



2011 ANNUAL REPORT

PEOPLE.

PROGRAMS.

GENEROSITY.



NATIONAL FRAGILE X FOUNDATION  

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*forward*

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## WHAT IS FRAGILE X?

The term “Fragile X” represents a group of genetic disorders, referred to as “Fragile X-associated Disorders” (FXD), 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.

# PEOPLE

THE STORY OF THE NATIONAL FRAGILE X FOUNDATION EMERGES MOST CLEARLY IN THE INDIVIDUAL STORIES OF THE PEOPLE IT IS COMMITTED TO SERVE. IN 2011, JUST AS IN EVERY YEAR PRECEDING IT OVER OUR 27-YEAR HISTORY, WE PROVIDED A WIDE VARIETY OF SERVICES TO THOUSANDS OF PEOPLE, EACH WITH A NAME, A FACE, A FAMILY, AND A STORY TO TELL OF HOPE, CHALLENGE AND TRIUMPH AGAINST OFTEN IMPOSING ODDS. NO REVIEW OF 2011 SHOULD START WITHOUT HEARING SOME OF THESE STORIES AND SEEING SOME OF THESE FACES. THEY ARE THE REASON WE GO TO THE LENGTHS WE DO TO PROMOTE THE LONG-TERM HEALTH AND SOLVENCY OF THIS FOUNDATION.

PEOPLE

PEOPLE

PEOPLE



# PEOPLE

## A NIGHT AT THE PROM

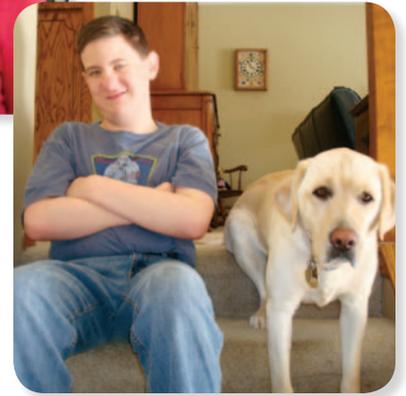
No student with special needs had ever gone to the prom in **Keadon Weidenfeller's** school district. That allowed him to be the first one in 2011, blazing a trail for fragile X syndrome that included the following observation from his mother: "Keadon took off in his new tux trailed by the fragrant smell of his boutonniere. With music blaring, young ladies in beautiful dresses and gentlemen in snazzy tuxedos, Keadon was on the dance floor sharing his moves with the girls. After, he and his buddies were arm-in-arm taking pictures. Seeing his sparkling eyes and joyous smile, I could tell this was a night to remember."



Lara



Keadon



Dan

## SUPPORT AND TENACITY

**Lara Bailey** says she is "not affected too much by fragile X syndrome, but school was not without challenges." Diagnosed at 8 years old after her teacher noticed she was struggling with math, Lara quickly got tutoring help and various accommodations from supportive teachers and parents. After graduating from high school, she managed to make the Dean's List throughout college and the Chancellor's List in her final semester before graduation with a 3.2 GPA. She currently works as the student services manager at her hometown university.

## DEFYING HIS DIAGNOSIS

After surviving many medical complications from the Pierre Robin Syndrome he was born with, **Dan Crippen** was then diagnosed with fragile X syndrome at age 7—the final piece in the puzzle of his development. Ten years later, Dan defies his "moderately to severely challenged" diagnosis on a daily basis, his mother reports, by being a "happy, loving, sweet, funny, clever and smart people-person." Master of his scooter, TV, VCR and DVD player, Dan is also the go-to person for the family's computer woes. "He has touched so many people's lives...especially ours! We are so blessed to be his Mom and Dad!"



Abby, Cara and Elizabeth



Lucas



Brendan

“Dance has kept their brains active, growing and going beyond the barriers set forth by this condition.”

## TRIPLE X

Abby and Elizabeth Jackson were 13 when their diagnosis of fragile X syndrome finally allowed their parents to understand the source of the twins’ learning and social difficulties. The couple’s then 4-year-old daughter Cara was diagnosed at the same time. Now in their final year of high school, Abby and Elizabeth are impassioned about dance, says their mother. “Dance has kept their brains active, growing and going beyond the barriers set forth by this condition.”

Cara also has pervasive development disorder, a high functioning form of autism.

“With her rapid speech, she is socially more outgoing and loves to tell a good joke. Plans are set for a service companion dog to help bridge her with the social world.”

## “WHERE’S THE BACON!?”

Life with 5-year-old Lucas Miller “definitely has its challenges,” reports his mother, “but his disability also brings a certain joy and meaning to life that we would not have experienced otherwise.” Lucas and his older and unaffected sister Ella form a mutual admiration society that allows them to “teach each other valuable lessons that could not be replicated by any other,” their mother says. “Lucas also loves to swim, play chase, play on Dad’s iPad (*Angry Birds*, in particular), watch and act out *Wonder Pets* episodes, and periodically yell out, ‘Where’s the bacon!?’ in a fun-loving manner.”

## FROM MELTDOWNS TO XBOX MASTERY

Brendan Jodouin is 14 years old now, navigating his city’s bus system with ease, riding his bike, devoted to hockey and wrestling, and “talking French and English about everything he sees,” his mother says. “And he’s the smartest kid I know on computers and xbox 360.” All of it a far cry from the 2-year-old toddler whose diagnosis of fragile X syndrome helped explain the frequent “meltdowns” that had long perplexed and concerned his mother. “If someone would have told me that my son would be doing so well now, I wouldn’t have believed it.”

# PEOPLE

## PARENT LEADERS REFLECT ON HOPE

### Ashley Nuesse, Arizona

My son was diagnosed with fragile X syndrome slightly more than a year ago. Since then, I have connected with other families through Facebook and started a LINKS\* group in the Phoenix area. Experience and advice from parents—especially those with older children—give me hope. I am inspired hearing about their journeys. It is reassuring that things will get better. I feel hope reading about new treatments and drugs. Recently, I received a voicemail from the mother of a newly diagnosed 2-year-old. Her voice shook. I could tell she had been crying. She was scared and needed support. When I called her, it was just like talking to myself a year ago. She thanked me for giving her hope. That is what makes these groups so important. We can be the beacon for others in their hours of darkness.



Lori



Ashley



Faye

### Lori Armer, Virginia

As a parent of a child with fragile X syndrome, I have come to depend on hope. I hope for good days, no accidents, no meltdowns. I hope for understanding friends. But more than anything, I hope for the future. I became a LINKS leader in hopes that no other family has to feel as alone as my husband and I did when we got our diagnosis nine years ago. Without hope, I would not have been able to plan fundraisers and raise awareness for Fragile X. Without hope, I would not have answered the phone recently when a mother who had gotten her diagnosis just four days prior called and was feeling scared and alone. And without hope, we would not be able to celebrate all of Jonathan's accomplishments. We *choose* hope.

### Faye Kuperman, South Carolina

When I think of hope in my Fragile X world, it brings forth a flood of emotions. Having worked my entire life in the medical field, I know how important medicine and research are. The incredible speed with which medication and treatment are being developed for Fragile X gives me hope! Twelve years ago Fragile X was a foreign term to our family, and to be honest, very scary. Without the NFXF or the Greenwood Genetics Center, we would not be where we are today. They are like our extended family. The National Fragile X Foundation's implausible dedication and commitment to our families and community is an unwavering source of hope!

\*For information on LINKS groups, see page 10.

# DEBUTS

SOME DEGREE OF CONTINUITY RUNS THROUGH EVERY SUCCESSFUL ORGANIZATION THAT REMAINS FAITHFUL TO ITS MISSION, AND SO IT WAS WITH THE NATIONAL FRAGILE X FOUNDATION IN 2011. THAT SAID, THE PAST YEAR WAS NOTABLE FOR THE MANY NEW INITIATIVES AND PROJECTS THAT FELL UNDER ONE OR ANOTHER PORTION OF OUR MISSION, WHICH IS TO:

“...UNITE THE FRAGILE X COMMUNITY TO:

- ENRICH LIVES THROUGH EDUCATIONAL AN EMOTIONAL SUPPORT;
- PROMOTE PUBLIC AND PROFESSIONAL AWARENESS;
- ADVANCE RESEARCH TOWARD IMPROVED TREATMENTS AND A CURE FOR FRAGILE X.”

THIS SECTION OF THE ANNUAL REPORT WILL THUS FOCUS ON SEVERAL NEW VENTURES THE NFXF EMBARKED UPON IN 2011 IN PURSUIT OF ITS MISSION.

# DEBUTS

# DEBUTS



“  
In a digital world  
where rapid-fire  
change and quick  
access is the order  
nearly every day,  
change came to  
fragilex.org in 2011.  
”

# DEBUTS

## BEHOLD THE NEW fragilex.org!

The old (and original) NFXF website was a treasure trove of information, sprawling across the Fragile X landscape with an inexhaustible wealth of material. So inexhaustible, in fact, with so many new sections and pages added to it over the previous 14 years of its existence, that it had come to resemble a creaky old house that had kept adding on rooms in every direction (including up!), and where visitors thus found it challenging to find the rooms they were looking for.

So, in a digital world where rapid-fire change and quick access is the order of nearly every day, change came to fragilex.org in 2011—in a dramatic, fresh, colorful new way.

Almost everything about the foundation’s new website changed—new design and navigation, brighter new colors, updated content, and an improved user interface that makes it easier for viewers to find their desired information.

What hasn’t changed is our commitment to have fragilex.org continue as the world’s premier resource for parents, educators, medical and therapeutic professionals searching for a comprehensive information resource for Fragile X-associated Disorders. We invite readers to return to the site often, where constantly updated content keeps the Fragile X community informed and connected as never before.





## A NEW “X” MARKS THE SPOT

Slightly preceding but very much paired with the new website was a new organizational logo that also lent a fresh and dynamic new look to all of the National Fragile X Foundation’s materials in 2011. Donated on a pro bono basis by a professional design firm, the new logo incorporates a multi-colored “x” with a slight break at the intersection of the two lines. It was also paired with a first-ever slogan—“forward”—signifying the great progress already made and the goals still remaining for the Fragile X community. The new logo now adorns all of the foundation’s newly created communications materials, including stationery, the *Foundation Quarterly*, and the website.

## SINGING IN HARMONY

Extensive and persistent communication across a broad range of platforms is an ever-more-critical function of the NFXF, and 2011 saw a concerted effort to coordinate and unify messaging among the many efforts we undertake in print, electronic and direct mail communications.

One example is the *Foundation Quarterly*, which has long served to connect the Fragile X community of parents, scientists and professionals by publishing a broad range of in-depth informational and inspirational articles. Last year, the *Quarterly* transitioned to themed issues that revolved around a single theme or idea (“Forward,” “The Impact of Fragile X,” etc.). The theme was also carried over, whenever possible, into other efforts such as the 2011 Annual Fund, which also used a “Forward” theme to anchor its messaging.

Regular meetings of communications committees at both the staff and board level now regularly visit the subject of coordinated messaging to repeatedly reach our audience with the most effective and desired communications.



# DEBUTS

## GOING SOCIAL

Social media wasn't new to the Fragile X community in 2011, but it reached heretofore unseen levels that were not only informative and supportive for its many participants, but also great fun. The foundation's ever-expanding presence on the social media sites of Facebook and Twitter was complemented by the debut of eight NFXF-produced videos, four of them informational and four of them celebratory postings on YouTube (tied to Mother's Day, Father's Day, the theme of thankfulness, and holiday reflections from staff).



In addition, a series of podcasts and electronic newsletters—*FragileXtras*; *Xcellent Advocacy* and others—continued to keep the Fragile X community informed and connected to the foundation and each other as never before. All these efforts are only expected to intensify in the future as the social media world matures and more friends of the foundation discover its rewards.



# PROGRESS

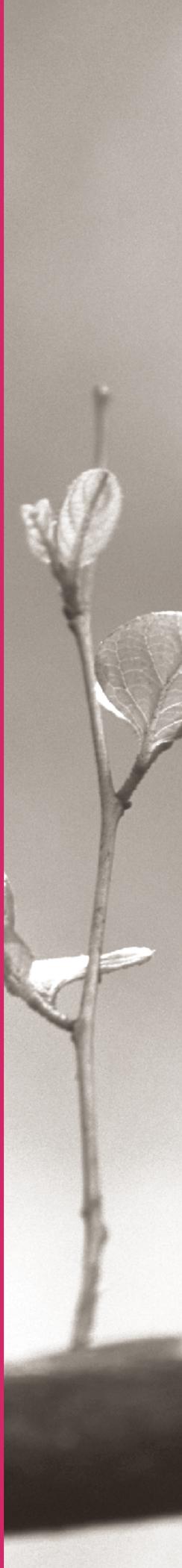
EVEN AS MULTIPLE NEW INITIATIVES OCCUPIED AND INSPIRED NFXF STAFF AND SUPPORTERS IN 2011, A NUMBER OF CONTINUING PROGRAMS, SOME OF RECENT VINTAGE THEMSELVES, ALSO CONTINUED TO EXPAND AND FULFILL THEIR ROLE WITHIN THE ORGANIZATION.

WE OFFER BRIEF SNAPSHOTS OF THEIR STATUS AND DIRECTION HERE.

PROGRESS

PROGRESS

PROGRESS



# PROGRESS

## LINKS PARENT SUPPORT NETWORK

The National Fragile X Foundation greatly appreciates the extraordinary efforts of our volunteer parent support groups and contacts. The LINKS Support Network continued its history of major accomplishments in 2011.

Three new LINKS groups joined the network, bringing the total of active groups to 48. This enhanced our mission of not only supporting but also connecting members of the Fragile X community with one another. In addition, 13 groups initiated and/or continued a Family Advisory Council in partnership with their local Fragile X clinics.



With a satisfactory representation of LINKS groups in nearly every state, the focus of the program was to improve the knowledge and capabilities of the current volunteer leadership.

### 2011 Activity Highlights

- Part-time **LINKS Project Assistant** assumed increasing responsibilities for developing new groups and facilitating FX clinics/LINKS partnerships.
- Launched an **online handbook** for LINKS Leaders.
- Awarded seven **Action Grants** to help newer groups accomplish their educational, social and fundraising goals.
- Provided **personalized support** for group start-ups, leadership transitions, and other events.
- Produced a **monthly e-newsletter** to communicate timely information to leaders and parents.
- Continued efforts to **recruit potential new leaders** and train current leaders.
- Included special **LINKS section on the new website** for document and calendar access.
- **Supplied free FX informational materials** for group events and activities, and conducted numerous monthly direct mail/email announcements for group events and activities.



## FX ADVOCACY DAY: SUCCESS UPON SUCCESS

The NFXF launched National Fragile X Advocacy Day in 2004 as a means to get Fragile X onto the radar of Congress and thus on the agenda for sorely needed research funding and other legislation helpful to families impacted by FX. By the time nearly 150 tightly organized, well-trained and articulate spokespersons for the cause gathered in Washington DC last March 2 for the 8th Annual Advocacy Day and fanned out across the Capitol Building to meet with their congressional representatives and staff members, they had become a familiar and friendly-but-persuasive force that continued to reap dramatic rewards for their efforts. Just two figures tell the tale of our Advocacy efforts:

- Research funding for Fragile X through the National Institutes of Health grew from \$20 million in 2004 to \$32 million through 2010—a 60 percent increase! Funding then remained stable in 2011, a year of severe austerity in the federal budget.
- Research funding from the other major funding source, the Center for Disease Control, rose from \$0 in 2004 to nearly \$2 million annually in recent years.

National Fragile X Advocacy Day is now firmly entrenched on the calendars and agendas of our Advocates and the nation's legislators, providing not only the intangibles of vast hope and inspiration to the FX community, but also the practical lifeblood of research funding that is doing so much to unlock the mysteries of Fragile X.

## A GROWING CONSORTIUM

The Fragile X Clinical & Research Consortium (FXCRC), another NFXF-founded entity, enjoyed a year of rising visibility, cohesion and progress in 2011 as the foundation successfully implemented a Centers for Disease Control (CDC) grant to build the critical infrastructure that allowed the consortium to grow to 25 members across the U.S. and 17 “Affiliate” members around the world. The NFXF then benefitted from a second CDC grant to administer a major data collection effort designed to provide researchers with an unprecedented amount and quality of longitudinal data on children and young adults with the full mutation of fragile X syndrome. The data is obtained when parents consent to their child's participation and visit a clinic close to them.



# PROGRESS

## RESEARCH ROCKS IN 2011!

This is an exciting time for research in the Fragile X field. Many studies utilizing breakthroughs from the past 10 years are now in human trials, and the great majority of scientists and clinicians working in the field are optimistic that new drugs will prove safe and beneficial for Fragile X. According to Elizabeth Berry-Kravis, MD, PhD, “New drug treatments targeted to underlying brain mechanisms in FXS have increased our hope for improvements in learning and behavior not only for those with Fragile X, but also for many individuals on the autism spectrum.” The NFXF supports and promotes research through:

- Direct funding of translational studies designed to advance the development of new treatments.
- The support of young researchers and summer student fellowships.
- Our legislative advocacy work in Washington, DC.
- Our organization of a biennial international conference that brings together many of the world’s leading Fragile X and genetics researchers with families.

As new opportunities for participation in clinical trials come to our attention, we post them for consideration by parents and families as part of our effort to serve as a clearinghouse for all known studies. All posted studies meet general guidelines established by our Scientific and Clinical Advisory Committee and by our Ethics Committee. Information on research and development of new treatments is available at: [www.bit.ly/fx-trials](http://www.bit.ly/fx-trials).

## SUPPORT & EDUCATION FULFILL PERENNIAL ROLES

As always, the Support and Education Committee of the NFXF kept abreast of a wide range of the Fragile X community’s needs in 2011. A sampling of the committee’s activities included:

- Completed a review of the previous NFXF website, identifying gaps in information.
- Developed a business-size card for adults with FXS to be used in case of emergency.
- Identified a list of topics to be included for the 13th International Fragile X Conference.
- Completed a review of family-friendly abstracts submitted for the conference.
- Worked with a college-level educator on a project called “Finding the Adult Services in Your State.” This information will go on the NFXF website and a presentation will be made at the International Conference in 2012.
- Produced a video in collaboration with the communications committee to showcase the talents of children with FXS. It will be presented at the International Conference.

“  
New drug treatments...  
have increased our hope for  
improvements in learning  
and behavior not only  
for those with Fragile X,  
but also for many individuals  
on the autism spectrum.



*Dr. Elizabeth Berry-Kravis*

# PRESIDENT'S REPORT

## EDUCATION, SUPPORT VIBRANT IN 2011

It has been my pleasure and privilege to conclude my two-year term as President of the Board of Directors of the National Fragile X Foundation in 2011. My comments here will focus on the education and support aspects of our mission, both of which saw dramatically strengthened efforts in the past year.



Central to furthering our educational function was the devotion of nearly our entire staff to the development of a new, brighter and modernized website ([fragilex.org](http://fragilex.org)). The website has long served as one of the foundation's primary interfaces with its constituents, and looks to be even more so moving forward. All content was scrutinized, updated and standardized throughout the site, making for a much improved user experience.

Our support function was enhanced with the continued expansion of our LINKS Network of parent support groups and our public policy efforts in Washington, DC. These came together nicely in 2011, highlighted by a vigorous effort to maintain federal support for Fragile X research. In light of a difficult year for all things financial, I'm pleased to report that CDC funding remained level, NIH funding remained relatively stable, and the Department of Defense has continued to include Fragile X-associated Disorders (FXD) in its list of conditions for which it will accept research applications.

In addition, our traditional support work—largely comprised of extensive telephone and email consultation—expanded greatly into the social networking realm where so many families have migrated in recent years. There, the critical work of advising families, providing emotional support and making referrals to the best specialists potentially benefits the entire group, not just the individual seeking assistance. Increasingly, referrals to professional resources are made to one of the 26 clinics that comprise the Fragile X Clinical & Research Consortium, or one of its currently 17 international affiliates. With the advent of a new, larger and longer CDC grant to finance the building of a longitudinal database, the FXCRC is playing an ever more important role in the life of families and the foundation. The past year was a very good one for both.

—Michael Kelley  
*President, Board of Directors*



# EXECUTIVE DIRECTOR'S REPORT

## CARRYING THE MISSION *FORWARD*

The year 2011, like every year in the 27-year history of the NFXF, was filled with purposeful action and improvement in all areas of our mission. I will focus here on describing research highlights from the year and leave other comments to our board president in his adjoining column.



In recent years, fragile X syndrome (FXS) has come to be seen as a condition on the cutting edge of research, with the goal of producing potential breakthrough treatments for affected families. Research has revealed areas where FXS overlaps significantly with autism, and the NFXF responded accordingly by sharpening its messaging, legislative advocacy efforts, and its work with pharmacological and diagnostic companies in order to describe the potential benefits, challenges and opportunities for both the FXS and autism communities.

Our research portfolio included the wrap-up of Dr. Randi Hagerman's minocycline treatment study and Dr. Renate Hukema's FXPOI study (results to be published in 2012). The year also saw the re-start of Dr. Len Abbeduto's language acquisition study (delayed due to a professional move) and the funding of six Rosen-Weingarden Summer Student Fellowships as part of our effort to help launch the next generation of clinicians and researchers.

Research on new drugs designed to treat the core symptoms of FXS also picked up steam in 2011, with three pharmaceutical companies either undertaking or preparing to undertake clinical trials. To assist those companies with the challenge of recruiting enough qualified trial subjects, the NFXF launched a fee-based service that provides mailings and email blasts to our 40,000-plus name database, in addition to our traditional free posting of studies on our website. With the help of our new ethics committee, guidelines and standards for our recruitment efforts were designed to ensure appropriateness and fairness in our dealings with all external companies and institutions, whether for-profit or non-profit.

In sum, 2011 was a year of significant expansion and involvement of the NFXF in supporting research efforts, undergirded by a continued focus on the ultimate goal of everything we do: improving the lives of families and those family members with FXS, FXTAS, FXPOI or any other Fragile X-related challenge.

—Robert Miller  
*Executive Director*

# FINANCIALS

IN A DIFFICULT ECONOMIC TIME, NATIONAL FRAGILE X FOUNDATION FINANCES CONTINUE TO REFLECT A COMMITTED AND INVOLVED CONSTITUENCY WHOSE INCREASING GENEROSITY PROVIDES A STRONG BASE OF SUPPORT FOR THE LONG TERM.

BOTH INDIVIDUAL AND CORPORATE CONTRIBUTIONS ROSE SIGNIFICANTLY IN 2011. (INDIVIDUAL FROM \$360,952 TO \$484,899; CORPORATE FROM \$30,997 TO \$44,450.) THE CHARTS ON THE FOLLOWING PAGES TELL A COMPELLING STORY OF AN ORGANIZATION EXPERIENCING STEADY GROWTH AND INCREASED PROGRAMMING DESPITE THE DIFFICULT HEADWINDS IN THE LARGER ECONOMY.

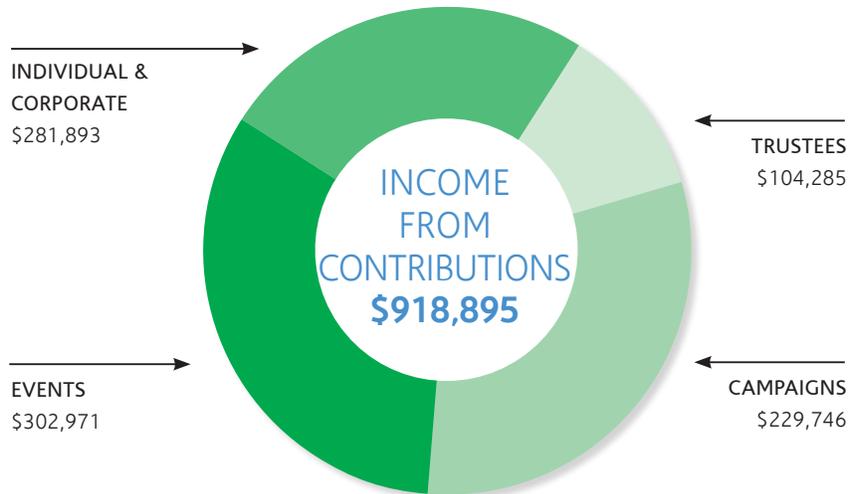
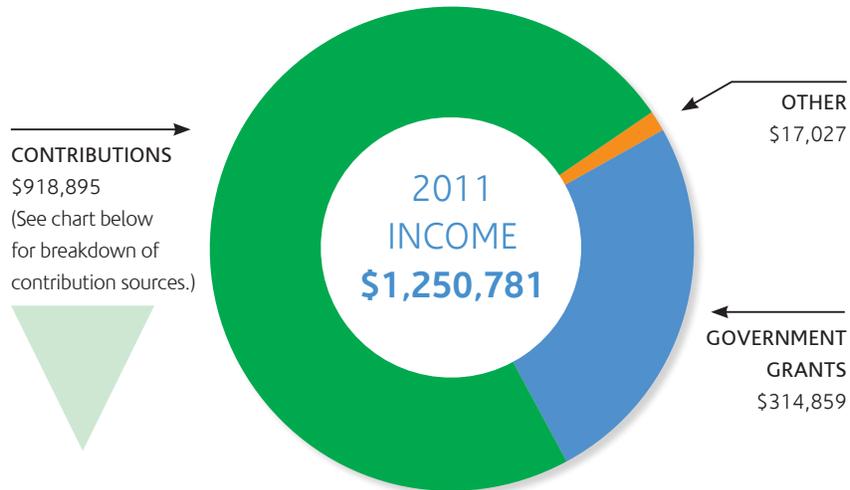
NOTE: THE FOLLOWING FINANCIAL INFORMATION IS DISTILLED FROM A FULL AUDIT CONDUCTED BY REGALIA & ASSOCIATES, CERTIFIED PUBLIC ACCOUNTANTS, IN ACCORDANCE WITH GENERALLY ACCEPTED ACCOUNTING PRINCIPLES. FOR THE FIRM'S FULL REPORT, SEE [fragilex.org/foundation/](http://fragilex.org/foundation/).

# FINANCIALS

# FINANCIALS



# FINANCIALS



“  
The foundation is a major part of our charitable giving because it has been there for us since diagnosis and is most important to our family. It continues to provide us with connections to invaluable Fragile X resources, and the staff does great things there every day. We want to see it all continue.  
”

—Andy & Tammy Selinger  
LINKS Leaders, Fragile X Society of Connecticut

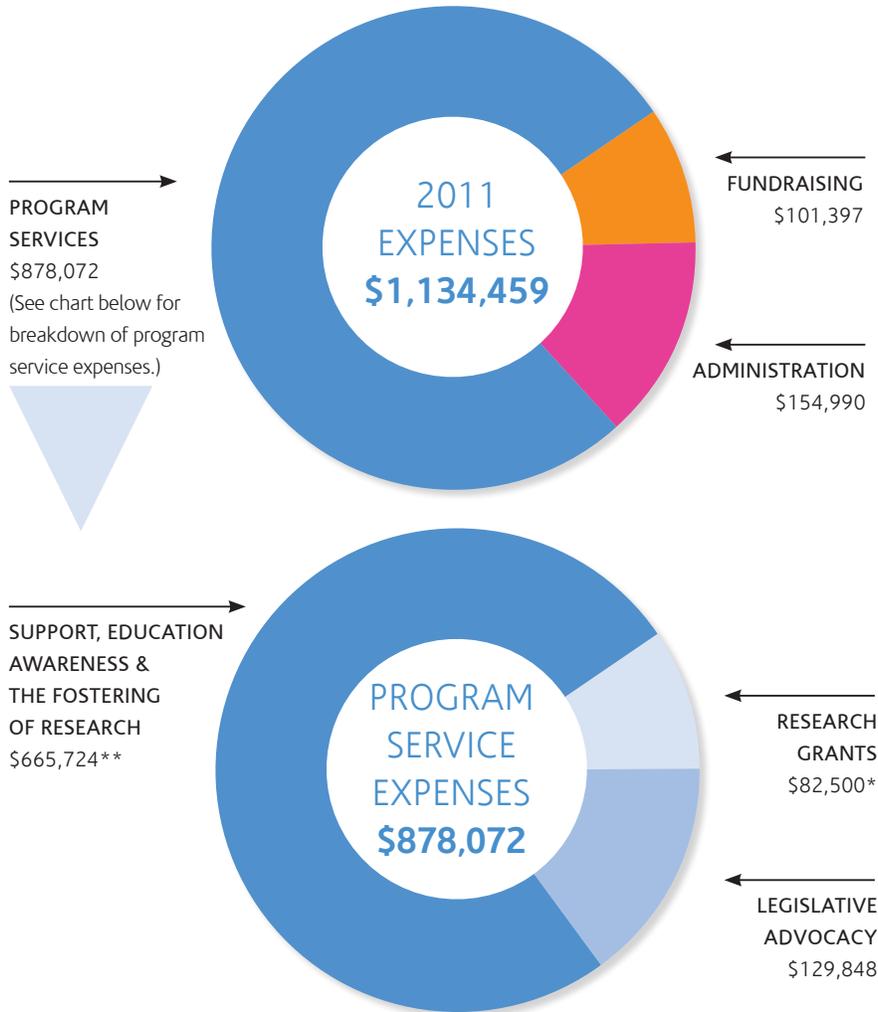


“

We've conducted fundraisers and given directly to the National Fragile X Foundation for over 10 years now because they have always given back to us. Ultimately, we're all here to help find a cure for Fragile X, and it takes a team to meet that goal. We look at our giving as part of the teamwork.

”

—Rose Jahnke  
Leader, Fragile X LINKS Group of Wisconsin



\* Research percentage reflects actual cash paid out for research grants in 2011 and will be different than grants "awarded" in a fiscal year.

\*\* In addition to making research awards to scientists and clinicians, the NFXF fosters and promotes research through its international Fragile X conferences and through its role as founder and partner of the Fragile X Clinical & Research Consortium.

# FINANCIALS

## DEVELOPMENT

Sustained support from donors enabled the NFXF to achieve another strong fundraising year in 2011. More than 3,800 contributions from individuals, foundations and corporations raised just under \$1.1 million. Individuals and LINKS parent groups around the country organized events, Trustees made multi-year personal giving pledges, and others supported the foundation through the Annual Fund, Awareness Day, and Advocacy Day campaigns. Corporate Partners lent support with cash donations and in-kind gifts. We note a multitude of events and donors below, all of which we deeply appreciate as essential support for carrying out our mission.

### Campaigns

- The **Annual Fund** continues to comprise a significant portion of our budget. Gifts from more than **715 donors generated \$187,467**.
- Our first-ever **Advocacy Campaign** in 2011 utilized direct mail to convey the significant return on investment seen in the form of federal research funding for Fragile X resulting from NFXF advocacy efforts. The campaign generated **\$26,471 from 221 donors**. This third direct mail campaign of the year will remain a permanent fixture on the development calendar.
- The **9th Annual National Fragile X Awareness Day Campaign** turned to the FX community to share personal stories of the many ways those with Fragile X are “more than their diagnosis.” Hundreds of families shared their stories and photographs on the NFXF website, depicting their loved one’s (or their own) interests, talents, hobbies, aspirations and more. The messaging carried over to the direct mail campaign, which raised **\$15,808 from 267 donors**.

### Trustees

NFXF Trustees provided the foundation with a base of financial support by pledging at \$1,200, \$2,400, \$3,600 or more annually for three years. By the end of 2011, Trustee donations totaled over \$104,000. The foundation looks forward to further expanding the program in 2012, and remains thankful for the sustained support of these long-term benefactors. (A full list of Trustees and other Major Donors can be found on pages 20 and 21.)

#### HIGHLIGHTS

CAMPAIGNS RAISED OVER  
**\$229,000**

CHICAGO VIRTUAL EVENT  
RAISED OVER  
**\$180,000**

TRUSTEES GAVE OVER  
**\$104,000**

## Foundations and Corporations

Corporations and foundations were major supporters again this year. The Corporate Advisory Council, which offers industry leaders the opportunity to partner with the NFXF in the search for scientific breakthroughs, continued to grow. A list of these key supporters and others is below.

### Corporate Advisory Council Members

Abbott Molecular, Inc.	Celera	Seaside Therapeutics
Asuragen	Roche	

### Corporate Donors, \$1,000+

Action Electric Sales, Inc.	Field Holdings, Inc.	Patzik, Frank & Samotny Partners Ltd.
Best Buy	Fox's Pizza Den	SBA Network Services, Inc.
Brown Shoe Famous Footwear	Goldman, Sachs & Co.	Spruce Private Investors, LLC
Canel, King & Jones	Jewel A Supervalve Co.	Wachovia Foundation Matching Gifts
Endurance Matching Gifts Program	Montanari Financial Partners, LLC	Wal-Mart Foundation
Farnam Street Financial, Inc.	Northern Trust Company	William DeWoskin & Associates

## Fundraising Events

Many generous and enthusiastic groups and individuals conducted fundraising events on behalf of the NFXF in 2011, led by a “virtual event” in Chicago which relied again on the oft-repeated efforts of the Canel, Cooper, and Fishman families to raise more than \$180,000. More modest but no less energetic efforts ranged from walks, motorcycle rides and golf outings to lemonade stands. Highlights are listed below.

### \$10,000+

Conquer Fragile X Event Palm Beach, FL <i>Harris Hollin</i>	Elephant Rock Cycling Festival Castle Rock, CO <i>Colorado Fragile X</i>	Chicago Virtual Event <i>Lynda and Scott Canel</i> <i>Cheryl and Carey Cooper</i> <i>Rebecca and Ira Fishman</i>
Raising Green in the Desert Scottsdale, AZ <i>Jay and Joan Canel</i> <i>Irv and Judy Gross</i>	Awareness Day Fundraiser New York, NY <i>Louis and Heather Barbera</i>	Red, White, & Blue Labor Day Party Coto de Caza, CA <i>Dave and Joy Justus</i>

### \$3,600+

Biggest Loser Challenge X Bootcamp Prescott Valley, AZ <i>Leanne Shearer and Amy Champ</i>	Walk for Fragile X, Bernville, PA <i>Jennifer and Luke Mathias</i>	Walk for Fragile X, Milwaukee, WI <i>Fragile X LINKS Group of Wisconsin</i>
Jackson Laughs Race, Kent, OH <i>Ben and Natalie Koberna</i>	Fragile X Endurance Bike Ride Cross Country <i>Eric Sheerin and Joe Wainwright</i>	Walk for the Faces of Fragile X, Olathe, KS <i>Fragile X LINKS Group of Kansas City, Missouri</i>
Walk for Fragile X, Canton, IL <i>Central Illinois Fragile X Resource Group</i>	Chicago Charity Golf Classic Romeoville, IL <i>SW Chicago LINKS Group</i>	Hat Party to Benefit the NFXF Lafayette, CA <i>John and Deborah Kwan</i>
Wedding Donations for Fragile X Marion, IA <i>Carolyn and John Tomberlin</i>	Wild West Relay Fort Collins Steamboat Springs, CO <i>Colorado Fragile X</i>	Walk for the Faces of Fragile X <i>Kansas Fragile X LINKS Group</i>

## Fundraising Events *(continued)*

### \$1,000+

Bowl-a-Thon for Fragile X, Batavia, IL <i>Matt and Alicia Brooks</i>	Fragile X Fun Raiser, West Chester, OH <i>Lauri Lupinetti and Fragile X Families of Greater Cincinnati</i>	Wine Tasting at Carmelina's, Hadley, MA <i>Fragile X Group of Western MA</i>
Valbella Wine Tasting Event New York, NY and Greenwich, CT <i>Dave Justus and Paul Capialli</i>	Finster Murphy's Fundraiser Fort Lauderdale, FL <i>Joey Dissette</i>	Lizzie's 7th Annual Open House <i>Nancy Reilly and Team Lizzie</i>

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