

Report for WFN Huntington Disease Research Group

August 13, 2011

A very successful Congress in Melbourne with over 500 attendants together with the International Huntington Association (IHA) held in September 11-14, 2011.

The next congress will be held in Rio de Janeiro. We are very happy that by a lot of efforts of the European Huntington Disease Network (EHDN) in the person of Prof Bernard Landwehrmeijer in collaboration with the RCHD a new network on HD started in Latin America. The first major step is the next meeting in September 2014.

One other important activity is the setup of the revised concept on the genetic guidelines for premanifest testing on Huntington disease. A first revision of our guidelines (dating from the nineties) was prepared by a working group in the EHDN, circulated in the HD community worldwide, professional as well as IHA. The concept was discussed during the world congress in Melbourne. A writing committee edited the last version, that is accepted and will be published in due time in the *Clinical Genetics**. A true example of collaboration in the world community on HD under auspices of the WFN RCHD. This new guideline/recommendation will be on the agenda every two years during the World congress.

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*Macleod R, Tibben A, Frontali M, Evers-Kiebooms G, Jones A, Martinez-Descales A, Roos R; Editorial Committee and Working Group 'Genetic Testing Counselling' of the European Huntington Disease Network. Recommendations for the predictive genetic test in Huntington's disease. *Clin Genet*. 2012 May 29;9999(9999). doi: 10.1111/j.1399-0004.2012.01900.x. [Epub ahead of print]