



## Infant Development Research

Children experience amazing development over the first few years of life, and we are interested in learning about the nature of development for infants with fragile X syndrome and the fragile X premutation. For this study, we will ask to see you and your child four times within the first two years of your child's life. Assessments may be done in your home or on campus at the University of South Carolina and are expected to last up to four hours. We adapt each assessment to meet your family's schedule and preferences; however, families may choose to not participate in any components of our study. The timeline below provides an overview of the research activities involved in our study.

6 months

Our **introductory assessment** involves three primary components. Prior to the assessment, we will mail you **questionnaires** about your child's development. During the in-person visit, we complete a few **play-based assessments** with your child to learn about their personality and abilities, and if you are willing, collect **heart activity** to understand how your child physiologically responds to the activities. Because we understand that children often behave differently depending on their mood and schedule, we also **ask you a series of questions** about your child's abilities and interests. This assessment lasts 1.5- 2.0 hours, and you will receive a **brief report** of your child's abilities and a \$75 payment upon completion.

9 months

The **first follow-up assessment**, which is completed when your child is 9-months of age, will consist of three primary components: (1) **questionnaires** mailed to you prior to the assessment, (2) in-person **play-based assessments** with your child during which **heart activity** is collected, and (3) **short interviews** about your child's abilities and interests. At this assessment, we often spend additional time interacting with your child to assess changes in their development. This assessment lasts 2.0 - 2.5 hours, and you will receive a **brief report** of your child's abilities and a \$75 payment upon completion.

12 months

At the **12-month assessment**, forms, activities, and interviews are similar to the 9-month assessment. With your permission, we will continue to collect **heart activity** during the in-person assessment. This assessment generally lasts 2.0 – 2.5 hours, and we send you a **brief report** of your child's abilities and development following the assessment. Compensation for this assessment is \$100.

24 months

Our **last assessment at 24 months** is similar to previous assessments, entailing forms, play-based assessments during which **heart-activity** is collected, and interviews. Activities and interviews will be adjusted to your child's growing abilities and the assessment is expected to last 3.0 – 3.5 hours. Following the assessment, we will send you a **brief report** detailing your child's abilities and development throughout the study. Compensation for this assessment is \$150.

Genetics  
(optional)

We ask that each family consider allowing us to collect a blood sample from child participants **one time** during the study. Samples are analyzed using **cutting edge assays** for markers related to the fragile X gene, which are analyzed to study how your child's genetics may relate to their development. If you are willing to participate, we have **multiple options** on how to arrange these blood draws: here at the lab, at a local facility near your home, or during your next family doctor's visit.

## Frequently Asked Questions

*Who are we? Who is leading this study?*

This longitudinal study on development, entitled *Autonomic and Sensory Dysfunction in FMR1 Conditions: Development, Mechanisms and Consequences*, is a research study at the University of South Carolina. All study activities are conducted by research staff at the Neurodevelopmental Disorders Laboratory under the leadership of lab director Dr. Jane Roberts.

*What if I only want to participate once or twice?*

The data we collect is valuable from a longitudinal standpoint and so we ask that you enroll only if you think that you could commit to following up with us at each time point. Of course, we understand that family matters or other unpredictable circumstances may prevent us from assessing according to this schedule and participants may withdraw at any time.

*What if I plan on moving?*

It is never a problem when a family moves to a different location, whether that be across the state or the country. In most circumstances, we will continue to do the assessments as planned.

*How are assessments scheduled?*

Our assessment team works with you to find a day and time that works best for you based on you and your child's availability and preferences, accommodating work schedules, nap times, feedings, etc. We offer flexibility in scheduling, including offering times on weekends and evenings.

*How rigidly do we have to follow the target time points?*

For the infant ages, it is important that we try to capture your child's development close to the target ages listed above.

*How important are the forms/questionnaires?*

The forms sent to your home prior to each assessment are a valuable component of the data collection. While we understand that each family is often pressed for time, we ask that you set aside time to answer the questions to the best of your ability prior to the assessment or immediately afterward (within two weeks of the visit).

*Will you diagnose my child?*

No. The purpose of this study is to analyze early development from a behavioral and physiological perspective. If you are seeking to be diagnosed or to receive other services, we will do our best to help you find community resources to meet your needs but are not able to give you a medical diagnosis.

*Is my personal data kept confidential?*

Your data is always kept confidential, and your name and personal information would never be published in a research study or poster presentation, in keeping with the regulations of our university's Institutional Review Board. The de-identified data you provide is extremely valuable and is used to publish papers and present at conferences throughout the year.

*Will we be able to see the results and how will they be relayed to us?*

Following each assessment, we will email you a brief summary report of your child's abilities, highlighting their development over the course of the study. The data we collect is also used to publish papers and present at conferences, and our publications are available on our website or can be sent to you upon request. We often also highlight findings from our publications on our website, social media pages, and annual newsletter.