

# 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 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](#)



## 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*

- 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](https://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.

The **SSI Savings Penalty Elimination Act** [H.R.5408/S.2767](#) and the **Supplemental Security Income Restoration Act of 2024** [\(H.R.7138\)](#) aim to reform the SSI program.

### **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.



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## LEGISLATION – MONITORING

Below is current legislation that has been introduced that we are monitoring in the 118<sup>th</sup> 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](#)

## 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 12<sup>th</sup>**.
- 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](#)

## NFXF ADVOCACY DAY 2024



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