

November
2012

**INSIDE THIS
ISSUE:**

President Speaks	1
Join us for updates at.....	1
School-Based Intervention and Consideration for IEP Planning with Dr. Braden	2
Bowling with Buddies hosted by OCSA	3
Mission to Lars Recap	4
Coming in 2014: 14th International Fragile X Conference	5
Spreading the Word about FX	5
FX on the Radio!	5
FRAXSOCAL Resource Directory	5
Loma Linda FX Interview	6
Membership Information	7
Resources	7
FRAXSOCAL Information	8

FRAGILE X PRESS

Fragile X Association of Southern California

Hi everyone,

Can you believe 2012 is almost over? I am proud that we were able to share with you so many different events this year. There were educational workshops, family fun day events, and lots of outreach at a number of community events throughout Southern California. However, our biggest event this year was the special screening of the film, "Mission to Lars" with special guests Dr. Randi Hagerman, from the MIND Institute at UC Davis, and filmmaker, Kate Spicer. I would like to thank you all for your support of this event. In addition to everyone who attended, we also received donations from families, individuals and businesses that made the event a success and allowed us to raise much needed funds for the upcoming 14th International Fragile X Conference in 2014. Please see page 4 for an overview of the event and some great pictures.

Before the year ends however, the Fragile X Clinic at Miller Children's Hospital and FRAXSOCAL, will be hosting an educational workshop with Dr. Marcia Braden, one of the leading experts in the field of Fragile X. Dr. Braden will be presenting a number of strategies to assist families in developing an effective IEP plan for children with FXS. This is a great opportunity to hear the latest from such an accomplished researcher. For more information, see page 2. Hope to see you all there!

Finally, we started this year with a family fun day bowling event and we are ending the year with another bowling event just for our teens and young adults. This event is being hosted by high school students from the Orange County School of the Arts (OCSA) who are members of the Fragile X Awareness Club. Please take a look at page 2 for more information.

This will be our last newsletter for the year and we would like to thank you all for the wonderful support we have received this year. Without your help we would not be able to provide all the great events FRAXSOCAL has organized. We look forward to the new year as there is still so much more to do and as we prepare for the 14th International Fragile X Conference coming to Southern California in 2014.

We wish you Happy Holidays and see you next year!

Janet Rivera, President

Join us for updates

- Facebook: www.facebook.com/fraxsocal
- Twitter: www.twitter.com/fraxsocal
- FRAXSOCAL website: www.fraxsocal.org

For additional information or resources please contact us at:

fraxsocal@yahoo.com or (818) 754-4227

También ofrecemos información y ayuda en español.



School-Based Intervention and Consideration for IEP Planning

Dr. Marcia L. Braden returns to the Los Angeles area to present strategies on how to be proactive in developing an effective IEP for children affected by Fragile X.

Saturday, November 10th, 2012

4pm — 6pm

Miller Children’s Hospital
Conference Room A2, Pavilion
2801 Atlantic Ave., Long Beach, CA 90806

Suggested Donation:

\$10 per person/\$20 per family

In order to properly prepare, please let us know if you are coming by

Wednesday, November 7th:

fraxsocial@yahoo.com or (818) 754-4227

(On-site registrations are also welcome.)

Free parking * Light refreshments * No childcare

For more information about this event, please visit us at

fraxsocial.org or at facebook.com/fxsocal

**FRAXSOCAL will be
hosting an opportunity
drawing at this event.**

- Prize Items
- iPod Shuffle
 - Madagascar 3 DVD
Giftbasket

- Tickets Prices
- 1 ticket for \$5.00
 - 3 tickets for \$10.00
 - 8 tickets for \$20.00

This event is co-sponsored by the Fragile X Clinic at Miller Children’s Hospital. For more information about scheduling an appointment at the clinic or to find out about current drug trials, please call Elyse Schoewald at (562) 728-5054.



BOWLING WITH BUDDIES!

AN EVENT FOR TEENS AND YOUNG ADULTS WITH FRAGILE X

HOSTED BY

**THE FRAGILE X AWARENESS CLUB FROM THE
ORANGE COUNTY SCHOOL OF THE ARTS (OCSA)**

SUNDAY, NOVEMBER 18TH from 2pm — 4pm

BOWLMOR LANES

**The District At Tustin Legacy
2405 Park Ave., Tustin, CA 92782**

Did you know that FRAXSOCAL is extremely lucky to have the support of an amazing group of arts students from OCSA, one of the premier high schools in Southern California? They have been staffing many of our events and would like to be more involved with students who have Fragile X.

OCSA students are planning an afternoon of bowling on Sunday, November 18th and would love to have middle, high school and college-aged students with Fragile X join them for fun and friendship.

FRAXSOCAL will be hosting parents, *who must stay on premises during the event*, at an adjacent area of the bowling alley for coffee and a chat. It is essential to RSVP so we can plan for a successful day.

Please call FRAXSOCAL at (818) 754-4227 or email us at fraxsocial@yahoo.com by Friday, November 16th to RSVP.

We hope you can make time for this great event! If all goes well, OCSA would like to plan more outings with our Fragile X teens and young adults.

For more information about this event, please visit us at fraxsocial.org or at facebook.com/fxsocal.

Highlights from the Special Screening of “Mission to Lars”

On October 7th FRAXSOCAL hosted a special screening of the film “Mission to Lars” with special guests Dr. Randi Hagerman and filmmaker Kate Spicer at the Barnsdall Gallery Theatre in Hollywood. The event was attended by over 150 people who were welcomed with a “British afternoon tea” themed reception prior to the screening. During the reception, guests had the opportunity to bid on a number of silent auction items including a drum head signed and donated by Metallica and an acoustic Fender guitar signed and donated by Tenacious D. Volunteers sold raffle tickets for items that included a flatscreen TV.

The film featured Tom Spicer, Kate Spicer's brother, who has Fragile X Syndrome and who is also a huge fan of Lars Ulrich, the drummer of the heavy metal band Metallica. The siblings' journey from England to the US to meet Lars is the story of the film and it is told in a way that is truly uplifting and inspiring. One of the best moments is when Tom finally gets to meet Lars backstage at a concert and you see Tom's magnificent personality come through. Following the film, Kate and Dr. Hagerman participated in a panel session where the audience had the opportunity to ask questions about the film and the latest in the field of Fragile X research.

Thank you all who attended and supported the event, including Keesle, Young, and Logan, Brooks and Kelly Wackerman, Metallica, Angels Baseball, Seaside Therapeutics, Two for the Show Media, United Labor Bank, itsmyseat.com, 3-OM Jewels, Chad Wackerman, Danielle and Victoria Torres, and the OCSA Fragile X Awareness Group.



Kate Spicer and Dr. Hagerman (middle) along with FRAXSOCAL Board members and Seaside Therapeutic representatives.



Volunteers from the Fragile X Awareness Club at OCSA assisting at the silent auction item display table.



Guests at the reception prior to the screening of the film “Mission to Lars.” The reception featured mimosas and tea sandwiches to go along with the “afternoon tea” theme. A number of volunteers sold raffle tickets and assisted at the silent auction table. Both FRAXSOCAL and Seaside Therapeutics provided informational brochures about Fragile X syndrome, resources available at the National Fragile X Foundation and current clinical drug trials.



FRAXSOCAL to Co-Host FX Conference in 2014

FRAXSOCAL is proud to be hosting the 14th International Conference in Orange County, California in 2014. Our co-host is the Fragile X Center of San Diego and we are excited to have this opportunity to work with such a great and energetic group. Please stay connected with us as we will be providing periodic updates about the conference as we move forward with planning events, meetings and fundraisers. We would like to invite you all to get involved and share your ideas with us. We have started fundraising already, but still have more to do. If you have a special talent or simply want to help, we would like to hear from you. We plan to be busy next year and need all of the help we can get. Give us a call or send us an email if you have any questions about the conference or about getting involved. Thanks!

Spreading the Word about Fragile X

In the month of October, FRAXSOCAL President, Janet Rivera and with the help of her mother-in-law, Esther Torres, attended the 2012 Disability Awareness Faire in the City of Whittier. They provided information in English and Spanish to families, students, and professionals about Fragile X syndrome, specifically about how to get tested and the characteristics of Fragile X.



Fragile X on the Radio!!

The Autism America Radio featured two segments on Fragile X with FRAXSOCAL Board member, Monique Johnson and Dr. Gary Feldman, Medical Director of the Fragile X Clinic at Miller Children's Hospital. You can listen to the interviews by internet radio on www.live365.com and iTunes Podcast, just search for Autism America Radio. You can also listen on Sirius/XM Channel 131.

- Sept. 29th – Monique Johnson
- Oct. 6th – Dr. Gary Feldman

Thank you Monique and Dr. Feldman!

FRAXSOCAL Resource Directory

One of FRAXSOCAL's goals for 2013 is to create a resource guide to help families locate services in surrounding areas. These services would include dentists, speech therapists, advocates, transportation services, and more. If you have a resource that can help other families, please email us at fraxsocial@yahoo.com with the information and we will include the resource in the directory. The directory will also eventually be available online.

Loma Linda University Interviews Fragile X Family by Anna Miranda

On October 3rd, my 9 year old son Christopher and I had a wonderful opportunity to be interviewed by the first year medical students at Loma Linda University. Dr. Gold, geneticist and course instructor, met us upon arrival. Dr. Robin Clark, geneticist, was concluding her lecture on Fragile X Syndrome. It was an opportune time to share information on Fragile X with future doctors, from a parent's point of view. The medical students called me the night before, and asked me the questions, so we could rehearse. The students really wanted Christopher to attend if possible, so I brought him along, with the disclaimer that he may take one look at the 50+ adults in the large auditorium and bolt, or....he may take the microphone and make himself at home! And so it is, for us with Christopher, time tells us what is in store. We armed ourselves with some high interest materials - his Student of the Month poster with family pictures and his light-up jelly fish water display, in case he felt like sharing, but mostly to divert attention to ease anxiety.

The students simulated a parent's initial interview with a geneticist: 5 medical students sat at the round table up front with Christopher and myself and asked questions re: birth and early infant history, milestones, what gave us cause to be concerned re: his development, and how he was eventually diagnosed. I was impressed by how interested they were in how the information was shared, who shared it, and what sort of information we were equipped with when we left the doctor's office. There was a consensus that there is improvement to be made in this area, in regards to delivering diagnostic information and assisting the family in accessing support and services. It was an opportunity to share information about the support provided by our Southern California Fragile X Association, the importance of assisting families by providing accurate information, accessing support, all the while realizing that this takes time, and is not an "in and out" visit to the doctor's office. We also shared our involvement with the medication trials (arbaclofen) and a recent research pilot study at the UC Davis MIND Institute on the Cogmed Working Memory Training Program. Dr. Clark also drew our family tree on the board, that showed the inheritance of FX in our family.

And our little star, Christopher, was so happy to answer questions into the microphone! He greeted and shook hands with everyone on the way out. One of the medical students shared his iPad with Christopher, so he sat happy as a clam off to the side with Dr. Gold while the students conducted the parent portion of the interview.



Anna Miranda and her son Christopher (first row) with students and staff from Loma Linda University.

I also saw this as an opportunity to emphasize the importance of early intervention. The take-home message? Always listen to your families. My experience, both personally and professionally working in early intervention, has been when parents have concerns, or suspect something is not quite right, they are usually right, more often than not. I encouraged early referrals to the Regional Center for early intervention assessment and services, when concerns arise.

I want to say how kind and accommodating the Loma Linda group was to Christopher and myself. Dr. Gold, Dr. Clark and the medical students thanked us for participating. Several students came up after the interview and shared their stories of siblings/loved ones affected by autism. We shared many of the same struggles with regard to education and services. We also shared joys and successes which affirmed our determination as parent and family advocates for our loved ones affected by these disabilities.

I will conclude with the final parent question that I was asked, being given the opportunity to respond, or not, however I chose. The question asked if, having already experienced what I have concerning this Syndrome, and Christopher was my first child, would this affect my decision to have more children, knowing they could be affected? Not really being a "what if" kind of person, retrospectively speaking, I tried to answer as honestly and candidly as possible. But in the end, the question begged another question. The question of what the future holds for our children, and how we are providing for them as a society. When the initial question is no longer relevant, I believe that we, as a society, will have arrived.

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:

**Stramski Developmental Center at
Miller Children's Hospital**
2650 Elm Avenue, Suite 301
Long Beach, CA 90806
Phone: 562-728-5034

**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

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