

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 2024 WHO SHOULD ATTEND?

Families, self-advocates, siblings, caregivers, doctors, researchers – anyone with a passion for raising awareness of Fragile X. Voices from home are the loudest! Showing up, telling your story, educating, and showing practical ways you Members can help is what makes a difference!

ADVOCACY DAY 2024 RESERVE YOUR HOTEL

Hilton Arlington Towers
The special room rate (\$179 + fees/taxes) is available until **January 26, 2024**, or until the group room block the NFXF has acquired is sold out, whichever comes first.

[BOOK NOW](#)

APPROPRIATIONS UPDATE FISCAL YEAR 24 ASKS - HOUSE & SENATE

We continue to await the FY24 budget announcement to be able to provide updates regarding our 'Asks'.



ADVOCACY DAY

JOIN US!!

FEBRUARY 26-27, 2024!

We will be hosting our 20th annual in-person advocacy event in Washington, D.C. Registration is open:

<https://give.fragilex.org/NFXFAD2024>

ADVOCACY ACCOMPLISHMENT

Up to \$11.4 M from the DOD awarded for the largest FXTAS grant to date!

Year after year we advocate with our Members of Congress to keep Fragile X as an eligible condition for funding from the Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP) Peer Reviewed Medical Research Program (PRMRP). That work has paid off! PureTech Health has been awarded a grant of up to \$11.4 million for their trial of LYT-300, oral formulation of allopregnanolone, in people with Fragile X-associated tremor/ataxia syndrome (FXTAS).

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

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

FRAGILE X SYNDROME INCLUDED IN ECONOMIC IMPACT STUDY

The NFXF is proud to be part of the EveryLife Foundation's newest report, [The Cost of Delayed Diagnosis in Rare Disease: A Health Economic Study](#). This report not only digs into each community's healthcare data, but it also provides future directions for policy and healthcare.

The time is now to develop policies to reduce the time to diagnosis, and the EveryLife Foundation is championing that work.

Learn more about this study: [Cost of Delayed Diagnosis in Rare Disease: A Health Economic Study | NFXF \(fragilex.org\)](#)

HOME AND COMMUNITY-BASED SERVICES (HCBS) RELIEF ACT OF 2023

Why is the HCBS Relief Act of 2023 needed?

In a 2022 report, over 70% of direct service providers reported they cannot fill vacancies for long-term services and support. Without a stable direct care workforce and provider network, families who need home care will need to make hard choices to care for their loved ones at home.

What would the HCBS Relief Act of 2023 do?

- Provide dedicated Medicaid funds to states for two years to stabilize their HCBS service delivery networks.
- Recruit and retain HCBS direct care workers.
- Meet the long-term service and support needs of people eligible for Medicaid home and community-based services.

How could the proposed funds be used?

- Increase direct care worker pay.
- Provide benefits such as paid family leave or sick leave.
- Transportation expenses.

If passed, the funds could help decrease or eliminate the waiting list for HCBS in the states.



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LEGISLATION – INTRODUCED

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

- **Home and Community-Based Services (HCBS) Relief Act of 2023** [S.3118](#)
- **Disability Employment Incentive Act (DEIA)** [S.3076](#)
- **PROTECT Rare** [H.R.6094](#)
- **SSI Savings Penalty Elimination Act** [H.R.5408/S.2767](#)
- **Keeping All Students Safe Act** [H.R.3470/S.1750](#)
- **Safe Step Act** [H.R.2630/S.652](#)
- **Accelerating Kids’ Access to Care Act** [H.R.4758/S.2372](#)
- **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)** [S.1214](#)
- **KEEP Telehealth Options ACT of 2023** [H.R.1110](#)

LEGISLATION – BEING MONITORED

Below is current legislation that the NFXF is currently monitoring and have yet to be introduced in the 118th Congress.

- **ABLE Employment Flexibility Act:** Permits employers to make tax-exempt contributions to ABLE (Achieving Better Life Experience) accounts in lieu of making contributions to existing tax-exempt defined contribution retirement plans.

RARE ACROSS AMERICA 2023

Nearly 20 NFXF Advocates representing 16 states participated in the EveryLife Foundation's Rare Disease Legislative Advocates (RDLA) program's Rare Across America in-district meetings in August! 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!

NFXF ADVOCACY DAY 2023



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