Breast Cancer Network Australia’s Seat at the Table program

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Background
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.

BCNA represents more than 75,000 individual members and 318 support groups from across Australia. Eighteen per cent of our members are from rural and remote areas and 31 per cent of our Member Groups are based in rural and remote areas.

Our mission is to ensure the voices of Australians affected by breast cancer are heard by policy makers, health providers and planners.

Breast cancer in Australia
Breast cancer is the most common cancer affecting women in Australia. In 2013, it is estimated that 14,940 women will be diagnosed with breast cancer. Most women survive breast cancer. The latest statistics (2010) show that the 5-year survival rate for women diagnosed with breast cancer is more than 89 per cent. Many women live long and healthy lives well beyond this period.

A snapshot of breast cancer in Australia:
- Australian women have a 1-in-8 lifetime risk of developing breast cancer.
- The risk of developing breast cancer increases with age.
- The average age of first diagnosis of breast cancer in women is 60 years.
- 75 per cent of new cases of breast cancer develop in women over the age of 50.

A diagnosis of breast cancer is generally a challenging and emotionally distressing time for women and their families. The diagnosis is only the first step in an ongoing journey. Women continue to seek up-to-date information and support long after the initial diagnosis and, for many, the impact of their experience is their driving force to instigate local community initiatives.

A history of advocacy
BCNA started as an organisation that would positively influence the way women with breast cancer received treatment and care. Our mission is to ensure all Australians affected by breast cancer receive the very best information, treatment, care and support possible.

In 1998, following public meetings in every state and territory, over 300 women came together at BCNA’s first National Conference, held in Canberra, to discuss issues affecting women with breast cancer. An action plan was developed and formed the inaugural Making a Difference Report, which set the advocacy agenda for BCNA’s work. BCNA was then officially launched at the inaugural Field of Women, a visual display of breast cancer statistics depicted through a sea of BCNA Pink Lady silhouettes, on the lawns of Parliament House in Canberra.

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Advocacy for women and their families has remained a central focus of our work. Our current policy development takes its broad direction from our members and our stakeholders.

**The Seat at the Table program**

Our Seat at the Table program is based on the premise that women with breast cancer should have a seat at any table where decisions are made about their treatment and care. The program ensures decision makers in the national and state health systems are connected to the experience of consumers – women affected by breast cancer and their families. Through this program, we invite, train, appoint and support women who have had breast cancer to become BCNA Consumer Representatives. Our Consumer Representatives participate on committees and research panels across the country and internationally, and contribute informed views to benefit women affected by breast cancer.

BCNA’s Seat at the Table program is internationally recognised as a successful model of consumer advocacy. BCNA Consumer Representatives have worked with scientists, researchers, clinicians, health service providers and planners since 2000 to improve the provision of treatment, services and care for those affected by breast cancer.

BCNA’s Consumer Representatives partner with and contribute to the work of scientific research programs by:

- representing women with breast cancer on decision making committees to ensure their voices are heard
- writing articles and other materials for publication
- contributing to the development of clinical practice guidelines
- assisting with the development of clinical trial ethics and consent documents
- supporting applications for research funding
- assisting with recruitment of women for scientific trials
- representing women in health policy development to ensure the relevance and accessibility of services
- communicating at conferences and other public forums
- raising awareness of research among women and the public.

I have been able to contribute to a wide range of research as a consumer representative. I've helped scientists to better communicate their findings to the broader community, resulting in a higher profile for them and increased public awareness of the importance of their research. I have also enjoyed being able to let women with breast cancer know about the research under way that may benefit others in the future. It’s very exciting. (BCNA Consumer Representative from rural NSW)

The program currently includes 72 trained Consumer Representatives. Eighteen women (24 per cent) live in rural and regional areas. This representation is invaluable in driving change and improvement for rural women at many levels, as women living in rural and remote Australia generally face additional challenges during their breast cancer diagnosis, treatment experience, and beyond.

Consumer Representatives in rural communities have strong communication skills, knowledge of breast cancer issues and the ability to reflect the needs, viewpoints and concerns of others affected by breast cancer who are living in rural locations. They understand the unique challenges facing rural women with breast cancer such as geographic isolation and limited contact with specialist health care workers.
Our rural Consumer Representatives use Skype and digital technology and are able to fully participate in major university studies providing a rural perspective.

I am the consumer representative on a research co-operative which focuses on clinical, genetic and epidemiological problems of familial breast and ovarian cancer. Even though I am from a regional area (and meetings are in a capital city), I have been able to participate fully. The bulk of the work takes place by email and teleconference, so it really wouldn’t matter where I was located. Of course I need to allow more time for travel for the two face-to-face meetings that are held each year. Through this work I can advocate for women with a strong family history of breast cancer, an issue I am passionate about. My location is not a barrier to being active and involved. (BCNA Consumer Representative from regional Tasmania)

Recent advocacy examples
Our rural Consumer Representatives have recently been involved in a number of activities including:

- Cancer Australia’s Rural Health Professionals Advisory Network
- providing feedback on a patient experience survey, part of a major surgical/radiotherapy trial in Western Australia
- Cancer Australia’s Breast Cancer Spaced Education Initiative Working Group
- Sydney International Breast Cancer Congress 2012 Reference Group

In my region there were no dedicated services for women with breast cancer, no breast care nurse and no support group. I am a fiercely private and independent person but soon came to realise the value these services could be to many women in the region. Bush women are notoriously stoic and self-reliant but a diagnosis of breast cancer is the time to reach out to let others give you that helping hand, the journey does not have to be taken alone.

I currently represent BCNA on the executive committee of the Australasian Society of Breast Disease (ASBD). ASBD includes all medical disciplines, involved with breast disease, and the primary role is organising scientific conferences, usually every two years, which include a consumer forum. BCNA is determined to keep these forums relevant to the needs of the women. I like to think that I am there as the reminder that the woman is at the centre of the treatment of breast cancer, just like the BCNA symbol, the woman. Advocacy is challenging but also extremely rewarding and personally fulfilling. (BCNA Consumer Representative from remote Queensland)

Who do Consumer Representatives represent?
BCNA maintains a register of women throughout rural Australia who have a range of experiences and are trained to represent the broad views of Australians affected by breast cancer. It is important that our advocates represent a defined, wider group of consumers.

I am passionate about getting a fair deal for women who are living and dealing with breast cancer in the rural/remote areas of Australia. My frustration grew after attending numerous conferences and forums where the rural issue was raised and then seemingly forgotten, usually placed into the ‘too hard basket’.

After communication with another frustrated rural woman, we decided to take action ourselves and Project BREAST – Building Rural Equality And Strengthening Ties – was born. We invited an inspiring group of women from every state and territory to join us, and then identified and prioritised the major issues rural women faced. (BCNA Consumer Representative from rural Victoria)
Trained and supported

Crucial to our organisation is recognition that many advances to breast cancer treatment and care have been driven by the collective voice and efforts of survivors.

BCNA presents three-day comprehensive Advocacy & Science Training programs which cover breast cancer science, treatment and advocacy skills. The program is largely delivered by clinical experts in the field. Topics include: genetic aspects of breast cancer, the psychosocial impact of breast cancer, future directions in treatment and care, clinical trials, making sense of research, breast cancer advocacy and workshops with experienced advocates.

Twenty-one women completed our last Advocacy & Science Training, including six women from rural, regional and remote areas. BCNA greatly appreciates the support of the Australian Government, through Cancer Australia’s Supporting women in rural areas diagnosed with breast cancer (SWARDBC) program, which assists rural women to participate in this program.

Advocacy work is sometimes very frustrating but also very rewarding. I generally tell people that I feel like a termite, constantly nibbling away in the dark until some light finally breaks through. Most of my time is spent trying to improve services for local people. At the local level I have advocated for a breast care nurse, lymphodema services, improving waiting lists for reconstructive surgery. At the national level I have been involved in Cancer Australia working parties such as the National Data Strategy Advisory Group. Never expect any appreciation or acknowledgment of your advocacy efforts and never give up, it always takes a long time to change government services. (BCNA Consumer Representative from regional Queensland)

Our database can match organisations seeking consumer representatives with individual BCNA women appropriate for their request. For example, if a treatment centre wants to develop policy or new information for rural women travelling to the city for treatment, we can appoint a rural woman with relevant experience.

The network’s support has been critical to the success of the study... I feel their input is invaluable. (Clinical Trials Coordinator)

Conclusion

The Seat at the Table program enables women who have experienced breast cancer to inform the work of committees, working parties, boards and project teams, including those of government, medical and research institutions. It demonstrates a powerful model for creating change.

In our experience, projects that include consumer representation from the very beginning reap the greatest results. Therefore, we encourage organisations to involve women at the planning stage of any project or research study, to gain the most benefit – both for the organisation and for women and their families.

The Seat at the Table program highlights our philosophy that through effective partnerships between consumers and health professionals, we achieve the best outcomes for women with breast cancer.

Our program has enabled women from rural Australia to make meaningful contributions and advocate for change, which ultimately supports other women from rural communities who will be diagnosed with breast cancer in the future.

I soon realised that my contribution was not medical – it was practical ... In fact I had a lot to offer. (BCNA Consumer Representative)

To request a BCNA Consumer Representative

If your research or policy program could benefit from consumer involvement and you would like more information, contact Breast Cancer Network Australia's Community Programs Manager, on (03) 9805 2500 or lallwell@bcna.org.au.