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
deadline 3/13)

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 signatures due March 10
- DoD (Lyme/CDMRP) 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 FACAs, 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]

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

The White House released the [Fiscal Year 2021 budget proposal](https://www.budget.gov/budget FY21.html) which includes a $14 million increase compared to the 2020 enacted level that focuses on tick-borne diseases.

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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/2020/20tbdrrppreann

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:
NOTE from Lyme Disease Association: Please do not contact us for information. Contact the CDMRP TBDRP directly. Thank you!

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](https://www.cdc.gov/lyme/)

View the LDA’s [Pregnancy, Breastfeeding & Lyme Bibliography](https://www.lymedisease.org/content.php?categoryid=9).
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.

TBDWG: Jan. 2020 Meeting in DC/In-person, Written Comments Accepted
The 11th meeting of the Tick-borne Disease Working Group (TBDWG) will be held on January 28 and 29, 2020, from 9:00 a.m. to 4:30 p.m. ET on both days (times are tentative). The HHS.gov site has announced that, for this meeting, the eight subcommittees will present their findings and potential actions for the TBDWG to consider. The TBDWG will hear updates from Public Comments and Inventory Subcommittees as well as advance discussions regarding plans for developing the 2020 report to the HHS Secretary and Congress on federal tick-borne activities and research. Information provided via Public Comment will be summarized and provided to the subcommittees for review and possible incorporation into the next TBDWG report.

The meeting will take place at the Hyatt Place Washington DC/US Capitol located at 33 New York Avenue NE, Washington, DC 20002. In-person attendance is limited to space available. Pre-reregistration for public members is advised and can be accomplished by registering on the HHS.gov site. Click Here to register to attend the 11th TBDWG Meeting in person.

To request an opportunity for in-person Verbal comments:

- Requests for verbal (in-person) public comment must be submitted via email by midnight Tuesday, January 17, 2020, ET to tickbornedisease@hhs.gov. In the Subject line please enter: Verbal Public Comment – January 28-29 Meeting.
- A total of 30 minutes has been set aside for verbal comments on both days. Each person will be limited to only 3 minutes so that as many speakers can be accommodated as possible. Speakers will be randomly selected if more requests are received than can be accommodated.
- In-person remarks will be heard over a live webcast.
become part of the archived meeting recording and summary which will be posted on the HHS.gov website.

To submit Written comments which will be posted on the HHS.gov webpage and accessible to the public:

- Written public comments must be submitted via email by midnight Tuesday, January 17, 2020, ET to tickbornedisease@hhs.gov. In the Subject line please enter: Written Public Comment – January 28-29 Meeting.
- Please include a statement indicating how you would like to be identified with your comment. You may choose to use your name or to be anonymous. You may also list your city and/or state. If you are providing comments on behalf of an organization, please include the name of the organization. The TBDWG cannot post your comment until you advise how you would like to be identified.
- Comments should either be provided in the body of your email, or in an attachment in Word format and equivalent to no more than 4 pages in Calibri or Times New Roman, 11 point font. Text that exceeds the 4 pages will be deleted.
- The TBDWG does not post graphics, images, text boxes, or tables. If included with your comment, they will not be able to retain them.
- The TBDWG can only create hyperlinks to “.gov” sites (local, state, or federal). For all other reference sites, please insert the full URL (e.g., http://learn.genetics.utah.edu/content/epigenetics).
- The TBDWG is unable to include attachments as supporting documentation to written comments.

Members of the public who cannot attend in-person may attend the meeting via webcast. Instructions for attending via webcast will be posted approximately one week prior to the meeting.

Click Here for furthered information on the HHS.gov website,
Nicole Malachowski: Unfit for Duty from Debilitating Tick-Borne Disease

From Department of Defense – CDMRP:

Nicole Malachowski recently medically retired from the US Air Force as a Colonel after 21 years of service as a career fighter pilot. She was the first woman in history to fly with the Thunderbirds (US Air Force Demonstration Squadron) and went on to be the Commander of the 333rd Fighter Squadron, where she trained more than 200 students to fly the F-15E fighter jet. She later served as the Deputy Director for US Air Force Readiness and Training for the Office of the Under Secretary of Defense for Personnel and Readiness. In addition, she served in the White House: first, as a fellow for the U.S. General Services Administration (2008-2009), then as the executive director of the White House “Joining Forces” Initiative (2015-2016). Ms. Malachowski was at the peak of a long and promising career.

Her medical retirement, however, was premature. At only 43 years old, she was deemed unfit for duty due to neurological damage from tick-borne illness.

Read full story here
NIH Releases Strategic Plan for Tick-Borne Disease Research

The NIH Strategic Plan for Tickborne Disease Research, October 9, 2019, is good news for everyone in the Lyme and tick-borne diseases community! The plan builds on the activities of the Department of Health and Human Services Tick-Borne Disease Working Group (TBDWG), which issued a 2018 report to Congress outlining research recommendations. Through inventories sent to government agencies to determine gaps in their research on tick-borne diseases (TBD), the Working Group uncovered the fact that NIH did not have a national strategy for TBD. The HHS TBDWG Report made the recommendation below in the November 2018 report:

**Recommendation 8.1:** NIH: Create an NIH tick-borne disease strategic plan, with public input during creation and implementation, to address tick-borne diseases, including all
stages of Lyme disease. Include in the strategic plan the coordination of research funding across NIAID, NINDS, NIAMS, and NIMH to increase knowledge of pathogenesis, improve diagnosis, and develop and test new therapeutics for tick-borne diseases. Update every five years.

The LDA President, Pat Smith, served as a TBDWG member that wrote the 2018 report. She was reappointed this year for a second term as it develops the next report to Congress due December of 2020.

In developing this strategic plan, as recommended by the TBDWG Report, NIH sought input from the research and medical communities, patient advocacy groups, pharmaceutical industry, and the general public.

The Lyme Disease Association submitted input to the NIH on a strategy:


The newly released NIH plan focuses on five scientific priorities important for advancing research and development over the next five years.

1. Improving fundamental knowledge of tickborne diseases, including the biology of tickborne pathogens; how they are transmitted to humans, evade the immune system, and spread within the body. Including determining the cause of persistent symptoms in some people infected with tickborne diseases, such as Lyme disease, and furthering the understanding of how tick-derived factors contribute to the establishment and severity of disease.

2. Advance research to improve detection and diagnosis of TBDs. Improving detection and diagnosis of tickborne diseases by developing rapid diagnostic tests that can detect a pathogen both early and late in infection and distinguish between active and past infections. NIH will
support the development of diagnostics capable of predicting treatment success and identifying human biomarkers of infection and persistent symptoms.

3. Accelerate research to improve prevention of TBDs. The new plan also prioritizes the acceleration of research designed to prevent tickborne disease infection, including vaccines, and immune-based treatments, as well as strategies to reduce the transmission of tickborne pathogens to animal populations that serve as hosts.

4. Focusing on research to develop new treatments for tickborne diseases and techniques to reduce disease complications.

5. Prioritizing the development of tools and resources to advance tickborne disease research by improving scientists’ access to biological samples, tickborne disease genetic data, and supporting preclinical development of promising products.

NIH intends to expand collaborations across its institutes and centers to promote a multidisciplinary approach to tickborne disease research, answer complex biological questions and encourage the application of state-of-the-art technologies used successfully in a range of scientific disciplines.

NIH Strategic Plan for Tickborne Disease Research

NIH Strategic Plan News Release

Congressman Smith praises NIH announcement (TAPinto.net)

Congressman Smith press release on NIH Strategy

Note from LDA: tick-borne disease is generally spelled with a hyphen. NIH has chosen to leave out the hyphen in its report.
10th Meeting of TBDWG – Sept 12, 2019 Summary

The tenth meeting of the Tick-Borne Disease Working Group (TBDWG) was held via webcast on Sept 12, 2019 from 9:00 a.m. to 3:00 p.m. ET.

- Subcommittee members were announced, and the Working Group received reports from the eight subcommittees that were formed during the June 4, 2019 meeting.
- Two subcommittee name changes were approved, since the Subcommittees felt names did not reflect the focus of the Subcommittees. Dr. Ben Beard, CDC, presented the change to the first committee, and Pat Smith, President LDA presented the change to the second. The two Subcommittees are now 1.) Babesiosis & Tick-Borne Pathogens and 2.) Training, Education, Access to Care & Reimbursement. Dr. Beard indicated his committee needed to include more of the tick-borne diseases and not just viral TBD. Ms. Smith was concerned because Working Group discussion had included Access to Care & Reimbursement and that without that aspect in the title, patients needs were being being removed from the focus of the Subcommittee.
- Public comments were presented by eight patients and advocates over a 30 minute time period. Issues shared
included alpha-gal, 2019 TBDWG membership as it relates to patient/advocate representation, and transparency of the TBDWG process.

- Three topic development briefs were shared with the Working Group. A common theme throughout the briefs was that the most existing research that had been collected in this process is either inconclusive or indicates that further research is needed in each of the three topic areas presented. The three topic development briefs were: 1.) Cause of increase for tick-borne diseases, 2.) Cause of persistent Lyme disease, and 3.) State of current testing for tick-borne diseases.

- The Working Group created a new subcommittee, Federal Inventory, to analyze the new Federal inventory content for use in the 2020 report to congress. LDA President and TBDWG member, Pat Smith, volunteered to Chair this committee and Sam Donta volunteered to be Co-Chair.

- Pat Smith also requested the list of NIH grants be released to the public.

- Timeline for subcommittee work and dates for the next two (in-person) TBDWG meetings were announced.

The next (in-person) public meetings will be held January 28 & 29, 2020 in Washington, DC and March 3 & 4, 2020 in Philadelphia, PA

For details visit HHS-TBDWG webpage

Comments to the TBDWG may be emailed directly to tickbornedisease@hhs.gov