Enroll -HD: A Prospective Registry Study in a Global Huntington's Disease Cohort

Status: Recruiting

Eligibility Criteria

Age: 18 years and over

This study is also accepting healthy

Healthy Volunteers: volunteers

Inclusion Criteria:

• Carriers: This group comprises the primary study population and consists of individuals who carry the HD gene expansion mutation.

• Controls: This group comprises the comparator study population and consists of individuals who do not carry the HD expansion mutation. These two major categories can be further subdivided into six different subgroups of eligible individuals:

• Manifest/Motor-manifest HD: Carriers with clinical features that are regarded in the opinion of the investigator as diagnostic of HD.

• Pre-Manifest/-Motor-manifest HD: Carriers without clinical features regarded as diagnostic of HD.

• Genotype Unknown: This group includes a first or second degree relative (i.e., related by blood to a carrier) who has not undergone predictive testing for HD and therefore has an undetermined carrier status.

• Genotype Negative: This group includes a first or second degree relative (i.e., related by blood to a carrier) who has undergone predictive testing for HD and is known not to carry the HD expansion mutation.

• Family Control: Family members or individuals not related by blood to carriers (e.g., spouses, partners, caregivers).

• Community Controls: Individuals unrelated to HD carriers who did not grow up in a family affected by HD. Data collected from community controls will be used for generation of normative data for sub-studies. Participant status will be captured in the study database using 2 variables: 1) Investigator Determined Status: this will be based on clinical signs and symptoms and genotyping performed as part of medical care, and will be updated at every visit; and 2) Research Genotyping Status: this will be based on genotyping conducted as part of Enroll-HD study procedures. Based on research genotyping, participants will be reclassified under this variable from Genotype Unknown to 'Carriers' or 'Controls'. Investigators and participants will be blinded to this reclassification.

Exclusion Criteria:

• Individuals who do not meet inclusion criteria,

• Individuals with choreic movement disorders in the context of a negative test for the HD gene mutation.

• For Community Controls: those individuals with a major central nervous system disorder will be excluded (e.g. stroke, Parkinson's disease, multiple sclerosis, etc.). Participants under 18 may be eligible to participate (if they have juvenile-onset HD).

Conditions & Interventions

Conditions:
Huntington's Disease
Keywords:
Huntington's Disease, Huntington Disease, Juvenile Huntington's Disease, Registry, Cohort, CHDI

More Information

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IRB
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