



# FORWARD-MARCH Database & Registry

## First There Was FORWARD

[Join FORWARD-MARCH study →](#)

Since 2012 the CDC supported the development of FORWARD Fragile X studies to expand understanding of Fragile X syndrome (FXS). The NFXF has been coordinating study efforts since the beginning and has been vital in ensuring its success.

The first FORWARD (which stands for Fragile X Online Registry With Accessible Research Database) study was launched in 2008 and piloted an infrastructure to study FXS across multiple sites. The [Fragile X Clinical and Research Consortium](#) was established and consists of a network of FXS specialty clinics across the United States who engage in collecting data.

The second study piloted the infrastructure for a registry and for longitudinal data

collection to support analysis of data over time in a large cohort.

The third study expanded FORWARD infrastructure even further. The data collected in FORWARD advanced knowledge about FXS, its co-occurring conditions, and outcomes.

The FORWARD study created the largest database of information on FXS in the United States. On September 1, 2021, the CDC issued a five-year award to continue to build upon the foundation of the three prior FORWARD grants in collaboration with CDC's [Study to Explore Early Development \(SEED\)](#) follow-up study.

This current study is called [FORWARD-MARCH](#).

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## What is FORWARD-MARCH?

FORWARD-MARCH is the next step following the highly successful FORWARD research study.

Data from the FORWARD study is being [used by researchers](#) to learn about the lives of people with FXS. Thanks to families who contribute to FORWARD, researchers are learning about important things like medication use, behaviors, and development over time. These findings are shared with other researchers and clinicians in order to help develop targeted therapies and treatments. FORWARD data can be used in a variety of ways:

- Help inform new treatments and therapies for individuals with FXS.
- Help develop resources to help families, such as the NFXF
- [Treatment recommendation](#) documents.
- Demonstrate the need and direction of future, more in-depth research.

The FORWARD-MARCH (Multiple Assessments for Research Characterization) project collects 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.

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## Who Can Participate in FORWARD-MARCH?

Individuals with FXS born between 2003 and 2020 are eligible to participate in [FORWARD-MARCH](#). This includes participants who were previously enrolled in the FORWARD study and those new to FORWARD.

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## What Does Participation in the Study Look Like?

The FORWARD-MARCH project collects survey data from parents and caregivers and conducts 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.**

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## How Can I Enroll My Child in the Study?

Families who want to join FORWARD-MARCH should contact their [nearest Fragile X clinic](#). Please note that not all clinics participate in the study. When using our clinic tool, look for the label "FORWARD participant."

Please also visit [Join FORWARD-MARCH!](#) for more information, including frequently asked questions.

# Find a Fragile X Clinic

Fragile X clinics provide comprehensive evaluation and treatment options for children and adolescents with FXS.

Locate a Fragile X Clinic



## Thank You

THANK YOU to all participating families for your willingness to share your life experiences for research. By giving families, doctors, scientific researchers, and policymakers an inside look into how FXS presents itself across the human lifespan, we can facilitate the actions needed to reach more positive health outcomes and an improved quality of life. Your participation in FORWARD will lead to better care and services for future generations affected by FXS.

## 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 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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## Publications Resulting from FORWARD Data

We are excited to share journal publications resulting from FORWARD data, with many more papers currently in development! The future for FXS research is bright as more rich data are gathered.

## SOCIAL PARTICIPATION IN CHILDREN WITH FRAGILE X SYNDROME (FXS)



### Summary

Researchers studied data on 830 children with FXS (ages 5-17) to understand how often they participate in social activities—like sports, clubs, community programs, or hanging out with friends—and what makes participation easier or harder. Most children were involved in at least one activity, but participation varied based on developmental and behavioral factors.

### Top Barriers Reported by Caregivers



72% Behavioral challenges



64% Time constraints



64% Lack of community resources

Transportation and financial limitations also played a role.

### What They Found



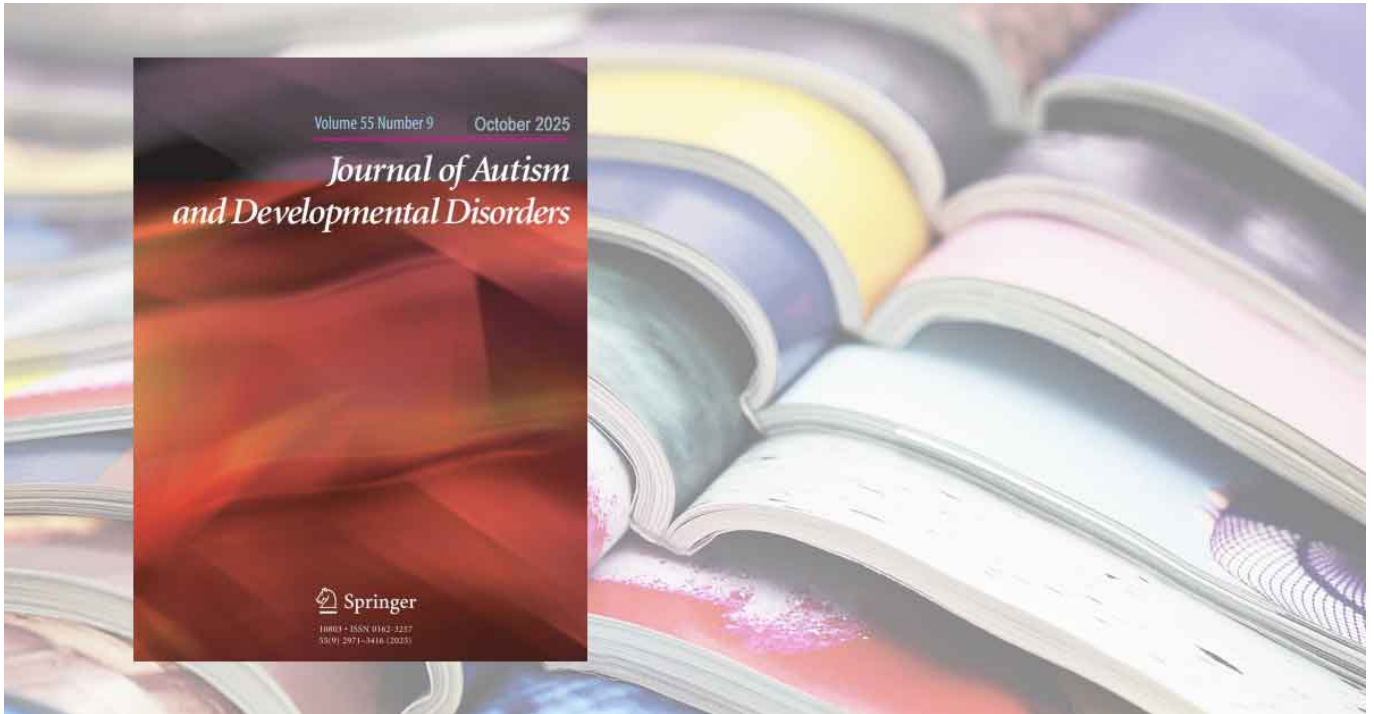
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## [Social Participation in Children with Fragile X Syndrome](#)

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03 min

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[Relationship Between Intellectual Disability and Behavioral Comorbidity in Children with Fragile X Syndrome](#)

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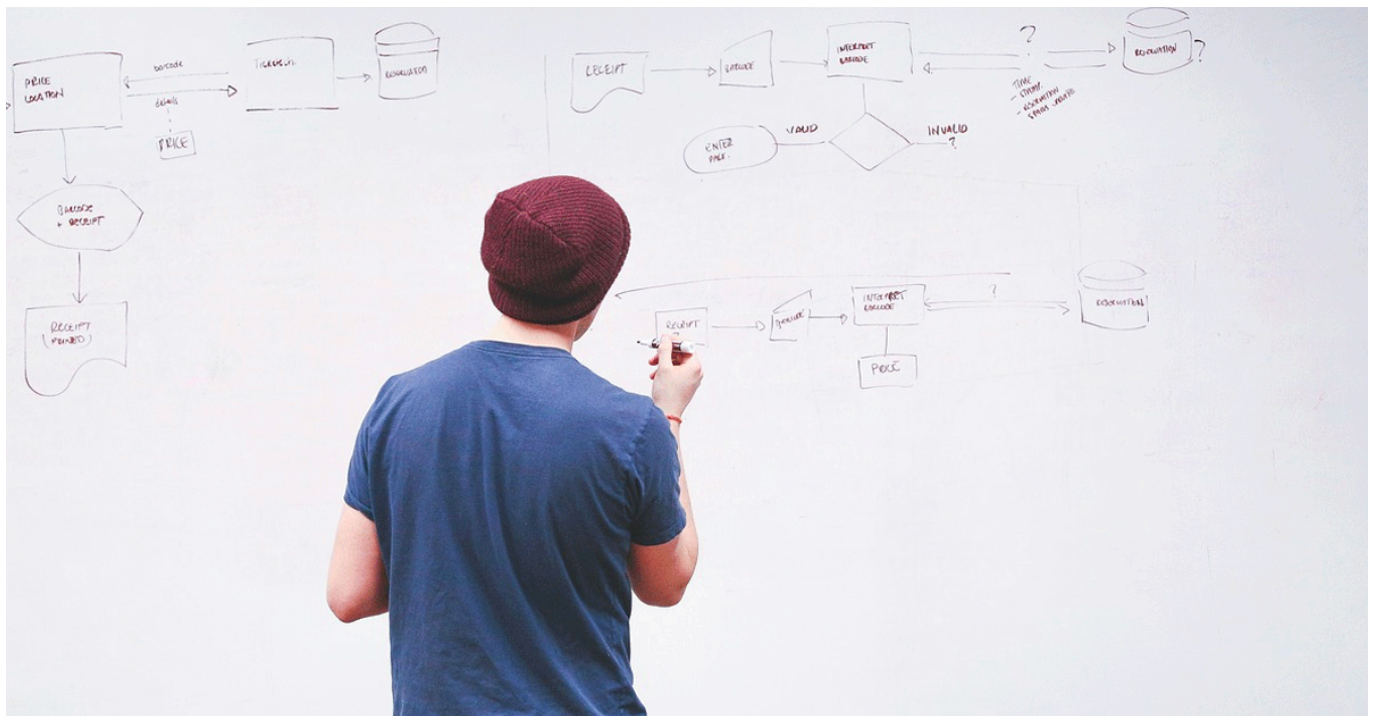
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### [Sensory Symptoms and Signs of Hyperarousal in Individuals with Fragile X Syndrome](#)

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## [Latent Class Analysis Identifies Distinctive Behavioral Subtypes in Children with Fragile X Syndrome](#)

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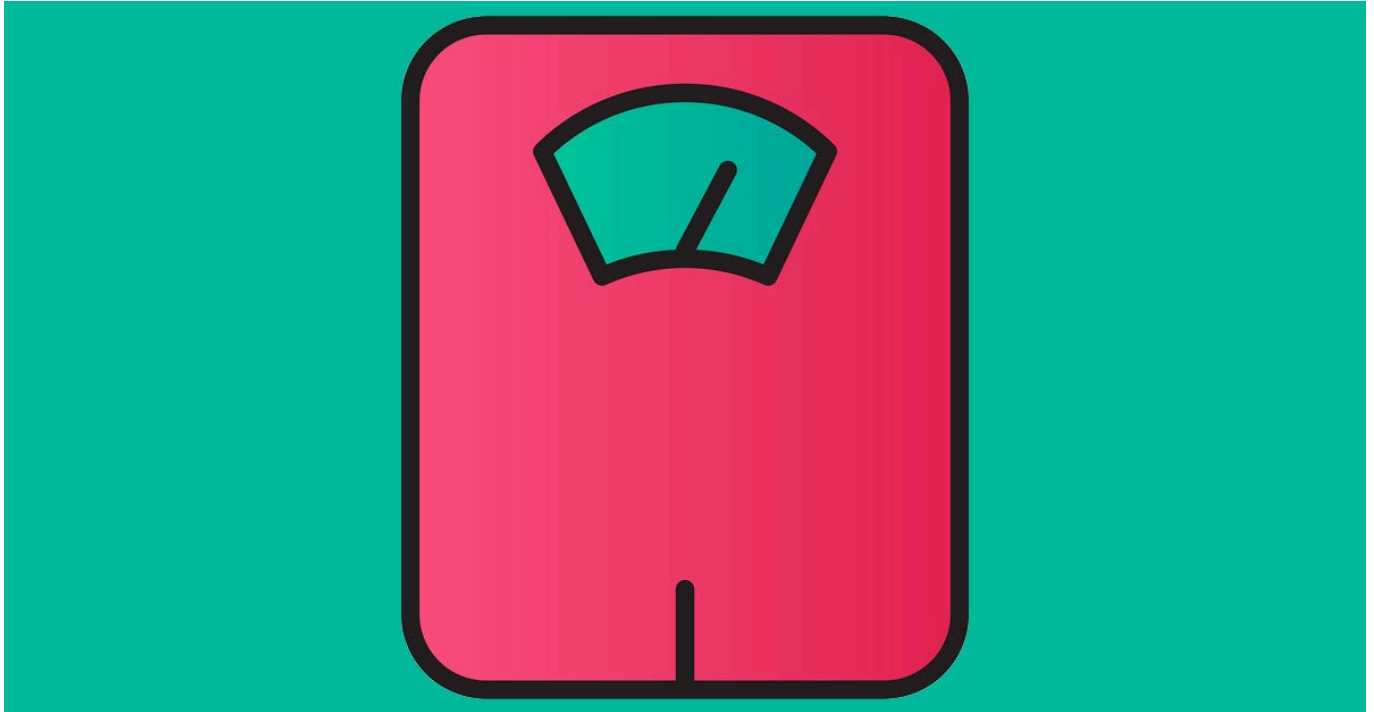
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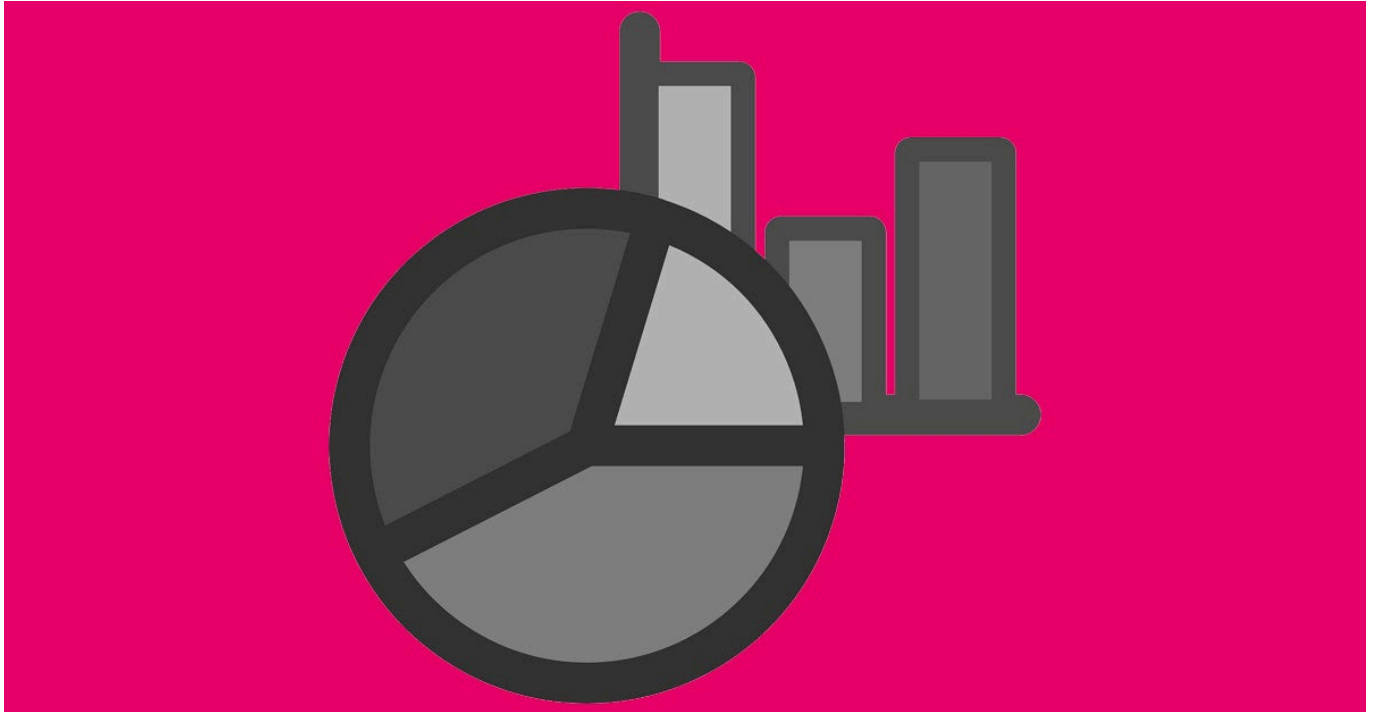
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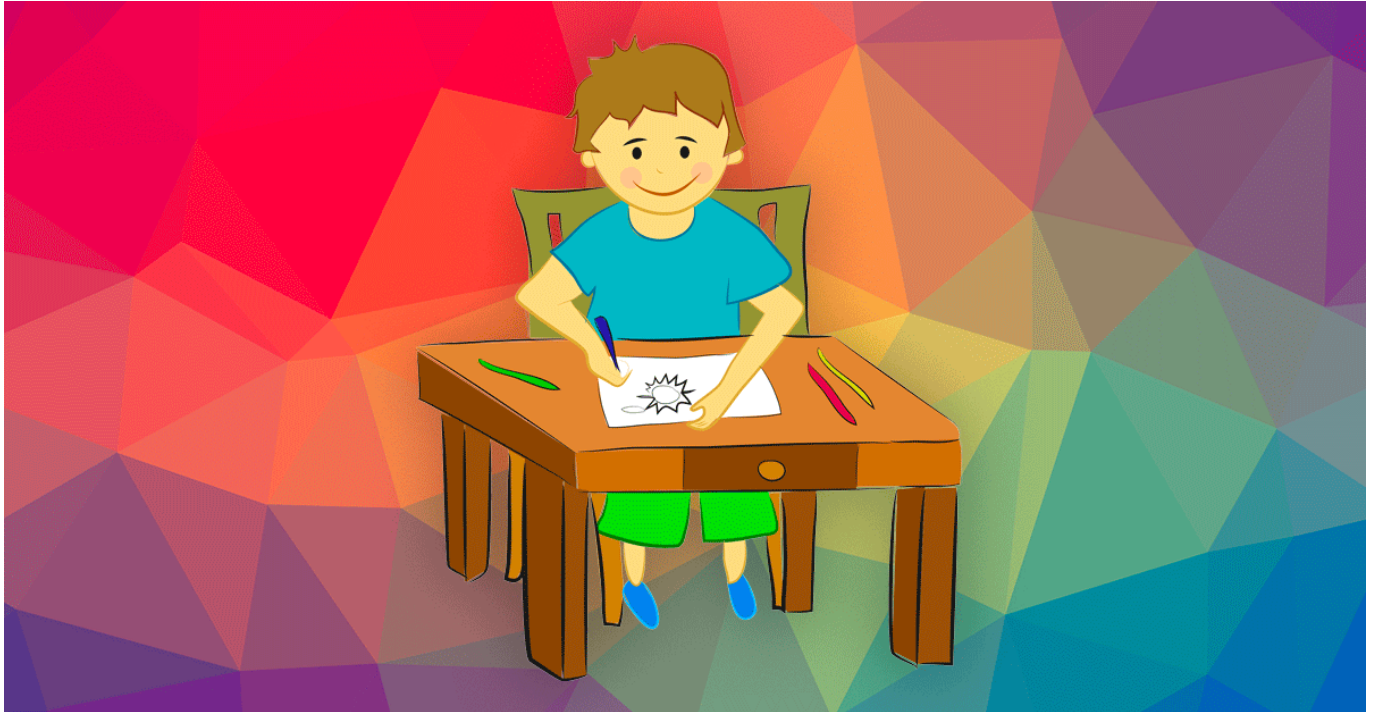
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[Longitudinal Trajectory of Seizures in Fragile X Syndrome](#)

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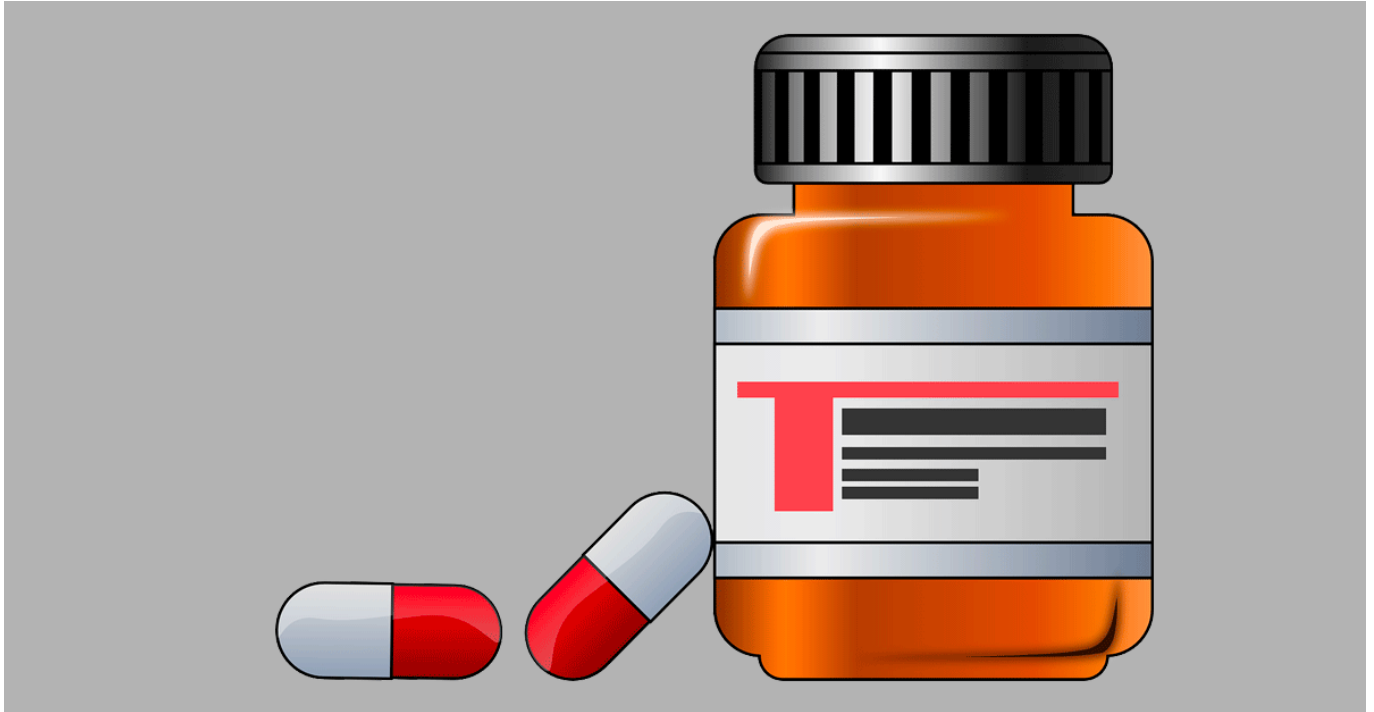
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### [Psychotropic Drug Treatment Patterns in Persons with Fragile X Syndrome](#)

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