

Dear House of Representatives, Health Committee, Hello my name is Beth Schultz and I am writing to you about SB916. I have Lyme disease that has been verified by 9 CDC Positive tests from 4 different Laboratories. My first test was December 10, 2004 when I presented with Optic Neuritis. That first positive test was not shared with me. The Doctor ran a second test which again was Positive and still never contacted me. I went back to that Neurologist after I had my second case of Optic Neuritis. That is when he said you have had 2 Positive Lyme tests but I do not believe they are accurate. I then went for my 3rd test and again it was CDC Positive for Lyme disease. I was told once again the test was wrong and I was diagnosed with Multiple Sclerosis.

Shortly after that the Oregon Health Department called me to see if I knew where I had obtained Lyme disease. I told them that my Doctor said I did not have it and she said I definitely did. She then proceeded to call my Doctor and let him know that I did have Lyme disease and I needed antibiotics. I was given a 30 day prescription of doxycycline. I noticed improvement and then the antibiotics ran out and it all came back and worse than before. I asked the Doctor for more Antibiotics and was told I had been successfully treated and if I wanted him to remain my Doctor I could not talk about Lyme disease any further.

I then got a new Doctor who tested me for Lyme and again it was Positive. That Neurologist referred me to an Infectious Disease Doctor at OHSU. We went to Portland for the appointment. The Doctors office called me in the morning to tell me they had a power outage and I would be rescheduled and to call back. When I called back the next day I was told the Doctor had reviewed my File and had no reason to even see me I did not have Lyme disease. I got very upset and insisted that he call me. The Doctor did call and went on to tell me without ever seeing me in person that I had what he calls "Lyme Disease.com" get off the internet, stop reading about it and it will go away. That is when I realized I was not going to find any help in my State of Oregon.

I spent many months researching and found a Neurologist in Connecticut. He was a teacher at Harvard that understood Lyme and Multiple Sclerosis. Before I went on that trip I saw one more local Doctor and asked for a Spinal Tap for Lyme disease. I wanted to have every possible test done before I travelled to Connecticut. That Doctor denied my request and wrote in my chart that I had "Strong Denial Syndrome" and "Obsession regarding alternative diagnosis." What I really had was CDC Positive Lyme Disease tests telling me I had it.

I was a struggling single Mom at the time with no other choice but to fly 3000 miles for medical care. The Doctor there tested me again for Lyme disease and again it was CDC Positive. He diagnosed me with Neurological Lyme Disease and gave me a prescription for 90 days of IV antibiotics.

My new Neurologist in Oregon had told me that if I got a diagnosis from someone who understood Lyme disease he would help me. When I returned home and went to his office he said he could not trust the Connecticut Doctor because he had faxed him the recommendations rather than calling and talking one on one. He said that was disrespectful and he could not work with him. I now had a prescription for IV antibiotics but no Local Doctor to order them and get me a PICC Line. It was almost a year until I actually got those antibiotics.

After the IV Antibiotics I had a follow up MRI and most of my brain lesions had disappeared. I thought it

was all over. I moved on got married and had a baby. After the birth of my Daughter I had a terrible relapse. I could not find a Doctor in Oregon again that would discuss Lyme disease. Back on a plane I went. That trip was horrible and made my relapse worse. Trying to get through an airport with no feeling in your legs, walking with a cane and crippling fatigue is not easy. My flights were delayed and it took almost 36 hours in airports before I made it to Connecticut.

This time I was diagnosed again with Lyme and Co Infections. I was given a 3 year antibiotic treatment plan. I am now in remission and work very hard to maintain my health with diet and a healthy lifestyle. Life is still different for me I have to take extra special care of myself. When I feel stress or do not sleep enough I can feel my body slipping. I also developed many food allergies I never had before. I will never be just a normal healthy person too much damage was done.

I am writing this because I never want to see anyone have to go through the years of pain I did. I can only imagine a life where I would have been diagnosed and properly treated when my Doctor received that first CDC Positive Lyme disease test. My kids lost their mother for many years and this has cost us tens of thousands of dollars out of pocket. Please listen to our suffering and make it right in Oregon. Thank you for taking the time to read my story.

Sincerely,

Beth Schultz

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Feel free to call with any questions
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