



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.

August 2018 Quarterly News Bulletin

Dear Enroll-HD Investigators and Site Staff,

Here are the monthly updates:

Recap of Enroll-HD Global Congress

- Enroll-HD Congress was held in Quebec, Canada from May 20-22, 2018. The event was attended by total of 518 attendees; as planned majority of the event participation was from the Enroll-HD Sites (**62%**). Remaining of the event participation was from Industry Collaborators, Community Colleagues, Academic Collaborators, Congress Speakers, Enroll-HD Governance Committee and Enroll-HD Study Team collectively (**38%**). Enroll-HD Congress was greatly valued by the attendees and per the feedback received, it will further enable their efforts in HD Clinical development. Please reach out to your site manager or language coordinator if you would like to receive a copy of the slide decks from the Study Coordinator Trivia Game and Study Coordinator panel via email.

Recruitment update

- As of **August 1st** there are a total of 16,565 **active participants** enrolled at **166 sites (159 of which are still active)** in **19 countries** around the world.

Regional startup and enrollment updates

EUROPE:

- 10,034 active participants have been enrolled at 93 active sites in Belgium, Denmark, France, Germany, Ireland, Italy, The Netherlands, Poland, Spain, Switzerland, Portugal, Austria and the UK.
- 27 additional European sites that will participate in Enroll-HD are in start-up.

NORTH AMERICA:

- 5,697 active participants have been enrolled at 58 sites in the US and Canada.
- An additional 6 sites are in start-up.

AUSTRALASIA:

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

LATIN AMERICA:

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

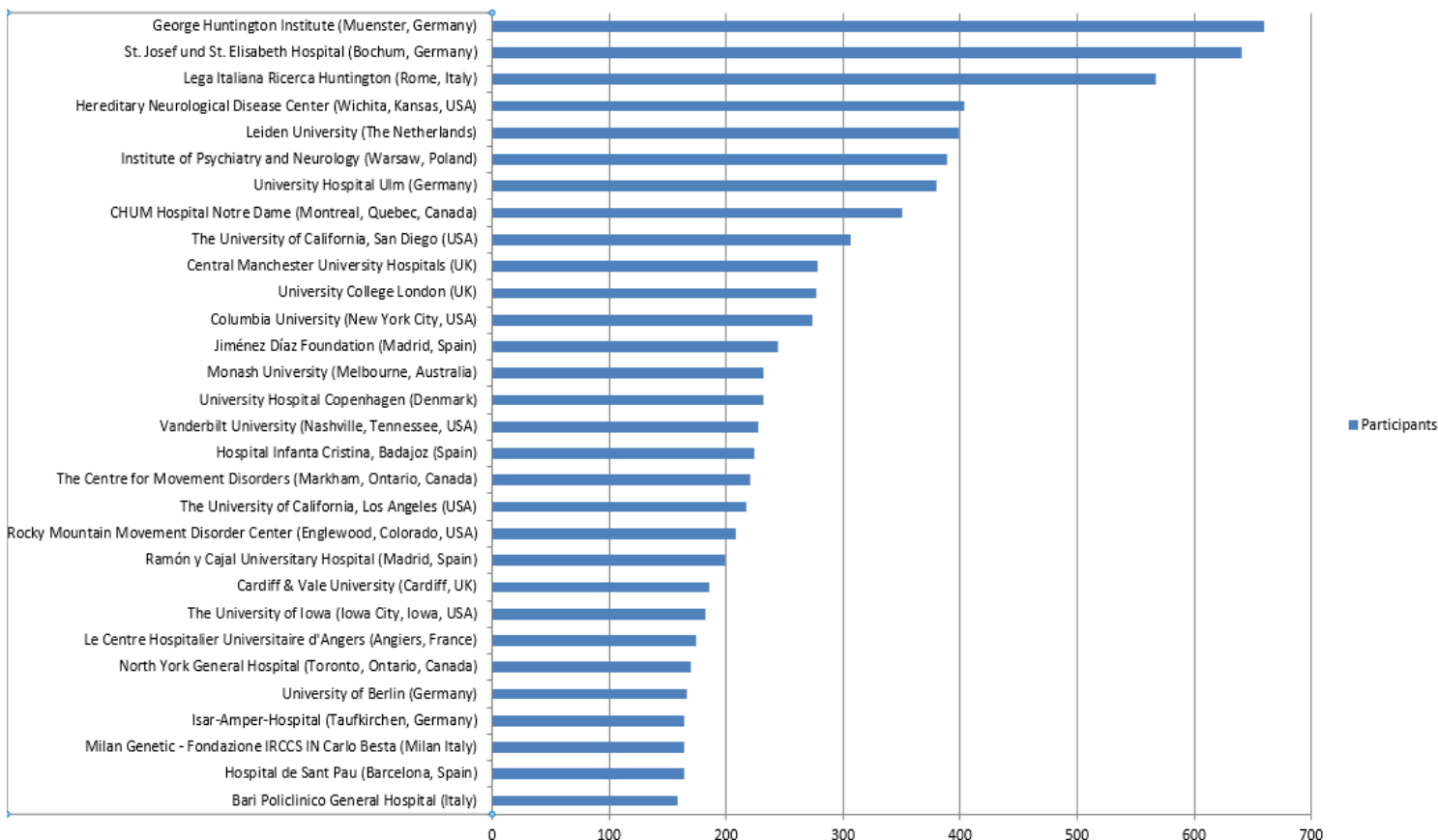
Latest Enroll-HD data release and website update

- **The periodic dataset No 4 (PDS4) is on its way**, with a planned data cut date of October 31, 2018 and a release date in December 2018. We are envisioning data of more than 12,000 participants to be part of the dataset. There is a high focus on the ongoing data monitoring task ensuring that participant's rights are adhered, and that data quality is high. The dataset structure will stay identical to the recent PDS3, with some gainful information added.

Momentarily (since December 2016) available on the Enroll-HD website is 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, 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 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.

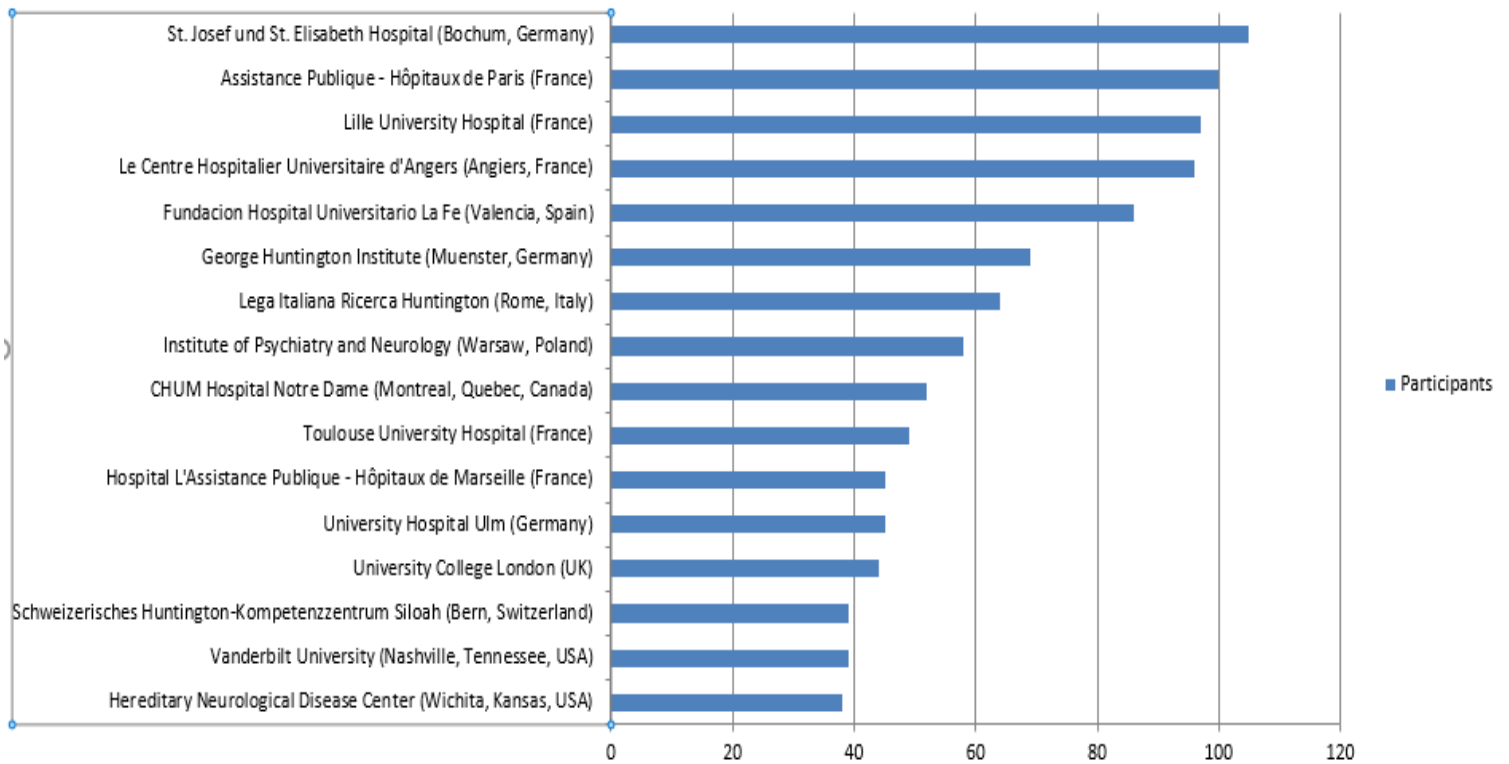
- You can also find on the Enroll-HD website lots of information about how the study is structured and the people who keep it running, from site staff to participants to clinicians to researchers. Please share the link with your colleagues and your participants and check back often for new articles,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

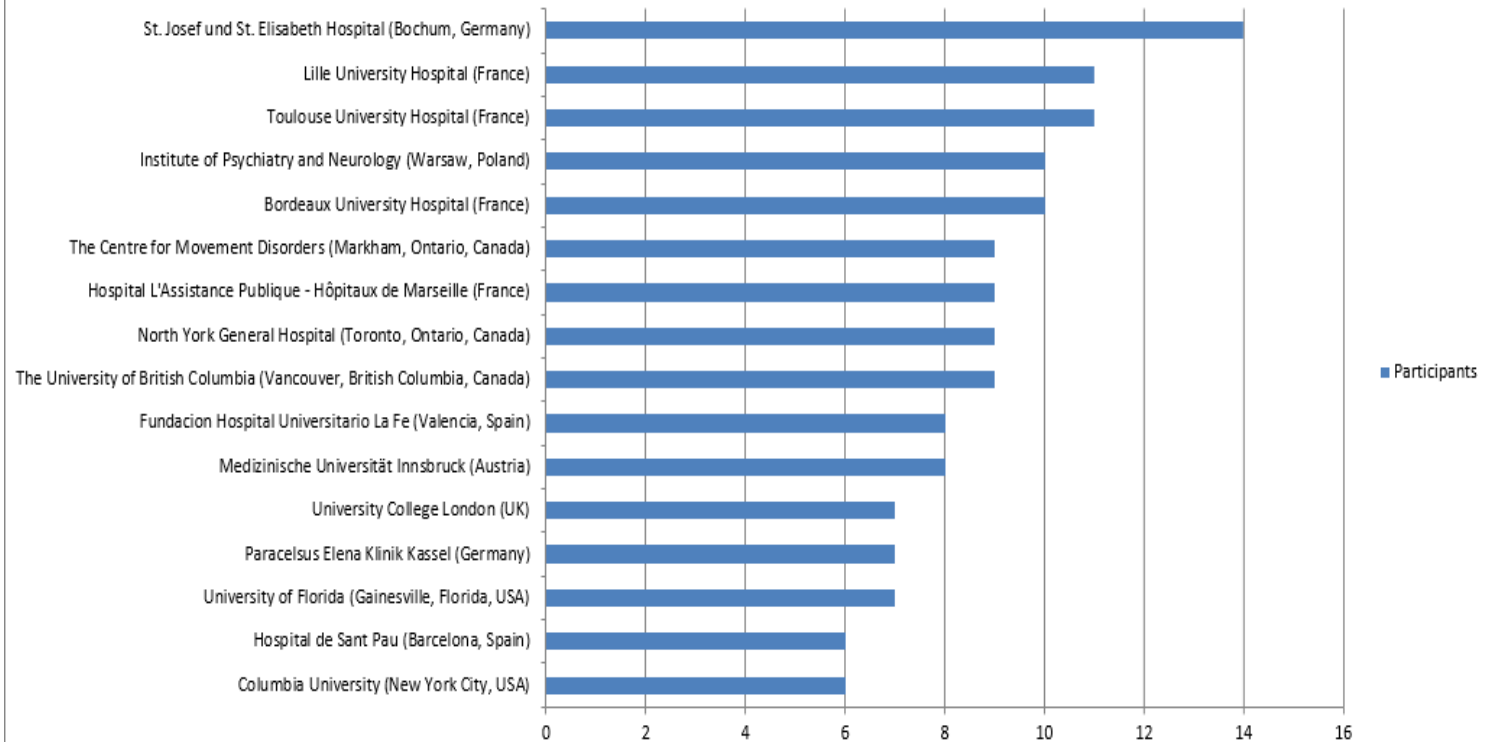


The top enrolling site is George Huntington Institute (Muenster, Germany) with **660 active participants** enrolled!

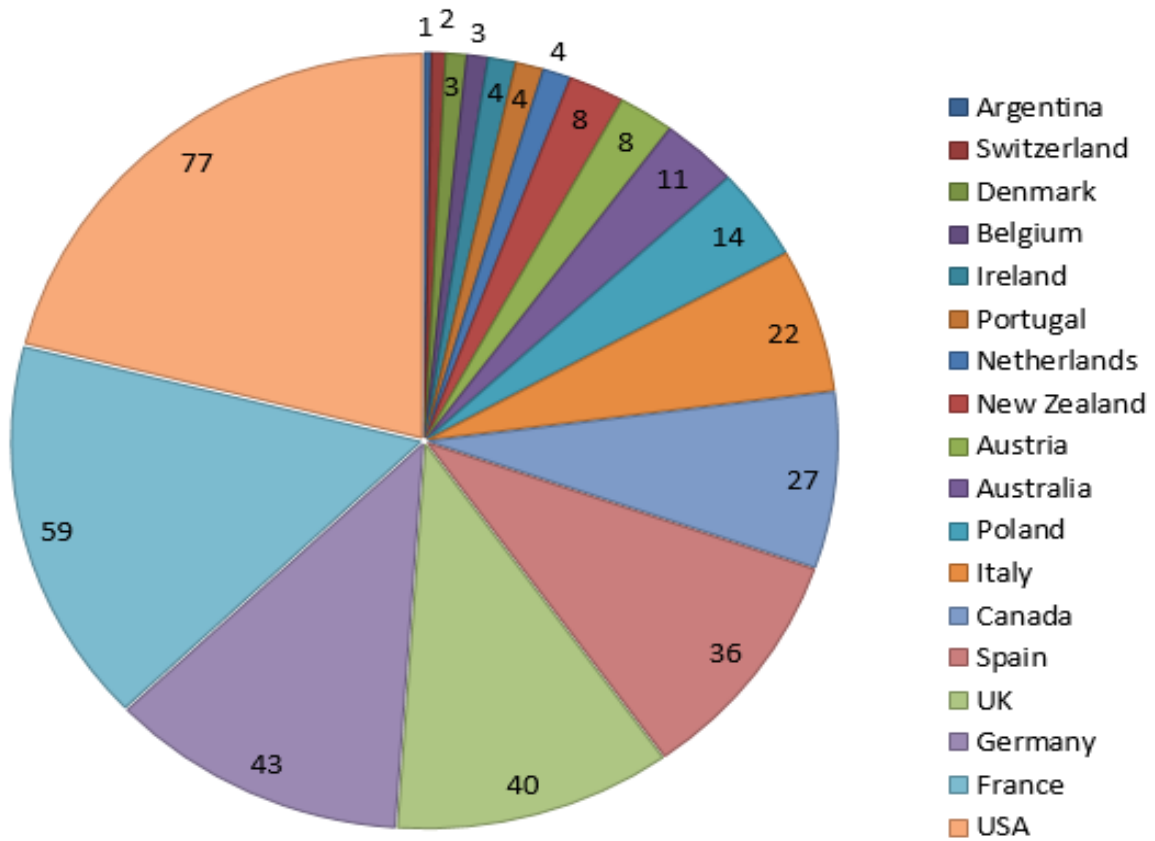
Top Enrolling Sites - Year to Date 2018 (Active Participants)



Top Enrolling Sites - Previous Month (July, 2018, Active Participants)



Participants Enrolled in July 2018 (By Country)

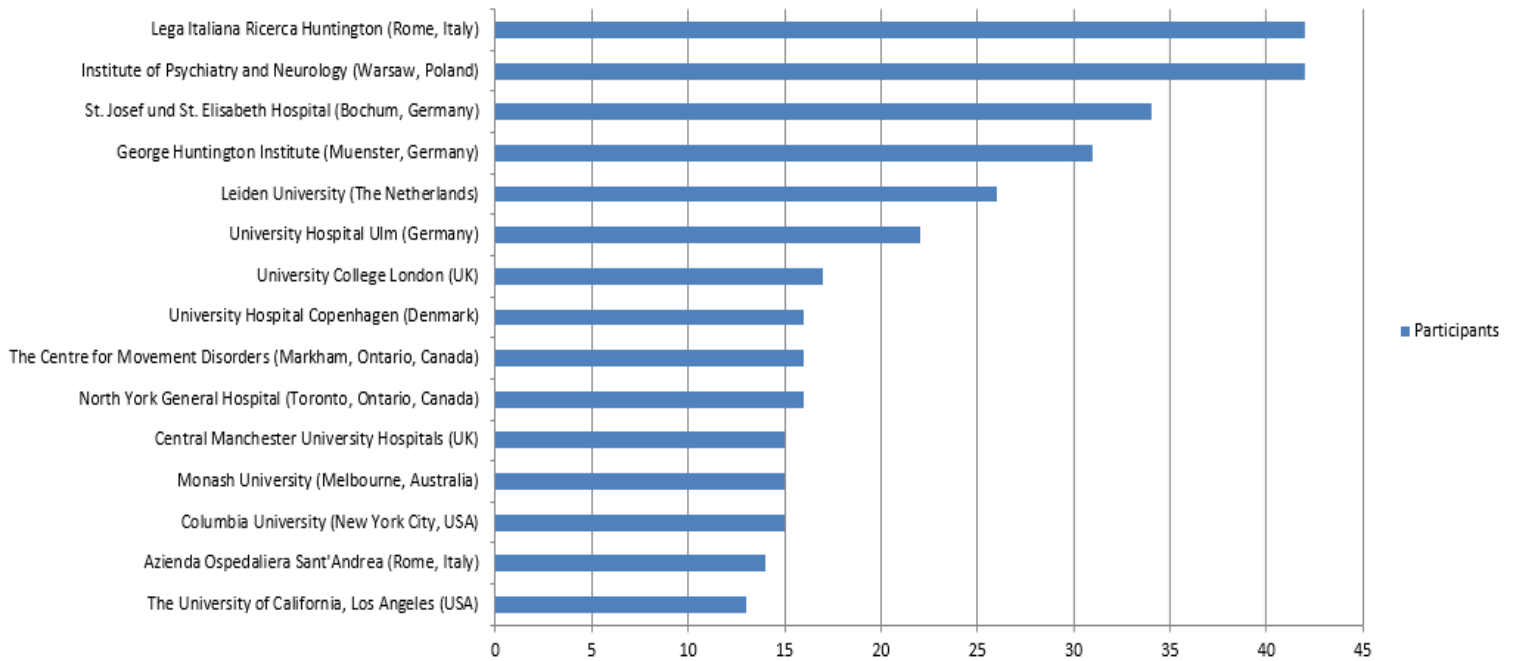


Follow Up Visits By Month



This graph shows the number of participants per month who have returned to their clinic for their annual follow-up visit.

Most Follow Up Visits Completed - Previous Month (July 2018)



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

The Enroll-HD Study Team

