



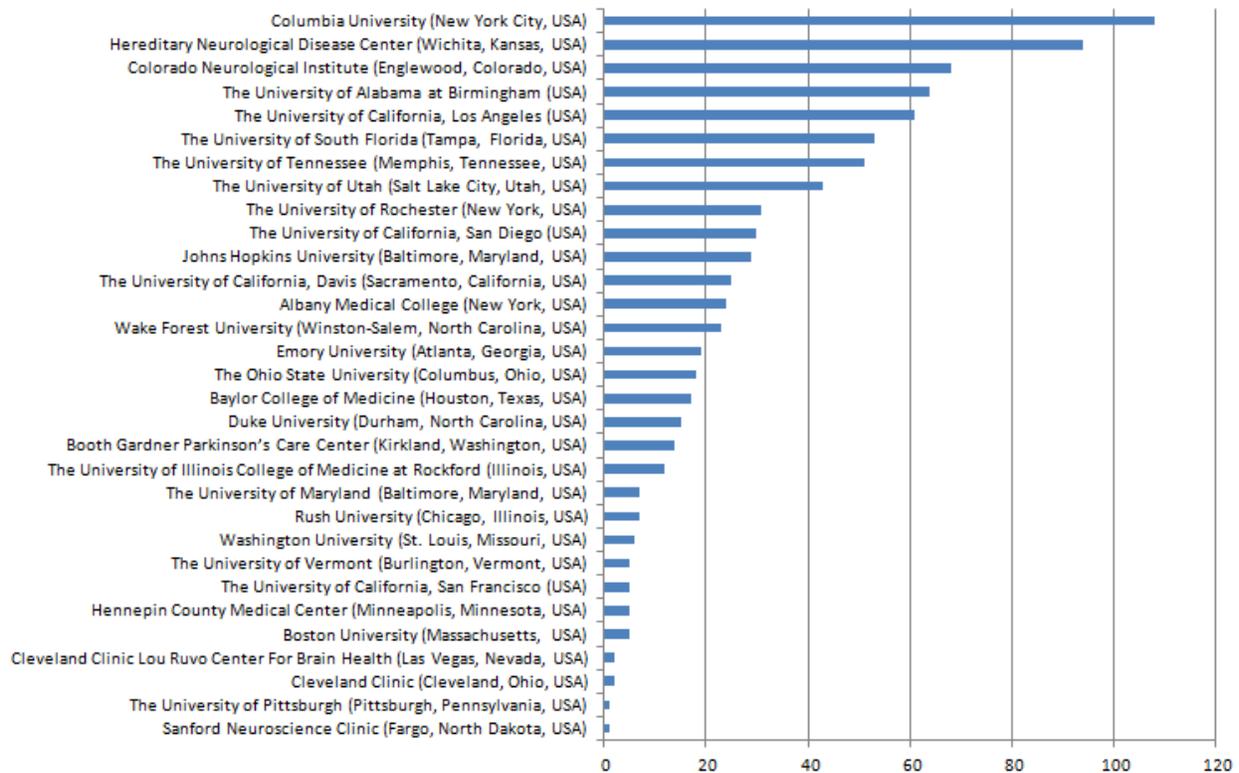
October 2013 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff:

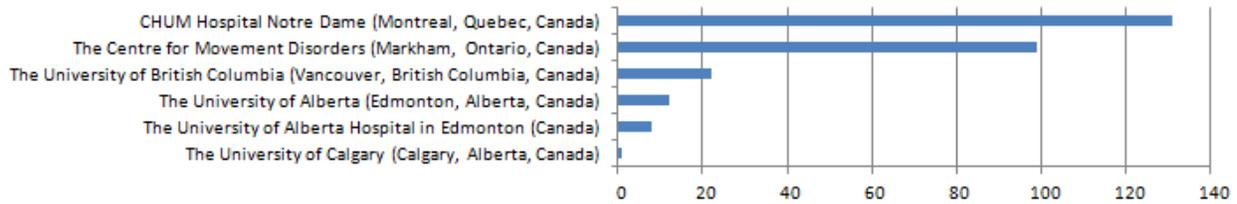
An Enroll-HD progress update over the past month:

- As of October 1st, a total of **1182 participants** have been enrolled at the following 40 sites:

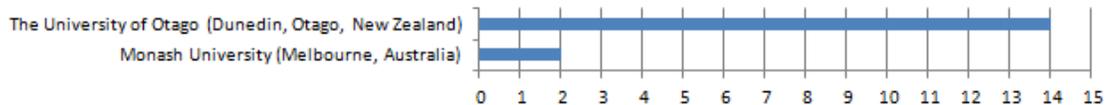
US Sites - Total Enrollment



Canadian Sites - Total Enrollment



Australia/New Zealand Sites - Total Enrollment



Latin American Sites - Total Enrollment



★ Top enrolling site is CHUM Hospital Notre Dame (Montreal, Quebec, Canada) with **131 participants** enrolled!

- The following sites have completed their two-part site initiation:
 - Auckland City Hospital (Auckland, New Zealand)
 - Loma Linda University Medical Center (Loma Linda, California, USA)
 - The Neurosciences Unit (Perth, Australia)
 - University of Washington Medical Center (Seattle, Washington, USA)
 - Virginia Commonwealth University (Richmond, Virginia, USA)

Process Reminders and Updates

- The Enroll-HD Steering Committee met in Rio de Janeiro, Brazil at the World Congress on Huntington's Disease on September 20th. The Medical Monitoring Plan, Scientific Strategy Plan (located at <https://www.enroll-hd.org/html/wg/spc/docs>) and a proposal for genotyping the full mHTT allele were approved by the committee. The committee also approved the addition of the following countries to Enroll-HD: Israel in 2014 and Columbia and Venezuela in 2015.
- A letter regarding the recruitment of Family Controls has been distributed to all participating sites. The recruitment of Family Controls is not to exceed 25% of the total enrollment at each site. Please limit the number of family controls to a maximum of every 1 in 4 persons recruited.
- The Data Safety Monitoring Committee (DSMC) held a teleconference on September 13th to review the Reportable Events and CAG discrepancies.

Regional Updates

NORTH AMERICA:

- The following sites have enrolled the most participants to date:
 - CHUM Hospital Notre Dame (Montreal, Quebec, Canada) with 131 participants
 - Columbia University (New York City, USA) with 108 participants
 - The Centre for Movement Disorders (Markham, Ontario, Canada) with 99 participants

AUSTRALIA & NEW ZEALAND:

- The University of Otago in Christchurch, New Zealand has enrolled 14 participants to date.
- Auckland Hospital in New Zealand had their site initiation visit on September 11th and plans to enroll their first participant in October.
- Westmead Hospital in Sydney, Australia has submitted the protocol and informed consent form to the Ethics Committee for their review.

LATIN AMERICA:

- Instituto Frenopatico in Buenos Aires has enrolled 48 participants to date.
- The first site in Chile, CETRAM (Centro de Estudios de Trastornos del Movimiento), has their Site Initiation Visit scheduled for October 10th.
- The Brazilian Investigator Meeting occurred on September 18-19, 2013 in Rio de Janeiro, Brazil.

EUROPE:

- Regulatory submissions have been completed for Germany, Italy and Spain and are planned for France, Poland, and Austria.
- The University of Ulm, Germany has received ethics approval and will be the first site to transition to Enroll-HD in November 2013.
- Sites in Austria, Norway, Russia and Switzerland have received their starter packs.
- Twenty-two site contracts have been fully executed.
- Special thanks to all of our colleagues at the EHDN who have been working tirelessly closing out the REGISTRY study and preparing for the transition to Enroll-HD – we would not be able to do it without you. Great job!

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

The Enroll-HD Study Team

