

Mark Your Calendar

Support Meetings

First Saturday of the Month
(No meetings in July, August & September)

When:

October 1, 2022
November 5, 2022

Business Meeting

10 - 11 a.m.

Support Meeting

11 a.m. - 1 p.m.

Where:

Berkley Public Library
3155 Coolidge Hwy
Berkley, Michigan

Special Events:

July 16, 2022

**FXAM Moms:
Let's Do Lunch!**
See page 2.

July 22, 2022

World Fragile X Day

August 13, 2022

FXAM Family Picnic
See page 2.

September 17, 2022

**FXAM Parents
Night Out**
See page 2.

October 22, 2022

**FXAM Father and Son
Picnic/Play 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...

World Fragile X Day! July 22, 2022!

Check out the 230+ venues
around the world
lighting up teal for awareness on July 22.

worldfragilexday.com

Thank you to Grosse Pointe Shores
City Hall for participating!

**Miracle League Baseball -
Hey Batter, Batter!**
Doesn't Michael look good?!



Keir - Started off his fourth visit to Camp Skyline having fun with a parachute and other campers!



FXAM Moms: Let's Do Lunch!

Saturday, July 16, 2022 at 11 a.m.

Can't make the trip to San Diego for the conference,
Come join us for some Mom-only time!

Seriously folks, we've got some of the best experts in our moms.

Email mblangan@hotmail.com so we so we can keep you in on our plans plus we'll discuss the plan on our FXAM Facebook page. We'll choose the venue to be a central location for those who RSVP!

Please note: This is not a free FXAM event. Each FXAM Mom will be paying for her own food/drinks.

FXAM Family Picnic

Saturday, August 13, 2022, Noon - 3 p.m.

Our annual picnic will be held at the
Tyler-Buikema home of Sulie, Jeff, Indigo,
Jarrett and Keir
3610 S. Livernois
Rochester Hills, MI 48307



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

Please join us at the Fragile X Association of Michigan (FXAM) Family Picnic!

The picnic will be held at the Tyler-Buikema home. FXAM will provide hotdogs, drinks, tableware and an Inflatable water slide.

Please **bring ONE** of the following: **appetizer, side dish, salad** (any kind: potato, tossed, coleslaw, fruit, etc.) **OR a dessert**. As you respond YES via Evite, please write what you will be bringing to avoid duplication. Please bring chairs, and swimsuits and towels for the water slide. We are looking forward to seeing everyone. We no longer have a dog, if that was a concern for anyone in your family. Please RSVP by August 6th.

If possible, please respond using the Evite link: evite.com/event/029E4U3CGQIXZAU3CEPM7SLJZHKGJY/rsvp

Email Sulie at Suliet@wideopenwest.com if you are not able to use Evite.

FXAM Parents Night Out

Saturday, September 17, 2022, Save the Date

The Hub Stadium Auburn Hills
auburnhills.thehubstadium.com/

Watch FB for more info or contact Mary Beth at 313-689-3340.

FXAM Father and Son Picnic and Play Day

Saturday, October 22, 2022, at 10:30 a.m.

Maybury State Park
49601 Eight Mile Rd
Northville, MI

(Picnic provided by FXAM)
Please RSVP to JTSolway@rocketmail.com

Three Cheers for Our Volunteers

FXAM Board of Directors

Tiah Solway - President
Sulie Tyler - Vice President
Heather Van Dam - Treasurer
Mary Beth Langan - Corresponding Secretary
Kailey Owens - Recording Secretary

Elina Gelfand
Joyce Kreger
Jodi Lerchenfeld
Karl Lerchenfeld
Frank Liberati
Nina Liberati
Laureen Majeske
Sheryl Roman
James Solway

FXAM is very grateful for our current and past volunteers who are needed to make this all-volunteer organization possible!

Many thanks to outgoing Executive Board members: President Heather Van Dam and Treasurer Karl Lerchenfeld

We are so very grateful for your years of service in these two vital roles. A special thank you to both of you! (especially for your work holding us together during the pandemic) AND thank you for remaining active and on the FXAM board!

The Top Ten Things You Should Know About Fragile X Syndrome

By Mary Beth Langan and Sally Nantais

1. It's **genetic**.
2. If a woman is a carrier (55-200 CGG repeats) she has a 50/50 chance of passing it on to her son(s) or daughter(s). **1 in 151** women are carriers. In the gray zone, defined as 45-54 CGG repeats, prevalence is 1 in 35 for females. **
3. If a man is a carrier he will pass it only to his daughter(s), and they will only be carriers. **1 in 468** men are carriers. In the gray zone prevalence is 1 in 42 for males. **
4. Fragile X Syndrome (FXS) does **NOT** discriminate; it doesn't care which ethnic group you belong to.
5. Fragile X Syndrome is a **spectrum disorder**. Symptoms may vary from mild learning disabilities (including shyness and social anxiety) to severe cognitive impairment (mental retardation).
6. **Fragile X-Associated Primary Ovarian Insufficiency (FXPOI)**, more commonly known as early menopause, is a condition that affects 20-28% of the female FXS carrier population.
7. **Fragile X-associated Tremor/Ataxia Syndrome (FXTAS)**, discovered in 2001, is a neurological disorder that can involve tremors, balance irregularities, difficulty walking and dementia which sadly is often misdiagnosed as Parkinson's and/or Alzheimer's. This condition is present in some older FXS carriers (typically after the age of fifty); usually in males but FXTAS can also affect female carriers.
8. There are minor physical traits noted in many persons with Fragile X Syndrome, but not in all. These are traits which may also be present within the typical population, nothing unique which would necessarily indicate FXS testing is necessary for your child.
9. When testing for Fragile X Syndrome, it is critical that the correct tests are ordered – the Fragile X DNA (Southern Blot) and Polymerase Chain Reaction (PCR) tests, (also known as the FMR1 DNA test) which is 99% accurate.
 - Inaccurate results occur far too often with the generic chromosomal panel.
 - Test for FXS to obtain a diagnosis or to **rule it OUT**. If you don't have what may be the correct diagnosis of FXS, then you will never be aware of improved treatments or the cure when it's found.
 - **New** - The FDA granted marketing authorization of the AmplideX Fragile X Dx and Carrier Screen Kit to Asuragen Inc. February 2020. Test results can be turned around in hours rather than week(s).
10. Where to go for more information on Fragile X:
 - FragileX.org - The National Fragile X Foundation
 - FRAXA.org – FRAXA Research Foundation
 - youtube.com/watch?v=BgcQi0bbaJQ - First Down Towards a Cure
 - youtube.com/watch?v=-6-J_YcVRi4 Fragile X – Hitting the Mark
 - content.time.com/time/magazine/article/0,9171,1818268,00.html – Fragile X: Unraveling Autism's Secrets
 - livingwithfragilex.com - Living with Fragile X
 - cdc.gov/ncbddd/fxs/video/FragileX-4.html - What causes Fragile X

** SeltzerMM, Baker MW, Hong J, Maenner M, Greenberg J, Mandel D. 2012. Prevalence of CGG expansions of the FMR1 gene in a US population-based sample. American Journal of Medical Genetics, October 2011,

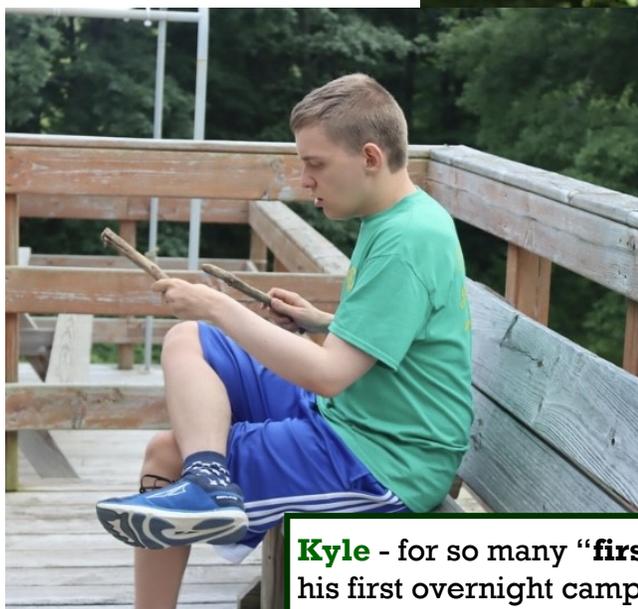
Mary Beth Langan and Sally Nantais are both Fragile X carriers; each has a son with Fragile X Syndrome and is a member of the Fragile X Association of Michigan (FXAM, fxam.org).

Don't Just

- Don't just learn, experience.
- Don't just read, absorb.
- Don't just change, transform.
- Don't just relate, advocate.
- Don't just promise, prove.
- Don't just criticize, encourage.
- Don't just think, ponder.
- Don't just take, give.
- Don't just see, feel.
- Don't just dream, do.
- Don't just hear, listen.
- Don't just talk, act.
- Don't just tell, show.
- Don't just exist, live.

~ Roy T. Bennett

Three Cheers for...



Kyle - for so many “**first**” accomplishments during his first overnight camp for five nights. Way to go Kyle!

Three Cheers for...



Ben Cyplik - Michigan Special Olympics Summer Games he ran track and field events and stayed in the dorm rooms. Ben had a blast and was super independent!

Three Cheers for...

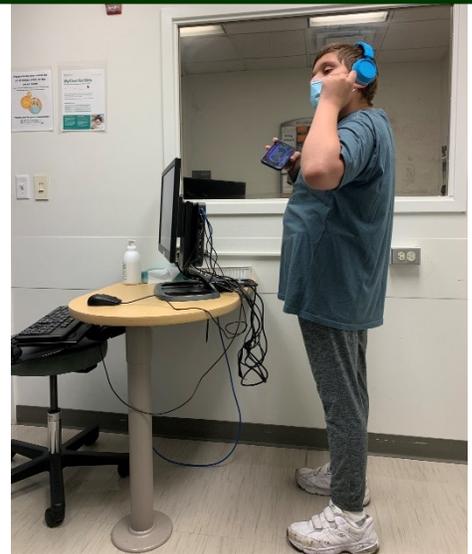
Fragile X Guru Dr. Elizabeth Berry-Kravis (EBK),
Neurologist at the Rush Univ Med Center (Chicago)

rush.edu/kids/treatments/fragile-x-syndrome-clinic



Andrew - with EBK, Mom/Mary Beth and Dad/Ted

Andrew - trying to wait patiently to see Dr. Berry-Kravis.



TWO Michigan families went to see Dr. Berry-Kravis on June 23: the Langan-Coutilish family AND the Gelfand family!

Three Cheers for...



Paul Fodor - finished up his sixth year at Mixer Institute of Transition in Lincoln Park. The program for young adults with autism focuses on job training and life skills. To kick off his summer, he and his family traveled to Wyoming where he explored hiking, horseback riding, fly fishing, and sightseeing.



Nicholas - at his end of school celebration. Plans now that school is done: "hang out with Papa!"

From the President's Desk *by Tiah Solway*

Hello FXAM Families! I hope everyone is enjoying the start of their summer! As I write this for the newsletter, today is my son Jonathan's first day of summer break while my daughter still goes to school through tomorrow. So, I still have a couple days of "somewhat-sanity" left, before chaos breaks loose. Bring on the sibling squabbles, boredom and non-stop snacking! (How many days left until school starts again?)



Every year around this time I tell myself I'm going to be the fun mom. Wouldn't it be fun to create a bucket list of summer activities and see if we can get through the entire list before the kids go back to school? Wouldn't it be fun to have a sand castle competition or attend an outdoor concert at a park, or go see fireworks? But sand can cause sensory issues for Jonathan which in turn will cause behavioral issues, concerts are crowded and loud, and don't even get me started on the drama that is my son and fireworks. The past few years I have created bucket list ideas with the kids only to find it dusty and forgotten on top of the fridge when the kids go back to school. Usually only a few things are marked off and all I can really remember about summer break was every line of the same movie we watched a thousand times.

This summer will be a little different than in years past. Isabelle will be attending camp for a week this summer and I will be heading to San Diego to attend the National Fragile X Foundation Conference, which will help in breaking up the monotony of summer. Add to that a family camping trip and a couple trips to some local splash pads and maybe we can get through this summer with all of our nerves intact and only watching a movie five hundred times instead of a thousand. However you are able to spend your summer – whether it be adventurous or relaxing or the same old thing – I hope you come out better on the other side.

Seriously. How many days left until school starts?!

Editors:

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