

Letter for Families

Fragile X Alert

We have recently learned that a condition called fragile X runs in our family. **This information could be very important to you and your blood relatives.** This letter tells you about fragile X so you can decide if you or someone else in the family should be tested.

Why is it important to know about fragile X?

- Conditions related to fragile X include fragile X syndrome, fragile X premutation, FXTAS and FXPOI.
- **Fragile X syndrome** is a common childhood cause of serious problems with thinking, learning, communication and behavior.
- **Fragile X premutation** is very common, and most people who have it do not know it.
- **If you have the fragile X premutation, there is a higher risk of having a child or grandchild with fragile X syndrome.**

What problems can fragile X premutation cause for children?

- During childhood, the fragile X premutation may cause no symptoms at all and presents only a slightly increased chance for mild behavior or learning problems.

What problems can fragile X premutation cause in adults?

- The fragile X premutation can affect the health and well-being of some adults.
- Some men can develop a nervous system condition later in life that effects movement, mood, and thinking. This is called FXTAS.
- Some women with the fragile X premutation can have irregular periods, difficulty getting pregnant, and may also experience anxiety or depression. This is called FXPOI.
- Some women may also develop milder nervous system effects of FXTAS later in life.
- People with the fragile X premutation have a higher risk of having children, grandchildren, or other family members with the premutation **or with fragile X syndrome.**

What problems can fragile X syndrome cause?

- Fragile X syndrome causes serious intellectual disability in children, but girls tend to have milder features than boys.
- It causes behavior issues that can be hard to manage.
- Fragile X syndrome causes difficulties with communication and autism for some.
- It can also cause health effects, such as seizures.

Is testing available for fragile X premutation and fragile X syndrome?

- Yes, your doctor can order testing on a small sample of blood or saliva.
- The test for the premutation is the same as the test for fragile X syndrome.
- To find out about getting tested, share this letter with your doctor.
- If you are pregnant or thinking about getting pregnant, talk with your doctor right away to learn about testing during or before pregnancy.
- If you have a child with learning or behavior problems, be sure to share this letter with your child's doctor.

Where can you get more information?

Learn more about fragile X syndrome and the fragile X premutation from these reliable sources:

- National Fragile X Foundation website: www.fragilex.org
- Center for Disease Control/fragile X: <https://www.cdc.gov/ncbddd/fxs/index.html>
- **Share this letter with your doctor**