

# FragileXpress

Volume 3, Issue 3

Summer 2001

## Message from the President

Neal S. Robb, President



Deborah LeCover, who has served as our President for the last two years, recently relinquished her gavel. For the past two years, Deb has been an energetic and caring President, and most if not all of FraxSoCal's accomplishments in that time could not have happened without her. At the 2000 International Conference in Universal City last July, Deb seemed to be everywhere at the same time-solving problems, giving instructions, and making introductions-all with her usual smile and grace. Although she has stepped down as the chief officer of our Board of Directors, we look forward to her continuing participation as a "regular" Board member.

We are enthused about the new members who are joining us on the Board of Directors. **Marie Lambert** is our new Secretary joining **Millette & Steve Arredondo** and **Miriam & David Ackermann**. We look forward to their participation in our organization and the new ideas and energy they will bring. We have lots to accomplish. The mission of our organization is three-fold: support families affected by Fragile X, raise public awareness of Fragile X, and support and/or facilitate research on Fragile X. While admirable effort has been made in all of these areas in years past, we can always do more.

We are looking for ideas, and your input is important. If you have any thoughts on what more we can do to provide family support, raise awareness, or facilitate research, send me an e-mail at [neal.robb@fraxsocal.org](mailto:neal.robb@fraxsocal.org). Your thoughts and suggestions will be appreciated.

Have a happy Summer!

## Farewell Message

Deborah A. LeCover, Past President



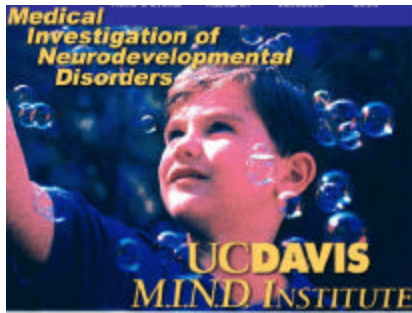
The past two years has been an eventful time for the Fragile X Association of Southern California and I look forward to continuing the commitment to our children. I was extremely fortunate to have a Board who kept giving of their time, energy, creativity and resources. Many thanks goes to our VP, Diane Bateman, who organized our meetings, parties and events with such expertise, **Charlotte Spahr**, Secretary, who has been taking minutes from the beginning of FraxSoCal; **Mary Seward**, Past-President/Founder, who keeps our Treasury secure, enables us to receive our mailings, offers family support and continues giving of her time and experience. Our dedicated Officers along with the Directors have contributed greatly to our Association. Our Directors, **Neal and Carolyn Robb** have brought new energy and strength to us and I especially look forward to Neal serving as our new President, Congratulations! To **Sali Farber**, Past-President, in whose capable hands, maintains our T-shirt fundraising and awareness campaign viable along with being connected with family support issues, which I must add has always been one of the outstanding accomplishments of our organization. To my husband **Stephen LeCover**, who has maintained our Website for the past 3 years as well as having been Conference Co-Chair for the National Fragile X Foundation's 7<sup>th</sup> International Fragile X Conference last July in Los Angeles in which we acted as official host.

Many thanks also to Board members who will no longer be serving on our Board. They are, **Maggie Robles**, **Cathy and Reid Halterman**, who along with son Jay (Congratulations to Jay on his recent graduation from Chaffey High School) and daughter Jillian have always energetically offered their support to the Fragile X community. **Molly Brown**, who has enabled Spanish speaking families to receive our information and lastly, to **Mat and Karen Weidenfeller** and their family for hosting events, Board meetings and promoted awareness in the community.

What has been so gratifying to me is the ease in which our FraxSoCal members give in the ways they do and it is very much appreciated by all. My best wishes to Neal, the members of our Board of Directors and to all of you.

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## M.I.N.D. INSTITUTE STUDY

The **M.I.N.D. Institute** at the U.C. Davis School of Medicine and Medical Center is seeking volunteers for a study of older Fragile X carriers. The M.I.N.D. Institute is also seeking non-carriers within the same family who will be part of a "control group" for comparison purposes. Volunteers may be either male or female, and should be 50 years of age or over.

Randi Hagerman, M.D., Director of the M.I.N.D. Institute and former Director of the Fragile X Treatment and Research Center in Denver will conduct the study, along with a visiting geneticist from France, Sebastian Jacquemont, M.D. Drs. Hagerman and Jacquemont are especially interested in older persons with tremors, balance problems, gait problems, or other potential neurological difficulties and who are either known or strongly suspected to be Fragile X carriers. They are looking for potential participants who live in California, although they also welcome participants from other states.

Participation would first require an interview over the telephone, possibly followed by about an hour visit with Dr. Hagerman and/or Dr. Jacquemont. Volunteers may need to visit the M.I.N.D. Institute in Sacramento, although if enough people in Southern California express an interest they may come here.

If any of you know of any potential participants who might be willing to volunteer, and/or if you wish to get further information about the study, you can call **Louise Gane at the M.I.N.D. Institute in Sacramento at (916) 734-8266.**

## GENERAL MEETING AT WESTSIDE REGIONAL CENTER

### IEP's and the IDEA

On June 9, 2001, FraxSoCal held an open meeting for its members and anyone else interested at the Westside Regional Center in Culver City. The topic of the meeting was IEP's and the IDEA. Two knowledgeable presenters spoke at the meeting: **Dina Ackermann and Bruce Bothwell, Esq.**

Dina Ackermann is a public school teacher who has a great deal of experience in special education. She has attended many Individualized Education Plan (IEP) meetings as a part of the school "team" that formulates goals and objectives for special-education students. She has also acted as an independent advocate for students and families at IEP's going outside of her school district.

Bruce Bothwell is an attorney in Long Beach, California who represents families seeking services from schools and regional centers for children with disabilities. Mr. Bothwell became an expert in the obligations of public schools (under the **Individuals with Disabilities Education Act, or "IDEA"**) and state regional centers (under the Lanterman Act) after his own son was diagnosed with autism.

Ms. Ackerman and Mr. Bothwell gave their impressions of how to get the most out of the IEP process, what pitfalls to avoid in IEP meetings, and how to obtain services if schools resist. Mr. Bothwell also talked about the corollary obligations of the regional centers to provide similar services, and the process for obtaining those services.

The Fragile X Association of Southern California greatly appreciated both speakers giving up their Saturday mornings to speak at the meeting.

Ms. Ackermann may be contacted at (310) 263-2200. Mr. Bothwell may be contacted at (562) 436-9911.

## CALENDAR OF EVENTS

### Sunday – August 19<sup>th</sup> FraxSoCal Family Picnic & Swimming

Fort McArthur Park  
San Pedro, CA - Flyer with details enclosed

### Saturday – September 15<sup>th</sup>

Association Meeting - 10:00am to 12:00pm  
**Westside Regional Center**  
*Drs. Randi and Paul Hagerman to speak*  
5901 Green Valley Circle, Culver City, CA 90230



### New Board Members Miriam and David Ackermann

“Our family’s awareness of Fragile X occurred when our two grandsons aged two and six months were diagnosed. Fortunately, the 7<sup>th</sup> International Fragile X Conference in Los Angeles was held just as we needed all the data we could find and found the Conference to be exceptionally relevant and essential as a rich source of hope and practical help. My background is as an educator, one of my four children is a special education specialist at a high school level and is a rich and willing resource and my husband David, is a retired Orthopedic Surgeon, and is eager to connect with the researchers who are involved in solving Fragile X.

Together, we bring a deep personal commitment to educating about and helping to solve the problems of living with the Fragile X gene. We want to work with those who are also involved to the same extent we are, and who can support and interact with us. May I add, the personal connections and support I’ve already experienced in my short exposure to the Fragile X Association of Southern California has been reassuring and remarkable for its ease and warmth.”

Welcome aboard Miriam and David!



Elisabeth Dykens, Ph.D. and Edward Ornitz, M.D. invite you to participate in a study of how boys with fragile X syndrome respond to sound.

We are particularly interested in how the response to a quiet sound affects the response to a loud sound when a quiet sound precedes a louder sound. Why is this important in fragile X syndrome? Based on studies with fragile X mice, it looks as if these mice are responding differently than we would expect to soft sounds, and also differently than we would expect to louder sounds. It is important to see if this same unusual pattern to sound is also seen in humans, and how it may relate to the sensory and behavioral difficulties seen in many boys with fragile X syndrome. If the patterns to sounds are similar in both mice and people, then ultimately we can use the mice models to evaluate potential pharmacological or gene therapy treatment that hold the most promise for boys with fragile X syndrome.

What do we specifically need from you? We would like to work with boys with fragile X syndrome aged 8 through 17 years and their parents for about three hours. We would assess the boys’ responses to sounds and administer a brief problem-solving task. Equally important, we would also ask parents about their son’s everyday adaptive skills and performance, and any negative behaviors that might get in the way of these skills. In return, we would give parents individualized written feedback about their son’s performance, as well as a token \$25 stipend and reimbursement for your mileage to and from UCLA.

If you are interested in participating or have any questions about this study, please call the project coordinator **Dr. Beth Rosner at 310-794-9201.**

Thank you in advance as we work together to improve the quality of life for persons with Fragile X syndrome and their families.

## BOOK AND VIDEO 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.

### My Brother Has Fragile X

by Charles Steiger

"filled with the fresh perspective of a younger brothers 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.

**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

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

## MEMBERSHIP DUES

If you haven't sent in your annual membership dues, photocopy this box and return along with your annual dues of \$25.00 made payable to:

**Fragile X Association of Southern California**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City, ST., Zip: \_\_\_\_\_

Mailing Address:

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

**Secure Tax Deductible Contributions & Dues can now be made on [www.fraxsocal.org](http://www.fraxsocal.org) with Visa or MasterCard. Visit us and click on MAKE A DONATION**

## TRIBUTES

*IN HONOR OF*

**MARY & GEORGE RUSSELL**  
from  
Sean & Julie Russell

**COLE THIRKILL**

from  
Grandparents Marilyn & Tom Keller

*IN MEMORY OF*

**YANNI DEMOS**

from  
Renee Young

**BAYARD COLE**

from  
Mr. & Mrs. Gary Warner

**Condolences**

to  
The Family of Diane Mumper

## DONATIONS

**Benefactor - \$500+**

Neal & Carolyn Robb  
Coldwell Banker, Brentwood East  
World Shoe Association

**Sponsor - \$100 to \$250**

Shirley Fidler Family  
Allan Bennison  
Anonymous

**Friend - \$50 to \$100**

Benjamin Tysch  
Anonymous

## FYI

**The Western Law Center for Disability Rights**

919 South Albany Street  
Los Angeles, California 90015  
213-736-1031

**UCLA Children's Dental Center**

Center for the Health Sciences  
University of California, Los Angeles  
310-825-5619

**Mommy and Me Picnics**

(San Fernando Valley)  
For more information  
Contact Mary Seward at 818-858-8415

## PARENT'S CORNER

### What's in a Name?

By Archie Hahn

Hello, my name is Archie. My father's name was Archie. My grandfather's name was Archie, so when it came time to name my son – I named him Ivy. Well actually, I nicknamed him Ivy. His legal name is... Archie. To be precise, he is Archie the fourth (roman number IV...Ivy, get it?). I swear I tried not to name him Archie, but my father took some perverse delight in persuading me to do it...oh well.

Ivy is six years old and is blessed with an excellent vocabulary and little self-restraint. He can be very direct, sometimes hilariously. He attends non-public school for special needs' children. He is one of six children in his class; many are autistic and he is the only Fragile X child. Recently he began a trial of Ritalin to help reduce his impulsivity and distractibility. Every day (for 3 weeks) I observed his behavior from the private observation room without his knowledge.

One day a young mother arrived in the classroom with her autistic son and a man I later found out was the boys' psychologist. The boy was difficult to contain and somewhat distracting. It was obvious from his mothers' faint apologetic smile she had hoped things would go better. She darted about wearing an expression of serene desperation. The psychologist, a large soft man with long hair and the bearing of a used sofa, made no effort to involve himself. He observed with clinical detachment as though no one could see him. He had not been introduced and made no effort to introduce himself. He made the teachers and aides uncomfortable because he gave no indication that he was actually in the room. The children were proceeding through their "Morning Greeting" during which each child performs a task. They seemed to take their disruptive guest in stride but could feel the mother's struggle. By the time he took his turn in front of the class everyone, but Ivy seemed

a little uneasy...awkward. The teacher asked Ivy to describe the weather. Without looking he said "Cloudy." She thought he might be guessing so she suggested he go to the window and make certain. Slightly irritated by her 'doubt', he graciously set out to accommodate her. Gradually people began to realize the route he chose to a window would take him right by the psychologist who had now fixed his probing unsupportive gaze onto Ivy. The room was heavy with anxiety, Ivy calmly and purposely made his way past his friend Matt. He said "Hi Man"...(Matt managed a weak "Hi") then he encountered the new boy and said "Hi"...(no response), as he walked by the mother he smiled warmly...knowingly. Relieved, she smiled back. Every eye was on him as he arrived at the psychologist. He paused and looked up into both barrels of the big man's gaze and without flinching said... "Whata' you lookin at?"

The tension in the classroom was released in a volcanic eruption of laughter. To his credit, the psychologist laughed the hardest. He had been busted, in an instant, by 50 lbs. Of incredulous six year old. As the laughter subsided into random chuckles... Ivy, now posed at the window, was gesturing skyward reminding the teacher that he was right... "It is cloudy!"

He didn't say "You gotta' problem with that?"... but it was implied.

The final score: Ivy 2 – Adults 0



### **NEWSFLASH!**

Timothy Seward received a "Blue Slip" at school for comforting a child who had fallen and was in stress. Sensitivity to others! Yea, Fragile X kids!

THE FRAGILE X ASSOCIATION  
OF SOUTHERN CALIFORNIA IS RUN  
ENTIRELY BY VOLUNTEER PARENTS OF  
CHILDREN WITH FRAGILE X SYNDROME.

WE ARE A CALIFORNIA NONPROFIT  
501 (C)(3) TAX EXEMPT CORPORATION  
AND YOUR TAX-DEDUCTIBLE DONATIONS  
HELP SUPPORT OUR MISSION AND ARE  
GRATEFULLY ACCEPTED.

VISIT OUR WEBSITE AT:  
[WWW.FRAXSOCAL.ORG](http://WWW.FRAXSOCAL.ORG)

MORE THAN  
100,566 VISITORS  
SINCE JUNE 5, 1998

## **FROM THE BOARD ROOM** *2001/2003 Board of Directors*

Neal S. Robb, President  
Diane Bateman, Vice President  
Mary Seward\*, Treasurer  
Marie Lambert, Secretary

### **Directors**

Miriam Ackermann	Deborah A. LeCover*
David Ackermann	Stephen D. LeCover
Millette Arredondo	Charlotte Spahr
Steve Arredondo	Carolyn J. Stokes
Sali Farber*	

\*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**  
**P0 Box 6924**  
**Burbank, CA 91510-6924**

ADDRESS CORRECTION REQUESTED