



## Females

*Note: For the purposes of this content, we use the term “females” to refer to individuals with two X chromosomes (XX). Common terms also used are girl, girls, woman, and women.*

## Upcoming Webinars

### Females with Fragile X Syndrome

The way that each female experiences Fragile X syndrome (FXS) is different. Females with FXS have a wide range of abilities. Females with FXS may also struggle.

Our [Females with FXS: Strategies for Developing Executive Functioning and Social Skills webinar](#) emphasizes that a diagnosis of FXS should be viewed as a tool to understand what the individual may be at risk for, not as a definitive outcome. This perspective shifts focus to proactive strategies and interventions. We invite you to take this approach as you read through this content.

The more we learn about females, the more effective interventions and support structures become in assisting them to live personally fulfilling lives.

## **Females with Fragile X Syndrome — Strategies for Developing Executive Functioning and Social Skills**

Barbara Haas-Givler, from the Geisinger Fragile X clinic in Pennsylvania, provides resources and strategies for implementing social skills support in the classroom, home, and community.

### **Symptoms & Characteristics**

**Though typically females experience milder symptoms of FXS, significant challenges can still exist.**

Females with FXS often have milder symptoms compared to males, but not always. Females can still experience cognitive, emotional, and behavioral challenges. These may include learning disabilities, speech delays, and social anxiety.

Many females with FXS also have heightened sensory sensitivities. They may be overly sensitive to lights, sounds, textures, or smells, leading to sensory overload and possible meltdowns.

Females are much less likely than males to exhibit physical characteristics of FXS. Some physical features are common in females with Fragile X syndrome, such as a long face, large ears, and hyper-flexible joints. These characteristics may not be as pronounced as in males, but they can still be present.

Females with Fragile X may also be at higher risk for other conditions, such as ADHD, anxiety disorders, depression, and, in some cases, autism spectrum disorder (ASD). It's important for parents to be aware of these potential co-occurring conditions to ensure proper diagnosis and treatment.

A percentage of females who have the full mutation will have no obvious signs of the condition — physical, cognitive, behavioral, or emotional. These females are often identified only after another family member has been diagnosed.

It's important to consider the unique needs of each female with FXS. Identifying

specific symptoms and needs helps prioritize the most relevant supports and interventions. Interventions may include educational, behavioral, employment, medical, and social supports. When a medication is recommended to help address symptoms or specific behaviors, it is important to consider the medication in combination with other therapeutic interventions.

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## Cognition and Learning

Females with FXS may have intellectual disabilities. Some girls do not experience an impact on their cognition, while others may have mild to moderate developmental delays. Separately, females may still experience difficulties with tasks like problem-solving and abstract reasoning.

### Academics

Academic difficulties may cause females with FXS to lack the confidence necessary to succeed in school. Many studies report deficits in attention in a global sense and math in particular. These deficits are common and often pervasive, with a negative effect on school performance. Often, the deficits are not identified or diagnosed until later years, causing a delay in supports.

### Understanding Money

Difficulty with math can also affect the female's ability to understand the use and value of money. Managing money and being able to budget may pose great challenges to females with FXS.

### Strategies:

- A potential solution is to teach how to track money using a software program like Quicken.
- Try limiting credit card use, changing credit cards into debit cards only, and organizing spending by using envelopes marked with budget items.
- Sometimes it is best to cash a paycheck and then divide the cash into categories in separate envelopes to pay the bills in a very concrete way.

## Executive Functioning

Lack of executive functioning (the ability to sum up intention, form a plan, and execute it) is another characteristic commonly associated with FXS in females. Lack of follow-through becomes a concern, as completing homework and keeping commitments can present challenges. School staff may see the female with FXS as lazy and unmotivated.

### Strategies:

- Providing visual supports to explain the planning-and-executing process often helps promote completion.
- Keeping a digital calendar on a smart phone with alarms set as reminders can be a helpful strategy for girls to remember scheduled events and appointments.
- Using iPhone apps that enable family members to add information and reminders from other devices to keep schedules, grocery lists, and assignments current.

You can find specific suggestions and strategies on executive functioning for young girls in this blog with presentation from Barbara Haas-Givler, [Executive Functioning Strategies for School-Aged Girls with FXS](#).

## Strategies to Improve Executive Functioning for School-Aged Girls with Fragile X Syndrome

Presented by Barbara Haas-Givler, MEd, BCBA. Also, read our [script](#) from the webinar.

## Personal Organization

Females with FXS frequently have great difficulty keeping their rooms organized, cars clean, or personal items tidy. While common sense would tell us that less is more, females with FXS often love collections and saving mementos, such as ticket stubs from football games and concerts. These and other ‘stuff’ make it more difficult to purge unnecessary clutter.

### Strategies:

- Providing a designated place for articles of clothing, shoes, and personal items

helps keep things organized.

- Having a crate in the car for items that may be occasionally needed is also helpful.
- A daily list of chores can be posted on a whiteboard as a simple visual reminder of what needs to be done before leaving the house.

## Visual-Spatial Skills

Females with FXS usually have difficulty with visual-spatial relationships. This causes them to get lost and struggle with navigating school environments and communities. Driving can pose additional challenges related to parking, finding desired locations, judging space between cars, and remembering rules of the road.

However, with good training and monitoring, females can learn to drive successfully, which gives them greater freedom and access to jobs, social events, and their communities. All this creates a positive loop for building confidence and self-esteem.

### Strategies:

- Google or Apple Maps or another navigation app may be a good support to those who often get lost or forget directions. This works well because the voice on the device alerts them to the map and offers directions for finding their way.
- Remind them they can call you when they're lost, which will help reduce anxiety on both ends of the line!

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Dixie

**What makes Dixie Xtraordinary to you?**

Dixie has worked so hard to overcome her disability despite all the hardship she has

faced! Being her father is the best thing that happened to me. She is Xtraordinary!

[Read more about Dixie](#)

## Language

Females with FXS may also experience delays in language development. They may have trouble with both expressive and receptive language skills. Speech therapy is usually needed to help with communication development.

Perseverative language is often a hallmark of conversation in females with FXS. As the individual becomes more scattered, they may repeat key phrases or attempt to emphasize a certain aspect of the conversation over and over. Challenges with emotion regulation can contribute to this tendency.

Females with FXS may struggle with attention deficits that can further complicate their social interaction. Being distracted, or forgetting important information from a conversation, can create challenges socially.

### Strategies:

- To help combat this issue, you may try videotaping conversations, providing the individual an opportunity to watch and hear the repetitious language.
- Sometimes it helps to use a counting device to document the number of times certain phrases are repeated, thus making the intervention more concrete.

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## Social Anxiety, Emotion Regulation, and Other Common Behaviors

Females with FXS are at increased risk to experience anxiety. Mood swings and depression may be present — most often during adolescence. Medication, counseling, and other interventions may help address these issues. Consultations with family physicians and experts with experience in Fragile X can be important in obtaining the assistance a person needs.

Social anxiety, shyness, and difficulty with social interactions are also common. Individuals may struggle to make and maintain friendships, understand social cues, or express emotions appropriately.

One of the most challenging symptoms associated with FXS in females is extreme shyness. It is not unusual to see young girls hiding behind their parents, crying when asked to participate in conversation, unable to separate from parents, and whispering or even appearing mute in social settings. Desensitization through repeated exposure may be helpful to build tolerance for social activities.

As these females grow older, their shyness often translates into significant social anxiety. This anxiety can manifest in a number of problematic behaviors that result from attempts to cope with its effects. For example, it is common for them to agree to a social plan and then spend the ensuing days physically ill with stomach distress or headaches because they're terrified of participating and don't know how to get out of the obligation.

Parents often find themselves in a position of running interference for their daughter or attempting to explain to others. The problem can then persist if the female faces further embarrassment about why she continues to let others down. Some females have even shared they have wanted to decline an invitation, but feared the fallout from saying no.

### **Strategy:**

- Solutions to this dilemma include having the individual memorize a set response when she wants to say no. This allows her time to separate from the intensity associated with the expectation. Phrases like "I'll have to check my schedule," or "I need to see what my family plans are," or a simple "I think I may have a conflict" can take the harshness out of saying no and afford the girl more time to think it through.

## **Behavioral Issues and Emotional Dysregulation**

Females with FXS may experience behavioral challenges such as hyperactivity, impulsiveness, and irritability. Emotional regulation can also be difficult, with anxiety, mood swings, or outbursts/tantrums.

Emotional and mental health support is crucial. Many females with FXS benefit from

therapy, including cognitive-behavioral therapy (CBT), to address anxiety, depression, and social difficulties. Family counseling can also be helpful.

### **Expressing Emotions; Nurturing Creativity**

Many females with FXS are excellent writers who create wonderful stories. One woman explained to Dr. Marcia Braden that she was much more able of expressing emotion through a fictional character than through her real-life experiences. Analogies and abstract literary techniques allow for expression of inspiring imagery and interesting stories. Females may be good readers who enjoy fantasy and fictional stories, therefore, using a journal to write down their feelings is often a successful therapeutic tool.

Others nurture their creative tendencies through art forms, crafts, and home decorating. Some enjoy paint-by-numbers, word searches, and pattern drawing. It appears that the structure is helpful and comforting, providing a sense of closure when the task is completed. The universality of art can hold great riches for females with FXS; loved ones can help by nurturing these impulses whenever possible.

### **Self-Injury, Bullying, and Other Behaviors**

Anxiety can manifest in certain negative behaviors, such as self-injury. Although not as severe as similar behavior seen in males with FXS, females tend to self-injure in a more subtle fashion.

For example, what begins as picking a scab can evolve into a persistent picking at arms or legs, causing scarring and extreme discomfort. The compulsion is so powerful that it can be feel impossible to stop, which may cause self-consciousness of the behavior, trying to cover her arms with long sleeves or cover the picked scabs with band-aids.

Females with FXS also report being bullied or isolated from others in school. Being unable to read social cues or understand social consequences can contribute to their alienation and avoidance. Female peers are often more socially motivated, which can make them less accepting of those with FXS.

When these conflicts manifest, girls with FXS may lack the confidence to confront their peers or express their feelings of hurt. Because they seem to be more sensitive to criticism and have difficulty communicating their feelings, they may be

perceived vulnerable. This stance does not bode well for maintaining a position of power and self-sufficiency. A sad result is they can become convenient targets for bullying.

### **Strategies:**

- Because many of these behaviors result from neurobiology, it is often good to consult a physician. Many girls are helped significantly by SSRIs and other anti-anxiety/depression medications.
- Also effective in building social assertion is providing concrete phrases for the girl to assert a position and then videotaping her responding to a specific event, or vignette, using the phrase she has practiced.

### **Avoidance and Routine**

Avoidance can also present in females with FXS. Many parents report that their daughters have difficulty with novel or unfamiliar tasks or activities. Fear of risk-taking can cause them to avoid engagement in new activities.

Routine is welcomed because it is predictable and reassuring. Routine can become so important that elaborate rituals and compulsive behaviors become a core piece of day-to-day life. Preserving sameness is soothing, and females may perpetuate doing things the same way over and over as a strategy to help them remain calm. This coping method can create challenges when it comes to variety and new experiences.

### **Strategy:**

- Try scheduling a novel activity that is well-supported and then follow it with a routine task or activity. This can help defuse fear and foster motivation to tolerate the new activity.

While there is no universal program or therapeutic intervention that works for everyone. The [What Works Clearinghouse](#) website is a great resource to help identify evidence-based programs and interventions.

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# XTRAORDINARY

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Laurel Tiare Kuperman

## **What makes Lauren Xtraordinary to you?**

Laurel just graduated May 2022 with honors from the University of South Carolina magna cum laude with a double major in animation/media arts & art studio.

[Read more about Laurel Tiare Kuperman](#)

## **Transition to Adulthood**

As girls with Fragile X grow into women, the challenges they face may change. They might require continued support as they transition into adulthood, including assistance with education, employment, and independent living. They may not. Early planning for these transitions is key to helping females with Fragile X lead fulfilling lives.

## Relationships and Dating

Relationships can pose a significant challenge throughout the lifespan for everyone. Teenagers can become enamored with pop stars, musicians, and actors. They can even fantasize romantic relationships and at times even believe they have a secret relationship with a celebrity.

Because of females with FXS's propensity towards shyness and challenges in expressing their feelings complicates relationships, they may gravitate to males who have ulterior motives. Initially, males may be attentive and offer emotional support, and then behaviors change. This can result in manipulation and exploitation of the female with FXS.

Allowing females to experience the "hard lessons" of life and apply them to relationships can be risky and may even estrange parents from their daughters. Giving advice or limiting access to a male friend only provokes feelings of resentment. While these things are true for all teenagers, it is important to recognize females with FXS may be more vulnerable on any number of fronts during this difficult developmental period.

The idea of having a relationship can be very powerful, as it makes someone like their peers, even special. This can bring angst to families and often requires specific interventions from a person trained to be impartial. Allowing the female to talk with a therapist gives her another voice of reason that may feel is less judgmental.

Some families insist that the couple attend therapy together to force discussion about responsible behaviors. Families have had to limit access to money, credit cards, and checkbooks when they sense manipulation. These challenges, although not entirely unique to females with FXS, can bring much distress to families.

Alternatively, some females fear relationships, getting married, and having children. They liken their future lives to one they may know well, perhaps riddled with difficulties and disappointments associated with a family member even more impacted by FXS than they are.

### Strategies:

The complexities of relationships have no easy solution, many people around the world have lifelong relationship challenges! Strategies for addressing those

challenges in females with FXS may include establishing friendship and dating rules such as:

- Never give out your phone number or address until the person meets your parent(s).
- Be friends first and then see how you both feel about deepening the relationship.
- Never give anyone your banking information or credit card.
- Split expenses when you go out.
- Attentive parents can help set a tone for all this by spending time with and taking an active interest in the relationship. Invite them to dinner, movies, and other family activities. This helps ensure the friendship develops on solid and observable footing, not in isolation from broader family relationships, norms, and values.

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## Genetic Counseling and Family Impact

Females — having two X chromosomes (XX) — can have their unaffected X chromosome reduce the effects of the impacted X chromosome, which typically leads to no or milder symptoms of FXS. This can be an important distinction, as many females with the full mutation may not say they “have” FXS.

Because Fragile X syndrome is inherited, genetic counseling can help parents understand the likelihood of passing the condition to future children. Family members should also be educated about the condition, as it may affect multiple generations differently.

### Talking with Your Daughter About Her Fragile X Syndrome Diagnosis

Are you wondering when and how to talk to your daughter about her Fragile X syndrome diagnosis? If so, you’re not alone. Many families struggle with deciding when the “right” time is and what to say.

This conversation does not have to be one-time; it’s an ongoing discussion targeted toward the appropriate developmental stage of your daughter. Studies have shown

that children prefer to learn about their condition gradually throughout childhood and adolescence. Allow for open and honest communication and encourage questions and remind your daughter that she is unique, supported, and loved.

## Learn More

[Talking with Your Daughter About Her Fragile X Syndrome Diagnosis](#)

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## Strengths and Interests



Take it from Carly, a female living with Fragile X syndrome who is achieving great things! Read her story,

The future for females — including girls and women —impacted by FXS is bright. They bring much joy to their loved ones and can be very helpful to family members and friends. They often become productive members of their communities and bring understanding to those who may be more impacted by Fragile X, serving as great friends, supporters, and confidants to their brothers and other relatives who may have more significant needs.

Though academic environments can be stressful, females often power through and

accomplish meaningful goals with great pride. Dr. Marcia Braden adds, “I have seen it happen, and they are not isolated events.”

Females with FXS have shown an interest in working at daycare centers, beauty salons, animal shelters, or veterinarian offices, amongst other career paths. Many attend community colleges and some earn college degrees.

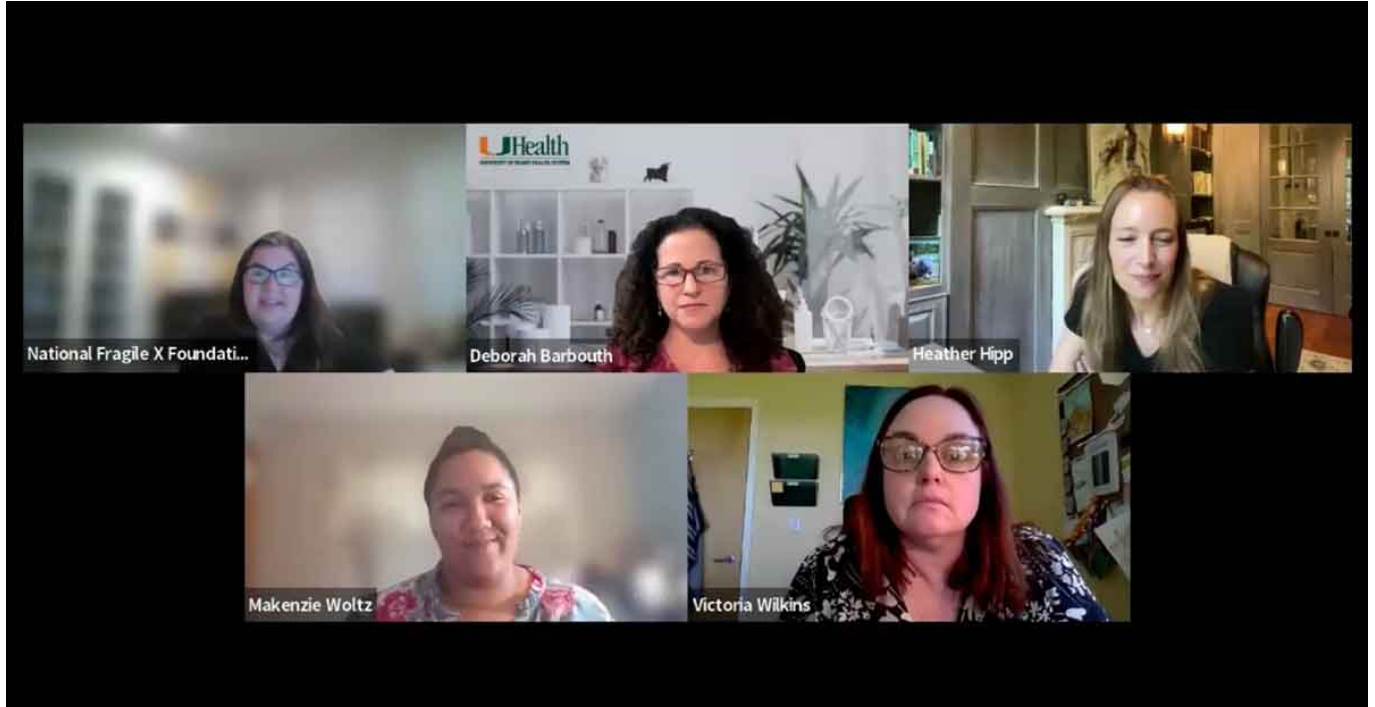
Females with FXS can benefit greatly from early interventions and support networks that help address their unique challenges and support their great successes.

Take it from Carly, a female living with Fragile X syndrome who is achieving great things! [Read her story.](#)

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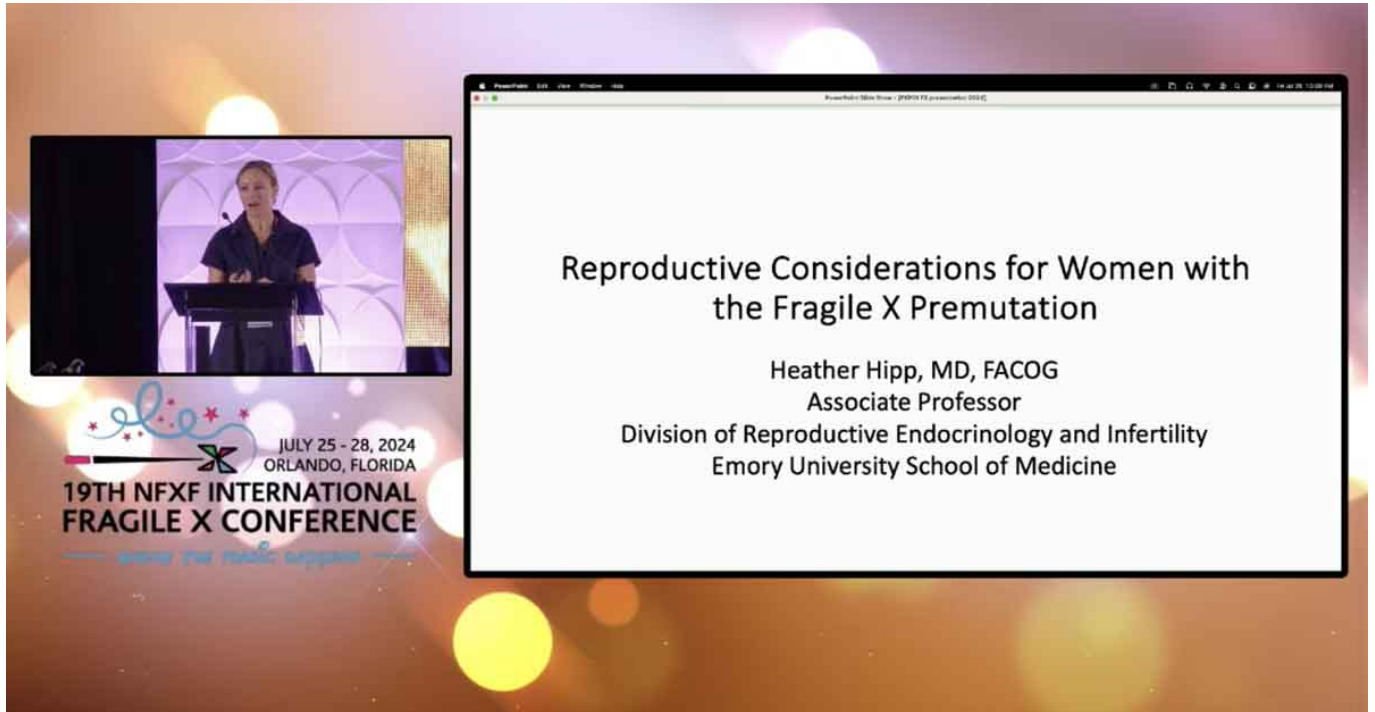
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