

Senate Inquiry Submission

Details

- [REDACTED]
- 58 yo
- [REDACTED]
- [REDACTED]
- Public

Summary

- I acquired Lyme-like illness from a tick bite in Pomona QLD (4568)
- I immediately became sick with flu-like symptoms after the tick bite and had a bulls eye rash at the tick bite site
- I did not connect the tick bite with my subsequent decline of health, and no doctor asked about tick bite history
- I was sick for 4 years before I diagnosed myself because a friend pointed out online information about bulls eye rash
- I have positive DNA Borrelia Burgdoferi blood tests from US lab
- I also have positive tests for Rickettsia (multiple strains)
- I have been clinically diagnosed with Babesia and Bartonella
- I've never had a full assessment by a Lyme-aware doctor
- I saw 17 doctors prior to diagnosis
- I had been diagnosed with CFS, query atypical Lupus, atypical Sarcoidosis, depression, fatty liver (although scans did not show that)
- No doctor would help, I had given up and was saying my goodbyes, my mother-in-law found Salt/C protocol online and within 18 months, while still disabled, I had quality of life back
- I've been on Salt/C protocol for 8 years, I'm very disabled compared to my pre-tick bite self, but I can participate in life
- I have a sympathetic doctor, but she is scared to treat Lyme-like illness because of AHPRA situation and would like support/training for Australian doctors

My Story

In 2002 I had a tick bite on my right arm that was 'different'. I immediately began to feel ill with strong flu-like symptoms and developed a strange rash. With a semi-rural property, multiple pets and kangaroos regularly visiting, I had had tick bites previously, but never symptoms like this. I researched online and found that it was a 'bulls eye rash'. It said it was 'rarely fatal', so I just continued with supplements to support my immune system and symptoms. To this day I wonder what would have happened if I'd found a Lyme disease website rather than an entomology site to research my rash.

Over the next few months I started to become unwell, but I didn't connect it to the tick bite. I was fatigued and couldn't find a reason. In August 2002 on a cruise to Alaska, I experienced a very severe and 'weird' flu-like illness. I had headaches, light sensitivity, and skin sensitivity amongst other symptoms. I couldn't even tolerate a sheet on my skin and had a rash on my hands. Again because I was unaware of the significance of a bullseye rash, I didn't connect this illness to the tick bite. My first career was a triple certificate critical care nurse, so I am typically very self-responsible with my health choices and management.

I had multiple visits to my GP over the next 2 years with early symptoms of fatigue, significant weight gain and elevated liver enzymes. In the first 4-6 years of trying to find answers, I had had referrals to multiple specialists including Infectious Disease Specialists (2 saying 'no Lyme in Australia'), Gastroenterologist, Cardiologists, Endocrine and Integrative GP (who stood up and kicked me out of the office). I had brain scans. CT scans of abdomen. stress echo. and extensive blood. urine & stool specimens. My GP was

By 2005-2007 I was critically ill. I could only walk about 10 steps, very low energy, pain from head to toe, incontinent of urine & stool, acid reflux, muscle weakness - if I squatted down I needed help to get up, I could no longer lift my leg to get dressed without propping myself, short of breath – unable to complete a full sentence, severe depression, brain fog and emotional lability, anxiety, arrhythmias and chest pain (I developed a mitral valve incompetence), migraine headaches with loss of vision, frequent sore throats, elevated liver enzymes, altered Vitamin D metabolism, elevated ACE, extensive Alzheimer’s-like symptoms (loss of memory, forgetting friends and family's names, forgetting how to drive, couldn't figure out the cold/hot taps and which way to turn, lost ability to multi-task, lost initiative and drive, lost ability to organise and plan, slow word recall, unable to read for pleasure or study), no visual scanning ability.

I had a SPECT brain scan which the doctor said was 8 out of 10 in severity of changes, indicating severe cognitive incapacity - he told me it was my 'pure determination and intellect' that was allowing me to even have a conversation." I had run out of ideas and was praying and planning to die. At this point (2007) I spent all her time on the couch.

Diagnosis

I have a nutrition business and through that business I have contacts with many U.S. doctors. I had the chance to interview one of them in 2006 and asked for help. He said, 'you need to get tested for Lyme disease' and gave me details of an American lab. I sent both my blood and my partner's (my partner, while mostly symptom-free, had had a different tick bite on the same property and had a different rash that was cyclical every 4 weeks). In December 2006 both of our blood tests came back positive for *Borrelia burgdorferi* via DNA testing.

To this date, a doctor has never properly and fully assessed me for Lyme-like illness and co-infections. Doctors have clinically diagnosed the co-infections of *Bartonella* and *Babesia* because of clinical presentation, but there could be more as no further testing has been done.

The Treatment

I had given up on doctors by this point – actually I became doctor-phobic. I could hardly string a sentence together and I definitely could no longer 'fight' doctors or stand up for myself. My daily life was torture and I had a plan for suicide and had started to say goodbye to my friends. My mother-in-law came for a visit, saw how sick I had become and went home to search for answers on the internet. She found the Salt and Vit C protocol on a US site and sent the details to me. I saw a glimmer of hope in what I reviewed and thought she I 'nothing to lose' at that point. It was a very, very difficult journey, but after 18 months I was about 70-80% improved.

I did have a Lyme-literate doctor for a short period and was about to have more intensive medical support, but he had treating restrictions placed by AHPRA so that support was withdrawn.

The Impact

My hopes and dreams for my future have been decimated. I have always been a committed, high achiever at whatever I put her hand to, but I've had to lead a very disabled life. Through loss of income and medical expenses, we have had to sell our entire property investment portfolio (10 properties) and we are facing losing our home at present. We were on track to be 'self-funded' in retirement but at this point, without a miracle, this goal appears to be shattered.

I have had to work very hard to 'focus on the positives' of what I still have rather than what I've lost. I still work towards acceptance of a 'disabled life'; but I'm not there yet and feel sad just writing this. Volunteering for others assists her in feeling like she can still contribute to society.

I remain on the Salt and Vit C protocol (15 gms of each per day) but it's not pleasant, causes daily nausea and mostly means it's safest to stay home. Going out impacts my ability to take it, which then impacts my health and I regress into worse symptoms. I can't stand long, walk far, learn new things, visually scan or read and retain. I've lost the ability to multi-task, organize, file or compare and analyse. It's 13 years since I became sick and my family can't remember the 'healthy [REDACTED]'. My children know me as the mum that sits in a chair. I'm concerned about the impact on my relationship – it's truly tough.

I dream of travelling to the US for expert and experienced treatment in order to get my full life back – but it's not a financial possibility.

I'm also extremely concerned about the new mandatory vaccination schedule. My children are 'at risk' for Lyme-like illness, are showing early symptoms. Vaccination is contraindicated for them and forced vaccination would be 'medical assault'. Vaccination is also contraindicated for adults with Lyme-like illness.

Reflections

I now volunteer for a Lyme charity. I'm devastated at what I see every day and just can't rest until the Australian governments and medical fraternities realize that there's a serious medical emergency in the emerging epidemic of vector-borne disease in Australia. "We're a 'laughing stock' on the world stage, if only it was a laughing matter".

I am astounded at the entrenched inaction of the Department of Health and the seeming conflict of interest and control that organisations like AHPRA and RCPA have in influencing decisions. Their actions are negligent, corrupt and seemingly devoid of accountability. In emerging illness situations, some flexibility is required, common sense must prevail and critical decisions made in prioritising research and empowering doctors to be discerning and pro-active.

This longstanding inaction by successive Health Ministers and Department of Health is culpable and tens of thousands of Australians are falling ill, regressing into permanent disability and death during their tenure. Shame on them.

Lyme-like illness patients get better with treatment. Government inaction is contributing to burgeoning and overwhelming burden of disease impact in our society.

I'd like to see immediate recognition by government of a Lyme-like illness in Australia and urgent, national education, support and protection for doctors in implementing treatment protocols with the 'best of the knowledge of the day', while research progresses. Lyme-like illness patients are all the evidence that is needed to confirm there's an emerging epidemic in Australia. Effective diagnosis and treatment gets patients back into quality of life, back to their families, communities and careers and to be fully contributing members of our society once again.

I would like to see the end of neglect, discrimination and abuse that Lyme-like illness patients experience in their attempts to get diagnosis and treatment in Australia. Currently, when patients present with symptoms that doctors don't have knowledge to understand, a psychiatric label is the 'go to' response – this practice must stop.

I would like to see all patients with the most commonly misdiagnosed conditions, like MS, CFS, Lou Gehrig, Motor Neurone, Rheumatoid Arthritis, ADD, Alzheimer's, and ADD/Autism be re-assessed for tick and other vector borne diseases.

I would like affordable and accurate testing, affordable treatment and disability support for patients and tick (and other vector) prevention and awareness education to be urgently rolled out in a national awareness program.