

Who is eligible to participate in COHORT?

For those 18 years of age and older the following individuals may participate:

- Individuals who have HD or tested positive for the HD gene.
- Parents, children, and siblings of individuals who have HD or tested positive for the gene.
- Grandparents and Grandchildren of those individuals participating in COHORT who have HD or tested positive for the gene.
- Spouses 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. These individuals must have a family member who has HD or tested positive for the gene participating in COHORT to be included.

For those under the age of 18, only individuals who have HD are eligible to participate.

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.

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. For those subjects 18 year of age and older, blood will be drawn to measure the HD gene and other genes previously shown to be important in HD.

Individuals over the age of 18 may also participate in the following optional procedures:

- Collection of family history information
- Collection of Biological Specimens:
 - 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

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.

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

You may also go to the Huntington Project website at:

www.huntingtonproject.org



COHORT 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
Graylands, Selby-Lemnos & Special Care Health Services, Mount Claremont, Australia
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
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 University Med Center, Winston Salem, NC
Washington University School of Medicine, St. Louis; MO
Westmead Hospital, Wentworthville, Australia

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

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COHORT Steering Committee

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Principal Investigator

Tatiana Foroud
Co-Principal Investigator

James Gusella
Co-Principal Investigator

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Madaline Harrison

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Elise Kayson*

Mark Morris*

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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.

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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 43 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.