

## Mark Your Calendar

### Support Meetings

No meetings in November, December and January

**When:**

February 7, 2026

**Business Meeting**

10 - 11 a.m.

**Support Meeting**

11 a.m. - 1 p.m.

**Where:**

Virtual information will be shared via email and FXAM Facebook page.

### Special Events:

**November 1, 2025**

**FXAM Fall Festivities**

**December 6, 2025**

**FXAM Holiday Party**

See page 11.

**July 16-19, 2026**

**NFXF International Conference**

Louisville, Kentucky  
Scholarship info on page 12.

**Fragile X Association of Michigan**

[FXAM.org](http://FXAM.org)

**Contact Information:**

313-689-3340

PO Box 1414

Troy, MI 48099-1414

### Save the date!

**FXAM Fall Festivities on Sat, Nov 1, 2025 11 am - 3 pm**  
at Upland Hills Farm (Oxford, MI)

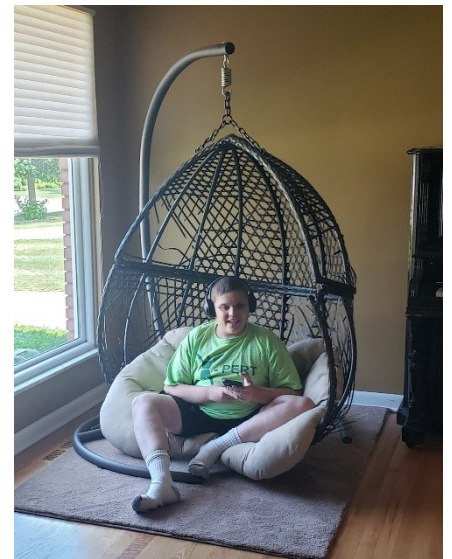
FREE for our families thanks to an *Eagles for Children* Grant (application by Lauren Sienko Majeske).

Fun, farm animals, and food - ALL FREE!

Stay tuned for more details. [uplandhillsfarm.com](http://uplandhillsfarm.com)

## Three Cheers for...

## FXAM Family Picnic



**Three Cheers for...**

**FXAM Family Picnic**



**Three Cheers for...**

**FXAM Family Picnic**



**Three Cheers for...**

**FXAM Family Picnic Selfies with Sally**



**Three Cheers for...**

**FXAM Family Picnic Selfies with Sally**



**Three Cheers for...**

**FXAM Family Picnic Selfies with Sally**



**Three Cheers for...**

**FXAM Family Picnic Selfies with Sally**



**Memories made and moments captured!!**

## Three Cheers for...

*Shared by The Village View of  
Grosse Pointe Shores, MI*



## GPS Communication Intern Sam Price Balances Storytelling, Advocacy, and Instagram Savvy — and Proves Every Doubter Wrong

[Sam Price](#) doesn't just tell stories — she *is* one.

Diagnosed with [Fragile X Syndrome \(FXS\)](#), a genetic condition often misunderstood and underestimated, Price has never let a label define her.

What defines her is heart and hustle.

She's transforming GPS's [Instagram feed](#) into a storytelling superpower — and as a reward she's being promoted from a volunteer to a paid intern.

Every post she shares reflects her talent and creativity.

Take the moment the GPS Sharks swim team finished the season undefeated for the first time in history on July 16. Price saw more than just a scoreboard triumph. She saw a narrative waiting to be told — one filled with the joy of teammates, the pride of a community, and the power of a perfectly timed post.

"I loved seeing all the photos come out from that swim meet," she said, recalling the excitement of choosing which shots would make it to Instagram. "Everyone was so excited, and that made the post stand out."

### Advocacy and Empathy

Price's strength comes from a well of resilience.

Diagnosed with FXS early in life, she was once told by doctors she wouldn't attend college. In April 2025, she graduated with a BA in Communication Studies with a minor in Marketing at [Western Michigan University](#) — and has already built a resume that proves them all wrong.

"Overcoming that obstacle was huge and so relieving," she said. "No doctor should be telling parents that after a life-changing diagnosis."

Her advocacy work with the [National Fragile X Foundation](#) — where she lobbied on Capitol Hill to help pass the [ABLE Act](#) — taught her empathy, confidence, and the power of voice. These are qualities she brings to every post, every interaction, and every piece of content she shares.

### From Volunteer to Voice of a City

In December 2024, Price joined GPS as a volunteer communication intern. She was assigned to manage the GPS Instagram account while she was wrapping up her senior year in college.

Posting while living in Kalamazoo presented challenges.

As it turns out, she isn't just managing content — she's creating stories with impact. Price uses her creativity, smarts and wits to find interesting tidbits, facts and stories to post from hours away.

"From day one, Sam has impressed with her professionalism, innovation, and joyful spirit," said [Ted Couti-lish](#), Chair, GPS Communication Committee. "Watching Sam grow into this role has been exciting and inspiring. She has a remarkable ability to find interesting content and present it with warmth, authenticity, and style. She has brought a whole new energy and creativity to our city. Her posts inspire and connect our residents in truly meaningful ways."



## She's Priceless *(continued)*

### Zooming In: Finding Beauty in the Details

When Price first began posting for the GPS Instagram account, she took a deep dive into the hidden details of her adopted hometown. The revelation? GPS is just 1.1 square miles — but with over 18 miles of Lake St. Clair shoreline, it's packed with scenic and historic charm.

"I wanted to post things that residents don't usually see on Facebook," she said.

Her mission was clear: celebrate the overlooked, the fascinating, and the deeply local.

With an eye for detail and a commitment to consistency (a lesson learned during her time as WMU's Alpha Omicron Pi's social media lead), Price creates a content cadence that invites interaction, curiosity, and pride.

### A Feed with Feeling

Photography, according to Price, is more than aesthetics — it's narrative. Whether she's sharing a city council video or a lakeside snapshot for her "MyPricelessPics" account, each image is carefully selected to tell a story.

"I've always loved photography," she said. "Photos can tell a story about what's happening — and then I add a fun caption or a song to match the vibe."

This emotional intelligence — paired with technical skills in Adobe Lightroom, Photoshop, and Canva — allows her to create content that resonates across demographics. From residents to city officials, from sorority sisters to summer campers, she speaks a digital language everyone understands.

### A Natural Collaborator

Behind every post is a team — and Price knows how to lead one. At WMU, she served as Vice President of Community Relations for Alpha Omicron Pi, where she didn't just post, she partnered.

"Brainstorming with our Executive Team came naturally," she said. "I wanted to know what everyone would like to see on social media."

This commitment to collaboration continued at [MSU Tollgate Farms and Education Center](#), where she managed daily camp blogs and helped run a photo-sharing system that respected privacy while building community. Whether working with teachers, city employees, or other creatives, she thrives on team energy and shared vision.

### Always Online, Always Inspired

"I'm always online," Price laughs, "so I see everything."

For her, this is an advantage. She tracks trends, follows creators, and studies digital behavior. From TikTok to Instagram Reels, she keeps tabs on what's hot — and what's heartfelt.

She's not just following the wave. She's studying it.

"I hope to find a fun, full-time social media, communication, or marketing job," she said. "I'm open to anything."

Whether it's managing a city's presence or a brand's voice, her goal is to keep growing — and glowing.

### Advocacy, Authentically

Her final semester at WMU was a burnout rollercoaster ride, but crossing the finish line brought a rush of relief and accomplishment. Today, now as a paid intern for GPS, she's seeing her work — and worth — grow and come full circle.

In August, she was hired and paid to help create content and manage all of the social media accounts during the three-day [Assumption GreekFest](#) in St. Clair Shores.

"It makes me feel like I'm doing a good job," she said. "It's rewarding."

Her advice for those entering the communications world, especially those who have special needs? Ask questions. Be yourself. Say yes — even when it's scary.

## She's Priceless *(continued)*

Because when Price steps into a role — be it advocate, photographer, or social media strategist — she brings her whole self.

And it shows.

“If I can help people feel seen — even through a post — then I’m doing exactly what I’m meant to do,” she said.

### Fast Facts About Sam Price

#### Education:

BA in Communication Studies, WMU, April 2025.

#### Early Advocacy Work:

From age 9, she advocated on Capitol Hill for the National Fragile X Foundation, helping pass the ABLE Act in 2014.

#### Overcomer:

Doctors once told her parents she’d never go to college due to her disability. Now, she’s an alumna.

#### Hidden Talent:

She’s a Broadway musical lover and former child actor who grew up performing in theater productions.

Original article: [gpshoresmi.gov/community/shores\\_spotlight.php](https://gpshoresmi.gov/community/shores_spotlight.php)



## **FXAM Holiday Party—Our Annual Potluck Gathering**

Saturday, December 6, 2025 at 5 p.m.

Let's celebrate and look ahead to 2026 with our FXAM Family at the home of  
Mike, Tina, Hayden, and Cynthia

Some parents make it a date night. Some bring the whole family.

Whatever works for you! Please watch the FXAM FB page in November regarding the # attending and what delectable you'll add to the gathering.

Contact Tina at [tmakris.fx@gmail.com](mailto:tmakris.fx@gmail.com) or 210-441-8566.

## **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](https://uofmhealth.org/conditions-treatments/ped-genetics)

Appointments can be scheduled in the UM Fragile X Clinic by requesting a referral from your family member'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](mailto: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.

## **FRAXA Research Foundation—Updated Medical Guide**

This [Medication Guide for Fragile X Syndrome \(Version 6, 2025\)](#) is offered as a gift to the community. It was created to support families and caregivers as they navigate treatment options for the behavioral and psychiatric symptoms of [Fragile X syndrome](#).

While each person with Fragile X is unique, many experience symptoms such as anxiety, hyperactivity, impulsivity, mood changes, and social difficulties. Medications can be an important part of managing these challenges, but finding the right treatment can be difficult, especially when healthcare providers are not familiar with Fragile X.

This updated medication guide helps bridge that gap. It offers clear, parent-friendly information about medications commonly used in Fragile X syndrome, including how they may help and what to consider. Whether you are exploring medication for the first time or want to better understand current options, this Fragile X medication guide is here to support informed decisions and stronger collaboration with your care team.

## National Fragile X Foundation (NFXF) International Conference

July 16-19, 2026  
Louisville, Kentucky

**The NFXF 2026 Conference will be in Louisville, Kentucky and now is the time to plan for the conference.**

The conference will be July 16-19, 2026. Louisville Marriott Downtown, Louisville, Kentucky

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. In an attempt to continue our FXAM Conference Scholarship while using donations to their fullest, here are some of the details to prepare families for the 2026 Conference Scholarship application.

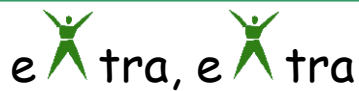
As always, conference scholarships will only be open to FXAM members. How do you know if you're a FXAM member? Connect with Mary Beth Langan, [mblangan@hotmail.com](mailto:mblangan@hotmail.com), FXAM Corresponding Secretary, if you are unsure. While membership is FREE, we need a membership form completed 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 2026 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.

In addition to these requirements, we will also ask for scholarship recipients to share with the group something about your conference experience with our FXAM group. 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 2026 NFXF International Conference from July 16-19 in Louisville, Kentucky.



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**313-689-3340**

**FXAM.org**

## The End

*This October it's time for change. In my 68<sup>th</sup> year of life I am retiring from the FXAM newsletter. First and foremost, I need to note that I could not have done it without Mary Beth, my co-editor.*

*Mary Beth and I first met at a FXAM support meeting in November 2002. For a couple of years there was a lot of discussion within our group about doing a newsletter for our local fragile X community. In January 2005, Mary Beth and I published the first edition of "eXtra, eXtra".*

*Eighty-four newsletters later it's time for change.*

*You will still hear from me and Mary Beth when we pass on information through our FXAM email group and on our FXAM Facebook (META) page. I will still maintain the FXAM website.*

*I am now a resident of Florida, but a summer-bird, coming back to Michigan during the summer. This may evolve depending on Jerry's mobility with MS. The two-story house in Wyandotte will eventually become impossible for him to navigate. I will still try to actively participate in the support meetings virtually. You have all become a very important part of my life and I just can't close the door completely on FXAM.*

*It's been a good run and thank you to all who have contributed to the newsletter over the years. XOXOXO, Sally*

Knowledge is power.

Knowledge shared is  
power multiplied.

~ Robert Boyce