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.

ADVOCACY DAY 2024

2024 OVERVIEW
Nearly 150 advocates, including self-advocates, siblings, parents, caregivers, physicians, and researchers from 29 states, united with a shared passion for raising awareness of Fragile X. 119 meetings took place, introducing Fragile X to many new offices!

ADVOCACY DAY 2024

2024 ‘ASKS’
Each year we prioritize Fragile X research funding and policies that facilitate treatment development and create opportunities for better lives for those living with Fragile X and other intellectual and developmental disabilities. Learn more about: 2024 ASKS

ADVOCACY DAY 2024

READ ABOUT DILLON KELLEY’S ADVOCACY DAY EXPERIENCE
Dillon is a self-advocate and Advocacy Ambassador to the NFXF Board. He shared his 2024 NFXF Advocacy Day experience. Read about it: HERE

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

- Over $550 million 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: $64M in active awards specific to FMR1-related conditions (104 Unique Researchers)
  - Over $32M in grants through the Department of Defense (DOD) program since 2010
    - This includes the recent $11.4 million award to Pure Tech Health for their trial of LYT-300, in people living 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 IS ON THE APPROVED LIST FOR FY24

Thank you NFXF Advocates! We are thrilled to announce that Fragile X was once again added to the approved list for the Department of Defense (DOD) funding in 2024 through the CDMRP PRMRP program!

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 syndrome and Fragile X-associated conditions.

Learn more about the funding opportunities: Research Funding Opportunity from CDMRP/PRMRP for Fiscal Year 24 | NFXF (fragilex.org)

ACCELERATING KIDS’ ACCESS TO CARE ACT (AKACA)

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.

This bill was unanimously passed out of the House Energy & Commerce Committee! We are hopeful it will be taken up by the full House of Representatives soon.

SUPPLEMENTAL SECURITY INCOME (SSI) BILLS

The SSI asset limits, set 40 years ago, remain unchanged, failing to empower the most financially vulnerable to prepare responsibly for the future.


What is the difference between the SSI Savings Penalty Act and the Supplemental Security Income Restoration Act of 2024?
Both bills aim to update eligibility criteria and increase asset limits: from $2,000 to $10,000 for individuals and from $3,000 to $20,000 for couples. The SSI Restoration Act additionally seeks to modernize the claim process and eliminate punitive benefit reductions.

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

RARE ACROSS AMERICA 2024

Registration is open for the EveryLife Foundation’s Rare Disease Legislative Advocates (RDLa) program’s Rare Across America in-district meetings this August 5-16, 2024!

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.

- Registration is open until Friday, July 12th.
- Meetings will occur August 5-16, 2024.
  - House meetings will take place at their in-district offices.
  - Senate meetings will be scheduled virtually.

RDLa offers training webinars to help prepare for your meetings and the NFXF will provide additional materials.

Register Now: Rare Across America 2024 - EveryLife Foundation for Rare Diseases