

# NEWSLETTER



## ONE OF OUR STRATEGIC PRIORITIES IS PROMOTING ADVOCACY:

We promote effective ways for families to successfully advocate for themselves and their children to meet the ongoing challenges of the Fragile X journey.

**Save the Date!**  
**NFXF Advocacy Day**  
**February 23 -24, 2026**

Join us in Washington D.C. Additional details will be shared later this year.

Questions? Email:  
[advocacy@fragilex.org](mailto:advocacy@fragilex.org)

**FRAGILEX.ORG/ADVOCACY**

## Advocating From Home: How to Make an Impact

**We are the dedicated voices for Fragile X. If we don't advocate, no one else will.**

The National Fragile X Foundation (NFXF) advocates at the federal level to advance research funding, healthcare programs, and public awareness. Federal policies shape national priorities and often influence how services are delivered at the state level.

By supporting thoughtful legislation and sustained research investment, our community can help improve outcomes for those living with Fragile X-associated conditions.



## Understanding Federal and State Advocacy

Knowing how different levels of government work helps effectively direct your advocacy efforts.

	Federal Government	State Government
<b>Role</b>	Creates national laws and funding guidelines	Makes and enforces laws within the state
<b>Who to Contact</b>	U.S. Senators & Representatives	State legislators & the Governor
<b>Where</b>	Washington, D.C.	Your state Capitol
<b>Focus Areas</b>	National research, healthcare, education funding	Local education, Medicaid, housing, disability services
<b>Why It Matters</b>	Sets national priorities and funding levels	Determines how services are delivered locally

Programs like Medicaid and special education are shaped by federal guidelines but implemented by each state.

## When to Advocate

### Advocacy is Year-Round



While the NFXF Advocacy Day is a powerful moment of collective action, it is important for advocacy efforts to continue throughout the year at the federal and state levels. Whether responding to a call-to-action, sharing updates with legislators, or inviting them to a local event, ongoing outreach builds trust and familiarity.

Reaching out to lawmakers regularly helps them learn more about Fragile X and shows them they can rely on you for insight and lived experience.

## Upcoming Key Opportunities

- **Legislative Recesses:** In 2025, the Congressional August Recess is scheduled for August 4–September 1. This is an ideal time to meet with lawmakers in your district or invite them to a local event. View the Congressional calendar [HERE](#). State legislatures also have periods with similar opportunities.
- **Budget and Appropriations Season:** Congress typically begins the federal budget process in March, which is why the NFXF hosts its annual Advocacy Day when it does. State budgets are usually set in the first half of the year. Check your state legislature's website for details and timelines.
- **Fragile X Awareness Month:** July is a great time to host events, request proclamations, and raise awareness your community, including with elected officials.

## How to Advocate from Home


You don't need to travel to Washington, D.C. or be a policy expert to make a difference. Here are practical ways to take action from anywhere:


- **Meet with Lawmakers Locally:** During recess, members of Congress return to their home districts. Request a meeting at their local office to share your story and highlight how Fragile X impacts your family.
  - Bring your [State Fact Sheet](#) and the [NFXF Policy Grid](#) as meeting aids and leave-behinds.
- **Attend Local Events:** Sign up for your legislators' newsletters to learn about town halls, festivals, and community events they may be attending. These are great opportunities to raise awareness and build relationships.
  - Bring [Fragile X Awareness Cards](#) to share.
- **Invite Lawmakers to a Community Event:** If you're hosting, organizing, or involved in a local program, such as a school activity, therapy session, or support group, consider inviting your legislator. Seeing the impact of Fragile X firsthand can leave a lasting impression.
- **Respond to NFXF Call-to-Action Alerts:** When important legislation is introduced, a quick email or call can help ensure the Fragile X community's needs are considered.
- **Regularly Update Your Legislators:** Email or call to share important updates about Fragile X; a short, friendly message makes a difference. You are developing a relationship, and it's nice to check in to share without making an ask.
  - Include the latest [NFXF Advocacy Newsletter](#) to keep them informed.


**Additional Opportunity - Partner with Other Advocates:** The Rare Disease Legislative Advocates (RDLA) program arranges congressional meetings during the August recess. Consider participating in [Rare Across America](#) with other rare disease advocates. RDLA arranges virtual Senate and in-district House visits for participating advocates by state. Time is limited, and not all participants may have the chance to speak.


## Self-Advocates: Your Story Matters



Sharing your lived experiences is powerful. Use the [NFXF "About Me"](#) template to share who you are, how Fragile X impacts your life, and what support you need. You don't need to be an expert, just be yourself.

My name is: \_\_\_\_\_  
I am a: \_\_\_\_\_  
I live in: \_\_\_\_\_  
I am **TRAORDINARY** because:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Fragile X is a challenge because:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Thank you for learning about me and Fragile X.  
Learn More: 

  
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2025  
National Fragile X Foundation | fragilex.org

My name is: Susie Smith  
I am a: Self-Advocate  
I live in: Anytown, OH  
I am **TRAORDINARY** because:  
I am good at remembering names.  
I like to smile and laugh.  
I like to eat cheeseburgers.  
Fragile X is a challenge because:  
Sometimes I talk too fast when I  
get nervous and anxious.  
Thank you for learning about me and Fragile X.  
Learn More: 

  
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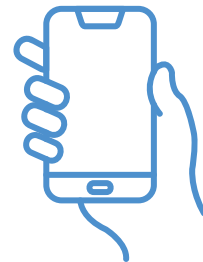
## State Advocacy: Make a Local Impact

State advocacy allows you to influence how policies are applied in your community.

- **Connect with State Legislators:** Discuss how education, healthcare, or disability policies affect individuals with Fragile X in your state.
- **Engage the Governor's Office:** Request a proclamation recognizing July as Fragile X Awareness Month or a designated Awareness Day.
- **Attend State Advocacy Days:** Many states host advocacy days, either virtually or in person, to help constituents meet lawmakers and discuss shared priorities.
  - Check your local [ARC](#) or [State Department of Developmental Disabilities](#) for local opportunities.

## Tips for Effective Advocacy

- **Be you:** Your story is your most powerful tool.
- **Be clear:** Focus on one or two key points and use everyday language.
- **Be informative:** You don't need to be an expert; your experience matters.
- **Say thank you:** Always follow up with a thank-you message after a meeting or exchange.



## Every Conversation Counts. Every Voice Matters.

When you connect with your legislators throughout the year, you build lasting relationships that help them understand and support the Fragile X community. These ongoing efforts make a powerful impact and bring us closer to lasting progress.

**Thank you, Advocates, for all you do!**

