

From: [EnrollHD](#)
To: [EnrollHD](#)
Subject: Enroll-HD February News Bulletin
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[image003.png](#)



February 2013 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff:

An Enroll-HD progress update over the past month:

- × As of February 8th, a total of 268 participants have been enrolled at the following sites:
 - The University of Tennessee Health Science Center (Memphis, Tennessee, USA)
 - The Centre for Movement Disorders (Markham, Ontario, Canada)
 - CHUM Hospital Notre Dame (Montreal, Canada)
 - Colorado Neurological Institute (Englewood, Colorado, USA)
 - Hereditary Neurological Disease Center (Wichita, Kansas, USA)
 - Johns Hopkins University (Baltimore, Maryland, USA)
 - The University of California, Los Angeles (USA)
 - The University of Utah (Salt Lake City, Utah, USA)
 - The University of South Florida (Tampa, Florida, USA)
 - The Ohio State University (Columbus, Ohio, USA)
 - The University of Illinois College of Medicine at Rockford (Rockford, Illinois, USA)
 - The University of Rochester (Rochester, New York, USA)
 - Wake Forest University School of Medicine (Winston-Salem, North Carolina, USA)
 - The University of Alabama at Birmingham (USA)
 - Top enrolling site is Columbia University (New York City, NY, USA)
with 56 participants enrolled!

- × The following sites have completed their two-part site initiation:
 - Albany Medical College (Albany, New York, USA)
 - The University of California, San Diego (USA)
 - Kansas University Medical Center (Kansas City, Kansas, USA)
 - Emory University (Atlanta, Georgia, USA)
 - Rush University (Chicago, Illinois, USA)
 - The University of British Columbia (Vancouver, Canada)

- The University of California, Davis (USA)
- The University of California, San Francisco (USA)
- × The following sites are scheduled for initiation:
 - Virginia Commonwealth University Parkinson's and Movement Disorder Center (Richmond, Virginia, USA)
 - Duke University (Durham, North Carolina, USA)
 - The University of Cincinnati (Cincinnati, Ohio, USA)
 - The University of Maryland (Baltimore, Maryland, USA)
 - Hennepin County Medical Center (Minneapolis, Minnesota, USA)

Training

- × A reminder to all sites regarding the sign-off of Case Report Forms (CRFs) in the Electronic Database Capture (EDC) system. All individual CRF forms must be signed by a site user after data entry is complete, and the visit itself (Baseline, Annual Follow-Up, General, Family History) must also be signed by a site user before the visit can be flagged as ready for monitoring and then approved for payment.
- × A new feature of the EDC system is the availability of the Research Participant ID (also called the Greenphire ID) in the Participant Overview Grid. The Research Participant ID is used by Greenphire to generate site payments for data entry. To maintain consistency and accuracy, all sites should check to make sure that the Research Participant ID log in their site binder is consistent and matches the version now found on the Participant Overview Grid in the EDC. If any discrepancies are found, please make the correction in the paper version in your site binder.
- × Please remember to monitor the number of biosamples kits you have on-site. If your site needs additional biosamples kits, please contact your Outcome Site Management representative. It can take up to 10 business days to receive your kits, so please plan accordingly and closely monitor the number of kits you have at all times.

Regional Updates

NORTH AMERICA:

- × The following sites have enrolled the most participants to date:
 - Columbia University (New York City, New York, USA) with 56 participants
 - The Centre for Movement Disorders (Markham, Ontario, Canada) with 54 participants
 - Hereditary Neurological Disease Center (Wichita, Kansas, USA) with 27 participants
- × As previously reported, the NIH has issued Enroll-HD a Certificate of Confidentiality (CoC). All informed consent forms (ICFs) must be updated to reflect this additional language. If your site does not yet have approved ICFs, the language will be inserted before approval. If your ICFs are already approved, they must be amended to reflect this change. Amanda Klock at CHDI (Amanda.klock@chdifoundation.org) will help facilitate this process. Please

note, per the NIH, the language relating to the CoC cannot be altered.

AUSTRALIA & NEW ZEALAND:

- Four of the five sites in Australia are ready to submit to their Ethics Committee, with the first submission expected to occur in within the next few weeks.
- The study protocol is anticipated to be submitted to the Ethics Committee in New Zealand this month.

LATIN AMERICA:

- The first site in Argentina is expected to be initiated in late February or early March 2013.
- Regulatory submissions for Chile, Peru and Brazil are anticipated in February or March 2013.

EUROPE:

- Regulatory submissions are scheduled to begin in late February or early March for the following countries: Belgium, Denmark, Germany, Ireland, Italy, Netherlands and the United Kingdom.
- The distribution of starter packs and site contracts will begin in February for the sites with regulatory submission in February or March 2013.

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

The Enroll-HD Study Team

