

# INTERNATIONAL HUNTINGTON ASSOCIATION

## President

### Statement on behalf of the International Huntington Association (IHA) and World Federation of Neurology Huntington Disease Research Group (WFNRG)

#### Predictive Genetic Testing for Huntington Disease

It has come to the attention of the IHA and WFN that genetic testing for Huntington Disease is sometimes carried out in circumstances that contravene internationally agreed guidelines. Examples include inadequate (or absence of) pre- and post-predictive test counselling and the predictive testing of children.

Huntington Disease (HD) is a progressive neurodegenerative condition for which there is currently no cure. HD is an autosomal dominant condition, i.e. each child of an affected parent has a 50% risk of inheriting the HD gene fault. Predictive testing by direct mutation analysis became available in many countries after 1993. The complete version of the International Guidelines for the Predictive Genetic Test in Huntington Disease is now available to read on line at:

<http://onlinelibrary.wiley.com/doi/10.1111/j.1399-0004.2012.01900.x/abstract>

We wish to highlight the following key principles of HD predictive testing:

- The request for predictive testing by an adult at risk of HD, should always be an autonomous decision. Any pressure to test from a third party (such as an employer or adoption agency) is unethical and in direct contravention of the Guidelines.
- HD is typically an adult-onset disorder, and the purpose of predictive testing is to help an at-risk person deal with the psychological consequences of uncertainty about their genetic status. Some find testing very helpful, but a majority of at-risk individuals prefer not to know in advance of developing symptoms. It is therefore inappropriate for parents to make this decision on behalf of their child. Predictive testing should not be carried out on children too young to make an autonomous decision for themselves.
- It is essential that all individuals considering a predictive test have access to pre- and post-test genetic counselling and support, regardless of their financial circumstances. Laboratories, which offer cut price genetic testing to at-risk individuals without the associated counselling, are violating the internationally agreed guidelines.
- It is highly desirable that genetic testing with the associated counselling should be available to all at-risk members of affected families. Members of the HD lay organisations are encouraged to work closely with governments on this point.
- Individuals should not be discriminated against in any way as a result of predictive testing for Huntington Disease.

If you require further guidance or explanation of the recommendations, please contact Ann Jones, President of the IHA email: [annjones@aapt.net.au](mailto:annjones@aapt.net.au)



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