HD Research Data Access

What data do you need?
Longitudinal data? Cross sectional data from multiple studies?
Ask us – we will help you!

Data managers: Enroll-HD, HDClarity: Mette Gilling Nielsen, mette.gilling@enroll-hd.org; Other CHDI studies: Darren Freeman, darren.freeman@chdifoundation.org

Study | Summary | Duration | # participants | Participant segment | Clinical data | Family history | Imaging data | Brain biomarkers & genomic data | GWAS | RNA-seq | Other | File format | Data Access
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Enroll-HD | Prospective, open-ended, multi-national, multi-center observational study without experimental treatments. | 2012-2017 | 23,000 | Manifest HD | Yes | No | No | Some | No | MSeq | CSIC, R | Methylation | CSV, TSV | How to access: www.enroll-hd.org
REGISTRY | Prospective, open-ended, European, multi-center observational study without experimental treatments. | 2004-2017 | 13,000 | Manifest HD | Yes | Partly | No | No | Some | No | MSeq | CSIC, R | How to access: Submit application to EHDN’s Scientific Advisory Board (SAB), www.ehdn.org
HDCSF/ HDClarity | Study to collect high quality CSF samples for evaluation of biomarkers and pathways that will enable the development of novel treatments for HD. Enroll-HD platform study. | 2017-present | 000 | Early Manifest HD | Yes | Yes | No | No | Some | No | CSIC, R | How to access: CHDI data use agreement
TRACK-HD | Multi-site international study aiming to establish what measurements were the best to use as ‘outcome measures’ for clinical trials in HD. | 2008-2011 | 402 | Early Manifest HD | Yes | No | No | 300 MR, 237 DRI | Yes | Yes | No | NIF | CSV, DCM | How to access: CHDI data use agreement
TRACK-ON | Extension of TRACK-HD | 2012-2014 | 245 | Early Manifest HD | Yes | No | 242 MR, 241 MRI, 239 MRI | Yes | Yes | No | CSV, DCM | How to access: CHDI data use agreement
COHORT | Observational study designed to collect phenotypic data and samples from people with HD and their family members. North America and Australia. | 2006-2011 | 2,318 | Manifest HD | Yes | No | No | No | No | R | CSIC, R | How to access: Contact Huntington Study Group, www.huntingtonstudysgroup.org
PREDICT | Purpose was to study early brain and behavioral changes in premanifest HD gene expansion carriers. | 2006-2016 | 1,481 | Pre-manifest HD | Yes | No | 3,779 MR, 103 MRI | Yes | No | No | CSV, NIF | How to access: CHDI data use agreement
iImage-HD | Multi-modal longitudinal MRI study in premanifest and early manifest HD patients. | 2006-2012 | 1831 | Pre-manifest HD | Partly | No | 83 MRI, 77 MRI, 63 DTI, 83 DTI | Yes | No | No | CSV, NIF | How to access: CHDI data use agreement
CARE-HD | Co-Enzyme Q10 (CoQ) And Remacemide ERTication in HD. | 1997-2002 | 347 | Early HD | Yes | No | No | No | No | SAS | How to access: CHDI data use agreement
2CARE | Coenzyme C10 (CoQ) In Huntington Disease. | 2005-2014 | 609 | Clinical features or confomatory family history of HD OR CAG >= 36 | Yes | No | No | No | No | RAS, XLAS | How to access: CHDI data use agreement
Morphometric/ Volumetric Neuroimaging | Automated pipeline using the long FreeSurfer analysis method with manual review. | 2017-2018 | 449 | Early Manifest HD | No | No | No | No | No | TSV | How to access: CHDI data use agreement
MTM-HD | Multi Tissue Monitoring. Improved insight into disease-specific pathways/ network alterations: Analysis of tissue samples from participating individuals will help to identify HD-related signatures. | 2015-2017 | 60 | Premanifest | No | No | No | Planned | Yes | Proteomics | CV, CTA, mRNAseq | How to access: CHDI data use agreement

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