

## Genetics and Insurance Committee

### October 2000: Huntington's Disease (GAIC/01.1)

The Genetics and Insurance Committee (GAIC) has today announced that the reliability and relevance of the genetic test for Huntington's Disease is sufficient for insurance companies to use the result when assessing applications for life insurance.

Professor John Durant, Chairman of GAIC said:

"Genetic test results are already used in certain circumstances by insurers and the Committee was asked to look at the reliability and accuracy of the genetic test for Huntington's Disease. We have considered carefully the application received from the Association of British Insurers for approval of the use of these tests.

The evidence presented demonstrates that the two tests for the Huntington's gene are reliable and that an abnormal result is associated with significant clinical effects and with an increased probability of a claim on a life insurance policy. This decision will mean that those with a negative test result will not be asked to pay more for life insurance because of their family history of Huntington's disease.

"This decision does not mean that individuals will be asked to have a genetic test for Huntington's Disease before obtaining insurance but, where individuals have already been tested as part of their medical care, then there is nothing to prevent insurance companies asking for that information.

"Many who have a family history of a genetic disorder such as Huntington's Disease have difficulty in obtaining insurance because of their family history. The approval of the two tests for Huntington's Disease will allow insurance to be provided at normal rates to those who have a normal test result. "

A significant amount of data has been collected concerning the effects of Huntington's Disease on life expectancy and on mortality risk as part of the process of reviewing this application. The Committee hopes that the insurance industry will use this information to look at the problems of those who have an abnormal genetic test result and of those who have chosen not to have a genetic test (who have a 50 % chance of carrying the abnormal gene if they have an affected parent).

The GAIC was asked to examine the actuarial evidence for using individual genetic tests. The insurance industry, through the main trade body the Association of British Insurers, has agreed to abide by GAIC decisions. If GAIC decides that the evidence on the reliability and relevance of a particular test is insufficient to justify its use, the Association have agreed to stop using them and retrospectively reassess affected individual insurance premiums. The broader social and ethical issues surrounding the use of genetic tests in insurance and employment have been referred to the new Human Genetics Commission.

An application for approval of two genetic tests for Huntington's Disease was submitted to GAIC by the Association of British Insurers (ABI) in July 2000. The application was sent to a clinical geneticist and an independent actuary for expert review and also to support groups for Huntington's Disease and to the Genetic Interest Group (GIG) for their comments. At their meeting on 28 September, GAIC considered the application, in the presence of observers from the ABI, GIG and Huntington's Disease Association. Their decision is announced today.

The committee recognises that this complex subject is an important issue to the public, industry and government alike. GAIC will work closely with the new Human Genetics Commission when they begin their inquiry into the use of genetic data including in insurance and employment later this year.