

Report for WFN Huntington Disease Research Group

April 24, 2013

Following the discussion on the international platform about premanifest testing in persons at risk for Huntington's disease during the World Congress in Melbourne in 2011 the writing committee delivered an article about this topic. (The ref is attached and was published on the WFN website). During the next World Congress in Rio de Janeiro next September, one session is planned for further discussion and development of this guideline.

Following this, the discussion was restarted about genetic testing of affected or probably affected persons from known and also unknown families. This will result in another publication which is now almost finalised. The lead for that is by Dr David Craufurd and Rhona Macleod.

The intention of the guidelines is to spread this among as many as possible colleagues around the world to improve patient care. In all processes the lay organisation for Huntington Disease is heavily involved.

MacLeod R, Tibben A, Frontali M, Evers-Kiebooms G, Jones A, Martinez-Descales A, Roos RA; 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. 2013 Mar;83(3):221-31.