

FRAGILE X INFO SERIES: FOR KIDS OF ALL AGES



Do You Know Someone with Fragile X Syndrome?

This information is for kids who know someone with Fragile X syndrome (or FXS, for short). This person might be part of your family, class, team, or neighborhood. You may not have heard much about Fragile X syndrome—lots of adults haven't either. Or, maybe you know only that having FXS might sometimes cause kids to act differently than others or have difficulty learning. You might be wondering why that is. Here are some answers.

What is Fragile X Syndrome?

Fragile X syndrome is a condition that some kids are born with. And sometimes, more than one person in a family can have it. You cannot catch it from another person or develop it if you never had it before. It is more common in some families than in others. Just like the color of a person's eyes, FXS is beyond anyone's control. It is one of the ways people are unique.

Kids with Fragile X syndrome:

- Often learn to talk, walk, and do other things later than other kids, and they often need extra help in school.
- Look the same as everyone else, though they may have some different behaviors, like flapping their hands.
- Like to do the same things as other kids, like play, see movies, and be included in activities.
- Sometimes have a hard time expressing themselves.
- May not understand things as quickly as other kids.
- Can get nervous or excited when a lot is going on, like at birthday parties or sporting events.
- Often have very good memories. (They rarely forget anything!)
- Like to play jokes and laugh—a lot.

How many kids have FXS?

- About 1 in every 4,000 kids have Fragile X syndrome.
- When you go to a professional baseball game, there are often about 30,000 people there. That means there may be about 7 or 8 people with Fragile X syndrome at that game. Another way to picture it is that about 100,000 kids and grownups in the United States have Fragile X syndrome. That is about the same as all the people who go to Disney World in one day!

Why do kids with FXS sometimes seem to get really excited or nervous?

- Kids with FXS sometimes get overly excited when there is a lot going on. They can have trouble when things seem too loud or confusing. When you walk into a room you might first see only a chair and a table, and then gradually see everything else. Kids with FXS, however, tend to see everything at once—every table, chair, book, toy, paper, and spot on the wall. It can be too much for them!
- It works the same with their hearing. When you're at a party, you can usually listen to just the person talking to you, but someone with Fragile X syndrome might hear everyone's conversations and music and the faucet running all at once. This makes some situations just too intense for them, and they may need a little break.



Some facts about disabilities:

- Having a disability means it may take longer to learn something or that parts of your body, like your muscles, work differently than they do in other kids.
- There are many types of disabilities. Not everyone with disabilities has Fragile X syndrome.
- Some disabilities affect only a person's body parts. Being deaf is an example. Muscular dystrophy or diabetes are others.
- Some disabilities, like Down syndrome and autism, mainly affect a kid's learning ability. Fragile X syndrome is like that.
- Some disabilities are caused by illnesses or accidents, though most of the time kids are born with their disabilities (as in Fragile X syndrome).

How do you act with kids who have Fragile X syndrome?

- Most of the time you can act just like you do with everyone else!
- Kids with FXS may take longer to respond to questions or instructions. Please be patient.
- Sometimes they may be hard to understand, so you might have to ask them to repeat themselves.

What should you do if someone with FXS gets really excited or walks/runs away to be alone?

- Let an adult know that the child was upset and what happened. Sometimes they just need a little time apart to settle or quiet down.

How do you include kids with FXS in activities?

- You might give them a little extra encouragement to join in activities. "Come play with us" often does the trick!
- Let them stand on the "sideline" and just watch, until they are ready to join in. You might say, "Join when you are ready."
- Explain things in simple terms and give them some extra time to finish things.
- Keep in mind that they may not want to be touched too much when they are involved in physical games.
- The most important thing is to treat them like you want to be treated, enjoy their company, and have fun!

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 conditions and disorders. The NFXF is dedicated to serving the entire Fragile X community to live their best lives by providing the knowledge, resources, and tools, until, and even after more effective treatments and a cure are achieved.

Learn more at <https://fragilex.org/welcome>.

If you have questions please reach out to us at treatment@fragilex.org or call (800) 688-8765.

