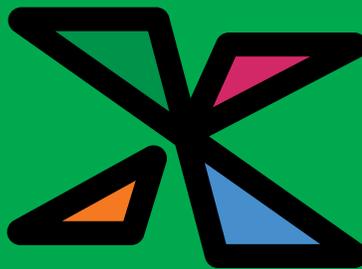




Rick Guidotti / Positive Exposure

*year of growth and transition
(& another International Fragile X Conference)*

Annual **2012** Report



A Note On Format

This is a more condensed Annual Report than we presented in 2011. At the National Fragile X Foundation, we have watched closely as paper and mailing costs continue to climb and almost limitless amounts of information can be presented electronically on nearly universally accessible machines. As we discuss more on page 6 of this report, we are adapting to these developments by reducing the scope and quantity of our printed materials whenever possible.

Hence this streamlined version that you see here, touching only briefly on the highlights of 2012 at the NFXF. It is supported by hundreds of pages of reports, analyses, financials and much else on our website at www.fragilex.org. We trust you'll find more than enough information there about the foundation that continues to be the leading organization worldwide for all things Fragile X.

Please enjoy this brief tour through the very productive year of 2012, then log on or call us directly at (800) 688-8765 for anything more you'd like to know. As always, we warmly welcome comments and contacts from those we are here to serve.



Kate Gindoff / Positive Exposures

forward!

*E*ven by the standards of an always busy and forward-moving organization, 2012 marked an extraordinarily active, expansive and dynamic year in the history of the National Fragile X Foundation. Our sponsorship and coordination of the biennial International Fragile X Conference always keeps foundation staff and the host city parent group volunteers far busier than enough, and Miami was no exception. (Thank you Florida Families for Fragile X!)

But the year also offered up new (and ongoing) progress in our communications efforts. They included 1) enhanced participation in social media, 2) continued expansion of our LINKS parent group network, 3) growth of the NFXF-initiated-and-managed Fragile X Clinical & Research Consortium, 4) greatly expanded clinical trials efforts by pharmaceutical companies testing new treatments for Fragile X, and 5) genetics research that continued to shed more light on the connections between Fragile X and autism. And much more...

We will only touch on some of these developments in this report, but suffice to say that if 2013 proves to be the continuation of this trend of dynamism in the world of Fragile X (as we fully expect it to be), then next year's report will no longer be able to use the term "extraordinarily active." That's because the pace of change and transition we have seen will simply become our new ordinary—and the world of the NFXF will thus continue to thrive.

to the sea

at the 13th International Fragile X Conference in Miami



*A*fter sponsoring and organizing 13 International Fragile X Conferences, we cannot say it is getting any easier. But it is getting more rewarding every time, and the only reason it doesn't get easier is because every conference is more multi-faceted than the last, drawing a mixture of both new and longtime parents, researchers, clinicians, educators and media to what is always a high-energy and invigorating five days.

A near-record 834 attendees included 145 faculty presenters who “Set Sail” (the conference theme) to Miami from July 25–29. Miami proved to be a lovely and hospitable venue in late July. The balmy nights with gentle sea breezes drew Fragile X'ers out all over town, while the large pool at the well-appointed InterContinental Hotel managed to keep many of the attending parents' children happily thrashing the water throughout the day.



“We learned a lot and are grateful for the all the hard work that goes into planning such an event. It was well organized!”

“I learned a lot and met many fantastic individuals. I feel confident that I will be able to apply concepts I learned at the conference to our everyday life that will improve the quality of my family's life.”



Conference highlights included a packed set of keynote speeches from stalwarts of the Fragile X world, including Drs. Elizabeth Berry-Kravis, Marcia Braden, Stephen Warren and Kimberly Huber, and NFXF Support Services Coordinator Jayne Dixon Weber, who delivered an affecting address on her family life with a son who has fragile X syndrome. In addition, “Positive Exposures” photographer Rick Guidotti shared his insights into the beauty of people living with disabilities and then went on to take many photos of children and their families attending the conference.

For keynote addresses: conference.fragilex.org/keynote2012

Positive Images photos: conference.fragilex.org/positive-exposures 



Finally, an ambitious video project engineered by NFXF Board Member and Communications Committee Chair Ted Coutilish was also very well received. Professional videographer Alana Crede of Prism Images taped many hours of interviews with parents of children with FXS. The sessions were distilled into 2–3 minute vignettes in which the parents shared the mix of joys, challenges and triumphs they have experienced in raising their children.

The 37 “Forward Thinking” video segments have been released systematically over the months via announcements in *FragileXtras*, our electronic newsletter, and then posted on our website. They can be enjoyed here: forward_thinking.fragilex.org. 



“Excellent science and the chance to talk with families. The best conference I have attended.”

“I came after not attending for eight years—mostly due to cost...I was reenergized and reminded that I don’t know everything, and attending the conference is a great thing to do!!”

“I’ve been to three conferences, and this was probably the most valuable to me. I was able to get more out of it because I knew what I needed to learn about.”



links program

Taking Parent Support to New Levels



*t*he modern practices of networking, group support and connectivity are perhaps nowhere more keenly appreciated than in the disability community. For centuries, those born with disabilities—along with the families who cared about and for them—were mostly isolated and even shunned, cut off from much needed educational and social supports. But with the rise of foundations like the NFXF, the disability community learned the value and necessity of establishing solid networking capabilities that would forever banish the sense of isolation so many families had experienced in the past.

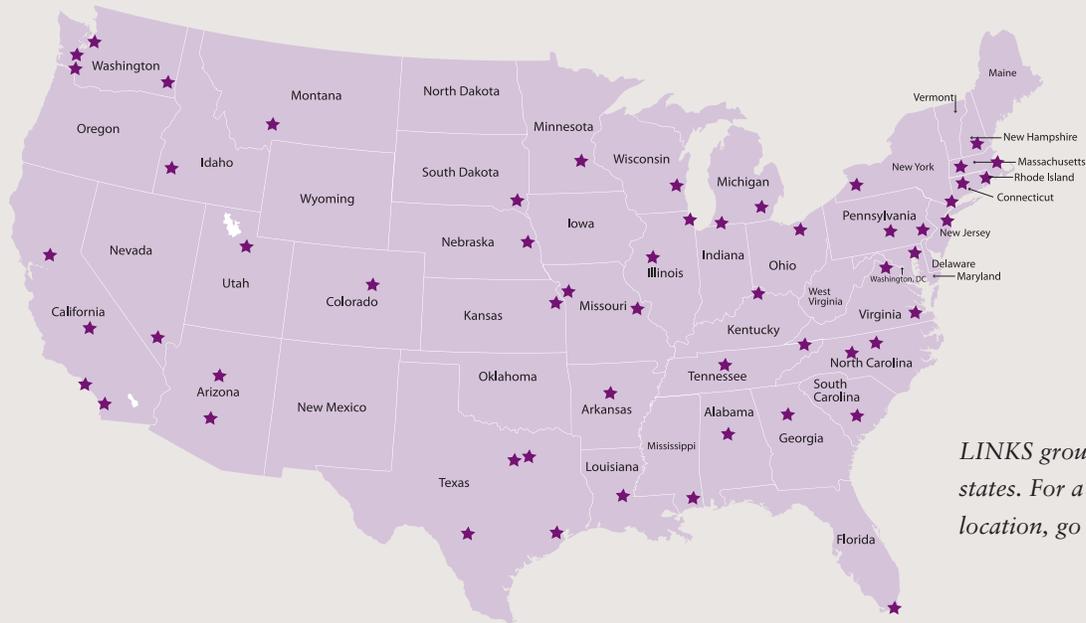
This positive trend has only intensified with the revolution in digital communications and the greater organizational outreach and connectivity it has allowed. The NFXF's LINKS Support Network has capitalized greatly on all these developments, and today, more families than ever before have ongoing opportunities to seek and access the support they need—or to offer it in turn to others.

The LINKS (LINKing Individuals Nationally in Knowledge and Support) program was established in 2009 and has grown steadily every year since. It consists of parent volunteers who join together in a defined geographic area (usually by state or region within a state) to collaborate in educational, social, advocacy and fundraising activities. One or two individuals are designated as leaders. Most groups get more active and connected over time, with members building on initial relationships that can and do blossom into lifelong friendships.

Forging Social LINKS

From a report by Melissa Welin, co-leader of the Fragile X LINKS group of Eastern MA, on a monthly social meetup for moms in her group dubbed "FX Mom's Night Out" (FXMNO):

"I can't overstate how good these nights have been for our group. It started as a periodic gathering whenever we could all find a common date, but we are all really busy so that became too cumbersome. We enjoyed it so much, though, that we decided to pick a firm monthly date and schedule the rest of our lives around it. Missing one of our nights out is a big disappointment—but it doesn't happen often these days!



LINKS groups are spread across 40 states. For a detailed map showing each location, go to: links.fragilex.org 

As 2012 ended, there were 57 LINKS groups spread across 40 states in the U.S. Nine new groups formed in 2012, and a tenth was just getting itself organized. Members were pleased to have an opportunity to join together for both formal and informal meetings at the International FX Conference in Miami.

Program highlights for the year included the establishment of an online “webinar” series that featured LINKS leaders as expert presenters addressing the following topics:

- Qualities of Leadership
- Ten Essential Skills of Leadership
- The Importance of Good Communicating
- Setting Goals and Objectives—Strategic Planning for Your Group

Other LINKS-organized 2012 activities included:

- 68 Social Events
- 27 Fundraising Events
- 22 Educational Events
- 14 “Awareness Booths” at various community events
- 3 Advocacy Events

All these activities well-serve the cause of spreading awareness and increasing the visibility and support for those affected by Fragile X. The NFXF is grateful and pleased to see the continued success and growth of the LINKS program.

Members of LINKS groups serve an increasingly important role in the Fragile X community, supporting the NFXF and each other with a variety of fundraising, educational, and social activities.



communications

Embracing the New World

in today's world, there is no resting on laurels after finishing major communications projects like the new website and logo we unveiled at the NFXF in 2011. Instead, those projects just lent more impetus to the ever-expanding communications efforts we undertook in recent years. Those efforts have included much greater, more timely and focused use of our website at www.fragilex.org, the social media platform of Facebook, and a series of videos we produced after interviewing a number of parents at last year's Fragile X International Conference.

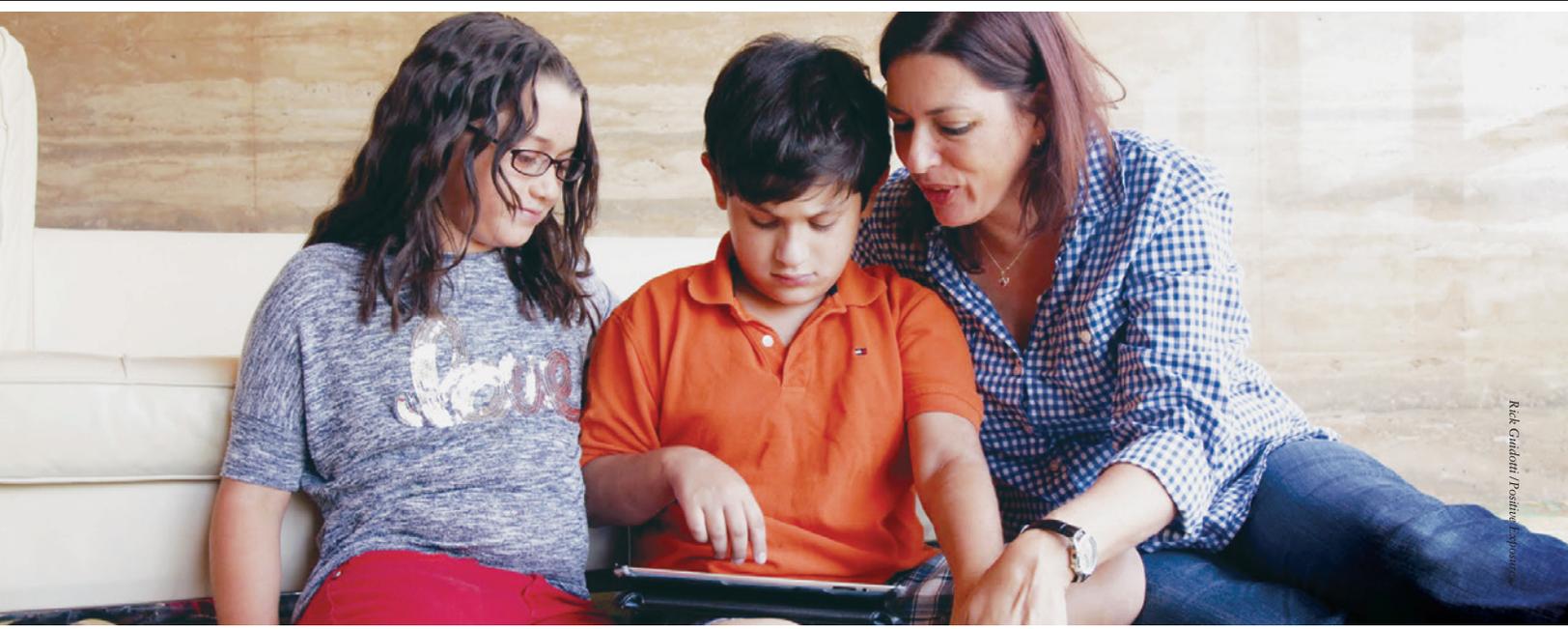


website As 2012 drew to a close, we entered a new phase in the evolution of our website by discontinuing our print publication, the *Foundation Quarterly*, and beginning to fold its contents into the website instead. The new web presence is supported by our weekly online newsletter, *Fragile Xtras*, which alerts readers to the articles with short introductions that then continue on the website.

Website articles feature the same in-depth information and reflections by a wide range of voices in the Fragile X community that used to appear in the *Foundation Quarterly*. Noted professionals in the Fragile X field, from therapists to scientists to parents and NFXF staff, offer the same helpful articles, but with a much shorter gap between writing and publication. Just as important is the radical reductions in paper, printing and mailing costs that make us a more cost-effective and “greener” provider of information to the Fragile X community.



facebook On any given day, an impressive array of Fragile X community members submit posts, comment on and enter into conversations on other posts, or simply log on to fb.me/natfragilex. They do so much as they would visit a neighborhood coffee shop: to see who is there and what they are talking about.



Rick Gordini / Positive Exposure

Facebook acts partially as a social meeting place, partially as an information-rich resource for parents seeking immediate help or feedback on some important issue with their child, and partially as a bulletin board for the NFXF, parents, LINKS Groups and others to announce events or items of interest to the FX community. All signs point to continuing growth in this media, along with Twitter, where the NFXF also maintains an active presence.

“forward thinking” videos As discussed on page 1 of this report, the NFXF produced a series of 37 videos that were recorded at the 13th International Conference in Miami. The effort was perfectly in line with the increasing emphasis on using electronic communication in a variety of forms to “tell the story” of Fragile X in a powerful and compelling way. We salute the many parents who, with courage, candor, and no small amount of heart, shared their journeys through Fragile X with appreciative viewers.

The video segments, some 2-3 minutes in length, were edited after the conference and began appearing, one every week, late in 2012. They were set to continue through 2013 and also maintain a presence at youtube.com/nfxf. 



Participants in the “forward thinking” video series include Tamaro and Jaime Hudson (top) and Mike Makris (below).



Rock Gindoff / Post Exposure

generosity

*t*he NFXF exists only because of generous donors who are drawn from all walks of life and all geographic areas, including families, businesses, and professionals. The following pages demonstrate their steadfast support of the Fragile X community.



Standing Up To Ensure NFXF Financial Future

A more concerted effort and clearer focus on ensuring the financial future of the NFXF continued to be a major goal of the foundation’s Development Committee in 2012. Fundamental to that effort has been growing a special group of financial supporters known as “Xceptionals.”

The idea behind the Xceptionals program is to establish a core group of generous supporters committed to donate specific sums to the NFXF over a multi-year period. The basic approach, used by increasing numbers of nonprofits, assures a steady baseline of income that removes some of the uncertainty of season-to-season fundraising and thus assists mightily in the planning and budgeting process.

Xceptionals commit financially to a minimum \$1,200 annually over three years. Other key benchmark levels include \$2,400 and \$3,600 annually, though any sum over \$1,200 qualifies for Xceptional status.

The program raised \$91,600 from 53 members in 2012, up 10 members from 2011, with more Fragile X supporters joining the ranks in the new year. We are deeply grateful to them, and list them here in recognition and thanks. For more information: xceptional.fragilex.org 

champions \$3,600+

Don and Pamela Bailey
Al* and Melissa Blount
Catherine Frey and Joseph Christoff*
Melanie and Kevin Heineman
Joy and Dave Justus*
Shirley and Steve Kaufman
Marc Valentiny

patrons \$2,400+

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Jonathan and Mara Dorff
Marla and Mark Gruzin
John and Stephanie Harrigan
Joseph and Tricia Judge
Lisa and Michael Kelley*
Marty and Terry Lang
Tom and Peggy Lang
Katherine* and Markus Roeders

supporters \$1,200+

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Carolyn and John Tomberlin
Brad* and Sherri Whitus

**Board Members*

major donors

Our 2012 donors responded to our various fundraising efforts with great generosity. By making gifts to campaigns, events, and in honor or memory of individuals, they provided essential support to our mission.

\$25,000+

Melissa and Al Blount
Irene Rothberg

\$10,000+

Mr. and Mrs. Edward Ortiz, Sr.
Lynda and Scott Canel
Carey and Cheryl Cooper
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Shorta Yuasa
Jerome Zeldis

major donors

Committed donors who personally donated or raised a minimum of \$5,000 for three consecutive years provided funding for specific programs and projects at the NFXF.

named funds

Christoff Research Fund <i>Joey Christoff and Catherine Frey</i>	Harris Hollin Conquer Fragile X Fund <i>Harris and Sande Hollin</i>	Rosen Weingarden Research Fund <i>Jeffrey and Arlene Cohen, Marlyn Weingarden, Cindy and Melvin Schwartz, Carrie and Roger Kushner, Romie and Jerry Acker</i>
Edward Behrman Memorial Fund <i>Fragile X Resource Center of Missouri</i>	Jennifer and Kimball Silverton Fund for Research <i>Silverton Skin Institute</i>	National Fragile X Foundation Fund
Norbert Jacob Education Fund <i>Stephanie Jacob and John Harrigan</i>	Justin Silver Fly With Me Fund <i>Shari and Brian Silver</i>	
Richard Kurtz MD Memorial Research Fund <i>Lynda and Scott Canel</i>		

Our LINKS groups help us fulfill the NFXF mission in multiple ways, and some make fundraising a top priority. We are inspired and grateful for their commitment.

links network groups

\$1,000+ Events/Contributions

Families for FX (Florida)	Colorado FX	Fragile X LINKS Group of Wisconsin
FX Families of Southwest Chicago	Western Massachusetts Fragile X Resource Group	Fragile X Society of Connecticut
Central Illinois Fragile X Resource Group	Fragile X Association of Michigan	Fragile X Association of New Jersey
Fragile X Association of Southern California	Fragile X Resource Center of Missouri	Fragile X LINKS Group of Eastern Massachusetts
Fragile X Center of San Diego	Kansas Fragile X LINKS	Fragile X Alliance of Ohio
Fragile X Alliance of Texas	Fragile X Association of Utah	Fragile X Resource Group of Greater Chicago

Foundations and corporations are key financial supporters of the NFXF. Many were active participants at the 2012 International FX Conference. The NFXF Corporate Advisory Council offers industry leaders the opportunity to partner with the NFXF in search of scientific breakthroughs.

foundations and corporations

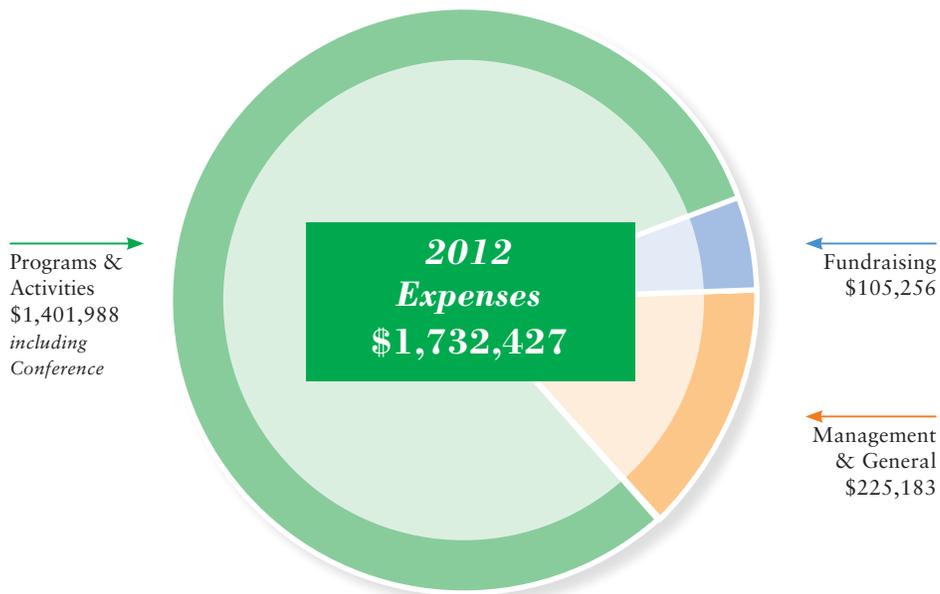
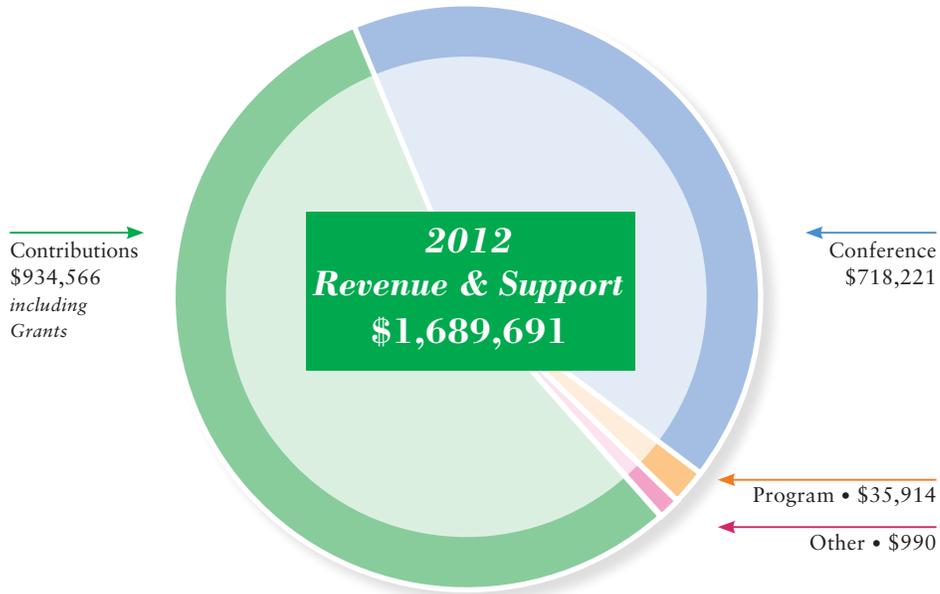
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corporate advisory council

Abbott Molecular, Inc.	Celera	Novartis Pharmaceuticals Corp.
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Asuragen	Roche/Genentech	

financials

The following financial information is distilled from a full audit conducted by Regalia & Associates, Certified Public Accountants, in accordance with generally accepted accounting principles. For the firm's full report, see foundation.fragilex.org.





What Is Fragile X?

The term “Fragile X” represents a group of genetic disorders, referred to as “Fragile X-associated Disorders” (FXDs), which have a variety of impacts on affected individuals and their families.

The disorders include:

- Fragile X syndrome (FXS)
- Fragile X-associated tremor/ataxia syndrome (FXTAS)
- Fragile X-associated primary ovarian insufficiency (FXPOI)

Approximately 1 million Americans have or are at risk of developing an FXD, and as many as 1 in 130 females and 1 in 800 males are carriers of the “FMRI” genetic premutation that can result in one of the conditions. Fragile X syndrome is the most common cause of inherited intellectual disability and the most common known genetic cause of autism or autism spectrum disorders.



NATIONAL **FRAGILE X** FOUNDATION

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forward!

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