

Oregon Lyme Disease Network
24780 Dodds Road,
Bend, OR 97701
541-410-2585
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Dear Chair of the Senate Committee on Health Care, Laura MonnesAnderson and the Senate Committee on Health

Thank you again for hearing from our patients as regards SB916. Today we tried to see the testimony provided by:

Board of Health
Nurse Association
Oregon Medical Association

We were only able to see one document provided by Anne Thomas of the Oregon Health Authority.

We were in general agreement with many of these associations on early Lyme Disease, however want to rebut that they discussed treatment of Early Simple Lyme Disease – they did not discuss or respond to early disseminated or late stage untreated illness, which this bill offers an answer to.

Additionally they did not respond to why they were closed to treatment beyond 28 days .

They did not answer with” NO “when asked if they know or have known of any MDs who have been harasses or limited by the boards.

Lastly, they have misinterpreted the language we believe this bill offers.

Issues we rebut from the Nursing Board, and Oregon Medical Association:

- A) The Oregon Medical Association is concerned our bill will restrict physicians. Our bill is allows FREEDOM of practice. SB916 clearly states that it PERMITS, it does not create a standard of care, it allows additional guidelines in diagnosis and treatment. (This is synonymous with the medical marijuana bill which allows (or permits) doctors to treat MS, pain, muscle spasm with marijuana without repercussion, in no way does it require that all pain, MS muscle spasms etc. be treated with that modality) . We refute the verbal twisting of the actual wording. However, to clarify things we authorize amendments reflecting any of the following:
 - a. To clarify the bill please see document submitted 5517 in the OIS
 - b. Allow amendment to make policy that any Lyme disease guidelines created approved IOM GRADE Criteria Guidelines or NGC standards be allowed without repercussion in the state of Oregon.
 - c. Allow amendment for physician protection who treat outside the current standard used in Oregon but remain consistent with guidelines created IOM GRADE criteria or NGC standards.

- B) Early Lyme disease is often missed because our state currently only includes a highly restrictive diagnostic standard (see Sharon Lees PowerPoint) which in turn creates a situation where patients are not diagnosed until later in the disease. Of paramount importance wording in that standard states if were not in an “endemic” area, no need to test. According to the Merck Manual and even 1997 and earlier CDC data Oregon WAS endemic. We changed the reporting standard which is why we are no longer “endemic”.
- C) Ms. Thomas, RN stated in verbal testimony that they don’t want any standard of care (SOC) because organizations break down and disappear. We are asking TO PERMIT not asking this be THE standard of care in the wording of our language.
- D) However, while Oregon doesn’t claim they have a SOC for Lyme disease, by de-facto they do. When the leading state Oregon Medical Assn stated “IDSA 2 weeks 28 days is the ‘gold standard’ and is the only evidence based guideline and the only guideline the CDC recognizes, they imply there is no other. In fact the other speaker a nursing board representative (whose name I do not have) stated they don’t diagnose Lyme Disease, their job is “to ensure compliance on treatment of Lyme disease” however if there are no SOCs and they refuse to allow information and evidence from ILADS in fact they do create a state recognized SOC.
- E) When the leading state IDSA experts the current standard used “is the only evidence based guideline” and the only guideline the CDC recognizes, they imply there is no other.
- a. False-- ILADS was accepted as the first Lyme disease guideline following the IOM GRADE criteria. Furthermore, the CDC recognizes that the IOM GRADE criteria guidelines (http://www.cdc.gov/od/science/quality/docs/trustworthy_gls.pdf) are evidence based, unbiased and generally perceived as authoritative.
- F) The IOM provides:
- Health component of the US National Academy of Sciences
 - Independent, non-profit, non-governmental organization
 - Aims to answer health- and healthcare-related questions posed by government and the private sector
 - Provides unbiased advice to health care decision makers and the public
 - Generally perceived as authoritative