



Down Syndrome Research Announcement!!!

WHY: We are recruiting children with Down syndrome to participate in an NIH funded study to identify genetic and environmental factors related to congenital heart disease in Down syndrome. This research is being conducted to look for genes and environmental factors that may help us to understand why some children with Down syndrome have heart defects and others do not.

WHO: We are looking to enroll 600 children born with Down syndrome and atrioventricular septal defect (AVSD), commonly called AV canal, and 600 children born with Down syndrome and **without** any structural heart defect. The children must be under the age of 18 years old.

WHERE: This study is part of a collaborative effort with sites at the Kennedy Krieger Institute, Johns Hopkins University, both in Baltimore, MD, and Emory University in Atlanta, GA.

WHAT: At their convenience, parents will need to complete a telephone interview (30 – 45 minutes) regarding possible exposures during pregnancy, familial risk factors and reproductive history. Additionally, parents will be asked to donate a saliva sample for DNA analysis. Adolescents will be asked to donate a small blood sample (1.5-4 teaspoons), and younger children will be asked to donate a smaller blood sample (minimum $\frac{1}{5}$ teaspoon) for DNA analysis. **The blood samples can be drawn during a regular visit to Kennedy Krieger or Johns Hopkins or by arrangement with your primary care physician.** We will ask to obtain your child's records (such as Karyotype & Echocardiograms). There are no direct medical benefits or significant risks for participating in the study.

HOW: If you are interested in participating, please contact us!

Charnan Koller, R.N., C.C.R.P.
Kennedy Krieger Institute
Research Coordinator
443-923-9131; 800-873-3377 ext. 9131
koller@kennedykrieger.org

George T. Capone, MD
Kennedy Krieger Institute
Director, Down Syndrome Clinic
Principal Investigator
RPN: 00-06-06-03



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