

ELIGIBILITY

Who is eligible to participate in COHORT?

- Individuals of any age who have HD or tested positive for the HD gene.
- Individuals 18 years or older who has tested positive for the HD gene.
- Individuals at least 15 years of age who are at-risk for developing HD due to a parent, child or sibling either having HD or testing positive for the HD gene.
- Grandparents and Grandchildren of those individuals participating in COHORT who have HD or tested positive for the gene.
- Spouses or caregivers of those individuals participating in COHORT who have HD or tested positive for the gene.
- HD family members who have tested negative for the HD gene

Are there risks to me as a participant in COHORT?

You may experience anxiety or psychological discomfort while completing the clinical evaluation, psychological, or the family history questionnaire. Drawing blood may cause pain and/or bruising where the blood is drawn.

STUDY PROCEDURES

What study procedures will occur if I am willing to participate in COHORT?

Each person will have a clinical evaluation, which includes standard tests to evaluate movement, mental function, and psychological and behavioral features of HD. A blood sample will be drawn to measure the HD gene and other genes previously shown to be important in HD.

Individuals may also participate in the following **optional** procedures:

- Collection of family history information
- Collection of Biological Specimens for future HD research:
 - ◆ Blood will be collected at each visit and stored in a specimen repository
 - ◆ Urine will be collected at either the 2nd, 3rd, or 4th study visit and stored in a specimen repository
- Linking of data from previous HSG studies to COHORT
- Analysis of Life Decision Survey (select sites)

How would I benefit by participating in COHORT?

There is no direct health benefit from participation in COHORT. You may provide information that could be useful to our understanding of HD.

CONTACT INFO

How do I find out more information about participating in the COHORT Study?

If you are interested in learning more about this study, please contact the Huntington Study Group at the toll free number:

1-(800) 487-7671

OR

www.Huntington-Study-Group.org

H • S • G

HUNTINGTON • STUDY • GROUP

Seeking Treatments That Make a Difference For Huntington Disease



PARTICIPATING SITES

Albany Medical College; Albany NY
Baylor College of Medicine; Houston, TX
Boston University School of Medicine; Boston, MA
Colorado Neurological Institute; Englewood, CO
Columbia University; New York, NY
Duke University Medical Center, Durham, NC
Emory University; Atlanta, GA
Hennepin County Medical Center, Minneapolis, MN
Hereditary Neurological Disease Center; Wichita, KS
Hotel-Dieu Hospital-CHUM, Montreal, Quebec, CAN
Indiana University School of Medicine; Indianapolis, IN
Institute for Neurodegen. Disorders; New Haven, CT
Johns Hopkins University; Baltimore, MD
Massachusetts General Hospital; Boston, MA
Medical College of Georgia, Augusta, GA
Ohio State University; Columbus, OH
Rush University Medical Center; Chicago, IL
The Centre for Addiction and Mental Health, Markham, Ontario, CAN
University of Alabama at Birmingham; Birmingham, AL
University of Alberta; Edmonton, Alberta
University of British Columbia; Vancouver, BC
University of Calgary Medical Clinic; Calgary, Alberta
University of California, Davis; Sacramento, CA
University of California, Los Angeles, CA
University of California, San Diego; SD & La Jolla, CA
University of California, San Francisco, SF., CA
University of Chicago, Chicago, IL
University of Cincinnati, Cincinnati, OH
University of Connecticut; Hartford, CT
University of Iowa; Iowa City, IA
University of Kansas Medical Center; Kansas City, KS
University of Maryland, Baltimore, MD
University of Melbourne, Kew Vic, Australia
University of Miami School of Medicine; Miami, FL
University of Pennsylvania; Philadelphia, PA
University of Pittsburgh, Pittsburgh, PA
University of Rochester; Rochester, NY
University of South Florida; Tampa, FL
University of Tennessee-Memphis, Memphis, TN
University of Texas at Galveston, Galveston, TX
University of Virginia; Charlottesville, VA
Wake Forest Uni. Med Center, Winston Salem, NC
Washington University Sch. of Medicine, St. Louis; MO
Westmead Hosital, Wentworthville, Australia

H • S • G

What is the Huntington Study group?

The **Huntington Study Group (HSG)** is an international association of more than 200 clinical investigators, coordinators, scientists and staff from 55 participating hospitals and universities in North America, Europe and Australia.

The HSG is supported by the Huntington's Disease Society of America (New York, NY), the Hereditary Disease Foundation (Santa Monica, CA), HP Therapeutics, Inc. (New York, NY), and the Huntington Society of Canada (Cambridge, Ontario).

Formed in 1993, the HSG strives to advance knowledge about the cause, process and clinical impact of HD in order to develop and test promising therapeutic interventions.

For more information about the HSG, please visit our website at:

www.Huntington-Study-Group.org

H • S • G

HUNTINGTON • STUDY • GROUP

Seeking Treatments That Make a Difference For
Huntington Disease

USEFUL LINKS

Huntington's Disease Society of America

www.hdsa.org

Huntington Society of Canada

www.huntingtonsociety.ca

Huntington's Disease Lighthouse

www.hdlighthouse.org

Huntington's Disease Advocacy Center

www.hdac.org

The Huntington Project

www.huntingtonproject.org

**HOPES: Huntington's Outreach Project for
Education at Stanford**

www.stanford.edu/group/hopes/

International Huntington Association

www.huntington-assoc.com

National Institute of Health Clinical Trials

www.clinicaltrials.gov

Hereditary Disease Foundation

www.hdfoundation.org

Sponsored by



COHORT

Cooperative Huntington's Observational Research Trial



The study is being sponsored by HP Therapeutics Foundation, Inc., a not-for-profit corporation that is sponsoring a variety of clinical research projects seeking to find treatments for Huntington's disease and is implemented and overseen by the Huntington Study Group.

H • S • G

HUNTINGTON • STUDY • GROUP

Seeking Treatments That Make a Difference For
Huntington Disease

OBSERVATIONAL

What is an observational study?

An observational study is a study in which people are examined over time without receiving any experimental drugs or treatments. An observational study differs from a clinical trial, where promising new experimental treatments are evaluated to learn if new medications are safe, tolerable and effective.

What is the COHORT study?

COHORT is a coordinated effort by approximately 42 HSG research centers in the United States, Canada, and Australia to collect ongoing information from individuals who are affected by HD and those who are part of an HD family. The HSG is collecting this information in order to learn more about HD, potential treatments, and to plan future research studies of experimental drugs aimed at postponing the onset or slowing the progression of HD.