



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.

September 2016 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 **second Enroll-HD periodic dataset that includes the clinical data from 4146 participants 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 **September 1st** a total of **11,634 participants** have been enrolled at **136 sites** in **14 countries** around the world.

Regional startup and enrollment updates

EUROPE:

- 6,390 participants have been enrolled at 71 sites in Denmark, Germany, Ireland, Italy, Netherlands, Poland, Spain and the UK.
- 28 additional European sites that will participate in Enroll-HD have begun the site start-up process.

NORTH AMERICA:

- 4,609 participants have been enrolled at 57 sites in the US and Canada.
- An additional 13 sites have begun the site start-up process.

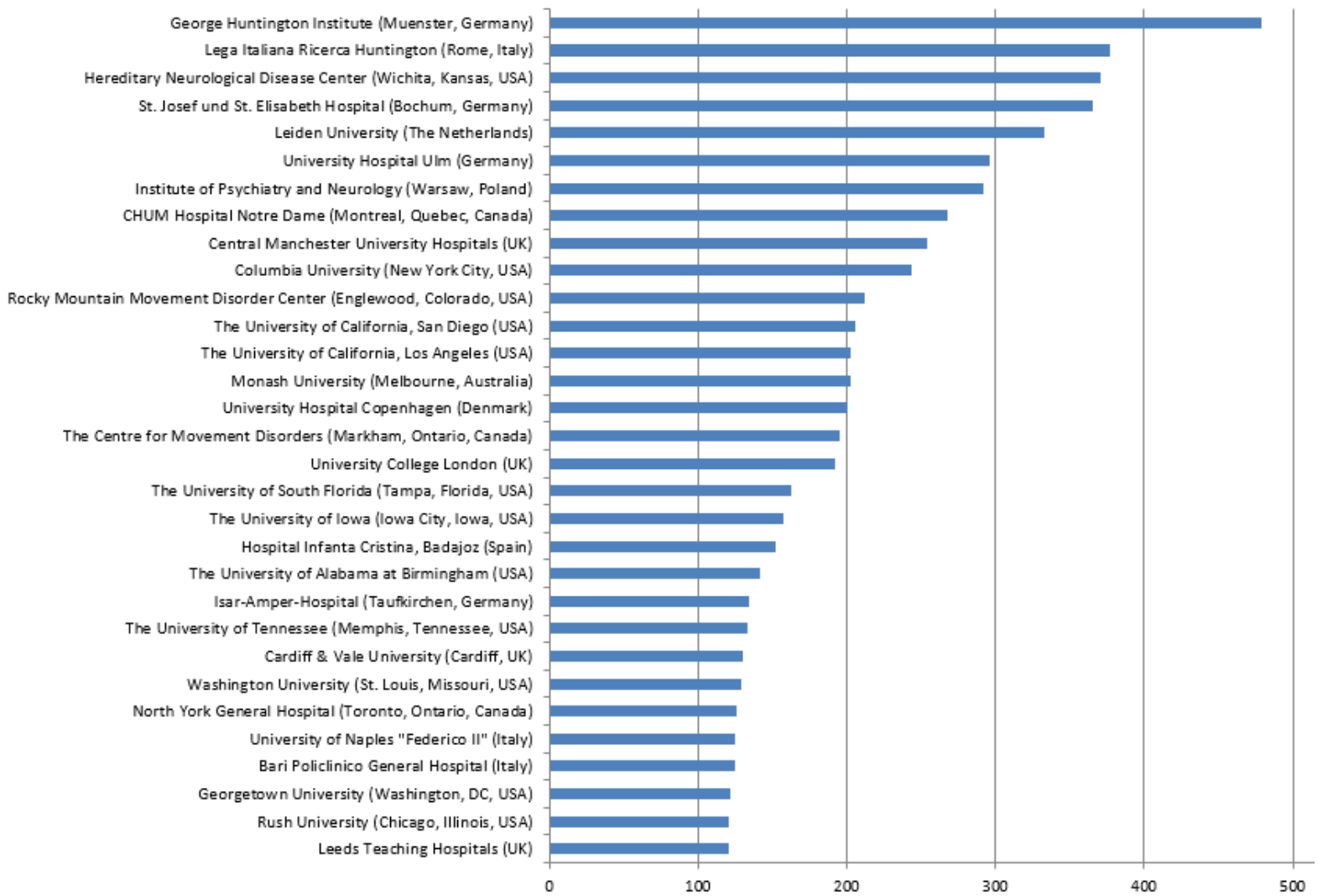
AUSTRALASIA:

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

LATIN AMERICA:

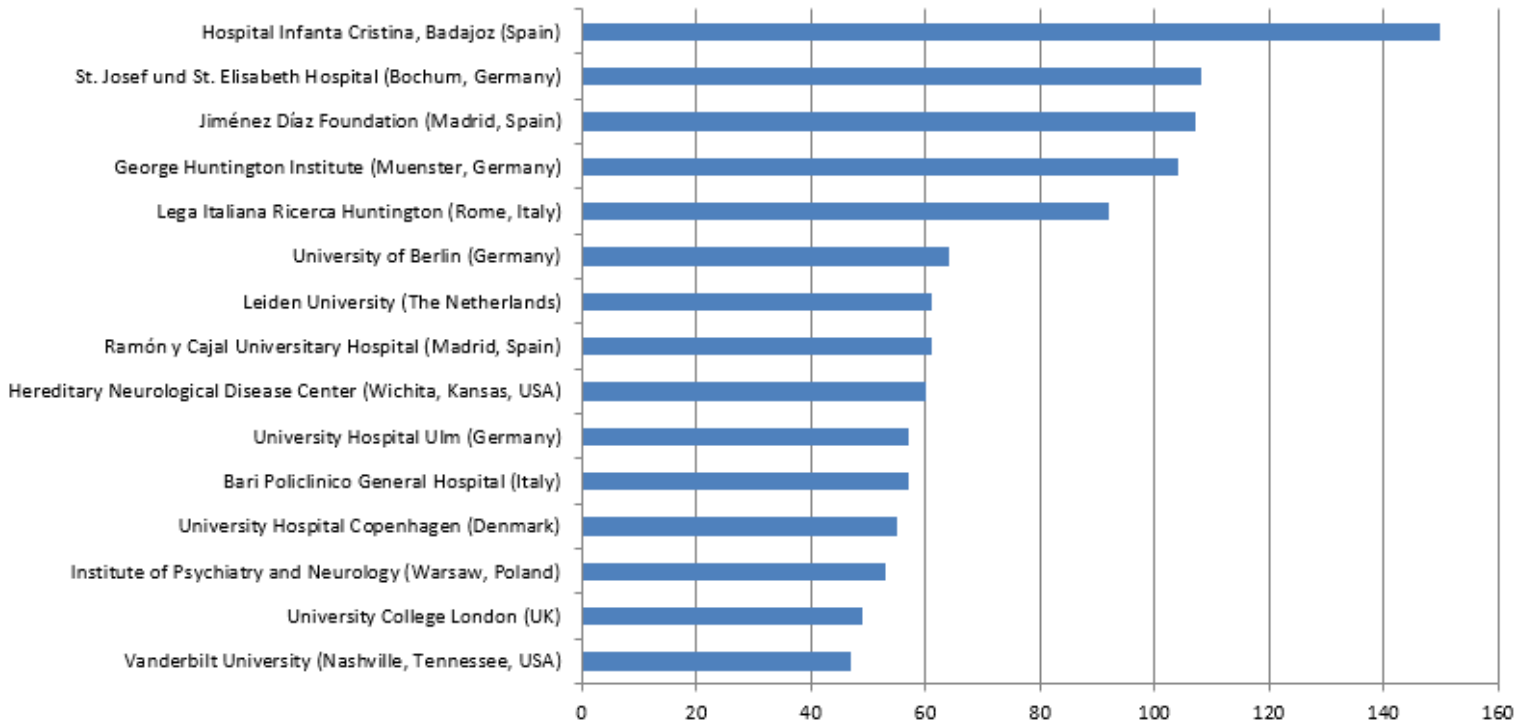
- 161 participants have been enrolled at three sites in Argentina and Chile.
- Start-up efforts continue at 10 sites in Argentina, Chile, and Peru.

Top Enrolling Sites - Since Study Start

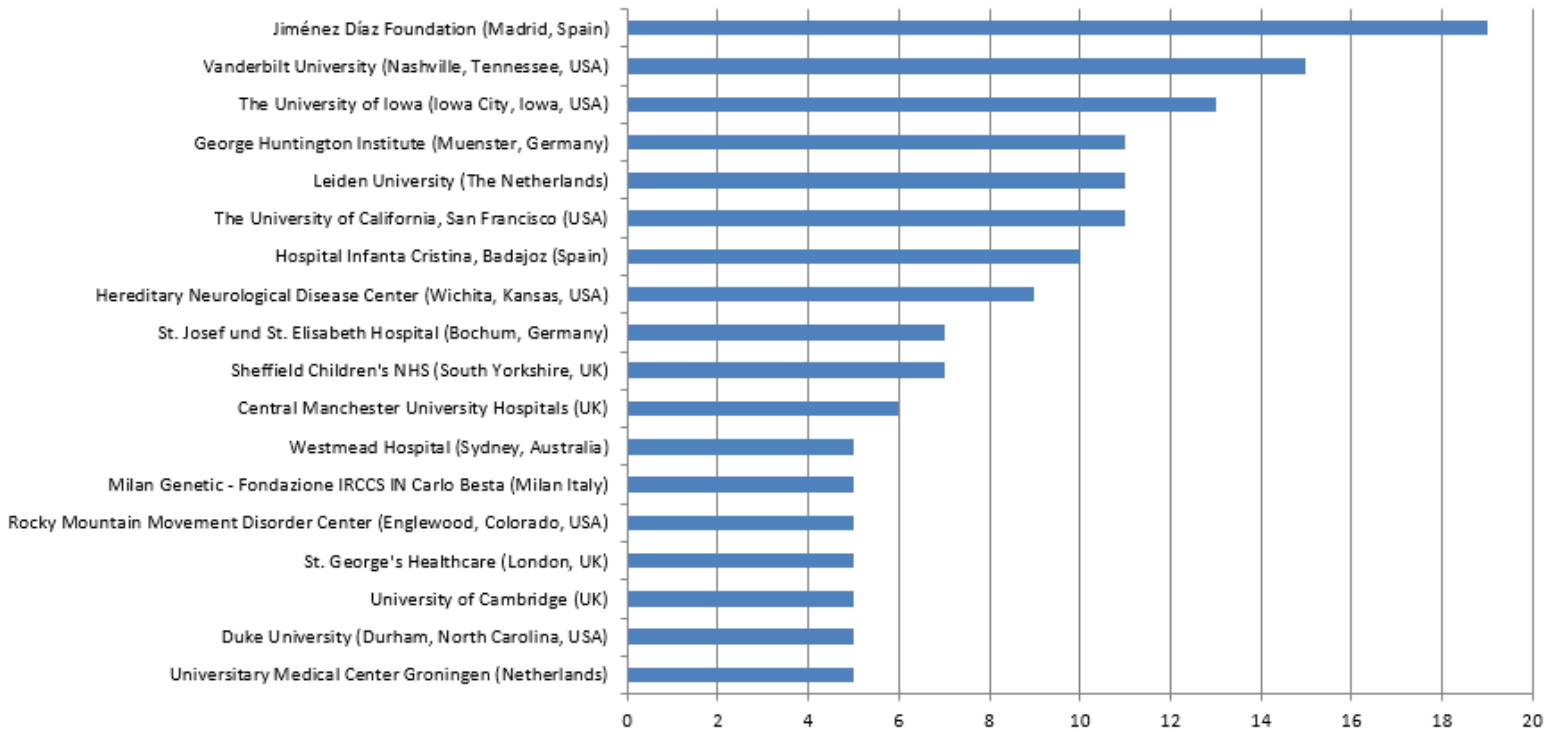


★ The top enrolling site is George Huntington Institute (Muenster, Germany) with **479 participants** enrolled!

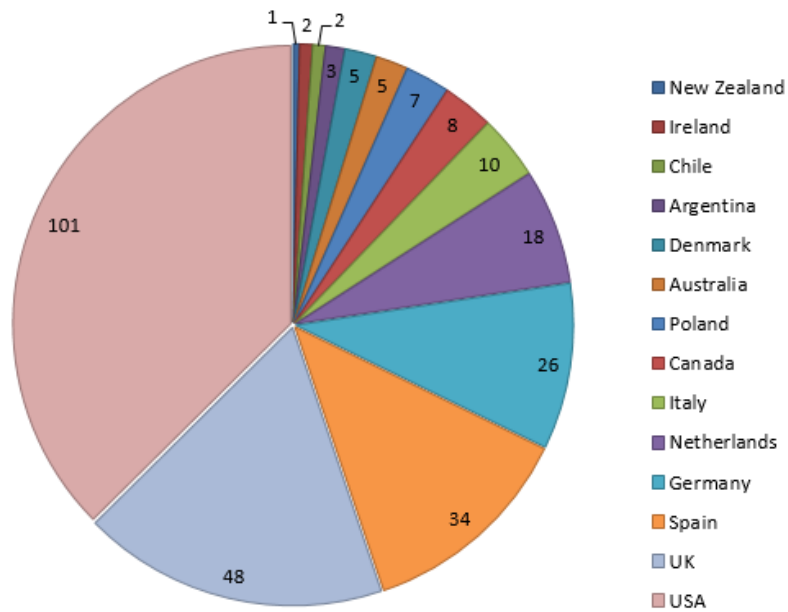
Top Enrolling Sites - Year to Date 2016



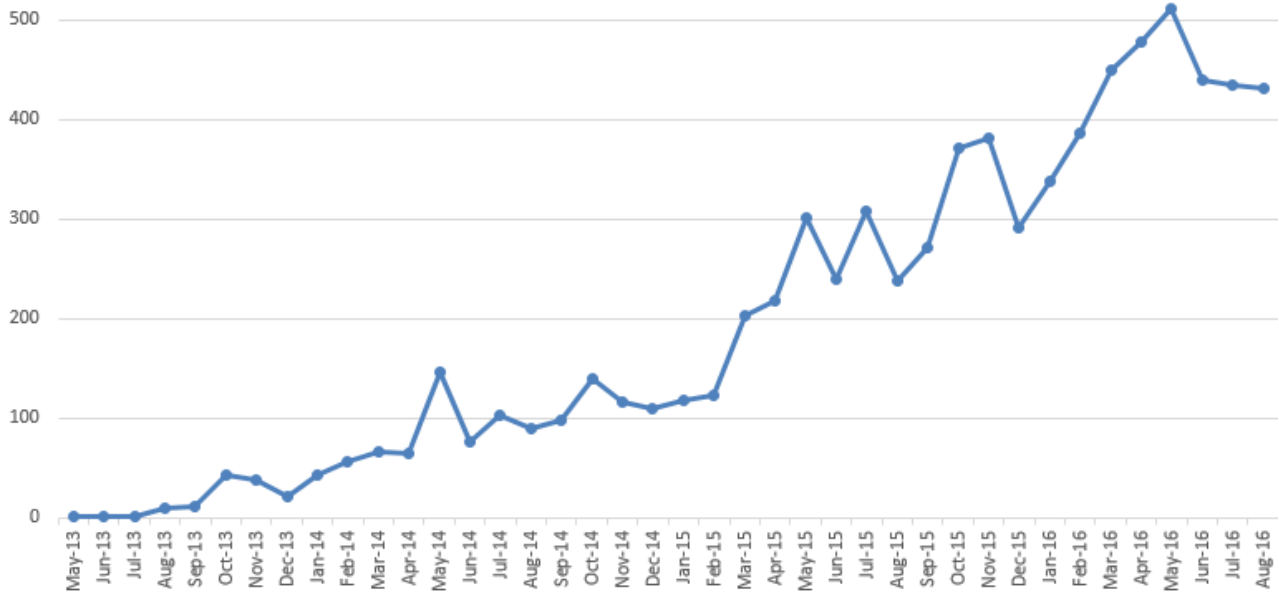
Top Enrolling Sites - Previous Month (August 2016)



Participants Enrolled in August 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.

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

The Enroll-HD Study Team

