



# *Lyme Disease Association, Inc.*

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March 31, 2015

**Testimony from: Lyme Disease Association, Inc.**

*a national non-profit raising funds for research, education, prevention, patient support*

To: Oregon Senate Committee on Health

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To: Chairman [Laurie Monnes Anderson](#) and Committee Members

At this time, your committee is considering Senate Bill 916, a worthy goal to help the public prevent future cases of chronic Lyme disease and to help those already afflicted. That goal is an integral part of the mission of the Lyme Disease Association, Inc. (LDA), designated by IRS as a public charity operating under 501(c)(3) non-profit status. (EIN # 22-3123551, Oregon Charities License # 31674), thus we support the passage of the Bill. LDA has associated groups across the country and has been partnering with groups in Oregon for a decade.

According to CDC, the incidence of Lyme surpassed the incidence of HIV in 2009<sup>i</sup>—only sexually transmitted diseases, salmonella, strep, fungal disease, and the flu had higher incidence rates. CDC also said in 2012 that Lyme was the 7<sup>th</sup> highest reportable disease<sup>ii</sup>

The Centers for Disease Control & Prevention (CDC) confirmed in 2013 that Lyme disease is underreported by a factor of 10 in the US, thus in 2013, 300,000 new cases of Lyme occurred in the US alone not the reported 30,000+. Cases have been reported in all 50 states at some time during the surveillance period 1990-through 2013. Additionally, Lyme disease is found in over 80 countries worldwide.

According to the last available official federal Centers for Disease Control & Prevention (CDC) annual case numbers, Oregon reported 43 new cases to the federal CDC in 2013 representing 430 cases which occurred in Oregon when underreporting is factored in. From 1990-2013, Oregon reported 465 cases of Lyme to the CDC, thus 4,650 cases occurred. Often in the Pacific Northwest, physicians do not even consider Lyme or other tick-borne diseases in their diagnostic workup, thus numbers are probably much higher.

Dogs are considered sentinels of Lyme disease. When dog cases are present and rise, human disease usually follows. The Companion Animal Parasite Council (CAPAC) reports that of 8,604 Oregon dogs tested in 2014 for Lyme disease and reported to CAPC, 1.45% were positive; as were 2.54% of dogs tested for *anaplasmosis*; and .93% for *ehrlichiosis*. That data is reported to CAPC from only two veterinary labs and comes from only about half of Oregon's counties, all in the Western portion of the state except one, and 12 counties had no reported data. Douglas, Josephine, Jackson, Deschutes, Clackamas, and Hood River are classed as high infection risk counties. According to CAPC, the data it collects represents less than 30% of the activity in the geographic region covered by the data reported. <http://www.capcvet.org/parasite-prevalence-maps/>

Early intervention and appropriate treatment are the answers for patients with Lyme to prevent the development of chronic Lyme disease, aka, post treatment Lyme disease, late disseminated Lyme, etc.

According to a Columbia University Lyme study, based upon 10-fold underreporting and on 10% of newly infected and treated patients developing symptoms that persist for more than 6 months, “the actual incidence of new chronic cases (PTLS) is...30,000” annually <sup>iii</sup>— many of them children, who often miss months/years of school and have their childhood destroyed. Showering, walking, talking, thinking can be a problem, and serious pain is a daily challenge. Children are at the highest risk of acquiring Lyme disease, and based on CDC’s Lyme reported cases numbers from 2001-2010 by age, LDA estimates that 37% of reported US cases were children, ages 0-18. <sup>iv</sup> Additionally, *Borrelia burgdorferi*, the spirochete that causes Lyme, has the ability to cross the placenta and cause birth defects or death of the fetus.

Lyme disease can attack every system in the body, and there is considerable research still necessary to understand the mechanisms of the disease. It is imperative that licensed medical professionals have the ability to treat patients in every case based upon their clinical judgment. This bill permits physicians to make choices from published guidelines that address patients who remain symptomatic after a few week course of treatment. This will broaden patient access to care and protect physicians and nurses who are helping patients maintain their health, keep their jobs, attend school, avoid financial ruin and in short, have a life despite having an often debilitating disease.

This bill will put Oregon doctors ahead of the spread of not only Lyme but other tick-borne diseases which are marching across the country. LDA just updated its LymeR Primer brochure which had 7 tick-borne diseases in its last rewrite and now has 15 including 364D rickettsiosis transmitted by *Dermacentor occidentalis* (Pacific Coast tick) found in Oregon and in California (it is the most common tick throughout that state). That tick also transmits RMSF and tularemia and has produced tick paralysis in cattle.

[Tickcounter](#)

Oregon is not alone in its foresight to ensure good patient care for those with Lyme and other tick-borne diseases. Other states such as Rhode Island, Connecticut, Massachusetts, New York, and California have passed some form of legislation that permits doctors to diagnose and treat patients in a manner consistent with the patient’s Lyme disease and based on clinical diagnosis and evidenced-based medicine which can be found in guidelines such as those from ILADS. [Lyme Disease Association State Legislation Chart](#)

Oregon’s relatively low Lyme numbers now may not remain that way. The newly published study in the science journal PLOS one (2-25-15) is one of the first to focus on birds as hosts for *Ixodes pacificus* ticks and as potential reservoirs of the Lyme disease spirochete, *B. burgdorferi ss*, in the far-western US. 623 birds from Northern California representing 53 species were examined by scientists who found the birds had a total of 284 *Ixodes pacificus* ticks on them. From the study: “Our findings underscore the importance of bird behavior to explain local tick infestation and *Borrelia* infection in these animals, and suggest the potential for bird-mediated geographic spread of vector ticks and spirochetes in the far-western United States.” In light of these findings, the implications for the spread of Lyme disease by birds to/ within the state of Oregon in the near future could be significant.

On behalf of Lyme patients in Oregon, I thank you for your efforts. Please pass the bill unamended. If the LDA can be of further assistance, do not hesitate to contact me.



Patricia V. Smith  
President

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<sup>i</sup> MMWR May 13, 2011 / 58(53);1-100

<sup>ii</sup> CDC website <http://www.cdc.gov/lyme/stats/>

<sup>iii</sup> *The Journal of Neuropsychiatry & Clinical Neurosciences*, 2013, Batheja S., "Post Treatment Lyme Syndrome & Central Sensitization"

<sup>iv</sup> From [www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org)

429,851 reported CDC cases from 1990-2011; 37% x 429, 851 = 159,044.87 reported from children 0-18 '90-'11; 10x= 1,590,448.7 actual children developing new LDA over that period that met CDC criteria

**ABOUT THE LYME DISEASE ASSOCIATION (LDA):** An all-volunteer national nonprofit 501(c)(3), dedicated to Lyme disease education, prevention, research, and patient support. LDA has been accepted into the Combined Federal Campaign 2014 as an approved national charity for Federal Workplace Giving. It's a [Guidestar.org](http://Guidestar.org) exchange gold level member, recognized for transparency and is an Environmental Protection Agency PESP Partner. LDA offers its LymeAid 4 Kids assistance program, which has given out \$250,000 for children to help with diagnosis and treatment for Lyme. LDA has awarded 98 research grants—its funded research has been published in 35 scientific journals and LDA helped fund the endowed research center at Columbia University in NY. LDA has provided 15 annual Continuing Medical Education Lyme & Other Tick-Borne Diseases conferences for physicians and researchers. It has awarded 102 educational grants resulting in publications, conferences, seminars and awareness activities. It has provided testimony on Lyme disease before two different US House Committees in Washington, DC.

[www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org)