

Mark Your Calendar

Support Meetings

First Saturday
of the Month
No meetings in
July, August
and September

When:

June 7, 2025

Business Meeting

9:15 - 10 a.m.

Support Meeting

10 a.m. - 12 p.m.

Where:

Gather + Grounds
or on Zoom
See page 2.

Special Events:

July 12, 2025

2025 Cincinnati
Family Fragile X
Conference
See page 2.

July 22, 2025

World
Fragile X Day
See page 3.

Fragile X Association
of Michigan

FXAM.org

Contact Information:

313-689-3340

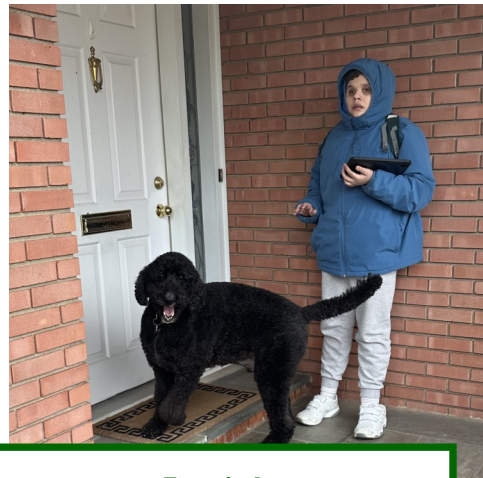
PO Box 1414

Troy, MI 48099-1414

Three Cheers for...



Austin— he picked this ride, you can see the sheer terror on his face, a 50 foot drop. At the end of the day, he picked this as his favorite ride.



Louie!

Our house guest for a month.

Cracker Barrel!

One of Andrew's favorite restaurants.



5 Things I Love About Fragile X by Mary Beth Langan

1. I have a world-wide family who understands our ups and downs although we may be at different places on the Fragile X spectrum.
2. There are carrier moms who have similar issues as me; I don't feel alone.
3. We have some wonderful FX gurus - my favorite is Dr. Liz Berry-Kravis!
4. Being able to share experiences (and questions) with other families on Facebook and at conferences (and locally!) has been so helpful over the years.
5. Andrew isn't embarrassed to have kisses and hugs from me at age 24!

June Support Meeting



Gather + Grounds
gather-grounds.com
 25709 Van Dyke Ave.
 Center Line, MI 48015
 Saturday, June 7, 2025
 Business Meeting 9:15 - 10 a.m.
 Support Meeting 10 a.m. - 12 p.m.



Can't make it in person, Zoom is still an option:

<https://us06web.zoom.us/j/5604266326?pwd=xBR8HStWuxnbwJTaa92v4qA4NIIM1w.1>

Meeting ID: 560 426 6326 Passcode: 21kVUq

About Gather + Grounds

There are no community places where intellectually disabled young adults can gather, spend time and experience love, connection, and conviviality. Most public places make them feel awkward. As a result, they seek out comfortable, passive social activities, such as phones and social media, from the security of their own homes.

Enter: Gather + Grounds, a **bistro** by day and gathering place by night. We provide a positive, caring space for young adults with special needs and all community members. Young adults gain important job skill training during open daytime hours and can spend time socializing with friends in the evening.

2025 Cincinnati Family Fragile X Conference



Saturday, July 12, 2025
8:30 a.m. - 5 p.m.

Top experts will be presenting on a broad range of topics. Topics include, but are not limited to, the latest research and treatments, practical skills for different life stages, behaviors, interventions, self-advocacy, pre-mutation carriers, FXTAS, and Fragile X community positivity.

We welcome families and researchers to register for this opportunity to learn and connect!

The conference offers complimentary food and child/adult care services. **To ensure we order enough food, we kindly ask that you register for the event early.**

No cost to register (there is an option for a donation).

Register at: web.cvent.com/event/3c926471-8622-401c-86c8-06bb384d3bb8/summary

Can't make it in person? Good news! This event allows for virtual attendance! Watch sessions live or access recordings of presentations post-conference! Register if you'd like to have access to these virtual sessions and recordings.



WORLD FRAGILE X DAY ***JULY 22, 2025***

Every year on July 22, FRAXA Research Foundation and partners celebrate World Fragile X Day with communities around the world. Join Us!

[World Fragile X Day](#) (WFXD) celebrates families impacted by Fragile X syndrome and highlights advancements of research to find effective treatments and ultimately a cure. On World Fragile X Day we shine a light on Fragile X by illuminating monuments and landmarks around the world. We gather with friends and family to celebrate loved ones who shine in the face of Fragile X. FRAXA launched World Fragile X Day in 2021 uniting Fragile X families and organizations all around the world.

Learn more at: fraxa.org/world-fragile-x-day/

Michigan Organizations Supporting Disabilities

The Arc Michigan is a leading advocacy organization dedicated to protecting and promoting the rights of people with intellectual and developmental disabilities (IDD) across the state. As part of a nationwide movement, we work to ensure that individuals and families in Michigan have access to the information, resources, and advocacy they need to support full inclusion and participation in their communities—at school, at work, and in life. . Many county Arc's provide virtual and in-person workshops, and don't forget to check out your neighboring counties. The Arc of Western Wayne county offers a great "After I'm Gone" program to assist in preparing for the future.

Find your local Arc at arcmi.org/find-your-local-arc/.

Michigan Alliance for Families is a statewide resource to connect families of children with disabilities to resources to help improve their children's **education**. We help facilitate parent involvement as a means of improving educational services and outcomes for students with disabilities. Michigan Alliance for Families can assist you in knowing your rights, effectively communicating your child's needs, and advising how to help them develop and learn. Don't forget to check out their events page, numerous workshops are presented throughout the year with topics from basic IEPs through adult transition programs.

Learn more at: michiganallianceforfamilies.org/

Be a Hero

"Heroes didn't leap tall buildings or stop bullets with an outstretched hand; they didn't wear boots and capes. They bled, and they bruised, and their superpowers were as simple as listening, or loving. Heroes were ordinary people who knew that even if their own lives were impossibly knotted, they could untangle someone else's. And maybe that one act could lead someone to rescue you right back."

~ Jodi Picoult, *Second Glance*

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.

On the Research Front.... with Sally

October 2024 newsletter was filled with many research participation opportunities, for children, adults and premutation carriers. A lot has happened since then and I'd like to share with you some of the updates.

Reconnect Study:

Harmony Biosciences Holdings, Inc. (Nasdaq: HRMY) today announced the presentation of updated data from its Open-Label Extension (OLE) study (ZYN2-CL-017) evaluating the safety and effectiveness of ZYN002 in children, adolescents, and adults with Fragile X syndrome (FXS). The data showed clinically meaningful improvements in irritability-related symptoms prevalent in individuals with FXS. There are currently no U.S. Food & Drug Administration (FDA) approved treatments for FXS.

Read more at: finance.yahoo.com/news/harmony-biosciences-presents-promising-open-120500495.html

Tetra (now a subsidiary of Shionogi & Co., Ltd) aka Shionogi's EXPERIENCE Phase 3 Clinical Trial of Zatulmilast in Fragile X Syndrome:

We have an update on the progress of Shionogi's EXPERIENCE clinical trials (also known as BPN14770-CNS-204, BPN14770-CNS-301, BPN14770-CNS-302 and the Tetra studies): As a result of an unprecedented surge of interest by this incredible community, enrollment for the adult study in Fragile X syndrome (EXPERIENCE-301) is nearly at capacity and screening will close today. Clinical trial sites are working with Shionogi to accommodate previously scheduled appointments for potential new study participants. Notably, clinical trial sites are no longer able to accommodate new appointments as the clinical trial cannot recruit far beyond the planned 150 individuals without putting the protocol integrity of the trial at risk and exhausting the total clinical trial drug supply.

The adolescent study in Fragile X syndrome (EXPERIENCE-204) is in its final phase of enrollment. All scheduled screening appointments will proceed as planned; however, no additional screening appointments are available. On behalf of our team and our partners at Shionogi, we are grateful for the support of the community in both raising awareness of and participating in these studies.

Please note the open-label study (EXPERIENCE-302) is ongoing for individuals who have completed EXPERIENCE-301 or 204. We look forward to sharing the results from these studies.

Read more and watch the video from Shionogi's CEO at:

fraxa.org/shionogi-experience-phase-3-clinical-trial-of-zatulmilast-in-fragile-x/

On the Research Front.... with Sally (continued)

New, something to watch for BK channel openers

BK channel openers are substances that increase the time BK channels, also known as large-conductance calcium-activated potassium channels, remain open. BK channels are crucial for regulating neuronal excitability and various physiological processes. Opening these channels, in turn, can lead to decreased excitability of neurons and other physiological effects.

BK channel openers are being explored as potential treatments for various conditions, including:

- Neurological disorders (e.g., Fragile X, Parkinson's, Alzheimer's).
- Conditions involving hyper-excitability or smooth muscle dysfunction.

SPG601

This investigational therapy is designed to address synaptic dysfunction in FXS by targeting BK channels. By activating these channels, SPG601 aims to restore proper synaptic function and potentially alleviate FXS symptoms.

A single dose of [Spinogenix](#)'s investigational oral therapy SPG601 led to significant reductions in a measure of abnormal brain activity among men with fragile X syndrome, according to top-line results from a Phase 2a trial.

Read more here: fragilexnewstoday.com/news/spg601-reduces-measure-abnormal-brain-activity-fragile-x/

KER-0193

Kaerus Bioscience (www.kaerusbio.com), a clinical-stage biopharmaceutical company created by Medicxi for the development of therapeutics for rare genetic syndromes of neurodevelopment, today announces the successful completion of its Phase 1 clinical trial of KER-0193, a novel BK channel modulator the company is developing for Fragile X syndrome (FXS) and other neurodevelopmental conditions.

Read more here: biospace.com/press-releases/kaerus-bioscience-successfully-completes-phase-1-trial-and-demonstrates-proof-of-mechanism-with-its-novel-bk-channel-modulator-ker-0193-being-developed-for-fragile-x-syndrome

Through The Maze Featured Website

Liv Joy Foundation

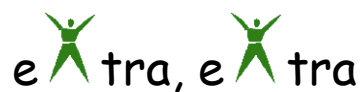
livjoy.org/

LivJoy was founded in 2023 to find, fund, and share programs that enable girls with fragile X to live a life full of joy. For the founders, it is the landing point they wish they had when searching for answers for females with fragile X. They hope it helps families, at all stages of diagnosis and life, find both resources and reassurance that there are other people going through the same experience.

What Every Parent Should Know About Supplemental Security Income (SSI) and Your Child Turning 18

The Social Security Administration (SSA) manages TWO different programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

1. **When a child with a disability turns 18, they can file for Supplemental Security Income (SSI).**
 - At 18, when they apply, it's based on their income ALONE, not yours.
 - If your family exceeds the income cap, you cannot apply prior to 18, if you make an appointment prior to their 18th birthday YOUR income will be included.
 - If you make the appointment after their 18th birthday only the applicant's income counts.
2. **What is considered Income(resource)?** Savings and checking accounts, mutual funds, savings bonds, certificates of deposits, joint accounts, real estate and other resources in the applicant's name will come into play. Any earned or unearned income. Any asset in their name that could be sold and converted to cash will be counted as a resource, part of their income. Be cautious with trusts. Special needs trusts (not in the child's name, but designed to benefit the child) may provide an opportunity for additional funds outside of the income cap. If special needs trusts are not set up correctly, they can end up jeopardizing the person's ability to collect SSI and eligibility for Medicaid.
3. **How far back do they look at income during the application process?** In our case they went back three years; this could change. If you have savings bonds, mutual funds, college funds, and/or stocks in your child's name (even if they only have joint ownership) you may need to dissolve or move the accounts out of your child's name. Plan for this well in advance, this is not something you want to do a week or two before your appointment. It may be nice that relatives provide savings bonds at each birthday or Christmas, but keep in mind **these do add up**. They will be listed as income and when your child applies it could make them ineligible to receive SSI. Another thing to be aware of is any wills or beneficiaries your child is listed in, any large sum of money that goes to them directly (even in the future) will make them ineligible for SSI and may also impact their ability to receive Medicaid.
4. **Guardianship/Power of Attorney.** You will need to decide if you will obtain guardianship or have a durable power of attorney. This is a personal choice, you need to do what's right for you and your child. Guardianship from state to state, and in some cases county to county may vary. You may need to obtain legal assistance. Your local Arc or a neighboring Arc, or a parent advocate group may be able to assist you with this matter. Find your nearest Arc at thearc.org.
5. **Will your child/dependent pay rent or will they share in the household expenses?** If your child shall pay you rent/room and board, you need to report the amount they will pay. If you charge rent, you will need to account for this on your taxes. If your child will share in the household expenses, you need to be prepared at the Social Security appointment to list everyone who lives in the household, their SS number(s) and monthly household expenses (mortgage, gas, electric, water, cable, groceries, etc). Most importantly, you do not want to say you will provide for all their needs during your interview, this will drastically reduce the amount they may be entitled to, decide before the appointment rent or share.
6. **Online application.** If you want to save time at the appointment, fill out the application online and make your own copies for your records and to submit at your appointment. Bring a printed copy of the application along with you, in our case all of the meds crossed over fine from the online form, but not all of the doctors information did.
7. **Identification.** Apply for your child's State ID card long before your appointment. This is necessary to create their financial account and setting up their SSI.
Applying for an ID - http://www.michigan.gov/documents/sos/Applying_for_lic_or_ID_SOS_428_222146_7.pdf
8. **Financial account.** If you want to use a direct deposit option, open your child's bank/credit union account prior to your appointment. Make sure you have the institution's routing number and your child's account number with you.
9. **Supports for your application.** Keep in mind, you/your child will grant the SSA access to all of their medical records but there are other pieces of information you may wish to include with your child's application, not available in the medical records, or available but you may wish for them to stand out. Bring copies of documents from throughout their lifespan. If you kept records of medications, doctors, therapies, evaluations, hospital stays, etc., throughout their lifetime it will be much easier to assemble your supports.
10. **Where to learn more:**
 - Social Security – Supplemental Security Income - <http://www.socialsecurity.gov/pgm/ssi.htm>
 - Off-topic - at 18 males must register for Selective Service www.sss.gov
 - Alternatives to Guardianship - <http://www.michiganallianceforfamilies.org/resources/guardianship/>
 - Guardianship Alternative Information Network, After I'm Gone program, and much more available through the Arc of Western Wayne County - <http://www.thearcww.org/programs-services/#GAIN>



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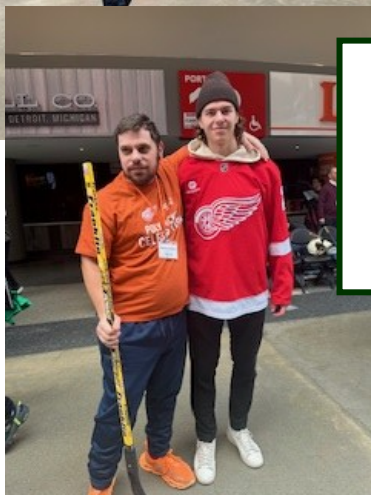
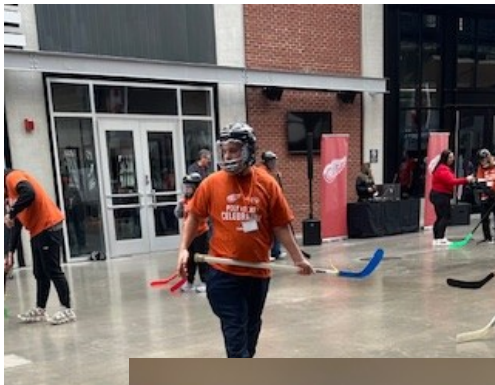
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Nicholas—loves his Red Wings day and Special Olympics Michigan Basketball.

Lexi— three cheers for you always sharing Nicholas with us!

