March 24, 2015

To: Oregon State Senate

Committee On Health

Re: SB916 / Testimony Outline for March 30, 2015

From: John E. Bruce

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Introduction. John Bruce, resident of Medford, Oregon. Chronic Lyme Disease patient.
Wife: Lisa , (CPA) OSU; Children: Katie (ASU), Daniel (Texas Wesleyan U.)
Former high school teacher/coach; B.S. (Willamette U.), M.S. (University of Arizona)
Licensed secondary teacher (TSPC), endorsements in Social Studies, History, Physical Education, Health

Am here today to support SB916, without any amendments. I have LD and many of the tick-borne co-infections that commonly accompany it, including Bartonella, Anaplasma, Ehrlichia, and Protomyxzoa. All of these pathogens have been both serologically and clinically diagnosed. These diseases, headlined by LD, have critically devastated my health and livelihood, not to mention the impact on my wife and family.

I have coached college and high school baseball for over 38 yrs. This chosen profession has found me on the baseball field for countless springs and summers in over a dozen states and half a dozen countries. In 2008, while coaching in the New York summer collegiate league that I was infected. Knowing that New York was ground zero for LD I asked our team doctor what the odds were of being infected. He thought it might be in the 15-20% range. I knew that percentage was way too high and got an amoxicillin Rx for 10 days. Little did I know at the time that Abx for that short a period of time was not enough and if anything made future treatment more difficult.

Over the next 12-18 months the first of the chronic symptoms began to set in, extreme fatigue, headaches, and brain fog. This evolved later over time to include more than 30 other symptoms associated with neurologic and psychiatric LD. Chills and sweats, incomprehensible muscle pain and twitching, sleep disturbances, never ending headaches, tremors, optic neuritis, neuropathy, seizures, memory loss, and cognitive problems are my daily companions. The latest addition, diagnosed just last year by an MD in Medford is called ‘hyperacusis’, a severe sensitivity to sound. My ENT Dr in Medford referred me to a specialist who was at OHSU at the time. Dr. Marsha Johnson in Portland is one of the few ‘hyperacusis’ specialists in the country, and I am not the first ‘lymie’ that she has treated. She has even written a paper on Lyme caused Hyperacusis. Dr. Paul Auwaerter, clinical director of infectious diseases at Johns Hopkins University School of Medicine describes hyperacusis as “a bit like the old fashioned AM radios. When you turn the ‘gain’ button up you get more stations, but you get a lot more static, too.” Simple, everyday sounds are uncomfortable; crowd noise, lawn mowers, and loud music are outright painful.

By the winter of 2010-11 I had seen numerous specialists in the Rogue Valley, including cardiologists, neurologists, sleeps specialists, and other doctors in my primary care doctor’s clinic. My chronic symptoms had now made it impossible to teach school consistently. I needed a full time substitute for much of the last spring semester that I taught.(Over the previous two decades of teaching I had been sick an average of 1 ½ days per school year.) When a family member suggested that I might have LD in early 2011 some doctors scoffed at me and suggested I see a psychiatrist when I mentioned it to them. (Fortunately, my primary care doctor has kept an open mind and been supportive of me.) Unfortunately, most Lymies like myself have been ridiculed or put down by many in the medical profession. I have had two physician assistants dress me down in the course of normal chart updating when I informed them that I had LD. I have many educated family members, four with doctorates, including my sister in law, a respected Portland psychologist and professor. They will all concur that I indeed, am not a hypochondriac. Spring semester of 2011 was my last year of teaching full time.

Please do not misunderstand me. I respect the medical profession and all that they offer. However, I lose that respect for health care givers when they put down their patients and ridicule them. I do understand that few of them are experts on infectious disease and LD in particular. They have been given and trust the information that they have been taught, unfortunately at the expense of those who are really suffering. The doctor I have had the most respect for in my six year plus journey with LD is Dr. Jose Montoya, the head of the infectious disease department at Stanford University Medical Center. He told my wife and I that his profession has not been listening to their patients, and that after listening to my story, sincerely apologized to both of us, and that this non-listening posture of the medical profession was problematic and needed to be addressed nation-wide.

It was well in to my third year of symptoms that we discovered that not only were doctors not considering LD as a possible diagnosis, let alone treatment, but they were purposely unwilling as well. Even when I told them that I was infected in the 'hot-bed' state of New York, they would never follow up with any common sense response. When I called the office of the only infectious disease doctor in our area and explained to them that I thought I might have LD the staff person told me that I should go elsewhere because their doctor does treat LD, and it would be wasting my time. The point here is that real people…are really sick. We do not make this stuff up. We do not want to leave our jobs that we love. We do not want to pay thousands of dollars for treatment that insurance companies do not help out with. We do not want to destroy our family's finances and turn our homes into mini-infirmaries. We do not want to miss family get-togethers, anniversaries, birthdays, weddings, and memorial services. We do not want to travel thousands of miles every year to receive treatment in California of Washington because it's too difficult here in Oregon. And, we do not purposely dream up our hideous affliction to get attention; personally, I'd rather be in the classroom or on the ball field any day.

This difficult journey of mine and my family has taken us to numerous doctors and clinics in three states for both diagnosis and treatment. I am very thankful for the doctors who have identified Lyme Disease and its co-infectious and given me treatment. Two MDs and two NDs have been instrumental in getting me treatment in getting me back on the road to health. I have tried numerous antibiotic and other adjunct treatments over the past few years. Hopefully, I am on the road back to health. Was I not diagnosed as early as I could have been? Absolutely. Was I misdiagnosed at times? Yes. If I could have been diagnosed and treated earlier in my illness it is my opinion that I would not be nearly as chronically ill, and even possibly back to work. There is a lot to be said for early detection and early treatment for most diseases.

I personally know scores of real people in southern Oregon whose lives have been devastated by LD; a neighbor, a daughter in law of a friend, a mother of one of my former students, a mother of one of my former players, not to mention scores of acquaintances and friends through our LD support group. All of us need awareness and help from the medical community. Science and medicine are not static, treatments and the playing fields constantly change. What was thought to be relevant and accurate decades ago may not be today, i.e. prostate screenings, understandings of cholesterol and heart health.   Please listen to the following quotes: 1) “Lyme Disease is the new AIDS epidemic,” Jane Marke, MD; 2) A lot of people don’t know this but it’s (LD) a plague,” singer John Hall; 3) I hardly know anyone whose life, their own or family member, is not being impacted by LD”, actress Karen Allen. Thank you for supporting this bill, and just as important, thank you for supporting us who are ill and giving us a voice. And, thank you for helping to allow physicians to help us.