

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

October 5, 2019
November 2, 2019
(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:

July 12, 2019

Parents Night Out

The Hub
 See Page 2.

July 27, 2019

FXAM Family Picnic

See Page 2.

September 7, 2019

20th Annual FXAM Golf Outing

See Pages 3 and 4.

October 19, 2019

FXAM Conference

Fragile X Association of Michigan

FXAM.org

313-881-3340

contact@fxam.org

Three Cheers for...



Keir Buikema -

School: Avondale High School
 Favorite Subject: Assemblies
 Future Plans: Will attend Avondale Skill Program.



Indigo Buikema -

School: Oakland Community College
 Earned her Associate in Applied Science in Library Technical Services
 Future Plans: Will be working on her next step this summer.



Alison Van Dam -

School: Lakeland High School
 Favorite Subject: Science
 Future Plans: Oakland Community College



The Fragile X Association of Michigan (FXAM) Board of Directors -

Back Row (L to R): Frank Liberati, Laureen Majeske, Elina Gelfand, Karl Lerchenfeld, Jodi Lerchenfeld, Nina Liberati, Mary Beth Langan, Joyce Kreger
 Front Row (L to R): Tiah Solway, Heather Van Dam, Sulie Tyler
 Missing: Cortney AbouElSeoud, Kailey Owens

What's going on ...

FXAM is the lucky organization that will receive 10% of all Detroit Dip Co. sales during the month of July! You don't have to use a coupon or mention us, we simply receive 10% of your purchases.



Visit TheDetroitDipCompany.com to shop or Look for Detroit Dip Co. and their products at:

Blake's Lavender Festival (Armada)
blakefarms.com/blakes-orchard-and-cidermill/lavender-festival/
July 12-14 from 10-5

Wyandotte Street Art Fair
wyandotte.net/arts_and_culture/street_art_fair/index.php
July 12-13 from 10-9

FXAM Parents Night Out: Let's Get Together!

Friday, July 12, 2019

7 p.m.

The Hub

thehubstadium.com

Last Fall, three awesome FXAM Dads (Aaron, Derek and Karl) threw axes there. Now we're expanding a night out there for all parents. Check out what they have!

Please note: This is not a free FXAM outing. This is arranged by FXAM but not paid by FXAM.

FXAM Family Picnic

Saturday, July 27, 2019

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 20th**, 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!

"Almost everything will work again if you unplug it for a few minutes... including you."

~Anne Lamott



20TH 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 7, 2019
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

____ I/We cannot make it for golf, but please include us for dinner. (Please fill in names and shirt sizes above and enclose \$50 per person.)



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



**20TH ANNUAL GOLF OUTING
HOLE SPONSOR & DONATION FORM**

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

When: Saturday, September 7, 2019
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 TIGER |
| ____ \$600 | THE PALMER |
| ____ \$300 | THE HOGAN |
| ____ \$150 | THE PLAYER |

____ 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:**

Make checks payable to the Fragile X Association of Michigan

Please mail payment/donation form 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

University of Michigan Fragile X Clinic *by Joe Jacher*

Hello from the University of Michigan Fragile X Clinic!

As always, if you would like to make an appointment or have any questions about clinical trials, Fragile X syndrome, or our clinic, please contact our office at 734-764-0579. More information on the Fragile X Registry and Database can be found online at forwardfx.org/.

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

Our upcoming 2019 clinic schedule is listed below:

August 1 October 3 November 2

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

Our family recently celebrated an enormous milestone. On June 2, our daughter Alison graduated from high school with a diploma. For many, this is a simple right of passage into adulthood. For a child with intellectual and developmental disabilities, this can seem like an impossible hurdle. Especially when not everyone believes your child can successfully reach such an achievement. Alison has struggled with reading and math all through school. We enrolled her in a summer reading program, worked diligently on math and reading skills daily at home, hired a tutor, and used many other tools. When Alison was in 5th grade, we were asked if we wanted to put Alison on a track to obtain a certificate of completion instead of a diploma. We were adamant that we would not agree to this and informed the school that it was entirely too early to make such a decision. Once a child is put on a track for a certificate of completion it cannot be reversed. We were not willing to make this

irreversible decision so early in Alison's academic career. We knew it would be a difficult road, but also believed in Alison and her ability to persevere. Middle school was by far the most difficult time. Every homework assignment was a battle filled with tears. Alison not only struggled academically but socially. We had what seemed like endless discussions about the difference between friends and acquaintances. We talked about bullying and how to deal with bullies and when to get an adult. The social learning curve in middle school was steep. So, when we made it to high school, it was a huge relief. She had a wonderful teacher consultant who took Alison under her wing and they developed a deep relationship. She became a safe place for Alison to go and a trusted source of guidance. She often stopped Alison in the hall to give her a hug, some candy, or just ask how she was. This made a tremendous impact on Alison and her ability to go to school even on the hard days.

In high school, Alison was enrolled in a social skills class and had classroom support that was available to all students in the class which helped Alison feel like she wasn't being singled out. During this time, Alison made friends with two great girls who accepted her as she is and encouraged her to be more social. In her senior year, she attended prom and the senior all-night party. We're so incredibly proud of Alison and her dedication to finishing. On her graduation cap she wrote "Never give up" and she certainly didn't. During her graduation party, many people congratulated me and Derek for all the hard work that our family put in to help her graduate. I must agree with them; it certainly took a village and we are so thankful for all the support and encouragement along the way. If you find that your family is struggling with some of these same issues, please reach out for support.

Our village is here to help.

Are you an Amazon shopper? Start your shopping at smile.amazon.com!

Do you know you can easily generate a donation to FXAM every time you shop? The first time, you'll need to choose to support Fragile X Association of Michigan.

After that, each time you shop at smile.amazon.com you'll see our name at the top and know you're supporting FXAM.



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Editors:

Mary Beth Langan 313-881-3340

mblangan@hotmail.com

Sally Nantais 734-282-7910

sallyn423@wyam.org

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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

Don't forget to keep up with activities, fundraising,
helpful local resources and more at FXAM.org

Fragile X
Association of Michigan

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Welcome to the **Fragile X Association of Michigan**

Fragile X
Association of Michigan

PO Box 1414

Troy, MI 48099-1414