Make a difference
– be part of a worldwide effort
to advance HD research.

For more information contact
your healthcare professional or
visit www.enroll-hd.org

Where can I get more information about Enroll-HD?

Contact your healthcare professional or
visit www.enroll-hd.org

Contact Dr. Neal Hermanowicz
University of California, Irvine
Department of Neurology
949-824-8116

Enroll-HD

Enroll-HD

A worldwide observational study
for Huntington's Disease families

Do you have Huntington's disease? Are you related to someone who does?

Ask your healthcare professional about participating in Enroll-HD, a worldwide observational study for HD family members. We're collecting data from families affected by HD in an effort to improve our understanding and treatment of the disease. There are no potential therapies or invasive procedures in this study.

Why should I participate?

- Be part of a worldwide effort to help find effective treatments for HD. Study participants are from: North America, Latin America, Europe, Asia, Australia, and New Zealand.
- Be in position to learn about upcoming observational and clinical research studies.
- Make a difference – help advance HD research.

Who can participate?

Any member of a family affected by HD can take part. This includes:

- Individuals who know they carry the expanded gene, whether or not they show signs and symptoms of the disease
- Individuals who are at risk of developing the disease (but have not undergone genetic testing)
- Individuals who have a family history of HD but know they do not carry the expanded gene
- Spouses/partners (not blood-related) of family members with HD

Children under the age of 18 with clinically diagnosed juvenile HD may be included in this study with the consent of a parent or legal guardian.

How long will the study last?

Enroll-HD is an open-ended study, which means it has no defined end time, but you can leave at any time you choose. You will attend one study visit each year.

What will happen during study visits?

During each study visit, you will undergo a series of movement and behavioral tests. Functional tests will be given to determine how well you perform tasks on your own. You will also answer questions to help the study team evaluate your emotional state and quality of life. Additionally, if you wish, you can choose to donate a small volume of blood at each visit to help the study team:

- Understand why and when certain symptoms appear
- Identify possible ways to develop new, effective drugs

What safeguards are in place for study participants?

To protect your privacy, your name, address, phone number and other information that identifies you will not be shared with anyone outside of the local study coordinators. To ensure your safety and confidentiality, there are strict regulations governing the conduct of clinical studies, including observational studies. This includes de-identification of the data and samples you may contribute by using a special coding process.

During a process called informed consent, you will receive all the facts regarding study participation prior to enrollment. If you decide to participate, you will sign an informed consent document. This document is not binding and you can leave the study at any time, for any reason at all. You may be asked to undergo a final safety assessment before leaving the study.

We encourage you to talk with your family before participating in this, or any other, study. You may want family members to accompany you to study visits or provide other assistance during your participation. Getting their support in advance may be essential.

Where can I get more information about Enroll-HD?

Contact your healthcare professional or visit www.enroll-hd.org