

Please find attached my story – I have three parts to my story – my experience as someone suffering with Lyme disease and the impact this had on my family (please also see my husband’s submission which goes into this in more detail), my experience as someone caring for children and other family members with Lyme disease (and the discrimination we suffer as Lyme disease patients in the health system), and my experience as the President of the Lyme Disease Association of Australia, as the Patient Representative on the Chief Medical Officer’s Clinical Advisory Committee on Lyme Disease (CACLD) and the patient representative on the Diagnostic Working Group of the CACLD who wrote the current Australian diagnostic guidelines for Lyme disease acquired overseas.

## **My Story**

- Name: Nikki (Nicole) Coleman
- Age: [REDACTED]
- My address is: [REDACTED]
- My postal address is: [same as above]
- You can contact me on: [REDACTED]
- I want my story to be public (with address and phone number not released to the public)

## **About my personal journey with Lyme disease & Lyme like illness – the impact on myself and my family**

- I acquired Lyme-like illness at: Nara, Japan in 1987, I was not diagnosed until 2005 by [REDACTED] at [REDACTED].
- Type of Bite: tick – my friend incorrectly squeezed the tick when she removed it. I got the classic EM rash but was living in Japan so was embarrassed because I thought I had ringworm and didn’t ask for help. I got quite severe flu like symptoms soon after (in the middle of summer), and was never fully well again after that.
- I have [positive] blood tests from Igenex
- I tested positive for Babesia.
- I have also been diagnosed - Chronic Fatigue, Irritable Bowel, Inflammatory Bowel Disease, Ulcerative Colitis, Lupus, Scleroderma, Fibromyalgia, MND (tentative diagnosis that I refused to accept, and asked for extra testing to be done, which was when I was diagnosed with Lyme disease).
- At my worst I was unable to eat solid food, haemorrhaging from the bowel with excessive continual diarrhoea and bowel incontinence for months at a time, unable to have periods, unable to wash, dress or feed myself, unable to walk unaided, bed

or wheelchair bound, and relying on the kindness of strangers and my family to look after me. During this time I was continually told by specialists that they could not find what was wrong with me, and that I should see a psychiatrist, either directly telling me it was all in my head, or implying that I was a hypochondriac. My extended family did not understand my illness, and more than once told me that I was just “putting it on for the attention”. I am now largely estranged from my extended family as a result of my illness. After I began receiving treatment for Lyme disease with the correct medication, I was able to recover to 90% of health within 18 months. This clearly shows that I was not a hypochondriac, did not have a psychiatric illness, and was not pretending to be sick for the attention – what I needed was the correct diagnosis and treatment, not pseudo-excuses blaming me for my illness.

- I have been medically retired by the church that I work for – I trained for 5 years to be a minister and then was unable to continue past my first parish because I became so sick the church had to retire me in my early 30s.
- I was diagnosed after I had my children – both my biological children have been diagnosed with Lyme disease (& Babesia infections), my husband has Lyme disease (& babesiosis) and 2 of my adopted children have Lyme disease.
- I have been yelled at by Drs who believe there is no Lyme disease in Australia – when I explain that I was infected overseas they repeat “there is no Lyme disease in Australia” and refuse to treat me, even though I was not infected in Australia.
- My daughter has been discharged from hospital three times due to her Lyme disease
  - the first time our daughter having difficulty breathing and unable her move any part of her arms or legs or head, and the infectious diseases doctors refused to come and give a consultation, and so the registrar discharged our daughter and told us to bring her back WHEN she stopped breathing. They were not prepared to treat her paralysis or difficulty breathing, because of her Lyme disease diagnosis.
  - the second time she was discharged whilst so immune compromised she was in isolation and unable to have visitors – both times it was because of her Lyme disease diagnosis and for no other reason. The [REDACTED] at [REDACTED], [REDACTED] heard that our daughter was being treated for Lyme disease at [REDACTED], [REDACTED], and rang our daughters treating doctor to put pressure on him to stop our daughters treatment, and when this did not work put direct pressure on the management of [REDACTED], so that our daughter was discharged at 8pm at night, when she was so immune compromised, and her white cell count was so low that she was in isolation. The only reason given for her sudden discharge was that the head of the [REDACTED] at [REDACTED] was unhappy that

██████████ was treating someone with Lyme disease, because it doesn't exist in Australia. We continued our daughter's treatment at home ourselves, in order to save her life. No one should be put in this position in Australia.

- The third time she was discharged was when she was undertaking rehabilitation in the physiotherapy department of ██████████ – the staff were helping her learn to walk again. We were advised that the Infectious Diseases department were unhappy with the physiotherapy department providing rehabilitation services to a Lyme disease patient, and so my daughter was discharged from the rehab program, even though she was still unable to walk.
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- My adopted son tested CDC positive to Lyme disease, but the doctors in the outpatients clinic of the Infectious Diseases department at ██████████ ██████████ (under the direction of ██████████ refused to accept his test because it was done in the USA (with Igenex), they refused however to test him in Australia, even when we requested that they repeat the test in a NATA accredited lab.
- I have been refused testing at ██████████, even though I had a history of recent travel to an endemic location (USA). Even when tests are requested by doctors for patients who are sick with Lyme like symptoms, a history of a tick bite and recent travel to an endemic area, the pathology labs can refuse to test the blood.
- Of my 6 children (2 biological and 4 adopted), 4 have been diagnosed and treated for Lyme disease. 3 of my children refuse to be publically named as having Lyme disease (and so are refusing to put in a submission to this inquiry), because they have concerns about being associated with Lyme disease for their long term career prospects. My husband is also infected with Lyme disease.

## My life

- Prior to my illness, I was an exceptionally active person – I played hockey (indoor and outdoor), swam regularly, was an active member of Girl Guides, and was a Rotary Exchange Student to Japan for a year in 1987. After I became infected with Lyme disease in 1987 in Japan (whilst patting a deer in Nara Park), I slowly got sick, until I was medically retired by my employer (the Uniting Church in Australia) in 2002, I will now never be able to work full time. I was unable to wash, dress or feed myself for 8

years. I had someone from community services come in to wash and dress me every day, and my husband cut up my food and fed me most days, whilst he was also working full time and looking after our small children.

- I was diagnosed in 2005 by Professor [REDACTED] but he was unable to treat me, partly because of distance, and partly because of the hospital politics that made it impossible for him to treat Lyme patients openly. For this reason my GP treated me with input from specialists in the USA – he was able to stop me from dying, but not to get well because he just didn't have experience treating Lyme disease.
- In 2009 I was treated by Dr [REDACTED] via telephone from [REDACTED] and I was able to get slightly better. My husband was able to take a posting to the US and so we went there for 9 months in 2009-2010 so that I could be treated by Dr [REDACTED], who is one of the world's leading Lyme doctors. I went over in my electric wheelchair, still needing to be washed and dressed (I was able to feed myself by this stage), but I returned to Australia not even needing to use a walking stick. After being medically retired by the church in 2002, I was able in July 2010 to return to work part time. I have continued to improve, and have almost completed my PhD in Military Bioethics, and have become a hot air balloon pilot, recently flying in the Canberra Balloon Spectacular. People who knew me when I was sick do not recognise me, because I am now able to stand up, having spent so many years in a wheelchair or lying in bed. People who know me only since I am well cannot comprehend how sick I was or how awful life was for my family having to wash dress and feed me for 8 years.
- My children and husband have borne the brunt of having to look after me when I was sick. My children from the age of 8 had to cook the family dinner and do our laundry. They were given respite services by St Nicks Young Carer Program in Canberra, but an 8 year old should be allowed to have a childhood and not look after their parent.
- My "sicker" daughter has been in a wheelchair for 7 years, and has almost died a couple of times (and was given last rites). She has borne this illness remarkably well, until towards the end of last year when the burden of having Lyme became too much and she tried to take her life. She has tried so many times to kill herself since then, I have lost count. I now have to mostly work from home to help look after her, mainly because of the impact on her mental health of being sick for so many years, and not believed by the medical community.
- When a member of my family gets sick, we don't go to the emergency department of the hospital, unless they are deathly sick, because we have been turned away so many times – they are happy to treat us, until they ask "do you have any other medical issues?", and as soon as we mention Lyme disease we are kicked out the door, even if we are in a life threatening situation.
- Our local doctor does not mention Lyme to his co-workers, and is always fearful that he will be reprimanded for treating us. Without his treatment under the guidance of

Dr [REDACTED] initially and now an Australian based Lyme specialist, both my daughter and I would have died (from Lyme disease), and my husband would be sicker than he is now.

- I am saddened that I have given this illness through the blood supply system to someone else (I was diagnosed not only with Lyme but also babesiosis a parasitic infection of the blood). I donated blood for many years before my diagnosis – when I contacted the Red Cross Blood Bank to tell them of my diagnosis, they didn't care, and refused to take my details to track down those I may have inadvertently infected.
- I am devastated that I gave this illness through the placenta to my biological children – this quite simply has ruined their life, and I am incredibly torn apart with guilt. They will never achieve their full potential, either academically or in their careers because of their Lyme disease and how it impacts on their life.
- I am deeply disturbed that even my adopted children have had their lives touched by Lyme disease – either in having to help look after their mother and siblings, or by being infected themselves.
- I am heartbroken that it appears I have given this disease to my husband sexually. His body fought it off for decades until he was under extreme stress at work, and then he became incredibly sick, with many of the same symptoms I had previously had (he tested positive as well).

**About my experience as the President of Lyme Disease Association of Australia, as the Patient Representative on the Chief Medical Officer's Clinical Advisory Committee on Lyme Disease and the patient representative on the Diagnostic Working Group of the CACLD who wrote the current Australian diagnostic guidelines for Lyme disease acquired overseas**

- On top of my personal experience with Lyme disease, I was also the President of the Lyme Disease Association of Australia for 3 years, and the patient representative on both the Clinical Advisory Committee on Lyme Disease appointed by the Chief Medical Officer of Australia, and a member of the diagnostic working group that wrote the current Australian guidelines on the diagnosis of overseas acquired Lyme disease/Borreliosis.
- I would be keen to be called to give evidence at a public hearing regarding the process of the diagnostic working group, and the Clinical Advisory Committee on Lyme Disease, particularly in regards to how the EM rash was deleted from the

diagnostic guidelines for Lyme disease acquired overseas, and why the guidelines only covered overseas acquired Lyme disease and not locally acquired Lyme disease.

- There is one last thing I would like to note having read some of the submissions from those doctors who believe that Lyme disease and Lyme like illness does not exist in Australia, and their belief that it should not be treated. They state in their submissions that as doctors they should do no harm, and I agree with them wholeheartedly. The difference is that these doctors seem to believe that it harms people to treat a potentially life threatening, and definitely life altering, infection with antibiotics. I, on the other hand, believe that not providing adequate treatment for these infections is doing the most harm to those patients, to their families and to the economy, with many patients and their carers lost from the workforce and becoming a burden on the health and social security system. The myth that Lyme disease and Lyme-like illness does not exist in Australia has already cost too many lives, it is time we applied scientific facts to the discussion around this disease and made people well again. In Brazil they could not find the bacteria making people sick, and instead of arguing about whether it existed or not whilst people continued to get sick, they simply named it something else (initially Brazilian Lyme-like disease, Brazilian human borreliosis and then finally Baggio-Yoshinari Syndrome) and just got on with treating patients (with the same treatment as for Lyme disease), whilst ALSO looking for the causative agent of what was making patients sick. If Australia is the clever country, why are we taking such a backwards approach to Lyme disease and Lyme-like illness, blaming patients, telling them it is all in their heads, and then prosecuting the doctors who are making them well?

I thank you for allowing me the opportunity to make this submission, and ask that you take leadership on this issue – tens of thousands of sick Australians are depending on the changes you can make to improve their lives – both those that are already sick with Lyme disease and Lyme-like illness, and those we can prevent from getting infected in the first place.