

Inquiry: the Growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients.

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I want my story to be public.

My story

I became ill in November 2011. I thought it might pass – it felt like a bad case of flu (without a cold). As there was no improvement after 2 - 3 weeks, I visited a GP who took a series of standard blood tests. All of these came back negative.

Over the coming weeks, I saw no improvement and began to get worse. I visited another 3 doctors who could still find nothing wrong with me. One GP did tests for a series of illnesses including Ross River Fever etc. to no avail.

By this stage I had missed weeks from work, I could not drive, and I was losing weight at a dramatic level. I heard through a friend that they knew someone who had similar symptoms after being bitten by a tick.

The idea that this could be relevant to me was because I had received multiple paralysis tick bites over 3.5 years since moving to Lamington National Park in Beechmont, Queensland in 2008. Until that time I had never seen or been bitten by a tick. [1] I was never warned that there was any danger in receiving a tick bite, hence the reason I did not mention this to any of the doctors I had visited over the past 10 weeks.

Immediately I saw a GP (Feb 2012) and asked them to test me for anything to do with a tick. I tested positive to Spotted Fever (*Rickettsia Australis*, tick-borne illness). Immediately my GP telephoned the Infectious Diseases Doctor (ID Dr) on the Gold Coast to ask for help on how to treat me. The ID Dr advised him to administer 10 days of Doxycycline.

As the days turned into weeks, I began to feel so ill that I could no longer leave my bed. My legs were twitching, and by now I had lost 14kg. I returned to see my GP, who informed me that my initial series of tick-based blood tests had come back positive for Lyme Disease (*testing: Sullivan Nicolades, Australia*). He called the same Gold Coast **Infectious Diseases Doctor** who informed him [2]“**Lyme Disease does not exist in Australia**”. He said that my blood would be sent to Westmead Hospital, Sydney for a second screening, and would undoubtedly come back as a ‘false positive’. As predicted, it did come back as a false positive, and not being educated in the flawed blood tests in Australia, we knew no better.

I now believed that my sole diagnosis/illness was Spotted Fever, and as I still showed no signs of improvement in my health after four months of being ill, I made an appointment to see the ID Doctor in person to see if he could shed some light on Spotted Fever. He advised me that the 10 days of Doxycycline (anti-biotics) previously prescribed were adequate for a full recovery, and that most people recover within 3 months.

After five months absent from work, I began a staged return, managing to work up to 10 hours per week. Fortunately the company I work for have been outstanding. My hours began to increase slightly over the coming months, but I could only manage to work part-time. In October 2012, I had a full relapse of the illness and I began to investigate Lyme Disease on the internet.

In early 2013 I made an appointment to visit a Lyme Literate Dr (LLD). After listening to all my symptoms and looking at my blood tests, he clinically diagnosed me Lyme Disease. I had been ill for FIFTEEN MONTHS before a Doctor recognised and acknowledged my illness. In this time, I had been misled, and because of this, the bacteria had set in deep throughout my system. It was in my blood, my organs, my brain and my eyes.

Since visiting this LLD in Feb. 2013, I have seen 2 more LLD's, both of which have clinically diagnosed me with Lyme or a 'Lyme-like disease'.

Blood tests were sent to Germany (Arminlabs) in 2015 and have shown positive results for Borrelia (Lyme), and Epstein Barr Virus (common in many Lyme patients). I have also tested positive for mould, candida and parasites.

As well as my daily symptoms of chronic fatigue, malaise, chronic migraine, insomnia, permanent swollen throat, vertigo and diminishing eye-sight, I have been admitted to hospital twice by ambulance with frightening neurological symptoms, and a biopsy of my lymph nodes showed they were 'necrotic' and full of puss.

This illness has disabled me. It has taken away my freedom. It has ruined my career. It has robbed me of my finances. Over the past four years, I have spent tens of thousands of dollars on doctors, naturopaths, tests, medicine and supplements.

Prior to my illness I lived as a couple on a 1.5 acre property. Now I live alone in a tiny studio.

Prior to my illness I was on a very good salary with excellent career prospects. Now I work up to 15 hours per week on an hourly rate in a basic role.

Prior to my illness I could exercise. Go on holiday. Have the energy to shop. Visit my friends and be sociable. Now I hardly leave the house.

Even my dog suffers as a consequence. I have to pay someone to walk him.

It is hard to believe that in 2016, in a country as advanced as Australia ('The Lucky Country') that people can be left to rot.

Not recognising this Lyme-like illness in Australia is an abomination. There are thousands of Australians suffering. We desperately need your help. There is no testing, no education, no Medicare, no sick or disability benefit, no insurance. People have lost their houses. People have committed suicide.

Please help.

[1] Tick warning signs are needed in prevalent areas such as National Parks & Forests in Australia, as they do in Germany.

[2] Lyme Disease testing in Australia is based on an American strain of bacteria from 20+ years ago, therefore Doctors claiming that 'Lyme Disease' does not exist in Australia are correct. What we have on this continent is a different strain of bacteria, hence the correct term should be "Lyme-Like Disease" or "Australian Lyme" or similar. Australia's 'Lyme Disease' blood testing is not relevant to our illness, hence the negative test results. A clinical diagnosis is the only reliable diagnosis.