

# COHORT – Cooperative Huntington’s Observational Research Trial



## Where

- 42 North American and Australian Huntington Study Group (HSG) sites.

## Purpose of this Study

- To collect information in order to learn more about HD, potential treatments, and plan future research studies of experimental drugs aimed at postponing the onset or slowing the progression of HD.

## Recruitment

- Individuals of any age who have HD, adults, 18 years or older, who have tested positive for the HD gene, or are part of an HD family.
- Older Adolescents (15-17 years of age) who have a parent enrolled in COHORT and who have either HD or who have tested positive for the HD gene.

## Study Visits

- One visit per year (except for older adolescents who will have one visit before the age of consent)

## Clinical Evaluation (Required for Everyone)

- Medical and neurological evaluation (18 years of age or older only)
- Standard assessments of movement, thinking, memory, ability to perform daily activities, and behavior
- Provide medical history and current medications

## Collection of Blood for Genetic Genotyping (Required for all subjects)

- Blood collected at the initial visit
- Blood will be genotyped for the CAG polymorphism and for other genetic changes, which may be important to Huntington’s disease.
- Genotyping is experimental, neither the COHORT participants nor the site investigators will receive the results of this genotyping.

## Collection of Family History Information (Optional for those 18 years of age or older)

- Family history data will be used to learn more about the natural history of the disease over several generations. This information may uncover new details about why there are differences in how HD affects different families and different members within a family.
- Only those with a family history of HD will be asked to participate.
- Questionnaire collects information about the extended family, including:
  - Family members’ names, birthdates, sex, and, if applicable, date of death
  - For any affected family members, age of HD diagnosis and whether a physician made the diagnosis will be collected.

## Collection and Storage of Samples for Future HD Research (Optional all subjects)

- Blood, urine, and other biological samples contain clues about HD that may be used to better understand the progression of the disease and to develop new therapies.
- Blood and urine collected and stored for future HD research.
- Samples will be labeled with a unique identification code and stored in a research facility.
- These stored samples will provide researchers with the resources necessary to study Huntington’s disease.
- Huntington’s disease researchers from institutions all over the world will be able to request samples for research in HD.

For more information contact the HSG at 1-800-487-7671 or [www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org) or visit the Huntington Project web site at [www.huntingtonproject.org](http://www.huntingtonproject.org).

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