Lyme Disease Needs Your Congressmen to Sign Onto Letters NOW!

ISSUE

At this time the Lyme Disease Association, Inc. is asking you to contact your Congress Member to ask him/her to sign on to 2 important letters from the US House Lyme Disease Caucus.

These bipartisan letters provide details that the Lyme Caucus is asking the 2 Appropriations Committees to include in their reports on FY 2021 Appropriations. This language will help provide direction for the monies and was developed with input from Lyme/TBD advocates.

LETTER LHHS Appropriations Committee (sign-on deadline 3/10)

LETTER DoD Appropriations Committee Lyme/CDMRP (sign-on
INSTRUCTIONS

1. Determine Who Your Congress Member Is

Click on “Find Your Rep” box below

Type in zip code (your Member or a Member who serves your group’s area, your work area, etc.)

FIND YOUR REP

2. Congress Members Already Signed on Letter as of March 6, 2020/ Do Not Contact

Christopher H. Smith (NJ), Caucus Co-Chair
Collin Peterson (MN), Caucus Co-Chair
Antonio R. Delgado (NY)
Brian Fitzpatrick (PA)
Tom Malinowski (NJ)
Chellie Pingree (ME)
Bill Posey (FL)
Max Rose (NY)
Elise M. Stefanik (NY)
Jennifer Wexton (VA)
Vicky Hartzler (MO)

3. Email or Call Your Congress Member’s DC office.

A. Below is an example of what you need to say to your Congress Member. Here are some examples of how you can identify yourself: I am a Lyme patient, family member, friend of, person concerned about Lyme, doctor, Lyme group leader, etc.

B. Cut & paste the red text below into an email to your Congress Member OR call and say the following verbally over the phone to your Congress Member:
Dear Congress Member,

I ask that you please sign onto the two letters from the bipartisan House of Representatives Lyme Disease Caucus – co-chairs Christopher Smith (NJ) and Collin Peterson (MN) – to the LHHS Appropriations Committee and to the DoD Appropriations Committee (Lyme/CDMRP). The important language in these letters will help Lyme patients across the country. Here are links to the draft letters:

- LHHS [bit.ly/2Vk21vt](bit.ly/2Vk21vt) signatures due March 10
- DoD (Lyme/CDMRP) [bit.ly/3bQGz77](bit.ly/3bQGz77) signatures due March 13

Please call or email Kelsey Griswold Kelsey.Griswold@mail.house.gov at the Office of Christopher Smith for information or to have your signature added. Thank you so much for your support on this important issue affecting hundreds of thousands of people in the US.

Sincerely, INSERT YOUR NAME, HERE

C. PLEASE NOTE: You are NOT supposed to email Kelsey Griswold. You are to instruct your Congress Person to email her directly.
CDC Report on FY2018 TBD Funding
The CDC released a report on FY 2018 tick-borne disease funding, which was requested by the Senate Appropriations Committee. The report includes an overview of the request from the Senate Appropriations Committee. It also provides an update on CDC’s work with states and progress in that area. This section includes information on Ticknet, a public health network and on the misuse of the CDC surveillance criteria including a physician survey published in Dec. 2019.

There is also a section that provides an update on how funds were spent when “in FY 2017, CDC received $10.675M for Lyme disease.” Twenty percent (20%) of that went to surveillance, research, and public health program implementation. Seventeen percent (17%) went to state activities, 14% went to Emerging Infection Program cooperative agreement for 10 state health departments who work with academic institutions, federal agencies, public health and clinical labs for vector-borne diseases. That funding also supported CDC’s infrastructure for surveillance, research and public health including integrated Pest Management for prevention of vector-borne diseases.

CDC is also working with Colorado State University to develop a new type of test using metabolomics to diagnose early Lyme disease, which CDC says may be more sensitive than the two-tier test.

FROM LDA: Read the 3-page report for more details, but note
that the report is unclear and appears to not only address how these monies were expended for Lyme/TBD but also for vector-borne diseases. Also note in the last paragraph of section III, that HHS still maintains an internal tick-borne disease working group with CDC, NIH, and FDA. Do not be confused. That working group is NOT the one Lyme patients and advocates were successful in getting created through legislation and is covered under FACA, meeting in public in DC. This working group meets and deliberates without the benefit of transparency and without a public voice.

Click here for the CDC report

President’s FY21 Budget Request Includes Increase for Vector-Borne Diseases

The White House released the Fiscal Year 2021 budget proposal which includes a $14 million increase compared to the 2020 enacted level that focuses on tick-borne diseases.

Excerpts from Budget of the United States Government, Fiscal Year 2021:
• “Prioritizes Critical Health Research and Supports Innovation” … “NIH would continue to address the opioid epidemic and emerging stimulants, make progress on developing a universal flu vaccine, prioritize vector-borne disease research, and support industries of the future.”

• “Advances Vector-Borne Disease Prevention and Control. The threat of mosquito and tickborne diseases continues to rise in the United States. Cases of tick-borne diseases, such as Lyme disease and Rocky Mountain spotted fever, affected nearly 60,000 Americans in 2017. The Budget includes $66 million for CDC’s vector-borne disease activities, a $14 million increase compared to the 2020 enacted level which focuses on tick-borne diseases. The Budget also invests in NIH research to improve the Nation’s understanding of vector-borne diseases.”

The White House also released a fact sheet titled Protecting our Nation’s Health and Wellness reinforcing the prioritization of critical health research and advances in vector-borne disease prevention and control. Congress will review and vote on the budget proposal within the coming weeks.

Click here to view Budget of the United States Government, Fiscal Year 2021

Click here to view supplementary document Protecting our Nation’s Health and Wellness
Researchers! Fiscal Year 2020 Preannouncement for TBDRP is Posted

The FY20 Tick-Borne Disease Research Program (TBDRP) Program managed by the Department of Defense (DOD) office of Congressionally Directed Medical Research Programs (CDMRP) has issued a preannouncement for the FY20 funding opportunity.

The link to the preannouncement can be found here: https://cdmrp.army.mil/pubs/press/2020/20tbdrppreann

FY20 funding opportunities available for the Tick-Borne Disease Research Program (TBDRP) include a Career Development Award and an Idea Development Award. Descriptions of each of the funding opportunities, eligibility, key mechanism elements, and funding can be found in the Program pre-announcement.

Submission deadlines will not be available until the Program Announcements are released.

Flyer on CDMRP TBD program highlights:


Point of Contact:
House Lyme Disease Caucus 2020

The House Lyme Disease Caucus is a bi-partisan group working together in Congress to take action on Lyme & tick-borne diseases. Under the leadership of Congressmen Chris Smith (NJ) and co-chair Colin Peterson (MN), it has initiated letters and actions to benefit Lyme patients, such as the inclusion of the monies for Lyme & tick-borne diseases into the Congressionally Directed Medical Research Program (CDMRP) and language and Lyme monies into Appropriations over the years and initiated favorable legislation. Additionally, it has queried government agencies over policies not favorable to patients. This has reminded the agencies that someone is looking over their shoulder. Many meetings have been held and educational sessions in DC for Congress.

If Representatives are interested in signing up they can contact the offices of Congressman Christopher Smith (NJ) or Colin Peterson (MN).
Pat Smith, President & Rich Smith, Vice President of the LDA met in Wall, NJ, with Congressman Chris Smith, Co-Chair of the House Lyme Caucus, to discuss what actions can be taken in DC to help those with Lyme and to stop the spread of Lyme & other tick-borne diseases, 4/19/2017

List of Current House Lyme Disease Caucus

Smith, Christopher H. (R-NJ-04), Co-chair
Peterson, Collin C. (D-MN-7), Co-chair
Cohen, Steve (D-TN-9)
Connolly, Gerald E. (D-VA-11)
Courtney, Joe (D-CT-2)
DeGette, Diana (D-CO-1)
Delgado, Antonio (D-NY-19)
Hartzler, Vicky (R-MO-04)
Higgins, Brian (D-NY-26)
Holmes Norton, Eleanor (D-DC)
Keating, William R. (D-MA-9)
Kennedy, Joseph P. (D-MA-4)
King, Pete (R-NY-02)
Krishnamoorthi, Raja (D-IL-08)
More about the Caucus

The bipartisan Congressional Lyme Disease Task Force, co-chaired by Rep. Chris Smith (R-NJ) and Rep. Collin Peterson (D-MN), is dedicated to educating Members of Congress and staff about Lyme and other tick-borne diseases, as well as advancing initiatives that are designed to help the estimated 400,000 Americans who develop Lyme disease each year and all of those living with the disease.

As co-chairs of the bipartisan Task Force, Rep. Smith and Rep. Peterson lead annual appropriations requests in support of Lyme disease research through the Department of Health and Human Services and for research funding at the Department of Defense. In 2015, the caucus secured for the first time ever, $5 million in funding in the House Appropriations Committee annual military spending legislation, which was adopted in the Fiscal Year 2016 funding bill which was signed into law, and
will provide resources for Lyme disease research through DOD’s innovative, high-risk, high-reward program. Subsequently, the CDMRP continued to be funded, and $7 million was secured for 2020.

The caucus helped advocates secure another major win for Lyme disease. In December of 2016, the United States House of Representatives passed, and former-President Obama signed, the 21st Century Cures Act. The Cures Act included language – similar to a bill that Rep. Smith introduced previously – which created the interagency Tick-Borne Disease Working Group. Specifically, the Working Group (WG) under the auspices of HHS, is comprised of federal and non-federal members tasked with reporting to Congress on scientific advances, research questions, surveillance activities and emerging strains in species of pathogenic organisms. Patients, advocates and treating physicians sit at the same table with government officials. In 2018, the WG sent a report to Congress with recommendations on Lyme and other tick-borne diseases.

CDC Focus on Maternal-Fetal Transmission of Lyme Disease
The Centers for Disease Control (CDC) updated its website to include information regarding maternal-fetal transmission of Lyme disease.

Updates from the CDC website:

- **Lyme disease Transmission page** under “Are there other ways to get Lyme disease?”: “Untreated Lyme disease during pregnancy can lead to infection of the placenta. Spread from mother to fetus is possible but rare. Fortunately, with appropriate antibiotic treatment, there is no increased risk of adverse birth outcomes. There are no published studies assessing developmental outcomes of children whose mothers acquired Lyme disease during pregnancy.”

- **Lyme Disease FAQ page** under “I am pregnant and think I have Lyme disease, what should I do?”: “If you are pregnant and suspect you have contracted Lyme disease, contact your physician immediately. Untreated Lyme disease during pregnancy can lead to infection of the placenta. Spread from mother to fetus is possible but rare. Fortunately, with appropriate antibiotic treatment, there is no increased risk of adverse birth outcomes.* There are no published studies assessing developmental outcomes of children whose mothers acquired Lyme disease during pregnancy.”
Pregnancy and Lyme disease poster: information on symptoms, diagnosis, and treatment. Regarding breastfeeding the poster states, “There are no reports of Lyme disease transmission through breast milk.”

LDA President, Pat Smith, said this about the CDC’s recent update, “The maternal-fetal aspect of Lyme disease, mother to baby transmission, has long been known but not well-publicized. The new CDC focus on this Lyme transmission method has been missing in Lyme disease education. A number of advocacy groups, including the LDA, have had information on their websites. LymeHope in Canada has been strongly advocating for wider recognition of this aspect, in particular nurse Sue Faber, who spoke before the HHS TBD Working Group in DC in January 2020. Now it is up to all of us to call attention to this CDC focus to ensure health departments and physicians are aware of the situation and that they take appropriate steps to ensure pregnant women get the necessary care.”

Visit the CDC Lyme disease website.

View the LDA’s Pregnancy, Breastfeeding & Lyme Bibliography.

TBDWG Subcommittee Reports Now Accessible

The HSS-Tick-Borne Disease Working Group subcommittee reports are now accessible on the HHS-TBDWG webpage. The TBDWG established eight subcommittees in June 2019. Each subcommittee identified priorities and developed a report
to the TBDWG that described current efforts, gaps in research, and potentials actions relevant to their topic. Read Subcommittee Reports

The TBDWG will discuss the subcommittee reports during the next public meeting taking place January 28-29 at Hyatt Place Washington DC/US Capitol, 33 New York Avenue NE, Washington, DC 20002.

In-person attendance at the meeting is limited to space available; therefore, preregistration for public members is advisable and can be accomplished by registering here. Members of the public may also attend the meeting via live webcast.

House Confirms Fiscal Year Spending 2020 for Lyme & Other Vector-Borne Diseases

The 116th Congress House Committee on Appropriations submitted a report in explanation of bill H.R. 2740, the Omnibus that funds Health and Human Services (HHS) including the National Institute of Health (NIH) and the Centers for Disease Control (CDC), and outlines the final legislative language and designation of funds for vector-borne diseases, including Lyme disease, for fiscal year ending September 30, 2020.

Highlights from the House Explanatory Statement include:

- The Committee encourages NIAID to intensify research and
development on Lyme and other tick-borne diseases, including research that will increase understanding of the full range of processes that cause Lyme disease infection. This should include research on the physiology of Borrelia burgdorferi and Borrelia mayonii, including the mechanisms of possible persistent infection, potential treatment protocols for extended or long-term symptoms attributed to Lyme and other tick-borne diseases, and development of more sensitive and accurate diagnostic tests for Lyme and tick-borne diseases, including next generation polymerase chain reaction (PCR) and new testing methodologies such as proteomics and metabolomics. The Committee directs NIAID to support research on the heightened incidence of Lyme Disease and vector-borne diseases due to global warming.

- The Committee encourages NIH to improve early diagnosis and treatment of Lyme and other tick-borne diseases (TBD) to prevent the development of late stage disease and more serious and longer-term disability, but also intensify research on diagnosis and treatment of late stage and chronic disease. In addition to development of highly sensitive and specific diagnostics for all stages of disease, a goal should be to develop diagnostics with appropriate sensitivity and specificity for the detection of infection. Treatments also should be developed for all stages of Lyme and other TBD, determining optimal combinations of new candidate or older drugs and exploring novel combinations.

A statement from a Congressional spokesperson further clarifies that, “The agreement includes an increase and encourages CDC, in coordination with NINDS and NIMH, to include in its surveillance the long-term effects. CDC is also encouraged to coordinate with NIH on publishing reports that assess prevention, treatment, diagnostic advancements, and links between tick-borne disease and psychiatric illnesses. CDC is encouraged to focus efforts in endemic areas as well as
Thank you to Congressman Chris Smith (NJ-4) for working with LDA to get some of this language included. Thank you to other advocates and legislators who also provided input into the process.

The CDC received a $2,000,000 increase for Lyme disease.

Click [here](#) to view the full H. Rept. 116-62 Explanatory Statement

Click [here](#) to view HR 1865 Division A

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**President Signs Tick Act into Law**

On December 20, 2019, President Trump signed the *Kay Hagan Tick Act* into law as part of an end-of-year spending package that had passed both Houses.

The bill had been introduced by Rep. Chris Smith (R-NJ) in the House and by Senator Susan Collins (R-ME) in the Senate. The bill language was changed in the Senate before passage out of the Senate HELP Committee. That language was changed slightly again at the House level before being incorporated into the
end-of-year Appropriations bill. The good news is, Lyme will get some monies for the development of a vector-borne disease national strategy and also for CDC grants to States to help provide funding for surveillance and other vector-borne diseases issues. The amount given for tick-borne diseases will not be known until the FY2021 appropriations process is complete since the bill includes all vector-borne diseases, mosquito, and tick-borne.

Text of Tick Act Signed by President

Click here for Congressman Smith’s News on Tick Act

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**URGENT: The Tick Act Needs Your Help Now!**

**TO:** Advocates/Patients  
**FROM:** Lyme Disease Association, Inc. Pat Smith, President, 11-20-19  
**RE:** Urgent & Immediate Help Needed  
(Click for easy **Steps to Take** or See Below)

**ISSUE:** On October 31, the Senate Tick Act (Collins, ME) was passed out of the Senate HELP Committee; however, it was a different bill than the one that was originally submitted to the Senate Committee that many Lyme groups supported. The HELP committee replaced it in its entirety with a Manager’s Amendment, submitted “in the nature of a substitute,” which still keeps the same bill number, S-1657, and it was renamed the *Kay Hagan Tick Act*.

The Senate bill has always been a vector-borne disease bill, meaning that mosquito-borne diseases such as Zika and West
Nile virus, as well as other vector-borne diseases, are included and eligible to receive monies. There were safeguards in the original Senate bill that would have ensured that Lyme received the funding it warrants, for example, monies would be allocated proportionately according to disease burden in the US. Those safeguards have been removed. The LDA was not aware of the bill substitution and now has been urgently working to assess—before it goes to the full Senate—what these significant bill changes mean, and the potential impact on what the bill does.

**Explanation of Tick Act Changes From the Lyme Disease Association & How To Help**

**LDA ASSESSMENT & ACTION:** We need to take several actions to try to minimize the impact of the changes on the Senate bill. LDA is working with Senator Susan Collins’ office and with Congressman Chris Smith’s office to try to rectify this language situation to provide necessary safeguards to ensure Lyme will get its appropriate share of the funds that are included in this new Senate bill.

**WHAT CAN BE DONE BY YOU:** The House version of the Tick Act, HR3073 (Smith, NJ) retains the original language that the Senate bill used to have. We want to ensure that the Smith House version of the Tick Act gets more co-sponsors so we have another possible route to passage. We need your help now with the action below.

**ACTION FOR YOU TO TAKE:** We have provided the list of current co-sponsors of the Smith House bill, HR 3073, below, which contains the original Senate language. If your Congressman/woman is NOT on the co-sponsor list, we need you to contact him/her immediately.
STEPS TO TAKE

Step #1: [Click here](#) to review the current list of co-sponsors of the HR 3073, Tick Act, in the House of Representatives. If your Congressperson is NOT on the [current co-sponsor list](#):

- Go to Step #2
- If your Congressman IS on the list as a co-sponsor, but you would like to call another from your state who is not on the list Go to Step #2

Step #2: If you DO NOT see your congressperson’s name on the list above, please visit [this website](#) to locate his/her contact information, and then:

- **CALL OR EMAIL YOUR CONGRESSPERSON** per the instructions directly below.
- **WHAT TO SAY TO YOUR CONGRESSPERSON:** Contact your House of Representatives’ offices and let them know you want them to co-sponsor HR 3073, Tick Act. Explain that it is important that the government develops a strategy for Lyme and tick-borne diseases and authorizes monies to fight this nationwide problem. About 427,000 new cases of Lyme disease occurred in 2017 alone, 20 different tick-borne diseases and conditions are now found in the US, and half of U.S. counties have already been found to harbor ticks that transmit Lyme disease. Thank him/her.
- If your group serves more than one congressional district, contact all Members of Congress in the area you serve with the same message.
LINKS TO THE TICK ACT BILLS:

To see the House bill, HR 3073, Tick Act, click here.

To see the original version of Senate bill, S-1657, click here.

To see the new version of Senate bill, S-1657/Kay Kagan Tick Act, that was passed through the HELP Committee, click here.

Thank You!