



Down Syndrome Research Announcement

Study conducted at Johns Hopkins and the Kennedy Krieger Institute

Genetic influences on learning and behavior in individuals with Down syndrome

What are the goals of the study?

- Measure cognition and behavior using tests optimized for people with Down syndrome
- Identify genetic contributions to cognition in Down syndrome
- Assess the suitability of the test battery as a “readout” for clinical trials

Who can participate?

Individuals with Down syndrome (DS), age 6 - 25 years

What will participants be asked to do?

- Complete up to 180 minutes of testing in one or two visits. Most tests will be done on a computer (similar to computer games) and testing may be coordinated with other visits to the Kennedy Krieger Institute
- For genetic analysis, provide a small blood sample (children) and a saliva sample (parents)
- Parents will be asked to complete questionnaires on medical history and their child’s behavior. Questionnaires may be completed online, over the phone, or in-person at the testing visit.

Will my child’s results be shared with others?

Results will be combined with information from other sites. But no personal identifiers will be included in the shared data. De-identified data may also be included in a national research database as required by the granting agencies.

When will this study begin?

January, 2010. We will spend up to ten years to complete this study for the Down Syndrome Phenotype Project.

What are the risks and benefits?

There are no significant risks or direct medical benefits for participating in this study.

Where will the study be conducted?

This is a multi-site study with many participating institutions, including:
Johns Hopkins University and Kennedy Krieger Institute, Baltimore, MD.
Emory University School of Medicine, Department of Human Genetics, Atlanta, GA.

Who do I contact to participate or request additional information?

Michelle Frank-Crawford, MA
Department of Behavioral Psychology
Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
TEL 443-923-9344
crawfordm@kennedykrieger.org

Roger H. Reeves, Ph.D.
Department of Physiology
725 N. Wolfe St.
Johns Hopkins University
School of Medicine
Baltimore, MD 21205
TEL 410-955-6621
reeves@jhmi.edu



IRB # NA_00031164
PI: Roger Reeves, PhD

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