

FragileXpress

Volume 2, Issue 1

Winter 1999

Fragile X Comprehensive Care Center

Update

Barbara Wheeler, Ph.D.
Children's Hospital LA/UAP/USC

In October, Dr. Randi Hagerman from the Fragile X Treatment and Research Center of Denver provided a full day of consultation with our clinic staff. She was a stellar speaker at Grand Rounds for our medical staff and residents. Dr. Robert Adler, Chair of Pediatrics at CHLA, was very impressed by Dr. Hagerman's presentation and her willingness to work with our hospital to build our Fragile X-pertise. Dr. Hagerman emphasized the great potential that our clinic has and the importance of putting resources into it. We will be meeting with Dr. Adler to discuss what the hospital can do to support the International Fragile X Conference in the year 2000. We are making progress; the hospital is beginning to catch the Fragile X wave--thanks to all of you.

In December, I met with Dr. Ian Tofler, a child psychiatrist who has just joined the CHLA faculty. His

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Clinic Without Walls

Fragile X Comprehensive Care Center Needs Names of Good Providers who know Kids with Fragile X

Barbara Wheeler, Ph.D.
Children's Hospital Los Angeles/UAP

To better meet the needs of families throughout the LA Basin, the Fragile X Comprehensive Care Center is building a "clinic without walls."

This is a term to describe an organized network of providers in the L.A. Basin who want to and/or have expertise in working with children with Fragile X. We are recruiting providers in occupational therapy/SI, behavior, speech/language, medication coverage. Many of you already have good providers so we are looking to the Fragile X Association to help us identify professionals we can formally bring into our network. What does this accomplish?

First, families can have providers do intervention right in their home community. We are too far from many families to be a resource for intervention and treatment. Having professionals right in your community is better for families.

Second, by belonging to our network; providers in your community improve their knowledge of Fragile X and good treatment methods. As a member of our network, providers will get information from us about "best practice" interventions and latest research findings. Also, we will hook them up with other disciplines in their area so they can coordinate what they do. That way a behavior specialist funded by regional center would know that they should be talking to the occupational therapist as well when figuring out how to work with a child with Fragile X.

Third, if a provider doesn't have a lot of experience with Fragile X but would like to build this expertise, we will

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special area of expertise is in ADHD and aggression management. He is very experienced in prescribing medications for these and other disorders in children. He is very interested in working with our children. Please call the Fragile X Center, (213) 669-4656 if you want your child to be seen by Dr. Tofler. Our other team members will also participate in the medication assessment and follow-up.

Please see the following article on other ways we are hoping to improve services to children with Fragile X in Southern California.

That's where we're at with the Fragile X Comprehensive Care Center you helped to start. It's a challenge, but we hope our plans for next year will help us get closer to being a resource for families, and building our expertise.

Happy New Year to all of you and thanks for all of your support. ❖

NATIONAL NEWS

National Fragile X Foundation Board Member and Conference 2000 Co-Chairperson Stephen LeCover announced at our January, 1999 Board Meeting that the 7th International Fragile X Conference date will be July 19-23, 2000 at the Century Plaza Hotel & Tower in Century City, (walking distance to Beverly Hills). Fragile X Association of Southern California is very proud to co-host this very important event. Save the date for this incredible educational and social experience.❖

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
P0 Box 6924
Burbank, CA 91510-6924

FROM OUR MEMBERS

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 or mail to:

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THE HORSEMAN

By Micah Piper (age 13)

That night, from the cliff, only the horseman saw the ships. There were three ships. Two had many people on board both passengers and crew, and one was completely empty. All were sailing north below the cliff. The empty ship was lit with a light from below the water. The horseman watched as in the distance in the sea, another light appeared, grew large, and from it rose a dragon whose three heads were each different from the others. All night the horseman watched as the ships, the dragon, and the lights moved about on the water. The horseman struggled to stay awake, but as the sun rose in the morning, he awoke to an empty sea.

He turned from the cliff and galloped away to tell of what he saw. As he rode through the forest he came upon a crumbling castle whose rooms still stood with their roofs. The horseman saw a shadow in one of the window. It was a sorcerer who raised his scepter and summoned three demons from the earth.

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CHARITY EVENT POSTPONED

The Casino Night Fundraising Event sponsored by Coldwell Banker, Brentwood CA benefiting Fragile X Association of Southern California and for the real estate industry and other interested parties has been temporarily postponed. We look forward to a new date within the next few months.

Stay tuned!

CALENDAR OF EVENTS

January 30th

Saturday - 3:00 – 5:00pm

Pizza and Bowling Party

Montrose Bowl

2334 Honolulu Avenue, Montrose,

see flyer for details - Bring a dessert to share

Saturday - March 20th -

Association Meeting - 10:00am – 12:00pm

SPECIAL NEEDS TRUST

Guest Speaker - Barbara Bergstein, Esq.

Westside Regional Center

5901 Green Valley Circle

Culver City, 90230

Meet our new Officers and Board Members. Join us for lunch after the meeting.

Saturday - May 15th

Association Meeting

10:00am – 12:00pm

East Los Angeles Regional Center

Topic to be announced.

June ??, 1999

Annual Family Picnic

We would like to find a new spot for this year's picnic ...let us know if your area has a special park or beach

MARK YOUR CALENDARS NOW for the following dates of Association Meetings for the remainder of 1999 Saturday, July 17th, Sept. 18th and November 20th.

March 15th- 20th

"Technology and Persons with Disabilities"

More than 390 speakers present at this conference at the Los Angeles Airport Hilton and Marriott Hotels. For more info call (818) 677-2578 or visit www.csun.edu/cod/

Exhibit Hall is FREE!

Scholarships are also available.

provide them with information and hook them up with other providers to consult with. This way, we will increase the number of professionals locally who know how to work with our kids.

Fourth, we will be better able to do research. By agreeing to participate in the network, providers will also agree to help us collect data on kids who are being treated. Network providers will let families know that they belong to our Fragile X network and ask them if they would like to participate in our research studies. To begin with, we would just like to follow kids and families and see what happens to them. So families will just be agreeing to let us get copies of their records. When we are successful in getting research grants, our studies may be more focused. Our network providers will be included in our research budgets so they can recruit families for us and help us collect data.

Fifth, we'll expand the number of **Fragile X-perts** in the LA Basin by creating a "learning community." Through this organized network, we will have an educational symposium annually and discuss what is happening. Our main invitees will be our Network providers, but we will also open this up to families and other professionals. We will have business meetings afterwards to discuss Network Issues. ❖

Please give us information on Providers in your area and send the following:

- Name of Provider (OT, Speech, Behavior, M.D.)
- Address
- Phone number
- Why you recommended

Send to:

Barbara Bentley, Psy.D.

USC UAP, MS#53

P.O. Box 54700

Los Angeles, CA 90054-0700

or

Fax to her at: (323) 953-0439

Barbara is our Psychologist who will gather this data based upon your recommendations.

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The horseman did not see the demons; he did not know they were there. With his scepter the sorcerer turned the demons to stone. They would wait as stone until the night when they would come alive again.

The horseman rode quickly to alert the king and his men. Coming into town he passed the baker whose shop already smelled of baking bread and rich, beautiful cakes. The villagers laughed at the horseman when he told them of the things he had seen and warned them of danger.

Note from Micah's mom:

This story was all his own creative work, I helped with the connecting words to make the story flow. I feel these kids have so much inside of them that they just cannot get out! ❖

HEADLINERS

Eric Farber was recently featured in the Irvine World News for his work as a team manager with the Irvine High football team. Congratulations to Eric on a job well done! His mother Sali, was also noted for her work as President of our Association and gave our website address for further information.

Timmy Seward and Mary Seward are both featured in the Koch-Young Family Resource Center at Lanternman Regional Center informational guide to support services.

Congratulations to **Matt and Kareen Weidenfeller** who have announced they are expecting their third child. ❖

TRIBUTES

We can help you honor your relatives, friends and associates or the memory of a loved one with a personalized Tribute. Acknowledgment will be sent to the recipient or their family. **Your tax deductible donation** will be acknowledged in future issues.

TRIBUTES

IN HONOR OF

Ethel Ellenbogen from **Regina Mitouer** on her Birthday

Jill, Ben and Max from Rachel Andres

Dianne & Gary Warner and Matt & Kareen Weidenfeller from **Sali, Jeff, Richelle and Eric Farber**- A Very Special Thank You

Mom from **Diane and Jim Bateman** Happy 70th Birthday

Alex, Emilie & George Fiedler from **Jane and Jeff Jones**

Timmy from **Mom, Dad and Liz** on your 8th Birthday

IN MEMORY OF

Morton LeCover from **Stephen & Deborah LeCover**

DONATIONS

PATRON - \$250 to \$500

Neal & Carolyn Robb

SPONSOR - \$100 to \$250

Jim & Diane Bateman

Robert & Deborah Goldstein

Dr. Randi J. Hagerman

Mr. & Mrs. Raymond Jankowski

Stephen & Deborah LeCover

Mark & Angie Degenhart

Tammy & David McLean

Dennis Seeto

Roger & Mary Seward

FRIEND - \$50 to \$100

Marvin C. Abrams

Leslie J. Nitta

Rachel Andres & Ben Tysch

SUPPORTER - \$25 to \$50

Charles Crutchfield

Jane & Jeff Jones

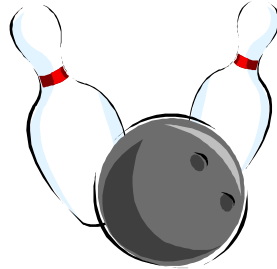
OTHER - \$10 to \$25

Stuart & Helen Arfin

Elaine Welch

FRAGILE X ASSOCIATION

of
SOUTHERN CALIFORNIA



FAMILY BOWLING PARTY

FREE PIZZA and DRINKS (Bring a Dessert)

Saturday, January 30th

MONTROSE BOWLERS CLUB
2334 Honolulu Avenue
Montrose, CA 91761

714-249-1733
NIGHT OF BOWLING, all
provided by the association. We will have
the party for ourselves. Bumpers
available so even the little ones can be
successful.

Cancelled

Call 818 754-4227 if attending and specify how many family members are coming.

FROM SAN GABRIEL VALLEY – Take the 210 West to the Oceanview offramp, exit, turn left. Go to Honolulu Avenue and turn right. Its on the left side of the street in between two bank buildings.

FROM ORANGE COUNTY – Take the 605 or the 57 North to the 210 Fwy West to the Oceanview offramp, exit, turn left. Go to Honolulu Avenue and turn right. Its on the left side of the street in between two bank buildings.

FROM THE WESTSIDE OF LA – Take the 10 Fwy East to the 110 North to the Golden State North to the 2 Fwy North to the Verdugo Blvd. Exit, (bear to the Right when approaching the 210), turn left onto Verdugo Blvd. which will become Honolulu without turning. When you pass the third signal (which is Oceanview) the alley is on the left hand side between two bank buildings.

FROM BURBANK – Take the 5 North to the 134 East to the 2 North to the Verdugo Exit. SEE FROM THE WESTSIDE OF LA AND FOLLOW INSTRUCTIONS STARTING WITH “to the 2 Fwy North”.

FROM DOWNTOWN LOS ANGELES – SEE FROM THE WESTSIDE OF LA starting with “110 north to the Golden State”.

FROM RIVERSIDE/CHINO/COVINA – Take the 10 West to the 57 or 605 to the 210 Fwy West to the Oceanview offramp. SEE FROM ORANGE COUNTY AND FOLLOW INSTRUCTIONS starting after exiting Oceanview offramp.

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 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 donations to help support our mission are tax-deductible and gratefully accepted.

Visit our Website at: www.fraxsocal.org
More than 12,000 visitors since June 5, 1998



NEWS FROM THE BOARD ROOM

The Fragile X Association of Southern California Officers and Board of Directors met on January 10th to discuss the priorities and direction for 1999. It was decided to alternate meetings between East Los Angeles Regional Center and Westside Regional Center and to hold one meeting a year in Orange County. We hope that this will make it possible for more families to participate. The meetings will now be held on a Bi-Monthly schedule, starting with our next meeting in March.

In an effort to improve the quality of services and support that we are able to provide to families and professionals, we will be asking for a membership fee of \$25.00 yearly. It is our hope that our families and friends will join us in support of our mission to increase awareness of Fragile X syndrome and to support those families affected by it.

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ADDRESS CORRECTION REQUESTED