Hello and Happy Holidays everyone,

I cannot believe that the year is over and the 14th International FX Conference is coming soon! Please see page 2 and 3 for updates about the conference and how you can help make this conference a fun and exciting event, especially with your feedback about the Aquarium of the Pacific in Long Beach.

I am happy to say that our year ended with a very informative lecture about Fragile X. With the help of Christina Aguirre-Kolb and Elyse Schoenwald from the Stramski Children’s Development Center we learned helpful educational strategies for our children. For more information please see page 4.

Our last Family Fun Day event for 2013 ended with a Halloween Party. Event Coordinator, Jack Blanco organized a Halloween Pumpkin and Costume Party in the City of Santa Monica and everyone had lots of fun. Please see page 4 for more information on this fun event. We are also very sad to say good-bye to Jack as he will no longer be able to help with our Family Fun Day events. We would like to thank Jack and his family for all the fun events they have organized for our families.

This year we were excited to be part of NFXF’s “Let’em Know! Virtual 5K Walk/Run for Fragile X” to help raise Fragile X awareness and funds for the FX Conference in 2014. We had a successful event and met our goal amount. We would like to thank everyone for all of their support and for coming to our events held in July. Please see page 5 for the final dollar amount raised.

To help continue our mission in spreading the word about Fragile X, we attended the Fiesta Educativa resource fair to help Spanish-speaking families learn about Fragile X syndrome and attended the Abilities Awareness Faire. Please see page 5 for more information.

In this issue of our newsletter we have three great inspiring stories from mommies who have found strength in writing their story. Please read pages 6 through 8 for their empowering articles.

As we find strengths within ourselves there are others that can help. Board member, Mary Seward writes about how a research study at the MIND Institute has helped her and her son. Please see page 9.

Also, we would like to thank everyone who gave us their comments on how we can develop a FRAXSOCAL support group. The need for a support group is one of our many goals to accomplish for next year and we will give you all updates on our support groups as soon as the information becomes available.

Thank you for taking the time to read our newsletter and continue supporting our mission. We wish you all a Happy and Safe Holiday and hope to see you all again in the new year, especially at the 14th International Fragile X Conference in Orange County.

Janet Rivera, FRAXSOCAL President

FRAXSOCAL Support Groups
We would like to thank everyone for your creative ideas on how we can start a FRAXSOCAL support group. We are still gathering information and we will make sure to keep you all posted on the outcome for the new year.

If you should have any questions or comments please do not hesitate to send us an email at fragilexassociation@gmail.com or on Facebook at www.facebook.com/fxsocal.
Thank you to everyone for attending our volunteer gathering in October and to those who were not able to attend the gathering but offered his or her assistance. We will keep you all up to date on upcoming events or information about the Fragile X Conference for next year. If you are interested in volunteering and can contribute your time and commitment to making the conference a truly memorable experience there is still time, please see page 3 to find out how you can help or if you have any questions please send email us at fragilexassociation@gmail.com. We are looking forward to working and seeing you all at the conference!

**Conference Announcement!!**

Coming 2014: A Fragile X evening at the Aquarium!!
The offsite family event for the 14th International Fragile X Conference will be held at the Aquarium of the Pacific in the City of Long Beach. To help others who have never attended the aquarium we would like to share your stories or comments about your family’s experience at the aquarium. Please contact us and let us know about your experience and what you recommend for other families. The National Fragile X Foundation will share your comments with other families attending the conference.

Send us an email at fragilexassociation@gmail or on Facebook at www.facebook.com/fxsocal

For more information about the Aquarium of the Pacific, please visit their website at http://www.aquariumofpacific.org/

*The Aquarium of the Pacific will be close to the public on the day of event.*
Check out the information below and learn how you or someone you know can be part of the 14th International Fragile X Conference.

Local Sponsorships:
Local or corporate sponsorship opportunities for conference. If you have a contact person or organization/agency, or a business that would like to sponsor the conference please let us know. For more information please contact Janet Rivera at tenajka10@gmail.com or Paula Paez at paulacpaez@gmail.com.

Volunteers:
If you know of a family member, friends, neighbors, church members or others who are not attending the conference but want to help at the conference let us know or if you need more information on how someone can volunteer please email Cindy Ross at cindykross@cox.net or Anna Miranda at amiranpt@aol.com.

Publicity & Media:
Contact information to local media opportunities to announce the conference. Resources can include radio, TV, local public newspaper, school districts, and radio for publicity opportunities. If you have a resource that can help publicize the conference please notify us or for more information please contact Paula Paez at paulacpaez@gmail.com or Janet Rivera at tenajka10@gmail.com.

Auction Chair:
Financial and/or in-kind donations for live auction items – trips, professional consults, exotic adventures (something that people would not ordinarily have access to). Help organize live and silent auction items at the conference and to plan overall event including display, auctioneer, and bidder registration and checkout procedures. For more information or if you know someone that would like to donate an item for the auction please contact Nicole Schweizer from the Fragile X Center of San Diego at nrschweizer@gmail.com.

Welcome Area:
Organizes welcome area for attendees. Coverage of welcome area during the conference. This area often becomes “Conference Central”; a good place to have location specific California information – maps, brochures, restaurant and entertainment information. If you can help gather materials for the welcome area or donate items for the welcome area please contact Charlotte Spahr at lovespurple92804@yahoo.com or Monique Johnson at johnskas@hotmail.com.

Entertainment and Decorations:
Create, gather decorations, and table centerpieces before the conference. Help to set-up decorations for stage and tables before the start of the events at the conference. If you know someone that can help with set-up or donations for decorations please contact Naomi Star at naomifstar@yahoo.com or Brandon Wetzler at bwetzler@gmail.com.

Registration Set-Up:
Help to organize pre-conference bag-stuffing before the start of the conference and registration activities. If you know anyone or organization that can help with donations for signage, printing, or other promotional items. (Examples of promotional items can include but not limited are stress balls, magnets, lanyards, key chains, note pads, and etc., please contact Sali Farber at salij401@cox.net or Jennifer Newsome at newsomefam@yahoo.com.

If you have any questions concerning the 14th International FX Conference, please send us an email at fragilexassociatioin@gmail.com.
FRAXSOCAL Halloween Party and Good-bye to Jack Blanco

On Saturday, October the 12th, we held our Fall Family Fun Day. It was a Halloween Pumpkin and Costume Party held at Virginia Avenue Park in Santa Monica. The Weather, The Park, The Atmosphere, and all The Decorations set stage for a perfect Family Fun Day!! We had 25 attendees who enjoyed decorating Pumpkins, Coloring, Gumnysack Races, Musical Chairs, and plenty of Tricks-&-Treats. Once again, it was all about the Children having a ball, while the parents shared and networked. A special shout out goes out to Maria Scremin, who not only donated the Park Area, but also put in so much time and energy into the success of this Family Fun Day. So Thanks Maria, Nick, and Maria’s Family who also supported our day.

I could not ask for a better segway into my next topic. It is time for me to pass the baton to someone else as the Family Fun Day Coordinator. For the past 10 years we have thoroughly enjoyed planning and organizing Family Fun Days. Jacqueline and I are very proud of what we have achieved, but even more, we are proud to see how our Families have come together to share, develop friendships, mentor, and Unite!! Our Mission to provide a forum for families to meet and share their ideas, was embraced and will be treasured. We (Jacqueline, Alexis, Justin, and I) look forward to seeing all of you at future events and are grateful for this great organization and for the friends and partnerships that have grown through the years. Thanks for your support, involvement, and Friendship!!!

Academics for Fragile X

Thank you to all who attended the “Academics for Fragile X” Lecture in November. It was well attended and informative. Thank you to Licensed Educational Psychologist, Christina Aguirre-Kolb and Nurse Practitioner, Elyse Schoenwald from the Stramski Development Center Clinic at Miller Children’s Hospital for the presentation! Both were very helpful in understanding what is Fragile X syndrome and strategies on how we can help our FX children in his or her education. If you have any questions for Christina and Elyse or you would like them to provide a Fragile X presentation for your child’s school district or an organization please do not hesitate to give them a call at the following phone numbers.

Stramski Children’s Developmental Center, 2650 Elm Ave. #301, Long Beach, CA 90806
Christina Aguirre-Kolb, MS, LEP, ABSNP - Phone: 562.728.5056 *Bilingual
Elyse Schoenwald MSN, CPNP - Phone: 562.728.5034

Save the Date

Conservatorship lecture with Christopher A. Poulos
Saturday, February 8th, 2014 from 1pm to 3pm
Whittier Senior Center, 13225 Walnut Street, Room 6 & 7, Whittier, CA 90602
$10 per couple or family
Free parking * No childcare * Light refreshments provided

RSVP is required. Seating is limited.
To RSVP or if you have any questions send us an email at fragilexassociation@gmail.com.
For more information: Law Office of Christopher A. Poulos, visit website: www.specialneedslawfirm.com

FRAXSOCAL Board member, Otilia Gaxiola will help with Spanish translations and materials will be available.

Traducción en español y materiales estarán disponibles.
“Let’em Know” Events
GRAND TOTAL: $2,065!!!!!!!

FRAXSOCAL would like to thank everyone who supported and helped us raise money for the NFXF’s Let’em Know! Virtual 5K Walk/Run for Fragile X 2013 and to celebrate National Fragile X Awareness Month in July. Our goal was to raise $1,500 and with all your help we exceeded our goal!!! A special THANK YOU to all of our families, the Sperber Family, Sprouts, Subway, Target, and Vons for their support!!

*Walk at the Beach held on Saturday, July 27th.*
*Walk at the Park held on Sunday, July 28th.*

**FX Awareness in Spanish and more!!**
FRAXSOCAL is proud to have bilingual board members to help families who speak Spanish. On September 27th, we attended a resource fair organized by Fiesta Educativa at the California Endowment in Los Angeles to help educate Spanish-speaking families and professionals attending the resource fair about Fragile X Syndrome. Another event that FRAXSOCAL attended was the Abilities Awareness Faire on October 22nd in the City of Whittier. FRAXSOCAL had the opportunity to give information to families and students about Fragile X Syndrome and network with other organizations to help with information and resources.

*Fiesta Educativa assist Latino families with resources and advocacy for their children with special needs. For more information visit: www.fiestaeducativa.org.*

*If you know of a community event and would like FRAXSOCAL to attend or would like information about FRAXSOCAL please give us a call at 818-754-4227 or send email us at fragilexassociation@gmail.com. FRAXSOCAL Spanish materials are available.*

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**Fragile X Articles and Key Findings**
If you would like to learn more about Fragile X Syndrome (FXS) breaking news, commentary, and archival information relating to FXS you can access this information from the National Fragile X Foundation (NFXF) website at www.fragilex.org and click on Fragile X-associated Disorders.

If you cannot find what you are seeking you can contact NFXF’s Support Services Coordinator, Jayne Dixon Weber at treatment@fragilex.org or send us email at fragilexassociation@gmail.com.

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**Helpful Resource**
YMCA
Phone: 800-872-9622
www.ymca.net

The YMCA has several programs and activities for individuals of all ages with disabilities. Regional Center clients can get a discount for membership and assistance with some programs. If you are not a Regional Center client the YMCA does offer discounts for their activities and membership.

For more information, please contact your local YMCA or talk to your Regional Center Coordinator.
First of all, I’d like to introduce myself to those of you I haven't meet plus reconnect with some of you I haven't seen in a while. My name is Erica Carvajal and I have two sons Matthew & Mark. My son Mark is affected with Fragile X syndrome. Our journey with fragile X has not been easy. As most of you know, it is a physically and emotionally hard job. Our Marky has many difficult behaviors that challenge us daily. We all deal with highly stressful situations differently.

I would say I’m a strong woman, I have lots of friends, I'm blessed to have a supportive husband and older son that watch my Marky so I can have "me time" or "girl time." If you saw me you would know that I usually have a smile on my face. Always had a smile. I'm the friend that is always there for you giving... you words of wisdom and encouragement. I love taking care of people and making them feel special. But over the past years I've been a great actress hiding my own pain. I've been letting the stress of having a child with special needs overwhelm me. I was in denial and not coping with things as well as I thought I was.... I let myself believe that I was this amazingly strong person, people praised me for, but behind the smile, and the funny girl I was slowly harming myself with overly indulging in food. Yes, food was my comfort. Although at my heaviest I never had any self esteem issues... my weight was starting to take its toll on me. Even tying my shoes was leaving me out of breath. I had lost 50lbs 7yrs ago, gained it all back and then some.... I had given up the fact that I would ever lose weight again. I had saved all my "skinny clothes" (size 12) hee hee hee. I took it all out of the storage bins and had decided to sell it... Who was I kidding I was never going to use these clothes again. The year was almost over and I came across a quote that seemed to wake something inside of me, it sparked a challenge in me. The quote read "A YEAR FROM NOW YOU WILL WISH YOU HAD STARTED TODAY" that was it....I didn't want another year to come and go and me wishing I should of started a year ago. It was time to focus on me and take care of me!! . I will start... the challenge to see what exercising and changing my eating habits would do was about to begin. I was determined to see where I would be in a year. I started on Jan 5th. I did this quietly and didn't want anyone to know... I didn't want anyone thinking it was just another unrealized New Years resolution. I started off walking half an hour everyday joined weight watchers and slowly each week the pounds started coming off. I asked a great friend of mine if she would help me. We started walking during our lunch break at work... little by little she would encourage me to run to the corner, then the next one, by the time I knew it, we were running a mile 3 times a week. I participated in my first 5k earlier this year where I ran about 80% of it and on our second run I ran the whole 5k !!!! I couldn't believe it!!! This December I plan to participate in the 5k Spartan Run that has many physically challenging obstacles. Nine months into this journey and I’ve lost 30 lbs. and 4 sizes. Although our lives continue to be a challenge, I have found that it’s better for me to take advantage of my support system and go for a walk, a run or to my favorite exercise class (ZUMBA!!!) instead of overly indulging in food. I'm taking the challenge and reminding myself everyday "A year from now you will wish you had started TODAY!!!! So what is your obstacle? Will today be the day you say I'm going to focus on me? Will it be the day you stop the challenges of having a child with special needs over consume you? Will it be the day you begin your journey? I'm excited what January 5, 2014 will look like.

Let's Start Today! by Erica Carvajal
Some people say that running is just about putting one foot in front of the other, but for me it is more than that. I began running when I was 14. I was mourning my brother’s death and running gave me a sense of comfort. I continued running, even when back home my country was taken over by the civil war. In the middle of all that chaos, I tried to escape from all the terrorism. I ran whenever I had a chance without putting myself in danger, again because running comforted me. I came to the US and continued running. Running took me to new places, dreams and goals. I always wanted to run a marathon and in 1990, I ran my first LA Marathon. Running was indeed a big part of my life, so I continued running marathons. Years later, I became a mother and that totally changed my life, because Max and Marky took over. I wanted to spend all my time with the boys, so running was left behind, but deep inside I missed my running years. When Max turned 13 he was obese and borderline with high blood pressure. I worried about what could happen to Max so I changed his diet and decided to buy a treadmill and motivated Max to get on it. It was hard at the beginning! The treadmill did not appeal to Max and he hated it. I decided to propose him a deal - I would go first and then he would do at least 10 minutes. After a few months he was doing almost 1 hour non-stop! Motivated by that, I began running again with the goal to run in the next the LA Marathon with the dream that perhaps Max and I would one day be doing the race together. A year later, I was in Chinatown with my guys, suddenly Max showed me a brochure for a race called “The Firecracker 5K & 10K” I thought to myself “Hum?? Max and I can do this,” the question was deciding on the 5K or the 10K? I love challenges, so I decided to push Max for the 10K and when I say push, I really mean it. I pushed and I pulled the boy for almost half of the race, the route was not easy, not even for me. There were some good hills for the majority of the route and my boy wanted to quit really bad. As we were getting closer to the finish line though I let him go ahead and he went. He crossed the finish line with the biggest smile ever! Tears of joy were rolling down my face, I was a so proud of my boy! A new journey began and we began doing more races. Max was craving more than just one race a year. It has been 4 years now and Max has completed about six 10K, five 5K and his first half marathon on his 18th birthday in July. I have completed 5 marathons, 8 half marathons, four 10Ks and 5Ks. Running for me is therapeutic, it's rewarding, it's my quality time alone, it's my time to think, to dream and to set new goals. So, one day as I'm running an idea popped into my head, “What if more kids with special needs became runners and got to enjoy this feeling? What if we start a team?” I recruited my younger boy Marky and I began training my little guy. He ran his first race in April and what a surprise, he ran the whole race without stopping! I must admit, I was concerned that Marky would get overwhelmed with the noise level, the crowd, sweating and pretty much the whole experience, but after the race, Marky was calm, relaxed and really proud of himself. Since then, Marky has run a 5K for the “Train 4 Autism” organization and now is training for a race in November and “the Firecracker” in February. I’m pretty sure we are going to nail the 10K! I’m encouraging all of you to give yourself and children an opportunity to run, and experience this sense of freedom. By running we release anxiety, stress, tension, toxins, we connect with nature, we mainstream into the community, and we give ourselves a chance to be healthy!! RUN HAPPY!!
One night as I sat with my son, Quinn, on my lap, he was unusually calm and relaxed. I savored the rare encounter with my darling boy; it wasn’t often that he let me hold him. Quinn was a constant buzz of energy and, at one year old, he had the will of a locomotive. I turned him around to face me, enabling me to look into his crystal blue eyes. He glanced away at first, but I acted uninterested just to see what he would do. After a moment, Quinn reached up with his fingertips and began touching the ends of my eyelashes, brushing over them ever so lightly. I watched his countenance closely for any clue into what he may have been thinking. He became very intent, penetrating his gaze on my lashes for several minutes, but never once looking into my eyes. He was in a world of his own.

Two years later, Quinn was diagnosed with Fragile X syndrome and autism, followed by my son, Shale, and daughter, Faith, all with the full mutation. In a period of three short years, I found myself the young mother of three children with significant disabilities. Like many of you, I had my life all mapped out—an exciting career path and a lifetime of dreams awaited me on the horizon. But I have yet to meet anyone whose life turned out exactly the way they planned.

In June 2013, twenty-one years after that night with Quinn, I published The Fragile Face of God: A True Story About Light, Darkness, and the Hope Beyond the Veil. It is my story—as a mother of three children with Fragile X syndrome, the impossible challenges we faced, and the triumphant miracles that brought us through. It is a story of hope—a story for everyone, regardless of their challenges in life. It is the story I wish I had read during the most difficult years with my children.

I wrote The Fragile Face of God for anyone who has needed hope but didn’t know where to find it. I wrote it for the benefit of countless parents of children with special needs, and for the families who would support them in their journey. I wrote it for the mothers of these special children, who feel at times like no one in the world understands what they’re going through. I wrote it for Quinn and Shale and Faith—to honor them for their magnificent path in life and the many lives they will bless for having walked it. I wrote it for me, and for my own heart. Because a mother’s heart is a sacred place.
**Research Study** by Mary Seward

We recently had the opportunity to participate with our son Tim, now 22, in a new research study at the UC Davis MIND Institute in Sacramento. We decided to take the time and energy to do this study for a number of reasons.

Tim had participated in the double blind study and then the open label study of Arbaclofen at Miller’s Children’s Hospital. We were sad when this ended and learned that some families had seen significant benefits in their child’s behavior and language ability while on the medication. Our experience with the drug was not all positive but we did notice Tim’s ability to use his language in social settings was improved. Unfortunately the study was not set up to measure language skills but other behaviors and so the path to FDA approval has been slowed and the open label study cancelled.

This current study at the MIND is designed to develop new testing measures in language usage and development in Fragile X Syndrome. These new measures can then be used by pharmaceutical companies who are trying to develop new drugs specifically for FXS. We are learning that developing new drugs to improve the core symptoms seen in FXS is difficult since you can’t do a blood test to see what improvement the drug has made. This was one of the reasons we chose to participate in this study.

Another reason was the opportunity to take Tim on an airplane. The study paid for our flight and expenses for the trip. There are direct flights from Burbank airport to Sacramento and the flight is only an hour. We knew Tim’s battery would last that long on his DVD player! We had also taken him on a special event, Wings for Autism, sponsored by Jet Blue at the Burbank airport last year. This event allowed families to go through security, board a plane and meet the pilot and stewards. Tim did great and was ready to get on the plane by himself and leave us behind! We felt it was time to hit the runway and let Tim spread his wings. It was also an opportunity for us to visit family and to have a mini vacation in a nice hotel!

The study itself involves three visits to the MIND Institute for a day of speech and language samples. The research team knows FXS well and they have the day planned to make it as successful and as fun as possible. Frequent breaks and snacks are provided and Tim worked really hard because he wanted that Target gift card of $5.00! We went for the first visit in October and the second visit in November. Our next visit will be in two years.

Please read below for more information about the study and consider calling them if you are interested in helping to increase the scientific base of knowledge of FXS and which may lead to better specific therapies for our loved ones.

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**Language Development in Neurodevelopmental Disorders**

**MIND Institute, University of California - Davis**

We are looking for boys and girls, adolescents, and young adults with fragile X syndrome to participate in a Research Study on **SPOKEN LANGUAGE DEVELOPMENT IN FRAGILE X SYNDROME**.

If you know someone with fragile X syndrome between the ages of **6 and 23 years of age** and would like to know more about this study, please call: 916-703-0226 or email: language.research@ucdmc.ucdavis.edu

*This project is funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development*
UC Davis MIND Institute
Cognitive Training for Fragile X Syndrome

We are currently looking at a non-pharmacological treatment that could improve working memory, attention and behavior in children and adolescents with fragile X syndrome. The purpose of our study is to determine if a computer-based cognitive training program will improve the behavioral aspects listed above. The cognitive training is an evidence-based program that has been an effective intervention for individuals with ADHD, Down Syndrome, and typically developing children so we are now looking to see if it would be good for fragile X as well.

Participation in the study would involve three visits to your home (so you will not have to travel here!) by a qualified UC Davis research staff member. Each visit will be approximately 4 hours and will include cognitive and behavioral testing for your child. After the first visit, you will help your child as s/he completes 5 weeks of training through various computer exercises. During this time, your child will complete 5 training sessions each week, approximately 25 minutes per session and a coach will be available to help you guide your child through the process. We will also ask you and your child’s teacher to fill out questionnaires about your child’s behavior. We compensate families $25 for each home visit and we will compensate your child’s teacher $10 for each questionnaire set completed.

If this is something you are interested in you can call Cindy Johnston at (916) 703-0121 or email the lab at T_pal@ucdmc.ucdavis.edu.

Who can participate?
- Individuals with a confirmed diagnosis of FXS.
- Males and females, ages 8-17 years old.

Where does the study take place?
- A qualified UC Davis staff member travels to your home.
- No need to come to the UC Davis MIND Institute clinic.

What does this study involve?
- Cognitive and behavioral evaluations during 3 home visits (~4 hrs/per visit).
- 6 weeks of online cognitive training for 5 days a week/25 minutes per day.
- Weekly phone communication for guidance and support with a staff coach.

What will I receive?
- Feedback on your child’s progress and assessment results

All Fragile X research studies are sent to you as a courtesy by FRAXSOCAL on behalf of UC Davis MIND Institute, Sacramento, CA. FRAXSOCAL takes no position and makes no claims involving any clinical studies.
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: fragilexassociation@gmail.com
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 fragilexassociation@gmail.com

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
For appts: Elyse Schoenwald

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
Email: natlfx@fragilex.org
Website: www.fragilex.org

FRAXA Research Foundation
10 Prince Place, Suite 203
Newburyport, MA 01950
Phone: 978-462-1866
Email: info@fraxa.org
Website: 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