TBDWG Subcommittee Reports Now Accessible

The HSS-Tick-Borne Disease Working Group subcommittee reports are now accessible on the HHS-TBDBG 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 potential 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 will 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, including the meeting agenda and more details on how to provide public comment.
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.
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 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
HHS Announces Sep 12 Tick-Borne Disease Working Group Meeting

The Department of Health and Human Services (HHS) gave notice that the Tick-Borne Disease Working Group (TBDWG) will hold a public meeting via webcast on September 12, 2019, from 8:30 a.m. to 5 p.m. ET (times are tentative and subject to change).

At the upcoming meeting, the TBDWG will receive updates from eight subcommittees that were formed and tasked with drafting a 2019 report for the HHS Secretary and Congress regarding activities and research related to tick-borne diseases, such as surveillance, prevention, diagnosis, diagnostics, and treatment (source, hhs.gov). The subcommittees will take into consideration the 2018 report and are expected to identify gaps in tick-borne disease research as well as offer suggestions (source, federalregister.gov).

The confirmed times and agenda items for the online meeting will be posted on the TBDWG page of the HHS website. Members of the public who wish to view this meeting online are encouraged to register. Click here to register for the September 12th TBDWG Meeting.

Article References: FederalRegister.Gov and HHS.Gov

View the announcement for the 10th meeting of the TBDWG on FederalRegister.Gov
TBD Working Group Meeting Summary/Public Comments Now Available – June 4, 2019

The federal Tick-Borne Disease Working Group (TBDWG) held their ninth meeting in D.C. on June 4, 2019 with a focus on developing the next report to be drafted for the HHS Secretary and Congress. The report will include an update on federal tick-borne disease activities and research findings.

Read Meeting Summary and Written Public Comments – June 4, 2019 TBDWG Meeting

Still pending: Archived Webcast, Slide Presentation

Pat Smith Appointed to New Panel of the TBDWG

Patricia V. Smith, has been appointed as one of the public members of the new panel for Health and Human Services Tick-Borne Disease Working Group (TBDWG). Pat is in her 22 year as President of the all-volunteer run national non-profit Lyme Disease Association (LDA) and has been a leading voice and advocate for patients for over 3 decades. She was
instrumental in writing and passing the legislation that resulted in the formation of this federally mandated TBDWG. This appointment was announced publicly during the first meeting of the new TBDWG on June, 4, 2019.

Pat Smith, HHS TBDWG meeting, June 4, 2019. Photo courtesy of LymeDisease.org.

As witnessed during the meeting, Pat will continue to be the voice of the patient and the growing numbers of chronically ill. The panel convened for introductions, to hear public comment, and to develop subcommittee topics and establish subcommittee chairs to begin the work toward the next report to Congress due November of 2020. Unlike last term, nomination for subcommittee members will not be publicly solicited, but will be selected by the prospective co-chairs for each of the 7 subcommittees determined at the meeting.

Swearing in of the HHS TBDWG members, June 4, 2019. Photo
Pat served on the inaugural panel of the TBDWG, which presented it’s first report to Congress in November of 2018. She is joined for a second term by other returning members:

Charles Benjamin (Ben) Beard, Ph.D.-Deputy Director, Division of Vector-Borne Diseases, National Center for Emerging and Zoonotic Infectious Diseases, Centers for Disease Control and Prevention;

Dennis M. Dixon, Ph.D.-Chief, Bacteriology and Mycology Branch, National Institute of Allergy and Infectious Diseases, National Institutes of Health

Captain Estella Jones, DVM- Deputy Director, Office of Counterterrorism and Emerging Threats, Food and Drug Administration

Other new public and federal members and their alternates were also announced at the first meeting of the new TBDWG panel, which took place June 4, 2019 in Washington DC, and include:

Public Members

The new Working Group will be chaired by David Hughes Walker, M.D., Professor of Pathology and Executive Director, University of Texas Medical Branch Center for Biodefense and Emerging Infectious Diseases. He is an expert in Rickettsial diseases, particularly RMSF; and Leigh Ann Soltysiak, Owner, Principal, Silverleaf Consulting, LLC.


Scott Palmer Commins BS, M.D., Ph.D.– Associate Professor of
Medicine & Pediatrics, University of North Carolina at Chapel Hill; Member, UNC Food Allergy Initiative, Thurston Research Center (Chapel Hill, North Carolina)

Sam T. Donta, M.D.—Infectious Disease Consultant, Falmouth Hospital; and Former Member, U.S. Department of Defense Tick Borne Disease Research Programmatic Review Panel (Falmouth, Massachusetts)

Eugene David Shapiro, M.D.—Professor of Pediatrics, Epidemiology, and Investigative Medicine, Yale University School of Medicine; Vice Chair for Research of the Department of Pediatrics; Co-Director of Education for the Yale Center for Clinical Investigation; and Deputy Director of Yale’s PhD Program in Investigative Medicine (New Haven, Connecticut)

Regular Government Employees (Federal Members)

Commander Rebecca Bunnell, MPAS, PA-C—Senior Advisor, Learning and Diffusion Group, Innovation Center, Centers for Medicare and Medicaid Services

Angel M. Davey, Ph.D.—Program Manager, Tick-Borne Disease Research Program, Congressionally Directed Medical Research Programs, U.S. Department of Defense

Leith Jason States, M.D., MPH (FMF)—Deputy Chief Medical Officer, Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services

Adalberto (Beto) Pérez de León, M.D.—Director, Knipling-Bushland U.S. Livestock Insects Research Laboratory, Agricultural Research Service, U.S. Department of Agriculture

Alternate Government Employees (Federal Members)

Chien-Chung Chao, Ph.D.—Research Chemist, Viral and Rickettsial Diseases Department Infectious Diseases Directorate, Naval Medical Research Center, U.S. Department of Defense
Captain Scott J. Cooper, MMSc, PA-C- Senior Technical Advisor and Lead Officer for Medicare Hospital Health and Safety Regulations, Centers for Medicare and Medicaid Services

Shahla Jilani, M.D.-Deputy Chief Medical Officer, Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services

David A. Leiby, Ph.D.-Chief, Product Review Branch, Division of Emerging & Transfusion-Transmitted Diseases, Office of Blood Research & Review, Center for Biologics Evaluation & Research, Food and Drug Administration

Commander Todd Myers, Ph.D.-Scientist, Office of the Chief Scientist, Office of Counter Terrorism and Emerging Threats, Food and Drug Administration

Samuel S. Perdue, Ph.D.-Section Chief, Basic Sciences and Program Officer, Rickettsial and Related Diseases, Bacteriology and Mycology Branch, National Institute of Allergy and Infectious Diseases), National Institutes of Health

Susanna N. Visser, Dr.PH -Associate Director for Policy, Division of Vector-Borne Diseases, National Center for Emerging and Zoonotic Infectious Diseases, Centers for Disease Control and Prevention

HHS TBDWG website

HHS TBDWG Members Press release
L. Johnson on Meaningful Patient Representation on the next TBDWG

Lorraine Johnson, JD, MBA, Chief Executive Officer of LymeDisease.org delves into the importance of meaningful patient representation on the Federal HHS Tick-Borne Disease Working Group (TBDWG) in her latest blog. This is especially important as we await the announcement of panelists to the new TBDWG charged with the next report to Congress due in 2020. A recent patient survey conducted by lymedisease.org found “To be a meaningful representative, patients chosen for a panel should: a) have or be a caregiver to a patient with chronic Lyme disease and b) should be an officer or director or someone vetted and approved by a recognized and trusted patient advocacy group (PAG) or someone approved by a PAG.” Read the entire blog by Lorraine Johnson here:


TBD Working Group Meeting
Summaries Now Available – May 10, 15-16 & Jun 21, 2018

The May 10, May 15-16, and June 21, 2018 meeting summaries of the HHS Tick-Borne Disease Working Group are now available. Click on the following links and then click on “Meeting Summary.”

- June 21, 2018, TBDWG Meeting (on-line)
- May 15-16, 2018, TBDWG Meeting (in-person)
- May 10, 2018, TBDWG Meeting (on-line)

Click here to view information on other TBDWG meetings

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