

Dear Representative Rayfield,

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:

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

Please take a moment to read my story below.

I contracted Lyme disease in 1980 at the age of 13 in Connecticut. I never saw the tick or rash, but I began to have symptoms and my health began to decline. I managed to cope with increasingly difficult symptoms until my health crashed in 1998, at which point I was quite debilitated by poor sleep, extreme exhaustion, joint and muscle pain, headaches, various secondary infections, and extreme brain fog. I was living in Seattle at the time and was not

properly diagnosed until 2007. After diagnosis, I finally began treatment and have been gradually improving ever since.

I moved to Oregon in 2009. I was disappointed to find that doctors here were not able to accurately diagnose or treat Lyme, nor were they knowledgeable about it. I found medical ignorance and close-mindedness about this disease. I have since learned more about the political reasons for this unnecessary lack of doctor training and awareness in Oregon.

I still have to go to Seattle to continue my treatment, but it would be much easier if I could go to a local MD. Please support ILADS training and treatment in Oregon.

Thank you,

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