

November
2008

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FRAGILE X PRESS

Fragile X Association of Southern California

Hello everyone,

This is our last newsletter of 2008 and I would like to say that we have had a great and productive year! I would like to start by thanking the FRAXSOCAL Board for their hard work and eagerness in continuing the mission of our organization. It is not easy to find the time to attend or plan events and fundraisers, yet, I think that the Board volunteers because we all believe that our work is critical for increasing awareness of Fragile X Syndrome, supporting families, and supporting research to find a cure.

I would also like to thank all of our FRAXSOCAL families for supporting the association. Without your continued donations, we would not be able to bring in speakers such as Diane Simon Smith, Marriage and Family Therapist, or Louise Gane from the M.I.N.D. Institute, and Tracy Stackhouse from the Developmental & Fragile X Resource Center. Along with Dr. Marcia Braden who will be lecturing on November 15, 2008, these speakers are experts in the field of Fragile X Syndrome and provide families with valuable information and resources. I hope that you will recognize the importance of your contributions and continue to support the association.

We are looking forward to all of the events that we have planned for 2009, including the Los Angeles premiere of the documentary *Living with Fragile X*, continuing our Coffee Talk LIVE! lecture series, more family fun days, and fundraisers such as the 4th Annual FX Yard Sale. We are also planning on continuing our presence at various events such as at Walk NOW for Autism and Fiesta Educativa and supporting Board members, such as Jackie Blanco who regularly presents to local community groups. Thanks to our Board member Aaron Finney, who recently redesigned the FRAXSOCAL web page, we will be able to keep families connected and better informed of upcoming events and research. I encourage you to go to our new site, it is well worth the visit.

Thank you all for a great year and I hope that we will continue to work together to make next year better than ever.

Janet Rivera,
President

Upcoming Events in 2009

- “Living with Fragile X” Film Screening
Saturday, April 18, 2009
- 4th Annual FX Yard Sale (June 2009)
 - Coffee Talk LIVE! Lectures
 - Family Fun Days



Supporting Your Child Inside and Out

Join us for an informative lecture on
behavior management techniques

Dr. Marcia L. Braden returns to Los Angeles to present a variety of strategies on how to effectively manage the behaviors of children affected by Fragile X Syndrome in the home and community environments. Dr. Braden is a clinical psychologist and a leading expert and researcher in the field of Fragile X Syndrome.

Date: Saturday, November 15th, 2008

Time: 3:00pm to 5:30pm

Location: Whittier Senior Center
13225 Walnut Street
Whittier, CA 90602

Suggested Donation: \$10.00

Contact: 818-754-4227 or fraxsocal@yahoo.com

*Please let us know of your anticipated attendance
by Monday, November 10th*

Free parking • Light refreshments • Spanish available • No childcare
Visit fraxsocal.org for more information

Coffee Talk LIVE! with Louise Gane and Tracy Stackhouse

by Paula Paez

This was our first lecture in a new series of talks called "Coffee Talk LIVE!" It was held at Children's Hospital in Orange County on Saturday, October 11, 2008. Overall, it was very informative and both speakers did a wonderful job presenting the latest in research findings and OT strategies that work. I think we all came away not just with a better understanding of Fragile X but how we can better support our kids and other family members.

Louise Gane from the M.I.N.D. Institute provided an in-depth description of the three identified syndromes related to the FMR1 gene. She described in detail how boys and girls are affected in various ways by Fragile X Syndrome. She also discussed FXTAS (Fragile X -Associated Tremor/Ataxia Syndrome) and FXPOI (Fragile X-Associated Primary Ovarian Insufficiency), both of which can also have devastating effects on families. Because these conditions have been more recently identified, Louise emphasized the importance of early detection.

FXTAS has shown to affect some older male carriers of the FMR1 permutation. Some of the symptoms include: intention tremors (shaking that often occurs when reaching for or pouring something), balance problems (ataxia), numbness in the extremities, mood instability, and short-term memory loss. FXPOI on the other hand, affects female carriers and is defined as menopause occurring before the age of 40. A recent study showed that approximately a quarter of carriers may experience this condition. More information on these conditions can be found at fragilex.org.

Our next speaker, Tracy Stackhouse from the Developmental & Fragile X Resource Center, began her talk by having us participate in a hands-on hyperarousal exercise so that we could experience what it must be like to be hyperaroused. If you have not gone through this exercise, it is well worth your time. I know that for me, it was a realization of what my kids might be experiencing everyday.

Tracy went on to say that her experience, after

working with children with Fragile X for 20 years, has shown that there are two critical issues parents need to learn about their kids: 1) triggers for hyperarousal and anxiety, and 2) unique learning styles. Being able to identify these can make all of the difference in managing behavior issues. Tracy then discussed strategies that we could all use at home and school to help our children to self regulate and to teach them to identify when they might need to take a break or have some quiet time.

The first set of strategies she described as routine based strategies. Having a predictable routine will help children with transitions, work through new activities, reduce stress when activities are altered and when activities do not have a specified beginning and end. Other interventions include language based strategies and sensory based strategies. She emphasized the importance of working with your child's occupational therapist to establish a sensory diet in the classroom and at home. Tracy provided the group with several hand-outs with more detailed information. If you would like to get a set, please let us know.

We would like to thank Louise and Tracy for their time and we look forward to continuing this series in the next year.

Contact Information

Tracy Stackhouse, MA, OTR

The Developmental & Fragile X Resource Center
90 Madison Street, Suite 202
Denver, CO 80206
Telephone: 303-333-8360
Email: info@developmentalfx.org
Website: developmentalfx.org

Louise W. Gane, MS

UC Davis M.I.N.D. Institute - Fragile X Clinic
2825 50th Street
Sacramento, CA 95817
Telephone: 916-703-0238
Email: louise.gane@ucdmc.ucdavis.edu
Website: mindinstitute.org

Shop at iGive.com and help raise funds for **FRAXSOCAL!**

Go to iGive.com and shop at over 680 brand name stores. A portion of each online purchase will automatically be donated to FRAXSOCAL and it will never cost you more.

For more information visit iGive.com or go to fraxsocal.org to register and start donating!



Community Awareness Day at SCE

by
Jacqueline Blanco

As a Parent Representative for the Inland Regional Center's Early Start Program, I am responsible for spreading awareness of the needs of regional center clients throughout my community. SCE, a local company, has been a regional center donor for the past three years and has helped fund new programs that my own children have been fortunate enough to take advantage of. For this reason, I was asked to speak about my own experience to SCE employees, who make these contributions possible.

At my presentation, I wore "two hats," one as a parent representative of the Early Start Program and the other as a Board member for FRAXSOCAL. I introduced myself and spoke primarily about Fragile X and how it affects children and families. I thanked them for their continued support and emphasized that without people such as themselves donating to our foundations, resources and programs would not be as easily available for our children.

I had a very enthusiastic crowd of 200 people. They asked questions and took with them literature on Fragile X and the regional center. I felt great knowing that I had been able to reach such a large group and make a difference!

Helpful Hints

Speech therapy — Universities offering courses in Speech and Language will often have a speech therapy clinic to provide services to the community and to provide clinical experience to their students. Most clinics are based on a sliding fee scale, which means families pay what they can afford. When calling, ask for the Communication Disorder Department.

Flat feet — One common physical problem for children and adults with Fragile X is flat feet. Shoe orthotics or inserts are the customary answer to this problem. The usual way to make a custom orthotic is to make a cast of the foot. Of course, not many children with FXS are going to be able to tolerate the sensory issues involved with putting wet slimy stuff on his or her foot or be able to sit still long enough for the cast to set. However, now there is a new way-- a computerized system that using a foot pad takes a dynamic picture of the foot when the child walks across it. It is quick, painless, and easy! Visit the website footmaxx.com to learn more about it and where to find a specialist in your area.

Save the Date

**"Living with Fragile X"
Film Premiere**

Saturday, April 18, 2009

Join us for this important screening of the documentary "Living with Fragile X." This film takes an intimate look at the lives of families affected by Fragile X Syndrome and the determination of researchers to find a cure. This will be a special screening for FRAXSOCAL families and friends followed by a panel discussion. More information coming soon.

Seeking Families to Participate in a New Longitudinal Study on Family Adaptation to Fragile X Syndrome

Researchers at the Waisman Center, University of Wisconsin-Madison are seeking to understand the challenges faced by parents who are caring for an adolescent or adult son or daughter with fragile X syndrome. This new study is funded by the National Institutes of Health and is part of the national network of NIH-funded centers on fragile X syndrome. This study is part of the only fragile X center grant to be focused on families.

The purpose of this 5-year study is to learn about the well-being of mothers and their children with fragile X syndrome, how mothers manage their day-to-day lives, and the stressful events which they may experience. We also want to learn about the quality of life of the sons and daughters with fragile X in regards to their social and recreational activities, friendships, and family relationships.

To qualify for the study, families must meet the following criteria:

- the son or daughter with fragile X must be 12 years of age or older
- the mother must be the biological parent
- the mother must provide documentation from an appropriate health care professional confirming that the son/daughter has the full mutation of the gene causing fragile X syndrome
- the son or daughter lives in the parental home, or the mother has at least weekly contact in person or by phone with the son or daughter

Mothers will be interviewed over the telephone and will complete self-administered questionnaires. We would like to interview each participant three times (once every 18 months) during the five-year study period. During the course of the study, periodic summary reports on the study findings will be shared with families.

All information will be kept strictly confidential. If you choose to participate, you can feel 100% confident that no one outside of the research project staff will know anything that you said, not even the other members of your family.

If you are interested in learning more about this study or would like to participate, please contact Renee A. Makuch (see below). Thank you.

Renee A. Makuch, Project Manager

Waisman Center
University of Wisconsin - Madison
1500 Highland Ave, Room 551
Madison, WI 53705
Toll free ph: 1-877-558-7595
Fax: 1-608-265-4862
Email: makuch@waisman.wisc.edu

Longitudinal Study on Family Adaptation to Fragile X Syndrome

Principal Investigators

Leonard J. Abbeduto, Ph.D.
Jan Greenberg, Ph.D.
Marsha Mailick Seltzer, Ph.D.

Family Fun Day at Keystone Lanes

by Jack Blanco

I am proud to report that we had our biggest turnout this year for Family Fun Day. Close to 50 FRAXSOCAL members came to our bowling event held on Sunday, October 19 at Keystone Lanes in Norwalk. We enjoyed the sport of bowling, great conversations, as well as snacks, drinks, and pizza. The staff at Keystone Lanes did a great job accommodating our group and provided us with enough space and lanes so that we could have our own FRAXSOCAL Bowling Tournament.

Dressed in bowling shoes and with the gutter bumpers up, our bowlers hit the lanes. Bowlers exhibited different styles in delivering the ball down the lane towards the pins. The underhand-under-the-legs was a popular maneuver, the put-the-ball-down-and-push was also up there, but nothing topped or amazed us like letting-the-ball-go-from-up-high-with-a-loud-THUD maneuver! The entire group had a “ball” (no pun intended).



The Blanco's (above) and the Finney's (below)



FRAXSOCAL Families



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, 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 of contact person(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 email addresses are confidential.*

Share a Story

Feeling creative or, got some great FX-related news?
Share it with us!!! We would love to have you write an article for our newsletter!!!
Please email your personal stories and pictures to info@fraxsocal.org.

Informative Web Sites

For more information about clinics and other organizations serving the Fragile X community, please see below.

Clinics:

UCLA Behavioral - Genetics Clinic
UCLA Psychiatry & Biobehavioral Science
Box 951759, 58-24C NPI
Los Angeles, CA 90095-1759
Telephone: 310-794-9516
Website: liliclairefrc.ucla.edu

UC Davis M.I.N.D. Institute
Fragile X Clinic
2825 50th Street
Sacramento, CA 95817
Telephone: 916-703-0238
Website: mindinstitute.org

Organizations:

National Fragile X Foundation
P.O. Box 190488
San Francisco, CA 94119-0488
Telephone: 800-688-8765
Website: FragileX.org

FRAXA Research Foundation
45 Pleasant Street
Newburyport, MA 01950
Telephone: 978-462-1866
Website: 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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