

Dear Representatives and House Health Committee,

I'm 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."

Senate Bill 916 is intended to allow physicians (MD's) and nurses (NP's) to diagnose and treat Lyme disease and associated illnesses per the evidence-based International Lyme and Associated Diseases Society (ILADS) guidelines if they and the patient so choose, rather than being forced to adhere to the grossly inadequate Infectious Diseases Society of America (IDSA) guidelines for fear of drastic censure by their professional boards, such as suspended licenses and/or bankruptcy due to court costs. The IDSA guidelines allow for only very short term antibiotic treatment, even if the patient is still very sick.

Please move this through the house committee and to the floor to vote, with the need to amend back to its original language.

I am a 69 year old female neuropsychologist, and was finally diagnosed with neurological Lyme disease in 2012 on the basis of a positive Western Blot test and an EM rash and clinical presentation typical for Lyme. Symptoms were progressive numbness in both hands and torso for over 1.5 years, partial paralysis of one arm, insomnia, chronic generalized pain and traveling flare ups of specific, severe pains.

After 20 plus years of misdiagnosis (fibromyalgia; generalized osteoarthritis; polymyalgia rheumatica) and of it being very painful to get up in the morning, to get up out of chairs, and to do just about anything, I had a bad flare up in 2012 and ended up in the Urgent Care and Emergency Departments with pain so bad I was unable to sleep, along with increasing numbness and paralysis.

At that point a wonderful M.D. ordered a Western Blot test, diagnosed me with Lyme disease, and started treatment with IV antibiotics immediately. However, she did not dare treat me for more than 3 months for fear of losing her license if she did, and therefore had to refer me to a naturopathic doctor for further treatment of my Lyme disease, which I had to pay for out of pocket.

I am one of the very lucky ones – I found a Lyme literate medical doctor and a Lyme specialist naturopathic doctor, and have the financial resources to pay out of pocket (an average of about \$1300 a month for the past 2 plus years). I'm thrilled to report that my generalized pain, numbness, paralysis and insomnia are gone, but it took 2 plus years of intensive treatment with different antibiotics and supplements, according to ILADS treatment guidelines, to reach this outcome. Had I been treated solely by IDSA guidelines dictating very short term treatment, I shudder to think how much I would be suffering now without hope.

However, many are not so lucky. Many doctors appear to be afraid to touch Lyme disease with a 10 foot pole due to misinformation, suppressed research, and a very realistic fear of losing their licenses and their livelihood. Therefore, Lyme literate health care professionals are very rare and hard to find in Oregon, and patient access to effective treatment is extremely limited. Your support of Senate Bill 916 could help change this dismal situation.

When left untreated, or under-treated, victims of this disease can suffer extremely incapacitating illnesses that can lead to significant health care costs, long term disability and reduced economic productivity, not to mention chronic suffering and even death in some cases.

Lyme disease is not a small problem in Oregon. Indeed, one naturopathic doctor who practices in a small southern Oregon town, estimates that he alone has treated about 500 patients with Lyme disease in the past seven years approximately.

The proliferation of Lyme disease is a threatening medical crisis in Oregon. The bill I am asking you to support would allow practitioners to act in the best interest of the patient without fear of punishment from the professional discipline system.

Please put your support behind this legislation to ensure that the growing number of sufferers from Lyme disease in Oregon receive effective treatment.

Thanks very much for your time and consideration!

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