

HDClarity

NEWSLETTER

KEY UPDATES

Thanks to the amazing support of the HDClarity sites and participants, the study and sample repository continues to grow. We're very happy to share the following achievements:

- 34 clinical sites open worldwide
- Over 200 Sampling Visits in 2023
- 47,000 CSF aliquots available

SITE UPDATES

The George Huntington Institute in Germany, which has been active in the study since 2018, is leading the way with the overall highest participant enrolment. Other sites such as Cenexel Rocky Mountain Clinical Research, USA, University Hospital of Ulm, Germany and the LIRH Foundation, Rome have also recruited 50 or more participants. Congratulations also to the LIRH Foundation for the opening of their new research facility that is now enabling them to perform study visits at two locations.



RECRUITMENT UPDATES

Most active sites have now successfully transitioned to longitudinal recruitment under HDClarity Protocol V4 (CLR4). UK sites, the first to transition to V4, are busy with Y1 visits and the first Y2 visits are expected this year.

HDClarity Protocol V2/V3

- 998 Screening Visits
- 891 Sampling Visits
- 120 Optional Repeat Sampling Visits

HDClarity Protocol V4

- 160 Screening Visits
- 152 Sampling Visits
- 23 Optional Repeat Sampling Visits

HDCLARITY INVESTIGATOR MEETING

Looking forward to 2024, we are pleased to announce that there will be an HDClarity investigator meeting taking place in September during the combined EHDN Plenary Meeting and Enroll-HD Congress in Strasbourg. We have previously held smaller meetings for groups of investigators, but this will be the first time that HDClarity teams from around the world will meet. It will be a great opportunity to share your experiences of the study, pass on useful tips to other sites and get any study-related questions answered. We'll confirm the date and provide more detailed information nearer the time.

What to do if...

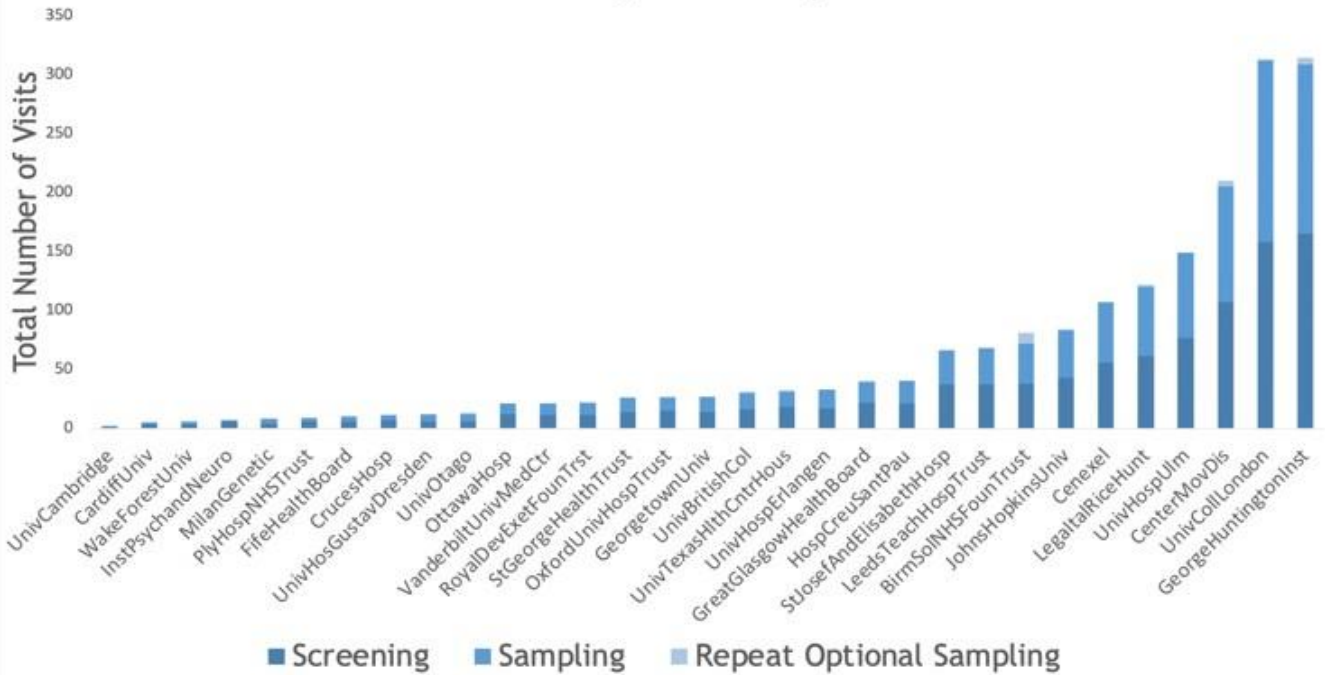
- **You require fewer than 5 new kits?**
Please contact HDClarity central coordination rather than placing a kit order in the EDC.
- **You experience processing delays?**
Please leave a comment on the EDC.
- **You experience storage delays?**
Store samples on dry ice AND add a comment to the EDC.

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!

CURRENT RESEARCH USING HDCLARITY SAMPLES

- 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

Total HDClarity 2/3 Visits per Site



Total HDClarity 4 Visits Per Site
Baseline and Longitudinal Visits Included

