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Tim Grimwalde
General Manager
Adjudication Branch
Australian Competition & Consumer Commission
PO Box 1199
Dickson ACT 2602

Dear Mr Grimwalde

Application for Revocation and Substitution Authorization Nos A30200 and A30201 lodged by the Investment and Financial Services Association

On the 12 December you wrote Ms Michele Kosky of the Health Consumers Council (HCC) inviting the HCC to comment on the above matter. Ms Kosky forwarded your correspondence to the Genetic Support Council WA (GSCWA) as she felt the GSCWA would be a more appropriate body to provide comment. Ms Kosky is a member of the Board of Management of the GSCWA.

The Genetic Support Council WA (Inc) is newly formed not for profit organisation that acts as a peak body for genetic support groups in Western Australia, in particular those groups who have elected to become members of the Council. Currently, some forty three genetic support groups in Western Australia have elected to become members of the GSCWA.

The need for this peak body to coordinate and enhance the effectiveness of community genetic support groups was identified in *The Review of State-wide Delivery of Genetic Services in Western Australia*, conducted in April/May 2000. Following that review, a number of genetic support groups established a working committee to bring this to fruition. The Committee proposed that the Genetic Support Council WA (Inc) fulfil the following roles:

- Promote awareness of genetic diseases in the community;
- Encourage and support effective and efficient management and service delivery practices within genetic support groups;
- Assist in the greater participation of consumers in policy, planning, research and service delivery across the genetic services field;
- Develop and contribute to policies of common concern to genetic support groups and;

- Provide genetic support information, resources and referral services to individuals and genetic support groups;
- To promote leadership and cooperation between non-government and community organisations within the genetic services field; and
- Act as a mentor for the genetic support groups.

The first Annual General Meeting of the GSCWA was held on the 20 May 2002 and a Board of Management appointed.

The Public Health Genomics Branch of the Department of Health has been responsible for allocating resources for the development of this initiative.

In relation to insurance and genetic privacy the GSCWA has held a forum with genetic support groups and discussions with a number of representatives from genetic support groups and interested parties as a part of its response to the *ALRC and AHEC Discussion paper 66: Protection of Human Genetic Information*. Additionally, many of the issues had been canvassed previously when providing a response to Issues Paper 26 regarding the same matter.

Every effort has been made to ensure that members views were fully represented throughout the GSCWA'S submission to the ALRC and responses are within the general theme of the discussions that took place. The general thrust of the GSCWA response may best be summarized as:

- That the highest standards be adopted in the protection of genetic information and the individuals privacy.
- That every attempt be made to harmonize legislation and integrate this at State/Territory and Federal levels.
- Consumer/community consultation is paramount in the establishment of any bodies or further development of legislation/regulation.
- That where possible, duplication of roles be avoided.
- That particular attention be given to matters of discrimination in areas such as employment and insurance. **Genetic support groups vigorously oppose the used of genetic testing in assessing insurance risk.**

Furthermore, the GSCWA wishes to participate in the process of ensuring that there is effective consumer/community representation by the genetic support community. This is particularly important in relation to Western Australia, but hopefully with the possible development of a national network of peak genetic support bodies in 2003, a much more national perspective will also be available.

The following is an extract from the GSCWA'S response to the ALRC with respect to proposal 24-1 to 9 and 25-1 and 2 and reflects the general opinions and views expressed by genetic support groups in Western Australia in relation to both Issues Paper 26 and Discussion Paper 66.

“24. Genetic Discrimination in Insurance

Proposal 24–1. *Although there is no demonstrated justification for departing from the fundamental principle underlying the market in voluntary, mutually rated personal insurance (namely, equality of information between the applicant and the insurer),*

where the underwriting of such insurance involves the use of human genetic information, the process of underwriting should be subject to the qualifications identified in Proposals 24–3 to 24–9 below.

Supported

Proposal 24–2. The proposed HGCA should monitor the experience of the insurance industry in using genetic information in underwriting, both in Australia and overseas, with a view to reviewing Australian insurance practices at a later time.

Supported

Question 24–1. Should there be a fundamental change to the way in which genetic information is used to underwrite personal insurance, such as the introduction of a two-tier system; a prohibition on the use of genetic information; or a public subsidy for poorer risks?

It would seem that genetic information should only impact on underwriting personal insurance if there is real increase in risk over and above that within the normal population. It is felt that reasons given by insurers for the perceived increase risk should be clear and meaningful and that they explain the actuarial or statistical basis for the risk. It would seem desirable to prohibit the use of genetic information outside these confines. Public subsidy for poorer risks would seem desirable if an individual cannot obtain insurance or the cost of premiums are excessive.

Question 24–2. Should an adult applicant for insurance be obliged to disclose the result of a genetic test undertaken while that person was a child?

It is difficult to see how information like this could be withheld if it would have a bearing on the level of risk. If however, the test was negative or did not constitute an increase in risk in relation to the insurance being sought, then emphatically no. There would need to be some safeguard for a situation where the person did not know they had undergone a test or did not have access to the results.

Proposal 24–3. No predictive genetic test should be used by insurers in underwriting mutually rated insurance unless the test has been approved for that purpose by the proposed HGCA.

Supported

Question 24–3. Would Proposal 24–3 be implemented most effectively through an industry code or legislation? If the latter, should this be through amendment to: (a) the insurance exemption in anti-discrimination legislation; (b) the duty of disclosure in the Insurance Contracts Act 1984 (Cwth); or (c) both?

It is felt that Industry codes have generally been found to be somewhat limited. Legislation is strongly recommended as the most effective means of achieving an appropriate outcome. The most important aspect of any legislation is that it is effective, that it does what it proposes to do which sometimes isn't the case, and that it can be easily enforced. Additionally, sanctions should be meaningful. Whether or not either of these pieces of legislation are the most appropriate to meet this need or new legislation is required may best be addressed by others better qualified in these matters.

Proposal 24–4. *The insurance industry, through its peak bodies and in consultation with the proposed HGCA, should develop and publish policies on the use of family medical history for underwriting mutually rated insurance.*

Supported

Proposal 24–5. *The Insurance Contracts Act 1984 (Cth) should be amended to clarify the nature of the obligation of an insurer to provide written reasons for an unfavourable underwriting decision. Where such a decision is based on genetic information, the insurer should give reasons that are clear and meaningful and that explain the actuarial or statistical basis for the decision.*

Supported.

Proposal 24–6. *The Disability Discrimination Act 1992 (Cth) and related legislation should be amended to clarify the nature of the information required to be disclosed by an insurer and to ensure that the complainant is entitled to access to the information so disclosed.*

Supported

Proposal 24–7. *The insurance industry, through its peak bodies, should develop a policy regarding the provision of reasons by an insurer to an applicant in response to an unfavourable underwriting decision based on family medical history. The policy should ensure that the reasons given are clear and meaningful and that they explain the actuarial or statistical basis for the decision.*

Supported

Proposal 24–8. *The insurance industry, through its peak bodies, should develop appropriate mechanisms for reviewing underwriting decisions involving the use of genetic information. Such reviews should be:*

- *conducted in a timely and efficient manner;*

• **Supported**

- *undertaken by a panel of individuals, each of whom is independent of the insurer that made the decision;*

• **Supported**

- *carried out by suitably qualified individuals with a demonstrated understanding of insurance law and anti-discrimination law, underwriting practice, and clinical genetics; and*

Appropriate community/consumer involvement should be included in this process to ensure the views of genetic support groups and their members are considered.

- *binding on the insurer but not on the complainant.*

Supported

Proposal 24–9. *The insurance industry, through its peak bodies, should review its policies and practices in relation to the training and education of industry members and their authorised representatives in relation to the nature, collection and use of genetic information in insurance.*

Supported

25. Insurance and Genetic Privacy

Proposal 25–1. *Insurers should review their consent forms, including medical authority forms, to ensure that they contain sufficient information about the collection and use of genetic information to allow applicants to make an informed decision about whether to provide the information.*

Supported

Question 25–1. *Does the practice of ‘bundling consents’ by insurers undermine the ability of an applicant to make an informed decision about whether to provide genetic information to an insurer? If so, what measures should be taken to address this problem?*

Due to the complexity of genetic information and the need for individuals to clearly understand what is required by the way of genetic information it would seem desirable that such requests are clear and concise. Relevant forms and documentation by insurers need to be presented in such a way as to enable informed decisions to be made. Currently this is not always the case.

Proposal 25–2. *Insurers should seek a Public Interest Determination under the Privacy Act in relation to the practice of collecting family medical history from applicants for use in underwriting insurance policies in relation to those applicants. A PID may have far reaching implications in terms of obtaining insurance and needs to be considered with great care. Adequate safeguards need to be considered for third parties unless these safeguards are in place, then the proposal is not supported.*

Question 25–2. *Is there evidence that genetic information is shared between various arms of insurance organisations? If so, does this practice raise concerns about the protection of the privacy of genetic information? How might these concerns be addressed?*

The GSCWA does not have any evidence to support the view that genetic information is shared in this manner. Protection of a individuals privacy of genetic information is a serious concern and if this can take place then legislation needs to be enacted to prevent the practice. The sharing of general non identifiable information is another matter. “

The GSCWA is aware that the Investment and Financial Services Association (IFSA) lodged an application with the Australian Competition and Consumer Commission (ACCC) in 1999, to avoid a possible contravening of the provisions of the *Trade Practices Act 1974*, seeking authorisation for IFSA members to work within agreements:

- not to require applicants for life insurance to undergo genetic testing,

- not to induce applicants to undergo genetic testing by offering discounts based on favourable test results.

It is the GSCWA understanding that this current application seeks to extend the time for IFSA members to continue their agreed practice to not require applicants for life insurance to undergo genetic testing for a period up to 31 December 2005. During this time, it is expected that the Report of the Inquiry into the Protection of Human Genetic Information will be completed, legislation and/or regulations will be drafted and the IFSA will be able to work within a new set of guidelines.

The GSCWA supports the proposal as it is consistent with anticipated developments in this area. Ms Kosky of the Health Consumers Council also supports the GSCWA'S position on this matter.

Yours Sincerely

Terry Keating
Executive Director