

Hello-

I am writing in SUPPORT of SB 916 and to follow-up on a letter I submitted to the Senators on 3/12/15. Please upload the attached documents to the Exhibits for SB 916, along with the following email text.

1. I have never been seen at OHSU for Lyme, but was mis-diagnosed by OHSU with neurally mediated hypotension in the mid-1990's after several fainting spells.
2. In 2014, Dr. _____ (Providence Neurologist) would not rely on my Igenex positive test, and instead recommended a lumbar puncture to verify Lyme.
3. Providence Health refers only to IDSA and John Hopkins for the treatment of Lyme.

Over the years, I have seen a variety of primary care doctors and cardiologists for my various symptoms but have never requested Lyme testing. In March 2014, I specifically searched for a Lyme Literate doctor in Oregon. Although I have not been refused Lyme testing, I feel the Oregon doctors should have recognized the early signs of my disease especially since I had the classic bulls-eye rash, joint pain and flu-like symptoms. Two additional Naturopathic Doctors (ND) in Oregon confirmed my positive Igenex tests and Lyme diagnosis (in addition to multiple co-infections). It is estimated that I have had undiagnosed Lyme for approximately 20 years.

I saw Dr. _____ (Providence St. Vincent Neurologist) in September 2014 who doubted my Lyme diagnosis even with reviewing my charts, numerous blood tests and Igenex CDC/ PCR positive results. Dr. _____ stated "Lyme just doesn't happen in Oregon." However, I was actually infected on the East Coast and I supplied this information to Dr. _____. It appears as though MDs do not realize that Oregon residents actually do move from and travel to different states. Also, I let him know that there are many patients who have been infected in Oregon. Dr. _____ stated he did not think I had Lyme and would not rely on the Igenex testing, but could not provide me with any other diagnosis. Therefore, he recommended I get a spinal tap and referred me to an Infectious Disease Specialist within Providence to see if my symptoms were related to Lyme. I did not follow his recommendation and at this point, I have not seen an infectious disease specialist.

I continued with my homeopathic treatment under the care of an Oregon ND, until September 2014 when I was prescribed oral anti-biotics.

In February 2015, I began intramuscular Bicillin (IM antibiotic) which is being administered at Providence Home Health Infusion clinic in Portland. Home Health and Pharmacy Services has been in contact with my ND on the treatment plan of 3-6 months, but at this point Providence will only cover the antibiotic medication for 30 days.

On 2/27/15, Providence Pharmacy Services informed me in person that they follow IDSA and John Hopkins standards for the treatment of Lyme. Providence Pharmacy Services also stated that a 2-4 week course of Doxycycline should have cleared the infection and the treatment plan with IM Bicillin was inappropriate. Providence was not aware of the ILADS treatment guidelines.