Hi everyone,

Every year we get off to a great start, and 2013 has not been the exception. I would like to thank all of the families and individuals who have supported FRAXSOCAL over the years. We want to assure you that with your assistance we will continue our mission of helping the Fragile X community, especially as we prepare for the 14th International Fragile X Conference coming to Orange County in 2014.

I am proud to announce that two new members have joined the FRAXSOCAL Board of Directors and they are Cindy Ross and Brandon Wetzler. Please take a look at page 2 to get to know Cindy and Brandon. Also, on page 3 Cindy shares her story about her daughter’s wedding and her son’s participation.

We had a number of activities in 2012, including a special bowling event for our young adults. The event was hosted by the Fragile X Awareness Club from the Orange County School of the Arts. We have included pictures and a short description of the event on page 4. It was a fun event for everyone who attended.

Board members Aaron and Crissy Finney will be participating at a couple of events coming up soon. See page 5 for more details. Participating in community events is one of the ways that FRAXSOCAL continues to spread the word about Fragile X.

In supporting scientific research for Fragile X, we have included information on page 6 about a study at the Fragile X Clinic in Long Beach closing on March 29th. Also, the clinic continues to schedule individuals with Fragile X to see Dr. Feldman. Contact information to the clinic is located on page 7.

Thank you again for your support and we look forward to having a great 2013!

Janet Rivera, President
**Why I joined the FRAXSOCAL Board**

This is a question I was asked recently. I say why not! I have had a heart for people with special needs as long as I can remember. My biggest reason is my son, Jeremy, who has Fragile X Syndrome. I grew up with an older male cousin making occasional visits with his mother. He had other lower functioning brothers that were institutionalized. I never really knew them. Fragile X was unheard of back then. When I think about it, I have more than enough reasons to join the Board! I am passionate about spreading the word about Fragile X Syndrome in my classroom, my community and beyond! If I can be instrumental in helping even one family get an early diagnosis of Fragile X, it will be rewarding for me. My son, who is now 30, got several diagnoses, but not 100% correct until he was 12! I don’t want other families to go through that. Thankfully we did get early intervention, therapy and the appropriate Special Ed classes.

I am honored to be a part of an incredible, devoted group of individuals who want to make a difference in the Fragile X world!
FRAXSOCAL Board Member,
Cindy Ross

I firmly believe that when someone lives through difficult circumstances in life, there is a greater capacity for that person to empathize with and understand others who have lived through similar circumstances. Such is the case in my own experience with fragile x syndrome. I am a carrier of fragile x, I have several family members who are carriers of fragile x, and I have several family members who have the full mutation of fragile x.

Personally, I’ve endured and struggled through high levels of anxiety, perseverating thoughts and depression among other fragile x carrier issues. I’ve seen the stress and hardship my family has experienced as carriers, and as those fully affected. I remember how draining, and overwhelming fragile x can be at its worst, and at its simplest just accepting the reality it brings is the most challenging hurdle.

I wonder if I am a better person for living through all this. Maybe or maybe not. I’m not sure to be honest. One thing I am certain of though is the compassion I have for children, families and adults who have come to the end of their personal resources trying to cope with fragile x. Actually, there is one more thing I’m certain of and that is hope. I have been at the most peace in life when I felt someone knew what I was going through and cared. And that brought me hope.

My wish for everyone who has to deal with fragile x directly or indirectly is to experience hope and peace. That is why I wanted to be a Board member of FRAXSOCAL; to let you know that you are not alone.

FRAXSOCAL Board Member,
Brandon Wetzler
Groomsman for a Very Special Day by Cindy Ross

My daughter, Megan, married Andrew “Andy” Clayton on November 3, 2012. My son, Jeremy, was asked by Andy to be a groomsman. We were thrilled! Where do we start? How do we prepare? We had conversations about what would happen that day. Megan and Andy decided to have Jeremy escort my mother and I down the aisle that day. Jeremy has always exhibited some form of tactile defensiveness, but has made some amazing progress over the years through tactile exposure. We practiced around the house as I first offered my arm to walk around the house. I instructed him as we walked until eventually I held his arm and we walked at an appropriate pace. Verbal preparation has been vitally important to Jeremy. This allows him time to organize what will happen next.

The day of the wedding he beamed as he walked two of his favorite women down the aisle. He knew it was a special day for the Ross and Clayton families! After the ceremony he proceeded to dance back up the aisle with longtime family friend, Kristin Cumming. He had observed the rest of the bridal party happily celebrating as they danced their way out of the ceremony. We didn’t know they were going to do that, but Jeremy joined in. It was also a comfort to be with Kristin, as she has always been gentle and kind to him.

Another concern was so many important photos to be taken that day. Would he make faces or get frustrated by so many demands? So, practice again. Say “cheese” and smile like this. That day he paid attention and got caught up in the excitement. He put his hand in his pocket, smiled, walked, jumped and posed as requested.

During the reception, as the bridal party was introduced, he galloped in with Kristin, waving with a huge smile. Afterwards there was dancing. Jeremy was more comfortable dancing off to the side, in a less crowded area, but was living it up!

Jeremy lovingly has nicknames for people in his life. Last February, on the day they got engaged, Jeremy announced that he was getting “his brother.” He wouldn’t dare call him brother until the big day.

With much prayer, practice and discussions, it all helped Jeremy. His loving and devoted sister, Megan, reassured him that she and Andy would always love him and be a part of his life! By the way, the photos turned out great, our family has wonderful memories and Jeremy has his amazing new brother! Yes, he affectionately calls Andy brother now.

Cindy Ross, left, with son Jeremy.
A year ago, Lauren and I founded the Fragile X Awareness Club at the Orange County School of the Arts when we discovered the lack of connections the student body had with students with disabilities. Our goal was to spread awareness for a variety of disabilities as well as to raise money for this wonderful association. Although, Lauren and I have connected with young people with special needs, we realized that our members never had the opportunity to bond and appreciate the gifts that individuals with developmental disabilities have to offer. So, we organized a bowling event for our members to interact with young adults with Fragile X at Bowlmor Lanes at the District in Tustin.

Five young men with Fragile X syndrome attended the event with their families. Watching these five young men shine in the bowling alley was such a pleasure! Our members who participated found it to be an eye opening experience. These young men demonstrated remarkable skills on and off the bowling lane and their happiness was infectious. As a club, Lauren and I look forward to planning more bonding events in the future and hope to see the club live on for many years to come since we are graduating soon. We would like to make new relationships with others as well as strengthen those we have already created. Working alongside the association has been fulfilling in so many ways and this bonding experience has brought everyone...
We are very excited to be hosting the 14th International Conference in Orange County, CA with the Fragile X Center of San Diego. Please keep in touch as we plan to provide ongoing updates about the conference as the date gets closer.

If you have any questions about the 14th International Conference, please do not hesitate in contacting us at fraxsocal@yahoo.com.

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**Spreading the word about Fragile X**

Stop by and say “hello” to FRAXSOCAL Board members Aaron and Crissy Finney at the following outreach events:

- **Los Angeles Walk Now for Autism Speaks**
  Saturday, April 20th, Pasadena Rose Bowl

- **Parents Place, 21st Annual Information Resource Fair**
  Sunday, April 28th, 1pm to 4pm

**SAVE THE DATE!**

Saturday, April 20th

A day at the Santa Ana Zoo with the Fragile X Awareness Group. More details coming soon.

**California Telephone Access Program (CTAP)**

CTAP is a program from the California Public Utilities Commission Deaf and Disabled Telecommunication Program (DDTP) that provides free specialize phones for individuals with disabilities. Phones that have big buttons to make it easier to dial, captioned phones that allows the caller to read incoming conversations, or picture dial phones. To learn more about these phones and how to apply to receive a free phone, call California Phones at [1-800-806-1191](tel:18008061191) or visit [californiaphones.org](http://californiaphones.org).
News from the Fragile X Clinic

Hurry, there is still time to join the Arbaclofen research study

We are looking for volunteers ages 5 to 25 who have been diagnosed with Fragile X Syndrome to participate in a research study about an investigational drug called arbaclofen and whether it can safely treat symptoms of Fragile X Syndrome.

Your participation involves coming to the Fragile X Clinic at Miller Children’s Hospital in Long Beach a total of six times over the course of four months. Most visits will last between one and two hours. Participants’ health will be checked during all visits while blood samples will be taken at three visits and an ECG will be done during two visits. Parents will be asked to answer written questions. A small payment will be offered to families for travel expenses.

Participants will receive study-related medical care, monitoring, and visits with Dr. Gary Feldman, the study doctor and expert on Fragile X syndrome. Information and possible treatment options will also be provided. Because this is an investigational study, there may or may not be direct medical benefit to your child. Enrollment closes March 29, 2013. For more information, please contact Nan O’Donnell at 562-933-5607.

Write a letter of support today!

Have you visited the clinic recently? Were you blown away by the expert care you received by Dr. Gary Feldman and his great staff? Well, help support the clinic by writing a letter to Miller Children’s Hospital and let them know how thankful you are for the wonderful service you received. The level of service provided at the clinic is difficult to come by and it is a resource that is not easily accessible anywhere else. Visitors and patients of the clinic can make a difference by letting the hospital know that the clinic is providing a good service to the community. That kind of information puts the clinic in a stronger position to compete for available funds that routinely get dispersed throughout the hospital, usually to other clinics. Act now and send your letters to Anne Tanner, Executive Director, Outpatient Centers Miller Children’s Hospital, Long Beach, CA 2801 Atlantic Ave, Long Beach, CA 90806.

Appointments available at the Fragile X Clinic

The Fragile X Clinic is part of the Stramski Children’s Developmental Center at Miller Children’s Hospital in Long Beach. The director of the clinic is Dr. Gary Feldman, who is a leading expert in the care of patients with Fragile X syndrome. He has put together a wonderful team that takes a look at patients from all angles, including medical, behavioral, psychological, school environment, medication and IEPs. The clinic has days set aside specifically dedicated to seeing patients with Fragile X and accepts Medi-cal and other insurances. If you have any questions about your child affected by Fragile X, call the clinic at 562-728-5034 and make an appointment.
**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:**

- **Fragile X Clinic at the Stramski Developmental Center**
  
  Miller Children’s Hospital
  
  2650 Elm Avenue, Suite 301
  
  Long Beach, CA 90806

- **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