



FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XII, Issue 2, April 2016

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

May 7, 2016

Free Childcare
see page 3.

June 4, 2016

(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:

May 21, 2016

Teen/Young Adult Event
See page 3.

June 10, 2016

Wrinkle Free for a Cure
See back page.

June 18, 2016

FXAM Moms:
Let's Do Lunch!
See page 3

July 20-24, 2016

15th International
Fragile X Conference
See page 2.

August 6, 2016

FXAM Family Picnic
Save the date.

Fragile X Association of Michigan

FXAM.org

Contact Information:

313-381-2834

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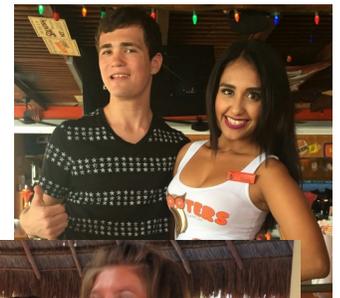
Three Cheers for...



Paul Fodor and Stephen Tolliver, Dearborn Special Olympics Basketball teammates and Fragile X brothers.

Grant Patterson & his sister, Abigail, just finished their 3rd performance with Sterling Civic Theatre in March 2016. The show was Willy Wonka Jr., and was performed at Henry Ford II, in Sterling Heights. Grant played one of Wonka's Oompa Loompas, and Abigail was Violet Beauregarde. They will be auditioning for their next show in May.

The Silverton Skin Institute "SKINny Dippers" took to the frigid waters of Lake Fenton for the annual Polar Plunge, raising money for Special Olympics. Team SKINny Dippers raised more than \$4,000.



Happy 18th Birthday Aidan!



Are y'all ready for a Texan conference? Go to fragilex.org for more information and to register for the National Fragile X Foundation's biennial International Fragile X Conference! Please note that early bird pricing is through May 18. Don't miss the discounted pricing! Hotel information is also at fragilex.org - reserve your room early to make sure you're at the conference hotel at the \$139 per night conference rate.

Once again, the Fragile X Association of Michigan is happy to be able to grant 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 Laureen Majeske (lmajeske1@comcast.net) and copy Sheryl Roman (romanjsr@aol.com) to let them know you are interested in the scholarship. Please mention in the email if you are applying for a scholarship for one or two family members and their names. Apply by Monday, May 2. By Monday, May 9, Laureen or Sheryl will contact applicants with confirmation of their scholarship amounts. If you have not registered by then, you'll have until May 18 for early bird conference registration. If FXAM is a part of the NFXF merchandise booth, recipients will be asked to work one or two hours during the conference. You will be notified prior to the conference and will have a choice of when you work. In late July, you'll verify that you attended the conference by submitting receipts (hotel, etc) and after verification, will be paid the scholarship money in early August. Each scholarship recipient will be asked to submit a short explanation of their favorite conference speaker. We'd like to schedule a great speaker for our 2017 Michigan conference! **NOTE:** *If you were awarded a 2016 NFXF scholarship, your FXAM scholarship will be a partial scholarship. If you were awarded a 2016 Rogers Neighborhood Family Fund Scholarship, you will still qualify for a full FXAM scholarship.*

From the President's Desk by Laureen Majeske

There is something about the fresh air and the bright sun today that makes me think summer might actually be on it's way. I love seeing my kids riding their bikes up and down the street, but it reminds me of how I also need to caution them about being safe near streets and strangers. One way to do something safe and fun with your kids is to attend one of the many family-friendly events we offer. You will find details in this newsletter as well as future announcements by email and in

our FXAM Facebook group. Please update all of your information on the enclosed membership form. Help us stay in touch!

The next International Fragile X Conference is this July in San Antonio, Texas. I highly encourage you to attend if you have never been. The wealth of knowledge you obtain, plus the amount of support you receive, is like nothing you can imagine. It is truly life-changing to spend five days with doctors, researchers,

clinicians, parents and more and be immersed in all of the newest techniques, research and therapies available to our families, with plenty of time to relax and have fun as well. Scholarship information is listed above.

Have fun with all of the end-of-year activities, graduation parties and weddings that are sure to be coming up, but also don't forget to take time for yourselves and your precious families. And don't forget, we are here for you too.

What's going on ...

Free Childcare at our May 7th Meeting!

We hope to see your whole family at the May 7th FXAM meeting.
6 - 9 pm free childcare available (during 6 pm Business meeting and 7 pm Support meeting)

RSVP by **May 2** to mblangan@hotmail.com with your child's/children's name(s) and age(s).
We'll have food & friendly caregivers for them!
Please bring something fun to share (game, toy, coloring book).
We'll have food for parents too.

FXAM Teen/Young Adult Event!

Fragile X Teen/Young Adult Event at MCSA
Saturday, May 21, 2016 from 5 - 7 pm
2980 Technology Drive, Rochester Hills, MI 48309
Check out their facilities at mcsa.me

We'll have music, fun, funky disco lights and food! Get ready for an obstacle course and using the MCSA gym equipment.

Friends, siblings and parents are invited.
You must be 13 or older for this event.
FREE but RSVP by May 16 to mblangan@hotmail.com

FXAM Moms: Let's Do Lunch!

Saturday, June 18, 2016

Place and time to be determined after we see who can join us for some Mom-only time!

Email mblangan@hotmail.com to say you're interested.

We'll look at the responses received by June 11 and decide on a central location for our lunch.

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

"A teacher affects eternity; he can never tell where his influence stops." ~ Henry Adams



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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.

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FXAM.org

Wrinkle Free for Fragile X! Friday, June 10, 2016

If you want to smooth your wrinkles away AND donate to a good cause, mark your calendars for June 10 when the 15th annual "Wrinkle Free for Fragile X" will take place at the Silverton Skin Institute in Grand Blanc. Each year, Jennifer and Kimball Silverton, of Grand Blanc, host an event, offering patients an opportunity to receive injections of a wrinkle smoothing product such as Botox at a charitably priced rate with all money going towards research. Participants will have the opportunity to learn about Fragile X, learn about smoothing away wrinkles and be able to enjoy delicious food! The Silvertons' son, 18-year-old, Aidan, has FX. The event has raised more than \$300,000 over the years. Dr. Kimball Silverton is a board certified dermatologist and fellowship-trained cosmetic surgeon. Jennifer is president of the National Fragile X Foundation.

Cost: \$275 *

Where: Silverton Skin Institute, 8245 N. Holly Road, Ste. #101
Grand Blanc, MI 48439, 810-606-7500 **

* \$50 non-refundable deposit required

** must call in advance to secure a spot; space is limited



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