

S.1657, The Tick Act – LDA Letter to Committee on Health, Education, Welfare & Pensions

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DC – Written Testimony, US House Global Health & Human Rights Committee

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& Human Rights Committee](#)

House Committee on Foreign Affairs, Subcommittee on Africa,
Global Health, & Human Rights, July 17, 2012

by Patricia V. Smith, President, Lyme Disease Association,
Inc.

Mt. Equinox, VT – 2016 Gear Up For Lyme Bike Climb

Remarks of Pat Smith, President, Lyme Disease Association, Gear Up for Lyme (VT) 2016

Welcome & thanks to all of you who organized, participated, or supported the bikers in this race today and in the past 11 races, since the first in 2004. From 2004-2014, the Manchester Rotary has raised a total of more than \$71,000 for the LDA for its Lyme disease research programs.

The Manchester Rotary recognized the significance of Lyme in 2004, when only 50 cases were reported from Vermont by the Centers for Disease Control & Prevention (CDC). In 2014, 599 cases were reported, which ranked Vermont #13 nationwide in case numbers. CDC says only 10% of cases are reported, so VT had about 6,000 cases in 2014.

The US total was 33,461 cases, times 10, 334,000+ cases. We have to wait for the official CDC 2015 numbers in about 2 weeks to see if the upward trend continues in VT and nationwide. For the 10 year period from 2005-2014, Vermont ranked # 2 in the US in Lyme disease incidence with 70.5 cases/100,000 population. (Overall US 2014 incidence is 7.9). LDA reports that 30% of Lyme cases are children 0-19 years old.

The Rotary raises both awareness & funds for Lyme by holding this benefit each year. LDA has used those monies to help fund research projects including one supported right here in VT at Lyndon State College, research published in the 2013 journal, Northeastern Naturalist. Dr. Alan Geise & others found *B. burgdorferi*, the bacteria that causes Lyme, in 8.9% of adult black-legged ticks they collected along the CT River in VT. The LDA has also used the monies for research coast-to-coast

including for the Columbia Lyme & Tick-Borne Diseases Research Center in NY, a center partially endowed by LDA, which focuses on chronic Lyme disease. We have provided millions of dollars trying to move the field of Lyme & tick-borne diseases forward and research we supported has been published in 39 peer-reviewed journals to date.

The LDA has many other programs including its annual Lyme & Tick-Borne Diseases continuing medical education conferences for physicians and researchers for which the public is also invited to register, jointly provided by Columbia University. This year, it's being held October 15, 16 in St. Paul Minnesota. It features current research that could alter the field. The Keynote speaker, Dr. Moir from Harvard will present his breaking results on Beta Amyloid, Alzheimer's and Lyme Disease. This will be followed by a talk by Dr. Miklossy, International Alzheimer Research Center, reviewing evidence suggesting a link between spirochetal infection and Alzheimer's disease.

The current Lyme tests are highly inaccurate, but new technologies (proteomics and nanotechnology) for improved Lyme tests has led to development of a nanotrap, presented by Dr. Luchini, George Mason University. A new species of *Borrelia* was recently discovered to cause Lyme in the US; this will be discussed by Dr. Pritt from the Mayo Clinic. Dr. Zhang from Johns Hopkins will discuss new in vitro antibiotic strategies to eradicate "*Borrelia* persists," that offer promise for more effective interventions for human Lyme disease. Dr. Aucott from Hopkins will present new findings regarding the human immune response in Lyme disease.

In the area of prevention, a novel mouse vaccine under development will be discussed by Dr. Zatechka, US BIOLOGIC. Work so new it is generating discussions from scientists around the world on the impact it might have on ecology in general will be presented by Dr. Esvelt, from MIT Sculpting Evolution Lab, his talk will address Community-Guided

Ecological Immunization to Prevent Tick-Borne Disease using CRISPR technology. Other speakers will address other tick-borne diseases, neurologic, arthritic and cardiac Lyme disease, and the spread of the ticks that transmit Lyme to ~50% of the counties in the US.

Last year, the International Lyme & Associated Diseases Society, ILADS, doctors who believe in and treat chronic Lyme, published in peer review their new long-awaited clinical guidelines for treating chronic Lyme disease. Those have been published on the federal government's National Guidelines Clearing House. They allow for long-term antibiotic Lyme treatment, if necessary. So today, please help us celebrate these hard fought victories for Lyme patients by helping yourselves remain physically fit and at the same time, raising funds for Lyme disease research. Thanks to the Rotary and its President Susan Howard, and to all of you from the LDA and the Lyme Community.

MA – Joint Committee on Financial Services

IRS EIN # 22-3123551 / Massachusetts exempt # 223-123-551

**10/20/15 Testimony to Massachusetts Joint Committee on Financial Services
(H901/S502)**

From Patricia V. Smith President, Lyme Disease Association, Inc. (LDA)

Thank you, Chairmen Eldridge & Michlewitz and Committee Members,

I have been invited to testify on Lyme in Massachusetts (MA) several times over the years, and I am glad to be back here again today to help a growing number of Lyme

patients in the state. In 1990, the Centers for Disease Control & Prevention (CDC) reported 117 Lyme cases from the Commonwealth of MA, which did not rank in the top 10 US states in reported case numbers. In 2014, CDC reported 5,304 Lyme cases from MA (*MMWR, 2014 Final 2014 Reports of Nationally Notifiable Infectious Diseases, 9-18-15*), which ranked number two nationwide, representing 16% of the US total number of Lyme case reports (33,461). Based on CDC's report of 10-fold underreporting of Lyme cases, MA likely had 53,040 new cases in 2014. Case numbers and the range of Lyme are increasing worldwide, with Lyme found in 80 countries.

My three plus decades of work as a Lyme advocate, including 18+ years as president of the all-volunteer run national non-profit Lyme Disease Association (LDA), have kept me in close contact with patients nationally. The political nature of Lyme and lack of recognition by some in the medical community and insurance companies have exacerbated the plight of patients and their families, many of which contain more than one Lyme victim. Medical bills rise; jobs are lost; education is interrupted. Divorce is not an uncommon result in these families, further complicating the picture. Often, these families are forced to seek government help, government which is already burdened with more debt than it is able to handle.

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, post treatment Lyme syndrome (PTLS), post treatment Lyme disease syndrome (PTLDS), 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." (*The Journal of Neuropsychiatry & Clinical Neurosciences, 2013, Batheja S., "Post Treatment Lyme Syndrome & Central Sensitization"*)

According to a "Database of 47 million persons enrolled in a wide range of US commercial health insurance plans, with 547,993 potential Lyme disease cases and 52,795 analyzed...Over 63% of the treated Lyme disease cases had at least one diagnosis associated with post-treatment Lyme disease syndrome(PTLDS)... Lyme disease and the ongoing symptoms that may occur after initial antibiotic treatment represent a significant source of health care utilization and costs. " (*Adrion, et al. Health care costs, utilization & patterns of care following Lyme disease. PLoS One. 2/4/15*)

Children have always been at highest risk of acquiring Lyme disease. Based on CDC's

Lyme reported cases numbers by age from 2001-10, LDA calculated that approximately 37% of reported cases in the US are children 0-18. Based on 1990-2015 CDC numbers adjusted for 10-fold underreporting, it follows that 1,962,665 children have developed Lyme disease. Many more children are probably not included in that figure because they did not meet strict CDC surveillance criteria— children who often go on to develop chronic Lyme disease—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.

As indicated, children with chronic Lyme frequently miss long periods of school and require home instruction (HI). MA law says students are eligible for HI after 14 school days. Also, students with chronic illnesses who have recurring home/hospital stays of less than 14 consecutive school days, when such recurrences have added up to or are expected to add up to more than 14 school days in a school year, are also eligible. Additionally, if a student has an IEP and will be out for more than sixty school days in any school year, the Administrator of Special Education is required as soon as possible to convene a team meeting to consider evaluation needs and, if appropriate, to amend the existing IEP or develop a new IEP suited to the student's unique circumstances. (MA 603 CMR 28.03(3)(c), 28.04(4) http://www.doe.mass.edu/pqa/ta/hhep_qa.html)

Pertaining to length of HI for children with Lyme, here are results of a 1992 CDC and NJ Department of Health study of NJ school children with Lyme. Of the 64 students studied, CDC found the median duration of Lyme at time of interview was 363 days; the median number of days the illness was said to have significantly affected normal activities was 293 days; the mean number of total school days lost was 140; **“the mean duration of home instruction, was 153 days...”** Only 26% of children under study were said to have fully recovered.

For the 90-91, 91-92 school years, five NJ school districts provided a total of 7,011 HI hours for students with Lyme. The HI cost, counting only the hourly salary of tutors, was \$132,199– \$231,315.25 in 2015 dollars. (US Bureau of Labor Statistics CPI adjustor).

In my school district during my terms as a board member (Wall Township NJ), HI costs rose 88% over one year due to students with Lyme; my own daughter was one of them (out 4 full years, 2 partial years). *(From a study I conducted of 9 NJ school districts in 2 counties in 1992 and presented to CDC & NIH in Washington, which*

directly led to CDC performing its own study, referenced above, later that year).

A 1998 Columbia University study documents improvement in IQ of 22 points in a 16 year-old after IV treatment for Lyme disease. (*Psychiatric Clinics of North America, 1998, Brian Fallon, MD, "The Underdiagnosis of Neuropsychiatric Lyme Disease in Children & Adults"*)

To help remedy the plight of children, the LDA provides grants to families without insurance coverage for Lyme to get their children diagnosed or treated. Since inception, LDA's LymeAid 4 Kids program has awarded \$260,000, with 9% of those grants (2004-2014) going to Massachusetts' children.

To support physician education, LDA is partnering with Columbia University to present its 16th Lyme & Other Tick-Borne Diseases Continuing Medical Education (CME) Conference for physicians & researchers in RI on Nov.14 & 15, with a conference faculty of 20 including one from CDC and one from the UK.

One of the most promising treatment topics, persisters, is being addressed by two world renowned researchers and could explain how Lyme becomes chronic and how to treat it. A Johns Hopkins study, Published in *Emerging Microbes and Infections*, focuses on ranking antibiotics which are most effective against persisters *in vitro*. "Our findings may have implications for the development of a more effective treatment for Lyme disease and for the relief of long-term symptoms that afflict some patients." In a press release (6/1/15) on a study in *Antimicrobial Agents and Chemotherapy*, Northeastern University Distinguished Professor Kim Lewis states, "It hasn't been entirely clear why it's difficult to treat the [Lyme] pathogen with antibiotics since there has been **no resistance reported for the causative agent of the [Lyme] disease.**"[emphasis added] The release indicates persister cells are drug tolerant, dormant variants of regular cells. Lewis proposes a pulse-dosing regimen of antibiotics.

These new avenues of research will lead to novel approaches to treating Lyme disease with antibiotics, reinforcing the need for passage of H901/S502, which will permit patients to be reimbursed for these new therapies when they become available.

Please pass these bills which will provide insurance coverage for Lyme treatment which could lessen the suffering of patients and help prevent the development of chronic Lyme. Preventing chronic Lyme can lead to people living more productive lives, holding jobs, and in the case of children, being able to be in school to

maximize learning, prevent development of mental health issues due to the isolation of students on home instruction, and avoid substantial home instruction-related costs. Thank you.

OR – Senate Committee on Health

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**
derek.sennes@state.or.us

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⁽¹⁾—only sexually transmitted diseases, salmonella, strep, fungal disease, and the flu had higher incidence rates. CDC also said in 2012 that Lyme was the 7th highest reportable disease⁽¹⁾

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 ^[111]— 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. ^[14] 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. [Tickencounter](#)

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

[i] MMWR May 13, 2011 / 58(53);1-100

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

[iii] *The Journal of Neuropsychiatry & Clinical Neurosciences*, 2013, Batheja S.,
“Post Treatment Lyme Syndrome & Central Sensitization”

[iv] From 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

LDA Position on FDA Laboratory Developed Test Guidance Proposal

The Lyme Disease Association, Inc. (LDA) formulated a response to FDA to be included in its comment period on its testing Guidance which will affect specialty lab Lyme tests. Groups who wanted to support the position taken by the LDA were able to join in on the letter. **Letter was submitted with 73 groups signed on.**

[Click here for LDA letter to FDA](#)

BRIEF HISTORY: FDA is moving forward in the process of finalizing its new Laboratory Developed Test (LDT) Guidance proposal. The proposal would move LDTs from under the jurisdiction of Clinical Laboratory Improvement Amendment (CLIA) regulated by Medicare & Medicaid Services to under the jurisdiction of the Food & Drug

Administration (FDA). The FDA now regulates non-LDT lab tests under “medical devices,” and “approves” or “clears” tests. Non LDTs are tests which are sold to other laboratories while LDTs are generally tests which are developed and used in one lab, commonly called specialty labs.

Click below for LDA article

[FDA Moves to Regulate All Lyme Tests](#)

LDA Position on Amendment in the Nature of a Substitute to HR 4701

The LDA requested Lyme leaders to sign on to a letter against the Amendment in the Nature of a Substitute to HR 4701. Letter with signups was sent 7/7/14 to Energy & Commerce with this note: “Attached please find a letter stating the position of 154 groups from over 35 states across the US opposing the Lyme disease legislation, ‘Amendment in the Nature of a Substitute to HR 4701’ that was passed through the Energy & Commerce Health Subcommittee on June 19, 2014. This information was collected over an approximate three-day period over the July 4 holiday weekend. We look forward to your response. Thank you.”

As a result of the letter, the bill sponsor, working with LDA and others, was successful in obtaining language that accomplished the goals of having patients at the table with a working group that operates in a transparent fashion. It also includes “chronic or persistent infection and co-infections” language. (Go to top of page to see new version.)

[Click here for LDA letter to Energy & Commerce](#)

Bill History

[Link to Bill History](#)

[House E & C Committee Passes Lyme Bill , HR 4701, July 23, 2014 version](#)

[Victory in the US House of Representatives: Lyme bill, HR 4701 – “Vector-Borne Disease Research Accountability and Transparency Act of 2014”](#)

ME – Committee On Labor, Commerce, Research and Economic Development

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 # C03875), thus we support the passage of the Act.

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

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" annuallyⁱⁱⁱ— 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. ^{iv} 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

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

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

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

iv From www.LymeDiseaseAssociation.org

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

CT – Joint Committee on Children

January 27, 2015

Connecticut General Assembly

Joint Committee on Children

State Capitol
Hartford, CT 06106

Dear Chairman and Committee Members,

I am writing on behalf of the Lyme Disease Association, Inc., (LDA) a national non profit which partners with groups in Connecticut and supports research in Connecticut (see ABOUT LDA below), to support the passage of Senate Raised bill 207.

The incidence of Lyme and other tick-borne diseases is on the rise, with the Centers for Disease Control & Prevention (CDC) indicating 300,000 new cases of Lyme being reported nationwide, meaning only about 10% of cases are reported. From 1990 through 2013, Connecticut reported 61,783 Lyme cases to the CDC—thus about 617,830 new cases of Lyme developed over that period in Connecticut. [\[1\]](#) That figure represents 12.4% of all US reported cases over that time.

Based on CDC's Lyme reported cases numbers from 2001-2010 by age in the US, the LDA estimates that 37% of reported cases were children ages 0-18. Children ages 5-9 & 10-14 are at the highest risk of acquiring Lyme.

According to CDC, the incidence of Lyme surpassed the incidence of HIV in 2009 [\[2\]](#)—only sexually transmitted diseases, salmonella, strep, fungal disease, and the flu had higher incidence rates. CDC also said in 2012 that Lyme was the 7th highest reportable disease [\[3\]](#)

The Companion Animal Council indicates that in Connecticut, it received reports of 76,869 dogs tested in 2014 for Lyme, of which 12,510 (16.27%) were positive, 1 out of 6 dogs. This figure represents 6.4% of US dogs who tested positive that year. [\[4\]](#)

Deer ticks carry/transmit a number of disease agents in addition to *Borrelia burgdorferi*, the agent of Lyme disease, including *Babesia*, *Anaplasma*, *Ehrlichia* (muris-like), *Bartonella*, *Tularemia*, *Borrelia miyamotoi*, and Powassan virus. Powassan cases have increased in the Northeast in recent years, and there is no cure for the disease, which is why the LDA awarded a 2014 grant to a researcher to study tick-borne viruses such as Powassan. Deer ticks can even transmit tick paralysis toxin—the related paralysis can only be stopped by finding the attached tick and removing it.

Tick attachment time is important. The longer the tick is attached, the greater the

risk of Lyme infection. Although some scientists have said it takes up to 24 hours to transmit the Lyme spirochete, Dr. Willy Burgdorfer, after whom the Lyme bacteria is named, said as early as 1999 at LDA's Lyme and tick-borne diseases scientific conference at Bard College, NY and in the peer reviewed journal *Acta*, that there is no such thing as a safety period; about 5-10% of [infected] ticks carry Lyme bacteria in their saliva & can transmit the disease as soon as they bite.

Since evidence shows that early diagnosis and appropriate treatment can prevent treatment failure causing chronic Lyme, aka, post treatment Lyme, preventing tick attachment or finding and removing an attached tick is critical to preventing long term symptoms of the disease. According to a Columbia University Lyme study,^[5] 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]. "

For these and many other reasons, it is necessary for the Connecticut General Assembly to pass this important bill which would provide funding for Lyme disease prevention programs in Connecticut and funding to develop and implement a regional community prevention program for Lyme disease and other tick-borne illnesses utilizing the BLAST Lyme disease prevention program model.

Thank you.

Sincerely,

Patricia V. Smith

President

^[1] LDA maps of Lyme cases reported to CDC
<http://module.lymediseaseassociation.net/Maps/> (click state for details)

^[2] MMWR May 13, 2011 / 58(53);1-100

^[3] CDC website <http://www.cdc.gov/lyme/stats/>

^[4] <http://www.cpcvet.org/parasite-prevalence-maps/>

[\[5\]](#) *The Journal of Neuropsychiatry & Clinical Neurosciences*, 2013, Batheja S., et al
“Post Treatment Lyme Syndrome & Central Sensitization”

NH – Exec. Depts. & Admin. Committee

January 27, 2015

New Hampshire House of Representatives
Executive Departments & Administration Committee
107 North Main Street, Concord, New Hampshire, 03301

Dear Chairman and Committee Members,

I am writing on behalf of the Lyme Disease Association, Inc., (LDA) a national non profit to support the passage of HB 0363, sponsor Rep. Pamela Brown. The LDA partners with groups across the US including groups in New Hampshire.

The incidence of Lyme and other tick-borne diseases is on the rise, with the Centers for Disease Control & Prevention (CDC) indicating 300,000 new cases of Lyme being reported nationwide, meaning only about 10% of cases are reported. From 1990 through 2013, New Hampshire reported 11,776 Lyme cases to the CDC—thus about 117,760 new cases of Lyme developed over that period in New Hampshire.¹ That figure includes 1,687 cases alone in 2013 reported from New Hampshire, which ranked the state number 8 in reported Lyme cases that year and second in incidence.

Based on CDC's Lyme reported cases numbers from 2001-2010 by age in the US, the LDA estimates that 37% of reported cases were children ages 0-18. Children ages 5-9 & 10-14 are at the highest risk of acquiring Lyme. According to CDC, the incidence of Lyme surpassed the incidence of HIV in 2009² only sexually transmitted diseases, salmonella, strep, fungal disease, and the flu had higher incidence rates. CDC also said in 2012 that Lyme was the 7th highest reportable disease.³

The Companion Animal Council maps indicate for 2014 data for New Hampshire, 53,328 dogs were tested for Lyme, 7,780 of which (14.58%) were positive, 1 out of 7 dogs. This figure represents 3.98% of US dogs who tested positive.⁴ Other tick-borne diseases are on the rise in dogs too, 8.7% of NH dogs tested positive for anaplasmosis and 1.64% for ehrlichiosis.

Deer ticks carry/transmit a number of disease agents in addition to *Borrelia burgdorferi*, the agent of Lyme disease, including *Babesia*, *Anaplasma*, *Ehrlichia* (muris-like), *Bartonella*, *Tularemia*, *Borrelia miyamotoi*, and Powassan virus. Powassan cases have increased in the Northeast in recent years, and there is no cure for the disease, which is why the LDA awarded a 2014 grant to a researcher to study tick-borne viruses such as Powassan. Deer ticks can even transmit tick paralysis toxin the related paralysis can only be stopped by finding the attached tick and removing it.

To stop the transmission of Lyme disease, tick attachment time is important. The longer the tick is attached, the greater the risk of Lyme infection. Although some scientists have said it takes up to 24 hours to transmit the Lyme spirochete, Dr. Willy Burgdorfer, after whom the Lyme bacteria is named, said as early as 1999 at LDA's Lyme and tick-borne diseases scientific conference at Bard College, NY and in the peer reviewed journal *Acta*, that there is no such thing as a safety period; about 5-10% of [infected] ticks carry Lyme bacteria in their saliva & can transmit the disease as soon as they bite.

Besides the deer tick, other ticks can now transmit serious diseases to humans and animals in New Hampshire including the American dog tick and less often, the lone star tick.

Another tick, the winter tick, which does not transmit Lyme and feeds on moose, is wreaking havoc on the moose population in New Hampshire. A study begun in 2001 through the NH Department of Fish & Game indicated moose carry about 35,000 ticks

but can have as many as 160,000. The ticks suck so much blood they become anemic and are unable to survive the winter. The moose scrape themselves on trees to get rid of ticks, scraping away their dark coats, becoming so called "ghost moose" in the spring. In 1992, 20% of the herd had some hair scraped off, now close to 100% have hair scraped off. 41% of deaths of NH moose over 5 years have been said to be from these winter ticks.

Lyme disease if diagnosed early and appropriately treated will less likely result in chronic Lyme, aka, post treatment Lyme, so preventing tick attachment or finding and removing an attached tick quickly is critical to preventing long term symptoms of the disease. According to a Columbia University Lyme study,⁵ 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]. "

For these and many other reasons, it is necessary for the House to pass this important bill which would provide May Lyme Disease Awareness month for New Hampshire, thus raising the profile of the disease, so that residents can take the proper precautions to prevent tick bites, or if bitten, understand how to properly remove ticks and know to seek immediate medical care to prevent long term symptoms if they do develop the disease.

Also, the addition of the International Lyme & Associated Diseases Society (ILADS) Lyme & Tick-Borne Diseases Guidelines published in 2014 as information which is promulgated in the State and on the State website is necessary as there are two standards of care for Lyme disease recognized in peer review. It is essential that doctors have the ability to practice medicine that is based on what is best for their patients from those standards and that patients also are provided with the current standards to help make their treatment choice.

Thank you.

Sincerely,

Patricia V. Smith
President

1 LDA maps of Lyme cases reported to CDC

<http://module.lymediseaseassociation.net/Maps/> (click state for details)

2 MMWR May 13, 2011 / 58(53);1-100

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

4 <http://www.capcvet.org/parasite-prevalence-maps/>

5 The Journal of Neuropsychiatry & Clinical Neurosciences, 2013, Batheja S., et al

“Post Treatment Lyme Syndrome & Central Sensitization”

scientific journal articles. LDA partnered with Connecticut's LRA, to endow the research center for chronic Lyme disease at Columbia University in 2007, the only center in the world devoted to chronic Lyme, and gave a grant creating a tissue bank there to store samples for Lyme disease research. Genome work initially funded by LDA through UMDNJ (now Rutgers) has shown that different strains of the Borrelia bacteria have the ability to exchange genetic material among strains, a trait greatly benefitting their survival and probably confounding the body's ability to eradicate the organism. LDA- initiated funding of genome mapping helped to lead to 17 strains being mapped. The LDA has funded work with the University of New Haven (CT) examining biofilms, a method Lyme bacteria are using to outwit the immune system and treatment and has provided scientific equipment loan to the University which has been used in several research projects. In the journal Veterinary Sciences in 2014, in an article coming from researchers at University of New Haven, LDA was acknowledged for its support of a study of Ixodes scapularis (deer) ticks collected from Southern Connecticut, which were evaluated for their potential to harbor filarial nematodes. The results from the studies demonstrated that filarial nematode infection was found in Ixodes ticks similar to what has been found in Amblyomma americanum ticks (lone star). The implications for humans have not yet been determined.