

**The Pediatric Neurology Research Group at the
University of California, San Diego (UCSD)
is conducting the following research studies on cystinosis:**

Brain and Cognitive Development in Cystinosis

The UCSD Pediatric Neurology Research Group is conducting a study to examine cognitive and brain development in individuals with cystinosis. Participants will include individuals with cystinosis ages 3-7 years and ages 12-17 years. This study will involve two 2-hour psychometric testing sessions that are scheduled at your convenience. The testing is non-invasive and behaviorally-oriented, and it helps us learn more about the cognitive and behavioral effects of cystinosis. Individuals will be asked to perform such tasks as putting together puzzles, defining words, and identifying or remembering pictures. Your participation in the psychometric testing is entirely voluntary.

As part of the study, Dr. Doris Trauner would like to conduct neurological examinations and Magnetic Resonance Imaging (MRI). Again, participation is voluntary. The neurological examination is a non-invasive exam that helps us learn more about an individual in terms of coordination, reflexes, sensory skills, language, and other neurologic functions. Individuals may be asked to do such tasks as kick a ball, stack blocks, and repeat sounds. MRIs are also considered safe and non-invasive and enable us to learn more about the structure of the brain.

Dr. Trauner hopes to examine any changes in the brain and cognitive development over time by seeing individuals for follow-up testing two years after their initial visit.

If you would like to participate in the Cognitive and Brain Development study or if you would like more information, please contact Jenny Williams at UCSD:

j7williams@ucsd.edu
858-822-6800

Executive Functioning in Cystinosis

The UCSD Pediatric Neurology Research Group is conducting a study to examine executive functioning, which includes behaviors such as problem solving, planning, attention, and impulsivity, in individuals with cystinosis. Participants will include individuals with cystinosis ages 8 years through adulthood. This study will involve two 2-hour psychometric testing sessions. The testing is non-invasive and behaviorally-oriented, and it will help us learn more about executive functioning in cystinosis. Individuals will also be asked to fill out a questionnaire regarding behaviors such as planning and attention. Participation in this research study is completely voluntary.

If you would like to participate in the Executive Functioning study or if you would like more information, please contact Lynne Babchuck at UCSD:

lbabchuck@crl.ucsd.edu
858-822-6800

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Thank you very much for your time and consideration. We look forward to seeing you! We greatly appreciate the time and effort that families have devoted to increasing our knowledge of the effects of cystinosis.