Dear members,

Now that school is back in session, we can’t believe that summer is long gone. We hope everyone enjoyed the sun and the time off with the kids. One of our summer activities was a wonderful event at the park with professional photographer Amanda Nielson who was in Los Angeles from Australia. Several new families came out for the event and it was great seeing old friends, too.

As you know, the 12th International Fragile X Conference was held in Detroit, Michigan at the end of July. Several members and their families attended, including FRAXSOCAL Board members, Jerad Chao and Naomi Star. Earlier this month, they presented an overview of the conference at the Whittier Senior Center as a way of bringing the conference home to those who could not attend. We have also included a summary of the conference from Jerad in this issue of the newsletter. If you attended the conference and would like to share your experience, please let us know. The next conference is planned for 2012 in Miami, Florida.

Before the year ends, there is a project we would like to get done, but this will require everyone’s help. In collaboration with the Fragile X Clinic in Long Beach, we would like to create a Community Resource Directory of service providers that have experience working with your family and that you would recommend to other families. Service providers would include, pediatricians, other physicians or specialists for our older kids, psychologists, dentists, occupational and speech therapists, behaviorists, and advocates. If you also know of centers that provide these services, including social skills groups, or had a great experience with a particular summer camp, we want to hear of those, too. We hope that the directory, will be of great help to all of our families.

Thanks again,
Janet Rivera, FRAXSOCAL President

We would like to inform everyone that our website is now up and running. We have added new updates and wonderful articles, plus we still have plans to add more exciting information.

Please visit our FRAXSOCAL’s new website at www.fraxsocal.org

If you should have any questions or need to contact FRAXSOCAL, please call us at 818.754.4227 or email us at fraxoscal@yahoo.com.
**Photo Fun Day at the Park**

We would like to thank everyone for coming to our event on Saturday, July 17th at Central Park in the City of Whittier to meet professional photographer, Amanda Neilson. Amanda is also a parent of three children with Fragile X and is in the process of publishing a book on Fragile X Syndrome to help bring awareness and educate others about this genetic condition. Amanda was able to take pictures of our kids and plans on sharing them with all of us in the future. These pictures were happily taken by FRAXSOCAL President, Janet Rivera. This was a picture-perfect event and a great opportunity to connect with other families.
On Sunday, August 8, the Fragile X Association of Southern California had its summer family fun day in Westlake Village. The day started out with a taco bar from Tu Tacos at about noon. The pool was heated to 87 degrees and a fun time was had by all. The kids especially enjoyed the waterslide. Several of them tried sliding down two at a time. They also attempted to shoot balls into the basketball hoop while on the slide. We had a chance to compare experiences with a diverse group of families from all over Southern California. We were glad that so many could attend!
The National Fragile X conference took place at the Hyatt in Dearborn, Michigan from Wednesday, July 21st to Sunday, 25th. Lectures and presentations went from 8:30am to 5:00pm. The conference concluded with a question and answer session on Sunday, July 25. There were multiple sessions every hour so one could choose which topic to attend.

I attended the family friendly sessions, and the major theme was that if you understand the etiology, you can improve your child’s chances for success. Etiology is the underlying cause of the behavior. In behavioral terms, it is the antecedent. The etiology of Fragile X includes attention deficit, hyperactivity, tendency toward hyperarousal, autistic behaviors and/or autism, intellectual disability, hypertonicity, poor fine and gross motor functioning.

As parents of Fragile X children, we have all seen these challenges in our children to some extent. We have to take these challenges into account throughout the lives of our children so that we might improve their potential.

Hyper arousal was a major topic at the conference. Hyperarousal is the tendency of the nervous system to become overwhelmed and overactivated by processing demands. As the nervous system becomes overstimulated, it tends toward fight or flight type responses and is no longer under the person’s self regulatory control. Since we know that our children tend toward hyperarousal, we need to learn strategies to prevent it and regulate it.

These strategies include reducing direct questions, model desired utterances to reduce perseveration, using the child’s interest to develop learning materials, visual schedules and using imitation and sense of humor. A red light/green light approach was also discussed. The red light would cue the child that he cannot do a behavior, while a green light would signal a readiness state.

Sensory diet was also discussed. Fragile X children respond to deep pressure and followed by joint compressions as well as trampolines, swings, heavy work, etc. A trained therapist needs to develop a program so that our children’s engines run just right. Therapist/parent/teacher should develop a schedule of activities to assist in the key events of the day and transitions.

We also need to make sure we take into account our children’s learning style. Our boys are simultaneous learners which is counterintuitive for many teachers and therapists. We need to remember to teach by showing the finished product first. They are also visual learners as opposed to auditory learners and they seem to learn through observation. Additionally, they have a strong memory for routines and interest areas.

There were sessions covering almost as many topics as you could imagine. However, I believe that the above theme was the most salient and covered multiple sessions. There was also some fun events including a meet and greet which included hot dogs and girls on roller skates delivering candy; a private showing of the Henry Ford museum; an awards luncheon and the silent auction and banquet. At the banquet, it was announced with much fanfare (like Lebron James) that the next National Fragile X conference would take place in 2012 in Miami at the Hotel Intercontinental. I hope to see you all there!
Referrals for the Fragile X Community Resource Directory

If you have referrals for professional services that you would like to share, please let us know. Referrals are a great resource for families who have a specific need. We are looking for pediatricians as well as physicians or specialists for our older kids, dentists, occupational and speech therapists, neurologists, behaviorists, psychologists, and advocates. If you know of social skills groups, after school programs, or summer camps, let us know about those, too. Providing us with your name and contact information would be helpful, but it is optional. Thank you.

Referral by: ___________________________ Phone: ___________________ Email __________________________

Profession: ________________________________________________________________________________
Name: ____________________________________________________________________________________
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Upcoming Events

FRAXSOCAL is hosting a free workshop on conservatorships, featuring, Christopher A. Poulos, a lawyer whose practice focuses on the rights of persons with developmental disabilities and their families.

Also presenting will be Mary Seward, FRAXSOCAL Board member, who has personal experience with conservatorships using Bet Tzedek Free Legal Services.

Date: Saturday, October 9th, 2010
Time: 10:00am-Noon
Location: Whittier Senior Center (Room 3)
13225 Walnut St.
Whittier, CA 90602
Contact: 818-754-4227 or fraxsocal@yahoo.com
(Please RSVP by October 4th, 2010, but walk-ins will be accepted)

Free Parking * Light Refreshments * No Childcare

FRAXSOCAL invites Dr. Randi Hagerman from the UC Davis MIND Institute for a presentation on Fragile X-associated Tremor/Ataxia Syndrome (FXTAS)

Date: Wednesday, December 8th, 2010
Time: 10:00am-11:30am
Location: University of California, Irvine
Contact: 818-754-4227 or fraxsocal@yahoo.com
More information coming soon.

For more information please visit us at:
www.fraxsocal.org
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

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/mindinstitution

Additional Organizations:
National Fragile X Foundation
P.O. Box 190488
San Francisco, CA 94119-0488
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
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Burbank, CA 91510-6924