

Oral Testimony for SB916

2015- 78th Session of The House Committee on Health Care

Honorable Representatives and House Committee on Health Care,

Thank you for hearing us on SB916, we appreciate your time

My name is Theresa Denham, in 1991 my daughter was bit by a tick and my daughter became progressively sick over ten years. We saw over 18 specialty physicians. Before reaching her teen years she suffered crippling arthritis, congestive heart failure, multiple daily seizures, a TIA and many complications that caused her to be hospitalized. She was finally diagnosed with Lyme in the fall of 2001 with a LabCorp CDC positive test, but her diagnosis was quickly overturned by OHSU infectious disease, stating her test was false positive. He never saw or examined my daughter, and treatment was ever offered. The protocol allowed in Oregon didn't allow for her diagnosis and therefore, subsequent treatment. We were only able to get care outside of this state using ILADS protocols, and with this treatment she improved.

In Dec 2001 I began the Oregon Lyme Disease Network, as a mother of an infected child, networking with others to prevent similar suffering. We are now a patient advocate group with 5 statewide support groups -- because this disease has affected many more than ever imagined.

Fourteen years and over 1500 patients later (814 currently served by one of our 5 support groups) one irrefutable fact stands out:

Those patients who have the financial means to travel out of Oregon and receive ILADS care do significantly better than those who do not. I say significantly because those who receive ILADS care often become fully functional and symptom free, while the balance who receive care in the state-- degenerate to complete disability.

Triple Aim initiatives in OregonShareⁱ creates access to quality and reliable care, reduces cost and improves health, and since Lyme can cause chronic disease, we can meet Initiative Goal 2 in the Triple Aim if we can restructure how Oregon diagnoses and treats Lyme.

We have proposed that Oregon allow physicians to use any protocols created using Institute of Medicine (IOM) GRADEⁱⁱ, or National Guideline Clearinghouse Guidelines (NGC) criteria in the diagnosis and treatment of Lyme disease in Oregon. The Center of Disease Control (CDC) clearly acknowledges that the IOM GRADE criteria delivers unbiased, generally authoritative protocols developed with evidence-based, patient- centered outcome goalsⁱⁱⁱ. Currently International Lyme and Associated Disease (ILADS) protocols meet IOM Grade criteria, and Infectious Disease Society of America (IDSA) meets NGC criteria, therefore it is our belief that both should be considered without question for use in Oregon, with informed consent.

Confirmed cases of Lyme disease in 2013 were only 43. ***But this wildly underestimates the true incidence of Lyme disease in Oregon, with terrible consequences for our citizens.*** If we normalize CDC data against the Veterinary data available, we have evidence and reason to believe it is much higher, somewhere between 400 and 800 new cases per year. As president of OLDN, I hear the same story over

and over: when a patient requests a Lyme disease test after a tick bite he is often told ‘there is no Lyme in Oregon’. This leads to undiagnosed, late stage illness.

In a small survey of our Oregon patients, 70% of the 105 responding patients had progressed to chronic illness **prior to Lyme diagnosis**-- resulting in disability and apparently hopeless life sentences of neurological disease (MS, ALZ, Parkinson's) , Autism, Arthritis, Cardiac issues and more. The cost of these misdiagnoses would result in cost to the state around \$15k-\$60K per chronically ill person per year --until death.

But, in the case of misdiagnosed Lyme disease, when the patient is effectively treated, they can actually recover and return to productive and fulfilling lives. The average cost of treatment is roughly \$10,600 a year for 2-3 years. This is a fraction of the lifetime cost of their previously diagnosed illness.

I don't believe ignoring the consequences is an effective strategy and undiagnosed Lyme disease is budget busting. We need to consider that chronic illness is the highest burden on our health care system, and the top chronic conditions are arthritis, cardiac issues and neurological disabilities^{iv}, in many cases those symptoms have a marked correlation with Lyme disease. Hypothetically we could make considerable inroads to reducing the cost of chronic illness in this state^v if we considered a Lyme disease differential diagnosis before diagnosing these chronic conditions. Chronic illnesses accounted for \$1.4 million in hospitalization costs alone.

A national study of impact of chronic illness on employers, the government and the nation's economy placed Oregon's direct cost \$3.4 B per year, indirect costs of \$13.1 B in lost productivity, for a total costs at **\$16.5B per year**^{vi}. Additionally, Oregon needs to meet the 5-Year Health Promotion and Chronic Disease Prevention (HPCDP) plan. Reasonable improvements in preventing and managing chronic disease could reduce future economic costs of chronic disease in Oregon sharply, by 26% (\$14.0 billion) in 2023. A plan to proactively address Lyme disease would help our state considerably.

It is clear that the narrow and restrictive current standard in Oregon isn't working --costing the state hundreds of thousands

But --This isn't just about the unnecessary burden to the state in medical cost and lost productivity, It's about patients in Oregon who are suffering. I hope you will take time to hear the SB916 oral testimony in Granicus videos. They are highly impactful, and when this number of patients go out of state for medical care and recover, one must ask the question. Why is this treatment not available in Oregon, what can we do to create an environment where physicians and patient have access to care similar to those in California, Washington, and many other states around the USA..

Our organization did a series of surveys over the past ten years and we found:

- ▶ Patients in Oregon are sick for an average of 9.2 years and see an average of 6.5 specialty doctors prior to diagnosis of Lyme Disease.
- ▶ 70% of those patients were disabled prior to diagnosis of Lyme disease.
- ▶ 83% of patients with clinical symptoms & CDC positive tests were misdiagnosed originally by Oregon MDs and Nurses.

- ▶ 89% of our CDC positive patients with early clinical signs of Lyme disease were denied treatment and re-diagnosed in Oregon by neurology, rheumatology, infectious disease or psychiatric specialty physicians.
 - ▶ Of those, the ones who sought out of state care recovered to a QoL that allowed independence and removed them from disability.
- ▶ *Misdiagnosed patients often undergo expensive unnecessary tests for symptoms caused by Lyme disease (MRI, CT, Echocardiograms, Cardiac Catheterization)
- ▶ 80% of our patients report being ostracized by specialists-- infectious disease doctors, neurologists, and in some cases, their PCP MDs .
- ▶ Families are not only fighting for medical needs, but being harassed by the community that should be helping them.
- ▶ Additionally many begin self-medicating because they aren't getting help -- often turn to illicit drugs to control the pain, tremors, and other disabilities. This creates its own additional sets of burdens to both family and society. Many patients become drug free if they can get adequate treatment for treatment for the disease.
- ▶ A majority of the untreated but CDC positive Lyme patients who could afford to travel out-of-state saw ILADS MDs and got well.

Thank you for the opportunity to testify today and I am happy to answer any questions you may have.

References:

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http://www.healthshareoregon.org/pdfs/Health%20Share_CCO%20Transformation%20Plan%20Narrative%2003.08.2013.pdf

ii Grading of Recommendations Assessment, Development, and Evaluation
<http://www.gradeworkinggroup.org/intro.htm>

iii http://www.cdc.gov/od/science/quality/docs/trustworthy_gls.pdf

iv <https://public.health.oregon.gov/DiseasesConditions/ChronicDisease/Documents/healthor.pdf>

v http://www.chronicdiseaseimpact.com/state_sheet/OR.pdf

vi <http://www.milkeninstitute.org/publications/view/321>

*For the purpose of simplicity, I am going to refer to multitude of tick borne illnesses as " Lyme Disease".

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And

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