

**Response to the ALRC and AHEC Issue Paper 26:
Protection of Human Genetic Information
Genetic Support Council Western Australia (Inc)**

The Genetic Support Council Western Australia (Inc) is the peak body for genetic support groups in Western Australia. The Council has held a round table discussion with representatives from the genetic support groups in order to gain an appreciation and understanding for their opinions of the issues covered in the Issues Paper 26 entitled "Protection of Human Genetic Information".

Although not specifically addressing the questions outlined in the Issues Paper by the inquiry, these views nevertheless provide an important indication of the opinions of genetic support groups in Western Australia.

Chapter 2 - Background and Emerging issues

The genetic support groups felt that genetic information is more unique than other forms of health information due to the vast amount of predictive information it provides, as well as the fact that genetic information is inherent in an individual, and is not acquired. Genetic information was viewed as particularly valuable and unique due to it being a source of information not only on the individual, but also on the individual's blood relatives.

In recognition of this uniqueness, the genetic support groups felt that genetic information should be held at a "higher standard", reflected in specific legislation dealing with the collection, use and disclosure of genetic information. This legislation should apply to research, the workplace, and in the storage of human genetic information particularly. These areas were identified due to their direct influence on the daily lives of individuals with genetic conditions or those with predispositions to genetic conditions such as some forms of cancer.

The genetic support groups believe that such legislation should be at the Federal level so as to ensure uniformity across Australia in terms of genetic information regulation.

Chapter 4- Privacy of genetic information

The genetic support groups felt that the Privacy Act (1988) was inadequate in covering genetic information in terms of its application to workforce issues. The groups felt that the Privacy Act should be modified to include current and past employee records.

Chapter 7- Human genetic databases

Key issues for the genetic support groups in terms of the storage of human genetic information were issues of privacy and confidentiality. They repeatedly voiced their view that protection needs to be given to "my right to have my information kept confidential". They strongly believed that researchers should only work with de-identified samples, and that a code of practice for de-identifying donor samples should be drafted at the federal level to ensure uniformity in practice. However they noted that more information on the de-identification process and what it means would be useful for the groups. Furthermore, the groups expressed the view that genetic

information should not be stored for research purposes for longer than a period of 2 years.

Current guidelines for the collection and use of genetic information for research purposes were seen as too weak by the genetic support groups. In particular, the issue of how consent can be properly obtained for future research purposes when those purposes are not known at the time of consent being given, was important. The groups believe that written consent from the individual should be obtained every time the genetic information is being used for a different purpose.

Although it might not be possible to obtain individual consent every time the information is used, the notion that greater individual control over their own genetic information was expressed strongly by the groups. Therefore, the groups support the concept that individuals have form of property right over their own genetic material in order to protect the privacy of this material.

Chapter 10- Employment and workforce issues

Although the discussion did not have a legal expert present to thoroughly explain current anti-discrimination legislation, it is worth noting that the groups expressed the desire to see specific reference to anti-discrimination on the basis of genetic information included in anti-discrimination legislation both at the State, Territory and Federal level.

The genetic support groups expressed the view that although anti-discrimination laws may already be in place and cover discrimination on the basis of genetic status, they felt that these laws would not make a difference to the workplace. This is due to the lack of knowledge held by the general community about genetic conditions. The groups felt this lack of knowledge would result in discrimination regardless of laws. In particular, the groups expressed the opinion that individuals with genetic conditions are discriminated against throughout life and therefore may be reluctant to take action for a variety of reasons, as illustrated in the example below.

Example 1

A man with a genetic condition felt that he was increasingly being discriminated against in his place of work, which he attributed to his genetic condition. Although aware of anti-discrimination legislation and despite the urging of companions within the genetic support group to which he belonged, he was reluctant to exercise these anti-discrimination rights. The primary reason for this reluctance was a fear of possible negative repercussion both immediately and into the future.

In terms of employers requesting genetic information or being allowed to request employees take a genetic test, the genetic support groups felt that it would be acceptable for employers to request such information only if it is related to an Occupational Health and Safety issue. Asking for such information simply as a matter of course in recruitment was deemed unacceptable. Further this information should be only be accessed by necessary personnel within the company.

The genetic support groups felt strongly that genetic tests should not be allowed to be requested by employers. For those individuals who have been diagnosed with a predisposition to a genetic condition, the degree to which that condition manifests itself or becomes a hindrance to a person's ability to fulfil the essential criteria of a job is unpredictable.

Chapter 11- Insurance

The genetic support groups were strongly opposed to the idea that their genetic information could be used by insurance companies for underwriting purposes.

The groups felt that insurance companies should not be legally allowed to request or use genetic information. This view stems from the concern that insurance companies may not understand the range of genetic tests available, such that a test for a predisposition to a condition not yet present may be treated in the same manner as a diagnosis of a current debilitating condition. The groups felt that genetic tests should be treated differently from other tests, such as urinalysis due to the variable predictive nature of genetic information. In addition, the range of effects the condition has on the individual's level of functioning and the possible over-estimation of this is of great concern to the genetic support groups.