



# Participants Needed: Study on BEFAHRS

## What is this study about?

This research study aims to identify the unique cognitive profile of Beck Fahrner syndrome (BEFAHRS).

## Why participate?

- Before clinical trials can be constructed to treat cognitive impairment in genetic diseases like BEFAHRS, scientists must first understand the cognitive phenotype of the disease in order to identify potential outcome measures.

## Who is eligible?

- Any child between the age 7 to 18 willing to be seen at the Kennedy Krieger Institute in Baltimore, Maryland. A copy of the child's genetic test results is required as part of this study to molecularly confirm the diagnosis.

## What does it entail?

- Caregivers will be given an online research intake form and consent form. In addition, a copy of your child's genetic test results is needed to confirm the diagnosis.
- Your child will be given a battery of cognitive tests (e.g., paper and pencil or computerized puzzles and games) that will take about 1.5-2 hours to complete.
- Caregivers will be given a battery of questionnaires to index their child's day to day behavioral functioning.

## Who do I contact to enroll in this study?

- If you would like to enroll in this study or have questions, please contact the principal investigator: Rowena Ng ([ngr@kennedykrieger.org](mailto:ngr@kennedykrieger.org)).
- *Please note, study enrollment and scheduling for this study at the conference are based on a first come first serve basis.*