



NATIONAL FRAGILE X FOUNDATION

Quarterly

A Journal for Families and Professionals

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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,” that have a variety of impacts on affected individuals and their families. The disorders include:

▪ **Fragile X syndrome (FXS)**—Caused by the *full mutation* of the Fragile X gene, FXS is the most common cause of inherited mental impairment.

Its effects range from learning disabilities to severe mental retardation and autism. Symptoms often include unique physical characteristics, behavioral disorders, and delays in speech and language development.

▪ **Fragile X-associated tremor/ataxia syndrome (FXTAS)**—A condition affecting some male (and in rare cases, female) carriers of the *premutation* over age 50, causing balance, tremor and memory problems.

▪ **Fragile X-associated primary ovarian insufficiency (FXPOI, or early menopause)**—A condition affecting some female carriers of the *premutation*. Fragile X can be passed on in a family by individuals with no apparent sign of the condition. In some families, multiple generations are affected, while in others, it may cause problems in only one person.

Since 1984, the National Fragile X Foundation (NFXF) has been helping individuals with Fragile X, their families, and the professionals who work with them. As research into Fragile X continues, our understanding of those it affects and how it affects them will grow. The NFXF is committed to:

- 1) supporting and funding all efforts that will increase awareness,
- 2) improving education,
- 3) advancing research toward improved treatments and an ultimate cure, and
- 4) keeping the Fragile X community always well-informed about the progress of these efforts.

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SERVICES OFFERED:

Telephone consultation and basic informational packet—*free*

Educational resources (books, videotapes, CD)—*fee*

Local, national, and international conference sponsorship

Referral to medical, genetic and support services—*free*

Legislative advocacy

Research grants

Membership with quarterly journal—*fee*

SERVICES OFFERED TO:

Individuals, families, professionals, institutions, and students involved with or impacted by Fragile X

Service Referral: Self or professional

Eligibility: All

Service Area: National and international

Dues-Paying Members: Over 1,100

Phone, Email and Postal Contacts: Approximately 10,000 annually

Unique Website Visitors: Over 600,000 annually

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MISSION STATEMENT

The National Fragile X Foundation unites the Fragile X community to:

- Enrich lives through educational and emotional support
- Promote public and professional awareness
- Advance research toward improved treatments and a cure for Fragile X.



13TH INTERNATIONAL FRAGILE X CONFERENCE

July 25-29, 2012 ✕ Miami, Florida

Intercontinental Hotel

*Gather with other parents, scientists and
clinicians at this premier international conference
devoted to all things Fragile X.*

See pages 18–20 for more conference information.



Scenes from the 12th International Conference in Detroit, 2010.

Online registration is open!

For more information and to register:
conference.fragilex.org





The Long Winding Road to Eureka

How did I wind up here???
Eight short years ago I had never heard of Fragile X, let alone CGG

repeats, carriers, and mGluR theory. As I settle (humbly) into my term as President of the Board of Directors of the National Fragile X Foundation, I find myself spending considerable time thinking of how all of those fit together—not to mention how I got here.



The Whitus girls, Kenney (left) and Christy.

The short answer is simple: Christy and Kenney...the two Daddy's girls in my life affected by Fragile X. But that explains only part of it. As a husband and father, one does whatever one can to contribute to the cause, but there are any number of ways one can support it. I chose the NFXF to make a down payment on a debt I can never repay.

As many of you know, before I learned of FX and CGG repeats, Sherri and I bounced from doctor to doctor, all of them highly educated and with the best of intentions. We were looking for an explanation for Kenney's "quirkiness." As parents, we knew it when we saw it, as did family and friends, but we could not put our finger on why...

- At three months, she wanted to drink her baby bottle while propped on couch pillows rather than while cuddling with Daddy.

- At three years, she could pick out a Judds song on the radio just a few bars in, and later memorize every word, only to sing along a few bars ahead of Wynonna.
- In grade 3, she read at middle school level, and could tell you about the lead character's red shirt in chapter 22—but not the theme of the book.

With every well intentioned-but-missed diagnosis came a similar misplaced intervention. (I shudder to this day looking

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back on those exercises at the dining room table forcing Kenney to maintain eye contact as we talked...I didn't see it then, but I am pretty sure there was smoke coming out of her ears from a little brain revving to 10,000 rpm.) This went on for the better part of 12 years (the searching, though thankfully not the eye contact exercises, which were only a short stop on our journey). We ultimately "settled" on an Asperger's diagnosis for Kenney, and set about accepting her "quirks."

Then along comes her little sister seven years younger, and "the search" begins anew. Unfortunately, while the manifestations were a little different, as were the (mis) diagnoses (Christy's "floppy baby syndrome" diagnosis was a new one to us), the frustration was the same.

After nearly five years of this déjà vu, we finally got our eureka moment. During a routine visit to the pediatrician, Christy's doctor recommended we get some genetic testing. He had recently read about a "rare genetic disorder" that manifested itself similar to Christy's bouncing, hand-flapping, tactile defensive self. I don't even recall him putting a name on it, but something in his reading made him suggest it more as a potential answer rather than just ruling something else out like so many of the tests before.

Fast forward, and the results came back positive: We were dealing with fragile X syndrome. Finally, we had a diagnosis.

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A Corner Has Been Turned

Sometimes there are so many things going on in the Fragile X world that it makes the most sense to write a column that is a hodgepodge of those things. Consider this to be one of those columns.

First, I simply want to state that from where I stand, a corner has been turned. No doubt about it. I recently had the honor of viewing the actual lab bench at the Baylor College of Medicine in Houston, where Dr. David Nelson, working in conjunction with his distant colleagues (Dr. Stephen Warren's team at Emory University School of Medicine in Atlanta and Dr. Ben Oostra's team at Erasmus Medical Center in The Netherlands), along with their respective teams, first discovered the Fragile X gene and its role in fragile X syndrome. That was 1991. Thanks to their groundbreaking work—and the work of so many others who have followed—we know vastly more about Fragile X today than we did in those pioneering days. (Just check out your back issues stash of this journal to get a glimpse of the long and steady procession of research studies and breakthroughs that have ensued over the past 21 years.) And as in so much scientific and technological work, the pace of discovery is only accelerating! Now it is up to those in the business of treatment—supported in every possible way that we can fathom here at the National Fragile X Foundation—to make sure that those discoveries reach everyone impacted by any of the Fragile X-associated Disorders. Twenty-one years from now, I hope to be fondly looking back at several more corners having been turned by the dedicated scientists and clinicians whose work we are privileged to learn from today.

You might have noticed from our cover and other pages in this journal that our **13th International Fragile X Conference** is even closer around the corner than the corners I mentioned above! I'm happy to report that almost 220 abstracts are currently being reviewed by members of our Scientific & Clinical Advisory Committee (professionals), our Support & Education Committee (parents) and the NFXF staff. Abstracts are grouped into three

main categories of “Family Friendly,” “Clinical Practice and/or Research” and “Basic Science.” Keep in mind that many of the Clinical Practice and/or Research presentations are also given in a way that most family members will understand and benefit from. Our keynote speakers in the general sessions are planning to give important, “big picture” talks on the development of new treatments, the future of Fragile X-related research, and the journey from childhood to adulthood for those with fragile X syndrome. And the host organization, Florida Fragile X Families, is planning on welcoming you with open arms to make sure that your visit is both educational and fun. (Not to mention inspiring.)

If you're an NFXF member, I'm sure it is no surprise to you that **clinical trials** of new treatments are ongoing. In addition, more trials will be starting up this year and those trials that began in 2011 may well be reporting results early next year, perhaps even late this year. To help speed this process along, the NFXF provides a variety of free and fee-based services to help clinics that are part of these trials recruit subjects. We apologize if, in conveying information on these recruitment efforts we are clogging up your email in-boxes or home mailboxes. But we're willing to risk your ire in the effort to improve interventions for all those affected in one way or other by Fragile X. By the way, please do take a look, when you have a moment, at the Research>Opportunities for Families>Clinical Trials section of our new website. Lots more information there to consider, and we update it regularly as news about trials reaches us.

As new treatments (pharmaceutical or otherwise) become available, **Fragile X clinics** will be one of the main places to which families will turn for evaluations, recommendations and, if appropriate, prescriptions. That's why the NFXF continues to play a leading role in the development of the Fragile X Clinical & Research Consortium. Now comprised of 25 U.S. clinics and growing, the FXCRC is committed to providing care that is based on the best scientific evidence and the consensus of professionals who regularly provide care. So if you haven't visited your nearest

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The Uniqueness of Females With FXS

Virtually all of my previous columns have addressed in one way or other the behavioral issues of males with fragile X syndrome. That is largely because males experience both greater frequency and severity of symptoms. But females with FXS do present a variety of challenges as well, so this special expanded column will be dedicated to addressing some of them.

Females with FXS show a high frequency of avoidant behavior, mood disorders, attention deficits and learning disabilities. They are significantly more withdrawn and depressed than their typical cohorts. This makes them most vulnerable to social anxiety and avoidance.

One of the most debilitating symptoms associated with FXS in females is extreme shyness. It is not unusual to see these young girls hiding behind their parents, crying when asked to participate in conversation, unable to separate from parents and whispering or even appearing mute in social settings. They seem to need consistent coaxing in order to participate in daily life. Desensitization through repeated exposure may be required in order for them to tolerate group activities.

As these girls grow older, their shyness often translates into significant social anxiety. This anxiety can manifest in a number of problematic behaviors that result from feeble attempts to cope with its effects. For example, it is common for such girls to agree to a social plan and then spend the ensuing days physically ill with stomach distress or headaches because they're terrified of participating and don't know how to get out of the obligation. Parents often find themselves in a position of running interference by making excuses for their daughter or attempting to explain the illness to others. The problem persists as the girl faces further humiliation about why she continues to let others down. Many girls have told me they know when they want to decline an invitation but fear the fallout from saying no.

Solutions to this dilemma include the girl memorizing a set response when she wants to say no. This allows her time to separate from the intensity associated with the expectation. Phrases like "I'll have to check my schedule," "I need to see

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Female peers are often more socially motivated, which can make them less accepting of those with FXS. When these conflicts manifest, girls with FXS tend to lack the confidence to confront their peers or express their feelings of hurt.
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what my family plans are," or a simple "I think I may have a conflict" take the harshness out of saying no and afford the girl more time to think it through.

SELF-INJURY AND BULLIES

Anxiety also manifests in certain aberrant behaviors such as self-injury. Although not as severe as similar behavior seen in males with FXS, girls tend to self-injure in more subtle fashion. For example, what begins as picking a scab can evolve into a persistent picking at her arms or legs, causing scarring and extreme discomfort. The compulsion is so powerful that the

girl is often unable to stop. She then becomes very self-conscious of the behavior and often tries to cover her arms with long sleeves or cover the picked scabs with band-aids.

Girls with FXS also report being bullied or isolated from others in school. Being unable to read social cues or to understand social consequences fuels their alienation and avoidance. Female peers are often more socially motivated, which can make them less accepting of those with FXS. When these conflicts manifest, girls with FXS tend to lack the confidence to confront their peers or express their feelings of hurt. Because they seem to be more sensitive to criticism and have difficulty communicating their feelings, they are perceived as weak and vulnerable. This stance does not bode well for maintaining a position of power and self-sufficiency. The sad result is they can become convenient targets for bullying.

Because many of these behaviors result from neurobiology, **it is often good to consult a physician.** Many girls are helped significantly by SSRIs and other anti-anxiety/depression medications.

Also effective in building social assertion is providing concrete phrases for the girl to assert a position and then videotaping her responding to a specific event or vignette using the phrase she has practiced. Another tool is to watch a favorite movie and pause it to discuss the nonverbal behavior of the characters. This may provide the girl with helpful cues to assist in adjusting her own behavior.

ATTENTION, SPEECH, ACADEMIC STRUGGLES

Girls with FXS also struggle with attention deficits that further complicate their social interaction. Being distracted or forgetting pertinent information from a conversation does not foster social viability.

Perseverative language is often a hallmark of conversation in girls with FXS. As the girl becomes more emotionally scattered, she tends to repeat key phrases or may attempt to emphasize a certain aspect of the conversation over and over. The lack of emotional regulation feeds this tendency and causes the listener to become bored with the conversation while dismissing its merits.

Solutions to this problem may include videotaping conversations in a therapy session, providing the girl an opportunity to watch and hear the repetitious language. Sometimes it helps to use a counter to document the number of times certain phrases are repeated, thus making the intervention more concrete.

Academic difficulties may cause girls with FXS to lack the confidence necessary to succeed in school. Many studies report deficits in attention in a global sense and math in particular. These deficits are common and often pervasive, with a negative effect on school performance. Often, the deficits are not identified or diagnosed until later years, and remediation is thus delayed.

Difficulty with math can also affect the girl's ability to understand the use and value of money. Managing money and being able to budget often pose great challenges to girls with FXS. Parents often report that their daughter spends money on frivolous items and often tries to "buy" friends by spending money on trinkets and other gifts for peers.

Possible solutions: Teach the girl how to track money using a software program like Quicken. Limit credit card use, changing credit cards into debit cards only, and organize spending by using envelopes marked with budget items. Sometimes it is best to cash a paycheck and then divide the cash into categories in separate envelopes to pay the bills in a very concrete way.



EXECUTIVE FUNCTION AND NOVEL SITUATIONS

Lack of executive functioning (the ability to sum up intention, form a plan, and execute it) is another characteristic commonly associated with FXS in girls. Lack of follow-through becomes a concern as completing homework and keeping commitments eludes them. School staff may see the girl with FXS as lazy and unmotivated. Providing visual supports to explain the planning-and-executing process often helps promote completion.

Keeping a digital calendar on a smart phone with alarms set as reminders can be a helpful strategy for girls to remember scheduled events and appointments. Using iPhone applications such as Cozi enables family members to add information and reminders from other devices to keep schedules, grocery lists and assignments current.

Many parents report that their daughters have difficulty with novel or unfamiliar tasks or activities. Fear of risk-taking can cause them to avoid engagement in new activities. Routine is welcomed because it is predictable and reassuring. As a matter of fact, routine can become so addictive that elaborate rituals and compulsive behaviors become enshrined. Preserving sameness is soothing, and the girls tend to perpetuate doing things the same way over and over as a strategy to help them

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remain calm. Obviously, this coping method competes with the human need for variety and new experience, and thus causes its own stress.

Possible solution: Schedule a novel activity that is well supported and then follow it with a routine task or activity. This can help defuse fear and foster motivation to tolerate the novel activity.

Unfortunately, the need to preserve sameness does not manifest as a skill in personal organization. Quite the opposite, actually, as girls with FXS frequently have great difficulty keeping their rooms organized, cars clean, or personal items

stored in an orderly manner. The obvious neurobiological culprits are attention and executive function deficits.

Common sense solution: Providing less is often more. Unfortunately, girls with FXS often love collections and saving mementos such as ticket stubs from football games and concerts. These and other paraphernalia make it more difficult to purge unnecessary clutter. Providing a designated place for articles of clothing, shoes and personal items helps keep things organized. Having a crate in the car for items that may be occasionally needed is also helpful. A daily list

of chores can be posted on a white board as a simple visual reminder of what needs to be done before leaving the house.

CAPITALIZING ON CREATIVITY

Many females affected with FXS are excellent writers who create wonderful stories. One woman explained that she was much more able to express emotion through a fictional character than through her real life experiences. Analogies and abstract literary techniques allow for expression of inspiring imagery and interesting stories. These girls are usually good readers who enjoy fantasy and fictional stories. **Using a journal** to write down their feelings is often a successful therapeutic tool.

Others nurture their creative tendencies through art forms, crafts and home decorating. Younger girls often enjoy paint-by-numbers, word searches and pattern drawing. It appears that the



structure is welcomed, providing them a sense of closure when the task is completed. Here is where the universality of art can hold great riches for girls with FXS. Parents and teachers do well to nurture these impulses whenever possible.

THE RELATIONSHIP CHALLENGE

Relationships pose a significant challenge throughout the life span. Teenage girls can become enamored with pop stars, musicians and actors. They often fantasize romantic relationships and at times even believe they have a secret relationship with a celebrity.

Their issues related to shyness and inability to express feelings complicates relationships. They may gravitate to males who have ulterior motives because the males are attentive and initially offer emotional support. This is likely to result in manipulation and exploitation of the girl with FXS.

Allowing girls to experience the “hard lessons” of life and apply them to relationships can be risky and may even estrange parents from their daughters. Giving advice or limiting access to a male friend only provokes feelings of resentment. (Yes, this may all sound virtually identical to typically developing teenage girls, but girls with FXS are far more vulnerable on any number of fronts, without ready access to typical defenses that can ease their passage through this difficult developmental period.)

The idea of having a boyfriend is very powerful, as it makes a girl feel both “normal” and “special.” This can bring angst to families and often requires specific intervention from a person trained to be impartial. Allowing the girl to talk with a therapist gives her another voice of reason that she may feel is less judgmental.

Some parents insist that the boyfriend attend therapy with the girl in order force discussion about responsible behaviors. Parents have had to limit access to money, credit cards and



Many girls with FXS attend community colleges and some earn degrees from four-year colleges. The girls often accomplish meaningful goals with great pride. I have seen it happen, and they are not isolated events.

checkbooks when they sense manipulation. These challenges—although not entirely unique to girls with FXS—can bring much distress to families.

On the other hand, some girls fear relationships, getting married and having children. They liken their future lives to the one they know well—perhaps riddled with difficulties and disappointments associated with a family member even more affected than they are.

This complex thicket of relationships has no easy solution, which reminds us again that the typical population has its own lifelong relationship challenges!

Strategies for addressing those challenges in girls with FXS may include establishing “dating rules” such as: 1) Never give out your phone number or address until the boy meets your parent(s), 2) Be friends first and then you see how you both feel about deepening the relationship, 3) Never give a boyfriend your checkbook or credit card, and 4) Split expenses when you go out.

Attentive parents can help set a tone for all this by spending time with and taking an active interest in the prospective “boyfriend.” Invite him to dinner, movies and other family activities. This helps ensure the friendship develops on solid and observable footing, not in isolation from broader family relationships, norms and values.

LOST IN SPACE

Girls with FXS usually have difficulty with visual-spatial relationships. This causes them to get lost and struggle with navigating school environments and communities. Driving can pose additional challenges related to parking, finding desired locations, judging space between cars, and remembering rules of the road. However, with good training and monitoring, such girls can learn to drive successfully, which gives them great freedom and access to jobs, social events and their communities. All this creates a positive loop for their building of confidence and self-esteem.

A possible solution for getting lost or forgetting directions is to teach the girl to use a GPS. This works well because the

voice on the device alerts her to the map and offers directions for finding her way. Also, the prevalence of cell phones now allows girls to call a parent when they are lost, which helps reduce anxiety on both ends of the line!

A BRIGHTENING FUTURE

Girls with FXS often show an interest in working at daycare centers, beauty salons, animal shelters or veterinarian offices. Many attend community colleges and some earn degrees from four-year colleges. Academic environments can be stressful, but the girls often power through and accomplish meaningful goals with great pride. I have seen it happen, and they are not isolated events.

The future for girls affected by FXS is bright. They bring much joy to their families and can be very helpful to family members and friends. They often become productive members of their communities and bring understanding to those who are more affected, serving as conduits to their brothers and other relatives who may have more significant needs.

The more we learn about these girls, the more effective our interventions and support structures become in assisting them to live personally fulfilling lives. ■



This column was supported by the work of Katherine Zwink, Having Fragile X Syndrome: A Personal Account, Advances in Mental Health and Intellectual Disabilities 2011.

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“Wat Up?” and Other Steps to Socialization

“Hey!” What do you do or think when someone says this? Hey what? Hey you. Hey yourself.

“Hey” was one of my son’s first words, and what he quickly learned was that whomever he said that to responded—with *something*. Usually it was with a smile and friendly tone to their voice, and you know how quickly our children pick up on that positive feeling.

I was amazed Ian would initiate this. We would be walking down the halls of his pre-school, he would hear

someone walking behind us, and he would turn around and say, “Hey.”

Even with his limited speech he had found a way to communicate.

Where did he get this? I cannot remember a specific instance, but based on how he learns, he must have heard my husband or me say this to someone. And most likely he saw the situation in which it happened, too.

“Hey” soon became “What are you doing?” Again, everyone

he said that to responded, and it was always in a positive way. The usual answer: “What are *you* doing?”

When Ian was young, I put heavy focus on his speech. I realized that the best way for him to learn to communicate, and to communicate appropriately, was by watching and listening to other people. I know speech is a challenge for many children, but it is always beneficial to look for ways to help your child communicate. It will help you both.

Ian was in an inclusive pre-school (children with and without disabilities together), and I pushed for inclusion in kindergarten. His speech blossomed. In first grade, I agreed to some pullout, but I was rapidly learning the value of Ian being exposed to the behavior and speech of typical children. He was listening and watching them. He was not up to their level, but I

knew it was being processed in his little head.

Through elementary school Ian was based in a regular education classroom, but he was pulled more for reading and math and when he needed a break. However, at every IEP meeting we emphasized the importance of Ian being exposed to typical children’s behavior.

I also took opportunities to help other children help Ian. He was playing at a neighbor’s house one afternoon when one of the children came over to say Ian was having a hard time. I went over there and all I heard from the children was what they didn’t want Ian to do. I responded, “Well, tell him what you *do* want him to do.” They looked at each other and said, “Oh, okay.” I chuckled and walked away.

It really paid off. Ian was invited to a lot of parties of typical children. While he didn’t socialize at their level, they met him at his level and were always trying to bring him into their activities. It was great to see so many children reach out to him.

At home we continued to do family activities as Ian would tolerate. We thought it important to expose him to as many typical events as possible. But we modified how we did things. Often the first time we went some place, we only stayed for a short time. As Ian became comfortable in situations and knew what to expect, his anxiety decreased and we were able to stay longer. We always had to be aware of transitions, though (see my article on that in the previous *Quarterly*, issue 43).

In middle school, I agreed to have Ian based in a life skills classroom on the condition that he would continue to be included in typical classes throughout the day. He was included in typical classes for about half of the day, a schedule that continued through high school.

It was around this time that I taught Ian what a “joke” is and how to joke with other people. He caught on quickly and it has become an important part of who he is now.

But while he was included in typical classes, the academic gap continued to widen. What I observed as Ian got older was that he came up with “pat” sayings to the typical children. “Wat up.” “Fairview Knights baby.” (His high school.) “Go

Broncos.” (Or Rockies or Avalanche or Nuggets—we live in Colorado.) The other children were fine with this and would often say, “Oh yeah, baby.”

In order to enhance Ian’s exposure to social situations throughout high school, I encouraged him to become the manager for the freshman football team and the school wrestling team. He also ran track. These were all great groups of people who went out of their way to accommodate him.

As Ian learned to tolerate more variance in social situations, we took him to most of our typical daughter’s sporting events—soccer and basketball. Once the other players and their parents got to know him, they would include him in their conversations. Ian also had plenty of opportunities to observe other adult conversations going on around him.

Ian works at our local grocery store; he recently celebrated his five-year anniversary. (He got a watch.) His co-workers really seem to like him; he jokes with everyone. I have had several friends come up to me to comment how socially appropriate Ian’s behavior is at work. He greets people, talks with them, and says “thank you” and “good-bye” when they leave. This is notable in that his speech can be difficult to understand. He has some “different” mannerisms: he doesn’t flap his arms, but he does shake them.

One thing we do on a regular basis is practice what Ian is going to say in certain situations. The uniform at work is a blue shirt, but he sometimes wants to wear a red shirt, say for Valentine’s Day. For this, he needs permission from Alana, his manager. He will then ask me what he should say. I ask him what he thinks he should say. He says, “Can I wear a red shirt

on Valentine’s Day?” I’ll say, “That’s right!” He will practice it a couple of times before he goes to work and then he goes and asks Alana independently.

I have also heard Ian practicing his speech up in his room. If we are going out as a family to see some friends, I often hear Ian practicing saying “hi” to them.

This didn’t happen overnight. Let’s take the red shirt as an example. The first time he wanted to wear a different shirt for a holiday, I went in to ask the manager. Next time I had Ian tell me what he wanted me to say, and I would say that. Next time I would say what Ian wanted me to say, but leave off the last word or two for Ian to fill in. Then I would go with Ian and say, “Ian has something to ask you.” Now he is pretty independent if he has a chance to practice what to say.

I want to encourage you to keep exposing your child to social situations, as difficult as they sometimes can be. I know the school situations will vary, but just be on the lookout for every opportunity to involve your child in the wider world. Emphasize “please” and “thank you”—they really are magic words! (Thank you, Barney.) Practice shaking hands. Teach your child what a joke is and how to joke with others. Have conversations with your child and practice turn-taking and staying on topic. And the easiest way to do all this is to model it yourself. Your child is watching and listening. ■

The author is the support services coordinator for the NFXF. Send your questions to her at: treatment@fragilex.org

A Fond Farewell to Meghan...



By the time you read this, Meghan McMurray, recent NFXF development coordinator, will have begun her international venture of living abroad with her husband Luke in Hong Kong. Luke received a great offer from his company to take on a position there, and like many young couples who are not tied down to a house or kids, he and Meghan felt this was one of those once-in-a-lifetime opportunities they shouldn’t pass up.

As excited as she was about her new adventure, Meghan expressed regrets about having to leave behind her job at the foundation. “I can’t put into words how lucky I was to work here—I feel sad even thinking about someone else taking ‘my’ job!” she told the development committee when she announced her departure. “I have learned so much, and my experience here has solidified my desire to continue on with a career in development.”

Everyone at the NFXF who has worked with Meghan—team members, development committee members and the board of directors—is, of course, thrilled for her while at the same time quite sad about losing a valued team player. Meghan has contributed a great deal to the foundation during her tenure, and her support, dedication, and enthusiasm will be sorely missed. We wish her all the best and much success in her future endeavors. ■



12 Questions About the FMR1 Gene

1. *What is a gene?*

A gene is a unit of heredity that is passed down from parent to child. Genes are located on chromosomes that are found in all of our cells, including the sperm and egg that make a baby.

2. *What is a gene made of?*

Genes are made of molecules or chemicals called DNA. The pattern of DNA will determine if the gene is working properly. For that, the DNA has to be in a certain pattern or order, like the numbers in a phone number.

3. *What do genes do?*

The job of a gene is to either make a protein, the building blocks of all the structures in the body, or to regulate other proteins in the body.

4. *How do genes work?*

A gene has different parts that work together like a factory or machine. It has a “promoter” that turns the gene on, like a light switch. It has sections that serve as “filler,” or a kind of place holder, called “introns.” The sections that are used to make a protein or do a job are called “exons.”

5. *How does a gene make proteins?*

The DNA in the gene is a code that is “transcribed” or “talks” to another kind of molecule called RNA. This is like one side of Velcro sticking to another that it matches up to. The RNA then “translates” the DNA to put together the protein.

6. *What is the gene that causes Fragile X called?*

Genes are named when they are discovered. Often the name isn’t exactly the same as the condition, in case it is later discovered that there is more than one gene involved in the condition. The gene that causes Fragile X is called “FMR1,” which stands for “fragile X mental retardation.” Though the

more accepted term is “intellectual disability,” the name of the gene is established in science and won’t change with the times.

7. *Where is the FMR1 gene located?*

The FMR1 gene is located on the X chromosome. We all have 46 chromosomes in every one of our cells, 44 of which are numbered 1-22 in pairs. Females have two X chromosomes and males have one X and one Y. Each chromosome has two arms, one called the “p” arm (the short arm) and one called the “q” arm (the long arm).

On each chromosome there are many genes, like houses on a street. Each gene is given an address, depending on where it lies on the chromosome. The address of the FMR1 gene is Xq27.3.

8. *What does the FMR1 gene do?*

The FMR1 gene makes a very important protein called FMRP (fragile X mental retardation protein). Though this protein is found in all our cells, it is most abundant in the nerve cells, and particularly in a part of the nerve cell that “talks” to other nerve cells. This part is called a “dendrite.”

9. *Does everyone have an FMR1 gene?*

Yes. When you hear someone state, “I have the gene for Fragile X,” they really mean they have a gene *mutation* for Fragile X. In most people, the Fragile X gene is “typical,” but in people who have, or are carriers for fragile X syndrome, it is not.

10. *What is an FMR1 gene mutation?*

A mutation is any change in a gene. Some mutations don’t cause any problems and we don’t even know about them (unless found in the laboratory). Mutations in the FMR1 gene involve an expansion of the DNA in the “promoter” area of the gene. When a mutation occurs in a gene, it can produce too little or no protein. In individuals with a “full mutation,” their FMR1 gene is shut down and they don’t make enough or any FMRP.

■ NFXF-Sponsored WILLIAM & ENID ROSEN SUMMER STUDENT FELLOWSHIP REPORT

ANNIE PALLY • UNIVERSITY OF HOUSTON

PROJECT: Regulation of the Central Cholesterol Pathway in an Animal Model of Autism

MENTORS: Dr. Gunter P. Eckert and Dr. MariVi Tejada-Simon



With the support of the NFXF William & Enid Rosen Summer Student Fellowship, I participated in a research project investigating the role of the cholesterol pathway in fragile X syndrome. FXS most notably results from the absence of FMRP, a protein essential in particular regulatory activities of

the neuron. Specifically, the study—conducted in the lab of Dr. Gunter Eckert at the University of Frankfurt, Germany—sought to clarify the role of certain cholesterol pathway intermediaries that may lead to the hyperactivation involved in events associated with the onset of FXS.

For me, the experience facilitated a fusion of both scientific and cultural exchange, creating an unforgettable

research experience that I will cherish forever. The opportunity to conduct research abroad allowed me to observe and use techniques specifically developed and specialized outside of the U.S., and to gain a fundamental, holistic understanding and appreciation for collaborative research at an international level. Research in FXS stimulated my interest in the study and practice of pediatric medicine—specifically the clinical correlate of pediatric neurodevelopmental disorders. Experiences and exposure within the research field bring a deeper understanding of the underlying mechanism and dynamic of disorders such as FXS, and encourages the scientific community to constantly question and actively seek to generate unique, unconventional potential solutions.

I would like to thank both Dr. Tejada-Simon at the University of Houston College of Pharmacy and Dr. Eckert at the University of Frankfurt for their invaluable support and encouragement throughout this project and for their roles as my research mentors and advisors.

Thank you, NFXF! ■

11. Are there different kinds of FMR1 mutations?

Yes. An individual can have a normal FMR1 gene, a “premutation” or a “full mutation.” There is also “intermediate” category which is not a full mutation, but an expansion somewhere between the normal FMR1 gene and the premutation.

12. What is the difference between the various mutations?

The mutation of the FMR1 gene involves a pattern of DNA called a CGG repeat. DNA is made of chemicals that are abbreviated ACG and T. A CGG repeat is a repetitive pattern of CGG triplets. In the FMR1 gene there is an area of the promoter rich in CGG repeats. When there is an FMR1 mutation, these CGG repeats can be excessive.

There are normally about 30 repeats of CGG in this area. Individuals with the Fragile X premutation have between 55-200 of these repeats. People with the full mutation have more than 200. When there are more than 200 CGG repeats, the gene is turned off by a process called “methylation.” Methylation happens to other genes too, when they are intentionally turned off (genes that humans don’t use, like to make a tail!). In fragile X syndrome, the methylation turns off the FMR1 gene, so no FMRP is produced. That is what causes the condition. ■

The author is the genetic specialist for the National Fragile X Foundation. Email: liane@FragileX.org.

Stoking the Fragile X Imagination

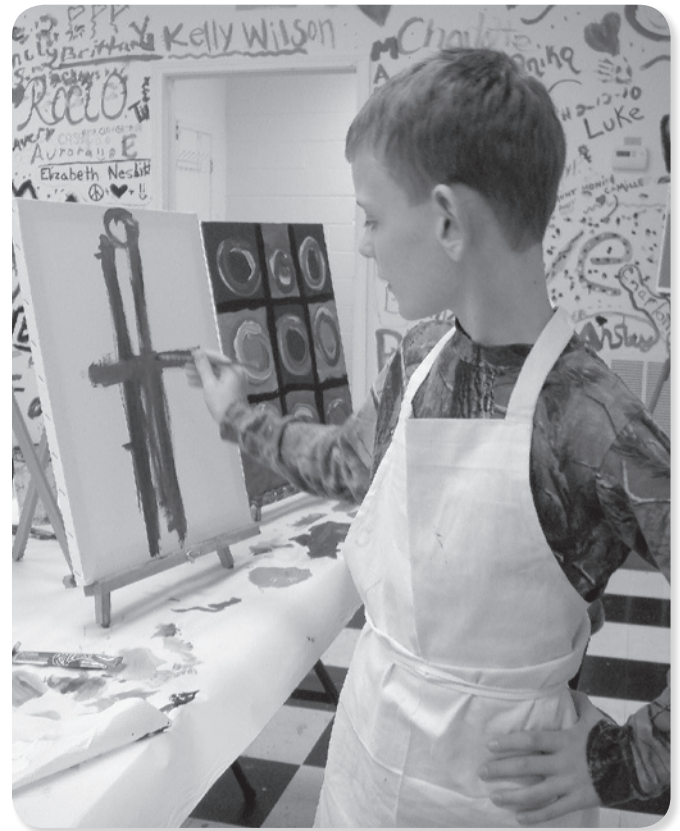
It's a scene that the instructors at Sips n Strokes in Atlanta, Georgia are well accustomed to: families and friends enjoying each other's company while creating their own versions of well-known masterpieces. The sounds of laughter and encouragement fill the studio and foster an atmosphere of warmth, creativity, and fun. Groups from family reunions to birthday parties have bonded over their own recreations of classic paintings such as Van Gogh's "Starry Night," so it comes as no surprise that the Fragile X community in Georgia strengthened its bonds doing the same. Through two painting sessions, one of which featured Wassily Kandinsky's "Squares with Concentric Circles," families found new ways to share their joys and triumphs with others who understand their challenges all too well.

The Xpressions in Art program, sponsored by the Emory University Fragile X Center, was created in 2010 to provide an additional opportunity for families affected by Fragile X to socialize and support each other. The first two sessions were such a great success that the program hopes to sponsor additional painting classes in the coming months. In the midst of IEP meetings, therapy sessions, doctor's appointments, and the day-to-day concerns of life in the

twenty-first century, it is all too easy for families to isolate themselves and forget to utilize one of their most powerful resources—each other.

"We don't interact with many other families affected by Fragile X, so it was wonderful to see individuals with Fragile X at so many different ages and get an idea of what to look forward to as Samuel grows," Wendy McKinnon, the mother of five-year old Samuel, recalls about their painting sessions. "This experience gave us a picture of what life and Samuel's development might be like, all in an atmosphere where everyone could just be themselves and enjoy each other's company."

The experience was also great for Samuel, who made friends with many of the older participants. "During the photograph of the kids and their finished paintings, several of



Samuel McKinnon, taking the measure of his canvas.

the older kids made sure to seek Samuel out and make sure he was in the front. Their encouragement and support for Samuel and each other was truly wonderful," said Wendy. This strong sense of camaraderie speaks to the importance of such social interactions for all persons affected by Fragile X.

In addition to fostering social interaction and a sense of community, the Xpressions in Art program hopes to provide a fun way to engage the visual learning strengths of those affected by fragile X syndrome. Being able to copy an instructor's brush stroke on their own canvas and in their own way gives these individuals (and their families) a chance to see their creativity shine, a feat that Wendy cites as one of the highlights of the experience. "[The program] gave Samuel a chance to express his imagination—something he generally has a hard time doing," she said.



The jubilant artists, holding their day's work aloft.

As every parent and teacher knows, opportunities that enable personal success are important for promoting a child's self-esteem and confidence. Combine that with the joy of painting and it is not surprising that the Xpressions in Art program sparked interest in multiple families from the greater Atlanta area. Sips n Strokes operates in only three southern states, but similar programs that afford families of all types—including those with special needs—the opportunity to create paintings, ceramics and other works of art are gaining in popularity around the country. Such activities offer parents a productive response to the perennial question of children: “What are we doing tonight?”

The numerous works of art created by the Xpressions in Art participants currently decorate the walls of Emory's Department of Human Genetics, the home of the Emory Fragile X Center. They will soon be auctioned off to the highest bidder at a fundraising gala, the proceeds of which will be used to create a targeted community outreach program to further increase awareness of all Fragile X-associated Disorders. We are all excited for another chance to socialize and support each other as we promote the interests of the larger Fragile X community. ■

The author is a research assistant at the Down Syndrome and Fragile X Clinic at Emory University's Department of Human Genetics. Email: jean.luan@emoryhealthcare.org

Write for the *Fragile X Quarterly!* Contact: editor@fragilex.org.

The Critical Role of Social Skills Training

Social skills instruction is a prominent feature in most special education classrooms. Teaching basic social skills ranging from simply initiating a conversation to complex peer resistance strategies increases the likelihood that students with disabilities will be successful in school social situations. In fact, the Individual Education Program (IEP) specifically calls for educators to address “social-emotional” goals. Identifying a



Lou Denti

particular measurable social skill and teaching that skill helps students learn how to express themselves and also gain self-control. Let’s look at what social skills are, what they portend for educators, and what resources are available to help teach them. The following questions address the general category of children with mild-to-moderate disabilities, yet they

have direct applicability to students across the wide range of intellectual ability we see with fragile X syndrome.

WHAT ARE SOCIAL SKILLS AND WHY ARE THEY IMPORTANT TO LEARN?

Social skills are simply the ability for people to interact and communicate with one another. They constitute the building blocks for socialization. Walker (1983) defines social skills as “a set of competencies that a) allow an individual to initiate and maintain positive social relationships, b) contribute to peer acceptance and to a satisfactory school adjustment, and c) allow an individual to cope effectively with the larger social environment.”

Social skills usually develop quite naturally through each of the developmental milestones and on into adulthood via involvement and interaction with salient others such as parents, teachers, coaches, siblings, and peers. Both verbal and non-verbal communication becomes more reciprocal, leading to increasingly meaningful exchanges and dialogue. The manner in which one uses social skills is contingent upon the social situation. For example, yelling at the ump while watching a baseball game might be socially appropriate for that venue, but yelling in church would not. Coming to understand these kinds of distinctions by “reading” the social milieu is a key to social maturity.



Learning social skills allows one to communicate and interact across persons, places, time and topics. Social skill development is required for everything from expressing an initial greeting response of “Hello!” to engaging children in sophisticated debates about culture and politics. But ensuring that one conveys and interprets proper non-verbal and verbal messages can be tricky for even the best communicators. In children with FXS, the challenges are magnified.

WHY DO SO MANY STUDENTS WITH MILD-TO-MODERATE DISABILITIES HAVE DIFFICULTY INTERACTING SOCIALLY?

Students with mild-to-moderate disabilities often experience difficulty understanding social cues and the nuance associated with a given social situation. For example, such a student might interrupt a playground basketball game in progress, hoping that the players will stop and ask him to play. But the opposite often occurs: the players shun him and laugh at or resent his awkward attempt.

Far more effective is another peer who watches the game from the sideline, dribbles and shoots in between games to show off his skills, and then waits for his chance to be selected on a team. The difference between the two approaches is that the second peer takes note of the situation, understands its various

nuances, and cues into what is required for acceptance. He *reads the situation*. Simple as this sounds, it requires a highly sophisticated level and range of social skills.

These skills represent what academics call “paraverbal skills” or “metacommunicative competence.” It includes skills that we often don’t even think about consciously, such as how and when to modulate our voice volume, when to remain silent and not interrupt a speaker, or how to insert ourselves into a conversation or social situation. Attending to non-verbal cues such as reading facial expressions, making eye contact and using appropriate gestures are critical to learning these skills and thus constructively controlling a social situation.

As we know, children with FXS often present a unique profile. On one hand, they experience great difficulty with such fundamental social interaction as eye contact. On the other hand, they often demonstrate acute observational and mimicking skills (even though they may give the appearance of paying absolutely no attention). How these skills can be harnessed to effectively overcome the difficulties posed by such children’s social deficits is a major challenge for their parents, educators and therapists. But it is a challenge that can be and is increasingly met on many fronts as the needs of students with FXS are addressed in the modern school setting.

HOW DO TEACHERS HELP STUDENTS LEARN SOCIAL SKILLS?

Over the years research has validated the importance of teaching social skills to students with mild-to-moderate disabilities. Some programs are geared for elementary students while others are oriented toward secondary or adolescent students. According to the National Association for School Psychologists (2012):

“Effective social skills programs are comprised of two essential elements: a teaching process that uses a behavioral/social learning approach and a universal language or set of steps that facilitates the learning of new behavior. Interventions can be implemented at a school-wide, specific setting, classroom, or individual level, but at all levels the emphasis is on teaching the desired skill, not punishing negative behaviors.”

At the classroom level, teachers model and then teach the skill to and with students. After the instruction phase, students practice using it, first in the classroom, and then in unstructured environments such as the playground, library or lunchroom.

✂

Identifying the right social skills program and then receiving the necessary training determines the effectiveness of implementation.

IS THERE ANY DOWNSIDE TO TEACHING SOCIAL SKILLS?

A social skills program requires considerable effort and training to put into practice. If the IEP indicates that a child needs to improve in a specific social skill area, then educators must address the goal. Identifying the right social skills program and then receiving the necessary training

determines the effectiveness of implementation. It must be noted that generalization of a social skill to different environments (home, community) does not always take place, even though it appears the student knows and uses the skill in the classroom. Therefore, researchers have increasingly advocated for a cognitive problem-solving model. This model uses the problem as the starting point and then identifies solutions and alternatives to solve the problem. Rather than teaching skills in the abstract, a problem-solving approach addresses skill development when a particular behavior occurs. It may include conflict resolution intervention when the student becomes argumentative with a peer, or guidance in reporting a bullying situation the student experiences on the playground.

Both approaches have merit, but when teachers use a social skills program with clearly identified steps and activities, they can measure program effectiveness more readily, as well as meet stated IEP goals. The cognitive problem-solving approach requires increased understanding of how to analyze behavior and then apply appropriate alternatives and solutions to the problem at hand.

IS IT IMPORTANT TO RECEIVE TRAINING TO IMPLEMENT SOCIAL SKILLS PROGRAMS?

Social skills programs can be purchased through various vendors. Most appear relatively easy to implement with clearly outlined steps and procedures (see resources below). However, in order to develop a measure of competence, it is best to receive at least a modicum of training. This can be gleaned from a number of sources. For example, I provide daylong or two-day training sessions on the Synergy Social Skills Program developed by Charles Meisgeier. The program has 70 lessons covering the areas of responsibility, communication, assertiveness, and

continued on page 21 →

■ Parents' Forum

By Trish Priscott

Embracing Oliver: A Grandparent's Perspective

Recently Louise Gane from the UC Davis M.I.N.D. Institute conducted a seminar in Auckland, which I attended to increase my knowledge of Fragile X. I wanted to learn how we might best support our son Andrew, daughter-in-law Stacey, granddaughters Morrigan and Mikaela, and of course, grandson Oliver, who has fragile X syndrome.

It was extremely illuminating to find out more about Fragile X, but upon reflection, I decided that all we need to do is continue to be grandparents!

On the fridge in our kitchen, a magnet reads, "God couldn't be everywhere so he made Grandmas." In my mind, that sums up the life of any grandparent—grandparents can do, and are available for, anything!

A few years ago, a friend and I were discussing how to measure one's success as a parent, and how to decide the strength of a family unit. We decided that the best indicator is how our children parent their children, and a strong family unit is often evident only when a family is challenged or faces adversity.

Our family was challenged in 2010, when we were advised that our grandchild, Oliver, had been diagnosed with fragile X syndrome.

We had known within weeks of his birth that Oliver's development was not as expected. Oliver was not Andrew and Stacey's first child, and they were persistent in getting assistance when he did not attain milestones as expected. However, it was not until he was admitted to the hospital for respiratory problems in August 2010 that genetic testing occurred. Two months later, Andrew and Stacey learned the results and they were shattered, since there was no history of genetic disorders on either side. The medical professional who informed them knew little about FXS; the information given to them was printed straight off the Internet and spoke of the condition in very negative terms. Thank goodness for the positive and informative Fragile X Trust NZ website, which we found within a week!

On hearing the news, we headed immediately to their home an hour away. To say they were distraught to see the hopes and dreams they had for their son change is an understatement!



Ollie, caught recently in a (rare) still moment with his grandfather.

— ✕ —
*The Oliver we have
in our family today
is the same little boy
we had the day
before a label was
attached to him.*

Family support at this stage was vital. Within two days, I was told by my daughter Rachel that "all the children and grandchildren need to be together." We were to prepare for an onslaught the following weekend as they were all coming home to celebrate Guy Fawkes Night. And so they did: mattresses on the lounge floor, a big dinner, fireworks, tears, laughter—and an outpouring of aroha* for Andrew and Stacey. It was a significant step in moving on.

Since then, we have continued to be grandparents—to all our grandchildren. We have Oliver to stay on his own sometimes, other times with his siblings and his cousins. We read, we play, we talk.

The Oliver we have in our family today is the same little boy we had the day before a label was attached to him. He is still a cheeky-faced little monkey, still a fearless, blonde, brown-eyed angel at times, a little terror at other times. He is achieving developmental milestones, albeit behind his peers. He annoys his big sisters like any little brother—and also cuddles them; he bowls into our house and heads for his toys, just as the other

grandchildren do. And just as his father did when he was little, he gets the old rocking horse traveling the length of the lounge.

All our grandchildren are unique; they all have special qualities and attributes; they are all endearing. One of our grandchildren has FXS—as I write this he also has chicken pox!

In our view, just as having chickenpox does not determine who he is or what his future holds, neither do we see Fragile X as defining Oliver. He *has* Fragile X, but we don't want people to say, "He *is* Fragile X," as such a statement implies limits. He is Oliver: a grandson, a son, a brother, a nephew. He has the

capacity to learn, to live a full life, to love and be loved, and to realize his potential—just like the other young people in the family. And we will ensure that happens. ■

**Aroha* is a Maori word that encompasses love in its broadest and warmest sense.

The author and her husband live in the Central North Island of New Zealand and have three children and five grandchildren. This article first appeared in a slightly different form in the Fragile X Trust (NZ) Newsletter, December 2011 issue.

The Long Winding Road to Eureka continued from page 2

As with everything else new in our lives today, we "Googled it." We also immediately tested Kenney, confident from our research that her autism spectrum disorder was also FXS. Not that we could run to the pharmacy and get a pill to "fix it," but finally knowing what we were trying to fix, and more importantly, that there were so many brilliant people focused like a laser beam on how we do it, to this day makes for quite an elixir for Dad.

As I would later learn, that reading material of Christy's doc was not a medical treatise or professional journal, but rather a simple postcard, sent to every pediatrician in the United States, in hopes of increasing awareness. That simple but brilliant idea was the work of the National Fragile X Foundation. I understand the importance of bringing down the age of diagnosis, and why for so many medical and research reasons awareness and early diagnosis is, and always should be, a pillar of the foundation's mission. But for me it's personal. The NFXF awareness campaigns literally and figuratively changed the lives of everyone in my family. I can only hope that my small contribution to the foundation's work might help

just one family get that clarity and hope I experienced with our diagnosis—but hopefully years before I did.

THANK YOU MARGARET ISRAEL!...

As this FXQ hits the streets, one of our valued and trusted board members is stepping down. Margaret Israel, a driving force behind all things St. Louis, including our 11th International Conference in her fine city, is leaving the board at the end of March due to term limits. Margaret, often accompanied by her son Sam, was a never-ending stream of new ideas to advance the foundation, and, with her husband Marty, a generous financial supporter of all things Fragile X. It was the support of Margaret and the St. Louis LINKS group that helped make the www.fxtas.org website a reality, dedicated to the memory of St. Louis's own Edward Behrman. Thank you, Margaret, for all you've done...and your promise to stay engaged in the mission going forward. ■

The author lives with his family in Houston, Texas, where he is an attorney. He began his two-year term as NFXF board president in January. Email: brad@fragilex.org

A Corner Has Been Turned continued from page 3

clinic, now's the time. And while there, be sure to ask about becoming part of the Registry and Database—thus allowing you and your family to help advance better treatments for all.

Finally, speaking of the FXCRC, the consortium has a **new national coordinator** in the person of Sharon Kidd, a PhD epidemiologist. Dr. Kidd is part of the NFXF team that works out of our main office in California. Her primary focus is on the longitudinal database for FXS that is part of the FXCRC's

grant from the federal Centers for Disease Control (CDC). Dr. Kidd replaces former grant coordinator Karen Fay, who played an important role in the implementation of a prior CDC/FXCRC grant. Our thanks and best wishes for the future go out to Karen. ■

The author has been executive director of the NFXF since 1999. Email: robmiller@fragilex.org

13th International Fragile X Conference

Land Ahoy!

It's Time to Plan for the



13TH INTERNATIONAL FRAGILE X CONFERENCE

July 25-29, 2012  Miami, Florida

Hosted by Florida Fragile X Families

Everyone knows Miami is a beautiful and vibrant destination that promises a fun time for every interest and taste! *Come join us!*

Conference headquarters at the Intercontinental Miami is just minutes from South Beach, Coconut Grove, Coral Gables, and the Port of Miami. That means when you're not absorbed in the many educational conference sessions on all things Fragile X, you can buy a new outfit at a nearby fashion boutique, sample innovative cuisine at one of the city's huge array of restaurants, or just lounge by the pool, basking in the warm tropical sun and cool bay breezes.

Yes, the National Fragile x Foundation is highly enthused about welcoming you to sunny and warm Miami this summer!

CONFERENCE HEADQUARTERS

InterContinental Miami
100 Chopin Plaza • Miami, FL 33131
Tel: 305-577-1000 • Fax: 305-577-0384
www.icmiamihotel.com

A discounted \$117 per night plus applicable fees and taxes.

This special room rate will be available for booking through June 21, 2012 OR until the group room block that the National Fragile X Foundation has acquired is sold out—which ever comes first. *Better still: If you would like to extend your stay, this special rate is available from July 21 through July 30, 2012.*



CONFERENCE REGISTRATION INFORMATION

Online registration for the conference is available now!

REGISTER EARLY AND SAVE!

Early Bird Registration Fee (2/1/12 through 5/15/12)

Individual	\$ 395
Family (2 family members)	\$ 760
Student (valid university student ID required)	\$ 335
Single Day (Thurs, Friday or Saturday)	\$ 205

Registration fees will increase by \$55 after May 15!

Registration fee includes:

Friday 7/27 luncheon and Saturday 7/28 banquet dinner tickets plus attendee premiums—Conference T-shirt and pin, tote bag, agenda, and other helpful items. *(Not available for single-day registrations.)*

Book your reservation online at www.fragilex.org or call 800-327-3005 (group code KUK).

CHECK OUT MIAMI

Take a tour of Miami at www.miamiandbeaches.com to see this fun-filled city full of great things to do in addition to the NFXF International Conference!

FRAGILE X NIGHT AT THE BALLPARK Friday July 27, 2012

Miami Marlins vs. San Diego Padres

Be some of the first 2012 baseball fans for the inaugural season at Marlins Park! This brand-new, state-of-the-art home of the Marlins is Miami's newest jewel—sure to be “a don't miss it attraction” in its first season. The ballpark has been thoughtfully designed for a completely new baseball experience, with special features including air-conditioned comfort, great food options to complement the spectacle of professional baseball games, and premium group entertainment.

TICKETS:

Adults: \$75 Children (*under 12 years of age*): \$25

TICKETS INCLUDE:

- Game seating in the Lexus Legend Level seating area.
- \$20 concession credit for food and beverages and/or retail purchases of Miami Marlins merchandise.
- Round-trip transportation (group buses) to and from the Intercontinental Hotel.
- A special Miami Marlins gift item for conference attendees only.
- An opportunity to share in the excitement of creating awareness about Fragile X to all of the fans in the park that night.

To learn more about the Miami Marlins and Marlins Park, visit www.marlin.com

CHILD CARE

Professional childcare will be provided by **KiddieCorp** during the conference at the Intercontinental Miami for children ages 2–16 years. Rates are \$54 per day per child plus \$10 per child for healthy snacks and lunch on Thursday through Saturday. Wednesday rate is \$21 per child and Sunday is \$19.50. **Registration for childcare is available online at [Conference/Childcare Details](#).** Learn more and register with KiddieCorp by visiting www.kiddiecorp.com.

TRANSPORTATION

Airport transportation, driving directions and parking information are available online.

TRANSLATION

Spanish translation will be available for many sessions and workshops during the conference and will be dependent on the number of Spanish speaking registrants.

EXHIBITOR SPACE

Exhibitor space for the conference is currently available. For further information, including booth size and rates, please visit us online or contact linda@fragilex.org.

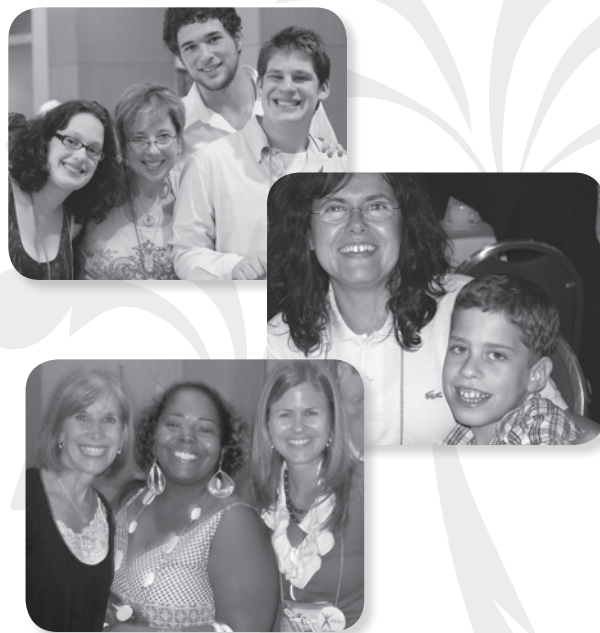
SPONSORSHIPS

The 13th International Fragile X Conference gives corporate sponsors the opportunity to demonstrate their philanthropic efforts to an enthusiastic audience of parents, researchers and treatment professionals.

Sponsorships are still available! Support through sponsorships gives the NFXF the resources to offer a wide range of dynamic programming to families and professionals while providing visibility opportunities to your organization. For more information on sponsorships, please visit us online or contact linda@fragilex.org.

VOLUNTEERING

If you are interested in being a part of the Conference volunteer staff, please see information on the following page. ■



Scenes from the 12th International Conference in Detroit, 2010.

nfxf
NATIONAL FRAGILE X FOUNDATION
forward



If your compass is pointed toward the 13th International Fragile X Conference in Miami this summer, the Florida Fragile X Families—official hosts of this extraordinary biennial gathering—could use your help.

Volunteers!

By volunteering for one of many absolutely vital jobs that need doing, you'll have an opportunity to contribute to our well-known hospitality to conference-goers from around the world. Our volunteers from past conferences invariably report that their enjoyment and sense of involvement in the conference is enhanced rather than curtailed by their participation. In return for your goodwill, you will receive a special goodie bag—and the warm glow that comes from engaging as a critical part of our conference team!

For more information please contact:

Marilyn Morgan (561) 272-6280
marewiz51@aol.com

Randy Green (561) 509-6420
mathmattx123@gmail.com

Conference Auction Items!

After arriving in Miami, be ready to bid on one-of-a-kind items during the conference auction Saturday, July 28.

You can make the auction even better by your contribution of a special item to be included in the lineup.

We are looking for:

Electronics, computer and gaming equipment, jewelry, sports packages, equipment, sports tickets, golf packages, hotel and time-share accommodations, vacation packages, airline tickets and other unique gifts.

Original artwork such as pottery, glass, woodworking, dolls, paintings, photographic art, sculpture or any other priceless gem are also welcome.

And remember, donations are tax-deductible and all proceeds benefit the NFXF.

To make a donation or for more information, contact:

Michele Kaplan michelemkaplan@yahoo.com

More Information: conference.fragilex.org

problem solving. It is aimed at students with mild-to-moderate disabilities from upper elementary through secondary school. General and special education teachers, speech pathologists, school psychologists, and administrators who take the training receive a comprehensive teacher and student manual and learn how to deliver the program.

For students with more severe intellectual disabilities, a social skills program I have found effective is *Model Me Kids*. This social skills curriculum includes videos and other high quality teaching tools for children with autism, Asperger syndrome, and other conditions. It may be highly applicable to many children with FXS.

WHERE DOES ONE LOCATE QUALITY SOCIAL SKILLS PROGRAMS?

Look below for a small sample of interventions and programs recommended by researchers and leading organizations such as the U.S. Department of Health and Human Services.

ENDNOTE

Educators should be patient yet persistent when teaching social skills. Just as they do in math or English, teachers must dedicate time and resources to effectively teach a social skills curriculum. But it is worth the effort, given its demonstrated capacity to help students with disabilities interact and communicate with newfound confidence in a variety of social situations. The students, their peers, their teachers and families all benefit in untold ways when such an integral human skill is developed to its fullest capacity. ■

The author is the Lawton Love Distinguished Professor in Special Education at California State University, Monterey Bay. His research interests include classroom management, literacy, inclusion, and social justice. His most recent book is Proactive Classroom Management K-8: A Practical Guide to Empower Students and Teachers (Corwin Press, 2012).

Email: ldenti@csumb.edu

Evidence-Based Resources for Social Skill Acquisition

“Stop and Think” Social Skills Program (Knoff)
www.projectachieve.info/project-achieve-program/project-achieve-overview.html

Primary Mental Health Project (Cowen et al.)
www.sharingsuccess.org/code/eptw/pdf_profiles/pmhp.pdf

The EQUIP Program (Gibbs, Potter, & Goldstein)
www.researchpress.com/product/item/4848/#5133

The PREPARE Curriculum (Goldstein)
www.researchpress.com/product/item/5063

The Walker Social Skills Curriculum—The ACCESS Complete Program (Walker et al.)
www.proedinc.com/customer/productView.aspx?ID=615

I Can Problem Solve: Interpersonal Cognitive Problem Solving (ICPS) (Shure & Spivack) <http://www.researchpress.com/product/item/4628>

Tough Kids Social Skills Book (Sheridan)
www.researchpress.com/product/item/8447/

Social Skills Training

Synergy Social Skills Program, by Charles Meisgeier (upper elementary through high school). Training available by contacting Dr. Lou Denti at ldenti@csumb.edu

Model Me Kids Social Skills Program
www.modelmekids-store.com/

Operation Respect-Schoolwide Program

Peter Yarrow of the legendary folk trio *Peter, Paul and Mary* desired to promote character education and social and emotional learning principles in school curricula. He thus founded “Operation Respect” in 1999, which disseminates the “Don’t Laugh at Me” (DLAM) Program. Its centerpiece is the song, “Don’t Laugh at Me” sung by Peter, Paul and Mary. Information: www.operationrespect.org/

References

Social Skills and Academic Achievement (2011). Evidence for Education. 3(2).

Retrieved Jan. 22, 2012 from <http://nichcy.org/research/ee/social-skills>.

The National Association of School Psychologists (NASP) (2012). Social skills: Promoting positive behavior, academic success, and school safety. Available online at: http://www.nasponline.org/resources/factsheets/socialskills_fs.aspx

Walker, H.M. (1983). The ACCESS program: Adolescent curriculum for communication and effective social skills: Student study guide. Austin, TX: Pro-Ed.



The 2011 FX Honor Roll

This regular column recognizes our major individual donors for their generous support of the foundation.

Sincere thanks goes out to all of our donors, at every level of giving. It takes a huge village of supporters to enable the work of

the NFXF to go on, day after day and year after year. Though we may be repeating ourselves, let

us do so anyway: We couldn't continue this critical work on behalf of the Fragile X community without you!



We recognize the following donors for their gifts in the course of the last year (Jan 1 to Dec 31, 2011)

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*The author was recently the development coordinator for the NFXF. (See page 9.)
For more about organizing or supporting fundraising activities, contact linda@fragilex.org.*

Chicago Again Leads the Way!

The National Fragile X Foundation would like to specially recognize **Carey & Cheryl Cooper**, **Scott & Lynda Canel** and **Ira & Rebecca Fishman** for their organization of the 2011 Chicago “Non-Event,” a virtual effort that raised over \$160,000! Through both real and virtual galas, the families have been supporting the NFXF since 2001. Thank you one and all!

Corporate Advisory Council

The NFXF recognizes the members of our Corporate Advisory Council for their financial contributions to the NFXF. Their membership dues help support our wide-reaching mission. **Abbott Molecular, Afraxis, Asuragen, Celera, Roche, Integrated Genetics, Novartis Pharmaceuticals, and Seaside Therapeutics.**

Honor and Memory Donations

Did you know that any donation to the NFXF can be made in honor or memory of a loved one? Help celebrate a special occasion or commemorate the life of a family member or friend by including the name and/or event and contact information with your donation. To learn more call (800) 688-8765.

By Linda Sorensen, Associate Director &
Holly Roos, LINKS Program Assistant

NFXF LINKS Groups in Action

It was quite a year for the leaders and members of the NFXF LINKS Groups in 2011. We knew it was busy, but really began to appreciate just how busy everyone was when we compiled the following list of events and activities that took place in 12 short calendar months.

Our congratulations and HUGE thanks to everyone who worked so hard to make an impact in their FX community. Your commitment to making a difference is quite evident in this long list below!

JANUARY

Fragile X Families of South West Chicago—Bowling Fundraiser/Social
Fragile X Association of Southern California—Family Fun Day at Discovery Science Center; Awareness Booth at Autism Conference; Educational Workshop With Dr. Randi Hagerman
Fragile X LINKS Group of Eastern Massachusetts—Play Group
Fragile X Alliance of Texas—Support Group Meeting
Fragile X Association of Michigan—Business and Support Group Meeting
Texas Fragile X Association—Fragile X Women's Social
Central Illinois Fragile X—FX Presentation to Graham School of Nursing Students
Tri-State Fragile X Alliance—Evening Social at Panera Bread; Meeting at Indianapolis FX Clinic

FEBRUARY

Fragile X Association of Washington State—Annual Fragile X Conference
Texas Fragile X Association—Valentine's Day Family Dinner/Dance
Fragile X Association of Michigan—Business and Support Group Meeting
Fragile X Alliance of Texas—February 26th Shopping for a Cause Event; Support Group Meeting
Florida Families for Fragile X—Billfish Tournament
Fragile X LINKS Group of Western Massachusetts—Awareness, Speaking at Local Colleges

MARCH

Fragile X LINKS Group of Kansas City—Meet and Greet
Central Illinois Fragile X—Awareness Booth at Special Needs Health Fair
Fragile X Association of Southern California—Slam Dunk Party at Clippers Game
Fragile X LINKS Group of Eastern Massachusetts—Parents' Night Out
Fragile X LINKS Group of Western Massachusetts—Awareness, Speaking at Local Colleges
Fragile X Alliance of Texas—ARC of San Antonio Resource Fair; Support Group Meeting
Kansas Fragile X LINKS Group—Business Meeting
Fragile X Association of Michigan—Business and Support Group Meeting
Fragile X Association of New York—Educational Group Support Meeting With Social
Louisiana Fragile X LINKS Association—Meeting
Fragile X Resource Group of Missouri—Family Pot Luck
Texas Fragile X Association—Scholarship for Advocacy Day, Washington, D.C.
Tri-State Fragile X Alliance—Family Evening With Dr. Erickson; Dr. Erickson Talk at Cincinnati Children's Hospital
Fragile X of Minnesota—Monthly Coffee
Fragile X Advocacy Day Attendance in Washington, DC—Tri-State Fragile X Alliance, Texas Fragile X Association, Fragile X Association of New York, Fragile X Association of Michigan, Kansas Fragile X LINKS Group, Fragile X Alliance of Texas, Fragile X LINKS Group of Eastern Massachusetts, Central Illinois Fragile X, Fragile X LINKS Group of Western Massachusetts, Fragile X Families of South West Chicago, Fragile X Resource Group of Missouri, Fragile X Association of New Jersey, Fragile X Society of Connecticut, Fragile X Association of Alabama, Fragile X Resource Group of Greater Chicago, Fragile X Center of San Diego, Fragile X LINKS Group of Kansas City, Fragile X Association of Rhode Island and Southern MA, South Carolina Fragile X Resource Group

APRIL

Texas Fragile X Association—6th Annual Spring Fling
Central Illinois Fragile X—8th Annual Walk for FX & 1st Annual 5K Run; Papa John's Pizza Night; FX Presentation to Graham School of Nursing Students, Girl Scouts Troop and Eastview Elementary School
Fragile X LINKS Group of Kansas City—Life Planning Seminar
Fragile X Association of Michigan—Business and Support Group Meeting
Fragile X Association of Southern California—Special Needs Trust Workshop
Fragile X Association of Southern California—Awareness Booth at Autism Walk
Fragile X Center of San Diego—Presentation at Autism Discovery Institute; Happy Hour for CA FX Awareness Day
Fragile X LINKS Group of Western Massachusetts—Awareness Booth at Autism Conference
Fragile X LINKS Group of Eastern Massachusetts—Play Group
Fragile X Alliance of Texas—Autism Walk FX Awareness Booth; Support Group Meeting
Fragile X Families of South West Chicago—Awareness Booth at Expo
Fragile X LINKS Group of Eastern Massachusetts and West MA—Visit With Seaside Therapeutics
Kansas Fragile X LINKS Group—1st FX Get Together
Fragile X of Minnesota—Monthly Coffee

MAY

Fragile X Resource Group of Missouri—Fragile, Not Broken Walk for Knowledge
Fragile X Resource Group of Western New York—Meeting
Fragile X Association of Southern California—Family Fun Fitness Day
Fragile X Center of San Diego—Kentucky Derby Party
Fragile X Association of Michigan—Business and Support Group Meeting
Texas Fragile X Association—Fragile X Day at the Dallas Arboretum; Hosted Dinner With Robert Miller for TX Families
Fragile X Alliance of Texas—Support Group Meeting
Florida Families for Fragile X—Parents' Night Out
Fragile X Association of Southern California—FX Research Presentation
Kansas Fragile X LINKS Group—Walk Meeting
Fragile X of Minnesota—Monthly Coffee

JUNE

Colorado FX—24 hour Mountain Bike Relay
Fragile X LINKS Group of Kansas City—Arts and Crafts Sale
Fragile X Association of New York /Fragile X Association of New Jersey—Educational Seminar
The South Carolina Fragile X Resource Group—Educational Seminar
Colorado FX—Elephant Rock Bike Ride
Fragile X LINKS Group of Kansas City—FX Day at T-Bones Baseball
Fragile X Association of Southern California—Annual Yard Sale; Family Fun Day at the Park
Fragile X LINKS Group of Eastern Massachusetts—Play Group Date
Fragile X Association of Michigan—Business and Support Group Meeting
Fragile X Resource Center of Western Massachusetts—Picnic in the Park
Fragile X Resource Group of Missouri—FX Booth at Wells Fargo Health Fair
Texas Fragile X Association—5th Annual Fragile X Splash at Cimarron Park, Valley Ranch; Partnered With Phoneraisers/Donate Old Phones to Raise Funds
Fragile X Alliance of Texas—Support Group Meeting; Family BBQ (Houston)
Fragile X Resource of Montana—Awareness Booth at Health Screening for Crow Indian Children

Kansas Fragile X LINKS Group—FX Get Together w/ Presentation on Navigating the Kansas Service System
Tri-State Fragile X Alliance—Airport Fire Fighters Golf Outing to Benefit local FX Efforts; Meeting w/Southwest Ohio ARC
Fragile X of Minnesota—Monthly Coffee

JULY

Fragile X Alliance of Texas—Baylor Genetics Resource Fair; Support Group Meeting
Louisiana Fragile X LINKS Association—Meeting; Awareness Booth
Fragile X Resource Center of Western Massachusetts—Wine Tasting Fundraiser
Fragile X Resource Group of Missouri—FX Family BBQ
Fragile X Association of Alabama—Family Social
Texas Fragile X Association—FX Info Booth at the Resource Fair for Children w/Special Needs
Kansas Fragile X LINKS Group—Walk Meeting; Mom's Night Out
Fragile X of Minnesota—Monthly Coffee

AUGUST

Fragile X Resource Group of Missouri—Behavior Workshop
Fragile X Resource Group of Western New York—Family Picnic
Colorado FX—Wild West Relay
Fragile X Families of South West Chicago—Golf Classic
Fragile X Association of Michigan—5K, Family Picnic and BBQ Fundraiser
Texas Fragile X Association—FX Info Booth at Stephanie's Day Resource Fair; When to Think Genetics Panel Discussion/Parent Representative
Fragile X Alliance of Texas—Support Group Meeting
Fragile X Families of Northern Virginia—Ice Cream Social
Fragile X Association of Southern California—Awareness Booth at Stephanie's Day
Fragile X Families of Southeast Virginia—Meet and Greet
Central Illinois Fragile X—FX Presentation to Graham School of Nursing Students
Fragile X of Minnesota—Monthly Coffee and Group Picnic
Seaside FXS Parent Advisory Board Meeting, Pittsburg, PA—Fragile X Association of New York, Louisiana Fragile X LINKS Association, Fragile X Families of Northern Virginia, Fragile X Families of Southeast Virginia, Fragile X Alliance of Ohio, Fragile X Association of Rhode Island and Southern MA, The South Carolina Fragile X Resource Group, Fragile X LINKS Group of Eastern Massachusetts, Fragile X Resource Center of Western Massachusetts, Fragile X Resource Group of Missouri, Fragile X Society of Connecticut, Central Illinois Fragile X, Fragile X LINKS Group of Kansas City
Seaside FXS Parent Advisory Board Meeting, San Diego, CA—Kansas Fragile X LINKS Group, Fragile X Alliance of Texas (Houston), Fragile X Resource of Montana, Tri-state Fragile X Alliance, FX LINKS Group of Wisconsin, Michigan Fragile X Resource Group, Fragile X of Minnesota, Albuquerque Fragile X Resource Group, Nebraska Fragile X Families Association and Support Group, Fragile X Association of Southern California, Fragile X Center of San Diego, Fragile X Families of Southwest Chicago, Fragile X Association of Michigan, FX LINKS Group of Wisconsin, Central Illinois Fragile X

SEPTEMBER

FX LINKS Group of Wisconsin—Walk for FX
Fragile X Society of Connecticut—FX Awareness Day With Radio and TV Interviews
Central Illinois Fragile X—1st Annual Bags Tournament; Talking With Students About Fragile X, Ingersoll Middle School
Fragile X LINKS Group of Kansas City—Fragile Xpedition Walk
Texas Fragile X Association—TXFX Family Fun Day; FX Presentation/Pediatric Neurology Fragile X Clinic
Fragile X Alliance of Texas—Support Group Meeting
Fragile X Association of Michigan—Golf Outing; Awareness Booth at "What About You" Walk; Ford Motor Co. Local 900 Poker Run
Florida Families for Fragile X—Marlins Night Out
Fragile X Resource of Montana Awareness Booth at WFLA Community Event
Kansas Fragile X LINKS Group—FX Get Together With Seaside Therapeutics Trial Presentation; Get Together and Walk/Business Meeting
Tri-State Fragile X Alliance—First Family Advisory Council Meeting, Louisville FX Clinic
Fragile X of Minnesota—Monthly Coffee; Group Meeting

OCTOBER

Fragile X Resource Group of Missouri—Mouse Races
Fragile X Families of Southwest Chicago & Fragile X Resource Group of Greater Chicago—Educational Seminar
Fragile X Resource Group of Missouri—18th Annual FX Symposium
Fragile X Association of Michigan—Golf Outing; Business and Support Group Meeting
Fragile X LINKS Group of Eastern Massachusetts—Mom's Night Out
Louisiana Fragile X LINKS Association—Rummage Sale
The Fragile X Association of Georgia—Annual Bowling Event
Fragile X Association of Southern California—Yard Sale
Texas Fragile X Association—6th Annual TXFX Fall Festival/Dance, Addison; Meeting With Seaside Therapeutics
Fragile X Alliance of Texas—Support Group Meeting
Central Illinois Fragile X—Awareness Table at Illinois Developmental Disabilities Nurses Association Conference
Fragile X LINKS Group of Eastern Massachusetts & Fragile X Resource Center of Western Massachusetts—FX Awareness Day Testimony
Fragile X Resource Group of Missouri—FX Booth at "Autism Speaks" Walk
Fragile X Families of Northern Virginia—Educational Conference
Fragile X Society of Connecticut—Awareness Booth at Health and Wellness Festival; Special Education Master's Program Presentation; Lions Club Interview
Kansas Fragile X LINKS Group—1st Walk for the Faces of Fragile X; Business Meeting
Fragile X of Minnesota—Monthly Coffee

NOVEMBER

Fragile X Alliance of Texas—1st Awareness Walk
Colorado FX Educational Conference
Fragile X Society of Connecticut—Educational Conference
Central Illinois Fragile X—Jukebox Comedy Club Fundraiser; FX Presentation to Graham School of Nursing Students
Fragile X LINKS Group of Eastern Massachusetts—Mom's Night Out
Central Illinois Fragile X—Family Play Date
Fragile X Association of Michigan—Business and Support Group Meeting
Fragile X LINKS Group of Eastern Massachusetts & West MA—LINKS table at CT Conference
Florida Families for Fragile X—5K Walk/Run
Fragile X Association of Southern California—Family Fun Day Gymnastics
Texas Fragile X Association—Play Wisely Brain Based Learning Card System
Tri-State Fragile X Alliance—Indiana Fragile X Family Conference
Fragile X of Minnesota—Monthly Coffee

DECEMBER

Fragile X LINKS Group of Kansas City—Potluck w/Santa
Fragile X LINKS Group of Eastern Massachusetts—Mom's night out
Central Illinois Fragile X—Family Bowling Day
Louisiana Fragile X LINKS Association—Fragile X—travaganza With Gumbo, Silent Auction, & Kid-Friendly Activities
Fragile X Alliance of Texas—Christmas Party
Fragile X Association of New York—Family Play Date
Fragile X Association of Michigan—Holiday Party
Fragile X Association of Michigan—Fundraiser at Tootie & Tallulah's
Kansas Fragile X LINKS Group—Holiday Adult Get Together Dinner
Tri-State Fragile X Alliance—FX Talk at Miami Univ., Special Ed Student Teacher Seminar Class
Fragile X of Minnesota—Monthly Coffee

Finally: This list is by no means complete! So please, if we have overlooked an event or activity, our sincere apologies and please let us know so we can correct it next time—thank you!

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