

FRAGILE X INFO: BACK TO SCHOOL RESOURCES



Overview

Fragile X is a group of conditions associated with changes in the Fragile X gene — called FMR1 and located on the X chromosome. The FMR1 gene can undergo changes, when inherited, which affects a pattern of DNA called CGG repeats. Typically, the FMR1 gene has up to 54 CGG repeats, though the range between 45 and 54 repeats, is called the intermediate or gray zone. A premutation carrier has 55–200 CGG repeats, and someone with a full mutation has more than 200 CGG repeats.

When a premutation or full mutation is present, it can result in a Fragile X-associated disorder (FXD). These include:

- Fragile X syndrome (FXS): An inherited condition affecting intellectual, behavioral, and social development. It occurs in both males and females who have a full mutation of the FMR1 gene.
- Fragile X-associated tremor/ataxia syndrome (FXTAS): An adult onset (over 50 years of age) neurological condition, more common and more severe in some male premutation carriers. It can cause tremors, memory, and balance issues.
- Fragile X-associated primary ovarian insufficiency (FXPOI): A condition affecting ovarian function that can lead to infertility and early menopause in some female premutation carriers.
- Other issues may be present in premutation carriers and researchers continue to study possible associations with these and other health issues in people with Fragile X premutations.

For Teachers & Anyone Else who Interacts with People with FXS

One thing every teacher should know about students with Fragile X syndrome (FXS): They are prone to hyperarousal and anxiety. It is how their nervous systems are wired.

Ideas:

- Don't force eye contact. We know that children and adults with FXS make wonderful eye contact when their level of arousal and anxiety are minimized, allowing them to feel comfort in the social situation. Eye contact will come naturally as the student becomes more comfortable with you.
- Expect inconsistency. Try to accept this to avoid frustration; your student will pick up on frustrated energy and that will exacerbate anxiety.
- Students are “simultaneous” vs “sequential” learners. Students with FXS are good sight word learners. This means that they are “gestalt” learners who need to see and understand the “whole” and not the parts that add to a whole.
- Allow and/or encourage frequent breaks. Accommodate attention difficulties by keeping tasks brief.
- Verbal expression is cognitively taxing. Avoid direct, open-ended questioning: prompt “The President of the United States is ...” vs. “Who is the President of the United States?”
- Think “indirect.” There are times when students with FXS enjoy attention, but most often they are averse to the limelight. Give compliments in the 3rd person about the student to others within earshot.
- Prepare for transitions. Give 10- and 5-minute prompts. Allow to be at the head or back of the line. Use social stories about routine transitions. Provide a purposeful errand so the focus is on the outcome (e.g., delivering an envelope) rather than moving from one place to another.
- Individuals with FXS are visual learners. Visuals function as an ongoing means of keeping hyperarousal in check. Do not fade this kind of support. The nature of the support may change — a visual picture schedule at age eight may turn into an iPhone calendar app at age 23.
- Work with an occupational therapist knowledgeable about sensory integration. A sensory diet consists of a carefully planned program of specific sensory-motor activities that is scheduled according to each child's individual needs. Integrate these activities throughout the day to sustain a calm, regulated nervous system: heavy work like rearranging desks, cleaning windows, or moving stacks of books; vestibular input, like going for a walk, doing wall push-ups, and swinging.
- Notice environmental triggers. Students with FXS often have sensory sensitivities to sound, light, textures, taste, and smell that provoke hyperarousal. Make adjustments to the environment as much as possible.
- It is critical to integrate knowledge of hyperarousal into any intervention strategy and especially for those treatments that come from a tradition of autism intervention.

Know the Strengths of People with FXS

- Common strengths associated with FXS a good visual memory, sense of humor, desire to be helpful, empathic nature, and gift for mimicry.
- Provide opportunities to be of assistance, encourage providing emotional support to peers, use modeling as a primary teaching technique.
- Embed academics into useful and practical tasks, such as taking attendance (counting) or ordering from a menu (reading).

Enjoy the individual with FXS!

Ideas for the Transition Back to School

- Going back to school after a relaxing summer can be quite a challenge. Several strategies can help in guiding a successful transition. If the student is going back to the same school with the same teaching staff, the transition process is easier and requires less support. When the student changes schools, neighborhoods, or programs, additional support is required.
- Say it with Pictures. Prior to the start of school, take pictures of the school, classroom, playground or school ground and school staff. These pictures can then be incorporated into a story about going back to school.
- Find a Friend. Whenever possible, it is helpful to find classmates to accompany the student with FXS when going back to school.
- Establish a Routine. Walking to school with a friend or sibling or riding together in a carpool or school bus is helpful. Routine brings predictability, which is self-calming and reassuring. When the early morning routine becomes habituated, entering the classroom and starting the day simply becomes an extension of that process.
- Tell a Story. If your child is returning to the same school in the fall, social stories can often assist in a less direct way while reducing anxiety about the upcoming school year.

Other Activities to Help Minimize Stress and Anxiety for the Transition Back to School

- Start planning for the day, the night before — lay out clothes, and plan breakfast and lunch.
- Set a morning routine — Use visuals if needed. Allow for plenty of time to make all the transitions.
- Know how the individual will get to school. Again, allow for time to make the transition.
- Plan a transition object for your child to take into the classroom, something simple as an apple or some flowers.
- Use a back-n-forth notebook with the teacher so you know what is happening at school, allows for discussion.
- Plan for a treat every Friday to celebrate the week.

Other Resources

Back to School Articles

<https://fragilex.org/education/back-to-school-articles/>

About the NFXF

The National Fragile X Foundation (NFXF) was founded in 1984 to support individuals with Fragile X syndrome (FXS), their families, and the professionals who work with them. Today, it is a comprehensive resource not only for FXS, but also for the conditions of Fragile X-associated tremor/ataxia syndrome (FXTAS), Fragile X-associated primary ovarian insufficiency (FXPOI), and other premutation carrier issues. The organization offers help for today and hope for tomorrow with personalized support, community, education, awareness, advocacy, and research. Get your free Fragile X 101 e-book, connect with your local chapter, learn about the upcoming conference, and more at <https://fragilex.org/welcome>.

If you have specific questions about what to expect, treatments, clinics, well, just about anything, please email treatment@fragilex.org or call (800) 688-8765.

