

What is the study?

The ChANGE HD study is a brain imaging study run by researchers at Columbia University Medical Center. Our research is about kids who have a parent or a grandparent who has Huntington Disease. HD causes parts of the brain to stop working like they should. Usually, this happens when a person is already grown up, but some people might have small problems in their brain for a long time before any bigger problems start. This study will try to find those early, small problems and measure them.



How do we study the brain?

We study brain structure (the different parts and how they're put together) and function (how all those parts work). To look at someone's brain, we use a special scan called Magnetic Resonance Imaging (or an MRI) to take a picture of it. We can use this picture to measure lots of stuff, like the size and shape of different parts of the brain. The MRI is safe, doesn't hurt at all, and it doesn't use any radiation. We also will do a blood draw for genetic testing to compare information of people who have HD in their family or not. To get an idea of how someone's brain works, we measure how they think and remember things, how they move and balance, and what they think of themselves and other people. To do this, we use a lot of puzzles and brainteasers, quizzes, and activities like walking silly or standing on one foot. It takes about 6-8 hours to get it all done. People who participate are paid for their time and work.

How will the results of this study help?

We hope that someday this study will help explain how HD can change the way a person's brain grows during their whole life. If we can find and measure the earliest changes in the brain and figure out when they usually happen, we hope that it will help other doctors and scientists find new ways to tell if a person has HD and make better ways to treat it sooner. We hope this research will find a way to identify the safest time for gene therapy during brain development.

Who can participate?

Kids or adults who are between the ages of 6 and 30 and who have a parent or grandparent with HD can participate in our study. Kids who have already participated can come back in a year or two for another visit to do the same tests, if they want to. Participating in this study is voluntary. You can stop participating any time for any reason.

How does an MRI work?

The MRI machine looks like a giant plastic donut with a tunnel in the middle. The special scan uses a big magnet and antenna to see inside your body. The antenna sends the information to a computer, and the computer makes it into a picture. The picture will show all kinds of cool body parts like muscles, bones, and organs – which all look different!

Does an MRI hurt?

No, the MRI scan does not hurt at all and it is safe. The MRI uses headphones to block the noise of the machine. There is even a TV to watch a movie while the scan is being done!

Why is there a blood test?

We will do tests on your blood to compare your blood to other people's. The tests will look at your DNA. Most of the tiny cells that make up your body have DNA. The DNA gives our body instructions it needs to grow and work.

Will you tell me how I did on the tests?

No, you and your family or anyone else will not know your answers to your test.

What if I don't like something in the study?

The study is voluntary. That means if you do not like something in the study, you can stop whenever you want.

Can parents come if I participate in the study?

Yes! Kids under the age of 18 will need to bring at least one parent with them when they participate, but more family members are welcome to come, too: parents, grandparents, brothers and sisters, maybe even aunts, uncles, and cousins! When you decide to start planning a visit, we'll talk about who you'd like to come along with you on your trip.

Where are the study sites?

We have sites in:

- Iowa City, Iowa
- Philadelphia, Pennsylvania
- New York City, New York
- Houston, Texas
- Sacramento, California

You can contact the sites directly or send us a message from our website, to our email, or call our toll-free phone number. Study staff will make sure you are put in touch with the site team you need.

How do I get to the study site?

All travel arrangements are taken care of by study staff. We'll ask when you want to come and how you want to get here. Then, we'll talk to a travel agent and have the trip arranged for you. Once everything is planned, we'll send you an itinerary, which is a schedule for your trip.

Who pays for my trip?

All travel-related expenses are paid for you by the study. This means that some things (like airfare, shuttles, and hotel rooms) will be pre-paid for you, while other things (like meals, gas, or tolls) will be paid back to you.

How do I find out more?

If you are interested in our HD study, you can find out more at our website: www.changehd.org
or come see us on Facebook: [@ChangeHDresearch](https://www.facebook.com/ChangeHDresearch)

You can also call our toll-free number: [1-866-514-0858](tel:1-866-514-0858) or send us an e-mail at: change-hd@uiowa.edu