Fragile X Association of Michigan

eXtra, eXtra

Volume III, Issue 3; July 2007

Three Cheers for Nathan Fischer

Nathan, bottom right, and the Golden Grizzly Band

When a child is born, parents have dreams about their new child's life--maybe they will be an athlete, a musician, an artist. Usually included in those dreams is a college education.

Throughout his K-12 education, our son Nathan, who has fragile X syndrome, was included in general education classrooms. It was natural that Nathan wanted to go to college and continue being with his typical peers once he finished high school. In the fall of 2003, Nathan was one of the first students in the Transitions Program on the campus of Oakland University. Students sit in on college classes; do volunteer jobs, and take part in a variety of campus activities.

Nathan has particularly liked his German, movie music, environmental science, broadcasting, and British literature classes. He has been a volunteer at the radio station and at Lowry Center helping with filing. He enjoys going to the rec center and taking water aerobics. However, Nathan's favorite two classes are Akwaba, the African Drumming Ensemble, and the Golden Grizzly Athletic Band.

In the African Drumming Ensemble, Nathan has played a variety of drums and has had several drum and lead vocal solos in their performances. Their director, Mark Stone, has been wonderful in recognizing Nathan's strengths and challenges the other students to have as much enthusiasm as Nathan has.

The Golden Grizzly Band plays for all of the men's and women's home basketball games. Nathan plays tambourine in the rhythm section and again is known for his team spirit. This March, the director, Dr. Ken Kroeche, made arrangements so Nathan and his dad could travel with the band to the Mid Con basketball tournament in Tulsa, Oklahoma. Both teams advanced to the finals, so the band got to play at six tournament games. Nathan really had a great time! Unfortunately, both teams lost in the finals. Nathan was hoping for a trip to an NCAA tournament game--maybe next year.

Three Cheers for Allison Cohen

Allison graduated from North Farmington High School on June 3, 2007.

This September, Allison plans to attend Oakland Community College. She will be enrolled in two courses: medical terminology and culinary arts. She's not sure where these will lead her as far as a career path, but is looking forward to this new phase in her life.

We are all very proud of her.

Arlene, Allison and Josh

From the President's Desk

By Laureen Majeske

The school year ended with wonderful stories from our families about sports championships, dance recitals, band concerts, graduations, proms and more! What a positive outlook for our community to see what our *fragile* children are able to accomplish! Though summer is now in full swing, the FXAM is already looking toward the fall with an upcoming Comedy Fundraiser, Annual Golf Outing and Fall Conference. Keep your newsletter handy for all of the dates, times and places!

Come join your friends or come and make new ones!

Let's have some fun

Thursday, August 9, 2007
8 p.m.
Comedy for a Cause
Joey's Comedy Club

36071 Plymouth Road
Livonia, Michigan
$15 per person plus $5 drink/food purchase
For tickets contact:
Mark and Malinda Popejoy at 734-414-0371 or
Kim Young at 248-674-2147

Saturday, September 8, 2007
Eighth Annual Golf Outing
Wesburn Golf and Country Club

5617 S. Huron River Dr.
South Rockwood, Michigan
(one mile west of I-75, exit 26)
Registration: 12:15 p.m., (four-person scramble)

Contact Frank or Nina Liberati for tickets, donations (cash or door prizes) or more information at 313-381-2834 or **ninaclare@comcast.net**

Contact Mary Beth Langan for additional invitations at 313-881-3340 or **mblangan@hotmail.com**

Between the Lines

Featured Book

The Oak Leaves

by Maureen Lang

Often our Featured Book is non-fiction, but many on the FRAXA Fragile X Family Listserv have been chatting about not being able to put down the newest novel by Maureen Lang, also a listserv family member. Lang's novel tells two stories in one tale, told from the perspective of two women in the same family living within two time periods, 19th century England and modern-day Chicago.

We've read many positive reviews and look forward to reading the book ourselves!

FXAM 2007 Conference

X-pert Advice: Understanding and Guiding Behaviors in Fragile X Syndrome

Tools for Success

Mark your calendar, the Fragile X Association of Michigan's 2007 Conference will be here shortly.

Date: Saturday, October 13, 2007

Time: 9 a.m. to 3 p.m.

Place: Beaumont Hospital, Administration Building, Auditorium.

Dr. Marcia L. Braden will once again be our key presenter. If you want advice from an expert on Fragile X related to behavior issues, Dr. Braden is who you would seek for expert advice.

Dr. Braden is a licensed psychologist with educational endorsements in elementary education, special education and school psychology. In addition to her PhD, she holds a masters degree in learning disabilities and emotional disturbances. She has written and published numerous articles related to education and behavior management strategies, techniques, and interventions.

Respected for her work internationally, Dr. Braden has presented at numerous conferences and workshops about Fragile X syndrome, autism, and other related disorders.

Watch your mailbox for conference details and registration information.

Research News

Latest Research News: Scientists may have uncovered a way to reverse symptoms of Fragile X Syndrome (FXS) in mice. The study suggests that inhibiting a certain enzyme (p21-activated kinase, PAK) in the brain could be an effective therapy for countering the symptoms of Fragile X Syndrome (FXS) in children, and possibly in children with autism as well

Researchers from the Picower Institute for Learning and Memory at Massachusetts Institute of Technology (MIT) genetically manipulated the mice to model Fragile X Syndrome (FXS), which is the leading inherited cause of mental retardation and the most common genetic cause of autism. Complete details were reported in the Proceedings of the National Academy of Sciences (PNAS)

www.pnas.org/cgi/reprint/0705003104v1.

Study Recruitment:

If you know of any boys/men who seem to have Fragile X but have tested negative for Fragile X, here's a research study that might interest you:

The typical mutation of the FMR1 gene that causes Fragile X syndrome is the CGG-repeat expansion. Diagnostic laboratories typically only examine this type of mutation even though there is no reason to believe other, more conventional, mutations do not occur in FMR1 (conventional mutations are deletions and/or sequence changes of the FMR1 gene). To address the lack of conventional mutations in FMR1, Dr. Stephen T. Warren's laboratory at Emory University has begun a NIH-sponsored study to uncover conventional mutations of FMR1 in patients presenting with aspects of Fragile X syndrome but without repeat expansion mutations. These would be boys who have features of Fragile X syndrome but have been tested as "normal" for the FMR1 gene test.

To learn more, visit the Emory FMR1 Resequencing Project website at **www.fmr1resequencing.org**.

For additional information, contact Stephen Collins at **sccolli@learnlink.emory.edu** or Dr. Warren at **swarren@emory.edu**.

Participate in the first national Survey for Families of Children with Fragile X Syndrome

This survey will look at how Fragile X affects families, including medical and nutritional needs of children with Fragile X, use of educational services and supports, and the cost of raising a child with Fragile X. The survey will be the first to gather national data from families that can be used to change policy and improve practice.

At least 2,500 families are needed for the survey, your participation is very important!

Enrollment

- August through December 2007
- Takes 20 minutes to complete
- Can be done on the Internet or by calling toll-free
- Asks for basic information about your family

The Survey

- Begins in January 2008 (you will be reminded 2 weeks before the survey begins)
- Asks more in-depth questions about your family
- Takes 35–40 minutes to complete
- Can be done on the Internet or by calling toll-free
- All responses will be kept confidential and no personally identifying information will be published in any report or given to any individual or organization

Dr. Don Bailey, an established Fragile X researcher at RTI International, is the Project Director. **If you have questions**, please call **Dr. Melissa Raspa**, Project Manager, at 1-866-860-5229

For more information about the survey or to enroll,
please visit the study website at fragilex.rti.org

Mark Your Calendar

Support Meetings:

When: **October** and **November**
First Saturday of the month.

Time: Business Meeting: 6 – 7 p.m.
Support Meeting: 7 – 9 p.m.

Where: Beaumont Hospital, Royal Oak
Admin Building, Private Dining Room

Special Events:

Aug 9: **Comedy for a Cause**
Joey's Comedy Club
36071 Plymouth Road, Livonia, Michigan

Sep 8: **Annual Golf/Dinner Fundraiser**
Wesburn Golf & Country Club
South Rockwood, Michigan.

Oct 13: **X-pert Advice: Understanding and Guiding Behaviors in Fragile X Syndrome**
Beaumont Hospital, Royal Oak

Electronic copies of our newsletter are available on our website. If you would like to share them with family, friends or professionals, please share our web address with them

Contact Information:

Phone: 313-381-2834
E-Mail**: fraxmich@hotlinemail.com**
Web: **www.Fragilex.org/html/michigan.htm**

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