

## Mark Your Calendar

### Support Meetings

First Saturday  
of the Month

#### When:

February 7, 2009  
March 7, 2009  
April 4, 2009

#### Time:

2010 Conference/  
Business Meeting:  
5 – 7 p.m.  
Support Meeting:  
7 – 9 p.m.

#### Where:

Beaumont Hospital  
Royal Oak Campus  
Administration Bldg  
Private Dining Room

### Special Events:

#### March 3-4, 2009

**Fragile X Advocacy  
Day in D.C.**  
See page 2

### Fragile X Association of Michigan

Contact Information:

**313-381-2834**

fraxmich  
@hotlinemail.com

Fragilex.org/html/  
michigan.htm

## Three Cheers for Sammi & Jake!



The children of Trish and Don Price grew and sold pumpkins in Fall 2008 as a FXAM Fundraiser. They raised \$70 and have the seeds ready to repeat the project in Fall 2009!

## Holiday Party

Andrew Langan Coutilish and Kyle Laske spending some quality time together at our December 2008 Holiday Party.



## Are you ready for 2010?

The Fragile X Association of Michigan (FXAM) is hosting the International Fragile X Conference in Dearborn, Michigan! We hope to see you at the FXAM business meetings!

## From the President's Desk by Laureen Majeske

Dear Friends

How exciting that we are beginning a new year with so much to look forward to! This group just gets better and better as we welcome new friends and make stronger bonds with old friends. The past year was a lot of hard work, but we had a wonderful family picnic which coincided with our annual Fun Run/Walk, another successful golf outing where we raised \$13,000, a fundraiser held by Mary Beth Langan and Tina Makris, and we began work on

the next international conference to be held in Detroit in 2010. We also had a holiday party held at the Langan-Coutilish home, held many successful support group meetings attended by families new and old, and had many families take advantage of the conference scholarships to attend the NFXF International Conference in St. Louis this past July. I know that the continued spirit of support will carry us through this next year as we hold up our friends and families as

they go through new diagnoses, hold IEPs, struggle with family issues and school issues, and just need a friend to lean on or a friend with whom to celebrate. I know it may be a tough road ahead, but it is a great road to be on together. Best wishes for a successful New Year to all of you!



Laureen

## Fragile X Advocacy Day, March 3 - 4, 2009, Washington D.C.

### Agenda:

**First Day:** Training will take place between 1 pm and 5 pm on Tuesday March 3, 2009.

**Second Day:** Capitol Hill meetings will take place anytime between 9 am and 5 pm on Wednesday, March 4, 2009.. Specific meeting times will not be available until your arrival in DC.

### Where to learn more:

[fragilex.org/html/public\\_policy\\_legislative\\_advo.htm](http://fragilex.org/html/public_policy_legislative_advo.htm)

Contact NFXF Public Policy Chair Jeffrey Cohen at:

734-407-2413 or [j.cohen@fragilex.org](mailto:j.cohen@fragilex.org)

### Advocacy Day Hotel:

Embassy Suites DC Convention Center  
900 10th St NW

Washington, DC 20001

All Hotel reservations can be made by calling the Hotel's Reservation Department  
202-739-2001 or 1-800-EMBASSY

Mention the NFXF Conference Rate: \$259, plus tax.

**ROOM RESERVATIONS MUST BE  
MADE BY FEB. 7, 2009**

## 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](mailto:mblangan@hotmail.com)

to change or confirm your email address. Thank you!

## Research Study—Waisman Center, Wisconsin

Researchers at the Waisman Center, University of Wisconsin-Madison are seeking to understand the challenges faced by parents who are caring for an adolescent or adult son or daughter with fragile X syndrome. This new study is funded by the National Institutes of Health and is part of the national network of NIH-funded centers on fragile X syndrome. This study is part of the only fragile X center grant to be focused on families. The purpose of this 5-year study is to learn about the well-being of mothers and their children with fragile X syndrome, how mothers manage their day-to-day lives, and the stressful events which they may experience. We also want to learn about the quality of life of the sons and daughters with fragile X in regards to their social and recreational activities, friendships, and family relationships.

To qualify for the study, mothers must meet the following criteria:

- ☞ the son or daughter with fragile X must be 12 years of age or older
- ☞ the mother must be the biological parent
- ☞ the mother must provide documentation from an appropriate health care professional confirming that the son/daughter has the full mutation of the gene causing fragile X syndrome
- ☞ the son or daughter lives in the parental home, or the mother has at least weekly contact in person or by phone with the son or daughter

Mothers will be interviewed over the telephone and will complete self-administered questionnaires. We would like to interview each participant three times (once every 18 months) during the five-year study period.

During the course of the study, periodic summary reports on the study findings will be shared with families.

All information will be kept strictly confidential. If you choose to participate, you can feel 100% confident that no one outside of the research project staff will know anything that you said, not even the other members of your family.

If you are interested in learning more about this study or would like to participate, please contact **Renee A Makuch**, the Project Manager, using the following information:

Waisman Center  
 University of Wisconsin - Madison  
 1500 Highland Ave, Rm 551  
 Madison, WI 53705  
 877-558-7595  
[makuch@waisman.wisc.edu](mailto:makuch@waisman.wisc.edu)

Want to get involved?  
 Check out the Fragile X  
 Research Registries to  
 stay connected with the  
 latest studies.

## Research Registries—Are you connected?

### The Waisman Center, Madison, Wisconsin

Phone: Len Abbeduto, 608-263-1737 or Susan Vial, 608-263-5192  
 Online: [www.waisman.wisc.edu/rpc](http://www.waisman.wisc.edu/rpc)

### The M.I.N.D. Institute, Sacramento, California

Phone: 888-883-0961  
 Online: [www.ucdmc.ucdavis.edu/mindinstitute/research/studysignup.html](http://www.ucdmc.ucdavis.edu/mindinstitute/research/studysignup.html)

### The Center for Interdisciplinary Brain Sciences Research (CIBSR) at the Stanford University School of Medicine

Phone: 888-411-BNRC (2672).  
 Online info on Studies: [spnl.stanford.edu/participating/participating\\_fragilex.htm](http://spnl.stanford.edu/participating/participating_fragilex.htm)

### University North Carolina—Chapel Hill

Phone: 866 744-7879  
 Online: [www.fpg.unc.edu/~FXSRegistry](http://www.fpg.unc.edu/~FXSRegistry)

### Vanderbilt Kennedy Center—Research Family Partners, Nashville, Tennessee

Phone: 615-322-8240  
 Online: [kc.vanderbilt.edu/site/services/studyfinder/rfp.aspx](http://kc.vanderbilt.edu/site/services/studyfinder/rfp.aspx)



Editors:

Mary Beth Langan

313-881-3340

mblangan@hotmail.com

Sally Nantais

734-282-7910

sallyn423@wyan.org

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[Fragilex.org/html/michigan.htm](http://Fragilex.org/html/michigan.htm)



## What's the Deal?

Our FXAM families, researchers and experts from around the world contributed to create this unique set of playing cards. Cards can be picked up at membership meetings or mailed directly to you.

**\$10 FXAM deck of playing cards**

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



P.O. Box 1414

Troy, MI 48099-1414