Hello Everyone!

Spring is here and I am delighted to report that FRAXSOCAL has been very busy. We had our first Family Fun Day event in January at the Discovery Science Center and then a Clippers Game in March. Not only are we having fun, but we are also spreading the word about Fragile X syndrome. Thank you to Board members, Charlotte Spahr and Diane Bateman for joining me in January at the Autism Conference in Long Beach. The conference was well attended and as always, it was an excellent opportunity to talk about Fragile X as a leading genetic cause of autism.

And, we will continue to be busy! We also have a number of events coming up. Later this month, FRAXSOCAL will have a booth at the Walk Now for Autism Speaks in Pasadena. If you plan on attending, please come by and say “hello!” Our 6th annual fundraising yard sale is coming up in June. It’s a huge success every year thanks to Board member Naomi Star, who hosts this event. We’re hoping to break last year’s record, so if you have items you would like to donate or feel like shopping, come and show your support.

Not only is Naomi a huge supporter of FRAXSOCAL, she is an admirable mom for her efforts in helping her son be an active participant at school and in their community. Please take the time to read “Mr. Ram” and their truly inspirational story. Finally, I would like to thank Neal Robb, who recently stepped down from the Board, for all of his many years of service to FRAXSOCAL. We will miss you!

I hope to see you all at the upcoming events!

Janet Rivera,
President

Visit FRAXSOCAL’s booth at
Walk Now for Autism Speaks at the Rose Bowl
on Saturday, April 23rd
For more information visit:
www.walknowforautismspeaks.org
This is the story of a group of students who are changing each other’s lives and helping to create true inclusion for people with disabilities.

My son, James Wackerman is a senior at a large Long Beach school, Millikan High. He was born with Fragile X Syndrome, the most common inherited cause of mental impairment worldwide and the leading known genetic cause of autism. Typical of males with Fragile X he is intellectually disabled, and has great difficulty with communication and social interactions. He is also an extremely gifted drummer, a talent he got from his father, a professional musician. This skill has enabled him to successfully participate in Millikan’s music program for four years and make great strides in many areas of his life.

Kevin Barnett, Jeff Timko and Paige Pelonis are all current or former students of Millikan. They are individuals of great passion and vision, obvious in all aspects of their high school and college careers. Both Kevin and Jeff first made James’ acquaintance in the music program, but it was through a club called Best Buddies that their friendships truly took off.

Best Buddies pairs students who have a disability with regular ed students. The goal is to spark friendships and acceptance for a population that often finds it hard to meet and hang out with their typical peers. As one of the many clubs at Millikan, Best Buddies is able to nominate and sponsor a student in a huge annual competition for senior guys, Mr. Ram, named after the school’s beloved mascot. The contest is for males at the school what Homecoming Queen is to females – a big deal. To our delight, James expressed interest and was nominated.

The confirmation process is rigorous and competitive. Participants have to have recommendations from five former teachers, submit bios, sign a student commitment and responsibility form and a Mr. Ram contract. The contest is judged by people unaffiliated with the school who are completely neutral. They base their scores on three different categories.

As soon as the nomination was confirmed the excitement and planning began. There was so much to consider: an act for the talent portion of the show, a costume to represent the theme, The Greatest Show on Earth, an escort and clothes for the formal attire portion, rehearsals for the group dance number to attend, not to mention the mobilization of a fan club to cheer James on and numerous lunchtime rallies to promote the event to the student body.

James, Kevin, Jeff and fellow Best Buddies pal Paige swung into action. They rehearsed at lunchtimes and on weekends. They created a facebook page to spread the word. They enlisted the help of the drama and music departments. His buddies accompanied James at rallies and classroom visits. And they did everything with so much enthusiasm it was contagious.

Excitement reached fever pitch by the night of the event. We had a large contingent of family and
friends with us. There was also an entire section of the auditorium filled with students who knew James, and even some that didn’t, carrying massive posters with slogans like: James for Mr. Ram”, “We love you James” and “James = Mr. Ram”. As the house lights dimmed a huge screen showed a humorous video of the contestants getting ready for the show. When James appeared on camera we got a taste of the roar we would hear every time he was featured during the evening.

The contest began in earnest with each senior strutting his stuff in costumes relating to the circus theme. The others whipped their shirts off, but James wasn’t comfortable doing that. Instead, he posed with his outfit on, holding a pair of drumsticks. Next was the all-important talent portion. Many of the acts were clever and well rehearsed, but James’ stood out as both different and entirely in keeping with the big-top theme. He drummed his heart out as a ring leader, while Kevin, Jeff and Paige mimed a clown routine with tons of sight gags, including Paige crossing a tightrope to James’ extended drum roll. The skit ended with James soloing as the others danced crazily, and the cheer that went up was almost deafening.

Lastly there was the formal wear segment. The contestants stood on risers with their finest clothes and club sashes on, and took turns parading on the catwalk with a beautiful escort on their arms. James sported the tux my husband wore at our wedding twenty-four years ago and looked like a classic James Bond. Paige wore an elegant, floor-length black gown; the two of them epitomized style and class.

Amazingly, James’ name was called to be one of the final ten contestants. As they lined up across the stage, winners of various categories were called. James won for Best Talent! I was thrilled by how well he’d done and thought that if this was as far as it went it would be one of the happiest moments of my life.

The final hurdle was yet to come. All ten remaining contestants left the stage and returned one by one to answer a question on the mic. When it was James’ turn he walked up confidently and clearly stated his name and contestant number. He was asked what his greatest struggle had been at high school and how he’d overcome it. His reply was that jazz band was great, but jazz band was hard.

The moment of truth arrived. Winners were announced starting with the fourth runner up. By the time the MC reached first runner up and James’ name still hadn’t been called I could barely breathe. Then came the magical words: “Ladies and Gentlemen, Mr. Ram, 2011 – James Wackerman!”. The place erupted. My husband and I cried tears of joy and pride. Everyone stood and gave James a standing ovation as the contestants on stage congratulated James and encouraged the audience to keep cheering for him. They did for a full minute and the sound still rings in my ears.

It was a night of triumph for James and also for Kevin, Jeff and Paige and the wonderful teacher that sponsors the Best Buddies club, Mrs. Weinberg. Not only was James the first student with special needs to be crowned Mr. Ram, but he received the highest scores for a winner ever recorded. It broke down barriers at Millikan High and demonstrated the power of friendship and inclusion. As a parent it proved to me that people can see beyond a disability to the person within. It gives me such hope for the future.

We’ve taken to calling James “Mr. Ram” since the competition. Sometimes he says he wants to be called James Wackerman again, but I’ve explained that he’s earned this title for a whole year so he might as well get used to it!
Family Fun Day at the Discovery Science Center

On January 22 we had our first Family Fun Day of the year. The event was held at the Discovery Science Center in Santa Ana. The day began at 9:30am with a private group viewing of the center and its exhibits. Later the group was led into a theatre where we had a viewing of “Dinosaurs of Patagonia.” After the 4-D Movie was over and we learned so much about dinosaurs, it was off to “Dino Quest,” a hands-on and interactive exhibit. Our day concluded with a group lunch. Each child also received a free pass to be used on a future visit. It is safe to say that this family fun day was a big success and that all in attendance had a great time and experience.

Thanks to all who joined us (14 families in all) and for those of you who weren’t able to make it, we hope to see you at a future Family Fun Day!!

Jack & Jacqueline Blanco
FRAXSOCAL at the Clippers Game

Oh! My goodness, I don’t even know where to begin in describing our event at the Clippers game. We had so much fun that we didn’t want the game to end. The game was held on Saturday, March 19th at the Staples Center. All of our children and young adults enjoyed the game tremendously. Parents were able to talk and even enjoy watching the game themselves. Everyone had a great time and we hope to have another gathering at the Staples Center next year. Thanks to our Clippers sales representative, Nelly, and everyone else who helped organize this event.
Family Fitness Fun Day
Sunday, May 22, 2011 from 10:00am to 1:00 pm
Pure Living Fitness
445 E. Route 66 Hwy, #B, Glendora, CA 91740
RSVP by May 15th: Jack and Jacqueline Blanco
951-906-5115 or blancojj@verizon.net
Lunch (Subway) provided from Noon to 1pm

Fitness Day includes:
Workout Demonstration & Techniques, Lecture on Benefits of Living a Healthy Lifestyle, Samples of Healthy Eating, Handouts, and much, much, more….

This event is designed for kids 8 years or older because of the equipment at the gym. However, younger children are more than welcomed to come. We’ll have activities with balls, aerobic steps, and music for the little ones.

For information and directions visit: www.purelivingfitness.com

THE 6th ANNUAL FRAXSOCAL YARD SALE APPROACHES!
Our annual fundraising yard sale, hosted by FRAXSOCAL Board member Naomi Star, will take place on Saturday, June 18th in Long Beach. Put the date on your calendar and start clearing out those closets and garages! Naomi will be able to store donations of gently used items from mid-May onwards. Help on the day would also be gratefully accepted.

For more information, contact Naomi at (562) 434-2791

Fragile X Research Study
A research study is being conducted with an investigational medication for people with Fragile X Syndrome who exhibit certain behaviors such as: listlessness, inactivity, isolation from others, fixed facial expressions, or lack emotional responses. Children, adolescents, and adults ages 12-25 are potentially eligible. Several research centers across the United States are participating in this trial.

For additional information please call:
Dr. Gary Feldman at 562-728-5034 or Nan O’Donnell at 562-492-6383
Miller Children’s Hospital Long Beach
**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
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