Hello,

I hope everyone had a wonderful and safe holiday season. A new year is just beginning and we are off to a great start. I would like to thank everyone for the incredible response we received from our Holiday letter. Donations well exceeded our expectations and it is absolutely wonderful to see the generosity of our members, families, and friends. As you know every little bit helps us continue our mission of raising awareness, supporting our families, and supporting scientific research for Fragile X Syndrome. With your donations we will continue to bring more quarterly Family Fun Day events, educational lectures, regular newsletters, and website updates for the new year.

As you can see, we are already well into planning for the new year. This is our first newsletter and already we have lots of information to get everybody off to a good start. We will also be having our first Family Fun Day for 2009 soon. Please visit our website at www.fraxsocal.org for more information. I would again like to remind you to “save the date” for our upcoming film screening of the documentary, “Living with Fragile X” at the Barnsdall Gallery Theater in Hollywood on Saturday, April 18th.

We hope to see you throughout the year and if you have any questions or a story to share please email us anytime at info@fraxsocal.org.

Janet Rivera,
President

Upcoming Events in 2009

- Family Fun Day at the movies (January)
- “Living with Fragile X” screening (April)
- 4th Annual FX Yard Sale (June)
- Coffee Talk LIVE! (September)
Would like to invite you to a very special screening of the film “Living with Fragile X”
Saturday, April 18th, 2009
6:30pm - 9:30pm
Barnsdall Gallery Theatre
4800 Hollywood Boulevard
Hollywood, California
Price per person: $40.00
(Parking and Pre-screening reception included)

This is a documentary that takes a rare and intimate look at the lives of several families who live with a member affected by Fragile X Syndrome, the leading cause of inherited mental disability and the leading known cause of autism. “Living with Fragile X” explains what Fragile X is and how it is passed, exposes the day-to-day challenges faced by those who have Fragile X and reveals the frustrations of parents and their fears for what the future holds. More information to follow soon.

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!
Does your child have Fragile X Syndrome? Does he/she need help to improve math, money and other cognitive skills?

We are conducting research using a software program to help children with Fragile X Syndrome learn new skills. The software uses a fun, reward-based learning paradigm to maximize your child's learning potential.

Participation involves:
- Cognitive testing
- MRI scan
- Intensive training at home on a laptop computer for 2 weeks

Benefits of participating:
- Potential improvement in math and money skills
- You will receive an honorarium of $100 for your participation
- The option to keep the software for free

For more information, or to enroll, contact:
Melissa Hirt (mhirt@stanford.edu) or Scott Hall (halls@stanford.edu)
(650) 498-4799 or toll free (888) 411-2672

For further information regarding questions, concerns, or complaints about research, research related injury, and questions about the rights of research participants, please call (650) 723-5244 or call toll free 1-866-680-2906 or write the Administrative Panel on Human Subjects in Medical Research, Administrative Panels Office, Stanford University, Stanford, CA 94305-5401.

☐ Please contact me regarding the possibility of participating in this project at Stanford University.
☐ I am not interested in participating in this study, but would like to be added to Stanford's Fragile X registry so that I may be contacted should other research/intervention opportunities arise.

Name: __________________________ Phone/Email: __________________________
Address: ___________________________________________________________________
Comments (optional): ________________________________________________________
One of the most prevailing fears for a couple when their child has a disability is that their marriage will be affected, perhaps it will likely end. In fact, one of the things that is told to couples is that 80% of them will be divorced because of the child. When couples tell me these statistics, I tell them that that is not my experience with couples who are parents of children with disabilities. However, it important to recognize the 50% of couples, in general, divorce and that statistic can be higher whenever a significant stressor hits the family.

Having a child with a disability is certainly one those stressors -- one that is chronic, one that requires enormous renegotiation of roles and reordering of priorities. Disability in a child challenges our most core beliefs about life and its meaning and challenges our dreams for the future. Other stressors and crises do that -- illness, unemployment, natural disaster, or a death in the family. But disability in a child carries with it particular obstacles that couples must navigate.

But first, let’s look at what the experts say constitutes a “healthy marriage”. In his book, 10 Lessons to Transform Your Marriage, Dr. John Gottman, who has made the scientific study of marriage his life’s work, says that “happily married couples behave like good friends.” He also says that “happily married couples handle their conflicts in gentle, positive ways.”(pg.3-4) Note that he does not say that healthy marriages have no conflict, but that how they handle that conflict determines their success as a couple.

In their book, Married with Special Needs Children, Laura Marshak and Fran Prezant say that, in a healthy marriage, partners: 1) feel connected through time, affection, and intimacy; 2) have good communication and conflict resolution skills; 3) have tolerance and respect for each other’s differences; 4) share a fair distribution of power and responsibilities; 5) feel like a team and are able to adapt to changing circumstances; 6) have a sense of their individuality and also the “we-ness” of the relationship; and 7) are committed to the marriage.

When children enter the relationship, there are certainly new challenges as the couple must adapt to their new roles as parents, while trying to stay connected as lovers and partners. And when one or more of the children has Fragile X Syndrome, or any other significant disability, there are a whole new set of challenges. In addition to dealing with the individual struggles of parenting a special needs child, we must simultaneously face the following challenges with our partner if the marriage is to thrive:

1) We need to connect with our spouse even though at times it seems that our child’s issues are all encompassing.
2) We have to try to accept that our partner may have different emotional reactions to the diagnosis of Fragile X Syndrome. In our minds, our partner may not be “grieving right.” On the whole, men and women tend to handle their feelings quite differently and that may be challenging to understand.
3) We may have to make adjustments to our marital and parental roles in a way that feels fair and doesn’t cause resentment. This may require occasional evaluation and re-adjustment.
4) We have to do our best to retain some gestures of romance so that we can see one another as more than “mom and dad.”
5) We need to develop a creative vision for the future, despite the challenges of the present moment Often the thought of the future, which was once the subject of much dreaming together, becomes a scary subject to be avoided. With time, couples can begin to dream again about their shared vision for their futures even if the future is next month.
6) We need to be on the same team. As on any team, each partner has strengths and weaknesses. As a team member, you strive to complement each other and have a strategy for getting back on track when correction is needed.

So, in the midst of the extraordinary demands of parenting, therapies, and making a living, how can we realistically take the necessary steps to make our marriages stronger so that they can “go the distance” and be flexible enough to respond to new and changing demands?
Here are some suggestions:

1) Plan some time alone together. First and foremost, couples need to carve out time together that is theirs alone. Of course, this is easier said than done because of the challenges of time, money, and finding babysitters, especially if there is no family around. This is the purpose of respite care. Use it to have sacred time for yourselves. Do something small like taking a walk or going to an early movie; it doesn't have to involve great expense.

2) Express appreciation sincerely and often. One thing that couples consistently tell me in therapy is that they often don't feel appreciated by one another. Acknowledgement for the big things is very important, such as “I really appreciate how you work so hard to support our family.” Or “you do such a wonderful job with the kids.” Yet, remember, the little things are important too. Try stating something very specific like, “I really appreciate that you helped me get the kids breakfast this morning.” Try for one acknowledgement each day and try not to follow up with “but….”

3) Share laughter and find humor in everyday things. Fragile X children can be charming and very funny. There is plenty to enjoy about that. Reclaim humor, irony, and laughter. It is a powerful weapon against despair and disconnection.

4) Praise frequently; criticize rarely. Research shows this formula is a predictor of marital longevity. Try for a 3:1 ratio to start.

5) Respect each other’s different ways of dealing with your child’s disabilities. Through conversation, listen to your partner’s experience of your child and accept that it may be different from your own.

6) Accept each other’s strengths and limitation. On a team of any kind, there are individuals who excel at one skill and do not do as well at another. It is important to remember that we each have our own limitations that our partners must accept well.

7) Develop a united front for parenting. A difference in parenting styles is a primary source of conflict between partners. Do not undermine each other’s parenting. Take your discussions and disagreements away from the children. If you fear your partner is very inappropriate in his or her parenting, get help.

Relationships are a challenge and an opportunity for growth, under any circumstances. Good relationships require showing empathy and taking responsibility. Think about what it is like for your partner to be the parent of a child with Fragile X Syndrome and what your partner might need from you. Share these ideas with your spouse. Then imagine your relationship as you would like it to be. Decide on the one thing you can do today to move you toward that vision and take that step to make your reality closer to that vision.

Diane and her son, Matthew, who is diagnosed with Fragile X, at the 11th International FX Conference in St. Louis.

Diane Simon Smith, MPH, MA, MFT (Licensed Marriage and Family Therapist)
20750 Ventura Blvd., Suite 245, Woodland Hills, CA 91364
Contact: 818-888-1524 or dianesmithmft@earthlink.net
**The Mighty Ducks**  
by Mary Seward

I recently received an e-mail about a special needs ice hockey team. Tim has always loved the ‘Mighty Ducks’ movies so I thought he might want to try it out. I contacted the organizer and she arranged for a loan of all the protective gear. I had never seen so much padding for a sport! Tim had never been interested in rollerblading or skateboarding so this was a complete unknown for us.

At first he was resistant when I told him about it days ahead of time. I have found that he needs time to process new activities ahead of time. I don’t push it I just put the idea out there and talk about it a little bit. By the day of the event he is excited about it and off we go.

It took about 45 minutes the first time to get all the padding and skates on him. The whole time I’m thinking, ‘I don’t even know if he will be able to stand up and get to the ice, am I crazy for trying this?’ He finally stands up and now looks like the Michelin Man and as he is somehow walking to the ice with a stick in hand he says ‘I look cool.’ My Tim of few words felt good about himself. The coach took over and somehow held him up for awhile and then let him fall and taught him how to get up. Tim was so determined to shoot a goal that he was on his knees shooting pucks into the goal. By his third session he was standing up and shooting goals and spent more time standing than sitting.

The next week the Finney’s two sons with FXS joined the group. Their older son (not affected with FXS) is a hockey player and helped out. It was fun to watch their success with this challenging sport.

If you are interested in joining us, please see the information below:

Valley Ice Center has a class to teach ice hockey to kids and young adults, with special needs. This is a wonderful opportunity to learn and play this exciting sport in a safe and supportive environment. Excellent coaches and high coach/skater ratio! Ability to skate is an asset but is NOT required.

**Fall/Winter and Spring:** (You may sign up and start at any time. )
Boys and girls, all ages welcome. Sundays 4:15 – 5:15pm
Cost: $15 per session, plus a one time only $13 registration fee. (Covers ISI Membership & Liability Insurance.)
Valley Ice Center provides skates and protective gear. However, players must have a hockey helmet with cage.*
Valley Ice Center is located at 8750 Van Nuys Blvd, Panorama City, CA. 91402. (www.valleyicecenter.com).
For more information, directions, and/or to sign up, call Rita Eagle weekdays at 310-792-4794, or email Rita at rita eagle@yahoo.com. *Call Rita Eagle to inquire about the helmet.

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**My Next Door Neighbor**  
by Autumn Orio

I think when you know a kid with a disability it adds a certain spark to your life. At least that is what Kenny has brought to mine. I met Kenny about 4 years ago when I moved right next door to him. At first he wanted nothing to do with anyone in my family except my dad. But the more we got to know him the more he started to ignore my dad and only wanted to be around me. Kenny is a kid who is full of energy, and is funny. He is always doing something and is non-stop. He is funny because my little brother is always following him around, but all Kenny wants to do is follow me around. Whenever I see Kenny he is always carrying 2 very special movies around, The Bee Movie and Ratatouille. Kenny just absolutely loves to come over. His father says that every day he asks to come to our house. When he is here he just loves to play tinker toys, figurines, and of course watch one of his movies. Sometimes we will even go out on the walkways and play. Whenever we are outside we play cars, red light green light, or hide and seek. But what I find really extraordinary is through all of this he manages to stay right by my side. Kenny is also the only person that I know that makes so many split second decisions. One minute he will be sitting and playing with us for hours and suddenly he’ll jump up and say “lets go home daddy.” Sometimes when someone sees a person like Kenny they don’t understand him and are not able to see through the disability. But when I look at Kenny I see a perfectly normal kid who is like a little brother to me. Kenny is one of those wonderful people, that if you’re lucky enough you will meet once in a lifetime. And, I just want to say I’m glad I was one of the lucky ones.

(Kenny is great little kid diagnosed with Fragile X and is the son of Board President, Janet Rivera.)
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 of child(ren) and age with Fragile X

Member’s information is never released to anyone. All email address are 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 personal stories and picture at info@fraxsocal.org

Informative Web Sites

Below are some websites where you can get more information about Fragile X Syndrome.

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<th>Clinics:</th>
<th>U.C. Davis M.I.N.D. Institute</th>
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<tr>
<td>UCLA Behavioral-Genetics Clinic</td>
<td>Fragile X Clinic</td>
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<tr>
<td>UCLA Psychiatry &amp; Biobehavioral Science</td>
<td>2825 50th Street</td>
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<tr>
<td>BOX 951759, 58-24C NPI</td>
<td>Sacramento, CA 95817</td>
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<tr>
<td>Los Angeles, CA 90095-1759</td>
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<td>Phone: 310-794-9516</td>
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<th>Additional Organizations:</th>
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<tr>
<td>National Fragile X Foundation</td>
<td>45 Pleasant Street</td>
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<tr>
<td>P.O. Box 190488</td>
<td>Newburyport, MA 01950</td>
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<tr>
<td>San Francisco, CA 94119-0488</td>
<td>Phone: 978-462-1866</td>
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<tr>
<td>Phone: 800-688-8765</td>
<td>Website: <a href="http://www.fraxa.org">www.fraxa.org</a></td>
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<td>Website: <a href="http://www.FragileX.org">www.FragileX.org</a></td>
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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 fraxisocal.org

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