Happy New Year Everyone!

We hope everyone had a wonderful and safe holiday season. A new year is just beginning and we are off to a great start. We 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 to 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.

This is our first newsletter for 2011 and already we have lots of information to get everybody off to a good start. We would like to start the new year with our first Family Fun Day Event at the Discovery Science Center in the City of Santa Ana and then in March we have a Clippers game for everyone to attend. Please see page 2 and 3 for more information. We also have some upcoming educational workshops planned this year.

I would like to take this opportunity to welcome our newest board member, Mrs. Anna Miranda. Anna joined the board in November and she has already started working on our mission to increase awareness Fragile X syndrome. You will read her story on our next newsletter in March. 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
Join us in celebrating our first family fun day event for the New Year at the Discovery Science Center!!

There will be a structured tour, interactive exhibits, a short 4D movie, demonstrations, activity booklets, and play area.

**Entrance is FREE and lunch (pizza & drink) will be provided.**

**When:** Saturday, January 22, 2011

**Where:** Discovery Science Center
    2500 North Main Street
    Santa Ana, CA 92705

**Hours:** 9:30am - 1:30pm
    (Tour starts at 9:45am and lunch at 12:30pm)

*Parking fee will be waived when you notify parking attendant you are attending the Fragile X Assoc. of So. Ca. event.*

**For directions visit:** www.discoverycube.org

For more information or to RSVP please contact:
    Jack and Jacqueline Blanco
    951-656-5291 or blancojj@verizon.net
RSVP for this slam-dunk party by email or phone to:
fraxsocal@yahoo.com or 818-754-4227
Dr. Hagerman at UC Irvine by Mary Seward

It was a day of Fragile X overload with Dr. Randi Hagerman filling up my brain with her wealth of knowledge on all things Fragile X. My brain and pen were not sharp enough to keep up with all the facts and figures she put forth so I am just able to impart to you the facts and feelings that were able to make it out the door with me.

Firstly and most importantly, if you are a carrier mom, eat a diet high in antioxidants, watch your blood pressure and reduce stress from your life. If you feel depressed it may not be just because you have a child with FXS, it could be due to your higher risk for depression because you are a carrier. Take your depression seriously and don’t be afraid to seek professional help. Carriers are also at higher risk for anxiety, lupus, Multiple Sclerosis, fibromyalgia, early menopause, hypothyroidism and pain, tingling and numbness of the lower extremities. The good news for those women who had early menopause or FXPOI is that this condition does not put you at any higher risk for developing FXTAS when you get older. You have the same risk as the rest of us carriers (8-16%); all for one and one for all! Also as a carrier, think twice before getting an elective surgery since general anesthesia is a toxin to the brain and can make your “carrier” brain shrink faster than normal aging already does.

I wasn’t really feeling depressed until I heard all this! I went home that night and ordered some Vitamin B12 and Folic Acid pills on the internet while I sipped on my green tea. I stopped short of buying the acai berry juice since I tried it once and felt it tasted like berries dipped in dirt. I also called my surgeon and cancelled the bunionectomy. I would like to quit my job to reduce my stress but then the stress of not having any money would be just as bad so I tore up my notice. But I determine to make my workplace a happy environment and to go to the gym everyday for the rest of my life and so that I can live forever and take care of my son, Tim, with FXS.

Now as for Tim, antioxidants are good for him as well so I added to his regimen a chewable B vitamin high in B12 and Folate which he actually likes. Dr. Hagerman also said that melatonin is an anti-oxidant and that he could take 1-3 mg a day, so I bought some of those pills and will ask his doctor about adding that back to his regimen. Dr. Hagerman talked about how they have gotten good feedback from families who started their kids on Minocycline. Minocycline is a mild antibiotic used for treating acne in teens, but some researchers at UC Riverside discovered that it works on the synaptic pathways in the brain that are affected by the lack of the FMR protein. There is now an official research study ongoing at the MIND Institute to see if it really works. She also mentioned that if your child is on Minocycline that you should do blood work every 6-12 months to test for the Anti Nuclear Antibodies (ANA) and make sure they are still doing okay. So I had Tim, who is currently taking Minocycline, get his blood drawn and asked the doctor to check his ANA levels.

Dr. Hagerman told us of several new drug trials at the MIND Institute that will be recruiting participants soon, one being the next phase of the RBAcetofen trial. The other trials include new drugs that target the mGlus for participants that are over 18 years of age. It is important to note that two big drug companies, Roche and Novartis, are involved in these trials. Dr. Hagerman calls the Fragile X protein the “uber protein” or the mother protein in the brain. She says the research on Fragile X may be the key to understanding and treating many other brain disorders such as autism, bipolar disorder, ADHD, depression and schizophrenia. If you are interested in finding out more about the clinical trials go to: www.clinicaltrials.gov. I wanted to sign up Tim for one of the studies, but I couldn’t since he can’t swallow pills required for one trial, and the other trial would have involved a trip to Sacramento every week or two for two months. I thought about adding that much stress to my new stress-free Fragile X carrier lifestyle that I have adopted (see paragraph three) and decided that I would wait for research closer to home or that required fewer visits.

I also learned that young carrier boys sometimes have significant problems and may have autism spectrum disorders, ADHD, shyness and social deficits. Early identification and treatment are really important for these little guys.

The main focus of the morning talk was on FXTAS which presents clinically with intention tremor, ataxia, neuropathy, and cognitive decline. She showed dramatic videos of one man who had a procedure with a deep brain electrical implant which greatly helped his tremors and ataxia. They are also enrolling subjects at the MIND for research into this new syndrome. I hope that they will find some good treatment before I get there.

The best part of the day was, as always, seeing the lovely Dr. Randi Hagerman, who always takes time to talk to each family about their own individual concerns. We also had a great leisurely lunch, just sharing time with each other. Thanks to Janet and Sali for making this a great day!
God has blessed me with two boys affected with Fragile X Syndrome. Nathan is 26; Jason is 20. Nathan was born the year the National Fragile X Foundation was founded. There were no websites to go on or support groups. We finally received the diagnosis when Nathan was 4 years old. I finally had a validation of my mother's instinct that something was wrong and I wasn't an inadequate parent. I didn't understand why other Moms could take their children to the market and they would sit in the cart and behave. I got all kinds of dirty looks and even some telling me that I needed to discipline my child. With the diagnosis came an odd relief but also was scary not knowing what was ahead. I remember thinking about all the dreams I had for my baby. I envisioned sharing my passions, buying him all the toys I never had and us playing together, having him achieve things I was not able to achieve, enjoying him playing sports, driving a car, getting married and I would finally have a girl in the family to do fun girl stuff with, etc. It breaks my heart that I will never have grandchildren.

I wanted a chance to re-do the things my parents did to prove that I could be a better parent than mine and relive great memories of growing up through my child. My husband told me that he wouldn't be able to deal with a child with a disability (his whole attitude changed the minute he met his son and he is a wonderful Dad). I loved Nathan and was in denial that he wasn't a typical baby but didn't understand why he didn't like to be cuddled, would cry a high pitched cry with colic, couldn't sit still (hyperactive), no eye contact, etc. (all symptoms of Fragile X).

Before Nathan was diagnosed with Fragile X, I got pregnant with Jason, not knowing that I could have another son with Fragile X. When Nathan was diagnosed, I prayed that the baby I was carrying would be a girl and unaffected or if affected, would have that extra X Chromosome to help. With Nathan's diagnosis, I went through all the stages of grief for dreams for my son that would most likely not happen. I was in shock and denial even though I had the test results. Then came the pain and guilt (I'm the carrier so I passed this to my son). Next was anger (why me?) and bargaining with God to take this away. Since that didn't happen, I realized that this wasn't going to change and became very depressed. I finally accepted it and became more functional and started seeking realistic solutions to problems caused by Fragile X and reconstructed my life with Fragile X.

I went into full-time Mommy/caregiver mode learning everything I could that would help my son be the best he could be. I found that I became stronger than I ever thought possible and did things that I would have never imagined (like drawing up a petition and speaking at a School Board Meeting - public speaking is one of my worst fears) I learned a lot with Nathan so it was a lot easier with Jason. I see the world differently now through my boys and don't see myself as a Mother who is a failure. I am honored and blessed that God chose me to be their Mom. I count it a privilege to be different. My boys have taught me more than I ever taught them. I have met and become friends with so many people that I would otherwise have never known through my sons.

My boys are sweet, have a great sense of humor, are very loving, very compassionate, good-looking...I could go on and on. I now realize that it's not about them getting into the private school, winning the championship, having a college degree, but the simpler things like saying their first word, having friends, making me laugh, not taking life so seriously and just enjoying it a minute at a time, that we can celebrate with the same joy and pride. I have learned to take one day at a time and look back and see their progress and my progress as a person through unconditional love. I have grown spiritually in my faith in God and know that He will never give me more than I can handle.

My boys are loved by everyone who takes the time to get to know them. Nathan has accomplished many things I never thought he would do like reading and writing, ride a bike, cooking, his computer skills are better than mine, and makes me appreciate the little things in life.

He is happy with his life and how many people can say that? He has loved Hilary Duff since he was a little boy watching Lizzie McGuire and has even met her twice and went to her concert. She has a family member with Autism so she understands and was very nice to Nathan. He loves the computer, all kinds of music, going for walks, basketball, and is a great young man. We recently got him a cellphone (smartphone) and I am amazed at how he figured out how to use it much faster than I have. He has Hilary Duff wallpaper background and has all kinds of music and videos on it and it has entertained him for hours. I've had to help him remember to get out things on mine!

Jason is so much like me and loves to socialize and is so funny and if you are his friend, he is loyal and compassionate. He loves sports of any kind. He can give you statistics on lots of teams and I am amazed at how much he knows about football! He is the "Manager" for the girls softball team at his High School and has made many friends that he loves and they love him. I am blessed to get to know their parents and be friends with them. We can never begin to thank the Coach/Teacher enough who made it possible for him to do this. He has been a good friend to our whole family and always there with support. Through him, Jason knows all the other Coaches, we go to all the Softball/Football/Basketball games and he has even got to walk out with the players for the coin toss and loves that they all know him. The Softball girls are so nice to him and make him feel so loved and needed. He never did as well as Nathan academically but is higher-functioning socially. They are opposites and their Dad says that as they get older that will help them in life because what one is good at and the other not, they will help each other. My husband is always telling me not to take things to heart when they say something hurtful to me. They always come to me later and say they are sorry and give me a hug (you Fragile X parents know the hug doesn't last very long but I love it.) I am a very emotional person and don't know if that is a characteristic of a Fragile X Carrier but I find that I have a lot of the same characteristics of other Fragile X Moms. I will be forever thankful to Mary Seward for starting the Fragile X Association of Southern California which started out as a support group of a few parents searching for other parents with Fragile X children. It was so comforting to share with other parents experiencing the same things as I was. I am on the Board of Directors and am blessed with the friendship and support of many parents through this. I am so happy when I can help someone else through something I have experienced and it's a great way to facilitate healing and bring good to other parents. Our organization was formed to promote awareness of Fragile X and provide a place for families of children with Fragile X to meet and share ideas, concerns and problems and support each other. We share not only each others problems but our successes. I pray that there will be a cure or treatment that will help with all of the symptoms of Fragile X that make life difficult. If not, I will keep putting one foot in front of the other and enjoy the boys that I love so much and couldn't imagine life without. It would be so boring! Looking back, I wish I would have taken time to enjoy the little things more and not been so focused on making them "normal". The longer I live, the more I realize there is no such thing as "normal". They have taught me to be more tolerant and accepting and appreciate everyone for who they are. I am blessed to be Nathan and Jason's Mom-they are the best-just ask me!
You can now connect with
FRAXSOCAL
on
Facebook

Visit us at
Fragile X Association of Southern California

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**Autism Society**
Winter 2011 Autism Conference
January 29-30, 2011
Long Beach, CA
www.greaterlongbeach-asa.org
Regional Center Vendor #PH0252

**The National Fragile X Foundation**
Advocacy Day 2011 at Washington DC
March 1-2, 2011
For more information and registration
www.fragilex.org
**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.*

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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 info@fraxsocal.org.

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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.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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