

Dear Representative Andy Olson

I am writing today because we have a very important bill which would affect many Oregonians. As you know, Governor Kate Brown recently proclaimed May as Lyme Disease Awareness Month. In fact, her proclamation states human caseload may be as high as 800 cases per year. . Many physicians in Oregon do not consider a diagnosis for Lyme disease, even when early symptoms are present. When not caught early, many patients will develop late stage Lyme disease which is far more difficult to treat and often accompanied by chronic, debilitating and costly conditions, often without insurance coverage.

I am one of those patients. We are asking you to consider re-amending the bill after reading the information below. Please take some time to hear the Senate testimonials on this [Video of Testimony in Senate](#).

While all the testimony is important we understand it is lengthy, so please be sure to review the following which clearly outline our concerns

1. EXHIBIT 1-10: Theresa Denham, Lyme Disease Network Task Force [00:05:40](#)
2. EXHIBIT 19-20: Beth Schultz, patient, Lyme Disease [00:56:15](#)
3. EXHIBIT 21: Mike Dewey, patient, Lyme Disease [00:59:36](#)
4. Compare this patient's outcome with the above testimony due to her inability to get care: EXHIBIT 22-26: Chris and Kara Chytka, husband and patient, Lyme Disease [01:02:37](#)
5. Why we believe Oregon is failing to recognize the seriousness of our Lyme disease problem: EXHIBIT 27-28: Sharon Lee, patient, Lyme Disease [01:09:10](#)

It is important to know that the IOM/NAM (Institute of Medicine / National Academy of Medicine) is a branch of the National Academy of Sciences and one of its key purposes is to provide unbiased and authoritative advice to decision makers and the public through evidence based guidelines.

The original bill was amended in the Senate and essential aspects were removed that were intended to provide beneficial care for Oregon Lyme disease patients. We need the House to add the following important language:

1. SB916 shall be re-amended to allow a physician, with informed consent from patients, to use any guidelines developed with IOM, PRIZM or NGC criteria for the diagnosis and treatment of Lyme disease and co-infections
2. The study needs to be well defined before voting and should include: Asking the question: Why are Oregon patients able to get properly diagnosed and treated with better health outcomes outside of Oregon versus their lack of diagnosis and care for their Lyme Disease within Oregon?

Study participants should be equally represented and include members of:

- Oregon Medical Association
- Oregon Naturopath Association
- IDSA (specialty society)
- ILADS (specialty society)
- Oregon Lyme Disease Network (Patient Advocacy)

Please take a moment to read my story **below**

I am a Lyme disease patient. I was sick for 20 yrs. before I got a correct diagnosis and by that point I was barely functioning. I was in bed or my recliner at least 85% of the time and could barely get a meal on the table. I suffered immensely and had 20 symptoms involving 5 major systems of my body. The diagnoses I was incorrectly or incompletely given were menopause, fibrocystic breast disease, plantar fasciitis, tendonitis, osteoarthritis, myofasciitis, and sacroiliac dysfunction.

Much to my relief in Nov. 09 my local Lyme Literate Naturopathic Doctor diagnosed me with Lyme disease and 2 co-infections. I am fighting 3 infections, two very complex bacterial infections and a protozoal infection (which is similar to malaria). The Lyme disease was CDC positive by blood test but since there criteria is so narrow the Babesia protozoa was suspect but not pos. by CDC standards but my doctor is trained to accurately interpret the antibody test and it was pos.

My other doctors did not ever connect the symptoms and ask why in my 40's and 50's was I so sick and in horrendous pain and exhaustion.

I had to quit my job as an RN, and treatment to get my life back is costing me huge amts. of money. For income I had to take my S.S. retirement and my husband has some income. He is self-employed and the income really varies. He will be working forever. I'm on Medicare which barely reimburses any of my doctor's appts. (Every 6 wks.) I fell into the medication gap last year with my Bicillin for the last half of the year. I'm in my 6th yr. of treatment using ILADS treatment protocol. ILADS is International Lyme and Associated Disease Society.

It is crucial that Oregon Physicians be able to diagnose and treat using these guidelines like they do in other states. Once they are free to do so and get trained for it people would get diagnosed sooner not be as sick and therefore recover faster with less expense and lost productivity. Now many are on OHP, S.S. disability, living with relatives or friends or using housing assistance and food stamps especially if they were the main wage earner in the family or their spouse has divorced them because they could not deal with living with a disabled person. The expense and suffering could be reduced. Also once Chronic Lyme disease is recognized as a legitimate disease in this state, insurance companies could be forced to cover the cost the same as for other treatable diseases.

PLEASE HELP! Under the current accepted Oregon protocols, Oregon patients have a difficult time with timely diagnosis and many are going out of state for care which compounds the difficulty and a lot of those appointments are phone only appointments due to the travel expense and difficulty.

The proliferation of Lyme disease is a complicated and threatening medical crisis, especially in Oregon. If we are ever to unravel the complexities of Lyme disease and find a cure, it is ultimately good science that will lead the way. In truth, that kind of good, decisive science probably is years away and too many patients are already suffering for not having access to all guidelines of care available.

One fact that is statistical and terrible and true is that a meaningful number of people do not get better after the current recommended treatment. And many of those people go on to develop chronic, disabling conditions that may last a lifetime. There are some who have used other guidelines not available to Oregon physicians to use, such as ILADS, and have recovered from the disabling grips of Lyme Disease.

I am asking you to support legislative action that protects patients' rights to work with physicians, and with their consent, receive the treatment of their choice. The bill that I am asking you to sign is exactly this kind of legislation. This bill would allow practitioners to act in the best interest of the patient without fear of punishment from the professional discipline system.

As you decide whether to support this bill, I ask that you think about what it must be like to be a patient who suffers with this illness. Try to imagine if it was you or your child. Please put your support behind this legislation to ensure that the growing number of sufferers of Lyme receive the treatment and recognition they deserve.

Thank you for your support.

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