12 January 2016

Hello my name is [redacted]. I am 40 years old and I would like to share with you the story of my family's journey with Lyme disease.

My sister [redacted] has recently battled Lyme disease and thanks to the amazing support of family, friends and complete strangers, we managed to raise enough money to get her to Germany, where she was able to receive radical treatment that was successful in giving her quality of life again. As an Australian, I consider us (like almost everyone) "the lucky country", however when you suffer from a debilitating illness or disease, and the only possibility of proper treatment is to leave your own country....I feel shamed, frustrated and appalled at how backward our medical association can be!! I will share this story with you now.

My sister has lived in her local area since the age of 6 and is now 42 yrs old. She is married with 2 teenage boys and currently lives in Central West NSW. She is employed at the local Vet Hospital as Practice Manager/Head Nurse, however due to failing health caused by Lyme disease and the co-infections associated with it, she was unable to work from July 2012 to late 2014/early 2015; only just recently being able to return to work on a full time basis.

We are desperately trying to raise public awareness of this terrible disease, as through my sister's experience we have found that most people have no idea what Lyme disease is or how you contract it. My sister was positively diagnosed with Chronic or end-stage Lyme which basically meant that she would have it for life.

She doesn’t ever remember being bitten by a tick at all, she didn’t get the tell-tale ‘bullseye’ rash that appears after the bite and the Lyme literate doctor she was seeking treatment from in Australia, believes it lay dormant in her system for more than 18mths, possibly longer, before she showed the first symptoms. When we look back now she had several issues with declining health over a period of about 2 years, which we now strongly believe, was due to Lyme disease. It all started with declining eye health in 2010, then other symptoms started to appear by early 2012. In June 2012, my sister started getting monster headaches, (the likes of which were physically crippling at times), neck pain, anxiety and nausea which led her on a lengthy diagnostic chase to find out what the hell was wrong with her. I’ll be honest in saying I feared the worst and expected she would be diagnosed with a brain tumour – such were her symptoms. She saw in excess of 12 different doctors/specialists from all over the state, had multiple medical tests, (including ultrasounds, Ct scans, & MRI’s), months of physiotherapy, spent masses of money funding this chase, multiple trips to numerous specialists (all of whom are situated hours away from her rural hometown), none of whom suggested even looking into the possibility of Lyme. On several occasions when she mentioned the possibility of Lyme, [redacted] was met with the same phrase that many other Australians like her have encountered ‘there is no Lyme disease in Australia, it's all in your head’. [redacted] was even told by more than one Doctor that she should seek psychological treatment for her “symptoms”. Can you imagine how this made her feel! My sister had never left this country prior to her trip for treatment in Germany, yet she had a raging positive test result for Lyme disease! Frustrating and annoying that the Australian Government will not support Aussies on this topic. My sister had to source her own Lyme Literate Doctor through a support group in

California USA and arrange and fund for her own blood to be sent to a lab in America for testing (Igenex Inc, 795 San Antonio Road, Palo Alto, CA, 94303). These blood tests cost anywhere between $700-$1500, depending on what bacteria they are looking for. She even had to physically take the vials of blood to a courier herself, to be shipped out to the USA for testing!! As mentioned her test results were confirmed as positive by her Lyme aware Doctor, for Lyme disease as well as other co-infections, such as Bartonella, Babesia and Mycoplasma Fermentans. [redacted] received her test results in November 2012 and embarked on an epic journey of treatment of all different kinds; to no avail. It became the biggest battle of her life (& ours too!), the pain, mental & financial anguish that this disease presents to an individual and their family is intense and I, as a supportive family member, cannot believe that families have to battle like this in their own country due to sheer medical ignorance. Every medical professional that she had to encounter (other than Lyme aware people) either scoffed at her, looked at her as though she was a hypochondriac or refused point blank to offer the help and services that she required. She had been told prior to diagnosis that she needed to see a psychologist; that Lyme is not in Australia and she simply did not have any of the symptoms. When we researched Lyme on the internet there is a list of about 100 symptoms and my sister was experiencing more than half of them, almost daily! These included:

- Neck pain
- constant headache
- intermittent migraines
- arm pain
- nausea
- fatigue
- unexplained chronic coughing
- sore ribs
- sore collarbones
- numbness in fingers
- armpit pain and swelling
- spine pain
- dizziness
- shaking in arms after use
- pain at base of ear
- pain in elbows after using arms
- insomnia
- anxiety
- stress
- low self esteem
- depression
- poor eye health
- calf muscles tore
- sore feet
- arthritis pains in knees
- arthritis pains in hips
- arthritis pains in hands
- inability to walk some days
- inability to use hands properly some days
- facial palsy

- gastrointestinal upsets
- short term memory loss (eg; forgot my toothbrush colour, forgot what street the doctor was in)
- confusion
- brain fog
- jaw pain
- unable to drive or concentrate for more than 10 minutes
- decreased hearing
- blocked ears
- changes in smell
- changes in taste
- heightened response to alcohol
- Low platelets
- POTS
- welts and rashes on skin
- diarrhoea
- chest pain
- slurred speech
- eye pain
- dental pain
- anger/agitation
- burning sensation in hands and feet
- fevers
- muscle pain and cramps
- muscle weakness
- twitching muscles
- mood swings
- light sensitivity
- sound sensitivity
- increased motion sickness
- heartburn
- constipation
- abdominal cramps
- heart palpitations
- air hunger, breathlessness
- word search, name block
- oedema below ribs
- food intolerances
- hypoglycaemic
- red nose
- loss of libido
- loss of feeling in fingertips
- pulsile tinitis

As mentioned she was unable to work, unable to function normally for a full day, unable to do her own housework and unable to drive longer than 10 mins; some days unable to walk! As you can imagine this was severely debilitating for her as well as her family. On top of this and the ignorance of the Australian Government and Medical profession, this disease is well known for the slogan ‘But you don’t look sick’ so trying to explain to people just why your life has been so affected is a task in itself. This strips you of your self-confidence and makes you feel very alone and alienated. This disease, if left untreated can destroy your life, your body and can lead to death.

[redacted] ongoing treatment included 30 tablets per day (various anti-biotics, and supplements to support her deteriorating organs), a lot of which she had to buy from America (these are ridiculously expensive as they are not recognised on our pharmaceutical benefits scheme), 2 intramuscular injections weekly (which she subsequently had to give to herself, as she was not supported by any of the medical practitioners in her local area – and also could not drive to get to appointments anyway), restricted diet, complete rest, massive detoxing, blood tests every 4 weeks and a trip to a Doctor in Sydney every 4 weeks (a 3 -4 hour journey one way). The medication alone costs hundreds of dollars every month and nothing was supplemented by the government on the PBS register. My sister was on this level of treatment for approximately 2 years and became very ill, quite quickly. It soon became evident that any treatment she received worked at masking some of the symptoms temporarily but overall just wasn't working. We needed to find something more drastic. We needed a cure! There had to be someone, somewhere that could help and we were willing to do whatever it took to find them. To watch a loved one go through all of this, and be unable to help make her well, for me, was the hardest thing I have ever been through. To have her children call me in tears and ask me to promise them she wasn’t going to die, was unbearable, as I simply could not promise something that I myself was not sure would happen.

We all made it our mission to research far and wide to find help. [redacted], with the help of her Lyme literate Doctor, family and various online Lyme support groups, found information on the St Georg Klinik in Bad Aibling, Germany. [redacted] spoke to other Australians and people from all over the world who showed amazingly positive results for treatment of Lyme disease and associated co-infections after the radical treatment received at the Klinik. All of those she spoke with had been given the “all clear” from Lyme disease at the end of the treatment. This meant hope, if we could get the money together to get [redacted] there.

With the help of family, friends, local community and complete strangers, we were able to raise $36000 to get my sister to Germany for this intensive treatment. Lyme disease is the fastest growing tick-borne infectious disease in Europe and America alone - not to mention other countries like Australia that refuse to acknowledge the existence of it in their backyard. Increased prevalence means more Australians are being exposed to Lyme disease both here and abroad. In Australia alone there are more than 15,000 people suffering from Lyme disease (and conservative estimates suggest another 200,000 undiagnosed people - possibly more). Lyme disease diagnosis is not common, but Lyme disease itself appears to be grossly under diagnosed in Australia and is on the increase worldwide every day.

I live on the South Coast of NSW, an area prone to ticks. Awareness of this disease is unbelievably important everywhere, yet surprisingly still unheard of by many people. During my sister's battle with Lyme I was unable to physically support her on a regular basis due to the distance between our home towns, however I embarked on running awareness campaigns, fundraisers and support networks to assist in getting the money we needed to get her treated properly. One of the fundraising events held attracted the President of the Lyme Association of Australia who came to talk about this disease and provide information to my local community. In total, I was able to raise over $3000 for the Lyme disease association of

Australia, as well as contributing to the fundraising of $36000 for my sister's treatment in Germany. We held local fundraising events in my town and hers, with anything from auctions of donated goods and services, head shaving and waxing (my mum and I proudly shaved all our hair off), simple tin collecting and even busking. We were able to raise $15000 in one afternoon due to the kindness of friends, family and locals supporting my sister. A huge bonus in all this was the fact that an extra 200-300 people walked away with a flyer about Lyme disease - who knows how many more people learned about this insidious disease just by the awareness raised on the day. A group of my friends banded together with me to compete in the Miss Muddy fun run in Sydney in 2014, where we all wore lime green tutus to show support for my sister and raise awareness on the day (see pictures below). I also set up a crowd funding site, in conjunction with the use of social media (flooding my pages daily with info about [redacted], Lyme disease, and asking for donations) which was absolutely invaluable in helping to raise the remainder of funds we needed to get my sister to Germany.

My sister and her amazingly supportive husband [redacted], flew out to Germany on 28 April 2014. Taking them to the airport, and saying goodbye, not knowing, but hoping that this last ditch effort would work, was so hard for all of us. During her stay at the Klinik, [redacted] received daily intravenous injections with various medications/antibiotics, whole body Hyperthermia, mineral supplements, ozone therapy, laser therapy, high dosage immune support, detoxification, colonics, magnetic and oxygen therapy and foot detox baths; all this bombardment of her body happened over just 16 days! To throw a spanner in the works, whilst there the German Doctors confirmed that this hideous disease is transferable so to make sure [redacted] was rid of it for good her husband [redacted] would need to undergo treatment as well. This is an unrelenting saga of poor information, differing opinions and an endless connection to your bank account!! Thankfully, after enduring the trauma of travelling to the other side of the globe when you aren’t even well enough to drive a car, undergoing the intensive treatment program and being told your husband potentially has the same disease too, [redacted] was on her journey home with a Lyme-free bill of health! To read the report from the treating Doctor, was like winning the lottery, we all still pinch ourselves to check if it’s a dream. More like a horrible nightmare!! [redacted] has been on a slow road to recovery since then. She still battles with various health issues, ongoing co-infections that can only be managed (not cured) and will probably never re-gain the health she enjoyed prior to acquiring Lyme disease, however, thanks to the medical staff at the St Georg Klinik in Germany - she is now able to go back to "normal" life, and work again. The sad part in all this, is the fact that none of this would have ever been possible on our own soil! I find it ludicrous we had to go to such extreme measures to get effective treatment, for a disease which can be treated with a course of antibiotics, found in any Australian chemist, if caught early enough. My sister's treating Doctor in Germany was horrified at how many patients he has treated from other countries, including Australia. The waitlist to get into the Klinik is very long, and simply put, if you can't come up with the money - you have to suffer the ill effects of this horrible disease – all on your own home soil! WHY????

Because a bunch of big wigs in suits say so!! Ridiculous. It's time for the Australian Governing bodies to take a stand, pull their heads out of the sand and acknowledge that Lyme Disease is here in Australia, It’s all over the world and people are suffering needlessly. Lyme disease recognition in Australia would mean “life” to so many of those who suffer from this disease and can’t afford the medication or treatment they need to become well again.

I would like every Australian to know my sister's story so that it may prevent or help someone like her to avoid the pain and suffering she has endured. I believe there are people out there who have been mis-diagnosed and who are suffering still. The Lyme Disease Association of Australia has all the facts and figures and I urge everyone to look it up on the internet, there is heaps of information and invaluable support available to those who need it.

The first step in prevention is awareness. The second, is a supportive government and medical association!!

There was a world-wide Lyme protest early in May 2013 to raise awareness globally, resulting in the Sydney Opera House and Niagara Falls turning green for a day (just two examples of many sites world-wide going green to help raise awareness to Lyme disease). I urge the Australian Medical Association to please do the right thing and formally recognise Lyme disease in this country, so that the way can be paved for those who needlessly suffer this disease.

I am more than happy to be contacted to verify any of the above information.

My contact details are below.

[redacted]

[redacted]

[redacted]

[redacted] and I are more than happy for this story to be made public – yet I would appreciate my personal details (address and phone number) to remain confidential please. I am also happy to yell my sister's story as loudly as it needs to be yelled to the ignorant that clearly need educating – face to face!!

Thank you for reading and my wish is that you, or any member of your family never have to experience what my sister has been through, or the emotional anguish that her husband, kids and we, her family have also endured in trying to support her through this insidious journey.

Below are some photos of our journey with Lyme…..

Thank you.