



# FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XIII, Issue 3, July 2017

## Mark Your Calendar

### Support Meetings

First Saturday of the Month  
(No meetings in July, August & September)

When:

October 7, 2017  
November 4, 2017

### 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:

#### Happy Fragile X Awareness Month!

August 5, 2017

FXAM Family Picnic  
See page 5.

September 9, 2017

18th Annual  
FXAM Golf Outing  
See page 3.

September TBD

FXAM Moms:  
Let's Do Lunch!  
See page 5.

Fragile X Association of Michigan

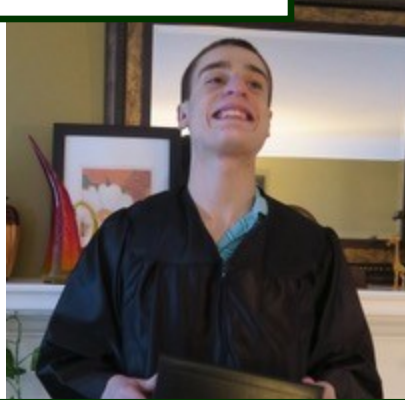
FXAM.org

313-881-3340

southeastMI@fragilex.org

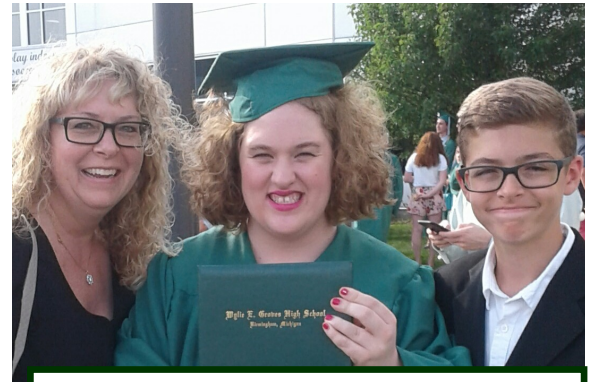
## Three Cheers for...

### Our Graduates



#### Paul Fodor

**School:** Dearborn High School  
**Favorite subject:** Art/Ceramics  
**Future plans:** Mixer Institute of Transition (MIT) program in Lincoln Park, see page 5.



#### Maggie Branch

**School:** Groves High School  
**Favorite:** US History  
**Future plans:** Seaholm Annex, adult transition program in Birmingham, see page 4.



#### Genevieve Nantais

**School:** Roosevelt High School  
**Favorite subject:** History  
**Future plans:** Neuroscience, Michigan State University, Go Green, Go White.



#### Aidan Silverton

**School:** Grand Blanc High School  
**Favorite subject:** Lunch/Track  
**Future plans:** Clemson University, see page 2.

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



Hello - It's your new president! Of the Fragile X Association of Michigan!! I am so honored to have been elected your new President. Many of you may be

wondering, who is Heather? I am a working mother that is trying to squeeze it all in, like so many of you. I have a Mustang named Sally. I love the Detroit Tigers! I like sunshine and reading books. Our family loves to camp. My life is loud, chaotic, busy, and unpredictable in a really great way. Our family motto is: Just keep swimming. My husband and I live in White Lake with our two children who have Fragile X syndrome. Our daughter Alison is

16. She will be a Junior at Lakeland High School in the fall. Our son Mason is 11 and will be attending Muir Middle school in the fall. Mason has a dual diagnosis of autism. We received our first Fragile X diagnosis in 2012. We are still very much at the beginning of our journey. I

am so tremendously grateful to be a part of this Xtra special group. The support, guidance, friendship, advice and shared experiences are truly special. I am dedicated to doing all I can to make FXAM even better. The annual FXAM Family picnic will be held at our home this year (see picnic details on page 5).



I would love to meet as many of our families as I can. This is a great opportunity to talk in a relaxed setting with many other families.

If you have an idea for an event you would like to see FXAM host or other ideas, please send me your thoughts at [fab4fam@comcast.net](mailto:fab4fam@comcast.net)

## Aidan Silverton

Aidan graduated from Grand Blanc High School in May and is headed off to college! Aidan is spending the summer working as a bus boy and greeter at Aubree's Pizzeria.

On August 18, he moves to South Carolina where he will be attending the ClemsonLIFE program at Clemson University. Aidan was one of twelve accepted out of 74 to the competitive program. Acceptance at ClemsonLIFE is not based on IQ

scores or academic achievement but rather, an applicant's desire to have a college experience, live independently with support one day and to obtain employment. ClemsonLIFE is a 2-4 year program geared towards independence and job skill training. Students live inclusively in the dorms with roommates and an ILA, Independent Living Assistant. Aidan will attend college courses, life skill courses,

volunteer his time, obtain employment and of course, run and ride horses. The entire program is supported. Proud parents Jennifer and Kimball Silverton are thrilled, but a bit anxious about the distance. They have big plans to get to know South Carolina very well!

Aidan can't wait to attend school at the home of the Football National Champions and become a Clemson Tiger!



# Let 'Em Know

FRAGILE X AWARENESS MONTH

[give.fragilex.org/team/122429](http://give.fragilex.org/team/122429)



FRAGILE X ASSOCIATION OF MICHIGAN



18TH 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 9, 2017

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 & Frank Liberati
9068 Quandt, Allen Park, MI 48101
313-381-2834/nliberati@yahoo.com

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

Hello from the University of Michigan Fragile X Clinic!

After a short hiatus, the Fragile X Clinic is once again up and running! As mentioned in previous newsletters, as part of our clinic we enroll participants into the FORWARD Registry and Database. The Registry is open to all individuals with a Fragile X premutation or full mutation and their family members. As part of the registry information, we include basic demographic information as well as interest in potential future research studies. The Database is open to individuals with a Fragile X full mutation only (there is no age limit) and includes questions about development, education, health, and behaviors. Personal

identifiers such as name, date of birth, address, etc. will never be shared without your permission.

For individuals interested in participating in the FORWARD Registry and Database: If you or your family members have not yet been evaluated by the University of Michigan Fragile X Clinic or if it has been more than six months since you were last seen in clinic, please call our office to set up an appointment to review your medical history and discuss enrollment in the study. Clinics are scheduled on two Thursday mornings per month in Ann Arbor at the C.S. Mott Children's Hospital. Additional clinics may become available on a limited basis if needed due to scheduling conflicts for patients and their

families. For anyone interested in scheduling an evaluation, our office number is 734-764-0579.

If you would like more information on the FORWARD Registry and Database please visit [fragilex.org/treatment-intervention/fragile-x-clinics/forward-registry-and-database/](http://fragilex.org/treatment-intervention/fragile-x-clinics/forward-registry-and-database/).

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.

Joe Jacher, MS, CGC  
Genetic Counselor  
Fragile X Clinic Coordinator  
734-764-0579

### 2017 Fragile X Clinic Dates

July 20	August 31
September 7	September 21
October 5	October 12
November 2	November 16
December 7	December 21

### Maggie (Mary Margaret) Branch

Maggie walked in commencement and received her Certificate of Completion. Her favorite subject was History because she had a crush on the teacher Mr. Sherman. She greeted him every morning with "good morning Handsome!" He was very sweet. In her

yearbook he wrote "everyday I feel more handsome because of you".

Maggie is still working at Simply Good on Saturday afternoons (a gourmet take out place around the corner from us that she can walk to). She has been there for a year.

They are very good to her and have dubbed her the "Chosen One" and embroidered it on her work hat! It is a gift that keeps on giving, she loves it there and it's great practice for a future job.

We have high hopes for her!

## Paul Fodor

Paul graduated with his Certificate of Completion May 25.

He was so anxious about participating in a high school graduation, that his teachers, administrators and staff allowed him to design his own personal

ceremony including a party afterwards. Everyone had a wonderful time and Paul handled being the center of attention like a champ!

Paul continues his activities with Dearborn Special Olympics and is

bravely trying soccer this summer. He's excited to begin his new school where many of his friends already attend.

## FXAM Family Picnic



Saturday, August 5, 2017  
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](mailto:fab4fam@comcast.net) by Friday, 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!

## FXAM Moms: Let's Do Lunch!

### Mid-to-Late September Saturday

Date, place and time to be determined via FB and/or email.  
After a long summer and the typical Back-to-School chaos,  
it'll be nice for Moms to gather and share some wild stories!

Email [mblangan@hotmail.com](mailto:mblangan@hotmail.com) if you have ideas to share on this.

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

"Somewhere along the line we stopped trying to fix the child that we had expected  
and started to enjoy the child that was." ~ Meg Blomfield

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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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**FXAM.org**



University of Michigan Fragile X Clinic Staff: Dr. Donna Martin (Genetics), Dr. Martha Carlson (Neurology), Dr. Jeffrey Innis (Genetics), Dr. Peter Todd (Neurology), Dr. Barbara Felt (Developmental Behavioral Pediatrics), Joe Jacher (Genetics), Dr. Jacqueline Kaufman (Physical Medicine and Rehabilitation). See page 4 for more info on Michigan's Fragile X Clinic.



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