

Dear Senator Monnes Anderson

First, I want to thank you for presenting our bill and giving us a hearing. A few follow up points from questions raised by Committee members:

1. There was some concern about adding specifically the ILADS standard and we understand. That was why we had recommended the IOM Grade guidelines because it doesn't name any one particular standard to follow it just "grades" the quality of the standard based on the rigor of the research included. Based on the Grade system we are not requesting any one particular system of diagnosis and treatment, just quality standards, which would then include ILADS, IDSA, and others. Perhaps the bill can be amended to reflect IOM Grade system instead.

2. As this is written, it is essentially a physician protection bill. Several of the senators struggled to believe that it was needed and we did not present any physicians to speak because 4 of them backed out this morning. We had a debate tonight at dinner after the hearing about how to reveal names of doctors to your committee. I was in favor of at least sending you the screen shot of the text message from one of the doctors who backed out because he has just been informed he is being targeted with an "ethics investigation." So he may never appear on any formal disciplinary hearing list from the OMB by the intimidation is felt. I advocated for releasing the names of the doctors we have known in similar situations but others felt we needed to protect the doctors. So our indirect method of bringing in patients who testified that we had to treat out of state may be the best we can do until the doctors feel safe testifying.

3. I think some of the inherent misdiagnosis is because doctors don't believe there is Lyme in Oregon. Even look at the veterinarian evidence and you will know that is not correct. But just to let you know Oregon Lyme Disease Network has contracted with two independent labs to do a tick sweep (counting the number of ticks in a sample location and then also testing them for *Borrelia* bacteria) starting next Feb. The last Oregon scientific tick sweep was done I believe in 1998 and you can imagine with a vector borne illness, a lot can change in almost 20 years. Secondly, fibromyalgia is pervasive here in Oregon and it has many of the hallmarks of Lyme. So we are in the process of writing a medical research study to test 100 fibro patients for Lyme. Theresa has some startling statistics from previous studies but I don't have access to the actual numbers.

If you have any other questions I would be happy to help in any way I can. As you could see by the testimony today, Lyme has devastated many lives and there are folks locally who are literally dying because of lack of treatment. I hope with your help we can change that.

Katie McLaughlin