# Lyme Disease In Oregon

Testimony

2015- 78th Session of the Senate Committee on Health

SB916

SUMMARY Directs Oregon Medical Board and Oregon State Board of Nursing to adopt rules regarding diagnosis and treatment of Lyme disease. Declares emergency, effective on passage

Sponsored by COMMITTEE ON HEALTH CARE

(at the request of Oregon Lyme Disease Network)

Good afternoon and thank you senators for introducing SB916. We encourage you to move this bill to vote without amendment.

International Lyme and Associated Disease Society (ILADS) is the first organization to issue Guidelines on Lyme Disease using the IOM grade process, a process recognized by Cochrane Collaborations and World Health Organization (WHO);

It is difficult to understand why Oregon Medical Boards and Oregon Nursing Boards have not yet adopted ILADS guideline as a standard and acceptable protocol for the diagnosis and treatment of Lyme Disease, when in fact these two standards have existed for over 10 years and efficacy in using the guidelines has been shown.

Currently Oregon only uses guidelines developed by individuals with financial interests which create conflicts of interest*. We need to adopt all published standards of care available, making options available to patients and their Oregon MDs without fear of disciplinary action and ones with positive patient outcome a primary focus.

I don’t believe ignoring the consequences of using a narrow and restrictive guideline is an effective strategy. Undiagnosed Lyme disease is budget busting, and the direct and indirect cost to Medicare, Medicaid and families is crippling Oregon.

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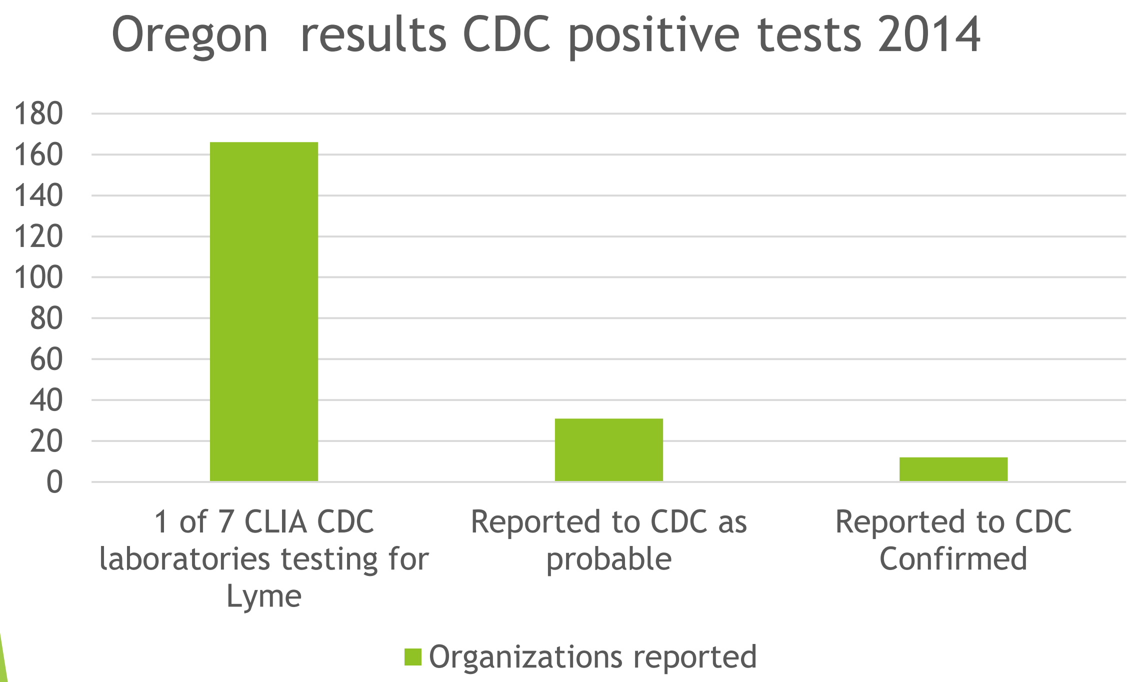
*see Conflict of interest PDF

- At 28 I began having neuropathies and was told by my primary care that I had MS. By 41 had very little strength in my arms and legs, and had neurocognitive and speech difficulties. I also had an array of other issues including recurrent kidney problems, cardiac problems, and poor liver function. At 41, I was diagnosed with Lyme Disease by an out-of state physicians. It took me two years to regain my health using ILADS standard of care guidelines, but today I am healthy with normal functions and tests. My previous diagnosis would have left me disabled and requiring disability, and unable to be productive and to raise three productive children.
- 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.
- 83% of patients with clinical symptoms were missed or misdiagnosed originally by Oregon MDs and Nurses. These patients had CDC positive results when tested by out-of-state physicians who recognized the symptoms.
- *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 .
- As a result of not getting medical needs met, many begin self-medicating -- 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.
- The patients who could afford to travel out-of-state and in many cases pay for their own care, showed improvement. They saw ILADS physicians who took their serious conditions seriously.

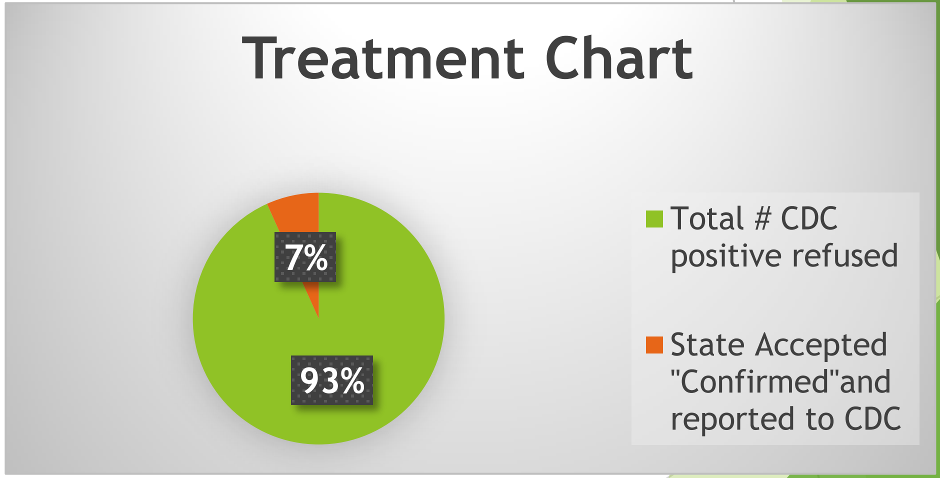
- **see slide 10 on pdf -- Avg MRI $1850, Avg CT $600, Avg Echo $2800, Avg Card Cath 7800*

**So why are patients ignored?**
*Guidelines guide how the state handles this serious illness --combined with reporting that is ineffective because doctors and health services are not recognizing the disease = no treatment.*

One CDC proficient CLIA laboratory reported to me **166 CDC positive Oregon Lyme** disease patients in 2014
Oregon Health Departments only reported **31 cases** to the CDC that same year. Of which **only 12 were "confirmed"**. That means **only 7% of the CDC positive patients** were given a diagnosis using the Oregon Standards. Sharon will share more about reporting issues.
We believe more physicians would be less fearful treat and report if ILADS guidelines were allowed in Oregon and they didn't fear disciplinary actions, and until cases are accurately reported, we won't know the true impact of tick borne illness in our state.

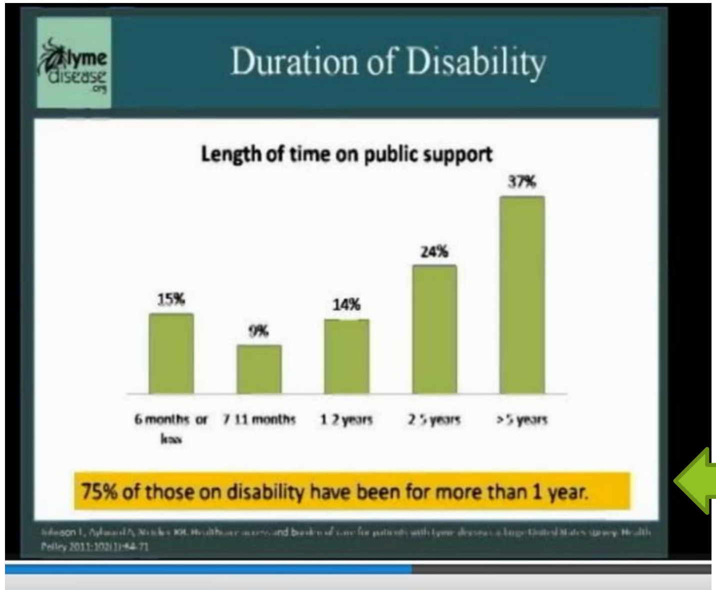


*http://www.cdc.gov/lyme/stats/chartstables/reportedcases_statelocality.html*



Is it safe to assume that since only 7% of the Oregon CDC positive patients in 2014 were reported, they also were the only ones to received treatment?

Prior to diagnosis, Lyme disease patients often have neurological, cardiac, skeletal , and depression issues which are followed generally as “chronic disease”. They also had lost wages and increased medical . So we need to look at the cost of Chronic illness and disability it creates.

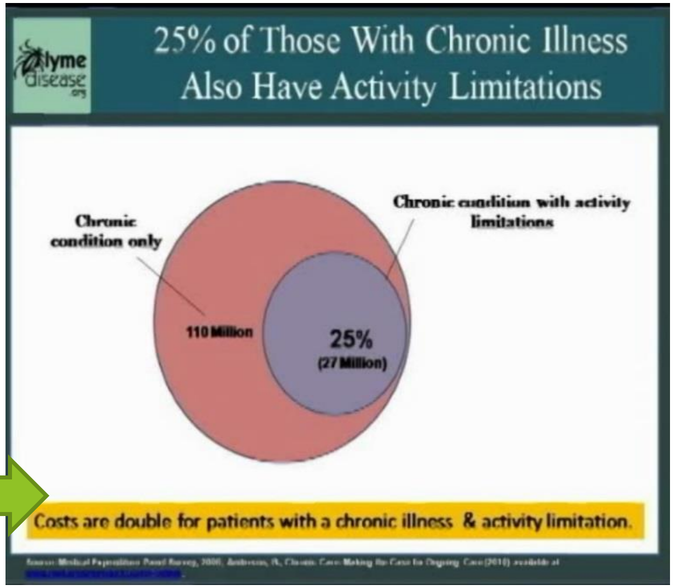


Duration of Disability

Length of time on public support

75% of those on disability have been for more than 1 year.

Result from nationwide Lyme survey on disability by Lorraine Johnson,
CALDA (CA Lyme disease association- lymedisease.org)



25% of Those With Chronic Illness Also Have Activity Limitations

Costs are double for patients with a chronic illness & activity limitation.

In Oregon chronic disease accounted for $1.4 million in hospitalization costs[4] alone ·

A national study to quantify the potential impact on employers, the government and the nation's economy.[2] placed Oregon's total costs at **$16.5B** *(included cost of treatment and lost productivity.)*
One needs to ask how many of these costs were associated with misdiagnosed chronic conditions that actually were undiagnosed, untreated Lyme disease. A bacterial illness that is treatable.

Imagine the potential impact if Lyme disease were differentially diagnosed and treated regularly in Oregon.

* 1,2 see pdf Lyme disease in Oregon

In fact 70% of the 105 surveyed patients progressed to chronic illness resulting in disability prior to their Lyme disease diagnosis. (often recovering after adequate treatment outlined by ILADS)

A considerable number of diagnosed chronic disease patients have been re-diagnosed with Lyme disease through clinical diagnosis and testing by out-of-state MDs and they are responding to treatment.

Let me be clear, we are talking about patients previously diagnosed with life sentences of neurological disease( MS, ALZ, Parkinson's) , Autism, Arthritis, Cardiac issues and more. Patients who have incurred thousands of dollars in costs trying to improve their health.

These patients when properly diagnosed and effectively treated became well at a fraction of the lifetime cost of their previously diagnosed illness. They also returned to productivity which offset social services costs, increased taxable income, and provided for happier healthier families.

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, Its about patients in Oregon who are suffering , and behind me you will hear about that suffering.

Science is emerging but if it's not getting recognized by Oregon Medical and Nursing Boards, we will continue to see gross losses.

We need to turn this around now
I urge you to adopt SB916 without amendment