



THERE'S
NOTHING
FRAGILE
ABOUT THE
FRAGILE X
FAMILY

*2006
Annual Fund*

Give to the



The National **Fragile X** Foundation

annual fund

Help us help our nuclear families, extended families, and the larger Fragile X family of research scientists, clinicians, and NFXF staff, as we join together in the common cause of developing treatments and an ultimate cure for Fragile X.

- **Fragile X Syndrome**
- **Fragile X-Associated Tremor Ataxia Syndrome**
- **Fragile X-Associated Premature Ovarian Failure**

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Holly Roos Parent

"It was one of those calls you never forget"

"When my children Parker and Allison were tested and diagnosed with fragile X syndrome in 2003, my husband Scott and I set out to discover as much as possible about the condition. Unfortunately, we'd been given poor, outdated information from a genetics doctor that left us in despair about our children's future. When I called the NFXF, I was put on a speakerphone with Deborah Kwan and Dr. Randi Hagerman. It was one of those calls you never forget. They assured me my kids could have a life, that we would be O.K. Then they followed up a few days later. There were many more phone calls after that. Whenever I needed them, they were there.

They understood.

I cannot over-emphasize how important that was to my family."



David Hessl Assistant Clinical Professor, UC Davis M.I.N.D. Institute

"The NFXF is the glue binding everyone involved with Fragile X."



"Researchers working in academic settings—even when we interact regularly with families who bring children in for testing and diagnosis—can sometimes become isolated from the broader implications of their work. This is just one area where The National Fragile X Foundation has a huge impact.

No other organization I know of does such an effective job

bringing together scientists, clinicians, and families. The efforts of those groups then percolate into an entity greater than the sum of its parts. That makes the 'Fragile X community' not just a mental construct, but a real, living thing—which the NFXF keeps connected and thriving. It's the glue binding everyone involved with Fragile X. Professionally, I see and appreciate the effect it has in funding research, and in keeping scientists quite aware of the impact their work has on families."

Marcia Braden Licensed Psychologist

"It's never lost an ounce of its idealism"

"When I see the good works that the NFXF performs every day, I feel like a proud parent watching a cherished child grow into maturity. I've been involved with the Foundation since its inception. It was so grassroots back then—we were just trying to make sure there was someone to answer the phones. My fear was that it would someday become too big and lose sight of its mission. But that has never happened. The Foundation has never lost an ounce of its idealism. It's always kept its balance and done wonderful outreach to both parents and professionals—all of it with a core commitment to uncover and serve the underlying spirit of every child. I'm so grateful for that.

The NFXF lives, breathes and personifies...

...the very best of what a nonprofit foundation can be."



Teddy Palmer NFXF Database Specialist

"We're like a small family helping its large extended family, every day."



"I knew about Fragile X before I accepted a job at the Foundation in 2002. I was delighted to join a group whose mission was so clearly in helping others. My delight turned to amazement when I fully realized how much the small staff was able to accomplish. Then, when I attended my first International Conference,

I fell in love with the kids, and had the privilege of connecting in person with many parents whom I'd come to know on the phone. In the office, we're like a small family helping its large extended family, every day. In everything we do for that family, we try to connect it back to our mission, which isn't just tucked away in a notebook somewhere. We focus on it, all the time. It has an honored spot on my bulletin board—right next to all the photos of the kids sent to me by parents."

Our 2005 Annual Fund Drive was an important source of income for a huge array of activities that helped the cause of Fragile X in the past year:

- We sponsored and organized the 10th International Fragile X Conference in Atlanta, Georgia, bringing together families, scientists, clinicians and educators in the largest such gathering in the world.
- We funded \$300,000 in basic science and clinical research grants to advance the causes of effective treatment and an eventual cure.
- We released our Adolescents and Adults Project video and manual to help smooth the transition to successful adulthood.
- We sent out more than 1,300 information packets, booklets, brochures, flyers, and other educational pieces to families in need.
- We produced four *Quarterly Journals*, filled with educational and inspirational articles that help connect the Fragile X community.
- We expanded our website to 3,200+ pages, adding more critical information on all Fragile X conditions.
- We answered the phone on our toll-free line more than 4,500 times when families called seeking information and support.
- We organized more than 1,000 advocates to reach out to their representatives in Congress on behalf of Fragile X issues



STRENGTH THROUGH: SUPPORT RESEARCH EDUCATION ADVOCACY AWARENESS

The National Fragile X Foundation (NFXF) was founded in 1984 by a group of concerned parents and professionals dedicated to providing support services for families affected by fragile X syndrome. Scientific discoveries in recent years have compelled us to expand our mission to assist in the related conditions of fragile X-associated premature ovarian failure (POF) and fragile X-associated tremor ataxia syndrome (FXTAS).



The National Fragile X Foundation
P.O. Box 190488
San Francisco, CA 94119

The NFXF is a nonprofit 501(c)(3) charitable organization. All donations are fully tax-deductible in accordance with IRS regulations. Please use the enclosed remittance envelope to help fund the organization's mission of enhancing Awareness, Education, Research, Support and Advocacy for the cause of Fragile X.

Parker and Allison Roos



www.FragileX.org