

Dear Honorable Members of the House Committee on Health Care,

SB 916 was a good bill for patients before it was amended. We ask you consider this bill with its original language and if it is to include a study it should be a panel that includes patient advocates, Oregon Lyme Disease Task force, specialty medical groups such as ILADS , Oregon Health Authority , and Oregon Medical Association.

Aug 1991 was when our world fell apart. Our daughter was bitten in the head while camping. She was just a toddler. Her mother removed the tick and was unable to get the head out so when we got home, she went to the doctor who removed the head. We asked if the red rash around the bite was possibly from Lyme disease the doctor assured us it wasn't here. About ten days later we returned to the doctor and our daughter had a rash, headache, stomach ache and a fever.

Over the next few months she developed a swollen knee and had recurrent trips to the doctor and two hospitalizations with Fever of unknown origins accompanied by rashes.

She was referred to an orthopedic specialist for her knee, who diagnosed growing pains. We asked about Lyme disease and were told again it's not here, no need to test. We were told to stop asking about Lyme disease.

Over the course of the next ten years, our daughter progressively became more symptomatic. By age 12 she had many MRIs (showing parietal bright spots), 3 cardiac catheterizations, many echo cardiogram and echo stress tests, EEGs, pulmonary function tests, and hundreds of blood tests, muscle biopsies, and a variety of other painful tests. It was heartbreaking to see her endure the invasive and painful tests. She was tested for HIV, EBV, and many other conditions, but they could not figure out what was wrong. She had 13 specialists, was on 18 different medications, including cardiac and seizure drugs not approved for pediatric use to control her symptoms. She continued to fail. We were told she probably had a host of genetic diseases that would take her life early, to go home and enjoy what time we had left. I questioned the diagnosis, as none of her 17 cousins, grand-parents , aunts and uncles on either side had anything like what she had. If this was genetic, we would certainly have seen in in current or past generations.

My wife had to quit her veterinary technician job to be a full time caregiver, which meant our boys also missed out on a "normal" childhood, watching their mom and dad exhausted from taking care of a very sick sister. At 10 or so years old, our son in a panic carried his limp sister down stairs yelling for help because she stopped breathing.

When our daughter was finally diagnosed with Lyme disease at age 12 by her Oregon primary care (A new Canadian import) both clinically and by the two tiered "gold standard" test, her doctor began treatment. However, he was reprimanded by the medical director at the clinic and referred us to OHSU infectious disease, Dr Bryant. Dr Bryant called and said she had a false positive test, and despite her symptoms to stop treating, yet he *never clinically examined her*.

We sought treatment on the east coast, where she was extensively tested and found to have not only Lyme disease, but Babesia and Ehrlichiosis and a Mycoplasma f. infection. In review of her charts he was dismayed that her absolute classical presentation was missed by any competent MD. In fact it was missed by multiple specialists in Oregon. She began improving using the ILADS standard of care. Due to the cost and the difficulty of traveling with a very ill child (sometimes up to 15 hours of plane travel).

We sought a closer doctor and found an infectious disease doctor who would treat here, or so we thought. He gave her 6 weeks of IV rocephin and declared her "cured".

While her symptoms had improved greatly, they were not resolved fully, and as soon as she stopped treatment for neurological and cardiac Lyme disease (30 days IV) she relapsed. This time her symptoms were worse, and she was sent to a plethora of specialists who handed her off to the next specialist, one after another for 6 weeks. She had a sleep study, saw rheumatologists, neurologists, pulmonologists and then a cardiologist who referred her back to infectious disease. She received a 2nd 30 days of antibiotics and improved greatly. We were told there was nothing more they could do, despite that symptoms were still present. Our daughter's illness progressed so that she had to have special educational needs due to "early onset Alzheimer's", fatigue, pain, and seizures and cardiac issues. She could not go to school and had to have an in home tutor. She spent the next year barely functioning.

We returned to Connecticut to continue treatment. Our Oregon doctor said he would continue if her east coast doctor would prescribe. For three more months, our daughter received treatment and became remarkably better. Her supporting doctor was harassed and called us at night and said he had to stop, but he would refer us to another doctor who may help. She treated for another 6 weeks, and she became harassed and told us she could no longer support our CT Doctor. We asked why, she got really quiet and my husband asked if it was the 98/2 rule, and she got huge crocodile tears in her eyes and just stood there. We had a prescription, but no medical doctor locally who would do supportive blood work and port care.

We had to again stop treatment, our Connecticut doctors were concerned she would die if she was not fully treated this go round and we flew back to Connecticut and had a "group" consultation with two CA doctors because California passed a physician protection act so these doctors could now help our daughter.

We began seeing a physician who was now only 9 hours away by car. A much cheaper and easier trip for our sick daughter. He also used the ILADS standard of care and continued the protocol set forth by her pediatric physician and neurologist on the east coast. He was able to continue treating our daughter and by the time she was 19 she was symptom free with exception of nerve damage which causes some pain.

As a young teen instead of doing sports, painting her nails, going to slumber parties, she had multiple hospitalizations, a probably TIA, administered her medication by chest port daily, and struggled to know normalcy.

In a local news interview when she was starting to recover, the reporter asked her "what will you do when you are all better" and her response was "I don't know what that is. I can't answer your question. I have always lived with life at the end of my fingertips where I just can't quite reach it".

Ashley is currently off all of her cardiac, seizure, headache, and arthritis medications and has been for 5 years. She has three beautiful healthy children. She works part time, spends time rock climbing and horse riding with her husband and girls. She gets to experience life. ILADS treatment works.

Please don't condemn more children to lose the best years of their lives. Our daughter never got a childhood. We were robbed of having the joys of parenthood, and our other children were all robbed from the normal things families do. We traveled to doctors for "vacation".

Our daughter had a bacterial infections that should have been treated with antibiotics, not adversity and harassment.

We can never get back those years, because our state standard does not allow a standard of care that would have prevented the unnecessary pain and suffering, loss and cost that we went through.

PLEASE PASS SB916 without amendment.

Sincerely

Marty and Theresa Denham

24780 Dodds Road, Bend, OR 97701

541-410-2624