



**Australian Government**

**Australian Law Reform Commission**

**Professor David Weisbrot  
President**

Mr Scott Gregson  
The General Manager  
Adjudication Branch  
Australian Competition and Consumer Commission  
PO Box 1199  
DICKSON ACT 2062



14 October 2005

Dear Mr Gregson

**Application for revocation and substitution (A90986 & A90989) lodged by the Investment and Financial Services Association (IFSA)**

Thank you for your letter received today, drawing to my attention the application lodged with the ACCC by the Investment and Financial Services Association (IFSA) seeking, in effect, an extension of the authorisations for its Genetic Testing Policy for a further five years (or for six months after any legislative action that touches on this policy).

As you are aware, the Australian Law Reform Commission (ALRC), and the Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council conducted a major, national inquiry into the Protection of Human Genetic Information, which culminated in the tabling in Parliament in May 2003 of the two-volume, 1200 page report *Essentially Yours: The Protection of Human Genetic Information in Australia* (ALRC 96, 2003). The full text of the report is available on the ALRC's website, at <http://www.alrc.gov.au/inquiries/title/alrc96/index.htm>.

The focus of the joint inquiry was on three key matters relating to human genetic information, and the tissue samples from which such information may be derived, how best to:

- protect privacy interests;
- guard against unfair discrimination; and
- ensure the highest possible ethical standards.

These central concerns were then tracked across a wide array of contexts, including (among other things): access to genetic testing; oversight of genetic research; the operation of human genetic databases, registers and tissue banks; the provision of clinical genetic health services; insurance; employment; immigration; sport; parentage testing, kinship and identity; law enforcement; and DNA evidence in court.

Australian Law Reform Commission  
Level 25, 135 King Street  
Sydney NSW 2000

Postal Address:  
GPO Box 3708  
Sydney NSW 2001 Australia

Tel (+61-2) 8238 6333  
Fax (+61-2) 8238 6363  
TTY (+61-2) 8238 6379  
DX 1165 Sydney  
Web [www.alrc.gov.au](http://www.alrc.gov.au)  
Email [president@alrc.gov.au](mailto:president@alrc.gov.au)

Part 'G' of the final Report (Volume 2, chapters 25-28) is devoted to a detailed consideration of the use of genetic information—both genetic *test* information as well as inferences drawn from family medical history—by the Australian insurance industry for underwriting/risk-rating purposes. The report also looks at how these issues are handled in other jurisdictions, including the US, Canada, the UK and a number of European countries.

The inquiry made 16 recommendations for reform in this Part of the Report, aimed mainly at improving consumer protection, ensuring fair and scientifically-grounded underwriting practices, and promoting greater transparency and accountability by the insurance industry. To summarise briefly, the ALRC:

- called on the Commonwealth to establish a Human Genetics Advisory Commission to advise, consult, educate and set standards on matters of human genetics—both the rapidly advancing science and technology, and the consequent ethical, legal and social implications. (This recommendation has been implemented, with the announcement in the May Budget that a Human Genetics Advisory Committee would be established as a new principal committee of the NHMRC, to come into existence in early 2006, and with an allocation of \$7.6M for this purpose.) The HGAC also should be assigned the specific role of advising on the suitability and interpretation of genetic tests for underwriting purposes, and maintain a 'watching brief' over the use of genetic information by insurers in Australia and overseas; and
- called on insurers (through IFSA) to:
  - develop and publish policies on the use of family medical history—a form of genetic information that is already heavily used for underwriting purposes (unlike genetic test information, which is still relatively rare);
  - provide applicants with clear and meaningful reasons for unfavourable underwriting decisions based on genetic information; in turn, the industry's review and appeal mechanisms should be expanded and improved to cover these types of adverse underwriting decisions; and
  - develop education and training programs about the use of genetic information for insurance agents and brokers—the persons who deal directly with members of the public.

The Report also examined the privacy protections afforded to genetic information in the insurance context. Although the insurance industry holds vast amounts of sensitive personal information, submissions reflected a reasonable degree of satisfaction with the industry's practices in this area. However, the inquiry identified three areas in which reforms should be made to ensure more effective privacy protection, calling on insurers to:

- review their standard medical consent forms to ensure that these contain sufficient information about the collection, use and disclosure of genetic information to allow applicants to make informed decisions;
- refrain from 'bundling' requests for consent to collect genetic information together with consent for other purposes; and

- apply to the Federal Privacy Commissioner for a Public Interest Determination under the *Privacy Act* if they wish to continue to collect family medical histories from insurance applicants.

IFSA's Genetic Testing Policy is specifically considered in Chapters 25, 26 and 27. The Terms of Reference for the ALRC-AHEC Inquiry did not ask us to address the anti-competitive effects (if any) of IFSA's Genetic Testing Policy—probably because that is normally the ACCC's brief rather than ours.

As a general matter, however, it would be fair to say that those aspects of IFSA's Genetic Testing Policy that gave rise to ACCC scrutiny are in accordance with the basic thrust of *Essentially Yours* in terms of developing sound public policy in this sensitive area. Predictive genetic testing is highly complex and contingent, and only should be undertaken for health reasons on the advice of a clinical geneticist, with appropriate pre- and post-test counselling. Any policy that would actively encourage people to undergo such genetic testing purely in pursuit of reduced insurance premiums would not be in the public interest.

As the ALRC noted in *Essentially Yours*, it is very important that we provide adequate protections against the *unlawful* use of genetic information; however, it is absolutely essential that we put into place measures and strategies to ensure that where such information may be used lawfully, it will be used ethically, fairly and intelligently.

Please do not hesitate to contact me if you have any questions or require any further information.

Yours sincerely,



Prof David Weisbrot  
President  
Australian Law Reform Commission