Hello everyone,

I would like to start out by thanking all of the wonderful families who attended our first family fun day event of 2009. The movie was great and the theater did a fantastic job accommodating us. It was really nice to meet new families and catch up with our old ones, too. Thank you again to the Blancos for another successful event.

Also, the Southern California premiere of the documentary “Living with Fragile X” will be on Saturday, April 18th, 2009 at the Barnsdall Gallery Theatre. We have an incredible night planned, including live music, food, drinks, and a panel discussion after the screening. Seating is limited, so hurry and buy your tickets.

Finally, I would like to take this opportunity to encourage you to share your stories with your local representatives. As we all know many of the Regional Centers and other service providers in Southern California are facing budget cuts that might affect your families. Although it sometimes seems impossible that we could affect change, it’s important that representatives know about FX and how much services are needed. Together we can make a difference!

Janet Rivera,
President

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**Upcoming Events**

- “Living with Fragile X” Premiere
  Saturday, April 18th, 2009

- 4th Annual Fragile X Fundraising Yard Sale
  Saturday, June 13th, 2009

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**FRAXSOCAL will be at the following event:**

- Sunday, April 26th from 1pm-4pm
  “Information Fair & Festival”
  Cortez Park
  2441 E. Cortez Street
  West Covina, CA 91791
FRAGILE X ASSOCIATION
OF SOUTHERN CALIFORNIA

Presents

“Living with Fragile X”

A documentary that takes a rare and intimate look at the lives of several families who live with a loved one affected by Fragile X Syndrome.

At the
Barnsdall Gallery Theatre
4800 Hollywood Boulevard
Los Angeles, California 90027

Saturday, April 18th, 2009

6:00 pm – Food, Drinks, and Live Music
FRAXSOCAL Prize Drawing: $5 per ticket

7:30 pm – Screening followed by a Panel Discussion with the filmmakers and some of the families and professionals featured in the documentary

Price per person: $40.00

Parking is free. Seating is limited.
Tickets are available at the Barnsdall Gallery Theatre ticket website at www.bgttix.com.
For more information visit www.fraxsocal.org or call 818-754-4227.

Thank you to Keesal, Young & Logan for their generosity and support of this event.
Fragile X Research Study

A research study is being conducted with an investigational medication for people with Fragile X Syndrome who have trouble with moodiness, irritability, tantrums or aggression.

Children, adolescents, and adults, ages 6-20 are potentially eligible.

Several research centers across the United States are participating in this trail, including a center located in Los Angeles and a center in Sacramento.

For additional information, please visit:
www.clinicaltrials.gov
Identifier: NCT00788073

Name of Study: Safety, Tolerability and Efficacy Study of STX209 in Subjects with Fragile X Syndrome.

Sponsored by Seaside Therapeutics, LLC

STATE BUDGET CRISIS AFFECTS REGIONAL CENTER SERVICES

Unless you have been living in a bubble then you are not aware that the state is slashing funding to the developmentally disabled of California. The Department of Developmental Services is asking for our input to consider ways to lower the budget by $100 million in addition to the 3% cut in operating costs and to community service providers. The services the Regional Center provides, enables each and every individual to reach their full potential while maintaining the family unit. By allowing our elected officials to compromise the services our children receive then as parents, guardians, family members and advocates, we have shunned our responsibilities.

We urge all of you to contact your Senator, Assembly member and the Governor and remind them that they too have a responsibility to the 240,000 developmentally disabled California citizens that they vowed to protect. When calling your legislators, state your name and address. Identify yourself as one of their constituents. Share your personal situation and be brief and to the point.

Procrastination will allow these policymakers to decide for us without being heard. The consequences of your inaction will further cripple the disabled community. Your voice must be heard, loud and clear as the future of the Lanterman Act depends upon it. It is our obligation.

We will be sending out an e-mail on how to get more in depth information on different ways to make the budget cuts from the Department of Developmental Services. These cuts have already been approved, but which part of the DDS takes the cuts is yet to be decided. You can also obtain more information at www.arccalifornia.org and click on 2009 Budget Tool Kit. If you are not already on our e-mail list please send us an e-mail to: fragilexassociation@gmail.com to be added to it.
A Fragile X Christmas by Naomi Star

My son James and his friend Daniel first met each other about eleven years ago. Daniel’s mother Hazel Richardson and I were serving on the Board of the Fragile X Association of Australia. We were both fairly new to Fragile X and were feeling our way through the early days of the diagnosis. Finding we hit it off, we began socializing outside of meetings and soon our families became close.

Both James and Daniel have many autistic behaviors on top of their Fragile X, making it hard for them to communicate with friends. But we discovered that they seemed to have intense radar when it came to communicating with each other. They were both interested in the same activities, games and DVDs, and could spend many hours together happily playing and making each other laugh. The boys often enjoyed sleepovers together and would spend half the night laughing at each other.

So, it was with sadness that we bid the Richarsons farewell when we moved to California almost five years ago. We knew James and Daniel would miss each other and might not find the same sort of connection with other friends.

Much to our surprise and delight, Hazel and her husband Neil announced that their family of five would be traveling to L.A for a vacation this past Christmas. They planned to stay somewhere nearby in Long Beach so the boys could see each other a lot, besides their other sightseeing. After some discussion, my husband and I decided it made more sense for the Richarsons to stay with us. That way the boys could hang out, the family would have more room than in a hotel, and it would be fun!

Oh yes – we also had my mother visiting from Sydney at the time, so there was the slight problem of fitting ten people into a three-bedroom house, cooking and serving Christmas dinner for twenty people (other relatives joined us on the day), keeping the noise level down to a reasonable level and worrying about whether our aging water heater would hold out. Not to mention keeping a lid on the almost certain explosion of anxiety that a household full of Fragile X carriers could result in!

In the end, things went pretty well. Between jet lag, tons of sightseeing and all the excitement, our visitors were fairly laid-back when they were at home. The boys warmed up slowly at first, but after a while settled back into their comfortable, but now more mature, friendship (not as many silly noises, thank goodness). Several times during their stay we split up so everyone could pursue their favorite activities: for James, Duncan and his younger brother Angus this meant arcades, parks and train spotting among other things. It was wonderful for all of us to see the boys reconnect, and great to reestablish our bonds as families. It was a Christmas we will never forget, and if the Richarsons are brave enough to do it again, we look forward to their next visit.

Update from Washington, D.C.

Representative Gregg Harper (R—MISS) launched a Public Service Announcement today in support of his 19-year-old son, Livingston, who lives with Fragile X and the National Fragile X Foundation Advocacy Day held Wednesday, March 4th.

"As the only member of Congress who has a child with Fragile X, I understand the challenges that face thousands of families who experience this condition," said Congressman Gregg Harper. "My wife, Sidney, and I are committed to making sure there is increased awareness and funding to help those families who are blessed with a child with Fragile X.

The NFXF is on Capitol Hill with 130 advocates from 35 states with one goal: to secure the resources necessary to find more effective treatments and ultimately a cure for Fragile X."
Family Fun Day at the Movies

On Saturday, February 28th we held our Family Fun Day Movie Matinee. The event took place at the Mann Village 8 Theatre in Westlake Village. It was an exclusive viewing of the blockbuster film by DreamWorks “Hotel For Dogs.” Our members came from near and far to have a great time and were not disappointed. A total of 51 members enjoyed snacks (popcorn, candy, drinks), a great movie, and most of all the togetherness we all long for.

It was a comfortable setting for all in a theatre that seats 150, and our families had the best seats in the house. Parents were able to converse before/after the viewing and several families exchanged contact information. The children enjoyed themselves and it was truly a memorable experience.

Now, it’s back to the drawing board, brainstorming, and planning our next event. We look forward to sharing and seeing you at our next Family Fun Day!

Jack & Jacqueline Blanco

Day at the Movies by Josephine DeFelice-Smith

Today I saw Fragile X for the first time. I attended a Family Fun Day for the So Cal Fragile X Association. We went to a free showing of Hotel for Dogs. It was hard, but at the same time, not. When I considered going I was scared, because besides my son, I haven't ever met anyone with Fragile X. With my son I really can't tell yet, so I was worried about what I would see, how it would look, what the behaviors would be like.....I didn't know if I was ready for the reality of what Fragile X is really like. I'm so glad I went.

It was hard "seeing" what it meant to have Fragile X, but there were so many degrees of severity. I realize now that so many times I've probably seen people with Fragile X and didn't realize that's what it was. It's funny how they are all so different, yet somehow all very similar. Some of the kids were hilarious. When I got home my husband asked how it was. I told him it was hard but wonderful at the same time. He can handle the various behaviors, etc, but his biggest worry are the tantrums we hear so much about. He's a man who loves going to restaurants, etc, and worries his life is going to drastically change. (Well....I told him to get ready cause it is!) He asked if any of the kids had any. There was one boy in front of me who was having a hard time. When I told him, yes, that there was one, he looked sad. But what was so amazing to me, and what I told him, was how no one bothered to even look. It was just so matter of fact. I loved that. I also told him that out of the entire room, there was only one tantrum and the rest of the kids in the group were laughing and enjoying themselves.

When the movie was over, one boy stood up and shouted, "Movie dismissed!" It was so sweet. My husband looked so relieved. I reminded him that our "normal" kid has more tantrums than we can count. I guess what's scary to him (and me, too) is that the terrible 2s/3s seem to just last a little longer. No matter how they were, however, it was obvious that they were all so loved by their family members around them. I met so many wonderful parents who are envious that I know so early. I am lucky to have the knowledge about my little guy. I know for many parents the hardest part is just getting a diagnosis. I will never have that worry, and for that I feel blessed. And I also wonder if how he is as a baby has any indication for how he'll be later. Who knows? I know he is going to be who he is and I will love him unconditionally. I hate myself sometimes for harping on it.

As a follow-up to her article about Marriage in the last issue, Diane S. Smith, MFT is interviewed by Disability Scoop, an online resource for special needs concerns. Visit disabilityscoop.com for the interview and responses to readers’ questions.

(See Page 6 for Diane’s “Healing the Mother’s Heart” retreat.)
Give yourself an early Mother’s Day gift. It will be a gift to your loved ones as well.

“Healing the Mother’s Heart”
A Retreat for Mothers of Children with Disabilities
at
LA CASA DE MARIA RETREAT CENTER
in beautiful Montecito (just south of Santa Barbara) on
Saturday, May 2, 2009, 9:30 am to Sunday, May 3, 2009, 12 noon

In the struggle to cope with the grief of having a child with disabilities, and “leaving no stone unturned,” many women find themselves depleted, burned out, or neglecting their own needs. Indeed, sometimes the very meaning of life as they once knew it has been challenged.

Through music, personal sharing, art, meditation, and the compassionate understanding of a community of women in similar life circumstances, this retreat will provide a safe atmosphere in which to explore your lost dreams and face the struggle to rebuild new ones. Surrounded by the peaceful beauty of nature, we seek to soothe the soul, mend the heart, and take away tools for living.

Facilitated by: Diane Simon Smith, MPH, MA, MFT
Cost: $250 (includes lodging, 3 meals, and snacks)

To register, please complete and return the form below by April 7th.

Diane Smith brings unique personal and professional experience to her work with families of children with special needs. She holds Masters degrees in Public Health and in Marriage and Family Therapy. As a Licensed Marriage & Family Therapist, she works with parents as they struggle with issues of loss and rebuilding new meaning while raising a child with disabilities. She leads parent and sibling groups, is a frequent presenter at workshops on families and disability. Her own two challenged children have been her greatest teachers.

Space is limited! Register early! Please return by April 7th (Call Diane at (818) 888-1524 for questions)

Name:____________________________________________________________________
Address:________________________________________________________________
City: ___________________________ Zip:____________________________
Telephone Home:__________________________ Work:__________________________
E-mail: __________________________________________________________________
Emergency Contact:________________________________________________________
Nature of child(ren)’s disability:______________________________________________
Age of Child(ren):__________________________________________________________

Mail this form and a check for $250 (by April 7th) made payable to:
Diane Simon Smith
20750 Ventura Blvd., Suite 245
Woodland Hills, CA 91364
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 address 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 picture at info@fraxsocal.org

Informative Web Sites

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

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<th>Clinics</th>
<th>Additional Organizations</th>
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<tr>
<td>UCLA Behavioral-Genetics Clinic</td>
<td>National Fragile X Foundation</td>
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<tr>
<td>UCLA Psychiatry &amp; Biobehavioral Science</td>
<td>FRAXA Research Foundation</td>
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<tr>
<td>BOX 951759, 58-24C NPI</td>
<td>P.O. Box 190488</td>
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<tr>
<td>Los Angeles, CA 90095-1759</td>
<td>San Francisco, CA 94119-0488</td>
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<tr>
<td>Phone: 310-794-9516</td>
<td>Phone: 800-688-8765</td>
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<td>Website: <a href="http://www.liliclairefrc.ucla.edu">www.liliclairefrc.ucla.edu</a></td>
<td>Website: <a href="http://www.FragileX.org">www.FragileX.org</a></td>
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<tr>
<td>Fragile X Clinic</td>
<td>FRAXA Research Foundation</td>
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<tr>
<td>2825 50th Street</td>
<td>45 Pleasant Street</td>
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<tr>
<td>Sacramento, CA 95817</td>
<td>Newburyport, MA 01950</td>
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<tr>
<td>Phone: 916-703-0238</td>
<td>Phone: 978-462-1866</td>
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<tr>
<td>Website:www.ucdms.ucdavis/mindinstitute</td>
<td>Website: <a href="http://www.fraxa.org">www.fraxa.org</a></td>
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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
www.fraxsocal.org

Fragile X Association of Southern California
P.O. Box 6924
Burbank, CA 91510-6924