



A worldwide observational study  
for **Huntington's Disease** families

Your previous participation in a Huntington's disease observational study to collect clinical data and biological samples is greatly appreciated. Your efforts have helped advance research that aims to improve our understanding and treatment of HD, including the development of drugs that can slow disease progression.

We now invite you to continue what you started by joining Enroll-HD, a worldwide observational study for HD family members. Families from the following regions/countries are participating:



**Make a Difference Around the World**

**For More Information**

Contact your healthcare professional or visit [www.enroll-hd.org](http://www.enroll-hd.org)  
Contact Dr. Neal Hermanowicz

University of California, Irvine  
Department of Neurology 949-824-8116

## How to Participate

- Notify your study site of your interest in Enroll-HD
- Give consent to participate

## Study Duration

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.

## Study Procedures

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 evaluate your emotional state and quality of life. If you wish you can choose to donate a small volume of blood at each visit to help doctors:

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

Enroll-HD is not a clinical trial, and potential therapies are not being tested. However, you can learn about upcoming clinical research studies that you might be interested in.

## Patient Confidentiality

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.



## Motivation for Staying the Course

**When you think about reasons to participate in Enroll-HD, consider the following:**

- You are part of a worldwide effort to help find effective treatments for HD.
- You have the attention and support of the Enroll-HD Team.
- You are not alone.
- You will be able to find out more about HD and the potential of new treatment approaches.

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