Re: Senate Bill 916

Dear Honorable Representatives;

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:

I am writing in support of Senate Bill 916 "Sponsored by COMMITTEE ON HEALTH CARE (at the request of Oregon Lyme Disease Network) which " Directs Oregon Medical Board and Oregon State Board of Nursing to adopt rules regarding diagnosis and treatment of Lyme disease."

Please move this through the senate committees and to the floor to vote as is, **IMMEDIATELY**, because for those of us suffering from Lyme disease and the co-infections that come with it, every single day without access to proper and effective medical treatments, and medical practitioners, only shortens our lives more and destroys what quality of life we have left!

I have late-stage/chronic Lyme disease. I am infected with (at least) b.burgdorferi as diagnosed by a Western Blot test. Prior to this test I was misdiagnosed for 20 years and have seen more than 100 doctors, most of them specialists in their fields. I have had several un-necessary surgeries including a cardiac ablation. I have been told by these doctors that I had specific diseases only to find out later it was not. Example: My first diagnoses 20 years ago: “I am sorry, you have MS, you will be in a wheel chair within 5 years and likely dead in 10 years”. Since that first diagnosis I have been told by doctors that I have Fibromyalgia, Lupus, Lou Garrets, ALS, Gillian Bar, MS, Rumatoid Arthritis, Osteoarthritis, congestive heart failure, and Mental Illness to name a few.

For the last 15 years I have expressed to these doctors that I thought I might have Lyme disease. EVERY TIME I was told by them “we don’t have Lyme here”, “your symptoms are not Lyme”, “Lyme does not cause this type of heart problems”, etc.. In the last few years, after months of research, I finally found a couple of doctors that AT LEAST were knowledgeable about Lyme, and my primary doctor was willing to learn. Thank God! However, none of these “knowledgeable” doctors was willing to treat me as was necessary, with long term antibiotics, for fear they would lose their license to practice even though each of them knew it was the only way I was going to get better.

So here I am, 20 years later, in terrible shape, and will likely die from this damn disease…. WHY? Why can’t my educated doctor, and myself the patient, take the best science and treat me the best we can for a disease we know can be treated? Haven’t I already lost enough of my life?

I was a Career Federal employee, an Outdoor Recreation Planner for both the US Forest Service and the Bureau of Land Management. I have lived in rural Josephine County most of my life (45 years). I have worked in the forests of Josephine, Jackson, Douglas, Coos, and Curry Counties throughout my career. I have been bitten by hundreds of ticks and have had several imbedded in my body over these years.

Due to Lyme disease I am disabled. I can no longer work and have lost my career job and my income at a time in my life when I was at the “peak” of my earning power. I have lost my home which I had invested EVERYTHING I had into…why?.. because I can no longer work. I am maybe (I stress “maybe) 30% of the person I used to be. Not only can I no longer work but I also no longer can take walks, ride bikes, play with my grandchildren, garden, hike, write letters (I can barely type for long) clean my own home, volunteer in my community, get to my favorite fishing hole, lift or carry much of anything of weight, cook Sunday dinners for family, or even be on my feet for more than 20 minutes without great pain and the need to sit or recline.

I have terrible nerve pain in my legs/feet/arms, so much so I have actually begged doctors to cut my arms off on several occasions. Almost EVERY SINGLE joint in my body is in constant pain. Most all of my cartilage surrounding these joints throbs with intense pain and swelling. My right rib cage goes into sudden spasms causing excruciating pain making it almost impossible to even breathe for hours at a time. My mind does not “compute” like it used to. I have severe fatigue daily.

My heart…now that has been a mess; I have severe electrical issues with my heart daily including V-tach, A-tach, A-fib, brachacardia, and so much more. I end up in the hospital ER room at least three times a year due to my heart mal-functioning and stay overnight usually once each year.

I cannot even begin to tell you how much this disease has cost me financially **to date.** My guess is about $800,000+ which includes the loss of my home and career **(to date)**. This figure does not include what my health insurance companies have had to pay, nor what my employer contributed to my health insurance. This figure also does not include what my health (or the lack thereof) will cost tax payers for as long as I live….it will be enormous.

I want to be treated for my Lyme disease. I want my life back. My children and grandchildren want me back. I want YOU to allow Oregon physicians to practice the same guidelines, such as the ILADS guide, used in many other U.S. States for the **scientifically proven successful treatment** of Lyme disease and other tick borne diseases.
My friends, neighbors, fellow workers, family and citizens of Oregon need your help. You must pass this legislation, you must allow doctors to adequately treat tick borne diseases before they become chronic, and you must allow doctors to treat the chronically ill patients of this disease before they die!!

Recently I called several Veterinarians in Josephine County. I asked them "what percent of dogs they test that are positive for Lyme disease or other tick borne diseases". They answered approximately 8%. I then called Josephine County Animal Control Office. I asked them "How many dogs are in the County?" they estimated about 80,000. You do the math. That would be an estimated 10,000 dogs in Josephine County with tick borne disease. Therefore it would reason "if the dogs have it, obviously so too do the humans". *Which leads one to better understand just how many people are walking around in Josephine County either misdiagnosed, or undiagnosed with tick borne disease AND just how much this disease is going to cost this State in the future!*

I beg you to support legislative action that protects patients' rights to work with physicians, and with their consent, receive the treatment of their choice. The bill that I am asking you to sign is exactly this kind of legislation. This bill would allow practitioners to act in the best interest of the patient without fear of punishment from the professional discipline system.

As you decide whether to support this bill, I ask that you think about what it must be like to be a patient who suffers with this illness. Feel free to call me or my family, talk to us, ask my little grandchildren what it is like to have to sit in hospitals with their Grandmother wondering if she is going to live this time. Try to imagine if it was you or your child. Please put your support behind this legislation to ensure that the growing number of sufferers of Lyme receive the treatment and recognition they deserve.

Thank you for your support and God Bless You,

Kathryn Wetzel
1680 SW Waterstone Dr., Grants Pass, OR 97527
Ph: 541-479-1869