

Three Cheers for...

# The Holiday Party



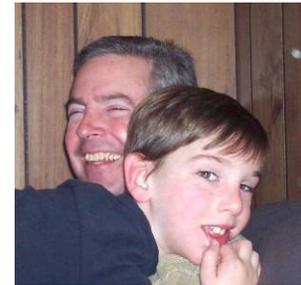
Josh Cohen



Adam and Malinda Popejoy



Jeff Cohen



Sean and Kevin Dacey



Tony Gelfand and Frank Liberati



Kim and Ally Young, Alli Cohen, Michelle Laske,  
Elina and Sam Gelfand

Special thanks to Angelo Liberati for being our photographer! ✕✕

Three Cheers for Ms. Candace Shay, 7<sup>th</sup> grade science teacher, Wilson Middle School, Wyandotte for inviting Sally Nantais into her classroom.

During December Sally gave five presentations on "Genetics and Fragile X" to 7<sup>th</sup> grade students who had just completed a section on genetics. It was a pleasure to work with the students and introduce them to Fragile X. ✕✕

## Upcoming Guest Speakers

**March 3, 2007**, Veena Rao, Staff Attorney of Michigan Protection & Advocacy Service, Inc. (MPAS). MPAS has offices in Lansing, Livonia and Marquette, Michigan. For info on MPAS, visit [mpas.org](http://mpas.org) or call 800-288-5923.

**April 14, 2007**, Cliff Weisberg, Senior Partner of The Law Center for Social Security Rights, a service of Weisberg & Walkon P.C., Attorneys at Law of Southfield, Michigan. For info on The Law Center, visit [ssrights.com](http://ssrights.com) or call 800-832-3471.

**National Fragile X Foundation  
Advocacy Day  
February 27 and 28, 2007**

The National Fragile X Foundation (NFXF) Advocacy Day Conference is focused on the legislative agenda of the NFXF. Primarily this agenda involves advocacy for increased funds for research and programming at numerous institutes under the umbrella of the National Institutes of Health (NIH), and the Fragile X public health program at the National Center on Birth Defects and Developmental Disabilities which is part of the Centers for Disease Control (CDC).

NFXF advocates are provided with comprehensive training which includes both the substance of this legislative agenda and also the "how to" part of being an effective advocate to members of Congress.

Training takes place on day 1 (**Tuesday Feb 27, 2007**) and then on Wednesday (**2/28**) meetings are scheduled for all advocates with all offices in their congressional delegation (2 Senators and 1 Representative in the House). Typically advocates attend these meetings with other advocates from their state and take turns leading the conversation. Every participant has at least three meetings set for Wednesday and often advocates attend additional meetings with influential Congressional offices interested in our cause. These meetings are all prearranged by the NFXF

While advocates can share their personal stories of how FX impacts each uniquely, all are also expected to stay "on message" and present a unified and consistent message which is part of the advocacy training session. Following advocacy day, advocates are expected to follow up by letter, phone or email and attempt to meet with their members of Congress or invite them to Resource Group meetings back in their home states. Follow-up is key as the process to move the budget forward begins each year in February and continues for a number of months thereafter. Advocacy Day is about relationship building and is just the first step. The objective is to educate members of Congress so they'll know what FX is and care more about it.

Please consider joining fellow families for the Advocacy Day Conference in February 2007. Without question, your participation will make a difference.

If you are interested in participating or learning more please contact Jeffrey Cohen, an active member of the Fragile X Association of Michigan and the Chair, Public Policy NFXF at [j.cohen@fragilex.org](mailto:j.cohen@fragilex.org). ✕✕

**From the President's Desk  
By Laureen Majeske**

Happy New Year to all of our families and friends. It is always wonderful to look towards the New Year with wonder about all of the possibilities that lie ahead. I know for me it gives me a renewed sense of spirit in our march towards fulfilling our mission of educational and emotional support for our families, promoting public and professional awareness and advancing research toward improving treatments and ultimately a cure for fragile X syndrome.

I want to begin this year by thanking each and every one of you for your past, and future, participation. No matter how big or how small, ALL of you make a difference. ✕✕

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*Quote for the Quarter*

**You must be the change you want to see  
in the world.**

*Mahatma Gandhi*

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**Between the Lines  
Featured Book**

**Fragile X Syndrome  
Diagnosis, Treatment  
and Research**

Third edition, 2002

Edited by Randi Jenson Hagerman, M.D.  
and Paul J. Hagerman, M.D., Ph.D.

This is one of the more technical of your library of "must reads" about Fragile X. The book has two major divisions of chapters subtitled *Diagnosis and Research* and *Treatment and Intervention*. Each division has multiple sections (Genetic Counseling, Academic Interventions, etc) written by top people in the Fragile X world (The Hagermans, Marcia Braden, Louise Gane, Karen Riley, Sarah "Mouse" Scharfenaker, Tracy Stackhouse, etc). There are also four appendices with important user-friendly information in each. ✕✕

## Emory Fragile X Studies

The Emory Fragile X Studies is a federally funded research project in the Department of Human Genetics at Emory University in Atlanta. We are examining how a gene called FMR1 is passed through the family and how the gene may affect learning, neurological function and the timing of menopause. Emory University has one of the longest-standing research programs on fragile X syndrome in the world. Dr. Stephen Warren, the Chairman of our department, actually discovered the gene that is responsible for fragile X syndrome. He and Dr. Stephanie Sherman are international authorities on fragile X syndrome and have been researching its causes since the early 1980s.

As for the studies, There are three major parts. If you agree to participate in one part of the study, you do not have to participate in other parts of the study. Participation would first involve submitting a signed consent form and cheek brush sample (so we can see what form of the FMR1 gene you carry).

**1. How does the FMR1 gene affect learning styles?** Some volunteers may come to Emory or have testers come to them to complete tests that look at individual learning styles. Volunteers may also be asked for a blood sample to measure factors related to the FMR1 gene.

**2. How does the FMR1 gene affect menopause?** Volunteers complete a short questionnaire about their reproductive history and may be asked for a blood sample to measure their hormone levels.

**3. How does the FMR1 gene affect learning and movement in older men and women?** Volunteers age 51 or older who are a carrier or have a family member with fragile x syndrome would complete a series of tests to evaluate learning styles and motor coordination.

Emory is still actively seeking participants, if you are interested in participating please contact Krista Harkreader at the Department of Human Genetics, Emory University School of Medicine, via phone at 404-727-6025 or e-mail at [kharkreader@genetics.emory.edu](mailto:kharkreader@genetics.emory.edu)

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*FXAM members Mary Beth Langan and Sally Nantais, along with family members have participated in different parts of this study. Feel free to contact them if you would like details from their viewpoint. Their contact information is on the back page. ✕✕*

## Waisman Center Language and Communication Study

The folks at the Waisman Center are recruiting families for a longitudinal research project designed to investigate the language and communication difficulties of children and adolescents who have fragile X syndrome. Children and adolescents with fragile X syndrome who are between the ages of 10 and 15 years are eligible to participate. Both males and females are needed. Participation would require visiting the Waisman Center on the campus of the University of Wisconsin-Madison. The costs for eligible travel expenses, including hotel and airfare, will be covered by the project. Because the project is longitudinal, we will ask families to return for additional testing at yearly intervals for four years.

For more information contact Dr. Len Abbeduto ([abbeduto@waisman.wisc.edu](mailto:abbeduto@waisman.wisc.edu) or 608-263-1737) or Susen Schroeder, ([sschroeder@waisman.wisc.edu](mailto:sschroeder@waisman.wisc.edu) or 608-263-5145). This research is approved by a University of Wisconsin-Madison Institutional Review Board for the Protection of Human Participants.

*FXAM member Sally Nantais currently has two children involved in this study. Please contact Sally if you'd like details from a parent's perspective (contact info on back page of newsletter). ✕✕*

## Through the Maze Featured Website

[www.fpg.unc.edu/~fxsregistry](http://www.fpg.unc.edu/~fxsregistry)

University North Carolina (UNC) Research Registry for Fragile X Syndrome

The FX Research Registry is for individuals who want to be notified about research studies on FXS that need participants. Individuals (adults or children) diagnosed with fragile X who live anywhere in the United States are eligible to participate.

The Registry refers individuals to studies while protecting their privacy.

**Who can enroll:** Anyone with an expansion of the fmr-1 (fragile X) gene: either a premutation/carrier or an individual with a full mutation (including mosaicism).

**If you don't have internet access but would like to participate in the research registry contact UNC toll-free at 866-744-7879. ✕✕**

## Mark Your Calendar

### Support Meetings:

**When:** February and March

First Saturday of the month.

**April – Second** 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:

**Feb 3: NFXF Adolescent and Adult Project**  
Discussion led by Arlene Cohen

**Feb 27-28: Advocacy Day, Washington D.C.**

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.

**Mar 3: Guest Speaker Michigan Protection & Advocacy Services**

**Apr 14: Guest Speaker Social Security Rights**

### Contact Information:

Phone: 313-381-2834

E-Mail: [fraxmich@hotmail.com](mailto:fraxmich@hotmail.com)

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

*eXtra, eXtra*

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