

Mark Your Calendar

Support Meetings

First Saturday of the Month
No meetings in March and May

When:

February 1, 2025
April 5, 2025
June 7, 2025

Business Meeting

10:15—11 a.m.

Support Meeting

11 a.m. - 1 p.m.

Where:

Virtual, Zoom details
us06web.zoom.us/j/5604266326.

Plans are underway for in-person meetings in April and June 2025. Stay tuned for details!

Special Events:

February 24-25, 2025

Advocacy Day
See page 3.

Fragile X Association of Michigan

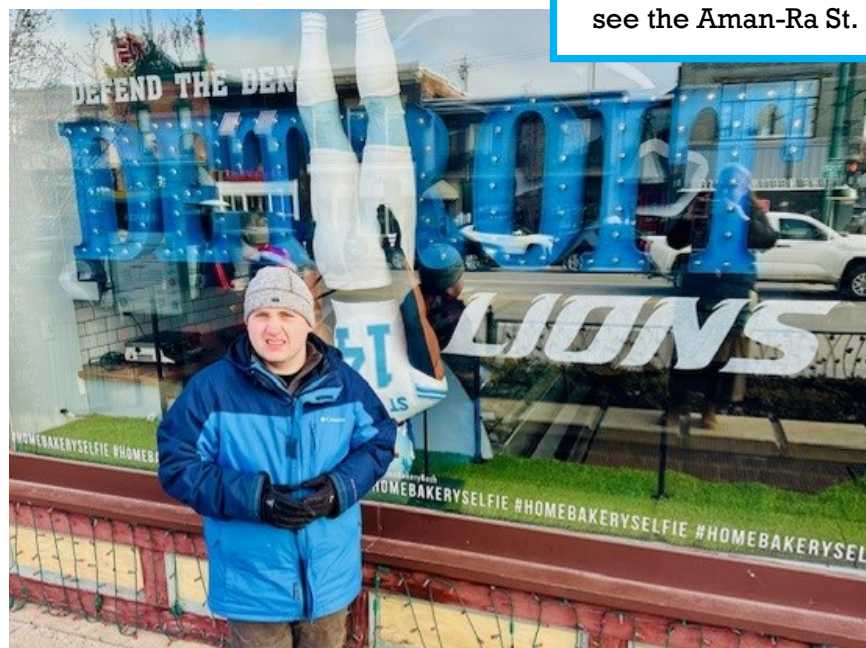
FXAM.org

Contact Information:
313-689-3340

PO Box 1414
Troy, MI 48099-1414

Three Cheers for...

Keir - and mom, Sulie, took a field trip to the Home Bakery to see the Aman-Ra St. Brown cake.



University of Michigan Fragile X Clinic

The University of Michigan Fragile X Clinic is accepting new patients! The clinic manages the care for both children and adults with Fragile X syndrome. Clinicians include a geneticist, genetic counselor, and developmental behavioral pediatrician.

uofmhealth.org/conditions-treatments/ped-genetics

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.

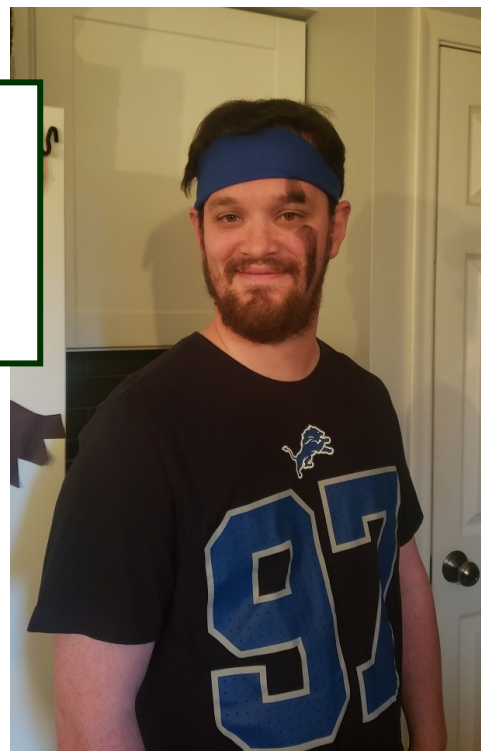
More information is available by calling 734-764-0579 or by emailing UMFragileX@med.umich.edu

People who are seeking appointments for FXTAS can contact the East Ann Arbor Health and Geriatrics Center at 734-647-5670. Please ask for an appointment with Dr. Peter Todd in the Ataxia Clinic.

Three Cheers for...

Andrew - enrolled in the Tetra study and he began the medication/placebo this January. Details on the Tetra study can be found in our October [newsletter](#) on our website.

Awesome Lions swag Andrew!



Jake, Abbie and Sam - made it to Cape Coral and back with no meltdowns or tantrums, 20 hours each way. We hope Mom and Dad were just as successful!



It doesn't matter how strong your opinions are. If you don't use your power for positive change, you are indeed part of the problem.

~ Coretta Scott King



NATIONAL FRAGILE X ADVOCACY DAY

FEBRUARY 24-25, 2025

Learn more and register at: [Advocacy Day 2025](#)

This year's training and visits to The Hill will be LIVE and in person February 24-25. February 24 is a training day and February 25 is Advocacy Day. Full details and Registration available at the link above.

Registration: \$40 per individual to participate; children up to age 10 are free.

Hotel - Hilton Arlington Towers

Rate: \$189 + fees/taxes, **Special Room Rate Deadline:** January 25, 2025

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 and Mary Beth Langan at mblangan@hotmail.com, by February 1, 2025, to apply for the grant.

Thank you for considering advocating for Fragile X!

From the President's Desk by Tiah Solway

Greetings FXAM Families! I hope this newsletter finds you and yours well and that all had a good holiday season. I hope you found your holiday season restful. After beginning a career, a couple years ago working with special needs students in school, I will admit that the favorite part of my job is that I get the same breaks as my kids. Being able to spend two weeks with them in the middle of all the hustle and bustle, playing board games and having family movie nights was the perfect way to spend a couple weeks in the middle of winter.

As an all-volunteer support group we are always looking to improve by supporting one another, raising awareness for fragile x and advocating for our loved ones. February, we have the unique opportunity to do all three. Above we have details on Adcocacy Day, if you wish to participate it is imperative that you connect with me and Mary Beth by **February 1**. On the FXAM website, the Advocacy page, we also have shared memories from FXAM members who have previously attended advocacy that may assist you in understanding the process.

I would also like to remind everyone that all support meetings are available on Zoom, and our login no longer changes, it will always be the same, us06web.zoom.us/j/5604266326. Please note there is not a support meeting in March and May this year.

Besides Advocacy Day we will have our annual picnic, typically in August and we are currently hoping to host a fall festival thanks to a donation we received from [Eagles for Children](#).

Stay tuned to our [facebook page](#) and/or make sure [Mary Beth](#) has your contact email to keep you informed of other popup events, that may not be included in the newsletter.

This year is not an International Conference year but 2026 will be here before you know it. The 2026 conference will be held in Louisville, Kentucky, not that far from Michigan. Remember we have changed policies for scholarship eligibility which can be found [HERE](#), the event page on the FXAM website.



eXtra, eXtra

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313-689-3340

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**FXAM Holiday Party
December 7, 2024**

