

Tick-Borne Disease Working Group

Meeting #5 | May 15-16, 2018

Arlington, VA

Day 2

Tick-Borne Disease Working Group



Welcome



John N. Aucott, M.D. (Chair)

Associate Professor, Division of Rheumatology,
Johns Hopkins University School of Medicine;
Director, Johns Hopkins Lyme Disease Clinical Research Center



Kristen Honey, PhD, PMP (Vice-Chair)

Senior Policy Analyst, OMB, Executive Office of the President;
Senior Research Scholar, Stanford University;
Member, Stanford University Lyme Disease Working Group

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Recap of Day 1

- Focus on producing the Working Group report to Congress and HHS
 - Identify areas of agreement and controversy
 - Identify overlap/synergies in content of subcommittee reports
 - Incorporate additional sources of information:
 - Inventories of Federal Actions
 - Public Input
- Decide process for writing the report with specific actions, recommendations

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Join us! Together, We'll Realize Our Vision

- This work needs all of us
 - Lived experience and perspectives
 - Technical and scientific knowledge
 - Interdisciplinary and problem-solving skills
- We will not always agree, but debate is good
- We are stronger when we find the common ground that we share and, together, unite
- If we shout different things all at once, all of our voices will be lost
- If we shout the same thing all at once, our shared priorities magnify the message



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Shared Vision

A nation free of tick-borne diseases
where new infections are prevented and
patients have access
to affordable care that restores health

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Mission Statement

Proposal for Mission Statement –

The Tick-Borne Disease Working Group's mission, as mandated through the 21st Century Cures Act, is to provide expertise and to review all efforts within the Department of Health and Human Services related to all tick-borne diseases, to help ensure interagency coordination and minimize overlap, and to examine research priorities. As part of this mandate, and in order to provide expertise, we will ensure that the membership of the working group represents a diversity of scientific disciplines and views and is comprised of both federal and non-federal representatives, including patients, and family members or caregivers, advocates of non-profit in the interest of the patient with tick-borne illness, scientists and researchers. A major responsibility of our mission will be develop and regularly update the action of HHS from the past, present and the future.

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Core Values

1. **Respect:** Everyone is valued
2. **Innovation:** Shifting the paradigm, finding a better way
3. **Honesty and Integrity:** Find the truth, tell the truth
4. **Excellence:** Quality, real-world evidence underlies decision-making
5. **Compassion:** Finding solutions to relieve suffering
6. **Collaboration:** Work with citizens and patients as partners
7. **Accountability:** The buck stops here

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Public Comment

- Order of Public Comment is:
 - Beth Carrison-van der Heide
 - Julia Bruzzese
 - David Conner
 - Anna Landragin
 - Enrico Bruzzese
 - Enid Haller
 - Allison Caruana
 - Josephine Bruzzese
 - Linda Osborn
 - James Bruzzese
 - Jennifer Platt
 - Christine Lorentzen
 - Adam Bruzzese
 - Jenna Luche-Thayer
 - Kathy Nodolf
 - Sofia Bruzzese
- 60 minutes of public speaking today
- 18 speakers
- 3 minutes each
- Written comments may be sent to:
tickbornedisease@hhs.gov



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Discussion of Recommendations:



Subcommittee Report on

Disease Vectors, Surveillance, and Prevention

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Discussion of Recommendations:



Subcommittee Report on

Testing and Diagnostics

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BREAK 10:40 A.M. EDT

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LUNCH BREAK 12:30 P.M. EDT

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 Process Decisions

Let the writing begin!

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How to Create Crosscutting Writing

- New co-leads and/or sub-groups for writing
- SharePoint: distributed content generation with documents for all to edit
- Ways to consider combining themes for new writing sub-groups
- Themed Buckets
 - EPIDEMIOLOGY AND ECOLOGY – Kristen, Ben
 - PREVENTION – Dennis for Vaccine, John (Non-Vaccine)
 - DIAGNOSIS – Richard, Allen, Lise
 - TREATMENT – Rob, Wendy, Richard
 - ACCESS TO CARE, PATIENT OUTCOMES – Bob, Coop, Pat

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Process for using Public Comment for the Working Group Report

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Public Input

- In-person public comment period is part of each Working Group meeting
 - In-person comments are limited to 3 minutes each
 - The total available time for all public comments is 30 to 60 minutes
 - Written comments are also accepted
- **Written Public Comments can be sent via email until July 1, 2018**
 - Identify your email as Written Public Comment
 - Note: Personally identified information will be shared with the Working Group, if included in your Written Public Comment

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Using Public Comment for the Working Group report

- Plan for how to extract and summarize verbal and written public comment as data to inform report
- Who will lead and synthesize and send to each of the new writing groups to be used as part of their report?
- Key themes to look for in public comment
- How to incorporate public comment

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Process for using the Inventory for the Working Group Report

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Inventory

- Inventory tool was developed using feedback from Working Group members
- Inventory sent to HHS, VA, and DoD in April
- Inventories were submitted to Working Group in May

Agency or Office	Status of Inventory
National Institutes of Health	Complete Submission
Centers for Disease Control and Prevention	Partial Submission (additional information forthcoming)
Assistant Secretary for Preparedness and Response	Complete Submission (no information to submit)
U.S. Department of Veterans Affairs	Forthcoming Submission
Centers for Medicare and Medicaid Services	Awaiting Response
U.S. Food and Drug Administration	Awaiting Response
U.S. Department of Defense	Awaiting Response

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Inventory of Federal Activities

- Who will lead and synthesize and send to each of the new writing groups to be used as part of their report?
- What type of data does TBQWG expect to focus on?
 - Types of activities (like research, surveillance, prevention, care, and treatment)
 - Level of funding, reach, and duration
 - Number of staff devoted to tick-borne disease activities
 - Agencies may need more time for complete reporting
- Structured process to evaluate Inventories and incorporate into report
 - Working Group will review available information and draw from it for the report
 - If data are incomplete or more time is needed, will seek input on case-by-case basis regarding ways to address remaining issues

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The “Parking Lot” for Next Report

Access to Care/Patient Services

- Patient Powered Research

Vaccines and Therapeutics

- Clinical trials in regards to including and excluding people with symptoms

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Discussion of Recommendations:



Subcommittee Report on

Disease Vectors, Surveillance, and Prevention

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Review of Meeting #5 and Next Steps

- Approved motions
- Next Steps
 - Writing groups work on Working Group report to HHS and Congress
 - Integration of Public comment and Federal Inventories
- Meeting #6 Tentatively scheduled for June 21st
- Adjournment

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Before We Adjourn . . .

Thank You!

**to everyone who worked to make
this meeting possible, and
to everyone who has provided input and suggestions,
and to those of you who have joined us today.**