

Ms Julie Dennett
Committee Secretary
Standing Committee on Legal & Constitutional Affairs

Cancer Voices NSW Inc
PO Box 5016
Greenwich NSW 2065
T/F 02 9436 1755
info@cancervoices.org.au
www.cancervoices.org.au

The voice of people
affected by cancer

Dear Ms Dennett

Inquiry into Patent Amendment (Human Genes & Biological Materials) Bill 2010

Cancer Voices NSW wishes to thank the Standing Committee for inviting us to make a submission to this parliamentary inquiry. We wholeheartedly support the Bill.

Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard.

We attach our submission, which we are happy to have published on the Committee's website.

We look forward to hearing the Committee's recommendations regarding this very important Bill

Yours sincerely

A large rectangular area of the document has been redacted with a white box, obscuring the signature and name of Sally Crossing AM.

SALLY CROSSING AM

Chair

19 February 2011

Inquiry into Patent Amendment (Human Genes & Biological Materials) Bill 2010

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Submission by Cancer Voices NSW

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We wholeheartedly support the issues addressed by this brief Amendment. They reflect and address those raised by Cancer Voices NSW and our member group, the Breast Cancer Action Group NSW's (BCAG NSW) in their submissions to, and appearances before, the Senate Inquiry of 2009. We believe that this Amendment clearly comes under the imperative of being in the public interest.

Our members, people affected by cancer, are extremely concerned about the threats regarding access to and ownership of breast cancer genes, which are posed by enforcement of international and Australian gene patents. Cancer Voices NSW is concerned that such threats have and will arise for other cancers and diseases and asks the Inquiry to recommend that this Bill is introduced to parliament as soon as possible. Too many human genes have been patented as a result of various interpretations of fairly unclear legislation. This Amendment will assist in clarifying the fact that patents should never have been, nor should be, allowed over naturally occurring human genes and biological materials.

As an ethical and philosophical principle, we do not believe that genes as natural parts of the human body, and other forms of life, should be patentable. We strongly recommend that Australian patent law be amended so that no part of a living thing can be patented.

We note that international case studies show that enforcement of gene patents reduces access and drives up testing costs dramatically for patients. Enforcement also hinders scientific research and the sharing of important medical knowledge (Luigi Palombi: Gene Cartels Biotech Patents in the Age of Free Trade, Scribe Publications 2009). And we have seen no evidence that offering patents is necessary to encourage the identification or isolation of human genes. That they are currently patented under Australian law is an anomaly which needs to be corrected. It has become standard practice for researchers to patent human genes simply to ensure that no-one else does so, reducing their access, and compounding the problem. The only supporters seem to be those who have a financial interest in the present situation being maintained – this we regard as not acceptable and a conflict of interest. It is certainly not in the public interest which itself should be supported by Australian legislation.

Cancer Voices NSW asks the Standing Committee to note the findings of the Federal District Court in New York which, in March 2010, ruled that patents were improperly granted to Myriad Genetics on two human genes, including BrCa1. Australia should be seen to be amongst the reformers in the world arena. We should be in the forefront of countries which recognise that when something is broke and we need to fix it.

We previously highlighted the following two points of particular concern to people affected by cancer:

High risk cancer families: Currently some people from **high risk cancer families** can access genetic tests for gene mutations associated with their cancer through public hospital familial cancer centres and testing facilities. Commercial monopolies of cancer gene testing, achievable through patenting, are likely to lead to increase costs, as evidenced by the costs which could be chargeable to individuals by Genetic Technologies P/L which has an international patent for the BrCa 1 and Br Ca 2 genes. A longer term outcome would be an increase in health care costs for cancer treatment, a cost that may well have been avoided.

Medical research & Pharmacogenomics: Cancer Voices NSW is very aware of the need for access to genetic material by medical researchers. We see the *development of pharmacogenomics, or personalised treatment* through the use of genetic testing of our tumour tissue, to be the light on the hill for we cancer patients. Personalised cancer treatment, using the recent surge in knowledge about human genes, will improve patient outcomes and reduce wastage of ineffective drugs and the overall costs of health care. We are all hoping that researchers will make progress quickly so that we, as well as those who follow us, can benefit. To this end we have successfully encouraged the Cancer Council NSW to fund a collaborative study over five years, and have warmly welcomed the International Cancer Genome Consortium, supported by the Australian Government to the tune of over \$20m. That project aims to speed up delivery of personalised treatment. If genes and genetic material can be patented, and if those patents are enforced, this vital area of medical research will be more costly, slower and less translatable to the end beneficiaries.

Cancer Voices NSW, in our role of representing the interests of people affected by cancer, strongly supports the **Patent Amendment (Human Genes & Biological Materials) Bill 2010**. It addresses our wish to see prohibition of the granting of patents over such natural materials as human genes. Apart from important ethical aspects, the understanding of the role of genes in cancer is an exciting new field with enormous potential for us all. We do not want to see it compromised by patent monopolies over human genes, badly limiting needed opportunities in diagnosis, prognosis and treatment of cancer (and many other diseases).

We have fully supported our national organisation, Cancer Voices Australia, to participate in a legal challenge regarding the BrCa1 gene patent, which we hope will be heard and resolved positively this year.

In parallel, we also commend the establishment of a National Genetic Framework as proposed by the Royal College of Pathologists of Australasia, to ensure that Australia has appropriate regulations for genetic testing in place.

Thankyou for the opportunity to make a submission to this important Inquiry and to express our support for this Amendment to the Patents Act 1990.

SALLY CROSSING AM, Chair, Cancer Voices NSW

19 February 2011