

## Mark Your Calendar

### Support Meetings

First Saturday  
of the Month

**When:**

**November 3, 2018**  
**February 2, 2019**

(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 10, 2018**

FXAM Dads Night Out  
See page 4.

**November 11, 2018**

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

**November 18, 2018**

Annual Board Meeting  
11 a.m.- 2 p.m.

**December 1, 2018**

FXAM Holiday Party  
See page 4.

**February 25-26, 2019**

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

Fragile X Association  
of Michigan

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

Contact Information:

313-881-3340

## Three Cheers for...



**Kier** - First Day of  
Senior Year!



**Kevin** - What happens  
when there are no  
more first days.



**Cade Lerchenfeld** -  
First Day of Pre-K!



**Mason Van Dam** - First  
Day of 7th grade!



**Cyplik kids** - Dillyn  
preschool, Ben 2nd  
grade, Gabe 4th grade



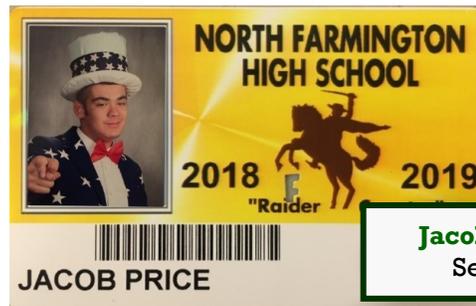
**Allison Van Dam** -  
First Day of Senior Year!



**As Lexi Weber noted** -  
Some of our pictures  
weren't successful!



**Logan Durham** -  
Age 9!



**Jacob** - Great ID!  
Senior Year!

**The Best Club You Never Wanted to Join!**

Check out our video at:

[youtube.com/watch?v=ORVtoR5yTqc&feature=youtu.be](https://youtube.com/watch?v=ORVtoR5yTqc&feature=youtu.be)

## Nineteenth Annual Golf Outing

The 19th Annual Fragile X Association of Michigan (FXAM) Golf Outing on September 8th was once again a huge success! The **128** golfers teed off at approximately 1:00 p.m. and everyone had a great time during the four-person scramble. Afterwards **159** people enjoyed steaks, potatoes, mostaccioli and more under the tent.

FXAM continues to be very grateful to **Nina and Frank Liberati and Lauren 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 19th Annual Golf Outing raised just over **\$28,000** for the Fragile X cause. Way to go Nina, Frank, Lauren 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  
Christopher M. Wouters Family Foundation

### The Palmer (\$500+ )

Mike & Stella Banich  
Jem Industries  
Anthony Iaquinto  
Martin Seward  
Julie & Bruce Simon  
Theresa Sternicki  
Watson Engineering

### The Watson (\$250+ )

Castella Products

Escalon Premier Brand  
Tomatoes  
Robert J. Finkel  
C. Hawker & Associates  
Gary & Donna Lebowski  
Charles Mascari  
Dave & Linda Mason  
Mr. Joe's Sports Bar  
O.K. Foods, Inc.  
Roselli Foods  
TNT Trailer Sales  
WarrenMott Class of 1983  
*(in memory of Bobby Beahn)*

### The Player (\$150+ )

Arnaldo's Banquet Center  
Epicurean Sales  
Fairway Packing Co.  
Family Dentistry, PC  
Father Saylor K of C #3774  
Fontanini Meats  
Green Lantern Pizzeria LLC  
The Hansen Family  
Mary Ann Hayes  
Kiwanis Club of Allen Park  
Mark Kontry, PC  
Lake Shore Utility  
Liberati & Sons Construction  
Litehouse Dressings  
Evelyn Mannino  
McInerney's Chrysler Dodge  
Jeep  
Mercedes-Benz of St. Clair  
Shores  
Milkins Jewelers  
Austin, Natalie & Genevieve  
Nantais  
Pia's Restaurant  
Pomponio Construction  
Malinda Popejoy  
Preferred Brands  
The Orchards Golf Club  
Russ & Danielle Rodriguez  
Julie Rosinski  
Sartori Cheese Company  
Sue Shannon  
Silverton Skin Institute  
Southfield Chrysler  
Turri's Italian Foods  
James & Cindy Vickey  
Greg & Felicia Wurth

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

Advantage/Waypoint  
Anthony Aratari  
Bob Asmussen  
Mr & Mrs D. Babbage  
Jim & Julie Bademian  
Rachel Bailey  
Marie Beahn  
Daniel & Beverly Buckley  
Friends of Darrin Camilleri  
Florence Coleman  
Nick & Stephanie Coleman  
Steven Fellows  
Flowers on the Avenue  
Karen Fodor  
Bob & JoAnn Forde  
Kathy Forde  
Joan Grab  
George & Barbara Jakubik  
Connie Jones  
Kelly Koson  
Langan-Coutilish Family  
Sam Lebowski  
Deborah Lee  
Caleigh LaForest  
Kate Liberati  
Tullio & Connie Liberati, Jr  
Peggy Majeske  
Tony & Dora Mangiapane  
Stella Marzano  
Sheldon & Jean Miller  
Sally Nantais  
Kailey Owens  
Grace Pizzo  
Rony's Body Shop, Inc.  
Dr & Mrs Lester Voutsos  
Bob & Liz Wallace  
Weight Watchers  
Mike Weiss  
Wesburn Golf & Country Club  
Karen Wiley  
Hank & Debbie Willard  
Greg & Felicia Wurth

"As we work to create light for others,  
we naturally light our own way."  
~ Mary Anne Radmacher

## History of the Fragile X Association of Michigan

*(look at all we've accomplished!)*

The Fragile X Association of Michigan (FXAM) was formed in 1987 by parents Mary Ann and Roland Fischer. FXAM was started by volunteers and remains a volunteer-led group. We were granted our 501(c)3 nonprofit status in 2004.

### Support Meetings:

- ◆ The first support meeting was held in 1987 at the Fischer Home with Mary Ann, Roland and one other parent in attendance; meetings have been held at Beaumont Hospital-Royal Oak since 1991
- ◆ Meetings began having a virtual option in January 2018
- ◆ Free child/adult care provided at two support meetings per year since 2014; we have seven meetings per year
- ◆ Guest Speakers are brought in from metro Detroit as well as Chapel Hill, NC and Chicago, IL
- ◆ Business meetings are held by the board of directors prior to support meetings and also additional times.

**Local Conferences:** For many families, traveling to the International Fragile X conference is not an easy or affordable option. Occasionally we bring the experts, and sometimes researchers, to Michigan. FXAM Conferences have been held for families and professionals in 1990, 1994, 1999, 2003, 2005, 2007 and 2015.

**Play Dates and Family Fun Activities:** We've hosted over ten formal Play Dates and numerous Family Fun Activities including Creative Arts Studio, Teen/Young Adult event, FXAM Basketball Party at Eastern Michigan University and a Family Fun Night at the Gym to name just a few. We have held annual FXAM Holiday Parties and Family Picnics since 1988.

**Moms' Lunches** (*organized by FXAM, not paid by FXAM*): FXAM Moms have been very busy. There have been over 11 formal lunches; in 2018, we took the lunch venue to Lansing to include some of our mid-state families.

**Dads' Nights Out** (*organized by FXAM, not paid by FXAM*): The Dads have not been as busy. November 2018 will be the second one but it's an exciting night of Axe Throwing! Word on the street is a few Moms are jealous and a few Moms are a little anxious questioning if a venue with axes mixed with alcohol is safe.

**Newsletters:** The Fischers printed and mailed many newsletters from 1988-2002. The current format began in January 2005. Mary Beth Langan and Sally Nantais co-edit the newsletter which is mailed quarterly to all FXAM members with copies provided for the Fragile X Clinic at the University of Michigan. 56 newsletters have gone to press since 2005; all available on our website with some great resources for our families.

**Website:** Our website, FXAM.org, was created by Mike Makris and went live in July 2009. The website has been maintained by volunteers from our group: Mike Makris, The Price Family and, for many years, Sally Nantais.

### Fundraisers:

- ◆ 19 Annual FXAM Golf Outings, raising thousands of dollars. The golf outing is organized yearly by Nina and Frank Liberati, and Laureen Majeske. The golf outing is successful thanks to our numerous volunteers and supporters. In October 2005, we first recognized our Golf Sponsors: we had two \$250 sponsors and thirty-three \$150 sponsors. Many of those sponsors are still active today.
- ◆ Other fundraisers: 7 Hansen Family Golf Outings in West Michigan, 5K Fun Run and Walk held multiple times, Dine Out for Fragile X, Poker Runs, Bowling Fundraisers, Comedy for a Cause and so many more! Our most interesting fundraisers may have been the years the Price Family sold pumpkins for Fragile X.

### Scholarships:

- ◆ \$62,705 in scholarships awarded since 2004 to FXAM families to help them attend the International Fragile X Conference (held throughout the U.S. every two years).
- ◆ \$2,750 in scholarships awarded since 2011 to families attending Advocacy Day (annual event advocating in Washington, D.C.).
- ◆ \$7,065 in scholarships awarded to local teachers/professionals to attend the 2010 International Fragile X Conference in Dearborn (FXAM was the local host of the conference).

### Fragile X Clinic at the University of Michigan:

- ◆ \$17,150 donated by FXAM to help support the clinic since it's grand opening in June 2012.
- ◆ \$35,000 research grant from the Toni Wisne Sabina Foundation in 2018 with FXAM's assistance.

### Support of the National Fragile X Foundation:

- ◆ \$56,000+ donated by FXAM to NFXF to support Fragile X awareness, research, advocacy and family support.

October 15, 2018

## What's going on ...

### Free Child/Adult Care at the meeting on November 3!

6 - 9 p.m.

Free child/adult care available

6 p.m. Business meeting

7 p.m. Support meeting

If you are bringing **children/adults requiring care, RSVP by October 28** to [mblangan@hotmail.com](mailto:mblangan@hotmail.com) with names and ages. Unfortunately, no infants; must be walking.

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 Dads Night Out!

**Saturday, November 10, 2018 at 5 p.m.**

**The Hub Stadium**

2550 Innovation Dr

Auburn Hills, MI 48326

[thehubstadium.com](http://thehubstadium.com)

Dads, need to de-stress with some axe throwing, food and drink?

Email [mblangan@hotmail.com](mailto:mblangan@hotmail.com) or get in on the FB conversation which will start soon.

*Please note: This is not a free FXAM event. Each FXAM Dad will be paying for their own axe time/food/drinks.*

### FXAM Moms: Let's Do Brunch!

**Sunday, November 11, 2018 at 11 a.m.**

Come join us for some Mom-only time!

Email [mblangan@hotmail.com](mailto:mblangan@hotmail.com) so we so we can keep you in on our plans plus we'll discuss the plan on our FXAM Facebook page.

*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 1, 2018 at 5 p.m.**

We will gather in Thanksgiving of our FXAM Family at our annual Holiday Potluck at the home of Don and Trish Price

Please RSVP by **November 26** and share what you'll be adding to the gathering by contacting Trish at [donandtrish@gmail.com](mailto:donandtrish@gmail.com)

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

Patience. Patience. Patience. It's a virtue worth practicing. For me, it's something I'm constantly working on. In my early adult life, I was terrible at it. As the years have passed, I've learned I can use this as a superpower with my kids. I can wait out the tantrums and use my calm voice and body language to relay a message of calm and patience. This works better than anything else I've tried. At the NFXF Conference in California, I attended a session where Laureen Majeske demonstrated the sensory overload that our kids feel and how that impacts their ability to process information and follow directions. It was an impressive eye opener. It made me realize that our kids are getting a lot of information at once

and it's my job as the parent to help them to stay calm, so they can do their best. Since that time, I've been even more inclined to practice the superpower of patience. Give it a try. I highly recommend it. Remember, the more you practice the better you'll get!

FXAM is always looking for new ways to engage the public and spread awareness about the world of Fragile X. This is a very important part of our mission. When we raise awareness, we make a better community for our children and all children who face challenges. As part of our commitment to raising awareness, we took out a two-page ad in Hour magazine's special edition GIVE

magazine. We hope this will serve a dual purpose: raising awareness and bringing in some corporate donations. If you would like to share this with friends and family, please visit - [hourdetroit.com/Give-Detroit/Fragile-X-Association-of-Michigan/](http://hourdetroit.com/Give-Detroit/Fragile-X-Association-of-Michigan/)

We're also very interested in new family event ideas. Do you have a fun, family-friendly spot you like to visit? Let us know and we might plan an event there!

Thanks for your ideas!



## University of Michigan Fragile X Clinic *by Joe Jacher*

I had an absolutely amazing time at the Fragile X Conference this summer. It was a wonderful experience being able to meet more families from Michigan and the Midwest. There are so many drug trials and other research happening across the country and globally that make it a very exciting time to be in the Fragile X community.

As mentioned in previous newsletters it is my hope to be a resource and advocate to FXAM and its members. Please feel free to reach out to me with any questions about Fragile X syndrome or our clinic (even if you've never been seen at the University of Michigan).

More information on the Fragile X Registry and Database can be found online at [forwardfx.org/](http://forwardfx.org/).

*Joe Jacher, MS, CGC*

734-764-0579

[jjacher@med.umich.edu](mailto:jjacher@med.umich.edu)

*Genetic Counselor, Fragile X Clinic Coordinator*

## Upcoming Fragile X Clinic Dates

November 9, 2018

January 10, 2019

February 28, 2019

May 2, 2019



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**313-881-3340**

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**FXAM.org**



**Thank You  
to all who  
supported our  
19th Annual  
Golf Outing!**



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