Enroll-HD is a worldwide clinical research platform and observational study for Huntington’s disease that has three main goals:

- To improve the design of clinical trials to rapidly provide clear outcomes - better, smarter, faster clinical trials will identify effective treatments as quickly as possible
- To better understand HD as it happens in people to give insight into developing new drugs
- To improve clinical care for HD patients by identifying the best clinical practices across all Enroll-HD sites around the world and ensure that all families receive that standard of care

In support of these goals, Enroll-HD is helping coordinate and expedite experimental medicine studies and the development of biomarkers and clinical assessment tools for HD.

April 2018 Quarterly News Bulletin

Dear Enroll-HD Investigators and Site Staff,

Here are the monthly updates:

Enroll-HD Global Congress
- Registration for the Enroll Congress in Quebec City from May 20-23, 2018 will close on April [ ]. Please contact Roohee Peerzada (Roohee.peerzada@chdifoundation.org) to confirm your attendance and register as soon as possible.

Recruitment update
- As of April 1st there are a total of 15,201 active participants enrolled at 153 active sites in 16 countries around the world.

Regional startup and enrollment updates

EUROPE:
- 9,090 active participants have been enrolled at 89 active sites in Denmark, France, Germany, Ireland, Italy, The Netherlands, Poland, Spain, Switzerland, and the UK.
- 36 additional European sites that will participate in Enroll-HD are in start-up.

NORTH AMERICA:
- 5,031 active participants have been enrolled at 58 active sites in the US and Canada.
- An additional 7 sites are in start-up.

AUSTRALASIA:
- 570 active participants have been enrolled at 5 active sites in Australia and New Zealand.
- 2 additional sites have are in start-up.

LATIN AMERICA:
- 178 active participants have been enrolled at 2 active sites in Argentina and Chile.
- 5 sites in Argentina, Colombia and Peru are in start-up.

Latest Enroll-HD data release and website update
As of December 15 2016, the third Enroll-HD periodic dataset that includes the recoded clinical data from 8,714 participants, including 3,598 participants from the European REGISTRY study, is now available on the Enroll-HD website to any researcher employed at a recognized research institution or company. You can learn more about the types of data and biosamples that are available and the simple and straightforward process to access the Enroll-HD dataset and biosamples at https://www.enroll-hd.org/for-researchers/access-data/. If you’re a principal investigator at an Enroll-HD clinical site then your login details for the EDC system will also allow you to access the periodic datasets.

You can also find on the Enroll-HD website lots of information about how the study is structured and the people who keep it running, from site staff to participants to clinicians to researchers. Please share the link with your colleagues and your participants and check back often for new articles, updates and announcements. https://www.enroll-hd.org

Please also check that the information listed on the website for your site is current and correct; please email any corrections to your site manager or language coordinator.

Top Enrolling Sites - Since Study Start (Active Participants)

George Huntington Institute (Muenster, Germany) - 633 active participants
ST. Josef und St. Elisabeth Hospital (Bochum, Germany)
Legende Risicousalz Berlin (Berlin, Germany)
Hereditary Neurological Disease Center (Wichita, Kansas, USA)
Leiden University (The Netherlands)
Institute of Psychiatry and Neurology (Warsaw, Poland)
University Hospital ULM (Germany)
CHUM Hospital Notre Dame (Montreal, Quebec, Canada)
The University of California, San Diego (USA)
Central Manchester University Hospitals (UK)
Columbia University (New York City, USA)
University College London (UK)
Jiménez Díaz Foundation (Madrid, Spain)
University Hospital Copenhagen (Denmark)
Monash University (Melbourne, Australia)
Hospital Infantil de Barcelona (Barcelona, Spain)
Rocky Mountain Movement Disorder Center (Englewood, Colorado, USA)
The University of California, Los Angeles (USA)
Vanderbilt University (Nashville, Tennessee, USA)
The Centre for Movement Disorders (Markham, Ontario, Canada)
Ramón y Cajal University Hospital (Madrid, Spain)
The University of Iowa (Iowa City, Iowa, USA)
Cardiff & Vale University (Cardiff, UK)
University of Berlin (Berlin, Germany)
Isar-Amper Hospital (Traunstein, Germany)
Milan Genetic - Fondazione IRCCS Ilo Carlo Besta (Milan, Italy)
North York General Hospital (Toronto, Ontario, Canada)
The University of Tennessee (Memphis, Tennessee, USA)
University of Naples "Federico II" (Italy)
Georgetown University (Washington, DC, USA)

The top enrolling site is George Huntington Institute (Muenster, Germany) with 633 active participants enrolled!
This graph shows the number of participants per month who have returned to their clinic for their annual follow-up visit.
Thank you for your support in helping Enroll-HD achieve its goals.

The Enroll-HD Study Team