



September 2012 Monthly News Bulletin

Dear Enroll-HD Investigators and Site Staff:

We are very pleased to announce that the following goals and study milestones were met this month:

- The University of Tennessee Health Science Center (Memphis, Tennessee, USA), the Centre for Movement Disorders (Markham, Ontario, Canada), and Columbia University (New York City, NY, USA) have enrolled 39 participants as of September 13th.
- The Study Team conducted the remote portion of the Site Initiation Visits at the following sites:
 - Hereditary Neurology Disease Center (Wichita, Kansas, USA)
 - Kansas University Medical Center (Kansas City, Kansas, USA)
 - University of South Florida (Tampa, Florida, USA)
- The Participant and Site Working Group held their last meeting on September 6th and have agreed upon a draft Site Council Charter that will be reviewed by the Steering Committee. Thank you to all of the members of this working group for all of your hard work!
- The Joint Steering & Scientific Planning Committee Meeting occurred on September 17th during the EHDN Plenary in Stockholm, Sweden to further discuss the scientific direction of Enroll-HD and finalize the strategic planning process. Once complete, the scientific plan will be made available to the HD research community.

Regional Updates

- NORTH AMERICA:
 - Columbia University enrolled their 1st participant on Friday, September 14th.
 - Please continue to contact Maggie Seay and Meherazade Sumariwalla at CHDI for all informed consent negotiations and issues. Maggie can be reached at (609) 945-9057 or maggie.seay@chdifoundation.org and Meherazade can be reached at (609) 945-9795 or meherazade.sumariwalla@chdifoundation.org.
- AUSTRALIA & NEW ZEALAND:
 - Template informed consents have been finalized.
 - Site start-up document packages are scheduled to be distributed to sites by the end of September.
- LATIN AMERICA:
 - The team is gearing up for regulatory submissions.
 - We plan to submit the regulatory documents for Argentina at the end of September 2012.
 - The team is also working to prepare regulatory submissions for Chile and Peru this year and Brazil in Q1 2013.
- EUROPE:

- The EU Transition Working Group is in the process of planning the regional transition activities from REGISTRY to Enroll-HD. The group is aiming for the first set of EU countries to begin submissions in Q1 2013 with site activations anticipated in Q3 2013. This group includes Denmark, Germany, Ireland, Italy, Netherlands and the United Kingdom.

Many thanks for your support in helping Enroll-HD achieve its goals.



The Enroll-HD Study Team