

Healthy Aging Research Study



Newsletter

SC Family Experiences Lab



Lab Director: **Dr. Jessica Klusek**

VOLUME 4
SUMMER 2026

Highlights

Study Continuing with
Extended Enrollment!

Upcoming
Conference
Presentations

New Faces,
Fond Farewells

Recently Published
Paper + Webinar Series



UNIVERSITY OF
South Carolina
Arnold School of Public Health



A Message to Our Participants:

We are incredibly grateful!

Whether you've recently joined our study or have been participating with us for many years, your time and commitment is what makes it possible for us to keep moving this work forward. We are so thankful to have you as part of our research community.

As we reflect on the past year and look ahead to the next, we're excited to share some updates from our team.



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STUDY EXTENDED!

Extend Your Participation Beyond the Initial 3 Years!

Thanks to continued funding from the **NIH P50 Fragile X Center of Excellence Award** our *Healthy Aging* study is continuing beyond the original 3-year study period!

This study involves women with the *FMR1* premutation and control women who do not carry the premutation. By continuing to follow participants over a longer period of time, we hope to learn more about how aging affects health and improve care for people with fragile X-associated conditions.

If you have already completed the initial 3-year study, our research team will be contacting you to invite you to continue participating.

We hope you will stay involved in this important research. Your continued participation is invaluable, and we are truly grateful for your time, commitment, and contributions.

Questions about participation? Has your contact info changed?

Contact us at scfamilystudy@gmail.com



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20th NFXF INTERNATIONAL FRAGILE X CONFERENCE

WHERE LEARNING MEETS LASTING MEMORIES
LOUISVILLE, KY • JULY 16-19, 2026

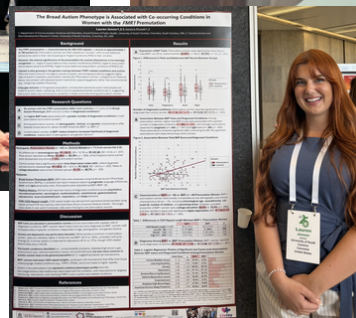
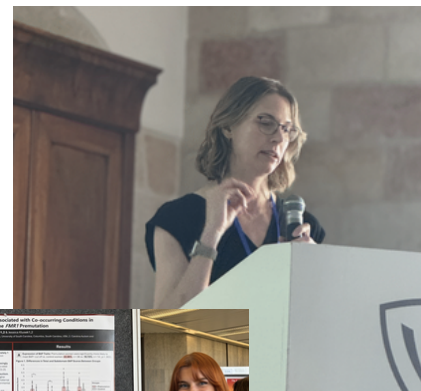
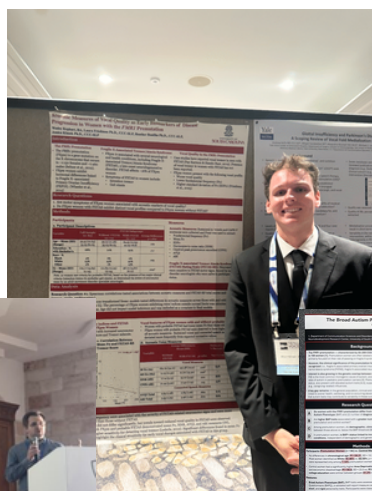
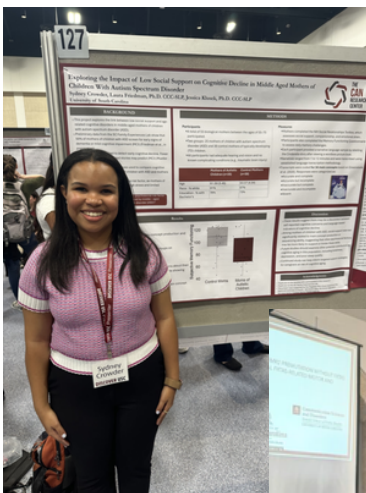
See you at the 20th NFXF International Conference in Louisville, Kentucky!

Friday, July 17th:

- Dr. Jessica Klusek -- "**Strategies for Early Literacy Skills**", 1:15-2:15 in Salon G
- Thomas Christensen -- "**Word Finding in Women with the *FMR1* Premutation and Its Association with FXTAS-Related Motor Symptoms and *FMR1* Premutation Allele Expression**", 5:00-6:30 in the Marriott Ballroom Lobby.
- Dr. Jessica Klusek -- "**Hearing Loss in Adult Women with the *FMR1* Premutation**", 6:30-8:00 in the Marriott Ballroom Lobby.

Saturday, July 18th:

- Dr. Lauren Jenner -- "**Just Knowing Put Together Things I've Been Wondering About My Whole Life": A Case Series and Thematic Analysis of Six Mothers with the *FMR1* Full Mutation**", 1:15-2:15 in Rose.
- Dr. Jessica Klusek -- "**Symposia: FXTAS in *FMR1* Premutation Carriers: Updates from Ongoing Research**", 2:30-4:00 in Bluegrass.



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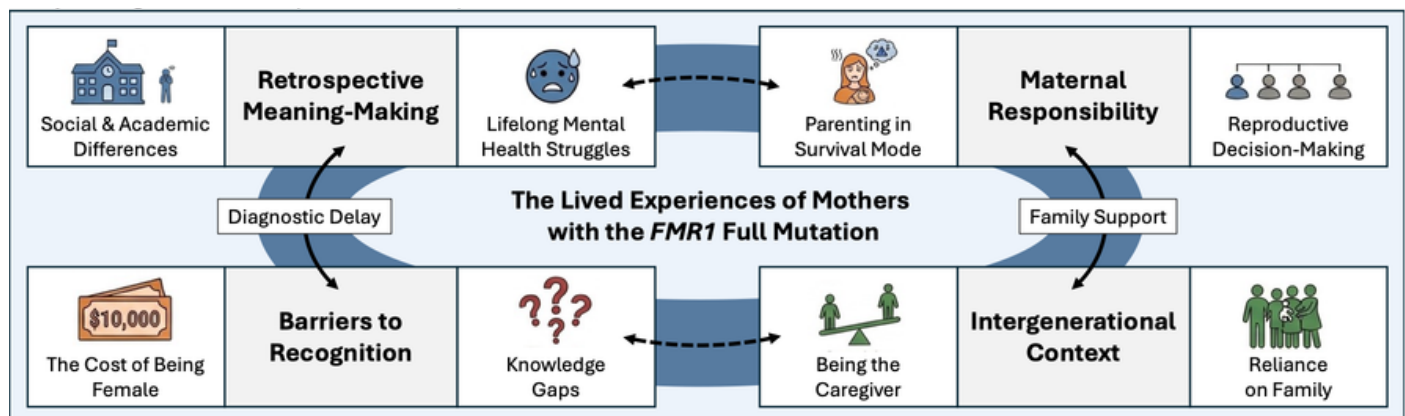
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New Research on Mothers with the Full Mutation

We're excited to share that our pilot study on mothers with the *FMR1* full mutation (>200 CGG repeats) has received an incredible response. We have already enrolled nearly our full sample!

Dr. Jenner will be presenting early findings from this project at this year's NFXF Conference. Her presentation will take place on Saturday from 1:15–2:15 pm in the Rose Room. If you're attending the conference, we hope you'll stop by! If not, we look forward to sharing updates once the study is published.

This project is the first study to focus specifically on the experiences of mothers with the full mutation. We are excited to see it adding new knowledge that can help improve understanding and care.



We are still recruiting! If you are a mother with the full mutation between the ages of 35–80, or know someone who may be interested, we would love to hear from you.



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Research on Adult Independence

We're excited to share a milestone in our research on adult outcomes in fragile X syndrome! Many of you may remember completing questionnaires about your adult son or daughter during a recent research visit. These questionnaires are helping us understand important aspects of adult life, including:

- Living arrangements
- Employment
- Education and transition programs
- Social participation
- Daily living skills
- Mental health and behavioral characteristics



Your participation is helping build a stronger understanding of adult outcomes and informing future research and support for individuals with fragile X and their families.

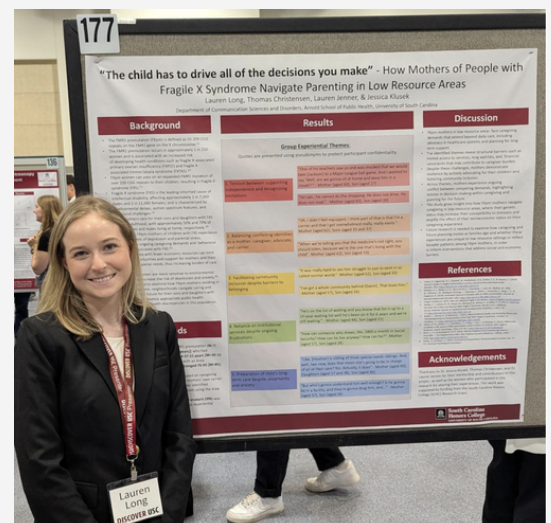


STUDENT SPOTLIGHT

On April, undergraduate student Lauren Long presented her research at the University of South Carolina's annual DiscoverUSC conference.

Her poster explored the experiences of mothers raising children with fragile X syndrome in underserved communities. Findings highlighted challenges such as limited access to services and long-term care planning, as well as the resilience and advocacy of these mothers.

Lauren will be completing her senior honors thesis this year, and hopes to pursue medical school after her graduation.





Welcome Heather and Lydia - our Newest Team Members

Heather and Lydia are excited to
work with you and your families in
upcoming visits!

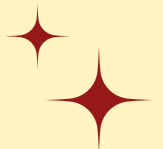


Heather Petersen graduated in 2025 from Lehigh University with her Bachelor of Arts in Psychology and Anthropology. She has over two years of previous research experience in the Lehigh Language Production Lab and the Yale University Phonetics Lab. She is interested in exploring speech-language pathology + clinical psychology as disciplines and building on her psychological assessment skills.

Lydia Bonecutter is a Psychology and Spanish graduate from Meredith College, with four years of experience working with children on the autism spectrum. She is a Registered Behavior Technician and served as a volunteer research assistant at the Carolina Institute for Developmental Disabilities. Her research interests include evidence-based interventions for neurodevelopmental disorders and improving access to services for diverse and Spanish-speaking families.



IT'S NOT GOODBYE, JUST SEE YOU LATER!



We're excited to celebrate the next steps our team members are taking in their academic and professional journeys! While we will miss them, we are incredibly proud of their accomplishments and wish them all the best in this exciting new chapter.



Our research specialist, **Zaynab Khan**, is beginning a master's program in **Genetic Counseling** at **Emory University**. Our project coordinator, **Blythe Vickery**, accepted a position as a **speech-language pathologist**. Another research specialist, **Nhi Ngo** is continuing with her master's in **Genetic Counseling** at the **Medical University of South Carolina**.



Many of you have met these team members during your visits. Thank you for being part of their journey, and please join us in wishing them continued success!



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Recently Published Papers

Cognitive dysfunction in women with the *FMR1* premutation during midlife: The LASSI-L reveals curvilinear CGG-dependent risk buffered by college education

Dr. Jessica Klusek and colleagues recently published a study on thinking and memory in women with the *FMR1* premutation. They found that:

- Some women with the *FMR1* premutation show subtle memory differences, such as remembering a related word instead of the correct one during a word learning task.
- These memory differences emerge as early as the 30s and 40s.
- Higher education helped buffer risk for memory difficulties in women with the premutation. This protective effect was strongest among women with mid-range CGG repeat lengths (approximately 80–100 repeats).
- These findings highlight midlife as a critical window for cognitive monitoring in women with the premutation and suggest that education and other life experiences may help reduce risk - particularly for certain genetic subgroups.

Interesting in learning more? To read the full article, [click here!](#)

Comprehensive, multidisciplinary care for fragile X-associated tremor/ataxia syndrome

Dr. Jessica Klusek and doctoral candidate Thomas Christensen recently co-authored a new article on caring for people with FXTAS.

- FXTAS can affect movement, thinking, and emotional well-being.
- A team approach to care can help meet each person's unique needs.
- Early recognition and ongoing care may help support quality of life.

To learn more, you can access the article [here!](#)



Links to other Recent Publications

- [Psychiatric difficulties in females with fragile X syndrome: a systematic review and meta-analyses](#)
- [Semantic and syntactic language differences associated with the *FMR1* premutation genotype](#)
- [Interaction of FXTAS Family History and College Degree Attainment Predicts Trajectories of Cognitive and Motor Symptoms in *FMR1* Premutation Carrier Women](#)
- [Women with the *FMR1* premutation: a within-family observational sibling study](#)



LivJoy + NFXF Webinar Series

The LivJoy Foundation and the National Fragile X Foundation launched the **Females with Fragile X Webinar Series**.

This new series aims to highlight the experiences of females with FXS – a group that is often underrepresented in discussions about the condition and whose needs can differ from those of males. The webinars focus on topics particularly relevant to girls and women with FXS, including physical and mental health, puberty and sexuality, and long-term life planning.



[Watch the inaugural session Here!](#)



We are hoping to enrich our recruitment for the following groups of women...



- Women with the **FMR1** premutation who are aged 70-80 years
- Women with the **FMR1** premutation who from racial backgrounds that are historically underrepresented in research, such as Black and Hispanic women.

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