

Senate Enquiry into Lyme Disease in Australia.

My Story.

[REDACTED]

I am in my sixties.

[REDACTED]

[REDACTED]

[REDACTED]

I want my story to be public.

About our journey.

My husband and I have lived at [REDACTED] for about 20 years since we bought our acreage property. The property was infested by many weeds and while clearing those, we received many tick bites. In about 2012 I started to become unwell and so did my husband, which was unusual because we had been very fit and active.

By 2013 in February I was suffering from chronic swollen glands, vomiting, headaches and rashes. By July 2013 I was suffering severe depression, aches and pains and whenever I got a tick bite it would often go black and poisonous. After one of the bites I got mastitis and the GP asked me what I thought was wrong with me. I showed him the last tick bite and said I thought my problems were caused by the ticks. The GP said that according to the AMA there was no Lyme disease in Australia, but he gave me a months worth of antibiotics and I felt better for a couple of months, then I went backwards. I had seen something about Lyme Disease in an email sent by the secretary of Gold Coast Rural Fire Brigade Group, warning about the risk of Lyme Disease from ticks (My husband and myself are in the local Rural Fire Brigade) and I visited the website he directed us to and discovered that our symptoms sounded much like the ones described on the Karl MacManus Lyme Disease Foundation website. I contacted them and asked if there was a doctor anywhere near me that knew anything about Tick Bourne diseases. She directed me to a Doctor on the Gold Coast who tested us and said that we had all the clinical signs of Tick Bourne disease and suggested that we send our bloods to Infectolab in Germany. In May 2013 we received the results which showed both my husband and myself had Borrellia and my husband also had Bartinella. That was extraordinary because at the time we didn't even have passports and we had never had a tick bite until we moved to the [REDACTED], so I know that we were infected in our local area.

By that time I was having trouble walking and the brain fog was frightening, while my husband was getting swelling in the skull.

Since then the doctor has treated us with antibiotics and while it was extremely painful and my husband was unable to work for about 6 months and could only manage to get from the bed to the bathroom and a chair, we both started to improve slowly. I had weakness particularly from the waist down, we both had headaches every day, rashes, joint pain, no energy, depression, brain fog and the housework was an effort or simply wasn't done. My husband's brain swelling was very worrying and it was changing his moods dramatically.

We both were improving and my husband had to go back to work, but the doctor will only let him work on Monday, Tuesday, Thursday and Friday so that he can rest on Wednesdays.

About a year ago I suffered from a serious bout of pneumonia and was hospitalised for around a week and was ridiculed because my GP had written on the letter to the hospital that I had Lyme disease. After that I went backwards again and it took months to recover from the pneumonia.

Early in 2015 we went to a Clinic on the Gold Coast to have whole body Hypothermia, Hyperbaric treatments and Vitamin C Intravenous therapy which I believe has improved our immune systems and we are feeling better although it doesn't take much for us to go backwards.

Recently my husband did too much and he went backwards and is still unwell.

I would like to make it very clear that in the last 2 and half years since my husband and myself first got our blood test results back from Germany when we were both very sick, we both started to improve with the regime of antibiotics. The Herxheimer reactions were very bad in the first few months, but then we improved dramatically. I believe that when my husband had the severe swelling in his head, the antibiotics saved his life and they certainly saved his sanity. Recently I got a 3 tick bites while 2 bite sites were just the usual swollen itch that worried me for a few weeks, the bite on my shoulder had a definite bulls eye rash.

When we go backwards, the doctor adjusts the medication protocol and then we continue to progress. Over the last year we have been taking antibiotics in the regime of 2 weeks on and 2 weeks off. We visit him about once a month or more if necessary.

I believe that a positive attitude, a good and compassionate doctor, antibiotics, alternative treatments, natural remedies, healthy lifestyle, no caffeine, no alcohol and early nights with plenty of rest are our only chance of being able to cope with this illness.

I have come to the conclusion that we have a chronic disease and we will have to manage it for the rest of our lives. All the patients that I've spoken to that have felt good and gone off the medication relapse, and have to go back on medication, although I know of a couple of people who have been

diagnosed early and have been cured.

It has cost us tens of thousands of dollars for blood tests, treatments medications and doctors visits and there is no end in sight.

It has changed our lives completely and we are always tired and prior to getting sick we were so active, now all our plans for retirement have gone out the window. We refuse to lie down and die, but sometimes it is hard to stay positive. Maintaining our property is exhausting but we will keep going as long as we can. We have friends and relatives that won't come to visit because of the fear that they will be bitten by a tick with Borrellia because they have seen what we have gone through over the last few years.

Please recognise that we are sick from Australian ticks and doctors need to be trained to recognise the disease and how to treat it. There are innocent people, young and old who are sick and have been misdiagnosed and therefore have no chance of recovery because the government has been in denial. We have to start educating the public how to prevent tick bites and what to do if they get a tick bite. It may be too late for many of us, but please start preventing that from happening to many more people.

[REDACTED]

[REDACTED] Lyme Disease