

Mark Your Calendar

Three Cheers for...

Support Meetings

First Saturday of the Month

When:

May 6, 2023

June 3, 2023

(No meetings in July, August & September)

Business Meeting

10:15 - 11 am

Support Meeting

11 am - 1 pm

Where:

Berkley Public Library

3155 Coolidge Hwy

Berkley, Michigan

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

Special Events:

May 6, 2023

Moms: Let's Do Lunch!

(after the May meeting)

See page 2.

July 22, 2023

Fragile X Awareness Day at Comerica Park!

See page 2.

August 26, 2023

FXAM Family Picnic

More info soon on our pirate-themed picnic!

Tigers and Fragile X - For more info on the connection between the two, see page 2.



April 22 - 11 am
FXAM Spring Clean Up



Fragile X Association of Michigan
FXAM.org

Contact Information:

313-689-3340

PO Box 1414

Troy, MI 48099-1414

GOAL: clean out our storage unit and give or throw away all items - a great task for Earth Day 2023.

ALL are welcome to come help and snag some free FXAM merchandise! Please meet at the parking lot of Public Storage to all drive in together through the locked gates and down to our FXAM unit.

If you cannot arrive by 11 am, please text Tiah at 226-344-2418 to gain entry.

Public Storage
1315 Chicago Road in Troy
(just N of Oakland Mall; off Maple and John R)

What's going on ...

FXAM Moms: Let's Do Lunch!

May 6, 2023, 1 pm
(after the May meeting)

Bagger Dave's
2972 Coolidge in Berkley
baggerdaves.com

We can walk over after the meeting!
If you're coming to lunch but won't be at the meeting,
let us know to save you a seat.
Dads who are at the meeting could also dine nearby.

Fragile X Awareness Day at Comerica Park!



July 22, 2023 - World Fragile X Day
6:10 pm game
Detroit Tigers vs. San Diego Padres



The Fragile X Association of Michigan has paid to be the nonprofit charity of the game so come help us raise awareness and cheer on the Tigers!

We'll have a FXAM table in the stadium to share info about Fragile X.

100 tickets are a part of our sponsorship. Tiah Solway will be taking requests for tickets on our FXAM Facebook page and via text or email (226-344-2418 or jtsolway@rocketmail.com).

You are not guaranteed tickets - you must reserve with Tiah and be told you've been awarded tickets.

Along with stating the **number of tickets** you want reserved for your family, please share the **sizes** you'll need for your free t-shirt to help spread awareness that evening and later.

Tickets will be distributed outside the stadium prior to 6 pm.

Additional details to follow.

Let's have a fun FXAM event cheering for the Tigers and our families!

Three Cheers for...



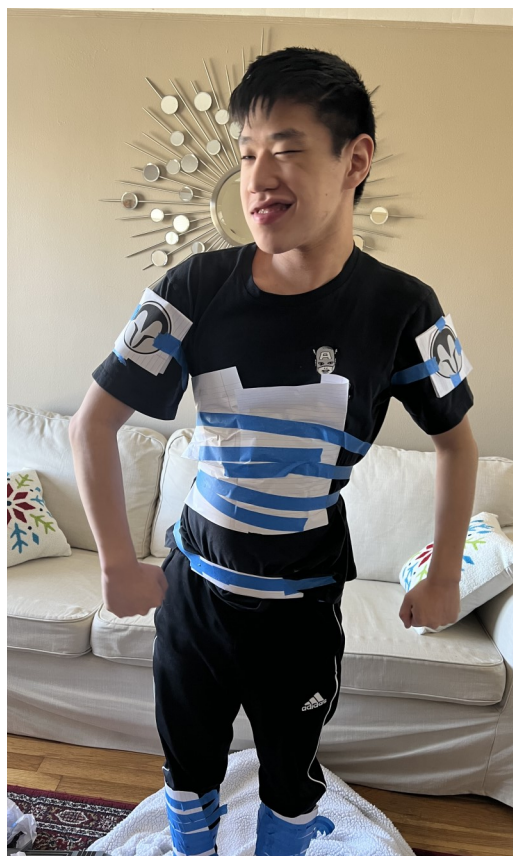
Evie & Henry - Evie enjoyed celebrating St. Patrick's Day this year and Henry got over his fear of costumed characters and is now good friends with the Easter Bunny at Glen Peters School in Macomb, MI.

Three Cheers for...



Evie loved celebrating Reading Month all through the month of March.

Three Cheers for...

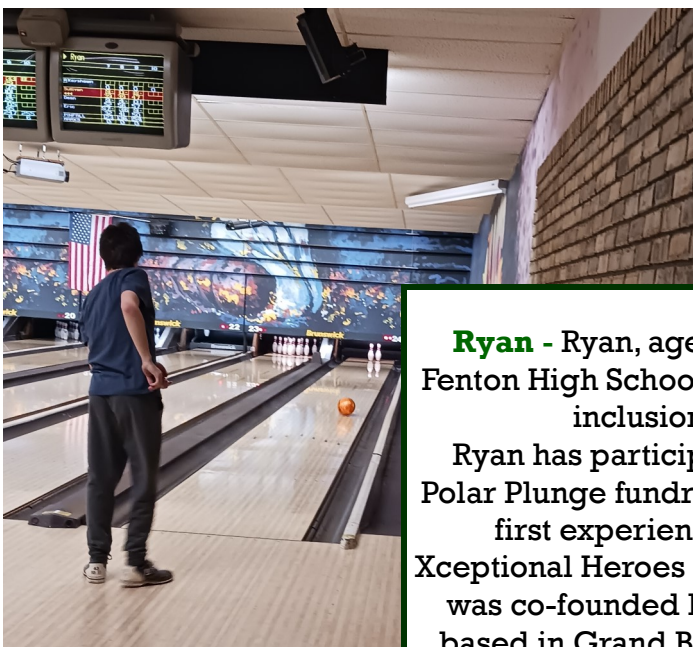


Michael and his creativity! - He spent Spring break designing superhero costumes out of notebook paper and painter's tape.

Three Cheers for...



Keir - volunteering at Scout Camp - he was a cook all weekend PLUS here he is doing some blacksmithing in Frankenmuth - he made a wand.
Great work Keir!



Ryan - Ryan, age 20, is a member of Unified Club through Lake Fenton High School. Unified Club unites typical peers to encourage inclusion in activities, sports and socialization.

Ryan has participated in Special Olympics bowling, basketball, Polar Plunge fundraiser, and Winter Sports Expo to Mount Holly. His first experience with snowboarding! Ryan has also joined Xceptional Heroes for activities and socialization. Xceptional Heroes was co-founded by fellow FXAM parent Jennifer Silverton and is based in Grand Blanc. Go to xceptionalheroes.org for more info.!

Three Cheers for...

Nick, Antonio & Nina - went to Mexican

Village in Detroit to eat and walked across the Bagley bridge that goes over I-75. Antonio loved being so high and watching the cars go by below us. Antonio had a great Easter. He loved looking for eggs, while eating the chocolate along the way.



Three Cheers for...



Kevin - and his family are enjoying spring and all that the season has to offer. When you need to haul bags of dirt, he's your man! We have a new CLS/Respite friend for Kevin. Her name is Tia and although it's only been about a month that she has joined us, we see a bond beginning with her! Last week, she took him to the movies to see Super Mario and they've been working on crafts together along with food prep!



Research News

Rett Syndrome Drug FDA Approval

FDA has approved Daybue (trofinetide) oral solution as the first treatment for Rett syndrome, a rare, genetic neurological disorder. Daybue is approved for the treatment of Rett syndrome in adults and children 2 years of age and older. Read more at:

[fda.gov/drugs/news-events-human-drugs/fda-approves-first-treatment-rett-syndrome](https://www.fda.gov/drugs/news-events-human-drugs/fda-approves-first-treatment-rett-syndrome)

And you may ask what does this have to do with fragile X? In May 2020, NIH published the results of the use of Trofinetide with fragile X patients. It was a brief, small scale study.

A Double-Blind, Randomized, Placebo-Controlled Clinical Study of Trofinetide in the Treatment of Fragile X Syndrome.

Abstract Conclusions: Trofinetide was well tolerated in adolescent and adult males with fragile X syndrome. Despite the relatively short duration of the study, a consistent signal of efficacy at the higher dose was observed in both caregiver and clinician assessments, based on a novel analytical model incorporating evaluation of multiple key symptom areas of fragile X syndrome. This finding suggests a potential for trofinetide treatment to provide clinically meaningful improvement in core fragile X syndrome symptoms Full journal article here: [pedneur.com/article/S0887-8994\(20\)30150-8/fulltext](https://pedneur.com/article/S0887-8994(20)30150-8/fulltext)

Clinical Trials Studies Recruiting Cincinnati Children's Hospital Medical Center

clinicaltrials.gov/ct2/results?cond=Fragile+X+Syndrome&term=&cntry=US&state=US%3AOH&city=&dist=&Search=Search&recrs=a&recrs=b

Clinical Trial Studies Recruiting Rush University Chicago

clinicaltrials.gov/ct2/results?cond=Fragile+X+Syndrome&term=&cntry=US&state=US%3AIL&city=&dist=&Search=Search&recrs=a&recrs=b

MyFXResearch Portal

fragilex.org/our-research/myfxresearch-portal/

The National Fragile X Foundation is committed to helping advance new and improved treatments and interventions for Fragile X-associated conditions and disorders. MyFXResearch Portal supports our commitment by eliminating the gap between patients & caregivers and researchers, and by providing guidance, resources, and support for our members and their families throughout the process.

Fragile X Research, Fraxa Research Foundation, Studies currently accepting participants

fraxa.org/fragile-x-research/clinical-trials/

Get Involved, Register!

The Fragile X Research Registry

fragilexregistry.org/

International Fragile X Premutation Registry

fragilex.org/our-research/projects/premutation-registry/

From the President's Desk by Tiah Solway

Hello FXAM Families and Happy Spring!

I hope you are welcoming and enjoying the warmer weather as much as I am. Spring has always been my favorite season. A time of coming alive after a long winter hibernation. The sun is shining brightly again, birds are chirping, and flowers are beginning to bloom. It's as if our little corner of the world is waking up from a deep sleep and starting anew. I love feeling the warmth of the sun on my face and breathing in the fresh spring air. It's a time for renewal and growth, and I always feel inspired to start new projects and try new things (with myself and with my children). I hope you're feeling the same sense of rejuvenation and excitement that I'm experiencing this spring.

In the spirit of new projects, FXAM will be meeting on April 22nd at our storage unit in Troy for a massive Spring Cleaning. All are welcome to come out that day to grab some free FXAM merchandise.

The gates are locked and we will need to know that you're coming. Additional information can be found on page one of this newsletter. In addition to that we have many exciting outings planned over the next few months, including a mom's lunch, a summer picnic, and maybe most exciting of all – a Detroit Tiger's game on World Fragile X Day. Be sure to look for additional details about these events and more throughout the newsletter, and together let's make the most of this beautiful season of renewal and enjoy all that it has to offer.

Hope to see you soon!



Caregivers Corner

My son regularly needs to get picked up early from school for hyperarousal episodes that we can't seem to control with any support (medication, behavior plans, visual schedule). Years ago, I decided to treat myself and after I pick him up and he's safely buckled up I go drive through Starbucks for my favorite iced coffee.

Another thing that works for me is my hobby of scrapbooking. Unlike some crafts, it's pretty typical to get out of the house and scrap at a store or retreat. Because I do it out of the house, my family can't interfere during my scrapbooking sessions. I'm looking at pictures of happy memories and chatting with friends. It's a win, win, win! ~ Sulie

Headphones have helped us save some of our sanity and help Andrew not bother others in public when he's watching (and re-watching...) YouTube clips of Jeopardy, Wheel of Fortune or Oswald (among others). We've gone through many sets of headphones in the past decade and a half, but right now the ones that are lasting the longest are the Altec Lansing MZX250 headphones that we purchase at Target. Regularly priced at \$19.99, we've seen them on sale for \$15. They come in blue and pink and fit my adult-sized head. When sound is getting on your next-to-last nerve, these can be a beautiful thing!

~ Mary Beth

After a long day, there are some evenings when one glass of wine really helps me relax and be able to transition to my sleep routine. Per the Mayo Clinic, "Red wine, in moderation, has long been thought of as heart healthy. The alcohol and certain substances in red wine called antioxidants may help prevent coronary artery disease, the condition that leads to heart attacks." ~Anonymous

eXtra, eXtra

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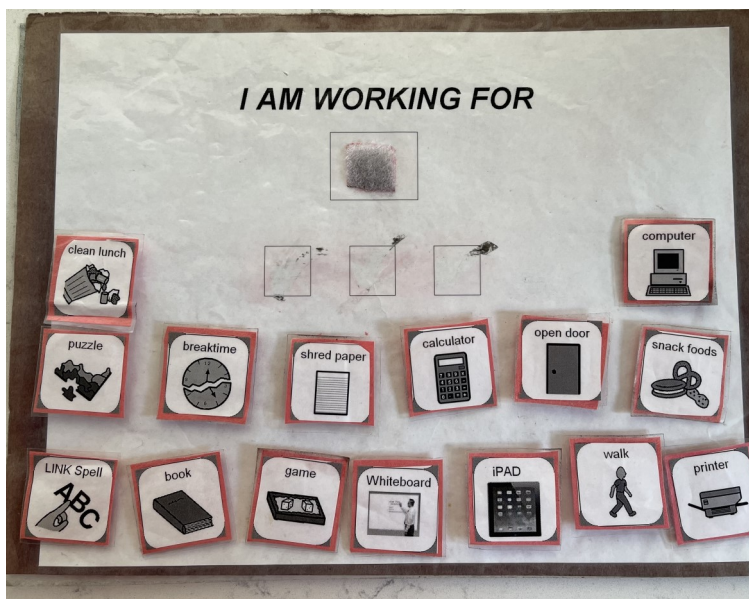
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313-689-3340

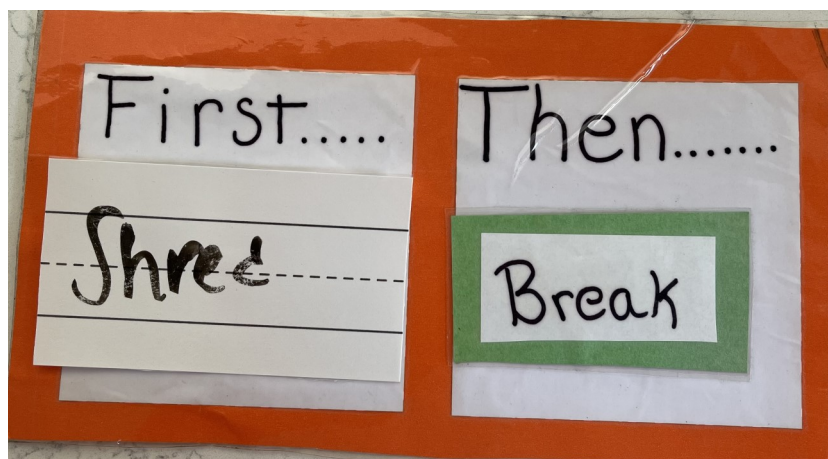
mblangan@hotmail.com

FXAM.org



You never know what you'll find when you do a deep clean. These were from Antonio's classroom. The first one, he picks a reward he's working towards and puts it on the top. The teacher puts a check one at a time at any time interval she decides. When he accumulates three of them, he gets the reward at the top. The second picture, the teacher writes down the task that has to be completed. Then what the reward they will get. It can be a break, or something that they like to do.

~ **Nina**



"Tell me and I forget. Teach me and I remember. Involve me and I learn."

Benjamin Franklin