

2024 Impact Report

This year, the National Fragile X Foundation celebrated its 40th anniversary. Whether you joined us in person at our unforgettable 19th International Fragile X Conference in Orlando, raised your voice on Capitol Hill at our 20th Advocacy Day, or accessed any of our on-demand content, your support made it all possible. Every page celebrates the strength of our community and the meaningful progress we're making—together.



LETTER from the EXECUTIVE DIRECTOR

What a year 2024 has been for the National Fragile X Foundation! As we close out our 40th year serving this remarkable community, I find myself reflecting on the deep sense of purpose and partnership that defines everything we do at the NFXF. This year has reminded us again and again that the heart of our work is the community we serve—individuals with Fragile X and their families, professionals, researchers, self-advocates, and friends who show up with passion and commitment every single day.

Together, we reached exciting new milestones. Nearly 800 people joined us in Orlando for our 19th International Fragile X Conference, making it one of our most impactful gatherings yet. From cutting-edge science to heartfelt stories, the conference captured the full spirit of our community: strong, informed, resilient, and, of course, fun!



We also celebrated our 20th Advocacy Day in Washington, D.C., where 150 advocates from 29 states met with 119 Congressional offices. In one of the most important years to date, Advocates shared their stories, underlining policies and research priorities that directly benefit our families and drive progress for all living with Fragile X.

Our 2024 webinar series covered essential topics like behavior strategies, financial planning, premutation awareness, and gene therapy. These webinars, shaped by your feedback, brought trusted guidance directly to homes across the country, even the world.

And through it all, we’ve remained deeply committed to moving research forward. This year we were proud to support 12 research awards, across our Summer Scholar and Junior Investigator programs, supporting emerging leaders working to uncover new insights and treatments across the Fragile X conditions.

These achievements—and many more highlighted in this report—are a testament to what we can accomplish together. Every advocate, clinician, researcher, family member, and friend has played a part in this Xtraordinary year. Your belief in our mission powers our progress.

The next 40+ years will be guided by the momentum of the past 40, and a clear vision for the future—that every individual with Fragile X is supported, understood, and empowered to thrive. Thank you for the opportunity to do this work alongside you, I cannot wait to see what we do together.

Hilary Rosselot,
Executive Director

LETTER from the BOARD PRESIDENT

Embracing the Xtraordinary: 2024 was a year to remember—and to celebrate!

We marked 40 years of the National Fragile X Foundation, four decades of heart, hope, and progress. We rallied for our 20th Advocacy Day on Capitol Hill, making sure our voices rang loud in Washington. And, we came together for our 19th International Conference—the ultimate highlight of our year—where connections were made, knowledge was shared, and our community shined.

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2024 proved that when we embrace
the Xtraordinary, extraordinary
things happen.

Guided by our strategic priorities—Advocacy, Education, Research, and Treatment—we kept our focus on what matters most: our amazing Fragile X community. This year brought stellar webinars, collaborations, and we celebrated Summer Scholars and Jr. Investigators. Our Clinic Consortium continues to grow—truly one of a kind—and our Belonging Project is deepening the sense of inclusion and support that makes our community strong.

2024 proved that when we embrace the Xtraordinary,
extraordinary things happen.

To our NFXF team and Board of Directors—thank you for your tireless dedication, work, and unwavering belief in the power of this community.

Here’s to the next chapter—together, we’ve only just begun!

Shine on,

Laurie Bridges,
Board President



NFXF 2024 BOARD OF DIRECTORS



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David Tillman, PhD
Victoria Wilkins, MD

Carolyn Tomberlin
Ambassador

THANK YOU to our board members whose terms ended in 2024.

Abby Gaunt | Jed Seifert

WELCOME to our newest board members whose terms begin in 2025.

Jill Dolan
Michele Kaplan
Kerry Stedke, PA

Self-Advocate Advisors to the Board:

Carly Dolan
Kelly Dunphy
Dillon Kelly
Summer Villalta

OUR FOUR STRATEGIC PRIORITY AREAS



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.



Providing Education

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



Improving Treatment

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

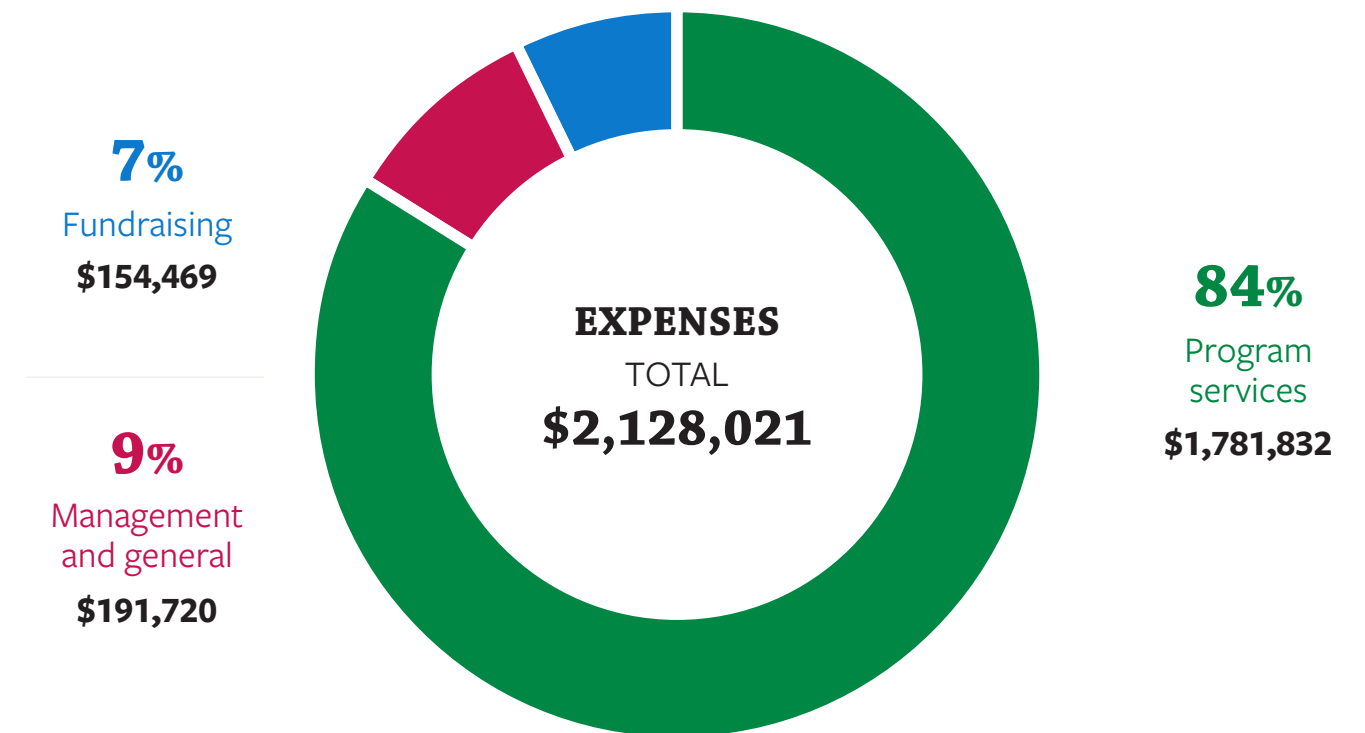
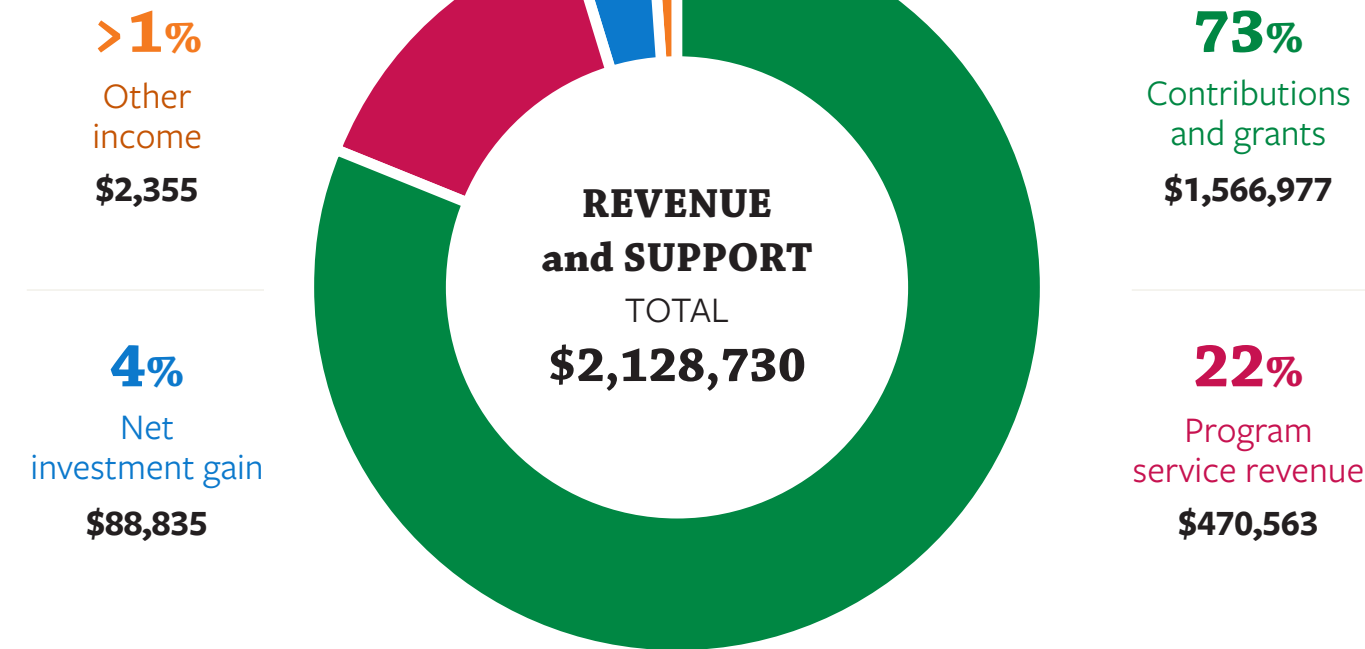


Advancing Research

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.



NFXF 2024 REVENUE and EXPENSES





20th Annual Advocacy Day

For over 21 years, a community of advocates has come together to educate members of Congress. On February 26-27, 2024, our team of 150 advocates from 29 states held 119 meetings with Congress members to advocate for research funding and legislation that supports the Fragile X community.

Advocates, including self-advocates, siblings, parents, caregivers, physicians, and researchers, train and work with a shared purpose and passion for raising awareness about Fragile X. Research funding from the NIH, CDC, and DOD is always a priority. Additional “asks” in 2024 included the SSI Savings Penalty Elimination Act, the Accelerating Kids’ Access to Care Act, and continued funding for FY25.

The federal government invests over \$50 million a year in Fragile X research between the NIH, the CDC, and the DOD. This varies yearly depending on the research proposals funded after the peer-review process. The CDC funding supports the FORWARD project, which in turn produces content that promotes awareness among professionals and the baseline for consensus guidelines. Advocates can continue to promote awareness and seek support with their members of Congress year-round:

Senate: Share your story and request that Fragile X be included as an authorized research area for the DOD’s Peer-Reviewed Medical Research Program. The Appropriations Committee approves the medical conditions, disorders, and diseases the program may research through report language each year. Which research is funded is decided by a peer review process.

House: Share your story and request support for Fragile X at the NIH and the CDC. The CDC has an annual line item in their budget request for \$2 million for Fragile X, and the NIH funds projects as they are peer-reviewed in addition to an important Fragile X-specific centers grant, Centers for Collaborative Research in Fragile X and *FMR1* Associated Conditions (P50).

“
Our advocates have been able to secure over \$550M in research funding over the past 20 years.

150 advocates

29 states represented

119 meetings

20 years

A Reflection on the CEO Commission’s 2024 Hill Day

NFXF Executive Director Hilary Rosselot and Advocacy Ambassador to the NFXF Board of Directors Dillon Kelley attended the CEO Commission for Disability Employment’s Employment Summit and Hill Day in September.

Advocating with partners like the CEO Commission is important because our collective voice is stronger and louder. Equity in employment and meaningful work are topics near and dear to our hearts, and so are many in the disability space.

It was an inspiring, action-packed few days, and Dillon shared his experience with employment and some of the things that have been challenging for him and other self-advocates.

“Self-advocates want to work! Everyone has different abilities, but we can and want to work, especially without the fear of losing our benefits. I enjoyed meeting other self-advocates at the event and hope to meet even more at future CEO Commission events and Hill Days.”



“Everyone has different abilities, but we can and want to work, especially without the fear of losing our benefits.”

DILLON KELLEY
Advocacy Ambassador to the NFXF Board of Directors

Advocacy & Federal Research

For over 21 years, dedicated Fragile X advocates have helped secure more than \$650 million in research funding—fueling critical progress toward effective treatments for Fragile X and FMR1-associated conditions.

During the [2024 NIH Fragile X Centers of Excellence Webinar](#), NIH-funded Centers shared exciting updates on preclinical models, ongoing studies, and promising therapies for Fragile X syndrome, FXTAS, and FXPOI.

Thanks to NFXF advocates, Fragile X remained an eligible topic under the DOD’s FY24 Peer-Reviewed Medical Research Program (PRMRP). At our [Information and Tips for Applying for DOD’s PRMRP Funding Webinar](#), the Deputy Program Manager provided expert guidance and practical tips to help researchers navigate the application process.

The NFXF also continued its role on the Steering Committee of the CDC-funded FORWARD project in 2024—contributing insights and collaborating with clinic partners and CDC leaders to help guide current and future efforts in Fragile X research and care.

Fragile X Advocacy Newsletter

We know keeping advocates and the entire Fragile X community updated on our advocacy efforts year-round was essential. Each newsletter contains updates on current asks, letters of support, and new and yet-to-be-introduced legislation we monitor. We first published Fragile X Advocacy Newsletters in 2023 and again for 2024, and will continue into 2025.

[Read the October 2024 issue](#)

[Read the June 2024 issue](#)

[Read the November 2023 issue](#)

[Read the July 2023 issue](#)



PROVIDING EDUCATION



Strategies for Addressing Aggressive Behavior in Adolescents and Adults with Fragile X Syndrome

Aggressive behaviors can be misunderstood and incredibly challenging. We addressed this crucial topic in a family-friendly manner to provide families and other caregivers with a better understanding of the possible causes of aggressive behavior, including recommendations for responding during and following an aggressive incident.

About Me Template

We created a 13-page “About Me” template to help individuals with Fragile X syndrome (and their loved ones) confidently explain what Fragile X is and thrive in any setting.

Happy National Disability Awareness Month

In honor of National Disability Awareness Month, we provided resources for educating yourself on existing supports and how to best advocate for workplace accommodations.

Monthly Webinar Series: Tackling Challenging Topics

We hosted seven new webinars in 2024, each thoughtfully designed around the Fragile X community’s top priorities, as identified through direct feedback and surveys.

Gene Therapy & the FXS Community: A Review of Community Surveys

With David Hampson, Anna De Sonia, Sarah Eley, Vivian Chen, Marisa Vomvos, and Dr. Rey Lozano

Navigating Challenging Behaviors

With Tracy Stackhouse, Lauren Moskowitz, Jennifer Epstein, and Missy Zolecki

Females with Fragile X Syndrome

With Barbara Haas-Givler, Cora Taylor, Nicole Tartaglia, Tracy Jordan, and Vicki Wilkins

Financially Empowering the Fragile X Community Through ABL Accounts

With Mark Raymond Jr. and John Finch

10 Basic Financial Steps for Special Needs Caregivers

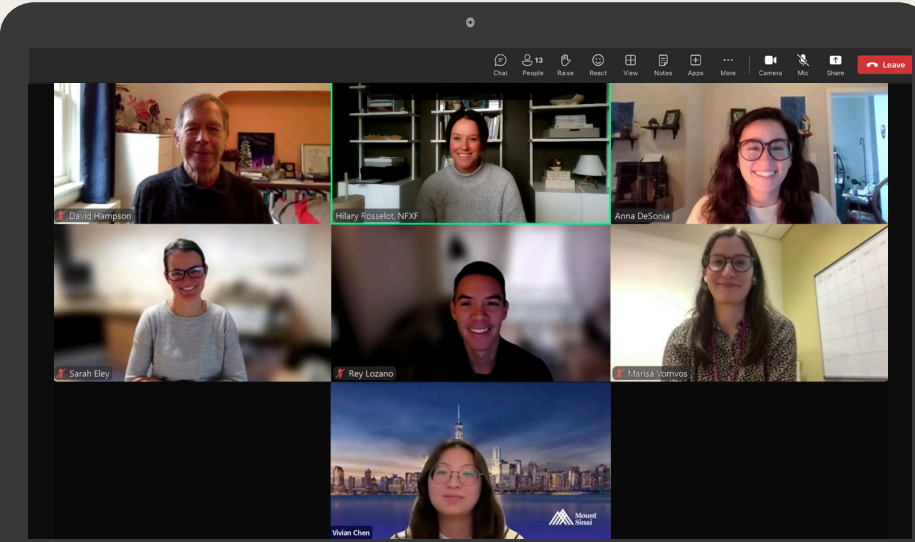
With Kelly Piacenti

I Have the Fragile X Premutation ... Now What?

With Deborah Barbouth, Emily Allen, Reymundo Lozano, and David Hessl

Introductory Discussion on Estate Planning

With Denny Haugen, Don Meyer, and Missy Zolecki



Embracing the Xtraordinary: Inspiration from the Fragile X Community—A Keynote Address

Some of the best education and insights come directly from families. Panelists Carly Dolan, Jill Dolan, David Tillman, and Tamaro Hudson inspired, empowered, and uplifted the audience with their resilience, courage, and unwavering determination shared during this keynote from the NFXF 19th International Fragile X Conference.

This keynote address was so inspirational, we released it just after the conference for all to enjoy!

“The topic of this panel is embracing the extraordinary. As I think about that, one of the things that I think about is the courage to wrap your arms around what makes this life an extraordinary one.”

DAVID TILLMAN
Dad to Miles, who lives with Fragile X syndrome

Fragile X Clinics Highlighted

There are over 30 clinics across the United States that are members of the NFXF Fragile X Clinical and Research Consortium (FXCRC) and specialize in services for individuals with Fragile X syndrome and the Fragile X premutation. This year, we started a clinic highlight, introducing you to each clinic one-by-one so you could get to know the dedicated professionals that serve the Fragile X community.



Fragile X Research and Treatment Center at the UC Davis MIND Institute



Fragile X Program at Thompson Autism and Neurodevelopmental Center, Children’s Hospital of Orange County



Cincinnati Fragile X Research and Treatment Center



The Michigan Medical Fragile X Clinic



“
The NFXF has given me
a community with other
experts, increasing my
knowledge base and
equipping me to clinically
serve patients.

FRAGILE X CLINICIAN



FORWARD Accomplishments in 2024

The longtime CDC-funded FORWARD study continues to be an important research project. Many publications result from this dataset, are commonly cited by others in the field, and contribute to our ever-popular Treatment Recommendations.

New: Sensory Symptoms and Signs of Hyperarousal in Individuals with FXS

FORWARD Behind Two of the Most Cited Papers



Partnering with the National Ataxia Foundation for Better FXTAS Care

We partnered with the National Ataxia Foundation to raise awareness for FXTAS with two webinars presented by two highly esteemed doctors and Fragile X researchers. The NFXF and NAF have similar missions and visions for the world, and we applaud their efforts to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.

All About FXTAS with Dr. Peter Todd, professor in the Department of Neurology at the University of Michigan.

Research and Treatment Development for FXTAS with Dr. David Hessel, professor at the UC Davis MIND Institute and director of the Translational Psychophysical Assessment Laboratory.

Randi J. Hagerman Summer Scholars Awards

Named for our co-founder and ultimate Fragile X mentor, Dr. Randi Hagerman, these awards importantly encourage mentorship and collaboration.



Thomas Christensen
Exploring Social Determinants of Health and the FMR1 Premutation Symptomology in Women
Thomas's mentor: Jessica Klusek, PhD

“My focus in research is on how we can better support people with neurodevelopmental disabilities and their families. I am particularly interested in how we can implement community support or other external supports.”



Manasi Inamdar
Identifying Translational Dysregulation Underlying Auditory System Dysfunction in a Rat Model of Fragile X Syndrome
Manasi's mentor: Benjamin D. Auerbach, PhD

“Participating in this program has also opened the door to future collaborations with researchers, clinicians, and advocates committed to enhancing the lives of those with FXS.”



Emily Peery
Women's Healthcare Provider Knowledge on FXPOI: Improving Understanding Through an Educational Tool
Emily's mentor: Emily Allen, PhD

“I look forward to continuing to see the growth in this field and hope to contribute to the care of women diagnosed with a FMR1 premutation as a genetic counselor.”



Emily Timm
The Neural Mechanisms Underlying Cortical Control of Gait and Cognition in Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS)
Emily's mentor: Joan O'Keefe, PT, PhD

“Without a doubt, the most rewarding part of the program has been meeting our study participants and learning about their experiences with FXTAS. [They] and their family members are so strong and eager to contribute to scientific research even if it doesn't directly benefit them.”

Junior Investigator Awards

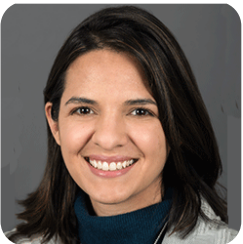
The Jr. Investigator Awards are a vital investment in the future of Fragile X research and care. By supporting early-career professionals to attend, network, and present at the NFXF International Fragile X Conference, these awards help cultivate the next generation of leaders dedicated to advancing treatment, discovery, and support for the Fragile X community.



Andrew Dakopolos, PhD
Developmental Links Between Cognition, Adaptive Behavior, and Intelligence in Individuals with Fragile X Syndrome



Lisa DeStefano, PhD
Visual Discrimination in FXS: Insights From Behavior and EEG



Caroline Dias, MD, PhD
Cell-Type-Specific Effects of the Fragile X Premutation in Human Brain



Brett Dufour, PhD
Evidence for Widespread Loss of Parvalbumin-Expressing GABAergic Interneurons Throughout the Human Fragile X Brain



Nell Maltman, PhD
Language Features Among Individuals with Symptoms of Fragile X-Associated Tremor/Ataxia Syndrome



Sarah Nelson Potter, PhD, CCC-SLP
Correlates of Parenting Stress in Mothers and Fathers of Young Boys with Fragile X Syndrome



Walker McKinney, PhD
Results from a Double-Blind, Randomized, Placebo-Control Trial of Lovastatin and Minocycline in Fragile X Syndrome



Kimaya Sarmukadam, PhD
Sensory Impairments Predict Anxiety Symptoms in Preschoolers with Fragile X Syndrome: A Cross-Sectional Study

New Lunch & Learn Series



Our new Lunch & Learn series brings cutting-edge Fragile X research directly to the community, connecting the science to its everyday impact. Each webinar features researchers sharing not just their findings, but why they matter, highlighting how their research moves us closer to meaningful progress for individuals and families living with Fragile X.

Single-Dose Medication Study Results in Fragile X Syndrome

FMR1 Carriers Report Executive Function Changes Prior to FXTAS: A Longitudinal Study

Drs. Berry-Kravis and Kaufmann on the Two Most Cited Publications

The Dos and Don'ts of Participating in a Clinical Trial

To help keep clinical trial data objective, it's important to be mindful of what and where we share about our trial participation. We never want to introduce bias! This simple but important checklist helps support thoughtful sharing.



Read about our meetup with the Summer Scholars and their mentors and view their presentations

Our Series on Gene Therapy

Gene therapy is generating excitement—and growing curiosity—across the Fragile X community. In 2024, the NFXF put a special emphasis on this topic, pulling together a group of experts who could help create content side-by-side with the NFXF to educate the community and prepare them for the future. While gene therapy looks to be a promising avenue for future FXS treatment, there is still a lot to learn and a long road ahead. We look forward to seeing where the future takes us!

 Learn more about the series on Gene Therapy



Gene Therapy
Conference Panel

At the 19th NFXF International Fragile X Conference, we hosted our first-ever gene therapy panel, kicking off our commitment to educating the Fragile X community. The session began with insights from the NFXF mini survey on family perceptions of gene therapy, followed by a dynamic discussion with leading experts. They shared their perspectives, addressed questions, and highlighted what excites them most about the future of gene therapy in Fragile X research.

Gene Therapy Simplified: What
is it and How Does it Work?

This article — written with the NFXF & Gene Therapy Committee — offers an accessible overview of gene therapy and its potential applications for Fragile X syndrome. It outlines four primary gene therapy approaches and how they work.

Gene Therapy & the FXS
Community: A Review of
Community Surveys

As gene therapy moves closer to reality, researchers are eager to understand how the Fragile X community feels—its hopes, questions, and concerns. This engaging webinar features an overview of gene therapy and its potential for Fragile X followed by summaries of recent community surveys, making it a must-watch for anyone curious about the future of gene therapy in Fragile X.

COMMUNITY HIGHLIGHTS



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Thank you, Drs.
Budimirovic and Protic,
for your dedication,
sustained interest in
Fragile X, and many years
of kind, compassionate
service to the
Fragile X community!

Our 2024 NFXF Awardees

The 2024 NFXF Awards were given out at the 19th NFXF International Fragile X Conference. Each award—Community Support Network, Research, Clinical, Hagerman, the AI and Melissa Blount Lifetime Achievement, and the Professional Lifetime Achievement awards—honors members of the Fragile X community who go above and beyond.

Our 2024 awardees included the Sibling and Self-Advocate Network, the Richter lab, University of Massachusetts Chan Medical School, Dr. Dejan Budimirovic, Dr. Dragana Protic, Dr. Emily Allen and Jay, Anne, and Alec Souder. Drs. Ave Lachiewicz and Jean Frazier were honored with our newest award, the Professional Lifetime Achievement Award.

Thanks to all our 2024 NFXF Awardees!



The NFXF Belonging Project

Our newest initiative in 2024, the Belonging Project, aimed to intentionally extend our reach to underserved communities across the United States. In partnership with the Fly With Me Fund and four Fragile X clinics, we’ve begun work to understand the challenges to diagnosis and treatment faced by Black, Hispanic, and Native American communities and the providers who serve them. And we’re proud to say we’re already having a major impact!

Each Belonging Project awardee made strides towards understanding the fundamental question, “How do we make sure that everyone in our Fragile X community feels like they belong?” With open ears and hearts, we endeavor to make the Fragile X community a better place and create scalable solutions that we can all adopt.

“
Since we started this project at the University of Utah
Fragile X Clinic, we have identified two new individuals
with a diagnosis of Fragile X syndrome in the Pacific
Islander and Native American communities.



Naterra Walker, NP
Principal Investigator
Children’s National Hospital



Victoria Wilkins, MD, MPH
Principal Investigator
University of Utah and Primary
Children’s Hospital



Debra Reisinger, PhD
Principal Investigator
Cincinnati Children’s Hospital
Medical Center



Anna De Sonia
Principal Investigator
National Fragile X Foundation

NFXF’S 40TH ANNIVERSARY TIMELINE

Over the past 40 years, so many volunteers, team members, donors, advocates, self-advocates, clinicians and clinic teams, researchers, therapists, educators, counselors, advisors, and others have worked toward a common single goal — improving the lives of those impacted by Fragile X. Thank you! The Fragile X community has always and continues to be at the heart of what we do.

We couldn’t include everyone who helped make the National Fragile X Foundation what it is today. Over the past 40 years, many volunteers, team members, donors, advocates, self-advocates, clinicians and clinic teams, researchers, therapists, educators, counselors, advisors, and others have worked toward a common single goal — improving the lives of those impacted by Fragile X. The community is at the heart of what we do.

'84

The Beginning

The National Fragile X Foundation is established.



A Global Fragile X Community

Shown: Drs. Randi Hagerman, Elizabeth Berry-Kravis, and Paul Hagerman

'90

The 1990s and the NFXF Becoming a True National Organization



How the NFXF Has Informed the Community Through the Years

NFXF launches its first website and a quarterly newsletter

'91

Identification of the Fragile X gene, FMR1

'00

Dr. Hagerman speaks to Congress about Fragile X for the first time

This may have been one of the first times that many members of Congress heard the words “Fragile X.”

'01

FXTAS is described as an FX premutation condition

'06

Improving Treatment Through Leadership of the FXCRC

The NFXF established nationwide Fragile X specialty clinics, later becoming the Fragile X Clinical & Research Consortium.



The first FXCRC meeting

'17

The Clinical Trials Committee is formed to help advise researchers, including biotechnology and drug companies, on developing and implementing their Fragile X programs.

'21

The NFXF-led Patient-Focused Drug Development Meeting for Fragile X Syndrome is held.

The People Who Are the NFXF

There have been dozens of staff, 100s of volunteers, and 1,000s of donors, and we extend our heartfelt thanks!

1980s1990s2000s2010s2020s

'87

NFXF International Fragile X Conferences

The first NFXF International Fragile X Conference is held in Denver, Colorado.

'87

The Early Years

NFXF volunteers did their best to share presentations with doctors and scientists worldwide. NFXF co-founder Dr. Hagerman crashed a meeting on X-linked intellectual disabilities in Australia.

There were still many questions about Fragile X since it didn’t seem to follow the established rules of X-linked inheritance.

'91

Fragile X-associated primary ovarian insufficiency is discovered

Researchers noticed that some females in families with a Fragile X male experienced premature menopause, later characterized as FXPOI.

'02

Legislative Advocacy

First NFXF Advocacy Day



Senator Barbara Boxer and NFXF Board Chairman John Harrigan

'08

A 40-Year History of Supporting Research

The CDC funds the first FORWARD study.



'24

Our 40th Anniversary



OUR CONFERENCES:

1987, 88, 89 Denver, Colorado | 1992 Snowmass, Colorado; 1994 Albuquerque, New Mexico; 1996 Portland, Oregon; 1998 Asheville, North Carolina | 2000 Los Angeles, California; 2002 Chicago, Illinois; 2004 Washington, DC; 2006 Atlanta, Georgia; 2008 St. Louis, Missouri; 2010 Detroit, Michigan; | 2012 Miami, Florida; 2014 Anaheim, California; 2016 San Antonio, Texas; 2018 Cincinnati, Ohio; | 2020 an online/virtual event; 2022 San Diego, California; 2024 Orlando, Florida.



EVENTS HIGHLIGHTS

The Marner Family Hosts Their 5th Annual Quad Cities Fragile X Golf Outing

June 22: Yet again, this year’s fundraiser was the most successful yet, with a record 35 teams—making it the first time they filled all available holes with teams.



Thank you to Andrea and Kevin Marner—and all of your guests, donors, and sponsors over the past five years—for making such an incredible impact on the Fragile X community!



The NFXF Heartland Chapter Hosts 9th Annual “Bike To X Out Fragile X”

June 1: Nancy Carlson and the NFXF Heartland Chapter hosted the annual event in Des Moines, Iowa. The 15.5-mile ride included going through nearby Waukee and began at 9:30 AM with meeting points at various locations to stop for food and refreshments.



Xtreme Wheels for Fragile X Syndrome: Fundraising Car Cruise-In

September 21: A fundraiser car show at Children’s Autism Center in Fort Wayne, Indiana, featured food trucks, live music, performances, fire and police vehicles, face art, balloons, and of course cool cars.



NFXF Western Massachusetts Chapter Hosts 5th Cork and Cafe 2024

September 29: More than 50 friends and supporters gathered to eat great food, taste various wines, bid for prizes, and raise awareness and funds to support the Fragile X community. The event was hosted by the NFXF Western Massachusetts Chapter and held at the Esselon Cafe in Hadley, Mass.



Fishing for a Cure: The Christoffs Have Done it Again!

October 19-27: Over two weekends in October, Joey Christoff and his family hosted their eighth fishing tournament near their home in Hilton Head, South Carolina. Their first tournament was over 10 years ago and in all they’ve raised more than \$100,000 total!

Fundraiser In Honor of Miles & the Harnett Central Swim Team

December 2: In honor of Giving Tuesday, David Tillman hosted a fundraiser with the HCHS Swim Team swimming for Xtraordinary Miles and The National Fragile X Foundation. With David matching the donation, the total raised came to \$2,000.

All of you who supported pushed this little fundraiser way beyond my expectations.

— DAVID TILLMAN

A Fragile X Christmas

December 9: This was Denny and Marcia Haugen’s third annual Fragile X Christmas party in Waverly, Iowa. Their nearly 100 generous guests enjoyed live Christmas music, food, and drinks while learning more about Fragile X. The three annual parties combined have raised more than \$75,000!



X Strides with Greater Chicago

July 13: More than 50 families and caregivers participated including heading to the park splash pad to cool off afterward. In addition to being out on a nice day and fundraising, they helped raise awareness as people approached to ask, What is Fragile X?



Western Massachusetts Fragile X 8th Annual Hadley Corn Hole Championship

March 3: With nearly 100 attendees, including 26 teams, it was a fun-filled afternoon, with 45 raffle items, prizes, delicious food, and a DJ. Organizer Denise Devine says that the event was success thanks to the dedication and help of her entire family and friend Kris Moriarty. The event raised \$4,000.



The Greater Chicago Fragile X Families Raise Awareness at the Brookfield Zoo Tree Trim

November 11: Families gathered to support the Brookfield Zoo and its annual Tree Trim event. Thirty-five children and adults sponsored an Xtra special tree, they added hand-made “X” ornaments, family pictures, and colorful strings of beads, with time left to visit the zoo animals.

THE 19TH NFXF INTERNATIONAL FRAGILE X CONFERENCE

The NFXF International Fragile X Conference is the premier educational event for the Fragile X community. This biennial event brings individuals with Fragile X and their families, caregivers, friends, and professionals together to learn from one another and celebrate Fragile X. This unique experience is not only educational but also empowering.

Nearly 800 participants—including self-advocates, caregivers, and professionals—gathered in Orlando, Florida for an inspiring four days of education and connection. Highlights included panel presentations throughout the day on popular topics related to both Fragile X syndrome and the Fragile X premutation, 80+ breakout sessions, and non-recorded support group sessions on managing aggressive behaviors in Fragile X syndrome, and for individuals with FXTAS and their caregivers. Thank you to our 2024 Conference Sponsors for helping make this event possible!



Watch recorded sessions from conference



“

For families, the experience is often—in their own words—life-altering. They meet other parents and caregivers of children of all ages, share their journeys, and learn from each other.



NFXF TEAM



Hilary Rosselot
Executive Director
hilary@fragilex.org



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and Communications*
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Your support empowers the Fragile X community
with knowledge, resources, tools, and hope!

Donate today at fragilex.org/donate



NATIONAL FRAGILE X FOUNDATION

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