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FORWARD

FRAGILE X ONLINE REGISTRY WITH
ACCESSIBLE RESEARCH DATABASE

FORWARD Family Newsletter

Visit www.forwardfx.org for more information about this important study.

A Look Inside the FORWARD Database

FORWARD is the largest resource of health, clinical, and social support information on people with fragile X syndrome (FXS) in the United States. This information is collected from parents and from clinicians who provide their care through clinics devoted to FXS. These data are collected at yearly clinic visits and grow in value each year to help better identify the needs of families.

Researchers have been busy examining the rich data that is being collected in the FORWARD Database. Knowledge is continuously being gained and medical journal papers are being written on important topics such as toileting, autism and FXS, preventative care services, medication use and many other important issues. Please visit FORWARDFX.org for a list of published papers.

Below we have put together a snapshot of participant demographics, clinical characteristics and longitudinal data in the FORWARD Database. These are preliminary findings.

You will also see a new addition to FORWARD that focuses on the health and support needs of adults with FXS to complement what we learn about children and adolescents. Soon we will have a full picture of the lives of people with FXS.

As of July 2018, about 1,432 individuals with FXS have contributed to FORWARD through their multiple visits to their FXS clinic. The goal of FORWARD is to help each person with FXS reach their potential. Thanks to the continued participation of families like yours, we've been able to grow this resource.



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FORWARD

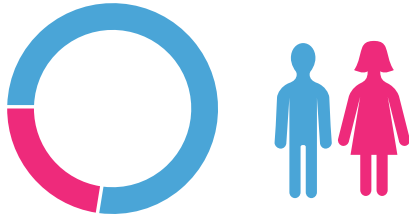
FRAGILE X ONLINE REGISTRY WITH
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Database Demographics and Clinical Characteristics

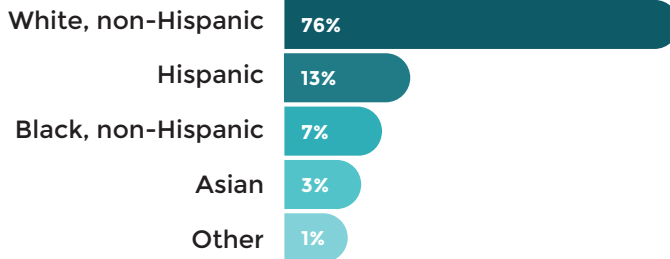
Based on *1,432 individuals with fragile X syndrome enrolled in FORWARD.

GENDER

77% Males
23% Females



RACE (of FORWARD participants)



AGE (at FORWARD baseline evaluation)



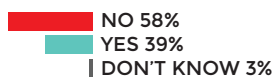
^A On medication for behavior?



^B Use of sleep medications reported by parent



^A Ever diagnosed with ASD?



^A Use of seizure medications reported by clinician



The Findings in this report
are preliminary.

*Total number of FORWARD enrollees (individuals with either a Clinician Form or a Parent Report Form)
A based on FORWARD Clinician Form, N=1,315
B based on FORWARD Parent Report Form, N=1,078

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Database Demographics and Clinical Characteristics

Longitudinal Data

Your continued participation in FORWARD is making a difference.

One of the unique and important features of the FORWARD Database is longitudinal data capture: participants with FXS who are enrolled in the Database are encouraged to visit their fragile X clinic on an annual basis so that clinic staff can conduct yearly interviews using structured forms in order to monitor and document changing health and support care needs. By observing, monitoring, quantifying and recording these changes over time in a uniform way across dozens of clinics nationwide, researchers and clinicians will be able to get a better understanding of how to treat this genetic condition.

We are excited to report that there has been enough longitudinal data accumulated to enable research to analyze change over time in key outcomes, e.g. factors associated with reaching toileting and language milestones, changes in social skills, educational attainment and employment. To date, over half of FORWARD participants have returned to complete at least one followup assessment, and some have completed as many as seven.



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Thank You



A special thank you to all participating families for your ongoing contributions to the FORWARD study. Please continue to visit your clinic to complete your child's annual FORWARD evaluation.

Adult-Specific questionnaires have been developed and distributed across 23 FORWARD contributing clinics all across the nation.

In order to get the full picture of how FXS presents across the human lifespan, it is very important to take a closer look at the adult FXS population and understand the specific medical, economic and social issues that they are facing. Approximately 19% of the FORWARD Database comprises of adults 19 years of age and older. We hope the development of adult specific questionnaires will allow us to grow this valuable informational resource.

Obtaining the full picture of how FXS presents itself, from infancy to late adult life, will propel us to reach more positive health outcomes and improved quality of life for those with FXS. Strong, evidence-based data may also help facilitate the legislative action needed to help create and improve available services to the areas most in need.

Together, we can move FORWARD to improve the care and quality of life for those living with fragile X syndrome.

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