

Dear Representative [Alissa Keny-Guyer](#) 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 wife's 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 that use IOM, PRIZM or NGC developed criteria for treating Oregon patients, when considering 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

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- It's hard for me to know how long I was sick before receiving a Lyme disease diagnosis as I do not recall a tick bite. I do know that I went to many doctors trying to figure out why my symptoms were getting worse and what was causing them. I did ask two of the doctors if it was possible that I had Lyme disease and I was all but ridiculed for asking. It was at least 3 years of searching for answers before I realized I needed a Lyme literate doctor to evaluate me. A Lyme literate doctor is one who has had the additional Lyme disease training from such experts as those in the International Lyme and Associated Diseases Society (ILADS). Lyme disease is very complicated and standard lab tests are often misleading. Therefore a Lyme literate doctor is best to provide a clinical diagnosis. The Center for Disease Control (CDC) states that Lyme disease needs to be a clinical diagnosis.
- I was diagnosed after a detailed clinical evaluation. At my next visit with my practioner I remembered to take in a lab test (taken previously by a MD in California) that said the results showed I did NOT have Lyme disease. My Lyme literate doctor reviewed it and said it DID show I had Lyme bacteria antibodies although I didn't meet the number of "bands" to be CDC positive for tracking purposes. That was 3 ½ years ago. I'm still dealing with late stage Lyme disease. I feel strongly that an earlier diagnosis would have prevented the extent and severity of my Lyme disease. I also feel that I would have been able to keep working. I'm still not able to work and have applied for Social Security Disability. I never imagined being so sick for so long with still a long road ahead.
- At one point early in my journey to find the cause of my symptoms, I went to one doctor who told me to go to a Chinese Medicine doctor. The MD didn't say I had Lyme disease and it's only in retrospect that I am sure he knew I had Lyme disease but didn't want to go on record stating that. I never did go to a Chinese Medicine doctor.
- The impact of my Lyme disease has been personally devastating. I wasn't able to keep working at a job I loved, and because I couldn't work I had to leave my apartment and put everything into storage. That was 4 years ago and things are still in storage. Friends had to help me move as I was too sick to pack. I was 5 days late getting out of the apartment because I was so sick. Since then I have stayed with friends, family and even lived for several months out of my mini van. It's affected every relationship I have and left me struggling to feel worthwhile and hopeful. It's a constant financial struggle to keep getting treatment. For awhile I was out of state to get treatment but I no longer have that option. If I get SSD I plan to go to a MD in Seattle who treats Lyme. If I don't get SSD soon I don't know how I will be able to keep going.
- I firmly believe that if I had been diagnosed and treated earlier in my disease I would have been able to keep working. If I had been treated using the current ILADS guidelines I feel I would have been able to recover more quickly and have a higher quality of life, and less of a burden to those who have helped me.