

22q11.2 Deletion Syndrome (Velocardiofacial Syndrome)

Autistic Spectrum Disorders and Brain Structure Research Study

Many people with 22q11.2 Deletion Syndrome (Velocardiofacial Syndrome) have a greater chance of having attention deficits, learning disabilities, and particular psychiatric conditions such as autistic spectrum disorders. While there is no known cure for this genetic syndrome, there is a lot of exciting research happening in this area. UCLA investigators have recently begun a study to further expand knowledge of 22qDS in humans. This research study is conducted jointly by investigators Carrie Bearden, Ph.D., UCLA Departments of Psychiatry and Biobehavioral Sciences and Psychology, and Katrina Dipple, M.D., Ph.D., UCLA Departments of Human Genetics and Pediatrics.

The goal of the study is to examine emotional adjustment, thought processes such as memory and attention, and brain structure and activity in children and adolescents with 22qDS, as compared to children and adolescents without the disorder. The study also aims to determine whether variation in the specific genes affected by 22qDS is related to differences in brain structure, function and behavior. Funding for this study is provided by the UCLA Center for Autism Research and Treatment (CART) and the National Institute of Mental Health (NIMH).

WHAT WILL PARTICIPATION INCLUDE?

Participation may take between one to two days (~6-7 hours for all study procedures). Participants will be given paper and pencil and computer tests of memory, attention and logic, and interviews about their mood, thoughts and behaviors by a trained staff member at the UCLA Center for Cognitive Neuroscience, and an MRI scan at UCLA'S Brain Research Institute. These tests will help us to learn more about how the brain works in people with 22qDS. A comprehensive assessment for autistic spectrum disorders will be conducted. The study also involves a review of medical records, to get information about birth and medical history, and an optional blood or saliva sample, to determine whether the genes affected by 22qDS may be related to differences in behavior. All procedures will be explained carefully and all participation is completely VOLUNTARY. There are minimal risks involved with participating in this study. You may withdraw from the study at any time. There is no financial obligation on the part of the participant. You will receive a brief report about the test results from the clinical interviews and cognitive assessments.

In addition, participants will be compensated up to \$60 for full participation in this study. If after the initial evaluation it is determined that you are not eligible for the study you will be compensated \$20 for your time. This is not a treatment study; however, it is hoped that the information gathered from this study may help to develop treatments for the disorder in the future.

WHO MAY BE ELIGIBLE TO PARTICIPATE?

1. Individuals between the ages of 6 to adult, with a confirmed diagnosis of 22q11.2 deletion.
2. No diagnosis of a disorder of the brain or nervous system (such as encephalitis, brain tumor, etc.)
3. No current drug or alcohol abuse
4. Able to complete the study measures and interviews in English.

CONTACT INFORMATION

If you are interested in finding out more about this research study, please call Jennifer Ho at (310) 825-3458 or email: beardenlab.ucla@gmail.com. You may also contact the Principal Investigator of the study, Dr. Carrie Bearden, at cbearden@mednet.ucla.edu

*Individuals under 18 must have their parents call.

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