

# Fragile X Research and Treatment Center Newsletter

March 2022



## Meet The Team



Sungeun Kang, PhD is our current psychology fellow who received her school psych doctorate from University of Iowa. Dr. Kang is interested in the implementation and cultural adaptation of evidence-based interventions.



Angelina Jones graduated with a B.S. in Psychology from the University of Alabama, Tuscaloosa. She is the lead Clinical Research Coordinator for the NIH Toolbox Study. She will be attending a clinical psych PhD program this fall!

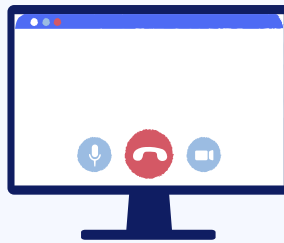
## Fragile X Results Spotlight

### Behavioral inflexibility in FXS: Accounts from caregivers and self-advocates

Behavioral Inflexibility = the inability or difficulty in changing one's behaviors based on environmental demands or social contexts; getting "stuck" in a repetitive loop of behavior

**The Problem:** Behavioral inflexibility is nearly universally present among individuals with Fragile X Syndrome, and when left untreated, negatively impacts quality of life for individuals and their families. BUT, there are limited measures to assess and track it in FXS.

**The Goal:** Develop a Fragile X-specific measure to accurately assess behavioral inflexibility across the lifespan and in response to treatment, and how behaviors interfere with individual/family life.



A psychologist ran virtual focus groups with 22 caregivers, 3 self-advocates, and 1 professional recruited through CCHMC and NFXF. Groups were asked questions like "If there is a known change in routine, what do you do to prepare your child?" and "Tell me about any routines or schedules your child has to follow." After, common themes from focus group discussions were identified.

### SIX THEMES:

1. Intolerance to change
2. Intolerance to uncertainty
3. Repetitive interests and behaviors
4. Family impact
5. Behavior across the lifespan
6. Impact of the COVID pandemic

These four themes will be used to develop a **new** FXS-specific measure:

Ratings of Inflexibility in Genetic Disorders associated with Intellectual Disability - Fragile X Syndrome (RIGID-FX)



Find the full article here:  
<https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1118652/full>



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## **Additional Study Opportunities**

**EEG Study of Brain Activity:** This study is looking at the mechanism and brain circuits underlying Fragile X Syndrome. It is a correlational study that enrolls individuals with FXS, their family members and control groups.

**Study of Visual Perception in Males with FXS:** This study aims to learn more about how distracting sensory stimuli impact visual processing and brain activity.

**Single Dose Drug Challenge Study:** This study is looking to see if medication can treat excessive sensitivity to sounds which is a common and distressing symptom of FXS. Three medications (Baclofen, Memantine, Roflumilast) and a placebo will be tested.

**FORWARD March:** This study uses data from families who have a family member with Fragile X syndrome and the clinicians they see to advance our overall understanding of Fragile X syndrome, from the diagnosis, to the evaluation and treatment of it in day-to-day life.

**Computer Based Cognitive Testing:** The goal of this study is to develop ways to measure cognition, in hopes we can use these in future clinical trials to help us understand which treatments work.

**Hearing, Language, and the Brain:** This study uses a cap that monitors blood flow and electrical activity in the brain, with the goal of finding a link between hearing, brain activity, and language impairment.

**Interested? Email [FragileX@cchmc.org](mailto:FragileX@cchmc.org)**

## **Study Spotlight**

### **RIGID-FX**

#### **Who?**

Any caregiver of individual with FXS or self-advocate with FXS

#### **What?**

Initial validation of a new study measure of behavioral inflexibility, RIGID-FX (see Fragile X Results Spotlight)

#### **What's Involved?**

20-30 minute interview with clinician or study staff regarding behavioral inflexibility and its impact on family life. Additional demographic information and measures will be completed if time allows.

#### **Contact**

[Angelina.Jones@cchmc.org](mailto:Angelina.Jones@cchmc.org)

# THANK YOU!

Our research team at Cincinnati Children's Hospital would like to thank you for your participation and interest in our research studies!



# FXS ADVOCACY DAY

For more information: <https://fragilex.org/get-involved/advocacy/>



Dr. Lauren Schmitt, one of our clinical psychologists, joined over 120 family and self-advocates on February 28 (Rare Disease Day) in Washington, DC to advocate on behalf of Fragile X Syndrome!



For over 20 years, the National Fragile X Foundation (NFXF) helps make FXS Advocacy Day happen. We hope to see you there next year!



## 2023 ASKS:

- 1) Maintenance and extension of access to telemedicine in the U.S.
- 2) Continued research funding dedicated to FXS from the NIH, CDC, and DoD.

# FRAGILE X CENTER EVENTS



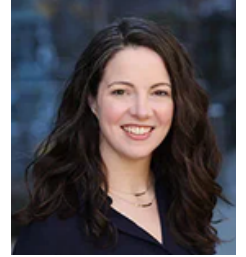
## **Virtual Table Talk: Infants and Toddlers**

Tuesday, March 7, 2023 at 7:00pm

With Drs. Kelli Dominick and Betsy Smith

Zoom Meeting ID: 999 6155 7942

Passcode: mj7Amr



## **Save the Date: Cincinnati Fragile X Center Conference**

Saturday, July 22, 2023, 8 am - 5 pm

Cincinnati Children's Hospital Medical Center

# COMMUNITY EVENTS

*MARCH 2023*

## **Managing Anxiety: Helping Kids with Developmental Disabilities Cope & Succeed**

Wednesday, March 8, 2023 from 5 - 7 pm

For caregivers of children ages 8 and older

Register at <https://tinyurl.com/DDanxiety>

## **Two-Day Toilet Training Class for Parents/Caregivers**

9am-12pm, March 16th and 23rd

Class with the goal to coach caregivers on a structured method for toilet training children at home. Following class completion, individual and/or intensive follow-up services are available if needed. One-time fee of \$15 per family (includes training manual) Registration closes March 8th: Email [jennifer.gastright@cchmc.org](mailto:jennifer.gastright@cchmc.org) or call 513-636-2742 to reserve a spot

# COMMUNITY EVENTS

MARCH-APRIL 2023

## **Adaptive Boxing 2023 Try-It (Ages 6+)**

March 18th, Imhoff School of Boxing in Hamilton, OH  
Limited spots left at <https://tinyurl.com/adaptiveBoxing>

## **Adaptive Sports Clinic**

Thursdays from 8am - 12pm

Medical Office Building, 3430 Burnet Avenue

For individuals with disabilities ages 5 and older who need help identifying potential opportunities for sport or recreation, require ongoing physical therapy intervention to safely return to sport, and need to master basic skills in preparation for starting a new sport

Email [otpt.be.well@cchmc.org](mailto:otpt.be.well@cchmc.org) to schedule

## **Sensory Saturday at the Cincinnati Art Museum**

Upcoming dates: March 25th

Email [access@cincyart.org](mailto:access@cincyart.org) to join the mailing list

More resources available at [cincinnatiartmuseum.org/access](http://cincinnatiartmuseum.org/access)

## **Adaptive Gaming Night**

Last Wednesday of Every Month (by appointment)

Anyone with a disability interested in gaming who has difficulty playing with a standard Xbox or Nintendo controller

Email [gamers@cchmc.org](mailto:gamers@cchmc.org) to schedule

## **Ohio Parent to Parent Support Parent Trainings - Virtual**

Every 1st and 4th Thursday

from 12 - 1pm or 6:30 - 7:30pm

Registration is Required!



# ONLINE PRESENTATIONS

Available at <https://fragilex.org/blog/2022-conference-sessions> and <https://fragilex.org/fxs/daily-living/lifespan-toilet-training>

## **Emotion Dysregulation in Fragile X Syndrome**

**Rebecca Shaffer, Psy.D**

This presentation focuses on the signs of emotion dysregulation in Fragile X syndrome and ways to respond including practical strategies and an Emotion Regulation Toolkit to take home.

## **Common Behaviors and Available Treatments Across the Lifespan**

**Debra Reisinger, PhD**

This presentation highlights how to recognize behavioral challenges in FXS and the most common behavioral difficulties and treatment options at each developmental stage. Specific tips will be shared that families can easily implement with their children or adolescents.

## **Toilet Training Across the Lifespan in FXS**

**Jennifer Epstein, Psy.D**

This workshop is for caregivers of individuals with FXS. It provides an overview of methods (general strategies with modifications for FXS and trip and schedule training) that support the practice of readiness skills. The workshop is also designed to increase caregivers' understanding of common hurdles affecting skill attainment. Following an overview of some successful strategies, questions are answered by caregivers.