Dear Representative Duane Stark,

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 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

My name is Sharon Lee. I have been an RN for 50 years and a nurse educator for 27 of those years. I contracted Lyme disease and 4 co-infections from a single tick bite while living in Northern California (Plumas County) in 1978. Even though I had the characteristic “bulls eye” rash, I was misdiagnosed for 24 years because the 5 different tests for Lyme disease were negative. I was given wrong diagnoses of Rheumatic Fever, Fibromyalgia, Lupus, Chronic Fatigue Syndrome & Multiple Sclerosis because the symptoms are similar. I was even 100% disabled for 13 years prior to getting a correct diagnosis of Lyme disease in 2002. After beginning treatment, I was able to return to full time work for 8 years prior to retiring and moving to Eagle Point.

Shortly after moving to Oregon, I realized there were no **(that is 0!)** MD's who treated Lyme disease and there were no support services in Southern Oregon. In fact, all six of the physicians I consulted told me there was no Lyme disease in Oregon! And, if there were, they would not even attempt to treat it for fear of losing their medical license. What? How can this be? Lose one's medical license for treating a Lyme disease case with long-term antibiotics? As a nursing professor, I had to research this concept.

In 2010, I contacted Theresa Denham of the Oregon Lyme Disease Network and quickly learned that Lyme disease was, indeed, a problem in Oregon. I then, with the help of another RN who also had Lyme disease (Judi Johnston), started a support group for those in Southern Oregon. Since then, we have amassed over 200 members of the Southern Oregon Lyme Disease (SOLD) support group. We have monthly meetings at the Smullin Center of Rogue Regional Medical Center. We have been interviewed by local TV & radio stations and we have had newspaper articles about Lyme disease in Oregon. Please view my You Tube video here:
https://www.youtube.com/watch?feature=player_detailpage&v=Jpd6-Is7IWU

In addition, we have had a community educational campaign called "Tick Talks" over the past three years. We began with the Jackson County Search & Rescue and now have presented at several district offices of the BLM, US Forest Service, Oregon Department of Forestry & the Oregon Parks Department throughout Oregon. We targeted these agencies because they are the personnel that are working every day in the tick infested areas. As a result of those presentations, we have identified and assisted over 50 government workers who have contracted Lyme & tick-borne diseases right here in Oregon. Many of those workers filed worker's comp. claims. Some are now disabled because they were not diagnosed early enough in their disease process (they contracted the disease many years prior to our "Tick Talks" and were given an incorrect diagnosis) and, I have been told, a couple have even died.

Since starting SOLD, I have discovered that there are NO **(that is 0!)** medical doctors treating Lyme disease in all of Oregon! We have only been able to recruit one physician to treat Southern Oregon Lyme patients. He is a naturopathic physician (ND). I had him trained by the International Lyme & Associated Diseases Society (ILADS). This society publishes guidelines for diagnosing and treating those who have Lyme and tick-borne infections which has been sanctioned by the Institute of Medicine (IOM). I had him mentored by two MD's in California who are considered to be "Lyme literate". This ND now has over 300 patients with Lyme and other tick-borne infections.

As a former public health nurse, I examined why there was a disparity between the reported numbers of Lyme cases in Oregon & the actual numbers we were helping to get diagnosed and treated. Much to my surprise, I found that the guidelines for determining who is an actual case is extremely restrictive. In fact, the Oregon Department of Health is even more restrictive than the CDC! According to Oregon Governor, Kate Brown's resent proclamation making May "Lyme and Tick-Borne Disease Month", the numbers should be over 800 a year rather than 43 cases as seen last year. Please see my previous testimony to the Oregon Senate Health Committee about this issue. In addition, I question what the Oregon health agencies (health department or vector control department) even knows about the current tick infection rate of Lyme disease since a tick infection survey has not been done in Oregon since 1998!

The Infectious Diseases Society of America (IDSA) guidelines (which are not sanctioned by the IOM) say that the Lyme tests are highly reliable and the treatment should be of a short (10 day) duration. In contrast, ILADS contends that the testing is unreliable over 60% of the time and treatment needs to be prolonged in order to achieve a full recovery. As I understand, the reason why Oregon MD's are afraid of treating a Lyme patient in Oregon is because they know if they do not follow the guidelines of the IDSA they will be brought up for review by their medical board. That is just wrong! MD's should be able to follow any guideline they choose, especially if that guideline has followed strict protocol for development by the IOM. Senate Bill 916 was created to allow medical doctors (MD's) and nurse practioner's (NP's) to follow any IOM sanctioned guideline for Lyme treatment that they choose.

I have only scratched the surface of the Lyme problem in Oregon. Please feel free to contact me for further clarification or even attend our monthly support group meetings (the third Monday of each month from 6:30-9:00 PM). I urge you to review the previous testimony of SB916 and vote yes to the aforementioned amended bill.

Thank you,

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