

e tra, X e X

Volume IV, Issue 4; October 2008

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

November 1, 2008 February 7, 2009

No Meeting in January!

Time:

Business Meeting: 6 - 7 p.m.Support Meeting: 7 - 9 p.m.

Where:

Beaumont Hospital Royal Oak Campus Administration Bldg Private Dining Room

Special Events:

November 22, 2008:

FXAM Holiday Fundraiser See page 3

December 6, 2008:

Holiday Party See page 3

Fragile X Association of Michigan

Contact Information:

313-381-2834

fraxmich @hotlinemail.com

Fragilex.org/html/ michigan.htm

What I did on Summer Vacation ...

You may not see Darienne, daughter of Laureen & Ron Majeske, on Dancing with the Stars, but dancing is how she loves to fill her time.



Antonio, son of Nina & Frank Liberati, loves to fish at his cottage. He caught this whopper all by himself. Fish tale anyone?



Andrew, son of Kim & Mike Young, participated in the Carolina Communication Project. He did quite well but especially loved having his own hotel room key card! He was very willing to go retrieve anything from the room if it meant he could do it alone. And he did. Over and over.



Andrew, son of Mary Beth Langan & Ted Coutilish, rode a horse a few times at First Impression Farm in Lenox, MI, He did not like the riding helmet, but he loved touching the horse.

Are you ready for 2010?

The Fragile X Association of Michigan (FXAM) is hosting the International Fragile X Conference in Dearborn, Michigan! More details on page 2.

etra, etra

From the President's Desk by Laureen Majeske

Dear Friends,

If you had not heard previous to reading the front page of this newsletter, the exciting news announced at the 2008 Fragile X Conference in the summer was that our group will be hosting the 2010 International Fragile X Conference! Mark your calendars... July 21-25, 2010 we'll be at the Hyatt Regency Dearborn for the conference with the family-friendly Thursday evening event scheduled for The Henry Ford Museum.

We have begun the planning process and the enthusiasm is boiling over! The greatest benefit for us that the conference is in Michigan, is that the conference is in MICHIGAN. It is an opportunity for us all to more easily educate our families, friends. teachers, doctors, therapists and all other professionals who support families affected by fragile X. This is our conference - with all of the world's fragile X experts - in our backyard. We are one big Michigan fragile X family and we hope each and every one of you can get involved in some way in this once-ina-lifetime event. It is here now; it is for all of us; it is for us to share Michigan and Metro Detroit with the fragile X world.

We will be sending you lots of information over the coming year to keep you up-to-date and offer opportunities to help. You will also be receiving a questionnaire where you can check the level of involvement you would like to have. We will be looking for sponsorships and donations to help put on the best possible conference. If you work for a company that awards grants, or a company that would like to donate promotional items or items for the Saturday-night silent auction, please let us know. We will have packets of information available for you to present to your company to help with this process or just let us know and we will do the rest. We will be happy to help in any way we can.

Also, don't forget that our major fundraiser to help us host the conference is still going on. The fragile X playing cards were printed this summer and are for sale for \$10

per deck. They would make great gifts for the holidays - for family, friends, teachers, therapists



and more! There is one low shipping price of \$10 to ship 10-60 decks to your home. If you would like to place an order for decks of cards, you can go to fragilex.org/html/michigan.htm for an order form (if not available, it will be in the near future). If you do not have web access or would like to pick up your cards at a support meeting or holiday event, please contact Kim at

248-396-0315 or fraxmich@hotlinemail.com.

Looking forward to working together with all of you to make this the best conference ever!

Annual Picnic and Fragile X 5K Fun Run & Walk

Our FXAM Annual Picnic Day included our 2nd Annual Fragile X Fun Run/Walk. After expenses (for awesome bounce houses, food and t-shirts), the day brought in \$1,300. Many families came out to run, walk, eat and/or talk with one another. It was a beautiful day!

We're already planning the 2009 event for:

Saturday, July 18

Please save the date and join in the fun! A special thank you to Kim and Mike Young, and all who helped organize this event to make the day a success!



Does FXAM have your correct email address?

In this electronic age, we try to send many of our updates and our event information via email to help our group save postage.

If you think we may not have your correct email address, please contact Mary Beth at mblangan@hotmail.com to change or confirm your email address. **Thank you!

Our annual potluck holiday party is set!



Saturday, December 6, 2008 4:00 - 9:00 pm



at the Langan-Coutilish home of Mary Beth,

Ted and Andrew



Please contact Mary Beth by December 2 at 313-881-3340 or mblangan@hotmail.com to let her know what holiday food you'd like to add to the festivities of the evening and how many from your family will be attending!

(you are invited to bring the whole family or have a "date night" and attend without children)







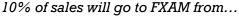


Mary Beth Langan and Tina Makris are hosting a

Holiday Fundraiser
to raise money for FXAM and the 2010 International Fragile X Conference



Saturday, November 22, 2008 1:00 – 4:00 pm





Lia Sophia Jewelry
Pampered Chef
Phat Threads Embroidery
Susan Mills Jewelry
Tastefully Simple
...and more



(same address & directions as above... contact Mary Beth for more info!)

The FXAM Fragile X Store

Over the years, FXAM has accumulated some great awareness pieces which are not doing their job while sitting in our storage unit! Pricing is reasonable. Consider one of these items for your holiday giving list or your own wish list!

- \$1 FXAM water bottles
- \$10 FXAM deck of playing cards \$100 for a box of 10 decks!

(pay a \$10 shipping fee for a pre-paid box which can ship anywhere from 10-60 decks to your home!)

- \$10 FXAM blue mini coolers
 (Mary Beth and Kim both use their snazzy FXAM coolers to pack their lunches!)
- \$15 FXAM golf/polo shirts (tan, lt blue and gray/black)
- \$15 **got FX?** navy short-sleeve t-shirts (the only FXAM clothing available in children's sizes M & L as well as adult sizes)
- \$20 FXAM lt blue hooded pull-over sweatshirts
- \$20 FXAM gray hooded pull-over sweatshirts
- \$30 **got FX?** navy hooded zipped sweatshirts

Our local conferences have been popular places to learn more about Fragile X. We have extra binders of information from our past three Michigan conferences.

FREE if ordered and picked up at FXAM support meetings or events \$10 if mailed to your home

- * 2003 version speakers were Mouse & Tracy (OT/SLP) and Doug Fisher (Inclusive Education)
- * 2005 version Dr. Marcia Braden (psychologist), Kelly Geddes (ABA) and Diane Simon Smith (therapist)
- * 2007 version Dr. Marcia Braden and Erin Carmody (Children's Hospital of Michigan genetic counselor)

If you would like to order decks of playing cards, please see the order form on (or soon to be on) our website fragilex.org/html/michigan.htm

For other items, or if you do not have web access to order cards, or to pick up your items at a FXAM event and avoid shipping costs, please contact Laureen (586-978-9079) or Kim (248-396-0315) or email FXAM at fraxmich@hotlinemail.com for ordering and/or shipping information.

etra, etra

Ninth Annual Golf Outing

Not only did our annual golf outing raise \$13,000, the sun was shining and it was a beautiful event! Our sincere gratitude goes to the following businesses, organizations and individuals for their generous donations:

The Tiger (\$1,300+)

The Nicklaus (\$1,000+)

Kenwal Steel Corp. Men's Wearhouse

The Palmer (\$500+)

Evelyn Kosch-Mannino Skanska USA Building, Inc.

The Watson (\$250+)

Flagstar Bank Watson Engineering

The Player (\$150+)

Allen Park Adult Booster Club Allen Park Football Committee Arnaldo's Banquet Center Jerry & Karen Bishop Freckle Face Candles Innovative Interiors, Inc. Italia Bakery Jeffery Cohen JD, PC Kiwanis Club of Allen Park Law offices of Miller & Miller, PC Liberati's Italian Deli & Bakery Liberati & Sons Construction Papa & Mama Rose Liberati Lincoln Park Credit Union Sandra & Douglas McClennen Preferred Brands Pomponio Construction Mark & Malinda Popejoy Charlie & Inez Roy Theresa Sternicki

Trenton Fire Fighters

Charities

UAW Ford Local 900 James & Cindy Vickey John & Nancy Warneck The Wurth Family Judith Zarkis

We would also like to thank the following businesses, organizations and individuals for their donations:

Terry Adams Agemy & Sons Market Dave & Fran Babbage Joe Batayeh Bob Callahan William & Shirley Cavataio Kerry & Isolina Carlini Florence Coleman Vito & Heather DiMaggio Eastern Michigan University Brian & Annette Foley Freckle Face Candles Mark & Tina Gaworecki Joan Grab Phil & Helen Groh Rosalie Guerra Craig Hawker William & Kim Holdsworth J. Goulasarian Contracting, Inc. Dave Jakobowski George & Barbara Jakubik Julia & Wanda Joseph K. F. Wren Mechanical, Inc. Levon & Gloria King Malcom Kurepa Kelly & Reatha Koson Jim Lada Ray Lalli LaMac's (Bill Hines) Larry Lamb Deborah Lee Liberati's Italian Deli & Bakery Tony & Dora Mangiapane Bob Mannino Marty & Lesa Melhorn Michaels & Associates **Bonnie Michels** Michlin Diazo Products Vince Militello

Ronald & Joanne Millner Jim Morrin Jerry & Sally Nantais Francis & Mary Jane Nazareno The Orchards Golf Club Jerome & Jeannette Pearsons Planet Beach Tanning Spa Kelly & Maria Pratt Joe Procopio Douglas & Lois Rich H. Ross Joe Salize Sadie Sclafani Tony & Sue Shannon Skanska USA Building, Inc. Frank Spina Susan Stearns Theresa Sternicki John & Susan Sturock This is Zip Printing Rose Tripepi Lester & Lisa Voutsos James & Charlotte Westbrook Weight Watchers Jim & Sheryl Wrobel Larry & Colleen Wurth Nazar & Sue Zain Rodney & Bonnie Zwonitzer





💢 etra, 💢 etra

Editors:

Mary Beth Langan 313-881-3340

mblangan@hotmail.com

Sally Nantais 734-282-7910

sallyn423@wyan.org

This newsletter is published quarterly and sent to all members and supporters of FXAM. Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

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.

Fragilex.org/html/michigan.htm



What I did on Summer Vacation ...

Our FXAM families created some very typical summer memories and some not-so-typical ones.

Sally Nantais traveled with daughters Genevieve and Natalie for them to participate in a research study at the M.I.N.D. Institute, U.C. Davis, Sacramento, California.

Their hard work in the study was followed by a day of fun in the sun at Pier 39 in San Francisco.

(continued from the front page)



P.O. Box 1414 Troy, MI 48099-1414