

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



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The voice of people  
affected by cancer

Dear Sir / Madam

### **Inquiry into Gene Patents**

Cancer Voices NSW wishes to express its appreciation that the Community Affairs Committee of the Senate is undertaking an inquiry into Gene Patents.

*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 to improve the cancer experience of the 40,000 people who are diagnosed with our disease each year. Established in 2000, we are interested 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 are supportive of our member group, the Breast Cancer Action Group NSW's (BCAG NSW) submission, noting the recent major threats to access to breast cancer genes. As a result, this submission largely reflects that of BCAG NSW.

Cancer Voices NSW is concerned that such threats may arise for other cancers and asked the Inquiry to recommend that the Australia Government amends legislation so that this cannot happen again. As an ethical principle, we do not believe that genes, as part of the human body, should be patentable. We strongly recommend that the patent law be amended in Australia so that this is no longer possible.

More specifically, Cancer Voices NSW wishes to make the following comments in relation to the terms of reference:

(a) *the impact which the granting of patent monopolies over such materials has had, is having, and may have had on:*

(i) *the provision and costs of healthcare*

Under the current health care arrangements, people from high risk cancer families can access genetic tests for gene mutations associated cancer, through public hospital familial cancer centres and testing facilities in NSW (and other states as well). Patenting genetic material could lead to commercial monopolies of cancer gene testing and subsequently increased costs. If such testing were not available, there would be an increase in health care costs associated with treatment for cancers that may have been avoidable.

(ii) *the provision of training and accreditation for healthcare professionals,*

- (iii) *the progress in medical research, and*
- (iv) *the health and wellbeing of the Australian people;*

Cancer Voices NSW believes that access to testing arrangements as set out below contribute to the health and well being of Australian people and their families:

- ◇ As a matter of equity, genetic testing for people from high risk families should be available and accessible. It should not depend on a person's capacity to pay. Consequently it is important for access to public testing through the Family Cancer Centres in public hospitals to continue.
- ◇ New technologies over time have improved the ability of testing to find the faults in a gene. It is therefore important for the Family Cancer Centres to have the capacity for ongoing testing as new technologies are developed
- ◇ It is important for genetic testing to take place in the context of Family Cancer Centres, where information and support is offered from highly qualified clinical geneticists and genetic counselors for making the decision whether or not to have testing done and to understand the implications of the results
- ◇ We want to see that processes for testing and management of test results are done in a private and confidential way in the Family Cancer Centres to ensure privacy, so as to not open anyone to discrimination in areas such as employment or insurance.

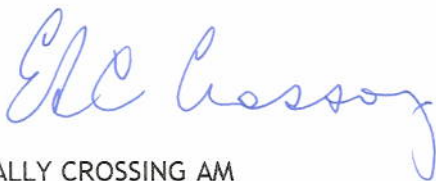
(b) *identifying measures that would ameliorate any adverse impacts arising from the granting of patents over such materials, including whether the Patents Act 1990 should be amended, in light of the any matters identified by the inquiry; and*

(c) *whether the Patents Act 1990 should be amended so as to expressly prohibit the grant of patent monopolies over such materials.*

Cancer Voices NSW supports an amendment of the Patents Act to prohibit the granting of patent monopolies over such materials. Apart from the ethical aspect mentioned earlier, as the understanding of the role of genes in cancer is a new and developing field, we would not want to see the ability to grant monopolies over such materials limiting the opportunities for research and translation to improvements in clinical practice in relation to cancer prediction or the development of tailored cancer treatments.

Thankyou for the opportunity to make a submission to this important Inquiry. We would be delighted to participate in the Hearings if this would assist the Committee's investigations.

Yours sincerely



SALLY CROSSING AM  
Chair  
19 March 2009