

Fragile X Research and Treatment Center Newsletter

December 2022



MEET THE TEAM



Dr. Elizabeth (Betsy) Smith, PhD, is a clinical psychologist who specializes in developmental cognitive neuroscience and autism. She uses neuroimaging techniques like functional near infrared spectroscopy (fNIRS) and electroencephalography (EEG) to understand how differences in social behaviors and communication emerge during early development in FXS and other neurodevelopmental disorders.



Anna Benedict is a graduate of the University of Notre Dame, where she received a B.S. in Neuroscience & Behavior and a supplementary major in English. She works with young children with FXS. She is the lead CRC for the Hearing, Language, & the Brain study with Dr. Smith and co-lead for the BABY FXS study.

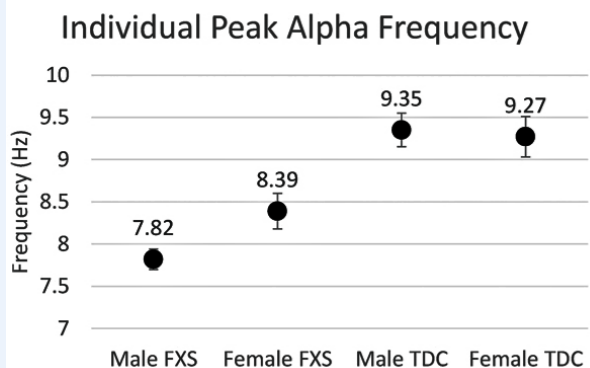
Fragile X Results Spotlight

Sex differences in resting EEG in FXS

Every person has a peak 'frequency', or speed, that their brain uses most. This is usually in the 'alpha' range (8-13 Hz, or cycles per second). Peak frequency is associated with things like sensory processing, cognition, and even relaxation.

Participants completed an EEG and cognitive testing, and parent report forms of behaviors.

EEG data was analyzed to find the average peak frequency for each participant, then grouped by sex and diagnosis.



Males with FXS had lower peak frequency.

Females with FXS had peak frequency intermediate between males with FXS and typically-developing controls

In a follow-up study, we found that peak frequency was related to clinical features of FXS



Lower peak frequency was correlated with more severe anxiety



Higher peak frequency is related to higher IQ

Why this matters

- Peak frequency is different in FXS across both sexes, but may be less altered in females with FXS
- Peak frequency may be a useful brain biomarker to track with clinical features and in response to treatment



Find the full articles here:
<https://doi.org/10.1016/j.jpsychires.2021.03.057>
<https://doi.org/10.1038/s42003-022-03395-9>



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Additional Study Opportunities

New Parent-Report Measure of Inflexibility in FXS:

Behavioral inflexibility is common in FXS and greatly impacts daily life. We developed a measure to better capture this symptom and need to test it out.

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.

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.

**Interested in participating?
Email FragileX@cchmc.org**

Study Spotlight

Hearing, Language, and the Brain

Who?

Infants and young children with FXS (ages 0-5)

What?

This study uses a cap that monitors blood flow and electrical activity in the brain while the participant listens to sounds. The study's goal is to find a link between hearing, brain activity, and language impairment.

What's Involved?

fNIRS-EEG, language measures, assessments, and hearing tests

Contact

Anna.Benedict@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!

ONLINE PRESENTATIONS



Emotion Dysregulation in Fragile X Syndrome

Rebecca Shaffer, PsyD

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

Individuals with Fragile X syndrome (FXS) can experience a variety of symptoms and behavioral challenges that change across development. This presentation will highlight 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.

COMMUNITY EVENTS

DECEMBER 2022 - JANUARY 2023

Sensory Santa

December 8th - 11th, 17th

Currently sold out – to be added to the waitlist, please email the Cincinnati Zoo's Access for All manager at annie.degroot@cincinnati-zoo.org



NATIONAL FRAGILE X
FOUNDATION



Educational Webinars

NIH Fragile X Centers of Excellence - 2023 Update



Department of
Human Genetics

BAYLOR COLLEGE OF MEDICINE
UNIVERSITY OF MICHIGAN MEDICAL SCHOOL
FRAGILE X CENTER AT EMORY UNIVERSITY
CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER



January 12, 2023, 7-8pm EST

Registration Details Available Soon

COMMUNITY EVENTS

JANUARY-MARCH 2023

Sensory Saturday at the Cincinnati Art Museum

Upcoming dates: January 28th, February 25th

Email access@cincyart.org to join the mailing list

More resources available at cincinnatiartmuseum.org/access

Executive Functioning and Organizational Skills for Individuals with Developmental Disabilities

February 13, 2023 from 5:30 - 6:30pm

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

Sensory-Friendly Princess & Frog

Wednesday, February 22, 2023 at 1:00pm

The Taft Theatre, 317 E 5th Street, Cincinnati, OH 45202

Special performance for individuals with developmental disabilities and their families (not for general public). Only a limited number of tickets will be sold.

<https://thechildrenstheatre.com/sensory-friendly-princess-frog/>

Ohio Parent to Parent Support Parent Trainings - Virtual

Every 1st and 4th Thursday

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

Registration is Required!

Save the Date - Table Talk: Infants and Toddlers

Tuesday, March 7, 2023 at 7:00pm

With Drs. Kelli Dominick and Betsy Smith