NATIONAL FRAGILE X FOUNDATION

2022 IMPACT REPORT

LETTER FROM THE EXECUTIVE DIRECTOR

Wow! I am proud and humbled to be in my new role as Executive Director of the National Fragile X Foundation. And I am especially proud to be on a team of such devoted professionals led by an energetic, creative Board of Fragile X advocates. The Fragile X community has welcomed me with open arms, and I continue to be inspired by the dedication, drive, and tenacity each of you displays daily.

Our long-time team member and former Executive Director, Linda Sorensen, paved the way for the NFXF to be what it is today. Her steady leadership, confidence in our team and their work, and her vision for the NFXF propelled us forward leaps and bounds. Linda has earned the utmost respect and her mentorship is something I continue to cherish. But she did leave large shoes to fill! As you read the impact the NFXF has had over the past year, you will see Linda's legacy firsthand.

The work that Linda, our team, and the Board have done to hone our strategic priorities leaves me feeling confident and excited about our strong future ahead. We organize our work around four strategic priorities—Advocacy, Education, Research, and Treatment—and at the center of that work is you, the Community. You are the reason we do what we do, and we could not do it without your insights and support.

My vision for the NFXF is to truly serve each individual living with Fragile X, from those living with Fragile X syndrome and their families, to those who have the Fragile X premutation and may experience FXTAS, FXPOI, and other associated conditions. To do that, we need to form and maintain strong strategic partnerships, provide exceptional, relevant content and resources, grow and invest in the next generation of Fragile X researchers and clinicians, and take an active role in creating and building infrastructure that supports the advancement of treatments. We made great progress in 2022, and we continue to dive deeper and stride forward.

The NFXF has done incredible things with and for the Fragile X community, and we are closer than ever to realizing our mission to serve 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. I hope you are proud of the work the NFXF has accomplished and look forward to what we can accomplish together just as much as I do.

Thank you for all you do.

Hilary Rosselot
Executive Director

LETTER FROM THE BOARD PRESIDENT

The X-Factor

1. A noteworthy special talent or quality.
2. The variable with the most significant impact on an outcome.
3. Indescribable excellence that makes someone unique.
4. An extraordinary quality that overshadows negative traits.
5. A situation with intense and surprising influence.

Looking back on 2022, the X-Factor is strong!

I feel privileged to be in this role, witnessing the profound impact of The National Fragile X Foundation on our community. It has been a year of growth and excitement. Linda Sorensen laid the foundation for success, and as Hilary Rosselot took over as Executive Director, she embraced the challenge. Working with Hilary and the NFXF team has been a pleasure. They each possess "xtraordinary qualities" that make them unique, and they work diligently to create "significant impacts" in our community. The NFXF team truly has the X-Factor!

Advocacy: 2022 brought us a virtual Advocacy Day. Many participated and this ongoing involvement continues to have a significant impact on our asks and "outcomes". I extend my gratitude to all those with "extraordinary" passion for advocating in Washington and at home. The X-Factor is strong in Advocacy!

Education: In 2022, we were able to come together in person at the San Diego Conference. It was so much fun and we learned a lot. The X-Factor surrounded us through the special "talents and qualities" of our team, presenters, families, self-advocates, siblings, clinicians, and researchers. The X-Factor is strong in Education!

Research: The National Fragile X Foundation places a priority on Research by incentivizing it through the Summer Scholars program and Junior Investigator Scholarships. And let's not forget the Data Repository™! The NFXF works hard to facilitate research that "impacts outcomes". The X-Factor is strong in Research!

Treatment: The NFXF Fragile X Clinic & Research Consortium stands out with its "unique qualities" that foster collaboration and improved treatment. Forward March is facilitating treatment and I am also excited about the progress made in the Premutation area. The X-Factor is strong in Treatment.

Community: The NFXF and our community consistently step up to support one another. Through X-strides, community events, calls, zoom meetings, advocacy, etc, YOU continue to make a "significant impact" and embody the X-Factor!

I extend my thanks to the NFXF team, the NFXF Board of Directors, donors, sponsors, clinicians, researchers, families, siblings, and self-advocates who contribute every day to create "intense influence" and make a difference in the "outcomes" of our everyday lives.

Keep rocking the X-Factor!

Laurie Bridges
President, NFXF Board of Directors

BOARD OF DIRECTORS

Laurie Bridges, President
Kara Frech, Vice-President
Anthony Fasciano, Treasurer
Abby Gaunt, Secretary
Jay Souder, Ambassador

Emily Mack, Past President
Joe Garera
Denny Haugen
Rey Lozano
Jed Seifert

Rebecca Shaffer
Shari Silver
Victoria Wilkins

THANK YOU to the following board members whose terms ended in 2022:

- Evan Davis
- Emily Mack
- Rajat Sarup

WELCOME to our newest board members whose terms begin in 2023:

- Jacquelyn Coleman (TX)
- Peggy Flanigan (OR)
- Susan Howell (CO)
- Tamaro Hudson (MD)
- David Tillman (NC)
- Carolyn Tomberlin, Ambassador (CA)

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.

ADVANCING RESEARCH

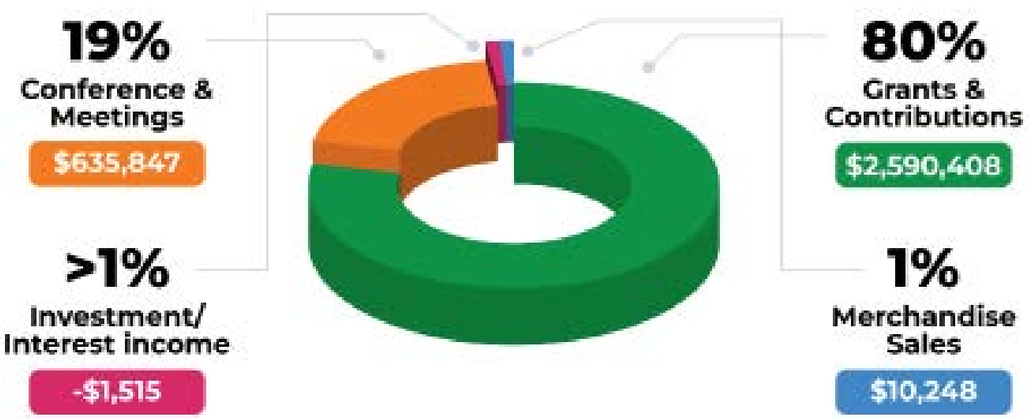
We facilitate research activities for families and professionals, underlining their value in the research process and how their active participation advances effective treatments and a cure.

IMPROVING TREATMENT

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

NFXF 2022
Revenue and Expenses

REVENUE & SUPPORT



TOTAL: $3,234,988

EXPENSES

TOTAL: $2,091,542

PROMOTING ADVOCACY

"It's just so comforting and uplifting to be in a community of people who are so like-minded in that we all want what's best for each other and our children!"

ADVOCACY DAY 2022 – VIRTUAL

Bringing Fragile X advocates to Capitol Hill

On March 1, 2022, we had 143 advocates representing 33 states participate in 153 virtual meetings with their Members of Congress in the House and Senate.

Our 2022 Asks included:

- Support Fragile X research funding for Fiscal Year 2023
- Cosponsor the STAT Act (H.R.1730/S.670).
- Support expanded opportunities for individuals with disabilities to participate in the workforce.

PROMOTING ADVOCACY

Forming strategic partnerships with organizations in our space maximizes our impact and reach on behalf of individuals living with Fragile X and their families. Our rich partnerships with these organizations leverage our shared interests for a larger impact in parallel to our Fragile X-specific advocacy efforts.

PARTNERSHIPS with the EVERYLIFE FOUNDATION and the NATIONAL ATAXIA FOUNDATION

Maximizing our impact by building strategic partnerships

We recently formed a strategic partnership with the National Ataxia Foundation. Our partnership enables us to align our advocacy asks with theirs to support those in our community living with FXTAS and their loved ones. This partnership also allows us to exchange information and resources, ensuring we have up-to-date information for the FXTAS community. We are excited about this new partnership and the opportunities it will bring! The National Ataxia Foundation now includes the NFXF's FXTAS Fact Sheet and our listing of FXTAS clinics around the world on their website.

The NFXF continues to align with the EveryLife Foundation legislatively and, more recently, physically! We have been a member of Rare Hub, which is a physical office space run by the EveryLife Foundation, for a few years now and have recently moved to using the Rare Hub as our address (1012 14th Street NW Suite 500, Washington, DC 20005). Because we have consistently worked with EveryLife to set our advocacy initiatives, our physical alignment with them makes sense long term as they have good name recognition and power in the rare disease space.

PROVIDING EDUCATION

"The greatest surprise was connecting with all the phenomenal people within the Fragile X community. The feeling of loneliness dissipated when I realized there were families in front of me, behind me, and on either side of me. No matter the stage of life or how FXS affected our individual or individuals, we were all in this safe space to gather information to support and advocate for our people with FXS."

18th NFXF INTERNATIONAL FRAGILE X CONFERENCE

July 2022 | San Diego, CA

The 18th International Fragile X Conference was our first in-person event in four years! It was invigorating to have the Fragile X Community together again to connect, educate, and empower. A virtual option was provided to further the conference reach to those unable to attend in-person. Over $100,000 in scholarships were awarded to the conference due to the incredible generosity from our donors on Giving Tuesday and from our CommunitySupport Network Chapters and Community Partners.

Attendees at home and in-person were able to ask panelists questions, providing a foundation for fantastic conversations with a variety of perspectives represented. We were also reminded that families find hope not only from professionals who have dedicated their careers to Fragile X but also individuals and families living with Fragile X.

Check out a few of the 18th International Fragile X Conference sessions:

- **https://fragilex.org/webinar/premutation-panel-conferen/**
- **https://fragilex.org/webinar/diagnosis-treatment-fxtas-hall/**
- **https://fragilex.org/fxs/daily-living/strategies-to-promote-social-skills/**
- **https://fragilex.org/webinar/fragile-x-executive-functioning/**

PROVIDING EDUCATION

Forming strategic partnerships with organizations in our space maximizes our impact and reach on behalf of individuals living with Fragile X and their families. Our rich partnerships with these organizations leverage our shared interests for a larger impact in parallel to our Fragile X-specific advocacy efforts.

18th NFXF INTERNATIONAL FRAGILE X CONFERENCE

July 2022 | San Diego, CA

This year's conference had several panels covering topics across the Fragile X-associated conditions and disorders. We heard from professionals about the latest clinical trials in Fragile X syndrome, learned tangible skills like emotional regulation strategies, shared ways to talk about FXTAS, FXPOI, and the Fragile X premutation, and heard from self-advocates and siblings about what life is like with Fragile X. We also heard from several industry partners, including Asuragen, a Bio-Techne company, Zynerba Pharmaceuticals, Healx, and Tetra Therapeutics on their Fragile X programs.

Hearing a variety of perspectives about a diverse group of topics created the ultimate educational experience! The NFXF is proud to provide relevant, up-to-date information to empower families with the knowledge and tools to make the best decisions for their loved ones with Fragile X.

PROVIDING EDUCATION

"The breadth of information given even within a single session surprised me - there was so much to learn about and so many amazing speakers. Getting to meet other parents of FX children was really amazing. Everyone was so open when sharing their personal journey and it was really great to be able to spend time with other people who "get it"."

WEBINAR SERIES - ADULT HOUSING

Answering your questions about one of the most challenging adult topics

Parents and caregivers have found it challenging to find suitable housing for adults with learning or developmental disabilities. Affordability, accessibility, and discrimination are just some of the many issues that have turned the housing challenge into a national crisis. Guided by moderator Jayne Dixon-Weber, our three panelists — Dushawn Powell, Anita Inz, and Susan Buchanan — answered questions about adult housing for individuals living with developmental disabilities from the perspective of parents and social workers.

Learn more: https://fragilex.org/webinar/adults-housing-options-webinar/

ADVANCING RESEARCH

"The NFXF inspires the collaborative nature between the clinical and research professionals in the Fragile X community. They bring everyone together to best individuals living with Fragile X and their families."

OBSERVABLE SYMPTOMS IN ANXIETY IN FRAGILE X SYNDROME

Optimizing outcome measures for Fragile X syndrome

Alongside professionals, the NFXF authored the publication, Observable Symptoms of Anxiety in Individuals with Fragile X Syndrome: Parent and Caregiver Perspectives. This publication furthers our collective voice to educate the scientific community as well as agencies like the FDA about anxiety as a pervasive challenge in Fragile X by presenting the results of a comprehensive survey led by the NFXF on observable behaviors seen when caregivers think the individual with FXS is experiencing anxiety. This work is influencing the development of an outcome measure about observable behaviors, like anxiety, that can be administered and validated as part of FORWARD-MARCH.

Learn more: **https://fragilex.org/living-with-fragile-x/fragile-x-original-research-articles/**

ADVANCING RESEARCH

"I was fortunate enough to get a deeper understanding of how research in the basic sciences can translate to future practices in medicine ... This in combination with hearing the stories of the families our networking event made me appreciate how my work fits into the larger Fragile X community and provides hope for the future."

NFXF RESEARCH AWARDS

We grew our two research award programs, the Randi J. Hagerman Summer Scholars and the Junior Investigators, into programs of the NFXF, furthering our investment in the next generation of Fragile X professionals.

RANDI J. HAGERMAN SUMMER SCHOLARS

This year we added Randi's name to the Summer Scholars program in honor of her dedication to mentorship and developing the next generation of professionals in the Fragile X field. The Randi J. Hagerman Summer Scholar awards are meant to introduce undergraduate or graduate students to research in the Fragile X field by providing funding for a summer project that adds to the body of knowledge around Fragile X in a meaningful way while providing a distinct training experience. Each Summer Scholar summarized their project in a 15-minute recorded presentation on our website.

Learn more about our 2022 Summer Scholars here: **https://fragilex.org/our-research/projects/summer-scholar-research-awards/**

JUNIOR INVESTIGATORS

The Jr. Investigators program exists to promote and grow future research and treatment professionals in the Fragile X field by providing the invaluable experience of attending, networking, and presenting at the NFXF International Fragile X Conference. We had a record number of Jr. Investigators this year, presenting research across the Fragile X-associated conditions.

Junior Investigators presented posters during the Poster Session at the 18th International Conference. In addition to presenting at Conference, each Jr. Investigator summarized their project in a 15-minute recorded presentation on our website.

Learn more about our 2022 Jr. Investigators here: **https://fragilex.org/our-research/projects/jr-investigators/**

ADVANCING RESEARCH

"This is such a special, precious community! I have met so many wonderful people...from doctors/researchers/specialists to parents/caregivers to the precious individuals with Fragile X... for me, hearing other parents talk about similar experiences helps me to also not feel so alone."

FORWARD-MARCH Study

The next phase of the FORWARD natural history study

Over the past 15 years, CDC has funded four FORWARD Fragile X studies to expand understanding of FXS. The NFXF has been coordinating study efforts since the beginning and has been vital in ensuring its success.

On September 01, 2021, the Centers for Disease Control and Prevention (CDC) issued a 5-year award to continue to build upon the foundation of the three prior FORWARD grants in collaboration with CDC's Study to Explore Early Development (SEED) Follow-up Study.

The most current study, FORWARD-MARCH, is conducting longitudinal follow-up studies of FORWARD participants with FXS, as well as enrolling new participants with FXS, to obtain information on health and functioning, service use and needs, and the impact of FXS on their families.

The data collected in the study is used to inform peer reviewed journal publications. 25 publications have resulted from FORWARD data to date and many more are currently being developed. Please visit the FORWARD webpage to learn more about these publications.

IMPROVING TREATMENT

INTERNATIONAL FRAGILE X PREMUTATION REGISTRY

INTERNATIONAL FRAGILE X PREMUTATION REGISTRY

A key piece of building infrastructure needed for future trials

In 2022 the International Fragile X Premutation Registry (IFXPR) reached over 1,000 registrants from around the world, including 49 U.S. States and 39 countries, in two languages, English and Spanish. Registries are key to demonstrating interest and willingness to participate in research around a specific topic; the IFXPR is a key piece of infrastructure supporting the future of Fragile X premutation research and treatment. The NFXF is proud to partner with professionals from all over the world to build this tool; it is clear individuals with the the Fragile X premutation and their loved ones are invested in the future.

Learn more about the International Fragile X Premutation Registry here: **https://fragilex.org/our-research/projects/premutation-registry**

IMPROVING TREATMENT

"As members of the Clinical Trials Committee, we are contributing to amazing work. The NFXF is being held up to other patient advocacy organizations as the way to move the dial in advancing future research."

TREATMENT & INTERVENTION RECOMMENDATIONS FOR FRAGILE X

Globally recognized gold standard treatment guidance for professionals

The professionals who are part of the National Fragile X Foundation's Fragile X Clinical & Research Consortium (FXCRC), involving more than 30 clinics in the U.S. and a dozen international sites, regularly review and update the Fragile X treatment recommendations. Consensus-based recommendations develop over time, as people work with more and more children, and more and more adults for a consensus to develop about what works and what doesn't. Coming to consensus takes time and thoughtfulness, involving much discussion and a critical review of the literature that already exists regarding the intervention.

In 2022, we published two updated treatment recommendation documents which include evidence-based recommendations gleaned from the information collected from all the families who participate in FORWARD and other scientific research.

Mosaicism in Fragile X Syndrome
Seizures in Fragile X Syndrome

NATIONAL **FRAGILE X** FOUNDATION
FRAGILE X CLINICAL & RESEARCH CONSORTIUM

NEW FRAGILE X CLINICS

Children's Hospital of Orange County (CHOC), CA
Children's Hospital New Orleans, LA
Children's Hospital of Philadelphia (CHOP), PA

IMPROVING TREATMENT

"Seeing the thriving teens and young adults living with Fragile X gave us hope for our family's future."

RAISING AWARENESS OF FRAGILE X

Finding and serving every family

The NFXF thoughtfully executed an education and awareness campaign to drive home our mission to serve every family living with Fragile X. The NFXF contacted Part C Coordinators at all 50 states' Early Childhood Technical Assistance Centers (ECTA) to offer an online presentation about Fragile X for their teams. 15 states brought together their ECTA teams to participate in a one-hour slide presentation conducted by NFXF staff, followed by a Q&A discussion. Two states also requested additional presentations for their regional staff, resulting in a total of 24 presentations. A presentation was also provided to Federal Head Start staff.

These efforts led to the creation of a **Fragile X webpage** on the Head Start staff training website, available in both English and Spanish.

EVENT HIGHLIGHTS

Volunteers are the heart and soul of our community! And the opportunity to get together in-person is often the “fun” in fundraising. We are so grateful to all of our donors and event organizers (some of whom are highlighted here).

Thank you all for your commitment to the NFXF!

X STRIDES – JULY AWARENESS MONTH

X Strides 2022 was an Xtraordinary success!

Thank you to all who registered for X Strides, attended walks, donated to a team, shared your photos on social media, and joined together to raise awareness of Fragile X and FX-associated disorders and conditions.

Congratulations to our top individual and team prize winners!!

- TOP INDIVIDUAL FUNDRAISER: Stephanie Sarup
- TOP TEAM FUNDRAISER: Greater Chicago Fragile X
- ADVOCACY DAY REGISTRATION WINNER: Team Leo
- PRIZE WINNERS: Cece Davis, Bianca Baez, Kara Frech and Jodi Selinger

EVENT HIGHLIGHTS

3rd ANNUAL QC GOLF OUTING

Organized and hosted by Andrea and Kevin Marner, the 3rd Annual Quad Cities Fragile X Golf Outing, held at the Byron Hills Golf Course in Byron Hills, Illinois last June, was a huge success — in spite of the threat of a downpour!

The event included a $10,000 hole-in-one challenge, first-through third-place team awards, and contests for longest drive, longest putt, and ball closest to the pin. In total, the Marners have raised over $25,000 in support of the NFXF through the QC golf event.

The Marners first became aware of the NFXF when their then 3-year-old son Reid was diagnosed with Fragile X syndrome. The NFXF website helped guide them and they eventually signed up for a clinical trial at a Fragile X clinic. Andrea says, “We love being able to help in any way we can and this is something Reid also had so much fun with! He was doing fist pumps to everyone, and everyone just loves being around him! He is such a goofy, fun-loving kid and it was awesome for everyone to get to see that in him!”

Thank you, Marners and all of your golf outing supporters!

FRAGILE X CHRISTMAS

Denny and Marcia Haugen have hosted Christmas parties in the past, but this year, they hosted a holiday party unlike any other. On Saturday, December 10, 2022, they brought awareness of Fragile X syndrome to over 100 people in Waverly, Iowa!

Guests watched a YouTube documentary about Marcia and Denny’s son, Aaron, called, “Not So Fragile”. Executive Director Hilary Rosselot spoke about the NFXF Randi J. Hagerman Summer Scholars program to grow future generations of Fragile X researchers and clinicians. Thank you to Denny and Maria and their supporters – who together raised over $16,000 in support of the National Fragile X Foundation!

Thank you, Marcia and Denny!

EVENT HIGHLIGHTS

SWIM FOR FRAGILE X

Moëz Cherif is training to swim 25 miles from Santa Cruz to Monterey, CA

Moëz Cherif is an Ironman triathlete, marathon runner, and open water swimmer. He has several endurance challenges planned over the next few years; one of these is to use his love for the ocean and swimming to fundraise for a cause that he cares deeply about. He is swimming 25 miles across the Monterey Bay to raise awareness about Fragile X, and raise funds for the National Fragile X Foundation. He’s swimming for his son, Noam, and the thousands of other individuals who are affected by Fragile X syndrome.

Moëz’s open water swim will be a solo, wetsuit-assisted swim, meant to comply with marathon swimming rules. This means, he will use no watch, no buoy, no life vest, no fins, no mask, and no breathing device. He will eat and hydrate without touching the boat or kayak that will escort him. This crossing, from Santa Cruz to Monterey, CA falls under the adventure assisted swim category, and he’ll be escorted by a professional and experienced crew, including a pilot, support person, and observer. Beyond the athletic feat, Moëz’s ultimate goal is to raise $25,000 for the National Fragile Foundation and help bring awareness about Fragile X to the general public. His crossing is projected to happen between September 2023 and September 2024 if conditions allow. He’ll be training mostly in Santa Cruz and the Bay Area, so if you’re in Northern California, be sure to follow him on Facebook to see where his next training is held and maybe you can catch him as he jumps into the ocean. If you would like to support his fundraiser visit https://give.fragilex.org/fundraiser/4069762

Thank you, Moëz! You are an inspiration!!

CONFERENCE HIGHLIGHTS

GROWING THE NEXT GENERATION OF FRAGILE X PROFESSIONALS

To realize our vision in which a world where every family is empowered to successfully navigate the Fragile X journey, we know we need more dedicated professionals committed to finding the most effective treatments and hopefully, a cure. During the conference Auction Live Appeal, we raised funds to invest in the NFXF Jr. Investigators and Summer Scholars programs.

Thank you to the following members of the Fragile X community who donated to the NFXF Conference Live Appeal:

Jennifer and Chris Barber
Kristin Bogart
Laurie and William Bridges
Nancy and Ken Carlson
Ana Cisneros
Chad Coberly
Alexis and Evan Davis
Maricela De La Rosa
Christine Dobal
Kelli Dominick
Kathleen Donahue
Kelley Dunphy
Dr. Craig Erickson
Lauren Ethridge
Paula and Anthony Fasciano
Abby Gaunt and Gabe Feldman
Mary Fox
Kara Frech
Jay Gibson
Carol Harlan
Marcia and Denny Haugen
Bridgette Kelleher
Dr. Reymundo Lozano
Jenn-Yih Eric Lu
Emily and Greg Mack
Louisa MacMahon
Stuart McCraith
Ann and Paul McIntosh
Richard Milani
Ashley and Brian Murray
Jennifer and Pete Newsome
Frandi Mars and Howard Pollock
Natalie Puha
Anastasia Puha
Raytheon Technologies
Michelle Rocker
Lindsey Romano
Hilary Rosselot
Maria J Salcedo
Stephanie and Rajat Sarup
Gail Harris-Schmidt and Stephen Schmidt
Lauren Schmitt
Niki and Jed Seifert
Rebecca Shaffer
Shari and Brian Silver
Gretchen Slusser
Linda and Kris Sorensen
Diane and Scott Southard
State Street Foundation
Kerry and Adam Stedke
Flora Tassone
Silvia Toda and Fabio Hirata
Carolyn and John Tomberlin
Victoria Wilkins
Heather and Jeff Woods
Brenda Wright
Mrs. Amy and Mr. David Young
Missy Zolecki

CONFERENCE HIGHLIGHTS

TOMBERLIN FAMILY PROVIDES MATCHING GIFT AT LIVE APPEAL

Carolyn and her husband John kicked off the Live Appeal at the NFXF International Fragile X Conference in July with a one-to-one matching challenge of up to $30,000 (which included a 1:1 corporate match from Carolyn's employer Raytheon). "We are committing to match dollar for dollar, up to $30,000, for money raised towards Growing the Next Generation of Fragile X Professionals at the conference. We are doing this in honor of Linda Sorensen and all she has contributed toward the stabilization, well-being and future vision of the NFXF!" Thanks to Carolyn and John's leadership, we met (and exceeded) their matching challenge, and raised a total of $63,023 towards expanding this program!

In Carolyn's words, "Donating to the NFXF has been an annual family goal ever since experiencing their outreach and support from the first year of our sons' diagnosis in 2000. This organization is focused on influencing the broader reach of Fragile X syndrome, FXTAS and the range of related medical issues. The NFXF is not just facilitating a search for cures and better medications that help individuals, but is also assembling and supporting resources that are 'in the trenches' with us – the army of caregivers and support teams who live and fight the day-to-day struggles with and for those individuals. They are there to support our community as a whole. And THAT is why this organization deserves our family's donations of money, time and whatever else we can offer to continue 'paying it forward'. "

The Tomberlins have been strong supporters of the NFXF since 2006. Carolyn has two adult sons, Theodor and Lars, who live with Fragile X syndrome. Carolyn served on the NFXF Board of Directors from 2015 to 2020, during which time she led the NFXF Research Facilitation efforts in its early stages.

Thank you, Carolyn and John, for your leadership and generosity, and for your ongoing support of the NFXF!

CONFERENCE HIGHLIGHTS

NFXF TEAM

HILARY ROSSELOT
Executive Director, Research Facilitation Lead
hilary@fragilex.org

KRISTIN BOGART
Senior Director, Development and Communications
kristin@fragilex.org

JAYNE DIXON–WEBER
Director, Community Education
jayne@fragilex.org

MISSY ZOLECKI
Director, Community Empowerment
missy@fragilex.org

KIM TOMAN
Operations Manager
kim@fragilex.org

JALEESA HOLDEN
Communications Manager
jaleesa@fragilex.org

ROBBY MILLER
Director, Clinic and International Relations
robby@fragilex.org

AMIE MILUNOVICH
FORWARD National Coordinator
amie@fragilex.org

NATIONAL FRAGILE X FOUNDATION
1012 14th Street NW, Suite 500
Washington, DC 20005 | fragilex.org