

Contentious Working Group Meeting Vote on CDC Posting Lyme Guidelines

Tick-Borne Disease Working Group

The thirteenth meeting of the [Tick-Borne Disease Working Group](#) (Working Group) was held online on April 27, 2020, from 9:00 a.m. to 12:30 p.m., ET. This meeting was open to the public, with request to comment accepted by April 19, 2020.



HHS Tick-Borne Disease Working Group

The Working Group reviewed the work of the Public Comment Subcommittee followed by the Federal Inventory Subcommittee. The Working Group had sent inventories with a series of questions to the federal agencies, and the Inventory Subcommittee of David Walker (Chair), Sam Donta MD, and LDA President Pat Smith developed recommendations based on gaps in agency programs/research. The WG voted on the various recommendations for each agency to be brought forward in the Working Group Report to be submitted to Congress.

The Working Group members engaged in heated discussion regarding one recommendation “that IF the CDC posts any Lyme treatment guidelines, that they include guidelines on persistent Lyme disease.” Pat Smith, Lyme Disease Association President, argued persuasively on behalf of the chronic Lyme patient community, in favor of this recommendation. After the vote to pass the recommendation, some members wanted to change votes. So a member moved to revote causing a long discussion on the advisability/legality of such a vote. The Working Group federal official researched the question and indicated it was a dangerous precedent. Despite that, a revote was taken to permit a revote. It failed. So the original vote accepting the recommendation stands. Ms. Smith asked when the actual inventories would be released to the public, and after a discussion, the federal official indicated they could be.

Two Votes Taken

“Recommend that IF the CDC posts any Lyme treatment guidelines, that they include guidelines on persistent Lyme disease.” Pat Smith moved, Sam Donta, MD seconded the motion.

Vote Results 6 YES, 3 NO, 5 ABSTAIN, 1 ABSENT

“Motion to have a revote on the last vote” Scott Commins, MD moved, Eugene Shiparo seconded the motion.

Vote Results 5 YES, 6 NO, 0 ABSTAIN, 1 ABSENT

Roll Call Vote of Members

- Captain Scott J. Cooper, PA-C (government member) Centers for Medicare and Medicaid Services (CMS), HHS
VOTE ON GUIDELINES RECOMMENDATION: YES VOTE ON REVOTE: NO
- Angel M. Davey, PhD (government member) Tick-Borne

Disease Research Program, Congressionally Directed Medical Research Programs, U.S. Department of Defense, DoD

VOTE ON GUIDELINES RECOMMENDATION: YES VOTE ON REVOTE: NO

- Dennis M. Dixon, PhD (government member) National Institute of Allergy and Infectious Diseases (NIAID/NIH), HHS

VOTE ON GUIDELINES RECOMMENDATION: YES *post vote, wanted to change to Abstain **VOTE ON REVOTE: NO**

- Sam T. Donta, MD –Professor of Medicine (ret.) (public member)

VOTE ON GUIDELINES RECOMMENDATION: YES VOTE ON REVOTE: NO

- Patricia V. Smith- (public member) Lyme Disease Association, Inc.

VOTE ON GUIDELINES RECOMMENDATION: YES VOTE ON REVOTE: NO

- Charles Benjamin (Ben) Beard, PhD (government member) Division of Vector-Borne Diseases, Centers for Disease Control and Prevention (CDC)

VOTE ON GUIDELINES RECOMMENDATION: NO VOTE ON REVOTE: YES

- Eugene David Sharpiro, MD (public member) Yale University School of Medicine

VOTE ON GUIDELINES RECOMMENDATION: NO VOTE ON REVOTE: YES

- David Hughes Walker, MD, (public member) TBDWG co-chair, UTMB Center for Biodefense & Emerging Infectious Diseases

VOTE ON GUIDELINES RECOMMENDATION: NO VOTE ON REVOTE: NO

- Scott Palmer Commins, MD, PhD (public member) – University of North Carolina

VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN VOTE ON REVOTE: YES

- CDR Todd Myers, PhD (government member) Food and Drug

Administration, HHS

**VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN VOTE ON
REVOTE: YES**

- Adablбето (Beto) Perez de Leon, DVM, PhD (government member) Department of Agriculture (USDA), HHS

**VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN VOTE ON
REVOTE: YES**

- Kevin R. Macaluso, PhD, MS (government member) University of South Alabama

**VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN VOTE ON
REVOTE: NO**

- Leigh Ann Soltysiak, MS (co-chair) (public member) Silverleaf Consulting, LLC Adjunct Professor, Stevens Institute of Technology

**VOTE ON GUIDELINES RECOMMENDATION: ABSTAIN VOTE ON
REVOTE: YES**

- Leith States (government member) Deputy Chief Medical Officer Office of the Assistant Secretary for Health, HHS

**VOTE ON GUIDELINES RECOMMENDATION: ABSENT VOTE ON
REVOTE: ABSENT**

The TBDWG, received verbal comments from the public on a range of topics including:

- Dorothy Leland, Vice-President of Lymedisease.org presented for Phyllis Mervine, President of Lymedisease.org comments on the need for Lyme disease treatment guidelines similar to COVID-19 guidelines as posted by NIH. She stated COVID-19 won't stop tick season, and for Lyme disease treatments, ultimately the choice of what to do for an individual patient should be decided by the patient and their treating physician, just as it is recommended in the [COVID-19 NIH treatment guidelines](#).
- Lucy Barnes, Lyme advocate, presented comments on the

Infectious Diseases Society of America's (IDSA's) outdated Lyme treatment guidelines, which she stated has discredited anything, and anyone, that disrupts their status quo, often resulting in name calling and demeaning the character of both patients and their treating physicians.

- Beth Carrison, from TBC united, commented on the unique health challenges faced by Alpha-gal patients in light of the current COVID-19 treatments. She pleaded for an urgent Health Alert to be posted in order to help protect these at risk patients.
- Stephen Rich, professor of Microbiology at University of Mass, TickReport Lab commented on the value of tick testing and prevention messaging that accompanies their tick testing reports. He urged the CDC to review their stance against tick-testing.

The meeting concluded after updates on the status of the writing groups for each of the assigned chapters being developed for the 2020 report to Congress on federal tick-borne activities and research. The next public virtual meeting is scheduled for July 8, 2020.

LDA encourages patients, advocates, caregivers and family of Lyme disease patients to submit verbal or written comments about Lyme disease to the TBDWG for the July 8th meeting and to attend the meeting online.

Read Lymedisease.org VP, Dorothy Leland's, Bizarre happenings at the TBD Working Group Blog [here](#).

Read Lymedisease.org, President, Phyllis Mervine's, NIH's COVID-19 guidelines offer useful advice for Lyme disease, too Blog [here](#).

Visit the [HHS TBDWG webpage](#) for more information, **including how to submit verbal and written public comments.**

Click [here](#) to view information about prior TBDWG meetings.

TBDWG Mtg 12: Training, Education, Patient Access to Care (Video)

The Lyme Disease Association Inc. (LDA) feels it is imperative that the Lyme Community and the public understand the continued resistance by government agencies to provide information pertaining to chronic Lyme disease on their websites and in their programs despite Lyme disease being around 45 years. LDA has provided video clips from the HHS Tick-Borne Disease Working Group meeting in Philadelphia which portray that resistance. Decades long advocate, LDA President, Pat Smith, the WG patient rep, rebuts these entrenched positions. Please note, however, that the federal government WG representatives are required by FACA WG rules to espouse and vote their agency's position, which may not necessarily their own personal position.

[TBD Working Group Committee Members](#) / [Meeting #12 Agenda](#) / [LDA Written Summary of Meeting](#)

Full Video: [March 3rd – Day 1](#) / [March 4th – Day 2](#)

Other Video Clips: [Sam Donta, MD and Other](#) / [Public Comment \(9 speakers\)](#)

Working Group (WG) Discussion on Training, Education, Access to Care, and Reimbursement Subcommittee Recommendations

Co-Chairs: Pat Smith, President; LDA / Captain Scott Cooper, PA; CMS

<p><u>1-Govt. Website Disclosures</u></p>	<p><u>10-B. Beard: Not Acknowledging Both Sets of Guidelines on Website</u></p>	<p><u>19-B. Beard: Raises Issue With Curriculum Recommendation – FACA Violation</u></p>
<p><u>2-CDC Surveillance Revisions</u></p>	<p><u>11-LA Soltysiak WG Co-Chair / D.Dixon NIH Response on Guidelines</u></p>	<p><u>20-P. Smith: Responds to Ben Beard FACA Violation Concern</u></p>
<p><u>3-Nationwide Lyme Clinical Training</u></p>	<p><u>12-P. Smith: Federal Agencies have not done their Job!</u></p>	<p><u>21-S. Cooper & WG Continue Curriculum Discussion</u></p>
<p><u>4-Govt. Website Disclosure Discussion</u></p>	<p><u>13-S. Donta: Agencies Must Revisit Failures/Limitations for Chronic/Persistent Disease</u></p>	<p><u>22-P. Smith: Rebuttal to CDC Curriculum Comments</u></p>
<p><u>5-P. Smith Defends Chronic Lyme Patients</u></p>	<p><u>14-B. Beard: Addresses what Chronic Lyme Patients have had to Endure and Complexity of Moving Policy Forward Within a Large Agency</u></p>	<p><u>23-WG Continues Curriculum Discussion & Votes</u></p>
<p><u>6-P. Smith Questions WG Process/FACA</u></p>	<p><u>15-Committee Edits/Votes on Government Website Disclosure Wording</u></p>	<p><u>24-P. Smith: Legal for D. Walker To Vote In Place of E. Shapiro / Answered by J. Berger, HHS</u></p>

<u>7-P. Smith Questions Communication Betwn. WG & the Non Transparent WG</u>	<u>16-P. Smith: Surveillance Revisions</u>	
<u>8-P. Smith: FDA Position on Guidance vs. Guidelines, Why Chronic Cannot be Acknowledged</u>	<u>17-Committee Discussion on Surveillance Revision / Vote: P. Smith, No!</u>	<u>25-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 1</u>
<u>9-P. Smith: NIH/CDC Agency Guidelines/Positions – why is chronic Lyme completely ignored?</u>	<u>18-S. Cooper & WG Discuss Nationwide Curriculum</u>	<u>26-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 2</u>

1 – P. Smith: Govt. Website Disclosures (5 + min)

9:59:06 to 10:04:38

35946 to 36278

2- P. Smith: CDC Surveillance Revisions (5+ min)

10:04:39 to 10:10:37

36279 to 36637

3- S. Cooper: Nationwide Lyme Clinical Training (4+ min)

10:10:38 to 10:15:35

36638 to 36935

4- Govt. Website Disclosure Discussion (10 min)

10:16:15 to 10:36:14

36975 to 38174

5- P. Smith Defends Chronic Lyme Patients (4+ min)

10:36:14 to 10:40:18

38174 to 38418

DAY 2

6-P. Smith Questions WG Process/FACA (1+ min)

2:18:37 to 2:20:12

8317 to 8412

**7-P. Smith Questions Communication Betwn. WG & the Non
Transparent WG (1+ min)**

2:20:12 to 2:22:02

8412 to 8522

**8-P. Smith: FDA Position on Guidance vs. Guidelines, Why
Chronic Cannot be Acknowledged (3+ min)**

2:22:02 to 2:25:15

8522 to 8715

**9-P. Smith: NIH/CDC Agency Guidelines/Positions – why is
chronic Lyme completely ignored? (9+ min)**

2:25:15 to 2:34:30

8715 to 9270

**10-B. Beard: Not Acknowledging Both Sets of Guidelines on
Website (11+ min)**

2:34:30 to 2:35:41

9270 to 9341

**11-LA Soltysiak WG Co-Chair / D.Dixon NIH Response on
Guidelines (4+ min)**

2:35:42 to 2:39:45

9342 to 9585

**12-P. Smith: Federal Agencies have not done their Job! (3+
min)**

2:39:45 to 2:43:13

9585 to 9793

13-S. Donta: Agencies Must Revisit Failures/Limitations for Chronic/Persistent Disease (6+ min)

2:43:14 to 2:49:17

9794 to 10157

14-B. Beard: Addresses what Chronic Lyme Patients have had to Endure and Complexity of Moving Policy Forward Within a Large Agency (2+ min)

2:49:27 to 2:52:00

10167 to 10320

15-Committee Edits/Votes on Government Website Disclosure Wording (26+ min)

2:52:00 to 3:18:38

10320 to 11918

16-P. Smith: Surveillance Revisions (1+ min)

3:18:56 to 3:20:20

11936 to 12020

17-Committee Discussion on Surveillance Revision / Vote: P. Smith, No! (15+ min)

3:20:23 to 3:36:16

12023 to 12976

18-S. Cooper & WG Discuss Nationwide Curriculum (9+ min)

3:36:29 to 3:46:10

12989 to 13570

19-B. Beard: Raises Issue With Curriculum Recommendation – FACA Violation (11+ min)

3:46:12 to 3:47:25

13572 to 13645

20-P. Smith: Responds to Ben Beard FACA Violation Concern (1+ min)

3:47:27 to 3:48:54

13647 to 13734

21-S. Cooper & WG Continue Curriculum Discussion (4+ min)

3:48:54 to 3:53:42

13734 to 14022

22-P. Smith: Rebuttal to CDC Curriculum Comments (1+ min)

3:53:42 to 3:54:51

14022 to 14091

23-WG Continues Curriculum Discussion & Votes (27+ min)

3:54:51 to 4:22:34

14091 to 15754

24-P. Smith: Legal for D. Walker To Vote In Place of E. Shapiro / Answered by J. Berger, HHS (50 sec)

4:22:34 to 4:23:25

15754 to 15805

25-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 1 (43+ min)

9:57:06 to 10:40:26

35826 to 38426

26-Entire Discussion on Training, Education, Access to Care and Reimbursement: Day 2 (2 hr 4 min)

2:18:37 to 4:23:27

8317 to 15807

TBDWG Mtg 12: S. Donta, MD: Lyme / Other Clips (Video)

[TBD Working Group Committee Members / Meeting #12 Agenda / LDA Written Summary of Meeting](#)

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Other Video Clips: [Training, Education, Access to Care Discussion](#) / [Public Comment \(9 speakers\)](#)

1-S. Donta: Pathogenesis, Physiology of Lyme	4-S. Donta: Clinical Aspects of Lyme Including Potential Sexual Transmission	7-Use of Doxy for RMSE
2-P. Smith: Comments on Lyme Carditis, Tissue Testing Prob.	5-S. Donta: Maternal Fetal Transmission / Congenital Lyme Vote	8-Rickettsial CME Education
3-S. Donta: Comm. Discussion/Vote on Lyme Issues	6-Diagnostics Discussion	9-Alpha Gal & Data Mining

Sam Donta, MD: Discussion of Pathogenesis and Physiology of Lyme Disease Subcommittee Recommendations (Day 2)

Co-Chairs: Sam Donta, MD; Prof. of Medicine (Ret) and Leith Jason States, MD, MPH; HHS

This section includes determining the mechanisms underlying the persistence of *B burgdorferi* in the host; determining the role of persistence of *B. Burgdorferi* or its components in the pathogenesis of Lyme arthritis and persistent Lyme disease; and determining the pathogenesis, pathophysiology, and effective treatment of Lyme carditis.

1-S. Donta: Pathogenesis, Physiology of Lyme

4:40:19 to 5:28:12

19619 to 19692

2-P. Smith: Comments on Lyme Carditis, Tissue Testing Prob.

5:28:13 to 5:30:07

19693 to 19807

3-S. Donta: Comm. Discussion/Vote on Lyme Issues

5:30:07 to 5:33:28

19807 to 20008

Sam Donta, MD: Discussion of Clinical Aspects of Lyme Disease Subcommittee Recommendations (Day 2)

Co-Chairs: Sam Donta, MD; Prof. of Medicine (Ret) and Captain Scott Cooper; CMS

This section includes conducting additional targeted controlled clinical treatment trials in patients with early and persistent Lyme disease, using different antibiotic regimens and longer durations of treatment than those used in previously conducted trials; educating clinicians as to the limitations of currently available tests in the diagnosis and in the monitoring of treatment of patients with persistent Lyme disease; further evaluating potential maternal-fetal transmission of Lyme disease and of congenital Lyme disease. (Passed); and further evaluating purported human-to-human sexual transmission of Lyme disease.

4-S. Donta: Clinical Aspects of Lyme Including Potential

Sexual Transmission

5:34:09 to 6:59:48

20049 to 25188

5-S. Donta: Maternal Fetal Transmission / Congenital Lyme Vote

7:35:30 to 7:44:41

27330 to 27881

Other Video Clips:

6-Diagnostics Discussion

3:47:25 to 3:50:35

13645 to 13835

7-Use of Doxy for RMSF

3:54:12 to 3:57:04

14052 to 14224

8-Rickettsial CME Education

4:06:40 to 4:12:37

14800 to 15157

9-Alpha Gal & Data Mining

8:30:00 to 9:28:01

30600 to 34081

TBDWG Mtg 12: Public Comments (Video)

At the start of the second day of the HHS Tick-Borne Disease Working Group meeting in Philadelphia on March 4, 2020, nine Lyme disease advocates and patients who preregistered either

called in or were present at the meeting in person to provide public comments. Their input was invaluable and helped Working Group members appreciate issues of concern throughout the country.

[TBD Working Group Committee Members / Meeting #12 Agenda / LDA Written Summary of Meeting](#)

Full Video: [March 3rd – Day 1](#) / [March 4th – Day 2](#)

Other Video Clips: [Training, Education, Access to Care / Dr. Donta, MD & Other](#)

Public Comments: Day 2, March 4th

Lonnie Markham, LD0-Tick Attachment Time	Phyllis Mervine, Pres LD0- 2 Standards of Care	Mira Shapiro, LD0-Big Data Research
Dorothy Leland, VP LD0-Process Integrity	Melissa Potter, LD0- Patient Registry-MyLymeData	Jennifer Platt,TBC United-Alpha-gal & lesser known conditions
Mark Liberto-Patient Story	Dr. Betty Maloney-CDC Treatment Recommendations	Jill Auerbach-Prevention Emergency

Lonnie Markham, LD0: Tick Attachment Time

1:41:57 to 1:44:42

6117 to 6282

Dorothy Leland, VP LD0: Process Integrity

1:52:05 to 1:55:17

6725 to 6917

Mark Liberto: Patient Story

1:55:18 to 1:59:11

6918 to 7151

Phyllis Mervine, President LD0: 2 Standards of Care

1:59:14 to 2:02:39

7154 to 7359

Melissa Potter, LD0: Patient Registry-MyLymeData

2:02:40 to 2:05:39

7360 to 7539

Dr. Betty Maloney: CDC Treatment Recommendations

2:05:40 to 2:08:47

7540 to 7727

Mira Shapiro, LD0: Big Data Research

2:08:49 to 2:11:55

7729 to 7915

Jennifer Platt, TBC United: Alpha-gal & lesser known conditions

2:11:55 to 2:15:04

7915 to 8104

Jill Auerbach, HVLDA: Prevention Emergency

2:15:05 to 2:18:01

8105 to 8281

12th meeting of the TBDWG- Summary



Tammy R. Beckham, Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP), US Health and Human Services (HSS)

The 12th meeting of the Tick-Borne Disease Working Group (TBDWG) took place over two days, March 3rd-4th, 2020, at The College of Physicians of Philadelphia in Philadelphia, PA. A summary of this in-person public meeting is as follows:

- Opening statements were presented by Tammy R. Beckham, Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP), US Health and Human Services (HSS).
- The TBDWG discussed and voted on recommendations for the format/template of the 2020 TBDWG Report to the HHS Secretary and Congress. There was full agreement by the TBDWG to use the same format/branding of the 2018 TBDWG Report for the 2020 TBDWG Report to HHS Secretary and Congress.
- Ben Beard, Deputy Director, Division of Vector-Borne Diseases, Centers for Disease Control and Prevention (CDC) provided an update to the CDC Tick Surveillance program. CDC has increased monies and [guidance](#) being provided to States to conduct active tick surveillance activities. In addition, the CDC will provide both tick identification and testing services for States that do not have the expertise needed to conduct these activities.
- Public comment was provided by eleven patients/advocates to the TBDWG. These patients/advocates provided

heartfelt comments on both personal experience as well as recommended research needs. ([click here for public comments](#))

- Each of the eight Subcommittee chairs brought forward their top three recommendations which were developed from the [reports each of the TBDWG subcommittees](#). The TBDWG discussed and modified each of the three recommendations from each subcommittee and then voted to accept the recommendations to include in the report.
- Writing co-leads were determined for each section of the report. And next TBDWG meeting dates were discussed for May/April and July, 2020, though not yet set.



LDA President, Pat Smith, at 12th meeting of the TBDWG, Philadelphia, PA

Though the TBDWG worked through many of the subcommittee recommendations with good consensus, discussions regarding the recommendations brought forth by LDA President, Pat Smith for the “Training, Education, Access to Care and Reimbursement” subcommittee became heated ([click here for video](#)) as Pat asked the Federal agency representatives for agreement on website disclosures to increase public awareness for the two divergent diagnostic and treatment and approaches reflected in guidelines for Lyme disease. ([video clips: Training, Education, Access to Care and Reimbursement](#))

Ben Beard, CDC, commented after reading an excerpt from a 1990’s report, that the situation patients face today is very much unchanged from what they faced back then and that this is a “heartbreaking, tragic, failure of Public Health.” However,

he also stated that “The vast majority of Lyme disease patients are served quite well by the guidance we have on our website. The diagnostic test is reliable in terms of it telling you what you expect to hear.”

During discussions, Pat implored to the TBDWG, “You have left out a whole entire group of people...the chronic people. These are the people that need the help.” She further stated that “it’s the chronic population that’s being neglected and marginalized.”

LymeDisease.org provides a video clip of Pat Smith’s continued strong advocacy for patient needs in Dorothy Leland’s March 5th, Touched by Lyme blog [here](#).

For upcoming meeting notifications please visit the HHS-TBDWG webpage [here](#).

Public comments may be made in writing directly to the HHS-TBDWG at tickbornedisease@hhs.gov

Associated Links

[TBD Working Group Home Page](#)

[TBD Working Group Committee Members](#)

[Meeting #12 Agenda / Summary / Written Public Comment](#)

Video Clips

[Training, Education, Access to Care](#)

[Dr. Donta, MD & Misc. Other](#)

[Public Comments](#)

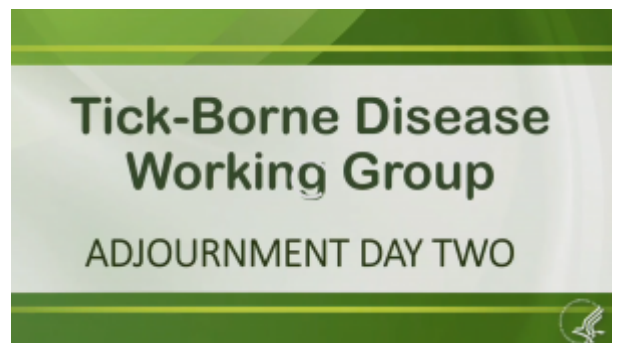
Full Video

[March 3rd – Day 1](#)

[March 4th – Day 2](#)

11th Meeting of TBDWG – January 28-29, 2020 Summary

The 11th meeting of the Tick-borne Disease Working Group (TBDWG) was held at the Hyatt Place Washington DC/US Capitol, 33 New York Avenue NE, Washington, DC.



During the two-day meeting, the Working Group 1) heard presentations on findings and actions for TBDWG to consider from eight subcommittees; 2) heard updates from the [Public Comment](#) and Inventory Subcommittees; and 3) continued discussion of plans for the development of the 2020 report to Congress on federal tick-borne activities and research.

The first day's meeting on January 28th went from 8:30 AM – 4 PM. Click [here](#) to view the meeting summary.

The second day's meeting on January 29th went from 9 AM – 4:30 PM. Click [here](#) to view the meeting summary.

In June of 2019 the TBDWG established eight subcommittees, each identified priorities and developed a report to the TBDWG that described current efforts, gaps in research, and potential actions relevant to their topic. Click [here](#) to view the subcommittee reports.

Click [here](#) to view Public Comments from the January 28-29 meeting.

For more information visit the [HHS.gov](https://www.hhs.gov) page.

Further questions or comments can be sent to:

James Berger, Designated Federal Officer for the TBDWG Office of Infectious Disease and HIV/AIDS Policy

Office of the Assistant Secretary for Health, Department of Health and Human Services

Mary E Switzer Building, 330 C Street SW, Suite L600

Washington, DC 20024. Email: tickbornedisease@hhs.gov; Phone: 202-795-7608

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 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

The logo for the Tick-Borne Disease Working Group features a green gradient bar at the top. Below it, the text "Tick-Borne Disease Working Group" is displayed in a dark green, sans-serif font on a light green background.

(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.,

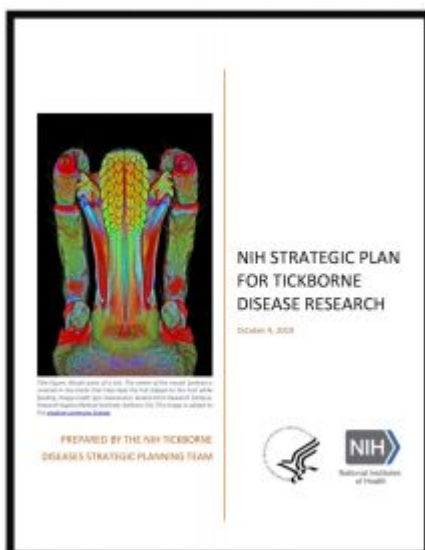
<http://learn.genetics.utah.edu/content/epigenetics>).

- 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.

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:

<https://lymediseaseassociation.org/news/lda-provides-input-to-national-institutes-of-health-strategic-plan-development>

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 avocates 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 tickboredisease@hhs.gov