

**2010
Annual Report
National Fragile X Foundation**



NFXF LINKS Network
Linking Individuals in Networks of Knowledge and Support



What is Fragile X?

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

How Many People Have Fragile X?

Over one-million Americans have, or are at risk for developing, a Fragile X-associated Disorder including approximately 100,000 with fragile X syndrome.

MISSION STATEMENT OF THE NFXF

The National Fragile X Foundation unites the Fragile X community to
Enrich lives through educational and emotional support,
Promote public and professional awareness, and
Advance research toward improved treatments and a cure for Fragile X

Highlights 2010

- ◆ *The National Fragile X Foundation organized the 12th International Fragile X Conference in Dearborn, Michigan, attended by nearly 800 family members and professionals from over 20 countries.*
- ◆ *The National Fragile X Foundation launched www.FXTAS.org, the world’s first fragile X-associated tremor/ataxia website devoted to patients and their families.*
- ◆ *The National Fragile X Foundation responded to over 100 new diagnosis calls and emails and thousands of phone and email inquiries.*
- ◆ *The National Fragile X Foundation awarded \$125,000 in new research grants while making installments on research awarded in the prior year. An additional \$25,000 in small grants was made to Summer Student Fellows and Young Investigators.*
- ◆ *The National Fragile X Foundation organized the 7th Legislative Advocacy Day on Capitol Hill with approximately 140 advocates.*
- ◆ *The National Fragile X Foundation organized, along with the CDC, the first-ever meeting designed to lower the average age of diagnosis of fragile X syndrome.*
- ◆ *The National Fragile X Foundation-founded Fragile X Clinical & Research Consortium continued to expand and, with the support of the U.S. Centers for Disease Control, began preparing for the advent of new treatments for fragile X syndrome.*

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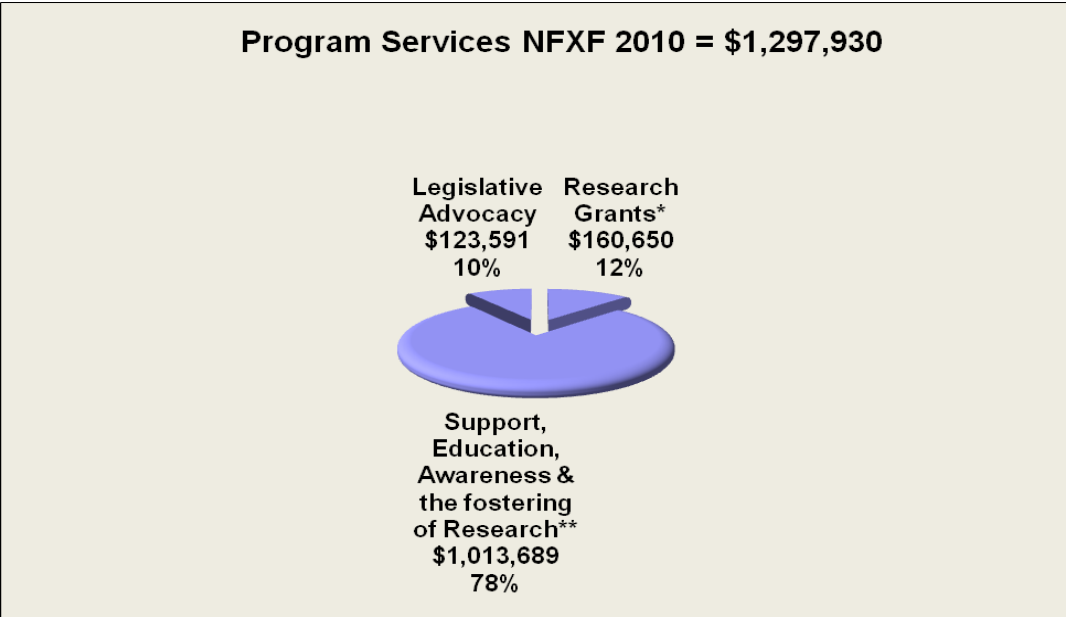
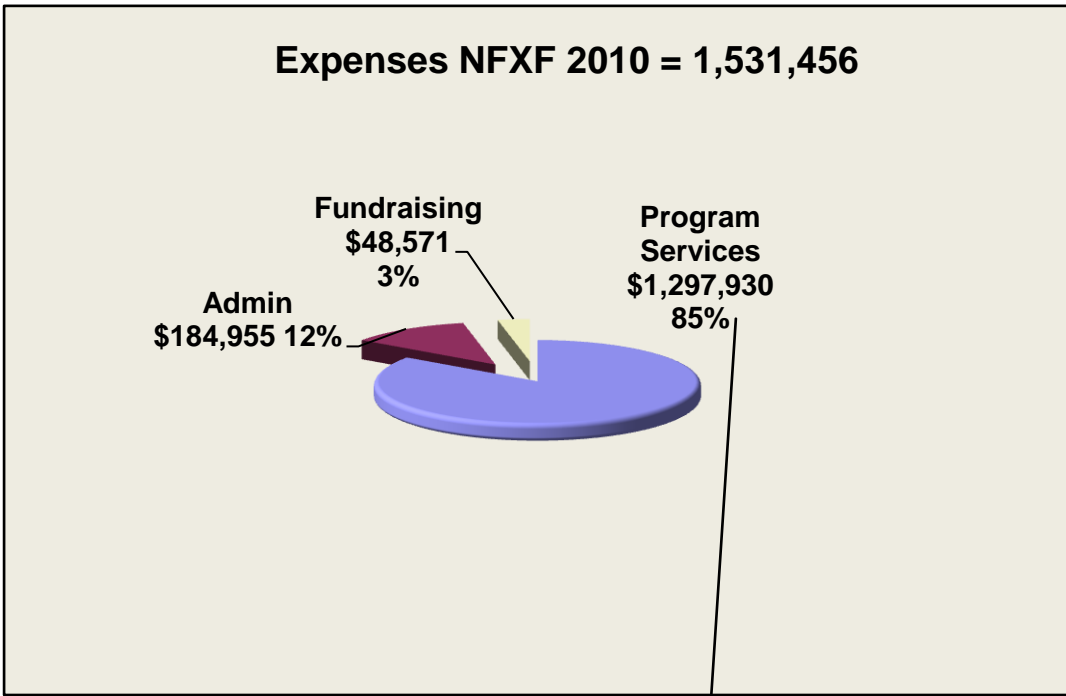
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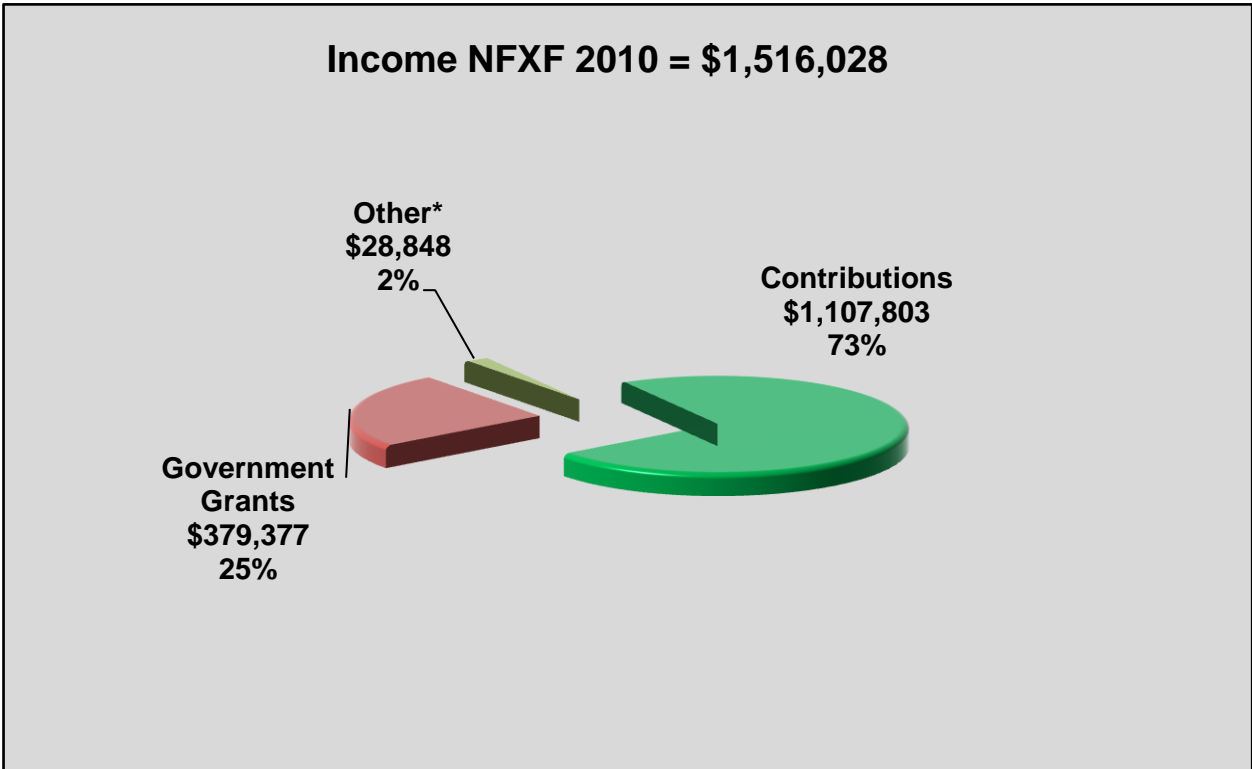
<http://My.FragileX.org>



Dollar amounts noted in the above graphs are taken from audited financial statements for the year ended December 31, 2010 and available from the National Fragile X Foundation by request or online at www.FragileX.org by selecting "About the Foundation."

** Research percentage reflects actual cash paid out for research grants in 2009 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.*



**Other includes membership and educational sales.*

The National Fragile X Foundation audit is conducted by the following firm.
 A copy of the audited financials is available upon request or online at www.FragileX.org by selecting "About the Foundation."

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OFFICER REPORTS

President

The board of directors meets four times each year as required in our by-laws. In addition to the fiduciary responsibilities of approving budgets, we engage in strategic planning, set new priorities to respond to changing events, and offer advice and consent to our Executive and Associate Directors.

As you will note in the annual report, the mission of the foundation continues to expand. Our efforts in advocacy lead to the CDC funding of the Fragile X Clinical and Research Consortium, among the most significant accomplishments ever for the NFXF. The FXCRC offers an infrastructure to promote the goals of the Fragile X community unlike any other. The potential impact to research and clinical services to a larger community is immense. The staff and board are committed to continue the growth of the FXCRC and will work steadfastly in 2011 to insure continued governmental support.

Our signature product, the International Fragile X Conference, held this past year in Dearborn Michigan, was again a monumental success. The efforts of staff and countless volunteers to ensuring this event is of the highest caliber every two years cannot be overstated.

You will also note several new board members. In our strategic plan of 2009, the board established term limits. The policy was put in place to insure the mission of the foundation was reflective of the changing population, to keep new and fresh ideas flowing into the board, and to increase the breadth of knowledge and availability of volunteers for service on our expanding board committees.

Two of those board members—Jeffrey and Arlene Cohen—marked the end of an era in July when they stepped off the board after 14 years of tireless service. Along with Mark Gruzin and Gail Heyman (whose terms expired at the end of 2010 after six years of service each), all have been hugely influential in leading the foundation to a higher plane. Their good nature, deep knowledge and phenomenal (volunteer!) work ethic inspired so many, including me, to follow them into service.

I encourage everyone to read the annual report to gain a true understanding of the incredible work of the foundation. It is testament to why your contributions to this organization are so very important.

Michael Kelley

President, NFXF Board of Directors

Secretary

The Board of Directors of The National Fragile X Foundation is required to meet four times yearly including two face-to-face meetings. During 2010, four meetings were held (an Annual Meeting 3/20-21 in Dearborn, MI, a second meeting on July 20 in Dearborn during the 12th International Fragile X Conference and teleconference meetings 10/21 and 12/31. Minutes were recorded at each meeting and all meetings were conducted in conformity with Roberts Rules of Order. Minutes were distributed to each board member, reviewed and accepted by vote of the board at each subsequent meeting. All minutes are kept on file at the National Fragile X Foundation and with the secretary.

The following committees were in place at the end of 2010: Executive, Development, Public Policy, Governance & Nominations, LINKS Groups, Communications and Support & Education. All board members serve on one or more committees and non-board members are eligible to participate as ad-hoc members. Committees meet by teleconference throughout the year and report to the full board at quarterly meetings. The Scientific and Clinical Advisory Committee is an independent body that meets annually and reports to the full board through its co-chairs who also sit as non-voting members of the board. During the international conference the SCAC switched to a subcommittee model with each having its own chair.

Joey Christoff

Secretary, NFXF Board of Directors

Treasurer

Each year the Foundation staff and the full Board of Directors participate in the development of an annual budget to ensure we have a financial plan that best spends our resources against the elements of the mission of the Foundation. At every board meeting, I review our actual financial results compared to that budget with the entire Board to ensure we are on-track with those intentions set out in the beginning of year budget. In advance of the board meeting, I review the financial results of the Foundation in detail with our Executive Director, Associate Director and our accountant. The financial statements are prepared from our accounting records which are updated each week and those records are reconciled to our bank accounts each month. Each year we ask our financial records to be audited by an independent auditor to ensure that our accounting records are accurate and our procedures are in accordance with highest standards and satisfy the needs of the Foundation. Our independent auditors also provide annual recommendations which ensure we have in place the financial "best practices" for not-for-profit organizations.

Our detailed audited financial statements for 2010 are available online or upon request.

Marty Lang

Treasurer, NFXF Board of Directors

Executive Director

A conference year is a “big” year for the NFXF and 2010 was no exception. As usual, staff members devoted an exceptionally large amount of their time on planning and organizing the 12th International Fragile X Conference in Dearborn, Michigan. Of course, even with an international conference to prepare for, we can never take it easy. That’s why we also were able to launch FXTAS.org, the world’s first fragile X-associated tremor/ataxia website devoted to patients and their families as well as undertake, coordinate, facilitate and/or organize all of the other things mentioned in this report!

12th International Fragile X Conference

Nearly 100 volunteers participated in the planning and execution of the conference which was hosted by the Fragile X Association of Michigan. With more than 125 sessions presented by almost 150 parent and professional speakers, plus 40 poster presentations, this conference covered nearly every topic under the sun; from toilet training to “Differences in Amygdala Activation Correlate with Molecular Measures in Male Carriers of the FMR1 Premutation.” As usual, the event was designed to bring parents and other family members together with the world’s leading researchers and treatment specialists. It was no surprise that there was an ever-steady buzz regarding the development of significant new treatments in the relatively near future, and many speakers addressed that issue in their presentations.

94% of Respondents reported they were Very Satisfied or Satisfied overall with the conference and I’ll let their comments speak for themselves.

- ◆ *It was an awesome conference! Thanks Michigan Group and NFXF!!!!*
- ◆ *Overall, I thought the conference was very well organized*
- ◆ *Had a great time and can't wait for 2012!*
- ◆ *Enjoyed it very, very much. One of the best I have been to. Michigan group did a great job!!*
- ◆ *Excellent conference and very well run.*
- ◆ *Overall a great experience, good location & hotel. It might help re expenses if the next hotels have micros and fridges. The buffet line for lunch was good and reasonable.*
- ◆ *It is always like coming to a family reunion! I love being among people who get it and have developed so many valuable friendships over the years with individuals that I now have regular contact with outside of the conference. It is a wonderful experience.*
- ◆ *The sessions giving young adults with FXS the opportunity to speak means so much to me. It gives hope to all of us who still have young children. I would love see these continue.*
- ◆ *Loved it. I learned so much. Thanks for all your hard work. I wish I could have gone to everything.*
- ◆ *It was an amazing experience and I can only imagine the amount of time that was put into planning such a huge event. You had a wide range of people attending and I know it must have been hard to accommodate all of the different backgrounds of those who attended. You did a super job!*

- ◆ *I loved the 12th international conference and I can't wait to see everyone in 2 years in Miami.*
- ◆ *Wonderful to meet everyone! Such an amazing community... I am PROUD to be a part of it.*

FXTAS.org

After nine months of hard work with dozens of professionals and family members contributing, FXTAS.org went live in the summer of 2010. The new website is dedicated to conveying information about FXTAS to families, health professionals, and others who are affected in some way by the condition. The creation of the website was driven by the ever-increasing knowledge surrounding FXTAS since its discovery in 2001 and the knowledge that no centralized resource for families existed. The NFXF takes its responsibility to help all families very seriously and this new website is just the first of many ways that we plan to expand our support to other family members impacted by any of the Fragile X-associated Disorders. The site was made possible by the Edward Behrman memorial fund.

Conclusion

No matter what the NFXF was doing in 2010, it was doing it with an eye on the future; positioning ourselves to advance research and to prepare for the advent of new treatments. The NFXF is committed to seeing that all Americans have access to new treatments regardless of their geographic location or economic status.

Our lean and efficient paid staff (10 employees – 7.0 full time equivalent) along with a small number of contractors and consultants (Used for very specialized and/or periodic activities), our dedicated group of volunteers comprising our Board of Directors, parent support (LINKS) network, and Scientific and Clinical Advisory Committee, the staff at the clinics comprising the Fragile X Clinical & Research Consortium, the professionals comprising the Collaboration to Promote Self-Determination, and many, many others stayed focused on our mission and our desire to make the world a bit better and easier for those impacted by any of the Fragile X-associated Disorders.

As always, readers of this annual report should remember that if they have any questions, comments or concerns about the activities of the NFXF I am more than happy to hear them and will give them my full consideration and response.

Robert M. Miller
Executive Director

ACTIVITIES & OUTCOMES

Research

◆ Translational Research Awards – 2010

Renate Hukema PhD

Research Award (1 year) = \$50,000

Erasmus MC

Fragile X premutation and FXPOI: analysis of ovaries from FMR1 CGG repeat mice

Len Abbeduto PhD

Research Award (2 years) = \$75,000

University of Wisconsin

Parent Mediated Language Intervention for Young Children with FXS: A Pilot Efficacy Study

◆ Ongoing Awards – 2009-2011

The following project was first awarded in 2009 and is ongoing with completion scheduled for 2011:

Randi Hagerman MD

Research Award (2 years) = \$100,000

UC Davis MIND Institute

A Double-Blind Randomized Controlled Cross Over Trial of Minocycline in Children with Fragile X Syndrome



(Harris Hollin - Conquer Fragile X Fund)

Christina Gross, PhD

Research Award 2004 = \$30,000

Emory University

Examining genetic and pharmacologic rescue strategies for excessive PI3K signaling in FXS

Ravi Muddashetty, PhD

Research Award 2004 = \$30,000

Emory University

Role of microRNA dysregulation in FXS

◆ **Young Investigators & Summer Student Fellows:**

Helping Secure the Future of Fragile X Scientific Research

Thanks to the generous support provided by the **Harris Hollin – Conquer Fragile X Fund** at the National Fragile X Foundation, the NFXF organized a “Young Investigators” Event within the 12th International Fragile X Conference. Each Young Investigator received a stipend to attend the conference. A total of twelve stipends were provided based on recommendations from members of the NFXF’s Scientific & Clinical Advisory Committee and a special gathering of these young scientists was organized where they met with senior scientists.

Along with the Rosen Summer Student Fellowship Program and other initiatives, this is one of the many ways the NFXF is working to make sure that the brightest minds in science are focused on Fragile X.

The Young Investigators - 2010

- | | |
|-------------------------|-------------------------|
| ❖ Anna Ludwig, PhD | ❖ Daman Kumari, PhD |
| ❖ Jeannette Lumaban | ❖ Surabi Veeraragavan |
| ❖ Giuseppe Lafauci, PhD | ❖ Chantal Sellier, PhD |
| ❖ Ravi Muddashetty, PhD | ❖ Elizabeth Walter, PhD |
| ❖ Christina Gross, PhD | ❖ Zane Zeier, PhD |
| ❖ Inge Heulens | ❖ Zachary Zalewski |

Rosen Summer Student Fellowships - 2010

The NFXF funded six basic science and clinical summer student research fellowships at \$2,500 each as a way to encourage young researchers to join and/ remain in the field of Fragile X.

- ❖ Matthew DeSalvo - Harvard Medical School
 - Role for FMRP and mGluR signaling in synaptic plasticity of Tsc1c mutant mice
- ❖ Rupinder Dhaliwal - Emory University School of Medicine
 - Fragile X syndrome and fragile X associated disorders in British Columbia
- ❖ Aurasch Moaven - Emory University School of Medicine
 - Altered regulation of the potassium channel Kv4.2 in brain and spinal cord of FXS
- ❖ Aubrey Rho - Stanford University
 - Neurodevelopmental Profiles of Infants and Preschool Age Children with FXS
- ❖ Cecilia Cappelloni - UC Davis MIND Institute
 - Assessing the Feasibility of a Visual Event-related Potential Paradigm in FXS
- ❖ Victor Kaytser - Rush University Medical Center
 - Quantification of Motor Stereotypies in FXS: A Potential Outcome Measure for Clinical Trials

The final reports from these projects are published in the quarterly journal of the NFXF as well as on its website.

All of these projects have made or will make an important contribution to the body of knowledge used to provide the best treatments possible for those impacted by Fragile X.

Awareness

The NFXF continues to promote awareness of Fragile X through all of its activities. During 2010 our focus remained on promoting awareness within professional circles and our efforts to develop and expand the Fragile X Clinical & Research Consortium had the greatest impact on that effort. With an ever-increasing turn towards the internet as a primary source of information, we focused on enhancing our websites while also laying the groundwork for a 2011 overhaul of our largest site, FragileX.org. Throughout the year, we also continued to provide free informational materials for awareness activities including flyers and brochures.

Education

Educational Seminars Co-sponsored by the NFXF

The NFXF supported the following events through co-sponsorship, advertising and/or free materials

Miller Children's Hospital Long Beach, California
Symposium on Fragile X Syndrome - January 8

Elwyn Fragile X Center - Pennsylvania
Maximizing Potential: Practical Behavior Strategies for Students with FXS - March 8

Guadalajara, Mexico
Mexican Conference on Fragile X and Autism - May 26-28

Detroit, Michigan
A Special Behavior Symposium: Strategies for Challenging Behaviors
A Pre-Session of the 12th International Fragile X Conference - July 21

Detroit, Michigan
12th International Fragile X Conference - July 21-25

Texas Fragile X Association
Fragile X Syndrome and Autism: Learning Styles and Intervention Strategies –
September 11

Families for Fragile X (South Florida)
Managing Behavioral Issues (In the classroom and home) associated with FXS and
Autism - September 25

Viña del Mar and Santiago, Chile
International Symposium Fragile X syndrome and Autism - October 5-7

FX Society of Connecticut - University of Connecticut Health Center
Fragile X: Educational, Behavioral and Social Interventions - October 16

FX Resource Center of Missouri
Addressing Behaviors at School and Beyond - October 30

Fragile X Association of Southern California
Conservatorship Workshop - October 9

Fragile X Association of Southern California - UC Irvine School of Medicine
Fragile X-associated Tremor Ataxia Syndrome (FXTAS) - December 8th

Podcasts

- ◆ Issues in Sensory Integration and Fragile X Syndrome with Tracy Stackhouse, MA, OTR and Sarah "Mouse" Scharfenaker, MA, CCC-SLP
- ◆ Talking with Students K-5 with Holly Roos
- ◆ Surviving the Holidays with Jayne Dixon Weber

Web and Print

- ◆ Published and distributed three issues and approximately 8000 copies of the Foundation Quarterly journal
- ◆ Received nearly 600,000 unique visitors to our websites
- ◆ Launched www.FXTAS.org, the world's first FXTAS site for patients and their families

Parent, Extended Family, and Professional Support

Parent, family and professional support continues to be a cornerstone of the National Fragile X Foundation's work. Not only does awareness of Fragile X-associated Disorders (FXD) continue to grow to include not just fragile X syndrome, but also fragile X-associated tremor/ataxia syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI), but the knowledge about the conditions and development of potential treatments has increased the demand for support. During 2010 we continued to have dedicated support staff handle the thousands of email and phone call requests for help, information and referrals. During 2010 we also saw an increase in the number of professionals contacting us for information.

While many of the calls pertain to the everyday issues of behavior, education and toileting, more parents are asking about getting involved in clinical trials. Partly due to that and partly due to the expansion of the Fragile X Clinical & Research Consortium, we have implemented a procedure by which we inform every family and professional who contacts us about the nearest Fragile X clinic whether they inquire about clinics or not. As calls and emails come into me (a parent of a child with fragile X syndrome), I have access to the expertise of the NFXF's genetic specialist who is also a certified genetic counselor. I also have the support of an occupational therapist, a speech therapist, a behavior specialist, and a number of medical professionals who are on contract with the NFXF. Access to these professionals allows me to give high quality, targeted information to families and doctors.

I still let families know that they can ask me about whatever topic they want. Inquiries come in on a wide range of topics: new diagnosis, early intervention, toileting, behavior, education, adults, sensory issues, and medications, to name a few. As families become more educated about the conditions, and take more control over their child's life, and with the increasing frequency in which medications are prescribed, concerns and questions about the side effects of medications will likely increase.

We continue to provide support through:

- ◆ Phone Calls and Emails – for fragile X syndrome: from parents of newly diagnosed children to parents in their 80's with adult children, doctors, and educational professionals; for FXTAS; and for FXPOI
- ◆ Referrals to clinics within the Fragile X Clinical & Research Consortium
- ◆ Doctor referral – through our database
- ◆ Information referral – to the NFXF website and other websites
- ◆ Finding/encouraging opportunities for parents to network – through our LINKS groups and our social network site: <http://my.fragilex.org/>
- ◆ Free informational packets to parents, relatives, professionals, and students by request
- ◆ Regular updating of written materials for families – including “Fragile X-Associated Disorders (FXD) – A Handbook for Families, Health Care Providers, Counselors, and Educators.”
- ◆ Articles written for the “Foundation Quarterly” about topics that parents request and/or experiences that other parents find helpful.
- ◆ Regular updates to the NFXF website, with an emphasis on topics of great interest such as toileting, home-schooling, and IEPs, along with keeping clinic contact information up-to-date.
- ◆ Assistance in setting the agenda for the International Conference, keeping in mind the call/requests that I have received from parents.
- ◆ Participation on the Support and Education Committee of the NFXF Board, which gives me an opportunity to meld the work of the staff with the needs of the families.

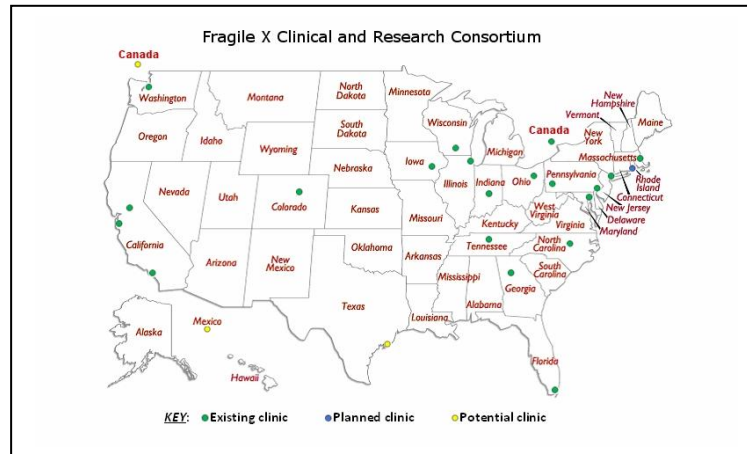
Jayne Dixon Weber

Support Services Coordinator

The Access to Credible Genetics Resource Network

The NFXF completed its involvement as a partner in the Washington, DC-based Genetic Alliance's CDC-funded project to help parents and professionals better evaluate information on genetics and genetic conditions. A specialized website called www.trustortrash.org was finalized and the NFXF continued to utilize the guidelines and recommendations developed within the network in the design of its own brochures, flyers, booklets and website. An example of the Trust or Trash tool can be found on the home page of the NFXF website, www.FXTAS.org.

Clinics



Beginning in 2006, and accelerating significantly in 2008 with the advent of a 3-year grant from the CDC, the development of the Fragile X Clinical & Research Consortium (FXCRC) further expanded in 2010. As founding partner of the FXCRC, the NFXF has been instrumental in the expansion of the consortium from 11 clinical care centers to 23 at the end of 2010 with clinics focusing not only on clinical care but also on shared research trials for new treatments. The founding goals of the FXCRC included:

- ◆ Development of a shared knowledge base of organizational, administrative and clinic funding structures that will assist current and future clinics with becoming more effective and efficient;
- ◆ Establish a structure for facilitating collaborative research efforts, including drug trials.

These goals continued to evolve in 2010 as the respective committees of the FXCRC developed consensus papers on treatment and an expanded database containing detailed (anonymous) medical and behavioral information about patients attending clinics.

In 2010, the NFXF continued to take the lead role with the facilitation and coordination of the consortium activities, including the recruitment of new clinics. Towards that end, membership requirements and guidelines continued to evolve.

The FXCRC held two, all-clinic meetings in 2010 at which its cooperative partner, the Centers for Disease Control, played an active role. The National Institutes of Health's National Institute for Child Health and Human Development also continued to send a representative to all meetings.

As of the end of 2010, the following sites/clinics were active members of the FXCRC:

Akron, OH: Akron Children's Hospital
Atlanta, GA: Emory University
Baltimore, MD: Kennedy Krieger Institute
Boston, MA: Children's Hospital Boston
Chicago, IL: Rush University Medical Center
Denver, CO: Children's Hospital of Denver
Durham, NC: Duke University Medical Center
Houston, TX: Texas Children's Hospital
Indianapolis, IN: Riley Hospital for Children
Iowa City, IA: University of Iowa
Long Beach, CA: Miller Children's Hospital
Madison, WI: Waisman Center, University of WI
Miami, FL: Mailman Center for Child Development

Minneapolis, MN: University of Minnesota
Nashville, TN: Vanderbilt Center for Child Development
Palo Alto, CA: Stanford University
Philadelphia, PA (area): Elwyn Center
Pittsburgh, PA: Children's Hospital of Pittsburgh
Providence, RI: Brown University Medical Center
Sacramento, CA: U.C. Davis M.I.N.D. Institute
Seattle, WA: Children's Hospital & Regional Med. Ctr.
Staten Island, NY: NY State Institute for Basic Research in Developmental Disabilities

Toronto, Canada: Fragile X Clinic, Surrey Place Ontario
Vancouver Island, Canada British Columbia Fragile X Clinic

Volunteers

The National Fragile X Foundation is sincerely appreciative of the extraordinary efforts of our volunteer parent support groups and contacts. Major accomplishments of the LINKS (LINKing Individuals Nationally in Knowledge and Support) Program were continued in 2010 including the addition of several new groups and partnerships with FX Clinics.



Eleven new LINKS groups joined the network in 2010 bringing the total of active groups to 29 enabling us to continue our mission of supporting and connecting members of the Fragile X community. An additional 17 groups are currently inactive with efforts to find new leadership underway. The LINKS Network also recruited an additional 11 new parent contacts to provide support and resources information to families locally.

2010 Activities:

- ◆ Facilitated the involvement of four LINKS groups with FX clinics partners in creating opportunities for FX to be included in Family Advisory Councils.
- ◆ Hired a part-time LINKS Project Assistant with FXCRC funding to assist with the development of FX clinics/LINKS partnerships along with the development of new groups
- ◆ Hosted LINKS recruitment meeting in conjunction with the 12th International FX Conference in Detroit; current LINKS Leaders shared their experiences and the opportunities created by the LINKS Network as part of a panel presentation
- ◆ Measured current groups performance against new program accountability standards resulting in downgrading of several non-active groups to parent contact status
- ◆ Organized the content for an online handbook for LINKS Leaders to access how-to guidelines and samples/templates; scheduled for spring 2011 launch
- ◆ Maintained NFXF membership rate among group leaders and parent contacts
- ◆ Provided personalized support for group start-ups, leadership transitions, special events and educational seminars
- ◆ Published monthly e-newsletters — *ConneXions* to communicate timely information to LINKS leaders and parent contacts
- ◆ Continued efforts to recruit potential new leaders and train current leaders to increase their leadership skills.
- ◆ Maintained NFXF-hosted group websites
- ◆ Supplied free FX informational materials for group events and activities
- ◆ Conducted numerous direct mail/email announcements for group events and activities on a monthly basis.

Linda Sorensen
Associate Director

Board Development

At the end of 2010, 16 of the 18 possible volunteer Board seats were filled however two of the members (Mark Gruzin and Gail Heyman) were scheduled to leave the board due to term limits. 2010 saw the addition of six new members. Brief statements from each appear below:

JC Planas: I first became aware of Fragile X when my cousin William was diagnosed in 2004. Since then, my family has become extremely active in raising awareness and participating in national events for Fragile X. As a member of the Florida State House of Representatives from 2002-2010 I was able to help secure start up funding for the Fragile X Clinic, which is part of the Fragile X Clinical & Research Consortium, at the Mailman Center for Child Development at the University of Miami. I have participated in three National Advocacy days in Washington D.C. and hope to start state advocacy days here in Florida as well. I am extremely proud to be on the Board and look forward to working to make life better for all families living with Fragile X.

Mark Dissette: My wife, Bonnie, and I are proud parents of four beautiful children...two sons, Jeff & Joey and, two daughters, Jenny & Julie. Our first born son, Jeff, was diagnosed with fragile X syndrome one week prior to his first birthday. The early 1993 diagnosis was a 'lucky stab in the dark'. At that time, little was known about the disorder and we struggled to find Fragile X-specific information, referral, intervention and support for the newly diagnosed. In turn, we sought a comprehensive resource network on Fragile X serving the medical community, affected families and disability groups and ultimately embraced the National Fragile X Foundation -- they turned out to be a vital resource!!! Their collective wisdom, educational resources, support, commitment to research and effective advocacy has been an enormous help to our family and have positively impacted many, many other affected families. I am truly honored to now serve on the NFXF Board and look forward to more actively participating in an organization that is near and dear to my heart. Together, let's find a cure!!!

Deborah Kwan: For over 30 years as a pediatric occupational therapist, I was fortunate to work with many children and families affected by FXS. I also volunteered with the Northern California Fragile X Clinic and Association and the National Fragile Foundation prior to becoming Robby Miller's first regular employee in 2001. After 6 years at the NFXF, I resigned to work with my husband's periodontal practice and Perioscopy Inc., a family dental business. We have two children Lauren and Aaron. I also have a 52 year old brother with Down syndrome.

Dave Justus: My wife, Joy, and I are the lucky parents of two amazing young boys. Our lives were forever changed when Tyler, our youngest son, was diagnosed with fragile X syndrome at eighteen months. Diagnosis day came in early 2010 after an exhausting twelve-month marathon of physician meetings, therapies, tests, diagnosis' and an emotional roller coaster ride because of false negatives. Despite the rough road to diagnosis, we consider it a blessing to have learned about Tyler's condition at an early age, because this has allowed us to capitalize on early intervention therapies.

Since Tyler's diagnosis day, our family has benefited from the overwhelming support, experience and expertise of many parents, professionals, and physicians in the Fragile X community, which was primarily made possible through the existence and effectiveness of the National Fragile X Foundation. A testament to the experience and expertise of the Fragile X community and the effectiveness of the National Fragile X Foundation was made very evident when Joy's dad was diagnosed with FXTAS, a condition he has suffered from throughout his life, within one month of Tyler's diagnosis. This is extraordinary considering no one in our extended families had ever heard of Fragile X or FXTAS before Tyler's diagnosis.

I am extremely honored to be a part of the National Fragile X Foundation board of directors, and look forward to embracing these new responsibilities by working with the Board, Foundation Team, and others that are committed to the cause of changing the world by finding a cure for Fragile X!

My wife and I are parents and advocates first, but both continue to work (Joy is a VP of Sales & Marketing for a human resources services company and I am a CFO for a technology company). We reside in Orange County, California, and are both excited about doing what we can to further the mission of the National Fragile X Foundation.

Jennifer Silverton: I'm thrilled and honored to be a member of the board of directors. My husband and I are the proud parents of two 'tween-age' kids in Grand Blanc, Michigan. Our son has fragile X syndrome while his younger sister does not and is not a carrier. Being a board member has really brought me full-circle as I vividly remember the day I called the Foundation just after our son was diagnosed, looking for answers, direction and an ear. While I still need all of those things, I hope to help provide answers, direction and an ear for other families as a board member. With my background in television reporting, I'm also hoping to assist the Foundation in its efforts to reach all Americans impacted by Fragile X and to helping pave the future with greater awareness, better treatments and, ultimately, a cure for Fragile X.

Theodore Coutilish: My wife, Mary Beth Langan, and I live in Grosse Pointe, Michigan, with our son, Andrew, 10, who is affected by Fragile X syndrome. We were typical parents who said 'Fragile what?' when Andrew was diagnosed at age 21 months in October 2002. Fragile X has become a big part of our lives. Mary Beth has FXPOI and her dad, Jack Langan, has FXTAS. Mary Beth is active in the Fragile X Association of Michigan. I have helped both FXAM and NFXF with marketing and communications for a number of years and am happy to now become even more involved as a member of the NFXF board of directors. In addition to my busy schedule as Andrew's dad, I am the Associate Vice President of Marketing at Eastern Michigan University and, along with Mary Beth, a columnist of 'X-tra Special Advice' in The Grosse Pointe News for parents of children with special needs.

Public Policy

In 2010, the NFXF continued to implement its public policy and federal affairs strategic plan. The Foundation's 7th annual Advocacy Conference convened in Washington D.C. in March. Advocates from nearly every state participated in our 2010 federal advocacy activities by traveling to Washington for Advocacy Day, meeting with their members of Congress in their home states, and/or supporting the effort through phone calls, letters and emails.

Our advocacy efforts were once again a resounding success resulting in a renewal and small increase in funding for the FX public health program at the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) to nearly 2 Million dollars yearly. Through this CDC program, in 2010 the NCBDDD again provided direct funding to support the NFXF organized, Fragile X Clinical and Research Consortium (FXCRC). Congress also directed federal health agencies to work with this expanding group which in 2010 expanded to over 20 sites throughout the U.S. and Canada. Congress again approved unequivocal directive language to eight institutes at the National Institutes of Health (NIH) to expand research and programming (approximately \$32M in 2010) related to all Fragile X associated Disorders (FXD). In 2010 the NIH continued to implement its FX roadmap of coordinated research strategies for Fragile X. This comprehensive plan was established by a Congressional directive after urging from NFXF advocates.

Additionally in 2010 and at the urging of NFXF Advocates, for the first time Congress included Fragile X Syndrome within a select group of conditions eligible for research funding from the U.S. Department of Defense. The program designates \$50 million through the FY 2010 Department of Defense Appropriations Act for the Peer Reviewed Medical Research Program (PRMRP). New FX research approved under this program will likely exceed \$3 Million in this first year of funding.

These were no small accomplishments considering the federal government's record budget deficits, a change in the majority party in the House in the 2010 mid-term elections, dramatic proposed cuts in social and health related programs, and the military actions underway in Iraq and Afghanistan. Nonetheless, NFXF Advocates convinced Congress that Fragile X, and the community of individuals impacted by it, are deserving of increased federal funding for research and programming. Our Congressional champions in 2010 were Gregg Harper (R-MS), William Delahunt (D-MA) and Phil Hare (D-IL) in the House of Representatives. Rep. Harper was reelected to a second term, Rep. Delahunt retired at the end of 2010 and Rep. Hare lost his bid for reelection. Rep. Eliot Engle (D-NY) has agreed to serve as our champion in the 112th Congress which begins in 2011. Senator Johnny Isakson (R-GA) and Debbie Stabenow (D-MI) continued to serve as our champions in the Senate. Senators Tom Harkin (D-IA), Thad Cochran (R-MS) and Representatives David Obey (D-WI) and James Walsh (R-NY) likewise supported FX in the appropriations process. The **House Fragile X Caucus** remained active in 2010 and oversaw the ever expanding FX agenda in Congress.

Yet another notable public policy success in 2010 was the tangible work product produced by grant recipients of the Fragile X public health program at the CDC. Within just six short years the NFXF developed and implemented its plan to create this public health program, secured Congressional appropriations to fund the program, and by 2010 grant recipients of this program were producing tangible results of benefit to individuals and families impacted by FX. The NFXF and numerous members of our SCAC have been beneficiaries of this funding. In the first six years that the CDC program has been funded, over Nine (9) Million Dollars in new federal funds have been allocated to FX research, awareness and educational efforts. Over this same period of time, and as a direct result of the efforts of NFXF advocates, the NIH nearly doubled its funding of FX research to nearly \$32 Million in 2010. As a result of this funding new targeted drug therapies for FX continued to progress through Phase 1 and Phase 2 Clinical Trials with positive results. If these results continue these new drugs may come to market within the next few years. This represents a substantial return on the Foundation's investment in public policy and advocacy activities.

This outcome, across the short timeline from concept, to implementation, to funding, to results, is a true testament to the dedication of our corps of grassroots advocates from all 50 states. This outcome also demonstrates that the Foundation's investment of time and resources into public policy and advocacy activities represent one of the most effective ways to leverage our limited budget to produce much greater investments in FX research, awareness and education by our federal government.

Lastly, the NFXF continued to actively participate as a founding member of The Collaboration to Promote Self-Determination (CPSD), a Washington DC based collaboration of national disability organizations dedicated to revolutionizing the laws and regulations that govern the lives of all adults with intellectual disabilities. In 2010 CPSD enjoyed another productive year of legislative progress in the federal public policy arena. CPSD continued to lead the dialogue on the development of innovative public policy reforms aimed at promoting employment first policies, effective educational and transition programs, meaningful asset development and economic advancement strategies, and highly-customized long-term supports and services for people with intellectual and developmental disabilities. Through the advancement of key legislative initiatives and the implementation of specific regulatory changes, the CPSD has articulated a pathway for true systemic change at all levels of government, which will eventually lead to a system that is focused on achieving meaningful post-secondary and educational opportunities in integrated settings for all adults living with intellectual and developmental disabilities.

The NFXF remains committed to supporting all of these important public policy efforts. We will continue to lead, actively participate, and work closely with the FX community, the disability community at large and with federal health agencies and Congress to assure that the voices of the community we serve are heard. It is only because of the financial support of our donors, members and friends that this comprehensive effort is possible.

Jeffrey Cohen

Chair, Public Policy Committee

Fundraising

Support from the Foundation's donors once again enabled us to achieve another strong fundraising year in 2010. With over 4,635 contributions from individuals, foundations and corporations, the NFXF was raised over \$1,281,000. Individuals and LINKS 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 Combined Federal Campaigns. Corporate Partners supported the Foundation with donations and in-kind gifts. Thank you to our many supporters - we couldn't do it without you!

FUNDRAISING EVENTS

We recognize the following Fundraising Partners for organizing events which generated \$1,000 or more in 2010.

- ◆ **Raising Green in the Desert – Scottsdale, AZ, February 22, 2010**
Joan and Jay Canel and Judy and Irv Gross
- ◆ **BMW Skyline Run to benefit the NFXF – Washington, DC, March 10, 2010**
Brian Hairston
- ◆ **Walk for Fragile X – Canton, IL, April 17, 2010**
Holly Roos, Andrea Schnarr, Scott Roos, Karen Hanlin, Tiffany Williams, Kristy and Paul Englert, Kim Lyons, Betty Cooper,Carolynn Schnarr, Jodi Wilcoxon, Lori Driscoll, Ashley Shoop
- ◆ **Fundraiser at Touch iBar – Chicago, IL, May 1st, 2010**
Traci Baez
- ◆ **“Fragile not Broken Fun Run/Walk for Knowledge” – Fenton, MO, May 8, 2010**
Diane Southard, Kim Eyermann, Linda Kuhn, Debbie Meis, John and Cindy Love, Maryanne Schnettgoecke, and Julie Warnecke.
- ◆ **Chicago Virtual Event – Chicago, IL, May, 2010**
Lynda and Scott Canel, Cheryl and Carey Cooper, and Rebecca and Ira Fishman
- ◆ **Elephant Rock Ride – Castle Rock, CO, June 6, 2010**
Ben Hinnen
- ◆ **Walk for Fragile X – Bernville, PA, June 19, 2010**
Jennifer and Luke Mathias
- ◆ **Biggest Loser Bootcamp – Prescott Valley, AZ, July 17, 2010**
Anytime Fitness (Amy Champ/Leanne Shearer)
- ◆ **Steelhead Ironman – St. Joseph, MI, July 31, 2010**
Jodi Feinstein
- ◆ **Cruise-In for Fragile X – Martinsburg, PA, August, 15, 2010**
Stacey and Mike Kopco
- ◆ **Lizzie's 6th Annual Open House – Geneva, IL, September 25, 2010**
Nancy Reilly and “Team Lizzie”
- ◆ **Fragile X-Treme Bull Blow – Out – Oak Grove, MO, October 2, 2010**
Rick Lunceford

- ◆ **“Fragile X-Pedition” – Olathe, KS, October 2, 2010**
Fragile X LINKS Group of Kansas City (Western Missouri)
- ◆ **Hat Party for Fragile X – Lafayette, CA, October 2, 2010**
Deborah Kwan and Stephanie Jacob
- ◆ **Chicago Marathon – Chicago, IL, October 10, 2010**
Katie Gerdes
- ◆ **Mouse Races for Fragile X – Missouri, October 16, 2010**
Dawn and Rich Erker, Margaret Israel, Mary Anne Schnettgoecke
- ◆ **Coupon Book Sales – Wisconsin, October 23 and November 6, 2010**
Rose Jahnke, Katherine Roeders, and the Fragile X LINKS Group of Wisconsin
- ◆ **Cocktail Reception to benefit Fragile X – Houston, Texas, October 28, 2010**
Brad Whitus
- ◆ **BBQ Fundraiser at CJ’s Saloon – Pleasant Hill, CA, November 6th, 2010**
Dodee Baldwin

ANNUAL FUND

This November-February campaign continues to comprise a significant portion of our budget. This year, gifts from nearly 700 donors generated over \$200,000 for the 2010 Annual Fund drive.

NATIONAL FRAGILE X AWARENESS DAY CAMPAIGN

The 8th annual National Fragile X Awareness Day saw its first email campaign in 2010. The message “Awareness Connects...” helped the campaign reach over \$15,000 on the strength of 93 gifts.

THE PROMISE CUBE RESEARCH CAMPAIGN

Research funding efforts continued in 2010 with the Promise Cube campaign. Promise Makers made good on their promise to support research funding and the Foundation, donating approximately \$3,500 in 2010.

COMBINED FEDERAL CAMPAIGN

The Foundation continued its membership with the Children’s Medical Charities of America in 2010, allowing federal employees to designate the NFXF as a recipient of monthly payroll pledges. The Children’s Charities of America campaign resulted in over \$8,500 in donations for the NFXF in 2010.

TRUSTEES

As always, Trustees provided the Foundation a great base of support through their personal contributions. 2010 acquisition efforts included a spring mailer followed by conference

recruitment. The year closed with 60 Trustees who contributed a combined \$86,000. The Foundation looks forward to further expanding the Trustees Circle in 2011, and remains thankful for the sustained support of these long-term supporters. (A full list of Trustees and other Major Donors can be found on pages 14-15.)

FOUNDATIONS & CORPORATIONS

Corporations and foundations were major supporters of the NFXF again this year. The Corporate Advisory Council, which offers industry leaders the opportunity to partner with the NFXF in the search for better treatments and a cure for Fragile X, continued to grow in 2010. Below is a listing of the Corporate Advisory Council, other Corporate Sponsors, and Foundations that supported the NFXF with gifts of \$1,000 or more in 2010.

Corporate Advisory Council 2010 Members

Abbott Molecular, Inc.
Genzyme Genetics
Hoffman-La Roche, Inc.
Afraxis

Asuragen
Celera
Seaside Therapeutics

2010 Corporate Donors

Action Electric Sales, Inc.
Best Buy
Brown Shoe Famous Footwear
Canel, King & Jones
Endurance Matching Gifts Program
Farnam Street Financial, Inc.
Field Holdings, Inc.
Fox's Pizza Den
Goldman, Sachs & Co.

Jewel A Supervalu Co.
Montanari Financial Partners, LLC
Northern Trust Company
Patzik, Frank & Samotny Partners Ltd.
SBA Network Services, Inc.
Spruce Private Investors, LLC
Wachovia Foundation Matching Gifts
Wal-Mart Foundation
William DeWoskin & Associates

2010 Family and Community Foundations

Betsy and James Feld Philanthropic Fund
Bill Bass Foundation
The Confidence Foundation
Duhr Family Foundation
Fieldman Sims Foundation
The Fine Foundation
The Gutman Family Foundation Trust
The Hattem Family Fund

Howard and Roberta Goss Charitable Foundation
Parsifal Foundation
Sacks Family Foundation
Melvin and Cindy Schwartz Philanthropic Fund
The Waterfield Foundation
Elizabeth and Jeffrey Wellek Philanthropic Fund
Wittenberg Family Foundation
The Zeldis Family Charitable Fund

LINKS Groups

In addition to those groups who helped by organizing fundraising events on our behalf, several of our affiliated LINKS Groups designated the NFXF to be recipients of their discretionary funds and/or funded conference registration scholarships in 2010. They were:

Central Illinois FX Resource Group	Fragile X Resource Center of Western Massachusetts
Denver Fragile X LINKS Group	Fragile X LINKS Group of Kansas City
Florida Families FX Foundation	Fragile X LINKS Group of Wisconsin
Fragile X Alliance of Ohio	Kansas Fragile X LINKS Network
Fragile X Association of Georgia	North Carolina Fragile X Resource Center
Fragile X Association of Michigan	Texas Fragile X Association
Fragile X Association of Southern California	Virginia FX Resource Group
Fragile X Resource Center of Missouri	

In-Kind Contributions

The donation of time and service by the NFXF Board of Directors cannot be measured in dollars, and represents thousands of hours of hard work by dedicated parents and professionals serving as volunteers. The NFXF could not exist without them. Webmaster Bill Patterson of WrightWay Management, copy writer and editor Andrew Hidas of Bridge Communications, Karen Ashton of Karen Ashton Graphic Design and Serena Lowe of AnereS Strategies all continued to provide discounts on their work on behalf of the NFXF.

Trustees Circle 2010

Pam & Don Bailey PhD	Marla & Mark Gruzin
Dean & Elizabeth Berry-Kravis MD, PhD	Randi Hagerman & Paul Hagerman MD, PhD
Al & Melissa Blount	John Harrigan & Stephanie Jacob
Marcia Braden & Ken Wood	Gail & Stephen Harris-Schmidt PhD
Joan & Jay Canel	Melanie & Kevin Heineman
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Joseph Christoff & Katherine Frey-Christoff	Richard & Anita Inz
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Debra Skinner
Diane & Gifford Smith
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Carolyn & John Tomberlin
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Sherri & Brad Whitus

Other Major Donors (>= \$1000)

David and Miriam Ackerman
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Alec and Sheila Engelstein
Lynn and Alan Fishman
Sherri and Brad Fishman
Rita Furst-Seifert and Alan Seifert
Irwin and Judy Gross
Bonzetta and Darryl Hairston
Ann Harris
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Helen Henrichs
Susan Hoff
Mitchell and Christy Hollin
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Jim and Gloria Mack
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Pamela Marks-Pappas
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Elaine Morrison
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James Petersilia
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Edgar and Judy Rainin
Sydney Rainin-Smith
Ron and Suzie Raskin
Beverly and Ed Robbins
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Kurt Schmidt
Kathy and Allan Schneider
Caryn and Bill Schuman
Brian and Shari Silver
Jessica Simon
Perry and Elaine Snyderman
Lori and Bill Spangenberg
Jim and Stephanie Spillane
Alan and Eva Unikel
Debra and George White
Dennis Wiczorek and Marla Weiner
Shorta Yuasa and Lisa Sevigny

Named Funds

Christoff Research Fund

The Cube Fund for Research

Edward Behrman Memorial Fund

Gerald McCabe Memorial Family Support Fund

Harris Hollin Conquer Fragile X Fund

Jennifer & Kimball Silverton Fund for Research

Marlyn Weingarden Family Support Fund

National Fragile X Foundation Fund

Norbert Jacob Education Fund

Richard Kurtz MD Memorial Research Fund

William & Enid Rosen Research Fund

The Strategic Goals of The National Fragile X Foundation - 2010

- I. Support and Education, Awareness
- II. Advocacy
- III. Research
- IV. Development
- V. Governance & Administration

I. Support, Education and Awareness

Goal: Provide enhanced and expanded emotional, informational, referral and educational support to families affected by Fragile X-associated Disorders throughout the lifespan.

Objectives:

- ❖ Enable national connectivity via social networking
- ❖ Work with strategic federal, corporate, and not-for-profit partners to expand resources available to the NFXF for developing and distributing a variety of informational resources & materials to individuals impacted by one or more of the Fragile X-associated Disorders, including caregivers, professionals, and the general public.
- ❖ Better utilize existing resource groups and build family support component of Fragile X Clinical & Research Consortium (FXCRC) sites.
 - ❖ Implement an open & transparent process for determining the future direction of the NFXF with respect to establishing a more formal relationship with the Fragile X Parent Resource Groups.
- ❖ Provide comprehensive information for all lifespan stages of Fragile X-associated Disorders.

Goal: Achieve national recognition of Fragile X-associated Disorders

Objectives:

- ❖ Establish a systematic approach in reaching all stakeholders through sophisticated messaging with multiple touch points.
- ❖ Developing and executing a comprehensive communications plan for the NFXF is the first-step toward achieving this objective.
- ❖ Promote the critical importance of translational research.
- ❖ Establish the Foundation as the pre-eminent organization providing information, research funding, support and services related to Fragile X-associated Disorders.
- ❖ Elevate global consciousness around Fragile X-associated Disorders within the confines of limited existing resources/funds.

II. Advocacy

Goal: Advocate and secure increased federal support of critical policies, research, programs, services and activities directly related to improving the lives of individuals impacted by Fragile X-associated Disorders.

Objectives:

- ❖ Ensure full funding and implementation of the NIH Blueprint on Fragile X- associated Disorders.
- ❖ Identify translational research opportunities where the NFXF can play an active role.
- ❖ Secure an increase in the direct funding of the FXCRC commensurate/ proportional with other similar disorders.
 - Approximately \$15 million/year by 2015.
- ❖ Significantly expand the CDC Fragile X Public Health Program.
 - \$10 million/annually by 2015.
- ❖ Determine future advocacy strategy with regards to the Single Gene Resource Network (and the NFXF's role in the continuation of the program).
- ❖ Secure Fragile X as an eligible area for biomedical research funding at the U.S. Department of Defense.
- ❖ Assess other opportunities for federal funding that directly supports key components of the NFXF's mission.
- ❖ Continue to advocate for high-impact public policy reform focused on improving the lives of adults with intellectual disabilities.
- ❖ Continue NFXF leadership role in the Collaboration to Promote Self-Determination.
- ❖ Secure passage of the Achieving a Better Life Experience (ABLE) Act.
- ❖ Develop infrastructure to support state-based pilot advocacy program.

III. Research

Goal: Lead efforts to promote and support the translation of current science into effective treatments and practices.

Objectives:

- ❖ Lead efforts to promote & support translational research.
- ❖ Scientific and Clinical Advisory Committee will conduct an internal review of its procedures.
- ❖ Establish and maintain a minimum annual budget for research.
- ❖ Fund Translational Research.
- ❖ Leverage dollars in partnership with other entities.

IV. Development

Goals:

- ❖ Provide sustainable and predictable income with a diverse and balanced portfolio.
- ❖ Implement a strategic development plan focused on four primary revenue streams:
 - Grants
 - Events/Special Projects
 - Corporate Partners
 - Personal Giving/Campaigns
- ❖ Create human resource plan to achieve development goals.
- ❖ Engage the Board of Directors to play a significant role in development.

Objectives:

- Grants
 - Secure new funding through private foundations and government grants.

- Increase level of giving from existing private foundations contributing to NFXF.
- Identify foundations that formerly contributed and solicit renewed support.
- Create stewardship program to fully immerse all grant providers in NFXF.
- Expand scope and increase funding of current CDC and NIH grants.
- Special Projects/Events
 - Support and encourage individuals and resource groups with successful fundraising events.
 - Create one new national fundraiser.
 - Support the creation of at least four major development activities annually.
 - Target every event as outreach opportunities to cultivate new permanent donors.
- Develop Corporate Giving Programs
 - Establish Corporate Advisory Council (CAC).
 - Increase Corporate sponsorship opportunities at International Conference.
 - Develop Corporate support for FXCRC.
 - Launch “Access to New Technology Initiative”.
- Increase Personal Giving
 - Significantly enhance the recordkeeping capabilities through expanded training and maximized use of DonorPerfect.
 - Reduce attrition rate of general membership by 50%.
 - Create two new annual campaigns around advocacy and support/education.
 - Increase number of “major donors “.
 - Grow Trustees Circle.
 - Create targeted “FXTAS” campaign for grandparents.

V. Governance & Administration

Goals & Objectives:

- ❖ Implement a leadership plan that will substantially increase the Foundation’s stature, influence, programs and financial resources.
 - Prepare a two year plan to implement a new leadership structure
- ❖ Grow and continue to develop the leadership, staff and infrastructure to achieve the strategic goals and perform all aspects of the mission statement.
 - Develop an organizational chart and job descriptions to coincide with leadership plan
 - Prepare transition plan for existing staff as duties and roles change to accommodate new organizational structure
- ❖ Transition the Board of Directors from active participation in day-to-day operations to one of strategic planning and development.
 - Board recruitment becomes the top priority of governance committee
 - Implement a program of goal setting, self assessment and review of all board members
 - Aggressively pursue new board members with focused and targeted outreach methods

Board of Directors – 2010

The following individuals served as volunteer directors for all or part of the year

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Michael Kelley
Maryland

Vice President

Brad Whitus
Texas

Secretary

Joey Christoff
Indiana

Treasurer

Marty Lang
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Past President

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Directors

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Arlene Cohen
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Georgia

Margaret Israel
Missouri

Deborah Kwan
California

JC Planas
Florida

Katherine Roeders
Wisconsin

Jennifer Silverton
Michigan

Scientific and Clinical Advisory Committee – 2010

Len Abbeduto Ph.D., Co-Chair
University of Wisconsin, Madison,
Wisconsin, USA

W. Ted Brown, M.D., Ph.D., Co-Chair
Institute for Basic Research, Staten Island,
New York, USA

Gary Bassell, Ph.D.
Emory University, Atlanta, Georgia, USA

Elizabeth Berry-Kravis, M.D., Ph.D.
RUSH University Medical Center,
Chicago, Illinois, USA

Marcia Braden, Ph.D.
Private Psychologist,
Colorado Springs, Colorado, USA

Jonathan Cohen, M.D.
Centre for Developmental Disability, Melbourne,
Australia

Kim Cornish, Ph.D.
Monash University, Melbourne, Australia

Brenda Finucane, M.S.
Elwyn Training and Research Institute
Elwyn, Pennsylvania, USA

Paul Hagerman, M.D., Ph.D.
University of California School of Medicine Davis,
California, USA

Randi J. Hagerman, M.D.
The M.I.N.D. Institute, University of California Davis,
California, USA

Gail Harris-Schmidt, Ph.D.
San Xavier University, Chicago, Illinois USA

David Hessl, Ph.D.
UC Davis M.I.N.D. Institute
Sacramento, California USA

Andrew Hoogeveen, Ph.D.
Erasmus Medical Center
Rotterdam, Netherlands

Vanessa Johnson, PhD, MS, RN-BC
University of Oklahoma
Tulsa, Oklahoma, USA

Walter Kaufmann, M.D.
Kennedy Krieger Institute,
Baltimore, Maryland USA

Frank Kooy, Ph.D.
University of Antwerp
Antwerp, Belgium

Andrew Levitas, M.D.
University of Medicine and Dentistry
Stratford, New Jersey, USA

Allyn McConkie-Rosell, Ph.D. CGC
Duke University Children's Hospital
Durham, North Carolina, USA

David Nelson, Ph.D.
Baylor College of Medicine
Houston, Texas, USA

Christopher Pearson, Ph.D.
The Hospital for Sick Children
Toronto, Canada

Feliciano Ramos, M.D.
University of Zaragoza
Zaragoza, Spain

Stephanie Sherman, Ph.D.
Emory University School of Medicine
Atlanta, Georgia, USA

Gail Spiridigliozzi, Ph.D.
Duke University Medical Center
Durham, North Carolina, USA

Vicki Sudhalter, Ph.D.
Institute for Basic Research, Staten Island
New York, USA

Jeremy Turk, M.D.
St. George's Hospital Medical School
London, England

Karen Usdin Ph.D.
National Institutes of Health
Bethesda, Maryland, USA

Stephen Warren, Ph.D.
Emory University School of Medicine
Atlanta, Georgia, USA

Staff - 2010

Liane Abrams
Genetic Specialist

Phil Campbell
Administrative & Program Assistant

Annie Daher / Meghan Spillane
Development Coordinator

Jayne Dixon Weber
Support Services Coordinator

Sam Jacob
Assistant Shipping Clerk

Robert Miller
Executive Director

Teddy Palmer
Database Specialist

Josh Prasad
Shipping Clerk

David Salomon
Meeting & Technology Coordinator

Linda Sorensen
Associate Director

The NFXF also wishes to thank its primary contractors and consultants in 2010 for their dedicated efforts on behalf of our mission.

Accounting
Gary Langsdale/Donna Hendren

Editing & Design +
Print & Mail brokering:
Bridge Communications
Andrew Hidas

Web Maintenance:
Wright Way Management
Bill Patterson

LINKS Assistant
Holly Roos

Senior Advisor for Public Policy and
Interim Director for Strategic Partnerships

AnereS Strategies
Serena Lowe

Developmental FX
Occupational and Speech & Language Therapy
Consultation

Sara Scharfenaker and Tracy Stackhouse

Behavioral Consultation
Marcia Braden

FXCRC Grant Coordinator
Karen Fay