

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.