Lyme Disease Association/Columbia University Important Announcement

Photo Credit: M. White/LDA File Photo

The Lyme Disease Association (LDA) and Columbia University jointly announce we have made a thoughtful but reluctant decision to postpone our annual fall 2020 CME Lyme & Other Tick-Borne Diseases Conference due to the worldwide coronavirus health emergency.

The safety and well being of everyone are primary concerns, and we hope everyone remains safe. See you next year! Thanks for your support.

LDA President, Pat Smith; Columbia University, Brian A. Fallon, MD
Need Congress Members to Sign/Columbia Study Participants/Maternal-Fetal Transmission/Alpha-Gal/Pres. TBD Budget/Longhorned Tick Infecting Cattle

Lyme Disease Needs Your Congressmen to Sign Onto Letters NOW!

Rep. Chris Smith
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](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.
Alpha-gal is a sugar molecule found in most mammals (not people, apes, monkeys) and in products made from mammals including medications, vaccines, cosmetics, gelatin and milk products. It is not normally found in fish, reptiles or birds. Alpha gal is also found in some types of ticks. Click here for CDC website on Alpha-gal

What is known is that Alpha-gal allergy is an allergy to that
alpha-gal molecule and it now appears to be associated with the bite of lone star ticks in the US. Other ticks may be involved, but the science is not yet settled in this newly emerging area. Alpha-gal is also found in other countries associated with the bite of different ticks.

**Symptoms can include:** Rash, Hives, Difficulty breathing, Drop in blood pressure, Dizziness or faintness, Nausea or vomiting, and Severe stomach pain, which commonly appear 3-6 hours after eating meat (e.g., beef, lamb, pork, venison, and rabbit) or exposure to products containing alpha-gal. They may not occur after every exposure and can vary with individuals.

**CDC:** Alpha-gal allergies can be severe, and even life-threatening. See a healthcare provider immediately if you are concerned about a severe allergic reaction.

Diagnosis can be made by an allergist, or other healthcare provider, through detailed patient history, physical examination, and a blood test for specific antibodies, IgE, to alpha-gal.

**Patients with Alpha-gal Syndrome:** There is a non-profit devoted to the identification, diagnosis, treatment, and prevention of tick-borne diseases, including alpha-gal, and other lesser known diseases. They are conducting a research study survey of people with Alpha-gal. If you are interested in more information on it: [See Alpha-gal on the TBC United website](https://www.med.unc.edu/medicine/news/chairs-corner/podcast/alpha-gal/) By clicking the link, you will have left the LDA website. The link is provided for you as a service. The LDA does not have a position on the information provided or on the study.

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

Experts Say New TBD Spread by Asian Longhorned Tick Threatens VA Cattle
According to a recent article in *The Culpeper Star-Exponent* researchers believe the protozoal parasite, named *Theileria orientalis* (*Ikeda* genotype), is transmitted through the saliva of the Asian Longhorned tick (*Haemaphysalis longicornis*), an invasive species, after being attached to its host for two to three days. Experts do not know how the preliminary infected tick arrived in Virginia.

*H. longicornis* was initially confirmed in Hunterdon County, NJ, on November 9, 2017, on a sheep farm, and a mystery still surrounds its appearance. The species survived the winter and was confirmed again in NJ in April 2018. The *Longhorned Tick Now Confirmed: NJ, VA, WV, AR, NC, NY, PA, CT, NH, KY, MD, & TN.*

So far, cases of *T. orientalis* in cattle have been confirmed in at least 21 counties throughout the state of Virginia including Madison, Fauquier, Orange, Greene, and Louisa. Symptoms include jaundice, anemia, lethargy, labored breathing, fever, diarrhea, anorexia, weight loss, and foamy nasal discharge. The disease is believed to cause abortions or stillbirths in pregnant cows, as well as cause a reduction in milk production by lactating cows. By the time cows are symptomatic, it may be too late to save the cow, and death can occur.

No medications exist for treating *T. orientalis*, and there is no vaccine. There does exist a “semi-effective” drug from New Zealand. It hasn’t been approved in the US and is said to cause issues that keep livestock off the market for up to 18 months.

Reference:


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**Two Columbia Studies Need Participants!**

Researchers at Columbia University Lyme and Tick-Borne Diseases Research Center are seeking research study participants for two studies. Women to serve as healthy controls are critical to conducting this first study on metabolomics, and patients with confirmed Lyme disease are needed for the second study on Lyme disease and Disulfiram. Please support these clinical studies.

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Dr. Brian Fallon,
Metabolomics study of Lyme disease: Columbia (Brian Fallon, MD) in collaboration with UCSD:

- Women in Manhattan NY area over next four weeks
- 6-10 healthy women ages 40-60 for controls come to Columbia lab for blood & urine testing, questionnaire, clinical evaluation, sensory testing
- Participants receive $75 & free copies of their bloodwork
- Email Lily Murray for details: lm3448@cumc.columbia.edu

Lyme patient Disulfiram study:

- 14 week disulfiram study (Brian Fallon, MD)
- Ages 18-65 with confirmed Lyme disease, persistent fatigue, don’t have other major medical comorbid problems, acquired Lyme within prior 16 years
- All research treatment is provided free of charge
- Inquiries on disulfiram study can be sent to: lymecenter@cumc.columbia.edu or can be made by phone 646-774-7503
- Weblink for this study: https://recruit.cumc.columbia.edu/clinical_trial/1661#

For details on these studies and other clinical research opportunities please visit Columbia University, Lyme and Tick-Borne Disease Research Center here.
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:

CDMRP Public Affairs
301-619-9783
usarmy.detrick.medcom-cdmrp.mbx.cdmrp-public-affairs@mail.mil

NOTE from Lyme Disease Association: Please do not contact us for information. Contact the CDMRP TBDRP directly. Thank you!
Lawsuit Update: Cigna Third Insurance Defendant to Settle

The Lyme Disease Association is providing the most recent update regarding Torrey vs. IDSA/Insurers, the federal lawsuit filed by 24 Lyme patients against six members of the Infectious Disease Society of America (IDSA) and eight insurance companies in the U.S. District Court for the Eastern District of Texas, Texarkana Division.

According to investigative journalist Mary Beth Pfeiffer, Cigna has now become the third insurance company defendant in the case to settle following Kaiser Permanente in November 2019 and Blue Cross Blue Shield of Texas (BCBST) in January 2020. Pfeiffer reports that, as was the case with the first two, the Cigna settlement is being handled in secret with sealed documents. The public may never know what the plaintiffs received, or what was accomplished during the hearings. The remaining defendants include the IDSA, five other insurance companies, and six Medical Doctors.

At this stage, this is all the information that has been made available. Details regarding the terms or amount of the settlements are unknown. The lawsuit was initially filed in 2017 on behalf of the group of Lyme disease patients who claim they have been denied care, as well as harmed, under existing
insurance and medical protocols. The litigation proceedings will continue in the U.S. District Court in Texarkana, Texas.

LDA will provide updates when we have them. You can also continue to watch for updates on Mary Beth Pfeiffer’s website and Twitter feed.

Click here to view the Notice of proposed settlement of Cigna Health and Life Insurance Company.

Click here to view the Notice of settlement of BCBS of Texas.

Click here to view the Settlement reached with Kaiser Permanente.

Referenced articles and websites:

