

## SUBMISSION TO SENATE ENQUIRY INTO LYME DISEASE

# Contact

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It's OK for my story to be public.



## My Lyme Story

My Lyme story is similar to many stories of Lyme in Australia I've heard - long periods of misdiagnosis, a recalcitrant medical system, a 'light-bulb' moment, a positive diagnosis, and back to dealing with a recalcitrant medical system.

I'm not sure where I acquired Lyme disease. I've worked in East Coast NSW forests since I left school in 1972. Tick bites were considered an occupational hazard. Some years maybe 4 or 6 bites. Other years 20 to 30 bites. Over 38 years that's a lot of tick bites. I've also travelled overseas in Europe and West Africa but don't recall any tick bites there. But somewhere along the line one of those ticks injected borrelia, babesia and bartonella into my bloodstream.

Early symptoms started in the 1980s - arthritis and gout in my feet and ankles. I was in my late 20s. Diagnosis: 'You played a bit of footy in your younger years. Its your old injuries playing up. We'll put you on anti-inflammatories'. I was on anti-inflammatories from 1982 - 2011. The drugs were treating the symptoms but not the cause. I now know the arthritis was caused by the Bartonella lyme co-infection.

Next came regular Baker's Cysts on the knees. Diagnosis: 'S#^t happens. We'll drain the cysts and put you on antibiotics for a week'. I now know that Bakers Cysts are a common symptom of Lyme disease. I developed fatty cysts under the skin at points all around my body. Diagnosis: 'Lipomas. They're benign. We can cut them out if you want.' I now know them to be cysts caused by the Bartonella lyme co-infection.

In the 1990s I developed chronic fatigue that still plagues me to this day. I wake up every morning feeling more tired than when I went to sleep and it takes an hour or two of activity to fire up and function for the day. In 1997 my 9 year old daughter died suddenly and the chronic fatigue diagnosis changed to 'depression' and I was placed on antidepressants from 1997 until I weaned myself off them in 2001. I now know that chronic fatigue and depression are classic Lyme symptoms.

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In the 2000s I started getting neurological symptoms - brain fog, unexplained migraines, disorientation, memory loss, sensory loss, paranoia. Diagnosis: 'The MRI is inconclusive. It's all in your head'. These symptoms persisted and became more frequent as the years went by. I now know these are classic symptoms of neuroborreliosis, or late stage chronic Lyme.

Then in 2011 - 30 years after the initial Lyme symptoms started to appear and consultations with a conga-line of ignorant and arrogant GPs - the 'light-bulb' moment came when I read an article in the SMH on Karl McManus, a Sydney man who had died from Motor Neurone Disease, whose autopsy revealed was caused by Lyme disease. I came to the realisation that our journeys were the same - that I had been misdiagnosed and just had my symptoms treated for those 30 years, and that I was looking down the barrel of Motor Neurone Disease unless I did something about it.

That article put me in touch with the Lyme Disease Association of Australia who put me in touch with lyme specialist Nicola McF in the USA, who after skype consultations and assessments said 'If you were in North America you'd have a clinical diagnosis of Chronic Lyme neuroborreliosis'. After over 30 years of suffering misdiagnosed symptoms in Australia, she will always hold a warm place in my heart for that diagnosis.

Nicola started managing my case, but said I would need a Lyme Literate Australian registered doctor to write the prescriptions and that it may be hard to find one nearby. I started canvassing my local surgeries. The first one I asked if they were Lyme friendly? Their response: 'Yes. We believe citrus has a lot of health benefits!' That statement said a lot about the Lyme consciousness of the Australian medical profession at the time. Fortunately they were open-minded as well and took me on.

All went well for 7 months. As supervised by Nicola, and prescribed by my local GP, I started a regime of bicillin injections, doxycycline, fasigyn and rifampicin to combat the Lyme infection. There were immediate responses. The arthritis I had tolerated for over 30 years (which I now know was caused by the Bartonella co-infection) disappeared and the neurological symptoms were going away. The fatigue, which I now know is caused by the Babesia co-infection, persisted.

But in July 2012 it all went pear-shaped. The pharmacist dispensing the antibiotics said they could no longer continue because their practitioner registration required an Australian registered doctor to manage the case, and combined with a government policy of restricting antibiotic dispensing, meant their practitioner licence was under threat. The local GP, a young registrar,

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said he was not going to put his career and practitioner licence on the line for me by managing my case. Treatment stopped. Despite the Hypocratic Oath for duty of care, the medical profession just turned their back on me and walked away. I was left on my own.

Four weeks later on 31.8.12 the now untreated Lyme bacteria infection chewed through a capillary in my brain and I survived a brain hemorrhage that erased a 5cm x 2cm x 2 cm section of my cerebellum.

The stroke was totally unexpected. An international stroke risk assessment test placed me on the lowest decile of the lowest ranking for stroke risk. I'm a non-smoker, non-drinker, exercise regularly, have no history of stroke in the family and have no heart problems. Despite the peer reviewed medical research evidence from around the world that confirmed that cerebella strokes can be attributed to Lyme disease, and that perhaps 5% of hemorrhage strokes are caused by Lyme, I could not get anyone in the neurology ward of the hospital to entertain the fact that Lyme had caused the stroke. I asked to see an ID specialist 4 times while in the neurology ward, but was refused. I eventually managed to see the head of the Infectious Diseases unit there as an outpatient 6 weeks later and was told 'Lyme doesn't occur in Australia, so it can't be the cause'. This ID specialist was also informing my neurologist.

On release from hospital I contacted Dr Ann M from Sydney Uni who is researching Lyme disease in Australia. She put me in touch with Dr Jacob F in Canberra, a Lyme aware, Australian registered doctor, who agreed to manage my case. I went back on to the regime of bicillin injections, doxycycline, fasigyn and rifampicin, and with bacterim added for the babesia, as well as natural supplements. I saw slow improvement in the Lyme symptoms, although the stroke side-effects plateaued and the MS-like ataxic shakes in the left hand and sense of balance persist. That treatment continued for 18 months until Dr Jacob F suddenly 'went on leave' and I was left without medical supervision again. I hear reports of many Lyme treating doctors in Australia suddenly having to 'go on leave', ceasing Lyme practice.

Following the brain hemorrhage in 2012 I had 2 years of intensive rehab, and with a lot of hard work, regained about 85% capacity. I regained my driver and motorcycle licences and eventually returned to my work as a Park Ranger on light duties 4 mornings a week.

However, in June 2015 I was medically retired from my job as a Park Ranger. We agreed that my persisting symptoms made it impossible to safely work in my job as a Ranger, and they had no positions available that would suit my current skill base. I currently have no income and 4 years until I reach

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retirement age. People with Lyme disease report that it is extremely difficult to obtain a disability services pension under current government guidelines. I will have to try when my savings run out.

About the same time that I was medically retired, my GP randomly called me into her office and said her practice again could no longer support any Lyme treatment. She gave no reason for that decision. She said I didn't have Lyme disease – it does not occur in Australia – that I had Chronic Fatigue Syndrome and there was nothing she could do for me, and that I “should go out and exercise”. I believe she was pressured into this position by either the NSW Dept. of Health or AHPRA.

This was a shock. Again I was left in the position of having to self manage my continuing Lyme infection without medical assistance. I've now joined a Facebook Lyme support group, and have extensively researched Lyme disease treatment and continue treatment on that basis, self-treating using many non-prescription anti-bacterials and supplements, and 'doctor shopping' for prescription antibiotics as relapses occur and symptoms flare.

I'm getting tired of fighting this battle without medical support. It's been 4 years now since my diagnosis. If it was a recognized illness I'm sure it would be cured by now. I'm lucky that I have tolerant family and friends who continue to support me. Many don't.

Lyme disease has destroyed my life. Coping with the symptoms during the 1980s and 1990s put stress on my relationships and destroyed my marriage. I was a career manager in the NSW Public Service with good prospects, but the debilitating symptoms of this infection reduced my capacity to working part time since 2003, and now I have no employment at all. Treating this illness has cost me my life savings. At a time in my life I should be looking forward to retirement and leaving a legacy for my children, I have not much to show at all. Lyme disease has taken it all away from me.