March 30, 2015

Dear Honorable Senators,

Please pass SB 916 with no amendments as soon as possible so that doctors and nurse practitioners in Oregon can diagnose and treat Lyme patients by any appropriate medical guidelines available.

I am a physical therapist and also have been a medical researcher at Harvard Medical School and Dartmouth hospital, so I am fairly familiar with the machinations of the medical world.

In 2007 while living in Bend, I started getting profoundly fatigued and was tested for mono (which was negative) and was treated for Chronic Fatigue and Adrenal Failure to no avail. By 2009 I was having such extreme joint pain in my ankles and knees that I had to crawl down the stairs in the morning. I have broken my ankle in multiple places, dislocated my shoulder, herniated discs in my back but this pain I was feeling was all together different and did not respond to any of the usual treatments. In 2011 I had to quit my job in Eugene as a PT at a chronic pain center because I was literally having to hold myself up on the walls, and after treating patients in the swimming pool I would have to take a nap in my car before driving 5 miles home because I didn't feel safe driving. By 2012, I was on crutches, paying for MRI's, testing and treatment out of pocket.

In 2013 a naturopath in Seattle tested me for Lyme and I came back CDC positive for Lyme. Having lived on the east coast for 12 years, I was aware of Lyme and I actually told her I didn't want that diagnosis and walked out of her office. After trying to "self-treat" with diet and other things, I finally conceded defeat and went back and got treatment. After just one month of treatment, I was able to walk without crutches and the brain fog that I thought was age or hormone related started to lift. I had enough energy to work again full time as a PT. I wasn't totally well, but I had my life back again.

I moved back to Eugene in 2014 to start my own physical therapy practice. I was told by a fellow Lyme patient that I couldn't get treated for my Lyme here in Oregon and I thought she was being a hysterical loonie because I had never heard of medical practitioners being restricted in what they could diagnose and treat. But after seeing multiple practitioners, I found out she was right. They would verbally discuss Lyme with me, but they wouldn't write it into my chart and they wouldn't treat it. I am still treating my residual Lyme, but I am able to be back working 50-60 hour weeks.

No one should have to go without proper medical treatment if it is available, which is why I am working with Oregon Lyme Disease Network to get this bill passed.

Doctors are trained professionals that should be able to select from all the appropriate options to diagnose and treat any diseases. To restrict medical professionals from appropriately diagnosing and treating Lyme is absolutely amazing to me, I have not heard of it with any other disease. The current IDSA testing protocol is only 19-56% sensitive for Borrelia, so there is a massive false negative testing rate. So even among the patients who get tested, many who actually have the disease are being told they do not and so are not appropriately treated. When they get other more sensitive testing (Western Blot IgG, IgM, pcr or culture testing) they are found to be positive but struggle to get appropriate treatment in this state.

We need to allow doctors and nurse practitioners to treat as they are trained, with all the evidence based tools available to them. The current narrow set of diagnostic tests with huge false negative results causes undue harm to patients.

Thank you for your time and consideration.