**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.

## November 2017 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff,

Here are the monthly updates:

**Enroll-HD Global Congress**
- The Enroll-HD Global Congress will be held from May 20-23, 2018 at The Château Frontenac in Quebec City, Canada. Sites will receive additional information about this event by the end of the month. Registration will open around year end.

**Recruitment update**
- As of **November 1st** there are a total of **13,742 active participants** enrolled at **147 active sites** in **15 countries** around the world.

**Regional startup and enrollment updates**

EUROPE:
- o 8,070 active participants have been enrolled at 81 active sites in Denmark, Germany, Ireland, Italy, The Netherlands, Poland, Spain, France and the UK.
- o 49 additional European sites that will participate in Enroll-HD are in start-up.

NORTH AMERICA:
- o 4,977 active participants have been enrolled at 59 active sites in the US and Canada.
- o An additional 7 sites are in start-up.

AUSTRALASIA:
- o 534 active participants have been enrolled at 5 active sites in Australia and New Zealand.
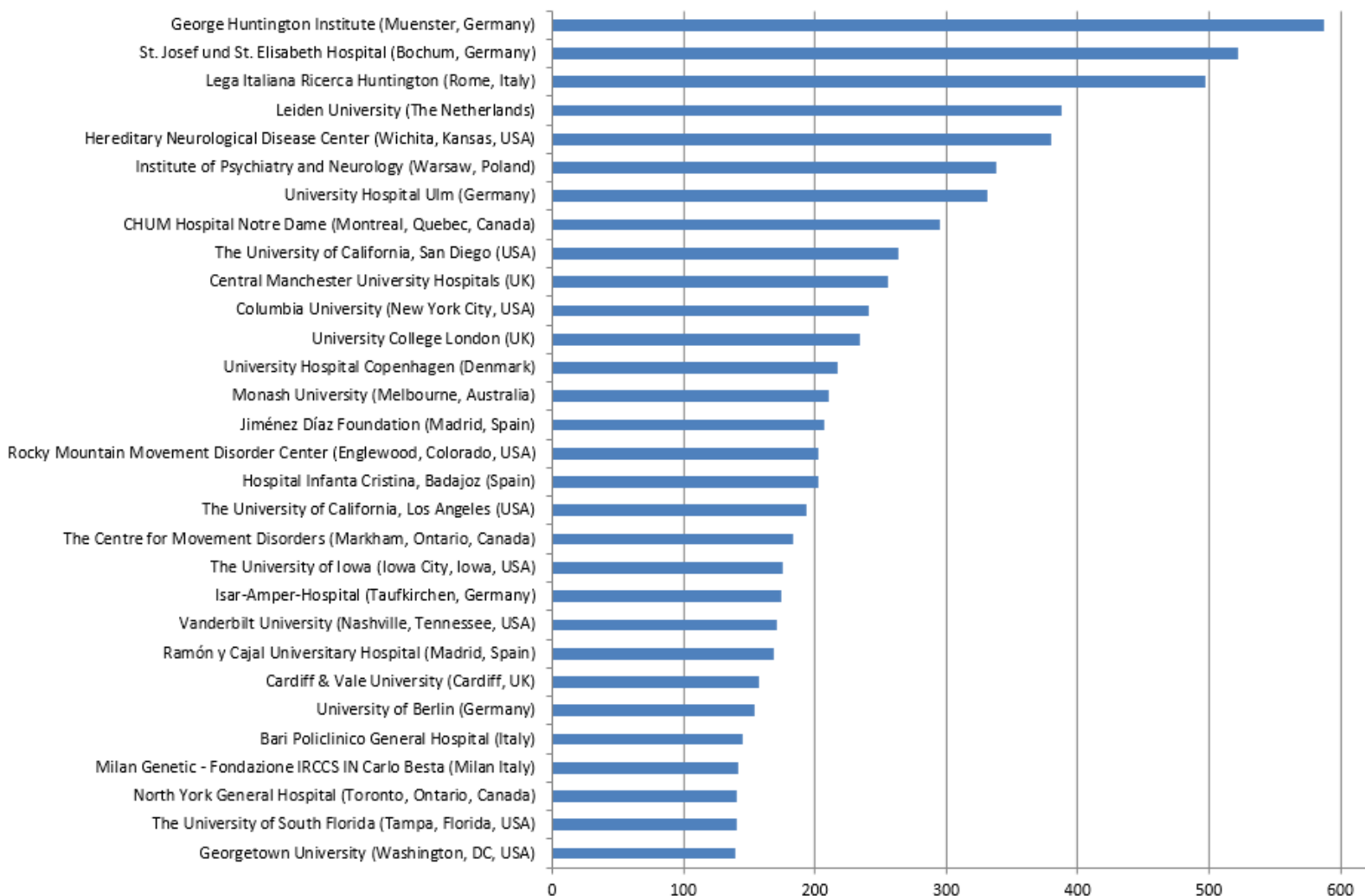- o 2 additional sites have are in start-up.

LATIN AMERICA:
- o 161 active participants have been enrolled at 2 active sites in Argentina and Chile.
- o 6 sites in Argentina, Colombia and Peru are in start-up.

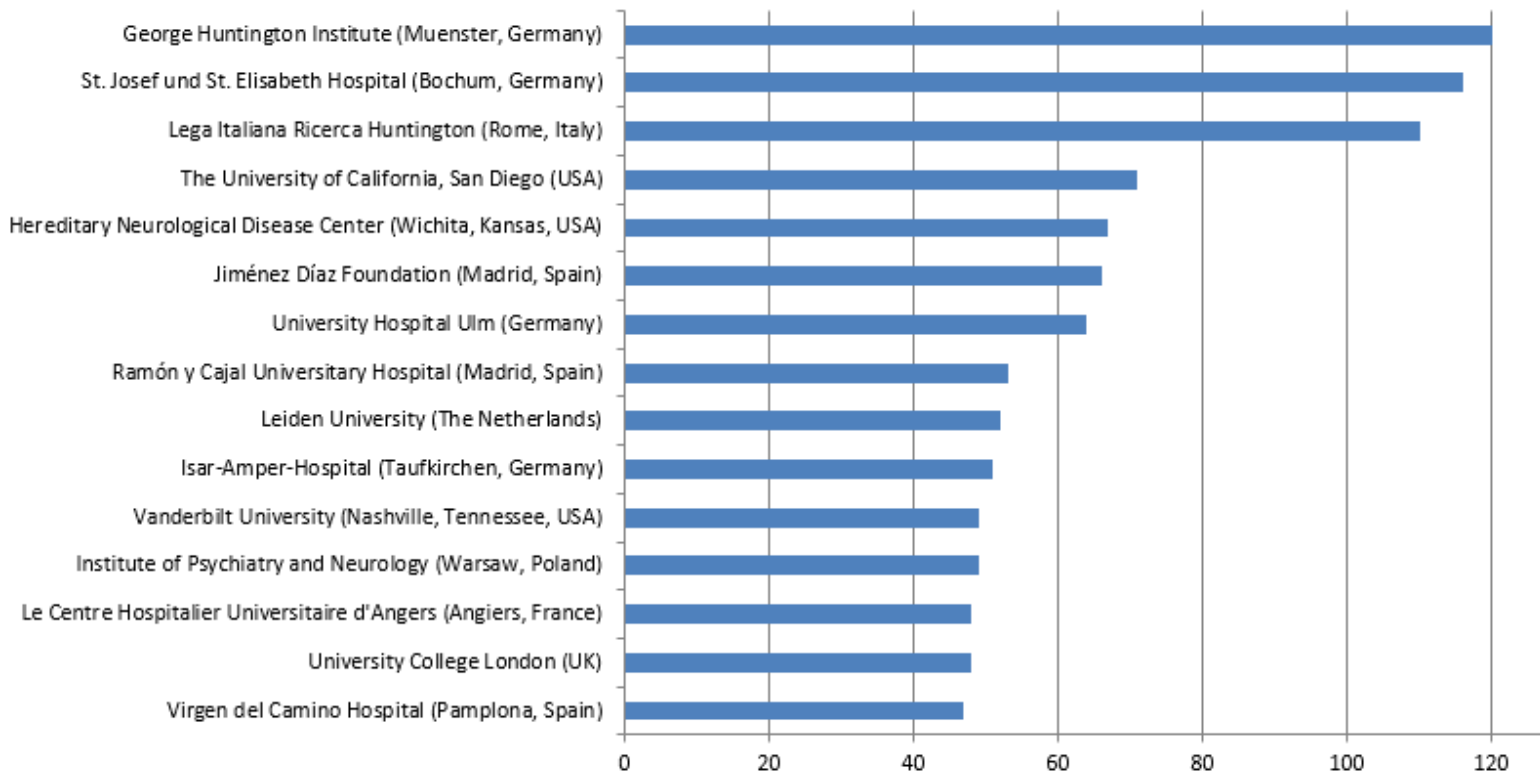**Latest Enroll-HD data release and website update**

- **As of December 15 2016, 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 <u>the types of data and biosamples that are available</u> and the simple and straightforward <u>process to access the Enroll-HD dataset and biosamples at https://www.enroll-hd.org/for-researchers/access-data/</u>. 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. https://www.enroll-hd.org
- 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

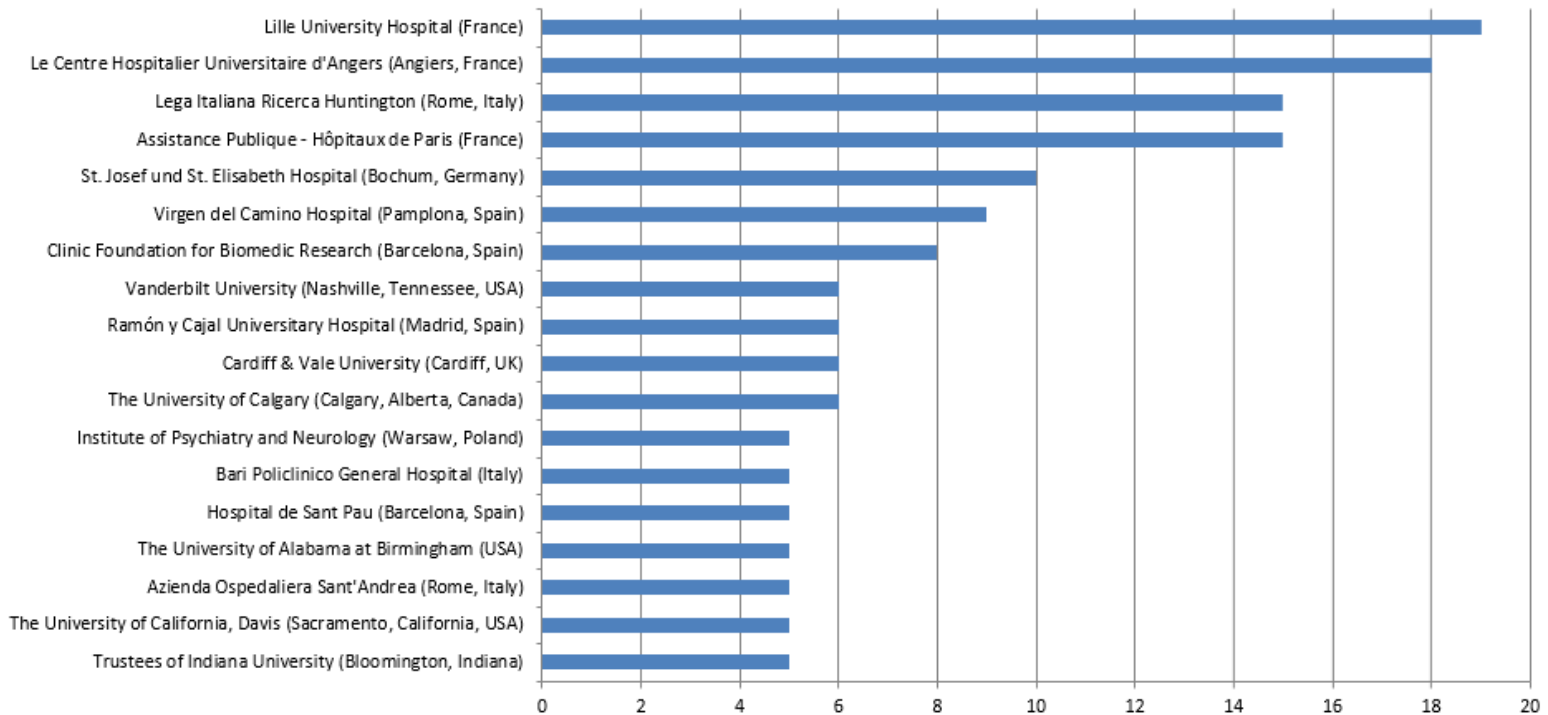## Top Enrolling Sites - Since Study Start (Active Participants)



☆ The top enrolling site is George Huntington Institute (Muenster, Germany) with **587 active participants** enrolled!

## Top Enrolling Sites - Year to Date 2017 (Active Participants)

| Site | |
|------|---|
| George Huntington Institute (Muenster, Germany) | 119 |
| St. Josef und St. Elisabeth Hospital (Bochum, Germany) | 115 |
| Lega Italiana Ricerca Huntington (Rome, Italy) | 111 |
| The University of California, San Diego (USA) | 71 |
| Hereditary Neurological Disease Center (Wichita, Kansas, USA) | 69 |
| Jiménez Díaz Foundation (Madrid, Spain) | 68 |
| University Hospital Ulm (Germany) | 66 |
| Ramón y Cajal Universitary Hospital (Madrid, Spain) | 54 |
| Leiden University (The Netherlands) | 53 |
| Isar-Amper-Hospital (Taufkirchen, Germany) | 52 |
| Vanderbilt University (Nashville, Tennessee, USA) | 50 |
| Institute of Psychiatry and Neurology (Warsaw, Poland) | 50 |
| Le Centre Hospitalier Universitaire d'Angers (Angiers, France) | 49 |
| University College London (UK) | 49 |
| Virgen del Camino Hospital (Pamplona, Spain) | 47 |

## Top Enrolling Sites - Previous Month (October 2017, Active Participants)

| Site | |
|------|---|
| Lille University Hospital (France) | 19 |
| Le Centre Hospitalier Universitaire d'Angers (Angiers, France) | 18 |
| Lega Italiana Ricerca Huntington (Rome, Italy) | 15 |
| Assistance Publique - Hôpitaux de Paris (France) | 15 |
| St. Josef und St. Elisabeth Hospital (Bochum, Germany) | 10 |
| Virgen del Camino Hospital (Pamplona, Spain) | 9 |
| Clinic Foundation for Biomedic Research (Barcelona, Spain) | 8 |
| Vanderbilt University (Nashville, Tennessee, USA) | 6 |
| Ramón y Cajal Universitary Hospital (Madrid, Spain) | 6 |
| Cardiff & Vale University (Cardiff, UK) | 6 |
| The University of Calgary (Calgary, Alberta, Canada) | 6 |
| Institute of Psychiatry and Neurology (Warsaw, Poland) | 5 |
| Bari Policlinico General Hospital (Italy) | 5 |
| Hospital de Sant Pau (Barcelona, Spain) | 5 |
| The University of Alabama at Birmingham (USA) | 5 |
| Azienda Ospedaliera Sant'Andrea (Rome, Italy) | 5 |
| The University of California, Davis (Sacramento, California, USA) | 5 |
| Trustees of Indiana University (Bloomington, Indiana) | 5 |

## Participants Enrolled in October 2017 (By Country)



Legend:
- Ireland
- New Zealand
- Argentina
- Denmark
- Chile
- Australia
- Netherlands
- Canada
- Poland
- Italy
- France
- UK
- Spain
- Germany
- USA

Pie chart values: 0, 0, 2, 1, 1, 4, 10, 15, 9, 34, 57, 71, 20, 35, 24
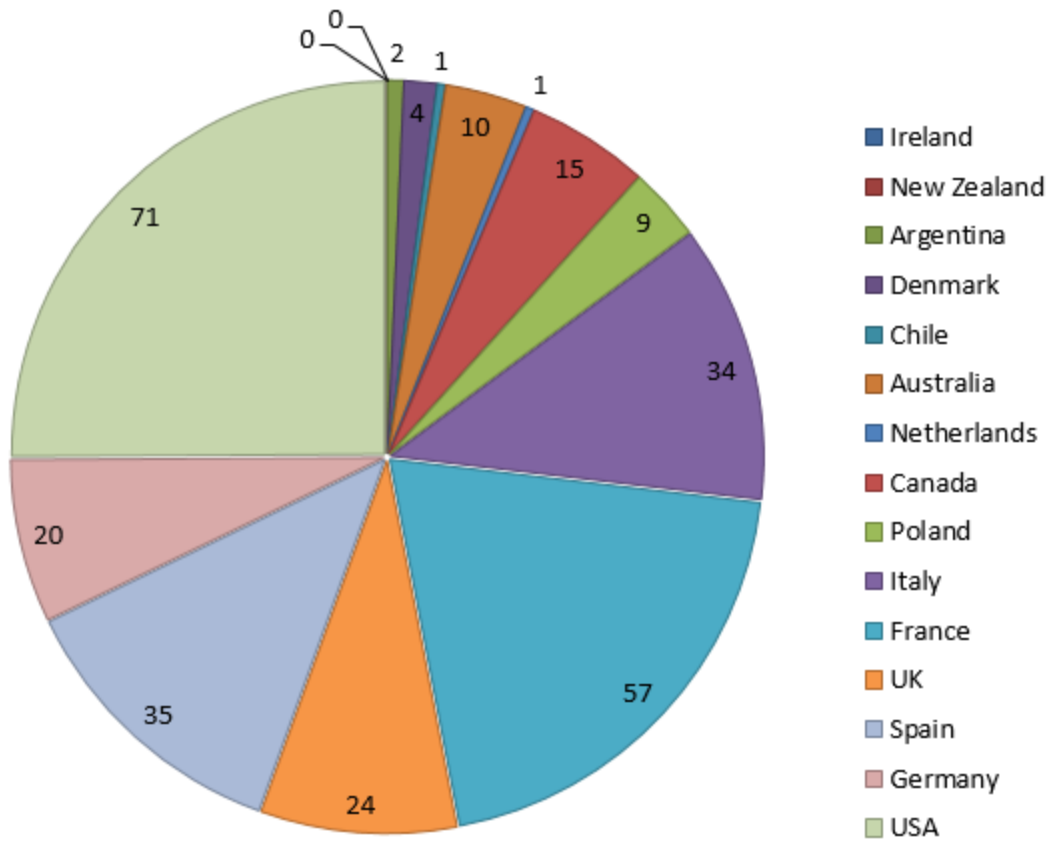
## Follow Up Visits By Month
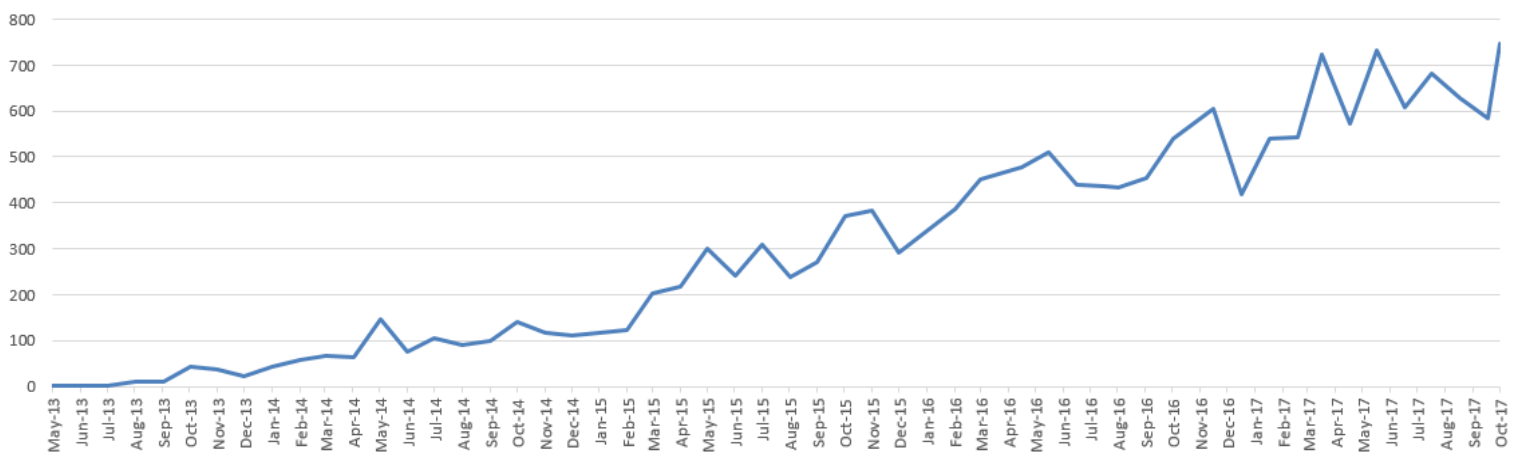


*This graph shows the number of participants per month who have returned to their clinic for their annual follow-up visit.*
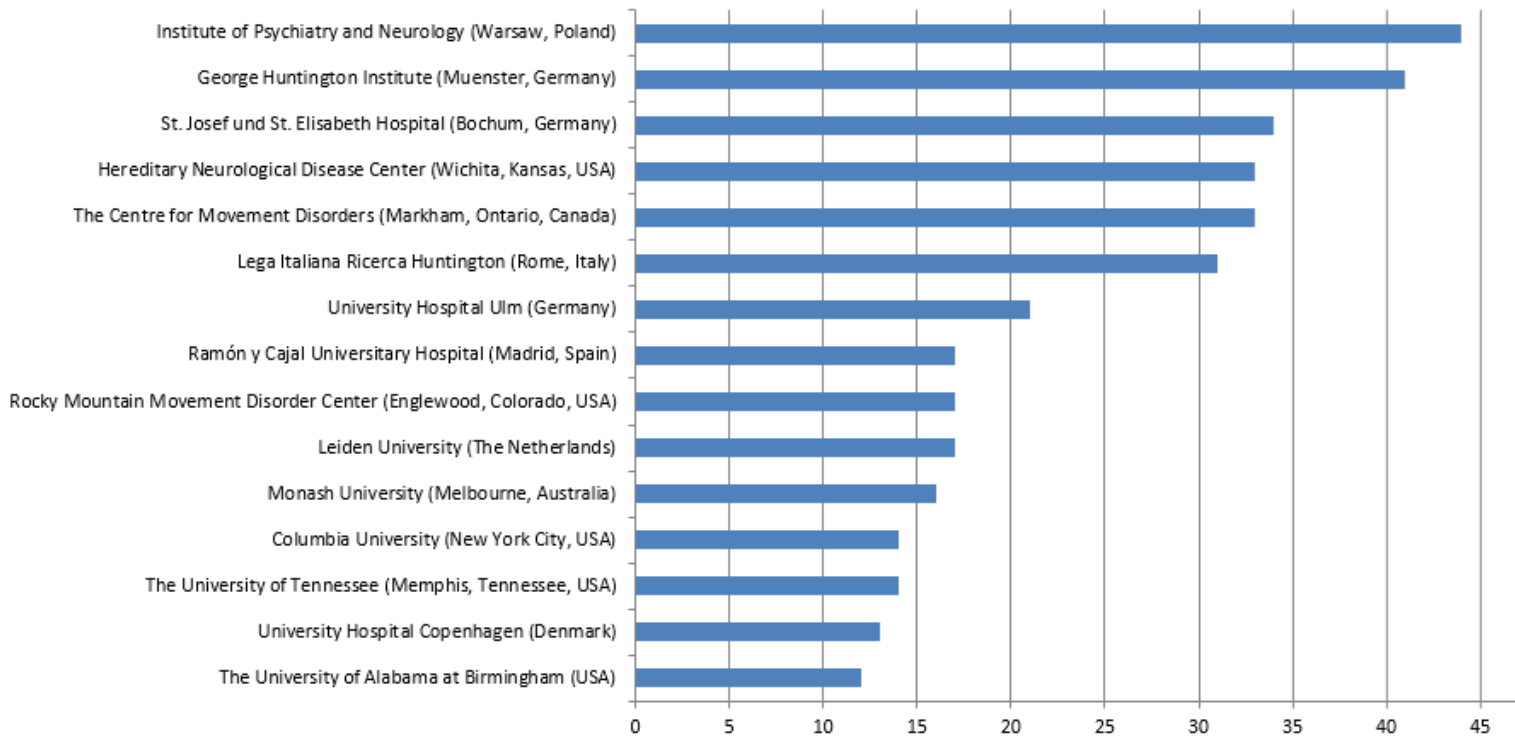
## Most Follow Up Visits Completed - Previous Month (October 2017)

| Institution | Visits |
|---|---|
| Institute of Psychiatry and Neurology (Warsaw, Poland) | 44 |
| George Huntington Institute (Muenster, Germany) | 41 |
| St. Josef und St. Elisabeth Hospital (Bochum, Germany) | 34 |
| Hereditary Neurological Disease Center (Wichita, Kansas, USA) | 33 |
| The Centre for Movement Disorders (Markham, Ontario, Canada) | 33 |
| Lega Italiana Ricerca Huntington (Rome, Italy) | 31 |
| University Hospital Ulm (Germany) | 21 |
| Ramón y Cajal University Hospital (Madrid, Spain) | 17 |
| Rocky Mountain Movement Disorder Center (Englewood, Colorado, USA) | 17 |
| Leiden University (The Netherlands) | 17 |
| Monash University (Melbourne, Australia) | 16 |
| Columbia University (New York City, USA) | 14 |
| The University of Tennessee (Memphis, Tennessee, USA) | 14 |
| University Hospital Copenhagen (Denmark) | 13 |
| The University of Alabama at Birmingham (USA) | 12 |

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

**The Enroll-HD Study Team**