

Lyme Disease Senate Submission v:2
18/1/2016

Firstly let me state that it is "very wrong" that sufferers who are brain damaged by this neurological disease must produce our defence, against well versed and healthy pathologists, doctors and scientists that are in the denial camp. The true breadth of suffering is not noted, due many too sick to fight, let alone write a submission. May this fact be considered by the Senate Committee.

Those suffering may have the support of few scientists and progressive doctors on side – but fewer will publically fight for us suffering Lyme like, due to fear of persecution. So consider this please – few are fighting for many in a very uneven ball park.

Let me stress this is an aggressive disabling body and brain infection, post vector bites in Australia – it kills, it disables, it is 'unfathomable torture'.

Sufferers are mocked and or humiliated when stating how sick they are at hospitals when lab tests prove inconclusive.

My name is Alex Patsan...Pre tick and flea bites late 2011 in NSW, I was a successful individual. I had a six figure income, working in the technology industry. I had a strong work ethic with High Distinctions achieved in business and management and about to undertake my MBA. I was healthy and exercised three times a week and focused on health and good living. Married with two gorgeous children, who were also thriving, until they too became ill post flea/tick bites in coastal NSW.

Immediately post bite I experienced paralysis in neck in muscles in back and down one leg. This must have been the paralysis tick bite? This was followed by a severe flu like event and arthralgia's in all my joints and deep bone pain. Diagnoses at this time by my GP was hay fever and or a viral event.

This was the progression over the following months:

1. Excruciating muscle cramps/pains, especially in upper back
2. Sudden onset of joint pains (almost every joint)
3. Sensation of thick blood being travelling through veins
4. Sudden dizzy spells - felt like brain spinning
5. Twitching muscles
6. Paralysis feeling in my neck, arms, thighs
7. Hand tremors
8. Wrist and hand joint pains
9. Mild off and on cycling fevers
10. Black blood spots on tongue and back of throat

11. Multiple Red blood spots emerged on skin, angiomas
12. Extreme lethargy – must sleep constantly
13. Very stiff neck - to later crunchy stiff neck
14. Painful stabbing / itching hot spots in muscles
15. Severe muscle weakness (cant brush hair / lift cup)
16. Heart rate missed beats
17. Easily fatigued – cant shower without chair
18. Muscle atrophy - noticed in shoulders and forearms
19. Hands not responding to what I want them to do
20. Pressure between the ears
21. Ticking sounds in ears
22. Severe memory loss
23. Mood changes and confusion (esp when pressure/pain felt in frontal lobe)
24. Weeping left ear
25. Sore bones and muscles base of skull
26. Noticed small cysts in neck
27. Massive big glands came up back of neck base of skull
28. Foggy head
29. Anxiety like feeling with heart racing
30. Heavy night sweats
31. Face numbness RHS
32. Hormone/Menstrual disturbance
33. Speaking problems
34. Word block
35. Seizure like activity
36. Walking problems
37. Sudden eye Floaters
38. Vision disturbance/wobbly vision
39. Sole of feet pain
40. Bone pain and soreness
41. Chest and rib pain
42. Tinnitus
43. Night vision went pixilated after behind eye pressure
44. Severe head pressure and brain pain
45. Skull bone pain

I did multiple GP visits, dashes to [REDACTED] Hospital where 4 senior doctors tried figure it out during an overnight stay, also Rheumatoid Diseases Specialist visits. All told me my labs were normal. One doctor who looked at my blood results said "ALEX, THERE IS NOTHING WRONG WITH YOU!" Under their care we were all declining.

In desperation to reclaim my health I undertook own research; I asked my GP to perform Lyme/Rickettsial serology. My GP was hesitant to do this test, just on my research and demand. Finally after 8 months of rapidly declining health she rang me up and apologised that 'YES' my test request had indeed come up positive.

YES it came back positive for 'tick bite bacterias' - Spotted Fever Rickettsia and Equivocal for Lyme - my four year old daughter who was having similar symptoms came back saying Lyme antibodies was detected. My son was also showing symptoms, but his tests were negative.

My four year old little girl had history of bites (tick kept), a bullseye rash (photographed), a positive Lyme antibody blood test (attached), severe arthritic onset pain, fevers, word block and neurological issues. YET still diagnoses unclear to doctors! Even as a lay person I knew what is was, and I knew we needed antibiotics!

This was my next challenge and fight finding a doctor who would prescribe antibiotics. My family GP who seemed fed up with my visits and desperation – suggested I find another doctor as she was not willing to prescribe antibiotics and had no knowledge of the disease.

After being dumped by my long time family GP, hospitals telling me their tests were normal, and specialists saying post viral event I almost gave up, and feared going to doctors. To be judged as anxious, hypochondria or drug seeking would be a tag I could never bear – so I started to prepare for disability or death without their support.

Researching to save my own and children's lives I found doctors that were Lyme literate who had ILADS training (International Lyme and Associated Diseases Society). Further blood tests were done and positives tests came back for Borrelia species, Babesia Duncani, Rickettsia, Bartonella, CPN. These were in alignment with my clinical presentation. In addition my Brain Spect-CT Perfusion scan showed posterior temporal > frontal hypoperfusion; This supports a Lyme diagnoses in other countries. And a CD57 of 10; This supports a chronic Borrelia infection based on International Lyme and Associated Diseases Society guidelines.

My health now in such a state I needed home care. I couldn't drive, walk or talk properly. I couldn't brush my children's hair or make them a lunch box. The pain unfathomable torture – To explain, it feels like meningitis, arthritis, acid skin burns, cramping muscles, infected bones, brain damage with weakness so severe its hard to function.

Oral antibiotics, antiparasitics, antifungals were soon started under the care of an ILADS trained doctor, I had clear die off and resolution of some symptoms; proof yet again of my infectious state.

My best improvements came after I got a picc line and started IV ceftriaxone, IV azithromycin, IV flagyl and Malarone. Unfortunately this started at year 4 post infection. Due this treatment I now can drive and parent again. I am now out of bed; I continue to improve as I continue my abx protocol.

I wish to recover to be an outstanding hardworking citizen again. I confidently know if my doctor can continue to treat me I will be that person again, and my children will get better. My children and I clearly reclaiming our health with our Lyme literate doctors.

We don't want to be disabled on benefits - we all want to be high achieving. Let our doctors treat us!

This Lyme-like fight will go on forever at the cost of children's and adults lives unless something is done NOW!

I call on the Senate Committee to:

1. Let our Lyme literate doctors continue to treat us without reprimand from any governing authority
2. Have national recognition that there is a Lyme like illness in Australia making Australians very sick. They need antibiotics, in some cases intravenously, and in some cases long term.
3. Rename this Lyme-like illness to Multi-System Multi-Infectious Disease or Vector Borne Illness. Move away from the Lyme name to stop the debate. That's an American label for their unique strain - Sufferers need an Australian label for our strains. Sufferers have called it Lyme or Lyme-like in the absence of a locally characterized species/illness.
4. Roll out training programs to doctors and hospitals how to recognise and treat this disease.
5. Public awareness campaigns are needed to prevent further infections.
6. We need have pathology tests available to Australians as per IGENEX in America and INFECTOLAB in Germany, which are world leaders in detecting vector borne diseases.
7. Funding need go to the Karl McManus Foundation that supports the Sydney University Tick Borne diseases unit.

Thank you

Mrs Alexandra Patsan