

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

October 6, 2018
November 3, 2018
(No meetings in July, August & September)

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:

August 4, 2018
FXAM Family Picnic
 Van Dam Home
 White Lake
 See Page 2.

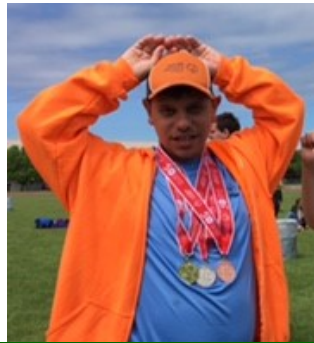
September 8, 2018
19th Annual FXAM Golf Outing
 See Pages 3 and 4.

Fragile X Association of Michigan

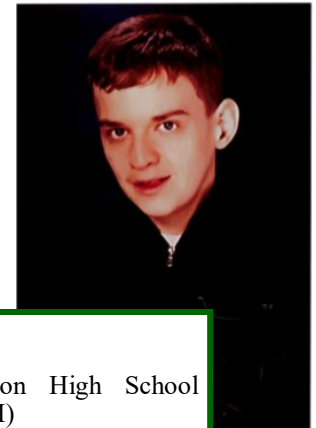
FXAM.org
313-881-3340

contact@fxam.org

Three Cheers for...



Nicholas Weber - Despite a foot injury collected some hardware (a variety of medals) in the track and field events at the Special Olympics of Michigan.



Kyle Laske - Graduate of Harrison High School (Farmington Hills, MI)



Moms from the Fragile X Association of Michigan "met in the middle of the mitten" for lunch in May.



Alison Van Dam - Job well done on making Honor Roll!



Ayden AbouElSeoud - successfully completed his 5th Grade Notables project with a presentation to families and community in February! The project started last November and included research, writing a paper, a timeline, and knowing enough about your notable to be able to answer questions as you were them for those who came to the presentation. Ayden's notable was Reverend W. Awdry who created Thomas the Train. He is pictured here presenting to our school Superintendent and then above right with his 5th grade teacher.



What's going on ...

FXAM Family Picnic

Saturday, August 4, 2018

12 - 4 p.m.

Our annual picnic will be at the Van Dam home

Heather, Derek, Alison & Mason

FXAM will provide hotdogs, drinks and a bounce house.
Families are invited to bring a side dish or dessert to share.

RSVP to Heather via text/phone to 248-343-2077 or fab4fam@comcast.net by Saturday, July 28, with the # of adults & children attending and what you'd like to add to the table!

Hope to see you at the FXAM Family Picnic!

University of Michigan Fragile X Clinic *by Joe Jacher*

Hello from the University of Michigan Fragile X Clinic!

I am excited to be attending my first International Fragile X Conference in Cincinnati! I hope to meet more Michigan families while at the conference. Please feel free to email me at jjacher@med.umich.edu.if you are interested in learning more about Michigan's Fragile X clinic

As always, if you would like to make an appointment, please contact our office at **734-764-0579**. More information on the Fragile X Registry and Database can be found online at <http://forwardfx.org/>.

Joe Jacher, MS, CGC

Genetic Counselor

Fragile X Clinic Coordinator

Our upcoming clinic schedule is listed below:

September 13, 2018

November 8, 2018

"Once you learn to appreciate the small victories there is no need for a finish line."

~ Jessica



**19TH ANNUAL GOLF OUTING
GOLF & DINNER REGISTRATION FORM**

Where: **Wesburn Golf & Country Club**
5617 S. Huron River Drive, South Rockwood, (one mile west of I-75, exit 26)

When: Saturday, September 8, 2018
12:15 p.m. registration, shotgun start at 1:15 p.m. (four-person scramble)

Cost: \$95 per person includes: open driving range before the start, hotdogs and refreshments before and during the round, golf and cart fees, dinner, participation gift, and door prizes.

**If you can't make it for golf, please come for dinner about 6:00 p.m. Dinner, refreshments, door prizes, and a participation gift included for \$50.

ALL PROCEEDS WILL GO TOWARDS RAISING AWARENESS, SUPPORTING RESEARCH AND AIDING LOCAL FAMILIES AFFECTED BY FRAGILE X

Please list members of your foursome below, along with their shirt sizes.

**If you are a single golfer or do not have a complete foursome, we will match you up.

1. _____
Name Size

2. _____
Name Size

3. _____
Name Size

4. _____
Name Size

Please mail payment/donation payable to the **Fragile X Association of Michigan** to:

Nina Liberati
9068 Quandt, Allen Park, MI 48101
313-530-4107/nliberati@yahoo.com



Fragile X

Association of Michigan



19TH ANNUAL GOLF OUTING HOLE SPONSOR & DONATION FORM

Where: Wesburn Golf and Country Club
5617 S. Huron River Drive, South Rockwood

When: Saturday, September 8, 2018
12:15 p.m. registration, shotgun start at 1:15 p.m. (four-person scramble)

ALL PROCEEDS WILL GO TOWARDS SUPPORTING RESEARCH, AND LOCAL FAMILIES AFFECTED BY FRAGILE X

.....
I/We would like to sponsor a hole. All hole sponsorships will be recognized in the event program and a sign will be posted at the tee box of your hole. (Hole sponsorships are tax-deductible.)

- _____ \$1,300+ THE NICKLAUS
- _____ \$1,000 THE PALMER
- _____ \$600 THE WATSON
- _____ \$300 THE PLAYER
- _____ \$150 THE MICKELSON

_____ I/We would like to make a tax-deductible donation, in the amount of \$_____ to help continue the fight against Fragile X. Your name/business will be displayed in the program.

_____ I/We would like to donate the following raffle item, _____, valued at _____.

Your name/business will be displayed in the program.

****List me/my family/my business in the event program as:**

Please mail payment/donation payable to the **Fragile X Association of Michigan** to:

Nina Liberati
9068 Quandt, Allen Park, MI 48101
313-530-4107/nliberati@yahoo.com

Or provide it directly to the member soliciting the donation.

The Fragile X Association of Michigan is a 501(c)(3) (fed. Tax ID# 56-2450171) charitable organization dedicated to raising awareness, supporting research, and aiding families affected by Fragile X Syndrome.

Fragile X Association of Michigan, P.O. Box 1414, Troy, MI 48099-1414

FXAM Member's Thoughts on the Conference

"I recently had the good fortune to attend the NFXF International Conference in Cincinnati, along with a strong contingent from Michigan. Besides making connections with people who feel like family, I was able to attend many amazing sessions. One that left a strong impression on me was called, "Supporting Your Daughters When They Experience Anxiety," with Jennifer Epstein. The reason it left such an impression is that she talked about the importance of practicing calming techniques when you don't need them yet. I had one of Oprah's "aha" moments. You don't wait until childbirth to learn Lamaze, you take classes ahead of time, and in a perfect world, you practice! So simple, and yet I'd never thought of it like that (well, the Lamaze thing is my own analogy, but it came out of what she said). My daughter and I have already talked about breathing, and how important a simple deep breath is when you're in the throes of anxiety. Oxygen to the rescue! Again, not that different than Lamaze, right? So right now, get your daughter and each of you put one hand on your chest, and one hand on your tummy, and take five deep breaths. Try to make the tummy hand really push out. You're both on the way to dealing with an overactive anxiety reaction that biology (not behavior) blessed you with." ~ *Sulie*

"We met some amazing people who we were able to share our stories with. We learned lots about how to manage our daughter's anxiety. We also got some tips on potty training our son; keeping Bradley on a schedule and wearing underwear so he can feel what it's like to be wet. . We also learned about some new medications to try. Overall it was an awesome conference!" ~ *Janet*

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

Happy summer! Sunshine, beach time and great books are what I hope the days are made of. This is only true for a few minutes at a time, but I'll take it. Usually it consists of a lot of the usual trying to keep up with the house work while being constantly interrupted by Mason. He is in what we are referring to as his "extra" phase. He is very needy and particular. We are consistently walking the line between amused and annoyed. He needs seven blankets on his bed. All of his movies within arm's reach at all times. An inflatable shark and large inflatable ring in his room. Fully inflated! He changes his clothes about 10 times a day and likes to wear the same shirt whenever we leave the house. I consider myself to be a go-with-the-flow person and I look at all of his quirks and try to remind myself that we are all a work in progress with our own set of quirks. For the most part, if he's happy and it's safe I'm ok with it. Even if it means doing his laundry every other day. I'm proud of the fact

that he can dress and undress himself.

In our home, summer means the kids spend extra time with Grandma & Gramps during the week. We are extremely fortunate that my parents are able to help in the summer and watch Alison and Mason three days a week. I know that for many families this is a big issue and makes it difficult to have two working parents. I'm incredibly thankful. The rest of the time will be mostly spent up north at our camper. This year, Mason is learning to paddleboard along with the rest of us. He LOVES it so far and spends most of the time yelling "COWABUNGA" and "I'M SURFING" it makes my heart happy to have him on the water with us. We will be entering new territory and sending Mason to day camp at Ohiyesa for a week. I am very nervous for him and me. Although I know this will probably be a wonderful time for him, I know we will miss him terribly.

Alison is getting ready to begin her

senior year. YIKES! I'm not sure what is more terrifying, the fact that she will be a full-fledged adult or the fact that I will be old enough to be the mother of a full-fledged adult! We will be getting senior pictures done soon and making preparations for the next phase of her life. Whatever that may be.

I can't wait to see everyone at the picnic! This year we will be shooting a video to shed light on FXAM and Fragile X-related disorders. If you don't want to be in the video, please let me know when you arrive and we will be sure to honor your request. Our home is an all-inclusive environment and judgment-free zone!! We will have a GIANT water slide, trampoline, small pool for the little ones, hot dogs and beverages. Please bring a dish to pass and a swimsuit. We have WiFi!

To all of my FX warriors- May the days be filled with hope and the nights be filled with rest.

eXtra, eXtra

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Electronic copies of our newsletter are available on our website.

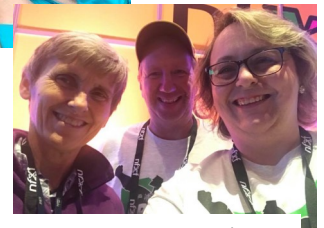
If you would like to share them with family, friends or professionals, please share our web address with them.

313-881-3340

contact@fxam.org

FXAM.org

**A glimpse of FXAM family members at the
International Fragile X Conference in Cincinnati from July 11-15, 2018:**



Join an upcoming event to hear about it. Maybe you'll want to go to the next conference in July 2020 in Orlando!

 **Fragile X**
Association of Michigan

PO Box 1414

Troy, MI 48099-1414