

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.