



# *Lyme Disease Association, Inc.*

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March 16, 2015

Diane Steward, Committee Clerk  
Legislative Information Office  
100 State House Station  
Augusta, ME 04333

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

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

**To: Committee On Labor, Commerce, Research and Economic Development (3-17-15)**

To Chairs: Senator Amy Volk and Representative Erin Herbig

At this time, your committee is considering “An Act To Improve Access to Treatments for Lyme Disease,” 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, Maine Charities License # CO3875), thus we support the passage of the Act.

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, and 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, Maine reported 1,373 cases to the federal CDC in 2013, almost 4% of the US case totals, representing 13,730 cases which occurred in Maine. In 2013, Vermont (107.6), New Hampshire (100.0), and Maine (84.8) ranked 1,2,3, respectively, in the US in incidence of Lyme: cases per 100,000 of population.

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

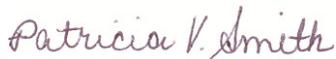
newly infected and treated patients developing symptoms that persist for more than 6 months, “the actual incidence of new chronic cases (PTLS) is...30,000” annually

<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 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 provides necessary provisos that will improve patient access to care and protect physicians 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.

If the LDA can be of further assistance, do not hesitate to contact me.

Sincerely,



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://www.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)