Hi Everyone,

Can you believe that we are halfway through the year? Well, with your continued support we have been busy with different events these last couple of months and there is still more to come before the year ends.

One of our upcoming events includes our 7th Annual Yard Sale in the City of Long Beach. FRAXSOCAL Board members and volunteers gather bright and early to help raise money to support our Fragile X community. For more information and to find out how you can help with donations, please see page 2.

Another activity that is coming up is our next Family Fun Day event in the month of August at Grant Rae Park in Montebello. Please join us in celebrating great summer fun with a barbecue and a free entrance to the petting zoo. See page 4 for more information. We hope to see you all there!

As always, another major focus of our group is to continue to spread awareness of Fragile X syndrome. We are very proud to say that Board members Aaron and Crissy Finney once again attended the Walk Now for Autism Speaks event at the Rose Bowl in Pasadena. They have attended every year since 2002! We are very thankful for their ongoing support and commitment to raising awareness of Fragile X syndrome. Don’t miss their wonderful article on Page 6.

Other upcoming community events are listed below. These events offer an opportunity to talk to other parents and service providers about Fragile X. If you happen to be in the area or attending the event, be sure to stop by to say hello!

The 12th International Fragile X Conference is coming up in the month of July in Miami and I hope to see some of you there. Several FRAXSOCAL Board members will be attending the conference. If you are planning to attend, please let us know. It would be great to meet all of the Southern California families.

I hope you all enjoy our June newsletter and hope to see you at one of our next events.

Thanks again,
Janet Rivera, FRAXSOCAL President

Visit FRAXSOCAL’s booth at the following events:

**3rd Annual Let’s Move Too!**
Saturday, June 23, 2012
Personal Involvement Center
8220 S. San Pedro,
Los Angeles, CA 90033
For more information visit:
www.LetsMoveToo.com or www.picservices.org

**Stephanie’s Day Resource Fair**
Saturday, July 14, 2012
CBS Studios
4200 Radford Ave.
Studio City, CA 91604
For more information visit:
www.cbsLA.com/stephaniesday
7th Annual Yard Sale

Our annual fundraising yard sale, hosted by FRAXSOCAL Board member Naomi Star along with Diane Bateman, is just around the corner and we need your help to make this the biggest event of the year!!!

Put the date on your calendar and start clearing out those closets and garages!

Donations will be accepted on the day of the yard sale. (Items must be already priced.)

Date: Saturday, June 16th
Time: 8:00am to 2:00pm
Place: 5300 E. Broadway, Long Beach, CA 90803

All the money we make goes directly to FRAXSOCAL to help fund research studies, family activities, newsletter costs, educational workshops and other important FX-related goals.

For more information, please email Naomi Star at naomifstar@yahoo.com
Fragile X Genetics and Drug Study Presentation

On May 13th, FRAXSOCAL welcomed Genetic Associate, Louise Gane, from the MIND Institute at UC DAVIS and Medical Director, Dr. Gary Feldman from the Fragile X Clinic at the Stramski Children’s Development Center in Long Beach. Louise gave a very informative presentation on Fragile X, which included testing for Fragile X, how it passes on from one generation to another, and information on other related disorders such as FXTAS and FXPOI. Dr. Feldman then joined Louise for a panel Q&A session where they answered questions about the latest research, drug studies, medications, and offered practical suggestions for families on addressing behavior and other issues. They also addressed questions about reproductive options for carriers and their families. As always, the presentation and discussion were amazing and very helpful. We would like to thank Ms. Gane and Dr. Feldman as well as everyone who attended this event. We would also like to thank United Labor Bank for their generous donation of lunch and Maria Carvajal for the wonderful cupcakes. If you would like to get a copy of Ms. Gane’s presentation, please let us know and we will email or send you a copy via regular mail.

13th International Fragile X Conference

July 25 to 29, 2012
Miami, Florida
Hosted by the Florida Fragile X Families

Why should you attend the conference:

- Discover the latest research by some of the world's leading Fragile X experts.
- Learn new techniques, behavioral interventions and coping strategies.
- Connect with researchers clinicians, educators, psychologists and parents.

For more information please visit the National Fragile X Foundation website at www.fragilex.org
“Save the Date” for the End of Summer BBQ Party

When:  Saturday, August 4, 2012
Where:  Grant Rae Park (Barnyard Zoo)
        600 N. Rea Driver
        Montebello, CA 90640
Hours:  11am to 3pm

Join us in celebrating the final days of summer with a family fun day barbeque.

Chef Jack will serve free burgers, hot dogs, chips, and refreshments.

Free entrance to the petting zoo.

For directions visit:
www.cityofmontebello.com
(Parking is free)

RSVP:
Jack and Jacqueline Blanco
951-656-5291 or blancojj@verizon.net

For more information visit us at:
www.fraxsocal.org
Two juniors from the Orange County High School of the Arts, Madi Wackerman and Lauren Chong started a club this spring semester called the Fragile X Awareness Club. It is focused on inspiring the youth at their high school to get involved in the Fragile X community as well as raise awareness and money to support the Fragile X Association of Southern California. Madi has a personal connection to Fragile X Syndrome through her cousin, James Wackerman, and she has learned about it through her family. In speaking with fellow students at her high school, she realized that many people were unaware that Fragile X Syndrome exists, even though it is the most common form of inherited intellectual disabilities. Together with her friend, Lauren, they approached OCHSA’s faculty with a proposal for a new club. 

The club has now been in existence since January and has over 20 members. They meet several times per month and plan activities, share information, and invite guest speakers. The club recently held a fundraiser at OCHSA on April 18th, which is California Awareness Day. They organized an ice cream sundae bar so that students could come and buy ice cream and in return receive an information slip describing Fragile X Syndrome. The ice cream social was a major success and over $300 in proceeds were raised and donated to the Fragile X Association.

In April 2012, I signed up Trevor for the EQUIP Equine Assisted Activities and Therapies program, which was recently implemented at the Rockin’ T Ranch in Yorba Linda, CA. I’d heard that horse therapy can be very beneficial and calming to those with special needs, and I’d been meaning to give it a try. Trevor is fascinated with animals, however he becomes quite timid and anxious when they approach. He has been going to the program once per week for the past five weeks and is enjoying it immensely! The first four weeks we worked with Buttercup, a full-grown miniature white horse. Trevor has brushed her, learned how to click, click when he wants her to start walking and saying WHOA when it’s time to stop. He’s decorated Buttercup with stickers, washable paint, and even hosed her off after a shampoo! This past Sunday, out came Tommy, a full grown Chestnut horse! With the help of some wonderful volunteer assistants, Trevor again brushed the horse and even led the horse around! I can’t believe this is MY Trevor!!! This Sunday is Get On The Horse Day. I can’t wait!

For more information on EQUIP Equine Assisted Activites and Therapies, please call Gary Mullen at (626) 347-5547 or visit their website at www.rocking-t-ranch.com.
Walking and Talking for Autism...er...Fragile X Awareness by Aaron and Crissy Finney

One of our favorite activities that we get to participate in for this association every year is the Walk Now for Autism Speaks (previously known as Cure Autism Now) Resource Fair. This event draws thousands of participants from all over Southern California to raise money for Autism Speaks, an organization which is dedicated to funding research, raising awareness, and advocating for the autism community. It’s been held at the Rose Bowl for the past 8 years, though it’s also been held at Dodger Stadium and Griffith Park in the past.

We first became involved in this event in 2002...as participants. Our two boys with Fragile X were actually diagnosed with autism prior to being tested for Fragile X, and the walk at Griffith Park was the first time we’d participated in any kind of large community event in the special needs community. We were certainly impressed with the number of people that showed up that afternoon in 2002, but we had no idea how big this event was going to become within a few short years.

By the time the next autism walk was held the following spring at Dodger Stadium, we had jumped in with both feet and joined the Board of Directors of the Fragile X Association of Southern California. At a Board meeting, someone threw out the idea that we could staff a Fragile X information table at the upcoming Autism Walk's resource fair, where it was predicted that thousands of people would attend to raise money for the organization Cure Autism Now. We jumped at the opportunity to help at the event. The fact that we had once been in their shoes, agonizing with the unknown of what had caused our children’s autism, and considering everything that we had gained from learning that it was actually Fragile X, made it extremely personal to us. Having the chance to spread the word about the link between Fragile X and autism to families who might be in the same situation we had been in was something we couldn’t miss.

Along with a couple of other Board members, we covered our table in brochures and information, and put a giant sign up in the front that read "WHY TEST FOR FRAGILE X?" It was amazing to have so many interested parents of children with autism stop by and talk with us, and most who stopped by had the exact same reaction that we had when our Regional Center psychologist first mentioned Fragile X to us: "Fragile what?"

Since then, we’ve been going to the walk every year, setting up our information table and signs, spreading the word to everyone we can. Except instead of hundreds of people stopping by the past few years, it’s been thousands. We’ve added a sign that reads "Fragile X is the leading known cause of autism" to our display, as well as giving out printed copies of specific articles about the relationship between Fragile X and autism, and we always hand out pens with the association’s contact information on them. Thousands and thousands of them!

It’s gratifying for us to know that we can possibly make a difference for even one family who is currently going through what we did, and that knowing about Fragile X could impact them the way it did us. We gained a whole new family of wonderful, supportive people, learned about targeted treatments and specific behavioral interventions for our kids, and were able to identify a genetic condition in our family that could affect future generations.

Some quick facts about the relationship between Fragile X and autism, as presented by the National Fragile X Foundation; this makes up the basics of what we have told thousands of people at autism walks throughout the years:

- Autism is a behavioral diagnosis, not a medical diagnosis. There is no blood test or scan that can diagnose autism, it is diagnosed using behavioral tools and tests.
- Fragile X is a medical diagnosis, which is diagnosed with a blood test.
- Fragile X can cause autism. It causes autism in between 15% and 33% of individuals with Fragile X.
- Fragile X is the leading known genetic cause of autism. Between 2% and 6% of individuals with autism will have Fragile X as the cause. While there are other genetic conditions which can cause autism, the underlying cause for the vast majority of individuals with autism is not known.
- Because there is a significant link between Fragile X and autism, and because a genetic condition like Fragile X can have far-reaching implications for families, it's recommended that anyone diagnosed with autism be tested for Fragile X.
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 and age of child(ren) with Fragile X

*Member’s information is never released to anyone. All information is 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 stories and pictures to info@fraxsocal.org.

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

**Clinics:**
Stramski Developmental Center at Miller Children’s Hospital
2650 Elm Avenue, Suite 301
Long Beach, CA 90806
Phone: 562-728-5034

UC Davis M.I.N.D. Institute Fragile X Clinic
2825 50th Street
Sacramento, CA 95817
Phone: 916-703-0238
www.ucdms.ucdavis/mindinstitute

**Additional Organizations:**
National Fragile X Foundation
P.O. Box 37
Walnut Creek, CA 94597
Phone: 800-688-8765
www.FragileX.org

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

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