HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Observational Studies in HD

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HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org

There is a continued investment into understanding Huntington's Disease, whether investigating biomarkers, disease progression or personal experiences. It's important for the HD community to understand how they can get involved in research initiatives globally and become empowered to share their voices to make change happen. This page summarizes some of the observational studies currently underway that pertain to the young people that HDYO serves. For a look at clinical trials, click here.

What is an Observational Study?

These studies collect information, or look at information that was already collected, about a population (e.g. people with HD), which can be in the form of surveys, questionnaires, and tasks. Observational studies can help us learn about the natural progression of HD as well as help discover new ways to measure HD, such as via new biomarkers, which can then be used in a clinical trial. These studies often include healthy controls (people who do not have the disease) to be able to measure things that might be different in populations with the disease compared to the people without the disease. Observational studies do not involve testing an intervention, such as a new drug.

Participating in observational studies can be a good first step to understanding if you would be comfortable participating in a clinical trial in the future.

Different Types of Observational Studies:

- **Surveys** - The collection of information from a sample of individuals through their responses to questions.
- **Registries** - A database that collects information about people with a specific condition or disease. Researchers can use registry data for observational studies to answer important health questions.
- **Natural History Studies** - A study that documents a specific disease's natural progression over time, without testing an intervention

These studies can be held in clinic, virtually or a combination of both.

To review other helpful research definitions, explore the HDYO Research Terminology.

In-Clinic Studies

Enroll-HD

- **Who is overseeing this study?** The CHDI Foundation
- **What's its current status?** Active and recruiting.
- **Where can people participate?** Argentina, Australia, Austria, Belgium, Canada, Chile, Colombia, Czech Republic, Denmark, France, Germany, Ireland, Italy, Netherlands, New Zealand, Poland, Portugal, Russia, Spain, Switzerland, United Kingdom, United States.
- **Who's potentially eligible?** Anyone from a HD family, aged 18+, and children under 18 with a diagnosis of juvenile HD.

- **What are they investigating?** Enroll-HD was launched in 2012 and has over 20,000 active participants. The goals of Enroll-HD include to better understand HD, to improve the design of clinical trials and to improve clinical care for HD patients. Participants visit their local study site annually to undergo assessments and give biospecimens.

Find Out More

CHANGE HD

- **Who is overseeing this study?** The University of Iowa
- **What's its current status?** Active and recruiting.
- **Where can people participate?** United States.
- **Who's potentially eligible?** Young people aged 6 to 30 who are at risk for HD.
- **What are they investigating?** CHANGE HD is a brain imaging study which will help explain how the gene responsible for HD affects brain development, and hopefully find a way to identify the best time for gene therapy during development.

Find Out More

Epidemiologic Study of SNPs

- **Who is overseeing this study?** Hoffmann-La Roche
- **What's its current status?** Active and recruiting
- **Where can people participate?** US, Canada, Argentina, Europe, And Australia/NewZealand.
- **Who's potentially eligible?** Adults ages 25-60 who are confirmed HD carriers
- **What are they investigating?** This study aims to understand the frequency of different SNPs among individuals who are HD gene carriers.

Find Out More

HDClarity

- **Who is overseeing this study?** University College London and the CHDI Foundation
- **What's its current status?** Active and recruiting.
- **Where can people participate?** Canada, Germany, Italy, Poland, Spain, United Kingdom, United States.
- **Who's potentially eligible?** Adults aged from 21 to 75, who fall under one of the following categories: healthy control, early pre-manifest, late pre-manifest, early manifest, moderate manifest, late manifest.
- **What are they investigating?** HDClarity is a study designed to collect cerebrospinal fluid, the fluid that surrounds the brain and spinal cord. The samples and information collected will be used to study HD, including identifying and evaluating biomarkers, which may help researchers better understand the disease. In the future, these

biomarkers could be used to help design clinical trials of new treatments.

Find Out More

HD-YAS 2.0

- **Who is overseeing this study?** University College London Huntington's Disease Centre
- **What's its current status?** Active
- **Where can people participate?** UK
- **Who's potentially eligible?** Adults between the ages of 18 and 40 years old who are at-risk and premanifest (show no clinical symptoms of HD), including those who carry the HD gene or those who do not
- **What are they investigating?** The purpose of HD-YAS 2.0 is to determine whether there is any change over time in adults ages of 18-40 years old who are premanifest (show no clinical symptoms of HD) at enrollment in the study. The 131 participants who took part in HD-YAS 1.0 are being invited back to undergo similar assessments so we can look at what has changed. In addition, new participants are also being included to account for participants from the first study who may not want to participate again. This will help us to guide the use of any potential future treatments, so that they can be given at the earliest and most effective time in order to prevent or treat HD disease progression.

Find Out More

Kids-JHD

- **Who is overseeing this study?** The University of Iowa
- **What's its current status?** Active and recruiting.
- **Where can people participate?** United States.
- **Who's potentially eligible?** Young people aged 4 to 30 years old with a diagnosis of JoHD.
- **What are they investigating?** This study is trying to identify and measure common symptoms and developmental patterns that might be happening in JoHD.

Find Out More

PREVENT-HD

- **Who is overseeing this study?** University of Wisconsin, Madison
- **What's its current status?** Active and recruiting.
- **Where can people participate?** United States.
- **Who's potentially eligible?** Adults from HD families who carry or do not carry the HD gene, people who have recently been diagnosed with HD and are in the very early stages of the disease, and people who are gene-positive, but are not currently

showing any symptoms.

- **What are they investigating?** This study aims to build a case for testing treatments much earlier in people at risk for HD. Starting treatment sooner may help delay the start of symptoms or slow down the progression of the disease. This study wants to plan for future clinical trials by finding and tracking subtle but measurable changes in behavior, cognition, and emotional responses that occur before the more visible HD symptoms appear.

Find Out More

Surveys

HDYO Survey Series

- **Who is overseeing this study?** Huntington's Disease Youth Organization and Monash University
- **What's its current status?** Active.
- **Where can people participate?** International
- **Who's potentially eligible?** HD community members at least 18 years and older.
- **What are they investigating?** HDYO is hosting a series of surveys to better understand behavior, stigmas, awareness and education around several areas of individuals impacted by Huntington's disease.

Find Out More

FOCUS Online

- **Who is overseeing this study?** The CHDI Foundation
- **What's its current status?** Active
- **Where can people participate?** International
- **Who's potentially eligible?** Individuals who are gene positive for HD, 18 or older, and can speak English
- **What are they investigating?** The purpose of the study is to determine whether the FuRST 2.0 Scale can reliably and accurately capture information about the functional abilities of people with HD.

Find Out More

MEND-HD

- **Who is overseeing this study?** FDA and University of Rochester
- **What's its current status?** Active and recruiting
- **Where can people participate?** International
- **Who's potentially eligible?** Adults ages 25-65 who have genetically confirmed HD in early or middle stages

- **What are they investigating?** This study aims to validate digital measures of gait (e.g., how a person walks) and chorea (e.g., the involuntary, dance-like movement often seen in HD) using wearable sensors to see if they can be used as clinical trial endpoints in people with HD. Participants will take part in 4 virtual visit and need to wear activity monitors for 2 weeks as they go about everyday activities.

Find Out More

To what extent can an AI Character offer peer support, motivation, self-efficacy and knowledge transfer for Preventive Neurology

- **Who is overseeing this study?** Experience & Empathy Lab [fEEL] and The Big Anxiety Research Centre at the University of New South Wales (UNSW) in Australia
- **What's its current status?** Active
- **Where can people participate?** International
- **Who's potentially eligible?** Adults aged 18-50, part of the Huntington's Disease community, interested in brain health, ability to speak English
- **What are they investigating?** This study will explore the potential of AI technology to enhance brain health. More specifically, they will explore to what extent an AI character (developed from lived experience) can provide peer support, enhance self-efficacy and motivation, and facilitate knowledge exchange for individuals who may be ambivalent, unaware, or unmotivated to engage with Preventive Neurology (brain health optimization).

Find Out More

Registries

JOIN-HD

- **Who is overseeing this study?** Huntington's Disease Youth Organization
- **What's its current status?** Active and recruiting.
- **Where can people participate?** Worldwide.
- **Who's potentially eligible?** People with symptoms consistent with JoHD, caregivers of someone with symptoms of JoHD and previous caregivers of someone who had JoHD.
- **What are they investigating?** JOIN-HD is an international registry where participants self-enroll and answer questionnaires online. The project aims to create a global community of families impacted by JoHD, to increase knowledge of this disease, and to facilitate future research.

Find Out More

HD-JUNIOR

- **Who is overseeing this study?** Leiden University Medical Center
- **What's its current status?** Active and recruiting.
- **Where can people participate?** The Netherlands.
- **Who's potentially eligible?** People in the Netherlands who developed HD symptoms before the age of 21.
- **What are they investigating?** HD-JUNIOR is a national registry for patients with JoHD. They will collect medical information from participants' doctors and contact information so they can get in touch about future research opportunities. There is also an optional questionnaire that the participant or caretaker can fill in.

Find Out More

LEAD-HD

- **Who is overseeing this study?** The Huntington Study Group
- **What's its current status?** Active and recruiting.
- **Where can people participate?** United States
- **Who's potentially eligible?** English-speaking adults age 18 years and older who can self-report they have been diagnosed with HD by a doctor, can currently take care of some of his or her personal needs, and have access to digital devices.
- **What are they investigating?** The goals of LEAD-HD are to obtain natural history data in HD, identify demographic characteristics that are associated with faster or slower disease progression, and determine and optimize the responsiveness and participant preferences of the Huntington's Disease Health Index.

Find Out More

MyHD Story

- **Who is overseeing this study?** The Huntington Study Group
- **What's its current status?** Active and recruiting.
- **Where can people participate?** United States with hopes of including international after pilot study is complete.
- **Who's potentially eligible?** English-speaking adults age 18 years and older who can self-report they have been diagnosed with HD by a doctor, can currently take care of some of his or her personal needs, and have access to digital devices.
- **What are they investigating?** This study will help to understand how Huntington disease (HD) affects patients, care partners, and those at genetic risk for HD.

Find Out More