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FRAGILE X PRESS

Fragile X Association of Southern California

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Dear Members,

This last month has been so incredible that I don’t even know where to begin. Let me start, though, by thanking each of you for all the help and support we received in premiering “Living with Fragile X.” The screening was held on April 18th at the Barnsdall Gallery Theatre. It turned out to be a wonderful event, almost like a family reunion. Several of our families, old and new, traveled long distances to come see the documentary and it was great to catch up with everyone.

The documentary showed the many sides of Fragile X and touched everyone. We asked some of our families and members to share their perspective of the documentary, which we have included in this issue. It was also an honor to be presented with a certificate of appreciation from the office of State Senator Dennis Hollingsworth. He is the sponsor of California Fragile X Awareness Day, which was officially observed on April 14th at the State Capitol. It is wonderful to know that our efforts in promoting awareness of Fragile X are not going unrecognized.

I would like to again thank all of the volunteers, especially The Chad Wackerman Trio, who volunteered their music and time and really brought the event to life. Also, my deepest appreciation goes out to Keesal, Young, & Logan for the fantastic food, drinks, and service. They went well above our expectations and made our event a true Hollywood premiere!

In addition to the screening, FRAXSOCAL has been busy attending community events, including the “Walk Now for Autism” fundraiser in Pasadena and the Parent’s Place Information Fair and Festival in West Covina. Both of these events were opportunities to talk to families about Fragile X and testing.

Finally, I want to remind you that our annual yard sale is coming up. I hope that many of you will be able to participate by either dropping off items to sell or volunteering that day. Not only do we fundraise but we also raise awareness of Fragile X by distributing information and talking to visitors about what Fragile X is and how it affects our families. You know you have touched someone’s heart when they don’t haggle and add a donation on top of the asking price.

We hope to see you at our events and please feel free to contact me about any ideas or stories you would like to share in our July newsletter. Take care and best of luck ending the school year on a positive note.

Janet Rivera, President

Upcoming Events

- Family Conservator Day - Saturday, May 30th
- 4th Annual Fundraising Yard Sale - Saturday, June 13th
- Fiesta Educativa - Monday, September 21st

“Living with Fragile X” Premiere

By Sali Farber, FRAXSOCAL Boardmember

On Saturday, April 18th we presented the documentary “Living with Fragile X” at the Barnsdall Gallery Theater in Los Angeles, California. The event was very well attended with over 130 people. The venue was wonderful, the food fantastic, and the entertainment enriched the setting.

Both of my “young adults,” Eric and Richelle, were brave enough to be part of this wonderful documentary that shows the strengths, challenges and different functioning levels of people affected by Fragile X Syndrome. Kathy Elder and Greg Mishey, the producers, did a wonderful job in portraying these differences. Through the participation of several families the documentary enabled them to show a broad range of ages, different school programs, work, sports activities, adult living options and how families are able to deal with the affects of Fragile X.

The documentary showed photos of Eric starting at about 6 months, his achievement during his Bar Mitzvah, moving day and how he functions in his apartment on his own. Eric is now 27 years old and lives on his own, works part time at a sporting goods store and gets additional support from an outside agency funded by the regional center to help with his independent living skills.

Richelle just turned 24 and has reached her milestone of wanting to live on her own. She moved out on April 11th. Richelle drives, has taken classes at a local community college, works at JC Penny and so far we have not had any midnight calls to come rescue her. However, she had lunch with me three times last week, came for dinner, had us over for dinner and spent the weekend with us. This is going to be a transition for her as well as us, as she does not get services from regional center.

The importance of this documentary was to provide public awareness about Fragile X in a way that was not textbook medical information, but something that was easy for the public to understand. Through this documentary we hope that more families will be tested, research will continue and eventually find a “cure” or at least provide a treatment that will help enrich the lives of people affected by Fragile X Syndrome.

It was a pleasure being part of this documentary and I thank the producers, committee that organized this event and all the other families involved for giving of their time and allowing their children and young adults to participate in this informative documentary.



Music by The Chad Wackerman Trio delights the crowd.



On behalf of FRAXSOCAL, Janet Rivera accepts a certificate of appreciation from the office of State Senator Dennis Hollingsworth.



Panelists, Neal and Carolyn Robb, Greg Mishey, Kathy Elder, Deborah LeCover, and Sali and Jeff Farber, respond to audience questions.

“Living with Fragile X” Premiere — Family Perspectives

Congratulations and thank you to all who are responsible for planning and organizing the “Living with Fragile X” premiere! The evening could not have been better and was truly a memorable event. The Barnsdall Gallery Theatre was a perfect location, overlooking the city of Los Angeles with a breathtaking view. The music, food, drinks and overall ambience was just perfect. What followed was even more amazing once we were escorted into the theatre. Socializing with all the wonderful people made me realize more than ever what a beautiful extended family we are honored to be apart of. The premiere was so enlightening...the tears that started to form quickly made me aware of all the others, not just my dear family. I know there is so much to learn and to be aware of. I give so much love, consideration, and credit to not only my son and daughter-in-law (Jack and Jacqueline Blanco), who are such wonderful parents to my lovely grandchildren Alexis and Justin ... but also to all the wonderful families affected with Fragile X Syndrome. The bond and support of all, that I saw and felt, will definitely help the concerns and mutual problems of our families. Once again, I thank you for this “heart wrenching” evening, for allowing me to share with others, and for putting into words our life story! I left the theatre knowing that we are not alone, that we have extended family with the same obstacles and that we are very fortunate to have ongoing research and support. We will continue to enjoy, cherish, appreciate and love Holland!! Thanks for allowing me to share & God bless you all.

Laura V. Blanco, Grandmother of Alexis & Justin Blanco

As parents of three recently diagnosed children with Fragile X Syndrome, we viewed this premiere as an opportunity to educate our friends and family. Our party of eight arrived to appetizers and a full bar while The Chad Wackerman Trio surrounded us with music. We also enjoyed the raffles, but were disappointed to not bring home the CSI scooter. The cocktail hour gave us some time to talk with other parents about their experiences.

The documentary showed the lives of several families and followed up with those families after three years. It also showed people from early childhood through adulthood, demonstrating how the disorder affects people throughout their lives. The movie showed that we should appreciate the journey with our children even if it is not exactly how we envisioned it when we set out. The documentary also followed some of the research beginnings with the discovery of the gene that causes Fragile X Syndrome at Emory University in 1991 by Dr. Steve Warren's team. The film followed the families to doctor's appointments at the UC Davis MIND Institute. Since our children will be seeing the Hagermans' in May, we feel like we know them already from the film. The scientists were all hopeful that a cure or an effective treatment is on the horizon.

The panel discussion made the evening especially memorable. Parents on the panel offered further insight and updates on their children. The most powerful message from the comments was the need to spread awareness of Fragile X Syndrome as it is not well known in the medical community or the community at large. As a result, Fragile X is under diagnosed. As we all know, the earlier we can accurately diagnose the problem, the more effective the intervention can be. We all owe a great deal of gratitude to Kathy Elder and Greg Mishey who spent a lot of time and effort putting together this thoughtful documentary. They mentioned that the documentary will soon air on the PBS station in San Francisco, and we all hope that it will eventually air throughout the nation and the world in an effort to raise awareness.

The evening showed us in depth how Fragile X affects families and gave us the opportunity to network and get to know other families who are affected. It also helped us raise awareness among our friends and family.

Jared Chao, FRAXSOCAL Member

Me siento muy contenta de haber tenido la oportunidad de asistir a este evento. Disfruté del ambiente familiar durante la recepción y el documental me pareció fascinante. Por primera vez pude ver a otras familias con niños afectados y darme cuenta que sus situaciones son muy parecidas a la de mi familia. El documental me ayudo a ver un punto de vista diferente. Como abuelita de dos niños con el Síndrome de X Frágil, muchas veces me he sentido triste porque yo soy la que se lo pase a mi hija y después ella a mis nietos. Ahora me doy cuenta que es más importante enfocarse en el presente y en la posibilidad de una cura. Soy una persona religiosa y una de las cosas que le pido a Dios es de que mis nietos puedan crecer y ser independientes y que sean felices. Me siento satisfecha de saber que yo también estoy poniendo de mi parte para que esto se logre. El documental también me ayudo a ver las cosas del punto de mi hija. Yo se que esta situación a sido difícil para ella y su esposo. Los admiro por la paciencia y dedicación que le tienen a mis nietos y yo se que con amor lograremos nuestras metas. Muchas gracias por darme la oportunidad de compartir mis sentimientos.

Margarita Carvajal, Abuelita de Christian y Alex Paez

These moms know true love

Mothers face tough challenges in raising children with disabilities, but there are rewards in the role.

By Sandy Banks

Los Angeles Times - May 9, 2009

Deedra Williams doesn't need breakfast in bed or a spa massage to celebrate Mother's Day tomorrow. She received her gift last weekend at a quiet Montecito retreat from 15 women who, like her, are mothers of children with disabilities. They hiked eucalyptus-shaded hills, listened to music and made collages with pictures cut from magazines. They talked for hours about the challenges of mothering children who may never be able to walk or speak, to go off to college or get married.

And everyone knew better than to interrupt, criticize or offer advice. "No one tried to fix it here," explained Williams, a mother of two sons -- a "developmentally typical" 7-year-old, and a 14-month-old whose newborn jaundice left him with brain damage, hearing loss and cerebral palsy. "We can relate to what each one is going through because we're all in the same boat," Williams said as we sat at table at La Casa de Maria Retreat with four other mothers. "What I took away from this weekend," Williams said, "is acceptance."

And what I took away was a new appreciation for the unconditional mother-love that many of us give lip service to, as we continually push our children to improve themselves, carrying around our mental check-list of all their shortcomings. Raising a disabled child requires a sort of hyper-vigilance. "Motherhood amplified," Nina Loh called it, describing life with her 7-year-old twins -- a "typical" daughter and a son with spina bifida, who has had 13 surgeries and may need more. "The stakes are so high. And there's really no end in sight."

Woodland Hills therapist Diane Simon Smith knows the feeling well. The mother of two disabled sons, she began offering "Healing the Mother's Heart" retreats six years ago, to give women a safe place to vent "the anger, the guilt, the joy . . . all the feelings." Smith's first child was born weighing less than 2 pounds. He was blind, mentally retarded and was never able to "walk, talk, sit, use his hands or feed himself," she said. He died of pneumonia at 17. His brother, two years younger and now 21, was born with Fragile X Syndrome, an inherited disorder that causes severe cognitive and behavioral problems.

I asked Smith if she felt cheated, robbed of some of the joys of motherhood. Not *cheated*, she said, with its implied resentment and bitterness. Just sad, sometimes, "when I hear my friends talking about what their kids are doing . . . going off to college, getting married."

Every woman around the table talked of feeling isolated, separated from the larger sisterhood of mothers. "I never wanted to be different," said Eileen Sunderland, whose 7-year-old son has autism. "I wanted to fit in. . . . But you can't go to lunch with all the moms at pre-school. You can't meet them in the park, because you always have a therapy appointment or a doctor visit to get to." And what do you talk about, anyway, with a mom who complains that her daughter wants pricey True Religion jeans, when you're trying to get your son to stop flapping his hands like wings.

Still, some said their children's diagnosis provided an odd sort of relief -- a validation of a mother's instinct that something was wrong, or a vindication of their parenting. "I thought I was an inadequate mother," recalled Lisa Hannifin, whose 4 1/2 -year-old son was diagnosed with autism. "I wondered 'Why am I so stressed out? Why can't I take my boy to the market?' Other kids sit in the cart and behave. There must be something very wrong with me."

For others, the verdict triggered fear, panic and disbelief. When her daughter, now 5, was diagnosed with autism three years ago, Julia Gosnell "was hyperventilating into a paper bag for 10 minutes." Gosnell had every prenatal test her doctor offered during her pregnancy, "because I did not want a child with a disability," she said. "I really considered myself too selfish. . . . I was a workaholic . . . not really cut out for raising kids."

But children can stretch a mother's boundaries. Since November, when Gosnell was laid off, she has been a stay-at-home mom. Last week, the child she once feared might not speak said, "Mommy, I want to teach you a magic trick." Tears spilled down Gosnell's cheeks as she shared the story. "Her progress has been so astounding in the last seven months, and everybody agrees it's because I'm home working with her. . . . I've learned about patience and love and how to give myself to someone else." And about how important a mother is to her child.

I had to admit on my drive home that I had visited the retreat to turn those moms into an object lesson. I envisioned this column as a reality check for mothers like me -- a "see, it could be worse" reminder to count your blessings this Mother's Day. But it was their spirit, as much as their stories, that took me down a different path.

The way every description of a child's disabilities also included the strengths their mothers see: The beautiful smile, the sense of humor, the determination, the innocence. The way they never labeled their other children "normal," just "developing typically."

How much freer would we all be to love if we could let go of our preconceived notions of what our children should do or be? If I worried less about my daughter's tattoo and appreciated her sense of humor more. Or focused less on the "C" in statistics class and more on the hard work she put in to earn even that. These women are not saints or martyrs. But they see gifts where others might see only hardships.

"Write this column for *them*," Smith told me, as the mothers packed their cars to head back to their families. They are not looking for pity or praise, just acceptance of their challenges. "We're not special," she said. "We're just human beings, doing what we do with love."

Just like every other mother.

sandy.banks@latimes.com

SPREADING THE WORD ABOUT FRAGILE X SYNDROME

Training Program Lecture on Fragile X

On March 18th I was asked to present to USC's University for Excellence in Developmental Disabilities (UCEDD), Children's Hospital Los Angeles, and the Leadership Education in Neurodevelopmental and Related Disorders (LEND) training program. I was one of several speakers on genetics issues including a genetics counselor and a nurse specializing in newborn screening for genetic disorders. My focus was on the parent perspective and obstacles to accessing services, sibling issues and how the diagnosis affects other family members. The audience of thirty students included dental interns, speech and language pathologists, physician interns and parent advocates. I presented each one with a folder full of our brochures and flyers, our newsletter and the Foundation quarterly.

Mary Seward, FRAXSOCAL Treasurer

Parent's Place 16th Annual Information Fair and Festival

I was very happy to have manned a table at the Information Fair and Festival sponsored by Parent's Place on Sunday, April 26th in the City of West Covina. With the help of my mother-in-law, Esther Torres, our afternoon was spent educating families about Fragile X Syndrome. Not only did we have the opportunity to talk to families but we also provided information to staff from different agencies who participated in the event and were not aware of Fragile X. The association's brochures and flyers made it much easier to explain Fragile X, especially to families who only spoke Spanish.

We ended the afternoon after speaking with a family with a set of older adult twin boys who had Fragile X Syndrome. The family wanted to get more information on how to help their boys and we were able to give the parents some resources. It was great to be able to assist this family and other families at the event and know that we are meeting our mission statement goals by promoting awareness about Fragile X Syndrome and helping affected families.

Janet Rivera, FRAXSOCAL President

Autism Speaks' Walk Now For Autism

For the 5th year (WOW time goes by fast!), Neal Robb, Aaron and I manned a Fragile X booth at the Walk for Autism. Approximately 15,000 people attended the walk and raised **\$1,015,947** for Autism awareness, advocacy, and research. The event was held at the Rose Bowl in Pasadena and featured a number of celebrities, including actress, parent and autism advocate, Holly Robinson Peete, "Days of our Lives" (my favorite soap! they even have a story line with a child diagnosed with Autism) cast members James Reynolds, Bryan Dattilo, Terrell Ransom, Jr., and Dylan Patton, United States Congressman Adam Schiff, Los Angeles City Councilman Dennis Zine, and James Denton from "Desperate Housewives" along with local bands and dancers.

We talked to hundreds of people about the famous question "What is Fragile X?" Every year more and more people are open to hearing about a genetic cause of Autism. We try to give as much information on Fragile X as the parent/caregiver/professional will endure listening to us talk. Information ranges from: what Fragile X is, how Fragile X and Autism are related, Tremor Ataxia, and POF. For those families with a Fragile X diagnosis we have on hand pamphlets on the MIND Institute and specific educational strategies on occupational therapy and speech and language needs. It is always nice to talk to families and network with caregivers and professionals. We all had a good time and look forward to spreading the word again next year!

Crissy Finney, FRAXSOCAL Boardmember



IT'S YARD SALE TIME!



Yes folks, it's that time of year again. Get ready to clear out your cupboards for a cause! The 4th annual FRAXSOCAL yard sale is just around the corner and we need your help to make this the biggest year yet. All you need to do is put aside anything you would normally be donating to places like the Goodwill, label it with a price (we try to make things pretty reasonable - after all, we don't want anything left over) and bring it with you as early as you can on Saturday, June 13th. Be prepared to haggle with customers, talk about Fragile X all day, eat lots of donuts and have a ton of laughs. All the money we make goes directly to the Association to help fund things like our family activities, newsletter costs, bringing experts to LA for seminars and other important FX-related goals. For more information, call Naomi Star at (562) 434-2791.

Date: Saturday, June 13th

Time: Crack of dawn (6:00am onwards)

Place: 5300 E. Broadway, Long Beach, CA 90803

Los Angeles Superior Court and Bet Tzedek, the House of Justice,
invite you to the second annual

Family Conservator Training Day

When: Saturday, May 30, 2009 from 10am to 1pm

Where: Ahmanson Senior Center (Exposition Park)
3990 S. Menlo Ave, Los Angeles, CA 90037

Who should attend:

All family conservators who wish to learn more about being a conservator, what resources are available, and how to connect with other conservators.

Lunch will be provided. Please RSVP by emailing Terese Bledsoe at tbledsoe@bettzedek.org or by calling (323) 549-5884.

Funded by the Los Angeles Superior Court in collaboration with Bet Tzedek Legal Services.

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
Voicemail: 818-754-4227

Information required:

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

Member's 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 at info@fraxsocal.org

Informative Web Sites

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

Clinics:

UCLA Behavioral-Genetics Clinic
UCLA Psychiatry & Biobehavioral Science
BOX 951759, 58-24C NPI
Los Angeles, CA 90095-1759
Phone: 310-794-9516
Website: www.liliclairefrfc.ucla.edu

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

Additional Organizations:

National Fragile X Foundation
P.O. Box 190488
San Francisco, CA 94119-0488
Phone: 800-688-8765
Website: www.fragilex.org

FRAXA Research Foundation
45 Pleasant Street
Newburyport, MA 01950
Phone: 978-462-1866
Website: 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 nonprofit 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**

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