My Story

- Name: [redacted]
- Age: 32
- My address is: [redacted]
- My postal address is: [same as above]
- You can contact me on: [redacted]
- I want my story to be public

About my journey

- My son acquired Lyme-like illness at: Kings Park WA, 6000 in November 2013
- We have left Australia. In December 2012 January 2013 we visited America and Canada, we were told by an Infectious Disease Specialist at [redacted] that it would not have been possible for him to have contracted it when we were over there as we were there at the wrong time and didn't go to the right parts of the country to contract it.
- Type of Bite: We are unsure of what it was that bite our son.
- He was sick for almost 2 years before he was diagnosed.
- He has had blood tests from Australian and Overseas Labs. He has had positive, detected and pending results from St John of God Pathology. Borderline cellular activity and Serological evidence of infection through Armilabs. Borderline result through Australian Biologics. Weak positive from [redacted] test but I have not seen and do not have a copy of those results.
- At St John of God he has tested detected to: **Rickettsia** (Spotted Fever Group- R. australis, R. honei, R. conorii, R. africae, R. rickettsii. **Borrelia Burgdorferi (Lyme)** IFA IgG- Detected Western Blot IgM and IgG- pending since May. It was asked that specific bands be reported on. Patient to receive copy was ticked and we have received all other results from this lab but not this one. Arminlab- **Ehrlichia/Anaplasma-EliSpot** indication of a borderline actual cellular activity against Ehrichia/Anaplasma. **Bartonella henselae/quintana** serological evidence of an infection of Bartonella henselae/quintana. **Chlamydia trachomatis EliSpot and Yersinia EliSpot** indication of actual celluar activity against both Chlamidia trachomatis and Yersinia. Australian Biologics **Borrelia burgdorferi OSP Mix** Borderline. Western Diagnostics **Lymphocyte Surface Markers (Flow Cytometry)** B Cells (CD19) 238.
- We have seen 10 doctors, specialists and medical practitioners on his journey.
- He has presented to the Emergency Department twice due to his symptoms.
- He has also been diagnosed with migraines (to explain his severe abdominal pain) and not eating enough fat in his diet (to explain his sudden unexplainable weight loss).
- He was denied testing from PHM who only did it after we as parents pushed hard for it, further treatment from specialists because while they agree he is sick he has been put in the too hard basket to treat and they won't acknowledge and treat the things he has tested positive for which do explain what is going on. We've had Specialists say they will help and then once we

tell them about the Lyme testing we've had done we have not received any follow up care and therefore none of his symptoms are ever really addressed. We have also had the Western Blot blood test from the St John of God Lab pending since May 2015 and are yet to receive those results.

My life

- Prior to his illness, his life was as any 7, 8 and then 9 year olds would be. He was always happy, inquisitive, our energiser bunny who never ever stopped except at bed time, super smart and full of facts. He loved to play, run, and just be a happy go lucky kind of kid. He has always had a love of life, has always lived it to its fullest. He has always thought more about others than himself, always wanting to help, be there for people and look after anyone that looks as though they need it. His caring and compassion goes way beyond his little years. At 4 years old he walked 25km to raise money for a local charity to help sick kids and babies. He did the same at 5 and 6. When he was 7 (pre bite) he walked 41km and then sprung out of bed the next day as though it was no big deal. The following year he walked a 42.195km Marathon which really is mere kilometres more than the distance he got through the year before but after having his unexplainable symptoms for 8 months we were shocked at the difference in his stamina and his ability to recover. Last year he was really struggling, we dropped after school sports, rested on the weekends, he gave up anything that wasn't a necessity and sometime even that had to go. There were days he was so fatigued he just couldn't get out of the car to go to school. We did everything we could to make sure he would have his best chance of being able to still do his walk which is the thing that means the world to him. He did his Marathon again but again his recovery was difficult. He couldn't even get out of bed to eat dinner two days later. Again this is a far cry from the 4 year old with the tiniest legs who trekked 25km in just over 8 hours or the 7 year old who conquered 41km as if it was nothing. We have been told by Doctors and Specialists "well if he manages to walk that he far he can't have anything too wrong with him." Every time that is said it breaks a little piece of my heart, the fact that these people can hold his achievements against him to make themselves feel better about not treating him is disgusting. They don't see what we do every other day of the year to make sure he makes it through that one day. They don't understand that the thing that has gotten him through the times where he feels as though he's losing his mind is thinking about his walk, thinking about the sick kids he's going to help an the hope that one day the kids like him will receive that help too. The reason he gets through that day has nothing to do with what is or is not going on in his little body, it comes down to his beautiful caring, determined, unbreakable soul that won't let it stop him. His ability to always look on the bright side, to try with all his might to stay above it all, to not take to heart the harsh things some Doctors have said in his presence, the fact that sadly for him this is now what he considers normal and he's just trying to get on with it and his loving supporting family and friends are what is keeping him going. He at times is stronger and has more faith in “the system” then me, he believes one day it will all be sorted and help will be given and if not then when he is Prime Minister then he will fix it. For his father, brother and I to have to watch him these past almost 2 years has been heartbreaking. The timeline of his illness was that he was bitten 21st of November 2013. The following day he came home from school crawled his way down the hallway to his room into bed and went straight to sleep. He had a cold sweat and I could not wake him for dinner. The following morning he woke with a bullseye rash on his legs, I went to the chemist and they said they hadn’t seen anything like it before but it was maybe an allergic reaction from being in the bush and getting bitten. In the weeks and months that followed he had excruciating tummy pain (possible appendicitis was suspected due to the level of pain but ruled out), aching joints, extreme fatigue, loss of bladder control (which is very upsetting to a 7 year old), dizziness, panic attacks, hallucinations, confusion, leg pain, numbness in his hands, high temps, odd liver results, broken capillaries over his face, back, underarms, tummy and upper legs, feeling unwell, vomiting, very pale, having such bad pain in his lungs and hearts he thinks he's having a heart attack. These symptoms would come and go in waves. In October 2014 his symptoms took a scary turn and included a lot more neurological symptoms, his headache worsened and was always there (and still is to this day), he began behaving erratically, would become aggressive, not himself, he would have periods of vagueness, loss of abilty both with coordination and knowledge, his legs would “power down” and he would fall over, pins and needles down his spine, hands, feet and arms, his feet would feel like they were walking over broken glass, to walk to the car some days was an impossible task which would leave him screaming and crying in pain, 2 lots of unconsciousness, popping under his skin, a zapping feeling through his body, feeling as though things are falling and crawling over him when there is nothing there, a “blackhole” feeling where he would zone out and be completely out of it. We were very quickly sent for scans to see if he had a brain tumour or if he was having seizures. It was neither of those, but there also wasn’t a diagnosis that fit what was happening. It went from, hey his symptoms are so serious it could be a brain tumour, to maybe we should look into anxiety. I will agree he was showing signs of OCD by this stage also but given everything he was going through and how he was feeling, and while he wouldn’t have all the symptoms all at once he was not having a day where he was symptoms free. It was then that my sister told me of a friend of hers who has Lyme Disease, I knew nothing about it but she urged me to look into it because we were going around in circles with the Doctors we were seeing so I decided to see what it was. As I read it, as I saw the picture of that bullseye rash, as I saw that his symptom timeline was exactly as this disease goes I was shocked that all that was happening that was far too much to be a coincidence, could possibly be the answer to everything that was going on. It frustrated me when I researched it more and realised that [redacted] had enough symptoms that if we were in the USA when presenting in those first stages he would have been given a clinical diagnosis and started treatment straight away. I was angry and frustrated when researching further and finding out that if treated within that first 3 month window then it most likely would have been problem solved with no ongoing problems.

- When going to the Paediatrician with my research, a clear picture of the bullseye rash and a timeline of his illness for the day it started to the day we were seeing her I was surprised when we were met with "it doesn't exist here, theres no evidence, etc, etc" I was offered to see an Infection Disease Specialist to further discuss and would see them through the Outpatient Clinic at [redacted]. When we saw the IDS she was not interested at all in looking at anything to do with Lyme Disease, she barley glanced at the photo of the rash, didn't even look through the timeline we had provided, and then continued to tell us that he doesn't even have any of the symptoms of it. If she had of bothered to look at what we had brought with us or just listened to what we were telling her then she would have realised actually he does have the symptoms of it and co-infections also. We were told that the only place we would need to worry about catching it was a few places in Europe and in Boston during Summer and even then if he returned with a rash like that she wouldn't even be very concerned and it would be unlikely he would have it. This is completely wrong and false information. One only needs to look at the warnings from the CDC in America to see that they are having huge problems with Lyme disease in the majority of their county. She asked if we saw a tick and we said no but we didn't actively look for one, he had been rubbing his shoes up and down the back of his legs after he was bitten by whatever it was and he could have knock its body off. She then went onto tell us that it is almost impossible to knock a ticks body from its head, my husband who has lived his whole life in the country politely told her she was wrong and he wasn't sure what ticks she was talking about but that is the problem with the ticks we have here and anywhere in the world, it is very easy to remove the body and leave the head in there. We pushed and said we at least wanted it tested. She agreed but only because she "knew" it would come back as negative, she also said that the test is unreliable (but only if it comes back positive, if its negative then its 100% accurate). On the blood form she wrote "Parents think he has Lyme Disease". When we left we were angry and frustrated at the lack of care our son received, she would have no idea what was wrong with him or what was going on because she didn't bother to examine him, or his notes and we believe she had her mind made up before even walking in the room and wanted to brush us aside as quickly as possible. There was a young Doctor who we met with in the room beforehand and he was interested in what we had to say, it is a shame that these young Doctors coming through may be swayed but her close-mindedness and inaccurate information. Almost two weeks later we had a meeting with a Doctor who does know about Lyme and co-infections. When he found out [redacted] had run tests he rang to get the results and said given the amount of time he's had it, it's possible that they wont find it in his blood as after time it goes into the tissue, it's not on the surface in the blood and is hard to find. He was told by the Lab that it was a weak positive. We decided that we would do further testing at Australia Government Accredited Labs, Australian Biologics and Armin Labs in Germany. A few days later I was rung by the young Doctor at [redacted] to tell me that there was nothing in the tests they'd run, they were all negative. I was shocked to hear this and confronted him saying my Doctor had rung a few days before and it was a weak positive so how was it that they were saying they were all negative? After some uncomfortable ummming he said that he did query the head doctor about that and because we've not travelled anywhere in the world that he could contract it they would consider it a negative. I honestly could not believe what I was hearing. He apologised and said they agree he's sick but its not an infectious disease issue and we should find a different specialist to see. I asked who should we see, we've seen you, the GP, Paediatrician, Neurologist, Psychologist, Gastroenterologist everyone says he's sick but no one can help. He had no suggestions for me. We decided to go ahead with the testing at our own cost because we just needed some straight answers (it was just over $3,000 which thankfully was donated to us to use to pay for it) Once we got the results back we went back to the Paediatrician who said it was good news that the IDS said it wasn't that and upon looking through the results suggested the private overseas lab results don't meet Australian Standards (its right they don't but they do meet the German Standards) and are paid for results who may give you the result you desire (they don't I know of people who have paid the same Lab and theirs have come back negative) and that they aren't reliable. Now it seems to me that these IDS etc want to have it both ways, its unreliable as a positive but absolute as a negative end of story. If its unreliable its unreliable you can't have it both ways to suit what you want. I was asked if I could be making him think he is sick when he is not. I can't tell you what a slap in the face it is to have that suggested. Anyone who knows me knows this could not be further from the truth, I'm the one that helps to push him along, keep him going, have my fingers crossed that today isn't going to be ruined by this terrible unpredictable disease. I don’t suggest or push for things to be wrong, he comes to me and says whats going on or I find him collapsed on the bed or the floor if he couldn't make it. I’m the one who says well I’m sorry my dear but theres not much we can do about it just try to keep going. I’m there to catch him and pick him up not to push him down and ruin him. I wish I was lucky enough to have never heard of Lyme Disease, I wouldn’t wish this on anyone especially not my son. Even with the symptoms, the photo of the rash and the test results mainstream Doctors/specialists still say no but we don't have any answers for you.

- I find it incredible that a country can take the stance of “its not here” its in Europe, America, Asia but no not here. My son said to me “Mum if the Government isn’t smart enough to realise that Lyme Disease is in lots of other places in the world and we have lots of people who travel in and out of these countries and then come back here and could bring a tick in on them then they are not smart enough to be running this country. And it is that simple. Does Australia live in a magical bubble where people couldn’t bring this in- NO, do we have a magical customs in the sky which makes migratory birds drop off the infected ticks they carry and rid the disease from their bodies before entering, NO. Do vets in Australia treat dogs for Lyme Diease- YES. Why are we not keeping up with research around the world? Asia, America, Europe are finding new strains of this bacteria, some which were previously thought not transferable to humans but they are now finding is. Maybe we are not looking for the right strain, or in the right place. Again overseas research is looking into Lyme Disease being spread by mosquitos, sand flies, in utero and it has been sexually transmitted.

- Even the people I know who have contracted it overseas are finding it impossible to get treated because it seems these “specialists” are so busy denying they aren't up to date with the most recent information.

- We all deserve a better level of care. I’ve never understood the “we cant treat until we find the vector” I think that point is null and void when you have many illnesses, diseases and disorders that can’t be proved with blood tests, or their causes aren't known. My youngest son has Autism, you don’t know the cause yet we still receive funding and treatment. MS, Motor Neuron disease, Parkinsons- you don’t know the cause yet people receive treatment. Chronic Fatigue, Fibromyalgia- don't know the cause, no definitive test yet people are diagnosed. I’m unsure why this should be any different. You have a very large number of Australians from all walks of life, all ages and in all areas of this great country so why don’t you listen and do something while you wait for that breakthrough in what causes it.

- My hope is that one day people can receive the correct care at the time its needed without the politics, without the head in the sand, without people wanting to protect their reputations, without Doctors getting into trouble for trying to up hold the oath they took to help sick people. I hope that one day no one else will have to go through what we and many others have had to. I hope that my beautiful son can keep pushing through. I hope that he never gets to the stage where he has to stop doing what he loves. I hope it doesn't change his beautiful soul and his gentle heart like it has mine. I hope he doesn't lose faith in the profession that he has wanted to be in since he was 2 and a half like I have. I hope that one day he opens his hospital that he talks about where he will have a train that takes the sick kids for rides around the city with doctors on board to cheer them up and where he will help everyone, even those kids with Lyme Disease, Lyme Like Illness or Tick Borne Disease, whatever you want to call he wants to just help them so they don’t go through what he has.

- My worry is, what if this lack of care, the amount of time its taking affects him long term? And where do we go from here? Do we treat but then how, with who and with what, do we wait, do we just hope one day it goes away like the doctors seem to or do we start having their attitude of “well he’s not dead yet so he’ll probably be ok”? None of those options really help us much at all.