

# TOURETTE NATIONAL ADVOCACY DAY & HOW TO COMMUNICATE WITH CONGRESS

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# CDC – TAA PARTNERSHIP



- ▶ Through public health efforts, we can bridge the gap:
  - ▶ Awareness
  - ▶ Knowledge
  - ▶ Resources
- ▶ TAA-CDC Partnership Program - over 20 years and counting!

# HOW THE PROGRAM IMPACTS YOU

## **TAA Resources, Materials, and Programs**

- ▶ Toolkits and guides
- ▶ Webinars and other online video resources
- ▶ Revamped web resources
- ▶ Online support groups

## **TAA Public Health Education**

- ▶ Programs to educate doctors, licensed medical professionals, teachers, social workers, the community, and families
- ▶ Continuing Medical Education and Continuing Education Unit programs for doctors, teachers, occupational therapists, social workers, and more

## **Collaborations with the TS Community**

- ▶ Partnering with TAA Centers of Excellence
- ▶ Connecting with TS & Tic Disorder local communities: TAA's Chapter Networks and Support Services, surveys, inquiries from families and individuals
- ▶ Small grants for TAA Chapters and support groups
- ▶ Youth Ambassadors, Jr. Youth Ambassadors, and Rising Leaders
- ▶ Other partners that support people living with TS (i.e. IOCDF, CHADD, Parent Training Centers)

# SUPPORT FOR RESEARCH IN TOURETTE SYNDROME

- ▶ Tourette Syndrome was discovered over 130 years ago.
- ▶ It is 2026 but we still have a lot to learn. The community needs major advancements in TS treatment.
- ▶ Recent successes in TS Research need to be supported and we need more progress in new areas of research.
  - ▶ Identified multiple genetic constructs, but many are yet to be identified.
  - ▶ Differences detected via neuroimaging in the structure of brain areas in TS patients.
  - ▶ Improve diagnosis process and develop better treatments.
- ▶ The TAA has been funding research since 1984. Progress has been made but this is not enough, and our funding resources are very limited.
- ▶ We need to encourage our leaders to increase government funding so that we can:
  - ▶ Educate and engage new scientists and clinicians to carry out research.
  - ▶ Provide expanded investments in important research.

# STATUS OF THE TAA'S FEDERAL AGENDA

**FY 26 FEDERAL BUDGET BECAME LAW TODAY!!!!!!**

## **WHAT DOES THIS MEAN FOR OUR COMMUNITY?**

- ▶ **\$2.5 million** for the CDC TS Research and Education Program
- ▶ **\$205 million** for the National Center on Birth Defects and Developmental Disabilities
- ▶ **\$2.805 billion** for the National Institute for Neurological Disorders and Stroke
- ▶ **\$2.190 billion** the National Institute of Mental Health
- ▶ Extension of telehealth flexibilities through **December 31, 2027**

**THIS IS A MAJOR VICTORY FOR US, AND IT'S ALL THANKS TO YOUR SUPPORT AND ADVOCACY!**

# A DAY OF ACTION - MARCH 4, 2026



# TOURETTE NATIONAL ADVOCACY DAY

*The term "Advocacy" means to speak up or to fight for a cause. Tourette Syndrome and Tic Disorder Advocacy is an important function of the TS & Tic Disorder Community.*

## WHAT DOES TOURETTE NATIONAL ADVOCACY DAY ACCOMPLISH?

- ▶ **Unifies** all people touched by TS
- ▶ **Amplifies** the voices in our community
- ▶ **Connects** Members of Congress to their constituents
- ▶ **Educates** Congress on TS and the needs of our community
- ▶ **Highlights** the policy priorities that will improve the lives of those with TS
- ▶ **Shares** personal stories and targeted messages through in-person meetings, action alert letters, phone calls, and social media
- ▶ **Guarantees** the attention of Members of Congress elected to represent YOU

**On Wednesday, March 4, 2026, Tourette National Advocacy Day, we will meet with Members and staff of the United States House of Representatives and Senate.**

# WHY IS THIS IMPORTANT?

Members of Congress are elected to serve their constituents on ALL issues.

- ▶ 435 Members of the House of Representatives
- ▶ 100 Senators

Congressional Staff:

- ▶ Represent their boss
- ▶ Advise their boss on key issues and legislation
- ▶ Advise their boss on the needs of their constituents
- ▶ Handle multiple issue areas of responsibility
- ▶ Have an overwhelming number of issues and priorities to track
- ▶ Flagging your priorities for their attention is appreciated
- ▶ Average Age of House staff is in upper 20's to low 30's
- ▶ Average Age of Senate staff is in the mid to upper 30's

We have many champions on Capitol Hill, but we could always use more!

# TOURETTE NATIONAL ADVOCACY DAY SCHEDULE

## March 3, 2026

- ▶ **3:00 pm – 5:30 pm** – Check-in for Advocacy Day only attendees – Hilton Mark Center in Alexandria, VA
- ▶ **6:00 pm – 7:30 pm** – Advocacy Day Kickoff & team meetings – Hilton Mark Center

## March 4, 2026

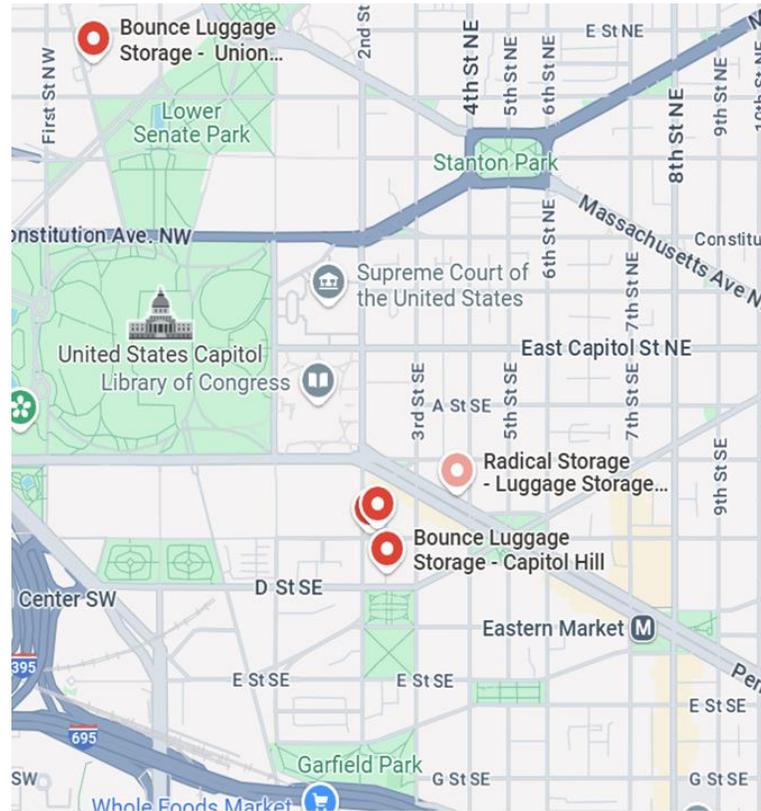
- ▶ **6:30 am** – Breakfast at the hotel
- ▶ **7:15 am** – Buses to depart to the Capitol (Assigned)
- ▶ **8:00 am - 8:45 am** – Group photo on Capitol steps and drop off luggage
- ▶ **9:30 am – Noon** – Meetings with your Senators and Representative in your team as scheduled (TAA will schedule all your meetings)
- ▶ **Noon – 1:30 pm** – Boxed lunch
- ▶ **1 pm – 4:30 pm** – Meetings with your Senators and Representative in your team as scheduled (TAA will schedule all your meetings)
- ▶ Buses will bring you back to the hotel at multiple scheduled times

# YOUR MEETINGS SCHEDULE

- ▶ All Meetings will be scheduled by the TAA/Soapbox
- ▶ We will provide a link to your state's draft schedule
  - ▶ Some states may have multiple teams for House meetings
  - ▶ All folks from a state will meet with the Senators
- ▶ Schedules may change until the time of your meeting
- ▶ Meeting times will vary based on team and your Representative/Senator's schedule
  - ▶ Will provide a list of things to do between meeting times if you have extra time
- ▶ Keep an eye on your emails and/or texts messages for any last-minute changes
- ▶ Folder materials will be published by **February 20**
- ▶ **If for any reason you are going to miss any of your meetings or forget to go to a meeting, please notify:**
  - ▶ **Kevin Schultz at [schultze@soapboxconsulting.com](mailto:schultze@soapboxconsulting.com)**
  - ▶ **or Lachlan Kerr at [kerr@soapboxconsulting.com](mailto:kerr@soapboxconsulting.com)**

# LUGGAGE STORAGE OPTIONS

- ▶ Hotel is a distance from Capitol Hill
- ▶ Book online now
  - ▶ Stasher Luggage: Capitol Hill Hotel-Capitol South Station
  - ▶ Bounce-Union Station
- ▶ Check your meeting schedule
- ▶ May have to skip group photo to store luggage



# WHAT TO EXPECT ON CAPITOL HILL

- ▶ We have participants including Advocacy Day attendees (including state chapter and support group leaders), Youth Ambassadors (and parents), Rising Leaders, Junior Youth Ambassadors (and parents) from 35 states from both the East Coast, West Coast and in between... including Hawaii and London, England.
- ▶ We will provide congressional packets of educational handouts along with our policy issues for you to leave at the end of your office visits. We also encourage Ambassadors to hand congressional staff the story sheet you will receive.
- ▶ Everyone is encouraged to participate on social media – more instructions to come as we get closer to the event.
  - ▶ [Follow our social media accounts](#) to stay up to date!
- ▶ We encourage you to contact us when you have a question or a concern.  
[olivia.woodrich@tourette.org](mailto:olivia.woodrich@tourette.org)

# WHAT TO EXPECT ON CAPITOL HILL



- ▶ Find your Senator's/Congressmember's Office
- ▶ It will be marked with the state flag and a plaque
- ▶ Introduce yourself to the front office staff
- ▶ Mention the time of your appointment
- ▶ Mention who you are supposed to meet with



# WHAT TO EXPECT ON CAPITOL HILL

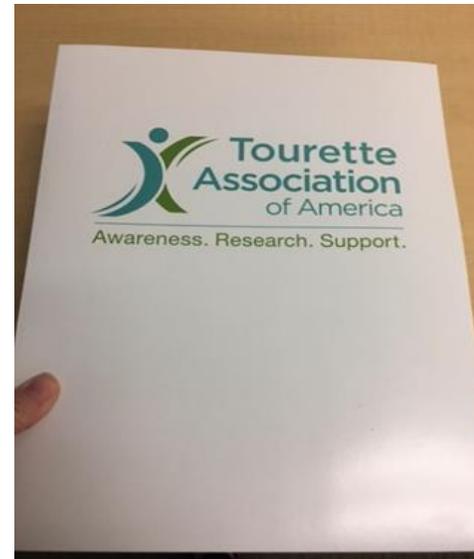


- ▶ You will be directed to a meeting room or space
- ▶ Some meetings will be in their office, conference room or even the cafeteria!



# HOW TO CONDUCT THE MEETING

- ▶ Thank the Senator/Representative/Staff for taking the time to meet (constituent from the district should lead in House meetings)
- ▶ Ask if you can take a photo (**No photos if you do not have permission**)
- ▶ Team designee should lead introductions of the group and guide discussion
- ▶ Tell your story as a team and tie individual stories to the policy priorities with all team members having a role
- ▶ Make sure you “ask” all asks on the one-pager Congressional asks handout (will be emailed to you with the recording of this webinar)
- ▶ Take notes on the responses to the “asks” (and submit on the evaluation form when the meeting ends)
- ▶ Ask them if they have any questions for you
- ▶ Thank the Senator/Congressmember/Staff for their time
- ▶ Post your photo and participate in our social media campaign (more information coming soon)



# CONGRESSIONAL ASKS

- ▶ Support \$2.5 million in continued funding in Fiscal Year 2027 (FY27) LHHs-Appropriations for the Public Health Education and Research Program on Tourette Syndrome at the Centers for Disease Control and Prevention (CDC).
- ▶ Support sustained FY27 funding for medical research at the National Center on Birth Defects and Developmental Disabilities, National Institute of Health's (NIH) National Institute of Neurological Disorders and Stroke (NINDS), and National Institute of Mental Health (NIMH).
- ▶ Continued support of disability-related programs for families at the Department of Education.
- ▶ Join The Congressional Tourette Syndrome Caucus.  
Co-Chairs; Congressmen Steve Cohen (D-TN) and Andrew Garbarino (R-NY).
- ▶ Co-sponsor and support passage of the Safe Step Act (H.R. 5509/S. 2903) to improve step therapy protocols and ensure patients are able to safely and efficiently access the best treatment for them.



# TEAM LEADER ROLE

- ▶ One Team leader determined for the Senate meetings, additional team leaders for House meetings based on the size of state delegation attending
- ▶ Get cell numbers or emails from your team members for notifications
- ▶ You will lead Team Practice at the end of the Advocacy Day Kickoff
- ▶ Arrive at the meetings and stand in the hallway 10 minutes early and text/email anyone on the group who has not arrived at that point with a reminder to join
- ▶ Verbally begin the meeting and close the discussion at the end per meeting guidelines
- ▶ If the conversation gets off track, help gently guide the conversation back to story/priorities
- ▶ Provide any necessary verbal connections to aid in meeting flow and help with comprehension. For example, "We are now going to share two stories about what it is like to live with TS."
- ▶ Remind everyone on the team to fill out an evaluation form at the end of the meeting and to send thank you emails (YAs attach story sheets)

# TELL PERSONAL STORY TIED TO KEY PRIORITIES

- ▶ How/when were you diagnosed? What challenges have you faced?
- ▶ Describe how you have benefited from the CDC Tourette Syndrome Program funding through its support of the TAA's Tourette Health Education Program (YA/RL Training, TAA Webinars, TAA toolkits and brochures, Online support groups, small grants for chapters/support groups, education specialist support, etc.) and its impact on you?
- ▶ Have you had issues getting the medications or treatments your doctor has prescribed? Would the Safe Step Act help with these issues?

# ESSENTIALS FOR COMMUNICATING

- ▶ **Keep it concise.** What is most important for them to know? Meetings are typically 15-20 minutes - so prioritize!
- ▶ **Keep it local.** Constituents are key to legislators. Members' offices pay more attention to personal communications from constituents than from any other source.
- ▶ **Keep it personal.** Personal forms of communication, such as visits like these, letters, emails, or telephone calls are important.
- ▶ **Keep it up.** The relationship you develop is not done after today! Keep in contact. Complete TAA Action Alerts, send emails on appropriations support you receive from your chapters, hold a meeting with the Representative or Senator in their district or state office.

# POST-MEETING EVALUATION FORM

- ▶ This form is VERY IMPORTANT to the TAA Public Policy team can follow up to finalize support
- ▶ One member of each family should fill out the form – more perspectives are always helpful since people hear different things
- ▶ Fill out after each meeting while your memory is fresh – use notes if helpful

## National Advocacy Day Hill Meeting Evaluation

Take future action with a single click.  
[Log in](#) or [Sign up](#) for FastAction

[@fastaction](#) ?

### Contact Information

First Name

Last Name

Street Address (Optional)

Postal Code

City

State/Province

Email

Home Phone (Optional)

Remember me so that I can use FastAction next time. 🗝

### Additional Information

Meeting Time



# WHAT YOU CAN DO YOU TO PREPARE

- ▶ We need volunteers to be Team Leaders for State Teams.
  - ▶ May be multiple teams for larger states/delegations for House meetings.
  - ▶ Please let Jay Nichols or Olivia Woodrich know if you are interested.
- ▶ Prepare your story tied to the priorities.
- ▶ Remember that Advocacy Day is not about partisan politics it is about TS.
  - ▶ We need support from all parties.
- ▶ Send the Take Action Letter before your Hill meetings (we will send you the link before March 4).
- ▶ Ask your family, friends, neighbors, chapter members, etc. to send the Take Action Letter to support you.
- ▶ Dress code is business attire for March 4; please wear comfortable shoes.

# QUESTIONS & ANSWERS

## CONTACT INFORMATION:

- Jay Nichols, VP of Public Policy, [Jay.Nichols@tourette.org](mailto:Jay.Nichols@tourette.org)
- Olivia Woodrich, Policy Coordinator, [Olivia.Woodrich@tourette.org](mailto:Olivia.Woodrich@tourette.org)





# Tourette Association of America

Awareness. Research. Support.

For more than 50 years, the TAA has provided **help & hope** to those affected by Tourette Syndrome, Tic Disorders, and co-occurring conditions. Join us to...

- ▶ **Raise AWARENESS** to combat stigma and increase understanding.
- ▶ **Advance RESEARCH** to develop new treatments and resources.
- ▶ **Provide SUPPORT** to transform and save lives.

Learn more at **[tourette.org](https://www.tourette.org)**