Dear members,

Well, I can’t believe we are well into 2010. With the holiday season and January now only a distant memory, we can finally start working on the goals we have set for ourselves and our families. I know that my goals range from small things, like doing a better job with keeping the house clean, to bigger goals like implementing a solid behavior management plan at home. I don’t think I have to tell you that having a child with special needs complicates things and things just take longer to do. I know it’s often a challenge for me to appreciate my day-to-day life, but I need to remind myself that it is just as important as achieving the goals I have planned. I hope that in the new year you can all remind yourselves of this, too.

In this issue of our newsletter, I would like to thank you for your generous response to our holiday letter. We have many more events planned for 2010, and without your support we would not be able to make them happen. These events include more Family Fun Days and as you will read on page 4, they are getting better and better. We are also planning a talk on FXTAS and continuing to support the newly formed Fragile X Clinic at the Stramski Developmental Center in Long Beach. On page 5 we have included a recap of the symposium on Fragile X recently hosted by the clinic. It was a real treat to have Dr. Randi Hagerman and Marcia Braden together at such a well attended event and best of all, speaking so eloquently about Fragile X and the latest in research.

This issue also includes some truly remarkable articles about our kids participating in activities that we might have never thought possible - ice hockey, football, and skiing. I hope you enjoy these very cute and inspirational stories.

Thanks again,
Janet Rivera, FRAXSOCAL President

We would like to send a special THANK YOU to all of you who supported FRAXSOCAL with your kind donations throughout 2009. Your generosity will make an immediate difference in the lives of families living with Fragile X Syndrome. Your donations will go toward supporting scientific research under the direction of several national research agencies, funding Family Fun Days, promoting public awareness at community events, organizing lectures, and much more.

YOU ARE MAKING A DIFFERENCE!!!

Thank you again for your kindness,
Fragile X Association of Southern California
SALT LAKE CITY OR BUST!
By Mary Seward

Once upon a time three boys joined an ice hockey team. Not that much of a fairy tale except they all had Fragile X Syndrome and according to the experts who diagnosed them, they were not supposed to be able to accomplish much of anything except maybe to live in a group home someday. But these young men loved to skate and play with the stick and the puck and they loved being part of the only special needs ice hockey team in California.

One day, the team Mom asked the parents if they wanted to take their kids to a special tournament in Salt Lake City. She didn't think anyone would want to make that long trip with their kids. But she was surprised when they all wanted to go. The parents were longing to give their special needs kids a taste of what others experience with their team sports and competitions.

So they piled into their cars and 10 hours later were staring at snow tipped mountains outside the Utah Olympic Oval which was the venue for the 2002 Winter Olympics speed skating events. The team was shown to the huge professional locker rooms and they quickly suited up to play other special needs teams from Colorado and Utah.

They also met other “family” members there. One family from Utah had three young men with Fragile X playing ice hockey and one family with a man in his forties with Fragile X played on the Colorado team. They even had the men in zebra shirts and whistles to officiate the play. Since they were there on Halloween the local team hosted a Halloween party for the kids after the tournament.

The team received their medals and they piled into their cars for the long trip home. Hopefully they will live happily ever after with some great memories of the journey to Utah to play ice hockey! For more pictures and more information about ice hockey, please go to www.calspecialhockey.com.
i9 Flag Football – A Positive Experience
by Leslie Chartier

It seems that football is a favorite for our kids with Fragile X. The very first Fragile X event our family attended was a fall picnic where all the boys started up a game of touch football. I often hear other parents tell about their boy’s interest in football. I’d like to tell you about a flag football league that has been one of the best experiences my son, Kyle, has ever had.

Since Kyle was a toddler, he has loved football. At age 2, he could throw a better spiral than I could. Now at age 12, he has a better arm than most typical kids his age. I don’t know if it’s the spinning motion of the ball that got him hooked or the game itself, but he’s been playing catch and tackling his dad in our hallway for years. I have the scuff marks on my wall to prove it.

Well about 3 years ago a flag football league started up in our area called i9. I called the league director to see if it would be appropriate for Kyle. I described Kyle and his needs and he told me he would personally pick a coach for him. Coach Chris was the perfect selection. He was patient and positive and set the tone for the team. They all accepted Kyle and helped and encouraged him. Nobody (including the parents on the sidelines) got upset if he made mistakes that cost the team. Unfortunately after that season Coach Chris moved away so Kyle’s dad, Brian, stepped up to coach Kyle’s teams and has ever since.

i9 has three seasons in a year and Kyle plays all three of them. i9 Sports has created such a positive and safe environment that it has been a great experience for Kyle. While they keep score and even have a championship tournament at the end of the season, the focus is really on having fun, learning the game, and building character. Each week a new sportsmanship value is taught to the team. After the game at the end of the week, the coaches select a player that most exemplified that trait. Rules have been put in place to ensure each child has equal playing time on offense and defense regardless of ability. The league director is at the field all day Saturday while games are being played. Because of this, he is available to maintain the positive environment and listen to any concerns parents might have.

Over the years, Kyle has made many new friends. He plays against former teammates and they are always glad to see him. Coach Brian has put Kyle in roles where he can be successful. On offense, he usually plays center. There he can snap the ball to the quarterback and then run a short pattern to be ready to catch a pass. He has made catches for touchdowns and the extra point conversion. He has also had opportunities to run with the ball and even be the quarterback. On defense he rushes the quarterback and tries to pull his flag. He’s gotten really close. The parents of former teammates always cheer for him even when he’s not on their team any more. All of the league’s referees know Kyle and enjoy talking football with him. Kyle and the League Director have had a special relationship talking about their favorite teams.

We have gotten letters from other coaches and parents that tell us how inspirational it is to see Kyle on the football field, that they are so happy that their sons have had the opportunity to get to know Kyle and how it has been a wonderful lesson for them. Once after a game, a coach from the opposing team told me that his team came to him before the game and said they wanted Kyle to score a touchdown. They didn’t just let him score, they chased after him, even diving for his flag, so that he could feel it was a great accomplishment. Another time, Kyle had his first opportunity of being quarterback. Now, picture the anxiety our kids must feel when players are rushing at them and there are several kids trying to catch or intercept the pass. The center snapped the ball over Kyle’s head into the end zone for a safety. For those of you that don’t watch football, that means that the other team gets 2 points and possession of the ball. Their coach came out on the field and told the ref to replay that down and give Kyle a chance to throw the ball. He made a couple passes before the game ended and he was absolutely thrilled. This past season, Kyle’s team won the championship game for the first time. Oh and by the way, i9 is a coed league so girls, get out there and play some football. Find out more about i9 Sports in your area at www.i9sports.com.
Family Fun Day at the Irvine Park Railroad
by Jack & Jacqueline Blanco

On November 22, 2009 we held our final Family Fun Day of 2009 and what a grand finale it was. Our event took place at the Irvine Park Railroad where our guests and family members were treated to loads of fun!! The fun began with a complimentary lunch from Subway (sandwiches, chips, cookies, drinks) and was followed by complimentary passes to the zoo, pony rides, and train rides.

When the kids were not enjoying themselves on the rides they could be spotted climbing the beautiful trees at our designated area or just running around having a ball. We are pleased to announce that this was one of our biggest turnouts ever, at a whopping “56” in attendance.

We really hope that this is a sign of what is to come and that all future Family Fun Days will be taken advantage of by more members. Like they say “the more, the merrier!!” Happy New Year to each and everyone one of you and we look forward to many more Family Fun Days in 2010 and beyond!!
FRAGILE X SYMPOSIUM
by Naomi Star

Two esteemed experts were the featured guests at a symposium on Fragile X on January 8, 2009. Held at Miller Children’s Hospital, the annual Katherine White lecture series is a chance for doctors, educators and the general public to delve into a specific disorder in depth. Thanks to the input of Dr. Gary Feldman, medical director of the new Los Angeles Fragile X Clinic at the Stramski Children’s Developmental Center in Long Beach, Fragile X was the topic of the day.

Dr. Randi Hagerman was the first speaker, and in her usual dazzling style covered the ‘family’ of Fragile X disorders: Fragile X Syndrome, FXTAS and POI (Primary Ovarian Insufficiency). The portion on Fragile X focused on how the Fragile X brain differs from ‘typical’ brains, how Fragile X relates to autism and recent, promising medication studies. More information on these topics can be found at the National Fragile X website: [www.fragilex.org](http://www.fragilex.org)

Psychologist Dr. Marcia Braden spoke next, concentrating on how best to assess the Fragile X student. She showed some interesting video clips, which clearly illustrated the need for clinicians to be creative in their interactions with this population. Three administrators from the Long Beach Unified School district spoke next, explaining the special education system in their district.

The parent perspective was covered by FRAXSOCAL Board members Naomi Star, who spoke about her son James, and Neal and Carolyn Robb, who talked about parenting their son Garrett. The audience seemed to really appreciate hearing from families living with Fragile X, and it was gratifying to be able to put a human face to the condition.

Speaking of ‘Living With Fragile X’, a trailer of the DVD was shown, and everyone in attendance was given a complimentary copy on his or her way out.

The morning finished with a lively question and answer session for the panel of speakers. The symposium was very well attended and hopefully it will encourage all the doctors and educators who were there to place Fragile X higher on their radars.

Things to Do: Go Skiing in Big Bear
by Paula Paez

Bear Mountain Resort is the home of a wonderful organization called U.S. Adaptive Recreation Center (USARC), which was founded in 1983 to ensure that access to skiing is available to people with all types of disabilities. From December to March, staff and volunteers offer one-on-one ski lessons to children and adults using the best adaptive equipment and teaching techniques available. The staff members are great and do their best to make the experience positive and memorable for participants and their families.

My boys have participated twice now and absolutely love it, even going on the lift! I was surprised how well they actually did. They were fine with putting on the boots and once on the snow had no problem strapping on the skis. I can’t tell you how excited my husband I were to see them jumping off the lift and coming down the slope with their instructors. Watching them on the snow made us forget about their disability and see them as two kids having a blast.

The staff is very accommodating and helpful. They have a small room with a TV in case your skier needs a break. In addition to the ski equipment, they have extra snow clothes, gloves, and sun glasses or goggles in case you need them, or in case you forget to pack them as we did. The lessons are for a full-day, from 9am to 3pm, with a short break for lunch. There is a fee for the lesson that includes the ski equipment rental, however it’s well worth it just to be able to see the kids have so much fun. Reservations are required, so call in advance since demand is high and space is limited. If you are not into snow, USARC also offers adaptive water sports on Big Bear Lake during the summer months. For more information call 909-584-0269 or visit [www.usarc.org](http://www.usarc.org).
Almost every single expecting couple share similar concerns prior to the birth of their child: “Will my child have all their fingers and toes?” “Who will my child look like?” “Will I be a good parent?” “Will my child be healthy?” However, within the last decade a very crucial addendum has been made to the latter: “Will my child have autism or any other disorder?” As more and more children populate the earth, the number of diagnosed cases of autism and other disorders continues to increase. According to a recent study published in the October issue of Pediatrics, approximately 110 of every 10,000 children in the U.S alone will be diagnosed with an autism spectrum disorder at some point in their life time. Additionally, according to the National Fragile X Foundation approximately 1 in every 3,600 males is diagnosed with Fragile X Syndrome, while approximately 1 in every 4,000-6,000 females will inherit the syndrome.

While a diagnosis of any kind is disheartening for every parent, not all hope is lost. With the appropriate care, the necessary treatments and therapies, and an immense amount of parental education any child with a disorder will have the ability to reach their full potential and live a fulfilled life. However, unfortunately with the growing budget deficit the government is cutting the funding for many crucial programs that will facilitate with the development of these children. Many therapies such as speech, occupational, and early development therapies are either being forced to endure for a very limited length of service time or they are being cut entirely. On the contrary, the government has found one service to be so exceptionally beneficial that they have refrained from denying this service at this present moment: Behavior Management Services.

During the course of Behavior Management Services, parents are taught the fundamentals of Applied Behavior Analysis as well as how to properly identify the functions of their child's behavior. In addition, the parents are also provided with an intervention plan which will help them to target and decrease the problem behavior. Eventually, by the conclusion of the services the parents will have the ability to carry out the devised intervention plan independently of the therapist as well as the capability to conquer any future behavioral issues. Thus, through the progress acquired from Behavior Management Services others services will have an easier time commencing.

Since the future is not always clear and despite all the advice parenting books have to offer, no one can fully be prepared for the journey on the path of parenthood. Additionally, it doesn't matter if you have one child or many children; each child is unique and has their own special way of learning and developing. The most important rule a parent must not forget is to never stop fighting for your child's rights and the therapies they deserve; for one single therapy may carry life changing results.

**Frequently Asked Questions about Behavior Therapy**

**Q**: How can I obtain these services for my child?

**A**: Typically, you must ask your regional center to assess your child to determine if these services, also referred to as intensive behavior intervention (IBI), are appropriate. These are typically provided in the home setting to maximize parent involvement and training.

**Q**: What if my child is having behavior problems at school?

**A**: The school, and not the regional center, is responsible for addressing behavior problems at school. You should make sure your child's IEP has a behavior support plan and that a behavior assessment has been conducted to determine how to best address the problem your child is having. Working on the goals for improving the child's behavior must be the responsibility of the teacher and other support staff, which may include a behavioral aid specifically assigned to your child.
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.

Informative Websites

Below are some websites 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 190488
  San Francisco, CA 94119-0488
  Phone: 800-688-8765
  www.FragileX.org

- FRAXA Research Foundation
  45 Pleasant Street
  Newburyport, MA 01950
  Phone: 978-462-1866
  www.fraxa.org

FRAXSOCAL events

More information coming soon!
- 5th Annual Fundraising Yard Sale in Long Beach
- Lecture on Fragile X Associated Tremor/Ataxia Syndrome (FXTAS)
- Presentation on New Research Studies at Stanford University
- More Family Fun Days!

Hamercaz Education Series
- Married with (Special Needs) Children, with Diane Simon Smith, LMFT,
  Wednesday, March 17 from 7-9pm
  www.hamercaz.org

Upcoming Events

National Fragile X Foundation
- Advocacy Day 2010, March 2 & 3
- Webcast: Sensory Integration Issues with Tracy & Mouse, Tuesday, March 30 at 6pm
- 12th International Fragile X Conference, July 21-25 in Detroit, Michigan
  Registration is now open. Scholarships are available.
  www.fragilex.org

Special Education Law Day sponsored by TACA
(Talk About Curing Autism)
Saturday, February 27 from 8am-5pm at UC Irvine
To pre-register call 714-698-0239
or, visit www.tacanow.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