Breast Cancer Network Australia (BCNA):
Submission to the *Senate Community Affairs Committee inquiry into services and treatment options for persons with cancer*

March 2005

Summary

Breast Cancer Network Australia (BCNA) is the peak national breast cancer consumer organisation, representing 117 member groups and more than 12,000 individuals in each state and territory. Its role is to empower, inform, represent and link together Australians personally affected by breast cancer. It is driven by women who have themselves experienced breast cancer. It influences key decision makers to ensure that the needs and issues of people affected by breast cancer are raised and addressed.

BCNA welcomes the opportunity to provide a submission to the Senate Community Affairs Committee inquiry into services and treatment options for persons with cancer.

Priority Areas Identified by Women

In 2004, BCNA held Australia's Second National Breast Cancer Conference for Women. This was an opportunity for women with breast cancer to come together and discuss the progress that had been made in breast cancer over the preceding six years since the First National Breast Cancer Conference for Women held in Canberra in October 1998.

Six hundred breast cancer survivors came together to hear progress reports from leading doctors, researchers, health professionals and advocates and to develop a series of recommendations about where BCNA's energies should be directed over the coming years.

At BCNA's 2004 Second National Breast Cancer Conference for Women, the clear message from women with breast cancer was that to improve the care of people with breast cancer it is necessary to:

- **Standardise the delivery of breast cancer services across Australia**
- **Implement nationally the National Breast Cancer Centre (NBCC) clinical practice guidelines and evaluate the extent of the implementation**
- **Require consumer input into all aspects of research and establish a clinical trials register**
- **Eliminate discrimination on the basis of a history of breast cancer or genetic information.**

Standardisation of services and guideline implementation will enhance equitable access for women to a range of services, in particular, early detection, radiotherapy and supportive and palliative care. In addition, it should provide the information women seek about issues such as the quality of care being provided and available services.

System support for health professionals to deliver best practice—such as Medicare rebates for participants at multidisciplinary case conferences—and improved data collection systems—such as national collection of data on the incidence of metastatic breast cancer—were identified as vital to achieve this.

Terms of reference

In addition to the points outlined above, a number of issues outlined in the terms of reference of this Senate Community Affairs Committee inquiry have been identified by BCNA as priorities for women with breast cancer. These include:

- **The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:**

(i) The efficacy of a multi-disciplinary approach to cancer treatment:

The following words of a woman with breast cancer reflect the importance of multidisciplinary care to women:

> 'Coaches surround me: doctors, surgeons, breast care nurses, oncologists, and radiologists. Ready to help me cross the line. Encouraging me all the time. My sport is my life. My challenge is cancer.'

The NBCC's *Clinical practice guidelines:*

- *for the management of early breast cancer;*
- *for the management of advanced breast cancer;*
- *for the management and support of younger women with breast cancer;* and
- *for the psychosocial support of adults with cancer*

all indicate that multidisciplinary care leads to improved physical and psychosocial outcomes for people at all stages of their breast cancer management.

BCNA supports the efficacy of a multidisciplinary approach to cancer treatment as outlined in the guidelines. The recommendations regarding multidisciplinary care from BCNA's Second National Conference for Women with Breast Cancer are that:

- All women should be provided with written information about the members of their multidisciplinary team, what and how information is shared between team members and the treatment plan.
- Multidisciplinary care should be included in the criteria for accreditation of cancer clinicians and services, both public and private.
- Financial and structural support is required to encourage the provision of care in a multidisciplinary model. This may include Medicare rebates for all participating clinicians and the introduction of simplified systems for claiming these rebates.

BCNA understands that having a designated multidisciplinary care meeting coordinator (often an administrative person) coordinate the meetings substantially improves the efficiency of the meetings. Current funding mechanisms do not provide for direct funding of these positions. In order to facilitate and enable widespread implementation of multidisciplinary care, new funding mechanisms are required to adequately cover the costs.

(ii) the role and desirability of a case manager/case coordinator to assist patients and/or their primary care givers:

This quote from a woman with breast cancer typifies how many breast cancer patients feel about their case coordinators/breast care nurses:

> 'This particular nurse is so attuned to me that I have only to say the word and the right professional is there to give advice.'

The *Clinical practice guidelines for the psychosocial support of adults with cancer,* cite the importance of identifying a coordinator of care amongst the members of a cancer patient's treating team. This team member may be a GP or, commonly in the management of breast cancer, a specialist breast care nurse or oncology nurse. However, the case manager could be any member of the treatment team that the patient nominates and who is willing to take on this role.

This is viewed as an increasingly important aspect of best-practice cancer care, particularly as cancer patients may be receiving services in a number of different areas of the health care system eg private, public, acute or primary health care. For rural and regional patients this is also important as coordination of treatment occurring at geographically diverse centres may be required at times.

The recommendations from the Second National Breast Cancer Conference for Women were:

- Every woman, in the public or private sector, diagnosed with breast cancer should have access to a breast care nurse either face-to-face, or by telephone if they live in remote locations.
- Every multidisciplinary team should include a breast care nurse.
- All breast care nurses (existing and future) should be trained to competently conduct psychosocial assessment in order to identify women at risk of anxiety and depression.

Barriers to implementation of the case manager role that have been identified by BCNA include:

- Poor access to breast care nurses by many women with breast cancer, particularly within the private health care sector
- Lack of communication between acute and primary health care centres
- Lack of financial incentives (eg Medicare rebates) for clinicians, particularly in private settings to engage in multidisciplinary case conferences or hand-over sessions to case coordinators.

(iii) differing models and best practice for addressing psycho/social factors in patient care

A young woman diagnosed with metastatic breast cancer and living in a rural region of Australia wrote the following words about her need for good psychosocial support:

> 'In those first dreadful months after my diagnosis with metastatic breast cancer I realised in my rare lucid moments that I craved contact with

> women who were also dying from the same bitch that had somehow snuck up on me'

BCNA believes that if the *Clinical practice guidelines for the psychosocial support of adults with cancer* were implemented consistently across all Australian health care settings, that the psychosocial care of cancer patients would be significantly improved.

Best practice psychosocial care of cancer patients begins with competent psychosocial assessment. The current tools available for the assessment of psychosocial morbidity by non-mental-health professionals are limited in their effectiveness. Funding is required for more research into the area of developing psychosocial assessment tools for cancer patients and in particular, for women with breast cancer.

The recommendations regarding supportive care from the Second National Conference for Women with Breast Cancer were:

- Best practice care, as identified in the National Breast Cancer Centre's *Psychosocial clinical practice guidelines: Information, support and counselling for women with breast cancer*, should be consistently implemented nationally in both private and public hospitals and community-based services.
- Where women are identified as being at risk of anxiety and depression, adequate referral mechanisms and access to psychosocial practitioners are required to ensure they receive appropriate psychosocial interventions.
- A wide range of consumer-focused information and support services should be made available to women throughout their treatment and beyond.

(iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians:

Rural women with breast cancer report significant difficulties associated with accessing various treatments for their cancer. Many of these difficulties arise from the need to travel to metropolitan centres to access specialist services such as radiotherapy and surgery—both good quality surgery for management of the breast cancer as well as reconstructive surgery following mastectomy. One rural women wrote the following words about her experiences:

> 'We are in my room on the second floor of the radiation clinic accommodation block. We unpack our things for a six-week-long stay. Clothes in the cupboard; toiletries in the bathroom; cereal, coffee and teabags on the shelf and food in the first-floor fridge.'

These difficulties can limit or dictate the choices available to rural women eg a rural woman may choose to have a mastectomy rather than a lumpectomy because she is unable to access the radiotherapy she would require following a lumpectomy.

The recommendations regarding rural and regional women from BCNA's Second National Conference for Women with Breast Cancer are:

- Following a review of the current administration system, a best practice (standardised nationally) Patient Assistance Transport Scheme (PATS) should be implemented.

- Accessible and reasonable cost accommodation for patient and spouse/carer close to treatment centres should be provided.
- Appropriate follow-up care and support in local communities should be provided after initial treatment at specialist centres.

In addition, BCNA emphasises that multidisciplinary care is equally important in rural settings as in metropolitan settings however it can be even harder to implement in rural areas. One way of overcoming the difficulties of achieving multidisciplinary care in rural settings is through the use of telemedicine, however a funding commitment is required to develop this technology in many rural areas.

(v) current barriers to the implementation of best practice in the above fields:

As identified above, some of the barriers to implementation of best practice cancer care include:

- Lack of financial incentives—such as Medicare rebates—for specialist clinicians—particularly those working in the private sector—to attend multidisciplinary team meetings or telephone case conferences and for multidisciplinary care meeting coordinators.
- Lack of funding models for breast care nurses/specialist cancer nurses to be employed in the private health care sector.
- Lack of funding models for psychosocial practitioners to be accessed by people in the private health care sector.
- A shortage of breast care nurses/specialist cancer nurses in rural and remote locations around Australia.
- The existence of different administrative and funding models for operating programs in different states eg the PATS scheme. This has particular implications for rural cancer patients living near state borders for whom the most convenient treatment centre may be in another state.
- The shortage of psychosocial practitioners to manage people identified as requiring psychosocial support.
- The lack of effective data collection about metastatic breast cancer. Cancer registries currently collect figures on breast cancer diagnosis and mortality but do not keep figures on recurrence of breast cancer or onset of metastatic disease. The NCCI national data-set only collects information on first recurrence but not on onset of metastatic disease as such.

Meeting the needs of individuals

In meeting the needs of cancer patients, acknowledgment of individual patients' requirements is essential. Patient needs will vary according to a person's age, where they live, their cancer type and whether or not they have early or advanced cancer. It can not be assumed that one person with breast cancer will have the same needs as the next person with breast cancer.

As an illustration of this, the BCNA young women's working party has identified some of the following issues that are of particular concern to young women diagnosed with breast cancer:

- The lack of access to appropriate forms of psychological support at different stages of the journey through breast cancer, particularly immediately at diagnosis, and post-treatment. This is despite the fact that research shows

that younger women diagnosed with breast cancer experience greater levels of emotional distress than older women.
- The lack of appropriate, peer-led support groups that are responsive to the unique needs of young women. This may be a particular issue for young women living in rural and remote Australia.
- A lack of support for young women at the times when they are shown to be most in need of them. For many young women the real process of emotional adjustment starts later after treatment ends, when support interventions are not always available.

Similarly, women with metastatic disease have particular requirements and require tailored care. One young woman with metastatic breast cancer made the following comment about her support needs:

> 'Yet, even with good family support and love, there are times when I need specialised psychosocial support: like the first six to 12 months after diagnosis, or when scan results are not so good, or at times of disease progression, or when the everyday problems of life get me down; or when friends and colleagues with breast cancer die.'

The recommendations regarding metastatic breast cancer from BCNA's Second National Conference for Women with Breast Cancer are:

- Collection on a national basis of data about the incidence of metastatic breast cancer is required so that resources can be properly allocated and managed.
- A nationally consistent approach to palliative care services for women with metastatic breast cancer should be implemented. Palliative care should be accessible and available to all women on an 'as needs' basis.
- Improved, affordable access to pharmaceuticals which can significantly improve quality and length of life is required.
- The NBCC's *Clinical Practice Guidelines for the Management of Advanced Breast Cancer* should be implemented nationally.
- All women with metastatic breast cancer should be assessed on an ongoing basis to determine their individual needs for practical, emotional and spiritual support.
- The shortage of psychosocial practitioners and appropriate support services should be addressed so that all women with metastatic breast cancer can have access to supportive care, regardless of their location or circumstances.

Complementary medicines

A large number of cancer patients use complementary medicines and it is therefore appropriate that this Senate Community Affairs Committee inquiry's terms of references include comments on less conventional and complementary cancer treatments with particular regard to:

- **How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:**

(i) **the extent to which less conventional and complementary treatments are researched, or are supported by research,**
(ii) **the efficacy of common but less conventional approaches either as primary or as adjuvant/complementary therapies, and**

(iii) the legitimate role of government in the field of less conventional cancer treatment.

This comment by one woman is an example of how some patients view complementary medicines:

> 'Why would I tell my doctor? They don't believe in non-hospital treatments. I don't know if it's working but I know it makes me feel better.'

BCNA supports the findings of the September 2003 report to the Parliamentary Secretary to the Minister for Health and Ageing by the Expert Committee on Complementary Medicines in the Health System, *Complementary Medicines in the Australian Health System.* In general, BCNA views the Australian government's response to the report—published in March 2005—as positive. In particular, we support:

- Government responses designed to improve the accountability of manufacturers of complementary medicines regarding efficacy claims they make about their products.
- Moves towards improved information flow between consumers and complementary medicine practitioners and manufacturers and also towards facilitating improved communication between clinicians and consumers re complementary medicines.
- Moves to greater regulation of complementary practitioners.

However, BCNA believes that a stronger commitment is required by the federal government in the area of dedicated funding for research into complementary medicines and therapies in cancer. Much is already known about complementary therapy use among cancer patients and the areas in which research into complementary therapies for cancer patients is required. The report states that 'the government believes no [research funding] decision can be made prior to consideration of research needs and priorities'. Notwithstanding this, the government is providing interim funding of up to $500,000 to fund projects for complementary medicine use in osteoarthritis. BCNA believes that similar interim funding should be made available for projects concerned with complementary therapy use in breast cancer.

The recommendations regarding complementary therapies from BCNA's Second National Conference for Women with Breast Cancer are that:

- The key recommendations in the *Complementary Medicines in the Australian Health System* report should be implemented, for example, governments should move more quickly to nationally consistent, statutory regulation (where appropriate) of complementary health care professions.
- Quality information about complementary medicines should be available to all women with breast cancer.
- High quality research into complementary therapies, taking account of quality of life and symptom control, should be a funding priority.

BCNA's ongoing commitment to improving services and treatment options for persons with cancer

Accompanying this submission is the full report from BCNA's Second National Conference for Women with Breast Cancer, 2004 and a separate report on the summary of recommendations.

We look forward to the results of this Senate Committee Inquiry and would be most willing to participate in a public hearing or in any future stages of consultation.

L.W. Swinburne

Lyn Swinburne
Chief Executive Officer
Breast Cancer Network Australia