Hello Everyone!

It is hard to believe the year has come to an end. I hope everyone had a very nice 2011 year and it will continue to the year 2012. I would like to thank everyone of you for all the wonderful support we have been given to continue our mission. Without your help we would not be able to continue to provide for our Fragile X community.

This year we had two successful Yard Sale Fundraisers, first at our usual location in Long Beach, and then at our new location in the City of Burbank. All proceeds will be used to continue our mission of awareness and for the support of our families. Please take a look at the great picture from both yard sales on page 3.

This year was also very rewarding for our Fragile X clinic at Miller’s Children’s Hospital. The Girl Scouts, Troop 4043, donated their time and raised the funds to provide a box filled with sensory and therapeutic items to give to every individual with FXS that attends the clinic. Please see page 6 for this heart warming story.

There is still much more for the year 2012 with many upcoming events. See below for an outline of events. We hope to see you all in the upcoming events for 2012 and if you have any questions or a story to share please email us anytime at fraxsocal@yahoo.com and follow us on Facebook.

Janet Rivera,

**Upcoming events for 2012**

- **More Family Fun Day Events:**
  - Bowling Beach/ Surfers Day

- **Annual Yard Sales**

- **13th International Fragile X Conference**
  - July 25-29, 2012
  - Miami, Florida
  - Details on www.fragilex.org

- **Fragile X Advocacy Day**
  - March 6-7, 2012
  - Washington, DC
  - Details on www.fragilex.org
Family Fun Day with Gymnastics
by Jack Blanco

Our last Family Fun Day for the year 2011 was held at Bug Fun Gymnastics in the City of Newbury Park. We had a very nice turn-out with a total of 38 in attendance. We received very positive feedback from our families and everyone was very appreciative.
I think it’s safe to say that this event was a success for everyone!!!!

Thank you to everyone who attended this event and we hope to see you all again in 2012.

SUPPORT GROUP FOR MOTHERS OF CHILDREN WITH SPECIAL NEEDS

This group is for you if:
You struggle with issues specific to having a child or children with special needs and
You would like a “safe” place to talk about your experience

Facilitated by Diane Simon Smith, MPH, MA, MFT
Fee: $120(for 6 sessions) payable at the beginning

Meetings will be held at
20501 Ventura Blvd., Suite 399, Woodland Hills, CA 91364
Fridays 9:30 – 11:00am
January 13 & 27, February 10 &24, and March 9 & 23

For more information or to register, contact: Diane Simon Smith at 818-888-1524 or dianesmithmft@earthlink.net
Shopping for a Good Cause
This year was another great success for our yard sale fundraiser. Our 6th Annual yard sale held in the City of Long Beach was bigger and better than last year. Our new location in the City of Burbank gave us the opportunity to raise additional funds and to bring awareness about Fragile X syndrome to a new area. All the money that was raised at these two yard sales have gone directly to the Association to help fund research studies, family activities, newsletter costs, educational workshops and other important goals related to Fragile X. Thank you to everyone who gave us their wonderful items to sell at both yard sales!
What is AB 1244 (Self-Determination)?

Assembly Bill 1244 is California legislation that, if passed will be presented to Governor Brown in 2012 for his signature. AB 1244 would give people the CHOICE to keep the services they have now OR choose Self-Determination.

Self-Determination Program Purpose:
The Self-Determination Program has the potential to give regional center clients flexibility to control their own service budget as an alternative to the traditional service system and limitations in regional center purchase authority.

Self-Determination Program Summary:
Participation in the Self-Determination Program will be VOLUNTARY. Participants will receive a budget allocation computed in a fair, transparent and equitable manner. The allocation for all people in the program will, in aggregate, be 10% less than historical cost. (7.5% dedicated to program cost, with the remaining unused funds returned to the State General Fund, and 2.5% to a risk pool.) *If participants are comfortable with Regional Center handling their services there is no need to participate in the Self-Determination Program.

To support participants in planning, budgeting, and locating community, employment, and life supports, people will use SERVICE BROKERS who are freely chosen by the participant and conflict of interest-free. The budget allocation will be held and dispersed through a conflict of interest-free fiscal management service that will make accounting and paperwork easy.

People will be able to spend their allocation on a wide range of supports and services, including but not limited to, hiring their own workers, purchasing goods and services, and negotiating for innovative services from traditional regional center vendors. If people hire their own workers, they will be able to hire who they want, manage their employees how they want, and dismiss them if they choose. AB 1244 would give those workers the right to organize to advocate to the state to protect the program and seek better funding for better pay.

Supporters of AB1244 include:
- Disability Rights California
- The State Council of Developmental Disabilities
- SEIU
- World Institute on Disability
- Disability Rights Education and Defense Fund (DREDF)

Opponents include:
- The Arc of California
- California Disability Services Association

FRAXSOCAL’s status as a non-profit, requires that we take a neutral position on this bill. However if you would like more information, please check with your regional center or contact Mark Polit at (510)343-8563 or mark.polit@seiu.org.
**Major Improvements**

**AB 1244 (Chesbro), Self Determination from Self-Directed Services (2005)**

Self-Directed Services (SDS) was signed into law in 2005 through the efforts of then Senator Wes Chesbro. However, that program never went into effect because of problems with federal approval. In 2011, Assemblymember Chesbro introduced AB 1244, Self-Determination (SD) to make major improvements over Self-Directed Services. These improvements are described below:

- Focuses the program on supporting people to achieve universal human aspirations, such as growing up with family or, for adults, a home of their own where they control who enters; real participation in their communities; having reciprocal long-term relationships; and earning income to lift themselves out of poverty.

- Requires an evaluation of the SD Program to be submitted to the Legislature every three years, to see if Self-Determination is actually helping people to achieve these outcomes.

- Adds a Self-Determination Advisory Committee to give program participants, family members, advocates, academics, and regional centers a means to oversee the program and to advise on how it works. The advisory board would be more than 50% program participants and family members.

- Adds provisions for those direct support workers that people employ directly: People would have the right to hire, supervise, train, schedule, incentivize, or fire their workers as they like. The state would set a minimum compensation level for those workers, and those workers would be able to organize to advocate to the state to protect the program and seek better funding for better pay. Should workers unionize, AB 1244 prohibits strikes and other work stoppages and any collective bargaining that would infringe on the ability of program participants to hire, supervise, train, schedule, incentivize, or fire their workers. (These workforce provisions would NOT apply to workers who are employed by an agency).

- Allows people to select any service broker they choose.

- Requires a statewide fiscal manager to hold and dispense funds. This will create simplified procedures and reduce costs, making it easier for consumers and families to get the necessary administrative/fiscal management support.

- Gives the state flexibility on how to receive approval from the federal government.

- SDS prohibits purchasing congregate services, because traditional congregate service are inconsistent with a self-determined life. AB 1244 seeks to relax that prohibition enough to allow purchases of innovative or periodic services from traditional service vendors and Supported Employment for people in real jobs at or above minimum wage.

- Clarifies roles and responsibilities of regional center service coordinators and mandates a designated caseload for the SD program that averages no more than 1:62. This allows for adequate training and specialization of service coordinators and the necessary monitoring, and assistance available to program participants.

- Rolls out Self-Determination first in the five regional centers that have piloted Self-Determination, followed the next year by all the other centers. This seeks to create good models for the program by doing it first in regional centers with the most experience with Self-Determination.
**Gifts for the Fragile X Clinic**

My Name is Sophia Wackerman. I am twelve years old, and I have a nineteen year old brother with Fragile X Syndrome named James.

My fellow girl scouts and I (Troop 4043 of Long Beach, CA) recently worked on our bronze award project, which can only be completed with twenty hours of service that no other girl scout has yet done. My mother suggested doing something for the new Fragile X clinic in Long Beach. It was a great idea. Ever since my mother went to the last Fragile X conference she has been so much more knowledgeable about Fragile X... ways to help with learning, anxiety and many other things. She also learned about something else: “B.O.B.” boxes, or “Biting Options Boxes”. They are activity boxes, but with things such as theratubing and stress balls in them, or other things that people with Fragile X can fiddle, play with, and chew on.

My troop members and I thought that we should put together activity boxes for the new Fragile X clinic in Long Beach, where the waiting room only has a few toys and a small television for playing movies. “James would always have a hard time in waiting rooms for long periods of time, especially when there was not much more than a T.V. screen,” said my mother, “and I imagine other children with Fragile X are the same. But if they had B.O.B. boxes to play with, they would be occupied with sensory activities.” I brought up the subject at the next Girl Scout meeting, and everyone loved the idea. So I got a group of girls together who were willing to participate in the project, Macy Boren, Isabel Olson, Jana Reyes and Kendall Lowry, and we got straight to work.

First, we assigned ourselves our own bit of research about things that might go into the B.O.B. boxes. We found things such as theratubing, theraputty, stress balls, etc. Then we needed to find all the money for this. We decided to hold a bake sale, because, and I don’t mean to brag, but we’re all pretty good cooks/bakers, and we could use the profits to put into the boxes. We made flyers and put them up around the neighborhood, and held the sale at the corner of our old elementary school (because it is a very popular spot) with the permission of the principal. We made all sorts of goodies and treats: butterscotch brownies, big warm chocolate chip cookies, lemon cakes, Kendall’s grandmother’s famous chocolate fudge cake, cupcakes that looked like pies, and much more. We ended up making over three hundred dollars, with nothing left to sell at the end! We were thrilled, and we made enough money to cover the whole project.

We then ordered the boxes and the things that would go in them. We visited the clinic to meet Dr. Gary Feldman, and we explained what we were doing and what great progress we were making. “Our goal is to make fifty boxes, which would be about a years’ worth. Each child that gets one may keep it, and bring it back the next time, and the next time, and so on and so on. They would also be able to bring them to other events that involve waiting rooms, such as the dentist or the doctor,” we explained. The clinic thought that this was a brilliant idea, and said they would find room to store the boxes. Later, we put them together and delivered them to the clinic; the final step of the project. They loved them, and thanked us very much. We had finished. We had finished and we felt good; we had done something good. We were on our way; small step by small step, to making the world a better place.

![Image of Girl Scouts and the Miller Children's Hospital Long Beach](image-url)
**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 requested:**
- 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.

**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](http://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](http://www.FragileX.org)

- **FRAXA Research Foundation**
  45 Pleasant Street
  Newburyport, MA 01950
  Phone: 978-462-1866
  [www.fraxa.org](http://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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