

WHAT IS FORWARD-MARCH?

FORWARD-MARCH is the next step following a highly successful research study called FORWARD (Fragile X Online Registry With Accessible Research Database) that was started in 2012. The FORWARD study created the largest database of information on fragile X syndrome (FXS) in the United States. Data from the FORWARD study is being used by researchers to learn about the lives of people with FXS, including medication use, behaviors, and development over time, and share findings with other researchers and clinicians.

The FORWARD-MARCH (Multiple Assessments for Research Characterization) project will collect more detailed information from participants with FXS and add it to the existing FORWARD database. FORWARD-MARCH continues the mission of FORWARD to better understand FXS in order to improve the lives of children and adolescents with FXS and the lives of their families.



A NOTE ABOUT PRIVACY

Records of participation in this research study will be maintained and kept confidential as required by law. This research project has a Certificate of Confidentiality from the Centers for Disease Control and Prevention (CDC) that provides additional protection from involuntary disclosure of information collected in the study.

This project was made possible by Cooperative Agreement 1 U01DD001298-01-00 from the Centers for Disease Control and Prevention.



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**FORWARD
MARCH**
MULTIPLE ASSESSMENTS FOR RESEARCH CHARACTERIZATION



Other Research Opportunities

Researchers expect to learn a great deal about FXS from FORWARD-MARCH. But participating in FORWARD-MARCH will also help advance fragile X research another way, by helping other researchers find people with Fragile X syndrome who wish to participate in studies outside of FORWARD.

Fragile X specialty clinics who are part of the FORWARD-MARCH study will do this by using the information from FORWARD-MARCH to quickly and efficiently identify people who might be interested in being asked to also participate in a different fragile X research study.



Helping Us Better Understand Fragile X

The FORWARD-MARCH project will collect survey data from parents and caregivers and conduct several tests with participants to understand their cognition (thinking), language, behavior, and autism characteristics. Combined with information already collected in the FORWARD study, FORWARD-MARCH will also better define paths of development in FXS. This is important in understanding the long-term effects of interventions and treatments designed to help people with FXS develop to their full potential.

The more individuals who enroll and participate, the more helpful this study will become in helping researchers understand FXS across the human lifespan. Your child's participation will help healthcare professionals and educators create better therapeutic and educational programs that could benefit millions of individuals with FXS throughout the world.



JOINING FORWARD

Individuals with FXS born between 2003-2017 are eligible to participate in FORWARD-MARCH. This includes participants who were enrolled in the FORWARD study and those new to FORWARD. If you want to join FORWARD-MARCH, please contact the Fragile X clinic nearest you. A list of participating clinics can be found at <https://-fragilex.org/our-research/fragile-x-clinics/>

To learn more about Fragile X, visit the National Fragile X Foundation online at [Fragilex.org](https://-fragilex.org). For more information about CDC's work on Fragile X, www.cdc.gov/FragileX.

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