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Dear Honorable Senator Thatcher:

I am writing to you in support of Senate Bill 916. This Bill has been sponsored by the 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 Bill through the Senate Committees and to the floor to vote without alterations.

I am one of many seriously ill Lyme disease patients in Oregon who need your help. Like far too many Lyme patients, my journey to a proper diagnosis has been a long and life altering one.

Prior to becoming mysteriously ill in 2008, I was an extremely bright, physically fit 49 year-old outdoor enthusiast, active in technical mountain climbing and other sports. More important, I was a meaningful contributor to a wide variety of business, civic and cultural organizations, serving in leadership positions on both public and non-profit boards. By 2008, the company I helped found with my husband in 2003 had become the fastest-growing private company in Oregon, ranked by Inc., Forbes and the Portland Business Journal. We were very busy building facilities throughout Oregon and Washington for several large and well-known tech companies, Oregon's medical and university infrastructures, many local and out of state businesses as well as being chosen as the contractor to renovate the State Capitol. I was a fully-engaged, deeply committed, model Oregon citizen.

By the end of 2008 I had developed a myriad of debilitating multi-systemic symptoms which included chronic pain and fatigue, intestinal, eye, heart, thyroid, OB-Gyn, dermatological, breathing, sleeping, and body temperature irregularities as well as serious cognitive abnormalities.

It would take four years, a loss of normal breathing, walking and executive functions, and over 25 different doctors and specialists in gynecology, endocrinology, ophthalmology, dermatology, immunology, rheumatology, neurology, neuropsychology, hematology, oncology and psychiatry before a leading neurologist at one of Philadelphia's best research hospitals, suspecting either multiple sclerosis, chronic lymphocytic leukemia or non-Hodgkin's lymphoma, finally uncovered my perpetually misdiagnosed Lyme disease through a Western blot test.

By this time my marriage had disintegrated along with nearly everything I had worked my lifetime to create. It would take another year before I finally cleared one of several long waiting lists to be seen by one of the nation's best Lyme-literate doctors, all located on the east coast, and finally began my care. By February 2013, I had visited multiple hospitals, undergone three biopsies, including one for bone marrow, and had been diagnosed with multiple autoimmune diseases affecting multiple organs as well as antibody and immune deficiencies and neuro-cognitive and nervous system disorders.

As traumatizing and debilitating as this was, it was only the beginning of what has now been two of the most physically painful, frightening and difficult years of treatment involving two insurance company denials requiring appeals to the Oregon Attorney General and Oregon Division of Insurance Department of Consumer and Business Services.

How was it possible for a patient like me to slip through so many medical cracks? Welcome to Lyme disease, the #1 fastest growing epidemic in the nation and one of the most severe and complex conditions that has confounded scientists, doctors, medical societies and public health organizations since its discovery in 1975 in Lyme, CT, for which the disease was named.

SB 916 is written to enhance options for patients who are seeking diagnosis and treatment for Lyme disease in Oregon. Under Oregon’s current accepted medical guidelines, patients experience great difficulty with timely and accurate diagnosis. Like me, proper diagnosis, too often, comes in the late stage of the illness. Left untreated, or under-treated, afflicted patients suffer extremely incapacitating illnesses that ultimately 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 this disease and find a cure, it is ultimately good science that will lead the way. In truth, like the HIV Aids crisis of the 1980’s, the kind of good, decisive science is probably years away but too many Oregon patients are already suffering by being denied access to all acceptable treatment guidelines and modalities of care that are readily available.

One terrible statistical fact is that a meaningful number of people do not get better after Oregon’s current and very limited standard of treatment. Those prevented further treatment go on to develop chronic, disabling conditions that may last a lifetime. Because of Oregon’s severe limitations, patients have sought out and used other states’ guidelines not permitted to Oregon physicians, including those of ILADS, and have achieved levels of recovery 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, to receive the treatment of their choice. The bill that I am asking you to sign would allow practitioners to act in the best interest of the patient without fear of punishment from the professional discipline system.

As you decide upon your support for this bill, I ask that you please 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. Try to imagine a beautiful life that you worked so hard to make truncated in the prime of your life with so much more to offer. 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.

Elizabeth Aaroe