

# 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](mailto:tickbornedisease@hhs.gov)

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### **Associated Links**

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[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