

HDClarity

NEWSLETTER

STUDY UPDATE

It was a record year for HDClarity in 2025 thanks to our amazing participants and site teams. On average, there were 35 successful sampling visits per month and an amazing 420 in total.

Over 1,200 participants from around the world have now taken part in HDClarity and many have given samples annually providing invaluable longitudinal information. Around 30% of participants have completed at least 2 annual visits and over 100 individuals have completed 3 or more. The record currently stands at 6 CSF collections!

HDCLARITY INVESTIGATOR MEETING

An HDClarity IM was held for active sites in North America and New Zealand during the HD Clinical Research Congress in October 2025. Cristina Sampaio, the CHDI Chief Medical Officer opened the meeting and also welcomed teams from potential new sites in the USA and Australia.

Chief Investigator, Professor Ed Wild, was joined by site PIs from UTHealth Houston, Johns Hopkins University, Georgetown University and Ottawa Hospital for a panel discussion. They provided expert advice to new sites on study start-up, sample collection, recruitment and retention.



The CHDI Medical VP, Swati Sathe, gave an update on some ICF issues specific to North American sites and the meeting concluded with scientific presentations describing uses of HDClarity samples, including insights from Doug Langbehn, University of Iowa, on combining HDClarity data into a statistical HD model.

Presentations from the meeting are now available on the HDClarity.net website.

PARTICIPANT ALLOWANCES

During the IM, HDClarity Central Coordination provided the following clarifications on payment of participant allowances:

- Travel distance should be calculated as a round-trip from the participant's home (or starting point) to the study site, e.g., if a participant lives 25 miles from the study site, they should be reimbursed for 50 miles of travel.
- In the event a participant has an HDClarity Screening/Rescreening Visit on the same day as a study visit for any other CHDI-funded study (e.g. Enroll-HD), the travel allowance is paid from HDClarity "Travel and Stipend" fund.
- If a participant stays overnight between Screening and Sampling Visits, it counts as a single return trip, and the participant should receive the sampling visit travel allowance as it is highest.
- Sites may request additional travel, meal and lodging allowances, in exceptional cases, but requests must be sent to HDClarity Central Coordination before the visit takes place.
- Flights or other long-distance travel to the site are permitted only if the PI determines it is in the participant's best interest. A procedure must be in place to manage potential adverse events. Please note, however, that the full costs may not be covered.

CHANGES TO SAMPLE PROCESSING

All sites have been sent an invitation to attend a short training meeting describing some minor changes to sample processing.

Sample volume is not changing, but in future serum samples will be divided into smaller tubes to allow for wider distribution. Currently the serum sample is transferred into 2 x 2mL cryovials, but these are being replaced by 15 x 0.5mL tubes. The clear cap tops will be exchanged for white tops and there will also be an additional matrix rack for shipment.



Because of the additional space required for the new matrix rack, shipments will take place when you have collected four participant samples sets.

A new lab manual has been sent to all sites including these changes and a few other minor updates and clarifications. Please ensure that your site switches to **Lab Manual Version 6.8** when your training is complete and you have received the new kits items.

Please remember....

■ New staff

If you have new staff joining your team, please inform HDClarity Central Coordination as soon as possible. New staff should not start working on the study until the updated delegation and training logs have been provided and Central Coordination have advised on required training.

■ Serum processing

Please remember that it is essential to allow samples to clot for at least 30 minutes before centrifugation to maximise serum yield.

■ Fewer Than 5 Kits Needed?

Please contact HDClarity central coordination rather than placing a kit order in the EDC.

■ Data entry

Please be sure to answer any queries on the EDC at your earliest convenience. This means that your site payments can be processed more quickly!

HDCLARITY SAMPLE USES

HDClarity samples have been provided for 40 projects and below are some selected publications and presentations using HDClarity samples:

- Perez-Perez J et al. "Neurofilament Light Chain and Mutant Huntingtin across HD-ISS in Huntington's Disease: A Cross-Sectional Analysis" Preprints with The Lancet
- Asgari AM et al. "24S-Hydroxycholesterol: A potential brain-derived biomarker of Huntington's Disease." medRxiv (preprint)
- Jim Rosinski "Nanoparticle-based proteomics by mass spectrometry in plasma samples from Huntington's disease cohort." HDTc 2025
- Edith Monteagudo "Exploratory analysis of PENK as an early marker of HD onset and progression." HDTc 2025
- Khetarpal V et al. "Lack of Evidence for Kynurenine Pathway Dysfunction in Huntington's Disease: CSF and Plasma Analyses from the HDClarity Study." J Huntingtons Dis. 2024 Dec

MORE INFORMATION

Further information about HDClarity, is available at www.hdclarity.net and www.clinicaltrials.gov. You can also follow for regular updates on https://bsky.app/profile/did:plc:uo6t3jw5l_cg7haaxbqymf7n.

The central coordination team are always happy to answer any questions (hdclarity-cc@enroll-hd.org).