

My Story

- Name: [REDACTED]
- Age: [REDACTED]
- My address is: [REDACTED]
- My postal address is: [REDACTED]
- You can contact me on: [REDACTED]
- I want my story to be Public with my name withheld

About my journey

- I acquired Lyme-like illness at: I believe I may have contracted Lyme disease in Western Australia after noticing a bullseye rash after holidaying in Lancelin. I was also holidaying in Denmark (WA) over this period. I don't recall being bitten. This may have been a secondary bite as I had already been suffering from symptoms prior to this rash and was diagnosed with Fibromyalgia.
- Type of Bite: [unknown]
- I have been sick for over 4 years and was originally diagnosed with Adrenal Fatigue then Fibromyalgia. Approx. 3 years after my first symptoms I was diagnosed with Lyme Disease by an LLMD.
- I have positive blood tests from Australian Biologics for Borrelia. I tested negative through Infectolab (Germany)
- I tested positive for Borrelia, Mycoplasma Pneumoniae, I have also received a clinical diagnosis for Bartonella and Babesia. I have also tested positive for Helicobacter Pylori and Blastocystis Hominis, MTHR mutation (C677T) and Pyroluria which is apparently quite common for Lyme sufferers. I am also gluten intolerant and have Fructose Malabsorption.
- I have seen over 20 medical practitioners in my journey including GPs, specialists, natural therapists and even a psychologist.
- I have only been admitted to hospital in Australia for a sleep study during my illness. However, I received treatment for Lyme Disease in a German hospital where I was an inpatient for 2 weeks.
- I have also been diagnosed with Fibromyalgia and Hypothyroidism and have numerous vitamin and mineral deficiencies.
- I received income protection insurance for two years however this was when my diagnosis was Fibromyalgia, not Lyme disease.

My life

- Prior to my illness I was a fit, healthy, active mother of two boys working full time. I would visit the gym at work most lunch times and managed to take my sons to various sporting activities along with running the household with cleaning, cooking, shopping etc. I had an active social life with a great group of friends who we

regularly caught up with, enjoying such things as dinners, movies, dancing and camping holiday together. I was very involved in my children's school and sporting communities which included the running of fundraising activities and any other support required. I was the manager of their basketball teams and was one of the age group managers at the Surf lifesaving club. I was an organised person so enjoyed taking on these roles.

- When I became ill I had to give up work for a few months and was supported with a return to work program which determined I could managed a part time work load of 20 hours per week with the flexibility of working from home. This was still very difficult at times but I feel it was important for my mental health to maintain my working life. I regularly took days off when I was bed ridden and unable to work but my work place was always very supportive and provided paid sick leave on these occasions. My modified working hours included 2 days working from home which meant I could rest as required and spread my work hours over the day.
- My social life diminished but I was very fortunate to have supportive friends and family who understood. Even when I did commit to a particular social event I would often have to cancel at the last minute or leave early but everyone always understood and were just happy to see me when I was up to it.
- I went from being able to jog on the beach, workout at the gym, and swim laps of a pool to barely being able to walk (dawdle) one lap of the local football oval
- I was unable to do any heavy housework and some days I didn't even have the energy to hang the washing on the line. My husband took on most of the housework and we paid a cleaner once a fortnight to keep on top of the bathrooms
- I lost my independence and felt I relied on others to do most of the things I could previously manage myself.
- The out of pocket medical expenses totalled \$15000 - \$20000 each year. These costs for medications, supplements, tests and consultations along with the reduction in my pay meant we had to make the tough decision to sell our dream home.
- Selling our house freed up money to help fund a trip to Germany for treatment. Flights, accommodation and treatment was in excess of AUD \$40000.
- This treatment included daily IV antibiotics and vitamins but the main treatment was hyperthermia where they heat your body to 41.7 degrees in order to kill the bacteria, this is done under sedation over a period of 6-8 hours while being closely monitored by an intensive care nurse. I underwent two of these during the fortnight I was admitted to the Clinic. This treatment caused my symptoms to flare for a few days afterwards while the dead bacteria was detoxed. The additional therapies provided helped support this.
- My husband was diagnosed with Borrelia but has no symptoms. Although he has been bitten by ticks in his life he has never had a bullseye rash. It is quite likely that he contracted the bacteria from me as it is known to be sexually transmitted.

- We made the decision to also have him treated while we were in Germany, the main reason was to avoid him re-infecting me on our return. Interestingly he suffered symptoms from the detoxing bacteria after the treatment also, very similar to myself.
- Following the treatment, I had 3 – 6 months of aftercare including supplements and medications plus detoxing therapies. This after care was a crucial part of the treatment as your body recovers from the intense treatment and the dead bacteria is removed.
- 3 months on from this treatment I am really feeling a difference. In the last week I have had a number of days where I have not required an afternoon sleep for the first time in years. My head is clearer and I am regaining my strength and fitness.
- Everyone around me is noticing a change in my energy and ability but the most significant was when my children have commented on having their old mum back.
- It saddens me to think of what I have missed out on over the years but I am one of the lucky ones as I still have the support of a wonderful husband and two beautiful boys who never gave up on me and were there for me in my darkest days. Having the support of my wonderful group of friends and such a supportive workplace have also helped immensely. I know many people suffer from depression but I believe that my positive attitude and the incredible support I have had around me have really helped me cope
- I was also lucky enough to have been taken seriously by all the medical practitioners that I consulted and although it took me a few years to get the diagnosis of Lyme disease I do feel that I was making progress treating other deficiencies, which ultimately helped me during my Lyme treatment

Medical History – Time Line

- 1996 (after first child) diagnosed with underactive thyroid, taken 200 mg Thyroxine ever since
- Reflux – treated with Pariet
- Rosacea – topical cream prescribed – Rozex gel (metronidazole)
- 2007 severe Vertigo – treated with Stemzine
- 2008 – Immune system struggling. Naturopath identified Gluten intolerance. Have been on a gluten free diet ever since.
- 2010 – gut issues constipation/bloating – treated with movicol
- 2011 Re-occurring virus (flu like symptoms aches/fatigue) tested for EBV, Ross River, CMV, all negative.
- 2011 – Severe fatigue, low iron levels were discovered – ferritin 7 – iron infusion, energy returned. Heavy periods lead to low iron levels (ferritin 14) within a few

months – another iron infusion but this time no return to energy. Suffered daily fatigue (mainly arvo) 2011-2016 requiring rest/sleep daily

- Prescribed multi vitamins, immune booster (metagenics)
- Mid Aug 2011 continued daily fatigue plus flare ups of viral symptoms – aching muscle/joints/upper back, migraines (over right eye/ear/head), sensitive to light, night and day sweats, dizzy, nausea, heavy head
- Oct11 – FIRST Hair Analysis indicated numerous deficiencies
- Nutritional Dr prescribed Zinc, Silica, Livton, Calcium Citrate, Vit E, Selenite
- Nov 2011 – Saliva test diagnosed adrenal fatigue prescribed Adrenotone (metagenics) 3 per day for 3 months plus continued with immune booster
- 2011 – Tried progesterone cream to reduce heavy periods unsuccessful - Mirena (IUD) in place (Nov11), reduction in heavy periods, eventual return to good iron levels, although fatigue and other symptoms remained
- Tests for Lupus – negative
- Referral to immunologist – diagnosed with Fibromyalgia – ENDEP (antidepressant) prescribed however stopped after 1 month as no change to sleep or fatigue
- Return of reflux – swapped from Pariet to Nexium
- Early 2012 – Bullseye Rash on Arm – treated with antifungal cream – did not report to Dr
- Jan 2012 – Nutritional Dr added Vitamin D 5000 IU, Aloe Vera Juice, Tyrosine
- Feb 2012 Referred to Rheumatologist who supported Fibromyalgia diagnosis
- Feb 2012 Nutritionalist – referred me to Dr Jacob Teitelbaum protocol for Fibromyalgia. Took me off Nexium, replaced with calcium powder after meals which helped ease my reflux.
- Stool Sample – positive H Pylori – treated with antibiotics and blastocystis Hominis – treated with herbs. Prescribed Low Carb/sugar diet, reduce yeast. Added Magnesium, B complex, Vit C, Adrenotone, probiotics.
- 20 Apr 2012 – sleep study – “normal”
- 2012 Mild vertigo – treated with Stemzine
- May 2012 – SE Lyme Serology (Clinipath) IGG/IGM Negative, Barmah Forest IGG/IGM Negative
- Jun 2012 – Nutritional Dr added Adrenal Support supplements which I stayed on for approx. 2 years. Also commenced DHEA 10mg per day.
- B12 injections – every 2nd day for 3weeks
- D-Ribose – tried taking for 2 months but did not feel any benefits
- Jan 2013 – added MACA (to assist with symptoms associated with estrogen drop around period) Added Endura Cell Plus to help with Aches (remained on until early 2015)
- Aug 13 – Nutritional Dr added fish oil to regime

- 23 Oct 13 - Nutritional Dr suggested IV Vit C to help assist with possible virus in my liver – high carotene levels indicate my liver is not converting Vit A as it should.
- Feb 14 – consulted with a new Dr who specialised in Fibromyalgia.
- Tests for Lyme/parasite/fructose intolerance
- 20 Feb Infectolab – Borrelia Burgdorferi – immunoblot and Elispot LTT Negative
- BIOSCREEN Script - 19 Mar 14 for 6 months. Roxythromycin, Nalcosamine, Probiotics, Leaky Gut, Mutaflor, ALK-MG-CA Powder, NA/K (HCO₃), Melatonin, Aloe Vera Juice
- 21 Mar 14 – Breath Test – positive for Fructose Malabsorption
- 27 May 14 Australian Biologics – Borrelia Blood – detected, Mycoplasma Pneumoniae – detected. Borrelia Serum and Urine – not detected.
- Clinically diagnosed with Bartonella, Borrelia and Babesia
- 18 Jun – 20 Aug 14 9 x infusions Vit C/B and Glutathione, some improvement in energy but didn't continue as too costly. \$250 per infusion
- Aug 14 commenced Lyme treatment (see separate details)
- Monthly blood tests, 6 monthly hair analysis, bi-monthly ECG, 6 monthly eye test
- Nutritional Dr continued to treat deficiencies along with MTHR and Pyroluria throughout Lyme treatment, adjusting vitamins/minerals and other supplements as required. I believe this was an important part of my treatment to support my body
- Aug 14 commenced Paleo Diet – continued throughout treatment
- Feb 15 Discussed option of going to Germany for Hyperthermia treatment with Doctor. He strongly recommended I wait until Babesia symptoms had gone prior to going as the treatment does not work for Babesia or Bartonella plus the heat treatment can actually feed the Babesia.
- Jul 15 Consulted with Lyme specialist Nicola MacFadzean via Skype for second opinion on treatment. Reviewed regime and adjusted with Australian Dr.
- Sep-Nov15 – removal of mercury fillings using rubber dams by dentist
- Sep15 – 23 and me tests – genetic profile
- Nov 15 – consulted with Naturopath to interpret 23 and ME results. Reviewed my supplements including those I would be on for my aftercare from the German Clinic. Advised NOT to have ozone therapy in Germany due Superoxide dismutase mutation as this could trigger Motor Neurone Disease (my mother died from this)
- Dec 15 – Hyperthermia treatment – St Georg Klinik Bad Aibling Germany

SYMPTOMS

Some days and weeks were worse than others but here is a snapshot of my symptoms.

The main symptoms I have had on a daily or weekly basis are as follows:

Daily Fatigue – rest/sleep is required every day

Heavy Head (tightening of the head like a head ache with no pain) relieved by laying down

Sore Eye/Ear/Head – sometimes develops into a migraine and can last up to 2 days (always on the right side of my head) Very sensitive to light when I have this pain and also find it very painful to have my eyes open and read or watch tv

Stiff neck

Frozen (left) Shoulder (this has improved but still very stiff)

Nausea (I believe this is from the antibiotics but can't be sure)

Tightness in Chest/ribs – usually relieved when laying down

In addition to these regular symptoms I also have the following but not every week

Air hunger

Dry cough

Joint/muscle pain

Stomach pain

Twitching – very slight, usually facial

Lyme Treatment

Aug 14 – Dec 15

Commenced Lyme Treatment in Aug 14 targeting Babesia and Bartonella first. Combination treatment of high dose Anti-biotics. These were introduced gradually and dosages increased slowly to reduce herxheimer reaction. I didn't suffer too badly from herxheimer however did get a few bouts of thrush due to the high dose of antibiotics killing off the healthy bacteria in my gut. I introduced high dose probiotics plus Nilstat 3 x daily and have continued with these throughout my treatment

Medications – Plaquenil – 1 x daily, Artesunate – 2 x twice weekly, Clarithromycin 1 x three times daily, Doxycycline – 2 x twice daily, Pyrimethamine 2 x daily

Supplements – Withania, Folic Acid, Sulphadiazine

Six months after commencing this Lyme treatment my doctor replaced Pyrimethamine with Malarone. I continued on this for 9 months. NB Malarone costs \$600 for one month supply

3 months into taking Malarone my doctor prescribed an 18 day course of Clindamycin however I experienced severe stomach pain including bloating and wind so it was decided to stop due to the risk of developing clostridium-difficile (C-diff)

After 5 months on Malarone my doctor added Pyrimethamine back to my regime along with the Malarone to try to nail the Babesia. It was necessary to stop taking Methylguard over this time to reduce my folate levels I had monthly blood tests during this time to monitor my B12 and folate.

I had monthly blood tests throughout the treatment to monitor my liver, kidney and white blood cells. I also had bi-monthly ECG to monitor any side effects from Clarythromycin and 6 monthly eye tests to check any damage from Plaquenil.

I had a skype appointment with a Lyme specialist in U.S. who also added herbs to my regime plus suggested some changes to my Babesia medications which were supported by my Australian Dr.

I have followed a strict Paleo Diet (no sugar, wheat, dairy, caffeine, alcohol throughout my treatment which I believe is one of the reasons I have been able to cope with the amount and variety of medications.

I also continued to take supplements to support my vitamin and mineral deficiencies, see list below. I believe this also helped support my body through the intensive treatment

I have had fortnightly massages and regular Epsom salt baths to assist with detoxing. I also found lemon juice in warm water helped with detoxing and was especially useful when herxing.

Exercising daily even on my bad days was good for me, I would always try to go for a walk no matter how I felt. I was only ever capable of short slow walks or I could suffer for days afterwards, on my better days I would walk for slightly longer but never very fast. Most times I would drive to the local football oval and walk around on a flat surface.

ANTIBIOTICS/MEDICATIONS

Artesunate 50mg caps – 2 x three times per week
Clarithromycin 250 mg – 2 x twice daily
Doxycycline 100mg – 2 x twice daily
Malarone 250mg/100mg – 1 x three times day
DHEA 10mg – ½ twice daily
Plaquenil 200mg – 1 x daily
Oroxine 200 mcg – 1 x daily
Nilstat – 500000 I.U. 3 x daily
Pyrimethamine (Daraprim) 25mg – 1 x daily

SUPPLEMENTS

Mediherb Withania complex – 1 x twice daily
Compound – Zinc(pic) 90mg, Selenium (pic) 200 mcg, Molybdenum (pic) 1000 mcg, Silica 75 mg,
Boron (pic) 3mg, Chromium (pic) 1000 mcg, Vit D3 4000 IU, Pyridoxal 5 Phosphate 80mg
Melatonin SR 3mg – 1 x night
Bouluke Lumbrokinase – 2 x daily
Fish Oil - daily
Magnesium – 1 x twice daily
Vit C – 1 tsp per day
Iodine Spray – 2 sprays per day
Solgar NAC 600mg – 2 x twice daily
Solgar Biotin 10000mcg – 1 x daily
MACA 500mg – 1 x twice daily
Lauricidin Monolaurin – 3 scoops daily
L- Glutathione (research nutritional) 1 tsp per day
Crypto Plus (Cryptolepis Herb) 40 drops twice daily

Probiotics High Strength Probiotic 10 powder 100 Billion Organisms – 1 scoop per day
Methylguard - 1 x daily
A-BAB – Byron White formula – 15 drops – twice daily
Research Nutritional = NT Factor – 3 x daily – Energy Multi-plex – 3 x daily
Note: Additional supplement regime added post St Georg Klinik treatment

SUMMARY

I feel it is very important that all doctors and especially GPs recognise the symptoms of Lyme disease and treat patients in the early stages of the illness

My GP sent me for testing via Clinipath only when I asked for this, when the results came back negative Lyme disease was ruled out.

My first tests through my Lyme Literate Dr were sent to Germany and cost me \$1200, they also came back negative.

I feel it's important for Drs to be able to treat for Lyme disease without positive test results, using clinical diagnosis and monitoring the response to treatment. If symptoms are improving, that is surely a positive sign.

The longer you have the bacteria it seems the worse your symptoms get and the longer it takes to treat. It took me over 12 months to treat Babesia and I didn't even begin to treat the Borrelia in Australia after deciding to go to Germany. The treatment in Australia was likely to take another 2-3 years.

Research into the Hyperthermia treatment which is highly successful in Germany should be a consideration in Australia. The costs and difficulties for very sick patients to travel so far can often make this option impossible for many sufferers.

We believe that it is also important for blood donors to be screened to avoid possibly passing on the bacteria via blood transfusions

This disease is sexually transmitted and can also be passed on from mother to child in utero, so why would it not be also be transferred by blood.

I am sure there are many more sufferers of this disease who don't even know it yet as they have been diagnosed with something else that mimics this or they have just been told that it's all in their head.

Finally, I believe recognising Lyme disease in Australia is not as important as recognising that there are thousands of Australian sufferers and to learn how to diagnose and treat them, allowing us all the best possible quality of life.

The cost to the country at the moment is enormous.