

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

**Clinical Trial Status:**

This study is currently enrolling individuals who have Huntington's disease, as well as individuals who do not have HD, as well as those that are related to someone with HD, but are unsure if they are carriers of the HD gene expansion mutation

**Clinical Trial Principal Investigator:**

Dr. James Boyd

**Clinical Trial Protocol Description:**

Enroll-HD is an open-ended, prospective study, where participants will be asked to complete as many annual study visits as possible. This will allow researchers to improve on the understanding of the disease spectrum. The information gathered in this study will also promote the development of evidence-based guidelines to improve health care outcomes and to develop beneficial treatments. Another goal of this study is to collect information that will aid investigators in designing clinical trials for HD.

Enroll-HD is being conducted world-wide at 131 sites, such as The University of Vermont. The study aims to recruit all participants willing and able; including approximately one-third of the HD affected population.

Study visits will take place once a year, and may occur at the time of the participant's regular clinical care visit. The initial visit will range from 45 minutes to 2.5 hours, depending on the number of assessments completed, and annual study visits that follow will take less time to complete. During the study visits, participants will have a mixture of motor, functional, behavioral and cognitive assessments.

**Clinical Trial Eligibility Criteria:**

In order to participate you must fall into one of these subgroups:

- Manifest HD: carriers of the HD expansion mutation with clinical features of HD
- Pre-manifest HD: carriers without clinical features of HD
- Genotype unknown: first or second degree relative, related by blood to an HD carrier, who has not undergone genetic testing for HD
- Genotype negative: first or second degree relative, related by blood to an HD carrier, who has undergone genetic testing 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: not related to HD carriers, and did not grow up in a family affected by HD

You will not be eligible to participate if any of the following criteria apply to you:

- Have a choreic movement disorder and a negative test for the HD gene mutation
- For Community controls-those with a major central nervous system disorder will be excluded (e.g. stroke, Parkinson disease, Multiple Sclerosis, etc.)

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Please contact the CRC with any questions