My Story

- Name: [redacted]
- Age: [redacted]
- My address is: [redacted]
- You can contact me on: [redacted]
- I want my story to be public.

My story begins like many others, a gradual accumulation of strange symtoms over a number of years. The progress was so slow, and the symptoms so varied, that even I didn't put two and two together for a very long time. This makes it difficult to determine when, exactly, they started.

I had a tick attached to my face when I was approx. 9-10 years old (1995-96). I was living in Humpty Doo, Northern Territory. There was a big tick problem, I remember our dog was always covered in them. At the time I didn't know that having a tick bite could be problematic, I didn't tell my parents about it, and even if I had, they wouldn't have known to seek medical treatment for it. The tick was engorged, so had obviously been attached for a long time. I don't recall if I got any flu symptoms or similar at the time. I have travelled overseas before, to Indonesia and Europe, but I have never had another tick bite that I've been aware of. My symptoms also pre-date my first international trip at age 14, and my second trip at age 20. I am not ruling out the possibility of internationally acquired illness, but regardless, whether I contracted it in Australia or overseas is irrelevant in the face of the lack of recognition, education, diagnosis and treatment options here. I am also a veterinary nurse, and since starting my career 10years ago I have worked in Perth, Melbourne and Darwin. This means that I work in a tick-prone industry, but again, I have never had another tick bite to my awareness.

At age 10-11years old I developed short-sightedness. No-one else in my immediate family has issues with eyesight. I also developed some OCD twitches and behaviours.

At age 12 years I started having intermittent panic attacks and night terrors. I also had excruciating shin pain. These symptoms lasted for about a year then suddenly stopped.

At 17years I asked a doctor about severe pain in my jaw that I had just realised that I had had for many years. He said that it was TMJ syndrome and that all I needed to do was chew on a pencil to resolve the issue. He had no other advice, did not order any tests, and was not interested in finding out the cause of the pain. His 'treatment plan' was ineffective.

At age 18 years, I had sudden onset depression. One day I was perfectly fine, then literally the next day I had a feeling that there was a grey blanket over the world. This lasted for many months, then suddenly stopped. I have then, over the years, had intermittent episodes of milder depression. At this time, I also started feeling tired most days. I also often had pain of unknown cause in my wrists and ankles. I went to the doctor about the wrist pain, he sent me for a CT scan, then said there was nothing in the scan so it must be an old injury.

By age 21 years I had been practicing martial arts since my early teens. I was very fit and trained 7 days a week in Muay Thai kickboxing, cardio/weight training and karate. I competed in 2 ring fights, had attained level one instructor rank and had also attained my 1st dan black belt in Zen Do Kai Karate. One evening, five minutes into a session, I was doing a round of skipping when I suddenly had a feeling like a crushing pressure and squeezing around the base of my skull. This turned into a throbbing, ongoing headache. I had to stop training immediately as the pain was too severe. My neck was stiff and I developed a sensitivity to light. I tried to treat the pain with Panadol and other over the counter drugs but nothing worked. After about 6 days of unrelenting pain I went to the hospital. I was triaged as non-emergency, and left in the waiting room for over 8 hours before I was seen. The doctors did an MRI, said it was clear and that there was nothing wrong with me. They made me feel like I was wasting their time and that I was making up the pain. They said that they could try doing a spinal tap but that it would probably show nothing. By this time I had been there 12 hours and was over being treated like an idiot and I opted to leave. I saw a chiropractor a few days later who did some adjustments in my neck and relieved some of the pain. I was able to function ok, but I was unable to continue my fitness training as it immediately brought back the head pain. I have had chronic neck stiffness and pain ever since. I now realise that I likely had bacterial meningitis as a result of Borrellia. The doctors at the hospital did not even explore that option, and were not interested in determining the cause of my symptoms.

At age 23 I developed full-blown fatigue. I was barely able to stay awake at work, and I had to have multiple sleeps during the day. I nearly fell asleep at the wheel whilst driving. I had a constant feeling of sand in my head, 'brain-fog' as it's referred to. I started to have difficulty recalling information when I spoke. The fatigue lasted approx. 9 months, then reduced in severity. Since then, it has fluctuated randomly, sometimes mild, sometimes more severe. When the fatigue is worse, the other symptoms also worsen. I recall saying to a friend at the time that "I feel like I haven't slept, that my head is full of sand." As well as my neck pain, I started having pain in my back, shoulders and between my ribs.

By age 25 years I had started asking doctors about different symptoms. I had blood tests done, vitamin levels checked, and was told that I was fine. Any time I asked about the fatigue, the first thing I was asked was "are you depressed?" and recommended antidepressant medication. I didn't believe that I had depression in the traditional sense, more that my symptoms and not knowing what was wrong with me, and feeling 'lazy' all the time because I could barely get out of bed was causing me to feel depressed, so I opted not to take the medication.

Every doctor fixated on that as the cause of fatigue, and when I told them that I wasn't incredibly depressed, only depressed because I felt so tired and sore all the time, they dismissed me and didn't try and dig deeper into possible causes. By this time I didn't bother seeing any more doctors as they couldn't or wouldn't help me.

I have also tried on a few occasions to undertake further study in times that I have been feeling "good" or on the high part of the cyclic progression of my symptoms. I have then after weeks/months been unable to complete course work due to the extreme fatigue. I have been unable to obtain refunds for course fees, so I am out of pocket thousands of dollars.

I had a light-bulb moment when I typed "TMJ pain, chronic fatigue and muscle pain" into a Google search. The first thing that came up was Lyme disease. I looked into it a bit, but was too afraid to talk to a doctor about the possibility as I had been dismissed and not taken seriously so many times in the past about my symptoms. Soon after this I became pregnant for the first time. My partner and I had been planning to get pregnant for a little while so we were very happy. Unfortunately at about 6 weeks I had a miscarriage. We were very upset, but tried again immediately. Over the next year I proceeded to have another 3 early miscarriages, all between 5-7 weeks. I did not think to seek medical help in determining why I kept having miscarriages, as by this time I was very unhappy with GP's in general and tried to avoid them.

I eventually got pregnant again, and managed to carry the pregnancy to term. I had hyper-emesis throughout the length of my pregnancy. I went into early labour at 37 weeks and 5 days. I had a very bad reaction to the use of gas and air during labour, quite unlike anyone else's experience that I had heard about. It made my pain worsen, and it made me go 'crazy' and out of it. I have since learned that the gas can affect people with chronic borrelliosis. Reading about other borrellia-affected people's experiences showed distinct similarities in my experience.

My baby was delivered naturally and was well formed but small at 2.7kg. When she was born she was very floppy and had to have oxygen supplementation and be helped with breathing. At the time of birth, the midwives commented on the umbilical cord being very thin and unusual, they were surprised that it had lasted throughout the pregnancy without any issues. I now know that Borrellia can be a contributing factor in problems relating to pregnancy and labour/delivery, and can cause miscarriage, premature labour and small birth weight in babies, among other things. No-one asked to keep the cord to send for testing to see if there was anything wrong. I combined pumping and breastfeeding my daughter for 6 months. [redacted]

I then got pregnant again with our second child. I suffered the same extreme hyper-emesis throughout the pregnancy. I also developed a lot of new symptoms that I had not had before. Other than the extreme fatigue, I had severe pain in my pelvis/hip joints, lower spine and legs. I also regularly got numbness/tingling in my hands and arms. I went into early labour at 36 weeks and 4 days. After a 36hour labour, I had an emergency caesarean as my son was stuck in my pelvis. His birth weight was 3kg. He was hypoglycaemic at birth and had to be put in the NICU for 48hours. I breastfed him for 3 weeks before transferring to formula. [redacted]

By this stage I had written a list of all of my symptoms. Some are constantly present, others intermittently so.

Chronic fatigue
Non-refreshing sleep/waking up tired (somnolence)
Chronic migrating muscle pain esp. neck/back/hips
Migrating Joint pain-knees, wrists, fingers, spine, ankles esp
Migrating bone pain-feet, pelvis, spine esp
Occipital pain/pressure
Scalp tenderness
Painful subcutaneous nodules esp neck/occipital area
Stiff sore neck
Painful soles of feet
Pain in the foot bones
Random shooting pains
IBS- wind, flatulence, diarrhoea
Mind fog
Worsening memory recall
Speech- slurring, difficulty forming words
TMJS
Bruxism
Constant thirst/dry mouth
Sensitivity to bright light

Motion sickness
Intermittent depression
Worsening mood swings
Irritability
Arms/hands going numb
Muscle weakness esp. Arms/hands
Exercise intolerance
Seeing things out of the corners of my eyes/'floaters' in vision/visual snow
Butterflies in stomach
Vertigo/dizzy spells
Bouts of nausea
Lightheaded-ness (like when fasting)
Tinnitus
Sore teeth esp molars
Glands in neck swollen
Hyperhydrosis
Night sweats
Weird vivid dreams
Hot flushes/sensitivity to heat
Intermittent stabbing pains in head
Disjointed from emotions
Allodynia
Chest pains
Pain in ribs and between shoulder blades causing pain when deep breathing.
Cough when inhaling
Tachycardia/heart palpitations

I had heard that a friend of my fiance's wife was being treated for Lyme disease. I asked her which doctor she saw, and she gave me contact details. I contacted the doctor (who is based interstate and travels up a couple of times a year to see his Northern Territory Lyme patients) and made an appointment. I had to wait 4 months until he came up. Before my appointment, the doctor had me do various tests, some covered by Medicare, some not, to get some initial lab results. One of these tests was for the coxiella burnetii bacteria (otherwise known as Q fever). I had a positive test reslt for this, and positive test results must be reported to the Department of Health. A couple of days later I received a phonecall from the Centre for Disease Control NT. The man I spoke to said that they had received my positive result. He then quizzed me for 15min asking if I had had flu like symptoms, fevers etc in the last 6 months. I hadn't, and I told him that. He asked if I'd been around farm animals etc, which I hadn't. He informed me that there had never been a positive result in the NT. He then proceeded to dismiss my result and say he wasn't going to record it as a positive, and that it was a false positive because I had not had any acute symptoms! He didn't even consider the possibility of it being a chronic vector-aquired infection from years past. When I queried this, he then said that he wasn't an infectious disease specialist, so he couldn't comment.

When I eventually saw my Lyme literate doctor (LLMD), he said based on my preliminary bloodwork and his cinical examination of me and my symptoms, it was very likely that I had borrelliosis and multiple co-infections, but would not treat me until he had positive lab results. He then, in consultation with me and my budget, sent me for further tests. I had to send bloods interstate to Australian Biologics and over to Germany, at great personal cost. In July 2015, after 10-12 weeks of waiting, I had results back confirming that the DNA of the borrellia burgdorferi bacteria had been found in my blood and urine, and that I had also tested positive to various co-infections. I started treatment immediately after that.

My treatment protocol started treating my coinfections first. Within 4 weeks of dietary supplements, antibiotics and antimalarials my jaw pain (TMJS) was completely gone. Within another -3 months, the pain in my feet and the majority of my joint pain was gone. I'm now almost 9 months into my treatment and while my tiredness is still there, the debilitating fatigue that made everyday life difficult, is gone. I am having more frequent periods of 'clarity,' windows of time, 10min or an hour here and there, of a complete absence of brain fog and sand in my head where I feel incredibly normal. I have a long way to go, and I haven't even started the protocol to attack the actual borrellia yet, but I have had positive progress so far with the long-term treatment my doctor has prescribed.

The cost financially however is very high. I am now back at work a few days a week, but it is up to my fiancé to be our primary income earner The costs of my medicine alone works out to roughly $200 a month and that's me taking only half of the things the doctor has recommended. Gold star treatment is not an option as we simply can't afford it, which reflects very poorly on the medical system in this country in relation to this Lyme-like illness issue.

The worst thing yet is that my family is now affected even more. Given that the borrellia bacterium is a spirochete, similar in shape to that of syphilis, it is able to be transferred in-utero as well as sexually transmitted to other people. My fiancé who has been perfectly healthy, and who is only 27 years old, has started developing symptoms in the last two years. Back pain, fatigue, muscle weakness etc etc. My doctor warned that this may happen, and now we have to spend more thousands of dollars getting him tested, which we are currently in the process of doing. I estimate that in the last 12 months we have spent over $20 000 on medical bills and medication for myself and the kids. The main fear is that if he becomes very unwell, who will look after our family??

I implore you to please take on board all of these patient stories and make research and education about this illness your absolute priority! I have been "not right" for so long that I almost forget what it's like to be normal, but I know that I am one of the luckier ones in that I am at least functioning on a daily basis. There are so many people, young and old, that are affected in far more debilitating ways, and that they cannot bear the brunt of the financial, emotional and physical cost to themselves and their families. The Australian government must act to make the testing and treatment accessible and affordable to everyone.

Thank you all very much for your time, I look forward to your response to the inquiry.