



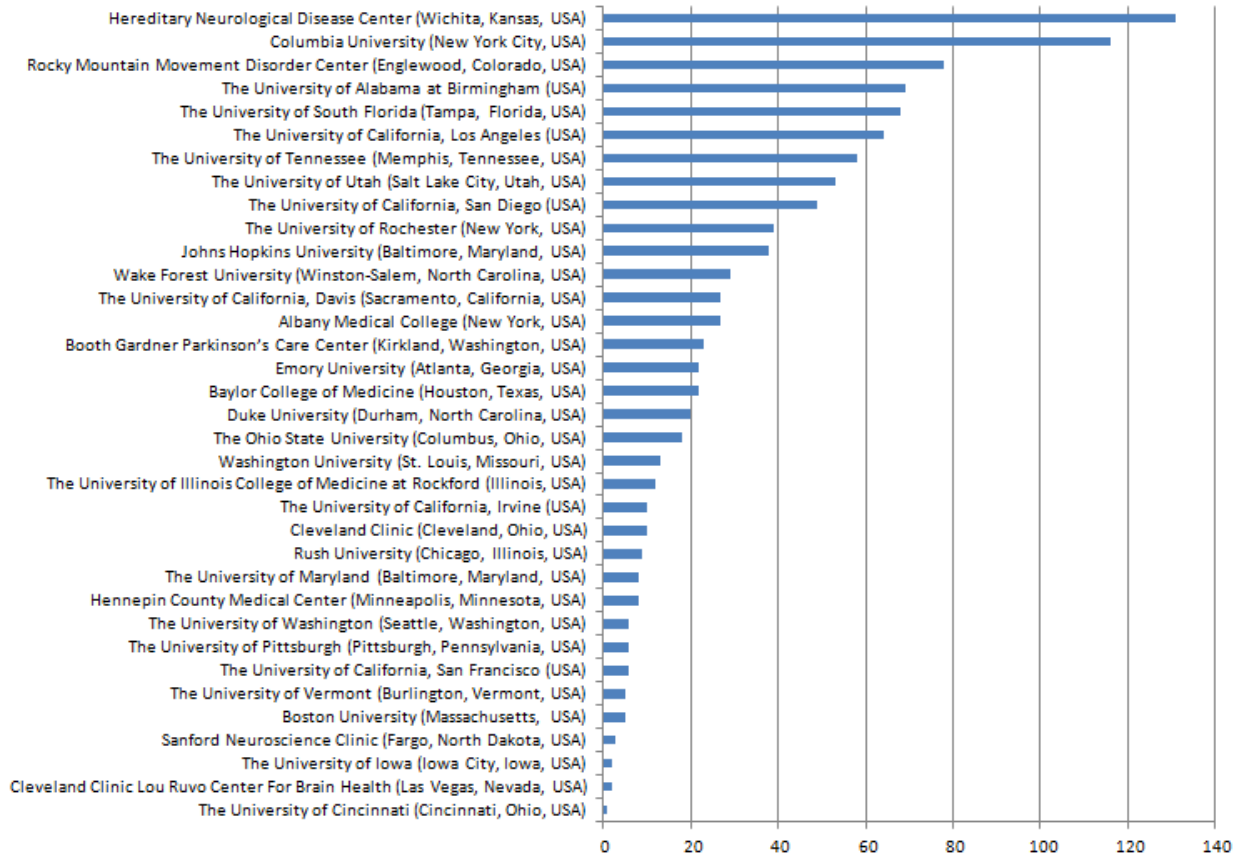
January 2014 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff:

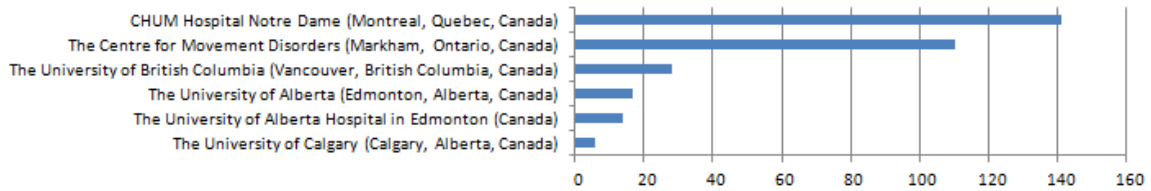
An Enroll-HD progress update over the past month:

- o As of January 1st, a total of **1484 participants** have been enrolled at the following 48 sites:

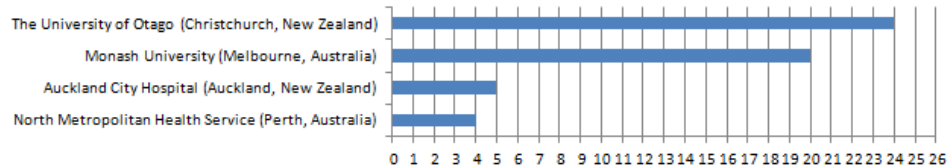
US Sites - Total Enrollment



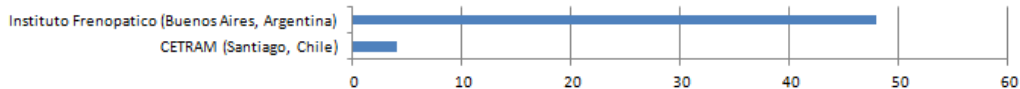
Canadian Sites - Total Enrollment



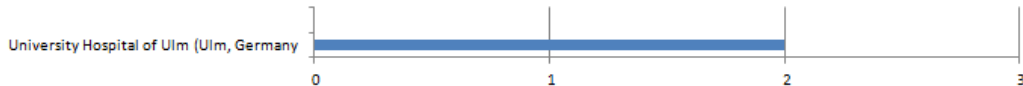
Australia/New Zealand Sites - Total Enrollment



Latin American Sites - Total Enrollment



European Sites - Total Enrollment



★ Top enrolling site is CHUM Hospital Notre Dame (Montreal, Quebec, Canada) with **141 participants** enrolled!

- The following sites have completed their two-part site initiation:
 - Georgia Regents University (Augusta, Georgia, USA)
 - Kansas University Medical Center (Kansas City, Kansas, USA)
 - Loma Linda University (Loma Linda, California, USA)
 - The University of Chicago (Chicago, Illinois, USA)
 - The University of Virginia (Charlottesville, Virginia, USA)
 - Virginia Commonwealth University (Richmond, Virginia, USA)

Process Reminders and Updates

- If your site is utilizing the direct data entry method for data capture, the following paper documents are still required: HDID creation page, Local CAG report (if available), PBA-s assessment, and all cognitive forms. The paper copy of any assessment not completed via direct data entry should be kept in your study files.
- When calculating the amount to put on a participant's ClinCard for travel cost deferral, round trip distance to and from the site should be used.
- If you are using test tubes without barcodes when shipping blood samples due to an issue with one of the pre-labeled tubes, only write the LabID on the tube. **Do not write the participant's HDID, name or any other identifying information.** The LabID is located on the Samples form in the EDC.
- When communicating via email to the Support Team, please use **only the first 4 digits of the HDID.**

- 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. The “I Have a Question” document circulated by the Quintiles Outcome Site Management team on December 13th, 2013 has been added to the FAQ sidebar link in the Operations Manual. (<https://studies.enroll-hd.org/manual/faqs>)
- 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:
 - CHUM Hospital Notre Dame (Montreal, Quebec, Canada) with 141 participants.
 - Hereditary Neurological Disease Centre (Wichita, Kansas, USA) with 131 participants.
 - Columbia University (New York City, USA) with 116 participants.

AUSTRALIA & NEW ZEALAND:

- Monash University is the leading enroller in Australia with 20 participants.
- The University of Otago at Christchurch is the leading enroller in New Zealand with 24 participants.

LATIN AMERICA:

- CETRAM in Santiago, Chile enrolled their first participant on December 26th.
- Instituto Frenopatico in Buenos Aires has enrolled 48 participants to date.
- Regulatory submissions for Brazil are scheduled for January.

EUROPE:

- The University of Ulm in Germany has enrolled 6 participants to date.
- Two site initiation visits are scheduled for the United Kingdom in January, with the first participant expected in late January.
- 122 of the 124 confirmed sites in Europe have received their starter packets. Twenty-six site contracts have been fully executed.

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

The Enroll-HD Study Team

