

## Mark Your Calendar

### Support Meetings

First Saturday  
of the Month

*When:*

November 5, 2011  
February 4, 2012

*No Meetings in*

*December and  
January!*

*Where:*

Beaumont Hospital  
Royal Oak Campus  
Administration Bldg  
Private Dining Room

**Special Event:**

**December 3, 2011**

**Holiday Party**  
see page 5

**FXAM Grants - NEW**

see page 3

**Save the Date:**

**Advocacy Day**  
**March 6-7, 2012**  
advocacy.fragilex.org

**Fragile X Association of Michigan**

Contact Information:

313-381-2834

**FXAM.org**

A member of the  
NFXF LINKS Network  
(Linking Individuals  
Nationally in Knowledge  
and Support)

## Three Cheers for...

**Mike Stockdale**, Plant Chairman, Local 900, Ford Michigan Assembly Plant Body and Stamping in Wayne, Michigan, hosted a Poker Run which benefited Fragile X! Many thanks for the monetary gifts that were given from the UAW and Ford Motor Co for the event. Special thanks to all those who attended. In the end, \$5,800 was donated to the Fragile X Association of Michigan! You're a **Royal Flush** in our eyes Mike!



Many thanks to FXAM members Malinda & Mark Popejoy who work with Mike at Ford.

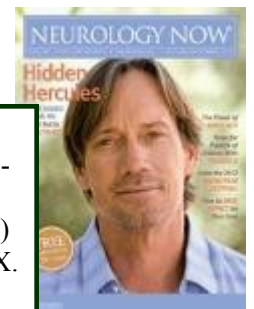


### Hail to the Victors!

Tyler Sutherby participated in Victory Day for a fun day of football with a couple of awesome mentors.



Fragile X in the news:  
Check out the Oct/Nov 2011 - Volume 7 - Issue 5, of Neurology Now (see page 37) for a great feature on Fragile X. Available online at neurologynow.org



## The Twelfth Annual FXAM Golf Outing

The 12th Annual Fragile X Association of Michigan Golf Outing on September 10 was once again a huge success! Although the constant rain during the previous days made the course a little soggy, everyone had a great time. At least the sun did shine down upon us all this year. The golfers, and dinner guests, enjoyed a delicious barbecued steak dinner under the big tent.

Once again, the Fragile X Association of Michigan (FXAM) is very grateful to **Nina and Frank Liberati** as organizers of this event. And we extend our gratitude to their family, friends and other FXAM members who assisted in many ways to make this event a success. The 12th Annual Golf Outing raised approximately \$12,000 for the Fragile X cause. Way to go Nina and Frank!

Thank you to everyone who contributed to our success!

The Mickelson (\$1,300+)

Kenwal Steel Corporation

The Nicklaus (\$1,000+)

The Palmer (\$500+)

Mike & Stella Banich

The Watson (\$250+)

Adams Holdings LLC

C. Hawker & Associates

Evelyn Kosch-Mannino

Steven Lebowski, PC

O.K. Foods

John & Nancy Warneck

The Player (\$150+)

Arnaldo's Banquet Center

Jerry & Karen Bishop

Jeffrey Cohen JD, PC

Mark & Joanne Colucci

Family Denistry, PC

Innovative Interiors, Inc

Kiwanis Club of Allen Park

Lakeshore Utility

Langan-Coutilish Family

Law Offices of Miller &

Miller, PC

Liberati's Italian Deli &

Bakery

Liberati & Sons Construction

Papa & Mama Rose Liberati

Lincoln Park Community

Credit Union

Mascari Sales and Marketing,

LLC

McCarthy & Smith

Construction Services

Mr. Joe's Sport Bar -

Southfield

Austin, Natalie & Genevieve

Nantais

Pia's, Inc.

Pomponio Construction

Mark & Malinda Popejoy

Charlie & Inez Roy

Silverton Skin Institute

Sue Shannon

Sorrento Cheese Co.

Theresa Sternicki

John & Susan Sturock

UAW - Ford Local 900

Weed Eraser, Inc

David Wujczyk

The Wurth Family

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

Agemy & Sons Market

Bill & Shirley Cavataio

Florence Coleman

Ray & Sue Demarti

Fontanini Meats

Fraternal Order of Police,

Lodge #110

Joan Grab

Rosalie Guerra

Mary Hancock

Italia Bakery

George & Barbara Jakubik

Levon & Gloria King

Jim Lada

Deborah Lee

M-Den

Tony & Dora Mangiapane

Marty & Lesa Melhorn

Jerry & Sally Nantais

The Orchards Golf Club

Kelly & Maria Pratt

Sam & Grace Pizzo

Virginio & Anna Reale

Rony's Body Shop, Inc

Roselli Foods

Sue Shannon

Florence Sienko

Susan Stearns

Rose Tripepi

Lester & Lisa Voutsos

Mitch & Fran Wolski

Larry & Colleen Wurth

Judith Zarkis, The Country

Store, Romeo

Weight Watchers

**eXtra special thanks to:**

**Bob Mannino**

for his continued support with donations and raffle items!

## FXAM Grant for the Xtra Xtraordinary

The Fragile X Association of Michigan will award community grants to local organizations that support our Fragile X families.

- ✘ each FXAM member family may nominate one group to receive a grant
- ✘ a group may be a nonprofit or a small not-for-profit organization
- ✘ examples of organizations you may nominate:
  - ✘ a nonprofit that runs your child's summer day camp
  - ✘ a therapeutic horseback riding program
  - ✘ a Special Olympics local organization
  - ✘ any group that enhances the life of a person with special needs
  - ✘ FXAM will not accept nominations of for-profit groups/therapists or state/national organizations
- ✘ the monetary value of the grants will be the same for all grants awarded
- ✘ the amount will be \$100 – \$250 depending on the number of nominations
  
- ✘ to nominate an organization, your family needs to do two things:
  - ✘ **send an email** to Laureen at [lmajeske1@comcast.net](mailto:lmajeske1@comcast.net) **by November 1, 2011** with:
    - ✘ the name and location of the group
    - ✘ Fed Tax ID # if the group is a tax-exempt nonprofit
    - ✘ website and/or contact info if available
    - ✘ an explanation of the group
    - ✘ how they support persons with intellectual disabilities
    - ✘ how your family is involved in the group
- AND**
  - ✘ **make a 3-5 minute informal presentation** about the nominated group at a FXAM meeting on **Nov 5, Feb 4 or Mar 3** (if you live more than one hour from Royal Oak, the way you fulfill this requirement is negotiable)

This grant program will –

- ✘ help us all learn more about organizations that support those with Fragile X
- ✘ help us support these organizations
- ✘ help organizations have more awareness of FXAM after receiving our grant!

Contact Laureen Majeske, FXAM President  
at 586-978-9079 or [lmajeske1@comcast.net](mailto:lmajeske1@comcast.net)  
with any questions regarding  
the FXAM Grant for the Xtra Xtraordinary!

## The Hansen 5th Annual Fragile X Golf Outing By Kate Hansen

On September 24, 2011, the Hansen Fifth Annual Fragile X Golf Outing was held at The Falls in Kent City, Michigan.

It was a beautiful day! We had 52 golfers and raised \$5,000 for the

Fragile X Association of Michigan.

Nina Liberati and her boys came up too - first time ever. It was so fun meeting them and having them golf with us!

All in all, it was a great day and we are all looking forward to the Sixth Annual Fragile X Golf Outing next year!!

## Development and refinement of diagnostic instruments for use with adults with ASD

Researchers at the University of Michigan and Weill Cornell Medical College are conducting a research project to adapt diagnostic observation measures to be more appropriate for use with older individuals with ASD.

### We are currently recruiting participants who:

- Are between 15 and 30 years of age
- Have limited language skills (nonverbal to phrase speech)
- Do NOT have a diagnosis of an autism spectrum disorder (participant may have other diagnoses such as Down Syndrome, Fetal Alcohol Syndrome, intellectual disability, etc.)

OR

- Are between the 15 and 30 years of age
- Are verbally fluent (complex sentences) OR have limited language skills
- Have a diagnosis of an autism spectrum disorder

All participants must also have a parent/caregiver who is able to provide information about the participant's early

## FAR Conservatory

The FAR Conservatory of Therapeutic and Performing Arts is celebrating its 60th anniversary of providing arts therapy and recreation services for people with mental, physical and emotional impairments.

FXAM member Maggie Branch has participated in FAR offerings beginning around the age of five.

She's taken therapeutic dance, has performed in the Flutes, Friends and Fa-La-La event and now is involved in the FAR and 4-H co-sponsored horseback riding at Bloomfield Open Hunt.

FAR's 11th annual Flutes, Friends and Fa-La-La event will be hosted on November 16, 2011, at Detroit Country Day School. Proceeds

from the inspiring event fund FAR scholarships.

For more information on the event or on the many opportunities for FAR programming available in Birmingham and Shelby Twp., visit [farconservatory.org](http://farconservatory.org) or call **248-646-3347**.

development and is willing to participate. Individuals are **not** eligible for participation if they cannot complete the research measures due to sensory or motor impairment (e.g., blindness, deafness, severe cerebral palsy).

Participants and parents/caregivers will receive \$25 gift cards for participation (for a total of \$50 per family). In addition, written summaries of assessment are provided.

For more information, please contact:

Vanessa Hus Bal  
vhus@umich.edu  
734.273.9883

This study has approval from the University of Michigan Institutional Review Board (IRBMED HUM00045004).

**"All that we behold is full of blessings."**

*William Wordsworth*

## From the President's Desk *by Laureen Majeske*

What a busy summer we've had with FXAM events! It was a beautiful day for our FXAM Family Picnic and 5K Fun Run/Walk, annually coordinated for our families by Kim Young. Two weeks later, Nina and Frank Liberati hosted our annual golf fundraiser. The rain stopped ten minutes before tee time and the sun shined down on us to the tune of \$12,000! Then in West Michigan, FXAM member Kate Hansen and her family and friends held their annual golf fundraiser which brought in an additional \$5,000! The Liberati family traveled to West Michigan for the event and had a grand time. Mike Stockdale, Plant Chairman, Local 900, Ford Michigan Assembly Plant Body and Stamping in Wayne, Michigan, along with FXAM members Malinda and Mark Popejoy, dealt us the perfect hand by raising another \$5,800 in their Poker Run! We appreciate these efforts by

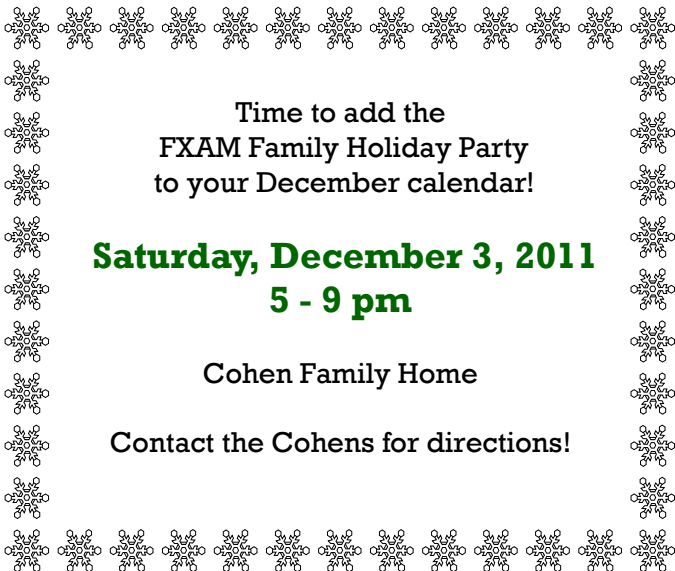
FXAM members, families and friends in support of FXAM and all of our families!

Another big thank you to Hannah Moreno, a wonderful young lady who chose FXAM as the recipient of \$924 she raised as a part of her Bat Mitzvah community project to collect money and promote awareness at local Hiller's Markets. We're grateful for your work Hannah!

FXAM also participated in the Healthy Edge Health and Wellness Fair and What About You Walk and 5K in Ann Arbor. This mighty event gave opportunity to 11 local non-profits to walk and raise money for their group, have an info/vendor booth and the chance to make a presentation about your group. While we didn't raise much money, our presentation raised awareness of fragile x and our face painter brought the crowds to our table where they

could learn about fragile x and make a purchase. Also, FXAM was featured on several radio stations for this event and an article appeared in the Washtenaw Community College newspaper.

Look for more events in the coming year starting with the Grand Opening Celebration of our new Fragile X Clinic at the University of Michigan where you will have a chance to meet our doctors and tour the offices. Mark your calendars with our annual Holiday Party on December 3, Advocacy Day in March and the next International Fragile X Conference in Miami in July. Have a favorite charity? Look for details in this issue on how you can apply for a grant to support their cause! We are not your average support group - get involved in our multifaceted FXAM LINKS group!



Time to add the  
FXAM Family Holiday Party  
to your December calendar!

**Saturday, December 3, 2011**  
**5 - 9 pm**

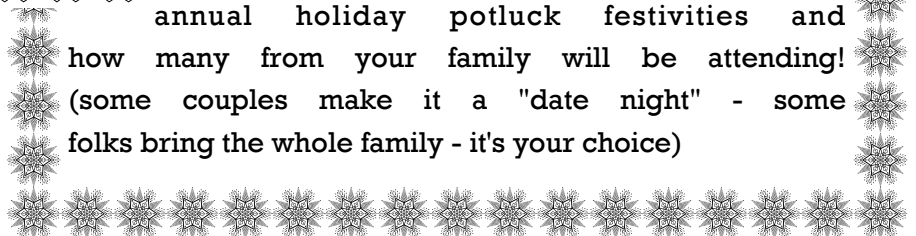
Cohen Family Home



Contact the Cohens for directions!

## Our annual potluck holiday party is set!

Please contact **Arlene**  
by **Monday, November 28**  
at **248-568-1236** or **arjsc@comcast.net**

to let her know what you'd like to add to our annual holiday potluck festivities and how many from your family will be attending! (some couples make it a "date night" - some folks bring the whole family - it's your choice)



e  tra, e  tra

Editors:

Mary Beth Langan 313-881-3340  
mblangan@hotmail.com

Sally Nantais 734-282-7910  
sallyn423@wyam.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.

[FXAM.org](http://FXAM.org)



**From the East to the West  
Golfing for Fragile X in South Rockwood  
and Kent City, Michigan  
Three Cheers for Golf!**



 **Fragile X**  
Association of Michigan

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