

SIMONS VIP CONNECT

VARIATION IN INDIVIDUALS PROJECT



Partnering *families* and *researchers* to better understand **small chromosome deletions and duplications**

This Simons Foundation project includes aspects of both research and community support - this brochure focuses on the research study portion of the project.

The Simons VIP Project

- The Simons VIP Project, sponsored by the Simons Foundation, is a new research initiative aimed at better understanding the medical, learning, and behavioral features of individuals with *small chromosome deletions and duplications* and the needs of their families.



Small chromosome deletions and duplications

may also be called:
copy number variants (CNVs)
microarray results
microdeletions/microduplications



- The project has assembled a team of experts at five university medical centers to collect detailed clinical information from families. This information will help clinicians and families understand the relationship between specific genetic changes and the brain's development.
- Information from the project will be stripped of any personal identifying information and made available to qualified scientists around the world.
- The goal is to improve clinical care and treatment for individuals with CNVs as well as those with autism and other developmental disorders.
- The Simons Foundation, a New York-based private foundation, is committed to finding science-based solutions and working towards the development of targeted treatments to improve the lives of individuals with genetic and developmental differences.



Benefits to Participation

- Participants will receive a detailed summary of the psychological testing and MRI results.
- Participating families will make an important contribution toward advancing knowledge about CNVs that could ultimately result in improved treatment and clinical care.
- Updates on the results of the group will be provided through the Simons VIP Connect website
- If results of research testing will impact health, individual results will be shared.

Register at: www.simonsvipconnect.org

Or call: 888-493-6682

Getting Involved in the Simons VIP Project

Eligibility Requirements:

- Participants must have a documented CNV deletion or duplication.
- Available biological parents and siblings are strongly encouraged to participate. Other family members may also be asked to participate.
- Families must be willing to travel (all expenses are paid) to one of our study sites for a minimum of two days.

Core Research Components:

- Families will be interviewed by telephone to collect their medical history and review medical records.
- Families will have an opportunity to ask questions about their genetic test results and speak with a genetic counselor.
- Eligible family members may undergo genetic testing for the chromosome deletion or duplication, if not already performed.
- Eligible families will be scheduled for a two-three day research assessment at the most convenient study location.
- Participants will receive a thorough medical and behavioral assessment, including magnetic resonance imaging (MRI) of the brain and a neuropsychological battery of tests.
- Blood samples will be collected from participants and family members and stored at the Rutgers University Cell and DNA Repository.
- Each individual with a deletion or duplication will be asked to consider providing a skin sample for additional research studies.
- The research team will remain in contact with participants and provide updates on the study. Families may be contacted for follow-up as researchers identify future opportunities.

Supplemental Research Components:

- Following completion of the core research components, eligible individuals will be asked to travel to a brain imaging site and participate in two additional days of advanced brain imaging (MRIs) and neuropsychological testing.
 - This advanced imaging will study the brain's structure and function in more depth than the preliminary MRI and will give the most complete information about brain function.
 - This visit will include two imaging sessions and one session of neuropsychological testing.

A Commitment to Community Advancement: Building a CNV Network

- The study may follow the progress of participants and their families over time, engage their participation in future research opportunities, and offer access to the research results and support. The project will work with families to develop a community for CNV families and provide access to cutting edge clinical and research information.

Our Network of Premier Research Facilities

- Baylor College of Medicine, *Houston*
- Children's Hospital of Boston; Harvard University, *Boston*
- University of Washington, *Seattle*

Our Network of Brain Imaging Facilities

- University of California San Francisco, *San Francisco*
- Children's Hospital of Philadelphia, *Philadelphia*

Simons VIP Project

www.simonsvipconnect.org

Simons Foundation

www.simonsfoundation.org

Contact Us

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