

**Mark Your
Calendar**

Three Cheers for...

Support Meetings

First Saturday of the Month

When:

October 7, 2023

November 4, 2023

(No meetings in August
and 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:

July 22, 2023

Fragile X Awareness

Day at

Comerica Park!

See page 13.

August 26, 2023

FXAM Family Picnic

See page 13.

September 23, 2023

Father & Son

Picnic and Playday

See page 14.

**Fragile X Association
of Michigan**

FXAM.org

Contact Information:

313-689-3340

PO Box 1414

Troy, MI 48099-1414

Andrew - Path to Supported
Employment. Read more on page 2.



Three Cheers for

Andrew - Path to Supported Employment by Kimberly Young

Our journey began just before Andrew aged out of school at 26. We obtained services with Michigan Rehabilitation Services (MRS) and Community Living Services (CLS). Somehow we won the lottery with our support coordinator at CLS and he has been moving mountains for Andrew since we connected with him.

Andrew had his first work assessment with MRS in the Spring of 2021. Things were still pretty shut down due to Covid, so options were very limited. They evaluated him at two different sites. Sitting through the results took me back to the early IEP days. Needless to say, it was not what I was expecting. They scored him just below the threshold on the first site and tanked him on the second (they put him in Big Lots, customer facing at the second one! Not sure what they were expecting to happen.) I was very surprised at how things work with MRS. As an organization whose mission it is to help those with disabilities obtain employment, they sure don't make it easy to get to the other side of the process.

Because of the mixed results and limited options, we were able to get MRS to agree to another evaluation, but they required him to do additional skill building before then. We encountered the same issues with finding skill building - limited sites, limited staff, long wait lists. Our CLS coordinator found us the most amazing organization in Northville that had openings, the Living & Learning Enrichment Center (LLEC). He was able to secure five-days-a-week programming with transportation. It really transformed Andrew! He gained so much confidence and independence. LLEC has such a strong presence in the community and a laundry list of sites from which to choose from.

MRS scheduled the second assessment for Andrew in the Fall of 2022. They agreed to allow LLEC to perform the evaluation as long as it was at a site Andrew had never worked at before. After his three week assessment, we reviewed the results. LLEC recommended that he was ready for supported employment. MRS declined to accept the results, even though they approved them to perform the assessment. They claimed the results provided were not scored and worded in the proper language because LLEC is not a CARF (Commission on Accreditation of Rehab Facilities) accredited facility. Even though they approved them to conduct it! So on to the third and final evaluation. We met to review those results, had really positive feedback, "punctual, uses good judgement, receptive to feedback, consistently positive attitude", yet MRS didn't recommend he was ready for supported employment. His case was closed with MRS.

I don't quit and Justin, Andrew's CLS coordinator, doesn't either. We decided we would figure it out without the financial support or resources of MRS. Boy did Justin deliver! He connected us with Dutton Farm in Rochester. They agreed to develop a job opportunity for Andrew in the Waterford area. Justin was even able to find the proper billing codes to submit to CLS for paid job development at Dutton Farm covered by Medicaid! Andrew was the first client at CLS to have this paid for. Since then almost a dozen other clients have been able to do the same.

Within one week of meeting with Dutton Farm, they had three options for Andrew to consider. One looked promising at a local gym, but after having the gym push the start date several times, we decided "not to put all of our eggs in one basket" and do some more searching. One week later we had a meeting at Elite Sportsplex in Waterford to discuss Andrew doing custodial work for them. I am proud to say that Andrew had his first day of supported employment and will be working one day a week for the summer, with the hopes of adding 1-2 more shifts once they get busier again in the fall.

Please feel free to reach out to me if you have any questions navigating this path with your own child. Drop me an email at young4mi@comcast.net. All of our kids deserve the opportunity to be valued contributing members of society!

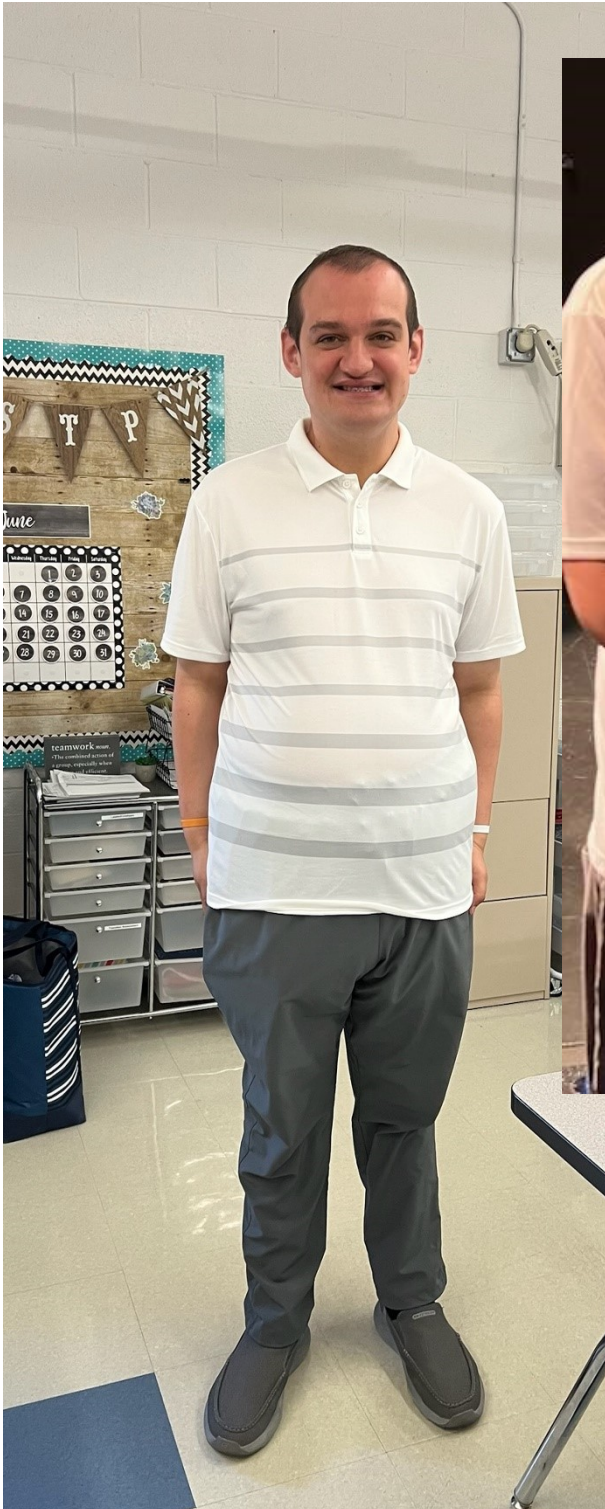
Three Cheers for...



Kyle - attended his Spring Gala at Embassy Suites. He sat through dinner (even though he didn't eat anything.) His buddies managed to get him to dance briefly. Bottom line, Kyle said he had fun. We **LOVE** the socks!



Three Cheers for... Our Graduates



Adam Popejoy

School:

Western Wayne Skills Center

Favorite subject:

going out in the community to job sites

Future plans:

Living & Learning Enrichment Center (LLEC) program and volunteer at a day care center.

**Three Cheers for...
Our Graduates**

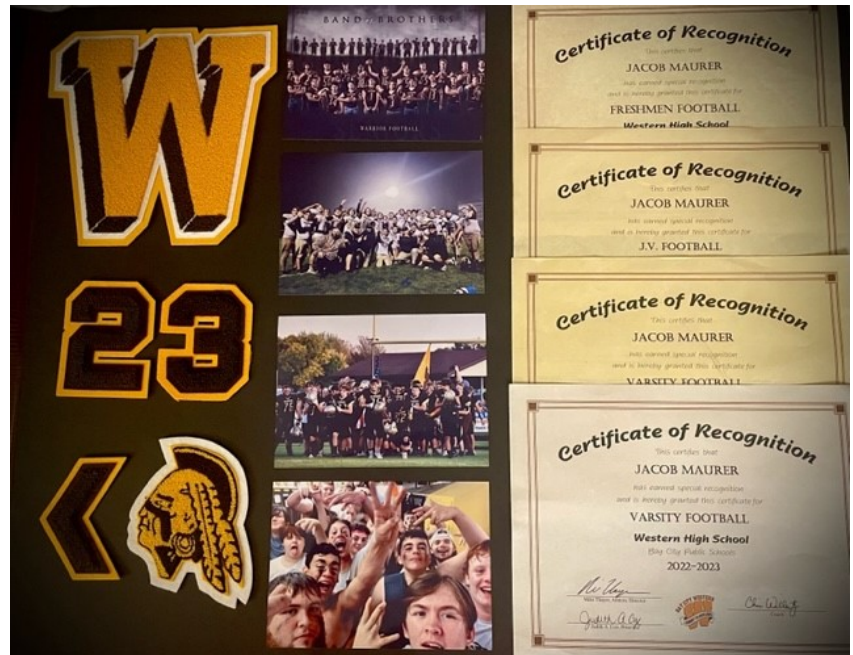


Jacob - was voted most likely to brighten your day by the Senior Class of 2023.

Jacob's last prom with his beautiful girlfriend. He grew leaps and bounds from his first nerve wrecking homecoming. He was confident and proud and ready to party with all his friends! Jacob survived four years of football!

Celebrating wins and being bummed out with his buddies when they lost. Out-of-town trips, dressing in bulky uncomfortable gear, cold and rainy games and working out everyday day.

We are so proud of him!

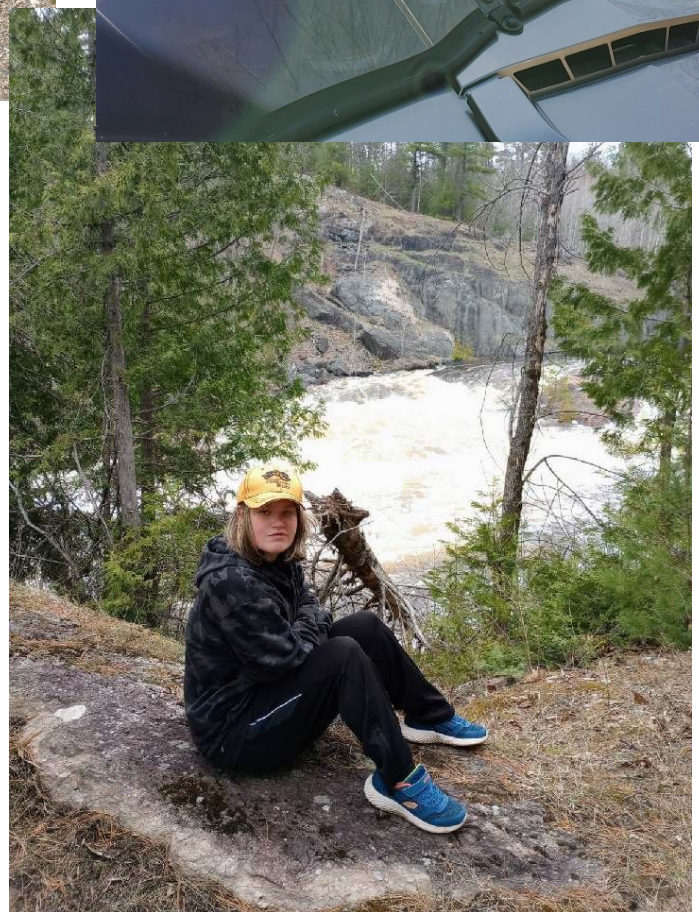


Three Cheers for...



Kayla - Loves the outdoors, enjoys fishing and also driving her side x side.

We are wishing you a very **Happy 21st Birthday in August!**



Three Cheers for...

Henry - is finding more vocabulary every day. His latest word is "sunglass", inspired by borrowing his Dad's shades

Hey Mom, where is the Corey Hart T-Shirt? Sunglasses at Night.



Evie - is becoming a seasoned bowler due to enrollment in the Kids Bowl Free program.

We think she's TNT, Dynamite.
You Rock Evie!!

Summer Vacation - the Lerchenfeld boys are having a blast!



Three Cheers for...

Ted - He's got new wheels, his first electric vehicle, same old plate.

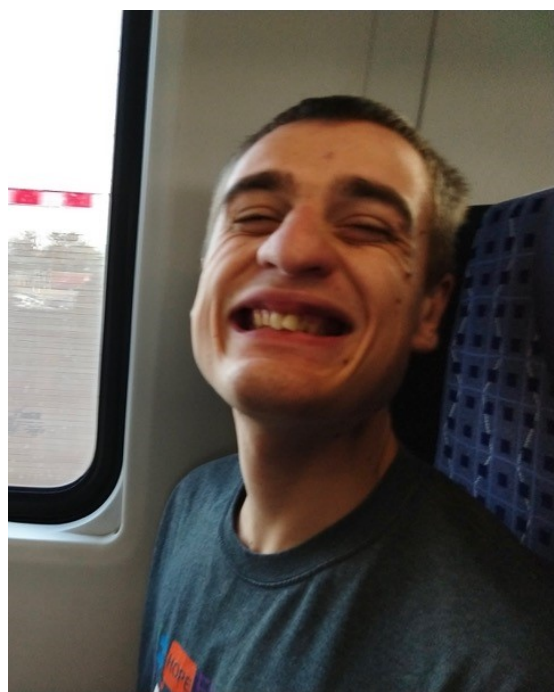
Go quietly FX Dad!
May you always be charged.



Ted News Flash!



Three Cheers for...



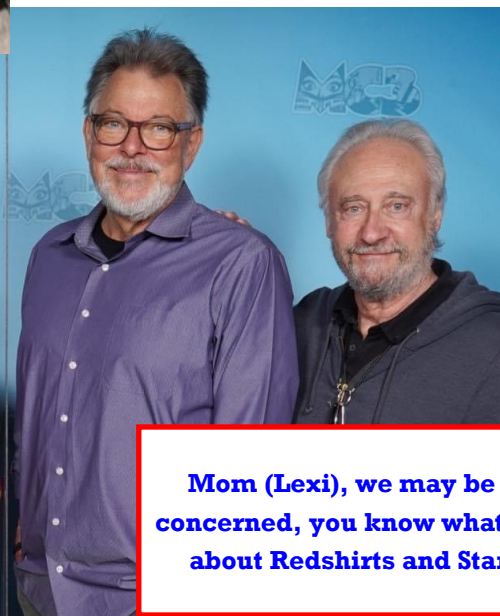
Paul - June has been a very full month for Paul Fodor. He has now completed three trips to Chicago for the Tetra study at Rush with Dr. Berry-Kravis.

Riding the train is his favorite.

Paul also went to Special Olympics state games where he earned a gold for shot put, silver for javelin and participated in the 100 m dash.

Three Cheers for...

Nicholas- now loves Comic-con. Here he is with Panda storm troopers, the Star Trek guys (William Riker and Data). And check out how he's loving the hug from the Guardian of the Galaxy guys (Kraglin and Yondo, with arm around Nicholas). He even did some Ghostbusting.



Mom (Lexi), we may be a little concerned, you know what they say about Redshirts and Star Trek.

Three Cheers for...



Andrew - for another successful annual trek to Chicago - waiting for Dr. Berry-Kravis, seeing her and relaxing in the car on the way home.



Research News

Innovative Breakthrough in Fragile X Treatment: The Promise of Antisense Oligonucleotide (ASO) Therapy

This changes everything!

In a paper published yesterday, "[Antisense oligonucleotide rescue of CGG expansion-dependent FMR1 mis-splicing in fragile X syndrome restores FMRP](#)" in the Proceedings of the National Academy of Sciences of the USA, FRAXA Research Foundation principal investigator Dr. Joel Richter and FRAXA Fellow Dr. Sneha Shah at UMass Chan Medical School and FRAXA investigator Dr. Elizabeth Berry-Kravis at Rush University Medical Center, describe a discovery that completely changes our understanding of [Fragile X syndrome](#).

Read more at:

[Innovative Breakthrough in Fragile X Treatment: The Promise of Antisense Oligonucleotide \(ASO\) Therapy • FRAXA Research Foundation - Finding a Cure for Fragile X Syndrome](#)

Bryostatin-1: a promising compound for neurological disorders

Abstract

The central nervous system (CNS) is the most complex system in human body, and there is often a lack of effective treatment strategies for the disorders related with CNS. Natural compounds with multiple pharmacological activities may offer better options because they have broad cellular targets and potentially produce synergic and integrative effects. Bryostatin-1 is one of such promising compounds, a macrolide separated from marine invertebrates. Bryostatin-1 has been shown to produce various biological activities through binding with protein kinase C (PKC). In this review, we mainly summarize the pharmacological effects of bryostatin-1 in the treatment of multiple neurological diseases in preclinical studies and clinical trials. Bryostatin-1 is shown to have great therapeutic potential for Alzheimer's disease, multiple sclerosis, fragile X syndrome, stroke, traumatic brain injury, and depression. It exhibits significant rescuing effects on the deficits of spatial learning, cognitive function, memory and other neurological functions caused by diseases, producing good neuroprotective effects. The promising neuropharmacological activities of bryostatin-1 suggest that it is a potential candidate for the treatment of related neurological disorders although there are still some issues needed to be addressed before its application in clinic.

Read more at:

[Bryostatin-1: a promising compound for neurological disorders - PMC \(nih.gov\)](#)

Get Involved, Register!

The Fragile X Research Registry

fragilexregistry.org/

International Fragile X Premutation Registry

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

Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning. ~ **Albert Einstein**

What's going on ...

Fragile X Awareness Day at Comerica Park!

July 22, 2023 - World Fragile X Day

6:10 pm game

Detroit Tigers vs. San Diego Padres

Tickets and details will arrive to you via email from Tiah Solway.

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!

FXAM Family Picnic



Saturday, August 26, 2023 at 4 p.m.

Our annual picnic will be held at the Tyler-Buikema home of Sulie, Jeff, Indigo, Jarrett and Keir



(please park on the side street Ruby, just south of the house)

Arrr mateys! X Marks the spot of the annual Fragile X Family Picnic!

The picnic will be held at the Tyler-Buikema home. We will provide hamburgers, hot dogs, beverages, and paper products, along with a few activities, canopies and tables. Please sign up to help us out with side dishes and desserts, activities and a new feature this year, a crunchy food bar with an offering of crunchy foods for our sensory seeking, food loving pirates, and we could use a few activities.

Avast ye! Bring along lawn chairs to rest your sea legs.

Ahoy - RSVP by August 10 or you might be walkin' the plank.

Respond by using this Evite link:

signupgenius.com/go/30E0F4DA4A82F4-argh

or, if that doesn't work for you,
email Sulie at Suliet@wideopenwest.com with your plans!

What's going on ...

Father & Son Picnic and Playday

FATHER & SON PICNIC AND PLAYDAY

Maybury State Park
Hickory Pavillion
49601 Eight Mile Rd
Northville, Mi



Picnic provided by FXAM
SEPT 23, 2023
10:30AM

Stay tuned for more details!



What's going on ...

FXAM Conference Scholarships for the NFXF International Conferences

by Tiah Solway, FXAM President

As always, when summer comes around my mind starts thinking about the NFXF International Conference. Whether I will be getting ready to leave in a couple weeks or I'm starting to plan ahead for next year, summer always brings with it the anticipation of the conference and gathering with hundreds of others from our Fragile X community. If you have never had the opportunity to attend, it can truly be a life-changing event. The Fragile X Association of Michigan has been fortunate through the years to be able to provide scholarships to assist our families attend the conference. However, as with many other charities, the impact of Covid, the economy and FXAM members only having so much time for all they want to do has made our incoming donations lower while we still want to support our families in various ways. In an attempt to continue our FXAM Conference Scholarship while using donations to their fullest, we are changing the application process. Here are some of the details to prepare families for the 2024 Conference Scholarship application.

As always, conference scholarships will only be open to FXAM members. How do you know if you're a FXAM member? Connect with Mary Beth Langan, FXAM Corresponding Secretary, if you are unsure. 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!

From the President's Desk by Tiah Solway

Hello and Happy Summer FXAM Families!

I hope everyone is having a wonderful summer break. I'm not sure about everyone else, but we are typically a "survive the summer" kind of family. This year we decided to get a permanent site at our local campground and have been spending the entire summer out here so far. The kids are loving it! Jonathan has become quite the social butterfly, riding his bike past other campers and talking to everyone as he goes. Isabelle has so many friends here that I hardly see her throughout the day as she's too busy playing and being a typical kid. It's so amazing to witness what this summer is doing for them both.



Summer 2023 also brings with it the opportunity to gather as a Fragile X community. We will be celebrating World Fragile X Day with the Detroit Tigers. One hundred members of our family and friends will be at Comerica Park to help cheer for the Tigers as they take on the San Diego Padres on July 22nd. For those of you who responded for seats to attend, your tickets will be sent to you very soon via email. Although most attendees will receive their t-shirts at the game, please change into them and wear them for the game. The Fragile X Association of Michigan, including all of us seated there, will be featured on the big screen around the 3rd inning and we want to make an impact!

Whether or not the Tigers game is a part of your summer schedule, we hope to see many of you on August 26th at our annual FXAM Family Picnic which will be hosted by the Tyler-Buikema Family in Rochester Hills. This year's theme is "X Marks the Spot" and as always, it is a family-friendly event so please bring your little pirates and buccaneers with you. See page 13 for more details on this event.

Usually the Solways are looking forward to the end of summer and the return of a school-year routine, but this might be one summer that we'll be sad to see end. I hope it's an amazing one for your family as well!

Caregivers Corner

I think we should all follow the advice of Miley.

"I can buy myself flowers
Write my name in the sand
Talk to myself for hours
Say things you don't understand
I can take myself dancing
And I can hold my own hand"

~ Anonymous

My favorite respite activity is doing things with my poor best friends (aka daughters).

Natalie and I just spent a long weekend in Virginia visiting Genevieve. Our next adventures include baseball with our favorite FX Family and three concerts, Ed Sheeran, Nickleback and Pink!
Mom's gonna be poor next. ~ Sally



eXtra, eXtra

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FXAM.org



All is well in New Baltimore, Michigan with Kevin. He celebrated his 29th birthday on July 2nd. Family had an ice cream cake for him along with a few friends and his favorite Chinese food restaurant takeout.

Kevin continues to get out in the community (traveling almost 10 miles in one direction to attend a movie with his CLS/respite friend, Tia). Kevin also attended New Baltimore's Bay-Rama Fishfly Festival in June.



Happy Belated Birthday Kevin!

We are all so proud of how often you are going out now, enjoying all the community has to offer.

Now we wanna know if you've mastered chopsticks.



"Live as is if you were to die tomorrow; learn as if you were to live forever."

— Mahatma Gandhi,