From:
To: Community Affairs, Committee (SEN)
Subject: My Lyme contraction in 1997 in the US
Date: Saturday, 2 January 2016 2:16:50 PM

To Whom it May Concern,

I am submitting this to you in the hopes that change will come for many Lyme sufferers like myself in Australia.

My story is a little different to many others as my Lyme was contracted overseas in the United States. It shouldn't matter where my Lyme was obtained though, I am an Australian born and raised, who is suffering physically, emotionally and most importantly financially from this Disease. Had a person contracted malaria the location of infection would not matter and we wouldn't be scrutinised, I don't know why this is such an issue with this Disease. We need support and treatment. Birds with ticks fly, animals are imported from overseas, there are many ways lyme could end up in this country and in my opinion it's naive to think otherwise.

You would think having contracted Lyme after patting a Deer in a Colorado Zoo on a Contiki Tour in 1997 that I would have a different experience than those that contracted in a country where Lyme doesn't exist (Yeah rrrright) but there is not the Drs or treatment/recognition in this country for me either and I cannot afford $30,000 to travel to Germany for hyperthermia so when I can afford it I see those Drs who recognise Lyme.

On my trip to the US in 97 I developed a bulls eye rash, but I knew nothing about Lyme Disease so dismissed it at the time, thinking it was a rash due to change in climate. Looking at bulls eye photos now I know definitively that it was a Lyme rash. The flu I had a few days later was the most horrific I'd ever had and I felt like I was literally going to die but after a week or so my symptoms abated.

My health was relatively okay until my son was born in 2005 and that's when my immune system started crashing. My initial symptoms were eye twitches, pain, pins and needles, buzzing sensations, fatigue, Irritable bowel syndrome and a constant lethargy.

10 years on and I have arthritic pain, chronic fatigue, fibromyalgia and the list goes on. I am suffering most days with something, if not migraines then crushing, burning, tightening sensations in my body or joint pain, chest pain, limb weakness, the pain and fatigue is something I wouldn't wish on my worst enemy.

I had been through nerve induction tests, ECG's, ultrasounds, Thermonuclear sweat testing & MRI's over the years since 2005 to work out what was wrong with me (pins n needles, buzzing sensations in my legs) I ended up being diagnosed with fibromyalgia at Concord Hospital in 2010. I initially saw Dr [redacted], Neurologist at Concord Hospital but was later referred to a rheumatologist who diagnosed the Fibromyalgia, this was a relief as I was convinced I had MS. I was prescribed Endep but that did nothing except make me put on weight. Little did I know Lyme was the culprit.

It wasn't until seeing a today tonight story in 2012 with symptoms similar to mine, that I suspected what I had been suffering with was Lyme Disease. A week later I put two and two together and remembered the Deer and my bullseye rash - I couldn't believe I'd forgotten about it. I contacted The Lyme Disease Association of Australia and soon after sent my bloods to America to Igenex for testing and the result was positive for Lyme Disease. At the same time I saw an IDS at Concord Hospital who tested me and told me I didn't have Lyme because it doesn't exist in Colorado, that made me laugh, what? do the ticks jump off the backs of the Deers when they are crossing state lines. He also tested me through Westmead Hospital and surprise surprise it was negative but in my opinion those tests aren't worth the paper they're written on. I have been treated by a few Drs who recognise Lyme as well as an Aussie naturopath who lives in the US. All of them believe I have lyme through test results and a clinical diagnosis. Excuse me if I don't name them. The sceptic in me thinks they should remain anonymous.

This disease has brought me to my knees. The only thing stopping me giving up is my son who is the light of my life and I will continue to fight and hopefully eventually overcome this disease.

Many people think that because I seem healthy on the outside that I must be faking. There is no way I would want this wretched disease for myself. I would love nothing more than to feel well enough to work and do all the things "normal" people do. I have fears that I may have passed this to my son and there is conflicting information relating to this but I am hoping that he is Lyme free. Syphillis which is closely related to Lyme is passed in utero and this scares me especially with Lyme testing being so unreliable.

As my Lyme was contracted in the US I won't have anyone tell me I don't have Lyme. I had the contact, bite, bulls eye rash, flu and failing health in the last 10 years but that doesn't really make a lick of difference treatment or health wise in this country, but at least I finally know what's wrong with me.

Lyme has destroyed two of my major romantic relationships. My ex husband left me because he thought I was lazy - before my diagnosis of course. This disease has taken it's toll on so many aspects of life and to have a disease that no one understands or recognises is just one more blow.

I know in my heart that I have the truth on my side and do everything I can to have quality of life while in constant pain.

Thank you for your time. [redacted] I hope I haven't left anything vital out.

Regards