

# Lyme Disease and Children, Critical Issues ©

Patricia V. Smith, President, Lyme Disease Association

PO Box 1438 Jackson, NJ 08527

**STATISTICS:** During 1992–2006, a total of 248,074 cases of Lyme disease were reported to CDC by health departments in the 50 states, the District of Columbia, and U.S. territories; the annual count increased 101% (9,908-1992,19,931-2006). Incidence was highest among children aged 5–14.<sup>i</sup> In 2007, Lyme disease case numbers rose 38% nationwide. According to CDC, only 10% of cases that meet surveillance criteria are reported,<sup>ii</sup> thus 274,440 new cases of Lyme developed in 2007. None of these figures reflect doctor-diagnosed cases that do not meet the CDC surveillance criteria. Estimates in literature range from 10-15 to 40% of Lyme cases develop into chronic disease (cases that have failed a standard treatment course and continue to be symptomatic)<sup>iii</sup> although many treating doctors think it is about 20%. Controversy exists in the area of chronic disease, which impacts upon the course and severity of disease.

**CHILDREN'S RISK FACTORS:** Some reasons children are at the highest risk of acquiring the disease may be because of their greater exposure to ticks due to their outdoor activities, their high risk activities such as walking in the woods, playing in the leaves, contact with pets, and their lack of knowledge of proper tick removal and Lyme disease acquisition, and lack of tick checks after spending time in tick habitats. Additionally, limited recognition of the signs and symptoms of Lyme by parents and physicians may be contributing factors.

**STUDIES ON CHILDREN & LYME:** The development of chronic Lyme disease can affect the child physically, mentally, emotionally and create severe problems in the area of education. An early CDC study of 64 school children in NJ with Lyme disease indicated the following: median duration of illness at the time of interview was 363 days, mean number of school days missed because the child was too ill to attend was 103 days (a range of 2 to 548 days), median duration of home instruction was 98 days, with a range of 5 to 792 days, 78% of the parents stated that their children experienced a fall in grade point average during the time of illness.

<sup>iv</sup>

A 1998 Columbia University study documents IQ improvement of 22 points in a 16-year-old after IV treatment for Lyme disease.<sup>v</sup> A 2004 Columbia University Study shows children with Lyme disease had significantly more cognitive and psychiatric disturbances. Cognitive deficits were still found after controlling for anxiety, depression, and fatigue, and the study indicated Lyme 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 and 11% had made a suicide gesture.<sup>vi</sup> A 2008 study from Columbia Teacher's College and the NYS Psychiatric Institute of 25 adolescents and 25 matched controls found in the Lyme group deficits in cognition (short-term visual memory, short term & delayed verbal memory, all forms of recognition), worse attendance, grades, and subjective reports of memory problems without differing in predisease achievement/depression. Deficits in visual memory exceeded deficits in verbal memory. Conclusion: adolescents with history of Lyme are at risk for long-term problems in cognition & school functioning. A 2002 study on Lyme disease in children describes how the Lyme bacteria persist in their gastrointestinal tract,<sup>vii</sup> perhaps one of the means by which it evades detection and eradication.

**COSTS TO SOCIETY:** A study in an Actuarial journal estimated a \$1 billion cost to society in 1992<sup>viii</sup> (case numbers are up 100%+ since then). According to a 1999 study in CDC's journal, *Emerging Infectious Diseases*,<sup>ix</sup> an early resolved Lyme case cost \$161, while a disseminated Lyme case could cost over \$61,000 in 1996 dollars. The above referenced 1992 CDC school district estimated medical treatment costs for 54 total of the study children at \$5.2 million, and more than one-third of families of the affected children had 3 or more members who had at some time been diagnosed with Lyme, including 40% of the mothers. A 1992 school district report from 9 NJ districts presented to CDC and NIH officials in Washington DC by a Wall Township NJ Board of education member showed a one year rise in home instruction cost to one NJ district of 88% due to Lyme disease cases.<sup>x</sup> Special education costs have certainly increased due to numbers of students with Lyme disease, improper classifications, and ignorance of effects of the disease on the students.

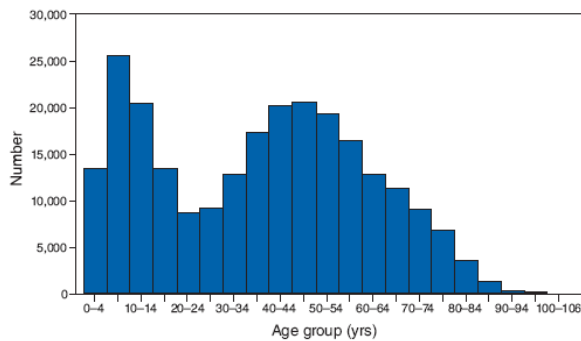
**REMEDIES:** On the local level, chronic Lyme disease often requires districts to re examine board policies, since a child may be out of school for extended periods of time. One example, the child may be capable of

attending a particular event, even lunch, but is not permitted. Absences of months to years often make a student a social outcast and recluse. The CDC school study reported 79% of children experienced a decrease in the number of friends. Allowing this minimal school interaction, and not questioning the child's, parent's or doctor's honest assessment of the illness can go a long way toward preventing the development of school phobia, thus easing a child's transition back to school when he or she is well enough to attend.<sup>xi</sup>

On the state level, in 1992, NJ passed a law<sup>xii</sup> which required the NJ State Department of Education and Department of Health to develop State-approved school curriculum guidelines for Lyme disease, recommended for use by New Jersey school districts in Lyme endemic areas. The law requires an annual in-service for educators who have students with Lyme disease according to those state-adopted guidelines. New Jersey remains the only state with such a state-adopted curriculum—other states should follow suit. States also need to increase education programs for both the public and physicians. All need to recognize the dangers posed by Lyme and seek an early diagnosis and appropriate treatment which can preclude chronic symptoms.

Lyme disease organizations have produced material to help students, parents, and schools. The Lyme Disease Association (LDA) has produced a book for children ages 8-12 with Lyme disease (*Lyme Disease Is No Fun! Let's get Well*), a free pamphlet for parents and educators (*The ABC's of Lyme Disease*), a free Internet based slideshow module for 6<sup>th</sup> grade through adult (*How a Tick Can Make You Sick*) available on [www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org). Connecticut group Time for Lyme has developed a school curriculum, and the California Lyme Disease Association, publisher of Lyme Times, has two issues devoted to Lyme disease in children, on sale on their respective websites.

**FIGURE 3. Number\* of reported Lyme disease cases, by age group — United States, 1992–2006**



**Graph**  
 CDC MMWR 2008  
 Lyme 1992-2006

\* N = 241,931.

i Surveillance for Lyme Disease --- United States, 1992—2006 MMWR

ii Meade, P. CDC epidemiologist, (NJ) Herald News 5-4-04

iii LDA review of various peer review studies

iv CDC & NJDOH field study on school children 1992, presented at Congressional forum in Wall Township, NJ, 10/92

v The Underdiagnosis of Neuropsychiatric Lyme disease in Children & Adults: Fallon, The Psychiatric Clinics of North America 1998

vi Tager, Felice, Fallon, Brian, et al, A Controlled Study of Cognitive Deficits in Children with Chronic Lyme Disease The Journal of Neuropsychiatry and Clinical Neurosciences, Fall 2004

vii Fried, Martin; Pietrucha, D, "Borrelia burgdorferi Persists in the Gastrointestinal Tract of Children and Adolescents with Lyme Disease," et al. Journal of Spirochetel and Tick-borne Diseases Spring/Summer 2002

viii Vanderhoof I et al, Contingencies '93

ix Martin I. , Meltzer, David T. Dennis, and Kathleen A. Orloski Centers for Disease Control and Prevention, Atlanta, Georgia, USA The Cost Effectiveness of Vaccinating Against Lyme Disease Emerging Infectious Diseases; Vol.5, No.3; 1999 May-June;5(3)321-8

x Smith, Patricia V. Washington DC meeting with CDC/NIH sponsored by US House of Representatives member Christopher Smith, 1992

xi Smith, Patricia V. The Effects of Lyme Disease on Students, Schools and School Policy, NJ School Boards Association School Leader Sept./Oct 2004

xii P.L. 18A 35-5.1-3 (1992)