

What is NFXF Advocacy Day?

NFXF Advocacy Day is an annual event where members of the Fragile X community come together in Washington, D.C., and meet with Members of Congress and their staff. Advocates share their stories, educate lawmakers, raise awareness, and present our collective Asks, which include continued and increased federal research funding as well as key policy and legislative priorities that support individuals and families living with Fragile X. We are the dedicated voices for Fragile X. If we don't advocate, no one else will.

Because of the long-standing commitment of the Fragile X community, more than **\$725 million in federal research funding** has been invested in Fragile X to date. The strong reputation our community has built on Capitol Hill has made this possible. By sharing your voice, your experiences, and the real-world impact of federal funding and policy decisions, you help continue this momentum.

The NFXF is a **non-partisan** organization, and Advocacy Day focuses on educating and empowering all lawmakers to support the Fragile X community.

Who attends Advocacy Day?

Advocacy Day brings together families, self-advocates, siblings, caregivers, clinicians, and researchers united in advocating for the Fragile X community and advancing our collective Asks.

What should I expect during the day on the Hill?

The day on the Hill can be an active and sometimes unpredictable experience. You have the option of taking a bus with fellow Advocates from the hotel to the Hill. We will take a group photo on the Capitol steps- rain or shine! From there, meetings begin.

Be prepared for:

- You may walk long distances between buildings.
- There may be times when you need to wait in security lines or outside of offices.
- Busy, crowded, and noisy hallways, especially when many groups are visiting.
- Short, fast-paced meetings, sometimes held in small rooms or even in the hallway.
- Sharing your story with staff or Members who may ask follow-up questions.

While many participants find the experience empowering, this environment may be challenging for some. We encourage individuals and caregivers to consider these factors when deciding whether attending advocacy day is right for you.

How can I advocate if I can't be there in person?

Advocacy doesn't only happen on Capitol Hill. Information on practical ways to take action from anywhere can be found in the <u>June 2025 NFXF Advocacy Newsletter</u>.

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Airport/Hotel

Which hotel has the NFXF contracted with for the event?

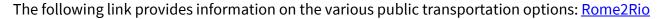
The <u>Royal Sonesta Washington D.C.</u>, <u>Dupont Circle</u> 2121 P St. NW, Washington, D.C., 20037. The special room rate (\$189 + taxes/fees per night) is available until **January 29, 2026**, or until the NFXF group room block is sold out, whichever comes first. <u>Book Now</u>.

What is the closest airport to the Royal Sonesta, Washington, D.C., Dupont Circle?

The closest airport is Washington Reagan (DCA).

Does the Royal Sonesta, Washington, D.C., Dupont Circle, have an airport shuttle?

The hotel does not provide a shuttle. Consider utilizing ride-share options such as Uber/Lyft or pub transportation options.



Is parking available at the hotel?

Self-parking is available at a rate of \$61/per vehicle per day/overnight. Daily rate for non-overnight parking \$21/day.

What amenities are available at the Royal Sonesta, Washington, D.C., Dupont Circle?

All available amenities and policies can be found on their website: <u>The Royal Sonesta Washington DC Dupont Circle – Best Rates</u>



Dress Code

What should I wear for the training on Monday, February 23rd?

You may wear casual, comfortable clothing. You may want to consider wearing layers.

What should I wear for the meetings on Tuesday, February 24th?

Business professional attire—think suits, dress pants, dresses/skirts. We will be providing t-shirts to wear under your suit jacket/with your dress pants/skirt. You may want to consider wearing easily removable layers, as you may be going in and out of buildings throughout the day. Hill Day requires a lot of walking, and you should be comfortable! It is OK for your footwear to be comfortable.



Virtual Training & Preparation

Will there be an opportunity to ask questions before I/we attend the event in Washington, D.C.?

Yes! We are hosting a <u>Zoom</u> on February 11th at 7:30 PM ET/6:30 PM CT/ 5:30 PM MT/ 4:30 PM PT designed for new advocates. This will be a time to ask any questions you may have. Register <u>HERE</u> to join the virtual meeting. All advocates are welcome!



Will there be training required before the mandatory in-person training on February 23rd?

Yes! Registered advocates will receive an email with information about the on-demand training once it is available (mid-February). It should take 20-30 minutes to complete. At a minimum, one individual per household must complete the training, but we encourage all advocates to complete it.

How can I prepare to tell my story?

Telling your story is the most important part of Advocacy Day. Use this <u>sheet</u> to think about how to concisely craft your story. Remember, it is important to share the celebrations and challenges that come with Fragile X.

What is an advocate leave behind?

Bring a photo or prepare an Advocate leave behind beforehand to help you tell your story--including lots of pictures that show your life with Fragile X! Be sure to have your name and address on your advocate leave behind. You can create an advocate leave behind in Microsoft Word or create a collage online with your photos through websites such as Walgreens, CVS, and Canva (each of these offer print options as well). Not sure where to start? Review examples HERE.

Consider printing a few so you can leave one with each Member's office you visit.

Where can I find my State Fact Sheet?

View and download at <u>Advocacy | National Fragile X Foundation</u>





In-person Training & Preparation

What are the Health and Safety preparations?

The NFXF is committed to keeping our attendees safe during their time at Advocacy Day by adhering to all local and state guidelines. While masks are currently optional, all attendees are encouraged to wear them if they prefer. We are closely monitoring the mandates regarding COVID-19 and will update our safety practices as needed.

What is the agenda for Monday, February 23rd?

- 12 1 PM: Lunch (provided by the NFXF), Registration check-in
- 1 5 PM: Training

What options are available for dinner on Monday, February 23rd?

Dinner is on your own. There is a restaurant in the hotel, and there are several nearby options: <u>TripAdvisor</u>.



Hill Day Logistics

Is transportation provided on the morning of Tuesday, February 24^{th,} from the Royal Sonesta, Washington, D.C., Dupont Circle?

Yes! The NFXF provides a bus to the Capitol. The bus will begin loading at 7:10 AM and will depart by 7:30 AM.

Why are we leaving by 7:30 AM when my first meeting isn't until later in the morning?

We'll be gathering on the steps of the Capitol for a group photo around 8:00 am. After that, Advocates will follow their meeting schedule.

Are we touring the Capitol and House floor after our photo?

There will not be a group tour. We are an inclusive organization, and our goal is to ensure that all advocates have the best possible experience. By adjusting the schedule and providing a later start time with fewer transitions, we are creating a more accessible and supportive environment for everyone.

This adjustment also allows advocates to bring snacks and drinks in their bags for the day, which was not previously possible due to restrictions when entering the Capitol.

These changes are designed to help all participants have a successful Advocacy Day.

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Are there tour options that I can arrange on my own?

If your travel schedule permits, we've included links below with additional information on tour options you can arrange on your own. You will receive your tentative meeting schedule on the Friday before. We ask that tours do not conflict with your scheduled meetings.

- https://www.visitthecapitol.gov/
- https://www.house.gov/visitors/tours
- https://www.senate.gov/visiting/
- https://freetoursbyfoot.com/self-guided-tours-washington-dc/

What can I do when I have a break in my schedule?

There are numerous dining options available for breakfast/snacks/lunch. As a reminder, there is a security checkpoint each time you exit and then re-enter a building. Please arrive early, when possible, for meetings, as there may be a line for security.

Where can I find dining options while on Capitol Hill?

There are numerous options available in the Capitol visitor center and in each of the various office buildings.

• https://www.visitthecapitol.gov/visit/capitol-cafe



https://www.house.gov/visitors/where-to-grab-food-on-campus



https://www.aoc.gov/about-us/organizational-structure/office-chief-operations/senate-office-buildings-jurisdiction/senate-restaurants



https://www.tripadvisor.com/RestaurantsNear-g28970-d564560 Senate and House Office Buildings-Washington DC District of Columbia.html





Are there any restrictions on items I cannot bring with me?

The following are items that are restricted:

- United States Capitol
- House & Senate buildings



- o Bags exceeding the size of 18" wide x 14" high x 8.5" deep.
- o Firearms including replica guns and ammunition.
- Weapons (to include but not limited to): Black jack, sling shot, sand club, sandbag, knuckles, electric stun guns, knives (with blades longer than 3"), razors, box cutters, martial arts weapons or devices. Knives with blades 3" or less are permitted.
- Explosives and explosive devices including, but not limited to, Molotov Cocktails, components of a destructive device, and fireworks.
- Pointed objects including, but not limited to, knitting needles, letter openers, or other pointed objects deemed a possible threat. Pens and pencils are permitted. This restriction does not apply to staff.
- Sealed envelopes and packages.

Departing for home on February 24th?

Meetings may continue until 5 PM. Please schedule your travel to allow sufficient time to return to the hotel and then proceed to your transportation.

You may check your luggage with the hotel while attending your meetings. Be sure to allow enough time to return to the hotel to collect your bag before heading to the airport. *

*Be sure to allow plenty of time in the morning to check your bag. The bus will depart at 7:30 am.

Hill Day Meeting Scheduling and Logistics

When will I know my meeting schedule?

Our partners at Soapbox Consulting schedule all meetings. Registered advocates will receive an email with their tentative (subject to change) schedule on the Soapbox mobile tool to the email provided at registration no later than Friday, February 20th. Any updates/changes will be available in real-time through the mobile tool, and a printed schedule will be provided on the afternoon of the training, February 23rd.

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What should I bring with me to my meetings?

- Water, snacks, beverages.
- Personal Family Sheet or photo to share in your meetings.
- Any other personal support items you may need throughout the day.
- Adults should have photo identification.
- Comfortable shoes.

My contact information is incorrect on my schedule, how do I correct that?

Contact the Soapbox Help Desk at 202-362-5910.

What do I do if I did not receive the confirmation text one hour prior to my meeting?

Verify your cell phone is correct under 'Your Settings" in your Soapbox mobile tool or contact the **Soapbox Help Desk** at **202-362-5910.**

I am unable to attend/running late for my scheduled meeting.

Contact the **Soapbox Help Desk** at **202-362-5910** immediately. They will contact the office on your behalf.

I have a question about one of the 'Asks'?

If you are in a meeting, let the staff or Member know follow-up will be provided to answer the question. Please enter the specific question in the mobile tool feedback form for that meeting.

What if the Congressional staff member is not available?

Please don't leave the meeting until you know for sure they aren't attending. Please call the **Soapbox help desk** at **202-362-5910** to discuss the next steps. We want to make sure the staff don't arrive for the meeting, don't see anyone, and they leave.

Is transportation provided back to the hotel?

Transportation back to the hotel is not provided due to varying meeting times throughout the day. Many utilize ride-share options such as Uber/Lyft.

If you have any questions for the NFXF Team, please email advocacy@fragilex.org.