

# Fragile X Advocacy Newsletter

*The National Fragile X Foundation's mission is to serve the entire Fragile X community to live their best lives by providing the knowledge, resources, and tools until, and even after, more effective treatments and a cure are achieved.*



## 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.

### ADVOCACY DAY 2025 2025 OVERVIEW

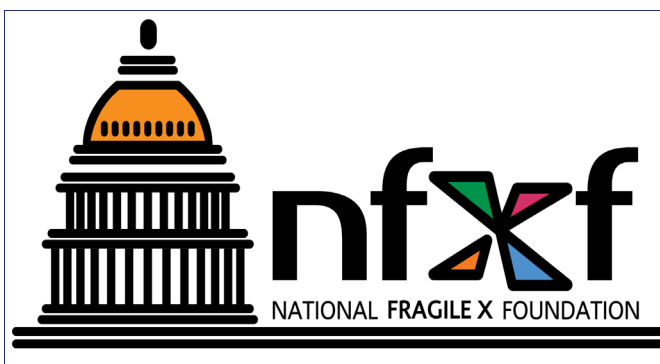
Over 130 advocates, including self-advocates, siblings, parents, caregivers, professionals, and researchers from 26 states and the District of Columbia attended 114 meetings. United in our collective voice, we educated and advocated with Members of Congress in support of Fragile X.

### ADVOCACY DAY 2025 2025 'ASKS'

We are the dedicated voices for Fragile X—if we don't speak up for Fragile X, no one else will. We lead the annual request for Fragile X federal research funding. We shared our [2025 NFXF Federal Research Funding & Legislative Priorities](#) grid, which outlines the key issues.

### ADVOCACY DAY 2025 ADVOCATE FROM HOME

Get ready to feel empowered! If you were not able to join us, you can still advocate from home by sharing our 'Asks' with your Members of Congress. Read this blog for the details: [Advocate for Fragile X From Home](#). Questions? Email: [advocacy@fragilex.org](mailto:advocacy@fragilex.org)



## SAVE THE DATE!!

## FEBRUARY 23 -24, 2026!

We will be hosting our 22nd annual in-person advocacy event in Washington, D.C. Additional details will be shared later this year.

# Advocacy Accomplishments

## A History of Success

Over \$650 M in Fragile X research between the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Department of Defense (DOD).

- CDC: \$2M/year which funds the FORWARD research program.
- NIH: \$104 M in active awards specific to *FMR1*-related conditions and disorders.
- Over \$21 M in grants through the Department of Defense (DOD) program since 2010

Thank you, Advocates, for your tireless efforts to improve the lives of those living with Fragile X. We are the dedicated voices advocating for Fragile X, if we don't, no one else will.

Learn more about the legislation we are currently monitoring and supporting at [fragilex.org/advocacy](https://fragilex.org/advocacy)

## FRAGILE X INCLUDED IN THE PRMRP LIST FOR FY25


FY25 funding for the [CDMRP PRMRP program](#) with the Department of Defense (DOD) was included in the Continuing Resolution (CR) passed on March 14, 2025. The DOD Appropriations Bill report language lists Fragile X as an authorized topic area.

We are awaiting the Program Funding Opportunities applications to be announced. We will share more information as it becomes available.


It is because of your efforts on Capitol Hill, advocating with your Members of Congress, that we can help advance further research for Fragile X-associated conditions.

## NFXF FEDERAL RESEARCH FUNDING & LEGISLATIVE POLICY PRIORITIES

This grid outlines the priorities and key issues that are important to the entire Fragile X community. We lead the annual appropriations request for Fragile X research funding. We actively monitor and support a range of important issues and policies.



# NFXF FEDERAL RESEARCH FUNDING & LEGISLATIVE POLICY PRIORITIES




## Lead

- Educate and promote awareness of Fragile X-associated conditions and their impact on the community
- Fragile X Caucus- House only

### Appropriations:

- CDC \$2M/year for FORWARD
- NIH \$104M + in active awards
- DOD Peer Reviewed Medical Research Program (PRMRP) authorized research area
- Proposed cost analysis to enroll adults in FORWARD




## Monitor

- Federal Research Funding Opportunities
- Telehealth Policies
- Drug Pricing and Access Policies

- Disability Services and Support Program Policies
  - SSI
  - Education/IDEA
  - Medicaid
  - Vocational Training & Employment Support
- Achieving a Better Life Experience (ABLE) Policies
- Caregiver Support Policies

- Rare Disease Interagency Coordination
- FDA Rare Hub Initiatives
- Rare Pediatric Disease Designation and Priority Review Voucher Programs




## Support

*\*Bill numbers from the 118th Congress*

- Accelerating Kids' Access to Care Act H.R. 4758/S. 2372
- SSI Savings Penalty Elimination Act H.R. 5408/S. 2767
- ENABLE Act H.R. 9614/S. 4539
- Creating Hope Reauthorization Act of 2024 H.R. 7384/S. 4583

- Home and Community-Based Services (HCBS) Relief Act of 2023 H.R. 6296/S. 3118
- Alleviating Barriers for Caregivers Act H.R. 8018/S. 3102
- Credit for Caring Act of 2024 H.R. 7165/S. 3702
- Transformation to Competitive Integrated Employment ACT 2023 (TCIEA) H.R. 1263/S. 533
- Disability Employment Incentive Act (DEIA) S. 3076
- Retaining Access and Restoring Exclusivity Act (RARE ACT) H.R. 7383/S. 1214
- PROTECT Rare H.R. 6094
- BENEFIT Act of 2023 H.R. 1092/S. 526
- KEEP Telehealth Options ACT of 2023 H.R. 1110
- Charlotte Woodward Organ Transplant Discrimination Prevention Act H.R. 2706/S. 1183



## Strategic Partnerships and Collaborations

- Centers for Disease Control and Prevention (CDC)
- National Institutes of Health (NIH)
- Department of Defense (DOD)

- NICHD Strategic Plan 2025 Request for information
- DOD CDMRP/PRMRP Strategic Goals Roundtable
- Everylife Community Congress working groups
  - Public Policy
  - Access & Value
  - Friends of NCBDDD
- Defense Health Research Consortium (DHRC)
- Partners that span sectors, other nonprofits, and patient advocacy groups

National Fragile X Foundation | [fragilex.org](https://fragilex.org)



Learn more about the legislation we are currently monitoring and supporting at [fragilex.org/advocacy](https://fragilex.org/advocacy)

View the [2025 NFXF Federal Research Funding & Legislative Policy Priorities Grid](#).

## LEGISLATION – MONITORING

The 119<sup>th</sup> Congress was convened on January 3, 2025. At the start of each new Congress, any bills that did not pass in the 118<sup>th</sup> Congress must be reintroduced to be considered again. We are monitoring the following legislation that may improve the lives of individuals with Fragile X and the broader disability community.

- **Accelerating Kids' Access to Care Act** [H.R.1509/S.752](#)
- **Ensuring Nationwide Access to a Better Life Experience Act (ENABLE)** [H.R. 1436/S.627](#)
- **Give Kids a Chance Act of 2025** [H.R.1262/S.932](#)
- **SSI Savings Penalty Elimination Act** [H.R.2540/S.1234](#)
- **Charlotte Woodward Organ Transplant Discrimination Prevention Act** [H.R.1520](#)
- **Alleviating Barriers for Caregivers (ABC) Act** [S.1227](#)
- **Credit for Caring Act of 2025** [H.R.2036](#)

## ACTION ALERTS

We will continue to champion Fragile X-specific priorities as well as broader disability policies. In these uncertain times, we recognize there are immediate concerns about programs and policies. The Action Alerts below make it easy to contact your legislators in just a few minutes about the issues that matter most to you.

- [Advocate for Fragile X From Home](#)
- [Action Alert: Protect the Department of Education](#)
- [Action Alert: Contact Congress Securing NIH funding for Fragile X | NFXF](#)
- [Action Alert: Contact Congress About the Importance of NIH Research Funding for Fragile X | NFXF](#)
- [Action Alert: Advocate for Medicaid and the Fragile X Community](#)

## RARE ACROSS AMERICA 2025

The Everylife Foundation Rare Disease Legislative Advocates (RDLA) is once again organizing in-district meetings this August. This is the opportunity to meet with your Members of Congress and educate them on the issues that are most important to you and the Fragile X community. Sharing your story is a key part of ensuring continued support for individuals with Fragile X.

Meetings will be held between August 4-15, 2025. Registration opens May 12, 2025. To learn more: [Rare Across America 2024 - EveryLife Foundation for Rare Diseases](#)

## NFXF ADVOCACY DAY 2025



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