Hello!
The summer is over and hope everyone had an exciting summer, especially with the NFXF 14th International Fragile X Conference this year in Orange County, CA in July!!
FRAXSOCAL was very excited to be hosting the FX Conference, not only help organize the conference, but to see our Southern California FX families and work with our wonderful volunteers. The FX Conference was well attended with lots of valuable information and lots of fun. FRAXSOCAL thanks everyone for their support for the FX Conference. We could not have organized the FX Conference without everyone’s help. Please take a look at page 2 for a recap, great pictures from the FX Conference, and how we celebrated July National Fragile X Awareness Day at Ruby’s Diner during the FX Conference. Thank you to everyone who helped us with the fundraiser at Ruby’s Diner!
As the summer ended many of our children are returning back to school early. To help prepare for the new school year Educational Psychologist, Christina Aguirre-Kolb from the Fragile X clinic in Long Beach has provide us with a simple worksheet that a parent can complete to help the new teacher or a substitute teacher understand their child. Please see page 4 and 5 to review the worksheets. If you have any questions please do not hesitate to email Ms. Aguirre-Kolb, and if you feel FRAXSOCAL should organize an IEP workshop with Christina Aguirre-Kolb, please let us know. Send us an email with your comments and ideas to fragileassociation@gmail.com.
To continue helping your child(ren) prepare for school on page 7 is an article on how Michael McCauley from the Friendly Hills Barber Shop in the City of Whittier can help with some ideas to have a successful haircut for someone.
Even though we have been busy with the FX Conference, we are still helping spread the word about FXS. We will be having our 2nd Annual Walk in Newport Beach on Saturday, September 27th. Please see page 3 for more information.
As we continue to spread the word about FXS we also had the opportunity to meet with the Europe FX Group Leader to talk about how we each help our FX families in our own country. Please see page 7 for an update on the meeting with FRAXSOCAL VP, Paula Paez and Europe FX Group Leader, Gianni del Corral.
We hope to see you and your family at our events soon!!
Please do not forget that if you have any questions give us a call at 818-754-4227 or send us an email at fragileassociation@gmail.com.
Thank you for taking the time to read our updates and supporting FRAXSOCAL.
Janet Rivera,
FRAXSOCAL President

Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to FRAXSOCAL.
AmazonSmile is the same Amazon you know. Same products, same prices, and same services.
Support FRAXSOCAL by starting your shopping at www.smile.amazon.com!!
**Overview of the 14th International FX Conference** by Charlotte Spahr

FRAXSOCAL was very excited to co-host the 14th International FX Conference this year! Thank you to FRAXSOCAL volunteers that did the hard work to make it happen! The energy, love and support from both old and new friends is an amazing thing! To be in a place with over 700 other people who totally "get" Fragile X is unexplainably remarkable as is walking in the hotel and seeing see Fragile X rock stars (doctors and scientists) who are approachable and willing to share their expertise! There were many moments of tears and laughter, but the best emotion is not feeling alone in this journey of Fragile X! It was nice to relax, re-connect with friends and meet new ones and soak in all the information to share with teachers, therapists, doctors, friends and family and learn from each other. One of my favorite sessions was when Dr. Randi Hagerman talked about and showed the slides about pre-mutation Carriers. One of my other favorites was the self-advocate sessions. These young adults were awesome and inspiring! It was very positive, encouraging and inspiring to hear them speak about their lives! The "Get by With a Little Help From My Friends" was a great way to interact and get to know people! FRAXSOCAL started a trend with a video announcement of announcing the location for the next Conference, but Texas being Texas had to do a bigger, better video of course which was awesome! Thank you to all who stopped by the FRAXSOCAL Welcome table. We hope you enjoyed the chocolate and other treats, were able to pick up a map or flyer if you were looking for fun things to do in the area, and we are thankful to those who picked up a Ruby's flyer and participated in the fundraiser to help us celebrate National Fragile X Awareness Month in July! Several people came to us and thanked us for hosting the Conference and told us how much they enjoyed it. I can't tell you how much that meant to know that all the time put into making the Conference enjoyable is appreciated! It was wonderful for many Facebook friends to meet in person! I know everyone will agree that we look forward to the next Conference in San Antonio!
FRAXSOCAL Updates

Walk for “Fragile X Syndrome”

Join us for our family fun annual walk at the beach to help spread awareness for Fragile X Syndrome (FXS) and spend some time with other FX families.

**Date:** Saturday, September 27th, 2014  
**Location:** Peninsula Park, 100 Main St., Newport Beach 92661  
**Time:** Stretch & Walk from 9:00am to 11am and Light Refreshments provided from 11am to Noon  
**RSVP (by Sept. 19th):** Email at fragilexassociation@gmail.com or call at 818-754-4227

**Suggested donation per family:** $20.00  
*(Cash or check only. Checks payable to FRAXSOCAL)*

To help spread awareness for FXS let’s get creative! Design your own tee with your own inspirations to talk about FXS.

HOPE TO SEE YOU ALL THERE!!

You can also support us by buying our t-shirt and license plate.

- $5.00 FRAXSOCAL “I ❤ Someone With Fragile X” License Plate
- $15.00 “SUPERCALIFRAGILELISTICXPIALIDOCIOUS” t-shirt

**Adult sizes t-shirts:** Small, Medium, Large, and X-large  
**Youth sizes t-shirts:** Small, Medium, and Large

P.O. Box 6924, Burbank, CA 91510  
Email: fragilexassociation@gmail.com * Website: www.fraxsocal.org * Facebook: www.facebook.com/fxsocal

*(All proceeds will go towards the association.)*
FRAXSOCAL Updates

Welcome to August! The month when it is still warm and sunny here in Southern California (invocations for rain are welcome and encouraged). It is time to prepare for school. Many of you may believe that because your school knows you and your child, you do not need to prepare. I would argue with you that you do.

- What happens when a substitute comes in?
- Are there new aides in the classroom?
- What progress would you like seen this year?
- Any information from this summer that should be shared?
- My child’s IEP is in October, I can wait until then. That is approximately 20 days of being in an environment or working on academics or goals that may have shifted due to the summer months.

Let’s start the school year off with a Positive Step! Below are two forms to review before heading into the school year for you to work on when you have a moment to pause and reflect. These forms are limited to ONE PAGE ONLY. This is not the time to write out stories about your child. These two forms are meant to be two positive snapshots; think bullet points.

Also note that Elyse and I are happy to continue our tour of schools in Southern California. Speak with your District Administrator to know when we can do our 2 hour presentation to your Special Education Department at no cost to them.

Lastly, to prepare for a December newsletter, I would like to get a set of examples together of IEP goals. If you feel any goal was well written, helped progress and was appropriate, please email them to caquirrekolb@memorialcare.org. Feel free to black out your child’s name, leave his/her age and grade at the time of this goal; although I will be removing his/her name and adding his/her age and grade too.

Ms. Aguirre-Kolb is Bi-lingual.

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Positive Student Profile for 2014-2015

Child’s Name:
Age:
Classroom

1. Describe your child:
How is s/he valuable in your family? What role does s/he fill in the home? What activities does s/he like to do during the weekend? How does s/he help in the home? What things is s/he interested in?

2. Strengths:
What does s/he do well? Does s/he hold things well? How does s/he show affection? Does s/he have a good memory of people and places? Can s/he follow single step directions well? Does s/he respond quickly to helping?

3. Progress made:
In what areas have you seen growth? What school activities have you seen acclimate at home? Does s/he speak better than before? Have you seen independence grow? Have you seen environments in which s/he has become more comfortable in?

4. Supports needed:
Do other students need to understand your child’s disability? Is there some way that other parents and students could learn about your child’s needs to allow for more positive interactions? Does s/he need clearer routines? Do learning centers need to be removed for a single location for academic tasks? Is the environment without unnecessary visuals or auditory distractors? Does the staff need additional learning or understanding about Fragile X? Do the teachers and staff understand the handicapping condition is the hyperarousal and anxiety and not the intellectual disability?

5. Goals:
What will your child be able to do better within one school year? Ideas: Capable in one academic task (fine motor skills), reduce time in calming locations, remove one negatively impacting behavior. What will your child do within 5 years’ time? What will your child be able to do in 10 years’ time? What do you dream is possible for him/her?

6. Other information to provide:
How have you felt about last year’s work with the school? What can be done to work better with the school? Are there parts of the day that can be shifted more moved? Are there alternatives to being called with negative behavior? Are there possible ways you can assist? Could you help prepare some school activities at home to allow him/her a chance to prepare for the upcoming day? What is the best way and times to connect?
**CONFIDENTIAL**

Special Education

<table>
<thead>
<tr>
<th>Personal</th>
<th>Case Worker</th>
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<tbody>
<tr>
<td>• Eligibility for SPED – Give primary and secondary eligibility. I also usually put in the statement given from the Info/Eligibility page (Describe how student’s disability affects involvement and progress in general curriculum).&lt;br&gt;• Information about your student’s personality, likes and dislikes.&lt;br&gt;• Any information about how to communicate with parents and how involved they are with their child’s education.</td>
<td>• Primary Contact:&lt;br&gt;• Email:&lt;br&gt;• Phone Extension:&lt;br&gt;• Please allow extra time for tests and quizzes during this time. All work can be placed in teacher’s box.&lt;br&gt;• Please notify I/I teacher of missing assignments or if student is having a difficult time.</td>
</tr>
</tbody>
</table>

**IEP GOALS**

• Copy these goals from the goal summary. See example below.

**ELA- Reading (1): By 04/15/2011, when given a series of comprehension questions on the benchmark exam, Kiki will read the passage and answer comprehension questions with 80% accuracy three out of four trials measured as measured by classroom tests Literary Response: Narrative Analysis of Grade-Level-Appropriate Text 3.2 Analyze the effect of the qualities of the character**

**Accommodations Included in the IEP (we are required to provide these by law)**

• Copy these from your services page in a way that is EASY to read. See examples below.

**May take and retake general education tests and quizzes in II or may have extended time on general education tests, quizzes and assignments for full credit until each quarterly grading period in II.**

**Curriculum and Programming Instruction**

• These are useful hints that are perhaps not in the IEP, but the GenEd teacher should know. See examples below.

**May need to borrow the notes or receive a copy of the notes to follow along. May need additional assistance keeping her work (essays, math homework, notes) organized. Present a small amount of work at a time.**

**Assistive Technology and Other Concerns**

• Use this space to share any requirements about assistive technology or health issues. See examples below.

**Student must be excused five minutes before lunch to check his insulin levels or student must have Franklin Speller available to use for all writing assignments.**
Dear Parents,

Under the direction of Drs. Randi Hagerman and Leonard Abbeduto, the Laboratory on Language Development in Neurodevelopmental Disorders at the MIND Institute UC Davis, is currently recruiting families with boys with FXS between 10 and 17 years of age to participate in a spoken language intervention. This flyer will provide you with some initial information about the study. We hope that you will contact us to learn more specific details and to discuss whether the intervention would be a good fit for your child and your family.

**Goal:** To teach parents some empirically-supported strategies they can use to support their child's spoken language development. We are calling the intervention a "parent implemented intervention" because we will work directly with you, the parent, and you will then work directly with your child as we support you with teaching and coaching. Our goal is to encourage your child to use more advanced spoken language skills.

**During the intervention:**
A speech/language pathologist will provide two types of support to enrolled families:

1. Educational sessions during which individualized information for supporting your child’s spoken language development will be presented; and
2. Real-time coaching of parent-child interaction to guide you as you practice using the targeted intervention strategies with your child.

We know that children learn to use more advanced spoken language when they participate in frequent back and forth conversational exchanges about a shared topic. We also know that boys with FXS face challenges in holding conversations that last more than one or two turns or that stay on topic. Our goal was to design a language intervention that would help your child with FXS to engage in longer and more advanced conversational exchanges. The intervention uses wordless picture books which provide parents with the opportunity to tell their child a story using more advanced vocabulary and grammar. As the child learns the content of the story, they can gradually take over some of the story telling so that the parent/child interaction becomes more like a conversation. The intervention is not about reading, it is about talking about what happens in a story by participating in a series of conversational turns that maintain a shared topic.

If the study is a good fit for your child and you decide to enroll in the study, your participation in the intervention will last about 4 months and you will need to travel to the MIND Institute two times: once before the intervention starts and once when the intervention is over. We are planning to start the next phase of the intervention study during the late fall of 2014. The pre- and post-intervention visits will each last about one full day.

The intervention sessions will be conducted by means of distance video-teleconferencing and scheduled to fit into your family’s daily schedule. We will lend you a laptop computer that has all the software installed that you will for video-teleconferencing. We will also lend you an Ipad that is pre-loaded with digital versions of the wordless picture books that you will use when you work with your child. The intervention will be implemented by a speech/language pathologist. Each week during the 12 weeks of intervention sessions, we will have two sessions with you by means of distance teleconferencing. The sessions will last about 45 minutes. The first session will be just with you to talk about the intervention strategies for the week. During the second session, you will interact with your child using the strategies that we have taught you and we will "coach" you using a blue tooth head set so that you can hear us but your child cannot.

We hope that you will be interested in learning more about this project. Please contact us by calling the study coordinator at 916-703-0484 or by emailing: andrea.mcduffle@ucdmc.ucdavis.edu.

*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.*
Approximately fifteen years ago, I was approached by a family member at Friendly Hills Barber Shop in Whittier, to ask if I could cut an Autism family member’s hair. As Autism family members know, it can be very challenging to address even the simplest needs of an Autistic person, which could include a task as easy as getting a haircut for a normal person, but at times, can be very difficult and scary to an autistic individual.

Friendly Hills Barber Shop is a kid friendly business which caters to children of all ages, as well as adults. To help us have a successful haircut of an individual with disabilities, such as Fragile X syndrome we provide toys, show a movie, and if parents allow us we will give candy to help make the individual’s haircut experience a fun and safe place while they wait to get a haircut or if they are already in the barber’s chair. We always go the extra mile, when a customer with a disability comes in for a haircut by using positive and easy language that they can understand. We like to reassure our customers with disabilities and their family that they will not get cut or hurt by their experience in the barber chair. We understand that our customers with a disability can be fearful of getting a haircut or just by saying the simple phase like “haircut” can terrify them. So I like to use the word “trim” instead of cut; which helps ease the process. I always say a little prayer first and ask Jesus Christ to help guide me when cutting individuals with disability hair and to provide me with the skills needed to give the best haircut possible to these very nervous individuals.

A lot of compassion is used when interacting with Autistic/Fragile X customers. I like to talk to them before I start and try to make them feel as comfortable as possible to eliminate their fears and unpleasant experience. I have them touch all the equipment that I will be using on their hair, i.e., combs, shears, and clippers. On most occasions, I will use only the shears in the beginning of the haircut because some Autistic/Fragile X customers are fearful of the vibration that comes from the hair clippers, which can be extremely sensitive to their ears. I talk to them before and after each step to ensure they still feel comfortable. If they don’t like something or feel uncomfortable, they will usually show me by pulling away from me or pushing my hand away.

Parents thank me all the time for having the patience to cut their child’s hair, but I feel it is the other way around. I tell the parents that they should be the ones acknowledged because it takes a lot of patience, commitment, and compassion to take care of a child with autism/fragile x syndrome.

Friendly Hills Barber shop cuts approximately, ten customers with disability hair a month ranging from toddlers to adults. We treat all of our customers, no matter who they are, with the upmost respect, dignity, and compassion. We always take our time when necessary, to cut their hair even if the customer has to return several days in a row to complete the haircut.

FRAXSOCAL VP meets with Europe FX Group Leader

I had the opportunity to meet Europe FX Group Leader, Gianni del Corral this summer in Santa Monica. We talked about the different services provided in his country of Italy compared to the services in California. Even though services are different for both countries it still remains the same how parents who have children with disability struggle to get services and to provide the best education we can for our children. I was also excited to hear from Gianni that he is trying to do a documentary about children with disabilities.

Gianni and his family came to California for vacation this summer and was able to attend the MIND Institute to visit Dr. Randi Hagerman and learn about many different ideas how he can help families in his FX Group.

Gianni is on Facebook if you would like to say hello!
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 fragileassociation@gmail.com or visit us at www.fraxsocal.org, www.facebook.com/fxsocal.org, or Twitter @fraxsocal

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