

Mark Your Calendar

Support Meetings

First Saturday of the Month
(No meeting in December and January)

When & Where
November 4, 2023

Business Meeting
9:30 - 10:30 am

Support Meeting
10:30 am - 12 pm
Gather + Grounds
25709 Van Dyke Ave
Centerline, MI
gather-grounds.com/

February 3, 2024

Business Meeting
10:15 - 11 am

Support Meeting
11 am - 1 pm
Berkley Public Library
3155 Coolidge Hwy
Berkley, Michigan

Zoom option details will be on FXAM FB page and FXAM.org

Special Events:

Please stay tuned for more details!

Fragile X Association of Michigan
FXAM.org

Contact Information:
313-689-3340

PO Box 1414
Troy, MI 48099-1414

Three Cheers for...



Andrew - waiting for the bus on 9/5/2023 and it came!



The Lerchenfeld Boys
go Back To School!



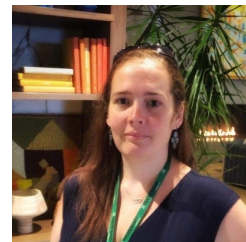
Do more than belong: participate.
Do more than care: help.
Do more than believe: practice.
Do more than be fair: be kind.
Do more than forgive: forget.
Do more than dream: work.

~William Arthur Ward

From the President's Desk *by Tiah Solway*

Hello FXAM families and Happy Fall!

I hope everyone had an enjoyable summer break. As I stated in the summer newsletter, my kids and I spent the entire summer camping. We reserved a seasonal lot and never left the camper. The kids had an amazing time. Isabelle was able to make some great friends and Jonathan was able to experience a sense of freedom that he could never get anywhere else. We're so disappointed that the camping season will soon be coming to an end, but there are always new and exciting changes around the corner.



With fall here now and pumpkin season in full swing it brought with it the return to school for both the kids AND me! After being a stay-at-home mom for the past 13 years, I am so very proud to say that I now work in our local public school working with children with special needs. During the week, the days are a little more hectic to say the least, but I get so much enjoyment from what I'm doing. I absolutely love going to work every day. We all know the feeling that we experience when our kids accomplish something they've been struggling with, or when they complete a task correctly, or even when they just have a good day. Imagine experiencing that over and over. As with anything, there are still struggles and rough days, but when you love what you do, the good always outshines the bad.

The Fragile X Association of Michigan also had a pretty great summer. We were able to supply 100 of our family members and friends with Tiger's tickets for World Fragile X Day on July 22. We celebrated as a group and spread awareness being the Tiger's Charity of the Game. Seeing our Fragile X families on the big screen was a highlight for me.

I would like to extend a special thank you to our Vice President Sulie Tyler and her family for their willingness to host the FXAM summer picnic once again. It was an X-marks-the-spot, pirate-themed picnic and those that came had a lot of fun. There are some photos from the picnic on the back page of this newsletter.

The return of fall also brings with it the return of FXAM's business and support group meetings on the first Saturday of the month. Please look for more details on page 1 of the newsletter for upcoming meetings and events AND keep in touch on our FXAM Facebook page for up-to-date info. Hope to see you all sometime this fall!

University of Michigan Fragile X Clinic *by Dr. Peter Todd*

We welcome Dr. Sloan-Heggen to the UM Fragile X Clinic!

Fragile X Clinic Director: Dr. Christina Sloan-Heggen

Fragile X Clinic Co-Director: Dr. Peter Todd

Fragile X Clinic Coordinator: In recruitment. For now, this role is being served by Dr. Sloan-Heggan with assistance from Dr. Todd.

To make an appointment for a patient with Fragile X Syndrome who is less than 25 years old, call UM Pediatric Genetics at 734-764-0579. Ask for an appointment with Dr. Sloan-Heggen.

To make an appointment for an adult patient with Fragile X Syndrome or FXTAS or other Fragile X-premutation related conditions, call the East Ann Arbor Health and Geriatrics Center at 734-647-5670. Ask for an appointment with Dr. Todd in the Ataxia Clinic.

Dr. Todd is also happy to have FXAM family members email him directly with questions:

petertod@med.umich.edu

Research Studies

University of South Carolina, scfamilystudy.com/participate/

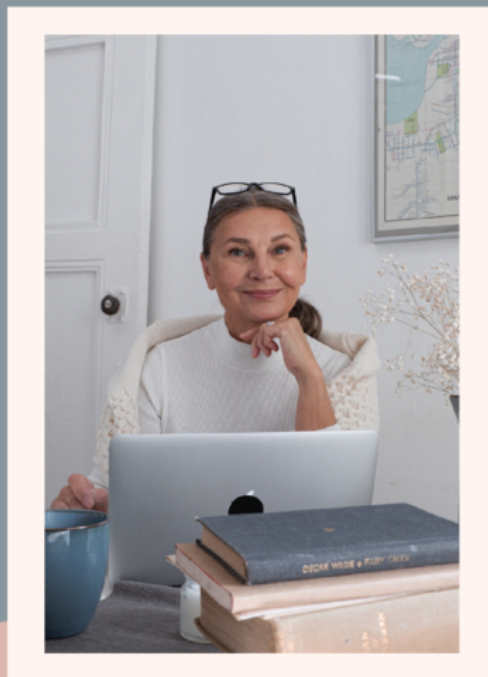
VIRTUAL
OR
IN-PERSON
OPTIONS

Recruiting Women Ages 35-75 with the Fragile X Premutation for a Research Study

Participation involves:

- assessments on cognition and language
- answering questions about your experiences
- providing a genetic sample (cheek swab) to index the *FMR1* gene

3-4 hours
\$80 Compensation



Contact the Family Experiences Lab

Email: SCFamilyStudy@gmail.com


Phone: (803) -576-7359

Website: SCFamilyStudy.com

Research Studies

University of South Carolina, scfamilystudy.com/participate/


**Research Study on
Aging in Fragile X Carriers**




**UNIVERSITY OF
South Carolina**

**NOW RECRUITING
FRAGILE X
PREMUTATION
CARRIER WOMEN**

**WHO ARE 45-78 YEARS OLD
&
HAVE A CHILD WITH
FRAGILE X SYNDROME**





STUDY PURPOSE

This study is focused on understanding age-related symptoms experienced by women with the fragile X premutation. The goal of this research is to help improve outcomes for both carrier mothers and their children with fragile X syndrome.

This project is led by Dr. Jessica Klusek, PhD, CCC-SLP

**WHAT DOES THE
STUDY INVOLVE?**

COMPLETE ASSESSMENTS, SURVEYS, AND GENETIC TESTING

Focused on:

- Cognition
- Language
- Mental health
- Social styles and preferences
- Family experiences
- Motor symptoms

Genetic testing will be done to index the FMRI gene.


LONGITUDINAL STUDY


This study involve one assessment per year for 3 years. Each year, you will be asked to fill out some questionnaires (~1 hour) and complete an assessment (~4 hours).


\$ RECEIVE \$100 EACH YEAR

NO TRAVEL REQUIRED

You can complete the assessments at the University of South Carolina and we will cover your travel costs. Or, we can travel to you.

 (803)-576-7359

 scfamilystudy@gmail.com

 scfamilystudy.com

Research Studies

University of South Carolina, uscnddlab.com/participate/

Parent liaison, Cortney AbouElSeoud (a FXAM member). Feel free to connect with Cortney at cabouelseoud@gmail.com

INFANT DEVELOPMENT RESEARCH

Lab Director: Jane Roberts, PhD



Children experience amazing development over the first few years of life. We are interested in learning about the nature of infant development and the experiences of infants' families.

Who can take part in this study?

We are recruiting infants 12 months of age or younger who:

- Have fragile X syndrome
- Have the fragile X premutation
- Are typically developing

Participation Entails:

- Five assessments between ages 6 and 24 months in your home (lasting up to 4 hours each)
- Summary reports of your child's development by infant development experts
- Compensation for participation (up to \$425 total)

Contact us at:

803-777-5676

uscnddlab@sc.edu
www.uscnddlab.com

Autonomic and Sensory Dysfunction in *FMR1* Conditions: Development, Mechanisms and Consequences is a research study at the University of South Carolina. This study is funded by the National Institutes of Health.



Research Studies

UMass, contact Dr. Jill Hoover, s2slab@umass.edu



Sounds2Syntax Lab at UMass Amherst

child language study seeking

Boys with Fragile X Syndrome

- 9 - 17 years of age
- speaking in at least 2-3 word phrases

Children with Down Syndrome

- 9 - 17 years of age
- speaking in at least 2-3 word phrases

Children with Developmental Language Disorder

- 4 - 8 years of age
- no known history of other disorders

Neurotypical Children

- 3 - 5 years of age
- no known history of speech, hearing, or language impairments

- 6-8 hours of activities (including breaks) that can be completed in 1 or multiple visits
- You will receive \$75 for participation
- You will receive a standard report following testing

If interested, please fill out our contact form:

tinyurl.com/s2slab

or contact:

Dr. Jill Hoover, Lab Director

(413) 461-0875

s2slab@umass.edu

Research Studies

Purdue University, kelleherlab.weebly.com/project-wellcast.html,
contact at wellcast@purdue.edu

FRAGILE X | ANGELMAN | PRADER WILLI | WILLIAMS | DUP15Q | & MORE!

NOW RECRUITING: PROJECT WELLCAST

SUPPORTING WELLBEING OF CAREGIVERS VIA TELEHEALTH

FOR CAREGIVERS OF CHILDREN WITH RARE DISORDERS

Eligible participants will receive FREE THERAPY OR RESOURCES,
available 100% via telehealth, as part of this research study!

WHAT?

If you qualify, you will receive free live mental health therapy,

- live behavioral parent training, self-guided resources, and/or live peer coaching from other rare disorder caregivers.

Caregivers will provide data about their experiences

- and feelings before, during, and after treatment and will receive up to \$100 compensation for their time.
- Black caregivers are also eligible for supplemental support related to racial trauma
- Up to 6.5 months of study activities
- All activities completed virtually

WHO?

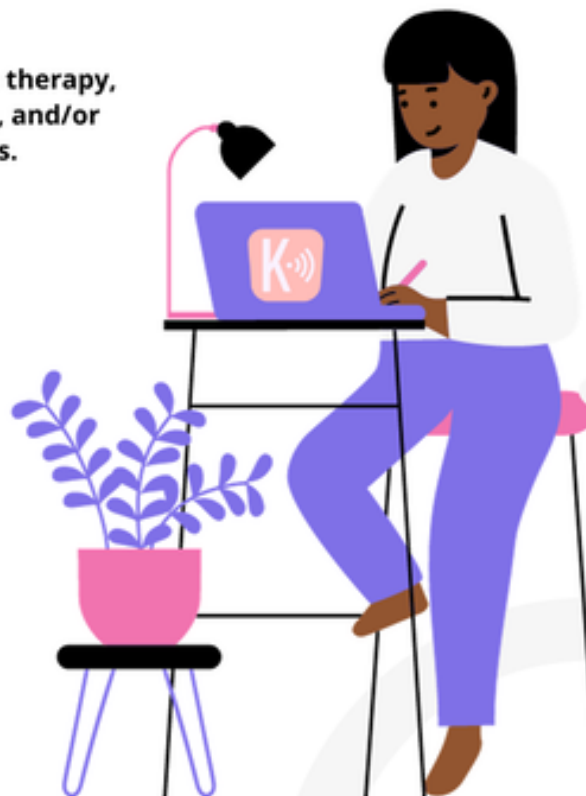
- Caregiver (age 18+) of a child (ages 2-35) with a documented neurogenetic condition associated with intellectual disability
 - Reside in the US, fluent in English

INTERESTED? CONTACT US

Email: WELLCAST@PURDUE.EDU



@kelleher.lab



Optimizing a Personalized Health Approach for Virtually Treating High-Risk Caregivers During COVID-19 and Beyond; IRB 2022-1058, PI: Bridgette Kelleher

Research Studies

Rush University, contact Loren_Escot@rush.edu

Tetra studies, at the beginning we were studying the effects of the drug on cognition and functioning.

Based on the positive results in these areas in a Phase II study of BPN14770, the drug is now being studied in a Phase III study for adults and adolescents with fragile X syndrome (FXS).

Research Study

Male Adolescents with Fragile X Syndrome Phase II Clinical Trial

Rush University Medical Center
1725 W Harrison St.
Chicago, IL 60612

For a map and directions, visit:
rush.edu/locations/rush-university-medical-center

What	The purpose of this clinical trial is to test the safety and efficacy of the study drug, BPN14770, when compared to a placebo sugar pill.
Who	Male adolescents, ages 12 to < 18 years with a confirmed diagnosis of fragile X syndrome with a full mutation.
Length	18 weeks, with 6 visits to Rush Clinic. Each visit takes approximately 3 hours. Participants will be invited to continue study participation on the actual drug for a year after trial ends.
Compensation	\$50 for each visit, up to \$300. Reimbursement is provided for hotel, flight, train, mileage, and food. Please contact for information on pricing.
Sign up	<p>For more information, contact us:</p> <p>Loren Escot at 312-942-2164 or Loren_escot@rush.edu</p> <p>Abigail Ayemoba at 312-942-2815 or Abigail_Ayemoba@rush.edu</p>



Research Studies

Rush University, contact Loren_Escot@rush.edu

Research Study

Male Adults with Fragile X Syndrome Phase III Clinical Trial

Rush University Medical Center
 1725 W Harrison St.
 Chicago, IL 60612

For a map and directions, visit:
rush.edu/locations/rush-university-medical-center

What	The purpose of this clinical trial is to test the safety and efficacy of the study drug, BPN14770, when compared to a placebo sugar pill.
Who	Male adults, ages 18 to < 45 years with a confirmed diagnosis of fragile X syndrome with a full mutation.
Length	18 weeks, with 6 visits to Rush Clinic. Each visit takes approximately 3 hours. Participants will be invited to continue study participation on the actual drug for a year after trial ends.
Compensation	\$50 for each visit, up to \$300. Reimbursement is provided for hotel, flight, train, or mileage. Please contact for information on pricing.
Sign up	<p>For more information, contact us:</p> <p>Loren Escot at 312-942-2164 or Loren_escot@rush.edu</p> <p>Abigail Ayemoba at 312-942-2815 or Abigail_Ayemoba@rush.edu</p>



Research Studies

Rush University, contact Nancy_Cao@rush.edu

We are studying a new assessment (NIH Toolbox Cognitive Battery) that measures cognitive skills among individuals with intellectual disability. The purpose of this research is to explore whether certain types of cognitive tests are reliable, valid, and sensitive to improvement in evaluating treatment responses. With the Toolbox Quillivant study, we want to test if the NIH Toolbox Cognitive Battery is sensitive to cognitive changes when individuals with intellectual disability and ADHD are taking a placebo or stimulant (Quillivant XR).

Research Study


Fragile X Syndrome Study

**Rush University
Medical Center**

1725 W Harrison St.
Chicago, IL 60612

For a map and directions,
visit:
rush.edu/locations/rush-university-medical-center

What	The purpose of this research is to evaluate specialized tests for tracking cognitive changes in children and young adults with intellectual disabilities.
Who	Individuals between 4 – 25, with a confirmed diagnosis of intellectual disability caused by Down syndrome, fragile X syndrome, or other unknown cause.
Length	1 - 3 visits to Rush Visit 1 and 3 typically lasts about 5 - 6 hours (including breaks), visit 2 lasts about 1 - 2 hours
Compensation	\$50 for each visit
Sign up	<p>For more information, contact us:</p> <p>Nancy Cao at 312-563-9329 or Nancy_Cao@rush.edu</p> <p>Abigail Ayemoba at 312-942-2815 or Abigail_Ayemoba@rush.edu</p>



Research Studies

Rush University, contact Nancy_Cao@rush.edu

Research Study

Fragile X and Down Syndrome Study in Aging Populations

Rush University Medical Center

1725 W Harrison St.
Chicago, IL 60612

For a map and directions, visit:
rush.edu/locations/rush-university-medical-center

What	The purpose of this research is to evaluate specialized tests for tracking cognitive changes in aging adults with fragile X and down syndrome.
Who	Individuals over 60 years of age with a confirmed diagnosis of fragile X syndrome or down syndrome.
Length	Up to 2 visits The first visit may last up to 5 hours (including breaks) Some participants may be invited back for a follow-up visit 1 month after the first visit. This visit will last 1-2 hours
Compensation	\$50 for each visit.
Sign up	For more information, contact us: Nancy Cao at 312-563-9329 or Nancy_Cao@rush.edu Abigail Ayemoba at 312-942-2815 or Abigail_Ayemoba@rush.edu



Research Studies

Rush University, contact Nancy_Cao@rush.edu

Research Study

Intervention for Children with Fragile X, Down Syndrome, & Other Intellectual Disabilities

What	A study to learn whether innovative tests that measure focus and thinking are sensitive to a commonly used medicine (to treat ADHD) in individuals with intellectual and developmental disabilities
Who	Children 6-17 years of age with a diagnosis of autism, fragile X, Down syndrome, or other forms of intellectual disability. Must also have ADHD or have symptoms of ADHD
Length	13 weeks
Requirements	Participants will come to Rush for an initial screening with their parents or caregivers Participants will be administered the active medicine 4 in-person visits for testing via an iPad
Compensation	The study will provide a \$50 gift card for each visit and a \$25 gift card for the screening
Sign up	For more information, contact us: Nancy Cao at 312-563-9329 or Nancy_Cao@rush.edu Abigail Ayemoba at 312-942-2815 or Abigail_Ayemoba@rush.edu

Rush University Medical Center

1725 W Harrison St.
Chicago, IL 60612

For a map and directions, visit:
rush.edu/locations/rush-university-medical-center



Research Studies

Rush University, call 312-563-7284 or email anniek_m_vanaarem@rush.edu or visit fragilexhelp.com/

Fragile X Trial Now Enrolling - RECONNECT

Learn more about the RECONNECT clinical trial evaluating an investigational topical cannabidiol (CBD) gel to see if it helps improve behavioral issues associated with Fragile-X. This trial is a double-blind, placebo-controlled trial where eligible participants are randomized 1:1 to either active study drug or placebo. The study drug is applied to the skin twice a day for the treatment of behavioral symptoms of Fragile X syndrome. The study drug is an experimental treatment, which means that it is not approved by any government regulatory agencies, including the United States Food and Drug Administration (FDA). For this reason, it is being tested to see if it is an effective and safe treatment. Qualified participants are closely monitored by study doctors and staff throughout the duration of trial participation, which will last for approximately 21 weeks. Patients who complete the RECONNECT trial may be eligible to enroll into an open-label extension trial.

Qualified participants for the RECONNECT trial must:

- Be between the ages of 3 and 22 years of age

- Have a diagnosis of full mutation FXS obtained through genetic testing

- Be experiencing behavioral symptoms of Fragile X Syndrome such as social anxiety/avoidance, irritability, and social unresponsiveness

- Otherwise be in generally good health

Additional criteria apply

EXPLORE OUR FRAGILE X SYNDROME CLINICAL TRIAL TODAY.

ABOUT THIS TRIAL

Zynerba Pharmaceuticals is currently conducting the Phase 3 RECONNECT trial to further explore investigational topical cannabidiol (CBD) gel to see if it helps improve Fragile X-related behavioral issues.

BENEFITS OF PARTICIPATION

Your participation in this clinical trial could mean that they see a board-certified study doctor and medical staff at no cost to you. They may also have access to investigational topical medication that may improve behavior related to Fragile X syndrome.

WHO IS ELIGIBLE

Eligible participants have been diagnosed, via genetic testing, with Fragile X syndrome and are between 3 and 22 years old. For a full list of criteria, please visit FRAGILEXHELP.COM.

BE A PART OF MEDICAL ADVANCES

Find out how to get involved in this important clinical trial today.

FRAGILEXHELP.COM | 833-680-1155

Three Cheers for...



Ayden - He celebrated 16 this summer and we asked family/friends from all over the US to send him his favorite - a fan!



Nicholas - participated in the Special Olympics State of Michigan games for soccer and baseball. The soccer team took bronze. He's the catcher for the baseball team.

Three Cheers for Sisters...

“A sister is a gift to the heart, a friend to the spirit, a golden thread to the meaning of life.” ~ Isadora James

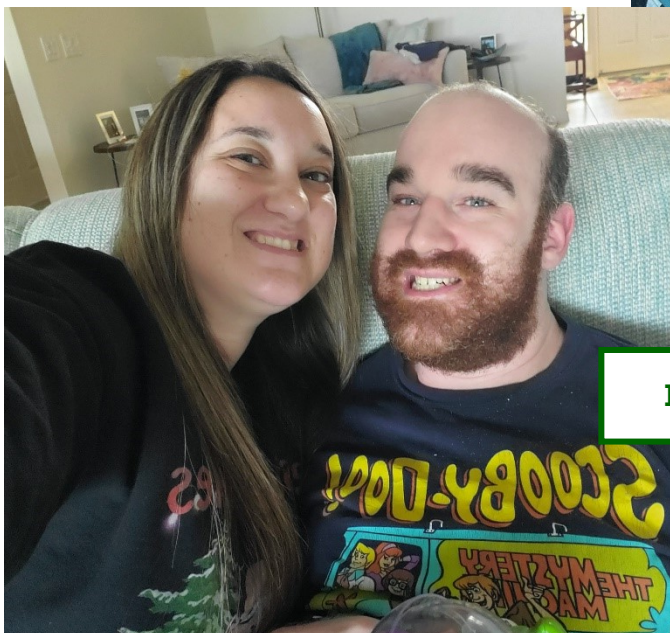
It’s hard when life takes them in a different direction.



Kevin and Helen



Genevieve and Austin



Natalie and Austin

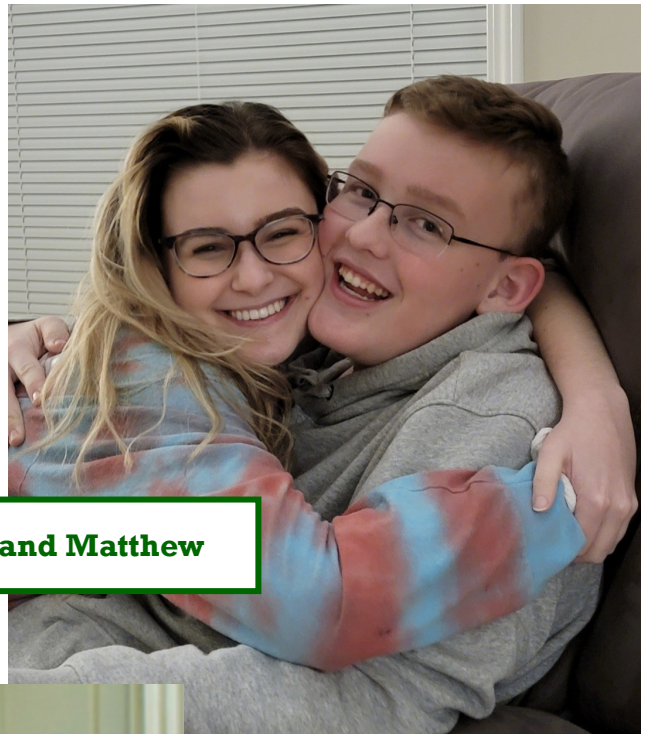
Three Cheers for Sisters...

“A sister is a gift to the heart, a friend to the spirit, a golden thread to the meaning of life.” ~ Isadora James

It's hard when life takes them in a different direction.



Aidan and Camryn



Alexa and Matthew



Kimberly, Paul, and Katie

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**FXAM
Picnic
2023**

