

## ORAL TESTIMONY TO OREGON REPRESENTATIVES:

Thank you Oregon Representatives for hearing testimony for SB916.

My name is Sharon Lee. I have been sick with Lyme disease and four other tick-borne co-infections since 1978. I am currently the co-leader of a 200+ member support group called Southern Oregon Lyme Disease (SOLD) which is an affiliate of the Oregon Lyme Disease Network.

Lyme disease has been a nationally notifiable condition in the United States since 1991. To help monitor the spread and number of Lyme cases, the CDC put out what is called a surveillance case definition. It was based on the early findings, and hasn't changed since that time. The CDC supports their criteria even though many studies have demonstrated they miss from 50-75% of cases.

The CDC protocol requires the following:

- 1) Presence of a bull's eye (erythema migrans) rash;
- 2) A culture or a two-tiered testing protocol, and
- 3) Documentation of several symptoms indicating advanced disease

In contrast, the Oregon Department of Health confines confirmation to only two items:

- 1) A physician documented rash over 2 inches; and
- 2) A culture or a two-tiered testing protocol.

Nothing else is to be taken into account according to their guidelines! As a public health nurse who has followed numerous guidelines for other communicable disease surveillance, I have yet to see the language the Oregon Department of Health outlines for Lyme disease. It was hard for me to read the overtly flippant remark contained in the criteria thus, "*Reduced sensitivity (i.e., exclusion of some reports that seem real) is the inevitable result. **GET OVER IT.** Most reportable cases will be presumptive*".

I can see where these remarks, alone, could set the tone for public health officials to discount criteria to support a confirmed case. I strongly encourage a committee of state health policy makers, with input from the Oregon Lyme Disease Network, to review these Oregon criteria and guidelines for Lyme disease.

In addition to the faulty criteria, we found that not all cases reported in Oregon receive proper follow up by the ODH officials. In 2014, one CDC proficient CLIA lab (Igenex) reported 166 positive CDC test results for Lyme disease to the Oregon officials. But during that same year, only 31 cases were reported to the CDC. This is a huge discrepancy!

In another survey conducted by SOLD, 24 people met the criteria based on lab results alone, but only 4 were contacted by Oregon public health officials for follow up to see if they had a bull's eye rash. And none of the positive lab reports that were done by Igenex lab were ever followed up. Not one! No wonder physicians are telling their patients that there is no Lyme disease in Oregon. It is because cases are not confirmed by the Oregon Department of Health even when reported.

In conclusion, SOLD supports the rights of patients to be advised that there is more than one evidenced-based, medically recognized standard of care for Lyme disease, and that they have the right to participate in decisions pertaining to their (or their children's) medical care. SOLD strongly advocates for legislative leadership and investigation into the past and present Oregon Department of Health practices, which permit guidelines to overly influence Oregon health care policy on Lyme disease.