

---

---

# COHORT COMMUNITY



---

This newsletter is especially for individuals participating in COHORT and their families.

---

**Volume 1 No. 1**

**2005**

---

## Welcome to COHORT....

We would like to take this opportunity to thank you for deciding to participate in the **Cooperative Huntington's Observational Research Trial (COHORT)**. This study was designed to collect a large database of clinical information, family history information, and biological samples, such as blood and urine, to be used to study Huntington's disease.

The COHORT Community Newsletter will be distributed once per year to provide you with information about the study as it proceeds. We plan to feature articles about the investigator's running this study, study results, and other activities and organizations working in Huntington's disease.

We encourage you to share this newsletter with any family members who may also be interested in participating in the COHORT study. We have included a map showing where COHORT research site are located across North America and Australia, along with contact phone numbers for each of these sites. Please feel free to contact your site investigator or coordinator throughout the year if you have questions or concerns about your participation in COHORT.

We look forward to working with you and your involvement in Huntington's disease research.

Sincerely,

The COHORT Research Team

Ira Shoulson (Principal Investigator)

Tatiana Foroud (Co-Principal Investigator)

James Gusella (Co-Principal Investigator)

Robi Blumenstein

Martha Nance

Michael Conneally

David Oakes

Jackie Gray

Kelley O'Donoghue

Madaline Harrison

Aileen Shinaman

Elise Kayson

Oksana Suchowersky

Karl Kiebertz

Julie Stout

Richard Myers

Teresa Tempkin



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.

## **Study Information**

### **Who is eligible to participate?**

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.

### **What will happen at each visit?**

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 2<sup>nd</sup>, 3<sup>rd</sup>, or 4<sup>th</sup> study visit and stored in a specimen repository.

### **When are the study visits?**

Each person that participates in COHORT will have **one** visit per year.

### **Are there any risks?**

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.

### **Is there any benefit?**

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

### **What if I don't want anyone to know I am participating in this study?**

Confidentiality is a central concern in the COHORT study. We have designed this study to protect the confidentiality of those participating.

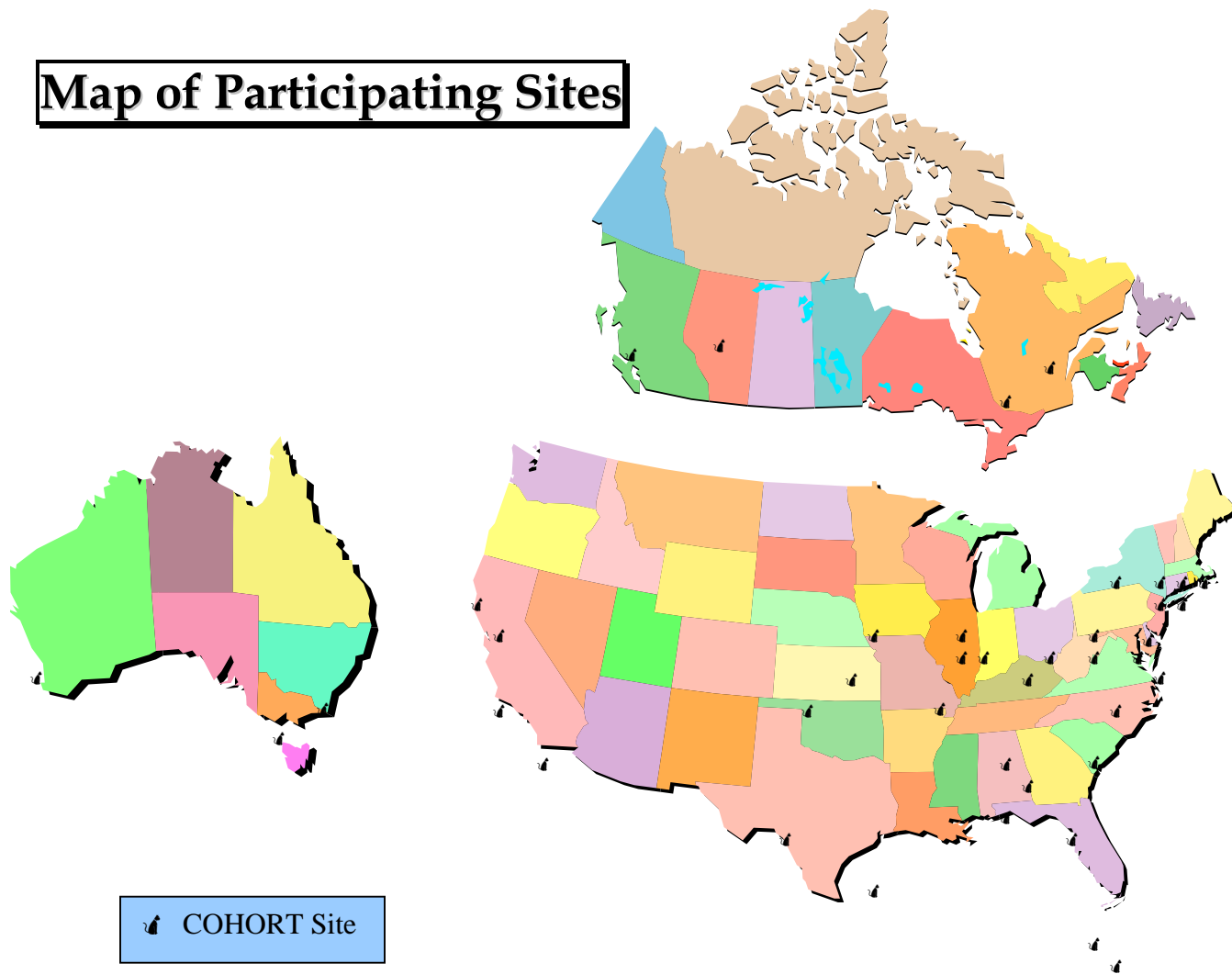
### **Will I receive the results of tests performed during COHORT?**

Since COHORT is a research study, all research results will be kept in a separate research chart and this information will not be available to you. If you decide to have the test for the HD gene, neither you nor any of physicians or coordinators at your site will receive your individual test result.

For further information about COHORT or the Huntington Project, see

[www.huntingtonproject.org](http://www.huntingtonproject.org)

## Map of Participating Sites



## Site Contact Number

### Alabama

University of Alabama at Birmingham  
(205) 996-7865 or 1-888-309-HUNT (4868)

### California

University of California – Davis Medical Center  
(916) 734-6278

UCLA Medical Center  
(310) 794-1225

University of California – San Diego  
(858) 622-5854

University of California – San Francisco  
(415) 502-2163

### Connecticut

University of Connecticut Health Center

(860) 679-4441

### Florida

University of Miami  
(305) 243-2259

University of South Florida  
(813) 974-6022

### Georgia

Emory University  
(404) 728-4956

Medical College of Georgia  
(706) 721-2798

### Illinois

Rush University Medical Center  
(312) 563-2900

University of Chicago  
(773) 834-1688  
**Indiana**  
Indiana University  
(317) 274-5744

## **Site Contact Number**

**(cont.)**

### **Iowa**

University of Iowa  
(319) 353-4307

### **Kansas**

Hereditary Neurological Disease Centre,  
Wichita  
(316) 721-9250 or (888) 232-4632

University of Kansas  
(913) 588-6983

### **Maryland**

Johns Hopkins University  
(410) 955-1349  
University of Maryland  
(410) 328-2294

### **Massachusetts**

Boston University  
(617) 638-7704  
Massachusetts General  
(617) 724-2227

### **Missouri**

Washington University of St. Louis  
(314) 362-3471

### **New York**

Albany Medical College  
(518) 452-0914  
Columbia University  
(212) 305-5779  
University of Rochester  
(585) 341-7519

### **North Carolina**

Wake Forest University School of Medicine  
(336) 716-7548

### **Ohio**

Ohio State University  
(614) 688-8672  
University of Cincinnati/Cincinnati Children's  
Hospital  
(513) 558-3112

### **Pennsylvania**

Pennsylvania State College of Medicine  
(717) 531-7591

University of Pennsylvania  
(215) 829-8560

University of Pittsburgh  
(412) 692-4916

### **Tennessee**

University of Tennessee Health Sciences  
Center  
(901) 448-1662

### **Texas**

Baylor College of Medicine  
(713) 798-7438  
University of Texas Medical Branch  
(409) 747-4567

### **Virginia**

University of Virginia  
(866) 290-4528

### **Canada**

Hotel-Dieu Hospital-CHUM, Montreal  
(514) 890-8123

University of British Columbia  
(604) 822-7928

University of Calgary  
(403) 210-8548

University of Toronto  
(905) 472-7082 ext.29

### **Australia**

Neurosciences Unit, Perth  
61-8-9347-6464

St. George's Hospital, Melbourne  
61-3-9272-0436

Westmead Hospital, Sydney  
61-2-9845-9139

61-2-9845-6793