

Dear Representative Barbara Smith Warner,

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 15
2. EXHIBIT 19-20: Beth Schultz, patient, Lyme Disease 00:59:36
3. EXHIBIT 21: Mike Dewey, patient, Lyme Disease 01:02:37
4. Compare this patient's outcome with the above testimony due to his wives inability to get care: EXHIBIT 22-26: Chris and Kara Chytka, husband and patient, Lyme Disease 01:09:10
5. Why we believe Oregon is failing to recognize the seriousness of our Lyme disease problem: EXHIBIT 27-28: Sharon Lee, patient, Lyme Disease 01:13:444

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 got bit by an infected tick when I was about 16 here in Oregon. I (and my parents) had no idea that Lyme disease causing bacteria existed in Oregon and we took no extra precautions after removal of the tick. My illness started with flu-like symptoms that lasted for about 2 months followed by horrible bladder infections and bladder bleeding, the loss of 20 lbs, migraines, stabbing abdominal pains, the development of 2 auto-immune diseases, years later a miscarriage, anxiety and depression. 20 years later I was finally diagnosed with Lyme Disease after presenting with all of those symptoms as well as the onset of neurological and cardiac symptoms. My doctor in Oregon couldn't treat it so I have to get care from Seattle without the help of my health insurance. I am a small business owner who has become disabled over the past 12 months and had to downsize our company to accommodate for my illness. I would love for doctors in Oregon to be empowered with the information, guidance and permission to treat Lyme Disease as well as insurance to consider covering it. After all, this illness is better treated at the onset and can often be cured at that point but beyond that it becomes a life long battle with very high physical, emotional and financial costs.

Thank you,

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