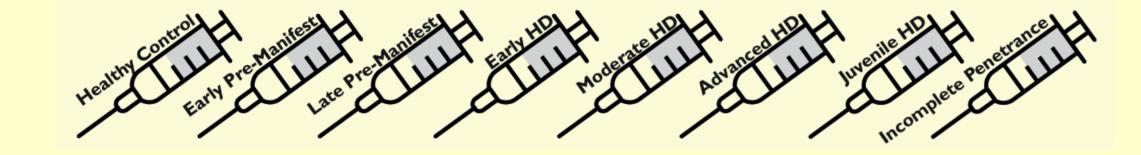


## What is The Aim of HDClarity?

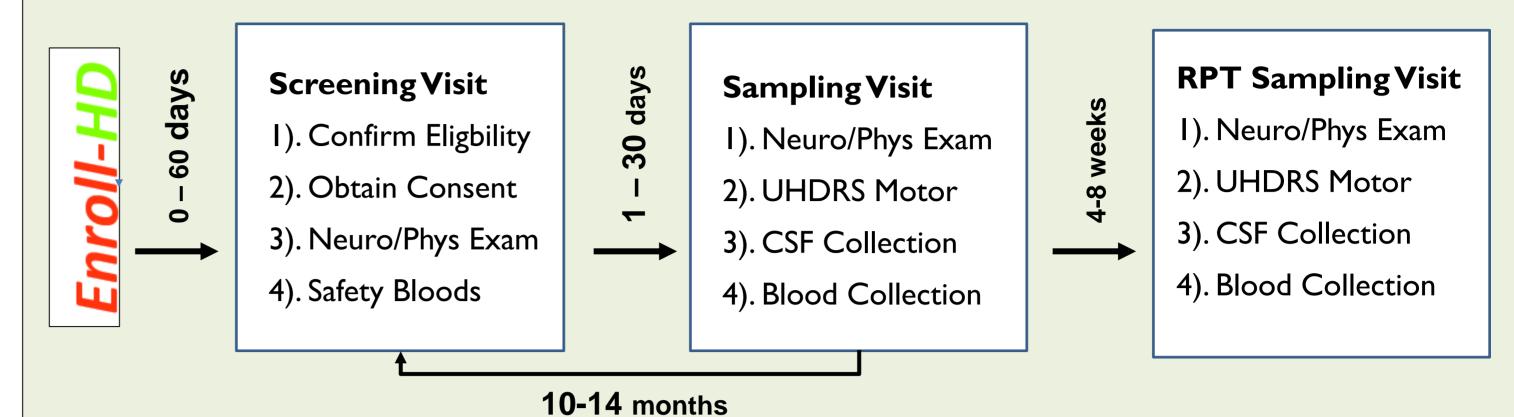
# **TO ADVANCE HD RESEARCH**

**COLLECT:** We are building a collection of high-quality cerebrospinal fluid (CSF), plasma and serum samples across 8 study groups for evaluation of biomarkers and pathways that will enable the development of novel treatments for Huntington's disease (HD):



#### What Does HDClarity Participation Involve?

Participants attend annually and take part in two visits (Screening and Sampling) within a 30-day window. Some may attend an optional Repeat Sampling visit 4-8 weeks later:



CSF is an ideal fluid compartment for assessing HD biomarkers, particularly pharmacodynamic markers, due to its proximity to the brain. High quality plasma and serum samples are also collected matching the CSF collections, which will be used to evaluate biomarkers and pathways of relevance to HD research.

HDClarity samples are processed, logged and deposited for long-term storage at BioRep s.r.l. For more information, please see HDClarity website at https://hdclarity.net

**DISTRIBUTE:** Samples can be requested by investigators around the world, allowing them to conduct groundbreaking research to identify new biomarkers and develop treatments for HD.

To request HDClarity samples for your research please see information at: https://enroll-hd.org/for-researchers/ access-data-biosamples

#### **How Safe Is HDClarity Participation?**

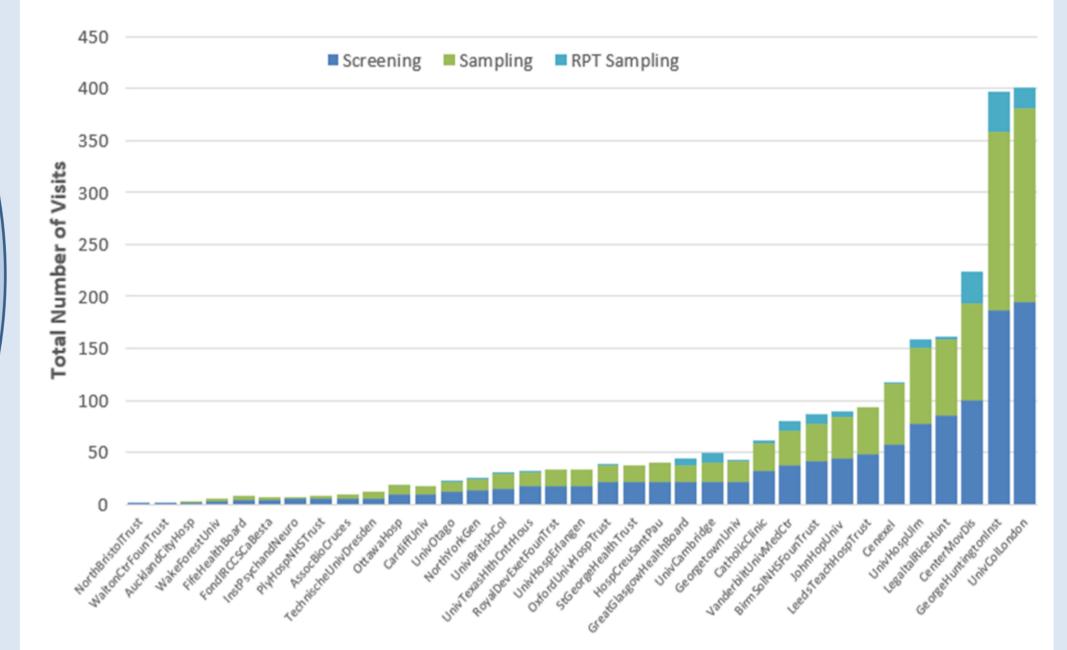
Very safe! A recent study found that after nearly 600 spinal taps, the most common side effect is a mild or moderate headache, which soon gets better. Only one severe adverse event was reported, corresponding to **0.17%** of the total number of sampling visits.

In total, we hope to enroll **2500** individuals.

#### How Many HDClarity Visits Have Been Conducted So Far?

In total, we have completed **1179** Screening visits, **1071** Sampling visits and **150** Optional Repeat Sampling visits.

> Total HDClarity Visits per Site Baseline and Longitudinal Visits Included

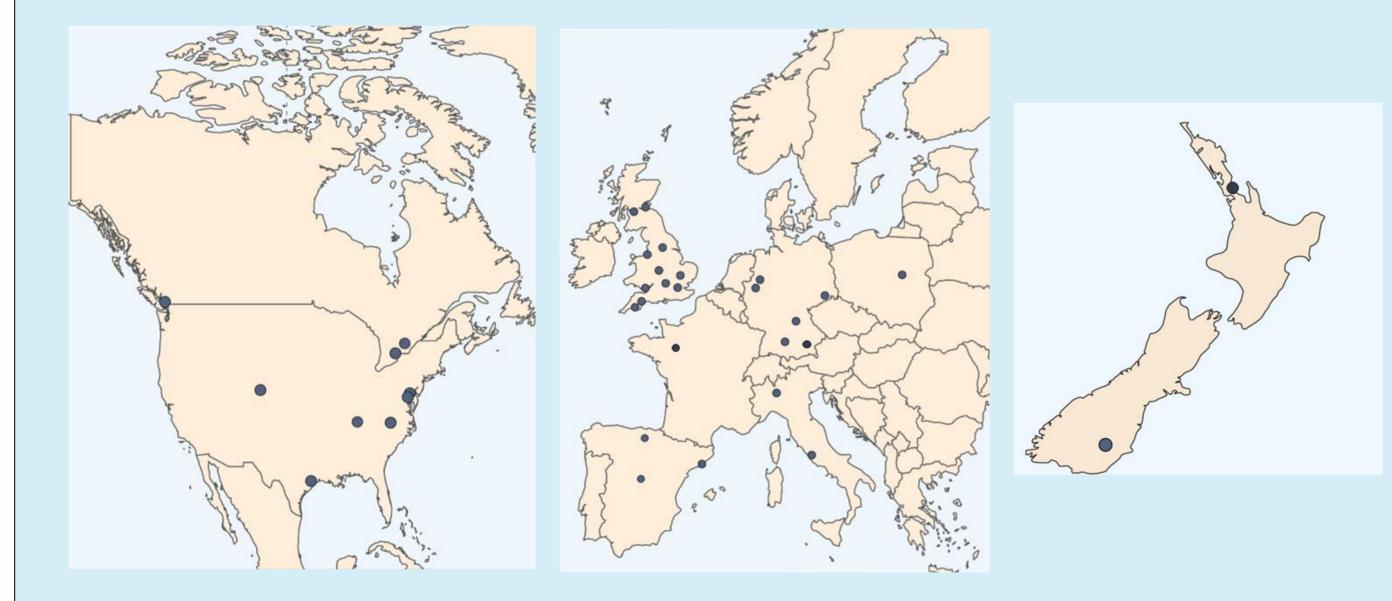


14 May 2024

**Clinical Site** 

### Where Are HDClarity Sites Located?

HDClarity has continued to expand and is now active in 36 clinical sites, across 9 nations worldwide.



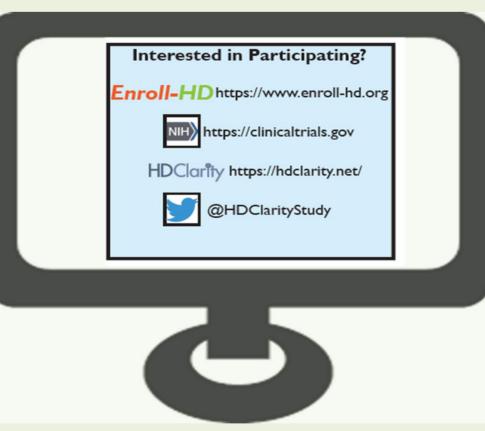
We are actively working to commence the study at more sites across Australasia, Europe, North and South America.

# How Can I Get Involved In HDClarity?

**Sites** – if you would like to join as a study site, please contact HDClarity Central Coordination (HDClarity-CC@enroll-hd.org).

**Participants** – you must already be participating in Enroll-HD and can speak to your site staff.

For more detailed HDClarity information, search for the study on the NIH clinical trials website.View our dedicated study homepage and follow us on twitter for regular study updates!



We would like to thank all the clinical sites and most importantly, the HD community, whose dedication and perseverance is vital to the success of HDClarity.

### How are HDClarity Samples Being Used in Research?

HDClarity

A multi-site cerebrospinal fluid

collection initiative

to facilitate therapeutic development

for Huntington's disease

Publicly available biomarker datasets derived from HDClarity samples

- CSF biomarker assay results, N=220. Neurofilament light, haemoglobin, total protein, mutant huntingtin, total huntingtin
- Somalogic proteomic data, N=579. Over 7,600 protein analytes in CSF and plasma

#### Selected publications and presentations using HDClarity data

- Pfalzer et al. "Alterations in metal homeostasis occur prior to canonical markers in Huntington disease." Scientific Reports 12.1 (2022): 10373.
- Rodrigues et al. "Safety and feasibility of research lumbar puncture in Huntington's disease: The HDClarity cohort and bioresource." Journal of Huntington's Disease 11.1 (2022): 59-69.
- Hassan et al. "Lumbar puncture safety and tolerability in premanifest and manifest Huntington's disease: a multi-analysis cross-sectional study." Scientific Reports 12.1 (2022): 18377.
- Niels Skotte. "Biofluid biomarker discovery in HD Current possibilities and limitations" HD Therapeutics Conference 2023
- William Griffiths. "Cholesterol and oxysterols as biomarkers for Huntington's disease?" HD Therapeutics Conference 2023
- Natallia Kalinava. "Optimizing assays for accurate reliable measurement of NfL and clinical validation of the measurements" HD Therapeutics Conference 2023
- Jim Rosinsky. "Multi-omic profiling of people with Huntington's disease (PwHD) for biomarker discovery: The future is bright!" HD Therapeutics Conference 2022

Chief Investigator: Professor Edward Wild, MD PhD CHDI Clinical Research Program Manager and Study Lead: Elena Pak CHDI Clinical Wet Biomarkers Unit Lead: Hilary Wilkinson, PhD CHDI Chief Medical Officer: Cristina Sampaio, MD PhD

HDClarity is sponsored by University College London, coordinated by UCL Huntington's Disease Centre and funded by CHDI Foundation, Inc.

Study Website: https://HDClarity.net Clinical Study Homepage: https://clinicaltrials.gov Twitter Handle: @HDClarityStudy

