

# 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 courtesy of LymeDisease.org.

Pat served on the inaugural panel of the TBDWG, which presented its 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.

*Robert Sabatino*– Founder and Executive Director, Lyme Society Inc., Staten Island, New York (Term expires in August 2019).

*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

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## 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:

*LYMEPOLICYWONK: Who represents Lyme disease patients? Why it matters.*

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# 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)

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[June 21, 2018, TBDWG Meeting \(on-line\)](#)

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[Click here to view information on other TBDWG meetings](#)

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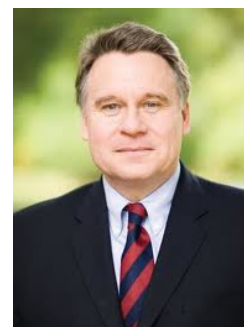
## **Solicitation of Nominations for Appointment to the Tick-Borne Disease Working Group**

<https://www.federalregister.gov/documents/2018/11/16/2018--25082/solicitation-of-nominations-for-appointment-to-the-tick-borne-disease-working-group>

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# **Congressman Chris Smith Press Release – 2018 Tick-Borne Disease Working Group Report Confirms Lyme is Spreading, Time for Action is Now**

First biennial report to Congress gives blueprint for federal response



**2018 Tick-Borne Disease Working Group Report Confirms Lyme is Spreading, Time for Action is Now**

Washington, Nov 14, 2018 | Matt Hadro ((202) 225-3765)

The 2018 Tick-Borne Disease Working Group Report to Congress—the very first report by the new HHS Working Group—confirms what Rep. Chris Smith (R-NJ) and other advocates have long warned of, that incidents of Lyme disease and other tick-borne diseases are increasing and that more federal attention to the problem is needed, Smith said on Wednesday.

**[Click here for full Press Release from the office of Congressman Chris Smith](#)**



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# Nov. 14: HHS Tick-Borne Disease Working Group Announces Release of Report to Congress; Centers for Disease Control & Prevention Announces Higher than Ever Lyme Disease Cases

Two major releases from the US Government today confirm what advocates and patients have long known – there is a growing Lyme & tick-borne diseases problem sweeping the land and Congress needs to take action to curb the spread.



In a release long awaited by the Lyme community, the US Department of Health & Human Services announced today that the federal Tick-Borne Disease Working Group (WG) issued its first report to Congress, the Secretary of the Department of Health & Human Services, and the public—with 2 more reports to follow over the next four years.

Recommendations to Congress include improvement in diagnosis & treatment including new rapid & accurate tests; development of antibiotic combinations and/or therapeutic options for acute and persistent illness; strengthening national surveillance;

pathogen-host interaction; federal strategic plan development; funding for TBD; and effects of TBD on national security/service members/veterans/families.

According to Lyme Disease Association, Inc. (LDA) President Pat Smith—one of the 14 members of the Working Group—speaking on behalf of the LDA, “Patients and advocates have waited decades for a government report that contains insights from Lyme patients/family members and advocates as this report does, both from WG members and from the public at large. The report is a first step to unlocking the political gridlock surrounding tick-borne diseases, particularly Lyme.”

She added, “Many of us are horrified that after 45 years of Lyme disease, new generations of babies continue to become infected and not receive the proper diagnosis and treatment needed to prevent lifelong suffering. Now this document, prepared using expert and “real world” input, will be used to inform Congress so they can act to provide the necessary funds to stop this tick-borne disease epidemic sweeping our country.”

**[Click here for Working Group Press Release](#)**

**[Click here for Working Group Report to Congress](#)** (Click on “2018 TBDWG Report to HHS Secretary and Congress – PDF”)

**[Click here for story on report & new CDC numbers](#)**

**[Click here for Congressman Chris Smith’s Press Release](#)**

**[Click here for Asbury Park Press – Lyme Disease: Federal panel recommends testing overhaul, more changes to Congress](#)**

**CDC Report on Case Numbers**

In a separate release by the Centers for Disease Control & Prevention (CDC) on the state of tick-borne diseases in the US, CDC introduced its new platform for reporting Lyme disease statistics. The release indicates that there has been an

increase in all tick-borne diseases, not just Lyme disease, and that it is the highest total annual number of Lyme cases ever reported at 42,743 cases, and a total of all reported tick-borne diseases of 59,349, which includes Lyme, anaplasmosis/ehrlichiosis, spotted fever rickettsiosis, babesiosis, tularemia, and Powassan virus.

The Lyme Disease Association, Inc. reminds the public that Lyme is underreported by a factor of 10, therefore, 427,430 cases of Lyme disease probably occurred in 2017 in the U.S. alone.

**[Click here for CDC Report](#)**

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## **Tick-Borne Disease Working Group 7th Meeting, July 24 – Online and Open for Comment**

<https://lymediseaseassociation.org/government/federal-government/govt-departments-a-policies/hhs-tbd-working-group/press-release-from-congressman-chris-smith-on-hhs-working-group/news>

**Update:** [Click here for Draft of TBD Working Group's report to Congress](#)

The seventh meeting of the Tick-borne Disease Working Group will be held on July 24, 2018, from 10:00 a.m. to 4:00 p.m. EDT. The Working Group will review and vote on the content of the five chapters that will be submitted into the Working Group Congressional Report. **Please Note:** If you would like to

receive a copy of the draft chapters, please submit a request to [tickbornedisease@hhs.gov](mailto:tickbornedisease@hhs.gov). The meeting materials will be emailed to you prior to the meeting. We encourage you to register [for](#) for the meeting.

**Update: Click here for Draft of TBD Working Group's report to Congress**

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**Please Note:** If you would like to receive a copy of the draft chapters, please submit a request to [tickbornedisease@hhs.gov](mailto:tickbornedisease@hhs.gov). The meeting materials will be emailed to you prior to the meeting.

We encourage you to register [for](#) for the meeting.

**Members of the public can attend the meeting via webcast.**

You must sign up [to](#) to watch the live webcast. Once signed-up, you will receive a link to access the meeting.

The conference call number to access the meeting is 1-888-935-0263 Passcode: 5409210

**Written Public Comment**

Additional comments will be added up through July 19.

**Public Comment – Information and Instructions**

The Working Group invites public comment on issues related to its charge. You have the option of verbal comment, written comment or both. Thus, if you provide verbal comment, you may also submit it as written comment or submit written comment on a different issue.

**Verbal (by phone) comments:**

- Requests to provide verbal public comment must be submitted via email **by July 19, 2018 EDT** to tickbornedisease@hhs.gov.
  - In the Subject line please enter: **Verbal Public Comment – July 24 Meeting.**
- A total of 30 minutes has been set aside for verbal comments. Each person will be limited to 3 minutes in order to accommodate as many speakers as possible.
- If more requests are received than can be accommodated, speakers will be randomly selected.
- Your remarks will be broadcast over a live webcast and will become part of the archived recording and meeting transcripts that will be posted on this website.

#### **Written comments:**

- Written public comments must be submitted via email **by July 19, 2018 EDT** to tickbornedisease@hhs.gov.
  - In the Subject line please enter: **Written Public Comment – July 24 Meeting.**
- Written comments will be posted on the Tick-Borne Disease Working Group website and accessible to the public.
- **IMPORTANT:** When you submit your written comment, please include how you would like to be identified with your comment. That is, you may use your name or request to be anonymous. You may also include your city and/or state. If you are providing comments on behalf of an organization you also may include your name, organization, and organization email address. We do NOT post phone numbers or personal email addresses.
- Comments should be no more than 4 pages in Calibri or Times New Roman, 11 point font. Text that exceeds the 4 pages will be deleted.
- Written comments should either be provided in the body of the email, or in an attachment in Word format.
- Please do not include graphics, images, or text boxes.

If included, we will not be able to retain them. Simple tables are acceptable.

- We can only retain links to “.gov” sites (state or federal). For all other reference sites, please insert the full URL (e.g., [https://www.jscimedcentral.com/ClinicalCytology/clinical\\_cytology-3-1085.pdf](https://www.jscimedcentral.com/ClinicalCytology/clinical_cytology-3-1085.pdf)).
- Do not include attachments as supporting documentation to your written comments; instead, please list them as references.

**[Click here for more information including Agenda](#)**

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## **Tick-Borne Disease Working Group 6th Meeting, June 21 – Online and Open for Comment**

From HHS.gov – The sixth meeting of the Tick-borne Disease Working Group will be from **9:30 a.m. to 6:30 p.m. (Eastern)** on June 21. The Working Group will focus on consensus of the six subcommittee findings and determine the major content of the five chapters that will be submitted into the Working Group Congressional Report. **Note:** If you would like to receive a copy of the draft chapters, please submit a request to [tickbornedisease@hhs.gov](mailto:tickbornedisease@hhs.gov). The document will be emailed to you prior to the meeting. We encourage you to **register** for the on-line meeting, where you can indicate if you would like to provide verbal and/or written public comment and receive updates about the Working Group. **Members of the public can attend the meeting via webcast.** You must **sign-up** to watch the live webcast.

From HHS.gov

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We encourage you to **register** for the on-line meeting, where you can indicate if you would like to provide verbal and/or written public comment and receive updates about the Working Group.

**Members of the public can attend the meeting via webcast.**

You must **sign-up** to watch the live webcast. Once signed-up, you will receive a link to access the June 21st meeting. Please use this conference call information to access the audio portion: 1-888-324-8114 Passcode: 5409210

Written Public Comment

**Public Comment – Information and Instructions**

The Working Group invites public comment on issues related to its charge. You have the option of verbal comment, written comment or both. Thus, if you provide verbal comment, you may also submit it as written comment or submit written comment on a different issue.

**Verbal (by phone) comments:**

- Requests to provide verbal public comment must be submitted via email **by June 18, 2018 (Eastern)** to [tickbornedisease@hhs.gov](mailto:tickbornedisease@hhs.gov). In the Subject line please enter: **Verbal Public Comment – June 21 Meeting.**
- A total of 30 minutes has been set aside for verbal

comments. Each person will be limited to 3 minutes in order to accommodate as many speakers as possible.

- If more requests are received than can be accommodated, speakers will be randomly selected.
- Your remarks will be broadcast over a live webcast and will become part of the archived recording and meeting transcripts that will be posted on this website.

#### **Written comments:**

- Written public comments must be submitted via email **by June 18, 2018 (Eastern)** to [tickbornedisease@hhs.gov](mailto:tickbornedisease@hhs.gov). In the Subject line please enter: **Written Public Comment – June 21 Meeting**.
- Written comments will be posted on the Tick-Borne Disease Working Group website and accessible to the public.
- Comments should be no more than 4 pages in Calibri or Times New Roman, 11 point font. Text that exceeds the 4 pages will be deleted.
- Written comments should either be provided in the body of the email, or in an attachment in Word format.
- Please do not include graphics, images, or text boxes. If included, we will not be able to retain them. Simple tables are acceptable.
- We can only retain links to “.gov” sites (state or federal). For all other reference sites, please insert the full URL (e.g., [https://www.jscimedcentral.com/ClinicalCytology/clinical\\_cytology-3-1085.pdf](https://www.jscimedcentral.com/ClinicalCytology/clinical_cytology-3-1085.pdf)).
- Do not include attachments as supporting documentation to your written comments; instead, list them as references.
- **IMPORTANT:** When you submit your written comment, please include a statement letting us know how you would like your comments to be identified. This information will be used to link you with your comments. 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 we will identify you and the organization, if you provide a statement requesting we include this information.

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## **Previous TBD Working Group Meetings on HHS.gov**

See summaries, transcripts, slide presentations, written public comment, transcripts of verbal comment, agendas, and webcasts.

May 15-16, 2018, TBDWG Meeting (in-person)

May 10, 2018, TBDWG Meeting (on-line)

February 12, 2018, Meeting (on-line)

December 11 and 12, 2017, Meetings (in-person)

See summaries, transcripts, slide presentations, written public comment, transcripts of verbal content, agendas, and webcasts.

May 15-16, 2018, TBDWG Meeting (in-person)

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February 12, 2018, Meeting (on-line)

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