Honorable Members of this Committee,

We ask you to vote for SB916 without amendments.

Our daughter was bit by a tick while camping when she was just a toddler. We asked her pediatrician if the red rash around the bite was Lyme disease, and she told us no way, not in Oregon.

Over the next 2 to 3 weeks, our daughter developed classical Lyme symptoms, including rashes. Over the next few months she developed a swollen knee, rashes, and fevers of unknown origin requiring recurrent trips to the doctor and two hospitalizations. There were dozens of nights of fevers requiring medical attention.

By age 12 Ashley had multiple invasive and expensive tests, 13 specialist doctors, 18 different medications, including cardiac and seizure drugs. She continued to fail. When we asked these doctors about Lyme, they basically said “no way in Oregon”, and some ridiculed us.

At age 12, Ashley saw a doctor who was new to Oregon. He diagnosed her with Lyme disease based on clinical symptoms and the two tiered “gold standard” test, and he began her treatment. He was subsequently reprimanded by the medical director at the clinic and ordered to stop treating Ashley.

So he referred us to an infectious disease specialist, Dr. Bryant at OHSU. Dr. Bryant called us on the phone—not having examined her—and told us that she had a false positive test despite her symptoms! He instructed us to discontinue antibiotic treatment.

Undaunted, we took Ashley to the East Coast, where she was examined, tested, and found to have Lyme disease, along with Babesia and Ehrlichiosis. Her Lyme doctor was shocked that her absolute classical presentation was ignored by her doctors and specialists. She improved using the ILADS standard of care. This doctor worked with Ashley’s PCP’s who could do supportive care in Oregon. Over the next several years, we and our daughter went through a cyclical routine of Oregon support doctors discontinuing her ILADS Lyme treatment and telling us residual symptoms were not Lyme. However, the symptoms recurred, and positive blood tests, including 2 positive PCR (DNA) tests indicated she was still infected. When we asked the East Coast and California Lyme specialists why she was so difficult to treat they said because she went for 9 years without any treatment, and the bacteria had penetrated bone marrow and brain.

Ashley stabilized to an almost normal life routine by age 20, but she missed having anything resembling a normal childhood and teen years. At this time, she is happily married and has 3 healthy children.

Our family was terribly impacted. Our “vacations” were often spent traveling to out-of-state doctors. Our children missed out on many normal family activities. We can never get back those years. We’ve spent approximately $185,000 out of pocket, but through ILADS treatment our daughter got better. We tried the IDSA protocol, and it failed her badly, preventing early diagnosis, and later preventing aggressive treatment. Our daughter had bacterial infections that should have been treated with antibiotics and science, not adversity and harassment.

PLEASE PASS this bill without amendment.

Sincerely

Marty and Theresa Denham

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