



The Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Secretary

Thank you for providing an opportunity for the National Health and Medical Research Council (NHMRC) to comment on the Senate Inquiry into Gene Patents. NHMRC notes that this enquiry, which aims to investigate the potential impact of gene patenting in Australia, follows on from both the Australian Law Reform Commission (ALRC) 2004 report "Genes and Ingenuity: Gene Patenting and Human Health", and the Australian Government's Advisory Council on Intellectual Property (IP) review, in the "Review of Patentable Subject Matter".

These reviews, as will the Senate Inquiry, have considered concerns raised regarding the impact of individual companies patent enforcement policies on healthcare. For example the IP relating to BRCA1 and BRCA2 genes.

The NHMRC has raised issues in the context of these previous reviews, relating to costs and access, equity, quality assurance and research. These are on the public record.

It is important to ensure that gene patenting does not pose a hindrance to acquiring further knowledge through research initiatives. In this regard, NHMRC notes the proposal from the Australian Government's Advisory Council on IP that research be exempt from provisions imposed by gene patents in Australia.

NHMRC though the expertise of its Human Genetics Advisory Committee (HGAC) provides advice on high-level technical and strategic issues in human genetics, and on the social, ethical and legal implications of human genetics and related technologies. HGAC's Terms of Reference are provided at [Attachment A](#) for your information.

I trust this information is of use and assists the Committee in its inquiry into gene patents.

Yours sincerely

A handwritten signature in black ink, appearing to read "Warwick Anderson".

Professor Warwick Anderson
Chief Executive Officer

12 March 2009

National Health and Medical Research Council

Human genetics Advisory Committee

Terms of Reference

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.

Functions

In carrying out its Terms of Reference the HGAC 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.