



## WHAT IS FORWARD?

**FORWARD**, the Fragile X Registry and Database, is the largest resource of clinical and demographic data of the Fragile X syndrome (FXS) population in the United States.

FORWARD was created to improve the care and quality of life for those living with FXS. By collecting and monitoring changing data, researchers and healthcare professionals can better understand the experiences of individuals with FXS and their families.

Information collected from families like yours will be used to develop best practice guidelines for the care of individuals with FXS around the world!

IRB #NA\_00028362  
PI: Dejan Budimirovic, MD  
Contact: 443-93-3850 or  
[Researchtrials@kennedykrieger.org](mailto:Researchtrials@kennedykrieger.org)

## A NOTE ABOUT PRIVACY

Identifying information is stored securely at the clinic where the participant is seen. This information will be used only to contact you regarding clinical care and to invite you to participate in research for which you and your participating child may be eligible.

Anonymous clinical and parent reported information is stored in a secure centralized repository and updated each year. No personally identifying information is entered into the centralized repository. This ensures that everyone's individual information is kept private.



*This project was made possible by Cooperative Agreement  
1U01DD001189-01 from the Centers for Disease Control  
and Prevention.*



# HELP US LEARN MORE ABOUT FRAGILE X!



# FORWARD >>>

FRAGILE X ONLINE REGISTRY WITH  
ACCESSIBLE RESEARCH DATABASE

[FORWARDFX.org](http://FORWARDFX.org)



## **THE REGISTRY: FOR RESEARCH OPPORTUNITIES**

If you are an individual with any type of Fragile X disorder or their family member, we invite you to join our registry!

You will only need to complete a short, one-time form with information such as your age and state of residence.

By joining, you can be provided opportunities to participate in research projects and clinical trials.

The registry will help facilitate research by allowing clinics to quickly and efficiently identify eligible participants who may be interested in a specific project.

## **THE DATABASE: HELPING US BETTER UNDERSTAND FRAGILE X**

The longitudinal database is reserved only for those with a full mutation of FXS and stores health and quality-of-life information. Updated information is collected annually during a clinic visit.

The more individuals who enroll and contribute annual information, the more helpful the database will become in helping researchers understand FXS across the 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 and families living with FXS who want to join FORWARD should contact the Fragile X clinic nearest them. A list of participating clinics can be found at [FORWARDFX.org](http://FORWARDFX.org) – select Clinics from the menu.

To learn more about Fragile X, visit the National Fragile X Foundation online at [FragileX.org](http://FragileX.org).

For more information about CDC's work on Fragile X, visit [www.cdc.gov/FragileX](http://www.cdc.gov/FragileX).

