

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

November 2, 2019
February 1, 2020

(no meetings in December & January)

Free Child/Adult Care 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:

November 2019

FXAM Moms:
Let's Do Brunch!
See page 4.

December 14, 2019

FXAM Holiday Party
See page 4.

February 24-25, 2020

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

Fragile X Association
of Michigan
FXAM.org

Contact Information:
313-689-3340

Three Cheers for...

Allison Bracci & the Detroit Dip Co. for helping FXAM raise \$663 in the month of July! AND to all FXAM members & friends who purchased Detroit Dip Co. products!



Play Dates for Parents - Fun was had by all at our summer play date at The Hub.

The
Detroit
Dip Company



Cade Lerchenfeld at his Horse Show at Banbury Cross TEC.



Creative Arts Studio Playdate



Kevin McLean has a new preferred method of transportation. He has developed agoraphobia when it comes to traveling by car or truck and now goes to many appointments by bike with his mom. Kudos to mom for making the trips by bike which can be up to eight miles long (round trip).



Maggie Branch - When a fellow student had a seizure on the bus, the bus driver asked Maggie to call 911. She did, and gave them an approximate location using main crossroads.

Twentieth Annual Golf Outing

The 20th Annual Fragile X Association of Michigan (FXAM) Golf Outing was on a sunny September 7th this year. 127 golfers teed off at approximately 2:00 p.m. and everyone had a great time during the four-person scramble. Afterwards 155 people enjoyed steaks, potatoes, mostaccioli and more under the tent.

FXAM continues to be very grateful to **Nina and Frank Liberati and Laureen Majeske** as organizers of this event each year. A BIG thank you to **Bob Mannino** and **Steve Lebowski** for being the driving force in getting donations. The 20th Annual Golf Outing raised just over **\$24,890** for the Fragile X cause. Way to go Nina, Frank, Laureen, Bob and Steve!

We would like to thank all those who came out to golf, sponsored holes, made donations and all those who volunteered. 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 Mannino

The Palmer (\$500+)

Mike & Stella Banich
First Independence Bank
Anthony Iaquinto
Jem Industries
Julie & Bruce Simon
Kenwal Steel Corporation
Kiwanis Club of Allen Park
Watson Engineering

The Watson (\$250+)

Castella Products
Escalon Premier Brand
Tomatoes
Robert J. Finkel
C. Hawker & Associates
Mr. Joe's Sports Bar
Lakeshore Utility
Gary & Donna Lebowski
Roak Brewing Company
Roselli Foods
Martin Seward

The Player (\$150+)

Arnaldo's Banquet Center
Epicurean Sales & Marketing
Fairway Packing Company
Family Dentistry, PC
Father Saylor K of C #3774
Fontanini Meats
Green Lantern Pizzeria LLC
Mary Ann Hayes
Evelyn Kosch-Mannino
Richard Lambert
Michael Lebowski
Sam Lebowski
Liberati & Sons Construction
Austin, Natalie & Genevieve
Nantais
Pia's Restaurant
Pomponio Construction
Mr. & Mrs. Michael Recchia
Rony's Body Shop
Russ, Danielle & Giovanni
Rodriguez
Julie Rosinski
Sartori Cheese
Sue Shannon
Sorrento Cheese
Turri's Italian Foods
Frank Urban
James & Cindy Vickey
Waypoint
Greg & Felicia Wurth

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

Anoir Agemy
Bob Asmussen
Rachel Bailey
Daniel & Beverly Buckley
Ian Campbell
Florence Coleman
Rick Coleman
Steven Fellows, Attorney at Law
Joann Forde
Bob & Joann Forde
Kathy Forde
Trish Forde
Joan Grab
Chris Grybel
George & Barbara Jakubik
Deborah Lee
Caleigh LaForest
Tony & Maria Lalli
Kate Liberati
Tullio Liberati, Jr.
Peggy Majeske
Tony & Dora Mangiapane
Sally Nantais
The Orchards Golf Club
Kailey Owens
Grace Pizzo
Malinda Popejoy
Ed & Marlene Sienko
Sulie Tyler
Dr. & Mrs. Lester Voutsos
Bob & Liz Wallace
Weight Watchers
Mike Weiss
West Branch Country Club
Wesburn Golf & Country Club

"You cannot do a kindness too soon because you never know how soon it will be too late."

~ Ralph Waldo Emerson

Research

Participate in Fragile X Premutation Research at Purdue University!

Brain and Behavior Study

Dan Foti, Ph.D. & Bridgette Kelleher, Ph.D.

Individuals with Fragile X premutation (FXpm) are at an increased risk for depression, other psychiatric conditions, and developing Fragile X Tremor/Ataxia Syndrome (FXTAS). We are interested in exploring the relationship between this risk and brain activity.

Who can take part in this study?

We are currently recruiting females between 18-60 who carry the FMR1 premutation.

Resources available to families!

We have trained, friendly staff that are available to play and spend time with any accompanying children or young adults. We provide a variety of community resources great for family fun and entertainment. Participants will be compensated for their time, \$20 per hour. Lodging will be provided; Travel costs may be reimbursed for those outside of Tippecanoe County.

What will participation involve?

Participation involves four types of data collection:

- (1) Web-based questionnaires
- (2) In-person assessments that involve responding quickly to shapes and viewing emotional stimuli
- (3) Gathering a variety of biological measurements such as brain activity (EEG and/or fMRI), heart rate activity, and a blood draw
- (4) Surveys about your feelings and experiences

Participants have the option to opt out or withdraw from any component of the study at any time.

How will this project help the Fragile X community?

We hope our data will impact the broader community of individuals with Fragile X premutation and depression by improving our understanding of brain mechanisms and treatment needs.

How can I get more information?

To learn more, please visit our website at sites.google.com/site/pacerlab/, send us an e-mail at babs@purdue.edu or give us a call at 765-496-0377. We look forward to hearing from you!

Research Study on Language and Brain Imaging

The Waisman Center at the University of Wisconsin-Madison

Eligibility: Males between 9 and 18 years of age and speaking in at least 2-3 word phrases.

Study activities include completing standardized tests, a conversation language sample, as well as an autism diagnostic evaluation. Parents will complete an interview about their son's behaviors and communication abilities. Participants will also undergo an MRI scan and we will ask parents to help make your son comfortable in the MRI scanner during the scan.

Families will receive \$150 for their participation and all travel costs (flights, mileage, and hotel) to the Waisman Center are covered.

For more information or to see if your son is eligible, please contact the study coordinator, Susen Schroeder, at sschroeder@waisman.wisc.edu or 608-263-5145.

Research (cont.)

Gait, Balance and Cognition Study, Rush University, Chicago Illinois

Male Carriers, between the ages of 40-90, without FXTAS

You may be able to participate in this study if:

1. You are able to walk for at least 2 minutes
2. You are able to stand unassisted for at least 30 seconds

Visit fxam.org/research.html to learn more and keep up with other studies actively recruiting.

What's going on ...

Free Child/Adult Care at the meeting on November 2!

6 - 9 p.m.

Free child/adult care available

6 p.m. Business meeting

7 p.m. Support meeting

Unfortunately, no infants; must be walking.

If you are bringing **children/adults requiring care**, RSVP by **October 29** to mblangan@hotmail.com or on our Facebook group with names and ages.

We'll have pizza and salad for all family members who attend.

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

Hope to see your whole family in November!

FXAM Moms: Let's Do Brunch!

November 2019

Let's get together for some Mom-only time!

We'll choose on our FXAM Facebook group whether this will be November 9 or November 16.

Email mblangan@hotmail.com if you are not on our Facebook group.

Please note: This is not a free FXAM event. Each FXAM Mom will be paying for her own food/drinks.

Holiday Party - Our Annual Potluck Gathering

Saturday, December 14, 2019 at 5 p.m.

Let's celebrate and look ahead to 2020 with our FXAM Family at the home of Andrew, Ted and Mary Beth

Please watch the FXAM Facebook page for a link to RSVP and say what you'll be adding to the gathering. If you are not on Facebook, feel free to contact Mary Beth at mblangan@hotmail.com or 313-689-3340.

From the President's Desk *by Heather Van Dam*

As we enter my favorite time of year - FALL - we as a family are on a new chapter of our Fragile X journey. When we were first diagnosed, I was very resistant to having our son and daughter on medication. Over the years, it became clear that I needed to let go of my social hangup of having medicated kids and look at it from their perspective. If our son and daughter suffer from stress, anxiety, and more, as their parent I need to figure out a way to help reduce that. In our case, one solution was medication. In my mind, if we could reduce their anxiety, our kids could be more successful in school and therefore reduce the compound stress of the social stigma of being different. I lost track of the number of medications we tried for Mason over the years. Some of them were Adderall, Ritalin, Zoloft, Abilify, Vyvanse, Focalin, Concerta, Effexor, Prozac and Metformin. We have struggled with their medications for many years, as I'm sure also happens in the lives of many of you. It seems the medications quit working and we

have to up the dosage or change to something else. During a visit to the Fragile X clinic at U of M, Dr. Felt asked if we had tried CBD oil for either of the kids. She suggested it might be a good fit. We mulled it over for a few weeks and did a lot of research. We wanted to be sure there was no THC in the CBD oil. The thought of taking him off all meds and starting over was daunting to say the least. This summer, we decided to make the leap and stop all of Mason's medications and put him on CBD oil. We put drops in his food every morning. It seemed to work very well. When the drops ran out, we decided to switch to a gummy. We felt the dosage would be more accurate and easier to give. Mason has done really well on the CBD oil. We have seen improvements in his speech and focus, along with reduced anxiety which has resulted in our ability to take him more places. Some examples from this summer: Mason and my husband Derek went kayaking on a lake. Mason had a successful four-hour wait in

the ER after Derek ruptured the tendon in his arm. He was even able to endure a three-hour wait at the Secretary of State office (how many of us can say that about ourselves?!). We've also seen his personality blossom. He started looking at books again, singing songs, spending less time in his room, going to Alison's riding lessons, initiating getting a shower, requesting a nail trim, asking to wash the dishes, loading the dishwasher and getting his own water. He is more engaged in the world around him. Although CBD is no miracle cure, for us it has been a better fit than any of the medications ever were. I wanted to write this to say we tried it and this is how it worked for us. I know for some this may be controversial, but remember this contains no THC (the psychoactive part of cannabis). As with any treatment, it's important to do research and ask questions. Remember, we all have to do what is right for our situation. We're so happy that this helped our family!

University of Michigan Fragile X Clinic

Great news for the Fragile X Lab at the University of Michigan!

Last year, Lauren Majeske, FXAM Board Member/Past President, and Dr. Peter Todd, U-M Fragile X Clinic Co-Director, wrote a grant application and were awarded \$30,000 to be used for Dr. Todd's research. Lauren and Dr. Todd reapplied for the same grant for 2019 with updated information from the past year's research. Not only was the grant awarded, but the 2019 research grant is for \$50,000!

Excellent work Lauren and Dr. Todd!

Visit fragile-x-clinic.med.umich.edu/home for more info on our Michigan Fragile X Clinic.

Upcoming Fragile X Clinic Dates: November 2, 2019

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**Thank You
to all who
supported our
20th Annual
Golf Outing!**



 **Fragile X**
Association of Michigan

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