# FEDERAL INVESTMENTS IN FRAGILE X-ASSOCIATED CONDITIONS & DISORDERS

NATIONAL FRAGILE X FOUNDATION

We are incredibly grateful for the bipartisan support for the federal government's investment to support research for Fragile X- associated conditions and disorders! Without this investment, we would not be able to make strides toward effective treatments for Fragile X. Over the past 22 years, our dedicated Fragile X advocates have helped to secure over $725M in research funding, which has led to significant advancements. These are just some examples of the remarkable impact of these federal investments.

## CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

- The CDC funds the Fragile X Registry With Accessible Research Database (FORWARD), the largest resource of health, clinical, and social support information on people with Fragile X syndrome (FXS) in the United States.
- FORWARD includes over 14 years of longitudinal (changes over time) data accessible to researchers. 27 publications have been generated from FORWARD data, with more to be released soon. Recommendations from many of these publications have been important for informing health management, identifying risk groups, gaps in care, and needs for intervention to improve the quality of life for individuals with FXS.

**CDC Funded FORWARD 2026 Update**

## NATIONAL INSTITUTES OF HEALTH (NIH)

- The NIH has $105M in active awards specific to *FMR1*-related conditions.
- The NIH updated its Strategic Plan for Research on FMR1-Associated Conditions & Disorders in 2019. This plan shared goals for specific FMR1-associated conditions, including cross-disciplinarity goals that encourage innovative, impactful research in Fragile X.
- NIH supports The Centers for Collaborative Research in Fragile X Program, with the common goal "of facilitating the translation of basic research findings from bench to bedside and bedside to community." This grant supports research to improve the diagnosis and treatment of Fragile X syndrome (FXS) and its related conditions and disorders, aiding premier FX Centers in increasing their impact in line with the NIH Strategic Plan for Research on FMR1-Associated Conditions and Disorders. The current awardees are the University of Michigan Medical Center, Emory University, Baylor College of Medicine, Cincinnati Children's Hospital Medical Center, and the University of South Carolina.
- Notable NIH-funded impact includes genetic understanding of Fragile X, animal models, clinical trial support and infrastructure including intradisciplinary collaboration, and general education and awareness for Fragile X. And there's still so much to learn.
- NIH funds multiple Career Development (K) awards, some of which have gone to up-and-coming professionals who are completing innovative projects in Fragile X. This pipeline of and for new researchers and clinicians is critical to advancements for Fragile X.

**NIH Funded Centers for Collaborative Research**

**NINDS Funded Advancing Clinical Trials - FXTAS**

## DEPARTMENT OF WAR (DOW)

- Congress continues to recognize Fragile X as an authorized medical research area.
- The DoW Peer Reviewed Research Program (PRMRP) has funded $21M in research projects related to FMR1/Fragile X-associated conditions.

# FISCAL YEAR 2027 ASKS

NATIONAL FRAGILE X FOUNDATION

## Support Fragile X Research Funding for Fiscal Year 2027

We commend the bipartisan work in securing the federal government's investment of nearly $72M in FY2026 for Fragile X research between the NIH, the CDC, and the DoW. There is still more to learn. You can support progress by:

- Senate: **Requesting Fragile X be included as an authorized research topic area for the Department of War (DOW) Peer Reviewed Medical Research Program (PRMRP).**
  - The Appropriations Committee authorizes the medical conditions, disorders, and diseases the program may research through report language each year.
  - Please include "Fragile X" in your appropriations request.
  - **Sen. Cindy Hyde-Smith** and **Sen. Cory Booker** are leading the letter. Contact either office for the latest draft and to cosign. *Please note, in order to reflect bipartisan support, signatories will be added to the final letter in Republican and Democratic pairs, with champion offices helping to identify matches.*

- House: **Requesting support for Fragile X at the NIH and the CDC.**
  - The CDC has an annual line item in their budget request for $2M for Fragile X that supports the FORWARD project, which collects longitudinal data on individuals with Fragile X and makes it available to researchers. The numerous publications that have resulted from FORWARD data have been instrumental in shaping the widely used treatment recommendations for Fragile X.
  - Significant NIH-funded research has advanced our genetic understanding of Fragile X, supported animal models, facilitated clinical trials, provided infrastructure for interdisciplinary collaboration, and enhanced general education and awareness.
  - **Rep. Joe Courtney** and **Rep. Chris Smith are leading a letter.** Contact either office for the latest draft and cosign.

## SSI Savings Penalty Elimination Act (S.1234/H.R.2540)

This bill aims to address the regressive, anti-savings asset limits for the Supplemental Security Income (SSI) program. Specifically, the bill would increase the asset limits that were established in 1984 from $2,000 to $10,000 for individuals and from $3,000 to $20,000 for married couples.

**We ask that you support this proposed legislation that will empower the most financially vulnerable Americans to take financially responsible steps to prepare for the future without worrying they will reduce or lose benefits.**

## Join the Congressional Rare Disease Caucus

The Caucus provides a collaborative, bipartisan forum to elevate the voices of individuals and families affected by Fragile X and other rare diseases. Aligning with the Rare Disease Caucus allows us to work alongside a broader community to strengthen awareness, advance research, and support policies that improve the lives of those living with rare conditions, like Fragile X syndrome.

Senate Co-Chairs: **Senators Roger Wicker (R-MS) and Amy Klobuchar (D-MN)**
House Co-Chairs: **Representatives Doris Matsui (CA-7) and Gus Bilirakis (R-FL)**

## Learn More About Fragile X

**What is Fragile X?**

**Ask Me About Fragile X - Female**

**Ask Me About Fragile X -Male**

**Questions?** Please contact the NFXF Team: advocacy@fragilex.org.

United States Senate

WASHINGTON, DC 20510

X, 2026

The Honorable Mitch McConnell
Chair
Subcommittee on Defense
U.S. Senate Committee on Appropriations
Washington, D.C. 20510

The Honorable Christopher Coons
Ranking Member
Subcommittee on Defense
U.S. Senate Committee on
Appropriations Washington, D.C. 20510

Dear Chair McConnell and Ranking Member Coons:

First and foremost, we commend your bipartisan work in completing the FY2026 Defense Appropriations bill. We are grateful for your continued commitment to sustaining federal investments in biomedical research focused on the treatment and cure of Fragile X syndrome (FXS) and its associated conditions. As you begin your work on the FY2027 Department of War Appropriations bill for FY2027, we respectfully request your continued commitment to this critical investment.

Mutations of the Fragile X (*FMR1*) gene result in behavioral, developmental, cognitive, reproductive, and potentially life-ending neurodegenerative conditions across generations in families and impact affected individuals from birth to death. Fragile X syndrome and associated conditions and disorders result from a single-gene mutation, which is the most common known inherited cause of intellectual disabilities. Up to 100,000 Americans have Fragile X syndrome, and up to 1,500,000 Americans have a variation of the Fragile X mutation and, as a result, either have or are at risk for developing one of the conditions associated with Fragile X and passing the gene mutation to their children. The known premutation issues are Fragile X - associated tremor/ataxia syndrome (FXTAS), a condition similar to Parkinson's, and Fragile X-associated primary ovarian insufficiency (FXPOI), which causes infertility and early menopause. Additional conditions and health risks associated with the Fragile X premutation are being further researched.

The Committee has previously and continues to support Fragile X as one of the research topic areas authorized for the Department of War (DoW) Peer Reviewed Medical Research Program (PRMRP). This has resulted in the funding of critical research that holds the potential to ease the burden of Fragile X and other intellectual and developmental disabilities on our military families. Military families are affected substantially by the financial and emotional costs of raising a child with intellectual and developmental disabilities, including Fragile X syndrome. Given the prevalence of the Fragile X premutation, there are likely many individuals in the military who are affected by this and its associated conditions. These factors and their impact extend to the performance and readiness of service members and their units. As a direct result of investments by PRMRP, strides are being made toward effective treatments for Fragile

X-associated conditions, including FXS, FXTAS, FXPOI, and other emerging conditions, while moving toward a cure. These treatments will help ease the burden on military families and on the broader American public.

Again, we thank you for the bipartisan support and ask that you continue to include Fragile X as an authorized research topic area for the DoW Peer-Reviewed Medical Research Program for Fiscal Year 2027 to address the needs of military families across generations. The potential for effective treatments is within reach, and continued support for Fragile X research is imperative. DoW research has been a significant contributor over the past decade to progress on Fragile X, and we respectfully request this continued investment in FY2027.

Thank you for your consideration.

Sincerely,

# Congress of the United States
## Washington, DC 20515

xxx xx, 2026

The Honorable Robert Aderholt
Chairman
Subcommittee on Labor, HHS,
Education, and Related Agencies
House Committee on Appropriations
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, HHS,
Education, and Related Agencies
House Committee on Appropriations
Washington, DC20515

Dear Chairman Aderholt and Ranking Member DeLauro:

First and foremost, thank you for your responsiveness to our request in FY2026 for continued and sustained investments to improve the health of children and adults living with intellectual disabilities in the United States. We commend your bipartisan work in securing the passage of the final FY2026 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. We respectfully request your continued commitment to sustaining federal investments in biomedical research and public health initiatives focused on the treatment and cure of Fragile X and its related conditions again for FY2027.

Mutations of the Fragile X (*FMR1*) gene result in behavioral, developmental, cognitive, reproductive, and potentially life-ending neurodegenerative conditions across generations and impact affected individuals from birth to death. Fragile X syndrome (FXS) and associated conditions and disorders result from a single-gene mutation, which is the most common known inherited cause of intellectual disabilities. Up to 100,000 Americans have Fragile X syndrome, and up to 1,500,000 Americans have a variation of the Fragile X mutation and, as a result, either have or are at risk for developing one of the conditions associated with Fragile X and passing the gene mutation to their children. The known premutation issues are Fragile X-associated tremor/ataxia syndrome (FXTAS), a condition similar to Parkinson's, and Fragile X-associated primary ovarian insufficiency (FXPOI), which causes infertility and early menopause. Additional conditions and health risks associated with the Fragile X premutation are being further researched.

The Committee's previous support for the important work underway at the Centers for Disease Control & Prevention (CDC) and National Institutes of Health (NIH) is advancing research towards more effective treatments and a cure for Fragile X and associated conditions. For instance, the CDC funds the FORWARD project, a longitudinal database and natural history study that now includes 14 years of data on individuals with Fragile X syndrome and additional data on individuals with the Fragile X premutation and other family members.

The knowledge gained from this effort has been integral to understanding the challenges facing younger individuals with Fragile X syndrome, however, there is a lack of data regarding older persons (above the age of 23) that hinders the ability for professionals and families to provide evidence-based intervention and support. The FORWARD projects have identified key areas of need, significantly contributing to what we know about Fragile X syndrome and

informed the way Fragile X is currently treated.

The NIH supports Fragile X research across multiple Institutes and Centers, with the primary one being the NICHD. This includes funding three national Fragile X research centers that focus on stimulating multi-disciplinary, multi-institutional research with a goal of translating basic research into treatments. We are seeing promising progress for many of the associated Fragile X conditions, FXS, FXTAS, FXPOI, including several currently in various phases of clinical trial. To ensure the rapid translation of ongoing research into near-term targeted treatments, we must continue these federal investments in the Fiscal Year 2027 Labor, Health and Human Services, and Education Appropriations bill.

Specifically, we respectfully request your continued support for:

- Maintaining dedicated support for CDC's national Fragile X public health program, including the FORWARD projects, without age limitations
- Report language encouraging NIH to expand the base of researchers and clinicians familiar with and trained in the Fragile X-associated conditions and disorders and promote collaboration between basic scientists and clinicians to enable researchers to better understand phenotypes, document variations in how the disorder presents itself, identify potential biomarkers and outcome measures, and develop new interventions.
- Continued support of the Centers for Collaborative Research in Fragile X and *FMR1*-Associated Conditions (P50).

To this end, we respectfully request the inclusion of the following report language regarding Fragile X:

**CDC**

*Fragile X and Fragile X-Associated Conditions and Disorders. -- The Committee commends CDC's efforts to identify and define the population impacted by Fragile X (FX) and all conditions associated with the gene mutation with the goal of understanding the public health impact of these conditions.*

*To help this effort, the Committee urges the National Center on Birth Defects and Developmental Disabilities (NCBDDD) to support additional strategies to promote earlier identification of all children with FX, such as voluntary newborn screening, proper and timely diagnosis. The Committee further recommends the NCBDDD support existing and future research initiatives across the lifespan of individuals living with Fragile X syndrome without age limits and for the associated conditions and disorders without age limitations.*

**NIH**

*Regarding Fragile X, the Committee notes the importance of expanding the base of researchers and clinicians who are familiar with and trained in Fragile X-associated conditions and disorders and promoting collaboration between basic scientists and clinicians to enable researchers to better understand phenotypes, document variations in how the disorder presents itself, identify potential biomarkers and outcome measures, and develop new interventions. The Committee commends the NIH for recognizing the ethical, legal, and social issues in premutation screening and testing and encourages the NIH to look at existing pilot studies that are looking at innovative ways to screen newborns, study Fragile X across the lifespan without*

*age limits, and to coordinate those efforts and research with the CDC as they look at screening solutions for all FMR1- related conditions.*

We are ever mindful that the Committee receives thousands of Member requests and must prioritize among them. We are grateful for the continued attention to Fragile X, which has such a significant impact on families across generations, on individuals throughout their lives, and on communities in every state and district. The potential for effective treatments is within reach, and continued support for Fragile X research and related public health activities is imperative. We look forward to continuing to work with the Subcommittee on this important issue.

Thank you for your time and consideration.

Sincerely,