



Lyme Disease Association, Inc.

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July 5, 2016

Honorable Governor Charlie Baker
State House/Office of Governor, Rm. 280
Boston, MA
By Fax: 617-727-9725

Dear Governor Baker,

In 1990, the Centers for Disease Control & Prevention (CDC) reported 117 Lyme cases from the Commonwealth of MA, which did not then 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 now ranked number 2 nationwide, representing 16% of US total number of Lyme case reports. Based on CDC's research-based report of 10-fold underreporting of Lyme cases, MA likely had 53,040 new cases in 2014.

Early intervention and appropriate treatment regimens 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. Families who experience chronic Lyme see medical bills rise, jobs lost, and education interrupted. Divorce is not an uncommon result in these families, further complicating the picture. Often, they are forced to seek government help, government which is already burdened with more debt than it is able to handle.

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 30% of reported cases in the US are children 0-19. Using 2014 CDC reported case numbers, adjusted for CDC's 10-fold underreporting, it follows that 100,350 children developed Lyme disease in 2014. 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 childhoods 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 eligible are 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. 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/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 of education 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. From 2004-2014, 9% of LDA's LymeAid 4 Kids program grants were awarded to Massachusetts' children.

One of the most promising treatment-related topics, persisters, is being addressed by two world-renowned researchers and could explain how Lyme becomes chronic and how to treat it. 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. 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.”** Both spoke at the Columbia University/Lyme Disease Association CME Lyme conference for physicians and researchers in 2015.

These new avenues of research will lead to novel approaches to treating Lyme disease with antibiotics, reinforcing the need for you to sign the Lyme amendment to the budget bill, which will help patients to be reimbursed for these new therapies when they become available.

Please sign the Massachusetts legislation including the Lyme language intact, which will provide insurance coverage for Lyme treatment which could greatly 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 and to prevent development of mental health issues due to the isolation of students on home instruction— all leading to the avoidance of substantial government costs for chronic illness.

Thank you.

Sincerely,

Patricia V. Smith
President