



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.

May 2019 News Bulletin

Dear Enroll-HD Investigators and Site Staff,

With this first bulletin of 2019, we would like to express our appreciation of your continued commitment and dedication to the Enroll-HD platform. We would like to reiterate the Enroll-HD recruitment strategy of focusing on the recruitment of **at risk, premanifest and early stage participants**. Some metrics on the recruitment strategy are provided in this news bulletin.

Here are the study updates:

EDC 1.10 release

- In February 2019, the EDC 1.10 version was released and was made available to all Enroll-HD sites globally. With the new version, not only the look changed, some functionalities were also updated and changed to support data-entry, monitoring and reporting. Release notes and other relevant details have been shared with you as site staff and are available on the Enroll-HD EDC webpage for reference. Please reach out to your assigned Lanco/Site Manager for further clarification.

Enroll-HD Newsletter

- Enroll-HD Newsletter will be published in Summer 2019. It will introduce you to some of the people including research participants that make this study a success. The newsletter aims at bringing updates to the wider HD community regarding the study's progress and explore the practical aspects of how the study is put together and what keeps it running smoothly.

Site Metrics Card

- Site Metrics Cards are focusing on strategic metrics such as recruitment of premanifest and early stage participants, as well as key metrics on data quality and study compliance. They give each site the overview between their current and previous status of recruitment. They were first issued at the Enroll-HD Congress in May 2018 and will be distributed twice a year each May and November.

PDS4 released

- **Enroll-HD Periodic Data Set (PDS4) was released on December 14, 2018.** The date of the data cut was October 31, 2018. The PDS includes data of 15,301 participants, including 3802 of the European REGISTRY study.

Longitudinal data from PDS4 data included participants with up to 20 study visits and 7 Enroll-HD study visits. As of April 1st, 2019, number of PDS4 downloads is around 60. To request access to the PDS go to: <https://www.enroll-hd.org/for-researchers/access-data-and-biosamples-login/> If you are a principal investigator at an Enroll-HD clinical site, then your login details for the EDC system will also allow you to access the application for the periodic datasets.

Recruitment update

- As of **April 1st**, there are 18,296 active **participants** enrolled at **163 sites** in **19 countries** around the world.

Regional startup and enrollment updates

EUROPE:

- 11,225 active participants have been enrolled at 92 active sites in Belgium, Denmark, France, Germany, Ireland, Italy, The Netherlands, Poland, Spain, Switzerland, Portugal, Austria and the UK.
- 20 additional European sites that will participate in Enroll-HD are in start-up.

NORTH AMERICA:

- 6,149 active participants have been enrolled at 61 active sites in the US and Canada.
- An additional 3 sites are in start-up.

AUSTRALASIA:

- 687 active participants have been enrolled at 6 active sites in Australia and New Zealand.
- 1 additional site is in start-up.

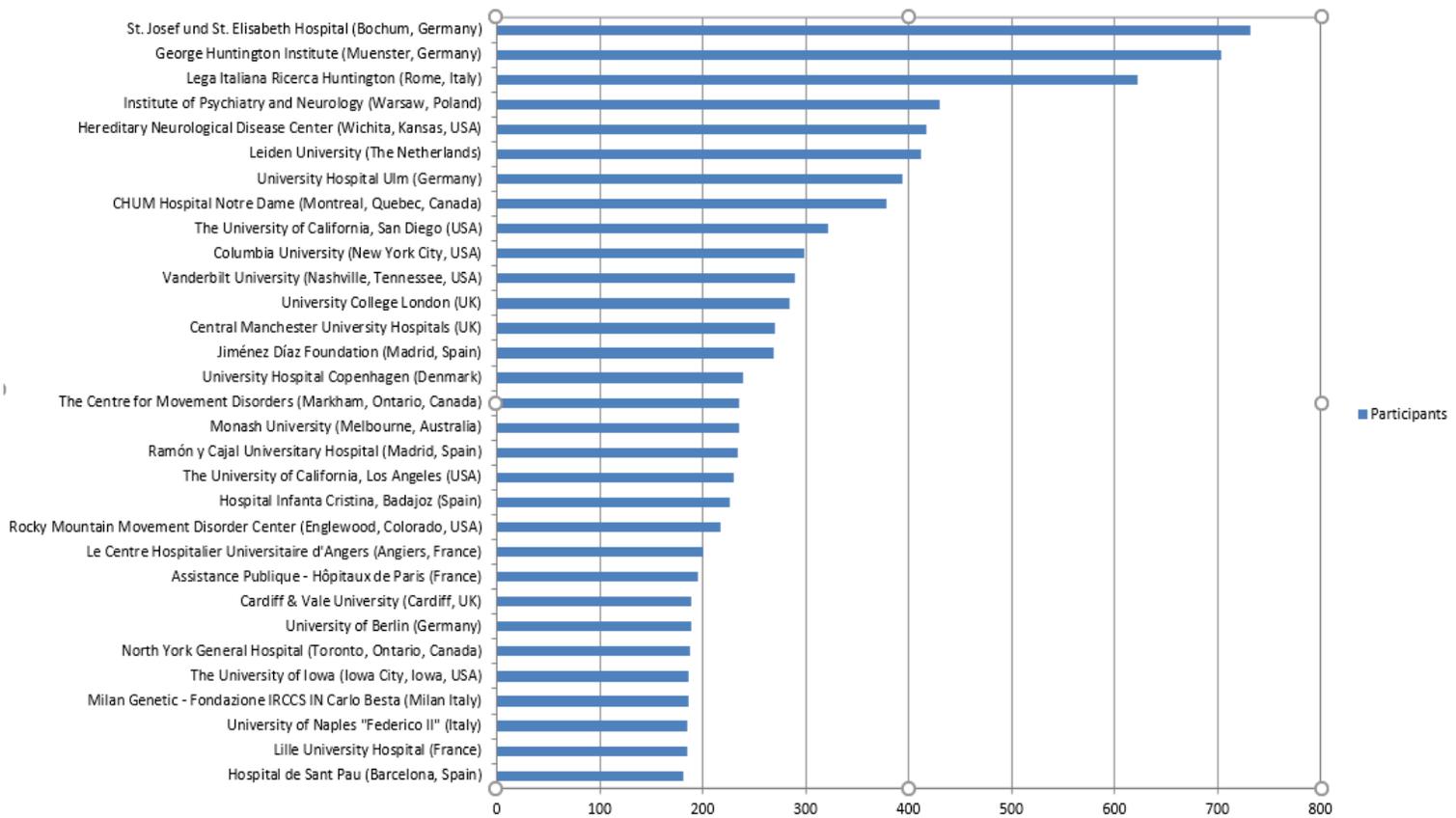
LATIN AMERICA:

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

Enroll-HD datasets and website information

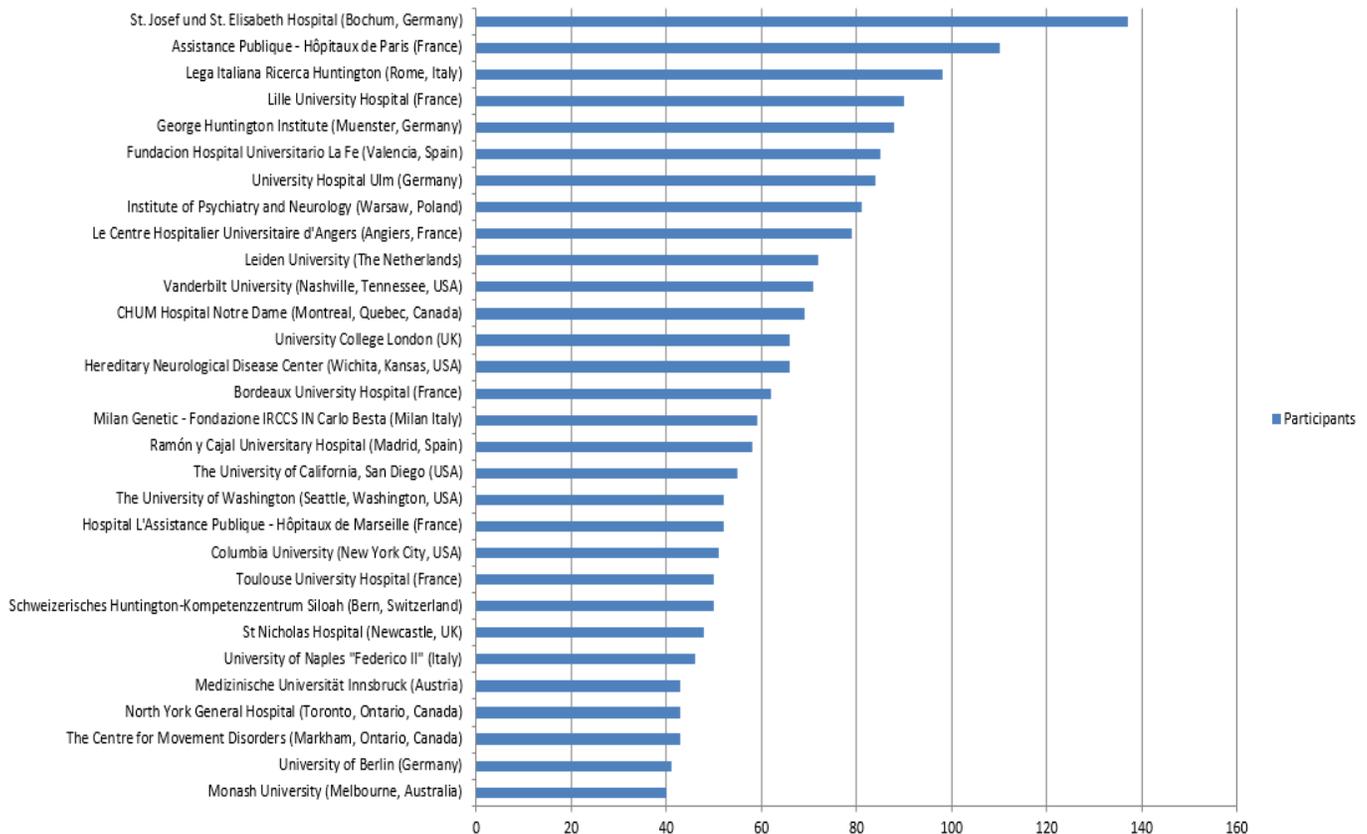
- You can find on the Enroll-HD website information about how the study is structured and the people who keep it running, from site staff to participants to clinicians to researchers. Please share the link with your colleagues and your participants and check back often for new articles, updates and announcements. <https://www.enroll-hd.org>
- Please also check that the information listed on the website for your site (<https://www.enroll-hd.org/participate/clinic-locations/>) is current and correct; please email any corrections to [your site manager or language coordinator](#).

Top Enrolling Sites - Since Study Start (Active Participants)

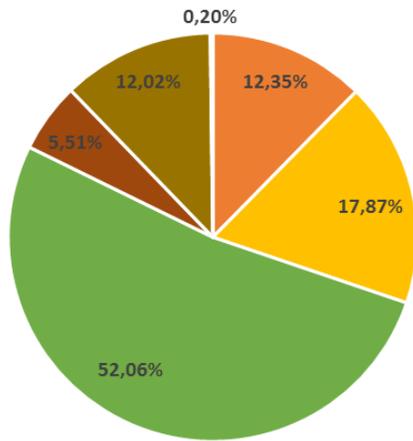


The top enrolling site is St. Josef und St. Elisabeth Hospital (Bochum, Germany) with **732 active participants** enrolled!

Top Recruiting Sites of Genotype Unknown, Premanifest and Early Manifest Participants (disease stages 1-2) recruited since January 2018

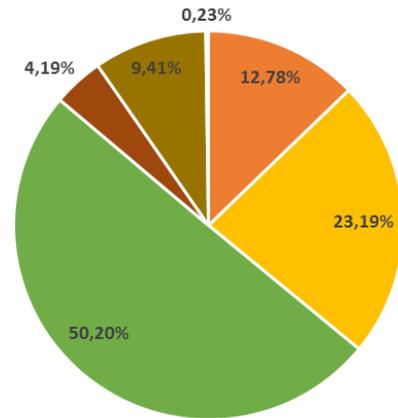


HD category distribution at baseline visit - before Jan 2018



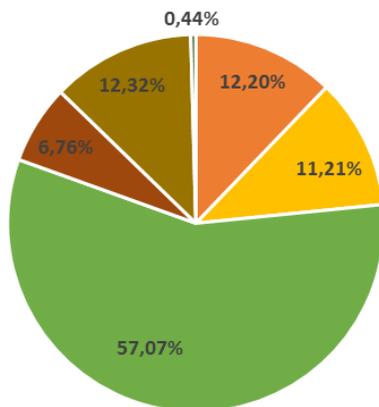
- Genotype Unknown ■ Premanifest ■ Manifest
- Genotype negative ■ Family control ■ Community control

HD category distribution at baseline visit - after Jan 2018



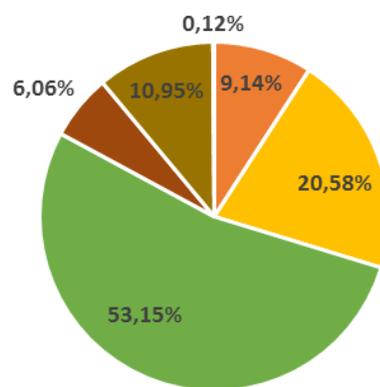
- Genotype Unknown ■ Premanifest ■ Manifest
- Genotype negative ■ Family control ■ Community control

HD category distribution at last visit - before Jan 2018



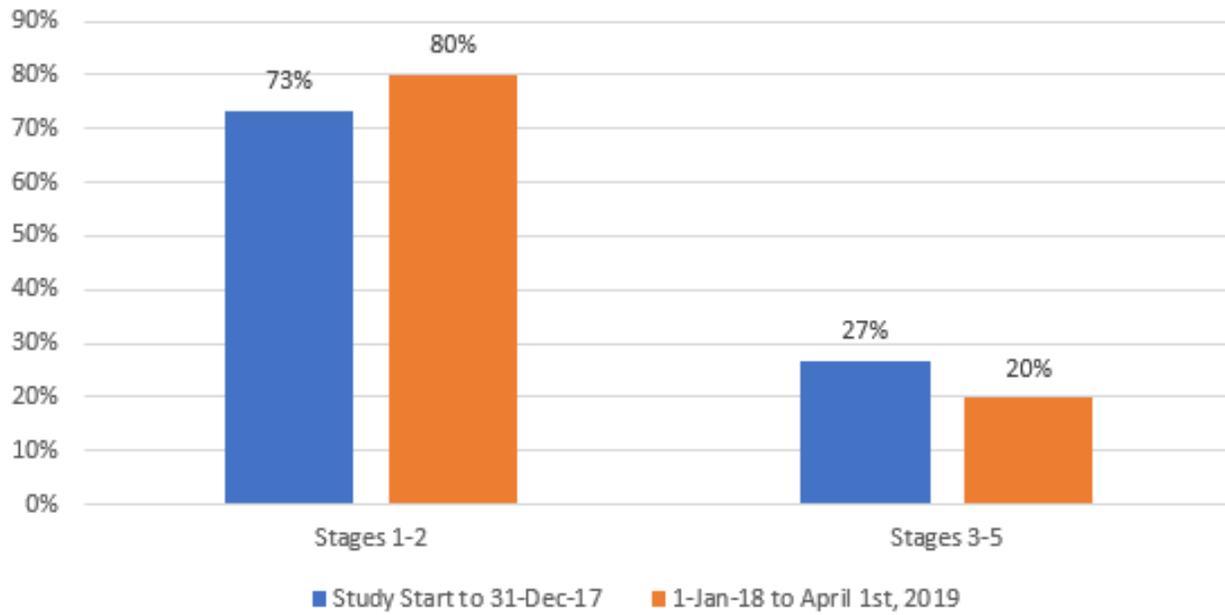
- Genotype Unknown ■ Premanifest ■ Manifest
- Genotype Negative ■ Family Control ■ Community Control

HD category distribution at last visit - after Jan 2018



- Genotype Unknown ■ Premanifest ■ Manifest
- Genotype Negative ■ Family Control ■ Community Control

Disease Stage distribution at the last visit (Manifest participants only)



Thank you for your support in helping Enroll-HD achieve its goals.

The Enroll-HD Study Team

