

**Access to Care Services/Support for Patients  
Subcommittee:  
Report to Tick-Borne Disease  
Working Group**

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**Tick-Borne Disease  
Working Group**

**Meeting # 4**

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# Disclaimer



Information and opinions are those of the presenter(s) and do not necessarily reflect the opinions of Working Group members or the Department of Health and Human Services.

# Background



This subcommittee was tasked with investigating any and all factors that might be helping or hindering patients with Lyme and other tick-borne diseases (TBDs) with regard to:

- Accessing care, which includes diagnosis and treatment of the disease(s) as well as any associated symptoms and co-infections
- Support for patients and their loved ones before and after diagnosis and treatment

# Methods – what was done in the subcommittee



## Current Subcommittee Members (10 Voting Members Total)

Members	Type	Stakeholder Group
<b>Kristen Honey, PhD, PMP, Working Group Vice-Chair, Leadership team</b>	Federal	Senior Policy Analyst (OMB)
<b>Commander Scott J. Cooper, MMSc, PA-C</b>	Federal	Senior Technical Advisor (HHS)
<b>Paula Jackson Jones</b>	Public	Advocate, patient
<b>Robert Bransfield, MD, DLFAPA</b>	Public	Provider
<b>Sherrill Franklin</b>	Public	Advocate, patient
<b>Anna Frost, PhD</b>	Public	Researcher, patient
<b>Holiday Goodreau</b>	Public	Advocate
<b>Colonel Nicole Malachowski</b>	Public	Patient
<b>Leonard Schuchman, DO, MPH, FAAFP</b>	Public	Provider
<b>Sheila M. Statlender, PhD</b>	Public	Provider, patient
<b>Kathleen Steele, LCSW</b>	Public	Provider

# Methods – what was done in the subcommittee



## Meetings and Information Gathering

- Participated in 9 teleconferences, 2 hours each
- Listened to 9 presentations by subject matter experts, including an investigative writer, clinicians, and patient advocates
- Reviewed journal articles and other publications
- Read and considered public comments and patient stories

# Methods – what was done in the subcommittee



## Development of the Report

- Multiple writing subgroups
- Agreed on potential action items during subcommittee calls
- Voted on the overall report via email
  
- Final count for the report
  - Approve without additional comment: 9
  - Approve with additional comment: 0
  - Abstain: 1
  - Disapprove: 0

# Background



## **CDC 2013 press release**

- 300,000 new cases per year rather than previously estimated 30,000

## **Access to Care depends on**

- Recognition of Lyme and other tick-borne diseases at all stages of disease and of the overall degree of associated morbidity and mortality
- Ability to accurately and affordably diagnose the disease(s)
- Ability to appropriately and affordably treat the disease(s) for each patient
- Education of patients, the general public, and healthcare providers
- Availability of accurate, appropriate, and affordable diagnosis and treatment for all patients, particularly those at highest risk and those most vulnerable

# The Present State of Access to Care & Patient Support



## **What is the current state of access to care and which supports are available to patients & families?**

- **Advocacy Groups:** What resources are available to patients and their families?
  - Direct patient resources
  - Legislative work
  - Political and social activism
  - Made up of current and former patients, their caregivers, family members, and friends, healthcare practitioners, as well as community members who take an interest in the group's cause
- State and Federal assistance programs (financial and treatment)
- Educational programs (free)



# The Present State of Access to Care & Patient Support



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  - Made up of current and former patients, their caregivers, family members, and friends, healthcare practitioners, as well as community members who take an interest in the group's cause
  - Some focus on serving the needs of patients within their own state, while others focus on providing education and support to a national audience
  - Some advocacy groups exist solely to fund research or train medical providers

# The Present State of Access to Care & Patient Support



## **What is the current state of access to care and which supports are available to patients & families?**

- State and Federal assistance programs (financial and treatment)
  - Many states offer free or reduced care programs to those that qualify, even with hardship programs in place, but most do not cover doctors' visits or treatment for Lyme disease
  - However, some national organizations and companies provide financial assistance for testing and treatment for those who qualify

# The Present State of Access to Care & Patient Support



## **What is the current state of access to care and which supports are available to patients & families?**

- Educational programs (free)
  - Many advocacy groups host free educational events, bringing in speakers that offer expert educational presentations on diagnosis and treatment and exhibitors that offer products and services that serve the needs not only of the patient but of the community at large, including providing free CME on Lyme and TBDs for practitioners
  - Many state and national advocacy groups, nonprofit organizations, and associations offer educational information on their websites and through their apps

# Awareness & Education



## Issue: Public Education

- Public awareness (Children & elderly often at highest risk)
  - Prevention
  - How to look for and remove ticks
  - Symptoms and signs of TBDs
  - Tick testing
  - Challenges associated with testing / Testing options
  - Where to go for information about TBDs

# Awareness & Education



- **Potential Action One:** Provide education regarding prevention and recognition of tick-borne diseases, ticks, tick bites and how to remove a tick correctly. Audience-specific messaging and outreach.
- **Potential Action Two:** Have a more comprehensive and interactive website at the federal level; app/technology (e.g., TickTracker.com)
- **Potential Action Three:** Federal government to include TBD curriculum in the school system, especially in endemic regions
- **Potential Action Four:** Treat Lyme and other tick-borne diseases as chronic illnesses. Even without definitive or settled science determining the exact cause, there is agreement that debilitating symptoms linger for at least 20 percent of Lyme disease patients. The approach for other chronic conditions is to address and manage the medical, social, economic, and psychological challenges faced by those with chronic conditions or chronic symptoms. Lyme and tick-borne illness should be no exception.

# Awareness & Education



## Issue: Patient Education

- Recognizing that they have a tick-borne disease
  - Having current information to work with
  - Knowing where to find the resources in their own state
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- **Potential Action One:** Add existing resources to state public health pages and behavioral health associations
  - **Potential Action Two:** Use Public Service Announcements to educate people
  - **Potential Actions Three:** Have pamphlets available at doctors' offices (tick removal, availability of tick testing, etc.) in very patient-friendly language—outlining symptoms
  - **Potential Action Four:** Educate that patients can present with any number of symptoms and in differing intensity, advise of many different types of rashes
  - **Potential Action Five:** Dispel myths and promote reality, update (and keep up-to-date) information that is promoted to provider and the public

# Awareness & Education



## Issue: Provider Education

Prevention and recognition of TBDs, tick bites

Diagnosis and treatment

Medical causation for mental health conditions

Lyme Literate Workshops (peer-to-peer training)

ILADEF

Free CME modules

- Primary Care Practitioners
- Specialty Care Practitioners
- Mental Health Practitioners

➤ **Potential Action One:** Formal and continuing education on tick-borne diseases, starting in medical schools and allied health programs and including, but not limited to: behavioral health practitioners, nurses, family nurse practitioners, physician assistants, nurse assistants

# Awareness & Education



## Issue: Legislation

- Laws to promote patient rights
- Laws to protect treating physicians and other practitioners



# Awareness & Education



- **Potential Action One:** Mandatory insurance coverage
- **Potential Action Two:** Enforcement existing laws
- **Potential Action Three:** Laws to protect patients' rights, including informed consent regarding the two published standards of care for Lyme disease.
- **Potential Action Four:** Laws to protect physicians who wish to treat according to clinical criteria and/or ILADs guidelines.
- **Potential Action Five:** Implement federal demographic reporting. Include a Lyme/Tick-borne Disease checkbox on health forms within the federal government to gather accurate data about prevalence, health impact, and cost of tick-borne diseases. Include a checkbox on medical intake forms within government healthcare institutions and programs.

# Awareness & Education



- **Potential Action Six:** Hold Congressional hearings to gather data and correct Lyme public health and human rights issues. Legislative oversight and investigative hearings or some combination of hearings may be critical to correct the public health and human rights issues facing tick-borne disease patients.
- **Potential Action Seven:** Adapting Maryland’s “Patient Information Disclosure Act” as a model for legislation—notifies patient when any diagnostic test is performed that lack a high level of reliability (not necessarily restricted to Lyme testing).
- **Potential Action Eight:** Federal government--Extend to Medicare and ERISA law

# Access to Affordable Medical Care



## Issue: Federal & State Government Barriers

- Dogma
- Negative/Improper usage of CDC surveillance criteria (never intended for clinical diagnosis)
- IDSA vs ILADS: Two Standards of Care
- Guidelines vs Standards of Care
- Federal influences on States
- Grants (facilities who rely on grants follow orders from above)
- State Licensing Boards (physician fear of disciplinary action)

# Access to Affordable Medical Care



## Issue: Federal & State Government Barriers

- IDSA vs ILADS: Two Standards of Care
- *Guidelines vs Standards of Care*

IDSA guidelines footnote [*emphasis added*]:

“These guidelines were developed and issued on behalf of the Infectious Diseases Society of America. It is important to realize that ***guidelines cannot always account for individual variation among patients. They are not intended to supplant physician judgment with respect to particular patients or special clinical situations.*** The Infectious Diseases Society of America ***considers adherence to these guidelines to be voluntary, with the ultimate determination regarding their application to be made by the physician in the light of each patient's individual circumstances.***”

# Access to Affordable Medical Care



- **Potential Action One:** Revert back to 2011 language on the CDC website that distinguished surveillance criteria vs. diagnostic criteria
- **Potential Action Two:** Post ILADS guidelines on CDC website
- **Potential Action Three:** Draw attention to footnote on the IDSA guidelines
- **Potential Action Four:** Allocate more balanced funding for Lyme and tick-borne diseases to match communication
- **Potential Action Five:** Establish tick-borne disease centers of excellence (Centers of Excellence already exist to serve patients facing serious health and public health challenges ranging from autism to cancer to minority health disparities)

# Access to Affordable Medical Care



- **Potential Action Six:** Hold a Congressional hearing about tick-borne diseases
- **Potential Action Seven:** Allocate increased funding for tick-borne disease in the area of research, treatment, and prevention (Proportional to cancer, HIV/AIDS)
- **Potential Action Eight:** Protection from job discrimination due to Lyme and TBDs
- **Potential Action Nine:** Protection for students of all ages from discrimination due to Lyme and TBDs
- **Potential Action Ten:** Increase research funding through Department of Defense Congressionally Directed Medical Research Program (DOD CDMRP).

# Access to Affordable Medical Care



## Issue: Insurance Blocks

- Denying services/treatment-based on IDSA criteria
- Out of Pocket expenses to patient
- Disability cost on the economy
- Lifetime cost for chronic illness (testing/treatment/support)

# Access to Affordable Medical Care



- **Potential Action One:** Insurance to cover Lyme treatment and limited Lyme testing
- **Potential Action Two:** Streamline reimbursement process for patients
- **Potential Action Three:** Streamline patient/doctor PA/appeal process
- **Potential Action Four:** Include mental health coverage



# Access to Affordable Medical Care



## Issue: Underrepresented & High-Risk Populations

- Children
- Low Income
- Mental Health patients
- Native Americans
- Military Service Members, Military Families, and Veterans
- Migrant Workers
- Pregnant Women
- Elderly

# Access to Affordable Medical Care



- **Potential Action One:** For healthcare provision to be available across demographics
- **Potential Action Two:** Educational materials in multiple languages
- **Potential Action Three:** Require entities that take federal money provide education
- **Potential Action Four:** OB/Gyn TBD training for potential gestational transmission during pregnancy

# Access to Proper Diagnosis & Treatment



## Issue: Proper Diagnosis & Proper Treatment

- Physician knowledge
- Acute vs Post-Treatment Lyme Disorder vs Chronic
- Late stage Lyme neuro-psychiatric symptoms
- Exploitation of patients with costly and extreme treatments
- A willingness to treat until better (remission)
- Affordable and reliable diagnostic tools
- All tick-borne illness including strains and species, sensitivity and specificity across the board

# Access to Proper Diagnosis & Treatment



- **Potential Action One:** Funding research to lead to accurate diagnosis and treatment of all stages
- **Potential Action Two:** Better physician training – med schools, especially endemic areas
- **Potential Action Three:** Include tick-borne disease education with mental health training
- **Potential Action Four:** Introduce Informed Consent Form into medical visits.

# Access to Proper Diagnosis & Treatment



## Issue: Affordable treatment options

- Insurance blocks (denying services/treatment)
  - Mainstream and Alternative options covered
  - Long-Term Recovery & Support
  - Physical & Occupational Therapy
- **Potential Action One:** Update coding – currently for acute, need for chronic and co-infections—to increase coverage as new norm for Lyme and TBD and make care more affordable for more patients
- **Potential Action Two:** Expand insurance coverage for complementary/alternative visits and treatment options (including but not limited to PT/OT, reiki, acupuncture)

## Challenges and Limitations

- Given the complexities of these diseases and the issues and controversies surrounding them, coupled with the competing responsibilities and duties that members also have in their daily lives as patients, patient advocates, caregivers, and practitioners, the timeline for the report was a challenge—but members tirelessly and successfully worked to overcome this challenge with this report as proof of that
- Federal staff, contactor support, and TBDWG leadership were invaluable to our efforts in this mission and we would not have been able to work through this deliberative process and complete our task without their support and guidance
- Each of our remaining members has shown great focus, professionalism, and empathy throughout what was, at times, a challenging process—through each person’s contributions to this team report, each member has demonstrated the extent of her or his individual commitment to this subcommittee’s particular and special responsibility as the voice of the patient for the TBDWG

# Summary and Discussion



This subcommittee believes that an increased emphasis on providing education about Lyme and tick-borne diseases to a broad and diverse audience; ensuring proper diagnosis and treatment for patients; and removing the barriers to affordable and accessible care for all patients will greatly reduce the unnecessary suffering and the avoidable human and societal costs associated with these diseases