

# PARTICIPATING SITES

## USA

Albany Medical College; Albany NY  
Baylor College of Medicine; Houston, TX  
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  
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  
University of Alabama at Birmingham; Birmingham, AL  
University of California, Davis; Sacramento, CA  
University of California, Los Angeles, 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 Pittsburgh, Pittsburgh, PA  
University of Rochester; Rochester, NY  
University of South Florida; Tampa, FL  
University of Tennessee-Memphis, Memphis, TN  
Wake Forest University Med Center, Winston Salem, NC  
Washington University Sch. of Medicine, St. Louis; MO

## CANADA

University of British Columbia; Vancouver, BC  
Hotel-Dieu Hospital-CHUM, Montreal, Quebec  
University of Calgary Medical Clinic; Calgary, Alberta

## AUSTRALIA

St. Vincent's Aged Psychiatry Service, Kew, Victoria

Cooperative Huntington's Observational Research Trial

# USEFUL LINKS

Huntington's Disease Society of America  
[www.hdsa.org](http://www.hdsa.org)

Huntington Society of Canada  
[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

Huntington's Disease Lighthouse  
[www.hdlighthouse.org](http://www.hdlighthouse.org)

Huntington's Disease Advocacy Center  
[www.hdac.org](http://www.hdac.org)

The Huntington Project  
[www.huntingtonproject.org](http://www.huntingtonproject.org)

HOPES: Huntington's Outreach Project for Education at Stanford  
[www.stanford.edu/group/hopes/](http://www.stanford.edu/group/hopes/)

International Huntington Association  
[www.huntington-assoc.com](http://www.huntington-assoc.com)

National Institute of Health Clinical Trials  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

Hereditary Disease Foundation  
[www.hdfoundation.org](http://www.hdfoundation.org)



# COHORT

Cooperative Huntington's Observational Research Trial

Are you between the ages of  
**15 and 17 years**  
and interested in participating in  
a research study ?



COHORT is now recruiting  
**Older Adolescents**  
(15 – 17 years of age)  
who are **at risk** for HD  
and who have a parent with  
manifest HD or pre-manifest HD  
enrolled in COHORT

23rd Annual HDSA Convention

June 5-7, 2009  
Phoenix, AZ

# 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 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.

## 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.

# FAMILY STUDY

For those **under the age of 18**, the following individuals may participate:

- Any individual under the age of 18 years who has clinical characteristics of HD
- Individuals 15 –17 years of age who are at risk for HD due to a parent having HD or testing positive for the HD gene. The parent(s) must be enrolled in COHORT.

## Why include older adolescents in COHORT?

The inclusion of older adolescents provides a new opportunity for those at risk for HD to participate in a research study and provide researchers a new opportunity to test whether there are biomarkers that can be identified much earlier in disease progression.

## As an older adolescent, what study procedures will occur if I am willing to participate in COHORT?

- You will have one visit before the age of 18 years.
- At this visit, you and your parent(s) will be asked questions about your current health, medical history, and medications that you have taken before.
- A clinic exam will be performed to test how you move, how you think, your memory, your ability to perform daily activities, and your behavior. It will take about 1 hour to do these activities.
- You will also be asked for a blood sample to measure information in the HD gene and other differences in the DNA that have previously been shown to be important in HD.
- You have the option of providing another blood sample for storage for future HD research. You do not have to take part if you do not want to. The reason we will be storing these samples is to allow HD scientists to use them to find ways to develop new

# HD RESEARCH

tests, treatments and ways to prevent HD.

## 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.

## 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 and your family are interested in learning more about this study or the inclusion of Older Adolescents (15-17 years of age), please have your parent(s) contact the **Huntington Study Group** at the toll free number:

1-(800) 487-7671

OR

[www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org)

H • S • G

HUNTINGTON STUDY GROUP

Seeking Treatments That Make a Difference For  
Huntington Disease