

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

May 5, 2018

June 2, 2018

(No meetings in July, August & September)

Free Child/Adult care in May. See page 2.

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:

May 19, 2018

FXAM Moms:

Let's Do Lunch!

See page 2.

July 11-15, 2018

16th International Fragile X Conference
Cincinnati, Ohio
See page 3.

August 2018

FXAM Family Picnic
Van Dam Home
White Lake
Watch for details!

Fragile X Association of Michigan

FXAM.org

313-881-3340

contact@fxam.org

Three Cheers for...



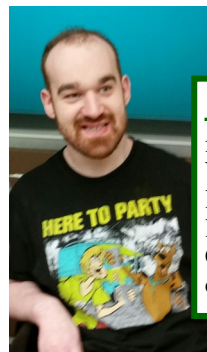
Laureen Majeske - Honored by the National Fragile X Foundation for her many years of service. Way to go Laureen; we are very proud of you!



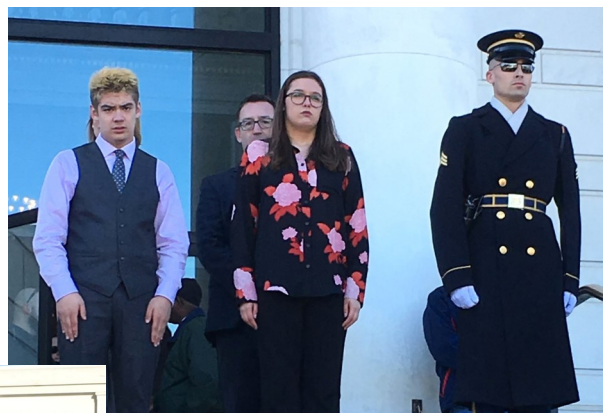
Nick Hansen - Center stage performing "Dueling Banjos" in the annual talent show at school.



Kevin McLean - Completes his All-Ways Care Services/Bridges Transition Employment Services (based in New Baltimore and Ira Township) on May 4. The next step, he will hopefully be employed as a janitor with Bridges School in Ira Township.



Austin Nantais - Participated in his first "Patient Panel" at Wayne State University. We saw a little anxiety (imagine that) but he loved talking on the microphone. Overall, a great opportunity to create awareness for future doctors.



The Price Family - In addition to annually participating in Fragile X Advocacy Day, in 2016 and 2018, the family laid wreaths at the Tomb of the Unknown Soldier in Arlington Cemetery. They are proud to honor the brave Americans who gave their lives for our freedom, including the freedom to advocate for what is important to us.



What's going on ...

Free Child/Adult care at the meeting on May 5!

6 - 9 p.m.

Free child/adult care available

6 p.m. Business meeting

7 p.m. Support meeting

Hope to see your whole family
in May!

If you are bringing
children/adults requiring care,
RSVP by **May 1** to
mblangan@hotmail.com with
names and ages.

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

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

FXAM Moms: Let's Do Lunch!

Saturday, May 19, 2018, 11:30 a.m.

BRAVO CUCINA ITALIANA LANSING

2970 Towne Centre Blvd.

Lansing, MI 48912

517-485-3779

bravoitalian.com/lansing.html

Come join us for some Mom-only time!

Email mblangan@hotmail.com so we know to expect you for lunch and
can keep you up to date with our lunch plans.

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

University of Michigan Fragile X Clinic *by Joe Jacher*

Hello from the University of Michigan Fragile X Clinic!

We have been working hard to revamp our clinic to make it as resourceful as possible for our patients and their families. I am excited to announce that Dr. Peter Todd will be staffing our Fragile X Clinics starting in July. Dr. Todd is a renowned physician and researcher of Fragile X Associated Tremor/Ataxia Syndrome and Fragile X Syndrome.

We are thrilled to have him in clinic with us in conjunction with our Pediatric Geneticists and Developmental Behavioral Pediatrician!

If you are interested in signing up for the FXCRC FORWARD Registry and Database, or would like to make an appointment for any other reason, please contact us at **734-764-0579**. More information on the Registry and Database can be found online at forwardfx.org.

Joe Jacher, MS, CGC, Genetic Counselor, Fragile X Clinic Coordinator

2018 Fragile X Clinic Dates

May 3

May 24

June 7

June 14

July 19

September 13

November 8

This is eXciting! The 16th International Fragile X Conference is in our neighboring state making it easier to attend!

If you've never attended a conference, please consider attending to connect with families, gather info from eXperts and come away with the supportive knowledge that you are not alone on this Fragile X journey.

If this isn't your first conference, you already know why you want to attend this Fragile X family reunion!

Go to fragilex.org for more information and to register for the National Fragile X Foundation's biennial conference! Please note that early bird pricing is through May 14. Don't miss the discounted registration fees! Hotel information is also at fragilex.org - reserve your room early to make sure you're at the Hyatt Regency conference headquarters at the \$149 per night conference rate.

Once again, the Fragile X Association of Michigan is happy to be granting conference scholarships to help our members afford to attend this important conference. The final amount of each scholarship will be decided after we have the final number of scholarship applicants. **To apply for the FXAM conference scholarship**, contact Heather Van Dam (heather@stylrite.com) and Sheryl Roman (romanjsr@aol.com) to let them know you are interested in the scholarship. Please mention in the email if you applying for a scholarship for one or two family members and their names. **Apply by Tuesday, May 1.** By Monday, May 7, Heather or Sheryl will contact applicants with confirmation of their scholarship amounts. If you have not registered by then, you'll have until May 14 for early bird conference registration. By July 31, you'll need to verify that you attended the conference by submitting receipts (hotel, etc) and after verification, will be paid the scholarship money by mid August.

NOTE: If you were awarded a 2018 NFXF scholarship, your FXAM scholarship may be a partial scholarship.

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

Spring is very slowly springing. The wait has been longer and more painful than usual. Each spring feels a bit like a rebirth, especially this year. I don't enjoy the cold weather and aside from going to work I try not to go out in the cold any more than is absolutely necessary. I like to spend the winter planning my summer.

For our family, this means getting prepped to take our camper up north for the summer. This has proven to be the best way for us to travel with Mason. He can take all his stuff and has his own space to retreat to if needed. In years past, we have camped at different parks across Michigan. This will be our first year as seasonal campers. We have stayed at this campground before, so we are very optimistic.

They have Wi-Fi, a beach and an ice cream shop within walking distance. Everything needed for a successful Fragile X summer!

As I'm sure you've heard, the NFXF conference is in Cincinnati, Ohio this year. This is a superb opportunity to meet families, specialists, kids, researchers, and other caregivers. The conference offers sessions that are family friendly, scientific, technical and behavioral. FXAM will be offering scholarships to help offset some of the cost for Michigan families wanting to attend. If you are interested, please email me and Sheryl Roman by May 1 - full details are above.

Over the last several months, FXAM has offered virtual meetings

to our families that are unable to attend our support meetings. If you can log in and join us, please do! We would like to continue to offer this and are looking for feedback to improve the connections with our families across the state.

By the time you read this I will have attended the Creative Arts studio event in Royal Oak. My daughter Alison loves to paint and this is one of her favorite events. If you have someplace great near you, let us know and we will consider having an event there. We are always interested in new places, ideas and events. Please watch for upcoming events on our Facebook page and in upcoming newsletters.

Let's all stay connected!

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

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**FRAGILE X ASSOCIATION
OF MICHIGAN**

The National Fragile X Foundation has done some restructuring. Some local groups have chosen to transition to being official NFXF Chapters; some (like FXAM) have transitioned to being NFXF Community Partners. This is why we have changed from the NFXF/FXAM logo back to our last FXAM logo.



Fragile X

Association of Michigan



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