

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

February 3, 2024
 March 2, 2024
 April 6, 2024

Business Meeting

10:15 - 11 am

Support Meeting

11 am - 1 pm
 Berkley Public Library
 3155 Coolidge Hwy
 Berkley, Michigan

Zoom option details will be on FXAM FB page and FXAM.org

Special Events:

February 26-27, 2024

Advocacy Day
 See page 3.

July 25-28, 2024

19th International Fragile X Conference
 Orlando, Florida
 See page 3.

Fragile X Association of Michigan
FXAM.org

Contact Information:
 313-689-3340

PO Box 1414
 Troy, MI 48099-1414

Three Cheers for...

The Holiday Party



The Price Family -
 thank you for hosting our
 first post-Covid FXAM
 Holiday Party!
 Thanks to all who attended!



From the President's Desk by Tiah Solway

Hello FXAM Families and Happy (?) Winter! As I write this, we are currently in the midst of our first winter storm and I am so happy to be able to say that I am staying warm and cozy inside and not stuck out in all that cold white stuff. I hope you all managed to survive the winter break with all your nerves intact. I thought long and hard about any resolutions I might want to make this year and the only one that felt like it spoke to me was to get off the sidelines. No more sitting on the sidelines watching life pass me by, I'm going to try jumping in the deep end! I'm going to go on trips, even if it's just weekend getaways. I'm going to try the new thing, eat the new food, and go a new way. Let's see where my life takes me this year. What are your resolutions for the year to come? What will you accomplish?



With the ringing in of the new year it is time for the Fragile X Association of Michigan to start planning our year. We are happy to report that we will once again be able to provide international conference scholarships to our active families. Over the past summer, FXAM released an announcement explaining the new rules and qualifications to be eligible to receive an international conference scholarship (see below). Please make sure at least ONE of the requirements is completed before applying. Look for a link to the updated application process to be posted in the Spring. Please keep an eye on our FXAM Facebook page and the April newsletter for more information. We will also be partnering with the Detroit Tigers once again to provide our families with a fun outing and Fragile X awareness at Comerica Park (possibly 5/24 - stay tuned!).

Between the conference, Tiger's game, our annual summer picnic, and the many support meetings throughout the year (in person and virtual options), we hope to see as many of our extraordinary families as possible in 2024!

FXAM Conference Scholarships for the NFXF International Conferences From 7/2023

Conference scholarships will only be open to FXAM members. How do you know if you're a FXAM member? Contact Mary Beth Langan, FXAM Corresponding Secretary, if you are unsure (mblangan@hotmail.com). While membership is FREE, we need a membership form completed so we have some details on who is a part of FXAM. You have to live in Michigan or be an Ontario family who lives close enough to be active. We need your info to help us know who we are serving. We need to know more about your family in case new families in your area need a close connection. Near or far in Michigan, we try to make sure FXAM families know they are not alone on their Fragile X journey via our support meetings, events, quarterly newsletters and FXAM Facebook page.

To apply for the 2024 FXAM Conference Scholarship, in addition to being a FXAM member, we will be requiring that scholarship recipients be active members in our group. What does that mean exactly? Being active could look completely different for each family, so we are providing a list of ways that you can remain active in our FXAM community. Moving forward, in order to qualify for a conference scholarship, you will need to fulfill at least one of the following:

- 1) Volunteered at a FXAM fundraiser or event in the two years since the previous conference.
- 2) Held a fundraiser in the two years since the previous conference where the proceeds were donated to FXAM (virtual, Facebook, lemonade stand, garage sale, etc).
- 3) Attended a minimum of 4 support group meetings, which are available virtually or in-person, in the two years since the previous conference. Since we only have one year before the next conference, we will be lowering that requirement to 2 meetings for the 2024 scholarship applicants.

In addition to these requirements, we will also ask for scholarship recipients to share with the group something about your conference experience in the newsletter following the conference (the October edition). This could be an article written about your experience, notes on something you learned, or photos from the conference. This is so that all FXAM members can share in your experience!

We hope you'll take this next year to become an active member of our FXAM community if you're not already, and most of all, we hope to see you at the 2024 NFXF International Conference from July 25-28 in Orlando, FL!



**NATIONAL FRAGILE X
ADVOCACY DAY** ***FEBRUARY 26-27, 2024***

Learn more and register at: fragilex.org/get-involved/advocacy/

This year's training and visits to The Hill will be LIVE and in person February 26-27. February 26 is a training day and February 27 is Advocacy Day. Full details and Registration available at the link above.

\$30 per individual to participate; children up to age 10 are free.

Hotel - Hilton Arlington Towers

FXAM offers an Advocacy Grant to help ease your budget and encourage more of you to participate! If interested in the FXAM Advocacy Grant, please email Tiah at jtsolway@rocketmail.com, by February 1, 2024 to apply for the grant.

Thank you for considering advocating for Fragile X!

"If we are to achieve a richer culture, we must weave one in which each diverse human gift will find a fitting place."

~Margaret Mead



ORLANDO, FLORIDA
**19TH NFXF
INTERNATIONAL
FRAGILE X CONFERENCE** ***JULY 25-28, 2024***

WHERE THE MAGIC HAPPENS

Save the Date! For the 19th NFXF International Fragile X Conference, **July 25-28, 2024**, at the Renaissance Sea World in Orlando.

Registration—including scholarship applications through the National Fragile X Foundation (NFXF)—will open in early 2024.

FXAM scholarship details to apply will be in the April Newsletter and on FXAM's Facebook page.

Reservations for Renaissance Sea World in Orlando are now open.

book.passkey.com/event/50499859/owner/210/home

To learn more about conference and register, visit:

fragilex.org/get-involved/international-fragilex-conference/

Through the Maze

Fragile X Syndrome & Associated Premutation Conditions Webinars

fragilex.org/family-resources/fxs-premutation-webinars/

There is so much we don't know that we don't know. If you'd like to become more educated, keep up with what the researchers know and/or what they are exploring, this is one avenue you can take from the comfort of your home.

Get Involved in Fragile X-related Registries!

International Fragile X Premutation Registry

Learn more at: fragilex.org/family-resources/premutation-registry/

Our Fragile X World

Learn more at: ourfragilexworld.org/

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Research has always been a very important part of my life.

Before the registries, Yahoo groups, and Facebook (Meta) groups all we had was the FRAXA Listserv. The Listserv was an initiative by FRAXA Research Foundation and hosted by Emory University. I don't miss the screeching of the connection on the old dial-up modems or the frustration when someone shared a picture and it would tank my connection. I do cherish the long-term friendships that began through the Listserv. The Listserv back in the 90's and 2000's was a godsend for any parent/guardian looking for support, wanting to learn more and wanting to get involved with research.

Our first study we participated in was with The Waisman Center, in Madison, Wisconsin, on Speech and Language, in April 2004. What a big first effort, it involved a plane trip and hotel stays. We practiced at a couple of local hotels before the trip and had a mom-sponsored field trip to Detroit Metropolitan Airport to expose Austin to as many of the "unknowns" for him as possible. The day before we left, my anxiety was lessened a little when staff from the Waisman Center called and said, if you get to the airport and you don't think he can do this, it's okay if you go home. Thankfully, Austin did very well and we didn't need to go home.

Since then, the family as a whole (the fragile X members) and I have participated in 57 studies (possibly more, life got busy at times, and I didn't update my resume.) I have had the opportunity to meet and work with experts in not only the fragile X field but autism as well. Once I participated in a usability study for an oral medication for ALS, it felt like I was in a spy movie, materials were sent to me in a locked briefcase. My only role was to read the medication instructions and pretend I was going to dose someone, while in a virtual meeting. At that time they gave me the combination to open the briefcase. And yes, I read the instructions, walked through the pretend dosing steps, only to discover I did miss a step (which hopefully, they made stand out a little more in their instruction pamphlet).

Sometimes we were only a part of a blood draw, once we did a clinical drug trial. I would love to have had Austin participate in more clinical drug trials but when he had Hemolytic Anemia, an autoimmune disorder, they removed his spleen and he can never again participate in a clinical drug trial. We've done studies at Wayne State, U of M (Autism studies with Dr. Lord), Rush University, Emory University, UC Davis just to name a few. We've been compensated well on some studies, and some studies we didn't break even but it was all worth doing.

If you can, get involved, start with a registry. ~ Sally, Newsletter co-editor

Three Cheers for...

Leader of the Pack: A student who has achieved the highest average or distinction in their grade or program.

Principal's Roll: A student who has achieved an average of 90% or higher.

Honour Roll: A student who has achieved an average of 80% or higher.

LEADERS OF THE PACK

Jad Ali
Cavan Ashton
William Bray
Makayla Kelly
Isaiah Loiselle
Lydia Mereszak
Jonathan Solway



Jonathan - winning the Principal's award.
Isabelle and Tiah - in Niagara Falls for the holidays and winning some jackpots at the arcade.

Three Cheers for...



The Lerchenfeld Boys - pointing out Christmas requests in the Wishbook!



Nicholas - had a visitor who randomly showed up at grandma and grandpa's house. He is ready for the big game with mom's dog, Go Blue!



Three Cheers for...

The Gelfand Boys - Busy and focused working on their holiday present for Mom and Dad.



Michael - makes an awesome Santa!



Three Cheers for...

Kevin - enjoyed spending time with his family over the holidays, including sisters Stefanie and Helen (and her cat Rori). He's been helping with the new Hello Fresh meal prep - peeling, chopping and mixing. Still trying to conquer his weather anxiety and agoraphobia and is now working with a new behavioral therapist Jacob. It's looking positive as we start 2024!

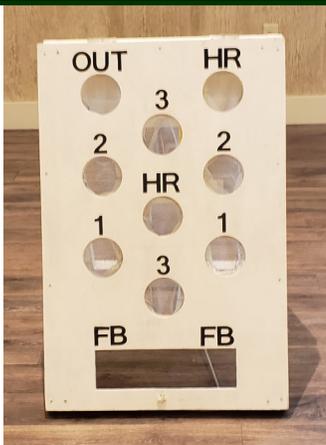


Three Cheers for...



Ted and Andrew - excited about playoff game day. Go Lions!

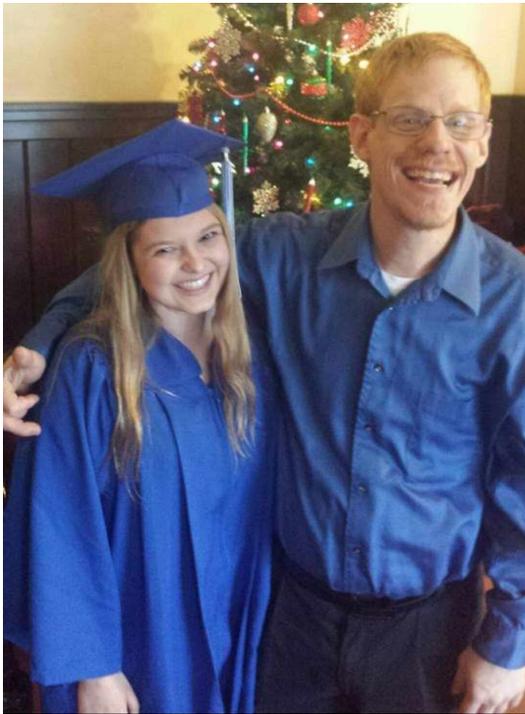
Austin - attended his first S.T.A.R. (Special Talented Adult Resident) program, in The Villages, FL this January: Bean Bag Baseball. There are a couple S.T.A.R. activities each month. His team lost, but had fun.



Three Cheers for Sisters... *Continuing with October's Theme*

“A sister is a gift to the heart, a friend to the spirit, a golden thread to the meaning of life.” ~ Isadora James

Svetlana and Nathan



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