

November  
2009

**INSIDE THIS  
ISSUE:**

President Speaks	1
Fiesta Educativa (Spanish)	1
Spreading the Word at the Orange County Health Fair	2
Helpful Hints: Writing Tools using Technology	2
Living with FX — Daily News Article	3
2009 FRAXA Research Founda- tion Boston Gala	4
“Healing” Exhibit Features Family with Fragile X	5
A Few Lines	6
Membership Information	7
Share a Story	7
Informative Websites	7
Information	8

\*Insert page  
Family Fun Day  
Information

# FRAGILE X PRESS

*Fragile X Association of Southern California*

Dear Members,

I can't believe this year is coming to an end. I hope everyone is having (had) a great year. This is our last newsletter of 2009, however, we are looking forward to continuing our newsletter with wonderful articles from all of you in the new year to come. We are having one more Family Fun Day event on Sunday, November 22 at the Irvine Park Railroad in the City of Orange. Please take a look at our insert and make sure to call Jack and Jacqueline Blanco for reservations. Hope to see you all there!

As you go through the newsletter, you will notice that we have been busy! Board members have attended community events or have been in the news where they have gotten the chance to spread the word about Fragile X Syndrome. Several Board members attended Fiesta Educativa and the Orange County Health Fair. Also, Board member Jared Chao attended a fundraiser for FRAXA Research in Boston and Board member Neal Robb and his family were featured in a newspaper article.

I would like to thank our Board for another great year and thank each of you for your support throughout the year. We are excited about next year and hope that you will continue to support our mission in 2010.

Best wishes,  
Janet Rivera, FRAXSOCAL Board President

## **Llevando nuestro mensaje a Fiesta Educativa**

Por Paula Páez

Este año Fiesta Educativa fue organizada en las oficinas del California Endowment en el Centro de Los Angeles. Esta junta se celebra cada año con el proposito de dar infomación sobre servicios que se ofrecen en el Condado de Los Angeles a familias con niños discapacitados. Representantes de centros regionales, distritos escolares, y agencias comunitarias reparten folletos con información de programas gratuitos o de bajo costo. Aparte de esta información, también se les ofrecen a los padres de familia que vienen al evento, platicas y charlas sobre temas como la educación de sus hijos, terapias para mejorar el comportamiento, y otras tecnicas para mejorar las vidas de niños con necesidades y de sus familias.

Naomi Star y yo participamos en este evento repartiendo folletos sobre el Síndrome de X Frágil a todas las personas que se detenian en nuestra mesa y nos preguntaban “¿frágil que?” Como pueden imaginarse, tubimos mucho de que compartir ese día.

### **Orange County Health Fair by Sali Farber**

Naomi and I recently hosted a booth at the Health Fair on October 13<sup>th</sup> at Orange Coast College. The fair was very well run. They had many tables giving information about various health issues some of which were lung disease, breast cancer, STDs, mammograms, free flu shots, and of course our table for Fragile X. This was a very different audience in that they were all college students and some faculty. Although everyone seemed to know of Autism, only two people had ever heard of Fragile X, one of which was doing a paper for his psychology class and the other was the cousin of Salvatore, one of the families in the documentary “Living with Fragile X.” It was interesting to see the reaction when we explained about Fragile X. We tried to stress the importance of it being “inherited” and that it could be diagnosed by a simple “blood test.” This was definitely getting the word out and spreading “awareness.”



FRAXSOCAL Board members,  
Naomi Star and Sali Farber

### **Helpful Hints: Writing Tools Using Technology by Janet Rivera**

Our son, Kenneth, who just turned 9 years old is still having trouble with his writing skills, but his typing skills are great! Our school district strongly recommends assistive technology for students who are not only non-verbal but also for students who have a difficult time writing. In the 1st grade, Kenneth started facilitated communication (FC), a process by which a facilitator supports the hand or arm of the student while using a keyboard with the aim of helping the student to develop pointing skills. Kenneth started with the Alphasmart 3000 and within a year he no longer needed FC. Kenneth was now typing on his own. With the help of the Alphasmart, Kenneth was able to learn to spell and type his name. Kenneth is now in the 4th grade and is currently using the Fusion. The difference between the Alphasmart and the Fusion is that the Fusion has features like “text to speech” and “word predication.” For example, when an individual types a word using the Fusion, the individual can hear the word and correct the word if misspelled. The Alphasmart is only for typing.

Both tools have been and still are very helpful for Kenneth. Kenneth uses the Fusion for classroom work and homework. Kenneth is currently being mainstreamed and is able to take his Fusion in his mainstream class to work on his assignments with help. We do, however, now need to be careful because he will go on the internet and search on Google and Youtube for things he likes by typing in the subject.

Below is the website for the makers of the Fusion and Alphasmart. If the cost is too high, you can always ask for a refurbish with a warranty or have your child assessed by the school district for assistive technology. The school will provide you with a free machine for the classroom and to take home. You can also contact Team of Advocates for Special Kids (TASK), for more information.



**Alphasmart**

**Fusion:** [www.writerlearning.com](http://www.writerlearning.com)  
**Alphasmart:** [www.neo-direct.com](http://www.neo-direct.com)  
**TASK:** [www.taskca.org](http://www.taskca.org)



**Fusion**

## Living with Fragile X

By Michelle Lanz

Published in the LA Daily News on 7/15/2009



Garrett Robb, who has Fragile X, listens to a DVD player in a room at his Manhattan Beach home. (Sean Hiller/Staff Photographer)

Neal and Carolyn Robb knew something was wrong when their 18-month-old son, Garrett, could no longer use the handful of words he had learned. Garrett had become increasingly aloof and removed, but friends, family and doctors insisted it was just a stage and that the boy was developing normally.

I started to think, "Am I crazy? Am I an over-protective mother and kind of kooky? Or am I really onto something?" said Carolyn Robb from her family's home in Manhattan Beach. "I had that mother's intuition and I knew something was not right.

The Robbs looked to speech therapists, pediatricians and neurologists to try to pinpoint the boy's problem. But it wasn't until 1998, just after Garrett's third birthday, that their son was diagnosed with autism, caused by Fragile X Syndrome.

Autism has become a household word thanks to organizations such as Autism Speaks and the outreach of celebrities, such as Jenny McCarthy, who have autistic children. But Fragile X, a genetic mutation and a leading cause of autism, is not something doctors routinely test for, let alone, understand.

"Unfortunately for a lot of people, they get the diagnosis of autism first, and think that is the diagnosis," said Neal Robb, an attorney in Long Beach. "Autism is just a description of behaviors, the psychological diagnosis, and it doesn't do anything to explain what's happening systemically or genetically.

Detectable with a DNA test, the syndrome affects the Fragile X gene, the X chromosome, and is the most common cause of inherited mental retardation. The transferable mutation appears in approximately 1 in 250 women and 1 in 700 men. Women have a 50 percent

chance of passing it to their children, while men are only able to pass it to their daughters, not their sons.

Dr. Gary Feldman of the Stramski Children's Developmental Center in Long Beach says the syndrome is not commonly discussed, simply because of lack of awareness. "It is just not on the radar screen and general pediatricians are not trained enough in developmental and behavioral disorders to think about it," said Feldman. "Even in children presenting with autism, not every general pediatrician will attempt to exclude Fragile X. The syndrome is caused when a gene in the X chromosome becomes mutated, shuts off, and the gene no longer produces the protein necessary for normal development. Males are more often affected because they have two X chromosomes, whereas females have one X and one Y chromosome.

Fragile X symptoms include autistic behavior, speech and motor delays, hyperactivity, and language problems, as well as physical attributes such as a prominent forehead, large ears and jaw, and double-jointedness. "It's like being trapped in a box where you can hear everything outside of it, but you can't say a word," explains Garrett's 10-year-old brother, Wyatt, who shows no signs of the disorder. Garrett is 13 now and though he still doesn't have his words, therapy has helped him to communicate with his family and he has learned to ski. He continues to undergo behavioral, speech and occupational therapy.

"Things that you once thought would be accomplished at that age; it's completely different when they hit that age," said Carolyn Robb. "If you want to make God laugh, tell him you have plans." To help spread the word about the disorder, the Robbs became subjects of the documentary "Living with Fragile X," for which they allowed filmmakers into their home for intimate interviews and footage of family life.

"Living with Fragile X, which took seven years to make, follows several American families dealing with the disorder. By devoting time, money and energy to groups such as the Fragile X Association of Southern California, the Robbs have become activists and supporters of other families with special-needs children. "You feel a certain responsibility for people who are on the same path or will be taking the same steps," said Neal Robb. "It helps to give back and to have other people benefit from your experience."

Though there is no cure, scientists at the M.I.N.D Institute at UC Davis, and research foundations such as FRAXA, are working to develop a more effective treatment and a potential cure for Fragile X Syndrome.

**FIND OUT MORE:** To learn more about the documentary, or to purchase a copy, go to [livingwithfragilex.com](http://livingwithfragilex.com).

## **2009 FRAXA Research Boston Gala**

**by Jerad Chao**

On October 8, 2009, I attended with my father-in-law, Harvey Hoffman, the 2009 Boston Gala to benefit the FRAXA Research Foundation. The honored guest was Doris Buffett and the featured speaker was Dr. Mark Bear. Other well-known guests included Dan Grimaldi, a Sopranos cast member and Jim Canotore, storm tracker on the weather channel. The event was held at the Seaport World Trade Center.

The event was well-attended with over three hundred people. They also raised money with a silent auction and a live auction. The food included Grilled Petit Filet of Beef and Pan Roasted Salmon Medallion and it was very good.

Doris Buffett, president of the Sunshine Lady Foundation, was the featured guest. Two years ago, she offered a \$500,000 challenge grant to FRAXA. When the FRAXA community exceeded that goal, she increased her offer to match any amount that was raised. The final amount was two million dollars. At the dinner, Doris Buffett stated that she initially felt bad about issuing the challenge grant, but that it definitely raised a lot of money. Because of the generosity of Ms. Buffett, the FRAXA foundation was able to fund almost twice the amount of research as in previous years and was able to host the 2008 FRAXA Investigators Meeting, the largest Fragile X research meeting ever.

Dr. Mark Bear was the featured speaker. Dr. Bear, Professor of Neuroscience, along with Dr. Kimberly Huber, led a team that discovered that many of the symptoms of Fragile X arise from overactivity involving the mGluR receptor on neurons. Drugs that can reduce mGluR activity have been shown to reverse symptoms in mice and are currently being developed by major pharmaceutical companies, including Seaside Therapeutics of which Dr. Bear is a founder.

Dr. Bear stated that money from FRAXA was being multiplied by 15 to 20 times because researchers can use the seed money to get grants from the NIH that are up to \$30 million. He stated that the goal is to have a targeted drug by the year 2012. However, even with a targeted drug, researchers will continue to have much work to do because more than likely there will be symptoms that remain.

The evening ended with a live auction and a silent auction. I bid and won an autographed picture of Doug Flutie's celebration of the famous Hail Mary pass while he was at Boston College, a true New England hero. We had a fun night for a great cause.



Harvey Hoffman and FRAXSOCAL Board member, Jerad Chao



Dr. Mark Bear and FRAXSOCAL Board member, Jerad Chao

### **Podcast Interview**

One of our members, LeeAnn Taylor, recently talked about her family's experiences with Fragile X Syndrome, as well as some of the challenges specific to being a mother. Hopefully it will be of inspiration to us all. Read more about LeeAnn's family on Page 6. To listen to the podcast, visit the site below:

<http://www.liveonpurposeradio.com/radio/2009/10/27/perfectly-imperfect/>

## **“Healing” Exhibit Features Family with Fragile X by Naomi Star**

On a beautiful fall evening recently, over two hundred people gathered in the foyer of the Carpenter Center in Long Beach to view a series of photographs featuring people with disabilities. Titled ‘Healing,’ the photos, by fine art photographer Linnea Lenkus, were a stunning and deeply moving collection of family portraits.

The families were selected because either one or more of their children attend the Stramski Developmental Center in Long Beach, headed by Dr Gary Feldman. Linnea Lenkus donated her talents to help raise awareness of the center and its work. Each photo was accompanied by a detailed explanation of the particular syndrome or condition the family is dealing with, from Fragile X and Autism to Angelman Syndrome, Rett Syndrome and cleft palate.

Our son James, who has Fragile X Syndrome, is one of Dr. Feldman’s patients and we were approached earlier this year about becoming involved with the project. The photo session itself was a very enjoyable experience, and surprisingly fast. One of the perks of the project was being able to select some of the shots for ourselves, and we now have some truly gorgeous family photos to display at home.

Seeing the photos hung in a gallery setting was both exciting and emotional for those of us who were featured. It is unusual to see such large images of people who are not famous, models or in some other way celebrated by society. But each shot was full of beauty, love and a direct truth that spoke to the hearts of the viewers.

In conjunction with the Steel Magnolias, a group that raises funds for the Stramski Center, Linnea plans to use the exhibition to spread awareness through a book and future exhibits, possibly around the country. You can see the photos for yourself by visiting [www.linnealenkus.com](http://www.linnealenkus.com) and clicking on the ‘Healing’ box near the top of the page. The Stramski Center will be the home of the new Southern California Fragile X Clinic, to be led by Dr. Feldman. More details about the clinic will be available soon.



FRAXSOCAL Board member, Naomi Star’s children, James and Sophia Wackerman



Photographer Linnea Lenkus, FRAXSOCAL Board member, Neal Robb and Steel Magnolias founder, Shirley Wild

## **Save the Date**

**Friday, January 8th, 2010**

**Fragile X Symposium at the Stramski Center in Long Beach**

**Featuring Dr. Randi Hagerman and Dr. Marcia Braden**

**More information coming soon...**

## “A FEW LINES” by LeeAnn Taylor Coleman



I was recently asked by the editor of an online magazine to write a few lines about what it's like to be the mother of three children with disabilities. I sat staring at her email, the words “a few lines” popping out at me like bold letters jumping off my computer screen. *A few lines?* I wondered. How could I possibly write about our tragedies, our triumphs, our struggles, our miracles, our moments and our decades living with Fragile X Syndrome in *a few lines*? How could I begin to describe the heart-breaking anguish contrasted with the transcendent wonder I have experienced being the mother to these remarkable children in *a few lines*? How could I illustrate the outrageous roller coaster ride that our life has been over the last eighteen years in *a few lines*? And how could I express the transformative life change that I have undergone as a mother in *few lines*?

My experience began like that of many new mothers, with all the excitement and thrills and hopes of budding motherhood. My first child, Jaede, was an exceptional girl in many ways – crawling early, walking early, and very bright. Just over a year later, my second child was born, my son Quinn. There was something very different about him, though, something that haunted me from early on. Well-meaning family and friends assured me that my baby was fine, but inside I knew something was wrong. I continued to watch Quinn very closely, hoping he would outgrow his unusual behaviors.

Two years later my next son, Shale, was born. He was playful and engaging, very different from Quinn, and I heaved a sigh of relief. We began therapies and early intervention for Quinn and, when he was three years old, we had him tested for a strange genetic disorder I had never heard of: Fragile X Syndrome. The test results came back positive. It was devastating and relieving all at once. We immediately started Quinn in special education programs. Meanwhile, Shale's development was delayed and I began noticing odd manner-

isms. At the age of two, we had him tested for Fragile X Syndrome...*positive* again. Life was changing rapidly and I was still trying to grasp the implications of the disorder. Quinn's cognitive tests measured in the profoundly affected range, as did Shale's.

A month after Shale's test results, my next daughter, Faith, was born. She was a frail little girl with a delicate disposition. In my study of Fragile X, I had read that the occurrence in girls was far less frequent than in boys. Besides, I reasoned, God wouldn't do that to us, right? After nine months of delayed development and mild symptoms, we had Faith tested for Fragile X. When her test results came back, my worst fears were confirmed: she had the syndrome, too. Four children in five years, and three of them had Fragile X. I was only 26 years old.

I went into full-time caregiver mode, and my world became one of nonstop diaper changes, feedings, therapies, meetings, classes, behavior management, frantic days, sleepless nights, and trying on some level to convince myself that I was not a failure as a mother. Over the next few years, I worked hard to manage my children, meet everyone's needs, be advocates for them, modify our home to accommodate our special needs, and keep our family strong. My husband had a vasectomy, and we soon became an example of triumph over adversity within our community. I found that I learned more from my children than I ever taught them, gained more wisdom than I ever imagined, and became stronger than I thought possible.

Then I discovered I was pregnant. A flurry of mixed emotions overwhelmed me during the nine months that followed. But something seemed very special about this unexpected pregnancy. And two weeks after my new daughter, Psalm, was born, I had her tested for Fragile X. When the test results came back, I cried harder than I had all three times previously combined: my baby was *not* disabled. It was a miracle!

Ten years have passed since that day, and numerous miracles have transpired – too many to mention here. I have changed. I see the world differently now – by the light in my children's eyes, by the glow in their countenance, by the brilliance in their soul. And through that light, I see myself, a mother who is *not* a failure. A mother who is proud – honored even – to have children with disabilities. A mother who counts it a privilege to be different. A mother who sees the beauty in imperfections, and the flawless in the fragile.

A “few lines”? Maybe not. And maybe there's a lot more that has yet to be written. In fact, I know there is. Jaede, Quinn, Shale, Faith, and Psalm are still teaching me...

## Membership

Are you a member of the Fragile X Association of Southern California?  
If not and would like to be a member just send us an email or call us with your information and you will soon receive information about conferences, support group meetings, family fun days and more. There is no fee to become a member, but we do ask for a donation of \$25.00 a year.

Email: [info@fraxsocal.org](mailto:info@fraxsocal.org)  
Voicemail: 818-754-4227

### Information required:

- Name(s)
- Address, City and Zip
- Email address and phone number
- Name and age of child(ren) with Fragile X

**Member information is never released to anyone. All email addresses are confidential.**

## **Share a Story**

Feeling creative? Or, got some great FX-related news?  
Share it with us!!! We'd love to have you write an article for our newsletter!!!  
Please email your personal stories and pictures to [info@fraxsocal.org](mailto:info@fraxsocal.org)

## Informative Web Sites

Below are some websites where you can get more information about  
Fragile X Syndrome.

### Clinics:

*Stramski Developmental Center at  
Miller Children's Hospital*  
2650 Elm Ave Suite 301  
Long Beach, CA 90806  
Phone: 562-424-4815

U.C. Davis M.I.N.D. Institute  
Fragile X Clinic  
2825 50th Street  
Sacramento, CA 95817  
Phone: 916-703-0238  
Website: [www.ucdms.ucdavis/mindinstitute](http://www.ucdms.ucdavis/mindinstitute)

### Additional Organizations:

National Fragile X Foundation  
P.O. Box 190488  
San Francisco, CA 94119-0488  
Phone: 800-688-8765  
Website: [www.FragileX.org](http://www.FragileX.org)

FRAXA Research Foundation  
45 Pleasant Street  
Newburyport, MA 01950  
Phone: 978-462-1866  
Website: [www.fraxa.org](http://www.fraxa.org)



### **Mission Statement**

Our organization was formed to promote public awareness of Fragile X Syndrome with special emphasis on educators and health professionals; provide a forum for families of children with Fragile X to meet and share their ideas, concerns and problems; and support scientific research on Fragile X Syndrome.

The Fragile X Association of Southern California is run entirely by volunteer parents of children with Fragile X Syndrome. We are a non-profit 501 (c) (3) tax exempt corporation. Your tax deductible donations help support our mission and are gratefully accepted.

**FOR MORE INFORMATION, PLEASE VISIT US AT [fraxsocal.org](http://fraxsocal.org)**

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