Fragile X
Association of Michigan

eXtra, eXtra

Volume XVII, Issue 3, July 2021

Mark Your Calendar

Support Meetings

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

When:

October 2, 2021
November 6, 2021

Business Meeting
6 - 7 p.m.
Support Meeting
7 - 9 p.m.

Where:
Beaumont Hospital
Royal Oak Campus
Administration Bldg.
Private Dining Room

Special Events:

August 14, 2021:
FXAM Family Picnic
See page 5.

TBD
FXAM Moms:
Let's Do Lunch!

Fragile X Association of Michigan
FXAM.org

Contact Information:
313-689-3340

PO Box 1414
Troy, MI 48099-1414

Bringing Your STX209 Data Home

The National Fragile X Foundation (NFXF), with the help of several professionals, has secured agreement to obtain STX209 trial participant data through a reconsent process. Science cannot move forward without your participation, so NFXF has partnered with Dr. Elizabeth Berry-Kravis to create an eConsent option for bringing your STX209 data home to the NFXF Data Repository.

Whether you were in the study for the long haul, or maybe it wasn't successful for your child, your data, your information is important.

Please follow this link for the consent process:

fragilex.org/our-research/projects/stx209-reconsent/

Three Cheers for Fragile X Awareness Day July 22, 2021

Mayor Baker and Troy City Council
On behalf of FRAXA, Ted Coutilish was excited to accept this proclamation from Mayor Ethan Baker and the Troy City Council recognizing July 22 as World Fragile X Day.

See FRAXA.org and FragileX.org for more going on during this month promoting Fragile X awareness!

Three Cheers for our Graduates…

Helen Weaver

School: Anchor Bay High School
Favorite Subject: Marching Band, she was one of three drum majors for the 200-student band!).
Future Plans: College in the fall and working at her part-time job at Target!

Genevieve Nantais

School: Michigan State University, Lyman Briggs College
Favorite Subject: Scuba Diving class during freshman year.
Future Plans: After completing my internship at MSU, in the lab studying mosquitos and malaria, a full-time position in the field of genetics

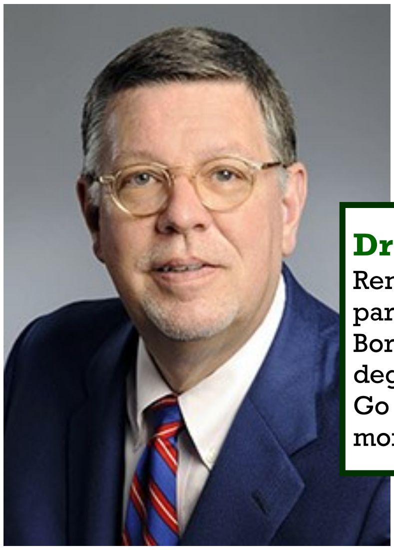
Andrew Young

School: Waterford Life Tracks
Favorite Subject: Work Study
Future Plans: Andrew completed his vocational assessment and we are waiting to hear MRS's recommendations for starting to look for employment.

In Memory of ...

Angelo Liberati, May 30, 1995 - June 3, 2021
Angelo, age 26, of Allen Park, MI, died June 3, 2021. He was the beloved son of our active FXAM members Nina and Frank, brother of Nicolo and Antonio and grandson of Florence Coleman - all of whom we know well from FXAM meetings, holiday parties, picnics, annual golf outings and seeing them at Liberati's Deli. We will miss Angelo's big smile and warm hugs. Donations can be made to Shelter to Home.

Read more...



Dr. Stephen Warren, 1953 - June 6, 2021
Renowned fragile X researcher who was a beloved part of our fragile X community had Michigan roots. Born in East Detroit, he earned his BS and PhD degrees at Michigan State University. Go Green, Go White! Donations can be made to FRAXA. Read more at Emory News

Peggy Branch
May 14, 1963 - June 12, 2021
Peggy fought a very quiet and noble battle with ovarian cancer. Wonderful mother to Maggie and Patrick - a true and loyal soul. Peggy and her signature spinach pie were at most of our holiday parties. She was also at many meetings, Moms lunches and other FXAM events. Peggy will be dearly missed by her family and friends. Donations can be made in her memory to the National Fragile X Foundation.

The Top Ten Things You Should Know About Fragile X Syndrome

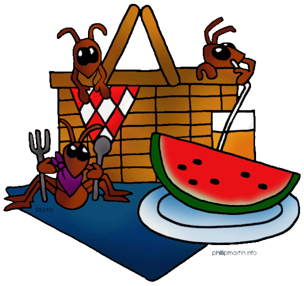
By Mary Beth Langan and Sally Nantais

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)**.**

FXAM Family Picnic



Saturday, August 14, 2021

Noon - 4 p.m.

After one year off due to Covid, our annual
picnic returns and will be held at
the Van Dam home of
Heather, Derek, Alison & Mason
1090 Porter Rd.,White Lake, MI

FXAM will provide hotdogs, drinks and a bounce house.
Families are invited to bring a side dish or dessert to share.

RSVP to Heather via text/phone to 248-343-2077 or fab4fam@comcast.net by Saturday, **August 7th,** with the # of adults & children attending and what you'd like to add to the table!
Hope to see you at the FXAM Family Picnic!

University of Michigan Grant and Clinic Information

We are excited to announce that we have received another $50,000 grant from the Toni Wisne Sabina Foundation for ongoing research at Dr. Peter Todd's lab at the University of Michigan. Many new groups had applied for grants this year as funds are scarce for most non-profits during this pandemic. Even though the Wisne Foundation received a record number of requests, they chose to continue to support fragile X research, for which we are truly grateful. The money will pass through FXAM to the Todd Lab as we continue our commitment to support research in our state. We are very appreciative of their consideration.

The Fragile X Clinic does not yet have a new Coordinator, but are still working on a replacement. Please be patient until that issue is resolved. You may contact Dr. Todd for scheduling at the number below.

For more information on the Fragile X Clinic or to make an appointment:

fragile-x-clinic.med.umich.edu/ **734-764-0579**

In other news, the university is hoping to host a Fragile X Midwest eXchange meeting in Ann Arbor in October. This will bring together a number of FX researchers from the Midwest, including researchers from Rush, Wisconsin and Cincinnati. These collaboratives are extremely important in moving research forward and working towards coordinating and complimenting each other's work.

> "Never let hard lessons harden your heart;
> the hard lessons of life are meant to make you better,
> not bitter."
>
> ~ Roy T. Bennett

Adventures with Super Cal

We'd like to introduce you to Super Cal!

Inspired by the character Flat Stanley, from a story by Jeff Brown, Super Cal is a new Fragile X Superhero!

Super Cal is visiting some FXAM families and enjoying creating memories of your daily routine, a favorite activity and/or an extraordinary excursion.

He can stay with you for a week or two and your parents can share the photos of him visiting your home on our FXAM Facebook page so we can all keep track of his adventures!

If you have questions about his travel plans, please email Sheryl at: romanjsr@aol.com

We look forward to seeing where he visits, who he sees and what they do together!

Go Super Cal!

Evie and Super Cal enjoyed swimming at Auntie Lanie's pool on the 4th of July. Nothing but excitement for another day of summer school to start! Waiting with Dillyn.

Adventures with Super Cal

Michael had a few in home adventures with Super Cal. Congratulations Michael on earning your letter for choir!!!

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