



International Parkinson and
Movement Disorder Society

Task Force on the Definition of Huntington's
Disease Meeting Agenda
Manchester Grand Hyatt: Balboa C
June 15, 2015 | 7:00-8:00am

Minutes, CR 10/20/15

Chair: Christopher Ross

Co-Chairs: Francisco Cardoso, Ralf Reilmann

Task Force Members Present: Blair Leavitt, Claudia Testa, Sarah Tabrizi, Anne Young, Zhong Pei, Julie Stout, Jamie Levey, Asuncion Martinez, Teresa Sjrager, Kevin Biglan, Elizabeth McCusker

Apologies: David Craufurd, Bernhard Landwehrmeyer,

Staff Liaison: Kristy Moeller

I. The meeting began with brief introductions of all in attendance

II. Discussion of Goals: The primary goal is to develop a refined set of diagnostic categories for HD and promulgate to the community and recommend revisions to the ICD.

- A. The group discussed the Diagnostic categories based on the MDS article (Reilmann, Leavitt and Ross 2014) as starting point to refine the diagnostic categories for Huntington's Disease
- Topics of discussion focused on dividing HD in a premanifest period and a manifest period, with the premanifest period to be further subdivided into Pre-symptomatic (no signs or symptoms) and Prodromal (subtle signs or symptoms not yet clearly definable as manifest HD).
 - There was discussion of the value of refining these categories for the purposes of research as well as clinical care, and administrative and psychosocial issues such as employment and disability determination.
 - There was also discussion of how to apply these categories to individuals who have had predictive testing for the CAG repeat expansion vs. those who have not been tested.
- B. The group then discussed the plan for publication in MDJ co-authored by committee members
- The conversation included discussion of alternative possible journals as well as the possibility that there may be publications focusing on specific issues such as cognition or disability. There was discussion that it would be important to disseminate the work of the committee beyond the movement disorder neurology community as HD patients are often seen by general neurologists, psychiatrists, geneticists, internists or other practitioners.
 - It was recommended by Prof. Cardoso to apply for open access
- C. President Matt Stern, who was present for the beginning of the meeting, shared his enthusiasm about the Task Force, and believes it can redefine the "playing field" and have an impact on healthcare policy. He suggested starting with small committees with manageable goals

III. Plan for meeting/Process

A. In Person meeting

- Discussion focused on where to have an in person meeting, and what the most appropriate time would be. The question of a standalone meeting or having one tied to another meeting was raised. If we have it in tandem with another meeting, one possibility would be to have it in tandem with the MDS meeting in Berlin June 19-23 2016.
- Additional attendees at an in-person meeting would include experts on imaging, health care policy, cognition, and other areas.

B. Website

- It was agreed that a web site should be set up to disseminate the work of the group, and to receive ideas and suggestions from members of the community
- Dr. Reilmann stated he was in favor of starting web based work to gather ideas and thoughts prior to an in person meeting, and this met with general agreement
- The website will include these minutes, the MDS article (Reilmann, Leavitt and Ross 2014), the review on which it is based (Ross et al 2014), and solicitation for comments, suggestions and ideas, and provision for individuals to register and make comments and suggestions.

IV. Funding

- A. CHDI has expressed interest and is renewing a contract with MDS. The question of where CHDI fits in was raised. It was also asked if funding from other sources may be accepted and if so what the process is.
- B. The process for applying to CHDI will need to be clarified so it can be pursued.

Action items:

The chairs will draft a timeline and milestones to include the need and location and timing of an in-person meeting and products needed.

***The Secretariat will also review the Commissioned Paper Process with the Chairs
There will be a call for volunteers for subcommittees***

The Secretariat will provide more information about the process for applying for funding directly to Dr. Ross

