

NEWSLETTER



ONE OF OUR STRATEGIC PRIORITIES IS PROMOTING ADVOCACY:

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

Thank You Fragile X Advocates

Advocating year-round in D.C. and from home for 20+ years, has resulted in more than \$725 M in Federal research funding has been awarded for Fragile X-associated conditions!

Questions? Email:

advocacy@fragilex.org

[FRAGILEX.ORG/ADVOCACY](https://fragilex.org/advocacy)

The 22nd NFXF Advocacy Day - An Empowering Experience

NFXF Advocacy Day is an annual event where members of the Fragile X community come together in Washington, DC, and meet with members of Congress and their staff.

Advocates share their stories, educate and 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.

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



Advocacy in Action

Through sustained advocacy and collaboration, the NFXF and our dedicated Fragile X advocates have helped advance progress for individuals and families living with Fragile X-associated conditions. We are deeply grateful to our congressional champions and partners who made this progress possible.

Key accomplishments include:

- Dedicated federal funding for Fragile X research, including continued support for the Centers for Disease Control and Prevention's FORWARD Project, advancing scientific progress and care.
- Continued inclusion of Fragile X in the Peer-Reviewed Medical Research Program (PRMRP) for FY26, ensuring researchers can pursue innovative, high-impact Department of War-funded research through the Congressionally Directed Medical Research Programs (CDMRP).
- The Accelerating Kids' Access to Care Act, improving access to out-of-state care for children with complex medical needs.
- The Give Kids A Chance Act and related provisions, including reauthorization of the Rare Pediatric Disease Priority Review Voucher Program, helping drive new treatments for rare diseases.
- An extension of Medicare telehealth flexibilities, expanding access to care from home.

Keeping Fragile X Front and Center on Capitol Hill

As part of our ongoing federal advocacy efforts, the National Fragile X Foundation (NFXF) has submitted written testimony for relevant congressional hearings and to House and Senate Appropriations Subcommittees. These efforts help ensure Fragile X remains top of mind with policymakers while supporting continued federal funding for research, services, and support programs.

Legislation We're Currently Monitoring or Supporting

- SSI Savings Penalty Elimination Act ([S.1234/ H.R.2540](#))
- Transformation to Competitive Integrated Employment Act ([S.2438 / H.R.4771](#))
- Charlotte Woodward Organ Transplant Discrimination Prevention Act ([S.1782/H.R.1520](#))
- Credit for Caring Act of 2025 ([S.925/H.R.2036](#))
- Lowering Costs for Caregivers Act ([S.1565/H.R. 138](#))
- Cameron's Law ([H.R. 1414](#))
- American Cures Act ([S.4494](#))

Rare Across America 2026 - August 10 -21, 2026

[Registration](#) is open for the Everylife Foundation's Rare Disease Legislative Advocates (RDLA) program's [Rare Across America](#) in-district meetings this August 10 -21, 2026.

- [Registration](#) is open until Friday, July 17, 2026
- Senate meetings will be scheduled virtually
- House meetings will be in-person at your Member's in-state, in-district office

RDLA offers training to help prepare for your meetings and the NFXF will provide additional materials. Please email us at advocacy@fragilex.org to let us know if you are participating!