Dear members,

Thank you again for taking the time to read our newsletter and for all the help we continue to receive. In this month’s newsletter you will see pictures of our first Family Fun Day event of the new year held in the month of January. The bowling event was a success. We were happy to have as our special guests movie Director, Canyon Prince and Actor, Michael Briggs, who were doing research for an upcoming movie featuring an adult with Fragile X syndrome.

I am also excited to announce that we continue to spread awareness about Fragile X syndrome. Please stop by and say “Hello” to Board members Aaron and Crissy Finney, who will be attending two community fairs in April. Events like these help bring knowledge to the community about Fragile X syndrome. Please see page 3 for more information.

The 12th International Fragile X Conference is coming up and I hope we will be able to see some of you at the conference. The 12th International Conference will be held in July 2012 in Miami, Florida. I will be attending and will be joined at the conference by FRAXSOCAL Board members Sali Farber, Charlotte Spahr, Mary Seward, and Naomi Star. If you are planning to attend, please let us know. It would be great to have all of the families from Southern California meet there. We will follow up with you as well for pictures and stories to include in our future newsletters. Please see page 3 for more information.

Also, in the month of May we have Genetic Counselor Louise Gane from the UC Davis MIND Institute, coming to do a presentation on how genetics plays a huge role in all aspects of families that carry the Fragile X gene. Please see page 4 for more information.

I hope you all enjoy our March newsletter and hope to see you at one of our next events.

Thanks again,
Janet Rivera, FRAXSOCAL President

Thank you to all of our donors!

Without your support, we could not continue to help families and spread awareness of Fragile X syndrome and research as we currently do. We would like to especially thank 3-om Jewels for their wonderful contributions.
LET'S GO BOWLING!!!!

On Saturday, January 28th 2012 we (FRAXSOCAL) held our first Family Fun Day of the year. The event was held at the Keystone Lanes Bowling Alley in Norwalk, CA. Families from near and far came together to enjoy an afternoon of Food, Friends, and Fun !!! The day started off with a Pizza Lunch and then we laced them up for a few games of Bowling. The six lanes that were designated for our group was filled with smiling faces, laughs, and excitement. The Fifty plus that were in attendance shared in a great time and a memory that will never be forgotten. Also in attendance were movie director, Canyon Prince and actor Michael Briggs. In closing it’s safe to say, even without the Gutter Ball Rails the Family Fun Day at Keystone Lanes was a "Strike" !!!!

Your Family Fun Day Coordinators,

Jack & Jacqueline Blanco
Visit FRAXSOCAL’s booth at the following events:

Walk Now For Autism Speaks
Saturday, April 21, 2012
Rose Bowl in the City of Pasadena
For more information visit
www.walknowforautismspeaks.org

20th Anniversary of the Information Fair & Festival sponsored by Parent’s Place
Sunday, April 29, 2012
Cortez Park in the City of West Covina
For more information visit
www.parentsplacefrc.com

Why should you attend the conference:
• Discover the latest research by some of the world's leading Fragile X experts.
• Learn new techniques, behavioral interventions and coping strategies.
• Connect with researchers clinicians, educators, psychologists and parents.

For more information about the conference and the availability of scholarships, please visit the National Fragile X Foundation website at www.fragilex.org
FRAXSOCAL invites
Louise Gane, Genetics Counselor from
UC Davis MIND Institute for a presentation on
Fragile X Syndrome (FX)

**Topics**
- Testing for Fragile X Syndrome
  - How FX is inherited
- How FX relates to other family members
- Implications of being an FX carrier (FXTAS & FXPOI)
  - Reproductive options for carriers
  - Practical suggestions for families
  - Latest research on FX

**Saturday, May 12th, 2012**
10:00am to 12:30pm
Whittier Senior Center
Rooms 6 & 7
13225 Walnut Street
Whittier, CA 90602

*Free Parking* *Light Refreshments* *No Childcare*

Please let us know if you can attend the presentation
by Monday, May 7th at
fraxsocal@yahoo.com or 818.754.4227

For more information please visit us at:
www.fraxsocal.org
You Are invited to a
Baseball Game
FREE

Join us for a great day for all Stramski kids, their families and staff. FOOD...FUN...GAMES!

When: Sunday, May 20th 2012
Pre-Game Activities: 11 A.M.
Game: 1 P.M.
Where: Blair Field (7th and Park, Long Beach, across from Wilson High)

Long Beach State Dirtbags
Vs.
U. of Pacific Tigers

Hosted By:
Steel Magnolias
"We help children's health blossom"
Dirtbags Long Beach State
Geraldine Stramski Children's Developmental Center

Get your FREE tickets from: Natalia Aguilar...or Sonia Villareal, at: The Stramski Children's Developmental Center Phone: 562-728-5034
Find out more about important clinical research studies on Fragile X Syndrome Conducted by Seaside Therapeutics

Today, there are no medicines for fragile X syndrome that are specifically approved to treat a core symptom—social impairment. This limits the ability of families and doctors to make progress in helping thousands of children, adolescents, and adults with fragile X syndrome. Social impairment associated with fragile X syndrome makes it difficult to participate in everyday activities, and can lead to increased lifelong financial, social, and emotional burdens for families. For this reason, finding targeted treatments that improve social function is critical.

Seaside Therapeutics is studying the science of the brain and working to deliver treatments that improve the underlying causes of developmental disorders like fragile X syndrome. Right now, Seaside is testing an investigational medicine for people with fragile X syndrome to see if it can improve social function. We are sharing this information with you because you are a caregiver to a person with fragile X syndrome who may have social impairment. Your family member may be eligible for 1 of 2 clinical trials listed below:

- **HARBOR-C for children with fragile X syndrome (ages 5 to 11)**
- **HARBOR-A for adolescents and adults with fragile X syndrome (ages 12 to 25)**

Your family’s participation in these clinical trials, or research studies, is voluntary but a very important part of finding out if this new type of investigational medicine could help change the way fragile X syndrome is treated. Please consider connecting with our clinical trial team.

Location of the clinical trial site closest to you:
Miller Children’s Hospital, Long Beach, CA

Contact Information:

Nan O’Donnell, RN, MS  
Research Nurse  
(562) 933-5607  
NODonnell@memorialcare.org  

Gary Feldman, MD  
Principal Investigator  
(562) 728-5034
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

Additional Organizations:
National Fragile X Foundation
P.O. Box 37
Walnut Creek, CA 94597
Phone: 800-688-8765
www.FragileX.org

UC Davis M.I.N.D. Institute
Fragile X Clinic
2825 50th Street
Sacramento, CA 95817
Phone: 916-703-0238
www.ucdms.ucdavis/mindinstitute

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

Fragile X Association of Southern California
P.O. Box 6924
Burbank, CA 91510-6924