



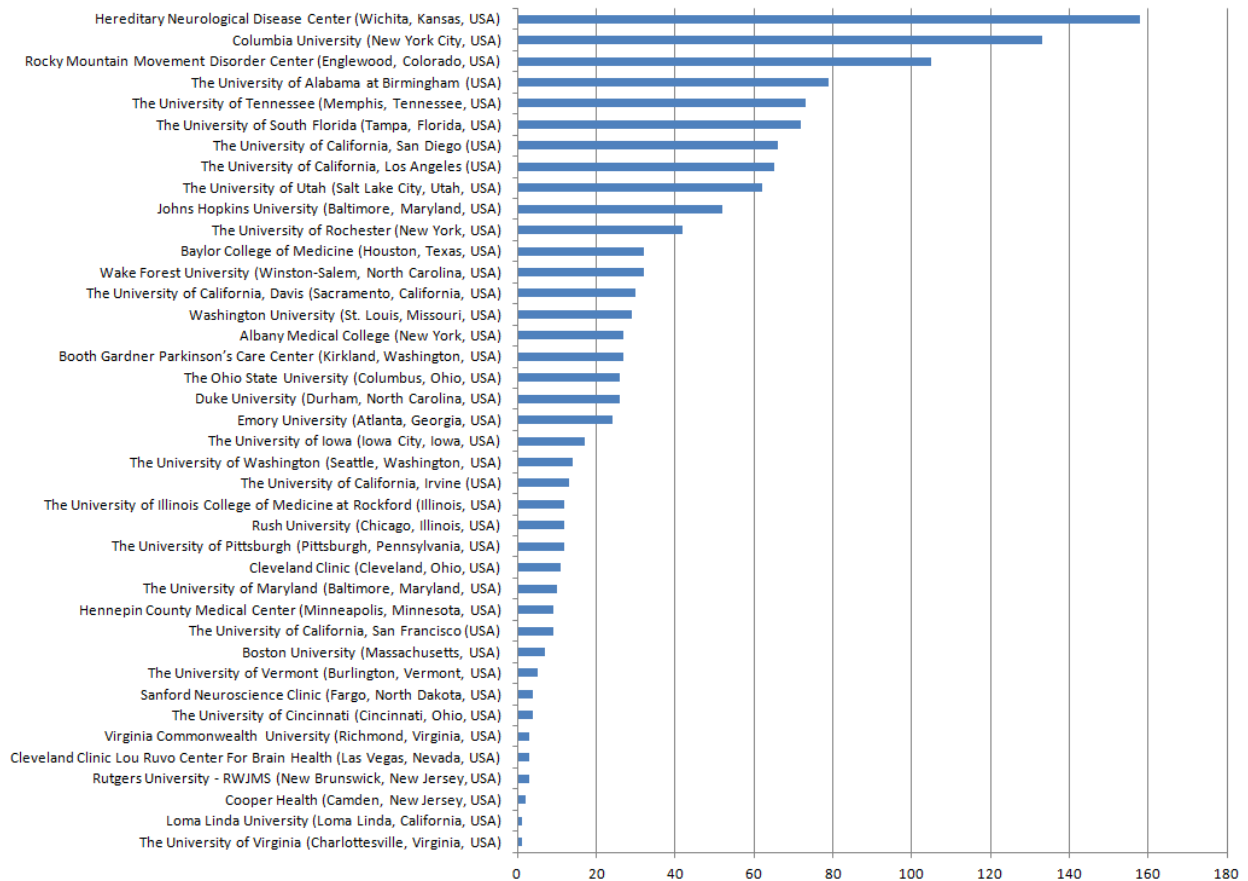
April 2014 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff:

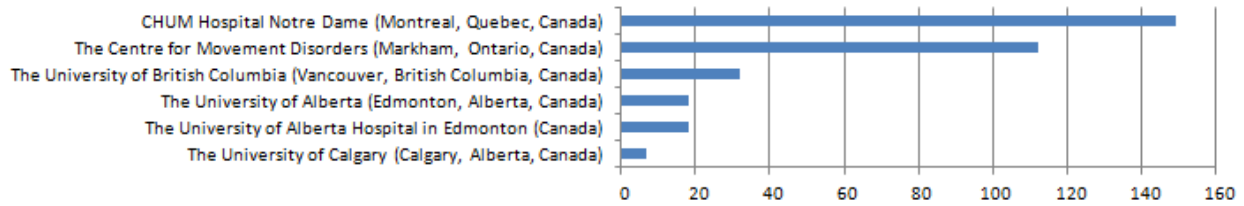
An Enroll-HD progress update over the past month:

- As of April 1st, a total of **1908 participants** have been enrolled at the following 62 sites:

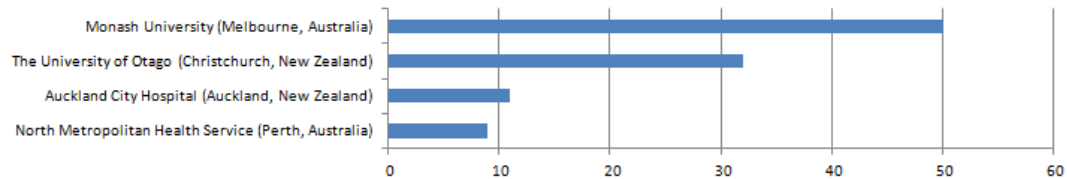
US Sites - Total Enrollment



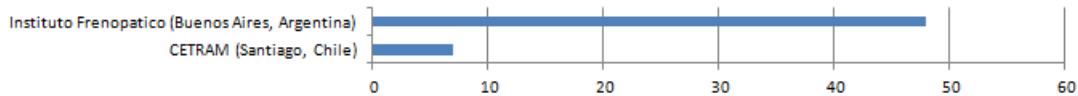
Canadian Sites - Total Enrollment



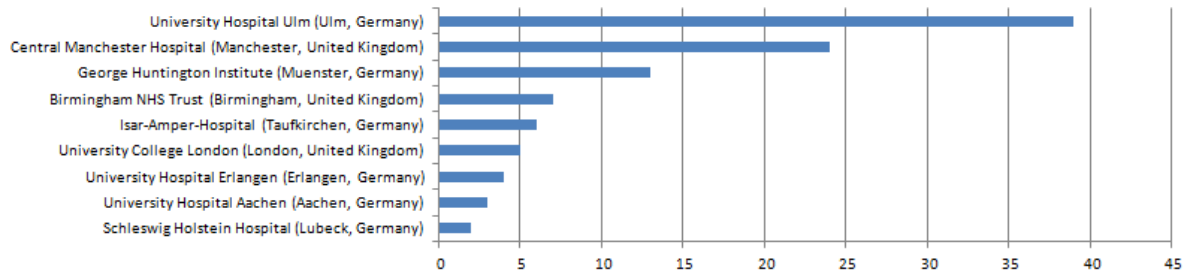
Australia/New Zealand Sites - Total Enrollment



Latin American Sites - Total Enrollment



European Sites - Total Enrollment



★ Top enrolling site is Hereditary Neurological Disease Center (Wichita, Kansas, USA) with **158 participants** enrolled!

- The following sites have completed their two-part site initiation:
 - Kansas University Medical Center (Kansas City, Kansas, USA)
 - Loma Linda University (Loma Linda, California, USA)
 - The University of Chicago (Chicago, Illinois, USA)

Process Reminders and Updates

- BioRep will be closed on April 21st, 25, and May 1st. They will still be able to receive biosample shipments on these days, but biokit re-ordering may be delayed. Sites are encouraged to order biokit shipments before April 16th to ensure there is no delay in their kits being received.
- Printed recruitment materials in English are available for use at your site – please contact Woody Kongsamut (woody.kongsamut@chdifoundation.org) for further details and/or high-quality print copies. These have been approved by Western IRB for use in the US and Canada but may also need to be approved by your local IRB. Local language translations of these materials are currently in process for European and Latin American sites

- The Operations Manual (available on the Enroll-HD EDC under the Operations Manual tab) provides detailed instructions on all aspects of the study, including biosampling, data entry, the informed consent process and Greenphire.
- All fees outlined in your site's contract, including start-up and IRB approval fees, must be requested through the Greenphire eClinical GPS system. CHDI cannot process payments for any paper copy invoices submitted. Please review the eClinicalGPS training materials if you are unsure of the process for submitting an invoice for fees <https://studies.enroll-hd.org/training/greenphire>

Regional Updates

NORTH AMERICA:

- The following sites have enrolled the most participants to date:
 - Hereditary Neurological Disease Centre (Wichita, Kansas, USA) with 158 participants.
 - CHUM Hospital Notre Dame (Montreal, Quebec, Canada) with 149 participants.
 - Columbia University (New York City, USA) with 133 participants.

AUSTRALIA & NEW ZEALAND:

- Monash University is the leading enroller in Australia with 50 participants.
- The University of Otago at Christchurch is the leading enroller in New Zealand with 32 participants.

LATIN AMERICA:

- Instituto Frenopatico in Buenos Aires has enrolled 48 participants to date.
- CETRAM in Santiago, Chile has enrolled 7 patients to date.
- Enroll-HD has been submitted to the Local ERB in Brazil on March 19th, with a reply expected by July 2014.

EUROPE:

- Nine sites have now been initiated in the UK and Germany and there are now over 100 participants enrolled in Europe.
- One further site started the initiation process in March and will soon be activated in full.
- Two further sites in the UK will be initiated in April and another in May.
- The next countries due to start Enroll-HD are the Netherlands, Poland, Italy and Denmark.
- In total, 141 sites have been confirmed for participation in Enroll-HD in Europe and 31 of these have fully executed contracts.

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

The Enroll-HD Study Team

