Hi everyone,

School is out and I hope you are enjoying the summer. We are excited to be part of NFXF’s “Let’s Know! Virtual 5K Walk/Run for Fragile X” to help raise awareness and to help us raise funds for the 14th International FX Conference in 2014. To join the fun please see page 2 and 3 for more information.

The campaign also celebrates National Fragile X Day on July 22. However, FRAXSOCAL also celebrated a statewide FX day on April 18th with an out-going organized by the FX Awareness Club, please see page 4 for an overview. Several FRAXSOCAL Board members also celebrated by attending community outreach events to educate the public about FX. See page 8 for events attended by our FRAXSOCAL Board members.

Unfortunately, not everything has been well in the FX community because as you know, we received the devastating news about the termination of the arbaclofen drug study due to lack of funds. Dr. Paul Wang from Seaside Therapeutics who managed the drug study sent a statement to share with our FRAXSOCAL families. Please see page 4 for Dr. Wang’s statement.

Even though many of us have had to make changes and adjust to the reality of no longer having access to arbaclofen, there is still hope as we all know how to find strength to help our children. One method to finding strength is to never stop believing in our children. Please read page 5 on how Board member Mary Seward found strength to seek employment for her son. To help continue supporting each other, FRAXSOCAL would like to start developing support groups and we need your help. See page 5 for more information.

As we seek help in supporting each other please do not forget that we have the staff from the Stramski Development Center to help us with medical and educational needs. Page 6 is an article by Educational Psychologist, Christina Aguirre-Kolb about working with FXS students in school. She is also bilingual and is a great resource to many of our families. Christina will be providing free lectures to school districts to learn more about FX, please see page 7 and learn how you can have Christina visit your school district.

Thank you for taking the time to read our newsletter and if you have any questions please do not hesitate to give us a call or send us an email. Hope to see you soon!!

Janet Rivera, President

Talking About Fragile X!!!!

“ACT Today” will be having a live stream show with Medical Director, Dr. Gary Feldman from the FX Clinic in Long Beach to talk about Fragile X Syndrome.

Date: Wednesday, July 24th  *  Time: 11am—Noon  *  Link: http://autismlive.com

*You will also have the option to ask questions during the interview.
As you all know, the month of July is National Fragile X Awareness month and to help celebrate FRAXSOCAL has joined the National Fragile X Foundation (NFXF) in the “Let’em Know Virtual 5K Walk/Run for Fragile X”.

There is no need for you to walk, but of course you can! The walk or run is for 3.1 miles and can be completed anywhere at any time.

If you don’t think walking or running the 5K is for you, no problem you can still participate by donating*. To donate please click the “Donation” link on our FRAXSOCAL event page at www.crowdrise.com/fraxsocalletemknow5k

All proceeds will be divided between the NFXF and FRAXSOCAL which will help us raise funds for the 14th Fragile X International Conference coming to Southern California in 2014.

FRAXSOCAL’s “Let’em Know” fundraiser goal is **$1,500.00**. Donate now and help us reach our goal by July 31st.

For more information & free gifts for your donation visit the website: http://www.crowdrise.com/NFXFLetEmKnow5k

You can also send us your questions at: fragilexassociation@gmail.com

We always like to hear from you!!!!

*Anonymity of your donation amount is guaranteed.
*If presented as a gift, you can send an eCard for free.

As we encourage you to make donations online you are also welcome to make a donation by check. Your receipt will be mailed by NFXF after July 31st. Please make your check out to NFXF and mail it to FRAXSOCAL at PO BOX 6924, Burbank, CA 91510. Indicate FRAXSOCAL on the memo line of your check.
Join us to celebrate the end of “Let'em Know” 5k Walk/Run and National Fragile X Awareness month. Don’t miss out as So Cal families come together for a weekend of fun activities and to help raise funds to support next year’s 14th International Fragile X Conference in Orange County, CA.

**Date:** Saturday, July 27th  
**Location:** Peninsula Park  
100 Main St., Newport Beach 92661  
Stretch & Walk from 9:30am to 11am  
Free bottle water and fruit  
Donation: $10 per person

**Date:** Sunday, July 28th  
**Location:** Grant Rea Park  
600 N Rea Dr., Montebello 90640  
Stretch & Walk from 10am to 11am  
Lunch from 11am to 1pm (Subway)  
Donation: $10 per person

TO RSVP EMAIL US AT FRAGILEXASSOCIATION@GMAIL.COM OR CALL 818-754-4227 BEFORE WEDNESDAY, JULY 24TH  
CASH OR CHECK ONLY. CHECKS PAYABLE TO NFXF. NO CREDIT CARDS ACCEPTED.  
HOPE TO SEE YOU ALL THERE!!!!!!!!!!!!!
On Saturday April 20th, the Fragile X Awareness Club had a bonding event at the Santa Ana Zoo. Similar to the previous events, students from the Orange County School of the Arts partnered with individuals who have Fragile X and shared the day together at the zoo. The parents were able to hang out for two hours while their children and the club members shared a day of fun. It was a memorable experience for all who participated and the Fragile X Awareness Club cannot wait for more events in the future. The students were able to share the day with wonderful people and have memories that they will remember throughout their lives.

As the current Presidents of the Fragile X Awareness Club are seniors, Madi Wackerman and Lauren Chong are more than excited to announce the new presidents for the Fragile X Awareness Club. Mallory Wackerman and Brooke Tobias are taking over and are enthusiastic and filled with wonderful ideas to expand the club and increase success in the future. Madi and Lauren would like to thank everyone in the Fragile X Community for being so welcoming and loving these past two years. The Fragile X Awareness Club has been so memorable and we cannot wait to see where it goes in the future. Thank you to all of the individuals who have been so kind; your compassion is truly remarkable and we were amazed by the love in which we were received. This is an exceptional community and we will always continue to be involved.

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**Seaside Therapeutics Statement to FRAXSOCAL Families**

Seaside is very sorry to be terminating our studies of STX209 at this time. There is no new safety concern regarding STX209, and we are still trying to prove to the FDA that it is helpful, but we simply don't have the resources to continue the studies. We are deeply grateful for the support that we have received from so many people and organizations within the FXS community. Please know that we have done everything in our power to continue the studies up to this point. We continue to seek funding for our work, and if our situation changes, we will certainly communicate that.

Although our studies are now terminated, we have not given up hope for STX209. We hope to have the results of the double-blind studies 301 and 302 by this summer. If these results are positive, we will go to the FDA for approval of STX209.

Thank you again for all your interest and support.

- Paul Wang, MD
  Vice President, Clinical Development
  Seaside Therapeutics, Inc.

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**FX Awareness Club at the Santa Ana Zoo by Madi Wackerman**

On Saturday April 20th, the Fragile X Awareness Club had a bonding event at the Santa Ana Zoo. Similar to the previous events, students from the Orange County School of the Arts partnered with individuals who have Fragile X and shared the day together at the zoo. The parents were able to hang out for two hours while their children and the club members shared a day of fun. It was a memorable experience for all who participated and the Fragile X Awareness Club cannot wait for more events in the future. The students were able to share the day with wonderful people and have memories that they will remember throughout their lives.

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FX Awareness Club members with FX students
Transition Time by Mary Seward

This is the time of year for many of us to be dealing with transition issues. I have attended lots of workshops and conferences during our journey with Tim. Transition times are especially important times to take the time and sit through presentations and hope to find something that may be a good fit for your child’s needs. Tim is now twenty-two years old and is exiting the school district. So, I have once again been on the workshop and conference circuit learning about job training, day programs, housing options, conservatorship, SSI, SSDI, Medical, IHSS and all the new lingo of the adult world. I always have found the best part of the conference is to visit all the resource tables and find out what vendors and services are out there and what they might offer. I recently attended a transition to adulthood mini-conference hosted by a local attorney who specializes in school and regional center issues. I visited all the tables and was somewhat disheartened to find most were seeking high functioning individuals for their college or independent living programs. But at one table they asked me how old Tim was and where we lived and then asked if we would be interested in participating in an employment seeking program funded by a state grant. I told them he wasn’t very high functioning and they said they were to have a wide range of applicants of all ability levels. They gave me the application and I filled it out and handed it back right then. I didn’t hear from them and found the card on my desk and sent a follow-up email. They then called and made an appointment to meet with us at our home. Today, they came and met Tim and in his “interview” he told them he liked “money” and getting his paycheck from his workability program and when asked what he would do with it he said “t-shirts”. He has quite a collection of t-shirts but always wants more! He was accepted into the program and will have an employment specialist who will get to know his interests and then they go knocking on doors of businesses to try and develop a job that is a good fit for his interests and abilities. This was the first time I felt that anyone really believed that Tim could be employed at a real job and had the resources to try and find a place for him.

The moral of the story is to never get weary and keep on going to these conferences and keep asking questions and keep believing!

FRAXSOCAL Support Groups

We are in the planning stages of starting a FX support group in the City of Huntington Beach or in the City of Whittier but to help us have a successful outcome we need your help. We would like to get your opinion on how you would like us to develop the support groups. We would love to hear what is best for you!!!!

For example we would like to know:
1. Would you attend the support groups?
2. What day and time are best?
3. What city would you prefer?
4. What type of topics would you like to discuss.

Send us your comments at fragilexassociation@gmail.com or on Facebook at www.facebook.com/fxsocal

A Marriage and Family Therapist (MFT Intern) would facilitate our support group.
Participating in the Special Education process takes a certain amount of sensitivity, something that does not necessarily occur at the first meeting in requesting services. Your ability to navigate the Special Education process will develop as you get to know the professionals who are working with your child. We frequently find professionals with a basic construct of Fragile X and the cognitive abilities typically associated with the gender of your child. The responsibility of sharing of in depth knowledge, typically resides with you - the families. As you develop these relationships, you may find that the other professionals working with your student turn to you for helpful hints when working with your child. One such area is the required Initial, Triennial or Requested Evaluations of your child’s Cognitive abilities. We intend to support you in this process by discussing our Stramski Children’s Developmental Center recommendations for the school’s review of your child’s thought process.

Dr. Marcia Braden, the National Consortium Fragile X Clinical Psychologist (and admirable guru) has established some helpful key points on the cognitive profile of children with Fragile X. Providing these three key figures allows the evaluator insight into the differences between children they typically see and your child. We would also like to prepare them for an evaluation beyond Standard Scores and/or Scales Scores supplied by the typical or atypical responses of your child but rather an evaluation of the very true sense - the appraisal of your child’s abilities.

First of all, the IQ (Intelligence Quotient, sometimes reported as General/Overall Cognitive Ability) is normally smaller than their peers with a Developmental (or an Intellectual) Disability. Secondly, the Achievement Core (the formal academic measures) of children with Fragile X is generally better than their peers with a Developmental Disability. Lastly, Dr. Braden reports that children with Fragile X have more variation across subtests than children with a Developmental Disability.

Another area to review is the manner in which to complete the formal Psychological and Academic evaluation. Dr. Braden has developed helpful techniques when working with children affected by Fragile X.

- Knowing initially that children with Fragile X can become over aroused very quickly and can take a long time to return to a calm state should assist the evaluator so they do not inadvertently diminish the outcome of the assessment.
- Casual introductions are the best manner to begin. Observe the child several times to note interests and their best response to which visual schedule is presented. This will be helpful when encouraging perseverance on trying tasks.
- Prepare the child to be out of the familiar environment, consider the use of a transitional object.
- Provide a visual schedule of the assessment process – what comes first, how much time will be spent and when it will be over.
- Break down the assessment into small increments and notice the child’s lead for breaks.
- Use icons, tokens or movement on visual schedule to note the end of segments, especially icons or tokens of interest to encourage motivation.
- Finally, when the professional is recording responses, note the approximations that children will say too. Frequently we find that the child does know the answer but does not provide the recommended response.

Lastly, the professionals may ask for which cognitive measure would best reflect the abilities of your child. Our Center and Dr. Braden both have recommendations of actual cognitive measures to use. We would like to take a moment to share a disclaimer about the cognitive measures. This will come in the form of an antidote. A few months back, several of us from the Stramski Children’s Developmental Center attended a conference to promote the correct methods a research group wanted us to follow when conducting their study. During the conference, the discussion surfaced about the cognitive measure they are using and their reasoning. I made a quiet, side statement about how the measure was “too broad.” They asked me to provide my reasoning for this statement, so we could share our recommendations for cognitive assessment with the presenter and other members of the group. Needless to say, they have a few more ideas. The cognitive measures we have available to us are few. Of that group, there are two that will do a better job at reflecting the abilities of your child, though please know that most are too wide in their applicability and do not reflect essential points.

Dr. Braden recommends the Kaufman Assessment Battery for Children, Second Edition. This evaluation is good because it has a benign time element, it has been used in a number of previous research articles, motor responses are not required and the materials are interesting and colorful. We also recommend the Woodcock Johnson Tests of Cognitive Abilities, Third Edition because the time element can be discreet, motor responses are not required, it has a better correlation to the cognitive phenotype than other measures and the RPI (Relative Proficiency Index) is a manner at which we can review your child’s predicted quality of performance on tasks similar to the ones assessed.

We at the Stramski Children’s Developmental Center realize that it is not an easy task to be the holder of information regarding Fragile X. We are here to support and we hope you find this information helpful as you work with other professionals. Please feel free to contact us if you there is any way we can help support your student.

Christina Aguirre-Kolb, M.S., L.E.P., A.B.S.N.P.
Stramski Children’s Developmental Center
2650 Elm Ave. #301, Long Beach, CA 90806
Phone: 562.728.5056
Stramski at School: District Presentations

The Stramski Children’s Development Center is sending the Fragile X Clinic on the road to your child’s school district!

Nurse Practitioner, Elyse Schoenwald and Licensed Educational Psychologist, Christina Aguirre have prepared a Fragile X presentation for your child’s school district.

Elyse and Christina plan to present during the scheduled fall teacher in-service.

To include your school district in their tour please email Christina at caguirrekolb@memorialcare.org with the name of the school and contact person before July 22, 2013.

If you have any questions, do not hesitate to call 562-728-5034.

Seeking Participants for fragxis Study

We are studying an experimental medication for Fragile X Syndrome. We hope to learn if this experimental medication is safe and how it affects symptoms of Fragile X Syndrome.

- Adolescents and adults with Fragile X Syndrome.
- Children between the ages of 5 to 17 years may participate.
- Cost for travel, accommodation, food for clinic visits will be reimbursed.

Contact Information:

Miller Children’s Hospital Long Beach, California

Nan O’Donnell, RM, MS
Research Nurse
(562) 933-5607
Email: N’Odonnell@memorialcare.org

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

This announcement has been sent to you as a courtesy by FRAXSOCAL on behalf of Miller Children’s Hospital Long Beach, California.
FRAXSOCAL takes no position and makes no claims involving any clinical studies.
Información

- Sábado, 27 de julio nos reúnimos en la playa para caminarn
- Domingo, 28 de julio nos reúnimos en el parque para caminar y almuerzo gratis

Fecha: Sábado, 27 de julio
Ubicación: Peninsula Park
100 Main St., Newport Beach 92661
Caminata de 9:30am a 11am
Botella de agua y fruta gratis
Donación: $ 10 por persona

Fecha: Domingo, 28 de julio
Ubicación: Grant Rea Park
600 N Rea Dr., Montebello 90640
Caminata 10am-11am
Almuerzo 11am -1pm (Subway)
Donación: $ 10 por persona

PARA CONFIRMAR SU ASISTENCIA MANDE UN MENSAJE A FRAGILEXASSOCIATION@GMAIL.COM O LLAME AL 818-754-4227 ANTES DE MIERCOLES 24 DE JULIO.
EFFECTIVO O CHEQUE SOLAMENTE. CHEQUES A NOMBRE DE NFXF. NO SE ACEPTAN TARJETAS DE CRÉDITO. ¡ESPERAMOS VERLOS A TODOS ALLÍ!
La Clínica X Frágil del Centro de Desarrollo Stramski está enviando a la enfermera, Elyse Schoenwald y a la Psicóloga Educativa, Christina Aguirre, a hacer presentaciones a los distritos escolares locales para hablar sobre los síntomas de X Frágil y como mejorar la educación de sus hijos.

Elyse y Christina planean presentar antes de que comience el nuevo año escolar. Para incluir a su distrito escolar en su gira, por favor mande un mensaje electrónico a Christina a la dirección caguirrekolb@memorialcare.org con el nombre de la escuela y la persona de contacto antes del 22 de julio de 2013.

Si usted tiene alguna pregunta, no dude en llamar al 562-728-5034.

Estamos muy contentos de ser anfitriones de la 14ª Conferencia Internacional de X Frágil del Condado de Orange, CA, con el Centro de San Diego X Frágil. Por favor, manténgase en contacto con nosotros. Le estaremos dando todas las actualizaciones sobre la conferencia ya que las fechas se acercan.

Estamos planeando algunos eventos divertidos y emocionantes para ayudar a recaudar fondos para la conferencia y esperamos que pueda unirse a nosotros.

Si tiene alguna pregunta acerca de la 14ª Conferencia Internacional, no dude en preguntar y enviar un correo electrónico a fragilexassociation@gmail.com o póngase en contacto con nosotros a través de www.facebook.com / fxsocal. favor.
Spreading the Word!!!
FRAXSOCAL Board members were busy this past couple of months in helping to educate people about “What is Fragile X?” Board members, Aaron and Crissy attended two resource fairs, the Autism Walk in the City of Pasadena and Parent’s Place in the City of West Covina, and just this month Board members, Brandon and Mary attended the Stephanie’s Day Resource Fair at the CBS Studios. Thank you to our Board members for spreading the word about Fragile X syndrome and thank you to everyone who visited our booth.

If you happen to know about an event in your community and would like FRAXSOCAL to participate, please let us know.

Just send us an email at fragilexassociation@gmail.com

Helpful Hints:
For those of you who receive In Home Support Services (IHSS) do not forget that starting September 1st a new method of completing timesheets will be required. Please contact your social worker/case worker for more information on how to complete your timesheet. If you would like a Powerpoint presentation on how to complete the new forms please send us an email at fragilexassociation@gmail.com and we will forward you the Powerpoint.

There is also information on the following websites:
- http://www.cdss.ca.gov/agedblinddisabled/pg1814.htm
**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.*

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**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

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**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.nfxf.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

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