

HELP NEEDED IMMEDIATELY! NEW BILL FOR CHILDREN WITH LYME DISABILITIES TO BE INTRODUCED



LYME DISEASE CAUCUS & CHILD ACT 2021: The Congressional Lyme Disease Caucus is a bi-partisan group working together in the U.S. House of Representatives to take action on Lyme & tick-borne disease issues. They have been staunch friends to the Lyme community. There is a new bill about to be introduced into the House of Representatives by long-time Lyme Caucus Chair Congressman Christopher Smith (NJ-04-R), and to date, there are several co-sponsors: new Lyme Caucus Co-Chair, Rep. Henry Cuellar (TX-28-D), Lyme Caucus Member Rep. Bill Posey (FL-8-R), and Rep. Josh Gottheimer (NJ-5-D), and Rep. Brian Fitzpatrick (PA-1-R).



Congressman Smith is seeking co-sponsors for the bill from the members of the Congressional Lyme Disease Caucus. A letter has been sent to them from the office of Congressman Smith asking

for Caucus Member co-sponsorship for the bill. The title of the legislation is “Children Inflicted by Lyme Disabilities Act 2021,” or “CHILD Act 2021.” 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.”

WHAT YOU CAN DO IMMEDIATELY (May 26 & 27): The Lyme Disease Association urges you to contact the Caucus members (listed below) by fax or phone and tell them it is important to sign on as a co-sponsor to this bill. Tell them they have received a letter from the Smith office. If they did not receive it, or they have questions, they can contact Kelsey Griswold at the Smith office.

You can also contact your own Congress Member if they are not one of the co-sponsors listed above. Tell them to contact the Office of Congressman Christopher Smith for details and to sign on to the bill. Must be done by Thursday night.

Provide them with examples you may know about of children with Lyme disease with persistent symptoms (chronic Lyme) who have been unable to attend school for months and even years, or if they did attend, were unable to function without significant modifications to their educational programs. Often schools did not recognize the need or did not understand what needed to be provided. Thank them for listening and understanding the plight of our children who are at some of the highest risk of acquiring Lyme disease. Children 0-19 years represented 29% of reported Lyme cases from 2001-2017 (**link for more info.**). Remind them the CDC now estimates that 476,000 people in the US each year are diagnosed and treated for Lyme disease (**link for more info.**).

WHAT LDA HAS DONE: 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 retired as a special services director in NJ. 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 a Lyme Kids and Schools website section ([link for more info.](#)).

INSTRUCTIONS

- On May 26, May 27
- Call or fax Members of the Congressional Lyme caucus from the table below
 - o DO NOT CALL Chris Smith, Henry Cuellar, or, Bill Posey
 - o They already are on the bill
- Follow instructions in the WHAT CAN YOU DO IMMEDIATELY SECTION above as to what to say and use your own experience when you can for why they need to sign on as co-sponsor to help pass this bill.
- Also, you can look up your own Congress Member online and call or email and ask them to sign on. Tell them to

contact Kelsey Griswold, Office of Congressman Smith, for details of the bill.

- o If your group covers several congressional districts, contact those Congress Members.

NOTE: If your mouse hovers over the bottom of the chart, you will be able to zoom in and make the chart bigger or download it.

Caucus Contacts May 2021_4