Dear House Health Committee Members,

I am writing in support of Senate Bill 916 "Sponsored by COMMITTEE ON HEALTH CARE (at the request of Oregon Lyme Disease Network) which "Directs Oregon Medical Board and Oregon State Board of Nursing to adopt rules regarding diagnosis and treatment of Lyme disease."

I am a Lyme Disease patient unable to get treatment, but diagnosed with clinical and supportive laboratory evidence and I need your help.

I remember getting sick, violently ill with massive headache, severe joint pain, and fevers. I very was sick for 6 months. I was tested for HIV, Lupus, RA and nothing came back positive, and they told me I must have chronic fatigue and said I needed to change my lifestyle. I did.

But things got worse,

I kept going to the doctor when they exhausted other things, I was tested for and got a positive Lyme disease test. But after terrible suffering of electric pains in the left side of my body and my face, I was re-diagnosed with Trigeminal Neuralgia diagnosis and my doctor said "wow, we have no idea how you got this". TN is known as the suicide disease because of the type of pain it causes. I was referred to OHSU Dr Burchiel, a top neurologist. He said "you don't have TN in the traditional way, but I don't know what you have". I asked him about Lyme and he said he can't talk about that and said there was nothing they could do and sent me home. No referrals, no options. Just to go home.

Then the pain started to migrate and made me investigate further. One neurologist thought I had MS, so I went to a MS specialist in Bend. She said I did not have MS, but recognized something else was going on and sent me to an infectious disease specialist Dr Lutz where I asked about Lyme again, since I had previous positive tests. I was retested, and I had some positive and some negative tests for Lyme. He told me "it's a like being a little pregnant" you really don't have it, and I'm not going to treat Lyme.

Since then, I have had gall bladder removed, hysterectomy, MVD surgery. I had 3 MRIs a spinal tap, complete diagnostic evaluation for my heart. Now I wonder if I had been treated for Lyme if those would have never been necessary!

I filed bankruptcy for medical costs trying to figure out what was wrong…now remember I HAD A POSITIVE LYME TEST through St Charles Hospital, they were trying to rule it out, with no success and STILL REFUSED TO TREAT.

Finally, just this year after 9 years of searching, a doctor said "it's Lyme but I can't treat you here in Oregon effectively" and she gave me a referral to a CA doctor who uses ILADS guidelines. It will be an enormous out of pocket expense, because my insurance pays for doctors in Oregon, not California.

I pay for good insurance here in Oregon and I want my regular physician to treat me here close to my home and employment. Why can’t my regular doctor treat me here?

And that leads me to my latest fear, the sicker I become the closer I will be to losing my lively hood, my career of almost 20 years that I love dearly. (as of the initial writing of this letter 4 weeks ago that I sent to Sen. Tim Knopp, I have been reduced to part time job due my illness and I have lost my medical insurance coverage, now I will have to rely on the state.)

I believe if physicians could practice guidelines similar to those used in other states such as ILADS that fewer patients would need state assistance, would be much healthier and would be less of a burden on the state. I'm not afraid to go to the doctor. I will go and go and go till something is resolved. I have been a very active and viable member of my community and don't intend to shrivel up and let Lyme take over my life.

I'm sick of being sick! Please help me live a better life

Please support SB916 so doctors in Oregon can be practice effective medicine.

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