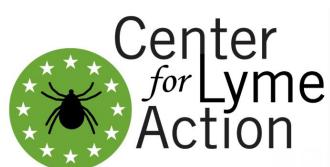


Center for Lyme Action Virtual Advocacy Day Training Session

February 2026



Center
for Lyme
Action

© Center for Lyme Action

Friendly Reminders

- Please **keep yourself on mute** during the presentation
- Please **use the chat feature to ask any questions**
- We will have a **Q&A discussion at the end** of this session
- This **training will be recorded** and available for you to revisit on

centerforlymeaction.org/2026advocates

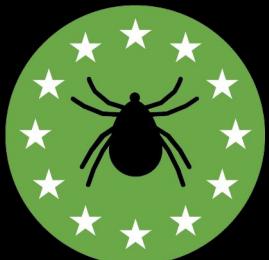
Agenda

- Welcome and Agenda
- Online Platform Logistics Overview – Advocacy Associates
- FY27 Appropriations Requests
- Overview of Meetings
- Example of Meeting Discussion
- Resources
- Q&A



Meghan Bradshaw, MPH

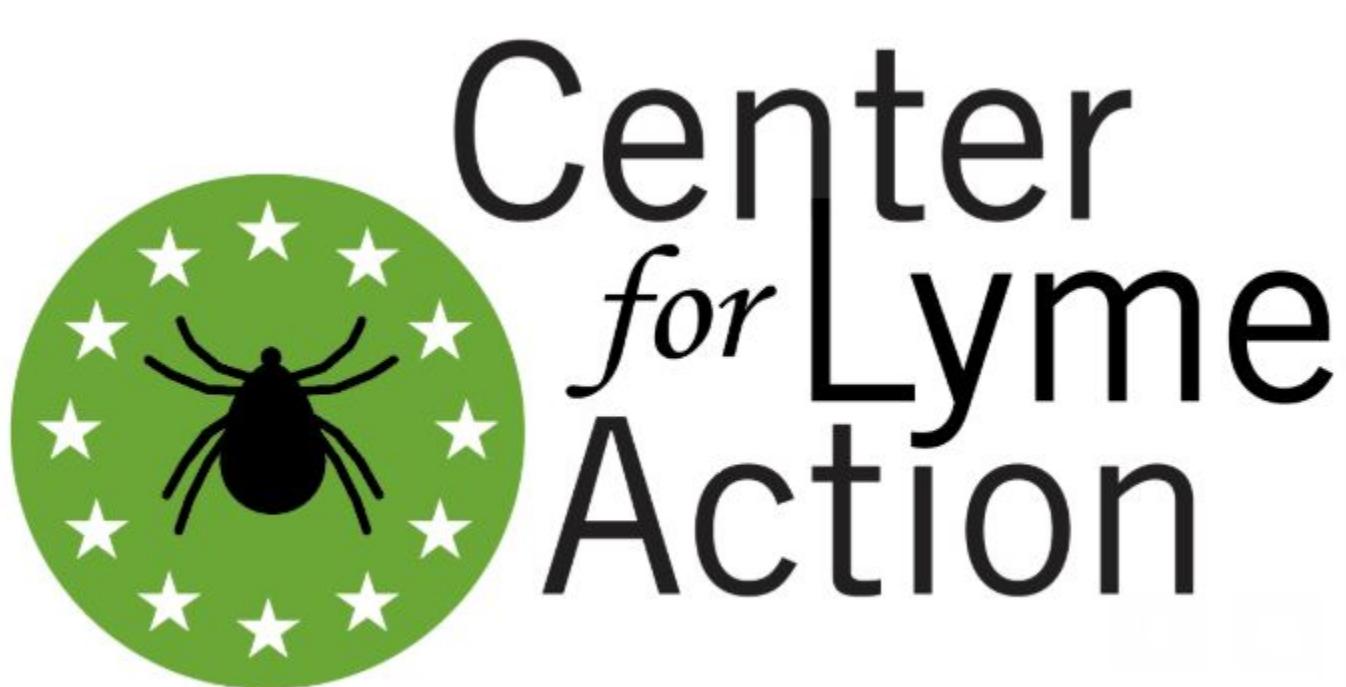
- CLA Executive Director and Lobbyist
- Tick-borne Disease Patient
- Consumer Panelist, DoW CDMRP TBDRP Peer Review Panel
- Subcommittee Member, 2022 HHS Tick-borne Disease Working Group
- Advisory Committee, Columbia Lyme and TBDs Clinical Trials Network
- Board Member, LymeTV & Tick JEDI Coalition
- MPH, UNC Chapel Hill Gillings School of Public Health



What You Will Learn Today

1. Some **background** on Center for Lyme Action
2. How to use the **Advocacy Day App**
3. Our **Fiscal Year 2027 Lyme and TBD appropriations** requests
4. How to **present** the requests and **organize** the meetings
5. Where to get **more information and help**

New 501c4 in 2019



Mission

Grow federal funding for
Lyme and tick-borne diseases

Strategy

Work with advocacy experts
to advocate for Lyme and tick-borne diseases in
the legislative and executive branches



Jeff Crater

Co-Founder & Board Member



Meghan Bradshaw
Executive Director/Government
Relations Specialist

Our Values

Bi-Partisan

Humane

Inclusive

Scientific

Thank You Key Members and Granters

Alexandra
Cohen



The
Fairbairn
Family

Laure
Woods

Driscoll
Family
Foundation

5 Year Advocate Recognition

Karen Tuhacek - Florida

Amy LeBoeuf - Louisiana

Andrea Hamel - Massachusetts

Kristy Brauch - California

Angela Rich - South Carolina

Thomas Kloc - Maryland

Karol Miller - Oregon

Emily Warren - Texas

Anders Karlsen - Oklahoma



Virtual Advocacy Day Objectives

Educate
Congressional Staff
and Members on
the problem of
Lyme and
tick-borne diseases

Influence increased
appropriations

Start completing
constituent-driven
programmatic
appropriations
forms

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Lincoln Clapper

Chief Sales Officer
Advocacy Associates





Online Schedules and Logistics Overview



Key Steps for the Virtual Advocacy Day

- **Step 1:** Prepare to meet with your U.S. Representatives and Senators
- **Step 2:** Meet with Members of Congress and/or their staff
- **Step 3:** Send Appropriations Forms collected from the offices to
Forms@centerforlymeaction.org
CLA Appropriations Forms Team will complete all forms

If you are interested in joining the appropriations forms team, email
Forms@centerforlymeaction.org

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REFRESHER: Regular Appropriations Actions and Schedule

January-February

State of the Union & President's Budget Request

Virtual Advocacy Day

March

House/Senate Budget Hearings

Constituent Submit Approps Requests

April

Joint Senators & Joint Reps. Letters to Approps Comm.
(CLA urges members to sign)

May - June

Approps Committee Markups

Advocates Letter to Committee

June - July

Vote on Floor

Aug - Dec

Conference

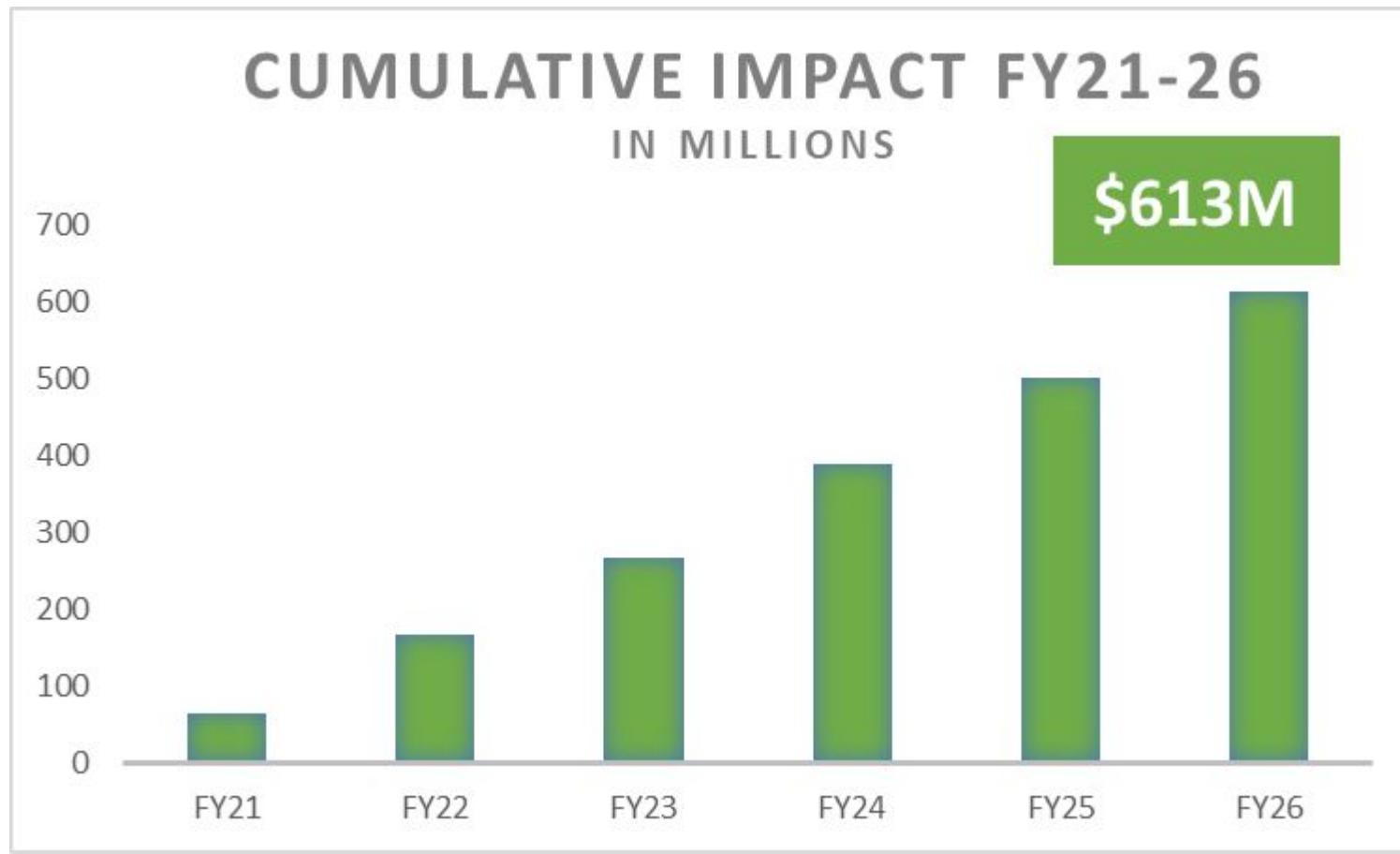
Community Letter - Conferees

Aug - Dec

Approps. Signed into Law

Celebrate

Grassroots Advocacy Works!



Appropriations Details

Summary of Lyme and Tick-borne Disease Funding (in \$ millions)

Agency	FY20 Enacted	FY21 Enacted	FY22 Enacted	FY23 Enacted	FY24 Enacted	FY25 SPEND EST.	FY26 ENACTED
	Final	Final	Final	Final	Final	Estimated Spend	Final
CDC Appropriations							
- Vector-borne diseases (incl. KHTA & Centers)	38.603 (+\$0 KHTA)	42.603 (+\$4M KHTA)	54.6 (+\$12M KHTA)	62.603 (+\$2.5M KHTA)	63.603 (+\$1M KHTA)	87.817	64.603
Kay Hagan Tick Act	0	4	16	18.5	19.5	19.5	20.5
Training, Evaluation, and Partnership Centers				8			
- Lyme and Tick-borne	14	16	20.5	26	27	27	27
NIH NIAID Appropriations							
- Tickborne Diseases (incl. Lyme)	40	96	119	99	122	122	110
HHS LymeX Innovation Accelerator							
	0	0	0	0	5	5	5
Department of Defense							
- CDMRP TBDRP	5	7	7	7	7	0	7
TOTALS	59	123	162.5	158.5	180.5	173.5	169.5
Total Impact Since FY20		64	167.5	267	388.5	503	613.5

gray rows are added to total

Note: Enacted FY25 appropriations bill did not provide a detailed appropriations for each line item as usual. Only high level appropriations. Executive branch was to provide update to Congress but reporting was spotty. Thus the estimated spend. CDMRP was the only casualty but restored in FY26 by both the House and Senate Appropriations Committees.

More FY26 Appropriations Details

Summary of Lyme and Tick-borne Disease Funding (in \$ millions)

Agency	FY26 PBR	FY26 HAC	FY26 SAC	FY26 ENACTED
	President's Budget	House Committee Approved	Senate Committee Approved	Final
CDC Appropriations				
- Vector-borne diseases (incl. KHTA & Centers)	87.817	65.603	64.603	64.603
Kay Hagan Tick Act	19.5	NA	20.5	20.5
Training, Evaluation, and Partnership Centers				
- Lyme and Tick-borne	27	27.5	27	27
NIH NIAID Appropriations				
- Tickborne Diseases (incl. Lyme)	122	110	110	110
HHS LymeX Innovation Accelerator				
Department of Defense				
- CDMRP TBDRP	NA	7	NA	7
TOTALS				169.5

Note: Gray highlighted areas are included in the totals

The Problem with Lyme & Tick-borne Diseases

TICK-BORNE DISEASE CASES INCREASING

The CDC estimates nearly 500,000 cases of Lyme disease each year. The 476,000 total Lyme cases in 2018 are nearly 5 times the number reported in 1991.

TICK-BORNE DISEASES ARE A PUBLIC HEALTH CRISIS

UNDERPERFORMING DIAGNOSTICS AND NO CURE

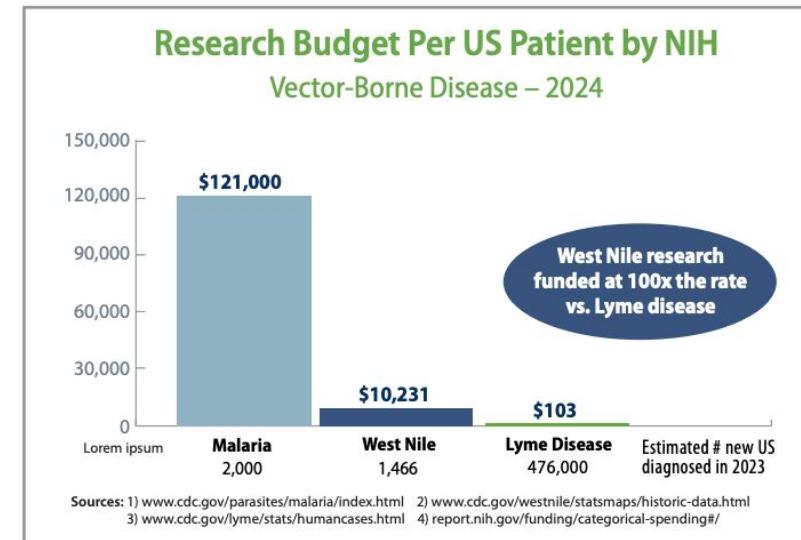
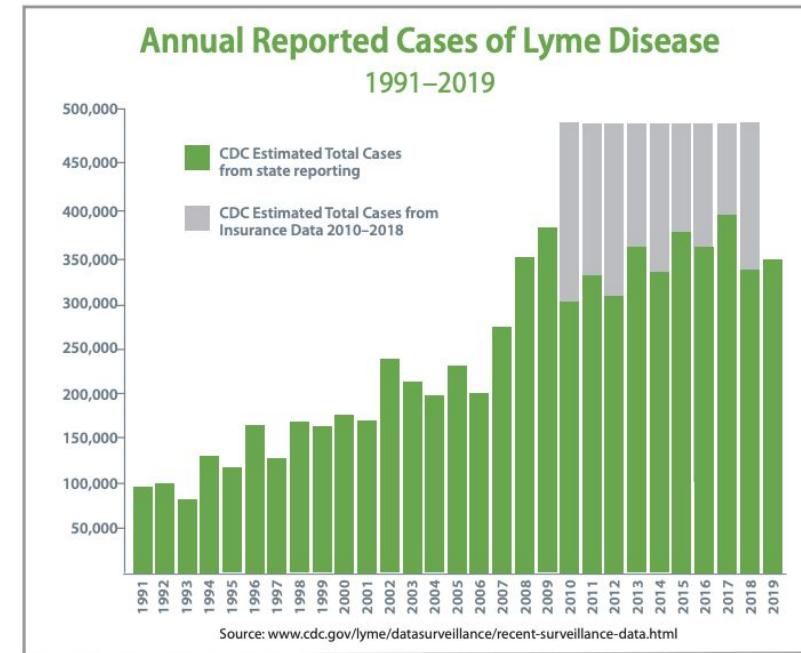
Most available diagnostics don't work—missing up to 60% of acute cases. Current treatments are insufficient for chronic patients and work for approximately 85% of acute patients.

NEED DIAGNOSTICS AND CURE

LOW FEDERAL FUNDING

Per patient, federal funding for Lyme disease is incredibly low at \$103 per patient. Less common diseases West Nile has 100 times, and Malaria has 1,100 times the amount of per patient funding.

MORE FUNDING REQUIRED



FY27 Appropriations Requests

1. \$74.5M CDC Lyme & Tick-borne Disease

\$30M – CDC – Fund Kay Hagan Tick Act

- FY26 \$20.5M
- FY27 \$30M

\$40M – CDC - Fund Lyme and tick-borne disease prevention programs

- FY26 \$27M
- FY27 \$40M

\$4.5M – CDC – Fund Alpha-gal Syndrome

- FY26 \$0M
- FY27 \$4.5M

2. \$5M – HHS LymeX Funding

- FY26 \$5M
- FY27 \$5M

3. \$135M – NIH NIAID Lyme & Tick-borne Disease Research

- FY26 \$122M
- FY27 \$135M

4. \$50M – Fund ARPA-H TICK Clinical Trials

- FY26 \$0M
- FY27 \$50M

5. \$9M – DOW CDMRP Tick-Borne Disease Research Program

- FY26 \$7M
- FY27 \$9M

1. Fund CDC Lyme & TBD Programs

REQUEST \$74.5M

DVBD, NCEZID, CDC, HHS

- Fully fund the Kay Hagan Tick Act (Request: \$30M)
 - \$10M for Centers of Excellence
 - \$20M for States and Tribes
- Fund Lyme and Tick-borne Disease Prevention Programs (Request: \$40M)
- Fund Alpha-gal Syndrome Healthcare Provider Education and Surveillance (Request: \$4.5M)



2. Fund HHS LymeX Innovation Accelerator

REQUEST: \$5M

Office of the Secretary, U.S. Department of Health and Human Services

- \$25M public-private partnership with Steven and Alexandra Cohen Foundation
- Foundation funds prize challenges for Lyme diagnostics
- Phase 4 teams are executing clinical validation plans and submitting to FDA
- \$5M needed for federal implementation



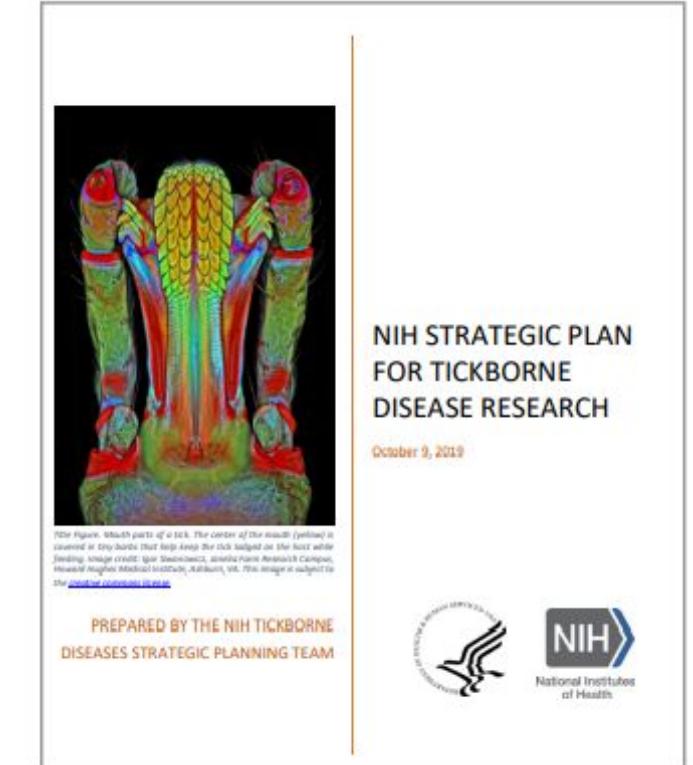
The graphic features the LymeX Diagnostics Prize logo at the top. Below it, the text "LymeX - Now in Phase 4" is displayed in green. A grid of logos for participating teams follows: BlueArc Biosciences, Drexel University College of Medicine, HELIXBIND, Northwestern Medicine Feinberg School of Medicine, GNOMX, and GALAXY. At the bottom, the Massachusetts General Hospital logo is shown with the text "MASSACHUSETTS GENERAL HOSPITAL". To the right, a section titled "What is LymeX Phase 4?" lists the following bullet points: Clinical validation plans, Regulatory submissions to the FDA, Awards up to \$3 million in prizes, and Additional prizes for FDA clearance. The source of the information is cited as <https://www.lymexdiagnosticsprize.com/phase-4-launches/>.

3. Fund NIH Lyme disease and other tick-borne disease research

REQUEST: \$135M

National Institute of Allergy and Infectious Diseases (HHS NIH NIAID)

- CDC estimates at least 476,000 (cases) Americans get Lyme disease in the US each year
- Only \$103 per patient is allocated toward Lyme funding for NIH NIAID research
- Underfunded compared to more rare infectious diseases:
 - West Nile (1,466 cases) - \$10,231
 - Malaria (2000 cases) - \$121,000



4. Fund ARPA-H TICK Clinical Trials Network

REQUEST: \$50M



U.S. Department of Health and Human Services

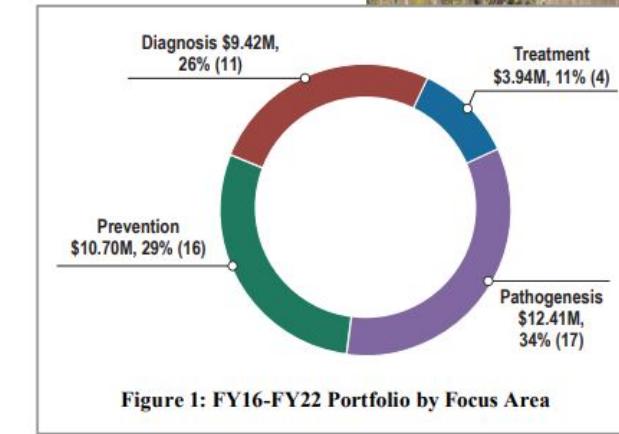
- Private sector does not fund clinical trials for Lyme and tick-borne disease therapeutics
- Building upon existing Lyme and Tick-Borne Disease Clinical Trials Network supported by Steven and Alexandra Cohen Foundation
- New ARPA-H TICK Clinical Trials Network fits ARPA-H model because program is high risk
- TICK = Tick-borne Innovation, Collaboration, and Knowledge

5. Fund Defense Peer-reviewed Tickborne Disease Research

REQUEST: \$9M

Department of Defense Programs, Defense Health Program, Department of War

- Peer-Reviewed Tickborne Disease Research under the **Congressionally Directed Medical Research Program** within Department of Defense (DOD CDMRP TITLE V)
- Unique peer review includes government experts and Lyme community experts
- Funded just 16% of proposals in FY24, could fund more with additional resources



SOURCE: <https://cdmrp.health.mil/tbdrp/pdfs/TBDRP%20Strategic%20Plan%202023.pdf>

TBDRP	Funding	Applications	Funded
FY 2019	\$5M	62	8
FY 2020	\$7M	39	8
FY 2021	\$7M	44	8
FY 2022	\$7M	30	6
FY 2023	\$7M	37	7
FY 2024	\$7M	43	7

Meeting Structure



Meeting Best Practices

- Ask the person you are meeting with **how much time they have today?**
- Ask **how familiar they are with Lyme and tick-borne diseases?**
- Some offices are familiar with CLA/the constituents they're meeting with-
 - “Great to see you again, I am sure you recall I am a patient/healthcare provider/researcher/caregiver from ____” is perfect!
- In House meetings - **keep your intro brief if not your home district meeting**
- In Senate meetings - **introductions will be determined by group size**
- Consider adding your district/hometown to your name in Zoom calls
- **Be mindful that other advocates have prepared to participate as well and we want to be respectful of this shared space**

Communicating Effectively with Congressional Offices

Elevating Your Voice Without Diminishing Your Story

Your personal experience with Lyme or tick-borne disease is powerful—and when shared strategically, it can be even more impactful in a Congressional meeting.

Keep introductions concise (no more than two minutes).

Time is limited, and brief introductions ensure your message is heard clearly and remembered. A focused opening helps establish credibility and keeps the meeting centered on policy solutions.

Communicating Effectively with Congressional Offices

Lead with a high-level overview and thematic storytelling.

Rather than recounting every detail, emphasize the broader themes your experience illustrates.

This approach allows Members of Congress and their staff to quickly grasp the systemic challenges facing patients, including:

- Delayed or misdiagnoses
- Financial strain and insurance barriers
- Limited access to knowledgeable providers
- Lost productivity at work or school
- Long-term health and quality-of-life impacts

Connect your story to the collective experience.

Your story is not just personal—it represents thousands of constituents. Framing your experience within shared patterns helps offices understand the scope of the problem and why federal action is necessary.

Communicating Effectively with Congressional Offices

Use follow-up communication to expand your personal narrative.

If you wish to share more detail, a follow-up email is the appropriate place to do so.

This allows staff to engage with your full story while keeping the meeting itself focused and effective.

Acknowledge the emotional weight of advocacy.

We recognize that participating in these meetings can be emotionally taxing, especially for advocates at different stages of their tick-borne disease journey. Your presence and willingness to engage is meaningful and appreciated.

Our goal:

To leave Congressional offices with a clear understanding of the challenges facing the Lyme and tick-borne disease community—and a compelling reason to act.

Strategic storytelling ensures your voice is heard, respected, and translated into policy momentum.

Organizing the Meeting

1. Review who is in the meeting at your Team Prep Call or through the Advocacy Day Application
2. Identify a Meeting Lead who will:
 - Welcome everyone
 - Thank the member or staff for attending and confirm timeframe
 - Facilitate a round of brief introductions
 - Discuss active tick-borne disease bills
 - Run through the FY27 Lyme and TBD 5 Appropriations Asks (~10 minutes)
 - Answer any questions the staff might have
 - Ask the staff if appropriations forms are available and where?
 - Point staff to <https://centerforlymeaction.org/2026congress/> for more information
 - Thank the staff again
 - After the meeting: Fill out a quick meeting report
3. After the meeting: Send the staff member or member the follow up thank you email in app

Meeting Demo



What You Will Learn Today

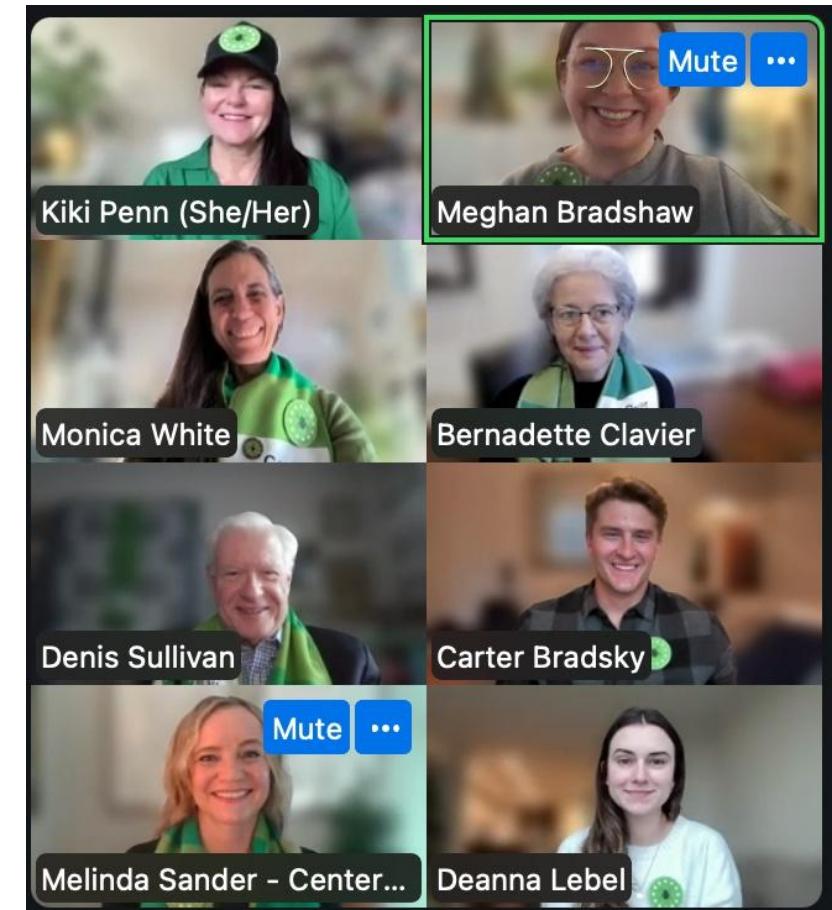
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Resources

- Advocates: <https://centerforlymeaction.org/2026advocates/>
- Staffer: <https://centerforlymeaction.org/2026congress/>
- Advocacy Application: review meetings, talking points, materials
- Team Leads
- For general questions about the event, ask your Team Lead or please email info@centerforlymeaction.org

State Prep Calls- Required

- You will have a meeting with your state team at some point in the next week ahead of 2/18
- If you need the info for this State Prep Call, reach out to melinda@centerforlymeaction.org
- If you're interested in supporting your state as a Team Lead or Co-Lead for the upcoming year, email Meghan@centerforlymeaction.org



Thanks to Generation Lyme

- Generation Lyme is an independent, patient-led 501(c)3 nonprofit organization that hosts online Meet-Ups several times a week for tick-borne disease patients and supporters worldwide.
- Meet-Ups are support group spaces where you can connect and get support from people who understand what you're going through.
- No one has to go through tick-borne disease alone. Gen Lyme is here to help.
- To learn more, visit genlyme.org.

GENERATION
Lyme

Special Requests

- Please take a photo or screenshot of your group on Zoom. We need a few for the CLA website.
- Meeting exceptions:
 - Some members may request another day besides February 18
 - If you can't make the meeting, notify your Team Lead and send an email to Meghan@centerforlymeaction.org

What We Covered Today

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Q&A

