



# FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XI, Issue 4, October 2015

## Mark Your Calendar

## Three Cheers for...

### Support Meetings

First Saturday of the Month

#### When:

**November 7, 2015**

**February 6, 2016**

(no meetings in December & January)

Free Childcare in November. See page 4.

#### 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:

#### December 5, 2015

**FXAM Holiday Party**  
See page 4.

#### March 2016

**Advocacy Day**  
More details in our January newsletter  
Washington, D.C.

#### July 20-24, 2016

**15th International Fragile X Conference**  
San Antonio, Texas

**Fragile X Association of Michigan**

**FXAM.org**

**Contact Information:**

**313-381-2834**

**southeastMI@fragilex.org**



### International Awareness

See page 3.

### FXAM

Creative Arts Studio Event!



### The Gelfands

participating in the Walk 4 Friendship event for The Friendship Circle!



### Dr. Braden in MI

See page 3.



### Best Buddies

Kyle & Grandpa Laske



**Maggie** Attending the Wish Upon a Teen Prom. See page 3.

## Sixteenth Annual FXAM Golf Outing

The 16th Annual Fragile X Association of Michigan Golf Outing on September was once again a huge success! The **110** golfers teed off at approximately 1 p.m. and everyone had a great time during the 4-person scramble. Afterwards, **135** people enjoyed steaks, potatoes, mostaccioli and more under the tent.

The Fragile X Association of Michigan continues to be very grateful to **Nina and Frank Liberati** as organizers of this event each year. The 16th Annual Golf Outing raised approximately **\$18,500** for the Fragile X cause. Way to go Nina and Frank!

We would like to thank all those who came out to golf, sponsored holes, made donations and all those who helped in setting up, working the par-3 closest-to-the-pin contests and clean up. We couldn't have done it without you!

Our sincere gratitude goes to the following businesses, organizations and individuals for their generous donations:

### The Mickelson (\$1,300+)

Steven Lebowksi  
Bob & Evelyn Mannino  
John & Nancy Warneck

### The Nicklaus (\$1,000+)

Adam Holdings, LLC  
Kenwal Steel Corporation

### The Palmer (\$500+)

Mike & Stella Banich  
Commerce Holdings, LLC  
Anthony Iaquinto  
Die Hard Lambert  
Gary & Donna Lebowski  
Bob & Evelyn Mannino  
Watson Engineering  
Joe Wisne  
David Wujczyk

### The Watson (\$250+)

Architectural Door & Millwork  
C. Hawker & Associates  
Escalon Premier Brand  
Tomatoes  
Mr. Joe's Sports Bar  
Koch Foods  
Mark Kontry, PC  
Martin Seward  
Ok Foods  
Sorrento Cheese Company  
Theresa Sternicki

### The Player (\$150+)

Advantage/Waypoint  
Arnaldo's Banquet Center  
Florence Coleman  
(In Honor of Richard)  
Family Dentistry, PC  
Fontanini Meats  
Green Lantern Pizzeria LLC  
William & Kim Holdsworth  
Raymond James  
Kiwanis Club of Allen Park  
Kelly Koson  
Lakeshore Utility  
Langan-Coutilish Family  
Gary & Donna Lebowski  
Liberati's Italian Deli & Bakery  
Liberati & Sons Construction  
Mama Rose & Papa Liberati  
Lincoln Park Community Credit  
Union  
Mama Rosa's Pizzeria  
McInerney's Chrysler Dodge  
Jeep  
The Orchards Golf Club  
Pia's Restaurant  
Richard Plawecki  
Pomponio Construction  
Rivers Edge Financial  
Rony's Body Shop, Inc.  
Roselli Foods  
Charlie & Inez Roy  
Sartori Company  
Silverton Skin Institute  
Sorrento Cheese Co  
Theresa Sternicki  
Telegraph Chrysler, Dodge,  
Jeep, Ram  
Kenneth Vance  
James & Cindy Vickey

David Wujczyk  
The Wurth Family

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

Anoir Agency  
Anthony Aratari  
Bob & Pat Asmussen  
Jim & Julie Bademian  
Cathy Bartolotta  
Daniel & Beverly Buckley  
The Cohen Family  
Florence Coleman  
Nick Coleman  
Rick Coleman  
JoAnn Forde  
Joan Grab  
Phil Groh  
Rosalie Guerra  
Mr & Mrs. Hancock  
Jeffrey Hollander  
George & Barbara Jakubik  
Levon & Gloria King  
Kelly Koson  
Ray Lalli  
Law Offices of Miller &  
Miller, PC  
Amber Lebowski  
Deborah Lee  
Olivia Liberati  
Tullio Liberati  
Tullio Liberati, Jr  
Tullio Liberati III  
Bob Mannino  
Stella Marzano  
Sally Nantais  
Sam & Grace Pizzo  
Natasha Pomponio  
Virginio & Anna Reale  
Marlene Sienko  
Bryan Sienko  
Rose Triepi  
Dr. & Mrs. Lester Voutsos  
Weight Watchers  
Greg & Felicia Wurth

## Three Cheers for International Awareness!

The Simpsons of Cadillac are working on international Fragile X awareness! Last year, they hosted Laura from Spain; this year Yuxuan aka Yoyo, from China, has joined their family of 6. The Simpsons are learning about other cultures and their exchange students are learning to live in a family affected by Fragile X. Their family includes parents Candice and John, Bobby (Candice's brother), James, Brenton, Keagan and his service dog Captain K-9. Bobby, Keagan, and Brenton are affected by Fragile X while Candice is a carrier. Brenton and Keagan also have varying forms of Autism. Cheers for awareness, every minute of every day!

## FXAM's X-Pert Advice A Day in the Life of Fragile X

We were thrilled to have Dr. Marcia Braden at our October 10, 2015 conference in Royal Oak. Her advice is sought by the international Fragile X community and she was the headliner at our local conference. There was a hint of an international conference with six people crossing the border from Canada to join us. We had 45 attendees from Kalamazoo, Lansing, Bay City, all over metro Detroit and nearly as far east as Toronto, Ontario. Visit [marciabraden.com](http://marciabraden.com) for information on her work and products. Launching very soon: her \$2.99 Logo Reading app for iPad and iPhone.

## Through the Maze - Featured website



Maggie Branch attended the Wish Upon a Teen Prom in June at the St. Regis Hotel downtown. The kids all had their hair and make-up done, had dinner and a DJ, a photo booth, and got some great gift bags that included the knit "love your melon" hats that are being made by a company for the critically ill kids who lose their hair from various cancer treatments.

Wish Upon a Teen has expanded some of their programs to kids on the spectrum (with no behavioral issues - some events got a little out of hand and they don't have therapists on staff), so Maggie and a few kids are able to participate in their cooking classes and various other events/activities.

Wish Upon a Teen is a 501(c)(3) organization dedicated to providing resources, time and opportunities to teenagers with severe life-limiting medical conditions and learning disabilities. Through creative, social, and educational opportunities, our goal is to normalize their environment and rebuild their self-esteem as they transition to adulthood.

## What's going on ...

### Free Childcare at the meeting on November 7!

6 - 9 p.m.

Free childcare available

6 p.m. Business meeting

7 p.m. Support meeting

RSVP by November 2 to [mblangan@hotmail.com](mailto:mblangan@hotmail.com) with your children's names and ages.

We'll have pizza and salad in the childcare room and for the adults at the meeting.

Please bring something fun to share (game, toy, etc).

Hope to see your whole family in November!

### FXAM Holiday Party Our Annual Potluck Gathering

**Saturday, December 5, 2015 at 5 pm**

We will gather in Thanksgiving of our FXAM Family at our annual Holiday Potluck.

Cohen Family Home  
West Bloomfield, MI

Please RSVP by December 1 and share what you'll be adding to the gathering by contacting Arlene at [arjsci@gmail.com](mailto:arjsci@gmail.com)

If your email has changed, please update it with [mblangan@hotmail.com](mailto:mblangan@hotmail.com) so you can receive email reminders about events/meetings - thank you!

### Time to Plan: The 15th International Fragile X Conference will be July 20-24, 2016

The biennial conference, sponsored by the National Fragile X Foundation, will be held in San Antonio, Texas, at the Marriott Rivercenter. The conference is a great opportunity to network with not only families dealing with fragile X but also the experts in the areas of fragile X disorders. Keep current with conference details at:

[fragilex.org/community/international-fragile-x-conference/](http://fragilex.org/community/international-fragile-x-conference/)

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



Greetings! Autumn is upon us and we are looking forward to the beauty of the Fall season and the sights and sounds of the upcoming holidays. This season began with our Annual Golf Fundraiser where we raised over \$18,500! The friendship, food and fun eclipsed the fact that many of us only lift our borrowed golf clubs for this one day of the year, while our better golfers were able to enjoy perfect golf weather as well. While it was a little chilly, our FXAM hoodies were the perfect accessory in their goodie bags.

We also just welcomed Dr.

Marcia Braden to Michigan for a one day conference at Beaumont Hospital, Royal Oak. Looking at a day in the life of a fragile x child we looked at behaviors from early childhood through adult, and from home to school to community to vocational. We always appreciate the insight that Dr. Braden gives us about our children and family members. Linda Netzel, OTR and I also did a presentation on the similarities and differences between fragile x and autism to start out the day. At these conferences, I am always reminded of how much our children go through each and every day and I always run home

to give my kids the biggest hug ever; they are my heroes.

At our November Business Meeting we will be working on our Action Plan for 2016. Please come and share your ideas for the coming year or email me things you would like to see happen in the future. We are always looking for new ideas to serve you.

Thank you to everyone who has come out to support our FXAM events!

Laureen

**Greetings from the University of Michigan Fragile X Clinic!**

*By Kailey Owens, Clinic Coordinator*

Look for an update on the University of Michigan Fragile X Clinic in our January 2016 newsletter.

Until then, if you are interested in a family member affected by a Fragile X-associated disorder seeing a clinician, call Kailey Owens at 734-615-3591.

As a reminder, in addition to appointments in Ann Arbor (A2), we also hold clinics in Marquette (MARQ) and Traverse City (TC).

**U of M Fragile X Clinic Schedule**

October 15 and 29 (A2)	December 10 and 17 (A2)
November 5 and 19 (A2)	December 10-11 (MARQ)
November 5-6 (TC)	

**Boo! Are you ready for Halloween?**

Halloween can be a little challenging for individuals with fragile X. Check out the resources below to make your Halloween successful.

[fragilex.org/treatment-intervention/daily-living-strategies/halloween-season/](http://fragilex.org/treatment-intervention/daily-living-strategies/halloween-season/)

Social Stories:

[abilitypath.org/love-laugh--live/family-fun/halloween-social.pdf](http://abilitypath.org/love-laugh--live/family-fun/halloween-social.pdf)

[iidc.indiana.edu/styles/iidc/defiles/IRCA/Halloween%20Social%20Story.pdf](http://iidc.indiana.edu/styles/iidc/defiles/IRCA/Halloween%20Social%20Story.pdf)

eXtra, eXtra

Editors:

Mary Beth Langan 313-881-3340

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

Sally Nantais 734-282-7910

[sallyn423@wyan.org](mailto: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.

**Contact Information:**

**313-381-2834**

[southeastMI@fragilex.org](mailto:southeastMI@fragilex.org)

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



**Thank You  
to all who  
supported our**



**16th Annual  
Golf Outing**



PO Box 1414

Troy, MI 48099-1414