

Why have a Fragile X Research Registry?

FXS is the leading known heritable cause of developmental and learning disabilities.

Advocates have raised awareness about FXS and the need for more funding for research. As a result, Congress and the National Institutes of Health have awarded funding for new studies to experts at UNC and other universities.

FXS research at UNC began in 1994 when Don Bailey was awarded funding from the US Department of Education for a longitudinal study of boys with FXS. Additional studies have been funded at UNC including an award for a Fragile X Center in 2003 from the NIH.

The Fragile X Research Registry is an important tool for linking these researchers with families who want to make FXS research a priority.

Together, families and scientists are working to improve the lives of individuals affected by fragile X syndrome.



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

The Fragile X Research Registry

is operated by the Neurodevelopmental Disorders Research Center at the University of North Carolina at Chapel Hill.

Support is provided by the National Institute of Child Health and Development.

FOR MORE INFORMATION PLEASE CONTACT:

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The Fragile X Research registry



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through research*

Neurodevelopmental Disorders
Research Center

The University of North Carolina
at Chapel Hill

The Fragile X Research

registry

Participants are matched to studies

using basic information (below) submitted by families that is kept on file. By using this information, the Registry staff can identify the appropriate people to send notices about particular research studies.

- Date of birth and gender
- Name and Contact Information
- Genetic results (pre or full mutation)

Privacy is critical

so the Registry adheres to strict federal, state and university regulations to safeguard individual rights and privacy.

Each individual's information in the Registry is private and confidential and is only used to determine study eligibility. Individual information is never released unless a participant gives explicit consent.

Study notices are mailed

from the Registry office directly to eligible individuals or families to notify them about research opportunities. Staff may follow up with a phone call.

When a family receives an information letter, they may choose whether or not to participate, and can contact the researcher if they would like additional information.

There is no obligation

to participate in studies. Participation in any study is optional and is not required to enroll in the Research Registry. Families may specify the number of contacts they want to receive each year about studies.

Participation in the Registry is voluntary and individuals may remove their name from the Registry at any time.

UNC research opportunities vary

because FXS research at UNC covers a wide range of topics from family adaptation to brain development. Medical studies may involve things like DNA testing, brain imaging, and drug testing. Behavioral and educational studies can include parent surveys, individual assessments, and observations.

Benefits

Families will receive a summary for each study in which they participate when the study is complete.

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

Enrolling is easy

on-line at

www.ndrc.unc.edu/~FXSRegistry

or by calling the Registry office toll-free

1-866-744-7879

Staff members at the Registry office will be happy to answer questions and mail enrollment forms.

Again, participation in the Registry is voluntary and families may withdraw at any time.

The Fragile X Registry

is a list of individuals who are willing to be notified when research studies need participants. Individuals (adults or children) diagnosed with fragile X who live anywhere in the United States are eligible to participate.

The Registry refers individuals to studies while protecting their privacy.

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