

FRAGILE X PRESS

By: Mary Seward

Welcome!

I hope your lives are settling into the routine of a new year at school or work. It has been a very exciting few months getting to know many of you and your families. I still can't believe we have found approximately 50 families in a very short period of time. Thanks to Sali Farber from Orange County and Susan Bry

for sharing the names they gathered in the past years. The regional centers and genetic clinics have been very helpful in sending our survey to their known Fragile X families. Many, many thanks to all of those who have helped us find each other. I hope that in the coming months you will be able to attend a meeting or event. We are trying to rotate around the county to make it convenient for families to attend one of the meetings. If you have a meeting place suggestion, speaker or event idea, let us know!

History

The beginnings of this group can be traced to November 4, 1993 when I received our son Timmy's (now 3 1/2 yrs.) diagnosis. Everyone seemed to assume that I could find the help I needed by contacting the National Fragile X Foundation and they would know of a local group. That path led me to Sali Farber who had been trying to start a group but had found no outside support to help her. Then I was assigned a peer parent from my regional center and Linda Landry came into the story. This lady is a walking resource directory and she knew Dr. Barbara Wheeler at Children's Hospital's University Affiliated Program (UAP). Dr. Wheeler had an interest in Fragile X for years and wanted to help if I wanted to get a group

going. I wasn't sure if I had the strength to do that and get through the initial pains of diagnosis. I decided that I could not let the opportunity of help from Children's Hospital be passed by. Dr. Wheeler then assigned a psychology intern, Debbie Langenbacher, to assist with the project. Debbie did the initial work of contacting the regional centers, genetics clinics and the National Fragile X Foundation to do the initial mailing of the surveys. It took several months to complete and in June of this year we had our first meeting. We hope that you will become a part of our history and join us in our endeavor to offer support to others and increase awareness of Fragile X.

!!! HELP NEEDED !!!

Yes, we need lots of help and energy to get the job done. If you have special skills or have a project in mind, let us know. Here are some of my ideas.

PHOTOGRAPHER. We need a photographer to make a slide presentation about the case histories of our group. We can use this presentation to educate doctors, therapists, teachers, etc. about Fragile X in a personalized way.

LEGAL HELP. We need to eventually incorporate and file for non-profit corporate status. Children's Hospital has experienced help but someone is needed to oversee the actual process and file the necessary applications.

FUNDRAISER. Money will be needed to keep the group moving and growing. Children's Hospital/UAP has been doing our printing and mailings while we are in infancy but

FRAGILE X PARENT GROUP

FAMILY POTLUCK PICNIC

**SUNDAY, AUGUST 21, 1994
11:30 TO 4:00**

**In the park on the campus of
Cal Tech, Pasadena
(See enclosed map for directions.)**

**Bring whatever you like to barbecue (we'll provide
the coals) and a dish to share with others.**

**If your last name begins with:
A to H please bring a salad or side dish
I to Q please bring a desert
R to Z please bring drinks (no alcohol)**

FOR MORE INFORMATION CALL:

Mary Seward (818) 845-5877

OR

**Deborah Langenbacher at
Childrens Hospital - University Affiliated Program
(213) 669-2300**

SEE YOU THERE!!

First Fragile X Parent Support Group

Wednesday, June 29, 1994

Our first meeting was held at the home of Mary and Roger Seward. There were ten parents in attendance.

Parents introduced themselves and spoke about their child/children with Fragile X. There was a wide age range of children represented: 2 years to 50 years.

Parents were encouraged to voice their concerns and hopes for the group. Many parents wanted information on IEP's. There was a concern that many professionals (in special education and pediatricians) lacked adequate knowledge about Fragile X.

A discussion was led by Dr. Barbara Wheeler on how parents could help educate professionals about Fragile X. Also considered was developing a name for the group and a mission statement.

It was decided by the group to meet on the fourth Wednesday of each month in the evening. Because of the widespread geographic location of group members, it was decided to hold each meeting in a different area of Los Angeles. It was suggested that meetings be held at the Regional Centers throughout the Los Angeles area and Westside Regional Center was suggested as a potential location for the next meeting on July 27th. A video presentation, "Educational Issues and Strategies for Children with Fragile X Syndrome," was offered as a possibility for the next meeting by Mary Seward, and was agreed upon by the rest of the group. Maggie Robles offered to help with Spanish translation for Hispanic group members in written information and at future group meetings.

A steering committee was formed. Members are Mary Seward, Maggie Robles, Karin Reinhart and Deborah Langenbacher. The steering committee will meet separately before the meeting on July 27th.

Respectfully Submitted,
Debbie Langenbacher



ChildrensHospitalLosAngeles

Thank you for your interest in the Fragile X Parent Support Group!

**Our first meeting will be on Wednesday, June 29th
at 7:30 P.M.
(Coffee and refreshments at 7:00)**

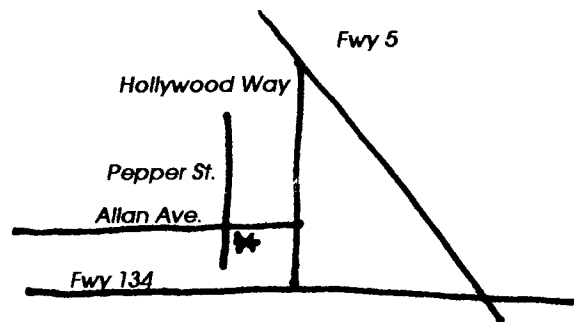
**Mary and Roger Seward will be our hosts.
Their home is at 1528 Pepper St. in Burbank.**

Directions:

From Fwy. 134 (Ventura Fwy) - Take Hollywood Way north to Allan St. Turn left one block to Pepper St.

From Fwy. 5 (Golden State) - Take Hollywood Way south to Allan St. Turn right one block to Pepper St.

**1528 is on the south-east corner of Allan and Pepper.
(or see your Thomas Guide, page 17 - A6)**



**For more information, please call:
Mary Seward (818) 845-5877
or**

**Deborah Langenbacher or Barbara Wheeler at CHLA
(213) 669-2300**

WE ARE LOOKING FORWARD TO MEETING YOU!!