Fragile X Association of Michigan

eXtra, eXtra

Volume XXI, Issue 3, July 2025

Mark Your Calendar

Support Meetings

No meetings in July, August and September

When:
October 4, 2025

Business Meeting
9:15 - 10 a.m.

Support Meeting
10 a.m. - 12 p.m

Where:
Gather + Grounds
25709 Van Dyke Ave
Center Line, MI

Special Events:

July 22, 2025
World Fragile X Day
See page 4.

August 9, 2025
FXAM Family Picnic
See page 4.

Fragile X Association of Michigan

FXAM.org

Contact Information:
313-689-3340

PO Box 1414
Troy, MI 48099-1414

Three Cheers for...

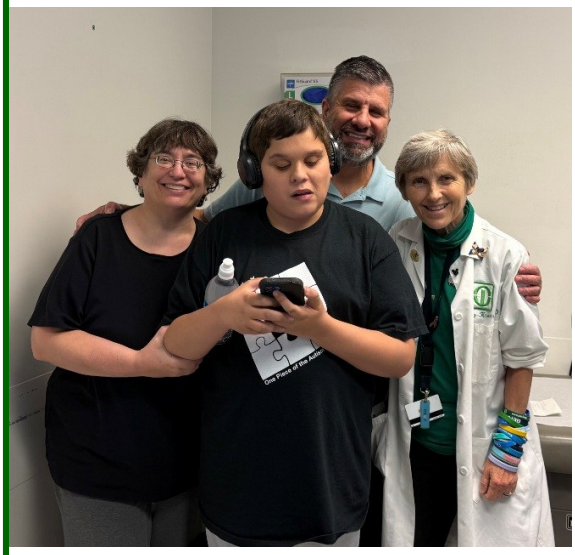
Our Graduate

Paul Fodor

Mixter Institute of Transition (Lincoln Park)
Favorite Subject:
Gardening and Wood Working
Future Plans:
Attending STEP program in Westland. STEP = Services To Enhance Potential; learn more at stepcentral.org

Fragile X Experts

Andrew had his annual visit with Dr. Elizabeth Berry-Kravis at Rush University this July. We celebrate her continued dedication to care for individuals affected by Fragile X Conditions.
Dr. Berry-Kravis is a prominent figure in Fragile X research and care. She established the Fragile X Clinic and Research Program at Rush University Medical Center in 1992, providing care to hundreds of patients with the condition. She is also actively involved in translational research, including clinical trials for new targeted treatments.



Sally's Adventure

2025 Cincinnati Family Fragile X Conference

Do you ever want to run away?

I did in July to attend the one-day Cincinnati Fragile X Conference and I must say it was good for my soul. The Cincinnati Fragile X Conference is a one-day event, held bi-annually, odd years, when there isn't an International Fragile X Conference.

Driving without my copilot, Austin, was sweet because I could turn the music up as loud as I wanted. When I checked into my room I sat there for a hour just taking in the quiet, nobody asking for anything, nobody vying for my attention, just me, I immersed myself in the complete silence.

It should be noted that you can teach an old dog new tricks. There was a wealth of information provided; too much for one newsletter. Here are a few things that stood out to me.

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Hilary Rosselot noted that the National Fragile X Foundation website, has been revised, **fragilex.org/**.

They have an option to download various awareness cards, **fragilex.org/wp-content/uploads/2024/11/FXS-awareness-cards.pdf.** When I complete the newsletter, I will take these samples and create a printable pdf in which if you have business cardstock you can simply print the pdf provided, two sided, creating the cards.

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Dr. Peter Todd made an excellent point about Fragile X-associated tremor/ataxia syndrome (FXTAS) and females, we need to reframe how we think about FXTAS. It is estimated that 10-15% of female fragile X premutation carriers may get FXTAS after the age of 50 but what we should focus on is that **85-90% of female carriers will NOT get FXTAS**.

Dr. Todd noted that soon there will be a reallocation of the NIH budget, it's critical that each and everyone of us reaches out to our representatives and emphasize the critical need to continue funding for fragile X research. Funding is needed to support fragile X research. There may be a FXTAS research study being conducted at the University of Michigan in the future.

Advocacy is not a once-a-year event, make it count folks, do your part. The NFXF has an action alert related to funding, **fragilex.org/advocacy/action-alert-2025-nih-fx/**

Keep in mind that many representatives are available in their home districts during the month of August, consider making an in-person visit with your children, put a face to Fragile X.

Download the Michigan Fact Sheet

fragilex.org/get-involved/advocacy/#download-your-states-fact-sheet

It was asked "Can you delay or prevent FXTAS?" There is no cure or magic pill you can take but what may make a difference is:

Exercise

Avoid neurotoxins (including alcohol)

Manage your other conditions: Hypertension, Diabetes, Obesity, Sleep Apnea, etc.

2025 Cincinnati Family Fragile X Conference *(continued)*

Dr. Todd sees patients once a week, The University of Michigan Health offers a monthly clinic dedicated to children and adults with Fragile X syndrome. The clinic provides multidisciplinary care with care providers from Genetics and Developmental Behavioral Pediatrics. Referrals to other subspecialists can be coordinated as needed.

Questions about the Fragile X clinic can be directed to 734-764-0579 or via email at **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.

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Dr. Debra Reisinger - Managing Behaviors. Dr. Reisinger was a wealth of information and helpful advice. She provided a link to her Therapy Resources and one of the files was her presentation at the 2019 International Fragile X Conference. A great deal of this was discussed during her Cincinnati presentation. You can view the presentation and other helpful handouts at:

drive.google.com/drive/u/0/folders/1DZKe_r0OeBWP01nmUteT1zTBc_mW7VJb

Key points:

- You need to Understand the Functions of Behavior - SEAT - **S**ensory, **E**scape, **A**ttention, **T**angible.
- Collect Data, it's like doing your own Functional Behavior Assessment (FBA) in the home
- Understand the Levels of Emotion: Wave of Crisis. At level 2 and 3 implement calming strategies (deep breathing exercises or exercises to refocus), problem solving, and redirect. . At level 4 and 5 (Crisis) they have lost control, this is where you should remain silent and focus on safety. One very important point she made was that one should practice the calming techniques often, when they are not in crisis, so when they are at Level 2 or 3 you can model calming strategies and they will know what to do.
- Give warnings and do follow through. All adults in the household must be on the same page, it won't work it Dad only gives one warning and Mom gives three. Be consistent.
- Sometimes you need to change your response. You are the vending machine, You want to teach the appropriate way for your child to get what they want from the vending machine. When a child throws a tantrum to address their needs and you are delivering after a tantrum you have just taught them that if they do A you will do B.
- When trying to change behavior things will get worse before they get better. It is **estimated** that it takes 21 days to change a behavior.
- If your child is not hurting themselves or others, don't be afraid to ignore behavior, ignoring behavior is no response.
- When possible provide choices. if you follow Sally's rule book you will manipulate the choices to get the positive outcome/choice you want that makes the entire family happy. Be prepared though once we listed "Sushi" as a dining out option and Austin picked Sushi. We did Sushi and Mom was able to get him Chicken Teriyaki and white rice.
- Check in with yourself. Do you have the energy to remain firm on your request or your stance? It's okay to answer no. If you know you don't have the energy, give into the request immediately! We do not want to teach our children that engaging in problem behavior gets them what they want.

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!

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/**

FXAM Family Picnic

Saturday, August 9, 2024 at Noon

Our annual picnic will be held at the Langan-Coutilish home (Mary Beth, Ted and Andrew)

51 Greenbriar

Grosse Pointe Shores, MI 48236

Please save the date and watch the FXAM Facebook page and email group for details on what will be provided and what you can bring!

Questions? Contact Mary Beth at **mblangan@hotmail.com** or 313-689-3340

Support Meetings

Support Meetings are changing. Our Meeting Plan for 2025-2026:

October: Gather + Grounds and virtual. *Business*: 9:15 - 10 am. *Support*: 10 am - noon
February: Virtual. *Business*: 10 - 11 am. *Support*: 11 am - 1 pm
April: Virtual. *Business*: 10 - 11 am. *Support*: 11 am - 1 pm
June: In person, TBD and virtual. *Business*: 9:15 - 10 am. *Support*: 10 am - noon

Closer to the date, details will be provided at **FXAM.org, Fragile X Association of Michigan Facebook (Meta)** page, and through the FXAM group email.

If you are not in our email group, please connect with Mary Beth at **mblangan@hotmail.com** to be added.

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) in each pregnancy. **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 recognized 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 people 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.
   - Tests typically cost between $200 and $600 and takes about two weeks for results.
   - Inaccurate results occur far too often with the generic chromosomal panel or microarray analysis. Do not use to identify fragile X, it may produce false negatives.
   - Test for FXS to obtain a diagnosis or to **rule it OUT or IN**. 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.
10. Where to go for more information on Fragile X:
    - **FragileX.org** - The National Fragile X Foundation
    - **FRAXA.org** - FRAXA Research Foundation
    - **time.com/archive/6685324/fragile-x-unraveling-autisms-secrets/** - Fragile X: Unraveling Autism's Secrets
    - **livingwithfragilex.com** - Living with 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, Note, prevalence is only a best guess, based on various small studies.

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

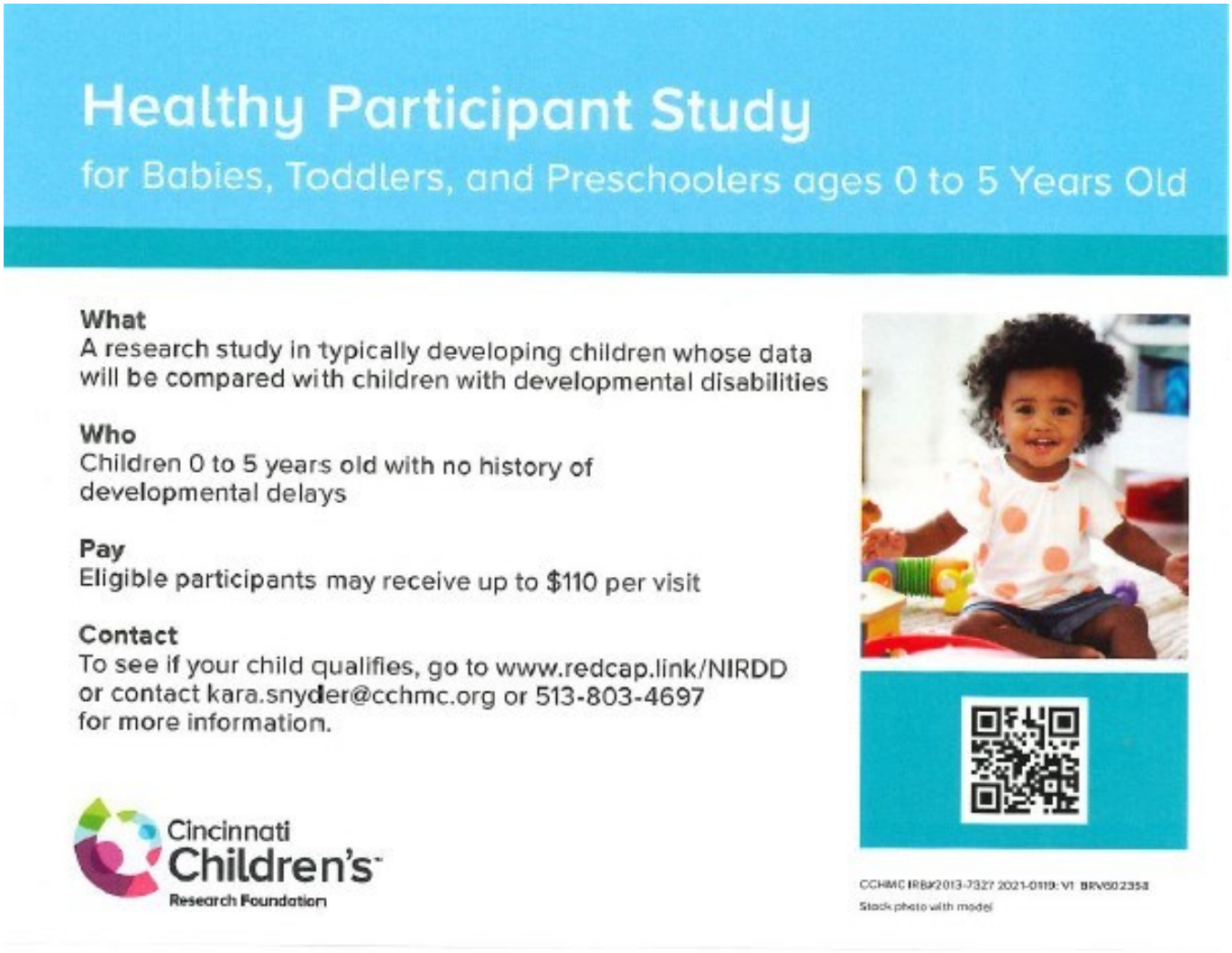
rev. 07/25

Research - Cincinnati Children's Hospital

Cincinnati Children's Research Foundation

Although the flyer states it's for healthy, typically developing children, children with Fragile X are also eligible to participate!

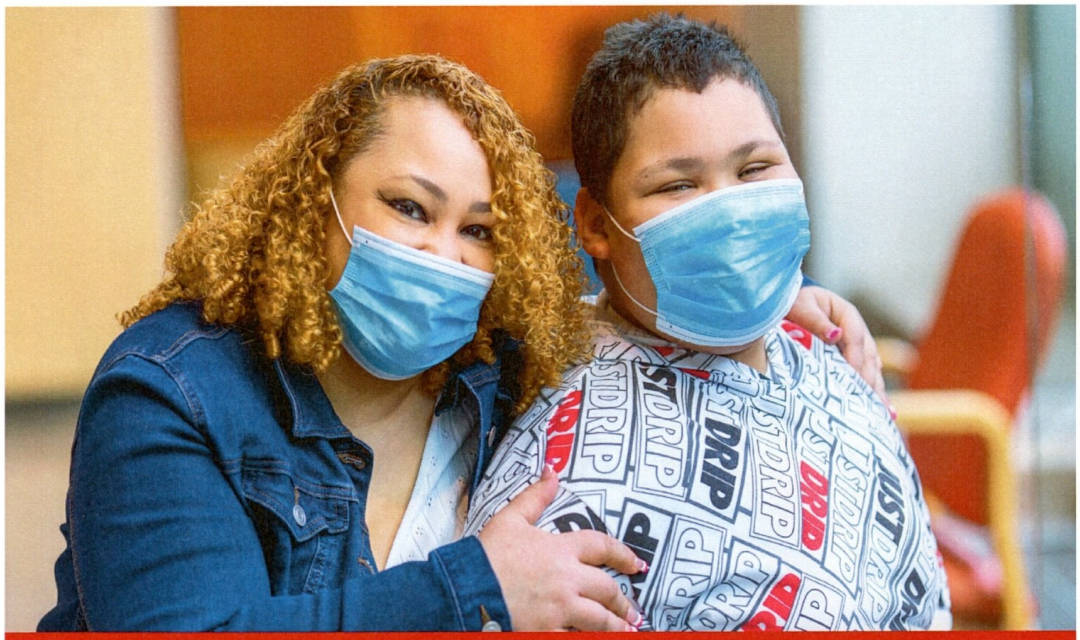
Contact info: **513-803-4697** or **Kara.snyder@cchmc.org**



Research - Cincinnati Children's Hospital

Cincinnati Fragile X Research & Treatment Center

Contact Info: **513-517-1580** or **Ashley.Dapore@cchmc.org** or **FragileX@cchmc.org**



FRAGILE X IN-HOME RESEARCH STUDY

What is this study about?

This study is to establish the feasibility of short, in-home research visits for individuals with Fragile X and to expand research access for those who may not be able to travel to Cincinnati. Participants will do an EEG and cognitive testing, and parents will fill out a few forms.

Who can participate?

- Anyone with an FMR1 full mutation
- Open to all - no previous research experience necessary!

Why participate?

- You may help us learn more about home visits and expand research in the future
- You will be compensated for participating in the study

Want to learn more? Contact the study team at:

513-517-1580

Ashley.Dapore@cchmc.org

FragileX@cchmc.org

CINCINNATI FRAGILE X RESEARCH & TREATMENT CENTER

v1

Research - University of Wisconsin-Madison

Waisman Center

Contact info: Amy Banasik at **608-263-5705** or **RIDDLL@waisman.wisc.edu**.

Research - University of Wisconsin-Madison

Waisman Center

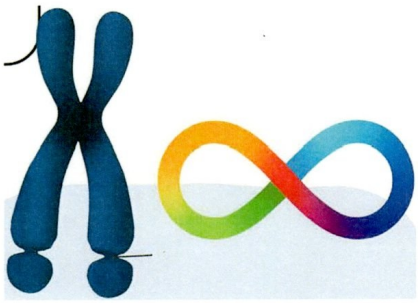
Contac info: **608-263-5145** or **sschroeder@waisman.wisc.edu**

WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON

Autistic or Fragile X RESEARCH PARTICIPANTS WANTED!

join us!

For a study on LANGUAGE EXECUTIVE & FUNCTION in 8-12 year old Girls



INTERESTED?

608-263-5145
sschroeder@waisman.wisc.edu

Why?

- To address gap in information about FXS & ASD effects on females
- To assess how executive function & language affect academic achievement & adaptive behaviors

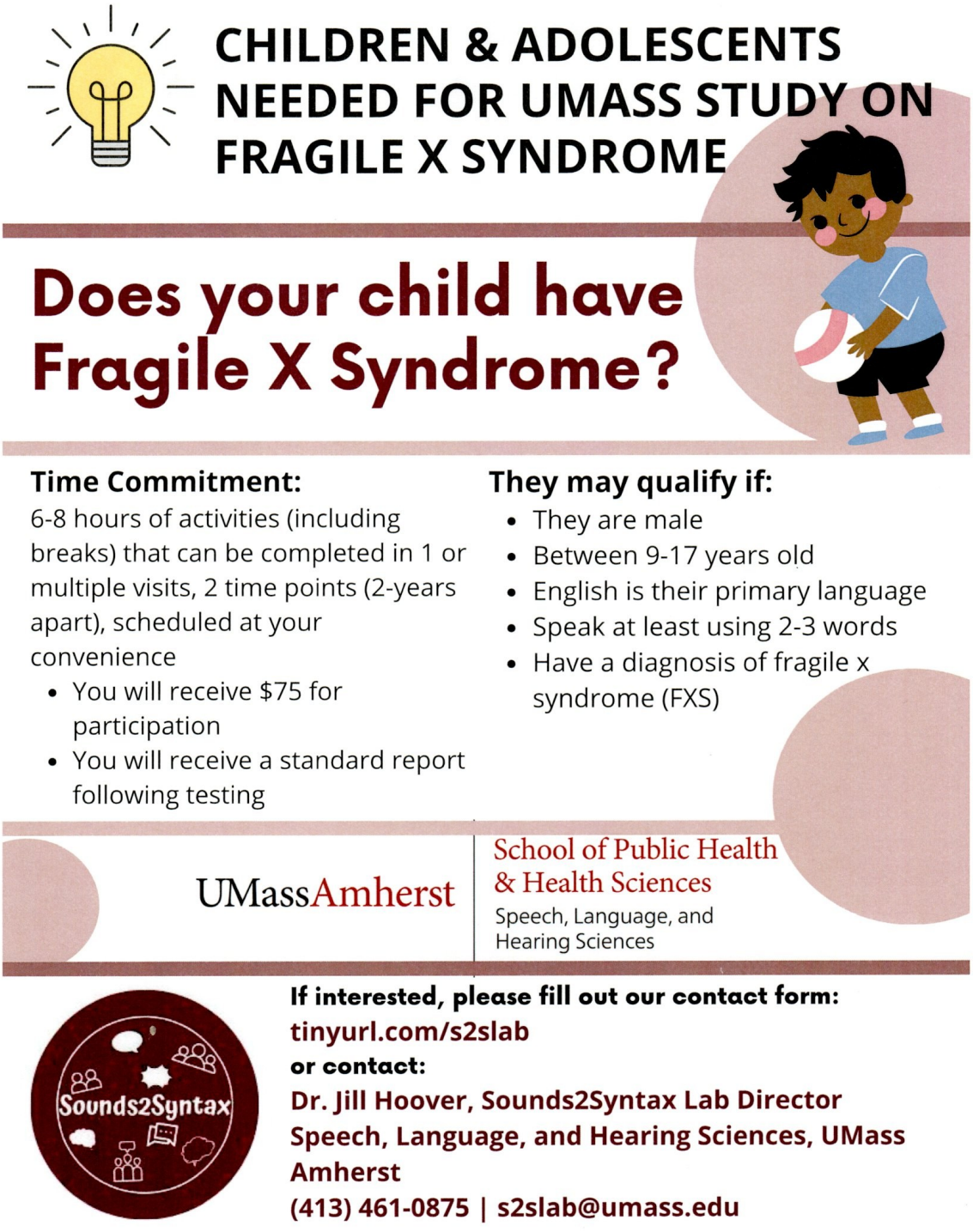
What?

- 2 in-person visits
  - 2 years apart
- Language & Behavioral testing
- $200 compensation
- Families receive a report with their child's assessment results

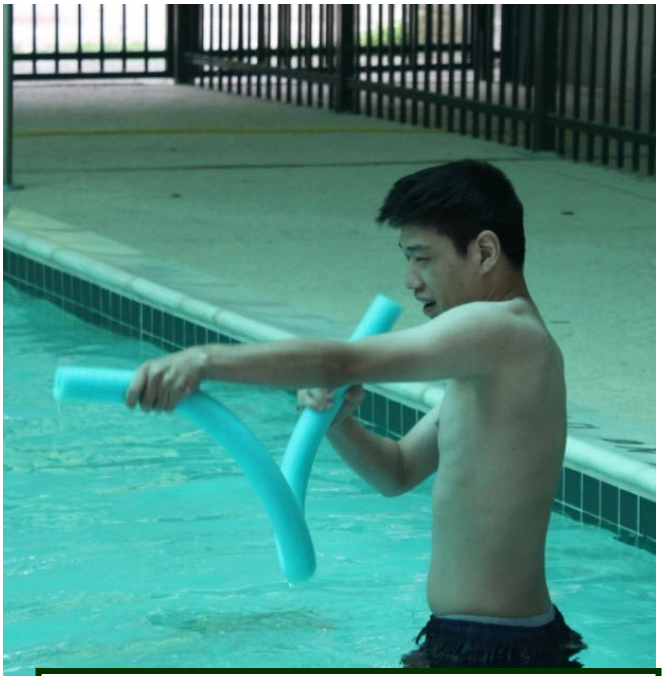
Research - UMass Amherst

School of Public Health & Health Sciences, Speech, Language and Hearing Sciences

If interested, please fill out their contact form at: **tinyurl.com/s2slab** or contact Dr. Jill Hoover at **413-461-0875** or **s2sla@umass.edu**.



Three Cheers for…



Michael and Camp Tamarack

Michael is part of the special needs group. Campers work at the camp half of the day and then spend time having fun the rest of the day. The camp is in Ortonville, Michigan

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FXAM.org

Three Cheers for...

Andrew's Day 1 of ESY 2025!

While Mom was in the shower, Andrew decided he needed to wear his winter jacket. With some coaxing took it off. Then he waited outside for the bus for 45 minutes but the new driver forgot to pick him up. After more coaxing, Andrew allowed Mom to drive him to Day 1 of ESY which turned out great!