

ChANGE HD Brain Imaging Study

What is the ChANGE HD Study?

The ChANGE HD Study is a brain imaging study that began at the University of Iowa. Our research focuses on young people ages 6-30 who have a family history of Huntington's Disease (HD).

HD has long been considered an adult onset disease. However, research has shown that brain changes are evident before motor symptoms begin. In fact, the gene responsible for HD plays a role in brain development and is present throughout the lifespan. With gene knockdown therapy showing promise for the treatment of HD, it is essential to understand how removing or disabling the gene could impact brain development.

What are we trying to learn?

We hope this study will help explain how the gene responsible for HD effects brain development, and we hope to find a way to identify the best time for gene therapy during development.

Who can participate?

Young people who are between the ages 6-30 and are at risk for HD are eligible to participate in this study.

“At Risk” means someone who has a parent or grandparent who has HD.

How do we study the brain?

We study brain structure and function:

To look at brain structure, we use a special research Magnetic Resonance Imaging (MRI) to take images that we can analyze to measure the size and shape of different parts of the brain.

To get an idea of brain function, we administer assessments that measure attention, reasoning, memory, movement, coordination and balance. We also use questionnaires that ask about moods, relationships, hobbies and talents.

A testing day takes about 6-8 hours, or about as long as a school or work day. We will ask participants to return and repeat testing once a year for 3-4 years. Participants are compensated for their time and effort.

Locations:

- University of Iowa
Iowa City, IA
- Columbia University
New York, NY
- Children's Hospital of Philadelphia and University of Pennsylvania
Philadelphia, PA
- University of Texas Health
Houston, TX



Travel considerations:

Travel-related expenses are paid by the study. Expenses that can be paid in advance (like airfare, shuttles and hotel rooms) will be arranged and pre-paid, while expenses that cannot be pre-arranged (like meals, tips or tolls) will be reimbursed.

Participants who are under age 18 will need to bring at least one parent or guardian with them when they participate. Families with more than one participant can make the trip and participate together. Study staff will take care of scheduling and travel arrangements according to each participant's needs.

How to find out more:

Try our website: www.changehd.org
or come see us on Facebook:
www.facebook.com/ChANGEHD

Call our toll free number:
1-866-514-0858 or send us an
e-mail: change-hd@uiowa.edu

