

# A Collaborative Research Registry Makes Sense



## You Can Make a Difference

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## The Fragile X Research Registry

### *A National Collaboration*

Linking researchers with individuals  
affected by fragile X syndrome and  
its associated disorders



*Working together for a better future*

The Fragile X Research Registry is supported by



Learn more at [www.fragileXregistry.org](http://www.fragileXregistry.org)

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### Who can join the Registry?

Children and adults with fragile X-associated disorders may join. The Registry is for families and individuals with:

- Fragile X syndrome – full mutation or mosaicism
- Fragile X premutation
- Fragile X-associated primary ovarian insufficiency (FXPOI)
- Fragile X-associated tremor/ataxia syndrome (FXTAS)

One of our goals is to have the Registry reflect the general population of the United States. We encourage individuals of all races and ethnic groups from across the country to sign up.

### What kinds of studies are there?

Research opportunities cover a wide range of topics including family adaptation, brain development, clinical trials, language, and genetic studies. Medical studies may involve things like DNA testing, brain imaging, and drug testing. Behavioral and educational studies may include parent surveys, individual assessments and observations. Some studies involve travel, others do not.

### Are Registry members obligated to be in studies?

No, participation in research is always voluntary. Joining a registry gives us permission to inform you about studies; you always decide whether or not you will participate in a study.



### What about privacy?

You will be asked to provide us with information that will be used to help us match you with studies. Your information is confidential and your privacy will be safeguarded.

We will send you a notice about a study if you meet participation criteria. Your name is not released to researchers unless you give us permission.

### What are the benefits?

- You will be connected to the fragile X research community and learn about the latest studies.
- You will receive annual newsletters with study updates and research findings.
- You will receive a summary of results for any study you complete.
- You will help us improve the lives of people with fragile X syndrome.

Some studies may offer compensation for completion and reimbursement for expenses if travel is necessary.

### How do I sign up?

You can easily enroll on our website [www.fragileXregistry.org](http://www.fragileXregistry.org)

### What is the Fragile X Research Registry?

It is a database of people who want to be notified about research studies on fragile X syndrome and fragile-X associated disorders. It provides a confidential, convenient way for individuals and families to learn about research.

The Waisman Center and the Carolina Institute for Developmental Disabilities have joined forces to expand and strengthen outreach to the fragile X community in order to help move research forward.

### Why do we need you?

Having a national registry creates a powerful advantage for fragile X research — more involvement means higher quality results.

Having volunteers ready to enroll in studies will save researchers time and accelerate progress in understanding and treating this complex disorder. Our best chance of success is to work together — researchers and families from across the country — in pursuit of advancements to improve the lives of people affected by fragile X.

### Studies Involve:

- Infants
- Children
- Teenagers
- Adults
- Families