



# FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XIV, Issue 1, January 2018

## Mark Your Calendar

### Support Meetings

First Saturday of the Month

#### When:

**February 3, 2018**

(See note on right!)

**March 3, 2018**

**April 7, 2018**

#### 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:

**March 5-6, 2018**

Advocacy Day  
Washington, D.C.

See page 5.

**March 31, 2018**

Creative Arts Studio  
Ceramic Painting  
Event

See page 5.

**Winter 2018 - TBD**

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

**July 11-15, 2018**

16th International  
Fragile X Conference  
Cincinnati, Ohio

Fragile X Association  
of Michigan

FXAM.org

313-881-3340

[southeastMI@fragilex.org](mailto:southeastMI@fragilex.org)

## Three Cheers for...

### The Holidays



**Riddick Martin** at Fantasyland-Lincoln Park. They were really nice there. Riddick didn't need to stand in line to see Santa. Santa came down to the main floor to snap this picture.



**Todd and Michael Suriano**

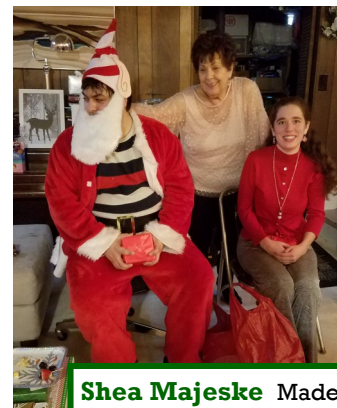


**Andrew Langan Coutilish**  
Visiting Santa Claus at Macomb Mall when there was no line! High five Andrew!

**Evie Ohnui** She enjoyed and was successful at her school's holiday bowling party this year.



**Mason Van Dam** Meeting Santa at the family Christmas party.



**Shea Majeske** Made a great Santa this year when the "real" Santa called in sick.

**IMPORTANT NOTE:** There will be **NO** business meeting on February 3. **The support meeting will begin at 6 p.m.** with a Special Guest Speaker. See back page for details. **You must RSVP.** Child/Adult care available. See page 5.

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

As we begin the New Year, I would like to congratulate all the parents who made it though the LOOONG holiday break. Nothing quite like time with extended family you rarely see, no school, complete abandonment of routine and trying to look decent to remind you what you're made of. For us, it was the most successful holiday break in years. For those still struggling, all I can say is – just keep swimming! Sometimes all you can do is just move ahead.

Looking ahead on the year, I'm filled with excitement about all the upcoming events for 2018.

March is Advocacy Day in Washington, D.C. This is one of my favorite events. It gives average citizens the opportunity to meet members of Congress and their staff in their offices to discuss policy and funding that directly affects those

impacted by fragile X. I was pleasantly surprised by the tone of the meetings. They had no political agenda and I found Representatives, Senators and their staffs to be eager to hear from constituents about how various policies would impact daily life. This is a wonderful opportunity to be a part of real change in D.C. If you can make this trip it will be very impactful!

In July, our family will be attending the NFXF International Conference in Cincinnati, Ohio. This will be our second conference and our first with the kids. We last attended the conference in 2014 in California. I would encourage anyone impacted by fragile X to attend this event. It's a rare chance to meet others who are passionate about fragile X. It will be filled with experts eager to share the latest news and interventions and it also offers the fun chance to meet

other parents and caregivers who understand the challenges of daily life. These are OUR PEOPLE!! I found it calming to be in a room full of people I've never met yet I have more in common with than most people in my family. Many of our kids have the same mannerisms and walk. They love the same shows and foods. The similarities are remarkable. Come to Cincinnati and experience it for yourselves!

FXAM will be offering scholarships to Advocacy Day and the NFXF Conference. If you are interested, please apply for a scholarship to help cover some of the costs. I think you'll find they are both well worth the time and money. You may even meet some new friends and we could all use friends who understand us.

I look forward to seeing you all soon!

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

### Hello from the University of Michigan Fragile X Clinic!

We would like to wish everyone in FXAM a happy new year! I personally want to thank the board of FXAM for allowing me to come speak at your support meeting this past November. It was a great experience for me to learn more about your organization and what you all are looking for in a Fragile X Clinic. 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 <http://forwardfx.org/>.

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

### 2018 Fragile X Clinic Dates

February 1	February 22
March 1	March 22
April 5	April 19
May 3	May 24
June 7	June 14

## **We are not in Kansas anymore** by Sally Nantais

When I picked the quote for the FXAM Quarterly newsletter “Toto, I have a feeling we’re not in Kansas anymore”, for some reason it really struck home.

Maybe it was because of the events in the fall, Austin spending sixteen days in the hospital, taking a mini-vacation to visit friends (first trip without children in years with my husband), my lovely mother-in-law receiving a cancer diagnosis and passing two weeks later, my father having a short-stay in a hospital and my mother who is exhibiting the signs of FXTAS. All of these events remind me of how precious life is, why we must appreciate today and how little we can control about tomorrow. All were a little more challenging because of a child with a disability.

I thought of the poem by Emily Perl Kingsley “Welcome to Holland” and it didn’t provide comfort, it crushed me with the fact that not only did I not make it to Italy but sometimes Holland stinks. I think I have the right to say that, after all I’ve been doing this for 25+ years.

I had to leave Kansas, it wasn’t my choice, and no matter how

long I follow the yellow-brick road or click my heels together I’m never going to get back to Kansas.

Now like “Welcome to Holland” I have met a lot of wonderful people, I have grown emotionally and compassionately over the years. I’ve had many adventures that would have never occurred without the trip to Holland but I still long for Kansas.

I am thankful for having a person like Austin in my life but let’s be honest at times I am so over it; I’m tired of the obstacles along the yellow-brick road. Maybe it’s my age coming into play, turning 60 was a celebration but it was also a reminder of what may never be, there may be no empty nest. Milestones with ages often hit home when you are in Holland, for our children turning 16 there is nothing sweet about it, it slaps us in the face when the reality is for many they will never learn to drive or be independent. Like in Holland, on a hot summer day the canals may begin to stink, life stinks.

In my life the wicked witch of the west and flying monkeys assimilate into many forms.

They could be my child during a meltdown, we’re not embracing “Welcome to Holland”, we’re living the “Strange Case of Dr Jekyll and Mr Hyde”. We do our best to identify possible triggers, to create redirection, to understand the hyperarousal but sometimes nothing works.

Sometimes it may be family and friends who just don’t get it, who don’t truly understand the everyday struggles, lose sight of hope, give up too easily and don’t appreciate what they do have.

There are times I feel like the wicked witch of the east being crushed by a house when someone in the disability community doesn’t understand my struggles because fortunately they have been dealt an entirely different hand. The diagnosis might be the same but the end results are very different and it’s not because of what I am or am not doing.

There is a constant, I am never going to get back to Kansas, and sometimes it bothers me. But that’s okay, I know sometimes it may make me angry. I just want you to know, when you are following that yellow brick road you are not alone.

**“Toto, I have a feeling we're not in Kansas anymore.”**

~ L. Frank Baum

**Save the Date - it's a Conference Year!**



Look for more details at [fragilex.org](http://fragilex.org) and in our April FXAM newsletter.

Conference Scholarships will be available to help FXAM families attend this unforgettable experience!

**Can't physically make it to a meeting, go virtual**

If you can't make it to the meeting in person please join us virtually.

To join using your **smartphone**: Download Zoom app. Click on – JOIN MEETING. Enter meeting ID number. Put yourself on mute. If you have a question type it in the message box

To join using your **computer**: Go to [zoom.us](http://zoom.us), Click on - JOIN MEETING. Enter meeting ID number. Put yourself on mute. If you have a question type it in the message box.

The meeting ID number will change from one meeting to the next. The meeting ID number will be posted in the Fragile X Association of Michigan facebook group prior to the meeting.

Email [fab4fam@comcast.net](mailto:fab4fam@comcast.net) a day or two before a meeting if you want the code and are not on Facebook.

**FXAM Moms: Let's Do Lunch!**

We'll be having discussions about a SE Michigan winter lunch date

AND a Lansing-area spring lunch date!

Stay tuned for a Facebook ([Fragile X Association of Michigan](#) group) discussion and more details to follow.

Come connect with other moms and enjoy lunch out!

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

# What's going on ...

## RSVP for February 3 Meeting

Saturday, February 3, from 6:00 - 9:00 p.m.

FXAM Support Meeting with Special Guest (see back page)

RSVP by January 29 to [mblangan@hotmail.com](mailto:mblangan@hotmail.com).

We need to know the number of adults who'll be at the meeting.

If you are bringing **children/adults requiring care**, please include their names and ages to ensure we have enough caregiving support. Please bring something fun to share (game, toys, etc).

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

Hope to see your whole family in February!



NATIONAL FRAGILE X *MARCH 5-6, 2018*  
ADVOCACY DAY

Learn more and register at:

[fragilex.org/shop/advocacy-day-registration](http://fragilex.org/shop/advocacy-day-registration)

FXAM offers a scholarship to help ease your budget if you'd like to participate in the NFXF Advocacy Day in Washington, D.C. This year, the event is March 5-6.

If you would like to apply for the

scholarship, please contact Heather Van Dam at:

[fab4fam@comcast.net](mailto:fab4fam@comcast.net)

248-343-2077

by **Saturday, February 3**, stating your intention to apply for the scholarship.

ad·vo·ca·cy

the act or process of supporting a cause or proposal. She was known for her advocacy of the Fragile X agenda.

## Creative Arts Studio Ceramic Painting Event

Saturday, March 31, from 4:00 to 6:00 p.m.

114 West 4th Street, Royal Oak, MI 48067

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

\$5 per artist. Adults are free. Pizza will be served. **Limit of 18 artists and adults.** Please connect with Joyce Kreger on our FB page (or if not on Facebook, email [mblangan@hotmail.com](mailto:mblangan@hotmail.com)) to reserve your spot.

Pizza and salad will be served between 5:00 and 5:30 p.m.

e tra, e tra

Editors:

Mary Beth Langan 313-881-3340

[mblangan@hotmail.com](mailto:mblangan@hotmail.com)

Sally Nantais 734-282-7910

[sallyn423@wyan.org](mailto:sallyn423@wyan.org)

This newsletter is published quarterly and sent to all members and supporters of FXAM. Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

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**

**[southeastMI@fragilex.org](mailto:southeastMI@fragilex.org)**

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



**Dr. Elizabeth Berry-Kravis** from the Chicago FX Clinic will be our special guest at our FXAM Support meeting on **February 3, 2018**. For many of our Michigan and Midwest families, she is a priceless resource in assisting families on the fragile X path. In the fragile X world, she is a renowned expert, assisting numerous families throughout the years and involved in hundreds of research studies. For many of us, she is the light at the end of the tunnel.

During this meeting there will be free Child/Adult Care. See page 5. **You must RSVP to [mblangan@hotmail.com](mailto:mblangan@hotmail.com) if you'll be attending AND if you are bringing family members requiring care.**

We hope many can join us and hear firsthand about fragile X-related disorders, current treatment and where research may be taking us in the near future.

More about Dr. Berry-Kravis at:

**[rush.edu/news/going-distance-children](http://rush.edu/news/going-distance-children)**



FRAGILE X ASSOCIATION  
OF MICHIGAN

PO Box 1414

Troy, MI 48099-1414