

Down Syndrome Research Announcement!!!

Study to begin 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 7-17 yrs

What will participants be asked to do?

- Complete 90-120 minutes of testing in one or two visits. Most tests will be done on a computer (similar to computer games)
- For genetic analysis, provide a small blood sample(children) and a saliva sample (parents)
- Parents will be asked to complete two short questionnaires on medical history and their child’s behavior

Will you get results back from the study?

Results from the KBIT-II instrument (done with the child) and SIB-R instrument (done by the parent) will be provided to parents and may be useful in understanding your child’s capabilities. Other tests are not currently used for diagnosis and these results will not be provided.

Will my child’s results be shared with others?

Results will be combined with other sites. But no personal identifiers will be included in the shared data.

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?

Johns Hopkins University and Kennedy Krieger Institute, Baltimore, MD.
Emory University School of Medicine, Department of Human Genetics, Atlanta, GA.
Oregon University Health Science Center, Portland, OR.
University of Wisconsin, Madison WI.
University of Arizona, Tucson AZ.

Who do I contact to participate or request additional information?

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