

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.

FRAGILE X CAUCUS

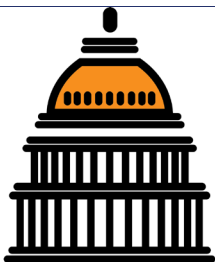
Each year, we ask our Members (**House only**) to join the Fragile X Caucus. There is no financial commitment or agreeing to any policy positions. To join contact: Maria.costigan@mail.house.gov in Rep. Joe Courtney's office or John.McDonough@mail.house.gov in Rep. Chris Smith's office.

APPROPRIATIONS UPDATE FISCAL YEAR 24 ASKS - SENATE

Sen. Stabenow led the letter requesting Fragile X syndrome remain an authorized topic for the Department of Defense Peer Reviewed Medical Research Program. We are awaiting the FY24 budget announcement.

APPROPRIATIONS UPDATE FISCAL YEAR 24 ASKS - HOUSE

Rep. Chris Smith and Joe Courtney led the letter requesting continued funding from the annual line-item request from the CDC and NIH funded projects. We are awaiting the FY24 budget announcement.



ADVOCACY DAY

SAVE THE DATE

FEBRUARY 26-27, 2024!

We will be hosting our 20th annual in-person advocacy event in Washington, D.C. Additional details to be shared later this year!

ADVOCACY ACCOMPLISHMENTS

- More than \$500M in federal funding for Fragile X research and programming.
- Authorized Fragile X as one of the areas of research at the Department of Defense's Peer Reviewed Medical Research Program with over \$20M in research awards since 2010.
- Continued NIH funding for Fragile X-specific projects. Currently there are \$68M in active NIH awards specific to *FMR1*-related conditions and disorders.
- Achieving a Better Life Experience (ABLE) Accounts and amendments to increase income limits.

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

TELEMEDICINE/TELEHEALTH UPDATE

The availability of telemedicine could assist in providing access to Fragile X clinics for every family. Eliminating significant travel costs and time helps provide equitable access for all individuals living with FXS. The department of [Health and Human Services](#) released information May 10, 2023 regarding the extension of the telehealth flexibilities through the end of 2024.

We are monitoring the **KEEP Telehealth Options ACT of 2023** [H.R.1110](#)

CURRENT TOPICS AND LEGISLATIVE PRIORITIES

The NFXF partners with other patient advocacy groups and legislative advocacy organizations to maximize our impact. Below are current letters of support that the NFXF has signed on and supported.

- **Friends of NICHD Letter:** Requesting continued support of NIH and NICHD funding.
- **The Defense Health Research Consortium:** Requesting continued funding of the Congressionally Directed Medical Research Program at the Department of Defense.
- **Charlotte Woodward Organ Transplant Discrimination Prevention Act:** Prohibiting discrimination on the basis of mental or physical disability in cases of organ transplants.
- **Accelerating Kids' Access to Care Act:** Helping reduce the time it currently takes children covered by Medicaid or Children's Health Insurance Program (CHIP) to access specialized care when providers in their home state cannot address their needs.



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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.

- **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.

- **Access to Rare Indications Act:** Allow Medicare and Medicaid to cover off-label use of FDA drugs based on thorough professional review. It will require private payers to create an expedited review pathway for formulary exception, reconsideration, and/or appeal of any denial of coverage for a drug or biological prescribed for a patient with a rare disorder.
- **Disability Employment Incentive Act (DEIA):** Increases the tax credit for employers who hire a person with a disability referred to them through a state Vocational Rehabilitation agency, a person receiving Supplemental Security Income (SSI) benefits, and a person who is receiving Social Security Disability Insurance (SSDI) benefit.
- **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.
- **SSI Savings Penalty Elimination Act:** Increases allowable limitations for SSI qualifying individuals from \$2,000 to \$10,000 and from \$3,000 to \$20,000 for married couples which in turn eliminates the marriage penalty for two SSI qualifying individuals who chose to marry.

NFXF ADVOCACY DAY 2023



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