

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.

Sincerely,

Kelly Donegan

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I am a Lyme Disease Patient and have had my life severely impacted by this terrible disease and the lack of resources available. We need your help.

About 8 years ago, I was misdiagnosed as having an auto-immune disease and given drugs for two years to suppress my immune system. This greatly exacerbated my symptoms and my disease became neurological. I went from being an ultra-marathon runner to someone who is no longer able to run at all and from a very competent academic to someone challenged at times when performing simple cognitive processes. During this time, I sought help from 7 doctors, including one at OHSU, but none correctly diagnosed my illness.

The standard diagnostic tool, ELISA did show antibodies to the bacterium which causes Lyme Disease but was below the level designated by the CDC for a positive test result. Therefore, I was incorrectly told that my test was negative and I didn't have Lyme Disease. It was only with follow up diagnostics by a Lyme Literate Doctor, using Western Blot analyses, that I was given the correct diagnosis.

Due to the lack of Lyme Literate Doctors in Oregon, I receive care for my Lyme Disease from a doctor in California. Unfortunately, despite my being a state employee and having decent health insurance, this is an out-of-pocket expense for me and adversely impacts my family's income.