

Bill to Help Children with Lyme Introduced in House of Representatives



NJ Congressman
Chris Smith

May 27, 2021 –Today, during *May Lyme Disease Awareness Month*, Congressman Christopher Smith (NJ-4-R) introduced a bill which could change the way our children with Lyme disease have been treated for decades. Co-sponsors are new Lyme Caucus Co-Chair, Rep. Henry Cuellar (TX-28-D), Lyme Caucus Member Rep. Bill Posey (FL-8-R), Rep. Josh Gottheimer (NJ-5-D), and Rep. Brian Fitzpatrick (PA-1-R). The bill, “Children Inflicted by Lyme Disabilities Act 2021,” or “CHILD Act 2021” will amend the Individuals with Disabilities Education Act (IDEA) by adding “including Lyme disease and other tick-borne diseases” in the Individuals with Disabilities Education Act (IDEA) after “other health impairments.”

The purpose of the bill is “To amend the Individuals with Disabilities Education Act (IDEA) to recognize more clearly that Lyme disease can cause disabilities that affect the education of children and to enhance educational services and related services for children with Lyme disease and other tick-borne diseases and for other purposes.”

The CDC now estimates that 476,000 people in the US each year

are diagnosed and treated for Lyme disease (**link for more info.**). Children are at some of the highest risk of acquiring Lyme disease— ages 0-19 years represented 29% of reported Lyme cases from 2001-2017 (**link for more info.**). After a course of treatment, 15-20% or more of patients have long term symptoms.

Children can have manifestations including cognitive impairment, mental confusion, memory loss, headaches, difficulty concentrating, speech difficulty, visual and hearing problems, dizziness, mood swings, outbursts, depression, sleep disturbance, OCD, and seizure activity, all of which affect their educational experience.

Lyme Disease Association (LDA) President Pat Smith had this to say about the introduction of the bill: “Students with Lyme disease face so many problems in their lives—out of school getting proper medical care and in school trying to overcome the obstacles that Lyme disease presents them with while developing relationships with their peers. These problems take place in a world where there is little understanding of the devastating physical, mental and emotional toll of Lyme disease. In my many years as a board of education member, I was called upon to advocate for these children in my own and other districts. Passage of this bill would perhaps go a long way to level the playing field for parents battling the bureaucratic educational system to get help for their children in that arena.”

LDA Scientific & Professional Advisory Board member Al Tagliabue, MEd (Sp. Ed), MEd (School Adm), a retired Director of Personnel and Community Services of the Jackson, NJ, School District has helped the LDA with children’s school issues for 25 years. He commented about today’s introduction, “I hope this bill will help both parents and professionals better understand the insidious nature of Lyme disease as well as the wide variety of educational challenges it presents for students.”

The Lyme Disease Association will be asking for help passage of this bill in the future.

WHAT LDA HAS DONE FOR CHILDREN: For decades, the Lyme Disease Association Inc. has been working with parents of children who have severe Lyme manifestations which interfere with cognitive and physical abilities to receive an appropriate education, since schools have not generally understood the magnitude of the problem. The LDA has provided programs for teachers, students, school nurses, and psychologists. LDA has a Professional Advisory Board member who is a retired special education school administrator. LDA President, Pat Smith, a former Board of Education Member, acted as a child advocate in the schools for students with Lyme disease. She met with teachers, special service teams, and administrators, and has worked with attorneys, and appeared in court with parents to try to resolve these issues. She has also in-serviced school staff and provided educational in-school programs for students on Lyme and TBDs as well as developed the LDA's ***ABC's of Lyme Disease***_pamphlet written especially for parents and educators. The pamphlet contains information from experts on the impact of Lyme disease on children's education, and hundreds of thousands have been distributed. The LDA also has **Tickles**, a prevention video, in the "Lyme, Kids and Schools" website section (**link for more info.**).

Click here for Bill Text