Dear Representative Davis:

I am writing today because we have a very important bill (SB916) which would affect many Oregonians.

As you may know, Governor Kate Brown recently proclaimed the month of May as Lyme Disease Awareness Month. I drafted the Proclamation on behalf of the Oregon Lyme Disease Network (OLDN) and I worked with Stacey Hall, on the Governor's staff, to get the Proclamation approved.

The Proclamation states that the human caseload for Lyme disease 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 advance to late-stage Lyme disease which is far more difficult to treat and often accompanied by years of chronic and debilitating conditions which are costly to treat, very 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 of the testimony is important and I appreciate that it is lengthy, I ask that you 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:

        - Oregon Medical Association
        - Oregon Naturopath Association
        - IDSA – Infectious Diseases Society of America (specialty society)
        - ILADS - International Lyme and Associated Diseases Society (specialty society)
        - Oregon Lyme Disease Network - Patient Advocacy 501(c)(3)

Please take a moment to read my story (attached).

Respectfully submitted,

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On May 11, 2007, I stood on the summit of Mt. Hood with my husband as the only woman with my Mazamas guide and affiliated rope team. At 48 years of age, it was my first technical ascent of what would be several of the most majestic Pacific NW mountains.

On May 11, 2012, at 53 years of age, divorced and forced into a year of homelessness by a Multnomah County Reference Judge, I was unable to stand in the shower of my parents' home where I had flown to be seen by eight of the top specialists in their respective fields at Philadelphia's most prestigious hospitals. All were trying to untangle a complex case that began as a diagnosed "spider bite" in 2008 that somehow triggered an inexplicable autoimmune thyroid disease that then flourished into multiple diseases and syndromes resulting in systemic pain, debilitating fatigue, loss of breathing, partial paralysis and severe brain malfunction requiring innumerable tests and three different biopsies, ALL of which stumped over 20 doctors in Oregon.

The five years from mountaintop to mattress top would be the most frightening and painful in my life and the most physically, emotionally and financially destructive. I had fallen into one of the deepest of medical mystery crevasses; I had misdiagnosed Lyme disease.

For every person that gets properly diagnosed there are literally thousands who don't because Lyme disease causes a debilitating range of symptoms that closely mirror those of other chronic diseases such as Multiple Sclerosis, Lupus, Rheumatoid Arthritis, Sjogren's, Chronic Fatigue, Fibromyalgia and Syphilis. Known as the *Great Imitator*, Lyme can cause seizures, vertigo, exhaustion, joint/muscle and bone pain, blood pressure and temperature irregularities, heart problems and in some cases death. Instead of receiving effective therapy for their ailments, Lyme patients are frequently told that their symptoms are somatic or psychosomatic.

I have been a resident of Oregon for 17 years. I live in Wilsonville along the Willamette River and my home and that of my surrounding neighbors is a haven for deer and diverse species of migrating wildlife. Many of us spend a great deal of time working in our gardens throughout the year.

My life…at least the one I had planned for, worked for, enjoyed and hoped would continue into old age has been decimated by Lyme disease and a co-infection called Babesia.

These insidious pathogens have stripped me of my once vital health, a 16-year marriage, the #1 fastest growing private company I created with my husband, my ability to work, my longstanding corporate, community and collegiate Board service, my athletic pursuits, executive functions, ability to travel, read a book, socialize with friends and very often walk, breathe, swallow, think and use my arms, hands and feet well or easily.

The Lyme parasite is not a singular infectious disease. Depending upon the tick or vector-borne insect that bites you, you will acquire whatever toxic dump of biological poisons it carries based upon the varied infections contained within the hosts it has fed upon.

Babesia is a protozoan infection so similar to malaria that it is hard to distinguish between the two under a microscope. These tiny parasites rupture your red blood cells, reproduce rapidly, lower your platelet counts and deprive you of oxygen -- which causes extreme fatigue, air hunger, chills, night sweats, bone marrow mast cell dysfunction, and vasculitis. It can be life threatening or fatal causing hemolytic anemia, heart attack, renal failure and disseminated intravascular coagulation. Unlike its more common east coast strain, my Babesia ("WA-1") is more dreaded because it doesn't die as easily. Its nickname is "Doomsday *duncani*" because the usual therapies, even when used for many months, sometimes don't phase it, and physicians must then resort to other, much stronger drugs in order to get rid of it and their cost is very high and often not included in insurance company drug formularies.

What's worse, the disease is notoriously relapsing in nature, meaning you can be treated and achieve a remission only to fall ill again, usually from triggers as common as stress.

Making matters worse, anyone can ALWAYS be re-infected with Lyme disease. Take a hike, play golf, rake your leaves, walk your dog, ride a horse, putter in your garden, go apple picking, camp in the woods or just sit in the grass at a summer outdoor concert…the most innocent and fun of activities cannot keep you safe from another tick bite and another Lyme disease infection.

Why is SB 916 a critical piece of legislation?

1. Lyme disease is bad enough but the co-infections associated with it make treating Lyme a far more difficult ordeal for even the most experienced Lyme-literate doctors. Eradication of these pathogens that reach late stage, as in my case, CANNOT be accomplished under Oregon's current 28-day maximum treatment guidelines and those used by and defended by the medical experts retained by the majority of insurance companies providing health coverage to Oregonians.

I am here to tell you that Oregon's current Lyme treatment guidelines are a one-size fits all recipe for disaster; at BEST they MAY work effectively ONLY for those patients with known immediate or early onset infection who have been quickly diagnosed and properly treated. At WORST, they leave patients like me, who went misdiagnosed and untreated for 5 years, by over 25 doctors, at incalculable risk of never getting better and enduring with little quality of life and diminishing hopes to live. Yes, you heard me right. The current#1 cause of death from Lyme is suicide. If that isn't a grim statistic, I don't know what is.

2. There was not a single doctor I saw in Oregon, between 2008 and 2012, who thought to think of Lyme disease, even though I presented as a textbook "*bull's-eye rash*" and "*summer flu*" case.

What's worse, after I was initially diagnosed through a *Western Blot* test by the neurologist in Philadelphia, suspecting MS, and months later by one of the top leading Lyme disease doctors in the U.S., who wrote one of the first definitive books on the disease, I COULD NOT find a single M.D. to carry on my care in Oregon. One insisted there was no Lyme disease in Oregon. Another said it was too complex a condition for him and a third said he didn't know how to treat it. All said I would be best served returning to the east coast for care.

I would come to learn in May 2012, newly diagnosed, that there were NO Lyme-literate MD's in Oregon and only a small smattering of Lyme-literate ND's throughout the entire state.

I would then learn from published reports, direct patient experience, doctor knowledge and word of mouth by some of the best Lyme doctors in the world, that Oregon was one of the worst states in the nation to be a Lyme patient and the first to have its medical board go after a Lyme treating doctor with the threat of loss of license or patients. I was told that ever since those early Lyme witch hunt years, the treatment of Lyme was effectively chilled in Oregon leaving a state with an increasing epidemic with no public health response for its citizens.

Since February 2013, I have been treated for my disease at a 3,000 mile distance.

3. Once I began treatment for my condition under the care of my Lyme expert doctor in Maryland, I was then confronted with the most frustrating and inhospitable patient care and insurance industry gauntlets here in Oregon.

I could be treated by one of the best doctors outside the state but my in person visits would only be covered at the out of network rate and my required monthly telephone appointments to review symptoms, reaction to medication, lab work, wouldn't be covered at all, leaving me with thousands of dollars of out of pocket expenses.

I could go to a local Lyme literate ND for all of the standard alternative Lyme therapies prescribed by my Lyme M.D. (acupuncture, Lyme-related IV's, associated heavy metals chelation, infrared sauna, UVB, etc.) but my insurance company would only pay for 8 naturopathic visits a year and NO coverage for any of the unapproved therapies, leaving me with thousands of dollars in out of pocket expenses.

I could get my PCP, 35 miles from my home, to administer my weekly and then bi-weekly Lyme injections, covered by insurance, but only if I could get a friend to make the drive with me in case I could not manage it in my condition and at the expense of more than a half a tank of gas – or, I could go to my Lyme ND only 7 miles from my home, using little gas and less time out of bed, and get the exact same injections but with no insurance coverage at all, leaving me with hundreds of dollars of out of pocket costs because I was often too ill to make the 70 mile round trip drive to my PCP.

While I was fortunate that my insurance company paid for some Lyme testing labs, they did not pay for thousands of dollars of other diagnostic tests which every Lyme expert MD or ND needs for proper evaluation and treatment.

While I was fortunate that my initial insurance company paid for my brain SPECT scan at the only hospital in the Pacific NW that had that sophisticated piece of equipment, it was out of network, leaving me with hundreds of dollars in uncovered costs.

My medical out of pocket costs for 2013 exceeded $33,000. My medical out of pocket costs for 2014 exceeded $27,000.

While I was fortunate that my initial insurance company paid for one of the best breast cancer surgeons in Portland to perform my port-a-cath surgery and 94 days of IV medication, I would find that after that insurer's COBRA coverage expired on 9/30/2014, my new replacement insurer refused to continue my care in October 2014, citing the existing limiting Oregon treatment guidelines, thereby creating a catastrophic break in service.

After intense efforts on the part of my doctor and IV infusion care provider, I was told my oral antibiotic regimen could continue in spite of my doctor specifically citing that I required the IV form of the drug.

Within 60 days, I landed in the hospital on December 3, 2014 having an emergency endoscopy and esophageal biopsy because the oral medication I was forced to take by the insurance company had ulcerated my entire esophageal z-line leaving me without any ongoing treatment at all, because I could no longer take the oral and because I was denied the IV.

I went 139 days WITHOUT proper treatment, setting me up for the risk of antibiotic resistance or a relapse. I relapsed on Christmas day 2014. From October 9, 2014 to January 2015, I appealed to the highest levels of two replacement insurers and sent detailed complaints to the Oregon Attorney General and Oregon Division of Insurance. It would take until February 2015 for me to receive an overturn of the denial and a return to my daily IV protocol.

Since becoming infected with Lyme and Babesia in 2008 my condition progressed so steadily until I finally became largely confined to bed in 2011 from where I have yet to emerge.

I now live alone, almost completely isolated but for my service dog in training and helpful visits from my neighbor. The basic chores of everyday life are still challenging and all of the truly great joys of life are still very much out of my reach.

After almost two years of treatment, with a four month gap due to insurance denials, followed by a four month relapse, I am clawing my way back to the slow progress I was making before my care was terminated. If my current care that I fought so hard to resume is denied, once again, I fear I will become yet another statistic, another life lost to the agony of trying to live with Lyme while trying to fight the present system in Oregon that is both anti-doctor and anti-patient.

Respectfully submitted,

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