March 12, 2015

Senator Alan Olsen
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Salem, OR 97301
Sen.AlanOlsen@state.or.us

Dear Honorable Senator Olsen:

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. I am a late-stage Lyme Disease patient and struggle immensely from this disease. Lyme patients and their families need your help now. Our main struggles include:

1. Inability to get properly diagnosed.
2. Once diagnosed, having a local Oregon doctor who is able to treat us.
3. Health insurance plans that deny the administration of the doctor recommended treatment.
4. Lack of awareness of the dangers of vector-borne illnesses, especially during pregnancy.

Since my diagnosis of Lyme Disease in 2014, I am absolutely shocked at the number of people that are struggling with a disease I previously knew nothing about. On a weekly basis, I run into at least one person in a grocery store, mall, work, church, etc. that either is struggling or has a friend/family member with Lyme disease. What is more disturbing is that these patients either do not have access to the ILADS treatment and/or their health care plan does not provide coverage in Oregon.

Overall, I am hopeful for a recovery because I have never taken the pain pills, steroid shots, or immune suppressant drugs that were recommended to me over the years. However, in order to get there, I have to pay the majority of my medical costs out-of-pocket which obviously puts my family in significant financial distress. I believe the lack of diagnosis, inability to find local medical care, and preventing patients from receiving long-term antibiotics is what makes it so hard for Lyme patients to recover.

I encourage you to support this bill so the health care industry in Oregon can understand the magnitude of this disabling and life threatening disease that is being ignored. Lyme patients have been misdiagnosed for so many years, denied health care coverage, and constantly have to defend our medical treatment decisions.

Please help! This legislation will enhance options for patients who are seeking diagnosis and treatment for Lyme Disease in Oregon. Under the current accepted Oregon protocols, Oregon patients have a difficult time with timely diagnosis and when they do get diagnosed it is often in the late stage of the illness. When left untreated, or under-treated, victims of this disease can suffer extremely incapacitating illnesses that can lead to significant health care costs and reduced economic productivity.

The proliferation of Lyme Disease is a complicated and threatening medical crisis, especially in Oregon. If we are ever to unravel the complexities of Lyme disease and find a cure, it is ultimately good science that will lead the way. In truth, that kind of good, decisive science probably is years away and too many patients are already suffering for not having access to all guidelines of care available.

One fact that is statistical, terrible and true is that a meaningful number of people do not get better after the current recommended treatment. And many of those people go on to develop chronic, disabling conditions that may last a lifetime. There are some who have used other guidelines not available to Oregon physicians, such as ILADS, and have recovered from the disabling grips of Lyme Disease.

I am asking you to support legislative action that protects patients' rights to work with physicians, and with their consent, receive the treatment of their choice that would be supported by the patient's health insurance plan. 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. 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.

My Lyme Journey

Although I immediately presented the erythema migrans (standard bulls-eye rash) and flulike symptoms about 20 years ago, no Oregon doctor ever mentioned or tested me for Lyme Disease and I went undiagnosed until 2014. In addition, my 4 years old son contracted the disease in-utero and is currently being treated for Lyme Disease too, which manifests in autism spectrum-like behaviors in children. Although the Red Cross prohibits patients with Lyme Disease, Anaplasmosis and other related co-infections from giving blood, blood banks do not test for these serious infections. Therefore, the diseases may be even more widespread then we know.

I grew up in upstate NY on fifteen acres of forested land and moved to Oregon when I was 17. I traveled back to NY and Cape Cod every year during the summer, areas endemic to Lyme Disease. However, I never thought about my any of my symptoms being related Lyme Disease nor was I educated on the topic. On the east coast, Lyme Disease is thought of as "hard to catch, and easy to fix" which is the motto of the CDC and IDSA. On the west coast, doctors believe it does not even exist. I would welcome those individuals to spend a day in the life of a Lyme patient.

In my early 20's, I started having fainting spells and severe muscle aches. One summer while visiting New York, I had the classic bulls-eye rash on my left hand and instantly my hand was arthritic. When I returned back to Oregon, I had the flu and went to the doctor who said the rash was just an allergic reaction to something while traveling and getting the flu after a trip was common. What I did not know then, was the rash and the flu were classic signs of early Lyme Disease. If I would have been properly diagnosed and treated at that time, my family would not be struggling with this disease 20 years later.

Since that trip, I continued to get the same rash and flu a couple times per year in addition to a variety of other skin rashes. I have seen several doctors over the years regarding the skin rashes, which were due to an "unknown allergic reaction." I have had many fainting spells, muscle weakness, and seizure like episodes over the years, and doctors in Oregon could not connect the dots with all the un-related symptoms. I had a tilt table test and diagnosed with neurally mediated hypotension in my early 20's. I had pneumonia about 10 times along with pleurisy during this time.

Over the years, doctors in Oregon said because I was young, never smoked, and never did drugs, there was nothing wrong with me. However, doctors were quick to recommend pain killers and cortisone shots, which I refused and instead did chiropractic treatment. I did not want to cover up the pain, I simply wanted to find out what was wrong in my body. Therefore, I learned to live with all these symptoms and go on with life.

When I was pregnant in 2010, I had pneumonia twice, pleurisy and kidney stones. After giving birth, my symptoms got increasingly worse with multiple types of skin rashes, memory loss, severe nerve and muscle pain, low grade fever, recurrent swollen glands, trouble breathing, difficulty walking, and difficulty speaking. The symptoms began within 12 hours of giving birth in the hospital. The hospital thought I was having pulmonary embolism, but could not find anything wrong through all the testing. The doctor said all the symptoms above were due to an "unknown allergic reaction."

In summer of 2012, I began falling and tripping over things and subsequently broke my foot and my toe on different occasions. In addition, these minor injuries never seemed to heal. In 2013, I was sick with respiratory illnesses for five months straight. Doctors could not explain why I was constantly ill and mentioned the possibility of throat cancer and Multiple Sclerosis. I had a gut feeling that was not correct, and did not pursue further since my faith and hope in doctors was limited.

I was diagnosed with Lyme Disease by accident based on information from a friend. In January 2014, I suddenly had a large lump/cyst and bulging vein on the back of my right knee and had been experiencing increased pain, difficulty walking, mental confusion and significant memory loss. These symptoms were increasing over the past several months.

My conventional doctor said nothing was wrong, as the standard tests all came back negative. He concluded the large lump was due to sitting in my office chair and suggested stretches. Really? Stretches can alleviate a cyst on the back of my knee, in addition to my memory loss and significant pain? Again, I had another diagnosis that did not make sense. I discussed my frustration and symptoms with a child-hood friend, who suggested the possibility of Lyme Disease and my search for a doctor began.

In March 2014, I was diagnosed by an Oregon Naturopathic physician with **late-stage** Lyme Disease (CDC and PCR positive) and many co-infections (Bartonella, HHV6, Epstein Barr, Mycoplasma Pneumonia, and Parvovirus). More severe symptoms exist because one of my co-infections is Anaplasmosis. When combined with Lyme Disease, death can result if not properly treated. According to the CDC:

> "Anaplasmosis can be a serious illness that can be fatal if not treated correctly, even in previously healthy people. Severe clinical presentations may include difficulty breathing, hemorrhage, renal failure or neurological problems. The estimated case fatality rate (i.e., the proportion of persons who die as a result of their infection) is less than 1%. Patients who are treated early may recover quickly on outpatient medication, while those who experience a more severe course may require intravenous antibiotics, prolonged hospitalization or intensive care. Because *A. phagocytophilum* infects the white blood cells and circulates in the blood stream, this pathogen may pose a risk to be transmitted through blood transfusions. *Anaplasma phagocytophilum* has been shown to survive for more than a week in refrigerated blood." The diagnosis of anaplasmosis must be made based on clinical signs and symptoms, and can later be confirmed using specialized confirmatory laboratory tests. Treatment should never be delayed pending the receipt of laboratory test results, or be withheld on the basis of an initial negative laboratory result.

http://www.cdc.gov/anaplasmosis/symptoms/

Because I had not been treated at the time of infection over 20 years ago, Lyme has advanced into my multiple organs, body tissues, brain and my spinal cord. This severe infection and inflammation caused a variety of medical issues including, but not limited to:

> Neurally mediated hypotension, vertigo, fainting, mitral valve prolapse, heart palpitations, poor circulation, recurrent pneumonia, pleurisy, gall bladder surgery, kidney stones, chronic fatigue, muscle weakness/severe muscle pain, difficulty swallowing, severe joint pain and swelling, baker cysts, difficulty walking and using arms/hands, migraines, ongoing low-grade fevers, mental fog, memory loss, inability to concentrate, inability/difficulty speaking, inability/difficulty reading, facial and muscle twitches, severe hand and body tremors, seizure like episodes, severe nerve pain, severe carotid artery inflammation, brain lesions, degeneration of cervical spine and lumbar spine, benign tumors on lumbar spine, Shingles, Lupus and Auto-immune Hepatitis.

During this Lyme journey, I discovered that Lyme can be actually be transmitted through pregnancy and breast milk. Prior to my Lyme diagnosis, my son Nathan was in speech therapy due to a moderate speech delay. He was tested for Lyme in July 2014 due to his previously diagnosed speech delay and some behavioral issues. Nathan now attends speech and occupational therapy on a weekly basis, and is improving with his Lyme treatment. The unexplained symptoms that I had after giving birth were attributable to Lyme Disease.

In September 2014, I saw a neurologist at St. Vincent's in Portland who informed me that "Lyme just doesn't happen here" and suggested I get a lumbar puncture through an Infectious Disease Specialist. He doubted the accuracy of the Lyme diagnosis, even though I was CDC and PCR positive. In addition, my March 2014 diagnosis was subsequently confirmed by two other Naturopaths in the area. I declined his lumbar puncture recommendation, as this can be significantly harmful to Lyme patients and would not provide me with any additional information.

In September 2014, I changed Lyme doctors as since my new doctor is covered under my insurance plan, started Acupuncture and began oral antibiotics. My current Lyme doctor is great at taking treatment slowly so I am not bedridden with Herxes, since I continue to work full-time. Some days are good and others are quite rough, but mostly impacts me at night day. With my test results, doctors are surprised that I am not in a wheelchair and have not suffered a stroke.

My parents, who moved back to upstate New York three years ago, were also impacted by Lyme. Within 6 months of moving back, my father developed dropped foot syndrome and within 1.5 years had severe muscle atrophy, lost 70 pounds and became bedridden. Doctors in New York could not identify any problem through standard tests and informed my dad that he just needed to stretch and lift weights! Prior to this, my dad had no significant medical conditions, was rarely sick, and took no medications. He retired from the Portland Public Schools and walked several miles each day, and then moved to upstate New York.

During the time my father was significantly declining in health, I was diagnosed with Lyme. Because my dad often picked deer ticks off himself after being outside in the woods with his dog, we thought his symptoms over the past couple years could be Lyme Disease. My father was in the process of being diagnosed with Lyme-induced ALS. However, we never got an official diagnosis because he passed away in his sleep on January 1, 2015 (9 months after my Lyme diagnosis).

My Health Plan Journey

I have been in contact with Providence Health Plan since January 2015 in regards to a pre-authorization request for the administration and coverage of the prescription antibiotic, Bicillin- LA. This is an intramuscular injection prescribed by my Lyme doctor for 2 times per week for approximately 3-6 months for the treatment of **late-stage** Lyme Disease. Lyme doctors often have difficulty with health plans in writing orders for IV and IM antibiotics, since they are not associated with the local hospitals.

I have spent countless hours discussing my case with Providence. Each of the various departments has given me contradictory information. My Lyme doctor and Providence Home Health received a fax on 2/10/15 from Providence Pharmacy Services Department (who handles pre-authorizations) that the Bicillin antibiotic "*...does not require prior-authorization. It is a covered medical benefit.*" However, this has since been retracted by Providence.

Although the antibiotic is a medical benefit not requiring prior authorization, the Providence Pharmacy Service Department is now requiring a pre-authorization and Providence Health Plan will not pay the benefit once billed. So, on one hand I am informed by Providence Home Health and Pharmacy Services Department that I can start the IM antibiotic treatment and no prior authorization is required. But once the antibiotic treatment is provided by Home Health and billed, Providence Health Plan will deny the claim because it was not properly approved. Then I, the patient, am stuck with medical bills that I was informed in writing to be a covered medical benefit.

Confused yet? Well, I certainly am. I believe this "bait and switch" tactic that Providence Health Plan has adopted is incredibly deceptive, in addition to the complete lack of understanding of Lyme Disease treatments.

Since intramuscular Bicillin is a medical benefit, not a pharmacy benefit, Providence Health Plan originally denied the claim for my local pharmacy to fill the prescription of this $1,200+ per month life-saving antibiotic that would be administered by my Lyme doctor. The antibiotic Bicillin is necessary in order to cross the blood-brain barrier, which is one of the many locations where Lyme spirochetes reside.

Providence Home Health Infusion stated they were authorized to administer the medication in their infusion suite. However, Home Infusion indicated that although the Bicillin may receive a pre-authorization approval via the Providence Pharmacy Pre-Authorization Group, only a 30 day supply would be approved due to the cost of the medication and quantity limitations.

Providence Health Plan is strictly relying on the inaccurate IDSA definition for Lyme Disease which recognizes only the <u>early stage</u> disease and only calls for up to a 30 day supply of oral antibiotics. This approach is not medically prudent for a **<u>late-stage</u>** patient such as myself. Lyme has a long generation time and transforms into a dormant stage, so treatment must be:

> "...continued to eradicate all active symptoms and prevent further relapse. If treatment is discontinued before all symptoms of active infection have cleared, the patient will remain severely ill and possible relapse further."

Therefore, only receiving a 30 supply of Bicillin would not be beneficial for me. I requested an extension of the standard 30 day pre-authorization to at least 3 months to maximum of 6 months. In addition, I requested an expedited review by a Pre-Authorization team member that is a Lyme Literate Physician and familiar with **<u>late-stage</u>** Lyme Disease. I am still awaiting the decision from Providence Health Plan on whether they will actually pay for my $1,200 per month antibiotic treatment.

Lyme Disease is at an epidemic rate larger than AIDS and also bears many similarities regarding the denial of medical service and coverage.

> "Seventy-seven peer-reviewed studies from 1977 to 2012 show that the Lyme infection can persist despite the [IDSA] recommended antibiotic treatment. Yet, because chronic Lyme disease is not recognized by the medical establishment, insurance companies insist that it does not exist and therefore refuse to pay for long-term treatment. Like AIDS patients in the early days, many Lyme patients with persistent symptoms have to go outside the system to get medications."

http://truth-out.org/news/item/21206-from-aids-to-lyme-will-we-let-history-repeat-itself

Although Lyme Disease has been notifiable to the CDC since 1991, the IDSA and Insurance Companies have incorrectly applied the case definition since that time in order to avoid paying for costly medical treatment.

> "Surveillance case definition is intended primarily for monitoring the infection rates, prevention and care on population level not a basis for clinical decisions for individual patients."

The CDC was encouraged by Public Law 107-116 (Signed by the President in 2002) to aggressively pursue and correct the misuse of this definition, but this has not been changed to date. As a result, many **<u>late-stage</u>** Lyme patients are suffering and not receiving insurance coverage for antibiotics in which there is no generic version.

Please see the following research studies that support extended antibiotic treatment for patients suffering from **<u>late-stage</u>** Lyme Disease and related co-infections. Lyme Literate physicians follow the ILADS (International Lyme and Associated Diseases Society) guidelines for treatment, which is not recognized by the conventional medical community in Oregon. According to ILADS:

> "Clinicians should continue antibiotic therapy for patients who have not fully recovered by the completion of active therapy. Ongoing symptoms at the completion of active therapy were associated with an increased risk of long-term failure in some trials and therefore clinicians should not assume that time alone will

> resolve symptoms. There is a wide range of options and choices must be individualized, based on the strength of the patient's initial response.
>
> Clinicians should retreat patients who were successfully treated initially but subsequently relapse or have evidence of disease progression. Therapeutic options include repeating the initial agent, changing to another oral agent or instituting injectable penicillin G benzathine or iv. ceftriaxone therapy. Choices must be individualized and based on several factors, including: the initial response to treatment; the time to relapse or progression; the current disease severity and the level of QoL impairments."

ILADS Diagnostic and Treatment Guidelines published in October 2008, by Dr. Joseph Burrascano Jr.

> "...It is suggested that the sustained therapeutic levels of penicillin were effective either by the inhibition of germ replication or by lysis of the spirochaetes when they were leaving their sanctuaries."

Annals of the Rheumatic Diseases 1992; 51: 1007-1008

> "Lyme arthritis in which patients were treated with oral antibiotics, the treatment failures often showed signs of neurologic involvement, suggesting that oral antibiotics may be insufficient to eradicate infection that may already be sequestered in the CNS compartment."

Fallon, B.A. Neurologic Lyme Disease in 12th International Scientific Conference on Lyme Disease and other Tick-borne Disorders. 1999. NY, NY.

There are many Lyme Disease patients in Oregon that are being denied life-saving antibiotic treatments from health care plans. Just two weeks ago after my first painful Bicillin treatment, I had two Providence Health officials enter the infusion suite and inform me in person that the Health Plan would not approve the medication for more than 30 days because the Lyme should have been resolved through a 2 week course of oral antibiotics.

I wonder how many patients with other life-threatening illnesses have to defend their medical treatment and doctor recommended medication after a painful treatment? Providence Health Plan indicated they follow IDSA and John Hopkins guidelines, and was unaware of the ILADS guidelines. In addition, Providence stated the $1,200 a month medication is too expensive and the 30 day quantity limit is enforced regardless of patient need. Keep in mind that I already pay $1,000 per month in health insurance premiums for my family, through my employer sponsored plan. At my next visit, I provided the entire ILADS guide to Providence and used this opportunity to educate them on Lyme.

Fighting for my own health is difficult with **late-stage** Lyme, but I am also fighting for my son Nathan and all other children so they can receive local and appropriate treatment without fear of being denied coverage through doctors and the health plans. Again, I urge you to please put your support behind this legislation.

Thank you for your support.

SENATE HEALTH COMMITTEE

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Thank you for your consideration and support of SB 916,