

FRAGILE X ASSOCIATION OF MICHIGAN

Mark Your Calendar

Three Cheers for...

eXtra, eXtra

Volume XI, Issue 4, October 2015

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.





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



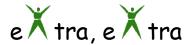
Dr. Braden in MISee page 3.



Best BuddiesKyle &Grandpa Laske



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



Sixteenth Annual FXAM Golf Outing

Architectural Door & Millwork

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 Lebowski 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+)

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 Mama Rosa's Pizzeria McInerney's Chrysler Dodge 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

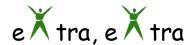
Anoir Agemy

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

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 Rav 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 Tripepi 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 for information on her work and products. Launching very soon: her \$2.99 Logo Reading app for iPad and iPhone.

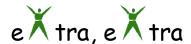
Through the Maze - Featured website



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 available6 p.m. Business meeting7 p.m. Support meeting

RSVP by November 2 to 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

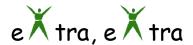
Arlene at arjscl@gmail.com

If your email has changed, please update it with 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/



From the President's Desk by Laureen Majeske

Autumn is upon us Greetings! 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! 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 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. conferences. Ι always am 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)	

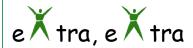
Boo! Are you ready for Halloween?

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/

Social Stories:

abilitypath.org/love-laugh--live/family-fun/halloween-social.pdf iidc.indiana.edu/styles/iidc/defiles/IRCA/Halloween%20Social%20Story.pdf



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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.

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FXAM.org



Thank You
to all who
supported our



16th Annual Golf Outing





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