

PREDICT-HD Participating Sites

North America:

University of Alberta; Edmonton, AB, Canada
University of British Columbia; Vancouver, BC, Canada
University of Calgary; Calgary, AB, Canada
University of Toronto; Markham, ON, Canada
Baylor College of Medicine; Houston, TX
Cleveland Clinic, Cleveland, OH
Colorado Neurological Institute; Englewood, CO
Columbia University; New York, NY
Emory University; Atlanta, GA
Hennepin County Medical Center; Minneapolis, MN
Hereditary Neurological Disease Center; Wichita, KS
Indiana University; Indianapolis, IN
Johns Hopkins University; Baltimore, MD
Massachusetts General Hospital; Boston, MA
University of California-Davis; Sacramento, CA
University of California-Los Angeles; Los Angeles, CA
University of California San Francisco; San Francisco
University of Iowa; Iowa City, IA
University of Rochester; Rochester, NY
University of Washington; Seattle, WA
Washington University; St. Louis, MO

Europe and Australia:

Cambridge Centre for Brain Repair; Cambridge, UK
Cardiff University; Cardiff, Wales
Clinical Genetics Centre; Aberdeen, Scotland
National Hospital for Neurology and Neurosurgery
London, UK
Hospital Ramón y Cajal; Madrid, Spain
University of Ulm; Ulm, Germany
University of Manchester; Manchester, UK
Graylands, Selby-Lemnos & Special Care Health
Services; Mt. Claremont, Australia
St. George's Health Service; Kew, Australia
Westmead Hospital; Sydney, Australia
University of Melbourne; Kew, Vic., Australia

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PREDICT HD v. 2.0

Study Chair

Jane S. Paulsen
The University of Iowa

Executive Committee

Robi Blumenstein

Mark Guttman

Michael Hayden

Marg Sutherland

Study Section Chairs

Biomarker: Blair Leavitt

Cognitive: Julie Stout

Ethics: Cheryl Erwin

Functional: Janet Williams/Leigh
Beglinger

Genetics: Marcy MacDonald

Imaging: Elizabeth Aylward, Vince
Magnotta, Peg Nopoulos, Ron Pierson,
Steve Rao, Chris Ross

Information Technology: Hans Johnson

Motor: Kevin Biglan/Ralf Reilmann

Psychiatric: Kevin Duff

Recruitment/Retention: Martha Nance

Statistics: Douglas Langbehn

PREDICT HD v. 2.0



Neurobiological Predictors of Huntington's Disease Version 2.0

A Clinical Research Study of

Predictors of HD Onset

H·S·G Seeking Treatments That Make A Difference For Huntington Disease
Huntington Study Group

HD EUROPEAN HUNTINGTON'S DISEASE NETWORK

Why is PREDICT-HD studying people at risk for Huntington's Disease?

- To refine prediction of disease onset using longitudinal measures
- To find and validate tests clinicians can use when detecting early symptoms
- To improve our knowledge of illness markers which may respond to therapeutic interventions

We hope that this study will provide some essential information for future trials of experimental drugs for HD. It is necessary to get information on the early stages of HD in order to develop drugs that can slow or postpone the onset of HD.

Who can participate?

Men and women who:

- Are 18 years of age or older
- Are able to commit to a minimum of 5 yearly evaluations
- Have a companion who can attend visits or complete surveys by mail
- Are able to undergo an MRI scan
- Are **gene negative** or **gene positive** individuals; specifically those at risk for HD who have been tested for the gene mutation but have not been diagnosed with HD (CAG \geq 36 for CAG-expanded group or CAG $<$ 36 for CAG-norm group)

What if I don't want anyone to know I am at risk for HD? How will my privacy be protected?

The PREDICT-HD study is designed to protect the confidentiality of research participants to the fullest extent possible. Names will not appear on study forms – instead, a code number will be assigned to identify each participant. This code will be used to identify all blood samples, DNA results, and brain scans.

Will my participation in PREDICT-HD prevent me from volunteering for clinical trials of possible new treatments?

No. There are several clinical trials for diagnosed HD currently ongoing and at least 4 being planned for premanifest volunteers within the next few years. All participants enrolled in PREDICT-HD will be eligible to participate in other clinical trials. Data from the two studies can be used together to better inform scientists of the possible treatments for HD. We will make every effort to keep you informed of possible experimental treatment studies at your annual PREDICT visit, if you desire.

Are there any risks or benefits to me as a participant in PREDICT-HD?

Uncertainties of not knowing when HD will start may cause distress. There are some minor risks involved when blood is drawn for the blood sample. These risks are further explained in the consent form, and the research investigator can answer any question.

There is no direct health benefit from participating in PREDICT-HD. However, participation may help to provide important information useful for understanding the onset of HD in persons at risk for the illness.

What can I expect at a PREDICT-HD visit?

The PREDICT-HD study uses a variety of tests to help examine the nature and pattern of brain changes that occur in the period leading up to an HD diagnosis. Changes in thinking skills, emotional regulation, brain structure and brain function are measured through computer tasks, paper and pencil tests, motor examinations, survey questions, yearly blood samples and MRI scans.

How do I get more information about participating in the PREDICT-HD study?

If you are interested in learning more about this study, please contact the **Huntington Study Group** toll free at **800-487-7671** or visit the website at:

www.Huntington-Study-Group.org

The following PREDICT-HD personnel and website are also available to discuss the study or any questions you may have:

www.uihealthcare.com/depts/huntingtonsdisease/index.html

Jane S. Paulsen

jane-paulsen@uiowa.edu

Stacie Vik

(319) 353-3716

stacie-vik@uiowa.edu

Anne Leserman

(319) 353-4307

anne-leserman@uiowa.edu