



NATIONAL FRAGILE X FOUNDATION



2023 IMPACT REPORT

LETTER from the EXECUTIVE DIRECTOR



We had another big year at the NFXF! Off-conference years provide us with the chance to dig deeper into our strategic priorities, finding opportunities to expand our work and expand your access to invaluable resources and knowledge. Our team says over and over again that there is no one-size-fits-all approach to Fragile X, and we are determined to provide you with high-quality, relevant information and support that best fits your unique needs.

With that notion as our guide, we continued to offer meaningful programming while thoughtfully expanding our work. We hosted more webinars than ever on a

variety of topics, topics that were informed by your feedback, making 2023 our best-attended webinar series yet! We organized meetings covering crucial concepts, like succession planning and transition services within the Fragile X Clinical & Research Consortium and the status of outcome measures with the FDA, to encourage progress. We hosted 133 advocates from around the country at Advocacy Day and created quarterly newsletters so those and other Fragile X advocates have natural touch points with their Members of Congress, creating opportunities for year-round, continuous dialog. These programs, initiatives, and opportunities to connect strengthen the bonds within the Fragile X community, ensuring a brighter future for us all. But our work is far from finished.

We are still learning about the Fragile X premutation-associated conditions and what it means to age with Fragile X syndrome. We are still advocating for legislation that enables equality and access to important services for our loved ones with Fragile X and the broader communities we fall into. There are still no effective treatments for Fragile X, but there are many studies, trials, and researchers actively searching for options. And there are still people who need knowledge, resources, and tools to live their daily lives.

The National Fragile X Foundation plays an integral role in these spaces now and we know our role will be essential in the future. I am thrilled to know the National Fragile X Foundation will be there with you through it all. Thank you for the opportunity to work and play alongside you and your families, I look forward to seeing what's in store!

Take care,

A handwritten signature in black ink, reading "Hilary Rosselot".

Hilary Rosselot, *Executive Director*

LETTER from the BOARD PRESIDENT

Have You Noticed?...

As we journey through another year, have you noticed the strides The National Fragile X Foundation has made in advancing our mission to serve the Fragile X community? I'm Laurie Bridges, your NFXF Board President, and I hope you have been noticing all the amazing work that was done in 2023!

Have you noticed Advocacy? The commitment to advocacy has continued to grow! We had an amazing Advocacy Day in Washington, DC. Our voices echoed through the halls (literally and sometimes loudly), advocating for policies and resources that benefit our community. Additionally, the advocacy newsletter is a source of information to help foster engagement.

Have you noticed Education? Education remains so important to our mission, and this year, the NFXF hosted many remarkable webinars, covering some important and meaningful topics. In addition, the Masterclass series for professionals and educators is also available and has been utilized by many to better support those living with Fragile X.

Have you noticed research? The NFXF is helping to support many studies going on all around the country. I've participated in 2 different studies this year involving those of us living with the Fragile X premutation. Significant progress is being made in supporting studies focused on the Fragile X premutation. Also, the NFXF Data Repository is being utilized and is helping the future of Fragile X treatment and care.

Have you noticed Treatment? Last October, I had the privilege of attending the Fragile X Clinic and Research Consortium meeting in person. Sitting in that room with this group of Xtraordinary professionals and watching them collaborate to improve outcomes for our families brought me to tears. It just reaffirmed to me the profound impact the NFXF has on supporting such amazing collaboration between our professionals.

It's a privilege to serve in this role, witnessing firsthand how the NFXF embodies its mission to serve the entire Fragile X community.

As we continue this journey together, let's look forward to 2024 including our conference in Orlando. It will be the



40th Anniversary of the Foundation so take notice and be a part of the difference we can make together!

In closing, I thank you for your continued support and dedication in helping The National Fragile X Foundation and all the families living with Fragile X. It's not easy but together, we are making a difference and helping those affected by Fragile X to live their best lives.

Shine on and please come find me at Conference,

A handwritten signature in black ink, reading "Laurie Bridges".

Laurie Bridges, *Board President*

NEXF BOARD of DIRECTORS

Board of Directors

Laurie Bridges <i>President</i>	Anthony Fasciano <i>Treasurer</i>
Kara Frech <i>Vice President</i>	Abby Gaunt <i>Secretary</i>
Jacquelyn Coleman	Rey Lozano, MD
Peggy Flanigan	Jed Seifert
Joe Garera	Rebecca Shaffer, MD
Denny Haugen	Shari Silver
Susan Howell	David Tillman
Tamaro Hudson, PhD	Victoria Wilkins, MD
Jay Souder <i>Ambassador</i>	Carolyn Tomberlin <i>Ambassador</i>

THANK YOU to our board members whose terms ended in 2023.

Anthony Fasciano | Joe Garera | Jed Seifert

WELCOME to this year’s new board members:

Jacquelyn Coleman Tamaro Hudson
Peggy Flanigan David Tillman
Susan Howell



Front row: Hilary Rosselot, Peggy Flanigan, Victoria Wilkins, Jacquelyn Coleman, Kara Frech, Denny Haugen, Jed Seifert, Susan Howell, Laurie Bridges.
Back row: David Tillman, Abby Gaunt, Tamaro Hudson, Anthony Fasciano.
Not pictured: Joe Garera, Rey Lozano, Rebecca Shaffer, and Shari Silver.



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

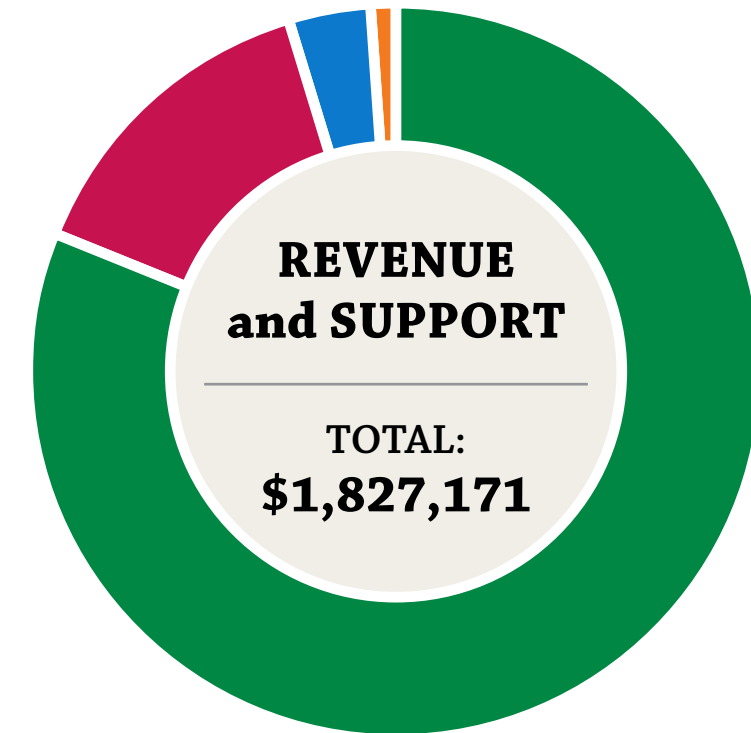
We facilitate research activities for families and professionals, underlining their value in the research process and how their active participation advances effective treatments and a cure.



NFXF 2023 REVENUE and EXPENSES

1%
Other income
\$132

3%
Net investment gain
\$66,401

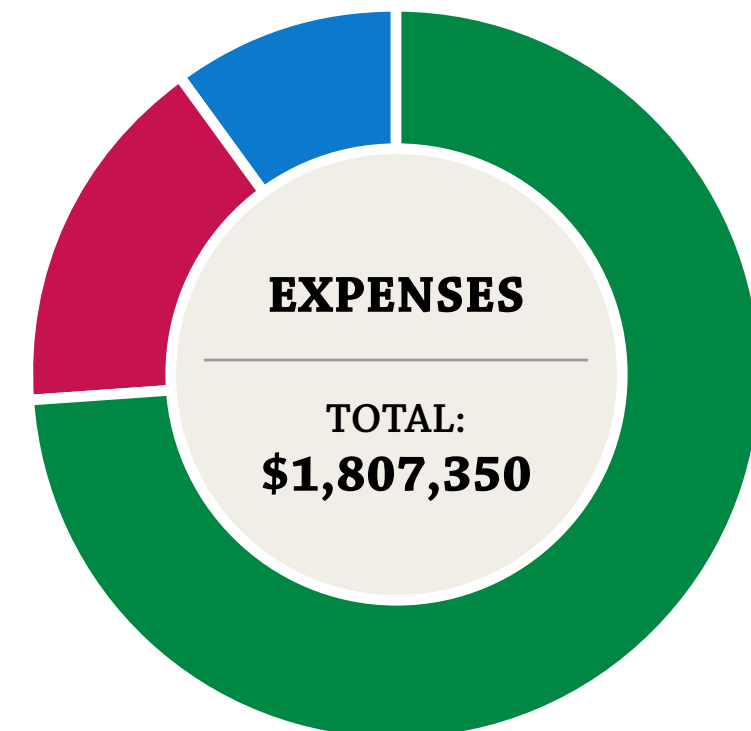


82%
Contributions and grants
\$1,500,864

14%
Program service revenue
\$259,774

10%
Fundraising
\$174,431

16%
Management and general
\$287,558



74%
Program services
\$1,345,361

PROMOTING ADVOCACY



“Over the past 19 years, NFXF advocates have aided in securing more than \$500 million in federal funding for Fragile X research and programming and support for many legislative initiatives like the ABLÉ Act.

Advocacy Day 2023

Our annual Hill Day brings the Fragile X community together.

Every year our Advocacy Day falls within the broader rare disease week, making our advocacy efforts even more impactful. On February 27–28, 2023, Capitol Hill was filled with individuals and their loved ones advocating for rare diseases. The Fragile X community was there in full force with 133 advocates,

representing 28 states, sharing their stories with their members of Congress.

Thanks to the generosity of the Sibling and Self-Advocate Network, the Greater Chicago, Heartland, South Carolina, Connecticut, New York, Southeast Pennsylvania, and Western Massachusetts Community Support Network chapters, and the Fragile X Research Center of Missouri, we extended 20 scholarships to first-time advocates who may not have otherwise been able to attend.



Our 133 advocates included self-advocates of all ages.

133
advocates
representing
28
states!

NIH Centers for Excellence Webinar – 2023 Update

NIH-funded Fragile X Centers share their most up-to-date research on the Fragile X-associated conditions.

Presented by Drs. Tracy King, Peng Jin, Peter Todd, and Craig Erickson

NIH representatives from each of the current NIH-funded Fragile X Centers of Excellence shared updates and answered questions about their progress to date.

- **Dr. Tracy King**
Intellectual and Developmental Disabilities
Branch of the National Institute of Child Health
and Human Development
 - **Dr. Peng Jin**
Fragile X Center at Emory University
- **Dr. Peter Todd**
University of Michigan Medical School, Baylor College of
Medicine, and the Fragile X Center at Emory University
 - **Dr. Craig Erickson**
Cincinnati Children’s Hospital Medical Center

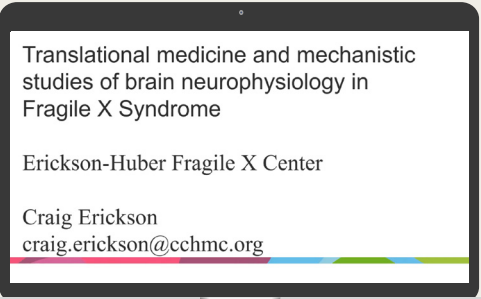
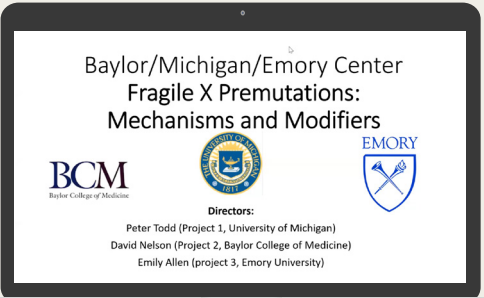
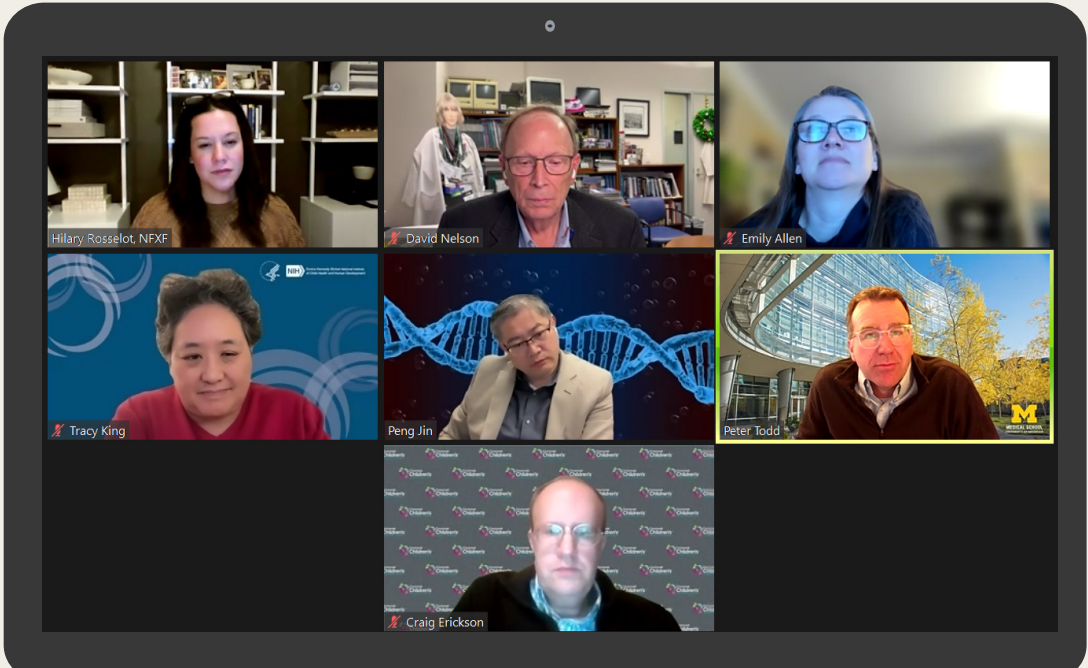
The updates began with a discussion on the purpose of the NIH and the importance of the [Centers for Collaborative Research in Fragile X](#) and [FMR1-Related Conditions Program](#).

Topics included preclinical (or non-human) models of Fragile X, potential treatments for Fragile X syndrome, FXTAS, FXPOI, and currently enrolling research studies.

 Click here to read more about:
[Centers for Collaborative Research in Fragile X](#) and [FMR1-Related Conditions Program](#)

“
The NIH Centers for Excellence work to support
multidisciplinary, multi-institutional research to encourage the
translation of basic research findings from bench to bedside and
bedside to community. Every contribution makes an impact.

[Watch
the webinar](#)



PROMOTING ADVOCACY

Advocacy Newsletter

Promoting effective ways to advocate for the ongoing challenges of the Fragile X journey.

We began publishing a new quarterly “Fragile X Advocacy Newsletter” so advocates can stay updated year-round on the status of our asks, current letters of support, legislation already introduced, and upcoming legislation we are monitoring.

We encourage advocates to use the newsletters as a point of reference when working with their members of Congress throughout the year.



“From picnics, to conferences, doctor’s appointments, **to advocacy days**, the NFXF has been by our side from the day we learned about our diagnosis. We are so grateful for all of the support on our journey.

Read the November 2023 issue

Read the July 2023 issue

2023 Monthly Webinar Series

More than a dozen relevant and dynamic panel discussions and Q&As with top experts.

We hosted a record number of webinars in 2023, all informed by you! We covered new topics and dove deeper into our most requested topics.

From January through December 2023, we covered:

- **NIH Fragile X Centers of Excellence 2023 Update**
Tracy King, Peng Jin, Peter Todd, and Craig Erickson
- **Peer-Reviewed Medical Research Program’s FY 23 Funding Opportunities for Researchers**
Kathryn Argue
- **Females with FXS: Strategies for Developing Executive Functioning and Social Skills**
Barbara Haas-Givler
- **Aging in Fragile X Syndrome**
Elizabeth Berry-Kravis
- **Housing Options for Adults With Fragile X Syndrome: Parents Share Their First-Hand Experiences – Part 2**
Susan Buchanan, Nancy Carlson, Tracey Franks, and Ileen Rissmiller
- **Educational Strategies for Success**
Jeanine Coleman, Tracy Stackhouse, and Marcia Braden
- **Reproductive Health (Puberty, Carrier Screening, and Reproductive Options and Family Planning)**
Heather Hipp, Susan Howell, and Vicki Wilkins
- **2023 Industry Updates**
Zynerba, Tetra, and Allos
- **FORWARD-MARCH Update**
Amie Milunovich, Liz Berry-Kravis, and Nicole Tartaglia
- **Employment and Fragile X Syndrome**
Jed and Darren Seifert; Paula, Ben, and Matty Fasciano; and Samantha Rhodes
- **FXTAS Clinical & Research Q&A**
Deborah Hall and Peter Todd
- **Multidisciplinary Treatment of Fragile X Syndrome**
Craig Erickson, Rebecca Shaffer, Kerri Chitwood, and Laura Hess



[View all Fragile X Syndrome & Premutation Associated Conditions Webinars](#)



“

Through the years NFXF materials have helped tremendously in getting things included in my son’s IEP that educators would not have thought of as they did not know about Fragile X. We now enjoy participating in the webinars about different topics that affect him in adulthood, housing for example.



PROVIDING EDUCATION

Spanish Translations

We heard from the community and are building up our Spanish language resources.

One of the things families, caregivers, and professionals asked for in the 2022 Community Survey last Fall was to have more resources available in Spanish. We have answered that request and now have several important resources available:

- **Fragile X Fact Sheet**
- **Treatment Recommendations:**
 - Fragile X-Associated Tremor/Ataxia Syndrome
 - Fragile X-Associated Primary Ovarian Insufficiency
 - Behavioral Challenges in Fragile X Syndrome
 - Medications in Fragile X Syndrome

As a reminder, we have more than 20 in-depth treatment recommendations reviewed by professionals from the Fragile X Clinical & Research Consortium. They are available to view online or download and we will be adding more of these in Spanish.



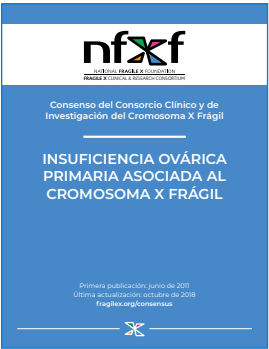
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This organization has given our family so much knowledge about Fragile X and being a carrier. We feel like we belong to a very special community.”



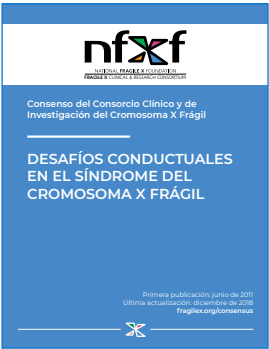
Fragile X Fact Sheet



Fragile X-Associated Tremor/Ataxia Syndrome



Fragile X-Associated Primary Ovarian Insufficiency



Behavioral Challenges in Fragile X Syndrome



Medications in Fragile X Syndrome

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The NFXF has provided essential training information in order for me to become a better teacher for my student with Fragile X syndrome.

Fragile X MasterClass™

Two new MasterClasses, by professionals, for professionals.



Tracy Stackhouse



Marcia Braden

NFXF MasterClass™ — Fragile X 101 for Educators
Presented by Tracy Stackhouse and Marcia Braden

This two-part course provides an overview and discussion of Fragile X syndrome, the FXS learning style, and the relationship between FXS and autism, including strategies to support individuals throughout the lifespan.



Susan Howell



Matthew Walsh

NFXF MasterClass™ — Genetics of Fragile X
Presented by Susan Howell from the Colorado Children's Hospital Fragile X Clinic, and Matthew Walsh from Emory University.

This course provides an overview of the genetics of Fragile X, including inheritance, indications for testing, the potential impact of the premutation and full mutation results, and resources to share with families.

CEUs are available through the National Society for Genetic Counselors.



Visit [NFXF MasterClass™](#)



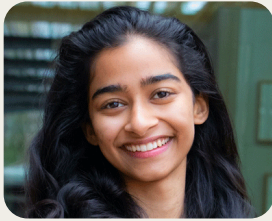
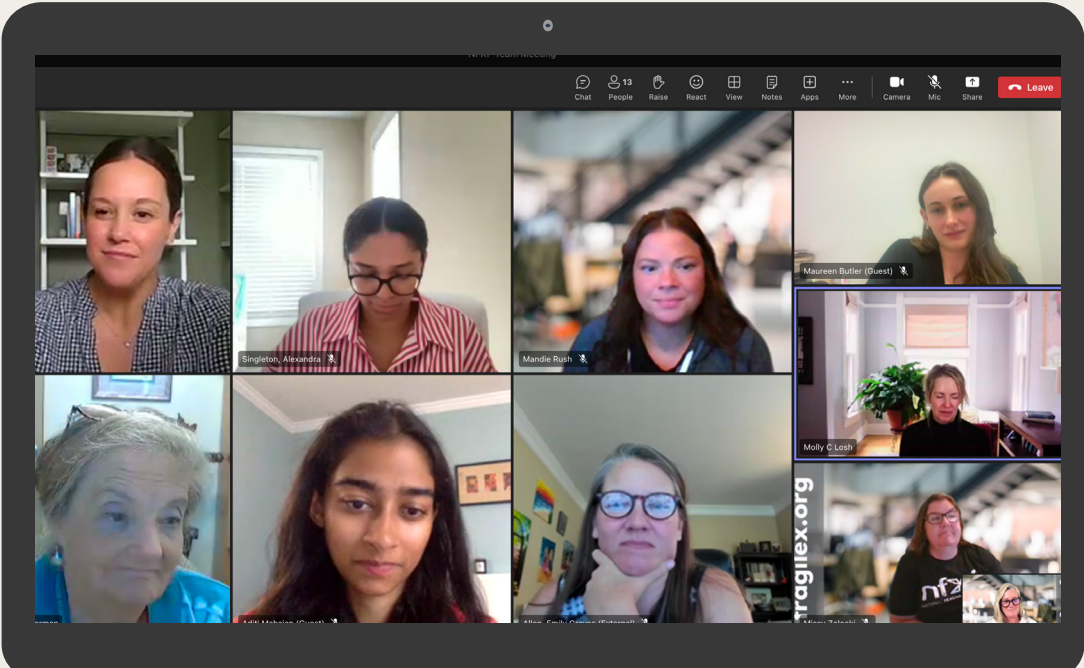
**FRAGILE X
MASTERCLASS™**

NFXF Research Awards — Randi J. Hagerman Summer Scholars

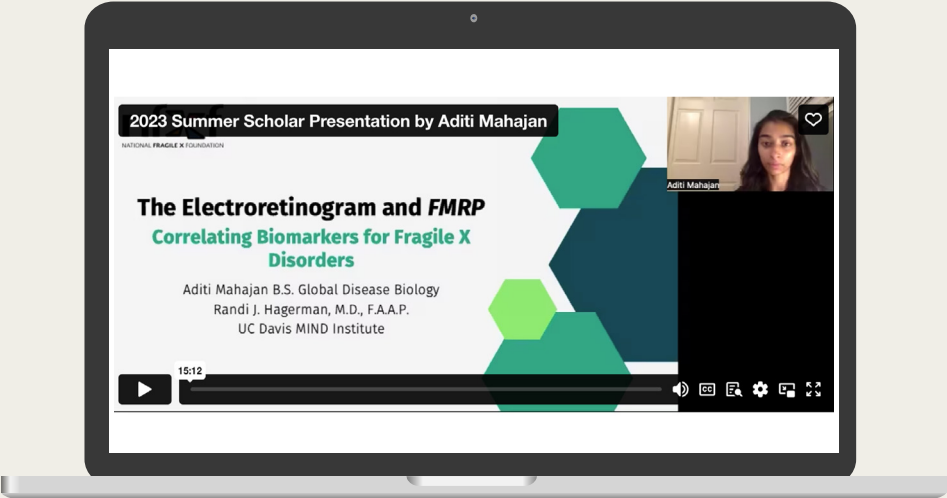
Congratulations Aditi, Alexandra, and Maureen!

Each 2023 RJH Summer Scholar was awarded \$2,500 for a summer project related to Fragile X, and the students presented their results in a short, family-friendly video at the end of the summer.

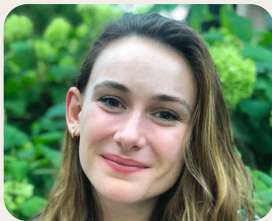
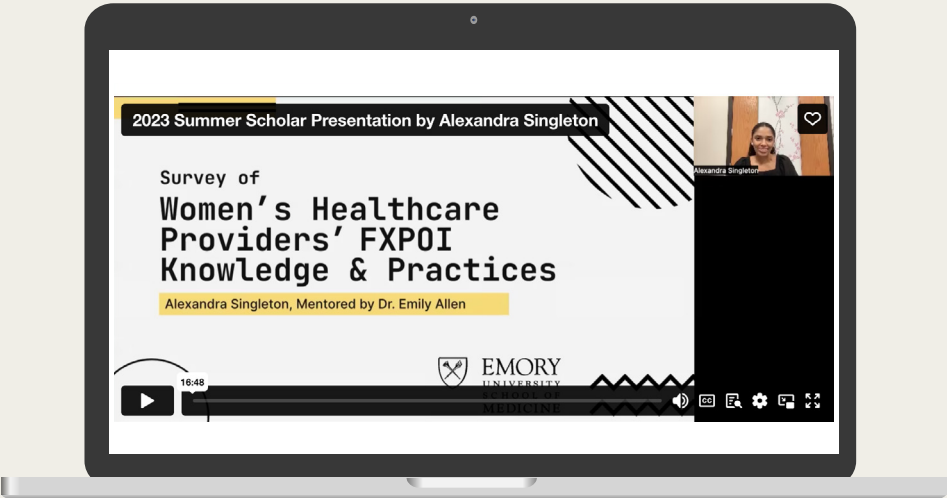
Join us in celebrating the future of Fragile X research and thanking these students and their mentors for their dedication to Fragile X!



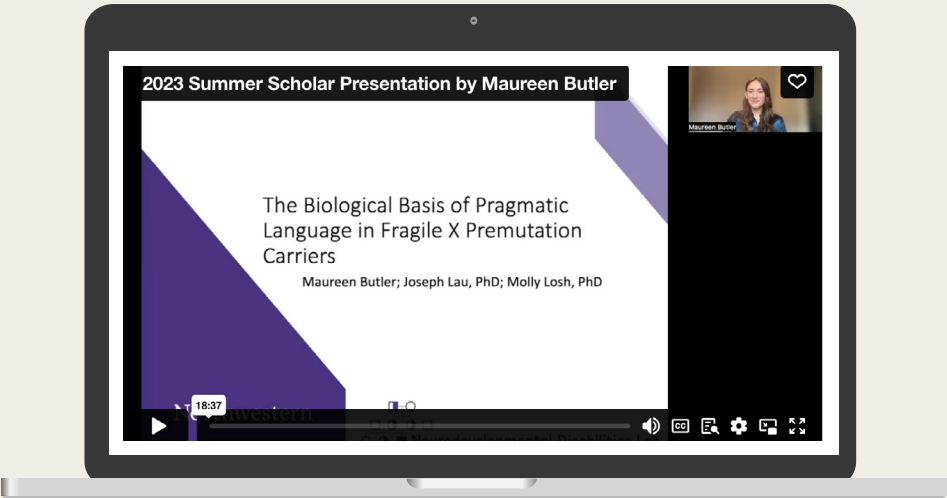
Aditi Mahajan
The Electroretinogram and FMRP: Correlating Biomarkers for Fragile X Disorders
Aditi's mentor:
Randi J. Hagerman, MD, FAAP



Alexandra Singleton
FXPOI Survey in Women's Healthcare Providers
Alexandra's mentor:
Emily Allen, PhD



Maureen Butler
The Biological Basis of Pragmatic Language in Fragile X Premutation Carriers
Maureen's mentor:
Molly Losh, PhD



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

“

For me, engaging with and sharing my work with the community has been the most rewarding and impactful element of this program. I am so grateful for this experience and am honored to have been selected to participate in the Randi J. Hagerman Summer Scholars program. — MAUREEN BUTLER, NORTHWESTERN UNIVERSITY



The NFXF Data Repository

A readily available, inclusive repository.

We opened the NFXF Data Repository for query, and had our first request for use of data. The Data Repository is meant to facilitate research by building partnerships with credible researchers who can best utilize participants’ samples to make scientific advances for Fragile X.



[Learn more about the NFXF Data Repository.](#)

“

Through the NFXF Data Repository, the paradigm shifts from the current model — where clinical trial data stays locked up with the sponsor, with no future use for the data — to a new NFXF model — where data is set free to become part of a treatment development cycle.

5th International Conference on *FMR1* Premutation Paper

A family-friendly research summary of a powerful meeting of the minds working on the Fragile X premutation.

The 5th International Conference on *FMR1* Premutation covered a variety of important topics related to the Fragile X premutation, the recent progress in the field, and what we need to do to learn more and serve those with the Fragile X premutation.

Presenters ranged from researchers and clinicians to patient advocacy groups and family representatives. Conference attendees wrote an incredible paper summarizing these presentations, “Insight and Recommendations for Fragile X-Premutation-Associated Conditions,” and it happens to be almost 80 pages long!

So we created a family-friendly summary highlighting the most recent research and its clinical impact.



Read the family-friendly version of this important research.

“Summarizing work like this ensures research results get back to the people they are meant to serve.”

Fragile X Clinical & Research Consortium and Outcome Measures Meeting

Networking, collaborating, and identifying new and ongoing efforts.

We hosted a fantastic combined FXCRC and Outcome Measures meeting with the FDA in October. We were able to network, collaborate, and identify new and ongoing efforts that can best support the FXCRC and broad Fragile X research process.

Our ability to attract and interact with the FDA through these efforts is impactful. Other groups have not had this type of success and the professionals were very complimentary of the NFXF for facilitating these interactions.

 [Read the summary.](#)



“Without the right tools to measure change, we cannot prove that the investigational treatment is making a difference. These tools are called outcome measures.”



Language in Fragile X Syndrome Treatment Recommendations

What language development may look like for individuals with FXS.

The Fragile X Clinical & Research Consortium’s Treatment Recommendation covers language. While most individuals with FXS will develop spoken language at some point, there are typically global expressive or receptive language delays.

This is important information for parents, speech-language pathologists (SLP), occupational therapists (OT), and behaviorists.

 [Read Language in Fragile X Syndrome](#)

“
Supporting individuals with FXS with their speech and language development is something that should be considered across the lifespan. Many of the strategies can be used regardless of age and are useful across a wide range of communication abilities.





“

The path is not often clear or easy, but no family should feel alone in the process.

— DR. AMANDA BENNETT

Mx. Granger, CCo, via Wikimedia Commons

Two New Clinics Join the Fragile X Clinical & Research Consortium

Clinics in Pennsylvania and Utah expand the reach of FXCRC’s 40+ U.S. and international clinics.

We are thrilled to announce the addition of two new Fragile X syndrome clinics from Children’s Hospital of Philadelphia and the University of Utah and Primary Children’s Hospital.

The Fragile X Clinic at University of Utah and Primary Children’s Hospital is run by Dr. Victoria L. Wilkins, whose family lives with Fragile X. The team offers psychological testing and genetic counseling and support, and works with patients’ local teams to aid them in day-to-day management. Dr. Wilkins will see individuals ages 0 to 21.

The Specialty Care Center at Children’s Hospital of Philadelphia is run by developmental pediatrician Dr. Amanda Bennett who previously provided medical consultation and services to those utilizing the former Fragile X clinic in Elwyn, Pennsylvania. Dr. Bennett will see individuals ages 0 to 18.



[Visit the Fragile X clinic finder](#)



The Children’s Hospital of Philadelphia

EVENTS HIGHLIGHTS

Annual “FORE! Fragile X” Golf Event Raises over \$250,000!

Jay and Anne Souder have hosted the annual golf event “FORE! Fragile X” since 2018 in honor of their son, Alec, who has Fragile X syndrome. Nearly 100 golfers and friends attended the 2023 event at Orange Tree Golf Course in Scottsdale, Arizona. Since 2018, the Souders and their friends have raised over \$250,000 in support of the National Fragile X Foundation.



The Souders have been active supporters of the NFXF since Alec, who is now in his mid-30s, was diagnosed at 5-years-old. They know that the landscape of managing life with Fragile X is constantly changing and presents a unique set of challenges for parents and caregivers. Jay and Anne’s drive to organize a charity fundraiser comes from the desire to give hope to all families and to raise awareness and funds for the National Fragile X Foundation.



The NFXF has always been there for us, and we want to do everything we can to make sure that other families will benefit from their work as much as we have. — ANNE SOUDER

Meet The Schutz Family and #TeamWally

In the fall of 2023, the Schutz family did a generous and amazing thing. They shared their family’s story and offered a 1:1 match for donations up to \$3,000 for an entire month.



“We share our story in the hope that we can educate so many more people to understand what Fragile X Syndrome is, to raise both funds and awareness. The National Fragile X Foundation has become very important to us because it helps support families affected by Fragile X and FMR1-associated conditions and disorders every day, by promoting advocacy,

providing education, advancing research, and improving treatments. In addition, Fragile X research benefits other conditions such as Alzheimer’s Disease, Parkinson’s Disease, Down Syndrome, Autism, and more.

“If not for the National Fragile X Foundation, we would never have been exposed to a treatment for Wally that has so positively changed our family’s life.”

[Read the full story](#), you’ll be glad you did.



Greater Chicago Fragile X

Greater Chicago Fragile X chapter families gathered on a sunny day in November 2023 to support the Brookfield Zoo and its annual Tree Trim event while raising awareness for Fragile X. October 2023



Zoom with the Sibling & Self-Advocate Network

The group hosts regular Zoom events including a nature occupational therapist discussing how to use all your senses while on a walk, and a Pilates instructor (and Fragile X mom) demonstrating how Pilates can be for anyone. September 2023



10th Cork & Cafe Event

The NFXF Western Massachusetts Chapter held its 10th Cork & Cafe fundraising event. Nearly 60 people attended and enjoyed appetizers, wine tasting with 70 different wines, and a silent auction of 25 generously donated items. Thank you to Denise Devine, Sean Barry, volunteers, attendees, and donors! September 24, 2023



Bike To X Out Fragile X

Organized by Nancy and Ken Carlson and a team of dedicated volunteers and supporters, the NFXF Heartland Chapter (Iowa and South Dakota) hosted their 8th annual “Bike To X Out Fragile X” event that attracted more than 100 participants who helped raise awareness and funds for Fragile X. June 3, 2023

Marner Family Hosts 4th Annual Quad Cities Fragile X Golf Outing

Andrea and Kevin Marner’s 4th annual golf event was the most successful yet! The 34 teams sold out the event and raised \$12,000! Their new neighbors, Laco and Anna Marquez, not only donated an amazing food spread, but they prepared and served it too!

The Marners — and the NFXF — thank their sponsors for making the event possible: MH Equipment, Blaze Restoration, Heritage Landscape Design, Sacco’s Family Properties, Evans Concrete and Excavating, Marquez Family, Russell Family, Wiegel Family, Wicked Stitches, Mark Carlson, and Jeff Murphy.



The golf outing has also connected the Fragile X community in our area. Our son Reid met another young man with Fragile X named Eli, whose family and friends came in support by creating four teams this year, led by his parents Chad and Julie. — KEVIN MARNER



Wen Huang, mom of a son with Fragile X



Dr. Randi Hagerman

Fragile X on the Farm

The Fragile X on the Farm fundraising event was made possible by Maryland Fragile X families pooling their resources. The fun and informative night included presenters Hilary Rosselot, NFXF Executive Director, Wen Huang and Ingrid Bell, parents of children with Fragile X syndrome, and Drs. Paul and Randi Hagerman, University of California, Davis MIND Institute professors. There were also games, picture-taking, whiskey tasting, and a performance by the Wootton High School live jazz band.

Parent organizer and NFXF board member Tamaro Hudson thanks all attendees and supporters who helped raise more than \$13,000!

EVENTS HIGHLIGHTS



Western Massachusetts Chapter Leader Attends Autism Connections Conference

The Annual Autism Connections Conference, held April 10, 2024, in Springfield, Mass., brought professionals and families together to learn more about autism and how to adopt strategies and therapies to help someone they know with autism.

NFXF Western Massachusetts Chapter leader Denise Devine attended this year's conference and came ready to educate and raise awareness about Fragile X. Denise handed out information and was on hand to talk with anyone interested in learning more about the similarities between Fragile X syndrome and autism, testing, and how research in both areas can benefit Fragile X and autism.

NFXF Western MA Chapter Host's 8th Annual Hadley Cornhole Championship

The 8th Annual Hadley Corn Hole Championship, organized by the Western Massachusetts Fragile X chapter on March 3, 2024, marked a day of camaraderie, spirited competition, and impactful fundraising. This not-to-be-missed event brought together 26 competitive teams and an estimated 150 attendees from the community, resulting in an impressive \$4,000 raised to support Fragile X awareness and research.

A total of 45 raffle prizes were up for grabs for the price of a ticket. The competitive spirit of the tournament proved to be the perfect platform for socializing with old and new friends, and of course, contributed to reaching fundraising goals.



Parents Night Out

The NFXF Greater Chicago Chapter organized a night out in Arlington Heights, Ill., with delicious food, shared experiences, and discussed challenges and strategies. September 9, 2023

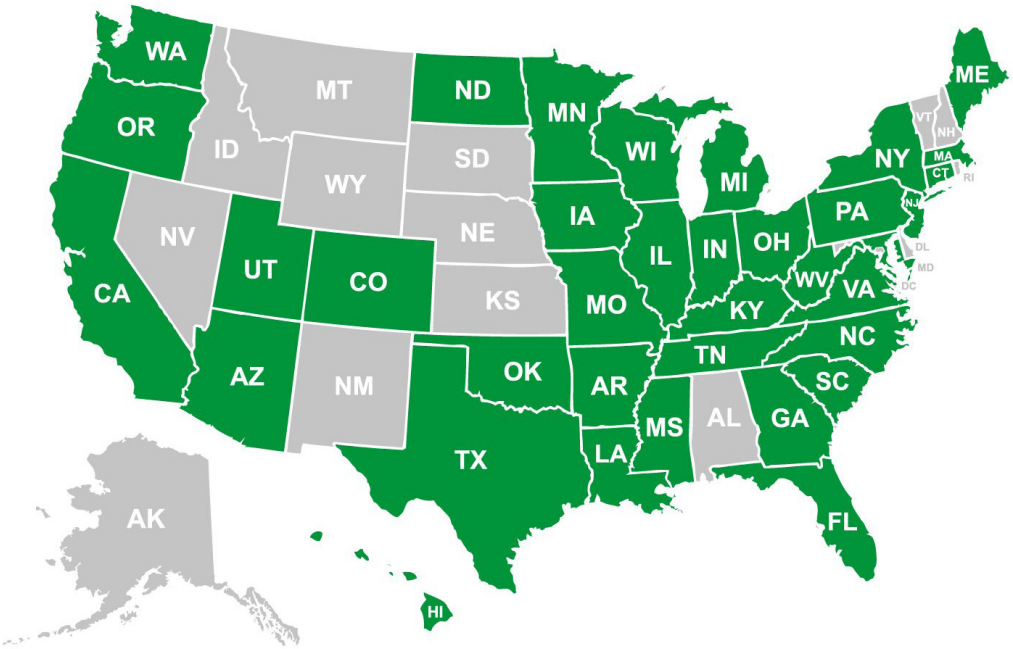
It was the best turnout we have had!

— DAWN BROWN, Chapter Leader



Family Pool Party

The NFXF Connecticut Chapter hosted a family pool party for families from Connecticut, Rhode Island, and Massachusetts. Guests from 2 to 92-years-old enjoyed perfect weather, pool games, good food, and great connections. August 13, 2023



X Strides

Thank you to the over 800 registrants and donors from across the country who participated in X Strides 2023 during Fragile X Awareness Month. Fragile X knows no racial or economic bounds. Because of you, the NFXF can further our mission of serving 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. Together, We're Stronger!



A New England Get Together

The NFXF Western Massachusetts and Connecticut chapters and the Sibling & Self-Advocate Network had an evening out with new and familiar faces. September 28, 2023



A Casual Night Out

After three years of hosting events online, the NFXF Western Massachusetts and Connecticut chapters organized an evening out for moms, siblings, and self-advocates. Connecticut chapter leader Tammy Selinger, said, "It was exciting to be back in-person and the evening was wonderful!" March 2023

XTRAORDINARY INDIVIDUALS



NFXF TEAM



Hilary Rosselot

Executive Director

hilary@fragilex.org



Kristin Bogart

*Senior Director, Development
and Communications*

kristin@fragilex.org



Anna De Sonia

Director, Research Facilitation

adesonia@fragilex.org



Missy Zolecki

Director, Community Empowerment

missy@fragilex.org



Kim Toman

Director of Operations

kim@fragilex.org



Robby Miller

Director, Clinic and International Relations

robby@fragilex.org



Jaleesa Holden

Special Projects Contractor

jaleesa@fragilex.org



Amie Milunovich

FORWARD National Coordinator

amie@fragilex.org



Mandie Rush

Development Assistant

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