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,
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.
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 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.

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 — 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. 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
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

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
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 20091 i–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. 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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i MMWR May 13, 2011 / 58(53);1-100

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


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
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
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.

[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
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, 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.

NY – Governor of New York State – The Honorable Andrew M. Cuomo

October 20, 2014

The Honorable Andrew M. Cuomo
Governor of New York State
NYS State Capitol Building
Albany, NY 12224

Dear Governor Cuomo,

I am writing on behalf of the Lyme Disease Association, a national non-profit that has a chapter and several associated Lyme organizations in New York. At this time, I request that you please sign the Lyme disease bill S07854/A07558B which passed both the NY Assembly and Senate this summer.

The LDA’s history in New York includes the establishment with a partner Lyme group of the endowed Columbia University Lyme & Tick-Borne Diseases Research Center, the only Center in the world devoted to chronic Lyme disease. Besides Columbia, LDA has provided grant funds in NY to institutions including Stony Brook University, New York Medical College, Rockefeller, and New York University. In addition to LDA’s
work directly with patients through its groups there, we have first hand experience with the circumstances of New York patients and treating physicians, as LDA holds an annual continuing medical education (CME) Lyme conference, jointly sponsored by Columbia University. The conference faculties consist of researchers and physicians worldwide, the former who are publishing cutting edge studies on tick-borne diseases, and the latter, treating patients with various stages of Lyme. Doctors, researchers, advocates and patients attend these conferences to keep current on Lyme/tick-borne diseases science.

I personally have a unique perspective on the history of the legislative process in New York pertaining to this current legislation before you. Early in the 2000s, the Office of Professional Medical Conduct (OPMC) was targeting at the same time almost all of the doctors in NY who were treating chronic Lyme, even though the OPMC denied it was targeting Lyme doctors because of the long-term treatment used for chronic Lyme disease. In 2001, I was invited to testify before the NY Assembly Health Committee Lyme Hearing and in 2002, before the NY Assembly Health, Education, & Codes Committee Lyme Hearing. In 2004, LDA was invited to help lead a team to attempt legislation passage for OPMC reform in New York State, based upon LDA’s success in getting the first doctor protection legislation in the US passed in Rhode Island. I worked with NY advocates and a bipartisan team of NYS legislators to craft a bill for passage. In the end, we overcame many obstacles and were successful in advancing the bill through the Assembly, but it stalled in the Senate. Next we supported a bill for doctor protection that passed the Assembly and Senate. We attended many meetings in Albany with legislators, the NYS DOH, and the Governor’s office on that bill, the then Governor Pataki’s office informed our team that he did not favor legislation. Instead, he compromised and agreed to a document into which I supplied input, the 2005 OPMC memo, the text of which now comprises a basis of the current bill before you.

At that time, because of the prevailing political climate and lack of understanding of the magnitude of the Lyme problem by many NY state officials despite a number of meetings to provide them with such education, we agreed to settle for the memo which stated in part, “this memorandum is intended to memorialize and endorse the principles that are currently in place in the Office of Professional Medical Conduct regarding the investigation of physicians, physician assistants and specialist assistants who use treatment modalities that are not universally accepted by the medical profession, such as the varying modalities used in the treatment of Lyme
disease and other tick-borne diseases. Consequently, it is contrary to the policy and practice of the Office of Professional Medical Conduct to identify, investigate or charge a physician, physician’s assistant or specialist assistant based solely on that practitioner’s recommendation or provision of such treatment modality.” The memo served its intended purpose for years. Unfortunately, like other internal policy statements, it eventually lost its clout, and physicians who primarily treat Lyme patients have again been investigated by the OPMC.

We must examine the changes which have occurred in the US, and, more specifically, in New York State since that time period, beginning with case numbers.

Beginning in 2008, some New York counties began to use an averaging system for the number of reported cases that occurred in that county, i.e., instead of validating all the cases of Lyme reported in that county and sending those figures to the Centers for Disease Control & Prevention, CDC, the counties used data they had and came up with an average which they then reported to CDC. The years and number of counties which averaged are as follows: 2008, 2 counties; 2009, 12 counties; 2010, 17 counties; 2011, 14 counties; and 2012, 20 counties.

The problem with averaging is, CDC has told the LDA they cannot accept averaging into their MMWR surveillance report. Thus, no Lyme case numbers for 2012 were counted in national surveillance for the following counties (taken from Senate Legislative Task Force Report): Albany, Broome, Columbia,* Dutchess,* Greene,* Nassau, Onondaga, Orange, Putnam, Rensselaer, Rockland, Saratoga, Schenectady, Suffolk, Sullivan, Tompkins, Ulster,* Washington, and Westchester ─ * denotes counties in the top 10 counties nationwide in prior county rankings. Thus, one-third of NY counties’ numbers were not included in the CDC national Lyme case reporting for 2012, impacting not only NYS numbers (formerly NY #1 nationally, now #3), but also the US total.

Not only is funding impacted when blatant underreporting occurs, but public and physician perception of the disease burden in NY and the US changes, i.e., there is less disease perceived, leading to fewer precautions, less diagnosis, and thus the disease does not get the attention it deserves on any front.

In 2013, CDC made two announcements confirming facts treating physicians and advocates already knew, Lyme has been vastly underreported, and it can and does cause death. The first in August said that about 300,000 cases of Lyme actually
occur in the US annually. The second, in December, was confirmation of the sudden Lyme carditis deaths of 3 young apparently otherwise healthy people with undiagnosed Lyme, including one from NY—whose Lyme was uncovered through the transplant process.

Since the 2005 memo, the science has changed significantly. There have been a number of animal study publications, e.g. monkeys and mice, documenting persistence of infection after treatment, including Monica Embers, Tulane University, “Persistence of Borrelia burgdorferi in Rhesus Macaques following Antibiotic Treatment of Disseminated Infection,” PLOS One, 2012; and Stephen Barthold, University of California, Davis, “Persistence of Borrelia burgdorferi Following Antibiotic Treatment in Mice,” Antimicrobial Agents and Chemotherapy, 2008. There was an NIH/CDC webinar featuring researchers talking about the animal studies/chronicity; and there was the 2014 peer-reviewed publication of evidenced-based guidelines by the International Lyme & Associated Diseases Society (ILADS), discussing the need for individualized treatment for chronic Lyme patients.

Congress held two US House hearings in Washington, DC, on Lyme disease, including testimony about a flawed process of NIH grant giving to researchers who may have held vested interests in the disease and did not believe in chronic Lyme and the intentional exclusion of other researchers who were open minded to the question of chronic Lyme. To view the hearing use the link below: http://archives.republicans.foreignaffairs.house.gov/hearings/view/?1455

This past summer, the first specific Lyme bill was passed through the US House of Representatives, providing for a working group on tick-borne diseases—with patient representation and treating physician representation at the table, and requiring a balanced viewpoint and transparency of operation. LDA led the charge with a letter signed by 154 groups nationwide favorable to the bill. At the state level, recognizing the increased Lyme problem, several more states enacted doctor protection statutes.

In an effort to move the science forward, the Congressional appropriations committees directed the NIH to sponsor a scientific conference on Lyme and other TBD, and further expressed that the conference should represent the broad spectrum of scientific views on Lyme disease and should provide for public participation and input from individuals with Lyme disease. In response, the NIH contracted with the Institute of Medicine in 2010 to conduct a “workshop.” An excerpt from that report
follows from Dr. Benjamin Luft, MD, State University of NY-Stony Brook: “the acknowledgement that Lyme disease may be a complex and chronic illness requires a comprehensive, multidisciplinary and patient-centered perspective. Patients are not interested in whether their illness is caused by Borrelia burgdorferi or another genotype of Borrelia. They want to be well again. Clinicians and researchers need to understand that the disease and its impact may intimately affect the severity and progression of symptoms. Because of the complexity of this disease, there is a need to develop better biological and clinical instruments to evaluate and measure the effectiveness of outcomes of treating its various manifestations….More than a quarter century after the discovery of Lyme disease, infectious disease specialists, neurologists, and psychiatrists still hold different conceptions of the disease. …The natural history varies greatly from person to person, leading to an absence of consensus about what is ‘active’ disease and what is disease impact. The management of chronic illness, with waxing and waning symptoms poses a challenge to our traditional office-based, single-specialty approach to management.”

Given this environment on the state of the science and the many complexities we know exist, but do not understand, it seems short-sighted to allow the targeting of physicians based solely upon the recommendation or the provision of a treatment modality that is not universally accepted by the medical profession. Physicians absolutely need to continue their medical education and to maintain high ethical standards, and certainly, they should have a healthy fear of how their decisions and recommendations will impact patient outcomes, but they should not be prevented from utilizing their knowledge, skills, and abilities in a prudent and thoughtful way to improve the well-being of patients.

Doctors’ ability to treat should not be subject to the changing political climate which readily allows a policy memo to be followed or not, since policy does not have the full force of law behind it. The time is here to end the uncertainty for doctors and patients. Lyme is not going away. More people now need doctors to diagnose and treat them. Although estimates vary, literature shows 10-20% and more of patients fail an early course of treatment. Yet NYS has again initiated investigations of the group of doctors who treat chronic Lyme disease, leaving thousands of families struggling to get help, many out of work or out of school. Signing this bill will be the first step to helping patients prevent chronic Lyme and helping those with it to be productive members of society.

Thank you. I can be reached at President@LymeDiseaseAssociation.org.
DC – Oral Testimony, US House Energy/Commerce Health Subcommittee

Oral Testimony before US House of Representatives Energy & Commerce Health Subcommittee
Patricia V. Smith, President, Lyme Disease Association, Inc. (LDA)
November 20, 2013

Chairman Pitts and Committee Members,

Thanks for allowing me to testify on the establishment of a Lyme & tick-borne diseases advisory committee. In 2009, CDC indicated that Lyme surpassed HIV in incidence followed by a 2013 announcement confirming a 10-fold under-reporting of Lyme cases, estimating 300,000 Lyme cases annually. A 2001 NIH sponsored study found the impact of Lyme on physical health status was at least equal to the disability of patients with congestive heart failure or osteoarthritis, and was greater than those with Type II diabetes or recent myocardial infarction. [1] Couple those facts with Lyme spreading worldwide to 80 countries and the discovery of many newly emerging tick-borne pathogens carried by many different ticks, then the passage of HR 610 is long overdue.

Other TBD in the US include anaplasmosis; babesiosis, bartonellosis; ehrlichiosis; Rocky Mountain Spotted fever; Colorado tick fever; Q fever; tick paralysis; tularemia; Powassan encephalitis; STARI, a Lyme-like disease; Rickettsia
parker Ricketsiosis found increasingly along the Gulf Coast and in the South; Borrelia miyamotoi, first disease case in Russia and now found here; an eschar-associated illness, Rickettsia species 364D, in the Pacific Region; and a newly discovered tick-borne virus in Missouri, Heartland. [2]

My education on Lyme began almost 30 years ago as a NJ Board of Education member whose district had a large number of students and staff out with Lyme disease. Only a few ticks were recognized as major health threats to humans. Now, the list includes: Ixodes scapularis (deer or black legged), Amblyomma americanum (lone star), Dermacentor variabilis (American dog), Dermacentor andersoni (Rocky Mt. wood), Ixodes pacificus (western black legged), Amblyomma maculatum (Gulf Coast), and Dermacentor occidentalis (Pacific Coast). One tick bite can often cause more than one disease.

My Lyme work, including 17+ as president of the volunteer-run national non-profit Lyme Disease Association keeps me in close contact with patients nationwide. Lyme’s complexity and difficulty in diagnosis 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.

Children are at the highest risk of acquiring Lyme. Based on CDC’s Lyme reported case numbers from 2001-10 by age, LDA estimates that 37% of reported cases were children. Using 1990-2011 CDC reported numbers adjusted for 10-fold underreporting, LDA then found 1,590,449 children have developed Lyme over that period. Many more children were probably clinically diagnosed, but not included in the CDC surveillance figure, which uses a strict reporting definition not meant for clinical diagnosis.

A 2001 Columbia study showed children with Lyme had significantly more psychiatric disturbances and cognitive deficits were still found after controlling for anxiety,
depression, and fatigue. Lyme in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments. Parents indicated 41% of children had suicidal thoughts, 11% had made a suicide gesture. [6]

Early intervention and appropriate treatment are the answers for Lyme patients to prevent the development of chronic Lyme disease, aka, Post Treatment Lyme Disease, late disseminated Lyme, persistent Lyme, Post Lyme Disease Syndrome, etc. While discussions continue on the justifications for various terms used for chronic Lyme, we cannot allow semantics to eclipse the need for research on chronic Lyme, the area producing the most human suffering and receiving the least research funding. According to a new Columbia 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.” [7]

Many major health threats including chronic fatigue have an advisory committee. Lyme does not, placing patients and advocates at a great disadvantage. We’ve lobbied for a research agenda which includes more effective treatments and better diagnostics, including detection of active infection. B. burgdorferi was recognized to cause Lyme almost 33 years ago, yet the two-tier testing system endorsed by CDC is very specific for Lyme disease (99%), gives few false positives, but the tests have a uniformly low sensitivity (56%)—missing 88 of every 200 patients with Lyme. [8]

DC – Written Testimony, US House Energy/Commerce Health SubComm

Written Testimony before US House of Representatives Energy & Commerce Health Subcommittee
Patricia V. Smith, President, Lyme Disease Association, Inc. (LDA)
November 20, 2013

Chairman Pitts and Committee Members,

Thank you for allowing me to testify on the need to establish an advisory committee on Lyme disease to ensure that government resources are being appropriately used to move forward the field of science and treatment in an area that is fraught with political, scientific, and medical obstacles, yet is dominating discussion on the worldwide stage. In 2009, the Centers for Disease Control & Prevention (CDC) indicated that Lyme surpassed HIV in incidence followed by a 2013 announcement confirming a 10-fold under-reporting of Lyme
cases, estimating 300,000 Lyme cases annually. A 2001 National Institutes of Health (NIH) sponsored study found that the impact of Lyme disease on physical health status was at least equal to the disability of patients with congestive heart failure or osteoarthritis, was greater than those observed in type II diabetes or in recent myocardial infarction, and chronic pain contributing to impairment was similar to that reported by patients with osteoarthritis. [1] Couple those facts with Lyme spreading worldwide to 80 countries and the discovery of many newly emerging tick-borne pathogens being carried by many different ticks, then the passage of HR 610 is long overdue.

The LDA just revised its comprehensive education and prevention brochure, LymeR Primer, which went from featuring 7 tick-borne diseases (TBD) in 2009 to 15 diseases. Besides Lyme disease, there are at least 15 other TBD of concern in the US: anaplasmosis; babesiosis, bartonellosis; ehrlichiosis; Rocky Mountain Spotted fever; Colorado tick fever; Q fever; tick paralysis; tularemia; Powassan encephalitis; STARI, a Lyme-like disease often with the same rash, transmitted by a lone star tick bite, pathogen cause unknown, but may be a bacteria similar to the Lyme bacteria; Rickettsia parkeri Ricketsiosis found increasingly along the Gulf Coast and in the South; Borrelia miyamotoi, a tick-borne bacteria which had been producing disease outside the US, now found in the US; newly found Rickettsia species 364D in the Pacific Region; and a newly discovered tick-borne virus in Missouri, Heartland, carried by the lone star tick. [2] One tick-bite can give someone more than one disease.

My education on Lyme began almost 30 years ago as a NJ Board of Education member whose district had a large number of students and staff out with Lyme disease. Then, only a few US ticks were recognized as major health threats to humans. Now, many ticks in the US are causing more human diseases, ticks including Ixodes scapularis (deer, black legged), Amblyomma
Americanum (lone star), Dermacentor variabilis (American dog), Dermacentor andersoni (Rocky Mt. wood), Ixodes pacificus (western black legged), Amblyomma maculatum (Gulf Coast), and Dermacentor occidentalis (Pacific Coast).

My Lyme work, including 17+ as president of the national volunteer-run non-profit Lyme Disease Association (LDA), has kept me in close contact with patients nationwide. The complicated nature of Lyme disease, the difficulty in diagnosis, and lack of recognition by some in the medical community 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, the families are forced to seek government help, government which is already burdened with more debt than it is able to handle.

Children have always been at the highest risk of acquiring Lyme disease. Based on CDC’s Lyme reported cases numbers from 2001-2010 by age, LDA estimated that 37% of reported cases were children. Using 1990-2011 CDC reported numbers adjusted for 10-fold underreporting, LDA found that 1,590,449 children have developed Lyme disease over that period. Many more children were probably clinically diagnosed but not included in the CDC surveillance figure, which uses a strict reporting definition not meant for clinical diagnosis. These are 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. A 1998 Columbia University study documents improvement in IQ of 22 points in a 16 year-old after IV treatment for Lyme disease. [3]

A 1992 CDC/NJ Department of Health study in NJ of 64 school children with Lyme showed that 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; the mean number of total school days lost was 140; the mean duration of home instruction, 153 days. Only 26% of children under study were said to have fully recovered. [4]

The direct medical costs per case incurred by 54 case-patients totaled $5.2 million, $8.7 million in CPI adjusted 2013 dollars. [5] The mean estimate was $96,569 ($274,412-2013); and costs of $100,000 ($166,891-2013) or greater were incurred by more then 1/5 of children. Some indirect costs were assessed totaling about $15,000 ($ 25,034- 2013) due to lost time caring for patient and parents’ lost time transporting children to medical treatment.

A 2001 Columbia study showed children with Lyme disease had significantly more cognitive and psychiatric disturbances. Cognitive deficits were still found after controlling for anxiety, depression, and fatigue. Lyme disease in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments. Regarding depression, parents indicated that 41% of children with LD had suicidal thoughts, 11% had made a suicide gesture. [6]

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, persistent Lyme, Post Lyme Disease Syndrome, etc. While discussions continue on the justifications for the various terms used for chronic Lyme disease, we cannot allow the semantics to eclipse the need for research on chronic Lyme, the area producing the most human suffering and receiving the least research funding. According to a new 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.” [7]
Currently, many major health threats including chronic fatigue have an advisory committee. Lyme disease does not, placing its patients and advocates at a great disadvantage. We have lobbied for a research agenda which includes more effective treatments for Lyme and other TBD and better diagnostics, including detection of active infection. B. burgdorferi was recognized in 1981 to cause Lyme, almost 33 years ago, yet the two-tier testing system endorsed by CDC is very specific for Lyme disease (99%), so it gives few false positives, but according to some sources, the tests have a uniformly low sensitivity (56%)—missing 88 of every 200 patients with Lyme disease. [8] Yet HIV was identified as the cause of AIDS in 1984, and tests were developed within a few years after and are 99% sensitive and specific. [9] Moreover, Lyme has not attracted industry funding for treatment approaches, which has allowed patients to develop severe mental and physical disabilities from the disease without help from science. There is also a need for educating doctors and the public about the state of the science regarding these diseases.

The above agenda requires the establishment of a venue where government agencies working on diverse aspects of tick-borne diseases (e.g., CDC surveillance, testing; NIH research funding- clinical trials, as well as basic and translational research; FDA drug, vaccine and device approvals; USDA research into natural tick prevention strategies; EPA tick prevention strategies) can present their activities, submit their proposed TBD agenda, and receive input from committee members who represent a wide variety of stakeholders with diverse scientific viewpoints on development of new diagnostics, treatment methods, and prevention strategies. Utilizing this format, government would ensure its agencies were providing the most judicious use of human and financial resources for Lyme and TBD. Using an already established federal advisory committee format ensures that the committee is only advisory in nature—committee members would not control nor dictate agency agendas, a concern that has been
expressed by an outside group in the past. However, those agencies should not be insulated from the public input and diverse scientific viewpoints this committee would provide in shaping an agenda and ensuring the wise use of tight federal dollars, which are provided by taxpayers. Another concern might be whether an advisory committee is worth the costs, including time, to support the operation of the committee. In the case of Lyme disease, the history of the past decades should lead to an easy yes.

One does not have to be a scientist to realize that it is premature and unwise to preclude further clinical trials studying a broader range of treatment regimens when there are numerous major and significant aspects of the bacteria’s known pathophysiology which have not been accounted for in studies conducted to date, when there are still many unknowns in that pathophysiology, and when we are learning more every day. While our knowledge of the pathophysiology of the bacteria continues to evolve, we must be open to additional clinical trials to document and establish better treatment regimens. There is preliminary evidence for more effective regimens, and a specific forum for open dialogue can help ensure we move forward and don’t get waylaid.

An open dialogue also could only improve the process of utilizing the pool of competent researchers- not in any manner that would interfere with established fair and open processes for grant-making, but only to increase awareness. It’s a fact that a small number -a handful- of Lyme researchers have individually received many millions of federal research dollars, many of whom shared the same set of biases and perspectives. Common biases and perspectives are not objectionable if they are based upon the best scientific evidence; open dialogue, information sharing, and transparency can help safeguard the process and the taxpayers’ money.

Patients want research which will restore their health. Their voice and the voice of the clinicians must be given the
necessary weight to legitimize the research agenda and the research process. Truth in science can be achieved through open discussion with diverse viewpoints in an independent process free from bias and conflicts of interest. The scientific process fails when one side of a debate controls the arena and sets the rules to ensure that its viewpoint prevails.

MAJOR POINTS SUMMARY

1. Lyme disease is increasing in numbers and range worldwide, with CDC announcing U.S. cases are 300,000 annually. It is found in about 80 countries worldwide.

2. A government study has indicated the impact of Lyme disease on patients is as severe as disability of patients with congestive heart failure or osteoarthritis, is greater than those observed in type II diabetes or in recent myocardial infarction, and chronic pain contributing to impairment is similar to that reported by patients with osteoarthritis.

3. Other tick-borne diseases are being discovered with greater frequency and people are becoming co-infected with a number of diseases.

4. More ticks are spreading different diseases to humans.

5. My work with the Lyme Disease Association has put me in close contact with patients who are sick and have other family members with the disease, which is costly to them financially and also impacts education and family structure.

6. Children are at the highest risk of acquiring Lyme disease. They often miss long periods of school and experience cognitive difficulties, severe pain, and may attempt suicide related to their Lyme disease.

7. There is a need for HR 610 creating an advisory committee which will permit all stakeholder input, including treating physicians, patients, and advocates, to be presented to government agencies. Currently patients have no voice.

8. The Committee would ensure that all sides of the science would be factored into the decision making process.

9. Government agencies need to interact with other government agencies, each bringing different perspectives and priorities to the table.

10. Having diverse stakeholders at the table ensures all perspectives are heard to develop a comprehensive coordinated
approach to tick-borne diseases, helping ensure that government funding is used widely.

11. Truth in science can be achieved through open discussion with diverse viewpoints in an independent process free from bias and conflicts of interest.

MA – Joint Committee on Financial Services

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

Testimony to Massachusetts Joint Committee on Financial Services Nov. 13, 2013 1-4PM
From Patricia V. Smith President, Lyme Disease Association, Inc. (LDA)

Thank you, Chairmen Petrucelli and Costello and Committee Members,

I have been invited to testify in Massachusetts on Lyme several times over the years. Today I regret to say Massachusetts now stands as number one nationwide in CDC’s reported case numbers for 2012. (5,138 Total; MMWR, 2012 Final reports, 8-13). With CDC recently releasing data confirming a 10-fold underreporting of Lyme cases, the State of Massachusetts then had 51,380 cases last year. Unfortunately, case numbers and the range of Lyme are increasing worldwide, with Lyme now found in ~80 countries.
My ~30 years of work as a Lyme advocate, including 17+ as president of the national non-profit Lyme Disease Association (LDA), have kept me in close contact with patients nationwide. The political nature of the disease and lack of recognition by some in the medical community 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, late disseminated Lyme, etc. According to a new 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—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 have always been at highest risk of acquiring Lyme disease. Based on CDC’s Lyme reported cases numbers from 2001-2010 by age, we know that approximately 37% of reported cases are children. Using 1990-2011 CDC reported numbers adjusted for 10-fold underreporting shows that 1,590,449 children have developed Lyme disease. Many more children were probably clinically diagnosed and not included in that figure because they did not meet strict CDC surveillance criteria—children who often go on to develop chronic Lyme disease. The remainder of my testimony will focus on the impact of Lyme on children and the added costs of caring for those children.

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 Dept. of Elem & Sec. Ed. 2005).

Pertaining to length of HI in children with Lyme, here are the results of a 1992 CDC and NJ Department of Health study in NJ of 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 five NJ school districts for 1990-1991 and 1991-1992, with a total enrollment of 23,904 students, that provided a total of 7,011 HI hours for students with Lyme, the cost of HI, counting only the hourly salary of tutors, was $132,199 (US Bureau of Labor Statistics CPI adjusted to 2013 $$ = $227,270).

In my school district (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). (This cost information is taken from a study I conducted of 9 NJ school districts in 2 counties in early 1992 and presented to CDC and NIH in Washington, DC, which directly led to CDC performing its own study, referenced above, later that year).
According to the CDC study, the direct medical costs incurred by study children were high, totaling $5.2 million* for 54 of the children. The median cost was nearly $50,000**, and costs of $100,000*** or greater were incurred by more than 1/5 of children. (*Adjusting according to the CPI, 1992 dollars above are equivalent in 2013 dollars to $8,678,366.*, $83,445**, and $166,891***).

For indirect costs due to lost time caring for patient, the study indicated only 24.6% parents provided information, and the mean cost was $11,418. Another indirect cost assessed was parents’ lost time transporting children to and attendance at a doctor’s office or hospital; 15% responded, and the mean cost was $3,519.

The LDA is favorable to the passage of H 989 which will provide insurance coverage for Lyme treatment, 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.

ABOUT THE 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 2013 as an approved national charity for Federal Workplace Giving. It’s a Guidestar.org exchange gold level member, recognized at the highest level for transparency and is an Environmental Protection Agency PESP Partner. The LDA offers its LymeAid-4-Kids assistance program for children without insurance coverage for Lyme, and it has funded over 93 research grants—funded research has been published in 33 scientific journals. LDA has provided 14 annual Continuing Medical Education Lyme & Other Tick-Borne Diseases conferences for physicians and researchers.