

# Senate Community Affairs Reference Committee Inquiry into Gene Patents

## The key issues for BCNA's members

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We empower, inform, represent and link together people whose lives have been affected by breast cancer.

The quotes below are from some of BCNA's members who have a strong family history of breast cancer or a known genetic mutation, and highlight the key issues around gene patents for women.

### Gene testing

*"It is extremely hard to understand and anticipate beforehand what a huge impact a positive result can have on your life, and on the lives of those around you. It completely sidetracked my life until my anxiety regarding my risk and options could be understood, grieved, prioritized and arranged. It is a process through which I required huge support. I am eternally grateful for the supportive genetic counselling I received and cannot imagine how I would have survived without it. Very few of the medical staff I have met before or since have understood the issues in the holistic way that the genetic counsellors appear to."*

*"... Had I known earlier I would have had the choice of preventative surgery as I did after I found out I had BRCA1 gene mutation & had my ovaries removed due to breast cancer in both breasts... I haven't told my 2 daughters yet as I know how hard it is living with the fact that you have BRCA1 & I don't want them to feel that yet."*

*"Testing positive to the BRCA2 fault made my decision to have my other breast and ovaries removed much easier as the FEAR of getting cancer in my other breast or ovaries and going through chemo again was much greater than losing my breasts. My sisters also made the same decision. Thank god for genetic testing! "*

### Fear of discrimination

*"...I do worry about what would happen if I decided that it was time that I apply for a higher level of insurance to adequately protect my wealth assets (house etc)."*

*"I found it so difficult to simply get a life insurance policy with a history of breast cancer that I don't want to go anywhere near genetic testing."*

*"I have a few worries about my four children (3 girls) and will allow them to make the decision to have the gene testing done if they wish but feel that if the test even shows a slight increase in their risk it could be a burden for them and affect life decisions."*

### Research

*"I hope that research will continue into the genetics of breast cancer."*

*"...Our family has donated various tissue samples (breast and ovary) following surgery for further research to KConfab."*

*"Growing databases on (gene) variants will establish clinical significance so it is important that these tests continue. It is to be hoped that gene patents do not hinder such genetic testing."*

Provided in Melb  
BCNA  
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Breast  
Cancer  
Network  
Australia



GIVING A VOICE TO AUSTRALIANS AFFECTED BY BREAST CANCER

293 Camberwell Road  
Camberwell VIC 3124  
ABN: 16 067 937 531

Telephone: (03) 9805 2500  
Facsimile: (03) 9805 2599  
Email: [beacon@bcna.org.au](mailto:beacon@bcna.org.au)  
Website: [www.bcna.org.au](http://www.bcna.org.au)  
Toll Free 1800 500 258