Senate Inquiry into Lyme Disease – Supplementary to Submission # 717

Supplementary to my original submission # 717, *My Three Girls*, 22nd March, 2016

I attended the Senate hearings in Brisbane, on 15th April and these are my observations.

I have become increasingly disturbed and angered by the incorrect information being provided to this Senate Inquiry by experts who know better, or should know better. The arrogance with which many of these experts dismiss people with stealth infections like borrelia and co-infections is tantamount to criminal.

I want to thank the Senators conducting this Inquiry for their time and diligence; it's a gruelling exercise and you don't need to be a doctor to get the message. However, there is another agenda on the table to do with politics, money and power; for the sake of the health of all Australians, I hope the Senators can see through it.

In short, the health system needs to be re-established, not just to take care of patients and families dealing with stealth and persister infections such as borreliosis, but to take care of all Australians. It's clear that the health system does not serve the majority with their health needs.

I hope that you can see this assignment in the larger context and make recommendations to start the process to overhaul the health system where there is no accountability to the public for the care provided.

Part 1: Things That Need To Be Said Out Loud

Diagnosis Terminology

A Rose by any other name . . .

The pedantic, academic argument about whether Lyme disease exists in Australia, if it is Lyme disease only if infection is by a tick bite, if it is Lyme disease only if the infecting bacterium is Borrelia Burgdorferi, is tantamount to absurdity on the one hand and criminal negligence on the other.

We've been advised that we don't have Lyme disease here in Australia, but for all intents and purposes (diagnostics and treatments), it looks for very like Lyme disease to many thousands of very ill people. Almost anyone finding their way through the Lyme maze will come across the documentary, "*Under Our Skin*" (MacAlexandra) [1].

To appease academic sensibilities and sensitivities, we call it Lyme-like disease. Now the so-called experts, ask us to define the term, "Lyme-like". Would the term "*borreliosis, co-infections, opportunistic infections and co-morbidities*" cover the condition to your satisfaction? This is labelled as "MSIDS – Multiple System Infectious Disease Syndrome" by Dr Richard Horowitz [2] (www.cangetbetter.com) and I like it because it is independent of the means of infection.

Get a rose and prick your finger with it. Drawing blood? Hole in your finger? Does it look like a pin prick? Oh, but wait, you can't call it a pin prick because you did it with a thorn on a rose. Unbelievable. Better still, put your hand in your pocket and the pin prick doesn't exist and the blood dripping in your pocket isn't there either.

We are literally sick and tired and dying of being told what we don't have and what treatments we can't have and what support we can't have. We're sick of being told by impossibly incompetent doctors like [redacted], that "It's all in your head" and that anyone "pretending" to have Lyme disease is a malingerer.

Frankly, we don't care what we don't have nor are we interested in erudite academic pedantic argument about particular strains of bacteria and ticks, and spurious proof of their non-existence. Could it be that we do not have the competence in the accredited laboratories to identify offending borrelia and co-infectious pathogens?

Why does it matter if the bacteria can't be found in ticks if they can be found in people? Does it matter if people don't have the classic borrelia burgdorferi infection but display all the signs, symptoms and co-morbidity of Lyme disease? We are still very sick and need help while you argue academic technicalities.

The issue of conspiracy keeps raising its ugly head in the politics and financial context of Lyme disease. There is a mountain of evidence that it's not theory, it was an actual conspiracy. Anyone interested should refer to the movement *Occupy the USDOJ* [3], where charges are being laid over the Dearborn scam and their deception of falsifying the 2-tiered testing standard (ELISA and Immunoblot) results.

It is my experience that patients do not want a diagnostic label of “Lyme” or “Lyme-like” or “post-treatment something-or-other” or some other made-up descriptive name that may sound very erudite but provides no answers in terms of getting well again. We don’t care much what the label is, provided it does not come with stigma, nor what the infection is or isn’t, unless it provides answers in terms of treatment or cure.

Research and Development Funding

With the expenditure of any kind of funding, particularly the scarce amount available to investigate and provide for borreliosis patients, there are a number of criteria that need to be applied in allocations:

1. Return on Investment
2. Due process
3. Accountability to the population at large and to borreliosis patients and their families in particular

The overriding goal of funding research and development is to find answers and solutions for patients.

Where NOT to Allocate Funding

The precious little funding available needs to be directed to research that will provide answers to those stricken with infectious diseases.

Providing funds to academics to rummage around looking for clues in wildlife will provide no answers for borreliosis patients, regardless of what they find. Even if something of interest is found, it’s expensive research with no practical purpose and no return on the investment.

If researchers want to continue there, let them get funding from elsewhere, not from any health-related research budget allocation.

Where to allocate research funds

1. Testing

The current testing arrangements are providing no answers, just academic squabbles. Look to testing people. We need fast reliable testing for both borrelia and co-infections in patients, their families, blood supply and organ donors. Look further than the traditional testing and give some broader thinkers like Jenni Burke (Australian Biologics) and John Kernow (Public Hearing, Brisbane, 15th April).

2. Treatments and Cures

Antibiotics seem to have limited application. We love that some doctors are trying to help but pharmaceuticals may be only a part of the answer.

We need more advanced thinking in terms of the patient rather than in terms of what the health system (as established) can provide; like the approach of Dr Richard Horowitz [2] and others who are advancing cures rather than just treatment of symptoms.

*Research and Examine all Treatments: Many treatments give temporary relief from symptoms but are not a cure. We need both mitigation of severe symptoms but we also need treatment for co-morbidities and ultimately a cure.

- are there new/different/better ways to administer antibiotics: antibiotic pulsing, salt/antibiotic pulsing
- see what else besides antibiotics is giving results
- examine results of other protocols

*Treatment needs to consider:

- stealth infections, principally borrelia
- co-infections
- co-conditions (opportunistic infections and comorbidities)
- consequential damage and organ failure or dysfunction (mitochondrial, metabolic, adrenal, digestive/gut, immunity)

*Clinical Studies and Practice: It is clear that treatment protocols need to be tailored to each individual and each protocols would have multiple facets:

- to establish treatment protocols
- to establish sequence of treatment
- to identify and avoid treatments that "clash"

3. Epigenetics and Microbiota

I know these two areas of research – epigenetics and microbiota – are new in the scheme of things, but there seems to be little dispute that they both significantly impact health and body function. As Borreliosis and other 'syndrome' patients have both compromised health and body function, there would seem to be mutual benefit to research, that is, advancement of research and relevance to patients.

Genetics

DNA: It's one thing to have the genetic mutation common to coeliacs but not everyone with the mutation is a coeliac. Not everyone with the MTHFR gene mutation has compromised methylation pathways; not everyone with the MTHFR gene mutation with a Borrelia infection has Borreliosis and it's not established that there is any consequential predisposition as a result of these "genetic disorders". Even if that can be established, it seems unhelpful – in the "so what" category; it doesn't help to know about such mutations if it doesn't help with diagnosis or treatment.

As an aside, rather than consider the genetic makeup, we might find more useful information if we look more into the field of epigenetics or gene expression and activation. If epigene status can be included in the profile of patients together with a microbiome profile, we might find more useful information than finding a March fly in Cape York with a mutated spirochaete on board.

Microbiome

Since the microbiome forms a large part of the immune system, almost everyone with poor immunity will have a poor microbiota profile. We've seen the devastating effects on people who develop C. diff, but this are the last line of degeneration resulting from a compromised microbiome. Lesser conditions are the inflammatory bowel diseases – irritable bowel, colitis, Crohn's disease, diverticulitis, et al, which are almost inevitable consequences; many people with any of the 'syndromes' – borreliosis, autism, ALS, etc., indeed any chronic illness or infection, will have a compromised microbiome.

Development Funds

Infrastructure for Infectious Disease Care

It is clear that the current paradigm for medical care – General Practitioners and Specialists who don't confer with one another – is not only unsuitable for the majority of people with chronic conditions, but certainly will not work for anyone with debilitating persister stealth infections.

The arrangement where a Chronic Disease Management Plan is available to some with chronic illness is a start in the right direction but is far too limited in this context.

*Establish Multidisciplinary Clinics/Treatment Centre/s, specialising in:

- diagnostics (laboratories shouldn't have all the say)
- treatment protocols for stealth infections
- not limited to suspected borreliosis, co-infections and comorbidities

A central facility or clinic is really the only viable option; patients need time on a treatment protocol with monitoring to get it right for each patient.

This type of facility should serve the needs of all patients who present with classic syndromes and "cause unknown" syndromes that the medical profession treats inappropriately with drugs; chronic fatigue, fibromyalgia, juvenile arthritis, rheumatoid arthritis, multiple sclerosis, scleroderma, lupus, ALS, Alzheimer's, chronic pain syndrome, Parkinson's, et al, all need better scrutiny for underlying causes and disorders, and better treatment.

*Management and Supervision of Treatment Protocols:

- Supervising specialists
- Long-term monitoring and treatment for persister infections

When patients have a treatment protocol developed for them and return home, they must have a skilled supervising specialists and/or a specialist physician to monitor and make adjustments as time goes by. They need to be able to adjust any treatments as the patient responds and they also need to be able to recognise problems immediately when they arise, which, in my experience can happen often and quickly. Patients of course need to be well briefed on adverse signs to look for and how to deal with them. Many patients should have an alert for emergencies and 24-hour telephone access for emergency help. It is not unreasonable that supervising physicians would need to make home visits regularly for some patients and an on-call system for emergencies.

A Word About **NOT** having General Practitioner Involvement

A number of references have been made about the role of GPs in the treatment of borreliosis, that they are best placed for diagnose and care. Patients with cancer or infectious diseases are always under specialist care. There is no question that borreliosis is far more complex and debilitating but we should believe that GPs are best placed. I think not.

With multiple infections, multiple system disorders, multiple factors requiring attention, borreliosis patient care cannot be in the hands of GPs (apart from the fact that it will take a decade to undo their current attitude and conditioning towards Lyme disease promulgated by the medical establishment). Monitoring and managing a protocol provided by a specialist in borreliosis, all different, and recognising when treatment needs to be modified, is for a specialist only, not in the hands of 10-minute physicians who do not have the information, skill, nor time to provide the care and oversight required. Specialist units at hospitals that can draw from a wide range of skill sets in-house is more appropriate and viable.

GPs and doctors in general know less than nothing about diet and nutrition; they dish out the same mindless and inappropriate claptrap about food and diet that comes through the media. Anyone with a compromised microbiome and compromised immunity will only get worse with the dietary guidelines advised with good intentions but lack of knowledge.

Immunity in the hands of GPs is at further risk with the symptom/blood test/pharmaceutical prescription paradigm. Even worse, prescription drugs are doled out like lollies for conditions that aren't apparent and conditions you may or may not have (the suck-it-and-see method); this is prevalent with antidepressants, NSAIDS and heartburn medication, all of which carry a burden on the immune system and will likely cause further organ damage with long-term use and provide no benefits. These medications are the basic cocktail for anyone with a borreliosis infection, none of which helps much, even in the short term.

Even worse, many medications do great harm. For many patients with multiple infections, inflammation is a by product of their body dysfunction or disorders. Such inflammation is always assumed to be some autoimmune condition and cortisone is prescribed to stop the 'over reaction' of the immune system from creating their inflammation and pain. It never seems to register that not all inflammation is autoimmune, certainly not to a GP with only 10 minutes available. Corticosteriods suppress the immune system, which is exactly what you DON'T want when trying to fight so much infection. Steroids are kryptonite for anyone with multiple infections. This is the dangerous trap of looking at symptoms and not having the opportunity to be curious to investigate for disorders; just one more reason that (all) patients are at serious risk with the GP system.

Worse still, because of the myriad symptoms with borreliosis and co-infections, some GPs will determine that it is inappropriate for the patient to be treated by a GP, that it is for a specialist. There is no specialist category for these patients so a choice has to be made and there is no good choice in this scenario, just bad and worse choices. Many are referred to a rheumatologist, where some autoimmune diagnosis like rheumatoid arthritis is likely. A worse choice is to a psychologist or psychiatrist (for sleep disorders) who may prescribe antidepressants, antipsychotics or sleeping pills, all of which are totally inappropriate. The most inappropriate, of course, is the "all-in-your-head" diagnosis.

The GP community at large is tainted with the current idiomatic opinion from more than a decade ago that became doctrine, then mantra, that there is no Lyme disease (a rose by any other name) in Australia and that sufferers are malingerers. This attitude will linger for years, even with an education program.

GPs as a group can NOT be relied on to provide the requisite treatment and care.

We applaud the efforts of the few GPs who do their best to help in the current health system infrastructure and we are very grateful to them, but they are in the minority and they cannot possibly keep up with advancements in treatment unless they can specialise. Is it possible to have a category of "specialist GP" for patients who are eligible for a Chronic Disease Management Plan?

*Patients' Self-Management

As with any illness, there are some things that patients can do to improve their immune systems. We know that fungus is a major contaminant of the environment, we know that processed food with additives and other contaminants increase the burden on the immune system and we know that inadequate diets, that is, diets lacking the nutrients for good health, diminish immunity.

A very detailed plan to eliminate contaminants, maximise nutrition and improve lifestyle in ways that improve the immune system is paramount.

A Postscript to Funding and Infrastructure:

This is a disturbing item extracted from Senate submission # 1041.

I'm unclear about the source of this paragraph and I hope with all my being that it is a misunderstanding, but it needs to be clarified for everyone needs help with stealth infections.

> Even before this Senate Enquiry Committee has undertaken it's review of facts & put forward its findings and recommendations, in relation to the recognition, treatment and treatment management of Lyme disease or Lyme-like disease symptoms in Australia, that the Australian Government intends introducing a system where by one GP only, (regardless of that GP's awareness or current knowledge of or attitude about Lyme disease/Borreliosis & its co infections, or Lyme-like disease symptoms), will be receiving annual funding for, and therefore being allocated all power of decision over the methods of diagnosis, the treatment (or lack of) and the symptom management available to any person in their care who is challenged by any chronic health conditions including Lyme disease or Lyme-like disease symptoms.

Part 2: The future of Borreliosis Recognition and Treatment

Diagnosis and Treatment

We need to avoid the traps of 10-minute medicine currently practiced by conventional medicine, that is, treat a symptom or serology results with one or more drugs. This paradigm rarely leads to a cure; more often leads to side effects, drugs for the side effects, drug dependence or drug intolerance which is particularly distressing for people who already have compromised immunity. Drugs are seen as the only option and this is a sad and intolerable state of affairs. Once upon a time, the common view was that drugs are for short-term use; indeed the pharmaceutical companies advocate drugs for short-term use but never discourage continuous use. On the contrary, physicians are encouraged to use multiple drugs continuously.

GPs are boxed into a paradigm where they are pushed for time, minutely scrutinised for their practices (blood tests and pharmaceutical prescriptions) and have little opportunity to treat the individual as a person, rather than a host carrying a set of symptoms that has to have a label in order to claim from Medicare and health insurance. The truth is, NO ONE IS GETTING CURED of anything; both doctors and patients are locked in to a system that doesn't work.

<u>Diagnosis:</u>

Adopt the approach of Functional Medicine.

The purpose of diagnosis is to:

- identify disorder
- identify cause

A symptom or group of symptoms is not a diagnosis although the health system revolves around symptoms and syndromes. Indeed the health system and health insurance require a label for claims; even worse they often proscribe what blood tests and treatments are required and what treatments are not acceptable. People with the same disorder, hypothyroid as an example, will show different symptoms and conversely the same set of symptoms can indicate multiple disorders. It could be said that chronic fatigue, fibromyalgia, tachycardia and dysautonomia (POTS) are symptoms of borreliosis, but that doesn't mean to say that everyone with these symptoms have a stealth infection. The ability of the GP to properly treat their patients has been commandeered by the system.

A sick person has, by definition, some body disorders – disease doesn't often occur in a body that is balanced, healthy and with a robust immune system;

> There is **NEVER** just one disorder or dysfunction resulting in a single symptom or set of symptoms – everything in the body connects to everything else; many consequences of a disorder may not have overt symptoms.
>
> Symptoms may be clues to the disorder/s but they are not the disorder itself.

Rarely can a blood test tell the story; the common routine blood tests are indicative at best, useless in general and used poorly or dangerously at worst (that is, as a basis for pumping drugs, especially where there is no evidence of a disorder; cholesterol is the classic for drugs to treat a non-existing condition).

<u>Treatment:</u>

Adopt the approach of Integrative Medicine.

The purpose of treatment is to:

- mitigate symptoms
- mitigate the disorders and re-establish internal biochemical balance
- eliminate or deactivate the cause, or minimise the effect of the cause on disorders

Treat the worst symptoms first, to make life worth living. These are often in just a few categories:

- pain category – muscular, neural, headaches and migraine, internal (organ) pain
- sleep disorder – insomnia, fatigue (non-restorative sleep), poor sleep profile, tachycardia
- brain function – disorientation, cognitive function, disassociation, poor memory

Treat the worst of the disorders next, to enable some improvement in function. This might be as simple initially as bringing body chemistry into balance with nutrition and non-invasive treatments. In any case, nutrition is always a factor that needs review: no matter how diligently a patient tries to have a healthy, balanced diet, the information and food available are not always suitable or correct; indeed advice about nutrition from the medical profession and nutrition 'experts' is patently wrong.

Treating the cause and treating the consequential disorders is where art, science, common sense and experience need to come together. It's all very well to consider medicine as an educated guess at the mix of art and science, but the common sense aspect of medicine has been missing for too long. When patients have such an extensive repertoire of disorders, clearly a clinic-style approach with a multidisciplinary team of experts and specialists is far superior to the current GP/specialist referral arrangement. The approach in conventional 10-minute medicine with a GP referring a patient to multiple specialists who do not confer does not work for anyone, least of all a patient with all or many of the symptoms of Lyme and co-infections, opportunistic infections, compromised immunity, organ failure, multiple 'syndrome' diagnoses, sleep disorders, neural pain and significant cognitive impairment.

Some experienced specialist Lyme doctors advocate tackling the co-infections first, and the validity of treatment sequence must be considered. The need for identification of all infections before treatment starts is paramount. In short, every patient needs to be treated as one whole body, not dissembled into separate bits for the various specialists to have a go, then reassembled like a set of Lego blocks.

There seems to be ample evidence that antibiotics have a place in the treatment protocols but not everyone responds and antibiotics can't address the myriad consequential disorders that can occur in chronic Borreliosis:

mineral depletion and imbalances, dysbiosis and poor digestion, malabsorption and malnutrition, neural damage, adrenal dysfunction, tachycardia, dysautonomia (POTS), methylation, hypothyroid, and on and on. Not all advances in treatment have come from conventional medicine and pharmaceuticals. In any case, as many patients are extremely ill with terribly compromised immunity, pharmaceutical drugs must be carefully considered in the context of the whole person – side effects are not minor. Certainly alternative medicine has made some significant progress in alleviating symptoms, but even these need to be administered with great caution. We do, however, need to look further afield.

However, before we go hurtling down the path of trying every treatment that is known to have benefit with a scattergun approach, we need to look at a number of different aspects:

1. What are the other effects of the treatment (not all side effects are negative but you need to look at them all, especially where the patient is already in poor health with multiple symptoms and multiple disorders)

   We especially need to know if there are any effects (positive or negative) on other aspects of the patient's health or disorders, as this needs to be considered when additional treatments are being considered

2. Are there any effects of concurrent treatments
   - On each other
   - On other than the intended target
3. Where a treatment works for some but fails others, we need to understand why. Some experienced Lyme doctors (R. Horowitz [2]) find that many treatments work for all patients if the terrain is right. This is where I think research and trials need to concentrate, to establish:
   - Which treatments work and which don't,
   - For treatments that work sometimes, we need to know:
     - what is the terrain profile when it works
     - what is the terrain profile when it doesn't work

It's this area of clinical treatment and protocols where I'm hoping that a grand slice of research and development funds can be allocated.

> An aside: At the Senate hearings, there was reference and discussion about the need for clinical trials. I know the medical profession and researchers holds great store in the "gold star" of clinical trials and studies, the double blind, placebo controlled study. Whether you believe that this is the 'proper' way to conduct trials or not (personally I think they're a load of rubbish for reasons too numerous to mention), this type of clinical trial is totally inappropriate for these stealth infections; every individual is different and responds or reacts differently to both the infection and treatments. In any clinical trials, it's these differences that are every bit as important as the similarities. The idea of a placebo in a clinical trial for borreliosis treatments is so absurd, I can find no words.

It is essential that the treating physicians know the exact nature of all infections in each individual case (inter alia) in order to develop a treatment protocol, so it seems that research funds to more easily identify offending infections in people rather than in wildlife would show a much greater return on the investment.

Indeed the advantage of developing fast, reliable identification is two-fold. What we do care a great deal about is that known sources of infection are prevented from spreading borrelia bacteria and co-infections. To this end, it is of utmost and immediate importance to identify these microbes in blood donors and organ donors. Donors are already screened for HIV, human herpesvirus 5 (CMV - cytomegalovirus) and hepatitis, but the consequences of spreading borrelia, bartonella, babesia and other potentially disabling infections becomes more critical each day.

> An important aside: The Red Cross submission (submission 992) gives a very detailed account of their stringent procedures and by all accounts, there appears to be no microbial contamination in the blood donor supply. If stealth infections all came from a tick, created a tell-tale erythema migrans rash and made the donor sick, there might be some chance of weeding out donors hosting these infections. In truth, it's unlikely that these conditions precede the majority of asymptomatic stealth infections, as we have witnessed from many of the submissions.
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> Anyone who is asymptomatic after infection will never be identified by the Red Cross screening process. As in America, if you have influenza or similar symptoms, sometimes the first and only hint of infection, blood

> donation cannot be done for some weeks after symptoms subside. There is no screening procedure at the moment that can identify one single asymptomatic person carrying a borrelia infection. It is possible that asymptomatic carriers greatly number known cases of borreliosis.

The issues of foetal transfer should take another significant share of research funding. Borreliosis affects far more people that HIV/AIDS, yet funds were allocated to find a way to prevent the transfer of HIV in utero. The incidence of in utero infection transfer of stealth infections is not insignificant; there are many more cases than my granddaughters identified in other submissions, and they are only the ones we know about. If the expert opinions are right and the increasing incidence of autism, ADHD and other conditions involving neural or brain damage at birth are due in part to in utero infection, then we need a new perspective altogether.

Allocating large amounts of research funding for the academic pursuit of unknown bacteria in random hosts and vectors, or even worse, only in ticks, and using identification markers only for known bacteria seems foolhardy in that there is no foreseeable practical advantage and frankly, I doubt that there is anyone with borreliosis who actually cares.

We don't much care what infections we have; we expect our medical professionals to find that out and provide the answers. To date, the medical establishment has no answers that we are privy to. Researching Lyme disease by the patients provides more answers than any other avenues available to them.

> Contrary to [redacted] opinion [redacted] and I stress 'opinion', patients stricken with "this condition" are of no personality type, it's not all in the head, there is no Munchausen's or Munchausen's-by-proxy as he implies and rehabilitation is not an answer when there is so much loss of function. Whilst I mean no disrespect to [redacted], I'm sure he believes in his opinion, but he is dead wrong and he needs to respect his patients; his attitude is humiliating and causes great harm to some patients who have an added burden of doubting themselves. So much for the Hippocratic Oath and "first do no harm".
>
> The form of "rehabilitation" he referred to, as I understand it, is inappropriate, traumatic, even torturous for patients with physical disability such as chronic fatigue patients and those with severe neural pain. It's particularly inappropriate for children who become confused about their own condition, and doubting of their parent's intentions and resisting any further treatment. It's extremely rare that children 'make up' illness and disability like this; this is serious illness here, not the tummy ache for getting out of school. Thus the physician creates more havoc and harm.
>
> Doctors can deride patients for using the internet and self-managing but contrary to the beliefs cited, patients know a lot more than you might think about their condition and about Lyme disease, far more than the majority of medical practitioners it would seem, and certainly more that [redacted]. These opinions have been debunked for decades but still they persist.
>
> These stealth infections are as indiscriminate and debilitating as HIV/AIDS. It seems to me that it's the psychiatrist who has a personality type or doesn't recognise a normal reaction to a severe, chronic, painful and debilitating illness which in most cases, affects brain function.

It may be of some academic interest to find hosts, vectors and perhaps hotspots in the wild or even in the back yard, but to what end. We can hardly propose a global eradication program. We could put up signs and teach people how to take some precautions against all insect bites, but such precautions may not be even a partial answer to prevention. The myriad agents of possible infection may well be mostly unknown or guesses at best; if a midge, march fly or mosquito is the vector, what hope is there.

References

1. ***Under Our Skin*** – the video; a film by MacAlexandra

Part 1, Nov 2012: The original film:

www.youtube.com/watch?v=RWFFiIZgr6U

Part 2, 2014: The follow-up film:

www.youtube.com/watch?v=eD3ZDCGUOYw

2. **Dr Richard Horowitz**

www.cangetbetter.com

Excerpts from Dr Horowitz presentation at the 2016 Chronic Lyme Disease Summit

From an interview with Jay Davidson on 7th April, 2016, with editing for simplification, spelling and sentence construction.

Why do some people, who follow the standard treatment regime for acute Lyme (after a tick bite, say) seem to get better and others never get well?

Dr Horowitz: It's really the crux of the problem, which is what all the doctors are trying to figure out; why people stay ill from this. After having seen 12,000 people in the last 30 years, I find that the Lyme does persist. A lot of the antibiotics we use to treat a bull's-eye rash, whether that be doxycycline or Ceftin, hit only one form of the borrelia infection.

Apart from the spirochaete form, Borrelia burgdorferi has a cell wall form where you need penicillins or cephalosporins. It also has a cystic form where it can go dormant for very long periods. For those forms, you need to use drugs like Flagyl or tinidazole or natural substances like grapefruit seed extract or even Plaquenil. Then, it goes inside the cells in the intracellular compartment. For that, you need tetracylines like Doxy, macrolides like Zithromax or Biaxin, rifampin, quinolones. Then, there are some newer drugs that I've been testing that I'll talk to you about in just a little bit, which are some of what I'll call "persister protocols" that I'm having great success with.

The latest research is showing that, where these bugs are protected by biofilms, if you don't hit all these different forms and open up the biofilms, that could be the reason that you don't pick up antibodies; the antibodies can be bound in complexes where the antigens are bound, so you don't get a positive blood test.

The bugs may hide under these biofilms so you have to treat all these different forms, treat the biofilms, treat the co-infections because the co- infections are playing a huge role in keeping people ill, especially babesia; this parasite acts very much like a malarial organism and the symptoms are similar. If you don't get rid of this babesia parasite, all forms of the borrelia bacteria and the other co-infections, people cannot get better.

There are other points on the [16-point map] that explain why people don't get better. You need to look for autoimmune manifestations to find out if the immune system needs to be balanced.

You must identify the source of inflammation and deal with that. Inflammatory molecules like Interleukin-1, Interleukin-6, TNF-alpha are the same inflammatory molecules that you see with rheumatoid arthritis, with Crohn's Disease, with MS, etc, that make people sick.

Then there are myriad toxins getting into people's bodies. Some people get sick because of mould toxins, heavy metals other environmental toxins; they may have food allergies driving inflammation; they likely have nutritional enzyme deficiencies.

The mitochondria, the part of their body that makes energy, doesn't work properly and that causes fatigue, nerve pain and dysfunction, cardiac problems.

They have neurological dysfunction and endocrine disorders.

When there is so much inflammation, the infections can shut off the pituitary, the master gland. We have men in their 20's and 30's with low testosterone, women who don't have periods, people who don't have enough growth hormone, the thyroid can be affected, they can’t sleep, because they have inflammation.

The bacteria can invade the autonomic nervous system, the part of their body which deals with blood pressure and pulse. The bladder and bowel can be affected.

Some people can't stand up because blood pressure falls quickly and that causes fatigue, dizziness, memory and cognitive problems. Thus they lose muscle condition.

We have found, for example, that POTS (Dysautonomia), this very low blood pressure, is probably present in at least a third of the people with chronic Lyme. Most of the healthcare practitioners do not measure both sitting and standing blood pressures determine if people have it. If you don't bring up their blood pressure and treat it, they won't get better, no matter how many antibiotics you administer.

The 16-point MSIDS map is like going into a doctor's office with 16 nails in a foot and if you don't pull out all the nails, y people will not get better. So the real key from my perspective is looking at this multifactorial list of these 16 points that make people sick, really going after all the forms of borrelia, the biofilms, the co-infections and the consequential disorders.

Kim Lewis' lab at Northeastern University has now shown that borrelia is a persister bacteria, that simply giving regular antibiotics may not be enough, you may need to pulse the antibiotics to get rid of it and that's what we're attempting to tackle now in our practice.

The most important underlying common denominator at this point for all these chronic diseases, whether it be autism, Alzheimer's, allergies, ADHD, what Dr Buchwald called the four As, or what I'll call the three Is—infections, immune dysfunction and inflammation, it is ultimately inflammation that is the common denominator.

If you look at the Alzheimer's patients, you will see that it is ultimately inflammatory molecules that are causing the cognitive issues. It's the same thing with autism. Environmental toxins and other things are making them sick. It's the same thing in cancer, in heart diseases and psoriasis and asthma. It's inflammation.

We need to look at the underlying common denominators that drive inflammation and think about it from that point of view; that basically means we look at infections. Infections means we need to look at immune dysregulation, at gut dysbiosis, at leaky gut for food allergies, sleep quality and quantity, getting rid of environmental and food toxins and detoxification, dealing with nutritional deficiencies, caused by compromised digestion, metabolism, malabsorption, hypothyroid and other body malfunction. In other words, anything that is driving the inflammatory response in the body has to be addressed.

You absolutely have to take out all of the inflammation sources. I have found that putting together the protocol to go after all of it at once is the best regimen. I believe that's going to really be the answer not just for Lyme, but many of these chronic diseases that are affecting us.

Later in the interview . . .

I'll give you an example. The mother of this 15-year old young girl from South Carolina contacted me some time ago, saying, "My daughter is in a wheelchair. She's seizing constantly. She can't eat. She's losing weight. She can't go to school. She's dying. None of the doctors in South Carolina — she's been to 8 different doctors, rheumatologists, neurologists, infectious disease — can figure out why she's sick."

The mother brought her to see me in New York in a wheelchair. We gave her the MSIDS questionnaire, the 38-item questionnaire on the website, CanGetBetter. The first question is "Do you have fevers, day sweats, night sweats, chills, flushing?" She says, “Yes.” So we think she most likely has babesiosis.

When we examined her, she had the tell-tale stretch marks in different parts of her body, very classic for Bartonella.

I moved to the questions on joint pain, muscle pain, tingling, numbness, burning, and, yes, she has those; she was on high-dose morphine for pain and it's not controlling the pain. I asked if it migrates around her body or keeps moving around without reason, with good and bad days. "Yes."
So we have diagnosed her already just from a clinical physical examination and history with Lyme, Babesia and Bartonella.

Then I tried to stand her up out of her wheelchair but she cannot stand; her blood pressure dropped 30 points. Her heart rate increased 40 points. She has POTS - Postural Orthostatic Tachycardia Syndrome or Dysautonomia.

So in the first instance, I discovered four nails in her foot which are making her sick.

I gave her the following antibiotics: Doxycycline with Rifampin, which will go after the Lyme and the Bartonella. I administered four Malarone per day with Artemesia (IV) which will go after Babesia. I gave her a high (sea) salt diet with fluids with Florinef, which is a drug to raise the blood pressure.

After one month, she's walking and out of her wheelchair. Her seizures have stopped. She's off morphine. She has no more pain. She's going out to parties with her friends. She’s completely well and functioning within one month of these targeted medications.

This girl was dying. Now, this was done on a physical examination just asking questions. All I did was put together a regimen to go after all of the bacteria and the parasites at the same time while treating the debilitating POTS condition.

And later . . .

The [health systems], health insurance companies, ILADS, doctors, the people in the Lyme community who are suffering, sociologists, everyone needs to come to the table to look at the research, look at the funding, [look at the whole person and the whole problem, not just the single infection. This is the number one epidemic spreading worldwide. We’re looking at millions worldwide, at least 6% of China’s population for a start; that’s over 60 million people.

We can't stick our heads in the sand and ignore this. This is important from the point of view of protecting the future generations, of bringing down the incidence and cost of chronic illness.

I think we're getting close to solutions but we’ve got to sort out the science and we've got to get rid of the politics.

3. **Occupy the USDOJ** - Protest the Dearborn Deception from *Bad Lyme Attitude*

The Department of Justice (USA) is being charged for its part in the suppression of information about Lyme disease and the Lyme vaccine. (The Lyme vaccine was purported withdrawn for lack of interest, but in fact it was knowingly based on doctored research results.

https://badlymeattitude.files.wordpress.com/2015/05/chargescomplete.pdf