

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Access to diagnosis and treatment for people in Australia with tick-borne diseases

Please note that this is an abbreviated version of my story. More information can be provided, specifically about the impact on my life and many more medical documents can be provided, but I believe this will cover what needs to be said.

My Details

Name – Stephen John Bloomer

Age – 59

Address –

Phone –

My story can be made public

Basic Facts

Bitten in Australia – Shoalwater Bay, Qld 4701 (Army training area), with a large EM rash.

From age of 2, until well after I was sick I had never left Australia, but I have since been overseas.

Sick for 14 years prior to diagnosis.

Positive Blood Tests – Yes

- Alfred Hospital – Positive Eliza
- Infectolab – Positive Eliza, Borderline Immunoblot
- IGeneX – Positive Eliza, Positive Western Blot
- Australian Rickettsial Reference Laboratory Foundation Ltd, positive Western Blot igM
- Infectious Diseases Specialist confirmed diagnosis Lyme-like tick borne disease

My Story

The Start

In September 1999, I was a member of the Australian Regular Army serving as a part of the Military Police support to major exercise in the Shoalwater Bay training area, Qld. On an afternoon about 5 days into the exercise whilst conducting personal hygiene I observed a large “EM” rash on the left side of my body centring about the base of my ribs. This consisted of a smaller center rash that was surrounded by a secondary circular rash about 25cm to 30cm in size. No medical support was provided as there was no pain and being bitten by a variety of insects is accepted as common whilst on military exercises like this.

Within days I had flu-like symptoms and fatigue. The fatigue was so bad that I was unable to make it through the day long periods of sleep.

At the completion of the exercise the fatigue continued and work became difficult to maintain. In early 2000 I was placed on antidepressant medication which assisted with the fatigue but daily life remained a struggle. My pre-existing knee issues also started getting worse without any apparent reason with constant pain. In 2001 this knee pain resulted in surgery on both knees and although this seemed to help, within 6 weeks my knees were worse than they were prior to the operation.

At this time, between the fatigue and knee pain I was unable to continue with my military career and I took long service leave prior to discharge in late 2002.

During 2002 and 2003, the knee pain continued to increase and by this stage I was relying on a walking stick. By the start of 2004 I was relying on a wheelchair and taking eight Panadeine Forte a day, but this level of medication did not even seem to take the edge off the pain. I was also getting repeated infections, like tonsillitis.

For the knee pain I was sent to a knee surgeon who said I had damage, but the damage did not explain the level of pain and disability. I was subsequently referred to a rheumatologist who could find no explanation for my symptoms. This was the first doctor to suggest that I was imagining the pain and that I had a psychological disorder, but he was unable to explain other symptoms, such as the repeated infections. I was also referred to an oncologist and other specialists with no assistance or direction provided. The only advice I was given was to try and learn to live with my condition. We also worked with physiotherapist for quite a while, but this only made the pain worse.

Living without a diagnoses

With no "normal" medical help being able to assist, my GP suggested I see a naturopath. Over the years that followed we found a number of naturopaths, and although they could not help with the cause, they were able to assist with symptom control. This enabled me to keep working, but every day was a struggle. The fatigue was always present and the wheelchair and infections were a major part of my life.

Every now and again I would go back to the doctor to try and work out what was happening. What we noticed was that each doctor would look at one symptom (that was in their area of specialty), but that nobody would look at them all as a group. Life continued, but we became more and more isolated.

Diagnosis

In 2013 a strange lump started growing on my neck. A biopsy was taken and it came back as a Granuloma Annulare. This was acknowledged as unusual and I was again referred rheumatologist. He was not able to understand this and I was subsequently referred to an Immunologist at the Alfred Hospital.

In late 2013 at the Alfred hospital the doctor went through my history and admitted that he had no idea as to what was causing my long ongoing issues, but he promised to keep looking until he found a cause. He then ordered a large amount of blood tests.

In early 2014 I returned to the Alfred hospital. By this time I was in a bad way, spending most of my time in a wheelchair and having difficulty with most areas of my life. During this visit, the doctor told me that I had received a positive bacterial serology for Lyme disease. Please note that at this time I had never heard of Lyme disease and I had no understanding of how the rash and fatigue I had experienced in 1999 was related to my current situation. He further stated that there was nothing further he could do for me and said that I would need to find a doctor with a real understanding of this disease. He also referred me to an infectious diseases specialist at the Alfred Hospital. A copy of those blood test results are attached and form part of my submission.

Whilst waiting to see the infectious diseases specialist we commenced learning about Lyme disease and the controversy within the medical institutions. As a result I went to see a Lyme Literate Medical Doctor (LLMD). This LLMD ordered further blood tests which included sending blood to Infectolab in Germany. He also confirmed a diagnosis of Lyme disease and co-infections.

On 29th April 2014 I attended the Alfred Hospital's Infectious Diseases Department. During this consultation I gave a rundown of my symptoms over the years and how I had come to see the Immunologist and how I had subsequently had a positive blood test and been referred to her. The doctor then took my pulse and blood pressure prior to telling me that I did not have Lyme disease. I then asked her what was wrong with me at which time she stated that she did not know, but that I should go home and get used to living with my condition. I then asked her what she was going to do at which time she reluctantly ordered some more blood tests to rule out cancer. This was a very short consultation and she told me that there was no point in making another appointment; however I did make another appointment.

During this time I received the results of blood tests performed by Infectolab. These tests also came back positive for Lyme disease and provided more details about this disease. A copy of those results were provided to the Alfred Hospital. Those results are attached and forms part of my submission.

On 24th Jun 2014 I again attended the Alfred Hospital's Infectious Diseases Department. During this consultation the doctor made the following statements:-

- I did not have Lyme disease.
- The blood tests from the Alfred Hospital were wrong.
- The blood tests from Infectolab meant nothing (when asked, she was not able to provide any scientific reasons for this and relied on the administrative reason that this was not an Australian recognised laboratory)
- That the only assistance she was willing to provide was a referral to a psychiatrist.
- When asked about the Granuloma Annulare on my neck, she stated that this was a "psychosomatic response" from thinking that I was sick.
- That I was to leave the hospital and that she would not allow me to make any other appointments.

Commentary

One of the reasons I was told by the doctor at the Alfred hospital that the test was wrong was because I had come back negative on the Lyme (Western Blot) test, which they consider a confirmatory test. The issue with this is at the Western Blot test is not a test for Lyme disease. It is a test for your immune systems response to Lyme disease, but after having the disease and its co-

infections for 14 years with no treatment my immune system was no longer functioning at a level to enable it to respond.

Treatment

About May 2014 I commenced treatment for Lyme disease under the care of the LLMD. This treatment has been hard and expensive to the point that within three months of treatment we had to sell our house to pay for the medication. This treatment has worked well. I have now packed away the wheelchair, I am not taking any pain medication and my life is starting to get back to normal. I still have many symptoms like fatigue, but this disease being in my body untreated for so long it is hard to say what is residual damage or the effects of the disease still being in my body.

I am now at the point where we believe that I may be approaching remission, but further time and tests will be needed establish that. As a result of my improved health and that I now have a better functioning immune system we were able to send blood for further testing which did provide a positive Western Blot result (IgM).

Where to from now?

About November 2015, AHPRA directed that the LLMD who had been providing treatment was no longer allowed to write scripts for antibiotics. With the limited number of doctors with the experience and knowledge to treat this disease this leaves us with nowhere to go. Although I may be approaching remission, if I start to regress I am at a loss as to where I can get help. I am highly stressed and I have only a future of pain and disease to look forward to.

AHPRA's treatment of doctors is now at a stage that my GP will not even run basic blood tests for the fear of reprisals. I am on my own. I refer to myself as being a "medical orphan" as there are no doctors willing to assist me.

Symptoms

Below is a list of symptoms that have been a part of my life

- Joint (Knee) pain to the point of relying on walking stick and wheelchair at times along with pain killer medications to help control pain
- Fatigue
- Night sweats and difficulty in maintain temperature
- Nausea
- Bad breath (really bad)
- Repeated infections, tonsillitis, shingles, testicular that all take much longer to treat than normal.
- Confusion and concentration difficulties (Brain Fog)
- Yeast infection causing repeated genital thrush. This causes issues with wife and has had a major effect on sex life.
- Bladder issues. During day, sometimes going to toilet every 30 minutes. At night, getting up repeatedly to go to toilet (1 to 5 times a night)
- Food intolerances (I can not eat many basic foods without a bad reaction and have to maintain a strict 'natural' and 'organic' diet)
- Increased effect from alcohol and worse hangover (two beers give a hangover)

- Painful neck and spine
- With my bowels, I fluctuate between constipation and diarrhoea. Most of the time I am constipated, but I also get diarrhoea with urgency
- Psychological stress - labile emotions, despair, depression, nightmares, feelings of 'impending doom' etc
- Anxiety and depression.

I know there are many doctors stating that there is no Lyme disease in Australia, but I am suggesting to you that although they claim there is no evidence of Lyme Disease; that there is evidence of Lyme Disease and that these doctors do not truly believe in evidence-based medicine. They are denying reliable blood tests which are also confirmed by medical histories.

What we need

- Acknowledgement that there is a Lyme-like disease in Australia, accompanied with an education program for doctors to look out, or at least consider, Lyme-like tick borne disease.
- Encouragement for researchers to study and publish in this area, so we can move towards a better blood test, a diagnostic paths and treatment options.
- A group like Lyme Disease Association Australia (LDAA) to have input into where research money is spent. The control can not be left in the hands of the same groups that have denied the existence of Lyme-like disease for so many years.

For your consideration

25 Nov 2024