



18 March 2008

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

Dear Sir / Madam

### **Inquiry into Gene Patents**

The Breast Cancer Action Group NSW wishes to express its appreciation that the Community Affairs Committee of the Senate is undertaking an inquiry into Gene Patents. BCAG strongly supports an inquiry of this nature, as it provides an opportunity for significant issues relating to access to genetic testing that impacts access to quality services to be explored.

The Breast Cancer Action Group NSW provides a voice for people affected by breast cancer in our state. Formed in 1997, our approximately 720 members live all over NSW. We aim to make a difference in the areas of diagnosis, treatment, care, support and research, and work in partnership with all stakeholders in the breast cancer world. We also provide a forum for women and men to share experiences and information. BCAG NSW publishes, together with the NSW Breast Cancer Institute, the first of its kind Directory of Treatment and Services - in both printed and electronic versions (see [www.bcagnsw.org.au](http://www.bcagnsw.org.au) )

The Breast Cancer Action Group NSW (BCAG 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:*

***The voice for people affected by breast cancer***

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PATRON: Her Excellency Professor Marie Bashir AC Governor of NSW

*(i) the provision and costs of healthcare*

Under the current health care arrangements, women and family members from high risk breast 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) – as can people in high risk families for other cancers where there are known gene mutations. We are concerned that patenting genetic material could lead to commercial monopolies of breast cancer gene testing and subsequently increased costs. If such testing was not available, there would be an increase in health care costs associated with women and men who require treatment for breast and ovarian cancers that may have been preventable.

*(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;*

Breast Cancer Action Group NSW has the following views in relation to access to genetic testing for women with a strong family history of breast cancer. We believe that the access to testing arrangements as set out below contribute to the health and well being of Australian people and their families:

1. We wish to see genetic testing for women and men from families with a strong history of breast cancer being 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.
2. For the majority of women from families with a strong family history a fault in the BRCA 1 or BRCA 2 gene is not found. However, this has been a developing field and 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
3. It is important for genetic testing to happen in the context of Family Cancer Centres, where women and their family members obtain information and support from highly qualified clinical geneticists and genetic counselors in making the decision whether or not to have testing done and in understanding the implications of their results

4. we are concerned that processes for testing and management of test results is done in a private and confidential way in the family cancer centres to ensure the privacy of women and their family members, so as to not open them 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.*

Breast Cancer Action Group NSW supports the amendment of the Patents Act to prohibit the granting of patent monopolies over such materials. The understanding of the role of genes in cancer is a new and developing field and we would not want to see the capacity 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



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