

**SB916 – SENATE HEARING – March 30, 2015**  
**3 MINUTE SPEECH – Elizabeth Aaroe**

Thank you for the opportunity to appear before you today in support of Senate Bill 916.

My name is Elizabeth Aaroe. I am a member of Oregon Lyme Disease Network and I applaud their years of hard work to bring this bill to your attention today and I thank the Committee on Health Care for sponsoring it.

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.

Summarizing my real life tragedy into three minutes of soundbites is impossible because I have spent the past seven years confronted with unimaginable, frightening, destructive, debilitating and incapacitating suffering. I went 4 years misdiagnosed and 5 years untreated. 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 duncani* aka WA-1 (named after the first man in WA state found with it). These insidious pathogens have stripped me of my once vital health, a 16-year marriage and the company I created with my husband, my ability to work, my longstanding corporate, community and collegiate Board service, my athletic pursuits, hobbies, executive functions, ability to travel, read a book, socialize with friends and very often walk, breathe, swallow, think and use my arms and hands well or easily.

As you are beginning to learn, 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 of the red blood cells. It is so similar to malaria that it is hard to distinguish between the two under a microscope without proper training. Upon infection, these tiny invaders cause *lysis* or a rupturing of your red blood cells. As the infection takes hold, the parasites reproduce rapidly and as your red blood cell depletion increases and your platelet counts lower, they begin to deprive you of oxygen -- which causes extreme debilitating fatigue, air hunger, chills, night sweats, bone marrow mast cell dysfunction, and vasculitis. It can be life threatening or even fatal causing hemolytic anemia, heart attack, renal failure and disseminated intravascular coagulation. Unlike its more common east coast strain, my *Babesia* 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 acute 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, particularly if misdiagnosed and able to widely disseminate and reach late stage, as in my case, CANNOT be accomplished under Oregon's current treatment guidelines and those used by and defended by the medical experts of 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 over a four year period, between 2008 and 2012, who even thought to think of Lyme disease even though I presented as a classic, textbook case.

What's worse, is that even after I was finally diagnosed through an initial Western Blot test by a leading neurologist in Philadelphia at one of the nation's best medical research hospitals, suspecting MS, and THEN by one of the top five leading Lyme disease doctors in the U.S., who had Lyme disease himself and who wrote one of the first definitive books on the disease, I could not find a single MD whether a PCP, a rheumatologist, an allergist/immunologist, or neurologist to help carry on my care here in Oregon or even be willing to shadow my care. 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 state. The entire state of Oregon.

I would then learn from published reports, direct patient experience and doctor knowledge as well as 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 either of two local Lyme treating ND's within 7 to 20 miles of my home for acupuncture, glutathione and related IV's, associated heavy metals chelation and infrared sauna therapies but my insurance company would only pay for 8 naturopathic visits a year, and NO coverage for any of the unapproved therapies, all of which are standard Lyme MD and ND treatment therapies for Lyme, leaving me with thousands of dollars in out of pocket expenses.

I could get my PCP who was 35 miles from my home to administer my weekly and then bi-weekly B12 and IM Bicillin 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 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 IV.

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 had ulcerated my entire esophageal z-line leaving me without any ongoing treatment at all, oral because I could not take it and IV because I was denied it.

I went 139 days WITHOUT proper treatment midway through my treatment, setting me up for the risk of antibiotic resistance or a relapse. I relapsed on Christmas day

From October 9, 2014 to January 2015, I appealed at the highest levels of to two replacement insurers and sent detailed complaints to the Oregon Attorney General and Oregon Division of Insurance. It would take 60 days after my emergency surgery 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 October 2011 from where I have yet to emerge, albeit on fewer but still the majority of days of the week. 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 but gradual 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.