



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.

December 2018 Quarterly News Bulletin

Dear Enroll-HD Investigators and Site Staff,

As 2018 comes to a close, we would like to thank you for your commitment and dedication to the Enroll-HD platform. We enjoyed seeing many of you at the Enroll-HD Congress in May. We would like to remind you of the new strategy to focus on **premanifest and early stage recruitment**. These metrics will be reflected in the next quarterly news bulletin.

Here are the study updates:

Participant recruitment

- **Total participants enrolled in the study reached 20,000!** The participant was recruited at the study site in Leuven, Belgium. This extraordinary milestone was made possible thanks to the efforts of the sites and the families. Thank you!

Site Metrics Cards

- Site Metrics Cards focusing on strategic metrics such as recruitment of premanifest and early stages participants, as well as key metrics on data quality and study compliance, were first issued at the Enroll-HD Congress in May 2018. In this new version we have also added an overview of the participants status. The second release of the Site Metrics Cards has been distributed via email from your Site Managers or Language Coordinators in December.

PDS4 released

- **The release date of the Enroll-HD Periodic Data Set (PDS4) is 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. There has been an intense focus on the ongoing data monitoring task ensuring that participants' rights are respected, and that the data quality is high. The dataset structure is the same as in PDS3. Longitudinal data from PDS4 data will include participants with up to 20 study visits and 6 Enroll-HD study visits. 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 **December 1st**, there are 17,583 active **participants** enrolled at **162 sites** in **19 countries** around the world.

Regional startup and enrollment updates

EUROPE:

- 10,741 active participants have been enrolled at 95 active sites in Belgium, Denmark, France, Germany, Ireland, Italy, The Netherlands, Poland, Spain, Switzerland, Portugal, Austria and the UK.
- 24 additional European sites that will participate in Enroll-HD are in start-up.

NORTH AMERICA:

- 5,949 active participants have been enrolled at 59 sites in the US and Canada.
- An additional 6 sites are in start-up.

AUSTRALASIA:

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

LATIN AMERICA:

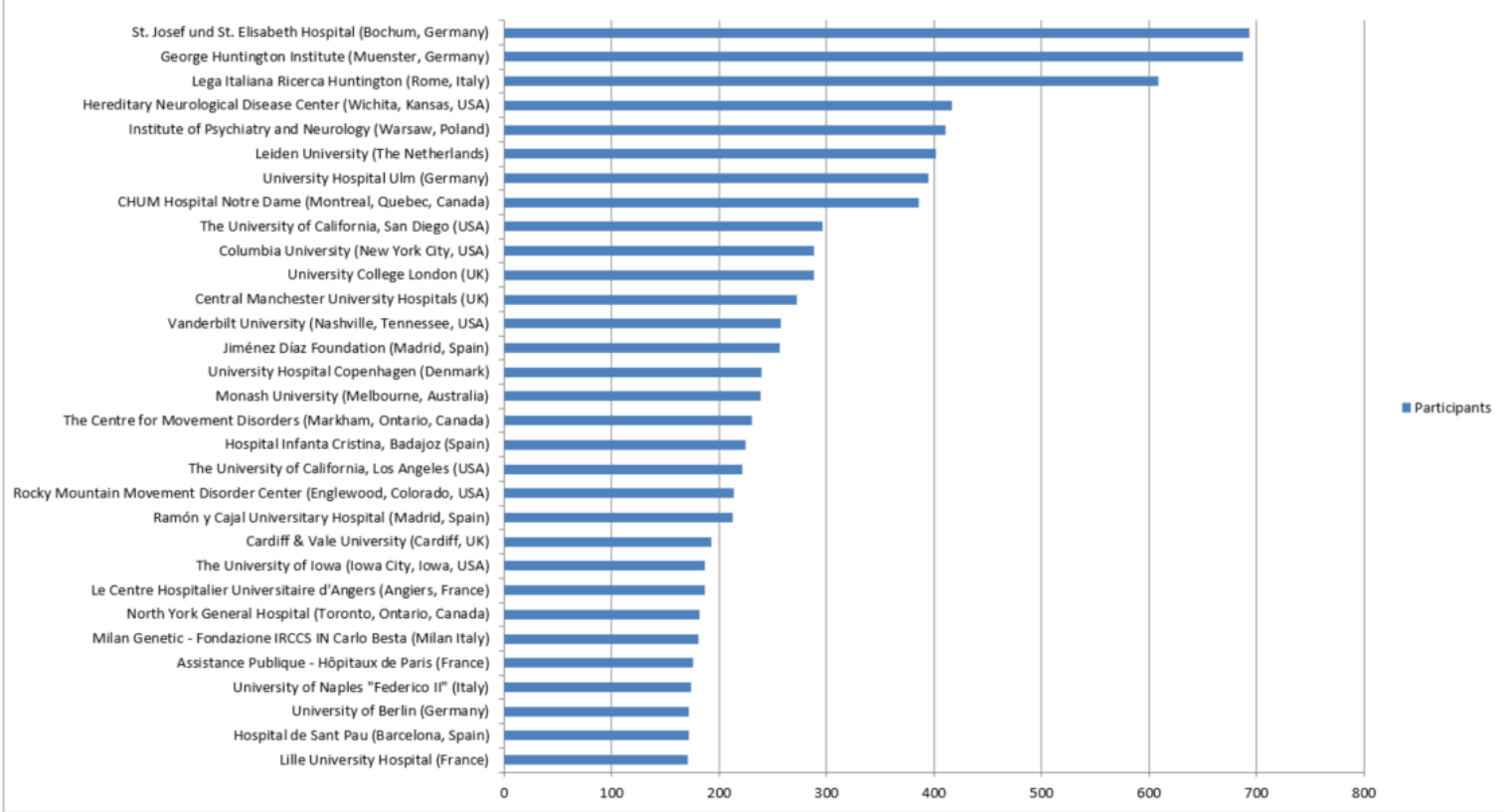
- 216 active participants have been enrolled at 2 active sites in Argentina and Chile.
- 5 sites in Argentina, Colombia and Peru are in start-up.

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](#).

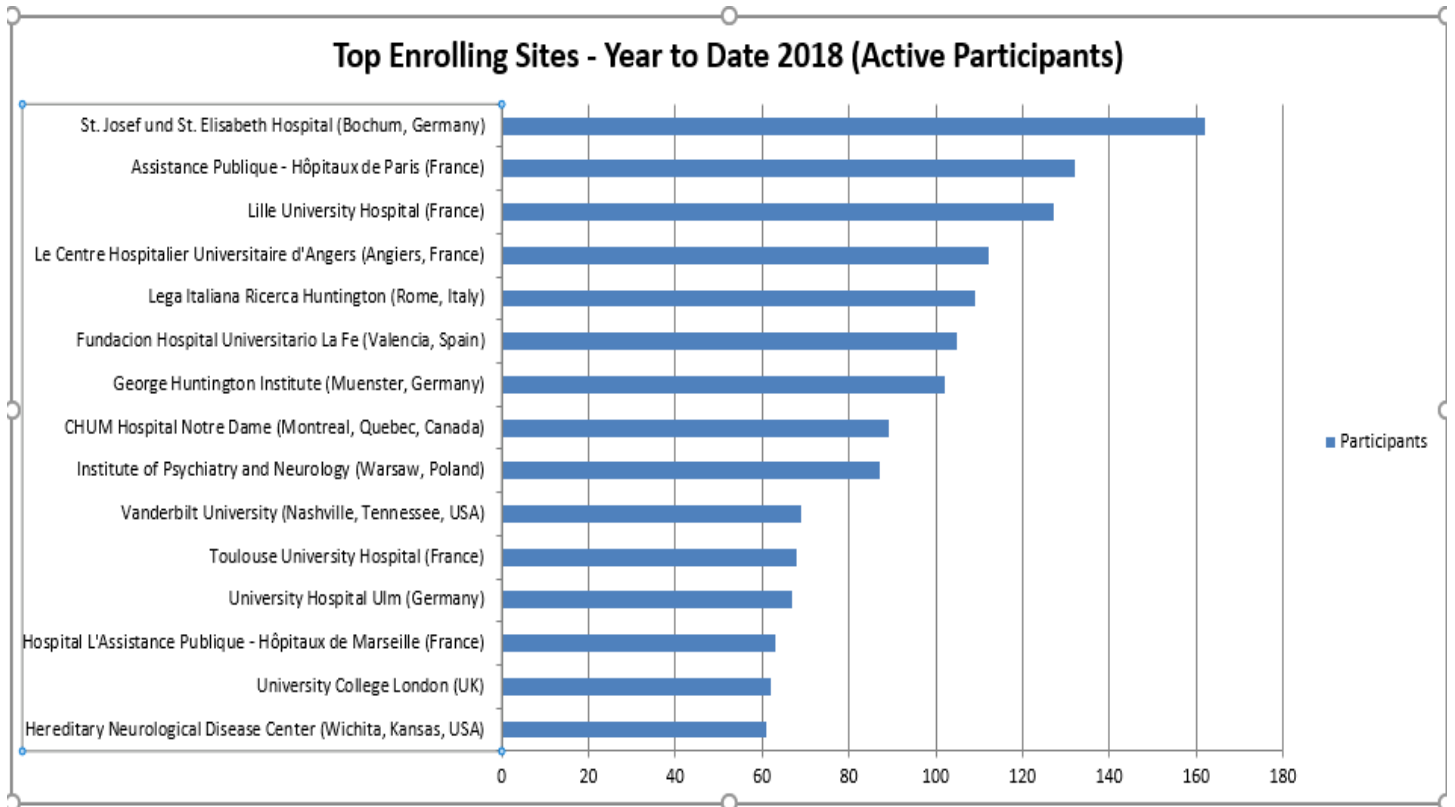
Happy holidays from the Enroll-HD team!

Top Enrolling Sites - Since Study Start (Active Participants)

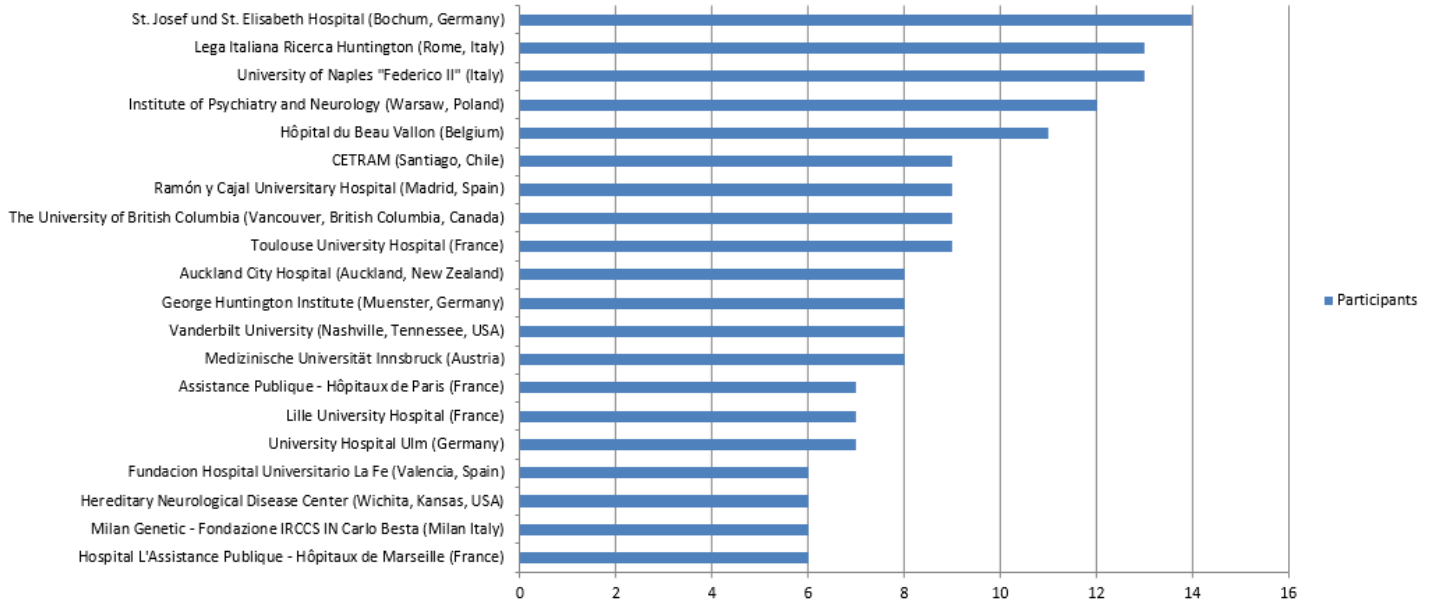


★ The top enrolling site is St. Josef und St. Elisabeth Hospital (Bochum, Germany) with **693 active participants** enrolled!

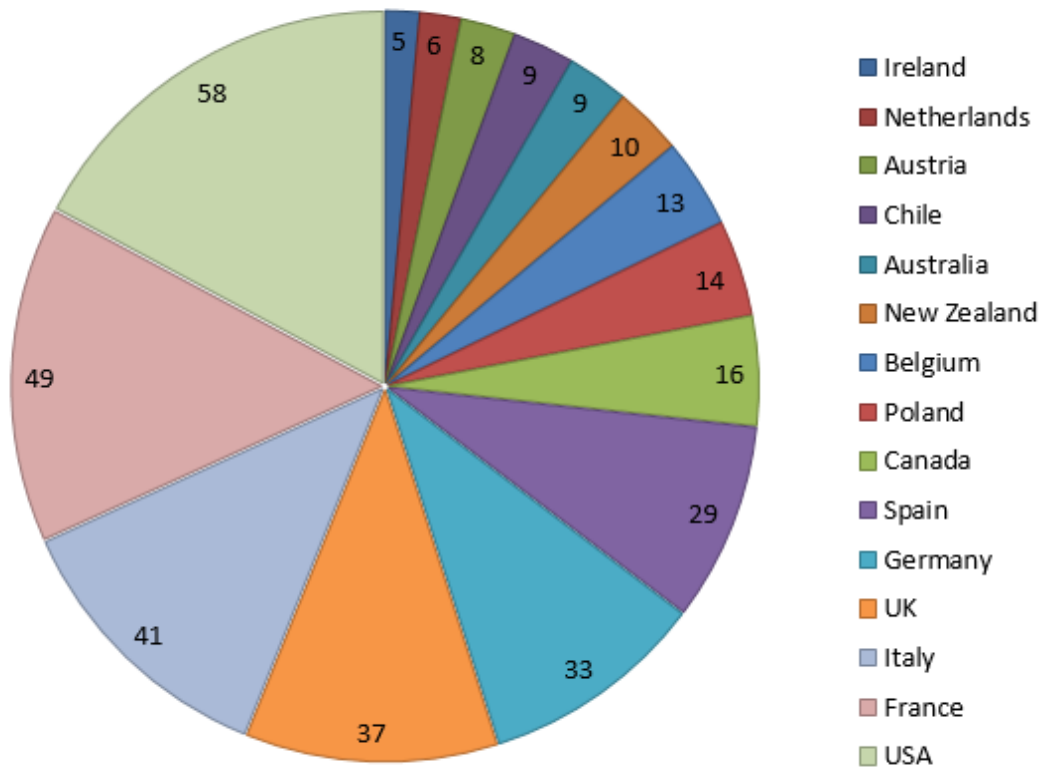
Top Enrolling Sites - Year to Date 2018 (Active Participants)



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



Participants Enrolled in November 2018 (By Country)

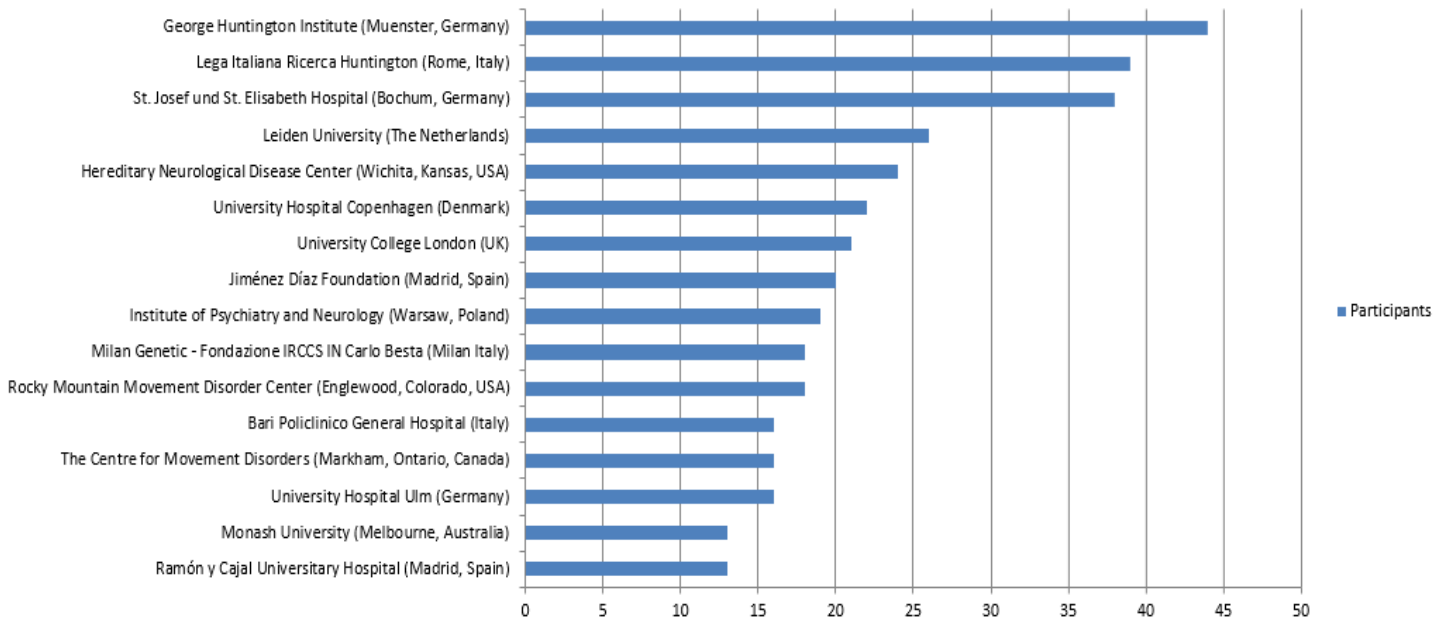


Follow Up Visits By Month



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 (November 2018)



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

The Enroll-HD Study Team

