**GIRL BAND UPDATES**
from the Center for Interdisciplinary Brain Sciences Research
at Stanford University School of Medicine

**RESEARCH UPDATES**
- We have seen more than 40 families of our goal of 100 from all over the US and Canada!
- We have submitted a review article to a scientific journal entitled "Closing the gender gap in fragile X syndrome: Review on females with FXS and preliminary research findings".
- Our research team is still actively recruiting and seeing families.

*The Stanford Girl BAND study: what we are learning with your help!*  
We are very excited to share what we are learning from our research with the help of your family!

This study continues to be one of the first to follow the development of young girls with fragile X syndrome into later childhood and adolescence. With our results we will better understand how girls learn and grow socially and behaviorally.

Please read on to find out more about what we are learning...

**FIND US HERE!**

@StanfordGirlBAND

@StanfordGrlBAND
In July, our Girl BAND Team attended the International Fragile X Conference in Cincinnati, Ohio!

**SUMMARY AND INSIGHTS**

### Quality of Life and Family Environment

Dr. Amy Lightbody presented information about a child's perceived quality of life and how this might be affected by the dynamic within her home and family. Below are insights based on information learned from this analysis:

- **Prioritize consistency and planning.** Provide structure and organization in the household. Clearly define your child’s responsibilities.
- **Make time for social and recreational activities as a family.** Encourage hobbies and activities outside of school and work. Reduce screen time. Invite friends to your home.
- **Model expressing frustration in a calm manner.** Work through issues together as a family, minimizing criticism.
- **Encourage open communication.** Model expressing feelings in a productive manner and encourage your child to do the same.

### Support Students with Classroom Adaptation

Cindy Lee introduced strategies for parents and teachers to create learning environments to support students with FXS. Talk to your daughter’s teacher about implementing some of these strategies!

#### Traditional Classroom
- Large, busy classroom may increase social anxiety
- Typically noisy
- Includes a variety of transitions including subject and physical transitions
- Long periods sitting at a desk

#### Adaptive Classroom
- Smaller classroom and/or small group work
- Noise level control
- Utilizes a visual timetable to promote predictability and reduce anxiety
- Flexible seating options to address student needs

### Brain Scans and Social Interaction

Dr. Jennifer Bruno described our work using imaging methods which allow us to capture information about brain functioning in naturalistic settings.

- **fNIRS allows us to investigate brain function during social interaction.** This is a challenge area for many girls with FXS and we hope that our results will help us better understand why those interactions are so challenging. Our preliminary results indicate that brain activation patterns are different for girls with FXS, but we need more data before drawing any conclusions.
- **MRI findings may help us plan targeted treatments.** Dr. Bruno also discussed results from a previous study with young boys who have FXS. This study suggested that MRI brain scans from early childhood can be used to define subgroups. We plan to apply this method to our girls study. If we do find subgroups among girls, we will gain a better understanding of FXS, which we can use to plan treatments. You can read the paper to learn more: [http://www.pnas.org/content/114/40/10767](http://www.pnas.org/content/114/40/10767)

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**HELP US RECRUIT!**

We are incredibly grateful for your support and active participation in this high-priority research!

We still need new families like yours to join our Girl BAND family.

You can help us by:

- Sharing our flyer
- Referring friends and family
- Reviewing us on social media

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**YOUR FEEDBACK IS IMPORTANT TO US!**

Help us improve by filling out a short survey about your visit:

https://is.gd/girlband_feedback

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![Image of a girl wearing a headset and headphones]