What is the FORWARD Study?
The Fragile X Registry With Accessible Research Database (FORWARD) is the largest resource for clinical and demographic data on the Fragile X syndrome (FXS) population in the United States. FORWARD is investigating medical, social and quality of life information in individuals with FXS. By collecting and comparing important data from families like yours over a long period of time, clinicians and investigators can gain a better understanding of this complex condition.

FORWARD objectives:
• Learn more about how FXS presents itself across the human lifespan.
• Understand the impact that treatments and services have on health outcomes and quality of life.
• Translate this data into treatments and services that improve the quality of life for individuals and families living with FXS.

How is the data being used?
Your contributions to FORWARD are making a difference. A Pediatrics supplement on FXS was published on June 1, 2017. Pediatrics is the official scientific journal of the American Academy of Pediatrics and is a leading resource for those studying, researching, and practicing pediatrics. This supplement contains two papers that were written using FORWARD data: FORWARD: A Registry and Longitudinal Clinical Database to Study Fragile X Syndrome and Autism Spectrum Disorder in Fragile X Syndrome: Co-occurring Conditions and Current Treatment. We would like to thank you for your ongoing support and contributions to FORWARD. This important work would not be possible without families like yours.

Please see pages 2-3 for a summary of each of the papers. Please visit the Centers for Disease Control and Prevention (CDC) web page for individual links to each article: https://www.cdc.gov/ncbddd/fxs/articles/supplement.html.

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FORWARD: A Registry and Longitudinal Clinical Database to Study Fragile X Syndrome


This paper describes the methods used to collect the clinician- and parent-reported data through FORWARD. FORWARD is now the largest source of clinical- and parent-reported data on people with FXS in the United States. These data can be used to better understand the impact of other conditions that occur in people with FXS, the impact of having FXS on day-to-day life, and health outcomes for people with FXS. This paper also explains how FORWARD data can be used to improve the health and quality of life of people with FXS and their relatives and caregivers.

Visit http://pediatrics.aappublications.org/content/139/Supplement_3 to read this article in its entirety.
Autism Spectrum Disorder in Fragile X Syndrome: Co-Occurring Conditions and Current Treatment


Many individuals with FXS also have a diagnosis of autism spectrum disorder. This new article takes a closer look at the effects of this dual diagnosis. Previously, the only information available to clinicians and researchers about autism among people with FXS was from small family studies and surveys. Thanks to FORWARD data, this paper presents new findings on co-occurring medical and behavioral conditions from a large number of people who have both FXS and autism.

This research suggests that half of males and almost 20% of females with FXS met the clinical criteria for a diagnosis of autism. This research also found that people with both FXS and autism were more likely than those with FXS alone to have seizures, sleep problems and aggressive behavior. In addition, individuals with autism and FXS had significantly higher use of medications to treat aggression (alpha-agonists and antipsychotics) than individuals with FXS alone. The paper reports that behavioral health services appear to be used less often in individuals with FXS and autism compared to individuals diagnosed with autism alone.

Tables 1 & 2: Seizures and Sleep Problems Associated With FXS+ASD and FXS Only, by Age Groups and All Ages, in Subjects Enrolled From September 7, 2012 Through August 31, 2014, FORWARD Database.


Visit [http://pediatrics.aappublications.org/content/139/Supplement_3](http://pediatrics.aappublications.org/content/139/Supplement_3) to read this article in its entirety.
NEW Adult-Focused Questionnaires

Many families of children with FXS struggle with the question “what will happen to my child as they age?” Little is known about how FXS presents itself in the adult population. To address this gap, FXS clinicians and researchers, and parents of children with FXS are collaborating to develop new questionnaires focused on the adult population. Since FORWARD data is collected on a yearly basis, these new questionnaires will help us understand the transition from childhood to adulthood using information from those who have been through this experience. The new questionnaires will gather data on medical, social, and economic needs of adults with FXS. The new adult forms should be ready by the first quarter of 2018.

Researchers are writing papers using FORWARD data, including the following:

**Autism Diagnosis**
- There is concern among specialists that there may a problem with the way autism spectrum disorder (ASD) is being diagnosed in individuals with FXS. FORWARD data is helping researchers to develop more accurate tools for the diagnosis of ASD for individuals with FXS.

**Toileting Milestones**
- Although toilet training has always been a major concern for families with FXS, very little data is available regarding typical age for training and other important factors. The FORWARD database is being used to learn about toileting topics such as the age of bladder and bowel training in males vs females with FXS, or if training hasn’t occurred.

**Drug treatment for Irritability**
- Efforts are under way to learn more about individuals with FXS who are currently being treated for irritability, aggression, agitation, and self-injury. Researchers will compare the group receiving treatment to the group of individuals who are NOT being treated for irritability, aggression, agitation, and self-injury to see how they differ.

**Sensory Processing Problems and Hyperarousal**
- Sensory and hyperarousal problems are commonly reported by families of individuals with FXS. There are very few studies describing the incidence and optimal treatment for this condition. Researchers are working to shed more light on this important topic and hope to provide more guidance on best treatment.

**Sleep problems**
- Investigators are characterizing type and frequency of sleep problems in FXS, identifying and investigating conditions showing increased risk of sleep problems in FXS, and hoping to help guide treatment of sleep problems in individuals with FXS.