FRAGILE X ADVOCACY

NEWSLETTER

ONE OF OUR STRATEGIC PRIORITIES IS PROMOTING ADVOCACY:

We promote effective ways for families to successfully advocate for themselves and their loved ones to meet the ongoing challenges of the Fragile X journey.

Save the Date!
NFXF Advocacy Day
February 23 -24, 2026

Join us in Washington D.C. Additional details will be shared later this year.

Questions? Email:
advocacy@fragilex.org

Building the Foundation for Progress through Advocacy

Year-round advocacy is essential for ensuring the needs of the Fragile X community remain visible at the federal level. The NFXF advocates help by engaging policymakers to advance research funding, healthcare/ education/ support programs, and public awareness.

Federal policies shape national priorities and often influence how services are delivered at the state level. These services provide support and resources that directly impact individuals and families living with Fragile X-associated conditions.

Together, we are the dedicated voices for Fragile X. If we don't advocate, no one else will.

nfxf NATIONAL FRAGILE X FOUNDATION

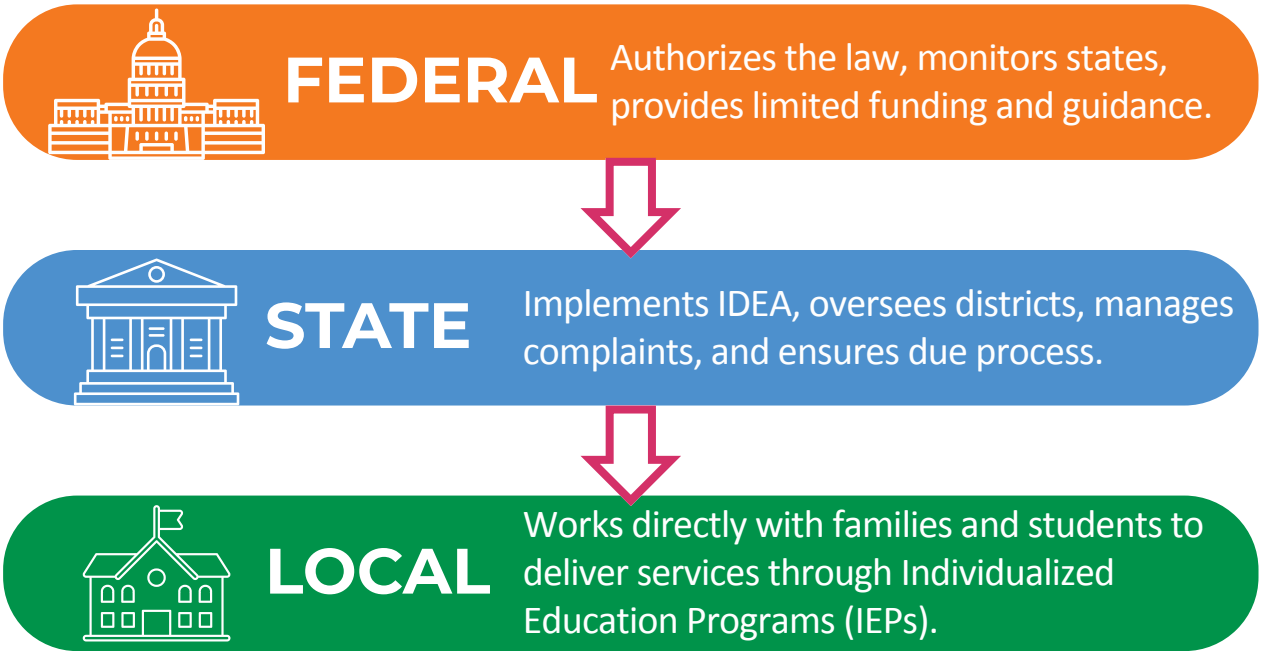
Understanding the U.S. Department of Education and its Role in Special Education

We understand there are concerns and questions surrounding recent reports of staffing changes at the U.S. Department of Education. Programs like Medicaid and special education are shaped by federal guidelines but implemented by each state. As parents, caregivers, professionals, and advocates, we all share a commitment to ensuring that individuals with Fragile X and other intellectual and developmental disabilities continue to receive the education and supports they are entitled to under federal law.

Special Education Law: A Quick Review

The Individuals with Disabilities Education Act (IDEA) is a federal law ensuring students with disabilities receive a free appropriate public education (FAPE). It defines student rights and school responsibilities. While IDEA provides the framework, each state is responsible for carrying out the law through its own education system.

Understanding Federal vs. State Roles: IDEA Implementation



What to Do If You Have Concerns About Your Child's Education

If you are concerned that your child's educational rights or supports are not being met, there are several ways to address concerns under IDEA:

- Start by discussing your concerns with your child's teacher or IEP team.
- If the issue isn't resolved, contact your school district's special education office.
- You can then file a state complaint, request mediation, or request a due process hearing.

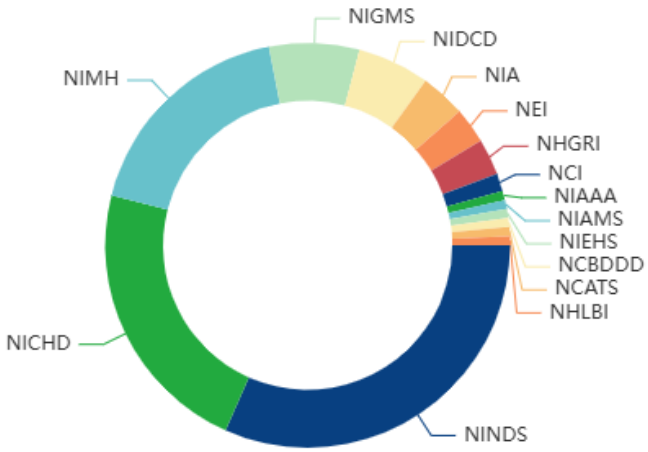
For additional resources, visit the NFXF's Learning, School, and Education page

National Institutes of Health (NIH) Investment in Fragile X/FMR1 - Associated Conditions

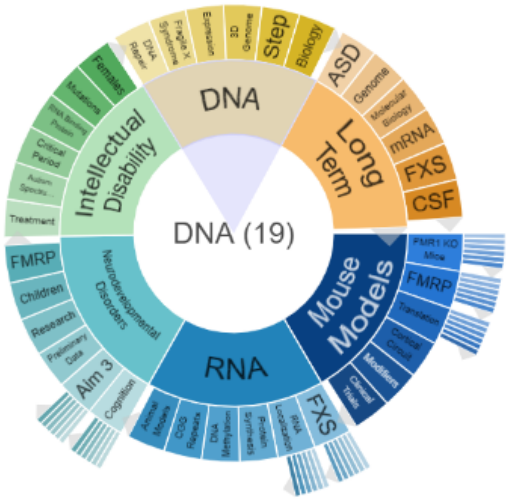
Over the past 21 years, the tireless efforts of Fragile X advocates have helped set the stage for meaningful federal research investments. By sharing their stories and experiences, advocates have shown policymakers the real-world impact of Fragile X, leading to continued funding for research and programs that make a difference.

We understand the community's concerns about reports on potential impacts to federal funding. Fortunately, despite these uncertainties, Fragile X research has continued to advance. We are deeply grateful for the continued commitment of our advocates and federal partners, whose support makes it possible to pursue effective treatments and improve outcomes for those living with Fragile X-associated conditions.

Funding Agencies



Funding Topics



National Institutes of Health. (2025). Initial public release of Modernized NIH RePORTER, version 2020.9, Release Notes. Data as of 11/03/2025. Retrieved from https://reporter.nih.gov/[1](https://reporter.nih.gov/release-notes).

$79 Million Awarded in 2025 for Fragile X/FMR1 Research

The ongoing dedication of researchers who work each day to advance understanding and improve outcomes for individuals and families living with Fragile X-associated conditions is inspiring. Their commitment to discovery and progress continues to move science forward, even in the face of challenges. We are excited to share more information about one of these awards, the NIH-Centers for Collaborative Research in Fragile X and FMR1-Associated Conditions.

NIH Centers for Collaborative Research in Fragile X and FMR1-Associated Conditions

The program is administered through NICHD's Intellectual and Developmental Disabilities Branch (IDDB). These Centers are geared toward stimulating multidisciplinary, multi-institutional research, with the common goal of facilitating the translation of basic research findings from bench to bedside and bedside to community.
The currently funded Centers include:

- Cincinnati Children's Hospital Medical Center
- University of South Carolina
- University of Michigan

Cincinnati Children's Hospital Medical Center

Principal Investigator (PI): Dr. Craig Erickson
Collaborators: University of California Riverside and the University of Texas Southwestern
Project Description: They propose studies across species (FMR1 KO mice and humans) and across developmental stages of brain neurophysiology (brain electrical activity) including work to evaluate the impact of new drug mechanisms on brain activity in Fragile X syndrome. The focus of our human work will in youth under age 18, and part of the work includes our first single-dose medication studies ever in 6 to 17-year-olds with FXS.

The human research occurs at the Cincinnati Fragile X Research and Treatment Center with mouse work happening at the University of California Riverside and the University of Texas Southwestern.

Dr. Erickson shared the following about the role of advocacy in supporting Fragile X Research:

"Now, in our third cycle of NIH fragile X center grants, we are extremely thankful for the advocacy of the National Fragile X Foundation and others who are the reason why the National Institutes of Health are required to fund three fragile X-related research center programs at any one time.

This advocacy has allowed us to conduct cutting-edge research, bringing together human science and bench lab science in ways that would be impossible without this funding mechanism.

We believe this research has helped change the field in positive ways that have improved our ability to link specific people with fragile X to specific treatment mechanisms under study."

University of South Carolina

Principal Investigators (PI): Dr. Jane Roberts
Dr. Jessica Klusek (Project 2) and
Dr. Abigail Hogan (Project 1)
Collaborators: Key collaborators include Drs. Elizabeth Berry-Kravis and Lilly Zhou (Rush University), Dr. Tatyana Adayev (Research Foundation for Mental Hygiene), Dr. Jeff Twiss (University of South Carolina), Dr. Marsha Mailick (University of Wisconsin–Madison), Drs. Federico Rodriquez Porcel, Christine Cooper, and Judy Dubno (Medical University of South Carolina), and Ms. VeVe Davis-Schofield of the Donavan Angel Foundation.
Project Description: "Translation of the FMR1 Premutation Phenotypes Across the Lifespan". This Center brings together a team of scientists, clinicians, and community partners who share one goal — to better understand how Fragile X-associated conditions develop and change over time, and how we can improve clinical care for people who carry the FMR1 premutation.

- Project 1: "Social Communication Trajectories as Predictors of FXAND in Young Children with the FMR1 Premutation". This project, led by Drs. Jane Roberts and Abigail Hogan will focus on preschoolers with the FMR1 premutation, studying how social communication and auditory processing relate to early behavioral differences.
- Project 2: "FXTAS in Women with the FMR1 Premutation: Establishing the Profile, Predictors, and Progression of Symptoms across Adulthood". This project, led by Dr. Jessica Klusek focuses on adult women with the FMR1 premutation, ages 35–80, to understand when and why FXTAS symptoms begin, and how clinical, genetic, and environmental factors may play a role.

Dr. Robert's shared the following about the role of advocacy in supporting Fragile X Research:

" The progress made in fragile X research would not be possible without the strong voices of the advocacy community. Events like the National Fragile X Foundation's Advocacy Day in Washington, D.C., bring together families, researchers, and supporters to raise awareness, encourage funding, and keep research moving forward.

By shining a light on the challenges experienced by carriers of the FMR1 premutation, like FXTAS and FXAND, advocates play a key role in ensuring that scientific advances translate into real change for families.

Drs. Roberts, Klusek, and Hogan are grateful for the leadership of the National Fragile X Foundation and the dedication and hard work of all in our Fragile X community, whose engagement is central to these efforts. Your commitment fuels discoveries and makes a direct impact on the lives of individuals living with Fragile X-associated conditions and their families."

University of Michigan

Principal Investigators (PI): Dr. Peter Todd (Project 1) and Dr. David Nelson (Project 2), and Dr. Emily Allen (Project 3)

Collaborators: Baylor College of Medicine, Rush University Medical Center, and Emory Fragile X Research Center

Project Description: "Fragile X Premutations, Mechanisms and Modifiers". Repeating sequences within the FMR1 gene can lead to a group of conditions known as Fragile X-associated conditions, including Fragile X syndrome (FXS), Fragile X-associated tremor/ataxia syndrome (FXTAS), and Fragile X-associated primary ovarian insufficiency (FXPOI). Currently, there are no effective treatments for these conditions.

This expert group will investigate the mechanisms by which this repeat causes disease while also identifying genes that modify the expressivity of Fragile X-associated conditions. By using an integrative methodology that spans from patient-derived samples, bioinformatic approaches, and clinical symptoms to rodent and human neuronal models of disease, they seek to understand how repeats elicit dysfunction with a goal of developing a more effective approach to therapy development in Fragile X-associated conditions.

- Project 1: "CGG Repeats as Pathogenic Driver and Therapeutic Target". These studies will provide critical insights into the toxic mechanisms by which CGG repeats elicit FXTAS while assessing rational therapeutic approaches and a novel potential disease biomarker.
- Project 2: "FXTAS: Mechanisms and Modifiers". In this project, they propose to confirm and extend identification of genetic modifiers through additional sequence analysis in a well-characterized cohort of FXTAS patients, analyze modifiers of FXTAS in multiple mouse models of FXTAS, and investigate the role of the premutation in ribosome biogenesis, a cellular phenotype they have recently uncovered.
- Project 3: "FXPOI: Mechanisms and Modifiers". The focus of this proposal is to identify the modifiers and mechanisms of the Premutation associated conditions (PMACs). They will test their hypothesis using a series of PM human and mouse models: they will examine environmental exposures as modifiers of PMACs, the molecular properties associated with phenotypic heterogeneity, as well as phenotypic modifiers within our established PM mouse models.

Every Conversation Counts. Every Voice Matters.

We are thankful for the commitment of our advocates and researchers whose ongoing efforts sustain progress in Fragile X. Your voices and partnerships with policymakers strengthen understanding and support at the federal level. Together, this collaboration continues to advance meaningful research and improve the future for those living with Fragile X-associated conditions.

Thank you, Advocates, for all you do!