FRAXSOCAL Updates

Hello everyone!

I cannot believe that 2014 is almost over. Well, I’m happy to report that we had another successful year because of you, our families, and friends! This year is also FRAXSOCAL’s 20th Anniversary. Please read page 2 for a wonderful story by FRAXSOCAL founder, Mary Seward.

Our biggest success this year was the NFXF’s 14th International Fragile X Conference. With the help of the Fragile X Center of San Diego we co-hosted the conference and had a wonderful time. Another wonderful opportunity we had this year was to meet new families at the 2nd Annual FRAXSOCAL Walk in Newport Beach. Over 100 members attended the walk. Participation doubled compared to last year!

Throughout the year we were busy with the FX Conference, but we continued to celebrate with our Family Fun Day events - a bowling event and a Clippers basketball game. We also attended several resource fairs to bring awareness to FX and continued our educational workshops with a conservatorship lecture.

As the year comes to a close, I would like to let you know about several upcoming changes. It gives me great pleasure to introduce you to your new President, Paula Paez and your new Vice President, Jennifer Newsome. Both are mothers of children with FX and knowledgeable about the challenges we face in the world of FX. If you have not already met Paula and Jennifer, please say hello the next time you see them at one of our events.

I would also like to introduce you to our new Secretary, Cindy Ross who has an adult son with FX. On behalf of the entire board, I would like to thank our previous secretary and past President, Naomi Star, her family, and her friends for all their contributions in support of families with FX. I’m also happy to announce that Mary Sward, was elected to continue as Treasurer of FRAXSOCAL. We our very grateful for Mary’s support.

I would like to close by saying that I have enjoyed being President over the years and have met and continue to meet wonderful families that have given me the strength to learn more about FX. I will continue to be involved with FRAXSOCAL and to meet the needs of our FX community.

We are all looking forward to an exciting new year and we thank you for all your help and generous support. Please do not forget that if you have any questions, give us a call at 818-754-4227 or send us an email at fragilexassociation@gmail.com. Thank you for taking the time to read our updates and for supporting FRAXSOCAL.

Hope to see you all in the new year!

Sincerely,

Janet Rivera

FRAXSOCAL Board Members

President Paula P.
V.P. Jennifer N.
Secretary Cindy R.
Treasurer Mary S. *
Sali F. * Otilia G.
Anna M. Janet R. *
Maria S. Charlotte S.

*Denotes Past Presidents

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Upcoming 2015 FRAXSOCAL Events

- Family Fun Days
- FX Club Events
- Educational Workshops
- 3rd Annual FRAXSOCAL Walk

If you have any suggestions for a FRAXSOCAL event please do not hesitate to let us know. Just send us an email at fragilexassociation@gmail.com.
FRAXSOCAL celebrates 20 Years!

It all started on November 4, 1994 when Tim’s pediatrician called with the results of the blood test for Fragile X. That was the phone call that changed our world and set the groundwork for our association. Times were primitive for information. There was no Facebook, no email and only sparse information on the internet, all of it very bleak. There were very few professionals who had even heard of the syndrome. It was the dark ages of Fragile X.

I immediately went into action and started calling and connecting with the regional center, the National Fragile X Foundation and eventually connected with Dr. Barbara Wheeler at Children’s Hospital LA-USC University Affiliated Program. I wanted to find other families with the same diagnosis, I wanted information. Dr. Wheeler assigned Debbie Langenbacher, a post-doctoral intern, to assist us in finding families to start a parent support group for FXS.

Our first gathering was held in my living room and about seven parents attended. We now have over 200 families. In 1996 we held our first big event, a symposium at Children’s Hospital with Dr. Randi Hagerman and her team of experts. In 2000 and 2014 we hosted the International FX Conference. The only group in the US to have done this twice! We have gone bowling, hiking, swimming, picnicking, visiting zoos and pumpkin patches and apple orchards. We have gone to hockey games and basketball games. We have hosted movie premieres. We have hosted new parent gatherings and Mom’s night outs. We have educated others about our kids through newspaper articles and sitting at tables at countless resource fairs. We have educated ourselves at numerous workshops and conferences with the top experts in the field. We have raised thousands of dollars for research. We have published brochures in English and Spanish. We have launched a website. And most importantly we became friends as we all traveled on a similar journey. We no longer felt alone.

It is through the dedication of the following volunteers who have served on the board that we have been able to accomplish these many events to improve the lives of our children and families. Each brought their own unique gifts to the board and together we hope that we have touched your life.

- Sali Farber
- Cathy and Reid Halterman
- Maggie Coronado Robles
- Molly Brown
- Phillip and Diane Briones
- Susan Bryant-Deason
- Deborah Langenbacher
- Charlotte Spahr
- Laurie Williams
- Stephen and Deborah LeCover
- Aaron and Crissy Finney
- Diane Bateman
- Marie Lambert
- Linda Hutchings
- Matt and Kareen Weidenfeller
- Jack and Jacqueline Blanco
- Steve & Millette Arredondo
- David and Miriam Ackermann
- Jerad Chao
- Brandon Wetzler
- Neal and Carolyn Robb
- Naomi Star
- Paula Paez
- Anna Miranda
- Monique Johnson
- Otilia Gaxiola
- Cindy Ross
- Maria Scremin
- Jennifer Newsome
- Janet Rivera

And, a special tribute to those who stepped up and provided their leadership abilities as President — Sali Farber, Deborah LeCover, Neal Robb, Naomi Star, Janet Rivera and now, we welcome Paula Paez as our next President.

Here’s to the next twenty years!

Mary Seward
FRAXSOCAL Treasurer and Founding President
**FRAXSOCAL’s Annual Walk** by Jennifer Newsome

We held our second annual 5K Walk/Run on Saturday, September 27, 2014 in Newport Beach, Balboa Peninsula. We had another great turn out and appreciate all the incredible support we received! It was another beautiful day in Southern California as we started our event at 9:00am by registering over 100 attendants and taking generous donations. Our first 40 participants to register received a FREE “Let em know” T-shirt that the National Fragile X Foundation used for their virtual walk back in July for National FX Awareness month. We were also very grateful for the donations we received! Sprouts, of Mission Viejo, donated $75 worth of fruit and healthy snacks for our event, Cindy Ross (Board Member) donated water bottles and granola bars, and a local Newport Bike Rental Shop donated a Surrey (see below) for our small children. We kicked off our 5K with a group stretching activity to warm up our muscles to prevent injury. We had runners, walkers and bikers at all different levels so some finished in about 20 minutes while others enjoyed their stroll, all along spreading awareness for Fragile X! Once the 5K was finished by all, we enjoyed some delicious fruit, cold water, and great socializing with our FX families and friends. This was a great event for us to bond in a mutual cause. Again, a special thanks to everyone who had a hand in putting this special event together, we look forward to our 3rd annual in 2015 (date TBD).
Journey to Fragile X by Paula Paez
(Originally written for Harbor Happenings, HRC Quarterly)

Christian was almost 3 years old when I got a call from the staff at his early intervention program that he may have had a seizure. They said they were not sure because it wasn’t a grand mal seizure, he just seemed absent for a few seconds and then he snapped out of it. They recommended that we take him to see a neurologist. We made an appointment right away and scheduled an EEG. Unfortunately, the EEG didn't go so well. I knew my son would not tolerate any kind of probes glued to his head and as much as we tried to get him to sleep through it, he woke up in the middle of the exam and pulled everything off. I remember thinking that it was not a big deal, since I was not convinced he actually had a seizure and that we were just going through the motions of being responsible parents.

Even when the neurologist asked me if Christian had ever gotten genetic testing, I brushed it off. I thought why would we ever consider a genetic test? After all, there was nothing wrong with my baby boy (in my mind) and there was no history of developmental delays in the family. To be honest, I didn’t even know what kind of genetic conditions we would be looking for, but we decided to do it anyway since it was a simple blood test. The first time, the test came back negative for four of the five things they were looking for. The fifth item, which tested for Fragile X Syndrome (FXS), was inconclusive and the lab asked that we do another blood draw to be sure. So a few weeks later, we drew blood again and that sample was tainted so it could not be used. By the time we made it back to the lab to do the third test, four months had gone by and I was pregnant with our third baby, unplanned of course, just like our other two. I was so sure that the genetic testing would be negative that I didn’t panic with the news of having a new baby.

However, a few days before the results were due for the third test, I decided to finally go online and look up Fragile X. I read the description, reviewed the symptoms, saw pictures and was absolutely devastated. I actually believe that my entire life changed that day. When the call came from the neurologist, it simply confirmed what I already knew. We then went through a series of testing, including my younger son, my unborn daughter, and me. We found out that I’m a carrier for FXS, my younger son Alex has a full mutation like his older brother, and my daughter is unaffected.

Fragile X, according to the National Fragile X Foundation (NFXF), is the most common cause of inherited intellectual disability and the most common known genetic cause of autism or autism spectrum disorders. Symptoms of FXS include a range from learning disabilities to more severe cognitive or intellectual disabilities. It is called Fragile X, not because it causes those affected to be physically fragile, but because the X chromosome of a person with a full mutation appears broken or “fragile” under a microscope.

I look back at our journey since we received the diagnosis in 2005 and I am amazed that we have come this far. For a number of years we were in shock and busy with a whirlwind of activities and therapies. Thanks to the support we received from the Harbor Regional Center, we were able to get the necessary services for our children. The parent training classes and the home-based behavior support program really have made a difference in our lives. I know that the boys would not have made the gains that they have made without the behavior services we received.

Recently, the Fragile X Association of Southern California, which is part of the National Fragile X Foundation’s Community Support Network, along with the Fragile X Center of San Diego, hosted the 14th International Fragile X Conference in Orange, California. We had over 800 participants, families and researchers, come together. It was one of the most rewarding experiences I have had since starting my journey. I felt that I could finally speak openly about my own experiences and help families get through theirs. I know we still have a lot more ahead of us, but I am more hopeful than ever before.
FRAXSOCAL updates

In the month of November FRAXSOCAL families attended a Clippers basketball game at the Staples Centers. The Clippers played against the Sacramento Kings, and although it was a hard fought battle, Los Angeles Clippers lost (Kings 98 vs. Clippers 92). It’s too bad they lost, because the game was well attended with FRAXSOCAL families - a total of 43 people watching the game. I was happy to see that our FX children and their families were able to sit and watch the basketball game. As for our 14 year old son, it was his first time at a basketball game and I was nervous about how he would do.

We entered the Staples Center perfectly fine and excited to watch the game. We requested assistance to our seats and started to go towards our seats when suddenly, our son stopped and did not want to sit down because of the noise. Even though our son had his earmuffs on, it was still too loud. We instead decided to walk around the Staples Center, have McDonalds, enjoy playing some of the activities around the center and people-watch. We did not stay for the entire game, but at least we tried and gave our son an opportunity to try something new. And, with our son we never know if we are going to have a successful outcome until we try. Even though we were not able to watch the game, the reduced ticket price encouraged us to try something that we otherwise would not be able to. After this experience, I’m looking forward to the next sports game and hopefully next time, we’ll get to actually watch.

Happy Holidays!

We would like to wish you and your family, a happy holiday season and thank you for your contribution of time and energy toward making FRAXSOCAL a great success this year!
FRAXSOCAL is very grateful and we hope to see everyone again in the new year.

¡Felices Fiestas!

Muchas gracias por la contribución de todos ustedes de su tiempo y energía para hacer FRAXSOCAL un gran éxito este año.
FRAXSOCAL está muy agradecido y esperamos que ustedes nos puedan seguir apoyando en el año nuevo.
Art Party!

Sunday, January 4th
10am to 12:30pm
Citrus Ranch Park - Tustin Ranch
2910 Portola Parkway, Tustin, CA 92780

The FX Club (students from the Orange County School of the Arts) and FRAXSOCAL are planning a fun day with arts and crafts activities.

Join us and create your own masterpiece!!!!

- This party is open to young adults between the ages of 14 to 24 years old with Fragile X Syndrome.
- Arts and craft supplies will be provided.
- Snacks will be provided but you are welcome to bring your own lunch.

Parents will need to stay on the premises next to the location of activity. Come and meet other parents while our young adult(s) enjoy the day with friends from OCSA. Light refreshments will be provided for parents.

It is essential to RSVP so we can plan for a successful day.
To RSVP by Monday, December 29th, please call FRAXSOCAL at (818) 754-4227 or Email us at fragilexassociation@gmail.com.

*Please look for FRAXSOCAL banner to locate site.

For more information or if you have any questions about this event, please visit us at:
- www.fraxsocal.org,
- facebook.com/fxsocal,
- Twitter @fraxsocal

For directions or more information about Citrus Ranch Park please visit their website at http://www.tustinca.org.
“SUPERCALIFRAGILELISTICXPIALIDOCIOUS”
$15.00 for Adults and Youth Shirt

FRAXSOCAL “I ♥ Someone With Fragile X”
$ 5.00 each license plate

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*Please make check payable to: FRAXSOCAL

Send your order to Fraxsocal, P.O. Box 6924, Burbank, CA 91510-6924
If you have any questions please send an email to fragileassociation@gmail.com

*All funds go directly towards the association.
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.

If you should have any questions or comments please do not hesitate to give us a call at (818)754-4227. Send us an email at fragilexassociation@gmail.com or visit us at www.fraxsocal.org, www.facebook.com/fxsocal.org, or Twitter @fraxsocal

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