

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 WHO SHOULD ATTEND?

Families, self-advocates, siblings, caregivers, doctors, researchers— anyone driven to elevate awareness, educate, and showcase actionable ways to support the Fragile X community! Your involvement is powerful and essential in driving meaningful change.

ADVOCACY DAY 2025 WHY SHOULD I ATTEND?

Your personal stories are powerful tools for change. By sharing your experiences, you spotlight the triumphs and challenges of the Fragile X community. Your presence and voice have a real impact, demonstrating that together, we’re making progress.

ADVOCACY DAY 2025 WHAT SHOULD I EXPECT?

Get ready to feel empowered! We handle all the details for you—training (both online and in-person), scheduled meetings, and all the materials you’ll need. We will provide resources to help you share your story! Questions? Email: advocacy@fragilex.org



ADVOCACY DAY

JOIN US!!

FEBRUARY 24-25, 2025!

We will be hosting our 21st annual in-person advocacy event in Washington, D.C. Additional details will be shared later this year.

ADVOCACY ACCOMPLISHMENTS

A History of Success

Since Dr. Randi Hagerman's testimony before Congress nearly 25 years ago, the NFXF has been tirelessly advocating for research funding, regulations, and policies to improve the lives of those affected by Fragile X-associated conditions. Accomplishments include:

- Expansion of the NFXF launched [Fragile X Clinical & Research Consortium \(FXCRC\)](#).
- CDC funded longitudinal, natural history study of FXS called [FORWARD-MARCH](#).
- Collaboration with other organizations that led to a coalition that ultimately resulted in Congress creating the [ABLE Act](#).

Thank you, Advocates, for your tireless efforts to improve the lives of those living with Fragile X.

Read more about the NFXF's role in Legislative Advocacy: [Improving Treatment Through Leadership of the FXCRC | NFXF \(fragilex.org\)](#).

RARE ACROSS AMERICA 2024

In August, NFXF Advocates participated in over 40 Congressional meetings during the EveryLife Foundation's Rare Disease Legislative Advocates (RDLA) program's [Rare Across America](#) in-district meetings!

Advocacy is about sharing your story and putting faces to Fragile X. By being vulnerable and honest, you can help your Members of Congress understand how Fragile X impacts you and your family's lives – the challenges and the successes.

Thank you for representing the NFXF and sharing your personal stories about Fragile X!

ACCELERATING KIDS' ACCESS TO CARE ACT (AKACA)

This bill was unanimously passed by the House of Representatives! It has been referred to the Senate Committee on Finance. We are hopeful this will be taken up in the full Senate for a vote!

Why is this ACT ([H.R.4758/S.2372](#)) important?

Sometimes individuals living with Fragile X-associated conditions must travel to another state to see a specialist or visit a specialty clinic. If the individual is part of a Medicaid program, this act will help to make a new, faster way for doctors to become a part of another state's Medicaid program. Everyone deserves the best care – regardless of who they are, where they live, or their income.

CONTINUED RESOLUTION (CR) INFORMATION

A Continuing Resolution (CR) was signed into law on September 26, 2024. This legislation allows federal agencies to keep operating at their current funding levels, avoiding a government shutdown.

Why is this important to the Fragile X Community?

A CR helps ensure that essential services like Supplemental Security Income (SSI), Medicaid, and special education programs continue without interruption by maintaining funding at current levels until a new budget is approved. This is crucial for individuals and families who rely on these services.

Current funding will continue for our appropriations requests, but we're awaiting the final Fiscal Year 25 (FY25) budget to provide an update on our 'Asks'.



Learn more about the legislation we are currently monitoring and supporting at fragilex.org/advocacy

LEGISLATION – MONITORING

Below is current legislation that has been introduced that we are monitoring in the 118th Congress, including policies that may provide the opportunity for a better life for those living with Fragile X.

- **Accelerating Kids’ Access to Care Act** [H.R.4758/S.2372](#)
- **Supplemental Security Income (SSI) Restoration Act of 2024** [\(H.R.7138\)](#)
- **SSI Savings Penalty Elimination Act** [H.R.5408/S.2767](#)
- **Home and Community-Based Services (HCBS) Relief Act of 2023** [S.3118/H.R.6296](#)
- **Disability Employment Incentive Act (DEIA)** [S.3076](#)
- **PROTECT Rare** [H.R.6094](#)
- **Keeping All Students Safe Act** [H.R.3470/S.1750](#)
- **Safe Step Act** [H.R.2630/S.652](#)
- **Charlotte Woodward Organ Transplant Discrimination Prevention Act** [H.R.2706/S.1183](#)
- **BENEFIT Act of 2023** [H.R.1092/S.526](#)
- **Transformation to Competitive Integrated Employment ACT 2023 (TCIEA)** [H.R.1263/S.533](#)
- **Cameron’s Law** [H.R.1350](#)
- **Retaining Access and Restoring Exclusivity Act (RARE ACT)** [H.R.7383/S.1214](#)
- **KEEP Telehealth Options ACT of 2023** [H.R.1110](#)
- **Creating Hope Reauthorization Act** [H.R.7384/S.4583](#)

CEO COMMISSION HILL DAY

Recently, Hilary Rosselot, NFXF Executive Director, and Dillon Kelley, Advocacy Ambassador to the NFXF Board of Directors, attended the CEO Commission for Disability Employment Summit and Hill Day. The CEO Commission’s mission is to advance disability-inclusive employment by inspiring and engaging business leaders to drive change through policy, practice, and culture.

The NFXF is committed to promoting inclusive employment and is a proud member of the CEO Commission. Addressing the barriers for individuals living with disabilities requires increased awareness, advocacy, and additional public policy solutions.

Learn more about the CEO Commission’s Summit and Hill Day along with Hilary and Dillon’s inspiring and action-packed few days [HERE](#).

NFXF ADVOCACY DAY 2024



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