

Name of Study: Autism Spectrum Disorders Genetic Study

Location: Vanderbilt University Medical Center, Nashville, TN

Principal Investigator: Dr. Jonathan L. Haines

Contact Information: Kelly A. Taylor, MS, CGC, Project Manager, telephone (615) 322-7195 or toll-free (888) 717-4319 ktaylor@chgr.mc.vanderbilt.edu

Dear Parent,

Researchers at Vanderbilt University Medical Center are trying to identify the genetic causes of autism-spectrum disorders. The principal investigator, Jonathan L. Haines, PhD is currently working to identify genes that play a role in the development of autism-spectrum disorders.

Though all of the specific causes of autism are not yet known, there is significant evidence of a genetic component. It is thought that in a specific individual, interplay between a subset of genes and environmental factors may lead to the development of autism. Though no specific genes have been identified, research by Dr. Haines has identified candidate genes that may be associated with autism. More research is needed to identify additional candidate genes and to determine which genes actually play a role in the development of autism. Identifying the genetic causes of autism-spectrum disorders may lead to improvements in the diagnosis of this disorder and in intervention options for individuals with this disorder. We invite you to participate in our research.

The criteria for the ASD Genetic Study are as follows:

- Families must have one or more children with an ASD (pervasive developmental disorder, not otherwise specified (PDD-NOS), autism or Asperger's).
- The children with an ASD and both parents must participate.
- Typically developing children do not participate.
- The child with an ASD must be between the ages of 4 and 21 years.
- Families must live within the target enrollment area (Tennessee, Southern Kentucky, Northern Georgia, and Northern Alabama).

Families who participate will be asked to complete a family history interview and to complete several psychological tests, including the Vineland Adaptive Behavior Scales, the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). A blood sample is needed from each member of the family who participates, including the individual diagnosed with an ASD. There is no cost to participate in this study. Travel to Vanderbilt University Medical Center is not required. Families are reimbursed \$250.00 for the time involved in participation.

Results of psychological testing will be made available to participants wishing to receive these results. Since genetic evaluations are currently exploratory and are not validated for clinical decision-making, we are not able to share specific genetic research results from this study with participants. We do let participants know about the overall progress of our research through a yearly newsletter and updates on our web site.

If you have any questions, we can be contacted at (615) 322-7195 or toll-free at (888) 717-4319. Additional information may be found on our web site at http://chgr.mc.vanderbilt.edu/content/autism_sd

Thank you on behalf of Vanderbilt University Medical Center. Our research would not be possible without the participation of individuals with autism and their families.

Sincerely,

Jonathan L. Haines, PhD
Principal Investigator, ASD Genetic Study

Kelly Taylor, MS, CGC
Project Manager, ASD Genetic Study

IAN ref: SR00121