt, but even trying to relax didn't work as pains would shoot throughout my body. Brushing my teeth, getting in and out of the bath, squeezing the washing up sponge, and the countless ordinary everyday activities became painful and difficult. I dreaded going to bed as there was no rest, just more pain. The future seemed very bleak. I was becoming reclusive. I loathed the thought of going out and being with healthy people who expected me to be healthy too, so I stopped going out.

I was ashamed of the state I was in, the state my home was in, and my inability to do anything about it - so I stopped inviting people around. I sensed that other people thought I could snap out of it. Someone told me I should flex my fingers when I woke up to get the blood moving. I didn't even try to explain that my joints were being destroyed. I couldn't resent the advice - apart from the fact there was nothing anyone could do to help me, I'd been as ignorant as they were just a few weeks earlier. I used to wonder how much longer I'd be able to live independently. How would I cope with being bossed about by the social services whose duty it would be to protect and help me?

I consulted the large arthritis research organisations for help and advice and found them thoroughly demoralising. They seem to advocate a 'mind over matter' approach. Sufferers must be brave, soldier on, make the best of it, buy gadgets to help around the house and in the garden, use arms to open doors instead of hands, and not let the pain get them down. They must listen to their doctors and take the medicine, even if

the side-effects can be as devastating as the disease. One site I was looking at the other day warned readers not to read research articles if they thought they might be upset by them.

The kind of information they had was concerning, with an estimated average of 6-10 years shorter life span for RA people as the body will start to attack and destroy vital organs as well as joints. The British Arthritis Research Campaign has published a complementary medicine survey but LDN isn't included.

In December 2008 I had finally presented my hot, swollen and painful joints to the GP and she said it was Rheumatoid Arthritis but also said it wasn't age-related. Looking it up on the internet, I learned that it could attack people of all ages and for the first time, I began reading about autoimmune diseases.

A short course of prednisone helped the pain a bit, but not for long. I had another course in January. Neither helped the mental and physical exhaustion and the pain, stiffness and swelling was reaching the whole body - my elbows hurt, so did my shoulders, knees, ankles and toes. No day was like another: Sometimes the exhaustion was worse, sometimes not so bad, and the intensity of pain would shift about.

A third, longer course of prednisone from mid-February to mid-March 2009 helped a lot more. For about ten days or so I even had a wonderful burst of energy before it faded, leaving me as washed out as ever. I spent most of that time pruning one of my apple trees. That burst of energy intrigued me - what had happened? Where had it come from? It seemed it must mean I still had energy within me that could be unlocked. The trouble was, of course, if I relied on prednisone, I'd soon have additional health issues like osteoporosis, etc, etc.

By this time an appointment with a rheumatologist had been arranged. This was a gruesome experience: He seemed bored, impatient with his job or his patients, or both – whatever. I felt like a nuisance, especially when my blood tests came back negative and the x-rays showed only moderate joint damage. I got the impression mine wasn't the kind of inflammatory arthritis he was interested in. He dismissed me with a prescription for Celebrex - I looked this up on the internet when I got home and chucked it into the fire.

I mentioned to the rheumatologist that I'd replaced painkillers and cortisone with Vit E 400 and large doses of omega 3 for the pain and inflammation, and that I'd felt some relief, but he wasn't interested. Nor was he interested in the fact that I'd gone gluten and casein-free which also seemed to help. I offered him a print-out of information about LDN, but he pushed it back at me after a cursory glance.

Mind you, it was in English and he was French, but I think it's fair to say that French doctors and scientists can all read documents in English, even if they find speaking English difficult. All in all, I felt he just wanted to deal with me as quickly as possible and what I had to say was a waste of time.

Awareness of LDN in France is virtually non-existent. An internet forum I joined is dormant - my message of introduction received no reply. It's thanks to the English speaking internet, of course, that I learned about LDN. A friend spotted an article on Dr Mercola's website describing LDN as a treatment for RA.

At first I thought it was just another flaky idea purporting to be a miracle cure, but I soon changed my mind. I spent about six weeks learning as much as I could about it. I learned a lot about MS and Crohn's, but information on Rheumatoid Arthritis and LDN was relatively thin on the ground. Still, I figured, if RA was an autoimmune disease, it should respond to LDN, so I wanted to try it.

Without really understanding why, it was internet advice I'd followed to go gluten and casein free and start using Vit E 400 and fish oil. A lack of funds, however; stopped me taking all the recommended supplements. On this regimen I felt so much better. I had begun to wonder if I needed LDN. I decided I had to go ahead though, because without LDN, as I understood it, my immune system would keep attacking my body - it wasn't enough just to make the consequences of RA bearable.

I began LDN on 22 April 2009. For the first couple of weeks I had some reactions - headachy, agitated, and the first hours in bed were unpleasant, with quivery and restless legs. My hips itched and burned, there was a peculiar tingling sensation in my hands and feet, and I had to keep getting up to go to the toilet. Then, usually around 2 or 3am in the morning I'd drop off.

During the day after, I'd feel groggy, fed up, and very tetchy. I began to hanker after bread and cheese. My feet got worse and I started limping. Any physical effort brought about trembling muscles, and I had no stamina whatever. Sometimes after a midday nap I'd feel better and more positive. I was disappointed that I had none of the vivid dreams others had talked about.

During this same time though, there were some positive changes too. There was still fatigue, but it felt somehow less profound, especially if I paced myself. I had been feeling breathless when walking up hills, and that stopped. I began to be able to relax again, to feel comfortable and cosy. I slept well once I'd fallen asleep, and I began to contemplate chores without a sinking heart. Getting up in the morning got easier - a lot less pain, just a bit stiff.

A most memorable moment was 4 days after starting LDN: I got up and picked up the kettle without thinking about it first AND with just one hand. According to the journal I keep, 30th April (8 days after starting) was the first time I got up and actually felt well. The next day I noticed my fingers felt a bit stronger, even if they still wouldn't bend much. My feet, which had seemed to be going numb as well as painful, began slowly to come back to life. My sense of balance came back and I could stand on one leg to put shoes on.

About this time I ran out of the Vit E and omega 3. New supplies arrived 10 days later but improvements still steadily continued, and there were other changes. As I mention above … last autumn, around Sep 2008 when the RA was setting in, my vision began to distort. The ophthalmologist had told me to come back in 18 months when it might be bad enough to do a laser treatment. He was as dismissive of what I had to say as the rheumatologist - they both seemed to be telling me I was going more or less blind and crippled, and that's all there was to it.

Well, on 9 May I wrote in my journal that my earlier feeling that my vision seemed more stable on taking LDN was confirmed. It is now mid July 2009, 3 months since I started LDN, and I hardly notice any distortion at all except when I'm tired or have overdone it. I hadn't expected this symptom improvement. Nor had I realised how puffy and itchy my eyelids had been till I suddenly realised they felt normal again.

An accumulation of something in my right eyelid has been diminishing. My skin feels smoother. Two patches of red, dry, flaky skin under my eyes is very, very slowly going away - so slowly that sometimes I think it's just wishful thinking, but no, today I can feel hardly anything. So far these types of improvements have been subtle, but consistent.

I'm stuck with deformed joints in my hands, and both my wrist bones are still too big; but ... as the muscles get stronger… this telltale RA deformity seems less and less noticeable. Without the internet I don't see how I would ever have heard about LDN.

And, what is also wonderful is the time and effort given freely by LDN old-timers, to help others understand it. I send my heartfelt thanks to them all. LDN itself does not fight any disease - it boosts and regulates a malfunctioning, disordered immune system, which then starts to perform the way it is meant to. This is why LDN can help with so many different problems.

For most people, it's while their body is readjusting to functioning 'normally' that strange things can happen. For most of us, if we just sit this out, and don't get scared away, it passes - although once the immune system starts working properly it can sometimes, I've heard, stir up pathogens that have been lurking in the body maybe for years. It can be scary, especially as most of us are on our own with this.

So many doctors know nothing about LDN, or they're not interested and can even be hostile. To my surprise, my GP aid 'yes' when I first asked for a naltrexone prescription that I could dilute and take in small 3ml or 4.5 ml doses. In April 2009 she couldn't see any problem. She even seemed pleased to let me try something I wanted to try, and said I should let her know how I got on. Since then, however; a friend of mine who was very impressed with my obvious improvement, asked my GP's colleague if she could try it too. That caused quite a ruckus, and when I next saw my GP she told me she couldn't prescribe it for me again.

I showed her my hands, and asked her if I didn't look so much better. She had to agree I did, but didn't want to discuss it. The laws about off-label in France are very strict, she told me, and she could be liable if anything went wrong. I still have a few months' supply, but then I'll have to pay for it - such a small sum for the health service, such a big sum for me.

Last Friday, 17th July, I saw my GP about another problem. Although LDN has transformed my life, my health and my future, I had this problem that suddenly began at the beginning of April - 2 weeks after the last course of prednisone and 3 weeks before starting LDN. It was diarrhoea.

Against everyone's advice I had doggedly refused to accept it wouldn't get better soon, which was stupid of me. Anyway, stool analysis showed no infection apart from candida - probably the result of antibiotics I'd taken for an inflamed colon 2 weeks earlier.

As far as I know the candida was the result of the antibiotics I'd taken for the inflamed colon, which presumably was the result of the diarrhoea. The diarrhoea started 3 months ago, early April and I still have it – as far as I know I didn't have candida when it started.

More surprisingly the TSH reading of my blood test was abnormal - 7.27 - whereas the normal range is 0.35 to 4.97. This, my GP said, was a thyroid problem, and prescribed Levothyron to correct it. There was no improvement following Leothyron. In fact, it got worse, so after speaking with my doctor I ceased Levothyron after only 2 days.

I spent some hours trying to relate my GP's advice to Internet thyroid information, but couldn't make head nor tail of it. As the diarrhoea started well before I began on LDN, it's unlikely to be related to that - though it could, I suppose, be related to my autoimmune disorder.

The diarrhoea and thyroid episode went beyond my understanding level, and the diarrhoea got worse after starting the Levothyron. When I phoned the doctor, she said to stop Levothyron, but gave me no further advice except to continue the SMECTA and eat yoghurt (I can't, I'm casein free), but I do take probiotics.

I took Imodium for 2 days and felt a bit better. I'm really surprised at how complicated these accounts become, so many seemingly disparate events, attitudes, and decisions all coming into play and quickly moving on.

Sadly, I sensed my GP's attitude towards me had changed since the LDN prescription episode - not so friendly and seemed to have stopped listening. She was probably overworked and tired, but I was seriously thinking of changing to another GP.

I was due to have an echograph on 30th July to check the condition of my thyroid. However I was feeling quite ill that morning so I rang my GP who said I should go to Emergency. This is what I did and it was they who decided to keep me in saying they wanted to investigate the weight loss. In the meantime they took me to have the echograph - the thyroid was pronounced 'small' but without nodules.

Because I hadn't expected to be hospitalised I had nothing (e.g. LDN) with me but a friend organised everything for me by the next day - and looked after my cat. I had been trying a homeopathic remedy, which matched my symptoms. The main improvement after 4 days of Jatropha curcas was less flatulence and less watery stools, less volume and urgency, but no stool formation, but it was to be only wishful thinking.

I had a colonoscopy on 4th August. There was no cancer, but there was an ulcer. As I understand it the gastro found nothing to explain the diarrhoea or the ulcer. He biopsied the ulcer and ordered tests, and I'm to see him again on 27 August. I had a chat with the junior doctor, and she speculated that such ulcers can be caused by anti-inflammatories (I had taken prednisone Feb-March).

They discharged me from hospital on 5th August, with a prescription for Pentasa granules 2 mg in the morning and at night. I told them, of course, about the low dose naltrexone and it struck me that no one batted an eyelid. The gastro made careful note of all the dates and remarked on the fact that as I'd started the ldn 3 weeks after the diarrhoea began, it wasn't that then!'

In view of the anaesthetic I stopped the LDN 3 days before, starting again the evening of 4 August. I was well cared for at our local hospital - everyone was so kind, everything was clean - a comforting environment at the same time as being an awful place to be, and I'm looking forward to some home rest.

UPDATE 19 August 2009

There's nothing particularly positive to report regarding the diarrhoea. It's the same, with no sign of improvement yet. I'm drinking more water - 2 glasses on getting up before my one coffee each day - 2 during the afternoon, 2 before going to bed or when I feel discomfort or slight pain which usually amounts to another 2 glasses.

It's possible there's a bit more flesh in my cheeks - slightly less sunken. So far the night-time diarrhoea seems less, but there's more in the morning. I'm on Pentasa (mesalazine), having 2mg granules twice a day

morning and night. I tried stopping it last Wednesday, but started it again Sunday as I started feeling queasy. I see it's a 'topical' anti-inflammatory, and hope it's not blocking the LDN. I'm having some very slight cramping above the ankles in the morning and slight restless legs before I get to sleep.

I'm doing gentle 'blood pumping' exercises to aim for a mild 'runner's high'. It was something Dr Zagon said in his interview with Mary Bradley that gave me the idea. It did get rid of the headache/neck-ache I was getting - either from being a bit dehydrated or from too long hours at the computer or a bit of both. But today I don't feel so good - very bad diarrhoea during the last 24 hours, though I did sleep okay.

I lost a lot of fluid and feel quite unhappy and anxious. So far there's never been any blood, which is a relief. The good news is that the RA is not giving me any trouble. My eyes are still good and I'm still free of that crushing fatigue - which to me means the LDN is still working - so I assume it will eventually do the job for the ulcer.

Since some time in April I've been taking fish oil and Vit E 400 – sometimes 3 times a day, sometimes less, sometimes I forget? I'm running out of them but will re-order today as I'm convinced they help against inflammation.

UPDATE: 9 September 2009

I ended up in hospital for a couple of weeks - just a couple of days before my appointment with the gastro! I learned how he'd found a small carcinoid tumour (a benign, non-cancerous tumour with malignant potential). He felt it could be the cause of the diarrhoea but that any operation or treatment would have to wait till they get the results of the scintigraph octreoscan and that can't happen till November - all results are otherwise normal.

Another scan they did at the local hospital showed nothing abnormal. Potassium levels are a problem at the moment - they were too low – so now I'm taking potassium tablets am and pm and having blood tests here at home twice a week to keep control of them. I'd lost another 5 kilos, so I'm down to 45kg now.

Also my blood pressure is only about 9 over 6 - usually 12 over 6. I'm also on Immodium, which does help and I'm trying to find the right level - which seems to be between 2/3 a day. The dietician gave me a low fibre diet to follow which isn't too bad at all.

I was so well looked after - a lovely room to myself with a small balcony but it was still gruelling. I'm such a light sleeper I'd rear up each time the nurses checked on me every couple of hours but the worst was having to separate my waste matter for inspection night and day. Gawd, it was horrible!

So, it's a long wait and I hope I make it without having to go back to hospital, but my friend Sue (who, fortunately for me, dragged me there against my will) is keeping a beady eye on me and we've been told not to hesitate, better make a fuss than allow things to get worse.

The octreoscan concerns the abdomen. The doctor said this type of tumour can secrete a hormone that provokes diarrhoea. He said an operation may be necessary - he would take it out plus a bit of the colon but I wouldn't need an 'artificial anus'. And/or it may just need medication to stop the action of the hormone.

He insisted the tumour he found is very small - the size of a semolina grain - and isn't cancerous. I got the impression he was surprised it could cause me such problems. The scan I had of the abdomen a couple of days after this last hospitalisation showed up nothing. I don't know whether he just wants to be sure or suspects there's more to it.

I'm not taking any probiotic, milk based or otherwise, since about 20 Aug, I think. On the other hand, the gastro says I have no celiac or other IBD, apart from colitis (so I ate what the hospital gave me - no gluten/casein free – because it all got too difficult to insist). As what I eat seems to make no difference whatever, I'm just going along with it for the moment - and buckwheat is on the 'not advisable' list in the diet I was given. Anyway I figured everything's going through me so fast it hopefully doesn't matter.

My potassium is low again (2.5 instead of minimum 3) so I'm now on 2 Diflu-K every meal-time – six per day in all instead of 4 per day - plus 85% black chocolate and bananas. I was on a k-enhanced dehydration drip most of the time I was in hospital, but I could only hold the needle a couple of days before it started leaking and had to be put somewhere else. The 9/6 equates to Blood Pressure of 90/60 - it's the way they read the twice-daily blood pressure readings in hospital.

UPDATE: 25 January 2010

Just to recap the last six months... In late June 2009 I was hospitalised for 4 days due to severe weight loss. They did a colonoscopy and told me they'd found colitis and an ulcer that was being biopsied, but that the gastro thought was benign. He prescribed Pentasa granules 2mg x 2 times per day which I took till about mid September with one short break.

About 21 August I was hospitalised again, this time for 10 days, during which time I was on drips and everything that went in and out was monitored. The gastro told me he thought the diarrhoea may be caused by a hormone expressed by a benign carcinoid tumour: That's what the 'ulcer' was. He said he needed to know if there were more tumours, and if not, he could remove the one he'd found.

If there were others he would give me medication to control them. Two octreoscan sessions were arranged but not before November as my vital organs were functioning normally and it was not urgent.
I came home still plagued by diarrhoea. The dietician told me to eat a low residue diet. A nurse came twice weekly for 3 weeks to check my potassium (I was taking potassium tablets to get the levels up).

Before these 3 weeks were up I noticed some lessening of the diarrhoea - then for a while everything was normal - confirmed by continued blood tests once a week for another 3 weeks. However, some weeks later, things began to get worse again - though not nearly as bad as it had been. I had started eating more vegetables, but no matter what I ate it didn't seem to make any difference.

On 14 January 2010 the gastroenterologist told me the octreascans (taken over 2 days on 24 & 25 November), showed no trace of any tumour in my body. He said he'd like to do another colonoscopy in a year's time. He reminded me of the colitis which I'd forgotten about and asked me to start the Pentasa again. I agreed and, at the time meant it, but when I got home I knew I really didn't want to.

All this time I was convinced that LDN would help my immune system deal with the carcinoid and the colitis, however: the diarrhoea continued and I learned that my guts were probably damaged. Others seemed to have benefited from the Specific Carbohydrate Diet and when I looked into it, I found it was much more straightforward and easy to follow than people had said, so I started on it.

I can eat most foods, including most vegetables with just cereals, sugar, potatoes not allowed. So I started it last Monday, 18 January 2010. There were signs of improvement the very next day, and within 5 days, the following Friday, everything was normal again.

I'm probably luckier than some - I don't have a sweet tooth, am used to doing my own basic cooking from fresh, local ingredients, preferably organic, and the almond flour 'bread' instead of ordinary bread and potatoes suits me fine. There are plenty of recipes available on the web thanks to generous SCDers. In fact, I'm enjoying the SCD and don't understand why it has such a difficult reputation.

I stopped taking the 160 mg aspirin last autumn (for proliferation of platelets). I wanted to see if LDN will keep my blood levels within normal - so far, so good, but I wonder if the haematologist will appreciate this. Another possible very significant change: Being unable to get a prescription for low dose Naltrexone, I instead diluted one 50mg tablet in 50ml of distilled water.

I was advised to shake the bottle before I draw my dose, but recently someone on the main LDN group (who said they were a chemist) suggested we shouldn't do this because it means we ingest the iron oxides in the tablet, which in turn can cause digestive issues for some.

He said the Naltrexone dissolves like sugar and doesn't sink and there's no need to shake the bottle. **So now after the initial shaking to dissolve the tablet, I let it settle, then pour off the dilution and throw away the deposit. I put the dilution back in the bottle and don't shake it again. Not taking the iron oxides may also be contributing to my improvement.**

I feel great, and I'm very surprised and very pleased... not least because I can still eat my vegetables as usual. I'm looking much better, less gaunt in the face, skin is clearer, though I still have to get a bit more weight on. Still I have what must be normal energy levels, and often sleep 8 hours straight through, though sometimes my sleep is a bit disturbed.

The RA is still improved and not giving me any trouble. I'm gaining strength in my hands and throughout my body. I can garden, and household chores are no problem now. I'm still pain free, but do my Chinese stretching exercises to keep that way. My eyes are still good.

During the past month I've stopped all medication apart from the LDN. I was only taking Piascledine 300 for osteoarthritis and Nutrof for the AMD.

Margaret, France

Margaret, France

"I showed her my hands, and asked her if I didn't look so much better. She had to agree I did, but didn't want to discuss it. The laws about off-label in France are very strict, she told me, and she could be liable if anything went wrong. I still have a few months' supply, but then I'll have to pay for it - such a small sum for the health service, such a big sum for me." Jul '09

51 Bentley's Parkinson's benefited from LDN & HBO – Destiny on behalf of Bentley, USA

LDN since October 2004
- story submitted February 2010
- story updated June 2010 (over 5.5yrs on LDN)

SPECIFICS:

DIAGNOSED
- Between 1992 and 1993 – Parkinson's Disease (PD)
- May 14, 2004 - Massive hemorrhagic stroke. (Background: during the second lead placement in a double-sided deep brain stimulation (DBS) surgery for Parkinson's. Due to the severity, he never had the second surgery to install the battery packs and turn on the stimulators. May 2004 to Oct 2004 - Bentley survived the stroke and made small gains, but his PD continued to progress.)

MEDICATION (pre LDN)
- 1993 to October 2004 - 10 x Sinemet 25/100
- 1993 to October 2004 - 3 x Permax .25mg
- 1993 to October 2004 - 2 x Artane 2mg

MEDICATION (post LDN) - PREVIOUS
Oct 2004 to Jun 2005 – Lowered by ¼ to ½ pill until using up to 4 to 5 x Sinemet 25/100
Oct 2004 to Jun 2005 - 3 x Permax .25mg (discontinued entirely in June 2005)
Oct 2004 to Jun 2005 – Lowered by ¼ pill until using up to 1 Artane 2mg throughout the day.
Oct 2004 to Jun 2005 - 4.5mg LDN

NB Following the introduction of LDN we were able to gradually reduce his reliance on other medications, and after 8 months, achieved an almost 60% reduction in his continuing medications, as well as a complete discontinuation of Permax. As at Dec 2009, the reduced level of medication has been maintained for 4.5 years (see below):

MEDICATION (post LDN) - CURRENT
Oct 2004 to present - 4.5mg LDN
June 2005 to present - 4 to 5 x Sinemet 25/100
June 2005 to present - 1 x Artane 2mg

OTHER TREATMENTS
Oct 2005 to Nov 2005 - 5 weeks x Hyperbaric Oxygen Therapy (HBOT)
Nov 2005 to present - Hyperbaric Oxygen Therapy (HBOT)

LDN DOSE & TYPE
a) Dose – 4.5mg Low Dose Naltrexone (LDN)
b) Time – nightly between 9pm and 10pm, or right before Ben goes to bed. (NB It interferes with his Parkinson's Disease medications if he gets it earlier.)
c) Type - Compounded capsules with pure Naltrexone powder and Acidophilous filler from Skip's Pharmacy

SUPPLEMENTS
- Multi vitamins, fish oil and blended greens

DIET
Proper nutrition and hydration (8 glasses of water a day)

EXERCISE OR INTERESTS
- Bicycling (stationary), weight lifting, news, movies, books

OUR STORY – February 2010

Bentley Lyon was diagnosed with Parkinson's (PD) almost 19 years ago. Our family never could have imagined where our choice to join him in his fight for recovery from PD and stroke would take us. I was 11 years old when I first saw Bentley playing Dixieland Jazz banjo, he was funny and a great musician. From the moment we met, I knew my mother, Bentley, and I would spend a lifetime together.

You might say Hall of Fame Wrestler, Bentley Lyon, is obsessed with life. The first Californian to become All American, Bentley is a Renaissance man. In High School he was both Student Body President and Co-

Captain of his High School football team. He became the first NCAA Wrestling Champion (1952) west of the Rockies from the University of California at Berkley and graduated with a BS in Forestry. He served as a Marine in the Korean War. During his career with the U.S. Forest Service, he learned to speak four languages and was sent all over the world to unusual places during extraordinary times. Upon retirement, he started a new career as a published mystery suspense author.

Bentley has always challenged himself. In the 1960's, he combined his love for the outdoors and exercise by running in the early mornings before going to work. Eventually he started marathon-ing, and at age 45 he ran the Boston Marathon in 2 hours 51 minutes and 26 seconds. We now joke that he is continuously preparing for the biggest marathon of his life.

May 14, 2004, Bentley suffered a massive hemorrhagic stroke during the second lead placement in a double-sided deep brain stimulation (DBS) surgery for Parkinson's. Due to the severity of his condition, he never had the second surgery to install the battery packs and turn on the stimulators.

Right after Bentley's stroke we realized that if we did not step in, he would die. The hospital staff was overwhelmed and understaffed and hoping for help from family or friends. Bentley's new life now required assistance 24 hours a day.

When you tell a physical therapist or doctor that your loved one has Parkinson's and a stroke, they are kind and helpful, but they know the statistics are not on your side. Bentley survived the ICU and Brain Trauma units, a nursing home and a second hospitalisation with us by his side. After six weeks, we brought him home to recover in a loving, familiar environment. Our fight for Bentley's recovery from Parkinson's and stroke was just beginning.

October 2004, Bentley's PD continued to progress using the standard forms of treatment. We thought that he had survived the stroke only to die from Parkinson's complications. A dear friend's patient persistence paid off, after months of assuring us that even though LDN was not a Parkinson's medication, it could help.

LDN is an opioid antagonist (it blocks opioids from the opioid receptors in your body) that tricks our biological systems into restoring homeostasis (i.e., the body's normal equilibrium). This is a remarkable drug in that it mobilizes the endorphin system for repair and prevention of disease. The FDA has approved Naltrexone for the treatment of alcoholism and opioid addiction.

However, when used at much smaller doses (approximately one tenth of the dose used for the treatment of addiction), it can help in alleviating pain, muscle tension, and other physically debilitating symptoms that occur with Parkinson's, Multiple Sclerosis, Arthritis, Crohn's and many other diseases: - Dr. Ian Zagon, Professor of Neural and behavioral Sciences at Pennsylvania State University's Hershey Medical Center. (www.fred.psu.edu/ds/retrieve/fred/investigator/isz1)

We decided to try this off label usage of a Food and Drug Administration (FDA) approved drug called Naltrexone, in low dose form or LDN (www.lowdosenaltrexone.org). It certainly seemed safe and at this point Bentley's very life was at risk if his breathing continued to worsen, and his neurologist did not seem to have any other suggestions.

It was miraculous, within four days of starting LDN we went from desperation to total elation at how quickly his body was responding to this generic medication that his neurologist had almost refused to prescribe. We could not believe that no doctor had ever suggested we try this drug that cost less than a $1.00 a day with minimal side effects.

We wondered what if we had known about LDN prior to Bentley's failed DBS surgery. As we watched the muscle tension that was affecting Bentley's breathing, causing tremendous stiffness and pain disappear, we knew we only had LDN, our dear friend and our wonderful family doctor to thank for saving his life. We called our friends and said we were using a miracle drug that everyone should know about and they said a few days was not long enough to make these declarations.

We observed Bentley over the next eight months, as we slowly lowered his Parkinson's medications from 10 Sinemet 25/100, 3 Permax .25mg, 2 Artane 2mg., to 4 to 5 Sinemet 25/100, no Permax, 1 Artane and 4.5mg LDN, almost a 60% reduction which he still maintains today five years later. We called our friends again and again, urging them to tell their relatives and friends about LDN. Over the last five years we have seen LDN help these same friends with Lupus, ankylosing spondylitis, cancer, MS and Parkinson's.

We only requested that each person we took the time to share LDN with, would do the same. It has been amazing to see how far reaching this one on one sharing and patient persistence has spread the knowledge of this incredible therapy. We have gone out as a family to speak to PD support groups, but realized that if some of these people could not get the support of their doctors or family they would not be able to use LDN until it becomes a more traditionally prescribed medicine. It is astounding to see how quickly this patient Internet movement is happening.

Due to the progressive stroke symptoms from his weakening left side, we decided to try Hyperbaric Oxygen Therapy (HBOT) October 2005 in conjunction with LDN. After the first treatment, Bentley was happier and more relaxed. After five weeks of treatment his speech had improved, he could eat without choking and his skin began to clear from dermatitis from PD and other irritations due to paralysis.

According to a recent study published in the American Journal of Physiology-Heart and Circulation Physiology, (http://ajpheart.physiology.org) hyperbaric oxygen treatments increases by 800% the number of stem cells circulating in a patient's body. Stem cells, also called progenitor cells, are important players in repairing the body after injury and in tissue regeneration. Stem cells exist in the bone marrow and are capable of changing their characteristics to become part of many different organs and tissues. When a body part is injured, stem cells are mobilized and provide the cells necessary for the healing process to occur.

Hyperbaric oxygen therapy (HBOT) provides an important trigger or stimulus for this mobilization. "This is the safest way clinically to increase stem cell circulation, far safer than any of the pharmaceutical options," said Stephen Thom, MD, Ph.D., Professor of Emergency Medicine at the University of Pennsylvania School of Medicine, lead author of the study. "This study provides information on the fundamental mechanisms for hyperbaric oxygen and offers a new theoretical therapeutic option for mobilizing stem cells... We reproduced the observations from humans in animals in order to identify the mechanism for the hyperbaric oxygen effect."

We spoke with Dr. Harch (www.hbot.com), the world's foremost authority on the use of HBOT for neurological applications. He is currently running a clinical trial treating our soldiers from this Afghanistan and Iraq wars for PTSD and Traumatic brain injury using HBOT. He told us that it is simply amazing how much our brains can recover from brain injury. Dr Harch's book, The Oxygen Revolution: Hyperbaric Oxygen Therapy: The Groundbreaking New Treatment for Stroke, Alzheimer's, Parkinson's, Arthritis, Autism, Learning Disabilities and More, is One of the most important and insightful medical books in 40 years. -Vance Trimble, Pulitzer Prize winner. Dr. Harch and his wife Juliette Lucarini's kindness and encouragement gave us the understanding and strength to continue using this amazing therapy with LDN for Bentley's daily fight for recovery.

We believe that LDN has saved Bentley's life, and in combination with HBOT, his general health, swallow, breathing, cognition, tone, movement, rigidity, balance continue to improve. These two miraculous therapies and our existing regimen of proper nutrition, hydration, rest, exercise and careful medication management enable us to live the best life possible while working towards a cure for Parkinson's.

UPDATE – June 2010

It is ironic that Bentley, a mystery suspense author and retired forester, would become the central character in his own medical mystery that would take us around the world over six years to discover that what had almost killed him could save his life.

May 2004, with each beat of his heart, Bentley Lyon's life changed further and forever as the neurosurgeon cut into his brain during the placement of a stimulator in his brain, a procedure called Deep Brain Stimulation (DBS) used to treat Parkinson's Disease.

An NCAA wrestling champion (1952 UC Berkley), marathoner, and lifetime athlete in the best of health, it was unthinkable that Bentley could suffer a hemorrhagic stroke. Almost quadriplegic, he fought for months to regain the use of his right side and today, continues to fight for recovery and a cure from both Parkinson's and left side paralysis.

After the fact, the surgeon and the anesthesiologist disagreed on when the stroke occurred. The surgeon said Bentley was ischemic, but why would they perform an elective surgery on someone who had greater than normal odds of stroke or death?

Researching Pubmed, we found that most DBS strokes are caused by multiple placements or a misplacement of the lead. Some bleeding during this surgery is par for the course, but it is usually absorbed back into the brain with no negative lasting effects. Whatever the cause - bleeding, a mistake - Bentley's was in for the fight of his life. And so were we.

Two days after surgery while still in Intensive Care, Bentley began to respond to the Dixieland Jazz music that we played for him day and night as we prayed for any sign of his recovery. One of the first casualties of his PD was giving up playing the banjo as the tremor in his right hand grew and became uncontrollable.

When we realized he was tapping in time to the music, we knew he wanted to live and in that moment we came together as a family to fight for his life. When you tell a physical therapist or doctor that your loved one has Parkinson's and has had a stroke, they are kind and helpful, but they know the statistics are not in your favor. Bentley survived the ICU and Brain Trauma units, a nursing home and a second hospitalization with us by his side 24 hours a day.

Finally though with no previous medical training, we brought him home, believing that somehow we could put the pieces back together and heal Bentley. Throughout the summer, we followed the advice of all the doctors, specialists, in home therapists and caregivers as Bentley struggled to regain the use of his right side, speech and swallow. He was fed through a tube in his stomach day and night until he was finally able to take that first swallow with the help of his therapist. We were incredibly grateful for their help as we came out of shock and began to understand what we were up against.

October 2004, Bentley's Parkinson's continued to progress even though we were attacking it with all the standard forms of neurological treatment. He had survived the stroke but it seemed like he was going to die from additional Parkinson's complications. Every day Bentley's breathing became more labored because Parkinson's was freezing the muscles in his chest. His neurologist did not seem to have any answers and suggested that this is what happened with Parkinson's. He tiredly looked at us as one more family that was in denial, almost angry that we would not accept his council. We couldn't believe that there were no other options and knew that if we were going to save Bentley's life we would have to find our own answers.

Our first step was deciding to take the advice of a friend who was using a drug called Low Dose Naltrexone, LDN (http://www.lowdosenaltrexone.org) for multiple sclerosis. She'd discovered it on the Internet and told us to read the website and talk with the doctor who was prescribing it off label. We spoke with Dr. Bernard Bihari of New York who had first used LDN to treat humans and Dr. Ian Zagon (http://www.fred.psu.edu/ds/retrieve/fred/investigator/isz1) the head of research at Penn State and the discoverer of the amazing effect of naltrexone in low dose form who had spent almost 30 years researching this drug.

When we added it to Bentley's meds, the effect was almost miraculous. Within four days the muscle tension in his body dissipated and his breathing returned to normal. Over the next 8 months we were able to lower his Parkinson's medications by over 60%. As each day passed we became more secure about our discovery giving us hope that we might be on the right track to beating this disease.

August 2005, Bentley's stroke symptoms were getting worse and he was slowly declining. When we asked his specialists what his options were they told us more medications and interventions that would eventually, inevitably, lead to surgeries that would guarantee that he could never walk or have use of his arm again. By the time we finished these conversations we understood again that we were all alone and that we would have to find our own way because Bentley's survival depended on us.

This time, our first step was to go on the internet to search for a possible solution. We found a neurologist, Dr. David Perlmutter (http://www.perlhealth.com) and Dr. Paul Harch, a physician and researcher specializing in hyperbaric oxygen (http://www.hbot.com) who discussed the many new options for treatment including hyperbaric oxygen therapy (HBOT). We decided that this was our next best step in fighting the stroke.

After the first treatment, Bentley was happier and more relaxed than he had been in months. After five weeks of treatment his thinking was clearer and his mood was better, he could eat without choking and the dermatitis and skin issues that often accompany PD and paralysis began to clear up. Bentley began to look and sound more like the man we remembered. After six years of networking around the world with cutting edge doctors, researchers, advocates, internet support groups seeking the best tools and information available, we began comparing notes with a small group of friends with PD, each of us using a different alternative method of care to stop or slow down the progression of Parkinson's. The only conclusion we could come to was that each method that showed promise somehow increased circulation to the brain.

This seemed to be supported by our own experiences and reports from Cleveland Clinic about Forced Exercise and improvement in motor function (http://www.clevelandclinic.org/innovations/summit/topten10/six.html) which demonstrated a 35% increase in symptom relief with no disease progression.

Just before Thanksgiving, a friend of ours, Sammy Jo (http://www.healingpowernow.com) who has multiple sclerosis, informed us that she had undergone a surgical procedure for a condition called CCSVI or chronic cerebrospinal venous insufficiency based on an Italian doctor's theory that restricted blood flow to the brain somehow causes many of the neurological problems that were the basis of her disease. His name is Dr. Zamboni (http://www.fondazionehilarescere.org/eng/index.html) and his studies had shown that there might be a possible vascular surgical solution for MS.

Our friend found additional research on another surgery available for Parkinson's patients and other neurological conditions including Alzheimer's and epilepsy. This surgery was discovered by Puerto Rican doctor, Dr. Fernandez Noda. He had performed a Thoracic outlet syndrome surgery (TOS) on a Parkinson's patient and incredibly, his Parkinson's symptoms got better. Dr. Noda and his associates performed thousands of surgeries for many different neurological conditions now called Cerebellar Thoracic Outlet Syndrome or CTOS (http://www.ncbi.nlm.nih.gov/pubmed/10064369 & http://free-news.org/jacamp03.htm {translation required}).

He believed that there was a compression problem in the arteries causing hypoxia and that once this was resolved the patient's brain could heal itself. Both Dr. Zamboni and Dr. Noda had demonstrated that neurological disease might not actually be a disease but rather a response to a vascular problem. We had always wondered if Bentley's neck injury from college wrestling might have contributed to his Parkinson's. In his mid forties he started having gran mal seizures which could not be explained. During his final seizure he slammed his head so hard as he fell that he broke the plasterboard on the wall of his home, shortly thereafter his Parkinson's symptoms began. He never had another seizure.

We asked other Parkinson's patients online if any of them had ever had a head, neck or shoulder injury or pain. Their responses read like an accident report, jet plane crash, motorcycle crash, thrown through a windshield, fell from a tree, kicked by a cow. We also heard from people who were athletes and musicians who through repetitive motion had developed neck pain prior to Parkinson's. We read studies that showed that this could be caused by a genetic defect in the veins or arteries, bone, scar tissue or muscle pressure restricting blood flow in or out of the brain.

So now the question was with so many possible ways to limit blood flow why do some people get PD and others MS? What determines which neurological condition one might end up with? Dr. Alexander Rauscher is a physicist and research associate at the UBC MRI Research Centre (http://www.hospitalnews.com/modules/magazines/mag.asp?ID=3D3&IID=3D142&AID=3D1723) who has developed and validated a new imaging technique that is extremely sensitive to iron, more accurate at assessing iron content, and yielding better and sharper images of the brain and veins than can be obtained with conventional MRI scans.

This new technique is called susceptibility weighted imaging (SWI) with multiple echoes. Excessive iron in the brain has been linked to the death of dopamine-producing brain cells in Parkinson's disease. With his multi echo SWI method, Rauscher has already found a good correlation between overall iron content in the substantia nigra, which is the area of the brain affected in Parkinson's disease, and disease severity, as measured by the 'Unified Parkinson's Disease Rating Scale (UPDRS)'.

This amazing view into the brain gives us more evidence of the vascular nature of these diseases and demonstrates the possible link between the best known neurological conditions of Parkinson's, Alzheimer's and multiple sclerosis.

What made the medical industry pursue neuropharmacology and electric stimulation without also considering looking at the vascular option? If we could understand how our circulation affects our brain's functioning then maybe we could either develop better surgical or therapeutic solutions that might help us manage or cure the great array of neurological conditions. Imagine a future world where, soon after you felt that first tremor, your doctor (instead of offering you a pill and a downward slide) could give you hope for a cure.

We wondered, could there really be a vascular solution for neurological illnesses?

February 2010, we sat in the office of a local vascular surgeon in Medford, Oregon asking him if a compression problem could have been the cause of Bentley's stroke during DBS. He said, "it was possible".

We asked a vascular surgeon in Madrid who is now performing surgeries for CTOS if he thought this compression problem may have been the reason for Bentley's stroke and he said, "It was very possible".

For the first time in years we're not afraid and have real hope that Bentley's Parkinson's can be managed and possibly cured.

We continuously work on the internet with friends and through an information sharing group on Yahoo called Healing Parkinson's (http://health.groups.yahoo.com/group/healingparkinsons).

As a family we continue to speak with Parkinson's groups, families, friends and patients trying to create greater awareness and hope. We believe Bentley's Parkinson's has stabilized and continue to use LDN, HBOT, BPM, exercise, supplements and good health practices while we investigate new possible treatments such as Upper Cervical Chiropractic (http://www.nucca.org) and STS Therapy (http://www.paindefeat.com), searching for the ultimate combination of therapies and a possible cure.

We have a better understanding of why these therapeutic tools are helping us manage Bentley's symptoms and look forward to him being a candidate for a vascular solution for his condition. We are not alone. There are a growing number of neurological patients and families worldwide who believe that we are on the verge of a paradigm shift in medicine.

The barriers of specialization must come down so neurology and the vascular worlds can connect in order to find the safest alternatives to heal all neurological conditions. We believe that what stems from the heart can heal the brain.

Destiny Marquez, USA
Bentley's daughter
http://health.groups.yahoo.com/group/healingparkinsons

Destiny, USA

We believe that LDN has saved Bentley's life, and in combination with HBOT, his general health, swallow, breathing, cognition, tone, movement, rigidity, balance continue to improve. These two miraculous therapies and our existing regimen of proper nutrition, hydration, rest, exercise and careful medication management enable us to live the best life possible while working towards a cure for Parkinson's.

46 Fibromyalgia and more - Bill W

LDN since 13 July 2007
- story submitted January 2009
- story updated April 2010 (over 2.5yrs on LDN)

SPECIFICS

DIAGNOSIS
- 1970 to 1973 – Connective tissue disease (Fibromyalgia had not been coined yet)
- 1973 to 1983 - Connective tissue disease 10-year period of remission
- 1983 to 2008 - Fibromyalgia symptoms returned and treated with various medications and supplements

TESTS
- Ruled out Rheumatoid Arthritis and Lupus

SURGERY/HOSPITALISATION
- none

MEDICATIONS/TREATMENTS (pre LDN)
- 1970 to 1973 - prednisone
- 1970 to 1973 - 5 aspirin every 4 hours, day and night, every day
- 1983 to Jul 13 2007 - Reproductive hormones rebalanced. On Bio-Identical Estrogen, Progesterone and Testosterone
- 1983 to Jul 13 2007 - Ibuprofen (800mg every 8 hours)
- 2000 to Jul 13 2007 - Thyroid hormones rebalanced. On T3 and T4 daily
- 2005 to Jul 13 2007 - magnesium
- 2000 to Jul 13 2007 - Hydrocodone x 30mg every 4 hours around the clock (Hydrocodone is the active ingredient in Vicodin - our preparation contained no acetaminophen)
- Jan 2007 to Jul 13 2007 - glutathione x 600 mg IV every 6 weeks or so

MEDICATION (post LDN)
- July 13 2007 to present - 4.5 mg naltrexone
- July 13 2007 to present – Ibuprofen 800 mg x 1 per day (sometimes two)
- Aug 2008 to present – Glutathione topically x 100 mg as often as remembered (4 to 5 times a week)

LDN - DOSE & TYPE
a) Dose - 4.5 mg compounded low dose naltrexone (LDN) capsules
b) Time – July 2007 to July 2008 - naltrexone taken at bedtime (usually around 10pm each night)
c) Time – July 2008 to present - Switched to AM dosing of the naltrexone due to never developing a tolerance to the sleep challenges.
d) Type - compounded capsules with lactose filler

DIET
- Tries to avoid whites and sugars.

SUPPLEMENTS
- As at Jan 2009 my wife was also supplementing with the following:
Multi-vitamins x 6 daily
Vitamin B Complex x 1 daily
Vitamin B-12 x 1 daily

ACTIVITIES & EXERCISE
- Since improving on LDN, my wife now tries to get a 2-mile walk in, daily.

HOBBIES & INTERESTS
- Can now do volunteer work much more aggressively. Took on an assignment that she fulfills each Saturday from 10am to 6pm, and functions well. Also has a teaching assignment on Sundays. Enjoys grandchildren as often as she can get them to come over. She recently had to stay the night, then every other night, with her elderly mother after she broke her hip. Would go at 4pm and come home the following day at 4pm. Was able to do it. With this we are now looking forward to being able to go on a 1.5 year mission for our church, where that would not have been possible previously.

Our Story - at Grandpa's Compounding Pharmacy - January 2009

First a little background ... Vicky Finlayson, a successful user of the Naltrexone for her Multiple Sclerosis, was putting together a fundraiser in the hopes of raising sufficient funds for a clinical trial of low dose naltrexone (LDN). Because I'm a local compounding pharmacist, she approached me to be an 'expert speaker' on naltrexone.

At the time I was approached, I had little knowledge of the medication - and I'd only dispensed one prescription for a Veterinarian (for his personal animal). I had no knowledge of what the vet was prescribing it for. I told Vicky this, but she said the event was six weeks away and that I had time to learn everything I needed to know by then.

Because of the type of business I'm in, trying to meet the needs of the people where standard medicine hasn't; I was excited at the prospect there might be something that didn't cost a lot, was easy to take, had a very low side effect picture, and had high hopes of helping.

I began to gather information and became more interested with each new article or person I talked to about it. I was fairly well-prepared for the presentation and enjoyed the whole experience, particularly the energy of those associated with it. The other speakers were great, I learned new information, and also gained a better understanding of how LDN might work.

Initially I was focused on LDN use for Multiple Sclerosis (MS), but during the next year I asked three Pharmacy students to do research into all the literature we could find on the treatment. We then put together booklets about a number of diseases and how Low Dose naltrexone (LDN) might help them.

The following year I asked another Pharmacy student to do more research and put together a single paper giving the proposed mechanisms of action, plus other information that most prescribers and patients might desire. During this same period, I went to the 3rd annual symposium in Nashville and met even more people who were using it. I also heard from prescribers and pharmacists that were dispensing it. It was a great experience that helped fuel my enthusiasm.

It was during that period of continuing research on low dose naltrexone (LDN) that my wife began taking it (after I'd carefully weighed up all the potential benefits and risks, and felt comfortable it could help and not hurt her).

My wife has FIBROMYALGA. It first appeared in 1970, and over the following three years she was taking prednisone, plus 5 aspirin every 4 hours, around the clock. She had great difficulty with even minimal physical exercise, so a group of wonderful friends came to help us - because at that time we had 7 children. As her medications were only treating symptoms, we decided to try alternative treatments: They did help, with the result that her Fibro went into remission by 1973.

But about 10 years ago, more or less, the Fibro reappeared. We did a lot of searching and trying various things. Some helped and some did not. The things we found that helped were; hormones balanced, thyroid, magnesium, glutathione IV every 6 weeks or so, Ibuprofen 800mg every 8 hours, and 30mg Hydrocodone (active ingredient in Vicodin) every 4 hours around the clock.

We couldn't use the commercially available Hydrocodone preparations for my wife because all the commercial preps included acetaminophen, which, at her higher doses, would have dramatically raised her risk of liver damage. So, we made the Hydrocodone for her at our Pharmacy so we would not have to include the acetaminophen in it. With this regimen, she was able to function, but just barely.

A typical Christmas for our family would be; go cut a tree one day, decorate a couple of days later, shop a few days later, etc. My wife had no energy reserves, so whenever she did anything it would cause her problems for the next 2 to 3 days. She'd been a volunteer, but she could no longer volunteer for anything that could add stress or require any appreciable energy expense, for if she did; she'd be wiped out for a number of days.

My wife took her first dose of low dose naltrexone (LDN) on 13 July 2007. Unfortunately, she did so WITHOUT stopping the Hydrocodone and getting it out of her system beforehand, because she said she didn't realize it would cause her so much trouble. Needless to say she went into withdrawal.

The pain that immediately set in, in combination with all her other symptoms, caused her two months of even poorer health. She ceased taking the Hydrocodone on the 13th of July and has continued only with the LDN since that date. I had to have her reassure me, frequently, that this was what she wanted to do, and that she was still convinced LDN was going to work for her (because of what she was having to go through). Then, all very subtly and gradually, the LDN began to make things better.

It is now January 2009 and my wife has been taking LDN for over a year and a half. After about a year we switched to morning dosing of the naltrexone due to her never developing a tolerance to the sleep challenges.

She's able to go to her mothers place every other night and stay all night with her, getting very little sleep, and come home the next afternoon. She did that for two weeks, in addition to a volunteer situation where we were leaving home around 10am and getting home around 6pm. She's obviously no longer on the hydrocodone and only needs Ibuprofen one to two times a day. Her sleep is still not perfect, but I have my sweetheart of 50 years, back.

I am so grateful that Vicky asked me to speak for her. That's what began it all for me, and many others that I've been able to get on LDN.

At the pharmacy, we still distribute the papers on how low dose naltrexone works in relation to autoimmune diseases.

More and more people have tried the medication for various auto-immune challenges. I've had to put a lid on some of my enthusiasm for it's use for any auto-immune disease, but because of the low incidence of side effects, the low cost and the high potential for benefit, I feel anyone with a significant challenge due to an auto-immune disease should try it for at least 3 months to see what it does for them.

As I'm in a unique position and have witnessed not only my wife's improved health but also those who pass through our pharmacy, I wish to share some of the successes we have seen following LDN use:

LYME DISEASE
So far, we've had four take LDN for Lyme Disease. One young fellow did a symptom list and rated the symptoms from 0-5. In the beginning he averaged 2.75. After 4 months his average was 0.45. The others seemed to fare as well and now none of them are taking the medication.

FIBROMYALGA
At present we have 6 or more patients that have reported to me specifically on their progress, in addition to my wife. All of them have had significant positive effects. Each varies individually in the way it has helped them.

CROHN'S DISEASE
Our most significant is an 8 year old that was diagnosed with Crohn's at the age of two. We have here at the pharmacy a copy of endoscopic pictures taken a year apart - the second set of images was taken after the patient had been on the naltrexone for two months. The pictures tell the full story. 'Before' - all bloody, necrotic, and ulcerated; 'after' - nothing but pink tissue. It is beautiful to witness.

MULTIPLE SCLEROSIS
We have a number of patients who have had reversal of some of their symptoms, each being a little different, and some others who've only experienced cessation of exacerbations after commencing on the medication.

HASHIMOTO'S DISEASE
We've had three patients use LDN for Hashimoto's Disease. All took the medication for a couple of months and reported that the disease had gone away - and now none of them are taking it.

POST POLIO SYNDROME
This is one where we postulated that if Lyme disease progressed from a bacterial invasion to an autoimmune condition, could Polio, a virus, have done the same thing? Our poster person for this one is a lady in her 80's that was having a number of symptoms. The naltrexone took all her symptoms away. We have two others that have had a reversal of many of their symptoms.

PSORIASIS
One fellow I remember had a complete reversal of all symptoms. Memory is vague on the others.

MULTIPLE DISORDERS
One patient has fibromyalgia, lyme disease, and an autoimmune thyroid disorder. She said, "The naltrexone has been a miracle for me". Her pain is gone, her joint problems are gone, she is less fatigued, and now she can sleep.

Almost daily, I receive a call from a different patient to say 'thank you' for recommending they consider the naltrexone, because it has done so much good for them. I could continue to add stories each day but if this is to do any good I must close and send it to those writing the book.

Here at Grandpas Pharmacy we only advertise in one local periodical twice a month, and about every second ad is about something that is helped through taking LDN. We don't make much money from it, but we sure do have a lot of satisfaction.

UPDATE April 2010

I am so much a fan of the LDN. Our pharmacy encourages many to try it for all types of auto-immune diseases and even some that haven't been identified as auto-immune. We recently, at the pharmacy, had a 'miraculous cure' with a dog that had an auto-immune disease and was within a week or so of death. It was a great recovery. The family and the doctor are all excited with the results.

Last year we only had 150 patients using LDN, way below what we ought to have based on the population we serve. I don't know how many scripts the other pharmacies in the general area are filling.

My wife is still on LDN. She still has Fibromyalgia, so she has to still take care not to do too much, but she continues to be able to do so much more that she could before the LDN. We are still trying other additive things to see what might be of any help.

Bill Wills, Pharmacist, USA
Grandpa's Compounding Pharmacy
http://www.grandpas-rx.com
info@grandpas-rx.com
7563 Green Valley Rd
Placerville, CA 95667
(530) 622-2323

Bill W, Pharmacist, USA

"Almost daily, I receive a call from a different patient to say 'thank you' for recommending they consider the naltrexone, because it has done so much good for them. I could continue to add stories each day but if this is to do any good I must close and send it to those writing the book." Jan '09

47 Autoimmune Disease vs LDN - Nettie

LDN since July 2008
- story submitted January 2009
- updated March 2009
- updated Feb 2010 (1.5yrs on LDN)

SPECIFICS

HISTORY & DIAGNOSIS
- Aug 2006 – first symptoms appeared – severe cramping in my abdomen, vomiting and diarrhea, diagnosed with dehydration - passing of blood occurred soon after, diagnosed possible internal haemorrhoids
- Dec 2006 - diagnosed with precancerous polyps
- Feb 2007 - While in hospital nurses noted extreme fluctuations in blood pressure, cause unknown
- Apr 2007 - No tests done to see why BP was fluctuating, but was diagnosed with Insomnia (PCP's word, not mine).
- Jul 2007 – diagnosed with anxiety
- Sept 2007 - electric shock symptoms, numbness in one foot, B/P had climbed to 170/110, then 170/120 within another 2 days. Paxil reduced, B/P meds introduced - developed extreme weakness in my legs resulting in diagnosis of Peripheral Neuropathy of unknown cause, possibly Myasthenia Gravis
- Oct 2007 - shooting pains in jaw, whole left side of my face tingled then went numb, still no diagnosis
- May 2008 - Endocrinologist diagnosed Hashimoto's Thyroiditis, Goiter, and found low levels of Vitamin D
- Aug 2008 - Gastroenterologist
- Sept 2008 – Microscopic Colitis (MC)

TESTS
- Dec 2006 – Colonoscopy - large polyp located high, on the bend between my ascending and transverse colon
- Dec 2006 – biopsy of polyp taken during colonoscopy – non-malignant
- Oct 2007 – CT scan, MRI, spinal tap – all revealed nothing
- Feb 2008 - Thyroid Peroxidase Antibodies (TPA) - 170 (normal range is less than 30)
- Sept 2008 – small pre-cancerous polyps removed, diagnosed Microscopic Colitis (MC)

MEDICATIONS (pre LDN)
- Apr 2007 to Nov 2007 - Temazepam 30mg (to aid sleep), Paxil 20mg/40mg/20mg
- Jul 2007 to Nov2007 - Effexor, Lexapro, Naproxen, various B/P meds
- Feb 2008 – I stopped taking Blood Pressure meds
- Jun 2008 to Jun 2008 – Levothyroxine (T4 Thyroid medication)

SURGERY
- Feb 2007 – surgical removal of polyp (NB while in hospital, nurses noted fluctuations in my blood pressure and suggested I see my GP after I'd recovered)

MEDICATIONS (post LDN)
- Jul 2008 to Jul 2008 – 1.5mg Low Dose Naltrexone (LDN) for 1 week
- Jul 2008 to Aug 2008 - 3mg Low Dose Naltrexone (LDN) for 3 weeks, then briefly tried 4.5mg
- Aug 2008 to Aug 2008 – Asacol (after LDN, for 4 days only)
- Aug 2008 to present – 3mg Low Dose Naltrexone (LDN) because the higher dose caused stiffer leg muscles
- Apr 2009 to present – 65mg Whole Thyroid (A whole natural thyroid - no brand, made by Pharmaceutical Compounders in Auckland - I buy it direct from my doctor.)

LDN - DOSE & TYPE
a) Dose – 3mg Low Dose Naltrexone (LDN) --- occasionally 4.5mg when I feel the need
b) Time – I take my Naltrexone first thing in the morning, when I wake
c) Type – My naltrexone capsules are compounded using pure Naltrexone powder with avicel filler.

DIET
- Jan 2009 - I recently changed my diet by adding more natural foods (raw foods, in their natural state), and I follow the 'Great Taste, No Pain' guidelines by Sherry Brescia. The basic rules are - no starch with protein, always consume fruit and fruit juices separately from other foods.
- Feb 2010 - My diet is concentrated on not eating any wheat - NO wheat since I am intolerant. It has made a big difference to my overall health.

SUPPLEMENTS
- Jan 2008 I began taking the following:
Vitamin B-12
Fibromyalgia (a supplement formulation)
Digestive Enzymes – when I eat anything other than raw food
Omega 3
Melatonin
- Jun 2008 I added the following:
Vitamin D x 1000mg
- Oct 2008 I added the following:

Probiotics Advantage x 1 daily
Selenium x 1 daily (for Thyroid support)
- March 2009 to present – This is my complete supplement list:
Vitamin D x 1000mg
Selenium x 200mcg
Probiotics Advantage x 1 beadlet containing 1 billion colony-forming units (CFU)
Omega Complex x 1200mg
Melatonin x 6mg (as need to aid sleep)
- Feb 2010 – I no longer take any supplements.

THERAPIES
- Jan 2008 – chiropractic treatment – reduced a lot of pain but then plateau-ed

ACTIVITIES & EXERCISE
Jan 2009 - I take a daily brisk walk and do regular household chores. If I do too much I suffer with muscle pain and stiffness. I believe I may have some sort of as yet undiagnosed neuromuscular problem, or else it is the lingering side-effects of Paxil, but I can live with it. Muscle twitching, pain, numbness and tingling and occasional jerks are just part of my every day life, but do not incapacitate me. I have double vision quite often, but this usually resolves with rest.
- Feb 2010 - Hiking with my husband in New Zealand's beautiful bush is a past-time I can enjoy with no restrictions, except that of a lack of hours in the day.

HOBBIES & INTERESTS
My family, playing Bridge, watching documentaries on health issues, researching or learning of Natural health alternatives. I'm moving in January 2009 and looking forward to finding a new, and hopefully fulfilling, career.

MY STORY – January 2009

For a time I kept a detailed diary, at least, up until I started to get well, because it was the only way for me to keep track of everything while traipsing from one doctor to another.

I have at least 5 foolscap, handwritten pages from less than a one-year period, and that was just dates and symptoms and treatments. I was misdiagnosed, mis-medicated, and eventually bumped from one specialist to another, which of course made everything worse.

I began taking LDN in July 2008 for Hashimotos, then was diagnosed with Microscopic Colitis (MC). Initially, the LDN didn't seem to help at all, but as soon as I added probiotics, digestive enzymes and a raw, natural diet to the mix I very quickly improved.

I think the enzymes and diet helped my system absorb the LDN much better and I have gone from 8 or 10 painful, watery motions a day to just one regular motion. After only 3 months on LDN my health had gone from seemingly hopeless to miraculous.

My time on LDN has been short compared to the time spent searching for answers, which I guess is pretty much the same for everyone on LDN. We all have health issues throughout our lives that we encounter and deal with.

My two-year nightmare began in August 2006 when I woke up with severe cramping in my abdomen, vomiting and diarrhea. A trip to the ER and lots of tests revealed nothing more than dehydration.

However, a month or so later I began intermittent bleeding from the bowel. My GP thought it was just internal hemorrhoids, but recommended a routine colonoscopy just to be sure because I was nearing the magic 50 plus years. The colonoscopy was performed a few days before Christmas.

The Gastroenterologist found a large polyp and informed me, while I was still lying on the table and as he took a biopsy, that there was a 50/50 chance it was malignant.

My early Christmas present was that it wasn't malignant, yet, but I had to have it removed surgically because it was high up, on the bend between my ascending and transverse colon, and impossible to remove by colonoscopy without the risk of perforating the bowel. By the way, a sigmoidoscopy would not have found this, so beware if you are ever in the same situation. Also, the bleeding did not recur once I had made the appointment, so I believe it was just God's way of getting my attention.

The surgery in February 2007 was straight forward, but while in hospital the nurses noted fluctuations in my

B/P and suggested I see my GP once I was recovered. He wasn't concerned, but Rx Temazepam as I was having problems getting a full nights sleep (due mainly to my snoring husband). Taking Temazepam turned out to be a huge mistake on my part, but I was ignorant at the time and trusted the doctor. He wrote the Rx for numerous repeats and I blindly took it, happy to get a few more hours sleep a night.

Within a few weeks I was experiencing tremors in my hands and rapid weight loss. I finally went back to the GP and got a different medication. I asked if the sleeping pills could be causing my problems but she said, "No, no - keep taking it - you need your sleep". She diagnosed anxiety and prescribed Effexor. Only took it for two days as it made me 10 times worse.

Then she Rx Lexapro, which I took for 3 weeks. It stopped the tremors but made my head buzz. She said that wasn't good so Rx Paxil. The tremors didn't return, but I continued to lose weight. (25lbs over a few months, without trying - in fact - I often drank two bottles of beer after work as it was the only thing that helped slow the weight loss).

I felt progressively unwell and in September I developed electric shock symptoms and numbness in one foot. Saw yet another doctor who told me I was 'obviously anxious as he could hear it in my voice' and told me to increase the Paxil and add Naproxen for the tarsal tunnel syndrome. This was despite the fact that my B/P had climbed to 170/110, but he ignored that and my protestations that there was 'something wrong'.

Two days later I called back into the clinic to have my B/P re-checked as I felt worse than ever. The nurse told me it was 170/120, that it shouldn't have gone up that much in two days and to see a doctor straight away. I saw doctor number 4, and at last I was viewed as someone who was sick.

He immediately reduced the Paxil and added B/P meds, referred me to a Neurologist, as well as ordering other tests. My blood pressure fell dramatically within a few days, but before I got to see the Neurologist I had one episode of extreme weakness in my legs, finding myself unable to stand for more than a few seconds at a time.

The Neurologist seemed concerned: I had stocking glove paresthesia in all four extremities and he told me I had Peripheral Neuropathy of which there could be a 100 causes, but he was most concerned about Myasthenia Gravis.

He ordered up a bunch of tests and said he would see me in a month for the results. I read up about PN and MG on the internet and found that the B/P meds that I had been given should not be given to patients with MG, and since my muscles were becoming weaker every day, I returned to my GP to have the Rx changed.

On October 30th while at work, my world turned upside-down when I developed shooting pains in my jaw while eating grapes, and then the whole left side of my face went numb. I felt it tingle and go progressively numb over just a few minutes.

I actually took a paperclip (working a desk job has its benefits) and stabbed both sides of my face to be sure. Panic ensued, co-workers gathered, husband was rung and he came immediately to take me to the ER. I found that my legs were very weak and would barely support me to stand, never mind walk without support.

A CT scan revealed nothing, but the Neurologist assured me, by phone, that the MRI he had ordered for next week was bound to tell him something. It was decided I couldn't return to work in the meantime as I had to drive half an hour each way and it was simply too risky. My symptoms came and went, but I never knew how I was going to feel one minute to the next.

With nothing else to do, I hit the internet, and a few days later, to my horror, I discovered that the drugs I had been given should never be taken together - not even within 14 days of each other!! The Temazepam should only have been Rx for a 10-14 day period and then re-evaluated. I was never told all the foods that I shouldn't take with it - and it turned out they were all my favorite foods. The only thing I was aware of when I began taking Temazepam was the warning that taking it with alcohol could make me drowsy. Duh! I was taking it to help me sleep, so what was wrong with that?

I went straight to my GP and asked that I be taken off Paxil and Temazepam.

He assured me there would be no withdrawal affects from the Paxil since I was on the lowest dose (wrong, but that's another story). He put me on a decreasing dose of Temazepam over a week to wean me off. If I thought I had had trouble sleeping before, this was something else, but I was determined to get through it.

The withdrawal was awful, but the damage was done - and November 2007 was the worst month of my life. Was it the drugs, did I have some yet to be diagnosed illness, was I going to get worse, or was I going to get better? All I could do was wait to see the Neurologist on the 19th.

What an anti-climax. Tests all revealed nothing, he said, and he recommended taking a wait and see approach. I was flabbergasted. He knew I was off work, he knew I had had a major collapse, yet he seemed not to care. So I laid into him with my findings about the drug reactions. He told me there was no way that the drugs could be causing my symptoms, so I left his office with an order for a Spinal Tap which was performed the following week. One of the new symptoms was electric shock sensations down both arms whenever I turned my head and I knew this could be an MS symptom, so I had to have the Spinal Tap to be sure. Results? Nada, but no surprise to me by this stage.

So where did all this leave me? I was convinced I'd been damaged by the drugs prescribed to me, but was without a doctor who would admit it, and without any help whatsoever to aid in my recovery. If I did have an underlying disease, it was either exacerbated or triggered by the drugs. But what did I have? Where would I turn? You guessed it - the internet.

To cut a very long story short (I know, too late) I basically dealt with each symptom separately, since looking at myself as a whole was too confusing. I wasted a lot of time waiting for appointments to see specialists (my GP tried to get me into Mayo, but they declined), and waiting for test results, most of which I asked my GP to run as I read more and more about my 'condition'.

I became convinced early on that I had developed a Thyroid condition, but which one? My symptoms continued to change on a daily and weekly basis, so my theories had to change too, but the Thyroid remained at the top of the list. Actually, the thyroid and drug withdrawal pretty much covered everything, but with no confirmation of my theories, it was impossible to just quit. I was also convinced that I was suffering from some sort of autoimmune disease or diseases and read books galore on the subject.

In January 2008, I found a wonderful Chiropractor who hit the internet too, researching everything I was telling him in an effort to understand and help me. He did reduce a lot of my pain but after a few months I had reached a plateau. When I lost my job and my health insurance and had to sell my car, I had no choice but to stop going to see him.

The third Neurologist I saw finally had a hit with a test for TPA (Thyroid Peroxidase Antibodies), which measured 170 instead of the norm of less than 30. He referred me to an Endocrinologist. More waiting. Finally was seen by her at the end of May and she diagnosed a goiter, Hashimoto's Thyroiditis and low levels of Vitamin D. I was relieved, for about 5 minutes, until she told me that my symptoms could not be due to the goiter or the HT and that I should take Vitamin D to improve my muscle strength, try T4 (though she doubted it would help), and get more exercise.

Now, I am not overweight, I have always eaten well, exercised regularly, and worked hard - 40 hours a week plus spent my weekends renovating my home - really hard physical work. Now I was simply not capable of exercising - muscle pain and weakness and fatigue made it impossible to do much more than care for myself.

I looked at the side-effects of the T4 and was horrified, once again, to read that it could cause all of the symptoms I was already suffering, and more. I told her I had chronic diarrhea, but she didn't appear concerned. In the last few months I had tested negative for Celiac and Whipples, so I think she decided I was simply lying about it. With no other options available to me I tried the T4, but it made me far worse. The diarrhea worsened (and I didn't think that was even possible). I had the worst 3-day migraine I have ever had, and so I after a month I threw the T4 in the bin.

It was time to speak up and take charge of my own health for once and for all. I had been reading over the preceding months about LDN and how it had been doing wondrous things for all manner of people with autoimmune diseases. I had asked numerous doctors about it during my appointments, but they all scoffed at such an idea. With nothing left to lose I returned to my GP.

God bless this man because he believed in me all along and ordered up every test I asked of him. I told him I was done with specialists and tests and all I wanted was a Rx for LDN - that if he wouldn't write it for me I knew people and I would get it - it would just take me a bit longer. He simply said, 'Yes, I know you have done your research - just give me some information on LDN for your file'. If only all our doctors could be as open and caring as this man. I had my Rx for 1.5mg up to 3 times a day, the very next day.

I took my first dose of 1.5mg on July 18th and continued taking that for one week, suffered no sleep disturbances, so increased to 3mg. Almost immediately I felt an improvement in my energy, the pain and dysesthesia in my knee all but disappeared, and I felt an overwhelming sense of hope for the first time in more than a year. I tried increasing to 4.5mg after a few weeks as the diarrhea would not settle down at all, but my leg muscles became stiffer so I dropped it back to 3mg.

Life was good, but I knew it could get even better. I had had an appointment arranged at one point, in early July, to see a Gastroenterologist, but had to postpone due to a clash with an interview with the INS. Anyone who has had dealings with this department knows you do not mess with the INS. I became a US citizen on August 6th, following that interview.

My new appointment was scheduled for late August and when I finally got there I was feeling so good, I didn't even bother telling him my whole history. I just said I wanted to be re-checked for any more pre-cancerous polyps, and while he was in there, to please take some biopsies to check for Microscopic Colitis. This was the only disease left that I could find that explained my unending diarrhea. He felt that it was probably caused by bacterial overgrowth, due to half my bowel and the ileocecal valve being missing, but agreed to the biopsies. He did prescribe a course of antibiotics in the meantime, but to no avail.

The colonoscopy was set up for September and to everyone's surprise, not only did I have a couple more pre-cancerous polyps (small and easily removed), I also had Microscopic Colitis. The Gastroenterologist wrote a prescription for Asacol. I had already studied the possible treatments and was far from happy with the prospect of taking yet another drug with horrible side-effects. This one even included possible hair loss, so I wasn't holding out much hope for a happy relationship with it. Four days!!! That was as long as I could tolerate it. I guess I can't complain - it stopped the diarrhea. It stopped me up so darn well, I may as well have had a cork plugged in me. And the nausea!! Terrible!!

Took me a week to go again, and in the meantime I began a diet called 'Great Taste, No Pain' by Sherry Brescia. Guess what? Once I got going again, no pain and no diarrhea. It was like a miracle. Between the LDN and the diet, I was cured. I say cured because unless I stray from my diet (and it isn't a difficult diet, just avoiding certain food combinations rather than eliminating any foods), I have no issues whatsoever!

I have cut my coffee consumption to one cup a day - I used to drink at least three - and I drink green tea instead. That is the biggest change I have made. To be honest, I don't miss the coffee, and often can't finish my one cup. Love the smell, but the taste just isn't the same anymore.

By the way, I have never before been contacted by a Pharmacy regarding a prescription I had been taking, but I was contacted - not once, not twice, but three times by the Pharmacy who dispensed the Asacol! I was encouraged to continue taking Asacol, that it was the only way I was going to get well, that I would never be able to cure the MC, just control it. Poppycock!! It just goes to show how much money the drug companies are making when they try so hard to keep patients on their drugs. And this crap was not cheap .. the first month cost me $45. (I should have taken back the 26 unused days worth of pills for a refund - lol).

This is my story ... It has changed forever the way I view the medical profession ... It has changed my whole perspective on life ... But most of all, it has given me the confidence to question, question, question and to demand what I believe is right, without exception.

No-one knows your body like you do, and no-one has the right to tell you how you feel or what is best for you. Fight on, my friends - we are not alone. LDN should be the first line of defence, not the final, last-ditch attempt. I will never quit taking it.

UPDATE: March 2009

No real changes for me except that I am now living in New Zealand and I've found a doctor who's just 20 minutes from my home and prescribes LDN. Could not believe my luck!! I continue to take 3mg of LDN each morning. I'm working 6 days a week full time in two very physical jobs with no adverse effects to my health. I hope to eventually get a job as a support worker for the intellectually handicapped and the physically disabled.

UPDATE: February 2010

Good health continues for me on 3mg of LDN and 65mg Whole Thyroid (compounded) per day. I am taking no other meds or supplements at all now.

I am now holding down a full-time job and two part time jobs, all in the Care Industry. Watching my diet (not eating any wheat) is the only other thing I am doing to keep myself fit and well. My diet is concentrated on NO wheat since I am intolerant, and it has made a big difference to my overall health.

Hiking with my husband in New Zealand's beautiful bush is a pastime I can enjoy with no restrictions, except that of a lack of hours in the day.

I actually have come across another whole theory on autoimmune disease, and it has to do with cows milk and the difference between A1 cows and A2 cows and the milk proteins they produce. If you search for info on 'The Devil in the Milk', you will find what I am speaking of. A university lecturer here in NZ wrote the book a few years ago and has been battling Fonterra (dairy producers), politicians and others regarding the research on this 'bad' protein in A1 milk. (A2 milk is available in most supermarkets but at twice the price.)

The really interesting thing in the book was that mice they were using in one of the experiments were being given naltrexone to block the proteins from getting to the brain. It was on reading this that the penny dropped and the whole theory came full circle for me as to why and how LDN may benefit.

The theory is controversial in the science world: Kinda like the whole thing of lack of Vitamin D causing MS, except the A1 milk theory holds way more water than the Vit D one. I would be interested in hearing what others think.

I hope this helps someone,
Nettie, NZ

Why I contributed my case study…
I contributed my case study because I had to search the internet really hard to find anything on LDN and Hypothyroidism and other 'lesser' autoimmune diseases. There is plenty of information, case studies, whole websites etc dedicated to Multiple Sclerosis, but I felt that people needed to know that LDN was effective for ANY autoimmune disease. Thanks to all the people who unselfishly shared their stories and made LDN the success it is today. I hope my story will help others in the future who are struggling with autoimmune disease.

Nettie, New Zealand

"This is my story ... It has changed forever the way I view the medical profession ... It has changed my whole perspective on life ... But most of all, it has given me the confidence to question, question, question and to demand what I believe is right, without exception." Jan '09

52 LDN helping Relapsing Polychondritis – Nancy

LDN since 15 July 2009
- story submitted August 2009
- story updated January 2010
- story updated June 2010 (almost 12 months on LDN)

SPECIFICS

DIAGNOSED
- 2004 – Breast Cancer Grade 3 with positive lymph node
- late 2004 to early 2006 – episode of pericarditis that lasted 16 months (resulted in a large hemorrhagic effusion & cardiac tamponade – but was finally relieved following treatment with colchicine)
- 2007 – Ophthalmologist diagnosed Sjogren's Syndrome secondary to a collagen disease – 2007 – ENT (Ear, Nose, Throat) Specialist also diagnosed Sjogren's Syndrome based on inflammation and sore cartilage in my throat
- late 2005 to late Feb 2009 – The first symptoms of Relapsing Polychondritis (RPC) were experienced in 2005 and continued until diagnosis in late Feb 2009.
- late 2008 to present – Lymphoedema following vigorous physical activity, improved somewhat but had lingered
- late Feb 2009 – Relapsing Polychondritis (RPC) – diagnosis based on symptoms and elimination of other immune system diseases

MEDICATION (pre LDN)
- 2004 to 2004 - two complete courses of chemotherapy and radiotherapy
- early 2006 to 2007 – colchicine (anti-inflammatory, relieved pericarditis)
- late Feb 2009 to early Mar 2009 - Celebrex (NSAID) x 200mg per day (for 1 week only, then reduced dose)
- early Mar 2009 to 15 Jul 2009 - Celebrex (NSAID) x 100mg per day (at reduced dose)
- mid 2004 to 15 Jul 2009 - Clexane, (anticoagulant) daily injection in the morning
- 2005 to 15 Jul 2009 – paracetamol as needed, often for several days every 2 weeks
- approx 2005 to 15 Jul 2009 - Karvea 300mg x once daily (blood pressure medication)
- early 2006 to 15 Jul 2009 – Nexium 20mg x once daily (reflux medication)

TESTS (pre LDN)
- 2007 – blood test – revealed Vit D deficiency
- Mar 2009 – blood tests – inconclusive for RPC

PROCEDURES/SURGERY/HOSPITAL TREATMENT
- 2004 - I had a grade 3 breast cancer removed, followed by an axillary clearance of lymph nodes when it was found one was positive for cancer, plus two complete courses of chemotherapy and radiotherapy.
- 2008 – Insertion of Punctum plugs

OTHER
- Jun 2009 to Oct 2009, with follow-ups – I enrolled in a Sydney University study that was measuring the effectiveness of weight resistance training on Lymphoedema. I was randomly allocated to the control group (i.e., no treatment).

MEDICATION (post LDN)
- 15 Jul 2009 to present - Celebrex (NSAID) x 100mg x RARE OCCASIONS
- 15 Jul 2009 to present - Clexane, (anticoagulant) daily injection in the morning
- 15 Jul 2009 to present – Karvea 300mg x once daily (blood pressure medication)
- 15 Jul 2009 to present – Nexium 20mg x once daily (reflux medication)
- 15 Jul 2009 to present – 4.5mg low dose naltrexone (LDN)
- Feb 2010 to present – Crestor 10mg x once daily (to lower cholesterol)

LDN DOSE & TYPE
a) Dose - 4.5ml low dose naltrexone (LDN)
b) Time - I take my LDN at bedtime each night, usually between 9pm and 10pm
c) Type – Liquid naltrexone: I mix one 50mg naltrexone tablet with 50ml cooled, sterilized water, and draw up 4.5ml with a standard syringe-type dose measure.

SUPPLEMENTS
- 2007 to present - Vitamin D capsules x 1000iu per day (recommended by the immunologist)
- 2007 to present - 3000mg fish oil per day (recommended by my ophthalmologist).

OTHER THERAPIES
- none

DIET
- Aug 2009 - Since starting on LDN, I have not craved sugar, so LDN has given me the opportunity to lose some weight. I still need willpower to eat just a bit less than I need, but as a result I've lost a few kilos.
- Jun 2010 - I stopped losing weight after the first month or so.

© Case Health Pty Ltd

EXERCISE OR INTERESTS
-

MY STORY – August 2009

My first degree was in Science, majoring in Zoology and Agricultural Chemistry. I have always had an interest in medicine but having children precluded that change in occupation. I taught biology for some years. So when conventional double blind, peer reviewed medicine was not available for my condition, I, like most other people, went looking for something else and that is how I discovered LDN.

I was not diagnosed with relapsing polychondritis until less than 6 months ago, early in 2009. It is a difficult disease to diagnose. It has so many symptoms in common with many other autoimmune disorders. It consists of a bunch of symptoms and very few signs. It is an uncommon disorder, with a frequency of 3.5 to 4 per million people in the US. Because of the rarity doctors are reluctant to diagnose it if some more common explanation is available. My blood tests were negative, as they often are in RP. Its chief indicator is inflamed ears, with other symptoms, and the elimination of other autoimmune disorders.

In late 2005 I had an attack of pericarditis, resulting in a large hemorrhagic effusion. This resulted in me going into cardiac tamponade and I felt my life shrinking to the stage where I knew I would not be alive the next day without treatment. My cardiologist later agreed with me here. There was no explanation for the pericarditis except for the strong possibility it was a metastatic breast cancer.

Obviously it wasn't that as I am still here. The pericarditis lingered for 16 months until I Googled a treatment, the use of colchicine, which had been used in a relatively few trials with a small number of patients. The colchicine got rid of the pericarditis, and I have since found out that is an anti-inflammatory substance sometimes used for autoimmune conditions. All the other symptoms of relapsing polychondritis rapidly followed the cessation of colchicine. Looking back, the pericarditis was probably my first symptom of relapsing polychondritis.

As relapsing polychondritis is rare, and everyone with RP has a different set of symptoms which can relapse and recur, very little research has been done on it and drugs used to treat RP are borrowed from those used for other autoimmune diseases.

About 6 months ago my state became so miserable, I was wondering if life was worth living. I did not intend to commit suicide, but it prompted me to go back to an immunologist and ask for some treatment. That is when he prescribed 200mg Celebrex per day.

The next week my GP told me I was to stop taking Celebrex immediately because its side effects could be so bad. I had no intention of stopping it - it would have been like taking away a dummy from a baby - but I reduced the dose to 100mg per day. I try to take any medicines in the morning. I remember to do so as I will not allow myself to drink until I have taken my daily injection of Clexane and other pills (blood pressure and reflux).

My RP was diagnosed only from my symptoms. I was diagnosed with Sjogren's Syndrome in 2007 by my ophthalmologist (secondary to a collagen disease), and by an ENT surgeon again in about 2007, again based on the inflammation and sore cartilage in my throat.

In 2004 I had a grade 3 breast cancer removed, followed by an axillary clearance when it was found I had a positive lymph node. I then received the full treatment of two separate courses of chemotherapy and radiotherapy. The lymphoedema only appeared within the last year, but after I had been doing some sandpapering prior to painting a room. The swelling gradually improved until it could be called a mild but pretty steady lymphoedema. I know this as I am involved in a Sydney University study to ascertain the effect of weight resistance training on lymphoedema, which is why I said I will have my arm re-measured in a few months.

Beside the blood pressure and the reflux pills, as well as the anticoagulant Clexane, I take vitamin D capsules (1000 international units per day) recommended by the immunologist as I was deficient in vitamin D, and 3000 IU of fish oil per day, recommended by my ophthalmologist. When the ophthalmologist suggested I take the fish oil to improve my tear film, I wondered whether I should eat it or put it in my eyes. It was the height of ignorance!

I have wondered if my relapsing polychondritis was triggered by a contaminated batch of Clexane. The heparin in Clexane is purchased in China and processed in the US. Several batches of Clexane have been removed from sale as they were contaminated by over-sulphated chondroitin sulphate. Over-sulphated chondroitin sulphate has some anticoagulant effect.

It's produced from cartilage such as found in pig's and cow's ears. The heparin which should have been in the Clexane is prepared from the intestinal mucosa of pigs. Chondroitin sulphate present in the extracellular matrix of cartilage and relapsing polychondritis attacks cartilage and similar tissues containing glucosaminoglycan molecules throughout the body. I had been using Clexane for a few months before getting the pericarditis in late 2004.

I forgot to add that I believe I've also had interstitial cystitis for a few months although this has not been confirmed by a doctor. Interstitial cystitis is probably caused by an autoimmune disease which breaks down the glycosaminoglycan molecules lining the urinary system. I forgot to add this previously as it is only another minor annoyance to me now. It improved when I started taking Celebrex and when I followed this with LDN.

I'm now over 70 and I've been taking LDN for the past 5 weeks.

I believe I've had Relapsing Polychondritis (RPC) for nearly four years ago now, but I wasn't officially diagnosed until just under six months ago. RPC is an autoimmune disease. In RPC the body can attack its own cartilage, connective tissue and interstitial tissue - in fact, just about everything.

It can result in some disastrous adverse effects on many parts of the body, such as collapse of the trachea, thickened heart valves and aortic aneurisms. However, generally, I experienced a mild version of RP, i.e., it had not yet threatened any organ system for me.

Even so, my life has been pretty uncomfortable these past four years. I have felt so miserable, and have had awful fatigue for much of the time. The next most uncomfortable thing has been sore muscles, particularly in the thighs and calves. For several days each fortnight they have been very painful, and I've had to take paracetamol to take the edge of the pain.

Imagine all the other places in your body where you have cartilage, and that is what hurt. My ears were red in places, the bridge of my nose made wearing glasses painful at times, my rib cage was sore and I had muscle cramps in the chest. My throat was sore, my voice was hoarse, and I became temporarily deaf in one ear, as well as developing tinnitus in that ear.

I've also been diagnosed with Sjogren's Syndrome with dry eyes, conjunctivitis and dry mouth.

Because the drugs for most autoimmune diseases are often quite nasty, they're reserved for more serious cases. For my mild RPC, I was prescribed Celebrex, a NSAID (a non-steroidal anti-inflammatory drug). This had a beneficial effect on my general feeling and I felt pleased to feel normal again. I was no longer fatigued and my sore spots were less sore than before, but Celebrex had no effect on the intermittent strong muscle pain.

I wanted more, so I went searching, found, and read all about LDN and thought that, as it seemed to have very few side effects, it would be worth a try. From what I read, it seemed the side effects of LDN were less than the possible side effects of the Celebrex.

I could not get a script for LDN from my doctors, so I imported some full strength naltrexone tablets and converted them to liquid LDN, using a scale of 1mg per 1ml liquid.

I started taking 4.5ml LDN each night, and ceased taking Celebrex at the same time (though I had scaled down my dose from 200mg to 100mg per day in the four months prior).

The first day after starting LDN, I felt well. In fact, as well as or better than I had when I was taking Celebrex.

Since then five weeks have passed. I have continued to feel well, with no fatigue except for one day during the first week. Since the second week, I've noticed some improvement in my symptoms. I no longer have a sore throat, my nose feels less stuffy and I notice the pads of my glasses do not hurt my nose as much.

My ears no longer wake me up when I sleep on them, although they still feel a bit tender when I press them. The lobes are not swollen and I can now find the holes to put the earrings in. My voice has almost returned to normal. My rib cage is not as sore, and I am no longer getting chest cramps as before.

When I wake up in the morning, I no longer feel like the conductor of an orchestra with all the instruments of pain tuning up for the day.

I no longer have the strong muscle pain I had previously, and have not taken a pain killer since I started taking LDN. My eyes are still red, but I can stay up a bit longer in the evening. Previously I had to go to bed by 9.00pm as my eyes were so painful. (In 2008 I had Punctum plugs inserted as a treatment for my dry eyes.)

Now the side effects:

The first few nights I had trouble falling asleep and woke pretty often. I wondered why my heart was racing when I lay down to sleep and after a couple of days realised that I was washing down the LDN with a sip of Pepsi, and then finishing the can. When I substituted water for that, I no longer had problems going to sleep.

I think, at least for me, that LDN is acting as a mild diuretic. I sleep in 2 to 5 hour blocks, punctuated by visits to the bathroom. Previously, I had been able to last the night without getting up. If I reduce my fluid intake after tea, I can now manage to sleep for 5 hours without waking up, but after I get up I'm thirstier than normal.

The surprise side effect was that I no longer crave sugar. In the past few years I've sat like a blob, eaten too much and put on a lot of weight. I'd go around searching for something sweet even after a full meal. I can't blame the RP. I've done that all my life. Now I do not crave sugar. LDN has given me the opportunity to lose some weight. I still need willpower to eat just a bit less than I need, but as a result I've lost a few kilos.

As I'm limiting my evening fluid intake, my mouth is dry when I wake in the mornings, but I have more saliva during the day than I had before I started LDN. I've even noticed a reduced swelling in one arm that has lymphoedema, but I'll wait a few months before I have it measured again.

Now that may seem strange to the reader, but the lymphoedema and sore muscles and tendons all appeared in one arm simultaneously, after I'd done some vigorous sandpapering. I wondered if the connection was inflammation, which was in turn causing the lymphoedema in my arm (the same arm where I'd had the axillary lymph nodes removed). It seems possible that the reduction in the inflammation due to the LDN might have resulted in a reduction in the lymphoedema.

I feel a little bit disappointed that I have some symptoms left and that my hair and eyebrows have not grown back luxuriantly. I was hoping for a miracle, but I think that all considered, my health and my life have taken a considerable turn for the better and I have no intention of stopping LDN.

In fact it is hard to recall how bad I felt before, as I am back to my previous energetic state of five years ago. I have been back painting again in the past few days and the lymphoedema in my arm looks pretty good to me.

UPDATE: January 2010

In June 2009 I enrolled in a Sydney University study to look at the effect of weight resistance training on lymphoedema. I was randomly allocated to the control group (i.e., no treatment).

The study lasted 6 months in total (June to October 2009), with follow-ups. The first month involved weekly checking of the lymphoedema, and the first two months involved weight resistance exercises (I was not in the control group, so no weight resistance exercises in my case). The study closed at the end of six months, but with follow-ups involving measurements – so my affected arm has been measured in many different ways.

I was not taking LDN during June 2009, the first month of the study, and did not begin on LDN until July 2009.

After taking LDN for 6 months I was looking forward to having my arm measured again as I felt that not only had LDN reduced my other symptoms, it had also reduced my lymphoedema. That opportunity came today. Tests showed that, as I had predicted, I no longer had lymphoedema. The strength in both arms, especially the right one, had increased greatly compared with what it was 6 months ago.

Lymphoedema is increasingly being connected to inflammation in the affected part. It has been hypothesized that it could be due to inflammation in the deep muscle fascias. Hence, it would seem logical that a reduction in inflammation could result in a reduction in lymphoedema.

The point of this posting is to suggest that;
a) people who develop lymphoedema should take an anti-inflammatory medication;
b) if the inflammation is caused by an autoimmune disease, the lymphoedema should decrease with the use of LDN, and;
c) an objective test for muscle inflammation could be in the measurement of the volume of the limb, its electrical impedance, and the strength of the muscles in that limb.

I wonder if others have noticed the connection between muscle soreness and Lymphoedema, and found that LDN resulted in improvement of the Lymphoedema.

UPDATE: June 2010

To recap, in 2004 I had my axillary nodes removed after a biopsy of the sentinel nodes revealed my breast cancer had spread to my lymph nodes. The lymphoedema appeared in about 2008.

In June 2009 I volunteered for a study run by Sydney University to document the effect of weight resistance training on lymphoedema. I was allocated to the control group which received no treatment, but during the first month a number of arm measurements were taken to make sure that my lymphoedema was steady and persistent.

I then started taking LDN in July 2009.

The lymphoedema in my arm was measured in a number of different ways during the trial. When follow-up measurements were taken again in January 2010, not only was my lymphoedema gone, but my arm was considerably stronger than it had been at the start of the trial. I believe this was due to the reduced inflammation in the arm.

It is now almost 11 months since I started taking LDN so I reviewed the information I provided earlier to see if there had been any changes in the last 11 months. Essentially I agree with what I wrote previously, though I stopped losing weight after a month or so.

All the side effects I listed from taking LDN have now disappeared; no more appetite loss, no more lost sleep, no more diuretic effects. My sleep is back to normal. I was regularly taking paracetamol, but I can't recall taking any paracetamol since I started on LDN.

I was hoping my hair might grow thicker, but it didn't. Maybe it was the effect of the previous chemotherapy or maybe I was destined to have thin hair as I got older.

My ophthalmologist told me after I had been on LDN for about 4 months that I now have an intact tear film. Previously, the tear film kept breaking up as he looked at my eyes and my eyes were still dry despite the punctum plugs I had inserted a couple of years ago. My eyes do not hurt as much as they used to.

An interesting result has been the apparent improvement in my kidney function since taking LDN. Around the time I first developed RP, my eGFR was 97%, indicating my kidney function was about 97% of what would be expected for someone of my age. The eGFR is a calculation based on creatinine levels in the blood but the interpretation should take into account things like body weight and muscle overuse.

After 4 years of having RP, my eGFR had fallen to 50%, indicating moderate kidney disease. However, after a few months of LDN, my eGFR rose to 75%. I suspect that the eGFR calculations in the past have been skewed by muscle inflammation. Less inflammation could indicate less excretion of creatinine.

Another interesting result was the loss of lymphoedema in my right arm, which had previously had the lymph nodes removed from the axilla. About 18 months before taking LDN, the lymphoedema appeared simultaneously with sore muscles, joints and tendons after I had spent an energetic few days sanding a room for repainting.

The lymphoedema persisted in a constant mild form, however; a few months after starting LDN, measurements of my arm indicated that the lymphoedema had disappeared. That sounds logical to me - less inflammation due to the LDN means less resistance to lymph flow.

Of course all these improvements might have been due to my RP going into partial remission, but two days during the last 11 months convinced me that it is the LDN improving my symptoms.

The first day after I forgot to take LDN, I felt quite fatigued all day. The second day after two missed doses all went well all day. I began to wonder if I did not need LDN after all, but in the evening the muscles in my right leg began to cramp up from the thigh to the foot, simultaneously. Then the muscles in my left leg also started to cramp too. This had never happened before. I went back to taking Celebrex for that evening to enable me to sleep.

That has not happened again since I went back to taking LDN every night.

Nancy, Australia

Quote: "I was hoping for a miracle, but I think that all considered, my health and my life have taken a considerable turn for the better and I have no intention of stopping LDN. In fact, it is hard to recall how bad I felt before, as I am back to my previous energetic state of five years ago. I have been back painting again in the past few days and the lymphoedema in my arm looks pretty good to me."

© Case Health Pty Ltd

Interviews & Perspectives

Health Professionals

© Case Health Pty Ltd

Dr Kamau B. Kokayi interviews…

Dr Bernard Bihari

Radio Interview Transcript
Global Medicine Review
September 23, 2003

Dr. Kokayi *The story about Low Dose Naltrexone is really fascinating. How did you get the idea?*

Dr. Bihari *Well, we were treating heroin addicts, and in 1984 a new drug for the treatment of addiction came out. It was called Naltrexone, and it was designed to block the heroin 'high' and it was a flop. I used it for a lot of patients, as did most addiction doctors across the country. At 50 milligrams a day, it made people feel terrible. Not that it blocked the heroin so much as it blocked their own endorphins, which is a source of our sense of well-being, so that people couldn't sleep.*

Dr. Kokayi *Your own opium, basically.*

Dr. Bihari *Right. Your own equivalent. That's what heroin is. And I knew from work that had been done by the National Institute on Drug Abuse in developing the drug that it had the ability to trigger the body into making more endorphins, but at the high 50 milligram dosage, the dose was too high. It blocks those endorphins.*

About six months later our addicts began dying in large numbers of AIDS. I ran HIV tests on about a hundred addicts, and fifty percent were already HIV positive. This was in 1985; currently it's eighty eighty-five percent around the country. And we began looking for some way to approach this new disease, with a view to the idea that this disease was likely to turn into a worldwide epidemic.

Dr. Kokayi *That was about the time where people were just being blasted with AZT with horrific results.*

Dr. Bihari *Right. There was nothing else available. When I discovered that people with HIV had less than twenty percent of the normal levels of endorphins, that meant that the virus not only kills the immune system cells, it also weakens the whole immune system, so that it's not as able to fight the virus.*

We began looking for ways to use this drug to raise endorphins without blocking them. We hired a laboratory scientist to measure endorphin levels.

© Case Health Pty Ltd

We'd measure in the afternoon, then we'd give the first dose at bedtime that night. Then we'd measure again at the same time the next day; then again at one week, and again at one month.

We found that doses in the range of 1.75 to 4.5 milligrams (which is just a fraction of the recommended dosage to addicts) would trigger or jumpstart endorphin production during the night.

Except with exercise, endorphins are made only between two and four in the morning. The brain sends a message out to the adrenal and pituitary glands and tells them to make endorphins. Giving a dose three, four, five hours before that, at bedtime, is enough to make that message from the brain much stronger.

Dr. Kokayi *Were you able to document that the levels of endorphins were then actually raised?*

Dr. Bihari *The level of endorphins went up by two hundred to three hundred percent. We then started a little foundation and did a placebo-controlled trial in which half the patients got the drug and half got sugar pills. A year later when we broke the code, we discovered that people with HIV who took the drug had only an eight percent death rate in the year, while people who were on the placebo had a thirty-three percent death rate. And of course they had many more infections and their immune system declined. That was a startling discovery.*

Dr. Kokayi *Now let me jump ahead, because I'm always curious about why this therapy hasn't gotten the kind of publicity specifically for this disease.*

Dr. Bihari *Well, at that time there was very little treatment. AZT came out about '87, and as you mentioned, it was not only a flop but made some people sicker. At the time we did the study, there was nothing available.*

So I met with doctors in New York and in San Francisco (where the largest number of HIV doctors were at that time) and described this drug and how it worked, and about forty to fifty doctors on the east and west coast began using it. Unfortunately, they measured effectiveness by whether or not the numbers of the immune system cells that are crucial in AIDS -- the CD4 cells -- were rising. On this drug, CD4 cells don't rise in people with AIDS. As I knew from the study, and have known since, they simply stop dropping. That means you can freeze the disease wherever it is. And if somebody is only mildly immune-suppressed, they stay that way.

Dr. Kokayi *That's so important…*

Dr. Bihari *It stops progression. It stops the count from growing. I have patients going back as much as seventeen years who haven't lost an immune system cell in that time. They're very healthy.*

Dr. Kokayi *Wow, that needs to be on the evening news.*

Dr. Bihari *The trouble was, we wrote a paper, but couldn't get it published. Nobody understood the concept.*

Dr. Kokayi *You're using the dose homeopathically. You're using it not for the effect that the medicine has on the person, but for the body's reaction to the medicine.*

Dr. Bihari *It strengthens the body's own defences. Rather than directly attacking, the way antibiotics attack bacteria, or the way chemotherapy tries to attack cancer cells, or the way anti-viral drugs attack viruses, the purpose of this is to take a weak defence (which people with AIDS or cancer have), and strengthen it so that the body can fight the disease more effectively.*

Dr. Kokayi *I've often made the point that therapies like acupuncture, therapies that are foreign to the cultural mindset of doctors and the American public, these therapies can be effective, but they won't be included or in mainstream medicine because the concept is so foreign.*

Dr. Bihari *It's a different model of understanding the body -- how it works and how disease works. I think eventually there will be changes in the paradigm of the way we think about diseases, and it's going to be a struggle. But I think oncologists in particular are getting more and more frustrated with the failure of chemotherapy.*

Dr. Kokayi *Well, about time.*

Dr. Bihari *The people I talk to at the National Cancer Institute, and the Food and Drug Administration, are very negative. All they get from drug companies are proposals to test new, more toxic chemotherapies, and they're really looking very hard for non-toxic ways of modifying the behaviour of the cancer cells so that they stop the cancer from growing.*

Dr. Kokayi *Over the years have you had to modify what you were actually doing with Naltrexone? Or is the initial model impetus pretty much on point?*

Dr. Bihari *The initial model was pretty much on point. A small dose at bedtime increases endorphin production during the night. In somebody who has a disease which is related to low endorphins, the endorphins go back up to normal by the next day.*

Dr. Kokayi *Can you tell us about some of the work with Naltrexone and cancer?*

Dr. Bihari *During that year, when we were doing our first AIDS trial, an old friend of mine called. Five years earlier, she'd had Non-Hodgkin's Lymphoma. It had initially responded to chemotherapy, but it had grown back*

© Case Health Pty Ltd

after her husband died. Her oncologist refused to treat her, saying it would be resistant to chemo the second time.

She knew what I'd been doing, and she called me and said, 'Bernie, do you think your AIDS drug would help my cancer?'

So I dug around and I found a large body of literature showing that when you give endorphins, metenkephalins, beta endorphins and even low dose Naltrexone to mice that had human cancer transplanted, that there is about an 80 percent recovery rate. I gave her the drug in the same dose we were using in the AIDS trial. She had large masses in her groin, her neck, her chest, and her abdomen, and they all slowly shrank and disappeared over a (inaudible) period. (Inaudible) taking the drug every night.

Dr. Kokayi *Wow! You know, even if that's just an anecdote….*

Dr. Bihari *Yes.*

Dr. Kokayi *I mean, everyone who has that disease deserves a chance to see if they're going to be an anecdote as well.*

Dr. Bihari *It was actually her idea. She stayed on the drug, and died about eight years later, in her late seventies, of her third heart attack, which was unrelated.*

Then I was in Paris the following summer, presenting a paper at an AIDS conference, and I met a woman who had a cancer called malignant melanoma. It starts in the skin, and in her case it had spread to the brain. She had four large brain tumors. The oncologist told her family that she had perhaps three months to live. When I got back to New York, I shipped her the drug from a pharmacy that was making it for our study. She started on it, and her neurological symptoms from the tumors in her brain slowly disappeared. Seven or eight months later she went back to the oncologist, had a cat scan of the brain done, and the tumors were gone.

Dr. Kokayi *Fantastic.*

Dr. Bihari *That was eighteen years ago, and she stayed on it.*

Dr. Kokayi *This is such a non-toxic, simple (inaudible).*

Dr. Bihari *There are absolutely no side effects. I continued doing a lot of the AIDS work, but the last four or five years I've gotten much more interested in other uses. We stumbled on the fact, also by chance, that the drug works very well for almost all, if not all, of the autoimmune diseases like multiple sclerosis, rheumatoid arthritis, lupus, sarcoidosis, and --*

Dr. Kokayi *When you say 'it works', what actually happens? What's been your experience?*

© Case Health Pty Ltd

Dr. Bihari *Well, what happens is that the disease activity stops, as long as people stay on it. If they have damage to the brain and spinal cord with multiple sclerosis, that doesn't disappear, because that's due to scarring, but they stop getting new attacks.*

I've had people on Low Dose Naltrexone for years. The longest is a friend of my daughter, who's been on it for eighteen years and has not had an attack as long as she stayed on it.

Dr. Kokayi *So it's almost as if it's up-regulating the endorphin production but somehow the endorphins actually block or inhibit the effect of the antibodies from attacking the tissue.*

Dr. Bihari *Not directly. It's more that the autoimmune diseases are beginning to look more and more like they're diseases of endorphin deficiency. (Inaudible) models of all the diseases I mention that can be bred in mice, the endorphin levels are always fifteen to twenty percent of normal compared with normal mice.*

(Female Voice) How can you naturally increase endorphin levels?

Dr. Bihari *There's only three or four ways that I know. First, Naltrexone increases them substantially, two to three hundred percent in people with low levels. Second, aerobic exercise increases them, but not as much. If you do an hour of exercise four or five times a week it will last three, four hours, and that's one of the reasons that exercise helps prevent cancer. A third way, oddly, is acupuncture. Acupuncture, especially when used in treating addicts, increases endorphin levels in the blood and the spinal fluid. And chocolate increases it.*

Dr. Kokayi *(Inaudible) will be glad to hear that.*

Female Voice *(inaudible) It actually works out, because you're going to eat your chocolate and then run to the gym.*

Dr. Bihari *Chocolate has a substance in it called Phenylalanine, which slows endorphins from being broken down in the body.*

Dr. Kokayi *And that's basically an amino acid that we find….*

Dr. Bihari *Yes, that's the food that has it in the largest amount. And only people with a rare disease called (inaudible) can't eat chocolate.*

Dr. Kokayi *So some people will run to the health food store and get Phenylalanine.*

Dr. Bihari *Well, Phenylalanine is helpful if you're raising your endorphins by other means. Then it keeps them from decaying. They last much longer.*

© Case Health Pty Ltd

But the crucial thing still seems to me to be the Naltrexone. Over the last five or six years, I've treated about 420 patients who have various kinds of cancer with low dose Naltrexone. Occasionally, for people who come to me with very advanced cancer, I add intravenous metenkephalin, which is an endorphin... intravenously, three times a week. It improved immune function substantially, and had no side effects, but that's generally not needed.

Among the people I've treated with Naltrexone for various kinds of cancer, on the average the cancer stops growing in about two-thirds. For half of that group, it eventually -- after six, seven, eight months -- goes on to slowly shrink and disappear.

Dr. Kokayi *And that's about forty percent.*

Dr. Bihari *Higher.*

Dr. Kokayi *Well, it's about forty percent of the total number.*

Dr. Bihari *Sixty-five percent actually benefit and don't go on to develop (inaudible). Thirty percent go into remission.*

Dr. Kokayi *That's phenomenal. I don't think there's any chemo or radiating oncologist with numbers like that.*

Dr. Bihari *There's no downside. One of the reasons that the war on cancer failed is that the oncologists doing the research failed to take into account that chemotherapy really wipes out the immune system, which the body needs to fight cancer cells. So they are giving drugs that kill cancer cells, but at the same time weakening the body's defence against cancer. Naltrexone strengthens the body's defence, and the increased endorphins kill cancer cells directly. Also, the immune system when it's strengthened kills cancer cells through its natural killer cells.*

Dr. Kokayi *What you're saying is, that a boost in endorphin levels also activates other components of the immune system.*

Dr. Bihari *The endorphins are the hormones centrally involved in regulating the immune system. About 95% of the regulation or orchestration comes from endorphins. People with cancer -- especially adults – have very low natural killer cells. They have a weakened immune system. I've discovered, after seeing such a large number of people, that the vast majority of them have experienced major life stresses lasting weeks, months to years – anywhere from two to six years before they get the cancer.*

Dr. Kokayi *That was one of my other questions. What really can keep those endorphin levels down in the body?*

Dr. Bihari *If a child gets sick -- children are supposed to outlive us -- so if a child gets sick and dies, or if you have a very bad marital break-up, or if you*

© Case Health Pty Ltd

discover a business partner is embezzling money and it takes a couple of years to straighten out… If you wake up every morning under stress -- really serious stress, not everyday stress -- really serious stress, this can lower your endorphin production, and it never returns to normal. So the person then walks around with low endorphins. The body makes cancer cells all the time, but usually the immune system kills them as they are forming. But if your endorphin levels are low, then your immune system is weak, the cancers grow and you become much more vulnerable. The same thing with exposure to really toxic substances.

Dr. Kokayi *Right. I'm wondering, I'm sure the listening audience would like to get an idea. If you could just run down a list of some of the cancers that you have successfully treated, types of cancers that have seemed to respond where the opiate levels play a prominent role.*

Dr. Bihari *Well, first one of the things we discovered was that almost all cancers have a lot of receptors for endorphins on the cell surface, and that seems to be necessary for it to work. Some of the cancers that respond most dramatically are Multiple Myeloma, Lymphoma, Hodgkin's disease, breast cancer, all the cancers of the gastrointestinal tract, like pancreatic cancer, non small-cell cancer of the lung, the kind associated with smoking. I've got several patients with tumors that have stopped growing; they have no symptoms, and then after a year, year and a half, in about half of that group, the tumors start shrinking and disappear.*

Dr. Kokayi *This is lung cancer?*

Dr. Bihari *These are lung cancers due to smoking.*

Dr. Kokayi *Because there's really --*

Dr. Bihari *Very common.*

Dr. Kokayi *It's very common, but therapeutic effectiveness --*

Dr. Bihari *There's nothing --*

Dr. Kokayi *There's nothing, right --*

Dr. Bihari *My own attitude about chemotherapy in patients I see with cancer, is if they have one of those rare cancers that's very sensitive to chemotherapy, like cancer of the testicle, I encourage them to do that, to take it, and take Naltrexone afterwards to prevent recurrence. These drugs are licensed to treat cancer. Naltrexone is not yet licensed to treat cancer, although it's a licensed drug. It's been on the market for nineteen years. It's use in these low doses is called an 'off-label' use. Any doctor can prescribe it. And growing numbers of oncologists and neurologists in the country are prescribing it.*

© Case Health Pty Ltd

Dr. Kokayi *I think it would be interesting you know just to talk a little bit about the process … a lot of physicians don't really know about it and it's not talked about. This is a big deal.*

Dr. Bihari *Well, I think it could turn out to be a big deal when it's picked up, if it's picked up. We set up a web site, www.ldninfo.org, which brings up about thirty pages of written material describing all the diseases, and how they respond, and how many cases we have of them. There's some small trials going on, there's two trials in people with Crohn's Disease, which is an autoimmune disease of the small intestine, one in Jerusalem, and one in New York. There's a trial in Israel for multiple sclerosis. The national cancer institute has copies of twenty charts of my patients who have agreed to share their charts. These are people who have done well on Naltrexone when nothing else could explain how well they've done. They intend to present them to a committee for recommendations as to whether to invest and test it in the network of cancer research.*

Dr. Kokayi *You know, when I think about Africa and AIDS, this is exactly the kind of medicine there needs to be there….*

Dr. Bihari *This is perfect. In fact, we've been working with the largest pharmaceutical company in the developing world called (inaudible) in India to get a trial going, probably in Africa, in the Republic of South Africa, in which half the HIV patients get the drug, half get a placebo, and they should be able to show in about nine months, using two to three hundred patients, that this drug stops progression.*

Once it does, it will be manufacturable at less than ten dollars per year per person. That's been the big problem -- the anti-HIV drugs are so expensive. The average income in Africa is about eighty dollars per year.

Dr. Kokayi *I can only imagine just the financial stress that you've had to go through just to keep this whole project alive. It's one thing to prescribe things as an individual doctor, but to get recognition within the scientific community is a bit difficult.*

Dr. Bihari *It really bothers me when doctors say, 'Oh, I can't prescribe that, because he hasn't done a placebo-controlled trial.' That's a full-time job, for two, three years involving eight or nine centers around the country. I'm working with a number of diseases in my office, and a lot of money goes out paying for the website, for patents to cover low dose naltrexone, and (inaudible) things like that. It's very, very expensive. But I can't stop doing it. My wife and I would love to do some travelling -- I think we've earned it -- but I really can't stop until the drug is out there. It's as much of a burden as it does a pleasure.*

Dr. Kokayi *I really hope that at least your sharing with our listening audience today helps to make people more aware. People should be clamouring for it. We're running out of time, but I wanted to go back to the*

treatment of autoimmune diseases. I always pictured them as the body is attacking its own tissues. I pictured these antibodies actually honing in there. But you're saying that, in large measure it's an actual endorphin deficiency.

Dr. Bihari *It's an endorphin deficiency, which weakens the immune system, so that certain cells in the body forget to distinguish between the body tissues and bacteria or viruses, so when these cells are activated by an infection they attack the bacteria and they attack you. Restoring the immune function to normal stops that. So far, the drug works dramatically in all the diseases that are labeled autoimmune diseases.*

Dr. Kokayi *And you've treated lupus with this.*

Dr. Bihari *I've treated -- I have two dozen cases of lupus. I have about the same number of people with rheumatoid arthritis. I have about twenty people with Crohn's Disease. A number of rheumatologists who specialize in these diseases in New York are now beginning to use it, because we have cases in common, and they see.*

Dr. Kokayi *Right*

Dr. Bihari *Because they're using cancer drugs*

Female Voice *Dr. Bihari, is this being used with children with ADD?*

Dr. Bihari *I doubt that it would work, knowing the nature of ADD. I doubt that it would work. It doesn't do everything for everybody. I don't think it would.*

Dr. Kokayi *Again, going back to the idea of giving a medicine that at ahigher dose actually blocks the chemical system, but a lower dose actually augments it.*

Dr. Bihari *And enhances the body's defences -- that's essential.*

Dr. Koyayi *This idea gives the pharmaceutical industry something to do, rather than giving people high doses of medication.*

Dr. Bihari *It certainly would. It will take this drug to be licensed, picked up by a pharmaceutical company and tested, licensed, and once it's widely used, then this approach to medicine -- every medical researcher will start thinking about it. It's an entirely different approach to the body and illness.*

Dr. Kokayi *What is the next step? Is there anything that the listening audience can do that might be helpful for to make this more -- not even make it more available, because it's just a prescription any doctor can write. I guess it's the information --*

© Case Health Pty Ltd

Dr. Bihari *The information, getting it from the website, getting doctors to prescribe it. I'm always happy to take calls from doctors and spend as much time as I need, because the more doctors prescribe it, the more widely used it will be. Currently, as far as we can calculate it, over eighty thousand people in the U.S. and western Europe are on the drug, and the numbers are increasing rapidly.*

Dr. Kokayi *I'd like you to give your website one more time and the number where people can reach you …*

Dr. Kokayi *Well with that, thank you again and I'm sure we will be talking to you again soon.*

...

About Dr Bernard Bihari

Bernard Bihari, MD, was the discoverer of the major clinical effects of low dose naltrexone. A private practitioner in Manhattan, Dr. Bihari was a Board-certified specialist in Psychiatry and Neurology. Dr Bihari passed away on Sunday, 16 May 2010 after a prolonged period of illness. He was 78. The flow-on effect of Dr Bihari's use of LDN in clinical practice did not just deliver hope to his own patients but to patients around the world, and his pioneering work resulted in real relief from real suffering, and real improvement in quality of life for tens of thousands, and we hope in the years to come... hundreds of thousands. Words cannot express how deeply his passing was felt by the thousands he has touched... whose quality of life was dramatically turned around due to his compassion for patients, and his pioneering work in their collective best interests, against all odds. We are forever in his debt.

Transcript by Gazorpa

Full credit and sincere gratitude to 'Gazorpa', pioneer LDN advocate, for transcribing this radio interview:
http://www.gazorpa.com/interview.html

'Dr Kamau B. Kokayi interviews Dr Bernard Bihari'

was featured on 'Global Medicine Review', September 23, 2003
WBAI Free Speech Radio Talkshow, New York City
http://globalmedicinereview.com

About WBAI Free Speech Radio

WBAI began as WABF in 1941 and moved to 99.5 FM in 1948. The station took a respite from broadcasting in 1953, and came back on the air as part of World Broadcast Associates, Inc (WBAI) in 1955.The Pacifica Foundation was launched by pacifist Lew Hill in 1949 with the first ever listener funded radio station - KPFA, Berkeley. The Pacifica Mission called for radio that would foster understanding amongst nations and individuals, encourage creativity, and promote innovative, uncensored distribution of news.
http://wbai.org/index.php?option=content&task=section&id=5&Itemid=28

Interview with

Dr David Gluck, USA

July 2009

Dr Gluck

We're all curious. When, and under what circumstances did you first meet Dr Bernard Bihari?

David G *His family moved into my family's neighborhood in Queens (NYC) when we were both in the 5th grade of public school.*

Cris *How did you first learn of Bihari's Low Dose Naltrexone (LDN) protocol?*

David G *We continued seeing each other socially over the years, even after our medical training. In 1986 he told me about the positive results in the clinical study he had done of LDN in patients at Downstate Medical Center. The patients had ARC (later called HIV infections and AIDS).*

Cris *Have you ever prescribed LDN, and if so, what were the circumstances and the outcomes?*

David G *Since I have been retired from active medical practice for many years now, I have recommended it to many, many people but only prescribe it for members of my family. There, the purpose in most cases is for preventive use (either primary or secondary prevention).*

Cris *What led to the setting up of the lowdosenaltrexone.org and ldninfo.org websites?*

David G *In 1999, I was no longer in the active practice of occupational medicine, and having heard of the continued excellent results Dr Bihari was having with LDN in his private practice, and having shared that information with my son Joel, who is an experienced programmer, my son and I decided to launch the website in order to let physicians and the general public know about LDN.*

Cris *Most of your fellow medical practitioners aren't even aware of Low Dose Naltrexone as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

David G *Detractors? I am blissfully unaware of it, if I do. I have certainly encountered many, many doctors who were dismissive.*

Cris *What helped you maintain your sense of purpose, your resolve, through adverse times?*

David G *As I told Bernie Bihari, when he first told me what results he was seeing from LDN, "This needs to be shouted from the rooftops!" After a lifetime in Internal Medicine, where one had to deal with insufficient medications for serious illnesses, the discovery of this new and harmless method of upgrading the immune system and thus enabling one to draw on the body's own powerful potential to fight disease, seemed to me a godsend!*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views are largely ignored. Why do you think that is?*

David G *For many reasons … Doctors become inured to dealing with apparently preposterous and unscientific claims that patients bring them. Physicians' long professional training deeply ingrains the understanding that the scientific method, and only the scientific method, of testing proposed therapies by double-blind clinical trials can hope to yield reliable information. These trials are very costly and generally require the support of large pharmaceutical companies.*

Cris *In your opinion, what will it take for the medical community, scientists, politicians, and journalists to apportion value to patient testimony?*

David G *In my opinion, if it's only 'patient testimony', the chances are that they won't. Even if a celebrity or major politician were to become ill with a disease that could be well-handled by LDN, these people are shielded by their VIP status, and thus are restrained to use only the medical hierarchy's traditional treatment models.*

I believe that the pathway to recognition for LDN is open to us in the form of continued successful outcomes in repeated small clinical trials run at academic centers. Each one of these that is published in a respected peer-review medical journal becomes another weapon in forcing the groups you mention to pay attention.

My hope is that the grassroots movement, which has brought LDN this far, will mobilize behind a collection of such medical journal reports (and there may be sufficient of them within the next year to act upon) and use them to bombard every governmental health-related committee to insist that 'Attention Must Be Paid!'. Should government be willing to listen (and perhaps LDN's cost-saving

© Case Health Pty Ltd

potential may do the trick), at that juncture, patient testimony may have its chance.

Cris *Dr Gluck, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... After receiving my first two LDN health success stories in 2003 and deciding to research further, I discovered your website. Since then I've often wondered, if not for your website, your credentials, and your son Joel behind the scenes, if I would have learned the true depth, breadth, and inequity of the LDN story.*

I want to take this opportunity to thank you sincerely for having the good grace, the courage, and the fortitude to freely share what you've learned with the rest of the world in what must, at times, have been an unwelcome or even hostile environment.

(1) David Gluck, MD, (NY Lic. #083512), is the editor of ldninfo.org and its mirror site lowdosenaltrexone.org. He is a Board-certified specialist in both Internal Medicine and Preventive Medicine. Dr. Gluck has served as medical director for JCPenney and MetLife, and is now semi-retired, living and working in New York City.

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

###

Dr David Gluck has worked tirelessly to raise awareness of LDN.

It is extremely difficult to get anything published about the benefits of LDN, however; the following 'Point of View' was published in the Genetic Engineering & Biotechnology News Vol. 30, No. 13, July 2010:

Point of View

NCI Needs to Get Over Its Alternative Treatment Bias

Government Agency and Big Pharma Complicit in Stifling Investigation of Nontraditional Approaches

David Gluck, M.D., 1 July 2010

An honest admission by the National Cancer Institute (NCI) some years ago recognized that the development of effective cancer therapeutics has been comparatively sluggish for many decades now; compared, say, to the meaningful advances against heart disease,

stroke, and infectious disease. The U.S. continues to experience, as it has for the past 50 years, almost 200 cancer deaths per 100,000 citizens annually. Thus each year, of every 500 to 600 Americans, 1 dies of cancer.

In order to improve results, NCI launched a novel program that brings together physical scientists and cancer biologists to uncover breakthrough approaches. This new research paradigm scrutinizes in yet more exquisite detail the specifics of the tumor process within cancer-ridden patients. This approach, however, simply continues the ineffective strategy of the past. One might view it as just another attempt to close the barn door after the horse is gone.

An effective protection against cancer that the NCI should be investigating is our own immune systems. Evidence is mounting that the immune system is the most powerful defender against cancer.

We know that from the time of fetal growth, billions of cells are multiplying constantly, and we also know that the copy success rate for the genome is not 100% perfect. Add that to the impairments from a variety of environmental assaults, and it totals up to a considerable number of chromosomal errors each day, week, and year. If mammals hadn't developed a marvelous defense mechanism to handle such carcinogenic defective cells over the past 500 million years of Darwinian survival, we wouldn't be around today.

We also know that medical treatments that interfere with immune system functions have led to a high risk of new cancer formation over and over again. And we know, too, that as we age, every passing decade brings a somewhat less effective immune system concurrent with further increments in cancer deaths.

Much information has been collected on how to safely strengthen one's immune system (although this is far from common knowledge). Everything points to our endorphins and metenkephalin as being the major beneficial regulators of the immune system.

Low-Dose Naltrexone

Ian Zagon, Ph.D., distinguished professor of neural and behavioral sciences at Pennsylvania State University, a long-time researcher into endorphins and metenkephalin, has found that low-dose naltrexone (LDN) will reliably upregulate a weakened immune system as a result of doubling or tripling the levels of endorphins and metenkephalin.

Many of his research articles have demonstrated the efficacy of both metenkephalin and LDN in mitigating the progression of a variety of human cancer growths in nude mice.

Burton Berkson, M.D., Ph.D., of the Integrative Medical Center in Las Cruces, NM, has published three separate articles in Integrative Cancer Therapies that report details on some of his patients with advanced cancers (either pancreatic cancer or B-cell lymphoma) who, treated with LDN (and in most cases with alpha-lipoic acid), are now apparently cancer free. He often sees patients in his practice who previously have been advised to choose palliative care. He estimates that the remission rate for that group is roughly 50%.

© Case Health Pty Ltd

LDN has proven of no interest to any pharmaceutical company because naltrexone has been off patent for many years. But LDN, as an off-label Rx, is easily available from experienced compounding pharmacies, is inexpensive, has virtually no significant side effects, has no toxicity, and is generally compatible with all other medications save for those containing narcotics.

LDN is not alone among available anticancer therapies that are quite unknown to Western medicine because they are essentially unprofitable to big pharma. These fall into one of two groups; either original patent rights have long passed or they are simply a natural substance within our normal human chemistry and can't be patented.

NCI Reluctance

Why isn't the NCI interested in exploring some of these alternative approaches? In the absence of any reasonable hope for profitability, we can quickly understand the reluctance of big pharma. However, for the NCI, the answers are not so obvious.

The NCI's reluctance to investigate nontraditional cancer therapies probably includes some or all of the following: its natural reluctance to expend scant resources on brand new paradigms; the lack of credibility assigned to atypical sources such as private practitioners both here and abroad; the unusual nature of the application mode (i.e., it is not being approached by an interested researcher or pharmaceutical company but simply by an individual who demands that the NCI take the information and run with it); the lack of proof at the molecular level to explain the putative mechanism; and, last but not least, the complete absence of tangible rewards in the way of potential support for new staff positions and/or research materials.

For everyone's benefit, NCI must change its stance on alternative approaches. Large-scale clinical trials must be implemented in a variety of cancers in order to test the outcomes of all kinds of cancer treatments. The lack of interest in these novel approaches, by both pharmaceutical companies and the NCI, is likely to negatively impact most patients with cancer in a serious fashion.

There are millions of lives at stake and attention must be paid.

David Gluck, M.D. is the editor of the Low Dose Naltrexone website.

2010 Genetic Engineering & Biotechnology News
http://www.genengnews.com/gen-articles/nci-needs-to-get-over-its-alternative-treatment-bias/3342/

Interview with

Dr Tom Gilhooly, Scotland

July 2009

Dr Gilhooly

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further??

Dr Gilhooly *A patient with MS in my NHS practice asked for LDN four years ago, in 2004, and I promised to at least look into it. I soon found out that there was little of the usual research and clinical support for the use of the drug. My experience in addiction medicine, where I had used the full-dose version of naltrexone, gave me the confidence to at least try the low-dose version. Fortunately this patient had a good experience and had a significant improvement in her hand tremor, so I was intrigued and wanted to look into it more.*

Cris *You've prescribed LDN for Multiple Sclerosis and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting MS patients?*

Dr Gilhooly *A significant proportion of patients with MS improve with LDN, but the main benefit is preventing deterioration. This is actually quite hard to prove but as part of our work on the LDN trial, we have developed a blood test, which helps determine who will respond and how well they have responded. We are still working to validate this test, but we are confident that LDN represents a major step forward for MS.*

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Dr Gilhooly *I have used it in some Chronic Fatigue patients with good effect but with the advent of the blood test, I plan to use it more widely. I have also managed to get a patient with severe rheumatoid arthritis off steroids using LDN, which is pretty impressive.*

© Case Health Pty Ltd

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Dr Gilhooly *I have not really had many bad reactions from my colleagues although they will not usually prescribe it for various reasons. One of our aims is to increase the numbers prescribing LDN substantially, and this can only be done through increased research and training for doctors.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Dr Gilhooly *LDN has really been kept alive by the patients worldwide who have derived a benefit, and of course it is very rewarding to help patients who have been to lots of clinics and had no improvement. We now feel that our understanding of how LDN works is improving, and it is less of an art and more of a science.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Dr Gilhooly *LDN has not emerged from the usual pharmaceutical company route, and there is a tendency among doctors to be conservative and to distrust anything that has not been through the various stages of development that most drugs have. LDN is effective across a broad range of conditions but proving that is complicated and time consuming.*

Cris *Dr Gilhooly, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

(1) Dr Thomas Cormac Gilhooly, MB ChB, MRCGP, of Glasgow, Ireland, graduated from Glasgow University Medical School in 1983 and entered General Practice in Parkhead in Glasgow's East End 1989.
Email drtom@theglasgowsolution.com
Curriculum VITAE http://tomgilhooly.com/drtom.html

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

© Case Health Pty Ltd

Interview with

Dr Jaquelyn McCandless, USA

July 2009, Updated July 2010

Dr McCandless

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Jaquelyn M *In early 2005 the lab director of Immunosciences, Dr Ari Vojdani, mentioned to me that the immune panels I was conducting on children with autism very much resembled the panels on MS patients he was finding in his laboratory. Soon after that I happened to come upon a website about patient-reported treatments and noticed LDN being high on a list of therapies being used to help MS patients.*

I looked up LDN on the www.lowdosenaltrexone.org site and also read in the autism literature about studies that had been done with varying doses of naltrexone a decade before with varying but some success, the researchers hoping that naltrexone might obviate the necessity to put the children on a casein free/gluten free diet to combat the opiates thought to be from the undigested large peptides going to the brain as caseo-opioids and gluteo-opioids. Naltrexone did not satisfy their desire for that outcome, and compliance was very bad in their studies because of the terrible taste of this opioid antagonist for children who for the most part could not swallow capsules.

The main thing that came out of these few earlier studies was that naltrexone could be helpful for some self-injurious children. (Note: We now know that the main cause of self-injury in autism is extreme pain in inflamed guts but children who cannot speak cannot convey the source of their pain.) Nothing was noted then about any immune benefit, and I am not sure anyone knew yet at that time about the importance of endorphins to immunity. I thought, "Maybe this could help my autistic patients".

I tried it for my granddaughter Chelsey and a few others who did not like it because of the bitter taste. I asked Dr Tyrus Smith at Coastal Compounding in Savannah, GA if he would help me create a transdermal carrier that would be effective, and he came up with a cream made with oil from the emu. (a) I found it to be odorless, hypoallergenic, and extremely effective, and parents could apply it to the bodies of their already sleeping children when they, the parents, went to bed.

Parents began reporting, sometimes the very next day or within a few days, a lifting of mood when their children awoke in the morning, calling it the 'happy cream'. The thing they loved the most was that the children started being more sociable, playing with their siblings and relating to their fathers for the first time. I have received many such reports since starting to prescribe LDN for children with autism. I have a yahoo group e-list for those interested in LDN's use in autism that has 2700 members. (b)

Cris *You've prescribed LDN for Autism and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting patients with Autism?*

Jaquelyn M *I have a large database that collected over 200 reports from patients until I finally stopped collecting them, with 75% showing a positive response to LDN. For autism, a very complicated and multi-factorial disorder needing varying therapies, this is considered a high benefit rate.*

LDN is by no means a sole treatment for autism, but ideally accompanies dietary restriction, healing gut problems, nutrient protocols, and detoxification protocols. Parents like knowing that it is helping their children's immune system, though this benefit does not show up for awhile; but they particularly report liking the mood elevation, the socialization, and better cognition and language that occurs in many children. It is also very easy to apply and is inexpensive, which they also like.

I routinely require all of my own patients with autism to be on the casein/gluten free diet, but when I did a study on a larger group that had children who were not on dietary restriction, I began seeing hyperactivity and insomnia as a side effect to LDN in about 15% of the children. Since one of the aspects of autism is gut inflammation and ineffectiveness of the DPP-4 enzyme which is necessary for proper breakdown of the large peptides into amino acids, I see this side effect as a clue that the children would benefit from dietary restriction, and when parents agree and implement the diet often these side effects are ameliorated, but not always. Some children have had to stop LDN because the interference with sleep was intolerable for the parents and the rest of the family.

Giving an opioid antagonist even in a tiny dose to children who may have opioid-like substances in their brains from their diets can apparently cause a withdrawal reaction that manifests as hyperactivity. Sometimes cutting the dose down would help, sometimes enforcing the diet would help, and

© Case Health Pty Ltd

sometimes the kids just got used to it and began calming down and some just had to stop its use. Even in the face of severe insomnia and hyperactivity, many parents were reluctant to stop it because of their pleasure at seeing their child be sociable for the first time. This actually became an incentive for some to finally tackle the restrictive diet, which brought even more health benefits.

One year ago I queried the three pharmacies most known for compounding for autism and learned that over 10,000 prescriptions had been compounded for LDN just by those three in the two years since being introduced by me to the autism community. Dr Tyrus Smith, who created the transdermal cream had generously given out his formula for the cream to at least 50 pharmacies, including firms located in Hong Kong, Scotland, and Israel where I had gone to teach doctors the bio-medical approach to autism, including the knowledge of LDN.

Cris *You went to Mali, Africa with your husband, Dr Jack Zimmerman, to trial LDN for HIV. How did that progress, and were the results in-line with or outside your early expectations?*

Jaquelyn M *I performed a series of immune tests on a group of children with autism, and discovered that 80% of them raised their CD4+ cell count in that 16-week period, and thought, "This has to go to Africa." I made some enquiries and learned that Dr Bernard Bihari, the discoverer of the clinical benefit of LDN in AIDS patients in 1985, had written a protocol and attempted to implement a research study in Mali Africa a few years before. This study could not get adequate funding and had been laid aside.*

I was led to Mr. Seyni Nafo from Mali who had spoken of this attempt to do a study in his country in one of the early annual LDN conferences and who was very desirous of it being resurrected. With Mr. Nafo's invitation to come to Mali to look into the research possibilities and meet the professionals there in Bamako who might conduct the proposed study, and my husband's willingness to conduct a social/communication study alongside the medical research with me, we went in the winter of 2006, liked what we saw and the people we met, and proposed the revival of that study.

The challenges have been major, one of them being the language and distance problem, but phones, faxes and internet have been powerful tools in working together between the two countries and to carry this project forward. Another challenge has been finding groups or persons to contribute to funding for the study; we were certainly surprised at the difficulty raising funds for what we deem as a very important project.

However, with a substantial amount of our own funds along with help from many others it actually happened: With adult male and female participants in each of the three groups, one with LDN only, one with LDN and HAART drugs, and one with HAART and a placebo, we have completed our study and are in the complex process of analysing the final results at the present time (July 2010).

The study took much longer than we had planned. The stigma associated with this disease in Mali makes those infected extremely reluctant to come forward for testing until they are already very ill, particularly the women, and this did make recruiting very slow. By the time many showed up for testing it was too late for them to participate in the research we were doing, which was to try to show that LDN can prevent the inevitable loss of CD4+ cells that usually culminates to the patient finally having full blown AIDS leading to their demise.

We have had to go back to the drawing board several times for changes; Mali has strict IRB regulations based upon US IRB regulations. We have found that many Africans are fearful of American drug studies that in the past have hurt their citizens by inadequate informed consent and other inhumane or negligent practices by large drug companies working there to get AIDS and other drugs accepted through research studies on their people. Their people are quite suspicious of drugs in general, and people have been found deceased from AIDS there with their cabinets full of HAART drugs which they were given but did not take.

With a literacy rate of 17% in this country, and much less than that for women, the counselling and education aspect is paramount and is the challenge that my husband has undertaken as his part of the study to help men and women communicate better. He has trained counsellors to work with groups, now ongoing, consisting of women only, men only, and men and women together. Anyone in the study taking the drugs has been permitted to invite their partners to participate in the counselling and communication groups even if they were not in the medical part of the study.

We hope to get our study results published in the next few months; I am unable to relate those yet but we are quite sure there will be some interesting findings when we complete our statistical analysis.

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Jaquelyn M *I have worked with Crohn's Disease (adolescents, children and adults), multiple sclerosis, chronic fatigue syndrome, fibromyalgia, Parkinson's Disease, Alzheimer's, and cancer patients. Everyone to whom I currently prescribe LDN (or their caretakers who give me reports) feels positive about the results, some ecstatically so. Some were disappointed that their illness was not reversed, particularly the MS patients, but eventually grateful that they felt stronger and better generally and were no longer progressing. I always need to stress to the MS patients that LDN cannot be expected to reverse/eliminate scar tissue already formed in the brain, but it is reported that 80-85% see progression of their disease stopping, and usually with only using LDN and general good health practices (such as eating well, taking important nutrients such as Vit D3, etc).*

My husband and I have been taking it for almost 5 years now and we love it; we think it is one of the best anti-aging agents around, and it definitely helps mood and libido as well as immunity. I have all my friends on it and some swear they never get ill anymore even with extensive travelling schedules, and wouldn't give it up for anything.

Cris *Do you usually advise patients to take LDN at a particular time of day, and if so, have you noticed any difference in outcomes dependent on the time of day the LDN is taken?*

Jaquelyn M *I always advise using LDN at night after 9pm, up until 2am, and rarely have had anyone have any problem with that time. That time is particularly good for children with autism who are usually asleep long before their parents go to bed. I advise parents to apply the cream to their children when they (the parents) retire.*

Cris *What symptoms might indicate a patient (child or adult) is experiencing withdrawal due to LDN blocking opioid peptides that some patient's digestive systems produce more abundantly than others?*

Jaquelyn M *An opioid antagonist, even in small doses, tends to create withdrawal reactions in those who are addicted to bread and milk; in general, and very specifically with Autistic children. The primary side effect with LDN in those not on a restrictive diet is restlessness, hyperactivity and insomnia. To me, this is a diagnostic indication that a gluten/casein-free diet would be beneficial, and if parents are able and willing to start the diet, usually not only do the children tolerate LDN, but respond better overall.*

30% of people have some degree of intolerance of gluten and would do better health-wise omitting bread from their diet, and; milk allergies are very common generally. The bottom line is, most everyone would be healthier without gluten and casein.

Cris *In your experience, when patients (children or adults) adopt a casein free/gluten free diet to minimize over-production of opioid peptides in the digestive system, do the withdrawal symptoms resolve fairly quickly... for most?*

Jaquelyn M *For most, usually within a week to 10 days, rarely longer unless gluten intake (addiction) is high.*

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Jaquelyn M *Actually most of my fellow practitioners happen to be autism specialists and alternative or anti-aging doctors, and are for the most part grateful to have another therapy in their armamentarium to treat difficult populations. I've heard a lot of stories about patients having difficulty even*

© Case Health Pty Ltd

getting a prescription, however, and the ignorance of my colleagues to even investigate the situation is very disheartening.

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Jaquelyn M *Primarily what has helped me the most is the support and love in a wonderful marriage of 35 years to a rare man who has actually gone beyond patriarchy and truly honors and enjoys having an empowered woman for a partner. And needless to say it has been especially heartening to see children previously thought to be untreatable getting better and being enabled to have much more independence in their lives than ever thought possible with the knowledge and treatments now available, including LDN.*

Writing a successful book on the biomedical treatment of autism 'Children with Starving Brains' that has sold over 60,000 copies in the US *and been translated into several different languages has also given me a lot of satisfaction, inspired by the love for my wonderful granddaughter with autism who though not completely recovered, has definitely benefited from my efforts.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Jaquelyn M *For one thing, autoimmune conditions are extremely complex and poorly understood by even most medical professionals, much less the lay public. Fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities are a few of these disorders that have up until quite recently been considered 'psychosomatic' and not 'real' illnesses by many in the past who had no idea what was causing the illnesses, or any knowledge of how to treat these kinds of patients. The sheer increase in these disorders has brought much more knowledge and understanding currently, so there is hope that these kinds of views will be more honored and investigated now than in the past.*

Secondly, LDN being made from a generic drug that no one can own creates a situation where large research studies that can only be conducted by wealthy drug companies will never happen, as corporate profits are not a motivation.

This is why I have gone to Africa to get a study done. Also, that country stands to benefit the most from an inexpensive non-toxic remedy that could help millions of unfortunate persons there with HIV+ status to survive if our study proves it to be effective, and especially if we can get it manufactured there. As more studies are conducted, I believe the situation will change.

Unfortunately, I believe that many busy doctors after starting practice get their primary continued medical education from drug reps, and drug reps are not about to talk about (or give samples of) a cheap generic drug that might compete with the profits being made by pharmaceutical companies.

© Case Health Pty Ltd

Update July 2010

Cris *Are you nearing completion of the Mali LDN HIV+ Trial?*

Jaquelyn M *We are in the process of conducting the statistical analysis of our results for the Mali LDN HIV+ Study Trial in preparation for medical publication, and so cannot reveal the results or pre-empt publication. However, I can say to all those who so generously contributed to our fundraising effort, you will not be disappointed by the outcomes.*

Cris *Dr McCandless, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

Jaquelyn M *You are very welcome, Cris; I hope many people take advantage of the knowledge and experience now being offered by grateful patients, the researchers, and writers like you who spread the good word. I would also like to take this opportunity to thank all the financial contributors who generously helped us make our African project a reality.*

(1) Jaquelyn McCandless, MD, *Certified by the American Board of Psychiatry & Neurology, Autism Specialist and Physician Trainer, Author, 'Children with Starving Brains, a Medical Treatment Guide for Autism Spectrum Disorder', 4th edition 2009, and 'Flesh & Spirit, the Mystery of Intimate Relationship, co-authored with Jack Zimmerman, PhD, 1998, both by Bramble Books.*

(2) Cris Kerr, *'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.*

References:

(a) Dr Tyrus Smith, Pharmacist, Coastal Compounding, 6709 Forest Park Drive, Savannah, GA 31406. Phone 912 354 5188 or 866 354 5188 Fax 912 355 3685 http://www.coastalcompounding.com. Email: mail@coastalcompounding.com

(b) LDN Discussion – Autism – Dr Jaquelyn McCandless
http://Autism_LDN@yahoogroups.com

As at July 2010, Drs Jaquelyn McCandless and Jack Zimmerman (Ojai Foundation Africa Project) have been commuting to Mali, Africa for over 2 years to conduct a clinical trial into the effectiveness of LDN for HIV+ and; in conjunction with investigators at the University Hospital in Bamako; will soon report their results.

Interview with

Dr Skip Lenz, Pharmacist, USA

July 2008, Updated February 2010

Skip

How and when did you first discover the potential benefits of low doses of naltrexone (LDN)?

Skip L *A patient called the pharmacy in 1999. He'd heard of this new drug and wanted to know if I knew anything about it. I contacted Dr Bihari and had several conversations with him prior to us dispensing it. Several months and several dozen patients later, we started to hear of very positive effects.*

Cris *The compounding of low doses of naltrexone needs to be exact and of the highest possible quality and consistency. Were there any early lessons learned when you first began compounding LDN, and if so, what effect did that have on your compounding procedures?*

Skip L *We started compounding using the commercial tablet, but we found the patients taking capsules compounded from commercial tablets were not getting the same benefits as the patients who took capsules compounded with naltrexone powder.*

It's now 2008 and we've learned a great deal since then. We now add food coloring to ensure the naltrexone is distributed evenly through each compounded capsule, and we now have our capsules assayed. The additional checks and balances we've introduced have resulted in an average distribution range of 99.7% to 100.3% of active compound in each capsule, exceeding any accuracy range published to-date.

Cris *At what point did you realise you wanted to learn more about LDN?*

Skip L *Within the first few months of hearing about it, in 1999.*

Cris *How many patients are presently using Skips Pharmacy to fill their prescriptions, and what is the degree of positive or negative feedback you've*

received? Have you recorded and measured that feedback to share with others?

Skip L *At present we're filling prescriptions for over 10,000 patients. We felt it was very important to track and measure feedback, and as a result we've recorded that 83% of patients using our pharmacy have a positive response to LDN.*

Cris *Since becoming more outspoken on the benefits of LDN and devoting more of your time to supporting patients taking LDN, what have you learned or experienced?*

Skip L *Each patient is different, so each time we dispense LDN we conduct an N=1 study. The power of the internet is extreme when it comes to any untoward effects; that is to say, there is a reverse-placebo effect that is inevitably highlighted through the internet. When one patient has an unexplained untoward effect, the first thing they blame is the filler. At the New York Academy of Science, an issue was raised that Calcium carbonate was not a good filler.*

The next year, at the National Institute of Health, I presented a paper on the disintegration profile of Calcium Carbonate and suggested that because of its inherent compact-ability, it was inappropriate to use as a filler. We then suggested Avicel would be the best filler because its hypo-allergenic and releases immediately, which is a highly desirable characteristic for this particular protocol. Subsequently an urban myth has grown around the use of Avicel, suggesting a large proportion are allergic to it. This is not true, yet it is still perpetuated.

Cris *With regard to LDN, what aspects, if any, are you most concerned about?*

Skip L *I'm concerned about the uncontrolled growth of patients using LDN without any concern for the science. We are getting more and more enquiries about LDN for diagnoses that do not have an auto-immune vector. Subsequently, if they begin LDN and the product fails, the medical establishment can point to LDN as another example of quack medicine.*

Cris *Are you aware of the range of diseases suffered by patients who fill their prescriptions through your compounding pharmacy, and if so, what are some long-term successful examples?*

Skip L *Our primary focus has always been MS. We have patients that have had no exacerbations in over 5 years. The longest time between exacerbations has been 9 years. This is significantly longer that any published data on any other MS drug.*

© Case Health Pty Ltd

Cris *With regard to LDN and the knowledge you've gained through patient support, what do you believe are key factors in successful patient outcomes or failures?*

Skip L *Realistic expectations most definitely improve outcomes for those starting on LDN. Over the years there've been hundreds of stories on the internet suggesting LDN is a miracle cure for many diseases. But, when patients are encouraged to slow down and do some research first, they learn what they can and can't expect from LDN. They learn LDN is not a miracle cure, but that it can reduce their exacerbations and decrease the rate of their progression. Those who know what to expect are those most likely to continue with the therapy, and subsequently benefit from it.*

Cris *You provided sponsorship for a couple of the now annual LDN Patient Conferences, and your wife Cyndi and son Adam have been heavily involved in videotaped records of those conferences. What first prompted this extended family involvement, and how has that impacted on your family?*

Skip L *I was going to the NIH conference and Cyndi asked to come along. At the time she was a film student and wanted to test her ability to create a documentary on LDN. Adam was also studying digital media at UCF and was our AV guy. After each conference we've filmed, there has been a coming together of the family around getting this information out.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Skip L *The scientific establishment holds anecdotal data as invalid. Physicians have become afraid of litigation stemming from the prescribing of novel drugs. We have forgotten that the vast majority of drugs available in the world are the result, not of well controlled placebo double blinded cross over studies, but of empirical experimentation by physicians.*

Update February 2010

Cris *I've been hearing lots of different rumours about the number of LDN prescriptions you fill each month - some as high as 25000. I understand it'd be a ball-park figure, not exact, but roughly how many 3-month scripts are being filled through your pharmacy each month?*

Skip L *Due to the recent developments with 4-ap. I respectfully refuse to answer this question.*

Cris *Is that because 4-Aminopyridine (4-AP), a potassium channel blocker used by some MS patients, was tweaked into a new sustained release product, Ampyra (formerly known as Fampridine-SR), and because of that; you're concerned the pharmaceutical industry could perceive your LDN script numbers*

as a growing market segment that could be exploited in a similar way... rendering LDN unaffordable for many?

Skip L *Yes, I believe that the international emphasis on obtaining LDN approval is going to have a drastic impact on the cost of Low Dose Naltrexone. If this happens, I believe that the vast majority of patients will have to go off-shore to obtain questionable quality product for a price that is affordable.*

Cris *You're a very committed and well-respected pharmacist, and a very vocal advocate for LDN. The depth of that commitment has seen you assign student pharmacists to survey the outcomes of patients filling, and significantly 'refilling', their LDN scripts through your pharmacy... to prove the efficacy of LDN goes way beyond the 'placebo effect'. What's a quick helicopter view of those survey results?*

Skip L *I've been dispensing LDN since 1999. I've been surveying and polling our LDN patient population consistently over recent years. I can state with complete confidence the results of 3 surveys and 2 polls have consistently resulted in this measure, to within a couple of percentage points: Since commencing on LDN, 83% of our LDN/MS patient population has not had a relapse or progression in over 3 years.*

Cris *Skip, in consideration of significant growth in the number of LDN prescriptions filled and refilled each month, and a statistical outcome that's remained relatively consistent since you first began surveying your patient population, we're privy to something with Nobel Prize 'yesterday' significance.*

But... it's the 'privy' part that concerns me most. I hope your survey statistics peak the interest of doctors and scientists, but also humanitarians and worldwide opinion leaders... those with a moral interest in improving health outcomes for people who are suffering unnecessarily... and I hope they also peak the interest of a few statisticians, mathematicians and national economists with a moral interest in sustainable health economies that have capacity to improve health outcomes and workforce productivity whilst reducing unnecessary suffering, hospitalisations, and health inflation.

Cris *Your survey measured the number of patients who used/are still using 'Skip's Titration Protocol'?*

Skip L *Yes, 10 years ago, a leading-edge neurologist was starting his patients on the top dose of 4.5mg LDN, and he complained to me about the side effects his patients were reporting (interrupted sleep, spasm, stiffness, tightness).*

In response, I suggested the following titration schedule for his patients:

Skip Lenz's LDN Titration Schedule
(1) 1.5mg naltrexone x 30 days
(2) 3mg naltrexone x 30 days

(3) 4.5mg naltrexone thereafter

Since the introduction of the titration schedule, some have said it's too conservative and others have said it's too aggressive: Can't please everybody eh?

I've conducted LDN surveys and am in constant contact with MS patients taking my compounded LDN formulations, so I know the titration schedule has helped minimize side effects for the majority of MS patients (in comparison to starting on the top dose of 4.5mg). This is why I stand by my protocol for the majority of MS patients.

For other conditions such as Fibromyalgia, Chronic Fatigue Syndrome, Crohn's Disease/Irritable Bowel Disease, etc; I recommend starting on the top dose of 4.5mg and putting up with some side effects for a short period.

If they're willing to deal with some minor side effects like interrupted sleep for a brief time, there'll be very few people who won't be able to continue LDN. They're getting the best bang for their buck going this way, and if you read Dr. Smith's papers on her use, you'll see she started her adult Crohn's Disease patients on 4.5mg, with some pretty remarkable results.

Cris *Skip, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you for everything you do to support patients, and thank you for continuing to provide a consistently high quality compounding service that's so integral to success with LDN - and is ultimately, a key partnering factor in the alleviation of suffering.*

An overview of Skip Lenz's LDN Patient Survey 2008 follows.

###

(1) Dr Skip Lenz graduated from Massachusetts College of Pharmacy. He received his doctorate with highest honors at the University of Florida after completing a rigorous Pharm. D. program. He has been practicing Pharmacy for over 30 years in many different settings including retail, manufacturing, long term care, home health, and research and development. Skip's Pharmacy, 21000 Boca Rio Rd, Suite A-29, Boca Raton, Florida 33433 Tel 561-218-0111 & 800-553-7429 Fax: 561-218-8873 Web: http://www.skipspharmacy.com

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

Skip's Pharmacy

LDN PATIENT SURVEY 2008

designed by Skip Lenz
conducted by pharmacy students

KEY STATISTICS

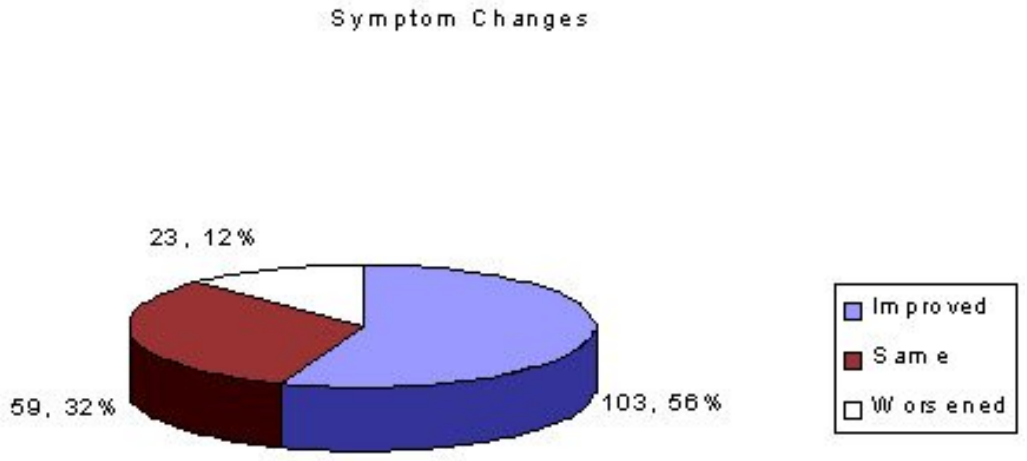
PATIENT SAMPLE SIZE (ALL)
185 patients – 138 / 75% female, 47 / 25% male

SYMPTOM CHANGE AFTER COMMENCING LDN (ALL)		
Improved	**56%**	**103**
Same	**32%**	**59**
Worsened	**12%**	**23**
ACTIVITY OF DAILY LIVING/QUALITY OF LIFE (ALL)		
Better	**52%**	**96**
No Change	**43%**	**79**
Worse	**5%**	**10**
WOULD RECOMMEND LDN TO OTHERS (ALL)		
Yes	**92%**	**170**
No	**3.7%**	**7**
Unsure	**4.3%**	**8**
CURRENT STRENGTH of DOSE (ALL)		
<3mg	**4%**	**7**
3mg	**55%**	**102**
3-4.5mg	**3%**	**6**
4.5mg	**30%**	**56**
>4.5MG	**8%**	**14**
LENGTH OF USE (MS)		
0-1 year	**56%**	**85**
1-2 years	**10%**	**15**
2-3 years	**13%**	**20**
3+ years	**20%**	**31**
other	**1%**	**2**

DIAGNOSES (ALL) including multiple diagnoses
153/83% Multiple Sclerosis, 5 Fibromyalgia, 43 Other
DIAGNOSIS TYPE – MULTIPLE SCLEROSIS (MS)
61 RRMS, 14 PPMS, 31 SPMS, 14 PRMS, 33 Undetermined
LENGTH OF DISEASE (ALL)
48% 0-9yrs, 31% 10-20yrs, 11% 21-29yrs, 10% 30+yrs

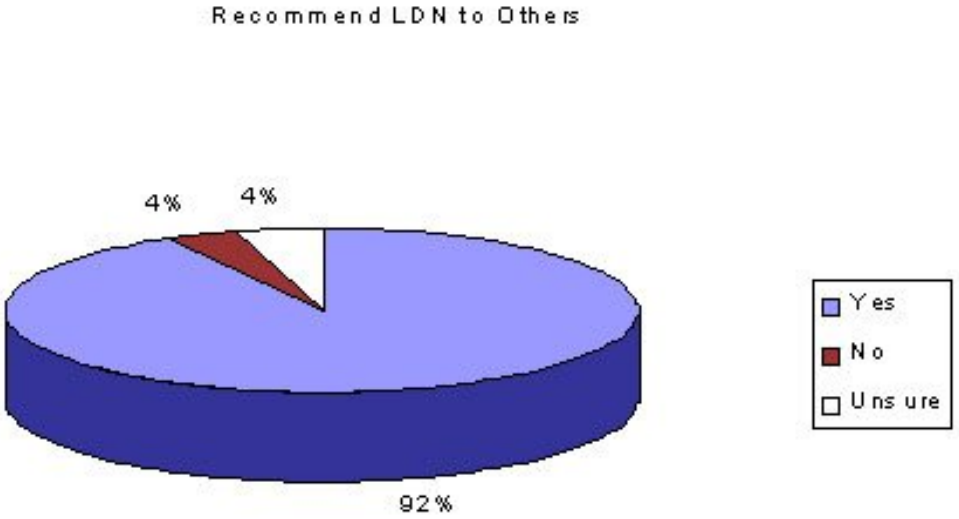
© Case Health Pty Ltd

SYMPTOM CHANGE AFTER COMMENCING LDN

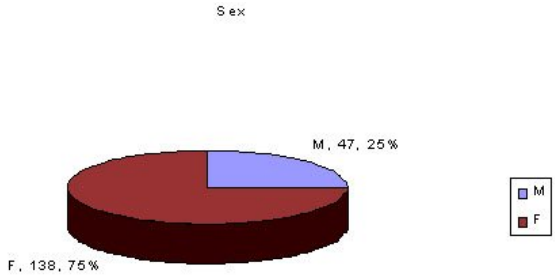


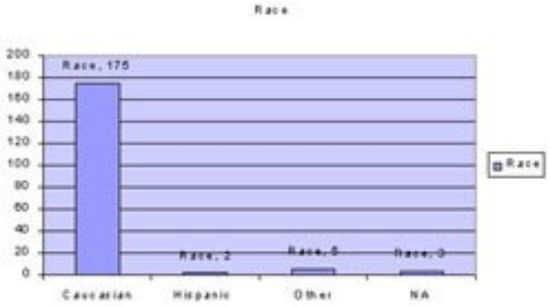
QUALITY OF LIFE AFTER COMMENCING LDN

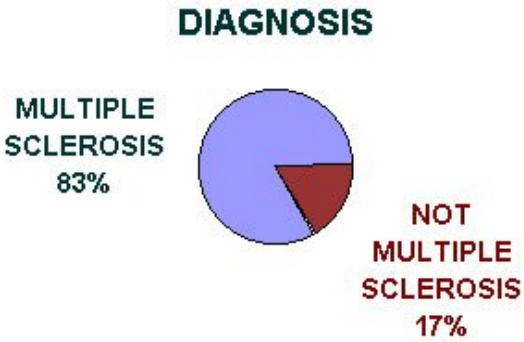
WOULD RECOMMEND LDN TO OTHERS

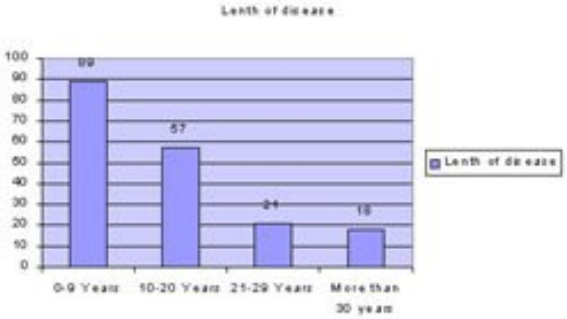


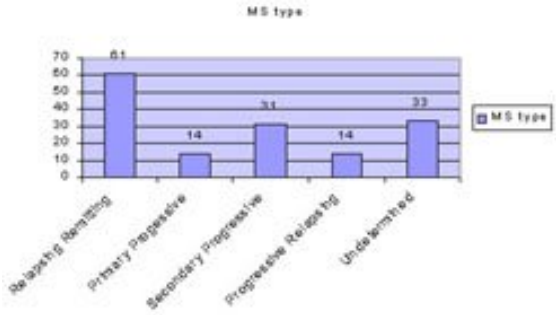
© Case Health Pty Ltd

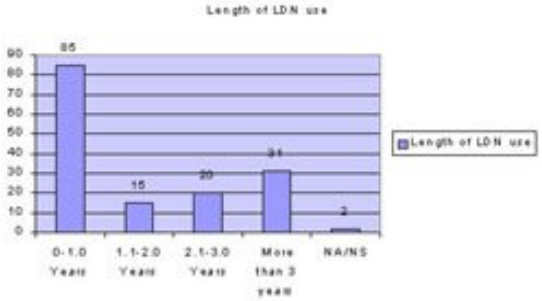

Sex
M, 47, 25%
F, 138, 75%
M
F

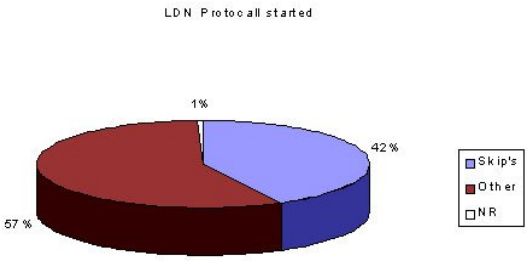

Race
Race, 175
Race, 2
Race, 5
Race, 3
Caucasian
Hispanic
Other
NA
Race

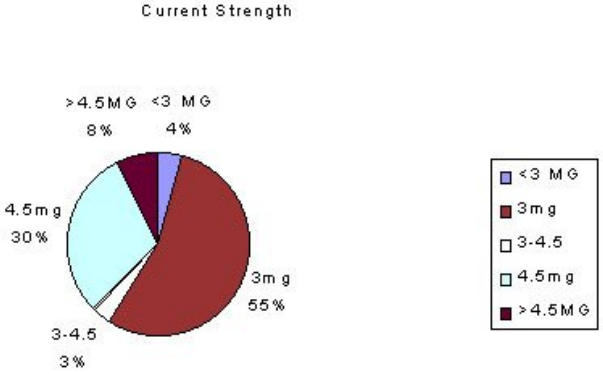

DIAGNOSIS
MULTIPLE SCLEROSIS 83%
NOT MULTIPLE SCLEROSIS 17%

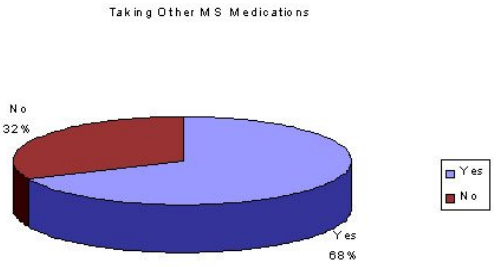

Lenth of disease
99
57
24
18
0-9 Years
10-20 Years
21-29 Years
More than 30 years
Lenth of disease

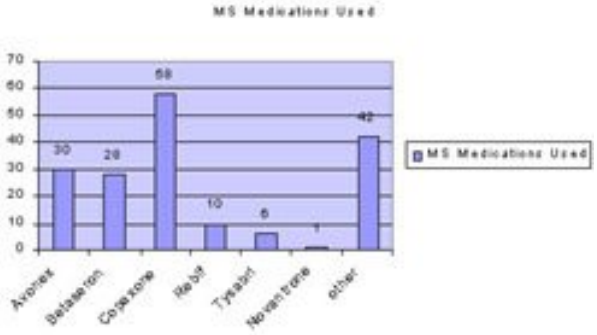

MS type
61
14
31
14
33
Relapsing Remitting
Primary Progressive
Secondary Progressive
Progressive Relapsing
Undetermined
MS type

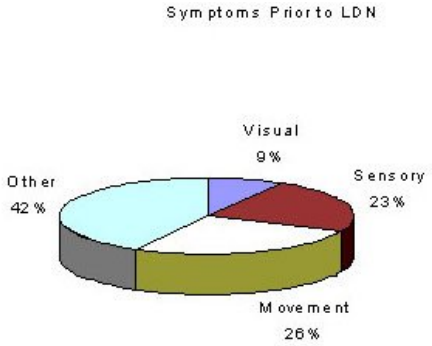

Length of LDN use
85
15
20
31
2
0-1.0 Years
1.1-2.0 Years
2.1-3.0 Years
More than 3 years
NA/NS
Length of LDN use

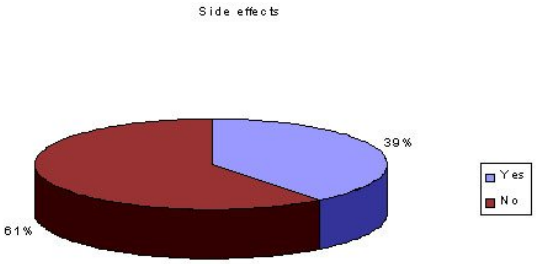

LDN Protocall started
1%
42%
57%
Skip's
Other
NR

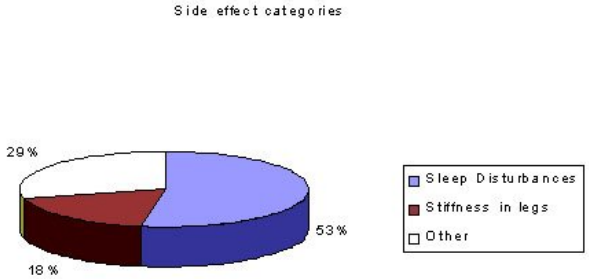

Current Strength
>4.5MG
8%
<3 MG
4%
4.5mg
30%
3mg
55%
3-4.5
3%
<3 MG
3mg
3-4.5
4.5mg
>4.5MG


Taking Other MS Medications
No
32%
Yes
68%
Yes
No


MS Medications Used
70
60
50
40
30
20
10
0
30
28
58
10
6
1
42
Avonex
Betaseron
Copaxone
Rebif
Tysabri
Novantrone
other
MS Medications Used


Symptoms Prior to LDN
Visual
9%
Sensory
23%
Other
42%
Movement
26%
Visual
Sensory
Movement
Other


Side effects
39%
61%
Yes
No


Side effect categories
29%
53%
18%
Sleep Disturbances
Stiffness in legs
Other

Dr Lawrence

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Bob L *I was first introduced to LDN by 'Goodshape', an internet medical advisor who was also using a modified form of Prokarin, histamine and caffeine treatment, initially formulated by Elaine Delack. He was using both LDN and his 'patch-less histamine therapy' for his wife, who had MS.*

This prompted me to seek further details and comments on this method from other sources on the Internet. I then spent a year both investigating and testing the method on myself before offering it to others, in both liquid and capsule form.

I now provide only LDN capsules directly but the liquid LDN may be obtained by prescription (either private or NHS) from Dickson's Pharmacy, in Glasgow. Details of the address and contact telephone number are available on request. The initial availability of the LDN capsules was published in an article in 'New Pathways', a magazine of the MS Resource Centre, which is a charity providing information and advice to anyone with MS (info@msrc.co.uk Tel: 01206 - 505444)

Cris *You've prescribed LDN for Multiple Sclerosis and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting MS patients?*

Bob L *The results of LDN use has been suitably assessed by the questionnaire provided by Linda Elsegood (www.ldnresearchtrust.org). Summarising the results of over six hundred MS patients on LDN, the survey shows a consistent success rate of 94%, in both improved symptoms and disease stability. My own experience has demonstrated dramatic improvements in symptoms in some cases, with a consistent and reliable stability following regular use of the method in most cases.*

© Case Health Pty Ltd

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Bob L *I have also prescribed LDN for other auto-immune diseases, including Crohn's disease, type one and type two diabetes mellitus, rheumatoid arthritis, ankylosing spondylitis, psoriasis and psoriatic arthritis, various forms of cancer, including non-Hodgkin's lymphoma, renal cell carcinoma, hepatoma, and carcinoma of the lung. Only one patient has withdrawn from the treatment, an elderly gentleman with cancer of the prostate gland, who despite a reduction and stabilisation of his PSA (prostate-specific antigen) level, decided to stop using the treatment.*

Auto-immune diseases show a variable response: Last year I had two patients with Crohn's disease, one recovering well. The other, a young man with Crohn's disease withdrew from the LDN treatment altogether. I assume this decision was prompted by his father, who was persistently reluctant to stop the azathioprine that was also still being used. He simply refused to acknowledge that this drug was blocking any benefits from the LDN, thus preventing any expected progress and improvement.

Last year, progress with a single patient with psoriatic arthritis was slow, partly I consider, due to the continuing use of anti-inflammatory drugs, which are detrimental to the method. He stopped using anti-inflammatory drugs, and now uses Gabapentin with some improvement in his symptoms.

A single patient with rheumatoid arthritis has largely recovered and uses only occasional paracetamol; an elderly patient with ankylosing spondylitis has gained significant benefit; diabetic patients have shown a pleasing and consistent reduction in blood sugar level of about 50%, with a coincident reduction in insulin needs of about one-third of their previous dose.

Cancer patients have often shown remarkable recovery: One patient, a man of 72, with a large inoperable lung cancer, was given just three months to live over two years ago (July 2007). Since starting on LDN, almost immediately after that prognosis, he has largely recovered. His pulmonary function has since doubled, his appetite and weight have increased, and he has since become active once again, gardening and playing bowls. Scans and bronchoscopy reviews have shown the cancer to have disappeared. His hospital reviews have now been extended to six-monthly check-ups. Despite re-examination of the original biopsy with confirmation of the diagnosis, the cancer, which had already completely disappeared, remains unseen and undetectable.

A second patient with a recurrence of a renal cell carcinoma at the site of a prior nephrectomy has shown a significant reduction in tumour size, with a generalised improvement in general fitness and vitality.

© Case Health Pty Ltd

Of three patients with non-Hodgkin's lymphoma, one with a six-year history on LDN, all remain well with no relapses or recurrence of the condition.

The single hepatoma patient remains fit and well.

Cris *What are your thoughts on adhering to Bihari's night-time dosing schedule, with regard to insomnia?*

Bob L *The insomnia said to be associated with the use of night-time dosing is usually apparent for only one or two nights. Within a short time sleep often improves. Insomnia is often associated with zinc deficiency, which is almost inevitable with auto-immune diseases.*

I have no precise evidence of the most effective time to take the LDN. I have simply accepted the principle suggested by Dr Bihari to take the LDN at night. He apparently was able to determine that this was the main time that the endorphins were actually produced. If this is true, then logically, this is the best time to apply the brief blockade of the endorphin receptors in order to achieve a strong positive response. In the absence of more precise, or different evidence, I see no reason to change this opinion.

The insomnia that patients mention is usually a very brief and temporary effect that fades within a few days. If the insomnia is more persistent than this, the simple answer is to reduce the dose to a lower level for a few days until the adaptive process overcomes the insomnia.

I feel that people trying LDN without research, full or adequate knowledge or professional advice may be simply unaware of this need for a period of adaptation that spurs the endorphins into an increased state of production.

Others too may also be unaware of the need and importance of a diet and nutrient therapy in association with the LDN. I have found that those choosing to not follow the diet or nutrient therapy advice tend to get a very poor response to the LDN. For an optimum response to be gained the body must be nutritionally adequate and capable of doing so.

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Bob L *Regretfully, those consultants who should be greeting this unique and simple treatment with the respect that it deserves are the ones that tend to treat it with greatest suspicion and contempt.*

Although I have hundreds of MS patients who've been stable and well for years on LDN, it is rare to find a neurologist who will acknowledge that it is this treatment that is making them well. Such improvement is simply dismissed as, "Spontaneous remission!" and then ignored. One consultant neurologist admitted recently, when assessing a patient who had recovered, "If I didn't

© Case Health Pty Ltd

already know that you had MS, I would not even consider this as a diagnosis", but he would not acknowledge that this improvement was attributable to the LDN!

Thankfully, many GPs have a closer relationship with their patients, and therefore develop the perception and insight to see that patients are actually recovering on this treatment. It has therefore, become possible to often convince these doctors to prescribe LDN themselves on the NHS. Over time I've persuaded perhaps five hundred or more GPs to prescribe LDN in this way.

For several years, use of LDN has also been encouraged by other LDN enthusiasts, such as Tom Gilhooly (Centre for Nutritional studies, Glasgow). Dr Gilhooly arranged for Dickson's Pharmacy in Glasgow to obtain a regular supply of naltrexone, then provide this treatment to both private patients and to the NHS.

Prices of the new supplies of LDN capsules from Dicksons Chemist are now £25-00 for 3 mg, and £30-00 for the 4.5 mg per month. In addition, despite some restrictions on bulk imports of LDN late in 2008, it has now also been established that individual supplies of LDN, for personal use only, may be freely imported from overseas pharmacies direct to the patient's home address.

Dickson's pharmacy will accept NHS prescriptions from anywhere in the country, and will send the LDN by post direct to the patient. Such a low cost has encouraged many more GPs to accept and adopt this method.

The method is also supported by other doctors in Ireland: Dr Patrick Crowley is using LDN widely in his general practice. Mary Bradley, who wrote the book, "Up the Creek with a Paddle" has a brother who is a doctor working in Galway, Eire. He has considerable experience in using LDN in a wide range of conditions.

In addition, because we have now been banned from importing LDN from Irmat Pharmacy, in New York, the only LDN available here is from Dickson's Pharmacy, 35 Mitchell Arcade, Glasgow, G73 2LS. Tel: 0141 6131238.

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Bob L *My greatest encouragement at such times is simply my own MS. After having symptoms of ankylosing spondylitis starting at the age of 26 years, and MS symptoms since the age of 34 years (I am now 67), it is my own stability and improvement that daily proves to me that this is a method that must ultimately be universally accepted and applied in all suitable cases. An appropriate quotation has been offered by a doctor with MS that I am presently treating with LDN. "All truth passes through three stages, first it is ridiculed; second, it is violently opposed; third, it is finally accepted as being self-evident". Schopenhauer.*

Of course, I am also reminded by the hundreds of patients I am currently treating with LDN, who are convinced that they have benefited by this simple method, also by the constant stream of new patients, who may occasionally struggle with the increased symptoms that sometimes occur at the beginning of LDN treatment, but who finally emerge both feeling and functioning better than they have been for many years.

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Bob L *There may be many reasons for this, most of which I may merely surmise. The drug companies ignore the facts of LDN use simply because there is virtually no potential for profit in this method. This is easy to understand, as drug companies exist only for profits for their shareholders. LDN is simply not commercially viable at the currently available price.*

It is more difficult to understand why doctors themselves are so resistant to a method that has proved itself over twenty-four years of continuous and increasing use.

Much of the bias against LDN is based on the traditional convention that auto-immune disease is due to over-activity of the immune system. It is simply suggested that the immune system needs to be suppressed by toxic drugs, such as methotrexate, azathioprine, or mitoxantrone.

I wonder why this fallacy, this perverse logic, is ever maintained, as even a cursory examination of the facts will demonstrate that quite the opposite is true. It is well-known that during a relapse of any auto-immune condition such as MS, the number of T-cells (which indicate the intensity of immune activity), falls precipitously. This cannot possibly indicate overactivity of the immune system! Such a dramatic fall in T-cell levels must therefore demonstrate immune dysfunction and under-activity.

This is further verified by a self-imposed experiment conducted by opiate drug addicts who, by taking an excess of opiate drugs, inhibit the production of brain endorphins, and reduce the activity of the immune system. This results in an INCREASE in the incidence of infection, cancer and auto-immune conditions, thus providing evidence the conventional view is completely wrong.

I wonder how many of those doctors who presently condemn this treatment method, will hang their heads in shame when LDN is finally accepted for what it is: a simple, safe and easy method that will effectively treat more conditions than has ever been possible with any other single drug.

Once fully proven by the increasing number of trials and studies currently being conducted or planned, this method will be seen as so safe, it could be made readily available, without prescription, over the counter. Like paracetamol now, it could be available from supermarkets and petrol stations

© Case Health Pty Ltd

everywhere. In fact, paracetamol is already acknowledged as considerably more dangerous than LDN. Fifty paracetamol taken as one dose will almost certainly cause death by liver failure. Fifty low-dose, 3 mg, naltrexone (a total of 150 mg) is, in fact, still within the normal, conventional, therapeutic range of the drug when used in the treatment of opiate drug addiction.

For generations, doctors have been seeking the ultimate panacea: a drug that cures all ills. With the vast range of diseases and conditions that LDN may be used for, I see LDN as the nearest we've ever been to this goal.

While the whole world seems to be looking to the heavens for different methods of treatment for so many varied diseases, they might be surprised to find the single answer for most of their problems is already lying at their feet.

Cris *Dr Lawrence, You attended the first European LDN Conference earlier this year, in April. That must have been exciting. What was a highlight for you?*

Bob L *Perhaps the most reassuring revelation about LDN was declared by Dr Phil Boyle, in Galway, who had been using LDN in association with natural hormone therapy to treat infertility. His research was presented at the very first UK LDN conference in Glasgow in April 2009. The conference was sponsored and presented by Dr Tom Gilhooley of the Wellness Centre, Glasgow.*

In order to maintain the effect of LDN in treating infertility, in fifty cases, he had also continued the LDN throughout the pregnancy. Not only was it shown to be safe, with absolutely no abnormalities detected, but the babies born of such mothers seemed to be stronger, healthier, and even better behaved than normal.

The latest news is presently the government sponsored LDN petition (Link at http://LDNNow.co.uk/), initiated by Mr Andrew Barnett with the aim of promoting further government involvement in LDN research and development.

Cris *Dr Lawrence, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

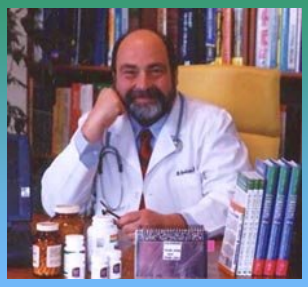
(1) Dr M R (Bob) Lawrence, GMC Registration No: 1717570; Degree: MRCS (Engl); LRCP (Lond) 1974; Managing Director: Dietary Research Ltd; Estab 1991. Dietary Research Limited, Gwynfa House, 10 Heol Gerrig, Treboeth, Swansea, West Glam SA5 9BP.Company Registered Number 2615367. Tel: 01792 - 417514.

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

(3) Dickson's Pharmacy, 35 Mitchell Arcade, Glasgow, G73 2LS. Tel: 0141 6131238.

© Case Health Pty Ltd

Interview with



Dr Burton M Berkson, USA

August 2008, Updated July 2010

Dr Berkson

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Burt B *I first heard about LDN from a patient. Mr. J., hardly walking with a walker, arrived at my office about 12 years ago. He told me that he was diagnosed with 'terminal' metastatic prostate cancer at a well-known university cancer center. He told me he also had lupus and rheumatoid arthritis and was told by his doctors that he had only a short time to live. He was told to go into a hospice.*

Mr. J told me he had a son that was mentally disabled and a wife who had Alzheimer's disease and that he must place them in a home before he died. He said that he needed some narcotics to help with the pain during the night. I said that I would help him.

Then he asked me if I ever heard of Dr. Bihari. I answered, no. He told me that he heard that Dr. Bihari was curing some forms of cancer and autoimmune disease. I said why don't you get to his office quickly. He said that he was in a small office in NYC. He asked, wouldn't he be with a big medical center if he was really curing cancer? I answered, no and told him my story about finding an inexpensive drug for regenerating organs at another university medical center. I told him that I was told that their business was transplanting organs, not regenerating organs.

Mr. J flew up to see Dr. Bihari and I did not see him for about 3 years. I thought he had died. One Monday he made an appointment and he walked in without his walker and he looked healthy. I asked him how are you doing? He answered that he had a cold or a sinus infection. I asked about the cancer and the autoimmune diseases. He answered that Dr. Bihari had cured him.

I was rather sceptical. My wife had two aunts with lupus and RA and they were on very expensive and potentially dangerous medications for their conditions. They continued to get sicker despite the drugs. I asked them if they would like to try the LDN. They answered, yes. Within one month following the administration of LDN at bedtime, they were off all of their lupus drugs and feeling normal.

I was amazed and tried LDN on many of my rheumatoid patients. Almost all of them improved quickly and were weaned off their drugs.

Cris *You've prescribed LDN for Cancer and have reported on successful outcomes at the LDN conferences. What's your overall observation of the likelihood of LDN benefiting patients with Cancer? May I also ask how many cancer patients you've treated, and if the number is known, the percentage of successes?*

Burt B *I prescribe the LDN in combination with Alpha Lipoic Acid (**Berkson Burt, the Alpha Lipoic Acid Breakthrough, Random House 1998**) and I suspect that I've probably seen 75 cancer patients with many forms of the disorder in the last few years. Most of these patients, by the time I see them, have been through the standard system and have been told that there's no hope for survival. They are often told to put their affairs in order and go into Hospice.*

About 10 of the patients have had pancreatic cancer with metastases to the liver. A few of them have been dragged in by a family member against their will, and are emotional and immunological 'basket cases'. There's no way of helping these people since they cannot cooperate and they're convinced that at any minute 'the next shoe will fall', and they will die.

Other people with the same condition are more optimistic and do very well. One man, who was told by one of the most respected cancer centers that he would die within a few months, went back to work after only a month of treatment. That was 8 years ago now and recently his PET scan showed, for the first time, no sign of cancer in his pancreas or his liver.

A woman from California, who was told that there was no hope for her metastatic pancreatic cancer, is free of cancer following 4 years of my protocol - evidenced by a recent PET scan. Another woman from California arrived at my office with metastatic pancreatic cancer, and within 6 months showed no sign of malignancy, however; when she returned home, she could find no doctor to continue therapy.

I would say that my success rate is about 50% with 'terminal' cancer patients. As a rule, I don't normally encourage cancer patients to come here since it is very emotionally draining for the patient, my staff, and me and the majority of my patients are people with hepatitis, diabetic neuropathies, lupus, rheumatoid arthritis, etc. These people do exceptionally well on my protocols. If you

© Case Health Pty Ltd

google 'Berkson BM' you will see what I do and can read several of my full text papers.

And I insist that cancer patients are followed regularly by an oncologist. There are at least two that I regularly work with and trust.

Cris *A high percentage of cancer patients arrive at your door after first exhausting mainstream treatment options. Approximately what percentage of your cancer patients bypassed mainstream treatments and chose your protocol first, and; are they more likely to be successful and represented within your approx 50% success rate?*

Burt B *I'd say that less than 10% of cancer patients bypass the conventional treatment. The statistics are not in, however, I'd say they generally do much better than the ones that I see after standard therapy. Two recent patients, one woman with metastatic pancreatic cancer and a man with B cell lymphoma appear free from cancer on their PET scans one year after commencement of treatment.*

Cris *What are some of the factors that enhance the likelihood of success or conversely, the likelihood of failure? For example; does previous treatment with any of the mainstream cancer treatments influence your treatment plans, protocols, or expectations in regard to successful outcomes, and if so, how?*

Burt B *Most of the patients that I treat have already had conventional treatment. Many of them have injured bone marrow, heart function, liver function, and kidney function and are emotional "basket cases" as a result of standard therapies.*

Most are told that there is no hope and that they should prepare to die. So, no matter what anyone does for them, they have prepared to die, and do die. Some are very strong willed and rebuild their immune systems with healthy life styles and a combination of ALA and LDN. These people usually recover.

Some of our patients refuse conventional therapies because of religious reasons etc. These people often do very well.

I never discourage patients from taking the conventional approach. I suggest that they ask their oncologist if the conventional treatment will cure their cancer? Most oncologists will tell them that conventional therapy will not cure their cancer but may prolong their lives. I tell the patient that after they understand all of the alternatives, they should make up their mind on what to do. Some decide to do the standard protocols, and that is fine with me. I still think that a person has a right to choose their treatment protocol after considering all options.

Cris *Some of your patients suffer from hepatitis, diabetic neuropathies, lupus, and rheumatoid arthritis, so you've prescribed LDN for many different diseases. Do all receive your Alpha Lipoic Acid/LDN combination protocol, and if so, is it*

© Case Health Pty Ltd

always administered by IV or is oral administration an option … under some circumstances? Also, is the success rate higher in non-cancer conditions, and if so, approx how much higher?

Burt B *People come to my office with many different conditions. After a long talk, an exam, and complete blood work, I plan a protocol for the person. Each person gets a different therapy depending on what I find out about him or her.*

The therapies for liver disease relies heavily on alpha lipoic acid (both IV and oral), selenium, and silymarin (Triple Antioxidant Therapy). My protocol for diabetic neuropathy is heavy on alpha lipoic acid (ALA), nutrition, and exercise. Cancer patients typically get ALA, LDN, Xanax, Artemesinin, curcumin, and other things (prescription drugs and other agents). Rheumatoid arthritis, lupus patients, and other autoimmune disease people get LDN, ALA, Xanax, NSAID's etc.

My best results are with liver disease, diabetic neuropathies, and autoimmune disease. If the patient follows the protocol, most improve and many are free of symptoms in a few months. About 50% of the terminal cancer patients improve and don't die. Some are free of cancer years after they are declared terminal. I'd say that 90% of the lupus and rheumatoid arthritis are free of symptoms and off the expensive and potentially dangerous drugs a month or two after starting their treatment.

Cris *Do you usually advise your patients to take LDN at a particular time of day, and if so, have you noticed any difference in outcomes depending on the time of day the LDN is taken?*

Burt B *I only give the LDN at bed-time.*

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Burt B *Why should doctors be aware of LDN? People only become aware of something relatively new when some group advertises this information. Since no one is making a lot of money on LDN, there is no incentive to pay advertising firms big dollars to advertise it. Doctors usually become aware of an effective drug when a pharmaceutical rep brings it to their attention. Since no drug company is interested in LDN, because it would be a losing venture, they don't tell doctors about it.*

Yesterday, I had a conversation with a very nice university rheumatologist from Chicago, who is a friend of my son. She told me about all of the new and very expensive immunosuppressive drugs at her disposal for the treatment of rheumatoid disease. I asked her about the adverse effects of these drugs and the possibility of keeping the immune system from controlling cancer. She told me that there was nothing else to do for these crippling diseases. I told her about my experience with LDN. She looked at me as if I had lost my mind.

Well, that is the rule rather than the exception. Most doctors are not open to any new material unless it is fed to them by their certification group, or a pharmaceutical company. I actually have a few local doctors that are patients of mine. They are usually afraid to tell their colleagues about their new and effective treatment.

As Dr Julian Whitaker wrote in the foreword to one of my books 'The Alpha Lipoic Acid Breakthrough'; 'many doctors would rather their patients die, then be saved by an unconventional approach'. Most people are afraid of being different, and doctors are just people.

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Burt B *I have always been an independent thinker and have always been very skeptical about what 'experts' tell me.*

For some unknown reason, I've always had a great deal of confidence in myself. I never worked for approval or really cared if most others liked me or not.

So, when people told me that I was wrong, and if I thought I was correct, I would usually continue with my endeavors.

When I discovered that lipoic acid could help regenerate organs, I saw this with my own eyes. So, when more experienced doctors told me that I was wrong, I did not care and continued with my work even though the system was geared toward expensive transplantation, rather than inexpensive regeneration.

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Burt B *The majority of people are in some type of hypnotic trance concerning the medical system.*

If the LDN treatment was any good, would it not be offered at the;

- *University of Chicago, or;*
- *Stanford?*

And why is it so inexpensive?

Are not only expensive treatments worth pursuing?

This is the mindset of the majority of people.

This was my mindset prior to seeing how things operate from 'behind the scenes'.

As we know, over the years, several doctors have developed very effective therapies for cancer and autoimmune disease. Consider the Durovic brothers and Dr Ivey, Dr Krebs and laetrile, Dr Buzynski and anti-neoplastons, Dr Burton and immuno-augmentative therapies, Dr Kelly and Dr Gonzales, etc.

Thousands of people have claimed that these therapies saved their lives. Do we hear anything about these doctors and their protocols in the mainstream press?

If there are not constant press releases and expensive public relations campaigns, the doctors and their therapies will be mostly forgotten even if hundreds of patients find the treatments very effective.

And why should any pharmaceutical company spend hundreds of millions of dollars to get LDN approved for autoimmune disease and cancer through the FDA process, if they know that there will not be any return on their investment… Medicine is just another business.

If you were a billionaire, would you spend hundreds of millions of dollars on LDN clinical trials, if you would not be able to earn a profit on your investment?

I don't want people to be required to take any specific therapy. I think people should educate themselves and should have the freedom to choose.

If people want chemotherapy, radiation, avastin, erbitux, humira, embrel, ribaviron, and interferon, let them have it. If a person wants to be treated with LDN or ALA, they should have this choice.

Cris *Dr Berkson, I appreciate you making time for this interview, and I thank you sincerely for championing a treatment with so much potential, but as yet, very little acknowledgement or support.*

I hope this interview also helps raise awareness of the unique Alpha Lipoic Acid-LDN protocol you personally developed, and its potential to alleviate unnecessary suffering.

(1) Burton M Berkson, M.D., La Cruces, New Mexico, USA.

BIOGRAPHY

BURTON M. BERKSON MD MS PhD

Dr. Burt Berkson practices integrative medicine in New Mexico and is an adjunct professor at New Mexico State University. He has worked as a researcher and professor at several institutions including the Max Planck Institute for Biological Science, the University of Illinois, the Autonomous Universities in Mexico, and Rutgers University.

In addition to his MD training {Case Western Reserve affiliated hospitals, (Internal Medicine, Pathology), Autonomous Universities, Mexico}, Dr. Berkson's education includes an earned Masters of Science degree, and a Ph.D. from the University of Illinois (fungal cell biology dissertation).

Dr. Berkson has many scientific publications in microbial cell biology and medicine. He is also an active researcher, and an international speaker at many universities and conventions. For instance, in Spring 2007, Dr. Berkson travelled to the National Cancer Institute to give an Invitational Presentation on his successful experience in treating various forms of cancer and autoimmune disease with Low Dose Naltrexone and Alpha-Lipoic Acid. In Spring 2009, he was invited to speak on LDN at the University of Glasgow and in Spring 2010 he presented two lectures in Tokyo.

In addition, He is the CDC expert consultant on lipoic acid and liver disease and a former FDA alpha-lipoic acid principal investigator.

He has authored, or co-authored 4 books; The Alpha-Lipoic Acid Breakthrough (Random House-Crown, 98), All About the B Vitamins (Avery, 98), Syndrome X (John Wiley, 2001, with co-authors) and A Users Guide to the B Vitamins (Basic Health Publications).

If you are interested in Dr. Berkson's professional work you can go to PubMed and type in 'Berkson BM', or you can go to Google or Google Scholar and type in 'Berkson BM'.

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

Book & Journal Articles by Dr Burton M. Berkson

'Alpha Lipoic Acid Breakthrough: The Superb Antioxidant That May Slow Aging, Repair Liver Damage, and Reduce the Risk of Cancer' – Burton M Berkson, Random House Inc, July 1998. ISBN-13: 9780761514572

'Alpha Lipoic Acid and Liver Disease' - Burton M. Berkson, Townsend Letter December 2007

'Reversal of Signs and Symptoms of a patient with a diagnosis of B-cell lymphoma using only low dose naltrexone' - Berkson, BM; Rubin D and Berkson, AJ. Integrative Cancer Therapies 6; 3 September 2007, 293-296.

'Long term survival of a 46 year old man with pancreatic cancer and liver metastases and treated with intravenous alpha lipoic acid and low dose naltrexone' - Berkson, BM; Rubin D and Berkson, AJ. Integrative Cancer Therapies 5; 1 March 2006,83-89

'A Triple Antioxidant Approach to the Treatment of Hepatitis C Using Alpha-Lipoic Acid (Thioctic Acid), Silymarin, Selenium, and other Fundamental Nutraceuticals' - Berkson, BM. Clinical Practice of Alternative Medicine 1:1 2000, 27-33.

'A Conservative Triple Antioxidant Approach to the Treatment of Hepatitis C. Combination of Alpha-Lipoic Acid (Thioctic Acid), Silymarin and Selenium- Three Case Histories' - Berkson, BM. Medizinische Klinik 94(3), 1999: 84-89.

'Alpha-Lipoic Acid (Thioctic Acid): My Experience with this Outstanding Therapeutic Agent' - Berkson, BM. Journal of Orthomolecular Medicine 13:1:44-48, 1998.

'Questioning Authority' - Berkson, BM. New Mexico Medical Society News 13(4), 1997.

'Pavlov's Dogs and Ader's Mice' - Berkson, BM. The Western Journal of Medicine New Mexico Society Newsletter 164(3), 1996: 2.

'The Ten Principles of Good Health' - Berkson, BM. New Mexico Medical Society News 12(5), 1996.

'Fungal Toxicology, Mushroom Poisoning, and Thioctic Acid' - Berkson, BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 162(5), 1995: 2.

'Mind Over Matter' - Berkson, BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 161(4), 1994: 2.

'Biotechnology: Expensive But Necessary' - Berkson, BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 160(2), 1994: 2.

'Beware of the Medical-Industrial Complex' - Berkson, BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 159(2), 1993: 2.

'Food for Thought' - Berkson BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 158(5), 1993: 2.

'Who is Robbing Us of Our Profession?' - Berkson, BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 157(4), 1992: 2-3.

'Biotechnology and the Future of Medicine' - Berkson, BM. The Western Journal of Medicine New Mexico Medical Society Newsletter 153(6), 1990: 619.

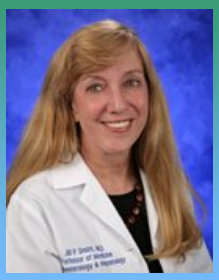
'Treatment of Four Delayed-Mushroom-Poisoning Patients with Thioctic Acid' - Bartter, FC; Berkson, BM; Gallelli, J and Hiranaka P. in Amanita Toxins and Poisonings, eds Faulstich, H., Kommerell, B., and T.Wieland, Verlag Gerhard Witzstrock, Baden-Baden, New York 1980.

'Thioctic Acid in the Treatment of Poisoning with Alpha amanitin' - Berkson, BM. Aminita Toxins and Poisonings, 1980. Amanita Toxins and Poisonings, 203 (Heidelberg: International Amanita Symposium, Nov. 1-3, 1978). eds Faulstich, H., Kommerell, B., and Th. Wieland, Verlag Gerhard Witzstrock, Baden-Baden, Koln, New York 1980.

'Thioctic acid in treatment of hepatotoxic mushroom poisoning' letter) - Berkson, B. 1979. New England Journal of Medicine. 300:371.

Interview with

Prof Jill Smith, USA



January 2009, Updated July 2010

Dr Smith

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Jill S *I have been involved in cancer research for over 2 decades. Along with my basic science partner, Dr. Zagon, we were investigating the role and use of opioids in the treatment of pancreatic cancer. Through this work and some former work Dr. Zagon had done with naloxone and naltrexone in cancer, we became interested in healing aspects and immunologic aspects of opioids.*

Cris *What led to your Phase I clinical trial of LDN for Crohn's Disease?*

Jill S *Through a thought from Moshe Rogosnitzky from MedInsight who is a forerunner and advocate of novel therapies and public education, we decided to conduct a pilot study testing the safety and efficacy of naltrexone in Crohn's disease.*

Cris *You've prescribed LDN for Crohn's Disease. What is your overall observation of patient outcomes?*

Jill S *In our pilot trial we noted marked improvement in up to 87% and remission in more than 1/2. Of interest was that 76% of our patients had either failed therapy with or went intolerant of infliximab. The drug appears to be safe without serious side effects. We are currently conducting two Phase 2 clinical trials in both adults and pediatrics.*

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Jill S *I only hold an IND # from the FDA to allow me to legally prescribe it for inflammatory bowel disease. I have had success in also treating people with autoimmune hepatitis. Also in our Crohn's studies we had patients who also had multiple sclerosis and lupus and their other autoimmune conditions improved with naltrexone therapy.*

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Jill S *Sound scientific controlled studies must be done to prove a treatment is effective. Once we have completed our research and published it in medical journals this will help convince the medical field. Anecdotal reports and doctors prescribing it off-label actually hurts the availability and process of getting naltrexone approved for other indications. I suggest that patients should participate in well-controlled studies rather than taking it on their own as in doing so this will ultimately help others.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Jill S *I know it works. I am not opposed to adversity...I just have to overcome it with good science.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Jill S *Again to emphasize...these reports hurt the progress of getting the drug approved. The mechanism by which naltrexone works is by blocking opioid receptors of which there are 4: μ, κ, δ, and OGFr. Some of these receptors are involved in the inflammatory response, pain perception, motility, and growth.*

The receptors are located throughout the body including their location on inflammatory cells, brain, cornea, and the gastrointestinal epithelium. Receptors bind their ligands and antagonists with different affinity so dosing may be very important. High doses would be expected to block the interaction of endogenous opioid peptides (enkephalin and endorphins) at their prospective receptors for longer time intervals.

The mechanism of action requires much more research. Dr. Zagon has been investigating the role of the nuclear opioid receptor OGF on growth and repair and has found by blocking this receptor corneal ulcers are healed. Together Dr. Zagon and I demonstrated that blockade of opioid receptors with naltrexone heals the mucosa and ulcers in the gastrointestinal tract of Crohn's patients. We have shown if you stimulate the OGFr receptor with OGF that you can inhibit growth of pancreatic cancer and other malignancies.

© Case Health Pty Ltd

This is a very fine-tuned system and if the wrong doses are used, the treatment with naltrexone could potentially stimulate cancer growth. This is another reason why I strongly believe in sound scientific studies, rather than random off-label use, for the protection of human subjects.

Cris *Dr Smith, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

RESEARCH UPDATE
July 2010

This is a current update on our research:

In our adult Crohn's study some patients thought naltrexone interfered with sleep so they took it in the AM. However, there was not any difference in response between those who took it in the PM versus the AM.

My partner Dr. Zagon advocates bedtime dosing because his lab has shown that there is a diurnal release of endogenous endorphins and enkephalins at night, and the evening dosing would be expected to affect this release; although we haven't yet done a large clinical trial comparing the dosing time and response.

When comparing side effects between naltrexone treated subjects and placebo treated subjects there was no difference in sleep patterns. The ONLY significant difference in symptoms was that those on placebo had more fatigue. This indicates that the side effect profile with naltrexone is small. Also a lot of what is written about side effects with naltrexone on the internet is not supported by scientific evidence.

We completed our placebo-controlled adult Crohn's study and there is a lot of bias on the part of journal reviewers which has prevented us from publishing the results, which were very favorable for naltrexone. Patients treated with naltrexone had mucosal healing and reversal of inflammation on biopsies obtained during colonoscopies whereas placebo treated subjects showed no change. I presented these results at Digestive Disease Week in New Orleans in May 2010. I have resubmitted this paper and hope to have it published soon.

We have also completed our pilot trial using naltrexone in children ages 6-17 with Crohn's disease and have not published the study results yet. However, based upon the exciting preliminary data and also the fact that the anti-TNF biologics are risky in children, I am happy to report that the FDA has granted

me Orphan Drug Status for the use of naltrexone in children for Crohn's disease under my FDA IND#. I have applied to the FDA for funding to continue our pediatric studies but have not heard yet if our grant was awarded.

I have a pending patent along with Dr. Zagon and Moshe Rogosnitzky for naltrexone in Crohn's disease. It has been over 3 years, but it looks like the US patent will issue. We have been trying to find a Pharmaceutical co to develop this compound at the low dose so that it is legal, FDA approved, and most importantly not expensive.

Sincerely
Jill P. Smith, MD

(1) Jill P. Smith, MD, Professor of Medicine, Penn State University, College of Medicine, H-045; 500 University Drive, Hershey, PA 17033. Tel 717-531-3694. Profile and publications http://fred.psu.edu/ds/retrieve/fred/investigator/jps12

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

Interview with

Dr Phil Boyle, Ireland

March 2009

Dr Boyle

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Phil B *I am a GP fertility Specialist. I first heard about LDN from my sister when her Husband's Neurologist prescribed it for his Primary Progressive MS in 2002. I thought, "Now that is an interesting choice of treatment!". At that time we were using high dose Naltrexone as part of our fertility treatment. About 1 year later I attended a presentation given by an MS patient (Robert) in Galway who described what LDN did for him clinically and I was blown away!*

He contrasted the experience of LDN with his previous treatment (interferon) and it was clear which medication was superior by a mile! I decided I would prescribe it for my fertility patients who also had auto immune problems such as Rheumatoid arthritis, Lupus, Psoriasis, etc to see if improving their general health might also have a beneficial effect on their fertility treatment. And it did! Today I prescribe LDN regularly for infertile patients who fit the clinical criteria for 'Endorphin Deficiency' and we have definitely improved our success rate since making this change.

Cris *You've prescribed LDN for infertility and have reported on successful outcomes at the LDN conferences. What's your overall observation of the likelihood of LDN benefiting patients with infertility? May I also ask how many patients you've treated, and if the number is known, the percentage of successes?*

Phil B *Naltrexone has been used as a component of fertility treatment in the USA since it first became available in 1985. Our goal with fertility treatment is to improve your general health prior to commencing hormonal treatment. LDN helps to improve well being making conception more likely. I have been expanding the inclusion criteria for women who could try LDN as part of their fertility treatment since I started using it more frequently in 2004. Today about*

50 % of women attending my practice would take LDN as part of their overall treatment.

A small number conceive with LDN alone, but the majority require additional hormonal treatment in order to conceive. It can also reduce the risk of miscarriage. Naltrexone was previously used in high doses up to 100mg throughout pregnancy and breastfeeding without ill effect to mothers or their babies. I have used Low Dose Naltrexone (LDN) during pregnancy for 4 years and the babies, if anything, are even better than those who did not have it during pregnancy.

Cris *I imagine a high percentage of patients arrive at your door after first exhausting their mainstream treatment options. Is that pretty close to the mark, and if so, has this delay been detrimental for any patients?*

Phil B *The old saying of 'A stitch in time saves 9' is true for medical intervention too. The earlier you intervene for those patients who require endorphin stimulation with LDN, the better your results. I have not found LDN very effective in severe cases of AutoImmune illnesses that are end stage. They have so much damage, that it is difficult to see the benefits of LDN for them. But some patients who have been ill with milder symptoms for 20 years have responded very well to treatment.*

Cris *Do some patients respond better than others, and if so, what are some of the factors that enhance the likelihood of success?*

Phil B *I recently watched a presentation by Dr. Tom Gilhooly on the LDN website http://www.lowdosenaltrexone.org/conf2008.htm and I would agree with his clinical experience. If we ignore diet and vitamin supplements our patients will not do as well as they could do on LDN. It is foolhardy to think that LDN alone will solve all of the problems.*

We need to get the foundations right and supplement as well. Dr. Gilhooly has excellent supplements available at www.glasgowapproved.com. He has a multivitamin called Baseline am and pm as well as supplements with Omega 3 that improve responsiveness to LDN. I also recommend food intolerance testing through www.camnutri.com. I check for 40 foods and candida antibodies. I treat candida if it is present and eliminate the offending antibody producing foods. This improves outcomes for patients. They are more likely to conceive and less likely to miscarry.

Cris *Have you prescribed LDN for any other diseases, and if so, what was the outcome?*

Phil B *PMS, Polycystic Ovaries, Endometriosis, Fatigue, Crohn's, Ulcerative Colitis, Lupus, Depression, MS, Fibromyalgia, Bechet's Disease. Most have responded well to treatment - about 75 to 80 %. This is not a placebo effect, as you would expect a 30% response with that. There have been treatment failures where LDN did not work at all or had to be discontinued due to*

© Case Health Pty Ltd

intolerable side effects, such as not sleeping, vivid dreams, headache or nausea. I prefer night-time dosing. I think LDN is usually more effective as a night-time treatment, although I have a few exceptions that require day-time treatment, to good effect.

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Phil B *Doctors are wary of trying new things that have not been published in the medical literature, and even if it is published many will be reluctant to try it without 'encouragement' from a pharmaceutical representative. These representatives will not be promoting LDN as it is a cheap generic drug with little chance of profit for drug companies. As physicians we can be slow to 'think outside the box' and we can justify our decisions by saying if it is worth trying the experts in the world would have informed us of it by now through large scale clinical trials. Doctors are less inclined to believe what a few physicians report from clinical experience….it is too subjective.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Phil B *I have not experienced any opposition to prescribing LDN….but when you get the clinical feedback from patients who explain they have got their lives back……it is very satisfying for physician and patient alike….this is motivation enough to keep prescribing the treatment….see testimony from a grateful patient (below) which says it all!*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

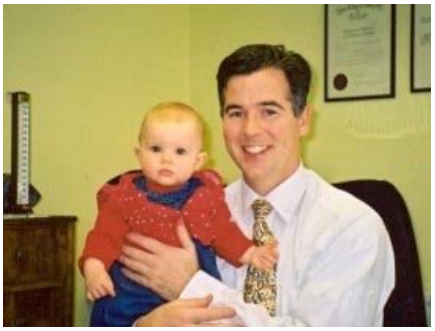
Phil B *I think patients are largely ignored because of the possibility of Placebo effect. 30% of patients will improve by believing in the treatment they are using even if it is just chalk dust! This effect can be very powerful and it may give the false impression of a useless treatment being very effective in some patients. Because of this, individual reports of clinical improvement have to be interpreted with caution. That being said doctors in clinical practice will continue to prescribe a medication if they see patients improve. When I started prescribing LDN for Autoimmune conditions the first 3 patients I treated responded fantastically well and because of my own clinical experience I continue to prescribe it today….if a doctor can be encouraged to begin prescribing LDN, they will often continue when they see what it does for their patients……with over 70% responding favourably to treatment.*

Cris *Dr Boyle, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

© Case Health Pty Ltd

(1) Dr Phil Boyle, MICGP MRCGP, GP Fertility Specialist, Fertility Care, Suite 11, The Galway Clinic, Doughiska, Co. Galway, Tel +35391 8720055.
Website: www.fertilitycare.net
(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

Dr Phil Boyle, GP Fertility Specialist in Galway, reported the following in 2008 …



" … I am confident that LDN is perfectly safe in pregnancy and in certain cases will actually reduce the risk of miscarriage. Thomas W. Hilgers, M.D, of the US, who developed the fertility treatment I provide, has used high dose naltrexone … up to 100mg throughout pregnancy and during breastfeeding safely without ill effect to mother or baby since 1985. I have been prescribing LDN regularly during pregnancy (for several years) and the results have been excellent. Clinical experience has proven to me that it is safe. … "

The statement appears on the ldninfo.org website and has been reproduced here with permission from Dr Boyle.

Heart-felt 'Thank You' from one of Dr Boyle's very happy patients

From: A Patient of Dr Phil Boyle
To: mail@fertilitycare.net
Sent: ***Friday, March 06, 2009*** *11:41 AM*
Subject: Att: Dr. Phil Boyle

Hi Dr. Boyle,

I had a consultation with you back in ***September or October*** *of last year where you* ***prescribed LDN for treatment of Fibromyalgia.*** *My apologies, I should have come back to you but things have been pretty hectic as I have not had the chance to get to Galway.*

I thought I should give you some feedback and say a big, huge, massive THANK YOU!!!!! for helping me get back to a normal life.

The morning after taking the first LDN tablet, I awoke, for the first time in years, and my hands were not swollen, the swelling did come back for a while after the first day free, but not anymore. My dreams were very vivid for a while but that has gone away now. I awake feeling not totally refreshed, but so so so much better than before. I can actually get up straight away and not have to wait a while until I feel able to.

The morning leg stiffness is gone. I no longer need to take a nap in the afternoon. I do not have the "mad woman" PMT that I used to suffer for 7 - 10 days each month. I got my period this month without either myself, or my 'long suffering' husband, even realising that it was even due.

I can now take exercise without having to pay the price for days with aching limbs. The best thing to come out of my recovery is to be able to enjoy playing with my two children again, going swimming was a thing of the past but now I have no soreness afterwards. I have been constantly on the run with our new house build and am certainly well able for it now, where as before I would be in pain after a couple of hours shopping for tiles, kitchens etc.

I do put a lot of my well-being down to food elimination, I was intolerant to a number of very common foods and since coming off the offending foods I have improved immensely. When I do eat something that I should not, my pain does comes back, not anything as bad as before, but it is certainly a reminder of how things were. It takes maybe 4/5 days to start to feel energetic and pain free again. I have even started to think that I would be able to hold down a job again, something I have feared that I would be unable to do.

To sum things up, I definitely believe the LDN is having a great effect on my well-being but I believe the food elimination is a major factor.

Again, THANK YOU from myself, and my family, for sticking your neck out and thinking outside the box and helping me back to a normal life.

If you would like me to visit for any reason or if you need me to have any test carried out by my own GP please let me know.

Interview with

Antony Condina, Australia

Antony

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Antony C *We first started compounding LDN in 2003 when a patient was trying to find a pharmacy to fill his prescription. At first I thought that the physician had got the dose wrong in comparison to the 50mg Revia tablet. After a discussion with the patient I was informed of a new treatment for Multiple Sclerosis trialled in the US and I then began to research LDN further. I contacted Dr. Bihari to find more information. A few months later we began to fill many prescriptions.*

Cris *The compounding of low doses of naltrexone needs to be exact and of the highest possible quality and consistency. Were there any early lessons learned when you first began compounding LDN, and if so, what affect did that have on your compounding procedures?*

Antony C *I wasn't happy using the commercial tablet but instead sourced a very high quality Naltrexone through one of my chemical suppliers. We mixed the Naltrexone with an inert filler and encapsulated capsules. Later we purchased a pharmaceutical V-Blender for mixing our powders and we found that doing a dilution of Naltrexone we were able to get a better homogeneous blend and naltrexone was evenly distributed through each compounded capsule. This was confirmed when we assayed each capsule for active compound.*

Cris *How many patients are presently using your pharmacy to fill their prescriptions, and what is the degree of positive or negative feedback you've received? Have you recorded and measured that feedback to share with others?*

Antony C *We are filling many prescriptions Australia wide. Many of our patients are involved in support groups for their conditions and spread the word of their success. We have not done a formal measurement of patient*

© Case Health Pty Ltd

wellbeing on the medication but results must be positive as patients get their repeat refilled. The patients that do communicate with us have noted no exacerbations of their disease.

Cris *With regard to LDN, what aspects, if any, concern you?*

Antony C *LDN treatment is not a conventional method for treating these diseases. I am concerned that patients may stop their conventional medications prescribed by their specialist to try LDN. From a compounding point of view I am concerned that if the compound is made differently at different pharmacies that this will have an impact on the effectiveness of the medication.*

Cris *Are you aware of the range of diseases suffered by patients who fill their prescriptions through your compounding pharmacy, and if so, what are some examples?*

Antony C *Our main focus has been LDN compounded for patients suffering from MS and PLS. These patients have not had exacerbations in all the years we have been compounding LDN. Recently we have dispensed LDN for use in certain cancers.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Antony C *Anecdotal evidence is heavily ignored in the medical establishment. Many physicians are afraid of the litigation arising from prescribing non-Therapeutic Goods Administration (TGA) approved medications. As the long-term benefits of LDN are not yet known, physicians are not going to jeopardise their patient's outcome with unproven treatments. There will come a time when double-blinded cross-over studies will occur with LDN and then physicians will become comfortable prescribing it.*

Cris *Antony, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you for continuing to provide a consistently high quality compounding service that's so integral to success with LDN - and is ultimately, a key partnering factor in the alleviation of suffering.*

(1) Antony Condina, Compounding Pharmacist, The Green Dispensary Compounding Pharmacy, 46 Beulah Rd Norwood SA AUSTRALIA 5067 Tel (08) 83637322 Fax (08) 83637244. Compounding Pharmacies in Stirling, Lobethal, Erindale, and Norwood, SA. http://www.greendispensary.com

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

Interview with

Larry Frieders, Pharmacist, USA

May 2010

Larry

How and when did you first discover the potential benefits of low doses of naltrexone (LDN)?

Larry F *I received a call from a customer in the late 1990s regarding LDN. She told me about the work being done in New York and asked me to call Dr. Bernard Bihari. During our first conversation, Dr. Bihari explained his work with AIDS and cancer patients and pointed out that LDN has great potential. He pointed out that it would be worth trying for just about any chronic condition that was in any way linked to the immune system.*

Cris *The compounding of low doses of naltrexone needs to be exact and of the highest possible quality and consistency. Were there any early lessons learned when you first began compounding LDN, and if so, what effect did that have on your compounding procedures?*

Larry F *Naltrexone HCl, UPS powder was not readily available, therefore, we initially used commercial naltrexone tablets - 50mg. We ground them up and mixed the powder with an appropriate capsule filler. This was as good as we could do at the time, however; we were painfully aware of the potential for dosing errors when starting with a commercial product.*

The industry standards allow for 10% potency variances. That means that any given batch of tablets would meet the potency guidelines if tablets varied from 45mg to 55mg. Compounding pharmacists focus on higher quality, usually 5% or less. Our tested compounds usually fall within a 1% window. We located a source of pure naltrexone HCl powder - a company that could demonstrate the actual potency of their product. We never used the commercial tablets once we obtained this pure naltrexone.

I learned - along with several compounding pharmacists and their customers - that the fillers we use are important. LDN seems to work best when it dissolves quickly after swallowing the capsule. Slow release fillers impede the dissolution. Therefore, the compounder should make it in a rapid release

formulation. Calcium can impede the absorption of the naltrexone, so it should be avoided. I find that many people with immune disorders also experience lactose intolerance to a greater or lesser degree. Therefore, I do not suggest using lactose as a filler - for any human capsule.

Cris *At what point did you realise you wanted to learn more about LDN?*

Larry F *After the first dozen or so customers began reporting how pleased they were with our preparations - and they were re-ordering regularly. Even though nobody was able to precisely describe how LDN worked, we observed the results.*

That began an interest that persists today. I must point out that I am not inclined to engage in any specific 'Scientific' study of LDN. I've been in the health field for over four decades and I am convinced that LDN offers benefits with minimal risks. I recall that Dr. Bihari once commented that he thought anyone could benefit from it, regardless of their problems. I even recall a nurse telling me that everyone in their office used it daily and that none of them had experienced the flu for years.

Cris *Of those presently using The Compounder to fill their LDN prescriptions, what is the degree of positive or negative feedback you've received? Have you surveyed, recorded or measured any LDN feedback that you can share with us?*

Larry F *I do not maintain detailed information, and I wouldn't do so. What difference does it make to me if I have a side effect and 10,000 other people report that they don't? What value is it if LDN helps a million people but doesn't help me? The fact is that LDN works for many - not all. It is safe for most - not all. What else would a person actually need to know?*

I can tell anyone, though, that the number of complaints are extremely small. Of hundreds of users, we may get a question or a concern voiced once or twice a month. Usually, too, it is associated with a comment a customer may have heard or read on the internet. The reality is that nothing is 100% safe or effective. Somebody, someplace can always have a negative experience - to anything.

Cris *Since being convinced of the benefits of LDN, how many patients have you supported on their LDN journey, and are there any learning experiences from that you'd like to share?*

Larry F *LDN is very safe and helps many people with a wide range of health concerns; cancer, AIDS, multiple sclerosis, irritable bowel disease, arthritis, and so on. It is reasonable to expect positive outcomes with few to no side effects. The amount used is low, but it has a potent effect. I do not ascribe to the reports that the dose is somehow related to homeopathic theories.*

© Case Health Pty Ltd

Naltrexone should not be used by anyone taking an opioid (narcotic). Even the tiny doses in LDN can bring on negative effects associated with opioid withdrawal. We've experienced this. People have experimented with different doses and frequency of administration. I've observed that the actual amount is basically irrelevant. Early groups used 3.0mg and that changed over time to a suggestion for 4.5mg. Today, over half of the people still use 3.0mg. Many use 4.5mg and there are just handfuls of people who use something different.

Cris *With regard to LDN, what aspects, if any, are you most concerned about?*

Larry F *I fear that some drug maker will understand the great market potential for this dose. They will do the research and gain FDA approval. Many users of LDN believe they will be well-served if this happens. They expect their doctors would be more willing to prescribe and that the insurance companies will be happy to cover the costs. I think the costs will skyrocket. What today costs a dollar a day, or so, could easily become several hundred dollars a month for a commercial FDA product.*

Cris *Are you aware of the range of diseases suffered by patients who fill their prescriptions through your compounding pharmacy, and if so, what are some long-term successful examples?*

Larry F *The vast majority are associated with multiple sclerosis. I must point out that the process of diagnosing is not a science, but an art. I have written extensively on this idea.*

In brief, multiple sclerosis is a name used by some people to identify a group of symptoms. Every effort to achieve greater scientific accuracy will fail. Still, the vast majority of people depend on diagnoses to tell them what they 'have'.

As I mentioned above, I agree that LDN might be helpful for anyone who is suffering in any way from the effects of any dis-ease. I suggest giving it a try. Of course, immune conditions are the most popular, but it is likely that LDN can help with anything. Yes, anything.

Cris *With regard to LDN and the knowledge you've gained through patient support, what do you believe are the key factors in successful patient outcomes or failures?*

Larry F *Take the dose every day at bedtime. Don't expect a miracle right away. Be happy when miracles happen. Don't focus your attention on a cure - whatever that means to you.*

Enjoy the experience of improvement. Don't dwell on the dosage amount or the specific times to take it. Don't try to fine tune or micro-manage doses. It works regardless.

© Case Health Pty Ltd

Sit back, relax, take it at bedtime - whenever that is - and know that what you are doing will probably be helpful for you because it has helped so many others. We're all different, but there is so much that makes us similar. Don't listen to 'naysayers'.

If your doctor refuses to let you try it, find another doctor. It does not have to be a neurologist. Don't depend only on LDN for symptom relief. Continue to use exercise, proper diet, relaxation, and meditation. We all need these elements in our lives. LDN is just another piece of helpfulness.

Cris *How would you describe your role within the collective 'LDN advocate community' which is striving to gain recognition and credibility for LDN?*

Larry F *I support the widespread use of LDN. I ask/allow people to have their doctors call me - even when there is no chance that I will be able to fill their prescription. I have decades of experience and a positive attitude. Often, a doctor will agree to prescribe it because I assured him or her - NOT because I could cite studies or send copies of published works. Doctors should trust the pharmacist - and most of them do.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Larry F *Money. I know its a cynical answer, but nothing runs without money and there is far too much of it being paid for current, ineffective treatments. Using a very inexpensive approach puts all of that income at risk. Unless some drug maker can figure a way to make as much or more with LDN, it will continue to be ignored in favor of ineffective injections, with severe side effects, and costing thousands of dollars a month.*

I advise anyone who has a health situation they want addressed to seriously pursue the use of low doses of naltrexone. If their doctor isn't on board, have him or her call me. I'm very persuasive. If that doesn't work, find another doctor.

Cris *Roughly, how many patients are filling LDN scripts through your pharmacy each month, and if known, what percentage of those use LDN for MS?*

Larry F *I'm not able to accurately answer that question. There are many and most of them are pleased - so pleased that they re-order regularly. It is likely that most users have what they have been told is multiple sclerosis.*

Regardless of the condition, using LDN relieves many symptoms in a safe manner. I am more concerned with that fact, than I am with what someone may chose to name their condition. While most people would prefer more hard data, I am not one of them.

© Case Health Pty Ltd

I find that the collective wisdom of the community at large is far more supportive of health than the results from any study - regardless of how careful the researchers might be. Studies can be faked and numbers can be manipulated. Regardless of what data arise, I can use it to support practically any claim.

Cris *Larry, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you for everything you do to support patients on their LDN journey, and thank you for continuing to provide a consistently high quality compounding service that's so integral to success with LDN - and is ultimately, a key partnering factor in the alleviation of suffering.*

(1) Larry J. Frieders, RPh, The Compounder, 340 Marshall, Unit 100 ~ Aurora, IL 60506, USA 60506. Tel 630-859-0333.
Email: larry@thecompounder.com Website: http://www.thecompounder.com
Twitter http://twitter.com/thecmpndr Facebook http://www.facebook.com/thecompounder
Sign up for our newsletter: http://bit.ly/Compounder-Signup

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

Interview with

Dr Patrick Crowley, Ireland

May 2010

Dr Crowley

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Pat C *I read about it in The Irish Times (Medical section on Tuesday) in 2004 and it sounded good. I met Dr Bihari in New York in early 2005 and filmed an interview with him.*

Cris *You've prescribed LDN and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting MS patients?*

Pat C *If I had my way all newly diagnosed MS patients would get it, much like all cardiac patients get aspirin. My impression is 70% of patients do well with no progression, 10-20% have a mixed response and 5-10% have a poor response.*

Cris *Do you have any patients who've been on LDN for 5 or more years, and if so, what's your overall impression of how long LDN will continue to benefit?*

Pat C *Yes and it continues to benefit them with no progression and very little in the way of relapse. Taken early on in MS is best.*

Cris *Have you prescribed LDN for diseases other than MS, and if so, what was the outcome?*

Pat C *Yes. Lupus, Rheumatoid arthritis, Fibromyalgis, ankylosing spondylitis have all responded very well. I have three cancer patients on it to prevent recurrence or stall progression.*

© Case Health Pty Ltd

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Pat C *Yes, usually from the highest level of academia. They should check Prof. Ian Zagon's research, or Prof. Gironi, or Prof. Jarred Younger.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Pat C *After initial scepticism of nearly a year, and now after six years use, I know the majority of patients have had a very good response and maintain their improvement.*

This drug works for most patients. Those with clinically defined/proven autoimmune disorders do best. Those whose immune systems are very compromised (e.g. excessive, steroids) are harder to improve and manage. Prof. Zagon's 40 years work in research amply proves LDN's ability to increase endorphin levels, improve T cell configurations and influence growth factor molecules.

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Pat C *The hardest thing to do is change a system, a way of thinking. We are up against this and big Pharma (read *****Machievelli's 'The Prince' 1513). It's still the same now as it was then.*

Cris *Is there anything else you'd like to add?*

Pat C *This is solid work by patients and their advocates. Avoid sensationalism. This is not a 'miracle' drug. It is a drug with practically no toxicity that can be used extensively in medicine. The admonition of Hippocrates 'first do not harm' is particularly appropriate here.*

Cris *Dr Crowley, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

QUOTE *Machievelli

" ... there is nothing more difficult to plan, more doubtful of success, nor more dangerous to manage than the creation of a new system. For the innovator has the enmity of all who would profit by the preservation of old institutions and merely lukewarm defenders in those who would gain by the new ones. The hesitation of the latter arises in part from fear of their adversaries, who have current laws on their side, and in part from the general scepticism of mankind which does not really believe in an innovation until experience proves its value. So it happens that whenever his enemies have occasion to attack the innovator, they do so with the passion of partisans while his supporters defend him sluggishly, so that both the innovator and his party are vulnerable … " **Machiavelli, Niccolo, 'The Prince', 1513**

© Case Health Pty Ltd

LDN Documentary

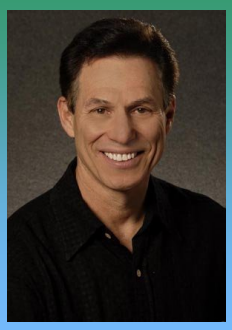
This earliest known documentary includes an interview with Dr Bernard Bihari by Dr Patrick Crowley, County Kilkenny, Republic of Ireland.
http://www.lowdosenaltrexone.org/_conf2006/P_Crowley1.mov

(1) Dr Patrick Crowley, MB, BAO, BCh, Dobst, MICGP, Kilmoganny Health Centre, Kilmoganny, Co Kilkenny, Ireland. Tel 051 648 007. Fax 051 648 008. Mobile 0862 561 584. Email drprowley@eircom.net

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

© Case Health Pty Ltd

Interview with



Dr Terry Grossman, USA

May 2010

Dr Grossman

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Terry G *I first used LDN about 8 years ago as one of my complementary treatments for patients with cancer. Since that time I have learned more about the safe use of LDN and I have added MS and several other conditions.*

Cris *You've prescribed LDN and have reported on successful outcomes. What's your overall observation of the likelihood of LDN benefiting MS patients?*

Terry G *I have treated several dozen patients with MS over the past few years. I have observed that there have been positive benefits for most patients. For some it is increased energy, for others less muscle spasm, and for some simply a general feeling of well-being.*

Cris *Do you have any patients who've been on LDN for 5 or more years, and if so, what's your overall impression of how long LDN will continue to benefit?*

Terry G *Yes several of my cancer patients and MS patients and Crohn's patients have taken LDN for up to eight years. They continue to do so because they feel they are receiving benefit.*

Cris *Have you prescribed LDN for diseases other than MS, and if so, what was the outcome?*

Terry G *I began using LDN as an adjunct in the treatment of patients with cancer. LDN is not the only treatment that I use for these patients - they also often receive high-dose intravenous vitamin C, special diets and nutritional*

supplementation - as well as conventional cancer therapies. As a result, I can't tell the precise role that LDN plays in improving the quality of life and survival of these patients.

I have been particularly gratified by the positive results seen in patients with Crohn's disease. A few Crohn's patients have been able to get off of their medications completely or to drastically reduce dosages as well as the frequencies of exacerbations.

We used LDN in our protocols for fibromyalgia and some patients have reported reduced pain. I have also used LDN in other autoimmune diseases such as rheumatoid arthritis and lupus with varying degrees of success.

We see many autistic children in our practice and often offer LDN for the parents to consider as well. Again we use many other dietary, nutritional and detoxification strategies for these children, so it is difficult to tell the precise role that LDN plays, however, the majority of our autistic children improve on our program.

I recommend that LDN be taken at bedtime. It works best if taken then. Only if it interferes with sleep, which it does on occasion should it be taken earlier in the day.

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Terry G *Conventional medical practitioners typically practice the type of medicine they were taught in medical school and in their residency programs, which does not include teaching or discussion of LDN.*

I haven't had any detractors in the medical community per se, although very few of my conventional colleagues are willing to prescribe LDN. It is not part of standard medical practice and they don't want to stray into what they regard as alternative medicine. It's my impression that most of my colleagues tell their patients that it is okay for them to continue taking it if they would like, but that they would not themselves be willing to prescribe it.

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Terry G *Anytime you practice alternative or complementary medicine, you open yourself up to censure from your colleagues and the licensing authorities such as state medical boards.*

I have had a few state medical board investigations over my 30 years of medical practice, which were the result of complaints from my colleagues - never from my patients - because they had concerns that I was practising non-standard theories.

© Case Health Pty Ltd

Whenever a physician is investigated by a state medical board, it is very stressful because there is the possibility of public humiliation and even the loss of one's ability to practice medicine.

I believe in the type of medicine that I practise and have seen many of my patients experience positive benefits. I feel that patients deserve access to these therapies and I will continue to offer them as long as I'm able. I also do not oppose conventional treatment of disease and feel that my therapies such as LDN simply complement, rather than replace conventional medicine.

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Terry G *Conventional physicians have a strong belief in randomised, double-blind, placebo-controlled studies. These studies, however, are extremely expensive and it now costs many millions of dollars to introduce a new drug.*

LDN involves naltrexone, a generic and inexpensive drug, which no drug company would be willing to invest in without patent protection and the ability to recruit their investment. As an interesting aside, however, it is estimated that fully 80 percent of the procedures utilized by conventional physicians have not been subjected to these types of randomised trials.

Cris *Is there anything else you'd like to add?*

Terry G *LDN is an important tool in my practice and I am encouraged by the numerous social networking sites, disease-specific message boards and other mechanisms by which more and more patients are finding out and accessing this safe, effective and inexpensive therapy. Thank you for this opportunity to discuss LDN!*

Cris *Dr Grossman, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

(1) TERRY GROSSMAN, MD is one of America's leading medical authorities in the field of anti-aging, longevity medicine and life extension therapies. His clinic, Frontier Medical Institute, emphasizes advanced nutritional therapies and complementary treatment of a wide variety of chronic disease conditions. Grossman has also developed numerous cutting-edge protocols for measuring and modifying biological age and promoting longevity. Frontier Medical Institute & Grossman Wellness Center, 2801 Youngfield St, Suite 117, Golden, CO 80401. Tel (303) 233-4247. Website: www.fmiclinic.com & www.grossmanwellness.com Email: terry@fmiclinic.com

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

© Case Health Pty Ltd

Dr Zagon

How and when did you first discover the potential benefits of low doses of naltrexone (LDN) and what were those potential benefits?

Ian Z *We (Dr. Patricia J. McLaughlin and myself) discovered 'low dose naltrexone (LDN)' in 1979. The discovery was purely serendipitous - as most discoveries are. By the way, 'LDN' is a misnomer as it is really 'intermittent opioid receptor blockade' that is the issue - naloxone, another opioid antagonist can do the same job.*

Cris *At what point did you realise you wanted to investigate the potential further?*

Ian Z *From the very beginning. However, we really did not know how it worked, much less to give it to patients. This was a good thing as high doses - or continuous opioid receptor blockade - could be harmful to some patients and certain conditions, and helpful to others.*

Cris *Do you know who first discovered/developed the drug naltrexone?*

Ian Z *Blumberg and Dayton - 1959. An interesting story.*

Cris *What other research have you performed since first discovering LDN as a potential treatment?*

Ian Z *We have about 200 publications on this. In essence, LDN is not the story - it is the body's own chemical system - the enkephalins (part of the endorphins). It took us until 1986 to discover which endogenous opioid is doing the trick, and we cloned the receptor/gene in 1999.*

Cris *Of your research to-date, what insights or outcomes have given you the greatest sense of accomplishment?*

Ian Z *The movement from bench to bedside. LDN has taken on a life of its own. LDN is now being used by patients all over the world in an 'off-label' fashion. And it is the internet where the information lies. We are trying to 'catch-up' by getting the drug approved by the FDA for its other uses. And the use of 'HDN' (high dose naltrexone) has extraordinary implications.*

In addition, we now have evidence that LDN works with Crohn's Disease (a study I initiated with Jill Smith), and for MS (preclinical studies that are spectacular - and clinical studies just being organized). Plus, there are agents that can 'up-regulate' OGF (opioid growth factor) that LDN utilizes for the health benefits.

Cris *When did you first learn of Dr Bernard Bihari's use of, and success with, LDN in the treatment of patients with HIV, and later MS?*

Ian Z *Dr. Bihari called me in December, 1983 after seeing the 2nd of two of our papers published on 'LDN' and 'HDN' in SCIENCE. We had already initiated patents on the use of naltrexone through Penn State University in 1982 - and these patents were successful a few years later. Dr. Bihari told me he was a physician (director of the clinics at Downstate Medical Center in Brooklyn) and thought our work was remarkable.*

In our conversation that day, Dr. Bihari asked me what dosages we could use for humans. In our patents we had already recommended 3-10 mg/day for humans based on our data and pharmacokinetics of naltrexone in the literature. I recommended a dose of around 4 mg for a 120 lb person. The next day he called me and said that LDN was fantastic. He was feeling wonderful - as I had predicted. I was shocked that he took the drug, but pleased that our predictions were correct.

It was some years later that I learned Dr. Bihari went into private practice and was prescribing LDN for all kinds of diseases. The downside of this was Dr. Bihari was charging $500/30 minute telephone call and giving a prescription without seeing many patients - or looking at the medical charts of these folks. Much later a web site was started by Dr. Bihari and this really caught the public attention. Unfortunately, there were misconceptions that arose because of the interactions of patients – and even from Dr. Bihari.

Cris *Did Bihari's use of LDN in the treatment of HIV and MS help validate for you, any theories, outcomes, or expectations, and if so, which ones?*

Ian Z *As I mentioned above, Dr. Bihari appeared to prescribe LDN for all kinds of diseases - without preclinical information or clinical studies underlying this advice. In many cases, patients tried LDN on their own and it was successful. So exactly what was going on is hard to understand.*

Cris *Your research has proven a temporary blockade of opioid receptors will boost endorphin production no matter what time of day LDN is taken, and that's comforting for those few whose sleep issues don't resolve after several weeks of night-time dosing. Have you ever measured what the actual increase in endorphin production is, and if so, what was the measure and was that measure consistent regardless of whether the LDN was administered at night or in the morning?*

Ian Z *The ultimate goal of LDN is to slow down DNA synthesis - cell proliferation. (Refer to *'Gene Peptide Relationships in the Rat Brain' paper on this subject).*

The enkephalin - OGF (how LDN operates) - that is working on cells is autocrine/paracrine - measuring this in cells is usually by way of staining with antibodies and then doing semi-quantitative densitometry. We have a very nice paper coming out just on this in which we have developed a tissue culture model of LDN in order to examine each piece of the mechanism.

NB The circadian rhythm - and lack thereof - related to systemic enkephalins is well-documented in the literature. Now, individual tissues may respond differently depending on the time of day. However, once you invoke LDN - or OGF - this lasts 24 hours.

Cris *(a) Does that mean the paper coming out contains time dependent comparative data, i.e.; increases in endorphins and OGF being dependent upon the time of day LDN is administered? (b) And if so, does it also contain observations of differing regulatory effects on individual cells or tissues, depending on the time of day LDN is administered/OGF is expressed?*

Ian Z *(a) There is no circadian rhythm to the endorphins - especially enkephalins. I have the abstract below. This was looked at 30 years ago. What you are dealing with is a lot of folks - layman and doctors - who do not read or know the literature.*

Some of these people - and I understand Dr. Bihari was promulgating the circadian rhythm along with a lot of other myths (e.g., "LDN will only work in the evening" - I had told Dr. Bihari to try this when he called me in 1983 - and I gave him the dosage we had worked out for humans and suggested the evening would be best to avoid any uncomfortable feeling for the 4-6 hours of deprivation of endorphins interacting with opioid receptors); "4.5 mg is THE dosage" - I told him 3-10 mg - with less being the best - and 3 mg is fine except for children).

That being said, there is circadian rhythm to some cells that proliferate; see a paper(6) we did to find this. However - LDN works no matter what - and remember, LDN works the entire day - so even if the cells have a lower period and a higher period of cell proliferation, things will be fine.

(b) LDN works no matter what. Please keep in mind - LDN is doing nothing but

acting as a decoy for OGF. It causes the body to up-regulate OGF and the OGF receptor. After LDN disappears - 4-6 hours - the remaining 18-20 hours you have the real effect – OGF interacting with OGFr and depressing cell proliferation. Moreover, all the other endorphins and opioid receptors are up-regulated and they also are fully working at a higher capacity.

Cris *Dr Zagon, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for discovering the potential of LDN to alleviate human suffering and for continuing to investigate its therapeutic potential.*

Ian Z *Thank you.*

(1) Ian S. Zagon, Ph.D., is Professor of Neuroscience and Anatomy at The Pennsylvania State University, College of Medicine, Hershey, Pennsylvania. Dr Zagon holds membership in the Specialized Cancer Research Center, Intercollege Graduate Program in Genetics, Cell and Molecular Biology Graduate Program Neuroscience Graduate Program, M.D./Ph.D. Program, and the Integrative Biosciences Graduate Program-Molecular Medicine, Neuroscience, and Cell and Developmental Biology.

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

References – Dr Zagon's papers

Dr Ian S. Zagon has published extensively. Here is a small sample:

(1) **Naltrexone modulates tumor response in mice with neuroblastoma.**
Zagon IS, McLaughlin PJ.
Science. 1983 Aug 12;221(4611):671-3.
PMID: 6867737
http://www.ncbi.nlm.nih.gov/pubmed/6867737

(2) **Duration of opiate receptor blockade determines tumorigenic response in mice with neuroblastoma: a role for endogenous opioid systems in cancer.**
Zagon IS, McLaughlin PJ.
Life Sci. 1984 Jul 23;35(4):409-16.
PMID: 6087062
http://www.ncbi.nlm.nih.gov/pubmed/6087062

(3) **Naltrexone modulates body and brain development in rats: a role for endogenous opioid systems in growth.**
Zagon IS, McLaughlin PJ.
Life Sci. 1984 Nov 12;35(20):2057-64.
PMID: 6092812
http://www.ncbi.nlm.nih.gov/pubmed/6092812

(4) **Endogenous opioid systems regulate cell proliferation in the developing rat brain.**
Zagon IS, McLaughlin PJ.
Brain Res. 1987 May 26;412(1):68-72.
PMID: 3607463
http://www.ncbi.nlm.nih.gov/pubmed/3607463

(5) **Endogenous opioids and the growth regulation of a neural tumor.**
Zagon IS, McLaughlin P.
Department of Anatomy, Milton S. Hershey Medical Center, Pennsylvania State University, Hershey 17033.
Life Sci. 1988;43(16):1313-8.
PMID: 2845218
http://www.ncbi.nlm.nih.gov/pubmed/2845218

(6) **Opioid Antagonist Modulation of DNA Synthesis in Mouse Tongue Epithelium is Circadian Dependent**
Ian S. Zagon, Yan Wu and Patricia J. McLaughlin, Dept of Neuroscience and Anatomy, The Pennsylvania State University, College of Medicine, 500 University Drive, Hershey, PA 17033, USA
Pharmacology Biochemistry and Behavior
Volume 48, Issue 3, July 1994, Pages 709-714
PMID: 7938126
http://www.ncbi.nlm.nih.gov/pubmed/7938126

(7) **Gene-peptide relationships in the developing rat brain: the response of preproenkephalin mRNA and [Met5]-enkephalin to acute opioid antagonist (naltrexone) exposure**
Ian S. Zagon *, Patricia J. McLaughlin
Department of Neuroscience and Anatomy, The Pennsylvania State University, The M.S. Hershey Medical Center, 500 University Drive, Hershey, PA 17033, USA
Molecular Brain Research 33 (1995) 111-120
PMID: 8774952
http://www.ncbi.nlm.nih.gov/pubmed/8774952

(8) **Inhibition of human colon cancer by intermittent opioid receptor blockade with naltrexone.**
Hytrek SD, McLaughlin PJ, Lang CM, Zagon IS.
Department of Comparative Medicine, Pennsylvania State University, College of Medicine, Hershey 17033, USA.
Cancer Lett. 1996 Mar 29;101(2):159-64.
PMID: 8620464
http://www.ncbi.nlm.nih.gov/pubmed/8620464

(9) **The biology of the opioid growth factor receptor (OGFr)**
Ian S. Zagon(a),*, Michael F. Verderame,(b), Patricia J. McLaughlin,(a)
(a) Department of Neuroscience and Anatomy, H-109, The Milton S. Hershey Medical Center, The Pennsylvania State University, College of Medicine, 500 University Drive, Hershey, PA 17033, USA
(b) Department of Medicine, The Pennsylvania State University, College of Medicine, 500 University Drive, Hershey, PA 17033, USA
Brain Research Reviews 38 (2002) 351-376
PMID: 11890982
http://www.ncbi.nlm.nih.gov/pubmed/11890982

(10) **Opioid growth factor-opioid growth factor receptor axis is a physiological determinant of cell proliferation in diverse human cancers**
Ian S. Zagon, Renee N. Donahue, and Patricia J. McLaughlin, Department of Neural and Behavioral Sciences, The Pennsylvania State University College of Medicine, Hershey, Pennsylvania, USA
Am J Physiol Regul Integr Comp Physiol 297: R1154-R1161, 2009.
PMID: 19675283
http://www.ncbi.nlm.nih.gov/pubmed/19675283

© Case Health Pty Ltd

Dr O'Flaherty

How and when did you first learn of the potential benefits of low doses of naltrexone (LDN), and at what point did you realise you wanted to investigate that potential further?

Edmond O *Just over 5 years ago.*

Cris *You've prescribed LDN and have reported on successful outcomes. What's your overall perspective on the likelihood of LDN benefiting immune system diseases, and of those diseases, which have you personally seen benefit?*

Edmond O *I have seen the benefits of LDN in MS, Fibromyalgia, Chronic fatigue, Rheumatoid Arthritis, recurrent chest infections, poor immune system, etc, etc. Many cancer patients are living much longer than expected, most of them still alive despite metastases in many cases.*

Cris *Have you personally prescribed LDN for MS, and if so, what was the outcome?*

Edmond O *I am very impressed by it. All local patients remain well. I am aware of one patient from far away who relapsed. Stability is the main aim. Fatigue usually improves on LDN.*

Cris *Do you usually advise your patients to take LDN at a particular time of day, and if so, have you noticed any difference in outcomes depending on the time of day the LDN is taken?*

Edmond O *I tell them to take it between 9pm and 3am. While this appears to be the common view, it is not agreed by everybody.*

Cris *Do you have any patients who've been on LDN for extended periods, say 5 or more years, and if so, for what conditions and what's your overall impression of how long LDN continues to benefit?*

Edmond O *One MS patient remains well for over 5 years with no relapse. In the year before LDN, they were hospitalised 3 times.*

© Case Health Pty Ltd

Cris *Most of your fellow medical practitioners aren't even aware of LDN as a treatment protocol, and those that are can be dismissive. Have you had your share of detractors?*

Edmond O *Plenty. One neurologist wrote a very hostile article on it in the local MS magazine. The patient mentioned above was one of hers and I have had considerable success with one of her chronic fatigue patients too. She came to me in a wheelchair the first time I saw her. She now comes on a motorcycle.*

Cris *If you have experienced opposition or adverse times, what helped you maintain your sense of purpose and resolve?*

Edmond O *I still study quite a lot and apply the latest knowledge. I even went to Sydney in 2006 for a course for doctors on nutrition in mental health. That was very useful too, and the success of LDN and the Pleiffer Course in Sydney has made my work far more enjoyable than it ever was before.*

Cris *Patients themselves say LDN is effective across a broad range of conditions linked by immune system dysfunction, but their views and testimony are largely ignored. Why do you think that is?*

Edmond O *Medicine is very much dominated by the drug companies who pay for the research. No research means many doctors will not use a product.*

Cris *You're a proponent of the multiple benefits of Omega oils. Could you expand a little on those benefits?*

Edmond O *See my website at www.omega3.20megsfree.com*

Cris *Is there anything else you'd like to add?*

Edmond O *I have always felt very privileged to be a doctor but never in my wildest dreams did I think I could do such useful work as I do in recent years with LDN and nutrition in mental health.*

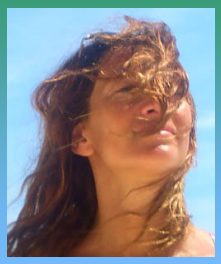
Cris *Dr O'Flaherty, I appreciate you making time for this interview. Before we wrap up, I'd just like to say ... thank you sincerely for championing the investigation of a treatment with much potential to alleviate suffering, but as yet very little support.*

(1) Edmond O'Flaherty, MB, BCH, BAO, BA, LRCPSI, DCH, DObs,MICGP), Gleneagle Clinic, Greygates, Mount Merrion, Co Dublin, Ireland.
Tel +353 1288 1425 www.omega3.20megsfree.com

(2) Cris Kerr, 'Advocate for the value of patient testimony' and its potential value for health & ehealth system frameworks.

© Case Health Pty Ltd

Personal Perspective – Low Dose Naltrexone



Dr Maira Gironi, Italy

March 2010

The following report represents my personal perspective, including doubts, about low doses of naltrexone (LDN).

Naltrexone was licensed as a drug to counteract the effects of narcotics. It performs this role by blocking opiate receptors.

When the drug is given at a lower dose, 2-4.5 mg/day, the opiate antagonist activity of Naltrexone is supposed to be abrogated. The temporary binding of the opioid receptors is, in fact, supposed to trigger a prolonged release of endogenous opioids (Beta-endorphins). Hence, a different dose turns the original opioid-antagonist activity of Naltrexone into an agonist one.

My first concern is about the exact dose that is performing this opioid-agonist role for each single patient. Some of our patients experienced a relief from symptoms soon after starting, at a dose of about 2 mg, but then subsequently lost any benefit, and in some instances claimed a worsening when they reached the 4 mg dose.

Other subjects reported amelioration of symptoms only when they reached the target 4 mg dose. Accordingly, I think we should better dissect the pharmacokinetic properties of this drug before recommending widespread use of LDN.

On the other hand, there are thousands of anecdotal reports claiming that LDN is remarkably effective for treating MS symptoms. And, a study[(1)(2)] supported by the National Multiple Sclerosis Society, recently published by Ian S. Zagon, PhD, of Pennsylvania State University, reported that a single daily dose of LDN significantly decreased neuropathology (demyelination and axonal loss) and behavioural symptoms in an EAE Mouse Model.

Moreover, despite the fact that our pilot study was not designed to specifically assess efficacy on MS symptoms, a significant effect on spasticity as well as some positive influence on fatigue and depression was observed.

The most striking result was the Beta-endorphin increase, which evidenced some of the biological activity of the treatment: The increase was evident from the third month after commencing therapy and remained evident one month after discontinuation of therapy.

© Case Health Pty Ltd

In consideration of all the pathological data and anecdotal evidence, I cannot deny LDN endows a beneficial effect on MS symptoms. However, clear-cut clinical-based evidence to support LDN's long-term effective benefit is still lacking. It should therefore, be mandatory to assess the cost-benefit ratio for each patient every time LDN is considered.

For obvious reasons I'd love to continue researching LDN but have now commenced a different, lengthy project.

The LDN/PPMS Pilot Trial background and results follow below.

Dr Maira Gironi, MD, PhD
(a) Division of Neuroscience, San Raffaele University Hospital, Via Olgettina 58, 20132 Milan, Italy
(b) CAM, Polidiagnostic Clinic, Monza, Italy
(c) Fondazione Don C Gnocchi, IRCCS, Milano, Italy

Perspective - References

(1) Opioid growth factor suppresses expression of experimental autoimmune encephalomyelitis.
2009 Nov 18. Brain Res.
Zagon IS, Rahn KA, Bonneau RH, Turel AP, McLaughlin PJ.
http://fred.psu.edu/ds/retrieve/fred/publication/19931226

(2) Endogenous opioids regulate expression of experimental autoimmune encephalomyelitis: a new paradigm for the treatment of multiple sclerosis.
2009 Nov. Exp Biol Med (Maywood). 234(11):1383-92.
Zagon IS, Rahn KA, Turel AP, McLaughlin PJ.
http://fred.psu.edu/ds/retrieve/fred/publication/19855075

NB These are just two of the 249 publications to-date by Dr Ian S. Zagon, PhD, Pennsylvania State University, PA, USA.

Dr Maira Gironi's Papers:

(1) 'Beta-endorphin concentrations in peripheral blood mononuclear cells of patients with multiple sclerosis: effects of treatment with interferon beta'; Gironi M, Martinelli V, Brambilla E, Furlan R, Panerai AE, Comi G, Sacerdote P.; Neurology Department, San Raffaele Hospital, Via Olgettina 48, Milan, Italy. Arch Neurol. 2000 Aug;57(8):1178-81. PMID: 10927798 (PubMed - indexed for MEDLINE)
http://www.ncbi.nlm.nih.gov/pubmed/10927798

(2) 'β endorphin concentrations in PBMC of patients with different clinical phenotypes of multiple sclerosis'; M Gironi1, R Furlan1, M Rovaris1, G Comi1, M Filippi1, A E Panerai2, P Sacerdote2; 1Department of Neuroscience, San Raffaele Hospital, Milan, Italy; 2Department of Pharmacology, University of Milan, Milan, Italy. J Neurol Neurosurg Psychiatry 2003;74:495-497 doi:10.1136/jnnp.74.4.495 (Received 27 August 2002, Revised 20 December 2002, Accepted 2 January 2003)
http://jnnp.bmj.com/content/74/4/495.abstract

(3) 'A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis'; Gironi Maira, Martinelli-Boneschi Filippo, Sacerdote P, Solaro C, Zaffaroni M, Cavarretta R, Moiola L, Bucello S, Radaelli M, Pilato V, Rodegher M, Cursi M, Franchi S, Martinelli V, Nemni R, Comi G, Martino G.; Institute of Experimental Neurology (INSPE) and Department of Neurology, San Raffaele Scientific Institute, Via Olgettina 58, Milan, Italy; Fondazione Don Carlo Gnocchi, IRCCS, Milan, Italy.; 1: Mult Scler. 2008 Sep;14(8):1076-83; PMID: 18728058 PubMed - in process.
http://www.ncbi.nlm.nih.gov/pubmed/18728058

DR MAIRA GIRONI'S LDN/PPMS PILOT TRIAL BACKGROUNDER

Dr Maira Gironi, a neurological researcher, was the Principal Investigator for the multi-centric trial entitled; *'A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis' conducted across 3 University Hospitals and 1 State (public) Hospital.

Dr Filippo Martinelli-Boneschi was the pilot trial's Statistical Co-ordinator and co-author of the trial paper; *'A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis'.

Dr Gironi has long held an interest in Beta-endorphin levels in MS patients, which resulted in her earlier research; 'Beta-endorphin concentrations in peripheral blood mononuclear cells of patients with multiple sclerosis: effects of treatment with interferon beta' being published in August 2000.

In ensuing years, anecdotes from MS patients reporting benefit from taking LDN were sufficient to pique Dr Gironi's interest in finding out what impact, if any, the treatment may have on MS patient Beta-endorphin levels. This is what prompted Dr Gironi to initiate further research into LDN, MS, and Beta-endorphins, and is what inspired her to design an LDN/PPMS trial in late 2004.

Aware of Dr Gironi's Beta-endorphin research, Dr David Gluck extended an invitation to speak at the 2005 LDN Conference in New York, where Dr Gironi revealed to the assembly that she was planning an LDN clinical trial.

Urged by Dr Gluck and other clinical and pharmacological researchers and advocates in attendance to proceed with her planned trial with haste, Dr Gironi returned to Italy, developed her scientific and ethical documentation, sought approvals, gained funding, and, under the supervision of Professors Comi and Martino, co-ordinated the trial for its duration.

It's important to note that a great deal of time and effort was dedicated to bringing this project to fruition, long before any trial patient was given LDN. For example, 10 months passed just between the application for trial funding and funding approval by the Federation Italian of Multiple Sclerosis (FIMS), and; the period between development of trial documentation and ethical and scientific board approval spanned a long 2 years.

Trial enrolment commenced in December 2006 with 40 patients, comprising in-patients and out-patients across 4 hospitals. The six-month trial took place between February and August 2007. The results of the trial were then recorded and submitted for publication, but were not published until September 2008.

continued

During the six-month trial period, a statistically significant reduction in spasticity was recorded in PPMS trial patients. Progression was recorded in only one PPMS trial patient. Two major adverse events during the trial were not associated with MS or LDN. One patient had previously unrecognised polycystic kidney disease and the other was diagnosed with metastatic lung cancer.

Outside of the trial, many other subjects were administered LDN on the same dosing schedule; 2mg for 2 weeks, then 4.5mg thereafter.

Dr Gironi now has other commitments but has continued contact with several patients since completion of the study due to her continuing interest in low dose naltrexone (LDN) as a potential oral treatment for Multiple Sclerosis.

LDN/PPMS PILOT TRIAL
ABSTRACT SUMMARY of RESULTS

***A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis**

1: Mult Scler. 2008 Sep;14(8):1076-83

Gironi Maira, Martinelli-Boneschi Filippo, Sacerdote P, Solaro C, Zaffaroni M, Cavarretta R, Moiola L, Bucello S, Radaelli M, Pilato V, Rodegher M, Cursi M, Franchi S, Martinelli V, Nemni R, Comi G, Martino G.

Institute of Experimental Neurology (INSPE) and Department of Neurology, San Raffaele Scientific Institute, Via Olgettina 58, Milan, Italy; Fondazione Don Carlo Gnocchi, IRCCS, Milan, Italy.

ABSTRACT

A sixth month phase II multicenter-pilot trial with a low dose of the opiate antagonist Naltrexone (LDN) has been carried out in 40 patients with primary progressive multiple sclerosis (PPMS).

The primary end points were safety and tolerability.

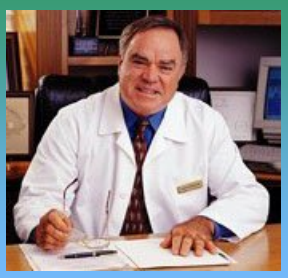
Secondary outcomes were efficacy on spasticity, pain, fatigue, depression, and quality of life. Clinical and biochemical evaluations were serially performed. Protein concentration of beta-endorphins (BE) and mRNA levels and allelic variants of the mu-opiod receptor gene (OPRM1) were analyzed.

Five dropouts and two major adverse events occurred. The remaining adverse events did not interfere with daily living. Neurological disability progressed in only one patient.

A significant reduction of spasticity was measured at the end of the trial. BE concentration increased during the trial, but no association was found between OPRM1 variants and improvement of spasticity. Our data clearly indicate that LDN is safe and well tolerated in patients with PPMS.

PMID: 18728058 PubMed - in process
http://www.ncbi.nlm.nih.gov/pubmed/18728058

Professional Perspective – Low Dose Naltrexone



Dr Julian Whitaker

July 2010

I wish to thank Cris for the invitation to contribute my perspective to her book, a worthy project offering hope and direction for many.

I have written of LDN previously in my newsletters, and the following letter is just one of the many stories I've received from patients and newsletter subscribers praising low-dose naltrexone (LDN).

> *"I am a registered nurse and certified nurse anesthetist. Nine years ago I came down with severe fatigue and achiness and was diagnosed with chronic fatigue and fibromyalgia. My internist tried anything and everything-heavy metals, sleep studies, supplements, and more. For two years there were days I never got out of bed. Of course, this put an end to my career.*
>
> *In December 2008, I read about low-dose naltrexone (LDN) in your newsletter. I got a prescription for 3 mg, and within five days, I felt like a different person. My fibro pain was gone, and over the next two months my fatigue subsided as well. Today, I continue to have the same great relief. Forty or so of the patients I work with in a support group are using LDN, all with some degree of relief. It seems like those with rheumatoid arthritis take longer but have a slow, steady climb.*
>
> *It boggles my mind that I had this drug in my anesthesia cart for over 30 years, not knowing that it would return my life to the way it was 10 years ago." - Joy, Michigan*

Similarly, many others describe remarkable improvements across immune system disorders. Maria's had multiple sclerosis for several years but since being on LDN has had significantly fewer episodes of urinary incontinence. Anna, whose ulcerative colitis caused her to waste away to 88 pounds, is thrilled with her rapid nine-pound weight gain.

LDN helps a wide range of other conditions. Lou says that since she started taking LDN, she no longer gets her 'annual colds' and D.G. hasn't had a cold sore in the three years she's been on the drug.

LDN's been shown to boost mood and energy and prevent allergies in sensitive individuals, and is reported to reduce the symptoms and progression of Parkinson's disease.

Dr. Jaquelyn McCandless reports the majority of Autistic kids become more social, exhibit better eye contact, interact more with others, get fewer colds and other infections, and sleep better after they start taking LDN, and now there are scientific papers confirming LDN's benefits in the treatment of cancer.

How can one drug have so many positive effects? It all has to do with the endorphin system. Endorphins are naturally occurring molecules similar in structure to morphine and other opioid drugs. Although endorphins are best known for boosting mood and blunting pain, they are active in almost every cell in the body. LDN binds to endorphin receptors, temporarily blocking endorphin utilization. Due to the perceived shortage of endorphins, there is a rebound effect where cells dramatically increase production of endorphins and with that, endorphin receptor sensitivity.

Once the drug has been excreted - and this only takes a couple of hours since the dose is so low - the endorphin receptors are able to utilize all the extra endorphins made in the brain, adrenal glands, and elsewhere that are now circulating in the blood.

This has profound effects on several aspects of immune function. It slows or halts undifferentiated growth of cancer cells. It also prevents immune system underactivity and overactivity, which is the crux of autoimmune disorders, and blunts the release of inflammatory and neurotoxic chemicals in the brain. Medical conditions marked by immune dysfunction are associated with markedly low levels of endorphins, and LDN simply restores these disease-fighting endorphins to optimal levels.

A promising area of treatment is cancer. Burton Berkson, MD, and colleagues published a paper last year describing four case histories of patients with metastatic pancreatic cancer who were treated with LDN plus intravenous alpha lipoic acid (a potent antioxidant). Before we go on, you need to understand that the prospects for patients with pancreatic cancer are terrible. Most of them live only a few months after diagnosis and the five-year survival rate is a dismal four percent. It's essentially a 'get your affairs in order' prognosis.

Two of the patients Dr. Berkson reported on, each with well-documented pancreatic cancer that had metastasised to the liver, were alive and well 78 and 39 months after presenting for treatment. A third patient who had the same diagnosis was disease-free, as evidenced by a PET scan, five months after beginning LDN/alpha lipoic acid therapy. The final patient had a history of B-cell lymphoma and prostate adenocarcinoma in addition to metastatic pancreatic cancer. After four months of treatment, his PET scan demonstrated no signs of cancer.

I'm also aware of good results in patients with melanoma, non-Hodgkin's lymphoma, and cancer of the breast, lung, prostate, kidney, and colon. Let me make it clear that I am not suggesting that LDN is a cure-all for any kind of cancer. But this safe, inexpensive drug is certainly a reasonable adjunctive therapy.

Autoimmune disorders also respond well to LDN. A recent pilot study found that LDN improves mood, cognition, and pain scores in patients with progressive multiple sclerosis, and researchers from Pennsylvania State University College

of Medicine demonstrated that 67 percent of patients with Crohn's disease who were treated with 4.5 mg of LDN for 12 weeks went into remission. Results of a follow-up to this study are expected to be published soon, and the lead researcher, Jill Smith, MD, is very optimistic about LDN's potential in the treatment of all inflammatory bowel diseases.

The buzz from patients is even better than the studies, which are limited because there's no profit motive to fund research on an inexpensive drug with an expired patent. (In fact, patients are so enthusiastic that they've raised funds to help pay for completed and ongoing studies.)

In my December 2008 newsletter I wrote about Vicki Finlayson, who suffered with debilitating multiple sclerosis. After 10 years of unbearable pain, horrible fatigue, growing depression, and dependence on Vicodin and morphine to control her pain, Vicki learned about LDN. Vicki's doctor initially refused to prescribe LDN, but she persisted. She weaned herself off opioid painkillers, started LDN, and got her life back. Vicki's been back at work a year and a half now, is off all other drugs and is feeling great.

Back in the 1980s when it was noted that naltrexone boosts endorphin levels, New York City physician Bernard Bihari, MD, contacted Dr Ian S Zagon to enquire about his LDN lab research. Bihari hypothesized that patients with AIDS, who have significant reductions in levels of circulating endorphins, could benefit from low doses of this drug, so he and his colleagues conducted a study in which AIDS patients took 1.75 to 4.5 mg of naltrexone at bedtime.

The results were incredible. The endorphin levels of those patients soared, and they not only felt better, their viral counts went down, they gained weight, and their health improved dramatically. The effects were so remarkable that Dr. Bihari began using LDN not only for AIDS but also for other diseases marked by immune system dysfunction. To his delight, the results were equally positive.

Dr. Bihari' clinical research proved endorphins play a central role in immune function, and that LDN enhances the immune response by stimulating endorphin production.

The best known endorphin is beta-endorphin, however, it's just one of a number of endorphins made in the brain, adrenal glands, and elsewhere that are utilised throughout the body and do far more than increase pain tolerance and a sense of well-being.

Opioid receptors are present on all types of immune cells, including macrophages, natural killer cells, T- and B-cells, and even stem cells. As a result, the flood of endorphins set into motion by LDN stimulates the entire immune system and enhances the body's ability to fight disease.

Over recent years some of the mechanisms have become better understood: We now know that when LDN is taken at bedtime, it binds to opioid receptors

© Case Health Pty Ltd

and temporarily blocks endorphins from attaching. This action signals the body to increase endorphin production, an effect that can last as long as 18 hours.

Ian Zagon, PhD, also of Penn State, is the scientist who first discovered the LDN-opioid link way back in 1979, and he's researched LDN and it's mechanisms of action in the years since. In recent years he's focussed his attention on what he believes is the most promising of the many endorphins LDN boosts; Metenkephalin.

Dr Zagon has been able to synthesize OGF, but because it cannot be absorbed when taken orally, it must be administered by injection. Nearly 100 studies have examined OGF and its role in cancer and other conditions: Dr Zagon has found it can regulate cell proliferation and inhibit tumor growth.

Although OGF is not available in the US at this time, LDN is, for now, still widely available. All it requires is a prescription from a doctor - but there's the rub. Naltrexone in its manufactured form (brand name Revia) is sold in drugstores in 50 mg tablets. It is approved for alcohol, heroin, and other opioid drug withdrawal, but ask your doc for a prescription for 3 mg to boost your immune function, and he'll likely think you're crazy. No drug company is promoting an unpatented drug that costs $20-$30 per month. None of them even manufacture it. LDN has to be made to an exacting order from a compounding pharmacy that employs strict quality control measures.

Although it's perfectly legal to prescribe an FDA-approved drug for off-label use, many docs are reluctant to do so. We've had patients come to California from all over the country because their physicians refused to prescribe this safe, inexpensive drug. But as Joy says in the conclusion of her letter, "It is a shame that something so low-dose, low-cost, and with no side effects cannot get the attention it needs. It would help so many!"

LDN is a major breakthrough, but like other innovative therapies, it's virtually ignored by conventional physicians. It's the same old song and dance: "If it were any good, I'd know about it." Yet this safe, economical drug stands to benefit millions.

So we're back to the same old question: Why don't conventional physicians prescribe LDN? First, they don't know about it. Doctors get most of their information from pharmaceutical reps and medical journals, which are essentially drug ads cloaked in the mantle of science. Because naltrexone's patent expired years ago, no drug company will ever research or promote LDN.

Furthermore, LDN is inexpensive (about $30US for a month's supply), so there's no profit motive. Plus, LDN would compete with newer, far more expensive drugs. Many patients with serious chronic disease spend hundreds or thousands of dollars on medications, and some cancer drugs cost more than $100,000 a year! No profit-motivated company is going to derail that gravy train.

Second, naltrexone has been approved by the FDA only for opiate and alcohol

© Case Health Pty Ltd

dependence. And although the 'off-label use' of a drug (prescribing it to treat conditions other than those for which it's approved) is perfectly legal, many doctors are too timid to do it.

Finally, most physicians are unwilling to think outside the box. If a patient asks me about a therapy and I'm unfamiliar with it, I'll check it out and, as long as it's safe and makes sense (as is the case with LDN), I'll help the patient give it a try. Unfortunately, most physicians are so stuck in their biases that they prefer to just say no.

This reminds me of the Dilantin saga. Jack Dreyfus has spent $80 million of his personal fortune trying to get doctors to recognize the extremely beneficial off-label uses of this safe, inexpensive, low-dose drug for treating anxiety and depression. Forty years later it's still ignored. Meanwhile, the pharmaceutical companies have made billions of dollars on antidepressants that are not only dangerous, but mind-numbing as well.

If you are suffering with any of the conditions discussed in this article, LDN certainly merits a therapeutic trial. Talk to your doctor, present the research and the sources, and if he isn't open to prescribing LDN, then find a new physician.

Truth be told, we've barely scratched the surface when it comes to the therapeutic potential of this drug, which is also helpful for leaky gut and other gastrointestinal problems, corneal ulcers, and overall immune support. Dr. McCandless calls LDN "the best anti-aging medicine going", and patients and physicians - including those at Whitaker Wellness - get consistently good results for general health enhancement and disease prevention.

The suggested dose is 3-4.5 mg per day, taken at bedtime. The only contraindication is narcotic drugs. LDN blocks their effects and could cause withdrawal symptoms, so it should be started only after those drugs are completely out of one's system. LDN is safe and well tolerated. Some people report vivid dreams at first, but in my clinical experience, sleep disturbances are rare. To avoid this, start with a lower dose of 1.5 mg and build up slowly over two months.

LDN requires a prescription and is available only from compounding pharmacies. Due to the need for accurate dosing, it's best to start with those compounders who have experience with LDN such as Gideon's Drugs (212) 575-6868, Skip's Pharmacy, (800) 553-7429, and McGuff Compounding Pharmacy, (877) 444-1133.

If your doctor refuses to write a prescription, consider calling the **Whitaker Wellness Institute**, Medical Clinic, 4321 Birch St, Newport Beach, CA 92660. Tel (800) 488-1500 or (949) 851-1559 (http://www.whitakerwellness.com) or joining Dr Whitaker's Heath & Healing newsletter (www.drwhitaker.com).

About the Author

JULIAN WHITAKER, MD, graduated from Dartmouth College and received his medical training at Emory University Medical School. He is a member of the American Medical Association and is board certified in anti-aging medicine. A popular speaker and lecturer, Dr. Whitaker is the author of 13 books, including Reversing Heart Disease and Reversing Diabetes, and the author of the widely-read monthly newsletter, Health & Healing. He is also a tireless crusader against abuses by the FDA and a champion for medical freedom.

References

Berkson BM, et al. Revisiting the ALA/N (alpha-lipoic acid/low-dose naltrexone) protocol for people with metastatic and nonmetastatic pancreatic cancer: a report of 3 new cases. Integr Cancer Ther. 2009 Dec;8(4):416-422.

Brown N, et al. Low-dose naltrexone for disease prevention and quality of life. Med Hypotheses. 2009 Mar;72(3):333-337.

Smith JP, et al. Low-dose naltrexone therapy improves active Crohn's disease. Am J Gastroenterol. 2007 Apr;102(4):820-828.

© Case Health Pty Ltd

Prof George Jelinek, Australia

February 2010

I am an academic emergency physician, and have MS myself.

While I do see patients with MS in my Emergency Department practice, I do not consult people with MS privately. However, I have a number of people who keep in touch with me, who follow the Taking Control Recovery Program http://www.takingcontrolofmultiplesclerosis.org, and who sometimes seek advice and assistance.

I have suggested to two of them that they might consider LDN in view of concerns about continuing deterioration despite the Program, and have received feedback on their experiences.

One had no benefit and has stopped the drug, but the other, a 45 year old man with a 7 year history of fairly rapidly progressive MS, who walks with a cane, noticed improvement immediately on 3mg a day of LDN. His deterioration had slowed significantly after starting the Recovery Program, but he was still concerned so tried LDN.

After some initial insomnia which settled, he noticed a major improvement in bladder function. Previously he had found the need to visit the toilet very frequently and this affected his social life. But within weeks of starting LDN, he found this settled back to a fairly normal pattern. He also noticed some improved mobility although still required the cane. Given the lack of serious side effects, I have no hesitation in suggesting people with MS who are concerned that they are deteriorating give LDN a try.

Professor George Jelinek

Professor George Jelinek is Professor of Emergency Medicine at Sir Charles Gairdner Hospital, Hospital Avenue, Nedlands, Perth, Western Australia 6009. General Tel 61 8 9346 3333

Taking Control of MS
http://www.takingcontrolofmultiplesclerosis.org
Book: 'Overcoming Multiple Sclerosis: An Evidence-based Guide to Recovery', by Professor George Jelinek, Publisher - Allen & Unwin, Feb 2010
http://www.takingcontrolofmultiplesclerosis.org/whatsnew_detail.php?ArticleID=82
Treatments: Low-dose naltrexone (LDN)
http://www.takingcontrolofmultiplesclerosis.org/index.php?mode=Low-dose Naltrexone
Paper: 'The influence of the pharmaceutical industry in medicine'
http://www.takingcontrolofmultiplesclerosis.org/article_pdfs/j09_v017_JLM_pt02_jelinek_neate_91.pdf
Latest LDN patient testimonies from Case Health
http://www.takingcontrolofmultiplesclerosis.org/articles_detail.php?ArticleID=90

© Case Health Pty Ltd

Professional Perspective – Low Dose Naltrexone

Paul Battle, PA-C

May 2010

In my three decades practicing as a physician assistant, I have never heard of a more dramatic discovery as low dose naltrexone therapy (LDN) and its many treatment applications. In addition to its effect on difficult diseases it is very economical, and virtually side effect free.

Our most difficult diseases to treat are cancer and autoimmune diseases. One of the reasons we have difficulty is we do not understand the pathophysiology of these diseases well.

Low dose naltrexone in its actions on the immune system are giving us a better understanding of cancer and autoimmune pathophysiology. Our current treatment of cancer and autoimmune diseases is thwarted with side effects and questionable effectiveness. We have only made real progress on a handful of cancers.

LDN has advantages in that it has little if any side effects and has shown effectiveness in diseases traditionally difficult to treat. Unfortunately we have only a few studies that show the efficacy scientifically. It has a 30-year safety record that shows it does not harm our patients. This is one of the goals of research studies, to show safety.

The side effect of temporary insomnia is dwarfed by the major side effects of other therapies. These side effects can end in death of the patient. They include such things as infectious sepsis, bone marrow suppression, osteoporosis, cancer risks, to name a few.

We do need more research to show LDN's effectiveness to validate its role in disease management to health care practitioners. There is a lot of anecdotal evidence out there. I personally have met people who have had their multiple sclerosis unmanageable painful neuritis resolve. Fatigue has greatly improved. There have been cases of wheelchair-bound, totally disabled MS patients returning to gainful employment.

In regards to Crohn's disease, Jill Smith M.D. has several studies that have shown excellent improvement - up to 89% in patients compared to 50% in very expensive, potentially dangerous therapy.

© Case Health Pty Ltd

Rheumatoid patients treated by Dr. Burt Berkson in New Mexico see their ANA levels (measures activity of disease) drop from 550 to 50 and many of them are able to stop their immunosuppressive agents.

LDN has the remarkable ability to balance the inflammatory and antiinflammatory cytokines. This balancing act allows LDN to suppress the autoimmune disease activity while at the same time helping prevent cancer and infections. It does this through two different systems. One system is the endorphin production and the other is the increased levels of met-enkephalins.

We need more studies to better understand how they exactly change our physiology to be effective. This is difficult to do. Since naltrexone is a generic drug there is no financial incentive for pharmaceutical companies to fund the studies.

The purpose of clinical studies is to determine the safety and efficacy of a treatment. Since LDN has been around for almost 30 years without any recorded severe side effects, what is left to study is LDN's effectiveness for certain diseases. In my view, since LDN is safe to use and is only about 20 dollars a month to purchase, the risk benefit ratio is low.

If I have a patient, for example, that is having severe side effects from the Tnf inhibitors for Crohn's disease, and the patient is doing poorly, why not consider LDN since it has been proven to be highly effective? And I speak from personal experience, because LDN therapy saved my son's life with his Crohn's disease.

I received a call from a gastroenterologist from another state who described a 24 y.o. male that had been hospitalised every month for 4 months. He could not tolerate any of the current drug regimens. This gastroenterologist did not have anything to offer him, so I instructed him on LDN dosages and learned 4 months later that patient had improved.

I believe with LDN's safety profile, that patients should be educated on LDN as a possible therapy in the future. We do have to be vigilant in performing more studies to show the healthcare community, convincingly, that it is a good option for patients with these difficult diseases. My goal is to have LDN readily available to anyone in the world when it could help them manage their troublesome disease.

Paul Battle PA-C
Broomfield, Colorado 80020
paulbatt@comcast.net

Paul Battle PA-C
Barolat Neuroscience
1721 E. 19th Avenue
Suite 434, Professional Plaza East,
Denver, CO 80218, USA

Paul Battle, Co-Founder
Boulder Longevity Institute LLC, 1136
Alpine Avenue, Suite 210, Boulder, CO
80304, USA
Tel 303/443-0848
Fax 720/836-3140
bli@boulderlongevity.com

© Case Health Pty Ltd

Related Health Articles

© Case Health Pty Ltd

USA MS Sufferer

Malcolm West

Ponders
WHY you won't hear about LDN

April 2010

Many of you are probably aware of the LDN patient funded ($25,000) study at University of California San Francisco by Dr. Bruce Cree. In this placebo controlled clinical trial, 80 people with MS received LDN for eight weeks and then swapped to the other study drug. Researchers found vivid dreaming was the only symptom reported as a result of taking LDN but due to a high drop-out rate among trial participants, concluded that larger scale trials are needed to determine the effect of LDN on overall quality of life.

Dr Susan Kohlhaas, Research Communications Officer at the National Multiple Sclerosis Society said, "We are really pleased to see results of this study published. The next step will be to complete larger, more detailed clinical trials to determine the potential of LDN as a symptom relief therapy for people with MS."

If you take LDN or are familiar with how the drug works, you will probably find this study a tad frustrating in that it was too short to determine whether LDN had a meaningful impact on disease progression. To do this LDN requires a two-year clinical study, ideally against an established interferon treatment, with MRI tests to measure MS lesions. But a study like this is very expensive and private pharmaceutical companies are unwilling to invest millions in a new use of a generic drug.

Advancing LDN research is therefore the responsibility of government health agencies and non-profit institutions. Here in the US where I live, that would be the National Institutes of Health (NIH) and The National Multiple Sclerosis Society (NMSS). These two organizations have a close relationship with NIH researchers often advising NMSS along with pharmaceutical companies on studies and trials.

Last year I invited several senior executives from NMSS, headquartered in New York City, to make the short train trip to Washington, DC to attend the 5th Annual LDN Conference at the NIH. They responded that it was a bad year financially and attending the conference was not in the budget plan. I next

offered to make a donation to NMSS to pay for their travel and hotel accommodations. They refused my offer.

When I saw the Dr. Susan Kohlhass' quote I decided to send her and Dr. Patricia O'Looney (Vice President, Biomedical Research) an email inquiring if NMSS had any plans to fund LDN-related research considering Dr. Cree's positive study results. Dr. O'Looney responded that while NMSS was receptive to receiving proposals, they had no plans to raise funds or take any initiative on LDN research.

NMSS to date has only made one grant ($40,000 in 2008) relating to LDN research, to Dr. Ian Zagon at Penn State.

Dr. Zagon, as well as other researchers, have made follow-up proposals to NMSS for additional funding: All have been rejected without comment by Dr. O'Looney.

By contrast, the NMSS and NIH are working together on a $19 million dollar study announced in July 2009 that combines the two established MS treatments Avonex (Biogen, Inc.) and Copaxone (Teva Pharmaceuticals, Inc.). Both Avonex and Copaxone cost about $2500 a month for a prescription and have been rising in cost at 20% a year. The four pharmaceutical companies that make MS drugs, Biogen, Teva, Bayer, Serono, and now Acorda Therapeutics, are big benefactors of the NMSS and you only have to open an edition of MS Today and see their full-page ads, to receive their direct mail, to attend their sponsored doctor seminars, to realize the true extent of big pharma's influence.

And here are a couple of interesting fun facts: The "lifetime value" of an MS patient using these drugs is estimated at $2 million, or around $40,000 a year. The annual marketplace for MS drugs is about $9 billion a year and the total marketplace for immune/inflammatory drugs is $68 billion a year and includes 350 drugs at 250 companies. Joyce Nelson, the CEO of NMSS makes approximately $500,000 a year in base salary with many other executives making over $250,000 annually.

$40,000 for LDN seems like a pittance, a drug that tens of thousands of people say is the most effective treatment they have ever taken for their MS. However, MS is an industry that supports the lucrative careers of many and makes millions for stockholders. Acorda Therapeutics, who recently released AMPYRA, a sustained release formulation of 4-aminopyradine ("4AP") charges over $1,000 a month for the drug which helps some people with MS walk better. 4-AP has been available for years through a compounding pharmacy and costs about .25 cents a dose. AMPYRA now costs $17 a dose, same drug in a graduated release formulation.

The shares of Acorda have soared, all of Acorda's management team have become multi-millionaires, and Acorda now has advertisements on the NMSS website and in MS Today.

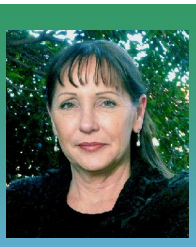
© Case Health Pty Ltd

Will the same thing ever happen to LDN? Maybe, but I doubt it; and that is why LDN Awareness is so important.

Because there is no money to be made from LDN, people like Dr. Patricia O'Looney, Dr. Susan Kohlhass and CEO Joyce Nelson have no real interest in LDN and likely never will. It's up us, the people who actually have, or love, someone with an autoimmune disease where LDN may help. Dr. Patricia O'Looney, Dr. Susan Kohlhass and CEO Joyce Nelson don't have MS, but if they were diagnosed tomorrow, I'm pretty certain they would visit lowdosenaltrexone.org and ldnaware.org.

Malcolm West
April 2010
http://www.LDNaware.org

Shared Vision for Health



By ***Cris Kerr***
Case Health – Health Success Stories
Advocate for the value of patient testimony to health frameworks & ehealth systems worldwide
July 2008, rev July 2009

Health systems should be recording and sharing successful health outcomes ... because success breeds success ... and because when the path to success is shortened, people suffer less and productivity from the same limited health resources is enhanced.

Premise

When you want to achieve success in any field the first thing you do is research how others have achieved success.

In the standard western medical system, successes and failures should be recorded and shared within a framework - alternately referred to as Evidence-based or Outcome-based Medicine - with the primary goal being the application of best long-term practice in diagnosis, patient care, and treatment outcomes.

Such a framework has obvious merits but historically, the patient's perspective hasn't been sought and included as corroborating evidence. Typically, the health system;

1) doesn't place sufficient value on confirming success or failure via the patient perspective, and;
2) doesn't record or recognize success or failure when/if it occurs outside the standard medical system.

Who is in the best position to provide evidence of health success or failure? Arguably, it's the patient.

Advocacy

The Case Health online database was created to fill this gap in the health system, and advocate the value of patient testimony. I encouraged individuals to freely share information on health success in the hope of making the path to health success shorter and less stressful for others.

The website collected and shared health success stories (personal or research)

through an online database. Keywords were attributed to each story and this framework served a dual purpose:

The database could be searched by symptom, condition, or treatment so patients could discuss what they'd found with their doctor. The database also collected significant research findings, so analysts could gain 'insights' into cause and effect and develop theories for curiosity-driven research, or gain insight into public health statistics, benefits, or risks.

There are many ways people can contribute to their communities but most haven't considered information as one of those ways. They can help improve another person's health by sharing detailed information on how they achieved their own health success - and if they do that, they contribute something more valuable than cash to their community.

Optimum health is a universal goal. Challenges and resources differ between countries - but we are all human and we all share the same desire - to acquire and employ knowledge that results in the least invasive and least expensive path to optimum health.

My Case Health website recorded its first controversial Low Dose Naltrexone (LDN) treatment health success story in November 2003. A significant increase in LDN linked success stories prompted me to write the article; * 'Drug Stops Multiple Sclerosis - But Sufferer's Can't Get it'. The article highlighted the growing number of LDN health success stories linked to many auto-immune based diseases, the absence of mainstream recognition of patient testimony, and; advocated for health framework reform.

The Case Health website remained at concept stage, however; the article *'Drug Stops Multiple Sclerosis – But Sufferer's Can't Get it' and supporting patient testimonies represented an inaugural proof-of-concept document.

'Case Health - Health Success Stories' was a free worldwide community health service website that collected and shared patient anecdotal evidence of success and news of significant research results. The site (casehealth.com.au & casehealth.com) was created in 2001 and though based in Brisbane, Australia, the site held stories from all over the world. The website operated for 8 years, closing in May 2009, but the primary mission of achieving long overdue recognition of the potential value of patient testimony continues unabated…

Proposal - Vision for Health Reform

With governments around the world presently considering or developing new health frameworks, I hope you'll agree the timing is right for visionary reform:

Our health systems should be recording and sharing health successes and failures (learnings), including patient perspectives because;

a) success breeds success and when the path to success is shortened, people suffer less, and;
b) because 'learnings' can alert us to risks associated with failure and hence, reduce risks.

What might a ***'Shared Health Accomplishments & Research Environment'*** **(SHARE)** *look like?*

1. A robust, secure health IT infrastructure sharing successes so they can become repeatable and sustainable, and; sharing failures so they can be avoided.

1a. A new Medicare rebate would be paid to all Health Professionals who're prepared to spend time documenting and sharing detailed patient histories of successes and failures (learnings) through a central database. Implementing this type of framework not only acknowledges quality patient care and treatment but ensures success is repeatable and sustainable, and; guards against treatment failure.

To substantiate the integrity of submissions, the patient would confirm or counter-sign. The database would build slowly, with integrity, and therefore grow more valuable with time, delivering ever-increasing dividends for the future.

A 'weighting' would be applied to each submission, depending on the qualification of the Health Professional. Submissions by less qualified allied health professionals would initially be assigned a lower 'weighting' but would attract a higher 'weighting' as the volume of corroborating testimonies increases.

1b. In acknowledgement that any person who's achieved success or experienced failure has information of value to share, the database would accommodate all health successes and failures; including those that occur outside the standard health system. Any individual could opt to submit their health story details, that is; how they achieved success or how they failed (what they learned) - so they may contribute to the volume of knowledge. Submissions would be 'weighted' accordingly but would attract higher 'weighting' with regard to public health benefits or risks, or when the volume of corroborating testimonies increased.

1c. The framework would be governed by systems and processes that promote equity and quality, and guard against infiltration of conflict of interest, commercialisation, or bias, in order to maintain database integrity and protect this valuable investment in the future health of all.

1e. Database searches (non-personalized details only) would be freely

accessible to all, including health researchers, analysts, and the general public. Names and addresses would be protected by law, secured, and shielded in a separate database - and would therefore not be accessible via search, however; special dispensation could be given for a rare event - such as research or analysis that indicates a major public health benefit or risk necessitating deeper analysis, evaluation or validation.

When Health Systems are documenting and freely sharing all successes and failures, including patient contributions, quality and productivity from the same limited health resources will be dramatically enhanced and people will suffer less.

The opinions expressed are those of the author of this article, not book contributors.
Supporting data for this article is in the form of untested patient testimony of health success in the form of case study records. I do not have the resources to validate each testimony.

(1) *Alternate version entitled 'Anecdotal evidence points to relief for MS sufferers' was published on ONLINEopinion Australia's e-journal of social and political debate, 3rd January, 2006
– URL onlineopinion.com.au/view.asp?article=3905

(2) Published by OnlineOpinion 23rd October, 2007:
- URL onlineopinion.com.au/view.asp?article=6531

(3) Revised July 2009 to note the closure of the casehealth.com.au and casehealth.com websites.

The author, Cris Kerr, is an advocate for the value of patient testimony, and its potential value for health frameworks and ehealth systems. Cris administered the 'Case Health-Health Success Stories' website (www.casehealth.com.au www.casehealth.com 2001-2009)

Bad Things Happen When Good People Do Nothing

By ***Cris Kerr***
Case Health – Health Success Stories
Advocate for the value of patient testimony to health frameworks & ehealth systems worldwide
July 2008, rev July 2009

"In any moment of decision, the best thing you can do is the right thing.

The worst thing you can do is nothing."

Theodore Roosevelt

The Low Dose Naltrexone (LDN) Clinical Treatment Protocol developed by Dr Bernard Bihari first came to my attention almost seven years ago in 2003, when I learned of LDN because I valued what patients themselves said was working for them.

I'm not a qualified health researcher, but what I've learned from the patients themselves through collecting and sharing their health case studies has provided insights and has been invaluable experience.

I've learned, for example; that you're unlikely to hear of a treatment option that has potential to halt or slow progression of a range of diseases linked by immune system dysfunction.

Your station in life, and the size of your bank account will not protect you from this. No-one is safe - young, old, rich, or poor - you or someone you love could be disadvantaged by this. In this injustice, we are all equal and as one.

"In this injustice, we are all equal and as one."

LDN is not a cure, and not everyone achieves success with LDN … but it does work, and it's been working for patients since the late 1980s.

As with most medications, there can be side effects to contend with. From observations, the most common is initial sleep disturbance, and; in the case of

© Case Health Pty Ltd

some diseases such as progressive forms of Multiple Sclerosis, there's also a possibility of exacerbation in the first six months of treatment.

I've also gleaned from observations that those who are most likely to experience exacerbations or who don't succeed with LDN can sometimes have a long history of medication reliance, or have deferred making complementary lifestyle changes. In particular, abrupt cessation of many medications, including opioid-based (narcotic) pain meds, steroids, and other immune system suppressants can result in withdrawal symptoms or rebound effects following a lengthy period of reliance and hence, abandonment of LDN as a treatment option.

"No one would have crossed the ocean if he could have gotten off the ship in the storm."
Charles Kettering

This is an understandable 'catch 22'. We want the 'high impact' health fix for many reasons: We can't afford time off work or for our boss to discover our health's been compromised, or we have families relying on us to care for them – and so we lean on the health solution that helps us get on with our day-to-day lives with the least interruption - but not necessarily in the least invasive way.

"The world hates change, yet it is the only thing that has brought progress."
Charles Kettering

Just as it takes more time and more precision to drive in a nail with a hand-held hammer than it does a sledgehammer, there's far less scope for error with LDN, and hence, a greater need for patient research and preparation, protocol precision and patience. Yet surprisingly, clinical trials of low doses of naltrexone have diverted from Bihari's well-established and successful clinical protocol; as did a German clinical trial that switched to morning doses in response to patient sleep disturbance, and hence, did not achieve the same degree of successful outcomes.*

"The good we secure for ourselves is precarious and uncertain until it is secured for all of us and incorporated into our common life."
Jane Addams

© Case Health Pty Ltd

Naltrexone has long been 'off-patent'. Pharmaceutical companies that initiate clinical trials do not perceive this particular unmet market need as potentially profitable and worthy of investment.

Commercialism can benefit markets - but there are distinct areas where commercial markets should not dominate, infiltrate, conflict, or otherwise influence to the detriment of the greater public good. Indeed, the story behind LDN infers the health market scales have long been tipped too far in favour of commercialism and are in dire need of re-balancing.

Clinical trials of LDN are needed, but as some would need to run for six to twelve months or longer, they'd be costly. It's my understanding over 200 disease types have been linked to immune system dysfunction, and the list keeps growing. Pick one of those diseases for an LDN trial, and sufferers of every other immune system disease remain abandoned, perhaps another 20 years.

'Optimum quality of life' is a basic human right that should stand tall, above all other rights. It is sacrosanct and must therefore be protected from the taint of 'conflict of interest'. Societies thrive in an environment of fair play and balanced needs, and there is no greater need for fair play and balance than in public health.

"Man Cannot Discover New Oceans Unless He Has the Courage to Lose Sight of the Shore"
Andre Gide

Meanwhile, a low-cost treatment with a reasonable safety profile and reasonable potential to alleviate human suffering is still being disregarded and summarily dismissed. Our fellow humans - our mothers, fathers, partners, children, friends, and neighbours – have been, or are still being denied a treatment option that might improve their quality of life or prolong their life – are being denied a chance where there may otherwise be none – a situation that is unjust, senseless, sad and haunting if you dwell, as I do, on its implications.

"We should all be concerned about the future because we will have to spend the rest of our lives there."
Charles Kettering

We know patients are being denied a treatment with potential to enhance their quality of life or alleviate suffering, and we know this is being justified by 'unproven efficacy', and in the interest of 'patient safety'. We also know denial of this treatment option has sometimes been weighed against the possibility of litigation.

Well, there are many ways to do harm. You can directly harm by doing something, and you can indirectly harm by doing nothing. Through a brilliant piece of satire, the final episode of the Jerry Seinfeld series confronts us with four observers who indirectly cause harm to another human being by doing exactly that, nothing.

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."
Margaret Mead

Most current knowledge of LDN efficacy and safety remains limited to a handful of small studies, clinical trials and patient testimony. It's spread randomly from one patient interest group to another, making it easy for the scientific community to ignore, disregard and summarily dismiss as they would a single grain of sand. To divide is to conquer, and while this continues, nothing will change.

Case Health has been striving to bring the evidence together in one central location, and has created this free book to help build awareness of the collective 'volume value' potential of patient testimony as case studies. The collective is greater than the single, and a grain of sand can become a beach stretching as far as the eye can see.

It's my greatest hope Case Health's increasing volume of patient testimony and this book will one day result in the scientific community acknowledging presently held tenets are not static or absolute, and that a central store of corroborating patient testimony;

- has immense potential to provide valuable 'insights and learnings' to validate and guide public health priorities;
- can help validate successful health outcomes, and;
- can attain 'volume value' in its own right.

"In ancient China the doctor was only paid when the patient was well. In modern health systems, perhaps your visible success should depend on health outcomes ... "
HRH The Prince of Wales, Prince Charles

I maintain faith our inherent human capacity for compassion and fairness will influence those who can help overcome resistance and progress the return of patients to their rightful place at the core of our health systems, in acknowledgement of the value they can add through their testimony.

"Through our scientific genius
we have made of the world a neighborhood;
now through our moral and spiritual genius
we must make of it a brotherhood."
Dr. Martin Luther King, Jr.

Governments around the world presently reviewing and implementing long-term visions for improving population health should welcome, accommodate, and integrate patient testimony as a valued, protected, and integral part of their public health and ehealth frameworks.

'A society grows great when
old men (and women) plant trees
whose shade they know they shall never sit in.'
Greek proverb

The opinions expressed are those of the author of this article, not book contributors.
Supporting data for this article is in the form of untested patient testimony of health success in the form of case study records. I do not have the resources to validate each testimony.

*Ref: Dr. Evers Trial in Germany for Multiple Sclerosis (MS)
http://www.lowdosenaltrexone.org/ldn_trials.htm

The author, Cris Kerr, is an advocate for the value of patient testimony,
and its potential value for health system frameworks and ehealth systems.
Cris administered the 'Case Health-Health Success Stories' website
(www.casehealth.com.au www.casehealth.com 2001-2009)

"Of all the forms of inequality,
injustice in health care
is the most shocking and inhumane."

Rev. Martin Luther King, Jr.

© Case Health Pty Ltd

LDN in the MEDIA

© Case Health Pty Ltd

LDN in the News
Attributed to Multiple Group & Individual Advocacy Efforts and Awareness Activities

Video News

'Wonder drug?'
Health Check - Article & Video by Ali Gormon, R.N.
Featuring Crohn's patient Pam Sweigart and Prof Jill Smith
Thursday, May 22, 2008 | 10:16 AM
Penn State College of Medicine, Hershey, Pennsylvania
LDN clinical trial for Crohn's Disease
ABC6 Action News, Philadelphia, Pennsylvania USA
http://www.abclocal.go.com/wpvi/story?section=news/special_reports&id=6156884

'Wonder drug?'
Health Check - Article & Video by Ali Gormon, R.N.
Featuring Multiple Sclerosis patient Lori Miles
CBS47 News, Jacksonville, Florida (on Youtube)
http://www.youtube.com/watch?v=Kz52KK5IhOc

'Drug Addiction Medication May Treat Other Diseases'
Health Watch - Article & Video by Dr Max Gomez
Featuring MS patient Ronnie Raymond and Dr David Gluck
May 26, 2008 7:33 am US/Eastern
CBS WCBSTV News Report, USA
http://wcbstv.com/topstories/lo.dose.naltrexone.2.732830.html

'An Update on Fibromyalgia'
The Stanford University Medical Center Health Hour
Speaker Sean Mackey, MD, assistant professor, Anesthesia, Stanford University Medical Center
http://www.researchchannel.org/prog/displayevent.aspx?rid=28078

'Q A Treatments - Low Dose Naltrexone & Avonex'
MS Learn Online
National MS Society, USA
M.D. Hughes, MD, MCG Health (first viewed March 2010 - upload date unknown)
http://www.youtube.com/watch?v=fFBtcoR-m4c

Radio Interviews

Low Dose Naltrexone Solutions for MS, Autism and other Chronic Illness
Chris Costello interviews Elaine Moore and Samantha Wilkinson, authors of 'The Promise of Low Dose Naltrexone'
Wellness Talk Radio - 2009
http://www.youtube.com/watch?v=w-CTaEjzWUo

Inner Circle interview with Burton Berkson, MD, PhD. by Dr Joseph Mercola
'Making Headway Against Autoimmune Diseases with Low Dose Naltrexone', May 11, 2009
http://www.youtube.com/watch?v=FRI5f69N2eo

© Case Health Pty Ltd

Political Proceedings

Scottish Parliament Petition
Petition Meeting No 1 - Low Dose Naltrexone, 2009
Bob Thomson, Celia Dawson, & Margaret Gachagan of LDN Now Scotland

Scottish Parliament Petition on Low Dose Naltrexone Meeting - Part 1
http://www.youtube.com/watch?v=aAERl8AD3uI
Scottish Parliament Petition on Low Dose Naltrexone Meeting - Part 2
http://www.youtube.com/watch?v=NqSiaFqUKFI
Scottish Parliament Petition on Low Dose Naltrexone Meeting - Part 3
http://www.youtube.com/watch?v=Z6-uLDu50xA
Scottish Parliament Petition on Low Dose Naltrexone Meeting - Part 4
http://www.youtube.com/watch?v=MlNRRzWi4oU
Scottish Parliament Petition on Low Dose Naltrexone Meeting - Part 5
http://www.youtube.com/watch?v=T0sd9Jd_NvE

Tabloid & Online News

'Back from the Brink: My MS Miracle'
An article featuring Linda Elsegood in 'My Weekly' UK magazine issued 27 March 2010
The magazine has a readership of 350,000
http://forum.ldnresearchtrust.org/index.php?/topic/1581-ldn-article-in-the-national-my-weekly-magazine/

Stem cells: will hope triumph over hype?
' … Goldberg, who lives in Totteridge, North London, also tells me that he has just started to take low-dose Naltrexone … '
New research into a cure for MS is a mixed blessing for thousands of sufferers
Penny Wark, The Times online, April 6, 2009
http://www.timesonline.co.uk/tol/life_and_style/health/article6031620.ece

'Could low doses of a drug for alcoholics ease the agony for sufferers of MS?'
Article By Sarah Spendiff
Daily Mail UK online, 25th August 2008
http://www.dailymail.co.uk/health/article-1049099/Could-low-doses-drug-alcoholics-ease-agony-sufferers-MS.html

'Telling the world how it feels'
Sydney Morning Herald, online, 24 April, 2008
http://www.smh.com.au/news/science/telling-the-world-how-it-feels/2008/04/23/1208743039836.html

'The Drug that gave me back my life'
by Sarah Spediff, Independent, Ireland, 5 May, 2008
http://www.independent.ie/health/case-studies/the-drug--that-gave--me-back--my-life-1367070.html

'Low Dose Nalrexone (LDN) and MS'
Article by Ronald Hoffman, MD, and Skip Lenz, Pharm D FASCP
Magazine of the United Spinal Association online, January 25, 2008
http://www.unitedspinal.org/publications/action/2008/01/25/low-dose-naltrexone-ldn-and-ms

'Firefighters help one of their own'
By Denise Sinclair, Daily Home online, Sylacauga, USA, 13 September 2006
http://www.dailyhome.com/news/2006/dh-sylacauga-0913-dsinclair-6i12v2419.htm

Addiction Remedy Studied For Crohn's Disease Relief

By David Wenner, staff writer for The Patriot-News of Harrisburg, Pennsylvania USA
http://www.newhouse.com/addiction-remedy-studied-for-crohns-disease-relief-2.html

Ask Dr. Gott: MS drug needs more research

Dr Peter Gott, Posted: 15 Mar 2009, Monterey County, The Herald, USA
http://www.montereyherald.com/health/ci_11918794?nclick_check=1

Naltrexone May Ease Fibromyalgia Symptoms

Preliminary Study Shows That Low-Dose Naltrexone May Be an Effective, Low-Cost Treatment for Fibromyalgia
By Miranda Hitti, WebMD Health News, Reviewed by Louise Chang, MDApril 17, 2009
http://www.webmd.com/fibromyalgia/news/20090417/naltrexone-may-ease-fibromyalgia-symptoms?src=RSS_PUBLIC

Stanford University Fibromyalgia Study

Science Daily article
http://www.sciencedaily.com/releases/2009/04/090417084002.htm

Naltrexone Halts a Patient's Advanced Parkinson's Disease

This story, reported in March 2008, titled "Naltrexone in tiny doses shows promise in treating autoimmune diseases", tells the story of Bentley Lyon, whose Parkinson's disease of many years had been worsening. His wife and daughter persuaded him to try LDN back in 2004 and positive results appeared promptly. "It was like a miracle," his daughter recalled. The article also quotes Dr. Ian Zagon, a professor of neural and behavioral sciences at Pennsylvania State University, "Naltrexone apparently works by stimulating the body's own immune system .... It's very simple," he said, "but it took a while to figure out."
The Mail Tribune of Southern Oregon, March 2008
http://www.mailtribune.com/apps/pbcs.dll/article?AID=/20080310/NEWS/803100308/-1/LIFE

Naltrexone May Ease Fibromyalgia Symptoms

WebMD Health News
Reviewed by Louise Chang, MD, April 17, 2009
http://www.webmd.com/fibromyalgia/news/20090417/naltrexone-may-ease-fibromyalgia-symptoms?src=RSS_PUBLIC

Ask the Doctor About LDN Therapy, A Possible Treatment for Leukemia

Thomas Cowan, MD, a physician in private practice in San Francisco, California, a board member of the Weston A. Price Foundation, and a regular contributor to 'Ask the Doctor' column.
http://www.westonaprice.org/askdoctor/low-dose-naltrexone-leukemia.html

Multiple Sclerosis Blog

by Julie Stachowiak, Ph.D.
About.com Guide to Multiple Sclerosis
Multiple Sclerosis Drug Prices. Whoa...
Tuesday July 21, 2009
http://ms.about.com/b/2009/07/21/multiple-sclerosis-drug-prices-whoa.htm

Presentation – LDN & Patients with Autoimmune Disorders

Niles Bauer, PhD candidate, Department of Microbiology and Immunology, College of Medicine, University of Arizona, supplied a copy of a presentation to his department in March 2007. He observed "profound" improvements within a month after the start of LDN treatment in people with a wide variety of autoimmune disorders.
http://www.lowdosenaltrexone.org/_mm/Bauer_Presentation_Mar_2007.pdf

The Drug that Changed my Life Should be Available to all

By Cheryl Stonehouse, Tuesday October 13,2009
http://www.express.co.uk/posts/view/133731/The-drug-that-changed-my-life-should-be-available-to-all

Latest LDN patient testimonies from Case Health

'Those Who Suffer Much, Know Much' 2009 featured on website of Professor George A Jelinek, Department of Emergency, Medicine, University of Western Australia, Nedlands Western Australia 6009
http://www.takingcontrolofmultiplesclerosis.org/whatsnew_detail.php?ArticleID=90
http://www.takingcontrolofmultiplesclerosis.org/article_pdfs/THOSE_WHO_SUFFER_MUCH_LDN_BOOK_wCOVER_Aug09_90.pdf

'Until There's a Cure there's LDN...'

by Cheryl Campbell, The Orcadian, 15th October 2009
http://www.ldnresearchtrustfiles.co.uk/docs/C&C.pdf

'Local Charity goes International'

featuring Linda Elsegood - copy of Let's Talk Magazine article available online
http://www.ldnresearchtrustfiles.co.uk/docs/1.pdf

'Hoping for MS cure with Steely Resolve'

The Herald, Newcastle, Australia, by Ian Kirkwood 20th October 2009

'Miraculous drug for MS'

Letter to the editor of Henley Standard UK by Silvia Lane
http://www.ldnresearchtrustfiles.co.uk/docs/Henley%20Standard%20letter1.pdf

'For me, LDN is life-changing'

featuring John Oag, Woking News and Mail, 17th December 2009
http://www.ldnresearchtrustfiles.co.uk/docs/Woking%20News%20and%20Mail.pdf

LDN Awareness Week article

in local 'Best Oxfordshire Village Newsletter', by Silvia Lane, October 2009
http://www.ldnresearchtrustfiles.co.uk/docs/Woodcote%20Correspondent2.pdf

Website News

'Those Who Suffer Much, Know Much' 2009

Latest LDN patient testimonies from Case Health: featured on website of Professor George A Jelinek, Department of Emergency, Medicine, University of Western Australia, Nedlands Western Australia 6009.
http://www.takingcontrolofmultiplesclerosis.org/whatsnew_detail.php?ArticleID=90
http://www.takingcontrolofmultiplesclerosis.org/article_pdfs/THOSE_WHO_SUFFER_MUCH_LDN_BOOK_wCOVER_Aug09_90.pdf

'The Faces of Low Dose Naltrexone'

Stanford Wellsphere, Patient Empowerment article, posted Sep 20 2009 10:10pm
http://stanford.wellsphere.com/patient-empowerment-article/free-ebook-now-available-for-international-ldn-awareness-week-the-faces-of-low-dose-naltrexone/806877

'The Faces of Low Dose Naltrexone': New Book Explores Cutting-Edge Autoimmune Disease Treatment

Thyroid-About, Tuesday September 22, 2009
http://thyroid.about.com/b/2009/09/22/low-dose-naltrexone-book-ldn-schopick.htm

'LDN, the drug that changed my life, should be available to all'

Source: The Daily Express ©2006 Northern and Shell Media Publications (13/10/09) Community Channel
http://www.communitychannel.org/component/option,com_rnyourvoice/task,view/id,3181/sectionid,10/Itemid,104/
http://news.patient.co.uk/newspaper.asp?ss=10&pc=11941
http://www.medworm.com/rss/search.php?qu=Daily+Express+-+Health&t=Daily+Express+-+Health&s=Search&f=source
http://www.allvoices.com/contributed-news/4379345

Life Changing MS Drug Could Save NHS £300 million a Year

http://www.sixtyplusurfers.co.uk/active2.html
http://www.thiis.co.uk/ms-300-oct09.aspx

LDN CONFERENCE VIDEOS

© Case Health Pty Ltd

LDN CONFERENCES

First Annual LDN Conference
11 June, 2005
The New York Academy of Sciences
New York, NY
USA

Post-Conference Report & Multimedia
http://www.lowdosenaltrexone.org/conf2005.htm

USA Conference Video Testimony
Captured by Cyndi & Adam Lenz, tdgr2 Productions, Florida, USA since 2006

'Denial of Treatment'
People Powered LDN Teaser
http://www.youtube.com/watch?v=H2oCcFwnZgo

Vox Pops – 2006 USA LDN Conference

Second Annual LDN Conference: 'The Future is Now'
National Institute of Health Campus, Bethesda Maryland
2006
produced By Cyndi & Adam Lenz, tdgr2 Productions
Main: LDN Conference 2006 - 'The Future is Now' DVD

'Bill Way speaks 2006'
LDN prescribed in 1990 by Dr Bernard Bihari. LDN for HIV for 16 years.
http://www.youtube.com/watch?v=ppWMN1Lb_Pw

‘The Future is Now 2006’ DVD Montage

Pat Crowley, Dr Phil Boyle, Dr David Gluck, Mary Boyle-Bradley, Dr Jaquelyn McCandless,
Dr Skip Lenz-Skips Pharmacy
http://www.youtube.com/watch?v=aA7VihTWBMU

Vox Pops – 2007 USA LDN Conference

Third Annual LDN Conference: ‘Breaking Down Barriers’ Vanderbilt University Campus - 20 October 2007 produced By Cyndi & Adam Lenz, tdgr2 Productions

Main: http://www.youtube.com/user/TropicalDawg

‘Dr Skip interviews Dr Gluck’

Skip Lenz, Pharmacist, interviews David Gluck, MD
http://www.youtube.com/watch?v=ONVebX1sMHk

'LDN Doctor Advocates Speak 2007' Prof Jill Smith, Dr Terry Grossman, Dr Joseph McWhirter, Dr Burt Berkson, Dr David Gluck

http://www.youtube.com/watch?v=DAZ1fQKdOC8

'Dr David Gluck Speaks 2007'

Progress of Dr Mira Gironi's MS clinical trial, Italy
Progress of Dr Bruce Cree's MS clinical trial, Univ of California, San Francisco
http://www.youtube.com/watch?v=ctnm7cv-EXY

'Dr David Gluck Speaks 2007'

Dr Gluck presents Dr Jaquelyn McCandless clinical results in Autism, and planned HIV trial in Mali, Africa
http://www.youtube.com/watch?v=1N3o4ggTnUI

'Dr Patrick Crawley Speaks 2007'

Dr Crowley is in Private Practice in Scotland
He shares his survey results on 50 MS Patients
http://www.youtube.com/watch?v=kclMin66Sf4

'Dr Phil Boyle Speaks 2007'

Dr Phil Boyle is a Family Physician & Infertility Specialist
Dr Boyle shares his clinical experience in prescribing LDN
http://www.youtube.com/watch?v=1sZGQqYTVBg

‘Dr Terry Grossman Speaks 2007’

Dr Grossman presents a case study: Treatment for Stage 4 Renal Cell Cancer, Claudia Feb04
http://www.youtube.com/watch?v=XbYC0R5uKzE

'LDN Patient Advocates Speak 2007'

Janet Kunselman, Susan Benz, Fritz 'Goodshape' Bell, Anon
http://www.youtube.com/watch?v=D0HsgCgboGk

'LDN Patient Advocates – Conference Opening 2007'

Susie Sedlock and Brenda Powell opening the Third LDN Conference
http://www.youtube.com/watch?v=CND5sp2ErDg

'Noreen Martin Speaks 2007'

Noreen Martin, Author, Surviving Aids & Cancer

© Case Health Pty Ltd

http://www.youtube.com/watch?v=_Nh-t3LA6e4

'Mary Boyle Bradley Speaks 2007'

Mary Boyle Bradley, Author, 'Up the Creek with a Paddle'
http://www.youtube.com/watch?v=WCTwLbRX2Ys

'Crystal Speaks' 2007

http://crystalangel6267.webs.com/videosonmsldn.htm

Vox Pops – 2008 USA LDN Conference

Fourth Annual LDN Conference: 'A Revolution in Research' USC Health Sciences Campus - 11 October 2008 produced By Cyndi & Adam Lenz, tdgr2 Productions

Main: http://www.youtube.com/user/TropicalDawg

Playlist: LDN 2008 Conference

http://www.youtube.com/watch?v=8sHEWweXfEo&feature=PlayList&p=5AE79E01B9A36CAC&index=0&playnext=1

LDN 08: Conference Opening Parts 1 & 2

Sunny Sedlock introduces Aletha Wittman, SammyJo Wilkinson, Vicki Finlayson, and Deidre Alejo
http://www.youtube.com/watch?v=kOkwBnRTKY8
http://www.youtube.com/watch?v=dvl9OmxnJM8

LDN 08: Dr Tom Gilhooley Speaks, Parts 1-4

LDN 08: Dr Tom Gilhooley Speaks Part 1
http://www.youtube.com/watch?v=pGcnzy8Gv5E
LDN 08: Dr Tom Gilhooley Speaks Part 2
http://www.youtube.com/watch?v=vJ0ZmKFUDT4
LDN 08: Dr Tom Gilhooley Speaks Part 3
http://www.youtube.com/watch?v=dzoWGI6s9kw
LDN 08: Dr Tom Gilhooley Speaks Part 4
http://www.youtube.com/watch?v=Qpgh9kfaAMY

LDN 08: Dr Burt Berkson Speaks, Parts 1-4

LDN 08: Dr Burt Berkson Part 1
http://www.youtube.com/watch?v=WqRwXEnPYKk
LDN 08: Dr Burt Berkson Part 2
http://www.youtube.com/watch?v=4bpRai9S03A
LDN 08: Dr Burt Berkson Part 3
http://au.youtube.com/watch?v=BLoS_U85g0Y
LDN 08: Dr Burt Berkson Part 4
http://au.youtube.com/watch?v=wxVUimTW6sQ

LDN 08: Dr Skip Lenz Speaks, Parts 1-6

LDN 08: Dr Skip Lenz Part 1
http://www.youtube.com/watch?v=3D3Ppq0W_7f7s
LDN 08: Dr Skip Lenz Part 2
http://www.youtube.com/watch?v=3DM6J=96wRc_O0
LDN 08: Dr Skip Lenz Part 3
http://www.youtube.com/watch?v=3DAazcy6ysKEM
LDN 08: Dr Skip Lenz Part 4
http://www.youtube.com/watch?v=3DWSGT9ylXXmc
LDN 08: Dr Skip Lenz Part 5
http://www.youtube.com/watch?v=3DzVZgTxg9DDM
LDN 08: Dr Skip Lenz Part 6
http://www.youtube.com/watch?v=3DjSEs1rQ_1yk

LDN 08: Dr Jaquelyn McCandless Interview

http://au.youtube.com/watch?v=30EGZzgKID4

LDN 08: Sammy Jo Wilkinson Speaks
http://www.youtube.com/watch?v=jRnUaDdrGBE

LDN 08: Sunny Sedlock O'Malley Interview, Parts 1-2
LDN 08: Sunny Sedlock O'Malley Interview Part 1
http://www.youtube.com/watch?v=ftykRVq76BA
LDN 08: Sunny Sedlock O'Malley Interview Part 2
http://www.youtube.com/watch?v=UNX3eeg4c_I

LDN 08: Aletha Wittman Interview, Parts 1-2
LDN 08: Aletha Wittman Interview Part 1
http://www.youtube.com/watch?v=8sHEWweXfEo
LDN 08: Aletha Wittman Interview Part 2
http://www.youtube.com/watch?v=oF_SC3OBEqE

LDN 08: Vicki Finlayson Speaks, Parts 1-4
LDN 08: Vicki Finlayson Part 1
http://au.youtube.com/watch?v=_OnYXB-NkX4
LDN 08: Vicki Finlayson Part 2
http://au.youtube.com/watch?v=V9TeagqH5xU
LDN 08: Vicki Finlayson Part 3
http://au.youtube.com/watch?v=hW_8Bum4xjQ
LDN 08: Vicki Finlayson Part 4
http://au.youtube.com/watch?v=TLNiiBCP85A

LDN 08: Deidre Allejo
LDN 08: Dee, with Sunny, Aletha, & Vicki
http://www.youtube.com/watch?v=dvl9OmxnJM8

2009 USA LDN Users Conference

LDN User Conference, 19 October 2009
Conference Organizer: Sunny (Sedlock) O'Malley
Location: Lister Hill Auditorium, National Library of Science, National Institutes of Health.

Speakers:
Burt Berkson, MD, PhD
Author Mary Boyle Bradley
Pharmacist Dr. Skip Lenz
LDN Advocates

Substantial support from Bellevue Pharmacy of St. Louis and Skip's Pharmacy of Boca Raton.

Funds raised for Dr. Jaquelyn McCandless' clinical trial of LDN in Mali, Africa.Full audio-visual coverage of the conference is here.
Main: http://web.me.com/clenz/Site/5th_conference.html

Vox Pops – 2009 USA LDN Conference

Fifth Annual LDN Conference:
NIH, Bethesda, Maryland USA
19 October 2009
produced By Cyndi & Adam Lenz, tdgr2 Productions
Main: http://www.youtube.com/user/TropicalDawg

LDN 09: Sunny O'Malley Pre-Conference Interview
http://www.youtube.com/watch?v=zMDsv94r5f8

LDN 09: Introduction: Sunny O'Malley
http://www.youtube.com/watch?v=mq6ZL507WkM

LDN 09: Dr Patric Crowley
http://www.youtube.com/watch?v=QgteG1WL1t0

LDN 09: Dr Skip Lenz
Dr Skip Lenz - Part 1
http://www.youtube.com/watch?v=qq2CTon0tb8
Dr Skip Lenz - Part 2
http://www.youtube.com/watch?v=4Qdbq-X-760
Dr Skip Lenz - Part 3
http://www.youtube.com/watch?v=BFMFQSrMNYU
Dr Skip Lenz - Part 4
http://www.youtube.com/watch?v=edw4mve4AF8
Dr Skip Lenz - Part 5
http://www.youtube.com/watch?v=9NK5imL2nk0
Dr Skip Lenz - Part 6
http://www.youtube.com/watch?v=kUwZIlslieM
Dr Skip Lenz - Part 7
http://www.youtube.com/watch?v=GTyE8swEXCQ

LDN 09: Dr Burton Berkson
Dr Burton Berkson - Part 1
http://www.youtube.com/watch?v=WHyUfHqR4PA
Dr Burton Berkson - Part 2
http://www.youtube.com/watch?v=xy65UGsVMac
Dr Burton Berkson - Part 3
http://www.youtube.com/watch?v=dRf8Xuqhb5Q
Dr Burton Berkson - Part 4
http://www.youtube.com/watch?v=RXz3VIuyHHk
Dr Burton Berkson - Part 5
http://www.youtube.com/watch?v=nttilGKpJvU
Dr Burton Berkson - Q & A - Part 1
http://www.youtube.com/watch?v=RsBN78Cl1s4
Dr Burton Berkson - Q & A - Part 2
http://www.youtube.com/watch?v=c29DAE4MGmo
Dr Burton Berkson - Q & A - Part 3
http://www.youtube.com/watch?v=nYxzDuKAdfI
Dr Burton Berkson - Q & A - Part 4
http://www.youtube.com/watch?v=nVjksCyDHCA

LDN 09: Mary Boyle Bradley
Mary Boyle Bradley - Part 1
http://www.youtube.com/watch?v=Y6kpxgcjlfs
Mary Boyle Bradley - Part 2
http://www.youtube.com/watch?v=-FSAI2c8_VA
Mary Boyle Bradley - Part 3

http://www.youtube.com/watch?v=ZuG2zKCaBTk
Mary Boyle Bradley - Part 4
http://www.youtube.com/watch?v=egpx8b9Yogo
Mary Boyle Bradley - Part 5
http://www.youtube.com/watch?v=SNkblXaAths
Mary Boyle Bradley - Part 6
http://www.youtube.com/watch?v=iS34hzs0Tyo

EUROPEAN CONFERENCE
VIDEO PRESENTATIONS & INTERVIEWS

First European LDN Conference
Glasgow Scotland 2009
http://glasgowldn2009.com

European 2010 LDN Conference
April 23rd & 24th 2010
Thistle Hotel, Cambridge St, Glasgow, Scotland
www.bigonldn2010.com

Conference Presentations

Intro by Dr Tom Gilhooly, speaker Linda Elsegood, LDN Trust
http://glasgowldn2009.com/2009/05/european-ldn-conference-video1

Presentation by Pharmacist Stephen Dickson
http://glasgowldn2009.com/2009/05/european-ldn-conference-video2

Presentation by Dr Burt Berkson, New Mexico - part 1
http://glasgowldn2009.com/2009/04/ldn-conference-video3
Presentation by Dr Burt Berkson, New Mexico - part 2
http://glasgowldn2009.com/2009/04/ldn-conference-presentation-video4

Presentation by Joseph Wouk part 1
http://glasgowldn2009.com/2009/04/ldn-conference-presentation-video5

Joseph Wouk Part 2+
Presentation by Dr Phil Boyle part 1, Fertility Specialist
http://glasgowldn2009.com/2009/04/ldn-conference-presentation-video6

Dr Phil Boyle part 2, and Plenary session
http://glasgowldn2009.com/2009/05/european-ldn-conference-video-6-dr-phil-boyle-part-2-and-plenary-session

Plenary session continued
http://glasgowldn2009.com/2009/05/european-ldn-conference-video-7-plenary-session-continued

© Case Health Pty Ltd

Conference Interviews – Video Testimonies

http://glasgowldn2009.com/category/conference-video-interviews

Interview - Linda Elsegood, LDN Trust

http://glasgowldn2009.com/2009/05/ldn-conference-video-interviews-linda-elsegood-ldn-trust

Interview - Brendan Quinn, Pharmacist

http://glasgowldn2009.com/2009/05/ldn-conference-video-interviews-brendan-quinn-pharmacist

Interview - Derek Farrar

http://glasgowldn2009.com/2009/04/ldn-conference-video-interviews-derek-farrar

Interview - Dr Phil Boyle, Fertility specialist

http://glasgowldn2009.com/2009/04/conference-video-interviews-dr-phil-boyle-fertility-specialist

Interveiw - Dr Patrick Crowley, Ireland

http://glasgowldn2009.com/2009/04/conference-video-interveiws-dr-patrick-crawley-ireland

Interview - Mitchell Krog, South Africa

http://glasgowldn2009.com/2009/04/conference-video-interviews-mitchell-krog-south-africa

Interview - Joseph Wouk

http://glasgowldn2009.com/2009/04/conference-video-interviews-joseph-wouk

Interview - Atif Aslam

http://glasgowldn2009.com/2009/04/conference-video-interviews-atif-aslam

Interview - Dr Burt Berkson, New Mexico

http://glasgowldn2009.com/2009/04/conference-video-interviews-dr-burt-berkson-new-mexico

Documentaries

LDN Documentary

This earliest known documentary includes an interview with Dr Bernard Bihari prior to his retirement
Dr Patrick Crawley, County Kilkenny, Scotland
http://www.lowdosenaltrexone.org/_conf2006/P_Crowley1.mov

Celebrity LDN Advocates

An associate of Dr Tom Gilhooly, Dr Chris Steele of British ITV Network UK advocates for LDN here:
http://www.youtube.com/watch?v=5p5nhzP2OaI

LDN ADVOCATES

© Case Health Pty Ltd

LDN Advocates – websites & media

LDN Advocates - Audio & Video Files

Blog Talk Radio – LDN Interviews
Mary Boyle Bradley's LDN Audio Archive

Mary Boyle Bradley Interviews on Blog Talk Radio
http://www.blogtalkradio.com/mary-boyle-bradley

Paul Battle presents 'Low Dose Naltrexone and its Regulatory Effects on Cancer Cell Growth and Autoimmune Disease'

Audio of Paul's LDN Presentation at the World Congress on Antiaging Medicine and Regenerative and Biomedical Technologies, Last Vegas, 12 December 2009
http://www.ldnresearchtrust.org/ldn-research/159-mp3-s.asp

PRESENTER
Paul Battle, PA-C (Physician Assistant), Broomfield, Colorado
TITLE
'Low Dose Naltrexone and its Regulatory Effects on Cancer Cell Growth and Autoimmune Disease'
SUB-TOPICS
(a) The Endorphin and Metenkephalin physiology in immune function
(b) Effects of Low Dose Naltrexone and Opiate Growth Factor in changing the immune response.
(c) Clinical studies and appropriate clinical applications that LDN has been used for.
(d) How patients use LDN.
POST CONFERENCE SUMMARY:
Attendance numbers were larger than anticipated - 4000 physicians attended the conference. The LDN topic was 'highly rated' so a larger lecture room was allocated for attendees, accommodating approx 150 physicians. The moderator for the afternoon was himself a prescriber of LDN. Terry Grossman (who spoke at the LDN conference in 2007) attended the lecture and said it went well. Paul will have a 10-20 page chapter in the post-conference book. The Antiaging Medicine Organization will publish and distribute the book to around 100 different countries in medical centers and libraries. Conference website: www.worldhealth.net

LDN Advocates – websites

(1) LDN Conference Media – Cyndi Lenz - Main: http://www.youtube.com/user/TropicalDawg
(2) Crystal's Website – http://crystalangel6267.webs.com
(3) LDN Research Trust, UK – Linda Elsegood- http://www.ldnresearchtrust.org
(4) Mary Bradley - Books & Internet Radio - http://www.marybradleybooks.com & http://www.blogtalkradio..com/mary-boyle-bradley
(5) LDNers - SammyJo http://www.ldners.org

(6) Proboards Bren - http://www.ldn.proboards3.com/index.cgi
(7) LDN Diary - LarryGC - http://www.larrygc.com/mystory - http://www.larrygc.com/ms
(8) LDN 4 Cancer – Dee - http://www.ldn4cancer.com
(9) **LDN PETITION-INTERNATIONAL**: Research into LDN for MS
http://www.thepetitionsite.com/1/sign-support-the-campaign-for-research-trials-in-low-dose-naltrexone-for-multiple-sclerosis
(10) Italian LDN website - http://www.ldnitalia.org
(11) German LDN website - http://low-dose-naltrexone.de
(12) German LDN website – Tom - www.ldn4ms.de
(13) German LDN website – General Info - Silvia - www.ldnhilft.org
(14) Norwegian LDN website - http://www.ldn.no
(15) Polish LDN website - http://www.ldn.org.pl/news.php
(15) LDN Database – John Donnelly - http://www.ldndatabase.com
(16) LDN Now UK – Jayne - http://www.ldnnow.co.uk/
(17) **LDN PETITION-UK**: A Barnett - UK Petition, UK signatories - Funds from the NHS budget to undergo trials for Low Dose Naltroxene: Petition Deadline 23 November 2009
http://petitions.number10.gov.uk/LowDNaltrexone/#detail
(18) **LDN PETITION-AUST**: Trevor Stephens – Australian Petition, International signatories - National Health Funding for Low Dose Naltrexone in Australia -
http://www.gopetition.com/online/28354.html
(19) **LDN PETITION CANADA:** Jayne Thomas – Canada Petition
http://www.thepetitionsite.com/1/funding-of-LDN-trials-in-Canada
(20) Honest Medicine – Julia Schopick - http://www.honestmedicine.com

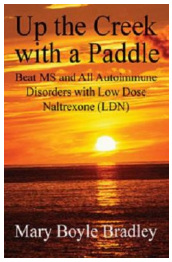
LDN Advocates – personal videos

Jayne Thomas, LDN Advocate
"We need your stories for the ebook *101 Reasons Why You Should Know About LDN*"
http://www.youtube.com/watch?v=MmBqPwV0es4

LDN Advocates - discussion groups

(1) **PRIMARY LDN General Discussion Group** – Dr David Gluck -
http://www.health.groups.yahoo.com/group/lowdosenaltrexone
(2) LDN Discussion - General LDN - Bren - http://www.ldn.proboards3.com/index.cgi
(3) LDN Discussion – General LDN - Crystal - http://health.groups.yahoo.com/group/LDN_Users
(4) LDN Discussion – Cancer – Dee - http://health.groups.yahoo.com/group/LDN_4_cancer
(5) LDN Discussion – Lung Cancer – Celia http://health.groups.yahoo.com/group/Lung-Cancer-Support-Group
(6) LDN Discussion – Autism – Dr Jaquelyn McCandless & Jack Zimmerman, PhD -
http://groups.yahoo.com/group/Autism_LDN
(7) LDN Discussion – General LDN - Cyndi http://groups.yahoo.com/group/ldnsupport
(8) LDN Discussion – Hepatitis - Joyce -
http://groups.yahoo.com/group/Hepatitis_Children_and_CAM_Alternatives
(9) LDN Discussion – General LDN - Germany - http://www.ldn4ms.de/forum/forum.php
(10) LDN Discussion – Crohn's Disease, Ulcerative Colitis, IBD & IBS – Ingrid -
http://health.groups.yahoo.com/group/LDNandIBD
(11) LDN Discussion – General LDN - http://groups.yahoo.com/group/Spotlight_ldn
(12) LDN Discussion - HIV/AIDS - http://groups.yahoo.com/group/LDN_HIVAIDS
(13) LDN Discussion – Primary Lateral Sclerosis - http://groups.yahoo.com/group/LDN-for-PLS-HSP
(14) LDN Discussion – Fibromyalgia – Judy - http://health.groups.yahoo.com/group/LDNforFibro
(15) LDN Discussion – Rheumatoidarthritis - Margaret -
http://health.groups.yahoo.com/group/rheumatoidarthritis-lowdosenaltrexone
(16) LDN Discussion – Raising Awareness UK – John Donnelly
http://uk.groups.yahoo.com/group/LDN_RaisingAwarenessUK
(17) LDN Discussion – General LDN – France - http://mellimello.free.fr/forum/index.php &
http://ldnaltrexone.free.fr/

LDN Advocates - books



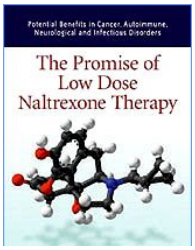
Up the Creek with a Paddle: Beat MS and All Autoimmune Disorders with Low Dose Naltrexone (LDN) from author Mary Boyle Bradley.

'Up the Creek' is first and foremost, Mary and husband Noel's a love story. A story of hope that details how a cheap, simple, nightly pill stopped Noel's Primary Progressive Multiple Sclerosis in the nick of time, back in September 2002. The book humanizes the complexities of getting an FDA approved drug recognized for a new use, and into the hands of people who desperately need it as much as Noel did. The implications extend far beyond the MS community - a 'must read'.

Mary Boyle Bradley, author, 'Up the Creek with a Paddle'

"It is the most depressing reflection of humanity that society accepts that potential financial profit determines whether or not potential uses for drugs should be investigated. … It is the duty of the LDN community to somehow set a precedent for future therapies … If we change the patent laws, it is like we are saying that it is OK to make a huge profit from sick people. It is not OK. … We will not be able to privately fund the research we need no matter how many fundraisers we have. We need our elected Governments to help us. It is their duty to listen to us. Our evidence as to the efficacy and safety of LDN far exceeds anecdotal." Jul '09

Details on the book and author available at http://www.marybradleybooks.com



about the book…

The Promise of Low Dose Naltrexone Therapy: Potential Benefits in Cancer, Autoimmune, Neurological and Infectious Disorders

By Elaine A. Moore & Samantha Wilkinson

Foreword by Yash Pal Agrawal, M.D., Ph.D. Grounded in clinical and scientific research, this book describes the history of naltrexone, its potential therapeutic uses, its effects on the immune system, its pharmacological properties, and how the drug is administered. It also lists fillers and compounding pharmacies, doctors who prescribe LDN, patient resources, and includes interviews with LDN patients and researchers.

Naltrexone is an opiate antagonist drug developed in the 1970s and approved by the FDA in 1984 for opiate and drug abuse treatment. When used at much lower doses in an off-label protocol referred to as low dose naltrexone (LDN), the drug has been shown to halt disease progression in Crohn's disease and certain cancers, to reduce symptoms in multiple sclerosis and autism, and to improve numerous autoimmune and neurodegenerative conditions, including Parkinson's disease and amyotrophic lateral sclerosis (ALS). Details on the book and authors available at http://LDNers.org

about the book…

201 Reasons Why… You Should Know About LDN
contains 201 patient testimonies
attributing LDN with
improved health

The book is free from the LDN Research Trust
Is produced to help raise awareness of LDN
and supports International LDN Awareness Week activities

LDN Research Trust
PO BOX 1083,
Buxton,
NORWICH
NR10 5WY
United Kingdom
Telephone 0844 41 45 295
http://www.ldnresearchtrustfiles.co.uk/docs/ebook.pdf

LDN Information

© Case Health Pty Ltd

LDN Research Trust Fact Sheet 2010

Committed to trials of LDN as a treatment for Autoimmune Disease

LDN Research Trust
PO Box 1083, Buxton, Norwich, NR10 5WY, UK
Telephone: 0844 41 45 295
Email: contact@ldnresearchtrust.org
www.ldnresearchtrust.org

Low-dose Naltrexone (LDN) in the Treatment of Multiple Sclerosis

Naltrexone is a class of drug known as an opiate antagonist. Its normal use is in treating addiction to opiate drugs such as heroin or morphine. The dose used for this purpose is usually between 50 and 150 mg daily.

Low-dose Naltrexone (LDN) has been used in the treatment of MS in the USA since 1985, but is relatively new in the United Kingdom. Despite the fact that the drug is used at a very low dose, the occurrence of significant introductory or long-term side effects cannot be excluded.

This method was devised and subsequently developed by Dr Bernard Bihari, a neurophysician in New York, USA. Dr Bihari was qualified in Internal Medicine, Psychiatry and Neurology. The main website is www.lowdosenaltrexone.org

Suggested Method of Therapy:

The introductory dose is 1.5 mg of liquid LDN for the first 2 weeks of treatment, increasing by .5 mg every 2 weeks until the individual find the dose that suits them best. If there is an increase in symptoms when taking a higher dose, it might indicate that this dose is too high. Lower the dose, and improvements should become apparent. The maximum dose is 4.5 mg. Liquid LDN costs £15 for one months supply, and capsules are available in 3 mg and 4.5 mg for £30. LDN should be taken between 9 pm and 3 am and only stays in the system for 4 hours.

It has been reported that those taking LDN for MS experience a range of benefits, including reduced spasm and fatigue, and improvements in bladder control, heat-tolerance, mobility, sleep, pain, tremor and others.

How Naltrexone Works:

The benefits of the drug are apparently due to the temporary inhibition of endorphins. This results in a reactive increase in the production of endorphins, which should result in a reduction of painful symptoms, and an increased sense of wellbeing.

Increased levels of endorphins should be expected to stimulate the immune system, promoting an increase in the number of T lymphocytes. This effect was observed in Dr Bihari's research. This increase in T-cell numbers apparently restores a more normal balance of the T-cells such that the effects of the disease process are significantly reduced. It has been observed that in those suffering the relapsing-remitting form of MS the number of relapses is reduced, and the rate of progression of the disease is diminished. In chronic progressive MS (either primary or secondary) there seems to be a similar reduction in the progression of disease symptoms.

The Use of Low-dose Naltrexone in MS, and the Occurrence of Side Effects

When starting LDN there might be a temporary increase in MS symptoms such as weakness, changes in sensation, muscle spasm, pain, fatigue or tiredness. These initial symptoms may also include changes due directly to the altered level of brain endorphins, such as disturbed sleep, occasionally with vivid, bizarre and disturbing dreams. These symptoms usually

© Case Health Pty Ltd

disappear within the first week of treatment, and are replaced by improvements in specific symptoms.

The initial increase in symptoms can also be explained when we consider the manner in which the drug works. Contrary to the common belief that MS is due to over-activity of the immune system, MS actually occurs due to a reduction in immune system activity. Specifically, it is the reduction in the number of the suppressor T-cells within the immune system that allows CD4 helper T-cells to do damage. Thus, during an acute relapse the overall number of T-cells is reduced, the normal balance of helper and suppressor T-cells is disrupted, and helper T-cells tend to predominate. This is most pronounced during an acute relapse, but a similar situation occurs although perhaps to a lesser extent, in chronic progressive MS.

It has been demonstrated that in the presence of LDN, the numbers of T-cells may increase by more than 300%. Therefore, when the number of T-cells is initially increased, the predominance of CD4 helper T-cells may increase the intensity of the MS, temporarily increasing some symptoms. However, as the number of T-cells continues to increase the normal balance of suppressor to helper T-cells is restored, the activity and intensity of the disease process is reduced, and symptoms once again diminish.

In less than five percent of cases treated, increased introductory symptoms may be more severe or more prolonged than usual, lasting sometimes for several weeks. Rarely, symptoms may persist for two or three months before the appropriate beneficial response is achieved.

Symptoms Related to the Endorphin Response

If the endorphin response is rapid and significant, there may also be some additional symptoms related to the increased level of endorphins, including nausea and constipation. The nausea usually fades within a few days, and can be minimized by taking a lower dose of the drug until the symptoms lessen. The constipation may take two or three weeks to resolve, during which time additional supportive measures may be required.

Intrinsic Toxicity of the Drug

From toxicity studies of naltrexone in the early 1980's, reversible liver changes were found to occur only in those receiving doses higher than 300 mg per day. This is on average one hundred times the dose used in LDN. The possibility of adverse side effects due to drug toxicity cannot be entirely excluded, but the likelihood of damaging side-effects is believed to be minimal. Long-term use of LDN has not yet been evaluated by a trial. However a trial is planned, and it is hoped that it will be conducted shortly when adequate funding has been found.

In the meantime, due to possible toxic effects of long-term use of LDN on the liver and kidneys, it is required that anyone suffering previous liver or kidney problems should report this condition before starting therapy. The risk is believed to be minimal, however, as the dose of the drug is extremely low, and it is expected to be metabolized and excreted from the body within three or four hours of ingestion.

Contraindications and Special Precautions:

LDN stimulates the immune system, whereas many of the drugs routinely used by the NHS in the treatment of MS suppress the immune system. Therefore, LDN cannot be used whilst taking steroids, beta-interferons, methotrexate, azathioprine, mitoxantrone or any other immune-suppressant drug.

Note LDN can be taken with copaxone**,** as this is not an interferon.

For information on filling a NHS or private prescription please contact us.

© Case Health Pty Ltd

LDN has been used for:

Alzheimer's Disease
Amyotrophic lateral sclerosis (ALS)
Ankylosing Spondylitis
Autism Spectrum Disorders
Autoimmune Polyendocrinopathy-candidiasis-ectodermal dystrophy (APECED)
Behcet's Disease
Bipolar Disorder
Some Cancers
Celiac Disease
Chronic Fatigue Syndrome (CFS)
CREST Syndrome
Crohn's Disease
Chronic Obstructive Pulmonary Disease (COPD)
Depression
Endometriosis
Fibromyalgia
HIV/AIDS
Infertility
Irritable Bowel Syndrome
Multiple Sclerosis
Murine Inflammatory Bowel Disease
Myalgic Encephalomyelitis (ME)
Obsessive Compulsive Disorder (OCD)
Parkinson's Disease
Pemphigoid
Premenstrual Syndrome (PMS)
Polycystic Ovarian Disease (PCOD) or Syndrome (PCOS)
Polymyalgia Rheumatica (PMR)
Primary Lateral Sclerosis (PLS)
Psoriasis
Rheumatioid Arthritis (RA)
Sacoidosis
Scleroderma
Stiff Person Syndrome (SPS)
Systemic Lupus Erythematosis (SLE)
Transverse Myelitis
Ulcerative Colitis
Wegener's Granulomatosis

© Case Health Pty Ltd

Filling a Fast-release LDN Compounded Prescription in the UK:
Phone Paula at Dickson's Pharmacy in Glasgow on: 0141 647 8032, she will organise everything for you. Or email homedeliverypharmacy@yahoo.co.uk

The liquid LDN suspension cost £15 a month and is sent monthly recorded delivery to your home.

There are no problems with fillers; it keeps 28 days out of the fridge, 56 days inside.

Capsules are also available at £30 monthly with Avicel filler.
Further costs are involved if you live outside of the UK.

LDN is available in liquid form or capsule, privately or with an NHS Prescription from Dickson's Chemist in Glasgow.

Dickson Chemist Ltd
35 Mitchell Arcade
Rutherglen
Glasgow
G73 2LS

AUSTRALIA

Filling a Fast-release LDN Compounded Prescription in Australia:

The Green Dispensary Compounding Pharmacy
46 Beulah Rd
Norwood SA 5067
Tel (08) 83637322
Fax (08) 83637244
Antony Condina, Compounding Pharmacist
acondina@nunet.com.au
http://www.greendispensary.com

USA

Filling a Fast-release LDN Compounded Prescription in the USA:

Skip's Pharmacy
21000 Boca Rio Rd
Suite A-29
Boca Raton
Florida 33433
Tel 561-218-0111 & 800-553-7429
Fax: 561-218-8873
Web: http://www.skipspharmacy.com

*The **LDN Research Trust Fact Sheet***
has been reproduced with permission from Linda Elsegood of LDN Research Trust.

LDN Pilot Trials, Studies, Research

© Case Health Pty Ltd

A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis

DR MAIRA GIRONI'S PERSONAL PERSPECTIVE can also be found in this 2010 edition.

1: Mult Scler. 2008 Sep;14(8):1076-83

Gironi Maira, Martinelli-Boneschi Filippo, Sacerdote P, Solaro C, Zaffaroni M, Cavarretta R, Moiola L, Bucello S, Radaelli M, Pilato V, Rodegher M, Cursi M, Franchi S, Martinelli V, Nemni R, Comi G, Martino G.

Institute of Experimental Neurology (INSPE) and Department of Neurology, San Raffaele Scientific Institute, Via Olgettina 58, Milan, Italy; Fondazione Don Carlo Gnocchi, IRCCS, Milan, Italy.

ABSTRACT

A sixth month phase II multicenter-pilot trial with a low dose of the opiate antagonist Naltrexone (LDN) has been carried out in 40 patients with primary progressive multiple sclerosis (PPMS).

The primary end points were safety and tolerability.

Secondary outcomes were efficacy on spasticity, pain, fatigue, depression, and quality of life. Clinical and biochemical evaluations were serially performed. Protein concentration of beta-endorphins (BE) and mRNA levels and allelic variants of the mu-opiod receptor gene (OPRM1) were analyzed.

Five dropouts and two major adverse events occurred. The remaining adverse events did not interfere with daily living. Neurological disability progressed in only one patient.

A significant reduction of spasticity was measured at the end of the trial. BE concentration increased during the trial, but no association was found between OPRM1 variants and improvement of spasticity. Our data clearly indicate that LDN is safe and well tolerated in patients with PPMS.

PMID: 18728058 PubMed - in process
http://www.ncbi.nlm.nih.gov/pubmed/18728058

© Case Health Pty Ltd

Pilot trial of low dose naltrexone and quality of life in MS

Bruce A.C. Cree *, Elena Kornyeyeva, Douglas S. Goodin
Multiple Sclerosis Center at UCSF, 350 Parnassus Ave., Suite 908, San Francisco, CA 94117
Email: Bruce A.C. Cree mailto:ubruce.cree@ucsf.edubruce.cree@ucsf.edu
*Correspondence to Bruce A.C. Cree, Multiple Sclerosis Center at UCSF, 350 Parnassus Ave., Suite 908, San Francisco, CA 94117

ABSTRACT

Objective:
To evaluate the efficacy of 4.5 mg nightly naltrexone on the quality of life of multiple sclerosis patients.

Methods:
This single center, double-masked, placebo-controlled, crossover studied evaluated the efficacy of eight weeks of treatment with 4.5 mg nightly naltrexone (Low dose naltrexone or LDN) on self reported quality of life of MS patients.

Results:
80 subjects with clinically definite multiple sclerosis were enrolled and 60 subjects completed the trial. 10 withdrew before completing the first trial period: 8 for personal reasons, 1 for a non-MS related adverse event and 1 for perceived benefit. Database management errors occurred in 4 other subjects and quality of life surveys were incomplete in 6 subjects for unknown reasons. The high rate of subject dropout and data management errors substantially reduced the trial's statistical power. LDN was well tolerated and serious adverse events did not occur. LDN was associated with significant improvement on the following mental health quality of life measures: a 3.3 point improvement on the Mental Component Summary score of the SF-36 (P=.04), a 6 point improvement on the Mental Health Inventory (P<.01), a 1.6 point improvement on the Pain Effects Scale (P=.04) and a 2.4 point improvement on the Perceived Deficits Questionnaire (P=.05).

Interpretation:
LDN significantly improved mental health quality of life indices.
Further studies with LDN in MS are warranted. Ann Neurol 2010.
http://www3.interscience.wiley.com/journal/123289912/abstract

Received: 2 July 2009; Revised: 8 January 2010; Accepted: 10 February 2010
Digital Object Identifier (DOI)
10.1002/ana.22006 About DOI
http://www3.interscience.wiley.com/doiinfo.html
Additional Material
Additional Supporting Information may be found in the online version of this article.

Annals of Neurology
Volume 9999 Issue 999A, Page NA
Published Online: 19 Feb 2010
Copyright 2009 American Neurological Association

***A Randomized Placebo-Controlled, Crossover-Design Study of the Effects of Low Dose Naltrexone for Multiple Sclerosis - Phase III Study - Principal Investigator: Bruce Kornyeyva, MD, PhD MS Center, UCSF - http://clinicaltrials.gov/ct2/show/NCT00501696

Fibromyalgia symptoms are reduced by low-dose naltrexone: a pilot study

Younger J, Mackey S.

School of Medicine, Department of Anesthesia, Division of Pain Management, Stanford University, 780 Welch Road, Suite 208, Palo Alto, CA 94304-1573, USA. jarred.younger@stanford.edu

ABSTRACT

OBJECTIVE: Fibromyalgia is a chronic pain disorder that is characterized by diffuse musculoskeletal pain and sensitivity to mechanical stimulation. In this pilot clinical trial, we tested the effectiveness of low-dose naltrexone in treating the symptoms of fibromyalgia. DESIGN: Participants completed a single-blind, crossover trial with the following time line: baseline (2 weeks), placebo (2 weeks), drug (8 weeks), and washout (2 weeks).

PATIENTS: Ten women meeting criteria for fibromyalgia and not taking an opioid medication.

INTERVENTIONS: Naltrexone, in addition to antagonizing opioid receptors on neurons, also inhibits microglia activity in the central nervous system. At low doses (4.5 mg), naltrexone may inhibit the activity of microglia and reverse central and peripheral inflammation.

OUTCOME MEASURES: Participants completed reports of symptom severity everyday, using a handheld computer. In addition, participants visited the lab every 2 weeks for tests of mechanical, heat, and cold pain sensitivity.

RESULTS: Low-dose naltrexone reduced fibromyalgia symptoms in the entire cohort, with a greater than 30% reduction of symptoms over placebo. In addition, laboratory visits showed that mechanical and heat pain thresholds were improved by the drug. Side effects (including insomnia and vivid dreams) were rare, and described as minor and transient. Baseline erythrocyte sedimentation rate predicted over 80% of the variance in drug response. Individuals with higher sedimentation rates (indicating general inflammatory processes) had the greatest reduction of symptoms in response to low-dose naltrexone.

CONCLUSIONS: We conclude that low-dose naltrexone may be an effective, highly tolerable, and inexpensive treatment for fibromyalgia.

Pain Med. 2009 May-Jun;10(4):663-72. Epub 2009 Apr 22.

PMID: 19453963
PubMed - indexed for MEDLINE
http://www.ncbi.nlm.nih.gov/pubmed/19453963

Low dose naltrexone therapy improves active Crohn's disease

Smith JP, Stock H, Bingaman S, Mauger D, Rogosnitzky M, Zagon IS.
Department of Medicine, Pennsylvania State University College of Medicine, Hershey, Pennsylvania 17033, USA.

OBJECTIVES: Endogenous opioids and opioid antagonists have been shown to play a role in healing and repair of tissues. In an open-labeled pilot prospective trial, the safety and efficacy of low-dose naltrexone (LDN), an opioid antagonist, were tested in patients with active Crohn's disease.

METHODS: Eligible subjects with histologically and endoscopically confirmed active Crohn's disease activity index (CDAI) score of 220-450 were enrolled in a study using 4.5 mg naltrexone/day. Infliximab was not allowed for a minimum of 8 wk prior to study initiation. Other therapy for Crohn's disease that was at a stable dose for 4 wk prior to enrollment was continued at the same doses. Patients completed the inflammatory bowel disease questionnaire (IBDQ) and the short-form (SF-36) quality of life surveys and CDAI scores were assessed pretreatment, every 4 wk on therapy and 4 wk after completion of the study drug. Drug was administered by mouth each evening for a 12-wk period.

RESULTS: Seventeen patients with a mean CDAI score of 356 +/- 27 were enrolled. CDAI scores decreased significantly (P= 0.01) with LDN, and remained lower than baseline 4 wk after completing therapy. Eighty-nine percent of patients exhibited a response to therapy and 67% achieved a remission (P < 0.001). Improvement was recorded in both quality of life surveys with LDN compared with baseline. No laboratory abnormalities were noted. The most common side effect was sleep disturbances, occurring in seven patients.

CONCLUSIONS: LDN therapy appears effective and safe in subjects with active Crohn's disease. Further studies are needed to explore the use of this compound.

PMID: 17222320 PubMed - indexed for MEDLINE
http://www.ncbi.nlm.nih.gov/pubmed/17222320

Whilst in the final stages of her Crohn's/LDN Paediatric trial. Dr Jill Smith presented an abstract on her LDN/Crohn's translational research and trial results at Digestive Disease Week 1-5 May 2010 in New Orleans, USA.

© Case Health Pty Ltd

Clinical Trials of low dose naltrexone therapy
AWAITING PUBLICATION

Three important clinical trials of LDN have each recently completed their planned studies and are now either undergoing final statistical analysis or are awaiting peer-review medical journal publication. Until that final step is achieved, we are in the interim pleased to observe that various useful outcomes will be reported by all three.

The trials involved:

- LDN effects in HIV/AIDS in Mali, Africa
- LDN for fibromyalgia - a randomized, double-blind study at Stanford University
- LDN for Crohn's disease - a Phase II, randomized placebo-controlled double-blinded study atHershey Medical Center, Penn State College of Medicine

Updates will be posted as they become available: http://www.lowdosenaltrexone.org/ldn_latest_news.htm

© Case Health Pty Ltd

Featured
LDN Papers & Research

Revisiting the ALA/N (α-Lipoic Acid/Low-Dose Naltrexone) Protocol for People With Metastatic and Nonmetastatic Pancreatic Cancer: A Report of 3 New Cases

Integrative Cancer Therapies, December 2009; vol. 8, 4: pp. 416-422.
Authors - Burton M. Berkson, Daniel M. Rubin, and Arthur J. Berkson

Abstract

The authors, in a previous article, described the long-term survival of a man with pancreatic cancer and metastases to the liver, treated with intravenous alpha-lipoic acid and oral low-dose naltrexone (ALA/N) without any adverse effects. He is alive and well 78 months after initial presentation.

Three additional pancreatic cancer case studies are presented in this article. At the time of this writing, the first patient, GB, is alive and well 39 months after presenting with adenocarcinoma of the pancreas with metastases to the liver.

The second patient, JK, who presented to the clinic with the same diagnosis was treated with the ALA/N protocol and after 5 months of therapy, PET scan demonstrated no evidence of disease.

The third patient, RC, in addition to his pancreatic cancer with liver and retroperitoneal metastases, has a history of B-cell lymphoma and prostate adenocarcinoma. After 4 months of the ALA/N protocol his PET scan demonstrated no signs of cancer.

In this article, the authors discuss the poly activity of ALA: as an agent that reduces oxidative stress, its ability to stabilize NFkB, its ability to stimulate pro-oxidant apoptosic activity, and its discriminative ability to discourage the proliferation of malignant cells. In addition, the ability of lowdose naltrexone to modulate an endogenous immune response is discussed. This is the second article published on the ALA/N protocol and the authors believe the protocol warrants clinical trial.

http://ict.sagepub.com/content/8/4/416.abstracthttp://ict.sagepub.com/content/8/4/416.abstract

© Case Health Pty Ltd

Opioid growth factor suppresses expression of experimental autoimmune encephalomyelitis

Journal - Brain research.
Citation - Brain Res.
Publication date - 2009 Nov 18
Authors - Zagon IS, Rahn KA, Bonneau RH, Turel AP, McLaughlin PJ
Investigators - Robert H. Bonneau, Patricia J. McLaughlin, Ian S. Zagon

Abstract

Naltrexone, an opioid antagonist, has been shown to modulate expression of experimental autoimmune encephalomyelitis (EAE), an animal model of MS, suggesting that endogenous opioids are inhibitory trophic factors in EAE. In the present study, we investigated the effects of one native opioid peptide, opioid growth factor ([Met(5)]-enkephalin), on the onset and progression of EAE. C57Bl/6 mice injected with myelin oligodendrocyte glycoprotein (MOG) received daily injections of 10 mg/kg OGF (MOG+OGF) or saline (MOG+Vehicle). Over 60% of the MOG+OGF animals did not exhibit behavioral signs of disease (EAE) in contrast to 100% of the mice in the MOG+Vehicle group. The severity and disease indices of EAE in the OGF-treated mice were markedly reduced from MOG+Vehicle cohorts. By day 30, 60% of MOG+OGF mice had a remission, relative to 4% in the MOG+Vehicle group. MOG-injected mice receiving OGF had significant reductions in activated astrocytes and damaged neurons compared to MOG+Vehicle animals. Unlike MOG+Vehicle and MOG+OGF mice with behavioral signs of disease, MOG+OGF animals without manifestation of disease had no lumbar spinal cord demyelination. Both OGF and OGF receptor were detected in splenic-derived T lymphocytes by immunohistochemistry. OGF treatment decreased both DNA synthesis and cell proliferation in comparison to vehicle-treated T cell lymphocyte cultures. These results indicate that an endogenous opioid, OGF, inhibits the onset and progression of EAE, and suggest that clinical studies on the use of OGF treatment for MS are merited.

Endogenous opioids regulate expression of experimental autoimmune encephalomyelitis: a new paradigm for the treatment of multiple sclerosis.
Journal Experimental biology and medicine (Maywood, N.J.)

http://fred.psu.edu/ds/retrieve/fred/publication/19931226

© Case Health Pty Ltd

Endogenous opioids regulate expression of experimental autoimmune encephalomyelitis: a new paradigm for the treatment of multiple sclerosis

Citation - Exp Biol Med (Maywood). 234(11):1383-92
Publication date - 2009 Nov
Authors - Zagon IS, Rahn KA, Turel AP, McLaughlin PJ
Investigators - Patricia J. McLaughlin, Ian S. Zagon
MeSH headings - Analgesics, Opioid, Encephalomyelitis, Autoimmune, Experimental Multiple Sclerosis, Naltrexone
MeSH qualifiers – metabolism, pathology, drug therapy, therapeutic use

Abstract

Preclinical investigations utilizing murine experimental auto-immune encephalomyelitis (EAE), as well as clinical observations in patients with multiple sclerosis (MS), may suggest alteration of endogenous opioid systems in MS. In this study we used the opioid antagonist naltrexone (NTX) to invoke a continuous (High Dose NTX, HDN) or intermittent (Low Dose NTX, LDN) opioid receptor blockade in order to elucidate the role of native opioid peptides in EAE. A mouse model of myelin oligodendrocyte glycoprotein (MOG)-induced EAE was employed in conjunction with daily treatment of LDN (0.1 mg/kg, NTX), HDN (10 mg/kg NTX), or vehicle (saline). No differences in neurological status (incidence, severity, disease index), or neuropathological assessment (activated astrocytes, demyelination, neuronal injury), were noted between MOG-induced mice receiving HDN or vehicle. Over 33% of the MOG-treated animals receiving LDN did not exhibit behavioral signs of disease, and the severity and disease index of the LDN-treated mice were markedly reduced from cohorts injected with vehicle. Although all LDN animals demonstrated neuropathological signs of EAE, LDN-treated mice without behavioral signs of disease had markedly lower levels of activated astrocytes and demyelination than LDN- or vehicle-treated animals with disease. These results imply that endogenous opioids, evoked by treatment with LDN and acting in the rebound period from drug exposure, are inhibitory to the onset and progression of EAE, and suggest that clinical studies of LDN are merited in MS and possibly in other autoimmune disorders.

http://fred.psu.edu/ds/retrieve/fred/publication/19855075

Note: Dr Ian S Zagon's decades of research has resulted in extensive publications.

Ian S. Zagon, Ph.D., is Professor of Neuroscience and Anatomy at The Pennsylvania State University, College of Medicine, Hershey, Pennsylvania. Dr Zagon holds membership in the Specialized Cancer Research Center, Intercollege Graduate Program in Genetics, Cell and Molecular Biology Graduate Program Neuroscience Graduate Program, M.D./Ph.D. Program, and the Integrative Biosciences Graduate Program-Molecular Medicine, Neuroscience, and Cell and Developmental Biology.

© Case Health Pty Ltd

A study of 24-hour profiles of plasma met-enkephalin in man

M.F. Shanks(a,b), Vicky Clement-Jonesa(a,b), C.J. Linsella(a,b), P.E. Mullena(a,b), Lesley H. Reesa(a,b), and G.M. Bessera(a,b), 1981

(a)The Institute of Psychiatry, London, SE5 8AF U.K.
(b)Departments of Endocrinology and Chemical Endocrinology, St. Bartholomew's Hospital, London, EC1A 7BE U.K.

Abstract

Met-enkephalin has recently been demonstrated to circulate in human plasma and using this highly specific extracted radioimmunoassay the fluctuations of plasma Met-enkephalin in man were studied over 24 h. The subjects were 6 healthy volunteers.

Following a 24 h adaptation period in the metabolic ward and sleep laboratory, an i.v. catheter was inserted. Blood samples were taken at hourly intervals through the day and at 30 min intervals between 23.00 h and 07.00 h. Sleep was monitored polygraphically.

There was no regular rhythm discernible in plasma Met-enkephalin levels throughout the 24 h, nor was there any relationship with sleep or food intake.

In a further 3 subjects B-LPH and B-endorphin levels as estimated by N- and C-terminal B-LPH radioimmunoassay were elevated on waking compared with 01.00 h, suggesting a nyctohemeral rhythm.

In contrast to the correlated circadian fluctuations in B-LPH, ACTH and B-endorphin levels therefore, the lack of circadian rhythmicity and dissociation of plasma Met-enkephalin from plasma levels of the former group of peptides suggests control mechanisms for the secretion of Met-enkephalin are quite different and adds support to the concept of separate Met-enkephalin precursors.

PMID: 6261889
http://www.ncbi.nlm.nih.gov/pubmed/6261889

Circadian rhythm of beta-endorphin in the plasma of clinically healthy subjects and in patients with adrenocortical disorders

Nicolau GY, Haus E, Lakatua D, Popa M, Marinescu I, Ionescu B, Bogdan C, Popescu M, Sackett-Lundeen L, Robu E, et al.

Endocrinologie. 1986 Jul-Sep;24(3):185-95.

Abstract

Immunoreactive beta-endorphin was determined in the plasma of 37 elderly subjects (73 +/- 7 years of age), in 3 young or young adult subjects without adrenal disease, in 4 women with clinical adrenogenital syndrome, in 1 man with Cushing's disease.

Immunoreactive beta-endorphin in plasma was measured by radioimmunoassay in six samples of each subject collected at 4-hour intervals over a 24-hour span. The observation of a circadian rhythm in circulating immunoreactive beta-endorphin with highest values during the late night and early morning hours is extended to elderly subjects in the 8th decade.

The beta-endorphin plasma concentrations in the few clinically healthy young adult subjects studied fell within the same range. The circadian variation of the group of elderly subjects was used as reference in the clinical evaluation of plasma beta-endorphin concentrations in patients with pituitary-adrenocortical disorders.

The need for circadian rhythm qualified reference values is shown by the observation of the circadian variations of circulating immunoreactive beta-endorphins in the patients with adrenogenital syndrome and Cushing's disease in whom abnormalities in the concentration of circulating beta-endorphin were found at certain circadian stages but not at others.

PMID: 2946069
http://www.ncbi.nlm.nih.gov/pubmed/2946069

© Case Health Pty Ltd

Circadian Pattern of Serum Leptin and B-Endorphin Levels in Obese and Non Obese Women

F. Perfetto; A. Piluso; A. Cagnacci; R. Tarquini

Biological Rhythm Research, Volume 33, Issue 3 July 2002 , pages 287 – 302

Abstract

To investigate diurnal profile of leptin and B-endorphin circulating levels and to assess any possible influence between these two peptides, 24-h serum concentrations of leptin and B-endorphin were examined in 24 obese (BMI 32.1 ± 1.3) women and in 12 controls (BMI 21 ± 0.5). Blood samples for leptin and B-endorphin determinations were drawn every four hours for 24 hours beginning at 8.00 am. Data were analyzed by unpaired t-test, linear regression and by inferential statistical procedures.

We found a significant circadian rhythm for both peptides, either in obese or in controls. The 24-h mean leptin levels were significantly ($p < 0.0001$) higher (32.1 ± 2.8ng/ml; mean ± SE) in obese women than controls (13.6 ± 1.1), with a peak time located after midnight in obese and controls. The 24-h B-endorphin mean levels were significantly ($p < 0.0001$) higher in obese than controls (30.6 ± 2 vs 22 ± 1.9pg/ml), with acrophase located in the early morning hours in both groups.

Finally, we found a positive relationship (R 2 = 0.303; p = 0.0005) between leptin and B-endorphin circadian mean levels. These results show that the time course of 24-h rhythm of leptin and B-endorphin are similar in obese and lean women. The positive relationship between 24-h leptin and B-endorphin mean levels allow us to speculate that leptin may be a likely candidate to increase B-endorphin levels in obese subjects.
http://www.informaworld.com/smpp/content~db=all~content=a714014319

© Case Health Pty Ltd

Association between circadian rhythms of endogenous hypothalamic opioid peptides and of natural killer cell activity

Nino Mozzanica, Aldo F. Finzi, Sergio Foppa, Giulio Vignati and Maria L. Villa

International Journal of Immunopharmacology
Volume 13, Issues 2-3, 1991, Pages 317-321

Abstract/Extract

' ... Natural killer cell activity and plasmas beta-endorphin levels showed a similar circadian rhythm with the peak in the morning (acrophases at 06.14 and 08.25, respectively), whereas the circadian rhythm of met-enkephalin was approximately in antiphase to the natural killer rhythm (acrophase close to 17.00 hours). ... We show here that circadian rhythms of some neuro-endocrine hormones of the hypothalamic-hypophyseal axis, i.e. beta-endorphin, met-enkephalin and alpha-MSH, are significantly coupled to daily oscillations of NK cell activity. ... '

PMID: 1649145
http://www.ncbi.nlm.nih.gov/pubmed/1649145

Methionine enkephalin-like, substance P-like, and B-endorphin-like immunoreactivity in human parotid saliva

D.L. Pikula1, E.F. Harris, D.M. Desiderio, G.H. Fridland and J.L. Lovelace

Archives of Oral Biology
Volume 37, Issue 9, September 1992, Pages 705-709

Abstract/Extract

' … These three neuropeptides were measured at daily baseline values by radioimmunoassay. … This is believed to be the first documentation of methionine enkephelin- and substance P-like activities in human parotid saliva and the first demonstration of B-endorphin-like activity in any type of human saliva. … Substance P-like activity was significantly higher in morning than evening samples; B-endorphin-like activity also tended to be higher in the morning samples. Substance P and B-endorphin-like immunoreactivities covaried in a significant positive manner, suggesting either common control mechanisms or similar responses to physiological variables.
http://linkinghub.elsevier.com/retrieve/pii/000399699290076K

© Case Health Pty Ltd

An about 50,000-dalton protein in adrenal medulla: a common precursor of [Met]- and [Leu]enkephalin

RV Lewis, AS Stern, S Kimura, J Rossier, S Stein, and S Udenfriend

Science, Vol 208, Issue 4451, 1459-1461, June 1980

Abstract

A protein that may be an enkephalin precursor has been identified in extracts of bovine adrenal medulla. This protein (about 50,000 daltons) appears to contain seven copies of [Met]enkephalin and one copy of [Leu]enkephalin. Digestion with trypsin and carboxypeptidase B yields [Met]enkephalin and [Leu]enkephalin in a ratio of almost 7 to 1. The enkephalins were identified by chromatography and by their binding to opiate receptors. Some characteristics of several other adrenal peptides that may serve as intermediates in the biosynthesis of the enkephalins are presented.
http://www.sciencemag.org/cgi/content/abstract/208/4451/1459

Processing of proenkephalin is tissue-specific

D Liston, G Patey, J Rossier, P Verbanck, and JJ Vanderhaeghen

Science, Vol 225, Issue 4663, 734-737, August 1984,

Abstract

Most neuropeptides are synthesized as large precursor proteins. These precursors undergo a maturation process involving several proteolytic events that generate the biologically active peptides. The enzymatic mechanisms underlying this processing are still largely unknown. The processing of the precursor protein proenkephalin was studied in two different bovine tissues, the hypothalamus and adrenal medulla. The high molecular weight enkephalin-containing peptides that accumulate in these two tissues were found to be different, indicating the existence of two processing pathways for this neuropeptide precursor.
http://www.sciencemag.org/cgi/content/abstract/225/4663/734

© Case Health Pty Ltd

Beta-endorphin and dynorphin mimic the circadian immunoenhancing and anti-stress effects of melatonin

Georges J.M. Maestronia and Ario Contia; Laboratory for Experimental Pathology, Istituto Cantonale di Patologia, 6604 Locarno, Switzerland

International Journal of Immunopharmacology
Volume 11, Issue 4, 1989, Pages 333-340

Abstract/Extract

' ... We found also that restraint stress or prednisolone treatment decreases the immunopharmacologic potency of B-endorphin and augments that of dynorphin 1-13. ... We found that B-endorphin and dynorphin 1-13 can mimic the immunoenhancing and anti-stress effect of melatonin. ... Most interesting, all these effects proved to be dependent on the time of administration, i.e. showed a circadian rhythm in analog with the effects of melatonin. ... '

PMID: 2570759
http://www.ncbi.nlm.nih.gov/pubmed/2570759

Circadian variation in the expression of cell-cycle proteins in human oral epithelium

Bjarnason GA, Jordan RC, Sothern RB.

Am J Pathol. 1999 Feb;154(2):613-22.

Toronto-Sunnybrook Regional Cancer Centre, Department of Medicine, University of Toronto, Ontario, Canada.

Abstract

At the tissue level, there is experimental and clinical data to suggest a cytokinetic coordination of the cell cycle with a greater proportion of cycling cells entering S-phase and mitosis at specific times of the day. The association of certain cell-cycle proteins with defined events in the cell cycle is well established and may be used to study the timing of cell-cycle phases over 24 hours. In this study oral mucosal biopsies were obtained from six normal human volunteers at 4-hour intervals, six times over 24 hours. Using

immunohistochemistry, the number of positive cells expressing the proteins p53, cyclin-E, cyclin-A, cyclin-B1, and Ki-67 was determined for each biopsy and expressed as the number of positive cells per mm of basement membrane. We found a statistically significant circadian variation in the nuclear expression of all of these proteins with the high point of expression for p53 at 10:56 hours, cyclin-E at 14:59 hours, cyclin-A at 16:09 hours, cyclin-B1 at 21:13 hours, and Ki-67 at 02:50 hours. The circadian variation in the nuclear expression of cyclins-E (G1/S phase), -A (G2-phase), and -B1 (M-phase) with a normal physiological progression over time suggests a statistically significant circadian variation in oral epithelial cell proliferation. The finding of a circadian variation in the nuclear expression of p53 protein corresponding to late G1 is novel. This information has clinical implications regarding the timing of chemotherapy and radiotherapy.
http://www.ncbi.nlm.nih.gov/pubmed/10027418

Glucocorticoids Play a Key Role in Circadian Cell Cycle Rhythms

---

To establish circadian cell cycle rhythms, cell-autonomous clock mechanisms act in concert with a systemic signaling environment of which glucocorticoids are an essential part.

Thomas Dickmeis(1), Kajori Lahiri(1), Gabriela Nica(2), Daniela Vallone(1), Cristina Santoriello1¤, Carl J. Neumann3, Matthias Hammerschmidt2, Nicholas S. Foulkes1*

1. Max-Planck-Institut für Entwicklungsbiologie, Tübingen, Germany
2. Max-Planck-Institut für Immunbiologie, Freiburg, Germany
3. European Molecular Biology Laboratory Heidelberg, Heidelberg, Germany

Author Summary

To guarantee normal growth and to avoid tumor formation, the timing of cell division must be under strict control. Remarkably, cells, from bacteria to man, often divide only at certain times of day, suggesting the influence of internal biological clocks. A central pacemaker structure in the brain controls diurnal rhythms of behavior and hormone release. However, biological clocks are also encountered in almost every cell type (so-called "peripheral" clocks), in which they regulate daily changes in cell biology, including cell division. Very little is known to date about how the two clock systems interact. Here, by examining zebrafish strains with defects in hormone production, we find that peripheral clocks require the steroid hormone cortisol to generate daily rhythms of cell proliferation. Interestingly, the daily changes in cortisol levels observed in normal zebrafish are not required to achieve this control; treating the cortisol-deficient strains with constant levels of a drug that mimics the effects of cortisol restores normal cell-division rhythms. Thus, it appears that internal cell timers cooperate with hormonal signals to regulate the timing of cell division.

' ... Together with the reduced number of corticotropes observed in the rx3 mutant embryos, this result strongly suggests that the corticotropes are required for the

establishment of the circadian cell cycle rhythms. ... Thus, the reduction of corticotrope cells in the strong allele mutant pituitary seems to strongly reduce cortisol levels, pointing to cortisol as a candidate systemic signal required for circadian cell cycle rhythmicity. ... Activation of Glucocorticoid Signaling Rescues Circadian Cell Cycle Defects ... These findings point to glucocorticoids as a requirement for high-amplitude cell cycle rhythms. ... '

http://www.plosbiology.org/article/info%3Adoi%2F10.1371%2Fjournal.pbio.0050078

Beta-endorphin: stimulation of growth hormone release in vivo

---

Andre Dupont, Lionel Cusan, Marie Garon, Fernand Labrie, and Choh Hao Li Laboratory of Molecular Endocrinology, Le Center Hospitalier de l'Universite Laval, Quebec, G1V 4 G2, Canada, and; Hormone Research Laboratory, University of California, San Francisco, CA 94143 USA

Abstract

Two micrograms of beta-endorphin (beta-lipotropin61-91) injected intraventricularly in rats that had been treated with antiserum against somatostatin led to a 6- and 10-fold stimulation of the concentration of plasma growth hormone (somatotropin) measured 10 and 20 min after injection of the peptide, whereas 400 mug of methionine-enkephalin led to a 4- to 6-fold increase of levels of plasma growth hormone at 10 min with a rapid return to basal levels at later time intervals. At doses of 5 and 25 mug, beta-endorphin led to a 20- to 30-fold stimulation of levels of plasma growth hormone, the maximal effect being measured between 20 and 30 min after injection. These data suggest the possible role of the endogenous opiate-like peptides in the control of growth hormone secretion.

Proc. Natl. Acad. Sci. USA Vol 74, No. 1, pp. 358-359,January 1977, Medical Sciences
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC393259/
Page 358, 359 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC393259/?page=1

Circadian cancer therapy

WJ Hrushesky and GA Bjarnason, Albany Medical College, Stratton

Veterans Administration Medical Center, NY 12208.

Journal of Clinical Oncology, Vol 11, 1403-1417
Copyright © 1993 by American Society of Clinical Oncology (Six known citations.)

Abstract – Results & Conclusion:

The medical literature describing molecular, cellular, and organismic time-keeping mechanisms, as well as circadian rhythms, in cytokinetic, pharmacokinetic, and pharmacodynamic parameters relevant to cancer chemotherapy, which support the predictable rhythmic relationship between dose and effect that occurs during each day, were reviewed. Advantages for optimal circadian scheduling have been demonstrated for diminishing side effects and increasing maximal safe dose-intensity of drugs of diverse class. The use of the predictable circadian relationship of dose and response provides another increment of progress in the treatment of cancer patients.
http://jco.ascopubs.org/cgi/content/abstract/11/7/1403

RANDOMIZED TRIAL

Comparison of Toxicity Associated with Early Morning Versus Late Afternoon Radiotherapy in Patients with Head-and-Neck Cancer: A Prospective Randomized Trial of the National Cancer Institute of Canada Clinical Trials Group (HN3)

Georg A Bjarnason, Robert G Mackenzie, Abdenour Nabid, Ian D Hodson, Samy El-Sayed, Laval Grimard, Michael Brundage, James Wright, John Hay, Pradip Ganguly, Carson Leong, Jane Wilson, Richard C K Jordan, Melanie Walker, Dongsheng Tu, Wendy Parulekar; Department of Medical Oncology, Sunnybrook Odette Cancer Centre, Toronto, ON, Canada

Int J Radiat Oncol Biol Phys. 2008 Sep 19;: 18805649 Cit:4.

CONCLUSION: In this proof of principle study, morning RT was associated with significantly less weight loss after 5 months and an apparent reduction in oral mucositis in a subset of patients receiving >/=66 Gy and in patients who smoked during therapy.
http://lib.bioinfo.pl/auid:1890851

More LDN References

© Case Health Pty Ltd

References

LDN Clinical Trials/Studies/Doctor Report/Med Info

(1) **CLINICAL TRIAL LISTING**

http://www.lowdosenaltrexone.org/ldn_trials.htm

(2) **STUDIES: LDN/CROHN'S DISEASE**

(a) **'Low Dose Naltrexone Therapy Improves Active Crohn's Disease**', American Journal of Gastroenterology, Prof Jill Smith, Professor of Gastroenterology, Pennsylvania State University, Jan 11 2007
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&list_uids=17222320

(b) '**The Efficacy of Low Dose Naltrexone Therapy in Children With Crohn's Disease (LDN-Ped)'** A Randomized, Placebo-controlled Phase II Study, July 2008 – Jan 2012 (Data Collection Date for Primary Outcome Measure), ClinicalTrials.gov Identifier: NCT00715117. Penn State University, Jill P. Smith, MD
http://clinicaltrials.gov/ct2/show/NCT00715117?term=naltrexone&rank=18

(3) **CLINICAL TRIAL: LDN/PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS (PPMS), ITALY**

A pilot trial of low-dose naltrexone in primary progressive multiple sclerosis; Gironi M, et al. PMID: 18728058 (PubMed - in process) – ' … Our data clearly indicate that LDN is safe and well tolerated in patients with PPMS. … ' http://www.ncbi.nlm.nih.gov/pubmed/18728058

(4) **STUDY: LDN/Multiple Sclerosis, USA**

(a) **A Randomized Placebo-Controlled, Crossover-Design Study of the Effects of Low Dose Naltrexone for Multiple Sclerosis - Phase III Study** - Principal Investigator: Bruce Kornyeyva, MD, PhD MS Center, University of California San Franciso, USA
http://www3.interscience.wiley.com/journal/123289912/abstract

(b) **STUDY: LDN/Multiple Sclerosis at UCSF, Dr Bruce Cree** – Q patient-funded trial
http://www.mscenter.ucsf.edu/research.htm

(5) **CLINICAL TRIAL – LDN/HIV**

Clinical Trial LDN/HIV in Mail, Africa: Jaquelyn McCandless, MD, Jack Zimmerman, PhD http://www.lowdosenaltrexone.org/developing_nations.htm

(6) **CLINICAL TRIAL – HEMATOLOGIC CANCER/LDN**

CLINICAL TRIAL - Hematologic cancer & LDN: 'Quality of life in hematologic cancer patients: a randomized clinical trial of low dose naltrexone versus placebo', American journal of applied sciences. 2008;5(7):872-875 (indexed in ISI) ISSN: 1 546-923 – Authors 1Mohammad Ali Seifrabiei, 2Mohammad Abbasi, 3Ali Montazeri, 2Fatemeh Shahnazari, 1Arash Pooya - Conclusion: Low dose naltrexone is an effective drug in improving quality of life in patients with hematologic cancer patients. http://www.scipub.org/fulltext/ajas/ajas57872-875.pdf Online Faculty Information System (OFIS), Hamaden University of Medical Sciences
http://umsha.ofis.ir/default.aspx?articles&member=1631&page=1
Hamaden University of Medical Sciences http://www.umsha.ac.ir/eindex.htm

(7) **STUDY:**

(a) **'Stanford Preliminary Study Shows That Low-Dose Naltrexone May Be an Effective, Low-Cost Treatment for Fibromyalgia'**. The study, which appears online in Pain Medicine, was a small, preliminary project to see if low-dose naltrexone showed promise. It did, so Younger and Mackey are already working on a new study that will test low-dose naltrexone in 30 fibromyalgia patients for 16 weeks: Fibromyalgia Clinical Trial http://clinicaltrials.gov/ct2/show/NCT00568555

(b) **STUDY ARTICLE: 'Low Dose Naltrexone for the Treatment of Fibromyalgia',** Stanford Systems Neuroscience Study: Stanford University: http://snapl.stanford.edu/ldn/ http://snapl.stanford.edu/research/ldn.html (USA NIH Clinical Trials website: http://www.clinicaltrials.gov/ct2/show/NCT00568555?term=Fibromyalgia&rank=79)

(c) **STUDY ARTICLE: 'An Update on Fibromyalgia'**, The Stanford University Medical Center Health Hour: Speaker Sean Mackey, MD, assistant professor, Anesthesia, Stanford University Medical Center http://www.researchchannel.org/prog/displayevent.aspx?rid=28078

(8) **MEDICAL REPORT:**

'Long term survival of a 46 year old man with pancreatic cancer and liver metastases and treated with intravenous alpha lipoic acid and low dose naltrexone' - Berkson, BM; Rubin D and Berkson, AJ. Integrative Cancer Therapies 5; 1 March 2006,83-89

(9) **MEDICAL REPORT:**

Revisiting the ALA/N (α-Lipoic Acid/Low-Dose Naltrexone) Protocol for People With Metastatic and Nonmetastatic Pancreatic Cancer: A Report of 3 New Cases, Burton M. Berkson, Daniel M. Rubin, and Arthur J. Berkson; Integrative Cancer Therapies, December 2009; vol. 8, 4: pp. 416-422. http://ict.sagepub.com/content/8/4/416.abstract

(10) **MEDICATION INFORMATION SUMMARY - NALTREXONE:**

Evidence of the hepatotoxic potential of naltrexone is derived primarily from a placebo controlled study in which naltrexone hydrochloride was administered to obese subjects at a dose approximately five-fold that recommended for the blockade of opiate receptors (300 mg per day). http://dailymed.nlm.nih.gov/dailymed/drugInfo.cfm?id=4682

Research References Relevant to LDN

(1) **'Naltrexone modulates tumor response in mice with neuroblastoma',** Zagon IS, McLaughlin PJ.; Science. 1983 Aug 12;221(4611):671-3. PMID: 6867737 http://www.ncbi.nlm.nih.gov/pubmed/6867737

(2) **'Duration of opiate receptor blockade determines tumorigenic response in mice with neuroblastoma: a role for endogenous opioid systems in cancer',** Zagon IS, McLaughlin PJ.. Life Sci. 1984 Jul 23;35(4):409-16. PMID: 6087062 http://www.ncbi.nlm.nih.gov/pubmed/6087062

(3) **'Naltrexone modulates body and brain development in rats: a role for endogenous opioid systems in growth',** Zagon IS, McLaughlin PJ. Life Sci. 1984 Nov 12;35(20):2057-64. PMID: 6092812 http://www.ncbi.nlm.nih.gov/pubmed/6092812

(4) **'Endogenous opioid systems regulate cell proliferation in the developing rat brain',** Zagon IS, McLaughlin PJ. Brain Res. 1987 May 26;412(1):68-72. PMID: 3607463 http://www.ncbi.nlm.nih.gov/pubmed/3607463

(5) **'Endogenous opioids and the growth regulation of a neural tumor',** Zagon IS,

McLaughlin P., Department of Anatomy, Milton S. Hershey Medical Center, Pennsylvania State University, Hershey 17033. Life Sci. 1988;43(16):1313-8. PMID: 2845218
http://www.ncbi.nlm.nih.gov/pubmed/2845218

(6) '**Gene-peptide relationships in the developing rat brain: the response of preproenkephalin mRNA and [Met5]-enkephalin to acute opioid antagonist (naltrexone) exposure'** Ian S. Zagon *, Patricia J. McLaughlin; Department of Neuroscience and Anatomy, The Pennsylvania State University, The M.S. Hershey Medical Center, 500 University Drive, Hershey, PA 17033, USA; Molecular Brain Research 33 (1995) 111-120. PMID: 8774952 http://www.ncbi.nlm.nih.gov/pubmed/8774952

(7) '**The biology of the opioid growth factor receptor (OGFr)'**
Ian S. Zagon(a),*, Michael F. Verderame,(b), Patricia J. McLaughlin,(a)
(a) Department of Neuroscience and Anatomy, H-109, The Milton S. Hershey Medical Center, The Pennsylvania State University, College of Medicine, 500 University Drive, Hershey, PA 17033, USA (b) Department of Medicine, The Pennsylvania State University, College of Medicine, 500 University Drive, Hershey, PA 17033, USA. Brain Research Reviews 38 (2002) 351-376.PMID: 11890982 http://www.ncbi.nlm.nih.gov/pubmed/11890982

(8) '**Opioid growth factor-opioid growth factor receptor axis is a physiological determinant of cell proliferation in diverse human cancers',** Ian S. Zagon, Renee N. Donahue, and Patricia J. McLaughlin; Department of Neural and Behavioral Sciences, The Pennsylvania State University College of Medicine, Hershey, Pennsylvania, USA. Am J Physiol Regul Integr Comp Physiol 297: R1154-R1161, 2009.
PMID: 19675283 http://www.ncbi.nlm.nih.gov/pubmed/19675283

(9) **'Opioid growth factor suppresses expression of experimental autoimmune encephalomyelitis'** 2009 Nov 18. Brain Res., Zagon IS, Rahn KA, Bonneau RH, Turel AP, McLaughlin PJ. http://fred.psu.edu/ds/retrieve/fred/publication/19931226

(10) **'Endogenous opioids regulate expression of experimental autoimmune encephalomyelitis: a new paradigm for the treatment of multiple sclerosis'.** 2009 Nov. Exp Biol Med (Maywood). 234(11):1383-92., Zagon IS, Rahn KA, Turel AP, McLaughlin PJ. http://fred.psu.edu/ds/retrieve/fred/publication/19855075

(11) **'An about 50,000-dalton protein in adrenal medulla: a common precursor of [Met]- and [Leu]enkephalin'**, Science, Vol 208, Issue 4451, 1459-1461, June 1980, RV Lewis, AS Stern, S Kimura, J Rossier, S Stein, and S Udenfriend. Science, Vol 208, Issue 4451, 1459-1461, June 1980 http://www.sciencemag.org/cgi/content/abstract/208/4451/1459

(12) **'β endorphin concentrations in PBMC of patients with different clinical phenotypes of multiple sclerosis'**; M Gironi1, R Furlan1, M Rovaris1, G Comi1, M Filippi1, A E Panerai2, P Sacerdote2; 1Department of Neuroscience, San Raffaele Hospital, Milan, Italy; 2Department of Pharmacology, University of Milan, Milan, Italy. J Neurol Neurosurg Psychiatry 2003;74:495-497 doi:10.1136/jnnp.74.4.495 (Received 27 August 2002, Revised 20 December 2002, Accepted 2 January 2003) http://jnnp.bmj.com/content/74/4/495.abstract

(13) **'The Role of Beta-Endorphin in the Modulation of Immune Responses: Perspectives in Autoimmune Diseases',** Paola Sacerdote, Dept of Pharmacology, Via Vanvitelli 31, University of Milano, 20129 Milano, Italy
http://www.springerlink.com/content/u760404l16118152/

(14) **'Circadian rhythm of beta-endorphin in the plasma of clinically healthy subjects and in patients with adrenocortical disorders'**, Endocrinologie. 1986 Jul-Sep;24(3):185-95. Nicolau GY, Haus E, Lakatua D, Popa M, Marinescu I, Ionescu B, Bogdan C, Popescu M, Sackett-Lundeen L, Robu E, et al. PMID: 2946069 http://www.ncbi.nlm.nih.gov/pubmed/2946069

(15) **'Association between circadian rhythms of endogenous hypothalamic opioid peptides and of natural killer cell activity'**, Nino Mozzanica, Aldo F. Finzi, Sergio Foppa, Giulio Vignati and Maria L. Villa, PMID: 1649145 http://www.ncbi.nlm.nih.gov/pubmed/1649145

(16) **'Methionine enkephalin-like, substance P-like, and B-endorphin-like immunoreactivity in human parotid saliva'**, D.L. Pikula, E.F. Harris, D.M. Desiderio, G.H. Fridland and J.L. Lovelace, Archives of Oral Biology Volume 37, Issue 9, September 1992, Pages 705-709 http://linkinghub.elsevier.com/retrieve/pii/000399699290076K

(17) **'Processing of proenkephalin is tissue-specific'**, Science, Vol 225, Issue 4663, 734-737, August 1984, D Liston, G Patey, J Rossier, P Verbanck, and JJ Vanderhaeghen http://www.sciencemag.org/cgi/content/abstract/225/4663/734

(18) **'Dynorphin and vasopressin: common localization in magnocellular neurons'**, Science, Vol 216, Issue 4541, 85-87, April 1982, SJ Watson, H Akil, W Fischli, A Goldstein, E Zimmerman, G Nilaver, and TB van wimersma Griedanus http://www.sciencemag.org/cgi/content/abstract/216/4541/85

(19) '**Circadian Pattern of Serum Leptin and B-Endorphin Levels in Obese and Non Obese Women'**, F. Perfetto; A. Piluso; A. Cagnacci; R. Tarquini; Biological Rhythm Research, Volume 33, Issue 3 July 2002 , pages 287 – 302. http://www.informaworld.com/smpp/content~db=all~content=a714014319

(20) **'Circadian variation in the expression of cell-cycle proteins in human oral epithelium'**; Bjarnason GA, Jordan RC, Sothern RB; Am J Pathol. 1999 Feb;154(2):613-22; Toronto-Sunnybrook Regional Cancer Centre, Department of Medicine, University of Toronto, Ontario, Canada. http://www.ncbi.nlm.nih.gov/pubmed/10027418

(21) **'Beta-endorphin and dynorphin mimic the circadian immunoenhancing and anti-stress effects of melatonin'**; Georges J.M. Maestronia and Ario Contia; Laboratory for Experimental Pathology, Istituto Cantonale di Patologia, 6604 Locarno, Switzerland PMID: 2570759 http://www.ncbi.nlm.nih.gov/pubmed/2570759

(22) '**Experimental Evidence for Immunomodulatory Effects of Opioids'**, Paola Sacerdote, Elena Limiroli, and Leda Gaspani, Department of Pharmacology, University of Milano, Italy. PMID: 12617569. Adv Exp Med Biol. 2003;521:106-16. Landes Bioscience - http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=eurekah.section.10979

(23) '**Role of nitric oxide in inflammation mediated neurodegeneration'**
PMID: 12076984
http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&db=PubMed&list_uids=12076984&dopt=AbstractPlus

(24) '**Opioids As Modulators of Cell Death and Survival** - Unraveling Mechanisms and Revealing New Indications'; Irmgard Tegeder and Gerd Geisslinger; Pharmacological Reviews; 0031-6997/04/5603-351-369; *Pharmacol Rev* 56:351-369, 2004 http://pharmrev.aspetjournals.org/cgi/content/full/56/3/351

(25) '**The Opioid Antagonist Naltrexone Improves Murine Inflammatory Bowel Disease'**; Gail L. Matters et al, Departments of Biochemistry and Molecular Biology, Pennsylvania State University College of Medicine, Hershey, Pennsylvania, USA http://www.ncbi.nlm.nih.gov/pubmed/18569389

(26) **'Gene Scan Shows Body's Clock Influences Numerous Physical Functions, From Immunity to Thyroid Hormones, Pineal Gland Exerts Effects on 600 Genes':** This study appears in the March 20, 2009 issue of The Journal of Biological Chemistry. The study's first author was Michael J. Bailey, of the NICHD Section on Neuroendocrinology. http://www.nih.gov/news/health/mar2009/nichd-30.htm

(27) **'Association between circadian rhythms of endogenous hypothalamic opioid peptides and of natural killer cell activity'**; Nino Mozzanica(2), Aldo F. Finzi(2), Sergio

Foppa(1), Giulio Vignati(4) and Maria L. Villa(3) --- (1)Department of Internal Medicine, University of Pavia, Italy --- (2)2nd Department of Dermatology, University of Milano, Italy --- (3)Department of Immunology, University of Milano, Italy --- (4)Laboratory of Endocrinology, Fornaroli Hospital, Magenta, Italy. PMID: 1649145 http://www.ncbi.nlm.nih.gov/pubmed/1649145

(28) **'Carbonic anhydrase inhibitor suppresses invasion of renal cancer cells in vitro**' … Acidification of the extracellular milieu of malignant tumors is reported to increase the invasive behavior of cancer cells. … ' - http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=15781

(29) '**Red Blood Cell Membrane Fluidity in the Etiology of Multiple Sclerosis'**; Gloudina M. Hon, Mogamat S. Hassan, Susan J. van Rensburg, Stefan Abel, Paul van Jaarsveld, Rajiv T. Erasmus and Tandi Matsha; Journal of Membrane Biology; Volume 232, Numbers 1-3, December, 2009 http://www.springerlink.com/content/m12227vwu063pg76/

(30) **'Membrane saturated fatty acids and disease progression in Multiple Sclerosis patients'**; G. M. Hon, M. S. Hassan, S. J. van Rensburg, S. Abel, R. T. Erasmus and T. Matsha, Metabolic Brain Disease, November 2009 http://www.springerlink.com/content/aj84253801970h74

(31) **'US scientists find clue to mystery of how biological clock operates on 24-hour cycle'**, Genes and Development journal, Dr. Sebastian Kadener & Uri Weissbein of Alexander Silberman Institute of Life Sciences, Hebrew University, Prof Michael Rosbash, Dr. Jerome Menet, Dr. Pipat Nawathean, Prof Sacha Nelson and Dr Ken Sugino from Brandeis University in the US, and Prof Phil Zamore, Dr Michael Horwich and Dr Vasia Vagin from the University of Massachusetts Medical School, November 25, 2009
http://www.medicalnewstoday.com/articles/172333.php

(32) **'A study of 24-hour profiles of plasma met-enkephalin in man'**; M.F. Shanks(a,b), Vicky Clement-Jonesa(a,b), C.J. Linsella(a,b), P.E. Mullena(a,b), Lesley H. Reesa(a,b), and G.M. Bessera(a,b) --- (a)The Institute of Psychiatry, London, SE5 8AF U.K. --- (b)Departments of Endocrinology and Chemical Endocrinology, St. Bartholomew's Hospital, London, EC1A 7BE U.K. PMID: 6261889 http://www.ncbi.nlm.nih.gov/pubmed/6261889

(33) **'Beta-endorphin concentrations in peripheral blood mononuclear cells of patients with multiple sclerosis: effects of treatment with interferon beta';** Gironi M, Martinelli V, Brambilla E, Furlan R, Panerai AE, Comi G, Sacerdote P.; Neurology Department, San Raffaele Hospital, Via Olgettina 48, Milan, Italy. Arch Neurol. 2000 Aug;57(8):1178-81. PMID: 10927798 (PubMed - indexed for MEDLINE) http://www.ncbi.nlm.nih.gov/pubmed/10927798

(34) **'Trends in physiological role of opioids in psychoneuroendocrine-immune network',** Jodar L, Takahashi M, Kaneto H., Department of Pharmacology, Faculty of Pharmaceutical Sciences, Nagasaki University, Japan. PMID: 7975925
http://www.ncbi.nlm.nih.gov/pubmed/7975925

(35) **'Participation of opioids and opioid receptors in antinociception at various levels of the nervous system',** A. Herz, M Millan. Farmakol Toksikol. 1989 May-Jun;52(3):5-12.
http://www.ncbi.nlm.nih.gov/pubmed/2551724

(36) **'Opioids and opioid receptors in peripheral tissues', T Hedner, J Cassuto.** Nihon Shinkei Seishin Yakurigaku Zasshi. 1994 Aug;14(4):195-214.
http://www.ncbi.nlm.nih.gov/pubmed/2888187

(37) **'Opioids act centrally to modulate stress-induced decrease in luteinizing hormone in the rat',** F Petraglia, W Vale, C Rivier. Endocrinology. 1986 Dec;119(6):2445-50.
http://www.ncbi.nlm.nih.gov/pubmed/2877862

(38) **'Naltrexone Antagonism of Exploration in the Rat'**, Richard J Katz, Mental Health Research Institute, Department of Psychiatry, University of Michigan, Ann Arbor, MI, USA. International Journal of Neuroscience, Volume

http://www.informaworld.com/smpp/title~db=all~content=t713644851~tab=issueslist~branches=9 - v99, Issue 1 1979 , pages 49 – 51
http://www.informaworld.com/smpp/content~content=a915062690&db=all

(39) **'Circadian cancer therapy**, WJ Hrushesky and GA Bjarnason, Albany Medical College, Stratton Veterans Administration Medical Center, NY 12208. Journal of Clinical Oncology, Vol 11, 1403-1417, Copyright © 1993 by American Society of Clinical Oncology (Six known citations.) http://jco.ascopubs.org/cgi/content/abstract/11/7/1403

(40) **RELATED RANDOMIZED TRIAL: 'Comparison of Toxicity Associated with Early Morning Versus Late Afternoon Radiotherapy in Patients with Head-and-Neck Cancer': A Prospective Randomized Trial of the National Cancer Institute of Canada Clinical Trials Group (HN3);** Georg A Bjarnason, Robert G Mackenzie, Abdenour Nabid, Ian D Hodson, Samy El-Sayed, Laval Grimard, Michael Brundage, James Wright, John Hay, Pradip Ganguly, Carson Leong, Jane Wilson, Richard C K Jordan, Melanie Walker, Dongsheng Tu, Wendy Parulekar; Department of Medical Oncology , Sunnybrook Odette Cancer Centre, Toronto, ON, Canada; Int J Radiat Oncol Biol Phys. 2008 Sep 19;: 18805649 Cit:4. http://lib.bioinfo.pl/auid:1890851

(41) **'Glucocorticoids Play a Key Role in Circadian Cell Cycle Rhythms'**, Thomas Dickmeis, Kajori Lahiri, Gabriela Nica, Daniela Vallone, Cristina Santoriello, Carl J. Neumann, Matthias Hammerschmidt, Nicholas S. Foulkes
http://www.plosbiology.org/article/info%3Adoi%2F10.1371%2Fjournal.pbio.0050078

(42) '**Beta-endorphin: stimulation of growth hormone release in vivo'**, Andre Dupont, Lionel Cusan, Marie Garon, Fernand Labrie, and Choh Hao Li Laboratory of Molecular Endocrinology, Le Center Hospitalier de l'Universite Laval, Quebec, G1V 4 G2, Canada, and; Hormone Research Laboratory, University of California, San Francisco, CA 94143 USA http://www.ncbi.nlm.nih.gov/pmc/articles/PMC393259/

(43) '**The role of prolactin in the pathogenesis of autoimmune disease'**, Istvan Berczi, Department of Immunology Faculty of Medicine, University of Manitoba, 795 McDermot Avenue, R3E OW3 Winnipeg, Manitoba, Canada Endocrine Pathology, Volume 4, Number 4, December, 1993 http://www.springerlink.com/content/90q037005l43l374/

Professional Papers/Presentations on LDN

(1) **ORAL PRESENTATION: IV International AIDS Conference in Stockholm,** Dr Bernard Bihari, June 1988 - http://www.lowdosenaltrexone.org/ldn_aids_1988.htm

(2) **NHS HEALTHCARE - UK MEDICINES INFO: 'What is the evidence for low dose naltrexone for treatment of multiple sclerosis?'** Medicine Q & As, Ref No 69.3, October 2009, NHS - Prepared by UK Medicines Information (UKMi) pharmacists for NHS healthcare professionals Expiry: 31st Oct 2011
http://www.nelm.nhs.uk/en/NeLM-Area/Evidence/Medicines-Q--A/What-is-the-evidence-for-low-dose-naltrexone-for-treatment-of-multiple-sclerosis/

(3) **PRESENTATION: National Cancer Institute meeting – April 2007**
Burton Berkson, MD, PhD
http://www.lowdosenaltrexone.org/_mm/Berkson_Presentation_Apr_2007.pdf

(4) **PATIENT REPORT: The long-term survival of a patient with pancreatic cancer with metastases to the liver after treatment with the intravenous alpha-lipoic acid/low-dose naltrexone protocol**, Dr Burton Berkson, PhD
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=16484716&query_hl=1&itool=pubmed_docsum

(5) **PAPER: 'Low-dose naltrexone in multiple sclerosis', Agrawal YP –** Med Hypotheses 2005;64(4):721-4 – Science Direct (Elsevier) -

http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6WN2-4F3FDWS-3&_user=10&_coverDate=01%2F01%2F2005&_alid=767767282&_rdoc=2&_fmt=high&_orig=search&_cdi=6950&_sort=d&_docanchor=&view=c&_ct=2&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=2bfd6cbcf74df22fc041c216f05caa24

(6) **MS & LDN SURVEY 2006: Dr Skip Lenz, Pharmacist**, Skip's Pharmacy, Florida http://www.mspeople.com/forum/index.php?s=dfe1764bb0265b16d51eff70e4a97fa5&act=Attach&type=post&id=14480

(7) **HYPOTHESES: 'Low-dose naltrexone for disease prevention and quality of life'**; Brown N, Panksepp J.; PMID: 19041189; Med Hypotheses. 2008 Nov 26 - http://www.ncbi.nlm.nih.gov/pubmed/19041189

(8) **PEDIATRIC MS NEWSLETTER: 'Promising MS Research'** www.pediatricmscenter.org/NewsLetter/Pediatric%20MS%20June%202008%20Newsletter.pdf

(9) **ARTICLE by Dr Tom Gilhooly: 'Low-dose naltrexone as a treatment for multiple sclerosis'**, Tom Gilhooly, British Journal of Neuroscience Nursing, Vol. 5, Iss. 11, 13 Nov 2009, pp 494. '… Published trials have supported naltrexone's potential to treat multiple sclerosis, however, it will remain unavailable until there is an extensive body of research to support its use … ' (By subscription or payment only from Internurse, UK online archive of Nursing Articles.) http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=45142;article=BJNN_5_11_494 & http://www.ldnresearchtrustfiles.co.uk/docs/BJNN.pdf

(10) **ARTICLE: 'LDN & Opioid Peptides – Gluten intolerance: a paradigm of an epidemic'**, Townsend Letter for Doctors and Patients, by Stacy Astor Shaul, Dec 2002, Page 3 - http://findarticles.com/p/articles/mi_m0ISW/is_2002_Dec/ai_94538644/pg_3

(11) **LETTER - PUBMED: 'Low-dose naltrexone for treatment of multiple sclerosis: clinical trials are needed',** Patel PN. http://www.ncbi.nlm.nih.gov/pubmed/17623758

(12) **PAPER: 'The role of endogenous opioids and their receptors in the immune system', D J Carr,** Department of Physiology and Biophysics, University of Alabama, Birmingham 35294-0005. Proc Soc Exp Biol Med. 1991 Nov;198(2):710-20. http://www.ncbi.nlm.nih.gov/pubmed/1656470

(13) **LETTER: Inhibition of human colon cancer by intermittent opioid receptor blockade with naltrexone.** Hytrek SD, McLaughlin PJ, Lang CM, Zagon IS., Department of Comparative Medicine, Pennsylvania State University, College of Medicine, Hershey 17033, USA. Cancer Lett. 1996 Mar 29;101(2):159-64. PMID: 8620464 http://www.ncbi.nlm.nih.gov/pubmed/8620464

Other Sources of LDN & Related Information

(1) **PRIMARY LDN Website**: **Low Dose Naltrexone** edited by David Gluck, MD - http://www.lowdosenaltrexone.org & http://www.ldninfo.org

(2) **Bernard Bihari, MD** – Curriculum VITAE & papers - http://www.lowdosenaltrexone.org/bbihari_cv.htm

(3) **LDN DOCUMENTARY: LDN Documentary featuring Dr Pat Crowley**, County Kilkenny, Scotland http://www.lowdosenaltrexone.org/_conf2006/P_Crowley1.mov

(4) **Ian S. Zagon, PhD** - Professor of Neural and Behavioral Sciences, Pennsylvania State University – http://www.fred.psu.edu/ds/retrieve/fred/investigator/isz1

(5) **Dr M R (Bob) Lawrence**, Dietary Research Ltd, Wales, UK - http://www.msrc.co.uk/index.cfm?fuseaction=show&pageid=651&CFID=4799847&CFTOKEN=68687005

(6) **LDN Research Trust,** UK – Linda Elsegood - http://www.ldnresearchtrust.org

(7) **Case Health - Health Success Stories** – Cris Kerr – (Created May 2001 - http://www.casehealth.com.au & http://www.casehealth.com Closed May 2009)

(8) **Dr Phil Boyle**, GP Fertility Specialist - http://www.fertilitycare.net/documents/LDNInfo_000.pdf

(9) **Dr Kamau B Kokayi interview with Dr Bernard Bihari** – September 23, 2003 – Transcript by Gazorpa – LDN Pioneer website: http://www.gazorpa.com/interview.html

(10) **ARTICLE & DISCUSSION: 'Dr Burton Berkson – LDN & Alpha Lipoic Acid Therapy'**
(a) **Article: Dr Joseph Mercola** http://articles.mercola.com/sites/articles/archive/2009/05/16/This-Antioxidant-Can-Smash-Insulin-Resistance-and-Autoimmune-Disease.aspx
(b) **Interview: Julia Schopick, Honest Medicine, Interview**: http://www.honestmedicine.com/2009/03/burt-berkson-md-phd-talks-with-honest-medicine-about-his-work-and-our-medical-system-the-interview-t.html

(11) **WIKIPEDIA: 'low dose naltrexone'** entry - http://www.en.wikipedia.org/wiki/Low_dose_naltrexone

(12) **MS & HUGHES SYNDROME: 'Hughes Syndrome: The blood disease that mimics MS' -** Hughes Syndrome, by Judy Graham http://www.msrc.co.uk/index.cfm?fuseaction=show&pageid=736&CFID=579952&CFTOKEN=15420960

(13) **ARTICLE: 'Can LDN Really Help Multiple Sclerosis, Rheumatoid Arthritis and Other Autoimmune Diseases?**' by Dr. Joseph Mercola http://articles.mercola.com/sites/articles/archive/2009/01/13/can-ldn-really-help-multiple-sclerosis-rheumatoid-arthritis-and-other-autoimmune-diseases.aspx

(14) **TAKING CONTROL OF MS WEBSITE: 'Low-dose naltrexone (LDN)' - Professor George Jelinek MD**, Professor of Emergency Medicine at the Charles Gairdner Hospital, Perth, Australia - Taking Control of MS website http://www.takingcontrolofmultiplesclerosis.org/index.php?mode=Low-dose%20Naltrexone

(15) **PRESENTATION: 'LDN & Patients with Autoimmune Disorders'**, presentation by Niles Bauer, PhD candidate, Department of Microbiology and Immunology, College of Medicine, University of Arizona http://www.lowdosenaltrexone.org/_mm/Bauer_Presentation_Mar_2007.pdf

(16) **ARTICLE: 'Low Dose Naltrexone in Experimental Model of MS, Efficacy of LDN Demonstrated**', Elaine Moore, Nov 13, 2009 http://autoimmunedisease.suite101.com/article.cfm/low_dose_naltrexone_in_experimental_model_of_ms

(17) **MS SOCIETY UK, DISCUSSION: Dr Alasdair Coles** http://www.mssociety.org.uk/applications/discussion/view.rm?post_id=840296&id=14320

(18) **CONFERENCE PRESENTATION: World Congress on Antiaging Medicine and Regenerative and Biomedical Technologies Presentation: 'Low Dose Naltrexone and its Regulatory Effects on Cancer Cell Growth and Autoimmune Disease'** by Paul Battle, PA-C, Mandalay resort in Las Vegas, Nevada, USA on 12th Dec 2009 www.worldhealth.net

(19) **ARTICLE by Ian S Zagon: 'Introduction to Low Dose Naltrexone'** by **Dr Ian S. Zagon**, Pennsylvania State University, October 2009 http://www.ldnresearchtrustfiles.co.uk/docs/Dr%20Zagon.pdf.

(20) **MS NEWSLETTER: Hounslow Branch of the MS Society** December Newsletter features 'LDN Daily Express Article' http://www.mssociety.org.uk/docs/bloy_December.pdf

(21) **WEB ARTICLE by MD: 'Naltrexone for Cancer',** Raymond Chang MD FACP, Meridian Medical Group, New York, 8 Feb 2009. http://cancerx.wordpress.com/2009/02/08/naltrexone-for-cancer/

(22) **LDN PIONEER WEBSITE: Goodshape** http://www.goodshape.net

(23) **OGF WEBSITE:** LDN Science Organisation http://www.ldnscience.org

(24) **LETTER: NCI Needs to Get Over Its Alternative Treatment Bias**, Dr David Gluck, Genetic Engineering & Biotechnology News, July 1, 2010
http://www.genengnews.com/gen-articles/nci-needs-to-get-over-its-alternative-treatment-bias/3342/

(25) **ARTICLE: Prolactin secretion and circadian rhythm**
http://www.informaworld.com/smpp/content~content=a713730526&db=all

LDN Books

(1) **BOOK: 'Up the Creek with a Paddle: Beat MS and All Autoimmune Disorders with Low Dose Naltrexone (LDN)**' by Mary Boyle Bradley. http://www.marybradleybooks.com

(2) **BOOK: 'The Promise of Low Dose Naltrexone Therapy: Potential Benefits in Cancer, Autoimmune, Neurological and Infectious Disorders'**; Medical Reference Book by Elaine Moore, co-author SammyJo Wilkinson, foreword by Dr Yash Agrawal, MD, PhD http://www.ldners.org

(3) **BOOK – LDN & HBO: 'The Oxygen Revolution: Hyperbaric Oxygen Therapy: The Groundbreaking New Treatment for Stroke, Alzheimer's, Parkinson's, Arthritis, Autism, Learning Disabilities and More' 2010 edition** soon to be released, by Paul G. Harch, MD & Virginia McCullough - page 120 references combination therapy HBOT & LDN
http://www.amazon.com/Oxygen-Revolution-Hyperbaric-Groundbreaking-Disabilities/dp/1578263263/ref=3Dsr_1_1?ie=3DUTF8&s=3Dbooks&qid=3D1263936617&sr=3D1-1

(4) **LDN BOOK: '100 Reasons Why *You Should Know About LDN*", 2009 edition,** LDN Research Trust, UK – 100 patient testimonies of health success attributed to LDN
http://www.ldnresearchtrustfiles.co.uk/docs/International%20LDN%20Awareness%20Week%20eBook.pdf

(5) **LDN BOOK: '201 Reasons Why *You Should Know About LDN*", 2010 edition,** LDN Research Trust, UK – 201 patient testimonies of health success attributed to LDN
http://www.ldnresearchtrustfiles.co.uk/docs/ebook.pdf

Health Reform Submission – Cris Kerr, Case Health

SUBMISSION: 'Building Capacity for Repeatable and Sustainable Improvements in Health Outcomes' (pdf doc); Submission to National Health & Hospital Reform Commission (NHHRC), Australia: http://www.nhhrc.org.au/internet/nhhrc/publishing.nsf/Content/056-ch/$FILE/56%20-%20Submission%20-%20CASE%20Health.pdf

Permissions:
© Case Health Pty Ltd grants permission to reproduce the latest version of these articles:
(1) 'Those Who Suffer Much Know Much' (2010 article version), and;
(2) 'Shared Vision for Health' (2010):
Permission is granted on provision the articles remain unchanged/unaltered in any way, up to and including publication details and include this permission advice. Postscript request to publishers: If you reproduce either of the above two articles, I'd sincerely appreciate a courtesy advice to (casehealth @ optusnet .com .au). **Unlimited reproduction of this book is granted to all, provided the book remains unaltered in any way, and remains free of any charge or expectation.**

Those who suffer much, know much 2009 edition
LDN Research Trust website – Files Section - http://www.ldnresearchtrustfiles.co.uk/docs/2009.pdf

Those Who Suffer Much, Know Much **2008 edition**
Is available online and is hosted here

LDN Research Trust website – http://www.ldnresearchtrustfiles.co.uk/docs/Cris%20book.pdf
Crystal's Website – 2008 edition http://crystalangel6267.webs.com/THOSE_WHO_SUFFER_MUCH_LDN_BOOK_Jul08.pdf
Keep Hope Alive website http://www.keephopealive.org/naltrexonecasereports.pdf

Supporting case study data for this book
is in the form of untested patient testimony of health success.

'Those Who Suffer Much, Know Much'

a proof of concept document
produced by
Cris Kerr, Case Health Pty Ltd

55 Webb Street
Stafford, Brisbane
Queensland, Australia 4053
Tel 61 7 3356 1777
casehealth@optusnet.com.au
(casehealth.com/au 2001 to 2009)