

Mark Your Calendar

Support Meetings

When:

October 5, 2024
November 2, 2024
(No meetings in December or January)

Business Meeting

10:15 - 11 am

Support Meeting

11 am - 1 pm

Where: Virtual

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

Special Events:

July 22, 2024

Fragile X Awareness Day

July 25-28, 2024

19th International Fragile X Conference
Orlando, Florida

August 24, 2024

FXAM Family Picnic
See page 3.

Fragile X Association of Michigan
FXAM.org

Contact Information:

313-689-3340

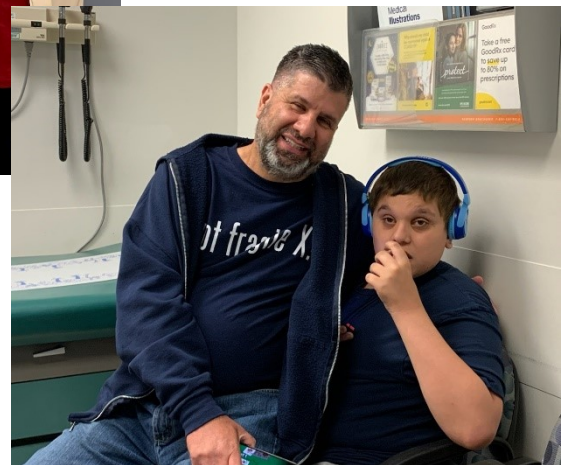
PO Box 1414
Troy, MI 48099-1414

Three Cheers for...

FX guru Dr. Liz Berry-Kravis



Andrew and parents Ted and Mary Beth made their annual visit to Rush University Medical Center in Chicago.



Austin, with the cool shades he got from his sister, and Woody, also visited Dr. Berry-Kravis in June.

From the President's Desk *by Tiah Solway*

I'm so happy to report that summer is finally upon us. While every one in Michigan has been off school and enjoying summer for a few weeks now, your Canadian friend has only just enjoyed her first full week of summer break. It's an added bonus that I work for the local school board so I get to enjoy a summer break from work with my kiddos.

Our summer started off with celebrations for my daughter Isabelle graduating from grade 8 (which I'm almost certain we only recognize in Canada). In the fall, she will begin a whole new chapter as she enters into High School.

July brings with it the added excitement of being a conference year for the National Fragile X Foundation. If any of our members are able to attend, we would appreciate you sharing your experiences for our October newsletter.

Rounding out our summer full of outdoor concerts, day trips, and pool parties have my kids finishing up their summer vacation attending camp for a week at Camp Grace Bentley. They both seem excited to go. With our fingers crossed and a lot of luck, we'll finish this summer off on a high note just how we started it!

Happy summer to all of our FXAM family!



Update on Andrew - Path to Supported Employment



Andrew is celebrating **ONE** year of supported paid employment! His favorite thing about his job is the people he works with.

Last year, in the July 2023 newsletter, his mom Kim provided an awesome article on their path to employment.

All newsletters can be found at:

fxam.org/support.html

What's going on ...

Through the Maze - FXAM Resources Page

We know how frustrating it is not to know where to go for help, get information, or find support and services that are available in Michigan. The FXAM Resources Page lists some, certainly not all, links, information and contacts that may be able to direct you to the right places.

Should you come across other items that you think would be beneficial to others, feel free to send them to [Sally Nantais](mailto:Sally.Nantais).

fxam.org/resources

Between the Lines - The FXAM Directory

Years ago we had a FXAM Directory to help FXAM families connect outside of our meetings and events - it was a great tool! An updated version is long overdue and nearly ready to be shared via email. Since April, Sally and I have tried to reach out to families multiple ways: via Facebook, group emails, individual emails and phone calls (and research to find folks for whom we don't have current info). If you are seeing this and you have NOT spoken with one of us, please contact Mary Beth at mblangan@hotmail.com so we get you connected!

FXAM Family Picnic



Saturday, August 24, 2024 at Noon

Our annual picnic will be held at the
Langan-Coutilish home
(Mary Beth, Ted and Andrew)
51 Greenbriar
Grosse Pointe Shores, MI 48236



Please save the date and watch the FXAM Facebook page for details on what will be provided and what you can bring!

Questions?
Contact Mary Beth
at mblangan@hotmail.com or 313-689-3340

“This is the power of gathering: it inspires us, delightfully, to be more hopeful, more joyful, more thoughtful: in a word, more alive.”

~ Alice Waters

What's going on ...

Vulnerable Impaired Person (VIP) Program

In Michigan, [MCL 722.774](#) and [MCL 28.274](#) allow a parent/legal guardian/power of attorney of an individual with special needs to voluntarily provide the Vulnerable or Impaired Person's (VIP's) fingerprints and photograph for inclusion in a State of Michigan repository that can be used to assist in identifying the VIP should he/she become lost in the future or find him/herself in a situation in which he/she cannot identify him/herself.

Fingerprints are captured electronically using a system known as Live Scan. Live Scan is a device that captures fingerprints by placing them on a lighted glass screen. Some Live Scan devices also have the capability to capture a photograph as well. A VIP's fingerprints and photograph (if captured) are stored along with additional demographic information, including the home address of the VIP and a contact person, email address, and phone number for the person legally responsible for the VIP.

Once enrolled in the VIP program, law enforcement has the ability to utilize a Live Scan device or mobile fingerprint scanner to access the information to quickly identify a VIP who may have trouble identifying him/herself. The goal of the VIP program is to return VIPs to familiar, safe environments, while maintaining their dignity.

Enrollment Process:

1. Download and complete the [BID-020 Individual with Special Needs Enrollment](#) form. Enrollment instructions can be found in the [BID-020i Vulnerable or Impaired Person \(VIP\) Fingerprint/Photo Enrollment Instructions](#) document.
2. Take the completed form to a participating Live Scan agency. Before going, it is highly recommended that you call the Live Scan agency to confirm the following:
 - The agency will print for the VIP fingerprint reason code, and whether there are certain days and times the agency will print for the VIP reason code.
 - If desired, find out if their Live Scan device has the capability to capture photographs
 - Ask about the cost. State of Michigan processing fees are now waived for this fingerprint reason; however, the fingerprinting agency may charge a fee to fingerprint an individual.
3. Once fingerprints are taken, make sure to get the completed VIP form back from the Live Scan agency. **To complete the enrollment process you must send the form to the Michigan State Police (MSP) within 30 days.** For audit and security reasons, if the signed form is not submitted to the MSP within 30 days, the VIP's fingerprints will be removed from the repository; fees will NOT be refunded. If fingerprints are removed, you may enroll in the future, but the process must be started from the beginning, including paying the fees again. The following are acceptable ways to send the completed VIP form to the MSP:

Email: MSP-VIP@michigan.gov

Mail: Michigan State Police, Attn: Autoprint Unit, P.O. Box 30634, Lansing, MI 48909

Fax: 517-284-3171

4. Look for an email confirmation that the individual's information was successfully stored at the State of Michigan. Please retain this email in the event that information needs to be updated in the future.

This information was originally shared in an email from Trina. She has enrolled her son Tyler in the program. Please reach out to Trina with any questions at Trina17@Ameritech.net.

Research - Northwestern University

Living with Fragile X Syndrome Seeking families to help us figure out the fragile X equation.

The Neurodevelopmental Disabilities Laboratory at Northwestern University is currently recruiting participants for an investigation intended to:

1. Study carriers of the *FMRI* premutation to determine how language and other skills developed over their childhood; and
2. Identify characteristics potentially related to the *FMRI* gene, and understand how they might relate to language and social traits evident in across development.

We're searching for individuals with fragile X syndrome or with the *FMRI* premutation and their family members, as well as people without fragile X or the premutation, and their families. We're currently recruiting families from Greater Chicago area and beyond.

Your level of participation is up to you. Your commitment can range from simply answering some questionnaires to full participation – doing some tasks involving words, sentences, pictures, and sounds; doing puzzles; solving problems; and completing some non-invasive brain-activity measurements.

This study is currently funded by the National Institutes of Health. All participants are compensated for their time, as well as for travel and parking.

Go here to get started: ndl.northwestern.edu/participation/

University of Michigan Fragile X Clinic

Appointments for evaluation for Fragile X Syndrome in the UM Fragile X Clinic will be available starting late Summer of 2024.

Appointments can be scheduled in the UM Fragile X Clinic by requesting a referral from your child's primary care physician or another specialist who follows them.

More information is available by calling 734-764-0579.
Ask to speak with Jessica for more information about the clinic.

For appointments for those affected by FXTAS, you'll still call the East Ann Arbor Health and Geriatrics Center at 734-647-5670.
Ask for an appointment with Dr. Peter Todd in the Ataxia Clinic.

Three Cheers for... Our Graduates

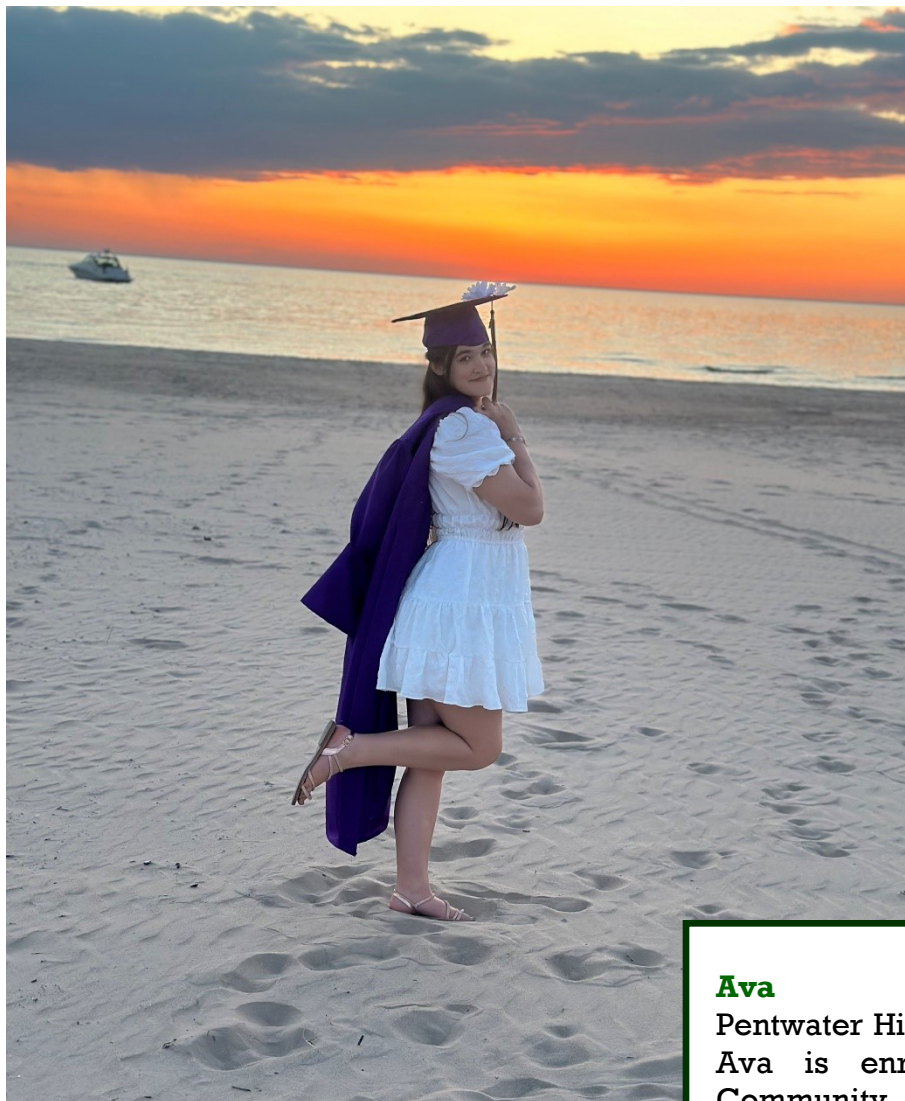


Kendra Jean Clemons

Fowlerville HS Class of 2024

Kendra favorite class in school was Yoga! She also loved making/selling popcorn every Friday to make money for her living skills class. Kendra's next adventure is attending LESA Adult Transition in Howell. There she will learn more life skills to hopefully become a little more independent!

Three Cheers for... Our Graduates



"If you can't fly then run, if you can't run then walk, if you can't walk then crawl, but whatever you do you have to keep moving forward."
~ Martin Luther King Jr.

Ava

Pentwater High School Class of 2024! Ava is enrolled at West Shore Community College in the fall and hopes to be a travel photographer in the future. Mom Tarra couldn't be more proud of this girl or the way she has overcome her struggles. Congratulations Ava!

Three Cheers for...

Detroit Tigers

FXAM is happy to have sponsored a Fragile X Awareness Tigers event for the second year! We are grateful for families who came out for the event to help us spread the word!



Three Cheers for...



Three Cheers for...



Three Cheers for...



Three Cheers for...



Three Cheers for...



Three Cheers for...

Happy Birthday Kevin - He celebrated his 30th birthday on July 2. We had a milestone party for him with a few close friends (not sure how this was going to go so we invited only people who know him well and have been kind to him with his FX behaviors). He's been making strides with his agoraphobia by trying new places close by home. The Michigan weather has been more tropical than normal lately so the weather has been a stumbling block. His anxieties revolve around fog, rain, thunderstorms and wind.



Three Cheers for...

Special Olympics



Nicholas –
competed in shot
put and the 100
meter dash.

Jacob – his team (Area 9) received a bronze medal in division one volleyball at CMU. This was his first year playing volleyball. He had a great time hanging out with all his teammates and enjoyed the special activities after playing some very tough games.



Three Cheers for

Special Olympics



Paul – who earned silver (standing long jump), fourth (shot put), and sixth (100 meter dash) at Special Olympics state games.



Dr. Brenda from the Dr. Pol Show – visited the Fowlerville Fairgrounds for a 4H presentation and took the time to have a picture with Nicholas.

Editors:

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