

LDA Money Available For Uninsured Kids

The “new” Lyme numbers from Centers for Disease Control & Prevention (CDC), an estimated 300,000 Lyme cases annually, only scratch the surface of Lyme’s impact. The numbers are really not new but confirmation that Lyme is vastly underreported to CDC by a factor of 10—figures that are probably not inclusive of most people who are clinically diagnosed by their doctor and do not meet strict CDC surveillance criteria—often used by insurers to deny Lyme treatment. The 300,000 cases bring us closer to actual numbers, valuable to gain attention, but not to conveying real suffering of Lyme patients, especially children.



According to LDA President Pat Smith, “Based on CDC’s Lyme reported case numbers, LDA found that 37% of reported cases are children. Thus from 1990-2011, adjusted for underreporting, 1,590,449 children have developed Lyme. More children were probably clinically diagnosed and not included in that figure— children who often develop chronic Lyme.”

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.



Early diagnosis and treatment are crucial to prevent development of chronic Lyme, yet parents often lack insurance coverage. The LDA created its LymeAid 4 Kids fund in 2003 with support from author Amy Tan, who has Lyme. LDA has distributed almost \$250,000, and thanks to generous donors, LDA still has monies available. Applications can be found on www.LymeDiseaseAssociation.org.

In 1992, CDC presented findings of its study with NJ Department of Health on NJ school children with Lyme. According to Ms. Smith, then a board of education member, who worked with CDC to facilitate information gathering from school districts: "Of 64 students studied, CDC found the median duration of Lyme was 363 days; the mean number of total school days lost, 140; the mean duration of home instruction, 153 days; 78% of parents stated their children experienced grades decreasing during illness."

Two Columbia studies of children with Lyme provide insight into children's lives. One study documents 22-point improvement in IQ in a 16-year-old after IV treatment; another found children with Lyme had significantly more cognitive and psychiatric disturbances. Parents indicated 41% of children had suicidal thoughts; 11% made a suicide gesture. Cognitive deficits were found after controlling for anxiety, depression, fatigue. Lyme in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments.

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 for transparency and is an Environmental Protection Agency PESP Partner. LDA offers its LymeAid-4-Kids assistance program and 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.