

FRAGILE X PRESS

Fragile X Association of Southern California

Volume 5, Issue 1

Summer 2004

Driving Experience

By Richelle Farber

I wanted to share a story with you on how I got my license to drive. Here is how it all started. I have Fragile X so things are sometimes harder for me to do but I really wanted to drive very badly,

later I was finally ready to take the actual driving test. Then in February of 2003 I went to the DMV and it was raining and I almost had to reschedule but then it stopped raining so I took the

test. I passed on my first try. I was so happy that I was crying. My mom and I went to the Cheesecake factory to celebrate. About two months later, with the money I saved

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and be like all my friends. So I went to driving school and took classes to get my permit. It was very hard and it took me 3 times but I finally passed by studying, studying and more studying. After I got my permit it was time to do behind the wheel training. Then I went and practiced with my parents. About a year



Richelle Farber, with her 2002 Ford Focus

Fragile X-Related Syndrome May Lead to Tremors, Balance Problems, Dementia in Seniors

Report by Neil Robb

In a study reported in the prestigious Journal of the American Medical Association (JAMA) on January 28, 2004, researchers reported that men carrying the "pre-mutated" form of the Fragile X gene may suffer from tremors, balance and movement problems, or mental difficulties as they grow older.

Researchers say many of the adults that suffer from this disorder, known as fragile X-associated tremor/ataxia syndrome (FXTAS), are misdiagnosed with other age-related conditions such as Parkinson's and Alzheimer's disease.

"FXTAS may be one of the

most common causes of tremor and balance problems in the adult population, yet is being misdiagnosed because neurologists who see adults with movement disorders are not aware that they need to look for a family history of fragile X in grandchildren or to check for the presence of the permutation in the fragile X

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Event Brief:

• CAN Walk, Orange County

August 29th

Anaheim Pond

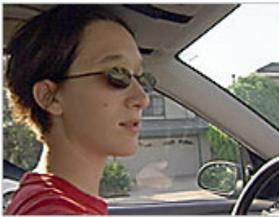
www.canfoundation.org

See the article about the Fragile-X booth we recently staffed at the Los Angeles CAN walk. We will be staffing a similar booth at the Orange County walk. Come join us!

Driving Experience

"I passed on my first try. I was so happy that I was crying."

***- Richelle Farber,
on passing her
driver's license test***



(Continued from page 1)

from working at Old Navy, I was able to get a car. It's a 2002 Ford Focus and its silver. I have had my license for over a year now with no accidents. I attend Orange Coast College working towards a certificate in hotel management/event planning. I am currently working at the Holiday Inn Express as a Front Desk Clerk. The best part of driving is being able to get to school, work and hang out with my friends and not having to have my mom or dad drive me everywhere.

Trevor Lambert Sets Swim Record, Turns Into a Prune at B-Day Party

By Marie Lambert

Trevor Lambert of Yorba Linda celebrated his dad's 40th birthday on Saturday, March 13, 2004, by swimming the entire time in the family's new pool. Trevor, 11, who is affected by FXS, swam from 11 a.m. to 7 p.m.-- 8 hours straight -- taking time out only briefly to raid the potato chip bowl before jumping back in the water. Wrinkled but otherwise unfazed by this test of endurance, Guinness Book was contacted for entry of the biggest prune ever produced at 96 lbs.

Trevor is an avid sportsman, and besides swimming he also enjoys soccer, basketball, bowling, and is in his sixth season of Challenger Little League, District 56, in La Habra, where he is hitting homers and stealing bases for the T-Ball Pirates.

Marie Lambert is the current Secretary for the Fragile X Association of Southern California. She can be emailed at mlambert@lacsdsd.org

From the National Fragile X Association

Dear Friends,

I am pleased to report that on April 6, 2004, a fragile X informational postcard was mailed to almost every practicing pediatrician in the United States (44,000). Thanks to our many financial supporters, our friends at the American Academy of Pediatrics, and the generosity of Rick Powell and the Production Management Group of Maryland, this long-planned project of the NFXF's Board of Directors has finally come true!

So the next time you visit your child's pediatrician, ask him or her if they have received it, and if they have any questions about the information on the card. (Since it was sent nonprofit 3rd class it may take up to a month for it to reach all recipients.)

After much discussion with pediatricians around the country, a simple postcard format was selected to increase the likelihood of the card being noticed and read.

You can view the card on the AAP website by clicking the second bullet, "post card," at <http://www.medicalhomeinfo.org/screening/FragileX.html>

Robby Miller

National Fragile X Foundation



Feeling Creative?

We'd love to have you write an article for the newsletter!

Contact Aaron or Crissy Finney

by email: aaron@wfi-inc.com

crissy@wfi-inc.com

or

by phone: 626-335-4766

Independence Day

By Sali Farber

Or should I call it "Moving Day". December 7, 2003 marked a milestone in our life. Our 21 year old son Eric, moved into his own apartment, with a roommate. Since Eric turned 18 he kept asking when can I live on my own? So I wisely said, when you are working and 21 you can move out. Between speech therapies, OT, IEP's, homework, making sure that school programs are appropriate who would ever think that this day would actually come and never realizing that the day would come upon us so fast. So moving day was quite emotional, we knew that we needed to let Eric move on but were very apprehensive about the move. Eric is quite independent, can ride public transportation has had various job internships since he was 14, can cook, do his own laundry but yet was he ready for this next step in life.

We had signed up for a HUD voucher when he was 18 with the expectation that his name would not come up on the list for about two to three years, but within 6 months we were asked to start the process. He was not ready so we put it on hold. Unfortunately by the time he was ready, HUD ran out of money and everything was back on hold. We waited and waited but no one could tell

us when the vouchers would start being issued again. Eric was getting so discouraged that we decided to bite the bullet and help subsidize his move. He was working part time at Wendy's and receiving SSI and we were able to find an income restricted apartment, in a high rent district, that would qualify for HUD when and if it came in. His apartment is in a great neighborhood, across the street from a center that has a movie theater, Albertson's, Rite-Aid, cleaners, restaurants, etc. and is only ten minutes from our house. He decided to room with a friend with Downs Syndrome that he has known since pre-school and who worked with him on the Football team in High School.

We signed up with Project Independence an adult provider funded through Regional Center. They come in 3x a week to help with Independent Living Skills which include food shopping, banking and house-keeping. Most of the time the apartment is neat, at least a lot neater than he kept his room.

We just got word that his voucher will be coming in April so it will make it more affordable, since with a voucher he will only have to pay 30% of his income and they will pay the remainder of the rent. Eric

loves living on his own and we are so proud of the transition he has made to Independent Living. So for you that are reading this article with little ones and think you will never get past potty training, there is light at the end of the tunnel. Have faith in your child/young adults as they can and will surprise you at their abilities when given the opportunity. Keep in mind that Independent living is not an option for everyone, but there are other alternatives such as group settings that can also allow them independence as well as socialization.

Sali Farber is on the board of directors of the Fragile X Association of Southern California, having previously served as President. She lives in Irvine with her husband and daughter and can be contacted via email at salij401@aol.com.

FXTAS

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gene," explained one of the study's authors, Randi Hagerman, MD, medical director of the University of California, Davis MIND Institute, in a news release.

FXTAS affects older men who carry a small mutation in the same gene that causes fragile X syndrome, which is the most common cause of inherited mental retardation.

In the study, researchers looked at the prevalence of tremor, balance disorders,

and dementia among 192 families belonging to the Fragile X Association of Southern California and the Northern California Fragile X Association.

Researchers say nearly one in 800 men have this mutation in the fragile X gene, and the study suggests that as many as 30% of these men may develop FXTAS later in life.

Initial signs of the disorder in men may include difficulty writing, walking, and using

eating utensils and become more severe with age. Other symptoms may include short-term memory loss, anxiety, loss of sensation, and muscle weakness.

"FXTAS is an enigma," according to Dr. Hagerman. "The disorder appears later in life in men who are generally healthy throughout childhood and early-to-mid-adulthood and have normal to above-normal intelligence, yet is caused by a defect in a gene known to cause mental retardation usually diagnosed in

childhood."

Researchers say the results show that screening for the genetic mutation in the fragile X gene in men is important, especially if the person is experiencing other symptoms of the disorder.

Neal Robb is the current President of the Fragile X Association of Southern California. You can email Neal at neal.robbs@fraxsocal.org.

FRAXSOCAL Highlights FXS-Autism Connections at CAN Walk

By Neal Robb

FRAXSOCAL had a booth, signs, and volunteers at the second annual "WALK NOW" fundraising walk at Dodger Stadium hosted by Cure Autism Now (CAN) on Saturday morning, April 17th. According to CAN, more than 4,500 people attended the walk, raising over \$700,000 for research into the cause and treatments for autism. The

walk also provided an excellent opportunity to increase public awareness about Fragile X syndrome and to educate people about the connections between FXS and autism.

The main event was a 5K (3.1 mile) walk, but next to the

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Fragile X Association of Southern California Contact Information

Below, you'll find contact information for the main organization as well as the individual board members of the Fragile X Association of Southern California. You can leave a voicemail or send an email to the main organization info address and someone will get back to you with more information about who we are and what we do.

In addition, any of the board members listed below would be thrilled to hear from families who might need help getting involved, or who want to talk about things related to FXS in their area. The board members have made a commitment to act as "point" persons and to help provide support to their local communities, and would love to chat with anyone who wants to talk!

Main Organization Contact Info

Email: info@fraxsocal.org

Voicemail: 818-754-4227

Board Member Contact Info

Dr. David and Miriam Ackermann

Palos Verdes

today.da@gte.net

ackermom.gm@gte.net

Steve and Millette Arredondo

Simi Valley

fhaces@pacbell.net

fullhouseaces@yahoo.com

Diane Bateman

Long Beach

(562) 439-1190

Sali Farber

Irvine

salij401@aol.com

Aaron and Crissy Finney

Glendora

aaron@wfi-inc.com

crissy@wfi-inc.com

Marie Lambert

Yorba Linda

mlambert@lacsds.org

Deborah & Stephen LeCover

West Los Angeles

dalecover1@sbcglobal.net

sdlecover@sbcglobal.net

Neal and Carolyn Robb

Manhattan Beach

neal.robb@fraxsocal.org

Mary Seward

Burbank

mbseward@yahoo.com

Charlotte Spahr

Anaheim

lovespurple92804@yahoo.com



Say Cheese!

Mike and Sally Moit, of Fontana, and Jack and Jaclyn Blanco, of Riverside, were enthusiastic guests at the March board meeting.

Books And Videos For Sale

Fragile X Syndrome - From a Mother's Perspective

by Dani Steiger

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.

Video - \$19.95 plus \$3.00 S&H

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.*

Book - \$15.00 plus \$2.50 S&H

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

Send Orders To:

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

Or contact order@fraxsocal.org for more info!



MEMBERSHIP DUES

If you haven't sent in your annual membership dues, photocopy this box and return it with your \$25 membership dues made payable to:

Fragile X Association of Southern California

Name: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Mailing Address:

**Fragile X Association of Southern California
P.O. Box 6924
Burbank, CA 91510-6924**

Did You Know?

You can make your *secure*, **tax-deductible** donation to the Fragile X Association of Southern California or pay your annual membership dues directly through our website at **www.fraxsocal.org** using your Visa or MasterCard! Simply click on "Make A Donation" at the top of the main menu!

FRAXSOCAL Highlights FXS-Autism Connections at CAN Walk

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starting line and registration area in Dodger Stadium's parking lot was a community resource fair and family fun festival. FRAXSOCAL's booth was located in the middle of the community resource fair, in location that maximized visibility of its signs.

Notwithstanding cool weather and a light rain, many of the walk participants spent some time either before or after the walk at the resource fair. Countless brochures and printouts about FXS were passed out. Other booths in the area featured educational resources, therapists, schools and recreational organizations available for children with disabilities, especially autism.

The walk was hosted by singer,



songwriter and community activist Chaka Khan. Celebrities were on hand included ABC7 Eyewitness News anchor Phillip Palmer, the official media host, who served as master of ceremonies, Tisha Campbell-Martin, star of the ABC series, "My Wife and Kids," Gabrielle Carteris, star of Beverly Hills 90210, Dave Clark, KCAL-TV 9 anchor, Jim Gott, Los Angeles Dodger pitcher, actress Sheila Kelley, Vince Neil of Motley Crue, Richard Schiff, star of NBC's "West Wing," Tim Conway, Jr., of KLSX 97.1, and Los Angeles City Councilmember Antonio R. Villaraigosa.

Editor's note: We'll be staffing a similar booth at the upcoming CAN Walk for Autism on August 29th, which is being held at the Anaheim Pond. You can get more

Let's Get Together and Talk!

Who? You!

What? A Live Internet Chat for the FXS Community!

When? Every Thursday Night, at 5pm Pacific Standard Time (8pm Eastern/7pm Central)!

Where? The Chat Room on www.fraxsocal.org, the Fragile X Association of Southern California's Website!

Why? Because we want to talk to you!

How? Simple! Just go to <http://www.fraxsocal.org/FraxChat.htm> and log in with your Name and State (or Country): E.g. John AZ or JSmith CA

The chat room features real-time, multi-language translation, so no one has to be left out! Come out and try it yourself, and we'll talk to you this Thursday!

FRAXSOCAL Donates \$5,000 to Fragile-X Documentary

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OF SOUTHERN CALIFORNIA

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USC University Affiliated Program
Assoc. Prof. of Clinical Pediatrics
USC School of Medicine

Fragile X Syndrome is the most commonly inherited cause of developmental disability, affecting approximately 1 in 2000 males and 1 in 4000 females worldwide.

It is second only to Down syndrome as a cause of mental retardation.

Both males and females may be affected with a wide variety of symptoms.

Fragile X syndrome appears in children of all ethnic, racial, and socioeconomic backgrounds.

July 12, 2004

Kathy Elder and Greg Mishey
Producers/Directors
"Living with Fragile X"
ThinkMedia
331 S. Branciforte Avenue
Santa Cruz, CA 95062

Dear Kathy and Greg,

I am pleased to advise you that the Fragile X Association of Southern California hereby contributes \$5,000.00 toward the making of your documentary film, "Living with Fragile X." Our organization is delighted to help you move forward with the completion of that film. We can think of no more worthy cause. Adding to the public's awareness of Fragile X is one of our primary purposes, and your film, when completed, will accomplish just that. We look forward to seeing it on national television sometime soon. Thanks from all of us for your determination and devotion to this tremendously worthwhile project.

Best regards,



Neal Robb

NSR:mam (940373)

7/31/04

Board of Directors
Fragile X Association of Southern California
P.O. Box 6924
Burbank, CA 91510-6924

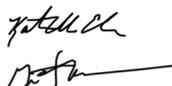
Dear Members of the Board of Directors:

We owe you immeasurable thanks for your generous donation for the completion of the documentary, "Living with Fragile X".

We are humbled by your belief in us and in this project. For us, it has become a labor of love. But, of course, our passion for the subject matter won't pay for videotape, voiceover talent, music licensing, and all the other myriad costs involved with creating a one-hour documentary. The \$5,000 your group donated will help to finance these costs and, in the end, allow us to create a higher-quality product than we could without it.

Your group's commitment to this project is further proof to us that many, many people believe as we do that fragile X syndrome needs to become much more well-known. We believe strongly that "Living with Fragile X" will address this need, once it is complete and broadcast. Please know that your generosity will propel us ever closer to reaching that goal. Thank you.

Sincerely,



Kathy Elder and Greg Mishey
Producer/Directors
"Living with Fragile X"



Deborah LeCover, former President of the Fragile X Association of Southern California, and son Daniel presenting check to Kathy Elder and Greg Mishey at Camphill Communities California, the site of recent filming for their documentary "Living with Fragile X." (left to right: Elder, Mishey, Deborah LeCover, Daniel LeCover)

Living with Fragile X

You can find more information about the documentary, "Living With Fragile X," on ThinkMedia's website, <http://www.thinkmediaonline.com>. In addition to details about the families being chronicled, there is an amazing, 13-minute video vignette of the film.

ThinkMedia

The Fragile X Association of Southern California is run entirely by volunteer parents of children with Fragile X Syndrome.

We are a California non-profit 501 (c)(3) tax exempt corporation. Your tax-deductible donations help support our mission and are gratefully accepted.

Visit our website at:

<http://www.fraxsocial.org>

2004 Board of Directors

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Sali Farber*	Charlotte Spahr
Crissy Finney	

* Denotes Past President

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.

Fragile X Association of Southern California
P.O. Box 6924
Burbank, CA 91510-6924

ADDRESS CORRECTION REQUESTED