



January 2013 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff:

An Enroll-HD progress update over the past month:

- As of January 21th, a total of 227 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)
 - Colorado Neurological Institute (Englewood, Colorado, USA)
 - Hereditary Neurological Disease Center (Wichita, Kansas, 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 50 participants enrolled!

- The following sites have completed their two-part site initiation:
 - The University of California, San Diego (USA)
 - Kansas University Medical Center (Kansas City, Kansas, USA)
 - Emory University (Atlanta, Georgia, USA)
 - CHUM Hospital Notre Dame (Montreal, Canada)
 - Johns Hopkins University (Baltimore, Maryland, 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)
 - Albany Medical College (Albany, New York, USA)
 - Rush University (Chicago, Illinois, USA)

- Duke University (Durham, North Carolina, USA)
- The University of Cincinnati (Ohio, USA)
- Hennepin County Medical Center (Minneapolis, MN, USA)

Training

- All North American sites received an email with useful information regarding the entering of International Statistical Classification of Diseases and Related Health Problems (ICD10 codes) into the Enroll-HD database, including a listing of the 50 most frequently used ICD10 codes in Enroll-HD.

Regional Updates

NORTH AMERICA:

- The following sites have enrolled the most participants to date:
 - Columbia University (New York City, NY, USA) with 50 participants
 - The Centre for Movement Disorders (Markham, Ontario, Canada) with 49 participants
 - Hereditary Neurological Disease Center (Wichita, Kansas, USA) with 25 participants
- As reported in last month's bulletin, the NIH has issued Enroll-HD a Certificate of Confidentiality (CoC). We are therefore obligated to include standard language provided by the NIH that explains what the CoC covers to Enroll-HD research participants. If your informed consent forms have already been approved then they will need to be amended. Amanda Klock at CHDI (Amanda.klock@chdifoundation.org) will help facilitate this process. Please note that the CoC language was given to us by the NIH and has to be inserted without being changed.

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 January.
- The protocol is anticipated to be submitted to the Ethics Committee in New Zealand in January or February.

LATIN AMERICA:

- The first site in Argentina has received Ministry of Health Approval and conditional Ethics Committee (EC) approval.
- Regulatory submissions for Chile, Peru and Brazil are anticipated in February or March 2013.

EUROPE:

- Regulatory submissions are scheduled to begin in Q1 2013 for the following countries: Belgium, Denmark, Germany, Ireland, Italy, Netherlands and United Kingdom.
- The distribution of starter packs and site contracts will begin in February for the sites with regulatory submission in Q1 2013.

We would like to welcome Amanda Klock to the study team! Amanda is a new project manager at CHDI and she will be working closely with Maggie and Meherazade.

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

The Enroll-HD Study Team

