



# FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XII, Issue 1, January 2016

**Mark Your  
Calendar**

## Three Cheers for...

### Support Meetings

First Saturday  
of the Month

*When:*

**February 6, 2016**  
**March 5, 2016**  
**April 2, 2016**

*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:

**February 15, 2016**

**March 30, 2016**

**FXAM Playdates**

See page 3.

**March 2016**

**Advocacy Day**

Washington, D.C.

See page 3.

**July 20-24, 2016**

**15th International  
Fragile X Conference**  
San Antonio, Texas  
More details in our  
April Newsletter.

**Fragile X Association  
of Michigan**

**FXAM.org**

**Contact Information:**

**313-381-2834**

**southeastMI@fragilex.org**



**Nick Hansen** for an awesome  
ugly sweater.



**Andrew Langan Coutilish** for standing  
still for a holiday photo

## Through the Maze - Featured websites

[cmski.org](http://cmski.org)

### Challenge Mountain

Boyne City, MI

Check out their website!

Challenge Mountain offers both winter and summer adaptive recreation programs.

Perhaps your child is interested in learning to ski this winter!

[f2fmichigan.org](http://f2fmichigan.org)

### Michigan Family to Family Health Information Center

The Michigan Family to Family Health Information Center (MI F2F) is part of a federally funded project. They are staffed by family members who have experience raising a child with special health care needs. They know how to navigate the maze of health care services and programs and understand the challenges families face. They provide help, information and resources on disability and health issues to families of children and youth with special health care needs and also work with health and other professionals.

MI F2F helps families make educated decisions and supports families to partner with professionals. They strive to make services for children and youth with special health care needs better. They have worked to build a new website for families, youth and providers to go to for help, information and resources. The website also features a calendar for trainings and other events of interest.

## Fragile X on Facebook

*By Mary Beth Langan*

Ever feel like the folks you see on a daily basis don't exactly understand your Fragile X life? You are not alone! Whether or not you can make it to FXAM meetings and events, you can always connect with Fragile X family members who "get it" via Facebook. The first article on this topic can be revisited at [fxam.org/support](http://fxam.org/support) in the FXAM April 2012 newsletter. Participant numbers in these Fragile X Facebook groups are much higher now, but the support and understanding remain the same - personalized to what you need. Here are some of the Facebook groups which may interest you to join with their current number of group member listed in parentheses:

**Fragile X (4,437):** This is the group where you can reach the largest number of Fragile X family members. It may be to share the ups and downs of your Fragile X life or ask for advice from others who have been in your shoes. Even at 3 am, you are likely to get a reply from a fellow Fragile X parent who may be awake in a neighboring state or around the globe.

**Fragile X Association of Michigan (240):** The official Facebook home for our Michigan link in the National Fragile X Foundation Community Support Network. A great place to ask local- or state-related questions and share Michigan and FXAM news.

**Fantastically Fragile X (1,644):** Ever had a day when you only want to hear Fragile X success stories and positive news? This is the place to go on those days!

**FXTAS (327):** Go to this group if you have a family member affected by Fragile X-associated Tremor/Ataxia Syndrome. Others are willing to share their path of diagnosis and journey with FXTAS in themselves or their family members.

**Fragile X Female Carrier Symptoms (1,335):** Fragile X moms/carriers do a lot of caregiving, but sometimes we need help knowing how to care for ourselves. Group members share their journeys with the various symptoms that can affect female carriers and how they navigate these symptoms as successfully as possible!

**Fragile X Man Cave (162):** Fragile X Dads need a Dad-only place to chat too. This is a Y-chromosome only group.

**Fragile X Nonverbal (102):** The name says it all. Some times you need a very specific venue to ask a question.

**Nat'l Fragile X Fndn Advocates (853):** We can all help make this world a better place for families affected by Fragile X! Join this group to be a part of the solution.

As illustrated by these groups and the number of members in them, you are not alone on this Fragile X journey!

*What lies behind you and what lies in front of you, pales in comparison to what lies inside of you." ~ Ralph Waldo Emerson*

# What's going on ...

## FXAM School Break Playdates

**Monday, February 15, 2016 at 10:15 am**

*2/15 is Keir's 16th birthday - come wish him a Happy Birthday!*

**Wednesday, March 30, 2016 at 10:15 am**

Come to Andrew's house for lunch and fun!

More info on the FXAM Facebook group closer to the dates or contact Mary Beth at [mblangan@hotmail.com](mailto:mblangan@hotmail.com) or 313-881-3340.



**NATIONAL FRAGILE X  
ADVOCACY DAY**

***MARCH 1 - 2, 2016***

**Learn more and register at:**

[fragilex.org/advocacy-2/advocacy-day/](http://fragilex.org/advocacy-2/advocacy-day/)

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 1-2.

If you would like to apply for the

scholarship, please contact Laureen Majeske at:

[lmajeske1@comcast.net](mailto:lmajeske1@comcast.net) or  
586-978-9079

by **Saturday, February 6**, 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.

## From the President's Desk *by Laureen Majeske*

Happy 2016!

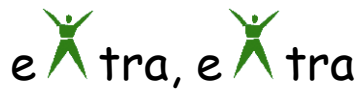
It's hard to believe it's 2016. I am looking forward to seeing what this year brings in new research and medication trials. Thank you to all of you who have participated in so many of these opportunities - you make a difference!

We will be holding our annual board meeting soon and would love to hear from you. We are always looking for new ideas, comments and suggestions, or if you want to host an event yourself. We have many families that volunteer so that we can more effectively serve our members and have a variety of events for all ages in

many different locations. Last year we held a family picnic, holiday party, seven Support Group meetings (including three with speakers: Jeff Cohen on The A.B.L.E Act, Dr. Deborah Hall on FXTAS and Kathryn Wotta, OTR on Sensory Needs), two Moms' lunches, Dads' Night Out, Winter and Summer play dates, Friendship Circle family event, Creative Arts Studio play date, our Annual Golf Fundraiser (where we raised almost \$20,000!) and an educational conference featuring Dr. Marcia Braden. We also supported our Advocacy Day participants and Wrinkle Free for a Cure, spread awareness in many college classrooms

and on TV, share support and news via quarterly newsletters AND held an annual board meeting where we did the planning to make all of these things happen! We know that this year we will continue to grow and are already making plans to hold a teen event and more satellite meetings. Be sure to let us know what else you would like to see happen.

I hope this New Year holds many new opportunities for you and your family and that you know that the Fragile X Association of Michigan is walking right alongside of you.



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

## Fragile X Clinic Update

Congratulations to Kailey Owens on her new position at Progenity, Inc., a genetics testing lab in Ann Arbor! Although she has left her position at the U-M Fragile X Clinic, she plans to stay on the FXAM board so we'll still see her and benefit from her knowledge and care for our community.

U-M will share with us when they have a new genetics counselor dedicated to our Fragile X clinic. In the meantime, Lisa Burke and Bruce Skinner at 734-764-0579 will help you set up your family member's appointment at the clinic.



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