2025 Impact Report

NATIONAL FRAGILE X FOUNDATION

Community: At the Heart of Everything We Do

Promoting Advocacy — We promote effective ways for families to advocate successfully for themselves and their children as they navigate the ongoing challenges of the Fragile X journey.

Providing Education — We provide valuable tools and resources to help families manage the day-to-day challenges of life with Fragile X.

Advancing Research — We facilitate research activities for families and professionals, underlining their value in the research process and how their active participation advances effective treatments and a cure.

Improving Treatment — We seek to improve access and availability of informed treatment options to promote knowledge for all patients with Fragile X.

Advocacy

Advocacy Day

On Advocacy Day, February 2025, 130 dedicated NFXF Advocates, including self-advocates, siblings, parents, caregivers, professionals, and researchers, representing 26 states and the District of Columbia, headed to Washington, D.C. Together, they held 114 high-impact meetings with members of Congress and their staff. They shared personal stories, raised vital awareness, and presented the NFXF's collective Asks. Their primary focus was securing sustained and increased federal funding for Fragile X research and advancing key policy priorities that uplift individuals and families living with Fragile X.

Read the April 2025 Fragile X Advocacy Newsletter

Education

Animated Video Series

To expand education and awareness, we launched a new animated video series, "What is Fragile X?," reaching over 50,000 people during Fragile X Awareness Month! These videos are proudly voiced by community members and provided in both English and Spanish. Videos include:

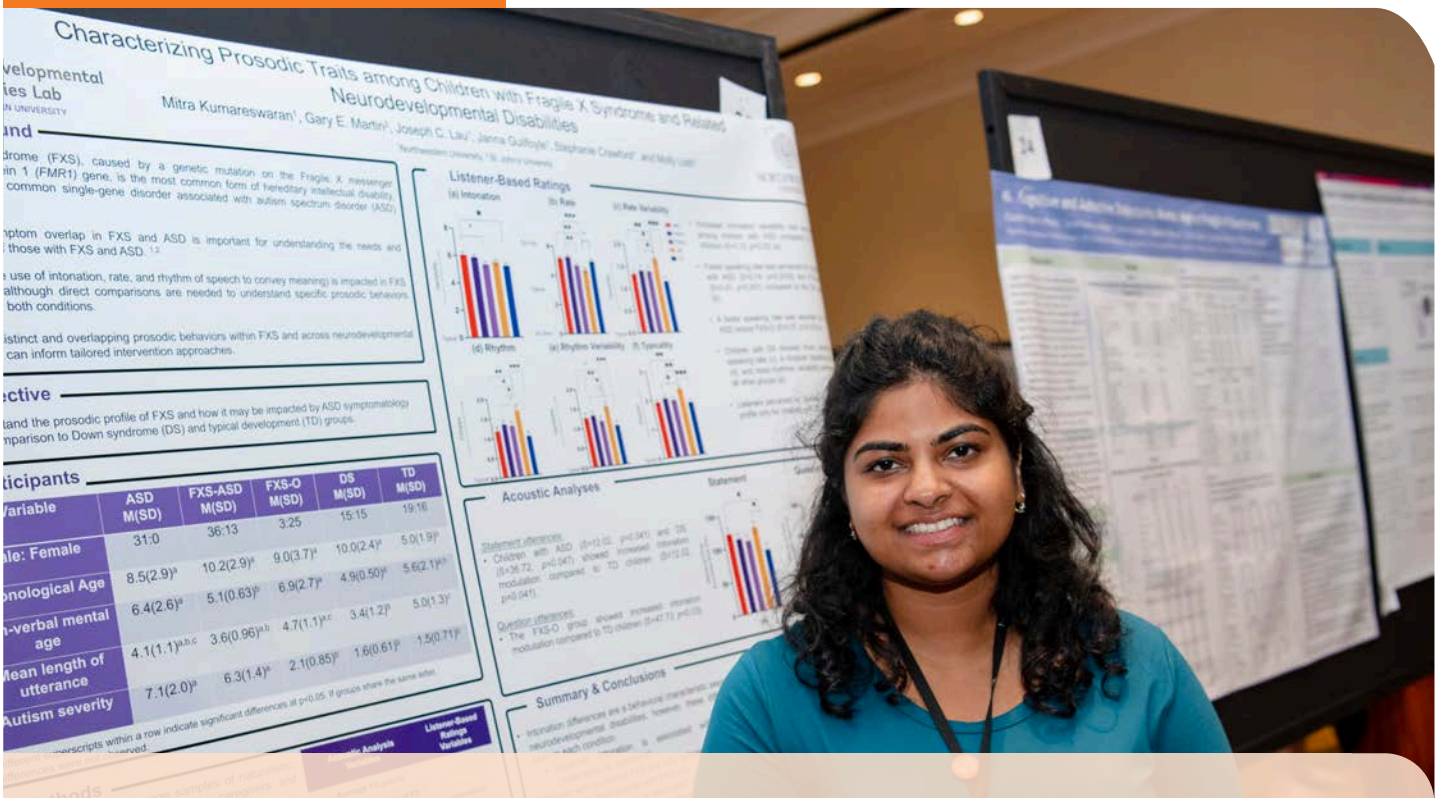
- What is Fragile X?
- What is the Fragile X Premutation?
- I'm a Female With Fragile X Syndrome and I Want to Tell You About Fragile X
- I'm a Male With Fragile X Syndrome and I Want to Tell You About Fragile X
- ¿Qué es la premutación del cromosoma X frágil?
- ¿Qué es el síndrome del cromosoma X frágil?

New & More Content — We're Listening

We are always open to hearing from the community and continue adding resources for families and professionals through webinars, videos, blog posts, social media, how-tos, templates, and articles. New, popular content created from community requests includes:

- How is Fragile X Syndrome Inherited? — *Video*
- The Genetics of Fragile X: Resources to Share — *Downloads*
- Resources and Support Around Grief and Loss — *Webinar*
- Creating a Letter of Intent — *Webinar*
- Top Financial Mistakes to Avoid for Special Needs Dependents — *Webinar*
- Gene Therapy & the FXS Community: A Review of Community Surveys — *Webinar*

Research



Research Awards

We continue to invest in the future of research. Through our Randi J. Hagerman Summer Scholars and Junior Investigators programs, we fund and mentor the next generation of Fragile X researchers — advancing critical work in Fragile X syndrome, FXTAS, FXPOI, and the premutation. **Meet Susana, Tanvi, and Shelby**, our 2025 RJH Summer Scholars.

We also expanded our investment in data and biobanking efforts to support clinical trial readiness in the FXTAS community—helping lay the groundwork for future breakthroughs.

Community

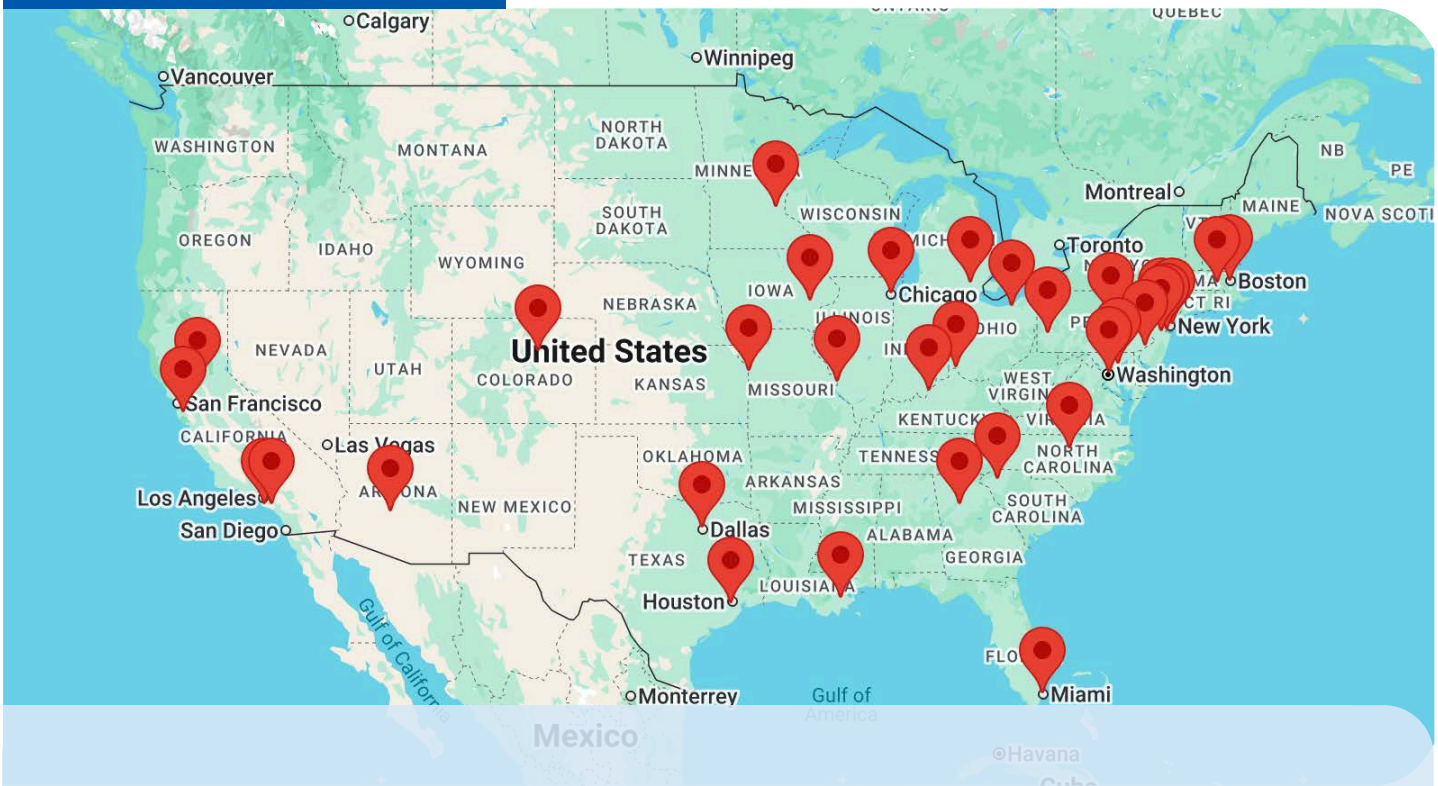
Fragile X Caregiver Stories

We partnered with Shionogi on a caregiver storytelling video series to ensure the voices of families living with Fragile X are heard and shared with the broader community. Watch Caregiver Stories:

- Denise
- Diane
- Kara
- Rene
- Jessie
- Ilana and Adam

SHIONOGI

Treatment



Treatment Recommendations

Each year, we publish updated Fragile X Treatment Recommendations — providing evidence-based guidance to inform care **across all Fragile X-associated conditions and disorders**. This year, we also held webinars so the community could ask questions about the latest publications. Updated treatment recommendations during 2025:

- Fragile X-Associated Primary Ovarian Insufficiency (FXPOI) **&** Associated Webinar
- Sleep in Children with Fragile X Syndrome — For Your Care Team
- Sleep in Children With Fragile X Syndrome

Specialty Clinics

We grew the number of specialty clinics serving families living with Fragile X around the country, easily located through our FXS Clinic Finder, FXTAS Clinic Finder, International Clinic Finder.

Thank you to our donors, volunteers, corporate sponsors, nonprofit partners, friends, and supporters for helping us deliver on our mission to serve the entire Fragile X community!

Together, We're Stronger!