

Cancer Voices NSW Statement to the Senate Community Affairs Committee's
Inquiry into Gene Patents

Sydney, 5 August 2009

Cancer Voices NSW wishes to thank the Senate Community Affairs Committee for holding this Inquiry.

Cancer Voices NSW provides the independent voice of people affected by cancer. It is the peak coalition for cancer support and advocacy groups in NSW, working in partnership to improve the cancer experience of the nearly 40,000 people who are diagnosed each year.

We are supportive of our member group - the Breast Cancer Action Group NSW's (BCAG NSW) submission, noting the recent major threats regarding access to and ownership of breast cancer genes, posed by enforcement of international gene patents. Cancer Voices NSW is concerned that such threats will arise for other cancers and asks the Inquiry to recommend that the Australian Government amend legislation to preclude them.

As an ethical principle, we do not believe that genes, as natural parts of the human body, should be patentable. We strongly recommend that Australian patent law be amended so that no part of the human body 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.

I would like to highlight the following two points:

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 familial cancer centres and testing facilities. Commercial monopolies over cancer genes, achievable through patenting, are likely to lead to increased costs, as evidenced by the projected charges 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 increased health care costs for cancer treatment that may well have been avoided.

Medical research & pharmacogenomics: Cancer Voices 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 reserachers will make progress quickly so that we, as well as those who follow us, can benefit. I firmly include myself among those hoppers! To this end we have successfully encouraged the Cancer Council NSW to fund a collaborative study, and have warmly welcomed the International Cancer Genome Consortium, supported by the Australian Government to the tune of \$20m. That project aims to speed up delivery of personalised treatment. We are concerned that 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 an amendment of the Patents Act, to prohibit the granting of patents over such natural materials as human genes. Apart from the 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, limiting badly needed opportunities in diagnosis, prognosis and treatment of cancer (and many other diseases).

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 of genetic testing in place.

Thankyou for the opportunity to make a submission to this important Inquiry and for the invitation to participate in this session today.

SALLY CROSSING AM, Chair Cancer Voices NSW
5 August 2009