



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

- To better understand HD as it happens in people to give insight into developing new drugs
- 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 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.

January 2017 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff,

An Enroll-HD progress update over the past month:

Latest Enroll-HD data release and website update

- **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](#). 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.
- Please also check that the information listed on the website for your site is current and correct; please email any corrections to EnrollHD@quintiles.com

Recruitment update

- As of **January 1st** a total of **12,631 participants** have been enrolled at **135 active sites** in **14 countries** around the world.

Regional startup and enrollment updates

EUROPE:

- 6,961 participants have been enrolled at 72 sites in Denmark, Germany, Ireland, Italy, Netherlands, Poland, Spain and the UK.
- 61 additional European sites that will participate in Enroll-HD have begun the site start-up process.

NORTH AMERICA:

- 4,792 participants have been enrolled at 56 active sites in the US and Canada.
- An additional 8 sites have begun the site start-up process.

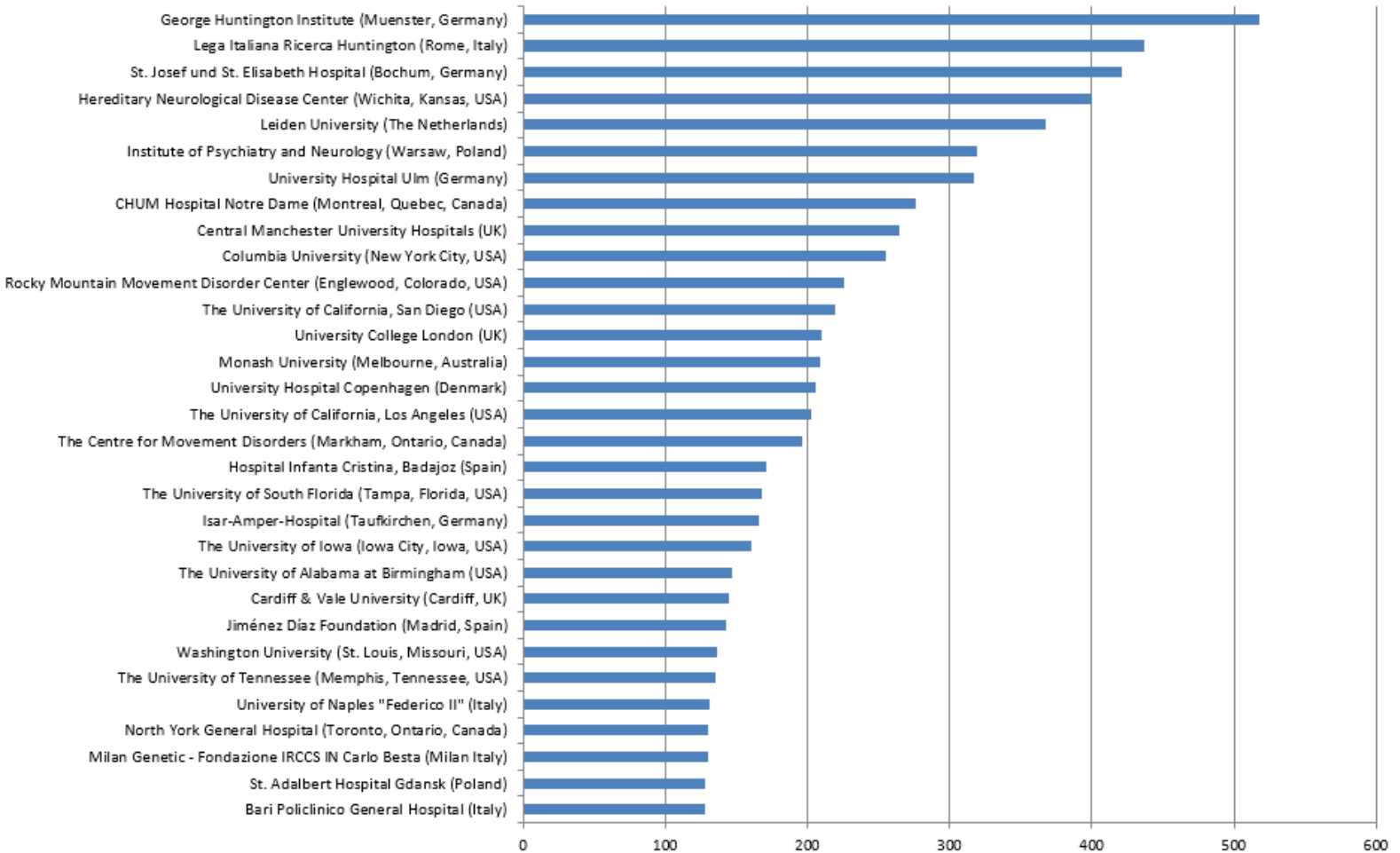
AUSTRALASIA:

- 511 participants have been enrolled at five active sites in Australia and New Zealand.
- Two additional sites have begun the site start-up process.

LATIN AMERICA:

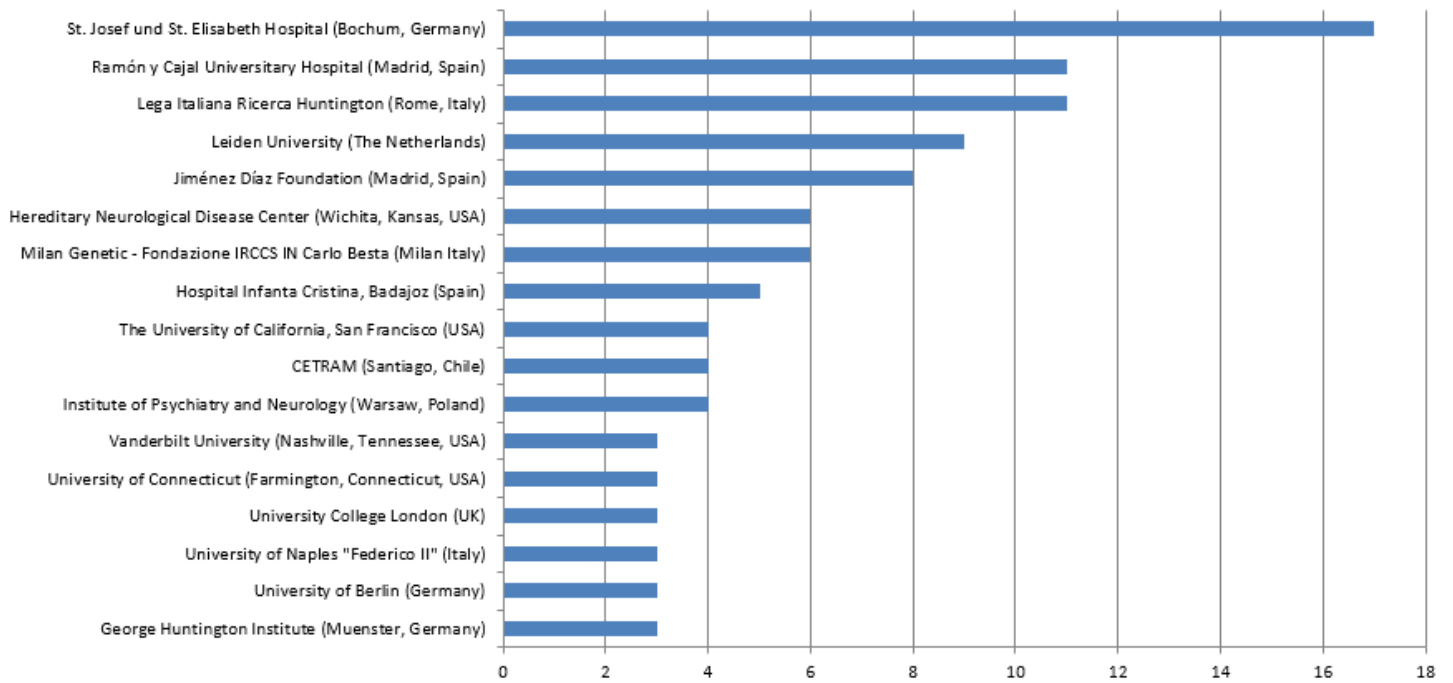
- 186 participants have been enrolled at two active sites in Argentina and Chile.
- Start-up efforts continue at 4 sites in Argentina, Chile, and Peru.

Top Enrolling Sites - Since Study Start

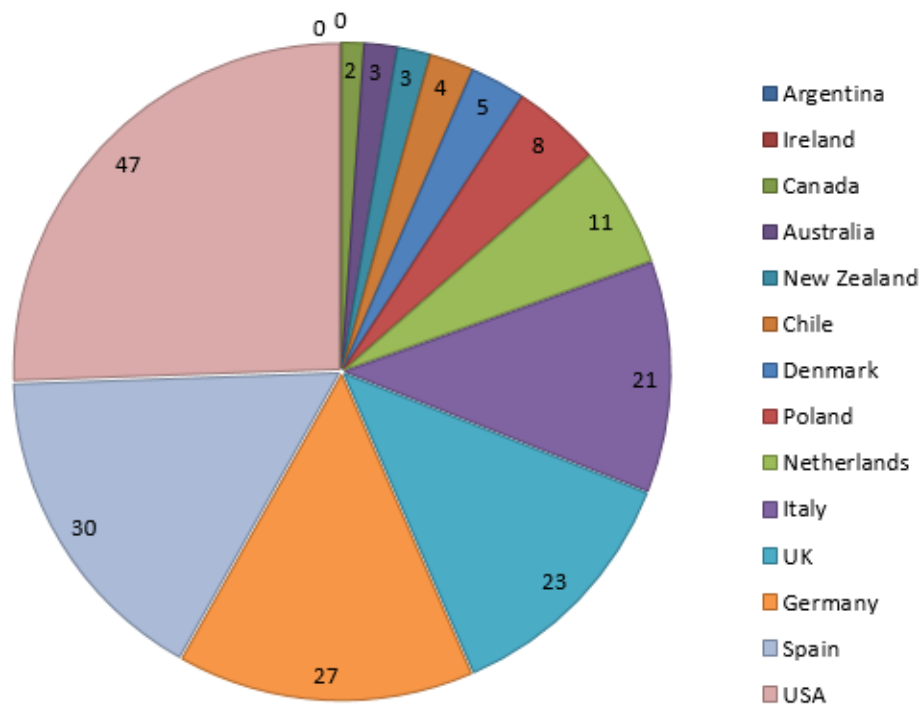


★ The top enrolling site is George Huntington Institute (Muenster, Germany) with **518 participants** enrolled!

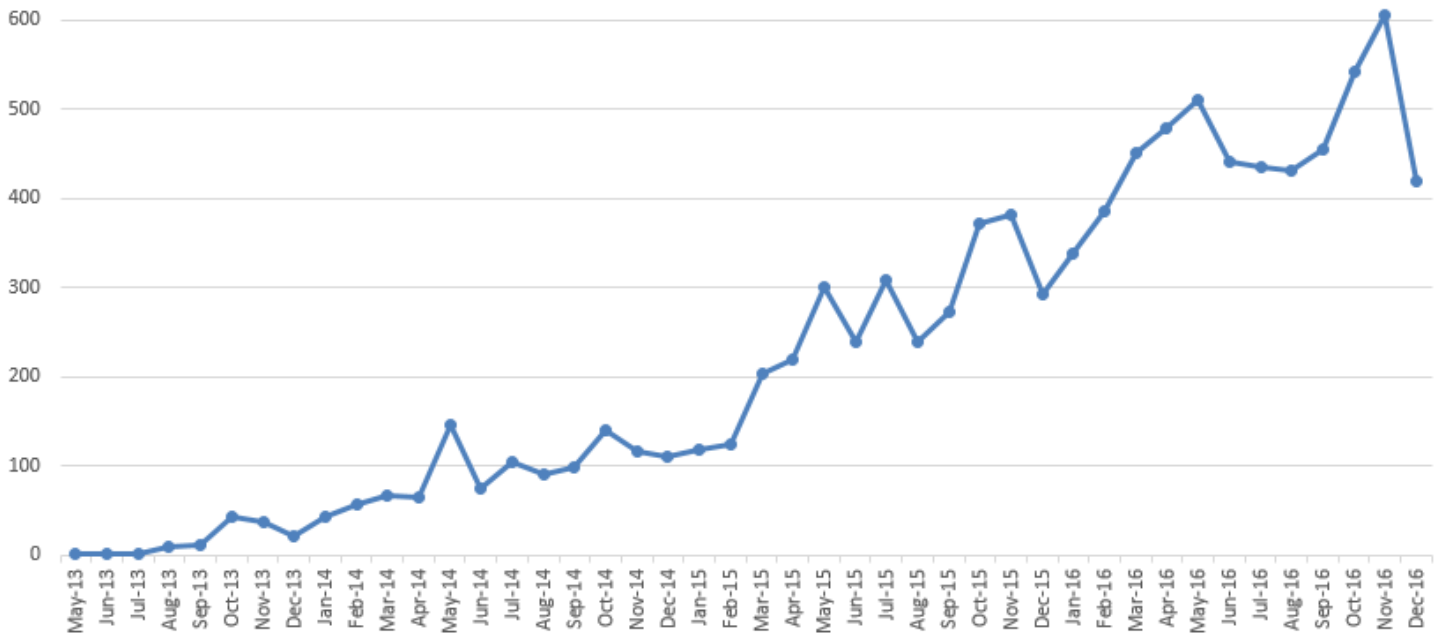
Top Enrolling Sites - Previous Month (December 2016)



Participants Enrolled in December 2016 (By Country)

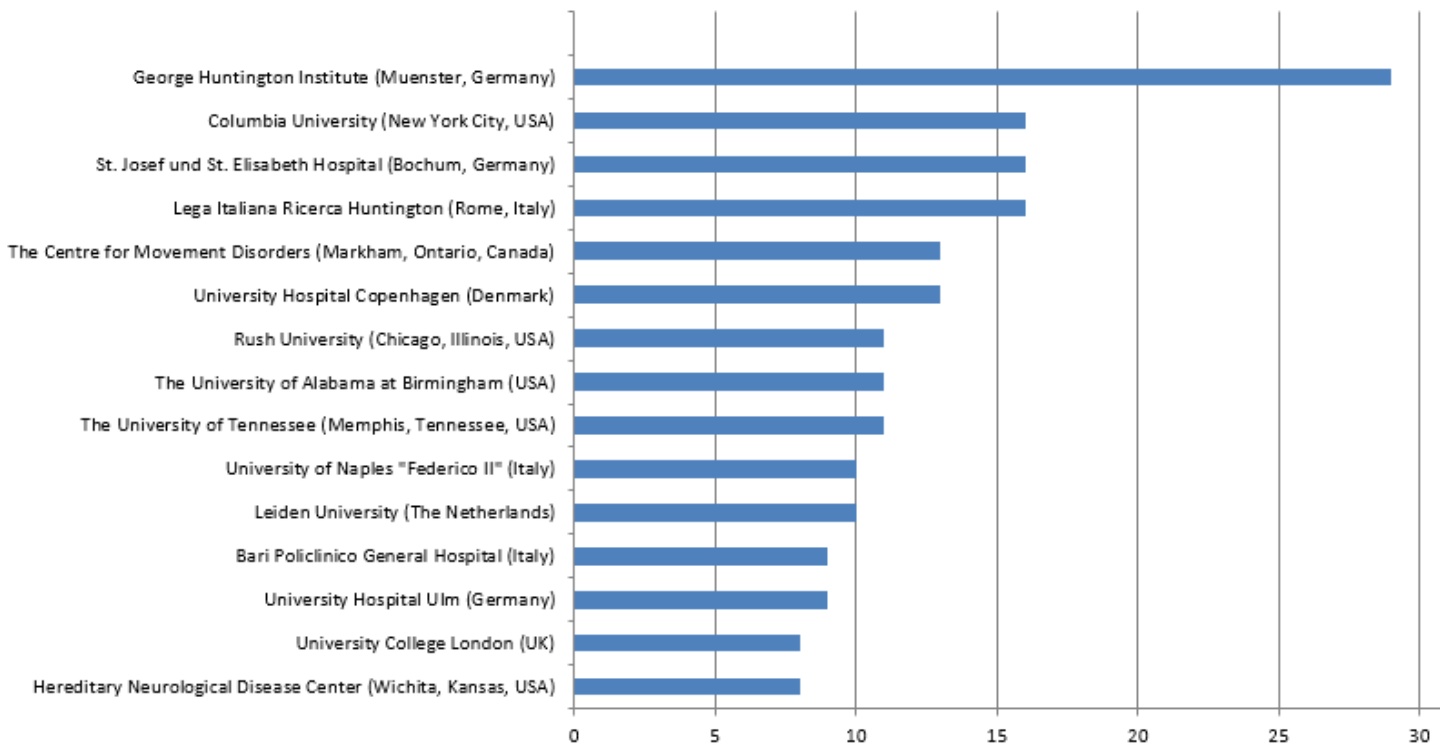


Follow Up Visits By Month



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 (December 2016)



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

The Enroll-HD Study Team

