Dear Members,

Summer is here and it’s time to have fun. The association would like to invite you and your family to come out to the next Family Fun Day, which we will be hosting at Scooter Jungle in Aliso Viejo on Saturday, July 18th from 9:30am to noon. This is definitely one of the best places for bounce house fun. Please see page 2 for more details. 

Also, I am happy to report that our 4th Annual Yard Sale at Board member Naomi Star’s home was a great success. Not only did we raise money for the association but most importantly we continued our mission of spreading the word about Fragile X Syndrome and educating the community. Thank you to Naomi and Diane for organizing this event again and to all of the volunteers who helped out that day. I am especially thankful to everyone who donated items. That old saying turned out to be very true, “one man’s junk is another man’s treasure.”

It is now my pleasure to introduce our newest Board member, Jerad Chao. We are very pleased to have Jerad join the Board. Although he’s busy with three little ones of his own, he is committed to helping continue the association’s mission and supporting Fragile X families. Please take a moment to read about Jerad and his family on page 6.

Don’t forget to email us with ideas, suggestions, or stories about your family. We love to hear about all the wonderful things our members are doing, especially in the summer. Thanks again and hope to see everyone at our next event.

Janet Rivera, President

“Spreading the Word” at the following fairs:

- **4th Annual Back to School Program**
  Sunday, August 30, 2009 from 2pm-6pm
  5300 Angeles Vista, Los Angeles, CA 90043

- **Fiesta Educativa**
  Monday, September 21, 2009 from 8am-4:30pm
  1000 North Alameda Street, Los Angeles, CA 90012
It’s time for another FRAXSOCAL Family Fun Day!
Please join us at
Scooter’s Jungle in the City of Aliso Viejo on
Saturday, July 18th 2009
9:30am – 12:00pm

For those of you who have never heard of this amazing indoor family fun place, it’s the ultimate playground!!

Our Family Fun Day will be held in the Ultimate Jungle, which includes:
   Huge, 24’ Inflatable Slide
   The Super-Ball Dome
   Scooter’s Rope Swing Play Yard
   Zip Line Bounce House
   Plus More Exciting Items
   Pizza, Snacks, Drinks

We really hope you can make it and look forward to seeing you there.
Please RSVP at 4blanco@sbcglobal.net or (818) 754-4227.

For more information go to www.scootersjungle.com.

Scooter’s Jungle is located at 25 Journey, Aliso Viejo, CA 92656
The annual yard sale was once again held in the Long Beach front yard of member Naomi Star, and once again, it was a huge hit! The sale was advertised from 8am – 2pm but we sold our first item at 6:30am to one of the many early bird shoppers and didn’t stop selling until 3pm! We made over $3,800.00!!! That’s a little less than last year but still very impressive considering the state of the economy. It was really a fun day, lots of laughs and lots of information about Fragile X handed out. Not only did we raise money but we raised awareness!! Can’t get better than that!

Naomi and I would like to thank the many volunteers that helped with pre sale pricing and organization; we could not have gotten it all together and priced without them, to our friends and family in Long Beach, Thank you!! We would also like to thank the many members of the Fragile X Association who helped on the day of the sale, showing up at 6:30am and staying until 5pm. WOW! Talk about tired! I’d like to name all those who helped but fear I would leave someone out. Let me just say, you know who you are, we could not have done it without you!!

We are looking for someone to host the sale next year. Naomi and I won’t be able to organize it in 2010. It can be anywhere in Southern California at any members yard/garage, just volunteer and pick a date! Let me know if you are interested and I will give you more information. Feel free to leave me a message at the FRAXSOCAL voicemail number (818)754-4227.

FRAXSOCAL would like to thank Naomi & Diane (left) for their years of dedication to this fundraising event, and Sophia (right) for her sensational singing, cheer, and lemonade.
Tim turned 18 this year. Hard to believe. Harder to believe that you have to go before a judge to file for a limited conservatorship to be able to legally handle his affairs and to help him make the decisions that he is unable to make. This is a hard thing to have to do since you are basically taking many of his rights away and then you wish that this was not really happening. It is painful, it hurts down deep, but we decided that it was the right thing for our family to do for Tim.

Another family from the Association had called me and told me that they had called Bet Tzedek (means house of justice in Hebrew) and had gone through their conservatorship clinic when their son turned 18. It is a free service. So I called them and they sent me the paperwork to get started. We had to fill out a questionnaire about Tim and his level of care, such as “Can he bathe without assistance?” We also had to answer questions about each of the proposed conservators. The court does a background check to make sure any proposed conservators are fit to serve and be responsible for another’s welfare. We chose to have both parents and his sister to be named as co-conservators for Tim. Tim’s doctor also had to fill out a declaration of capacity which states the doctor’s findings of his mental ability to make decisions, etc.

Then we sent all this to the clinic and made an appointment to go Downtown to the LA Superior Courthouse where the clinic is housed. It is in a big room with lots of people and lines. It was the same lost feeling you get when you walk into the DMV. But I asked at one of the windows that didn’t have a line and was told which desk held the sign-in sheet for the Conservatorship Clinic. So, I signed in and waited for awhile. When my name was called, I went back to a small cubicle where the attorney and a couple of assistants went through the paperwork for the actual filing for a court hearing. They sent me to a window and the clerk took the forms and stamped them and set the date for the court hearing. One of the papers that I filed was a waiver of the filing fees which are about $800!!

After waiting for another while, I was given a LARGE stack of papers all carefully clipped into packets with explicit directions for me to follow. This process at the clinic took about two hours. You get to take the papers home and figure out what you are supposed to do with them, but you still have to be sure to follow all the explicit directions. Before you leave the clinic, don’t forget to give them the names and addresses of grandparents, aunts and uncles so they can be notified of the hearing date. This was not done at my clinic appointment and had to be done later on.

The regional center is asked by the court to do a “core staffing” and send a report with their findings to the judge. So, all of the proposed conservators (both parents & his sister) and Tim had to find a time to all gather at regional center with his case worker & supervisor. It takes regional center about a month to do their report and send it to the court. The regional center discusses with everyone the seven powers that can be granted in a limited conservatorship. These include the right to decide financial matters, health decisions, educational decisions, where they live, who they socialize with and marry.
Regional center makes their recommendations about which rights the person should retain. Generally, they recommend that they retain their rights to choose their social contacts and the right to marry. Since this process takes awhile it is important that your court date be set far enough in advance to allow time for you to get everyone’s calendars to align for a meeting. This took longer than we thought and we had to ask for a continuance for the hearing. I started to wish I had watched more of those Court shows.

The court then appointed an attorney for Tim. He came to our home and met us and Tim and went over the process and what to expect on the day of the hearing. Bet Tzedek does not provide the parents/conservators with an attorney but they help you to file the paperwork and you act as your own attorney. Tim’s attorney was also the parent of a child with autism and was very knowledgeable about the process and the issues we faced with Tim. After he met Tim he did not think it was necessary for Tim to come to the hearing and that was a relief for us. Tim’s attorney is paid for by the County and he presents his fees at the court hearing and the judge approves his charges depending on how many hours were required.

The day of the hearing finally came and we went back to the LA Superior Court and waited outside the assigned courtroom. We were just one of many cases on the docket for our time frame. We were all called in and everyone stood en masse and took the oath. A couple of cases were heard and then we were called. We had to state our names and that was about all. Tim’s attorney answered a few questions and the judge ruled all seven of the powers be granted and it was over in about two minutes. Then the attorney filled out some of the papers and we could have gone back to the clinic to file them but since Tim’s sister could not be at the hearing to sign some of the forms we took them home and mailed them later.

Once all the papers got filed with the clerk and stamped, we got the final legal letters of conservatorship in the mail. The process takes time but the clinic staff was always available by email or phone if you need help. I urge all families to attend a seminar about conservatorships and find out if this is something that might benefit your family. These seminars are usually presented at special needs conferences or by the regional centers.

Information about Bet Tzedek

The Conservatorship Clinic can assist in filing limited conservatorships of persons and/or a small estate. The clinic will provide general information about the process, help you prepare the legal documents with your input, and satisfy notice requirements.

Please note: The Clinic does not represent individuals; assist you in the process, and you represent yourself. Services are free; however there may be a court filing fee if you do not qualify for a waiver of the fee’s under the court rules.

Locations and hours are:

<table>
<thead>
<tr>
<th>Los Angeles Superior Court</th>
<th>Norwalk Superior Court</th>
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<tbody>
<tr>
<td>111 N. Hill St. Room 426</td>
<td>12720 Norwalk Boulevard, Room 104E</td>
</tr>
<tr>
<td>Los Angeles, CA 90012</td>
<td>Norwalk, CA 90650</td>
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<tr>
<td>Mondays-Wednesdays 9:30am-12:30pm</td>
<td>Tuesdays 9am-12 pm</td>
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If you would like more information, please contact Jaclyn Rosenson at (213) 384-3243, ext. 102 or jrosenson@bettzedek.org or www.bettzedek.org.
Our FX Story
By Jerad Chao

Before January 9th, 2009, we were a family with three children who had various developmental delays, which included speech delays and low tone. We decided to see a geneticist to see if there was a link. The geneticist looked at our family histories, the reports from our speech and occupational therapists, and he stretched our children’s joints to examine whether they had loose joints. Our children indeed had loose joints and there were a couple of red flags in our family history including twinning, early menopause and a cousin with autism. The geneticist suggested we test our son Oliver for Fragile X Syndrome.

We had never heard of Fragile X Syndrome. I went home and looked up everything I could about it. I went on Amazon and ordered five books and looked at all the videos on Youtube. The first week was very difficult for me as I became convinced that Fragile X was the cause. But I couldn’t do anything until we received confirmation of the test. The test came back positive January 29th 2009. We then had our other two children tested and twenty-one days later both of their tests came back positive. At that moment, everything and nothing had changed.

Everything changed. Now we know that their delays are profound and that we need to do all we could to ameliorate their difficulties that they might have later in life. All of the therapy and early intervention that we had been doing took on a new urgency. We scheduled appointments with Regional Center, geneticists, developmental pediatricians and the MIND Institute. Our schedule is now a color-coded grid that determines who takes which kid to which therapy. We put swings right outside our back door so the swings are readily available, and we try to swing them multiple times per day. We informed family members of the situation and that they should be tested if there was a possibility of Fragile X Syndrome for their children. And our estate planning is much more complicated. We will do all we can to ensure that they will be able to thrive independently, but we also have to consider the worst case possibilities. It seems like it has been more than a year since we have been dealing with Fragile X. However, it has been less than six months.

Nothing changed. Lili, Oliver and Zachary are still the same little people. They are still happy and funny and enjoy each other. We already had all three in therapy and they had shown improvement over the last year. After the initial shock, and about a week of complete depression, our lives are basically the same as before, except we are busier with the doctor’s appointments and extra therapy sessions.

We made it our mission to find the doctors most experienced with Fragile X and increased all of the therapies for our three affected children so that they can have the best future possible. And their rate of improvement seems to have increased since we have intensified the therapies and introduced some pharmacological interventions. We also made it a point to network, and find people who have been dealing with Fragile X. Everyone who we have talked to has been so friendly and helpful. We have met many people who we would have never met. We have found a community we can rely on and be a part of and help others. And our family will only benefit.
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 picture at info@fraxsocal.org

Informative Web Sites

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

<table>
<thead>
<tr>
<th>Clinics:</th>
<th>U.C. Davis M.I.N.D. Institute</th>
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<tbody>
<tr>
<td>UCLA Behavioral-Genetics Clinic</td>
<td>Fragile X Clinic</td>
</tr>
<tr>
<td>UCLA Psychiatry &amp; Biobehavioral Science</td>
<td>2825 50th Street</td>
</tr>
<tr>
<td>BOX 951759, 58-24C NPI</td>
<td>Sacramento, CA 95817</td>
</tr>
<tr>
<td>Los Angeles, CA 90095-1759</td>
<td>Phone: 916-703-0238</td>
</tr>
<tr>
<td>Phone: 310-794-9516</td>
<td>Website: <a href="http://www.ucdms.ucdavis/mindinstitute">www.ucdms.ucdavis/mindinstitute</a></td>
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<tr>
<td>Website: <a href="http://www.liliclairefrc.ucla.edu">www.liliclairefrc.ucla.edu</a></td>
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<table>
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<tr>
<th>Additional Organizations:</th>
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<tbody>
<tr>
<td>National Fragile X Foundation</td>
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<tr>
<td>P.O. Box 190488</td>
</tr>
<tr>
<td>San Francisco, CA 94119-0488</td>
</tr>
<tr>
<td>Phone: 800-688-8765</td>
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<tr>
<td>Website: <a href="http://www.FragileX.org">www.FragileX.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 FRAXSOCAL.ORG

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