

## PARENT CORNER: SUPPORTING EACH OTHER

by Mary Seward

**F**ragile X Syndrome? What's that?" I asked our pediatrician. Little did I know then how those three words would change our lives.



*Mary and Roger Seward and their children Elizabeth and Timmy. Mary's efforts have connected many other parents of children with Fragile X Syndrome with each other.*

Our son, Timmy, was just two and a half when he was diagnosed with Fragile X Syndrome. I was devastated, confused and in need of help. My friends suggested I join a support group, but I soon discovered there was no such group for Fragile X Syndrome. I called Patricia Herrera at Lanterman and she matched me with Linda Landry. Linda, "a bubbling fountain of warmth, information and resources", became my peer support partner. Linda in turn suggested that I call Dr. Barbara Wheeler at Children's Hospital/University Affiliated Program (U.A.P.) who'd recently

been talking about the need for a Southern California Fragile X support group.

I was disappointed. It wasn't fair! Why must I start my own group? Someone else should have done that long ago. Finally, after feeling sorry for myself, I worked up the courage, put my tears on hold and called Dr. Wheeler.

Barbara's vision was of a parent-driven group which would establish their own goals and mission. To get such a group started, the U.A.P. would supply technical, clerical and professional support until the group was strong enough to stand on its own. This has proven to be a successful formula – in our first year, we've grown to over fifty

families. In addition to our regular monthly meetings, we've organized a family picnic and a holiday social and we're soon to be incorporated as the Fragile X Association of Southern California. Our future plans include a conference on Fragile X to be held this fall and we're actively involved in establishing a Fragile X Clinic at Children's Hospital.

The best part, though, is meeting and making new friends with other parents as well as with caring professionals. Together, as partners, we are making a difference.

## WHAT IS FRAGILE X SYNDROME?

**F**ragile X Syndrome is the leading known hereditary cause of developmental disabilities. Both females and males may be affected with a variety of developmental problems, including learning disabilities, mild to severe mental retardation, behavior management challenges, attention deficit hyperactivity disorder, sensory and perceptual problems, autism and autistic-like behaviors.

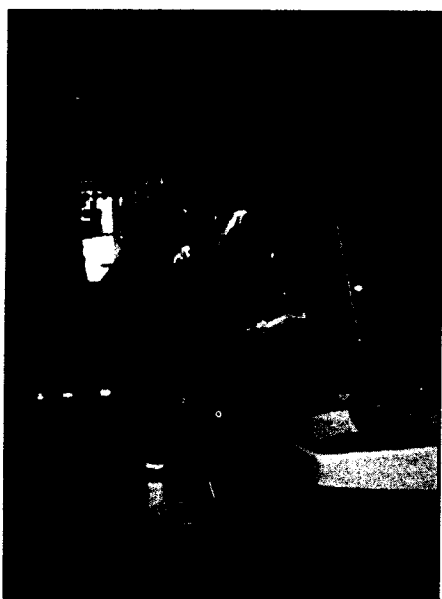
Fragile X has a wide spectrum of characteristics which may or may not be seen in a given individual. These include abnormal physical features, cognitive delays, speech and language problems, motor and sensory problems and behavioral difficulties. Specific medications, behavioral management techniques, educational strategies and appropriate inclusion programs incorporated with related services, such as speech and language therapy and occupational therapy, have been identified as tremendously beneficial for helping maximize the potential of individuals with Fragile X and improving the quality of their lives.

For more information on Fragile X Syndrome, please contact Mary Seward at the Los Angeles Fragile X Association, (818) 845-5877, or the Koch-Young Family Resource Center, 1-800-5-INFORM, for further literature on this topic.

Annette is thrilled with the many new independent skills Adam has acquired since he began public high school, which include standing in line at the school cafeteria, choosing his own food, and paying for it. He also selects his own clothes, and enjoys matching and color coordinating his outfits. Adam is now more outgoing with people, loves to be helpful, and he is well-liked by his teachers and students at school. Last spring, Adam's school bus driver remarked to Annette, "Adam's a nice guy."

It was a long, painful road to find appropriate services for Adam, and as many parents of children with fragile X syndrome can testify, the future is almost always uncertain. But, for now, Annette and Gene are extremely happy to see the wonderful progress their son is making. Printed in *The Cheshire Herald's* article, Annette credited the Cheshire School System and Pupil Personnel Director Paul Calaluce for working to include Adam in the high school. "The feeling of the Ben Haven staff and of our staff was that Adam could be taught in a class at CHS [Cheshire High School]," Calaluce said. "It's working out well, and I'm very pleased with the progress Adam has made."

A big congratulations goes once again to Adam Genovesi for being selected for "The Winner Circle!" Annette and her husband should also be credited for their love, advocacy, and unrelenting search for appropriate services for Adam that led to his progress. Annette says, "Adam really blossomed in the last year!" Hopefully, Adam will continue to blossom and find continued happiness and success in his future! ♣



Adam works at a local bowling alley.

## SOUTHERN CALIFORNIA PARENTS AND PROFESSIONALS WORKING TOGETHER TO MAKE A DIFFERENCE!

Mary Seward, Parent Coordinator

Fragile X Association of Southern California, Los Angeles, California

**W**e may love L.A.! But when families were diagnosed with fragile X syndrome, it was not the place to find experts or family support! But times are changing as the Fragile X Association of Southern California celebrates its very busy first year.

It was November, 1994, when Timothy Seward, age two and a half was diagnosed with fragile X syndrome. His mother Mary quickly discovered there was no group active in L.A. Soon she linked up with Barbara Wheeler, Ph.D., at Children's Hospital of Los Angeles, University Affiliated Program. Barbara had a long-standing interest in fragile X and wanted to lend technical and professional assistance to starting a parent group. The U.A.P. is a training ground for post-degree work in the field of developmental disabilities. Dr. Wheeler then assigned a psychology intern, Debbie Langenbacher, to work with Mary in finding families and organizing meetings.

We first contacted local state agencies that provide services for the population with developmental disabilities. We also contacted local genetics clinics. They sent our interest survey to their known fragile X families. We had an initial response of about forty families. Our first meeting was held in June, 1994.

We decided to hold monthly meetings in a different geographic area each month. Since L.A. is very populated and spread-out region, we try to make it convenient for every family to come to at least one meeting. We have some very dedicated families who drive hours and come every month. We have had speakers from the community with expertise in genetics, speech therapy, pharmacology, estate planning and occupational therapy. Cathy and Reed Halterman were parent leaders for one meeting and led us into very interesting discussions. We have discovered that other parents are sometimes the best resource on fragile X.

We have had two family picnics and a holiday adult party. Our last picnic was held June 25th at a private park, at a local university. It was easy for parents to watch their children and be able to meet and talk to others. The kids had a great time



Jason Spahr and Tim Seward play together at the Family Picnic.

playing baseball, basketball, frisbe, and volleyball. There was also a nice sandy playground with slides and swings for the younger set. Over forty family members attended this year.

One of the first projects was the writing of an informational brochure about fragile X syndrome and our association. Many families helped with suggestions and corrections. But since L.A. has a large Spanish speaking community, we then needed to do a translation. Fortunately one of our mothers, Molly Brown, volunteered many hours of her time to translate the brochure in Spanish.

At the suggestion of one of our parents, we started a family photo album for the group. Now when new parents or professionals come to our meetings we can show off our kids. No more searching in our wallets for photos!

We are beginning to develop a parent speaker group. On May 19th, five parents participated in a panel discussion at Fiesta Educativa, a parents and professional resource conference, targeted for the Latino community. Mary Seward and Debbie Langenbacher each spoke about fragile X and our association. Amalia Guerreo, Molly Brown, Phillip and Diane Briones and Maggie Coronado-Robles spoke about their children with fragile X. Each of their stories was interesting and informative, and covered an age range of individuals with

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**NAME SONG**

The two similar songs are very useful for learning children's names (first and last), giving directions ("Nancy is your first name, what will you do? Please get your notebook now!" or "Time to wash your hands for lunch!) In the Name Game song, the child named can perform the activity through a second singing of the song by the rest of the class, who will also be learning the child's name. Rhythm instruments may be added ("Can you beat the drum like this? Play the tambourine like this? etc.) :a

Note: **KIDSTECH** by Jim Heller will be back in the next issue.

**Name Game Play Song** ©Lee Beull

**What is your first name?** ©Lee Beull

Also use: "Can you snap your fingers like this?"  
 "Can you touch your nose like this?"  
 "Can you wiggle your fingers like this?"  
 Make up more.  
 Have child respond "I can clap my hands like this."

OR: What is your first name, first name, first name,  
 Tell me your first name, I'll sing it back to you.

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fragile X from three years to over fifty. We hope to do many more in the future. Also as part of our educational outreach, we presented a poster session at the AAMR Convention in San Francisco on June 2nd. The poster included information about our association's history, activities, and featured pictures of family members and our group activities.

One of our members, Karen Reinhart, has donated many hours typing and editing our quarterly newsletter. It has featured articles written by our parents and keeps everyone informed about upcoming events, locally and nationally. Many parents who cannot come to our meetings are very grateful for a way to keep informed of our activities.

The Association has also participated in several planning meetings with the UAP in developing an assessment and treatment clinic for persons with fragile X. This clinic would be at Children's Hospital of Los Angeles. We hope to provide an interdisciplinary team approach for our families and others. It is being developed with an emphasis on what the families need and want the clinic to be. Parental input is a vital component of the planning for this much needed clinic.

If planning a clinic isn't exciting enough, we are also working on a fragile X conference for early 1996. Arrangements are being made to have Dr. Randi Hagerman as our keynote speaker. The presentation will be a part of Grand

Rounds, which is a part of their physician education program at children's Hospital. We are currently seeking sponsors for the conference, so that we can bring in more experts in other areas, such as speech and occupational therapies, behavior management and educational techniques.

We have been very careful about confidentiality in our group. There is a phone directory for parents, but only those who have signed a release form are listed. Some families have elderly grandparents who they feel are not ready to hear that their gene pool caused their grandchild's disability. Others have not told their school districts, for fear of labeling. Whatever the reason, we feel it's important to respect everyone's privacy.

But some of us want to go public and get the media's attention. We have had one article published in one major paper and soon will be featured in the Glendale News Press. We are still hoping to find a family

with major connections to the media industry of Los Angeles.

At the end of our first year, we have a membership of sixty affected family members, ranging from one month to fifty-plus years old. We all have different needs, but we often find answers from talking to others in our group. We drive miles and miles to see each other. But we think it is well worth the effort it takes.

For more information about any of our activities, please call Mary Seward, parent coordinator at (818) 845-5877 or Debbie Langenbacher, Ph.D., professionals coordinator at (213) 669-2300. :a



Parents and their children enjoying themselves at the Family Picnic.