



Testimony for Oregon Senate Bill 916

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Victim of Lyme Disease 37 years
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Lyme Disease (SOLD) Support
Group

- Information about my 37 year struggle with Lyme disease
- Information about the Southern Oregon Lyme Disease support group
 - Includes survey results
- Information about how the CDC and Oregon Department of Health confirm & count Lyme cases

MY Written Testimony

9 Pages

Includes documentation of studies and links to reports



Oregon Department of Health Confirmation of Lyme Cases

Physician and Laboratory Reporting Requirements

- Physicians and other clinicians are required to report Lyme Disease cases within one working day of diagnosis to Oregon Department of Health (ODH) in their county.
- Labs are required to report positive test results to Oregon Public Health in the patients county of residence.
- County public health officials follow up on cases to confirm
- Each county's confirmed cases are reported to ODH who, in turn report them to CDC

Erythema Migrans (EM) Rash

- Often the rash is described as a “bulls eye”
- However, atypical forms of this rash are seen far more commonly
- No other disease has an EM rash
- Fewer than 50% of Lyme disease cases develop an EM rash
- Basic Information about Lyme Disease. By ILADS retrieved March 24, 2015 from <http://www.ilads.org/lyme/about-lyme>



Lyme Disease Case Definition

CDC—Confirmed Case

- A case of EM with a known exposure, **OR**
- A case of EM **with** laboratory evidence of infection and without a known exposure, **OR**
- A case with at least one late *Musculoskeletal, Nervous or Cardiovascular system* manifestations **with** laboratory evidence of infection.

ODH-Confirmed Case

- Physician-documented EM rash **and**
- Laboratory evidence of infection

Laboratory Evidence

- Culture
- Two-Tiered Lyme Test
 - Tier 1—ELISA
 - If negative—no Lyme disease
 - If positive, confirm with Western blot
 - Tier 2---Western Blot
 - Positive per CDC criteria
 - IgM-2 starred bands
 - IgG-5 starred bands

EM Rash and Two-Tiered Lyme Test

- Researchers from the CDC and New York Medical College report that 60% to 71% of Lyme disease patients presenting with an erythema migrans (EM) rash tested **negative** for the disease by the CDC's two-tier Lyme disease criteria.
- Molins, C. R., Ashton, L. V., Wormser, G. P., Hess, A. M., Delorey, M. J., Mahapatra, S., Schriefer, M. E., Belisle, J. T. (2015) Development of a metabolic biosignature for detection of early Lyme disease. *Clinical Infectious Diseases*, pii:civ185. [Epub ahead of print] Retrieved March 24, 2015 from <http://www.ncbi.nlm.nih.gov/pubmed/25761869>

Oregon Department of Health Guidelines for investigators

- The case definition for Lyme is restrictive and intended to enhance the specificity of surveillance data.
- Reduced sensitivity (i.e., exclusion of some reports that seem real) is the inevitable result.
- Get over it.
- Most reportable cases will be presumptive.
 - <http://public.health.oregon.gov/DiseasesConditions/CommunicableDisease/ReportingCommunicableDisease/ReportingGuidelines/Documents/lyme.pdf>

SOLD Survey Results

- 20 SOLD members had a positive Two-tiered test for Lyme disease
 - Only 4 were contacted for follow up by the ODH
- Not one member who had a positive Western blot from Igenex Lab was contacted for follow up.
- Of 24 SOLD members who had a positive blood culture for *Borrelia burdorferi*, not one was contacted by the ODH

Oregon Lyme Statistics

- 2010-2013
 - Only 33 confirmed cases of Lyme disease
- 2010-2015
 - Six Oregon support groups
 - 100-200 members in each
- One Southern Oregon Physician alone has over 150 Lyme patients!
- WHY ARE PEOPLE BEING TOLD OREGON HAS NO LYME DISEASE?
- WHY IS THE ODH NOT CONFIRMING CASES?

Please move SB916 to a Senate
Health Committee Vote
AS IS
with no amendments