



Professor Alan Pettigrew

Mr Scott Gregson
General Manager
Adjudication Branch
Australian Competition & Consumer Commission
PO Box 1199
DICKSON ACT 2602

Dear Mr Gregson

I refer to the interim response from the National Health and Medical Research Council (NHMRC) dated 11 October 2005. I am now making this submission on behalf of the NHMRC on the request from the Investment and Financial Services Association (IFSA) to revoke Authorisations A90857 and A90869 and substitute them with Authorisations in identical terms.

The content of clauses 10.1 and 10.3 appear reasonable and in line with the relevant recommendations in the joint Australian Law Reform Commission and Australian Health Ethics Committee report *Essentially Yours: The Protection of Human Genetic Information in Australia*.

As you are aware, the Australian Government has provided funding of \$7.6 million over four years from 2005-06 to establish the independent expert advisory body on human genetics recommended in *Essentially Yours* as a principal committee of the NHMRC – the Human Genetics Advisory Committee (HGAC). The Minister for Health and Ageing, the Hon Tony Abbott MP, has agreed to the terms of reference and composition of the committee, a copy of which is attached. Membership of the HGAC is currently being identified, and it is expected that the HGAC will commence operations in January 2006.

In relation to the approvals requested by IFSA, it is consistent with the Terms of Reference for the HGAC that it could consider the application of a genetic testing policy to insurance if requested to do so. Bearing in mind that the HGAC will only be established from January 2006, and without wishing to pre-empt its work program, I envisage that it might take the HGAC some time to fully consider this matter, including the wider issues of consent forms, privacy, disclosure, storage of data and the extent to which genetic information provided to an insurer might be shared within the organisation (see for instance clause 10.10 of the IFSA Standard).

The application requests that an extension of either 5 years or 6 months after legislation to implement the recommendations of the HGAC is enacted, whichever happens the soonest, be granted. As the HGAC is an advisory body it is not possible to predict the nature of any recommendations it might make. Clearly, any recommendation that involves legislation would need to be considered by Government before implementation.

Taking the above into consideration, and having regard to the historical life of similar authorisations, it seems reasonable to allow an extension for two years, pending consideration of the issue by the Human Genetics Advisory Committee and advice to the ACCC.

The contact officer in the NHMRC is Dr Greg Ash on (02) 6289 9860.

Yours sincerely

A handwritten signature in black ink, appearing to read "Alan Pettigrew". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Professor Alan Pettigrew
Chief Executive Officer

4 November 2005

cc Dr Kerry Breen, Chair, Australian Health Ethics Committee

Human Genetics Advisory Committee

Functions

The Human Genetics Advisory Committee, through Council, will provide on-going, high-level advice on:

- the technical and strategic aspects of current and emerging issues in human genetics and related technologies, particularly the expected impacts on human health and healthcare;
- the ethical, legal and social implications arising from developments in human genetics and related technologies, including consideration of any impact on human rights; and
- other matters as the Minister from time to time determines.

In exercising these responsibilities the Committee will provide:

- relevant expertise and a consultative mechanism for the development of policy statements and national guidelines in the area of human genetics and related technologies, where appropriate in association with other government agencies or the relevant industries and organisations;
- national leadership in the process of change relating to human genetics and related technologies, including engagement of the public on these issues;
- national leadership in identifying genetic tests that have particular concerns or sensitivities attached to them and thus may require special treatment;
- assistance with the development and coordination of community, school, university and professional education about human genetics;
- advice and a consultative mechanism to assist relevant bodies in identifying strategic priorities for research in human genetics and related technologies; and
- a focus for the coordination and integration of various national, regional and international programs and initiatives.

Constitution

The Committee should be comprised of up to 12 members, plus the Chair, with expertise covering the following areas:

- health and medical researchers, with an emphasis on human genetics;
- community representatives, including health consumer advocacy and genetic and disability support groups;
- business experts relevant to human genetics;
- medical practitioners with experience in health services;
- genetic counsellors;
- persons with experience in the ethics of health and medical research;
- lawyers with experience in privacy, discrimination and health law matters;
- science communicators;
- persons with experience in data management, health informatics or information security; and
- Aboriginal and Torres Strait Islander communities.

The membership should also:

- include at least one and no more than two from any of the above categories so as to be balanced and cover a broad-based range of expertise, experience and perspectives;
- be balanced as to gender and geographic distribution; and
- include a member in common with the Australian Health Ethics Committee (in accordance with subsection 36(2) of the *National Health and Medical Research Council Act 1992*).