

Fall 1998  
Volume 1, Issue 4

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Fragile X Association  
of Southern California  
P.O. Box 6924  
Burbank, CA 91510-6924  
(818) 754-4227

# Fragile Xpress

## Upcoming Events

### October 17<sup>th</sup>

Association Meeting  
10:00am – 12:00pm

East Los Angeles Regional Center  
1000 S. Fremont, Alhambra  
(818) 299-4700 (for directions only)  
**Diane Simon Smith, MFCC will be our guest speaker.**

### October 23<sup>rd</sup> & 24<sup>th</sup>

#### Getting It Straight About the IDEA

with Reed Martin JD

Learn the facts about the new IDEA and Section 504 at Children's Hospital LA call (818) 543-4631 for information

### November 17<sup>th</sup>

Association Meeting  
10:00am – 12:00pm

East Los Angeles Regional Center  
**Guest Speaker will be Dani Steiger, parent.** Topic will be accessing services for your child in the school system. Bring your questions for a lively discussion period.

### December 5<sup>th</sup>

#### Board Meeting 10:00am

Board members must attend, all others are welcome. Please call us at (818) 754-4227 if you plan to attend so we can give you the details.

### January 30<sup>th</sup>

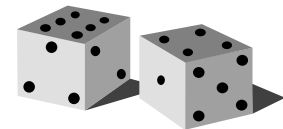
3:00 – 5:00pm

#### Pizza and Bowling Party

Montrose Bowl  
2334 Honolulu Avenue, Montrose  
Bring a dessert to share

## CHARITY EVENT FOR FRAGILE X

An announcement from Mathew and Karen Weidenfeller was made by our Vice-President, Deborah LeCover at our regularly scheduled September meeting of the Fragile X Association of Southern California that on January 23, 1999, "a Casino Night fundraising event will be sponsored by Coldwell Banker, Brentwood, CA for the real estate industry, other interested parties and members of the Fragile X Association of Southern California.



*The Fragile X Association of Southern California has been designated as one of several charities to be the beneficiary of the proceeds from this event.*

*The Casino Night will be a Black Tie (tuxedo or dark suit) affair featuring Las Vegas style gambling. The cost to attend will be \$50.00 per person and will include a buffet dinner, drinks, \$25.00 worth of gambling scrip and music. The location will be at a newly built private estate located at the Brentwood Country Estates."*

The Association is thrilled and very grateful to the Weidenfeller's for this opportunity.

## NATIONAL NEWS

The National Fragile X Foundation has appointed Stephen LeCover to serve on their Board of Directors. We are so pleased to have one of our members selected to serve. Good Luck Stephen!

## FROM THE PRESIDENT'S DESK.....

May this newsletter find everyone well rested from their summer. We have had a wonderful summer. Eric turned 16 and was part of our district school work program again. This summer he worked at Carl's Jr. and learned many new tasks. However I think his favorite part of the job turned out to be a tie between the "employee discount" he received on his lunches and his "Carl's Jr. uniform". He ended his summer by going to an "Easter Seals" camp in Big Bear for a week and had a wonderful time. The staff was very supportive and very well trained. The first part of the summer Richelle did volunteer work at our community park as a CIT(counselor-in-training) and then finished the summer having lots of fun at camp going on different excursions each day.

For those of us with school age children I hope the transition back to school has gone well for you. I know we are in full gear with homework and have had several tests already. I haven't decided yet who is more upset at the "Homework" the kids or "us". I surely thought I had graduated many, many years ago and here I am back in 8th and 10th grade, and it is definitely "not" more fun the 2nd and 3rd time around.

Jeff and I, along with six other families from California attended the 6th International Conference in North Carolina. The conference was very informative as well as being parent friendly. It was especially beneficial meeting families from all over the world and sharing experiences. There is new and continued research that is very optimistic, both in finding a cure and in current treatments. We came back with lots of ideas for the 7th International conference that will be in Los Angeles in 2000. We will need lots of volunteers and will start planning committees in the near future. So get ready!

Our new brochures are finally finished and they look fantastic. We have begun our "public awareness" campaign via mailings to local SELPAS, occupational

therapists, speech pathologists, physicians and other health professionals in the local areas. We are very thankful for the donations we received from several of the Regional Centers to help with printing and mailings.

We are back on schedule with our monthly meetings which are held the 3rd Saturday of each month at East Los Angeles Regional Center. Please check your mail for details. We continue to gear our meetings toward a variety of educational speaker's as well as social gatherings. I hope to see as many of you as possible. If you have any suggestions for future meetings, or would like to share your experiences at one of our meetings, please call me. I look forward to meeting our new families and seeing all the familiar ones.

Sali Farber, President  
**(714) 544-9551**

**Late News Flash** Dani Steiger and her family will be featured on the 11:00 PM news on CBS Channel 2 on OCTOBER 7th. Many more people will know what Fragile X is after this airs. Thank you to the Steigers for sharing your story with the public.

### NEW BOOK AND VIDEO

Dani Steiger's son Charles has written a heartwarming book about his brother with Fragile X. Dani has generously offered that a portion of every book we sell will be donated to the Association. She has also made the same offer for her video that was released last year.

### "Fragile X Syndrome - From a Mother's Perspective" A great video about inclusion!!

Now you can help provide a positive mainstreaming experience for your child with the help of this real-life video, produced by UCLA's Family Support Community Program. Her perspective and heart-warming presentation helps set the stage for a successful school year for Daniel. This video is sure to have a positive impact

on you, your child's teacher, your child's school and ultimately your child.

### My Brother Has Fragile X by Charles Steiger

*"filled with the fresh perspective of a younger brother's insight into fragile X"*  
*"This book chronicles the special experiences of living with a brother with fragile X syndrome and a should be read by all siblings in families impacted by fragile X"*

Randi Hagerman, M.D.

My Brother Has Fragile X



BY CHARLES STEIGER

We have them available for purchase at our meetings. You can also order these on our website at [www.fraxsocal.org](http://www.fraxsocal.org) or send your order to:

**Fragile X Association of Southern California**  
PO Box 6924  
Burbank, CA 91510-6924

**Video - \$19.95 plus \$3.00 S&H**  
**Book - \$15.00 plus \$2.50 S&H**

**Buy both for \$34.95 plus \$4.00 S&H**

### TECHNOGIVING

Did you know that you could earn money for our Association just by turning on your computer and starting with a visit to our website! Our association earns money each time you visit. It adds up quickly, with just a few of us doing this we have earned over \$60.00 in a few months. That pays for the printing costs of this newsletter! So please get over your phobias of technology and help us

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by signing on with "EYEGIVE". First go to our website [www.fraxsocal.org](http://www.fraxsocal.org) and click on this logo:



Follow the directions from there on how to sign up. If you have problems with any of the steps call us (818) 754-227. and we'll help you or e-mail: [webmaster@fraxsocal.org](mailto:webmaster@fraxsocal.org).

## HOLIDAY SHOPPING on the Internet

This year you can make your holiday shopping benefit our Association. Just visit our website and click on "**DO GOOD IT'S FREE**". You must then CLICK on the EYEGIVE Logo, register once then go to the merchant's site. That's it! If you buy from these merchants, they agree to pay us a portion of the proceeds ranging from 2-10%. In fact, the pricing is the same for you whether or not you go through EyeGive, so you have nothing to lose except the chance to help us.

One of these merchants is **Books.com**, which has the lowest prices for books. So why fight the crowds at the mall, let your fingers do it all this year!

## FROM THE MEMBERS

I am so excited that many family members have written articles for me this month. I only had to twist their arms a little bit!! Won't you share a special story with us or help your son or daughter write one? You can e-mail it to [newsletter@fraxsocal.org](mailto:newsletter@fraxsocal.org) or mail it to:

**Fragile X Association of Southern California**  
**P0 Box 6924**  
**Burbank, CA 91510-6924**

## I LOVE THIS GAME!

by *Dan LeCover*

I went to a Dodger baseball game last month. The Dodgers played the Pittsburgh Pirates. The game was tied and the Dodgers won in the bottom of the 9th inning!

The most interesting part of the game was the food. I ate nachos, popcorn, Dodger dogs and I had a Coke. Also I met The Incredible Hulk, Lou Ferrigno and had my picture taken with him. Jon Lovitz sang the Star Spangled Banner and he signed my program. I liked watching the pitcher pitch and later, my friends Suzanne and Phil took me to the private Dodger box where I was given an official Dodger pin.

I love this game!

## A SIBLINGS'S POINT OF VIEW OF THE CONFERENCE

by *Jill Halterman (14 years old)*

The 6th International Conference was a great experience for me. I got to meet many great people from all over the world. I was able to attend the Sibling Workshop, and found many more siblings there than at the last conference. These siblings ranged from about 5-17 years old. I got to know one especially well, his name is Matthew, he is 14. He has a brother with Fragile X that is 16 and his name is Daniel. We have been communicating back and forth, sharing experiences and things that are troubling us. I also met and got to know many other siblings. It is really great to be able to communicate with people who are going through the same things. I recommend that if you are a sibling and are going to the LA Conference in 2000, that you attend the Sibling workshop, I know I will try my best to be there!

## My Experience at the Conference

by *Jay Halterman (19 year old young man with Fragile X)*

I loved the conference. It was really good. "When I spoke a lot of people clapped, I got a standing probation (ovation). People were very proud of me when I spoke about Fragile X syndrome. I learned about handicapped people in wheelchairs like Greg. I learned Holman was diagnosed with Fragile X when he was very young. He learned to talk and speak very clearly. Holman is a very nice kid, he loves his family, friends, relatives, God and faith. Holman also got a standing ovation.

## A HEARTWARMING STORY

by *Stephen LeCover*

Our son Daniel, in addition to the much later diagnosed Fragile X syndrome, was born with a ventricular septal defect(vsd) with a diagnosis of a moderately large hole in the wall of the left ventricle. At 14 months, he had a cardiac catheterization done that made that determination and ruled out others. However, his fear of doctors, white coats and hypodermics was sealed! I won't belabor the incidences of having shots through the years, but since he is bigger and stronger than either of us, his two hands somehow become 4 hands if necessary to ward off any invasive acts. We are usually worn out afterwards when he utters words to the effect "*Nice Shot!*"

Well, it has been about 17+ years since his last cardiac evaluation with the last one just prior to age 5 concluding that the hole in the left ventricle was now moderately small. We are awaiting the results of the echocardiogram done yesterday, but I will say that at age 22 (23 next week) it doesn't hurt to have an echocardiogram administered by a young pretty technician in a semi-dark room.

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Before the echocardiogram, Dan had to have an EKG and wow, imagine sticking things onto a tactile defensive person while watching the fear develop as long wires with clips come out to be attached to those sticky things already on his body! We were so proud of him, he was scared, but through his maturation, he didn't completely lose it. I managed to get one electrode attached and he saw that nothing was going to hurt him so he didn't resist further although still fearful.

When the EKG was completed, he said to the Doctor, "I have a good heart". You know... he's right! No matter what the medical diagnosis is he, like all of our special kids, does have a good heart. For that alone, we will fight the fight until the battle is won and a cure is within our reach.

**The Follow-up:** Great news! The cardiologist called and said that there was no evidence of abnormality of either the aorta or the mitral valve. The cardiologist's concern was alleviated (as was ours) since he had told us that these are two areas of usual cardiac expression of those affected with Fragile X and that the echocardiogram presented an uncomplicated finding in Dan's case. So, now we know that Dan also has a good heart medically as well!

## A FUNNY THING HAPPENED ON MY WAY HOME FROM SCHOOL

by Eric Farber (age 16)

A few weeks ago I was taking the #65 bus home from school in Irvine like I always do. We made several stops and I was almost home when the bus driver announced that because of an accident he would be going a different way. Some of the kids got off the bus but I decided to stay on since it not my regular stop. I also wanted to see where the bus was going. We made several more stops, passing Tustin Market place which is near my house, but too far to

walk. We kept getting further and further away from my house. I thought about what I needed to do and that was to try and call home. I waited until I saw a telephone at one of the bus stops. I was now in Santa Ana at the Civic Center, I tried to call my mom at work but she was not there. I called home and no one was there either. I looked at the street sign, and I left a message telling my mom where to pick me up. I waited a few minutes and tried to call again. Still no answer. I knew I had to get home so I crossed the street, looked for the #65 bus stop, and took the bus going the other way. I arrived home, my dad was there and I told him of my adventure. Everyone was very proud of me, but reminded me that I should have talked to the bus driver and asked where the closest stop would have been to my house. I wasn't even scared because I knew that the bus would take me back to my neighborhood. The End

Footnote from a mom that lost ten years of her life when I got back to work from lunch there was a message from Eric to pick him up, but I couldn't understand what street he said. Eric had mobility training through his job coach last year, and he had been riding the bus for about a year now. They went over emergency situations, like an accident, where the bus breaks down, but never instructed him what to do in case of a detour. Eric is very shy, but also likes to think he is very independent and did not want to ask the bus driver for directions. We are very lucky that Eric thought the situation through and made it home safely. However, where he got off to make his phone call was rather far from our house, and not in a very good neighborhood. Luckily from the time I returned to my office and received the message, only about 15 minutes had passed until he walked into the house. It was the longest 15 minutes Jeff and I ever spent. Make sure that if your child is receiving mobility training that they go over all instances that may deviate from the normal, everyday situations.

## PEOPLE FIRST LANGUAGE

A handicap has been defined as an obstacle which society imposes on a person with a disability, i.e inaccessible transportation or buildings. Handicapped is not a term to describe human beings. A disability has been defined as a body function that operates differently. People First Language seeks to put the person first and the disability second! People with disabilities are people, first and foremost. Examples are:

- \* People with disabilities (not disabled people) people with mental retardation or he has a cognitive disability
- \* My son has autism
- \* He uses a wheelchair or is a wheelchair user (not confined to a wheelchair)

\*typical instead of normal

Think before you speak this week. Be a good example to others, ask them to use it also.

## NEWS BULLETIN: FRAGILE X TO RAISE MONEY LONG DISTANCE!

The Fragile X Association of Southern California has joined forces with **WorldxChange Communications** to help you save money while helping us raise funds for promoting public awareness, education and research on Fragile X syndrome. It's called the **Contributor Plan**.

**WorldxChange Communications** will send at least 10% to us of every long distance call made using this plan. You get a low rate of 10 cents per minute. It's that simple. Just dial 10-10-629 plus 1 (area code) and phone number plus 100110 (to activate the Contributor Plan

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the first time). For international calls you simply dial 10-10-629 plus country code, the phone number and 100110 (the first time). For all future calls, just dial 10-10-629 and 1 + phone number.

There are no minimum usage requirements, Monthly Fees or Charges and you do NOT have to switch from your present Long Distance Company. The rate is good 24 hours a day, 7 days a week.

It's simple to do, start today.

Note: There is also a 9 cents per minute plan (two minute minimum) and a 7 cents per minute plan (1 minute minimum) with a \$4.95 Monthly Access Fee on the latter Plan.

For additional information, please call Stephen LeCover at (310) 276-3432 or e-mail: [webmaster@fraxsocal.org](mailto:webmaster@fraxsocal.org)

## TRIBUTES

### Fragile X Association of Southern California

We can now help you honor your relatives, friends & associates, or the memory of a loved one with a personalized Tribute. An acknowledgment will be sent to the recipient or their family.

Your **tax deductible donation(s)** will be acknowledged in future issues of FragileXpress (which will also be on our website) without disclosing the amount of your gift. You will receive an acknowledgment of your generosity for your records. please mail Tributes to:

**Fragile X Association  
of Southern California  
PO Box 6924  
Burbank, CA 91510-6924**

We have received donations in honor of the following special people and events:

### In Memory of Herb Gelber

**Regina Mitouer  
Stephen and Deborah LeCover**

## BOARD OF DIRECTORS

Sali Farber – President  
Deborah LeCover – Vice-President  
Diane Bateman – Treasurer  
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Reid Halterman  
Stephen D. LeCover  
Maggie Robles  
Laurie Williams

We welcome all interested parties to our Board meetings please contact us for information on how to get involved.

### Fragile X Association of Southern California

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