140 Poster

Everyone can be an advocate – empowering consumers to find their own voices

T. Smith. *Breast Cancer Network Australia, Melbourne, Australia*

Breast Cancer Network Australia (BCNA) has developed a comprehensive program to improve breast cancer advocacy in Australia, starting with information. The act of providing consumer driven information to women is both helpful and political.

As the national voice of Australians affected by breast cancer, BCNA works at many levels to improve services and treatment for Australians affected by breast cancer. In providing information we hope to enlist as many people as possible in our efforts to raise the voices of breast cancer consumers. We believe that a single voice anywhere in Australia can make a difference.

BCNA has produced a comprehensive information resource, the *My Journey Kit*, that is available free of charge to all Australian women diagnosed with breast cancer. This is a unique resource, developed by breast cancer survivors.

Whilst the Kit is an excellent information resource for women at the difficult time of their diagnosis it has a further agenda. It provides a gentle but consistent message that ordinary women have a lot to say about breast cancer treatment, care and services.

Throughout the Kit women are encouraged to be active participants – to ask questions, seek a second opinion, talk to others in a similar situation, ask for their pathology results, check whether their surgeon is accredited and make sure their psycho-social needs are met.

While most breast cancer survivors will not go on to be active system advocates many, many women gain confidence and a better understanding of the health system when we resource them to engage in advocating for their own needs. In turn this individual advocacy contributes to improved service systems as health professionals are faced with better informed consumers.

The Kit has been available for 18 months and the response from the women receiving it has been overwhelmingly positive. The women have subtly become advocates. Over that time BCNA's membership base has almost doubled.

This individual advocacy is complemented by BCNA's Seat at the Table Program which formally recruits, appoints, trains and supports consumer representatives.

At its heart the *My Journey Kit* quietly and skillfully encourages every woman affected by breast cancer to be an advocate in her own health care. Individual women can be empowered to be active participants in their care and this leads to better services.

141 Poster

Unlikely allies – football and breast cancer

T. Smith, L. Swinburne. *Breast Cancer Network Australia, Melbourne, Australia*

In May 2005 Breast Cancer Network Australia (BCNA) presented an awareness raising event that captured national media over several weeks and forged an ongoing link between breast cancer and the football community.

Breast Cancer Network Australia is committed to keeping breast cancer on the public agenda, to ensure ongoing political support for the best possible care and treatment for those affected by breast cancer. BCNA's *Field* of 11,500 pink silhouettes has been planted each year since 1998 to represent the number of Australian women affected by this disease. In 2005 rather than planting the silhouettes we presented 11,500 live women before a major national football match.

The *Field of Women – Live in 2005* demonstrated in a passionate, powerful and 'pink' way the huge impact of breast cancer in Australia. It was a moving, supportive and healing event for the 11,500 women (and a small number of men) who participated on the night. Perhaps most importantly it raised awareness of breast cancer for a new audience.

The event was an outstanding success. Some of the outcomes are listed here:

- Unprecedented and sympathetic media exposure – leading up to the event, on the night and over the weeks and months to follow.
- Increased awareness in the community of the number of women affected by breast cancer in Australia.
- Key messages were communicated to men about the supportive role they can play.
- Increased awareness of BCNA's Pink Lady brand which will assist in further advocacy efforts.
- The development of supportive partnerships with sporting and corporate sponsors which facilitated the staging of the event.
- Considerable funds were raised to support BCNA's ongoing work.

The *Field of Women* live is an inspiring example of advocacy at its best. It placed breast cancer on the front page of newspapers and on national television broadcasts. It demonstrated that corporations, large sporting bodies and consumer groups can work together to promote an important message and raise funds for a worthy cause.

NB. This story could be powerfully presented as an oral presentation incorporating a 4 minute DVD – that brings to life the passion and emotion of this extraordinary advocacy activity.

142 Poster

How do patients want to learn of results of clinical trials? – results of a survey of 1431 breast cancer patients taking part in the TACT Trial

L. Johnson[1], P. Barrett-Lee[2], P. Ellis[3], J. Bliss[1]. *On behalf of the TACT Trial Management Group.* [1]*Institute of Cancer Research, Section of Clinical Trials, Sutton, United Kingdom;* [2]*Velindre Hospital, Department of Oncology, Cariff, United Kingdom;* [3]*Guy's & St Thomas' Hospital, Department of Medical Oncology, London, United Kingdom*

Introduction: The Taxotere as Adjuvant ChemoTherapy (TACT) trial (ISRCTN79718493) randomised 4162 (4124 UK; 38 Belgian) early breast cancer patients to FECx4 followed by taxotere x4 vs standard anthracycline regimens of similar duration (FECx8 or epirubicinx4 followed by CMFx4).

Aim: to identify methods preferred by health care professionals (HCPs) and patients in clinical trials of conveying results to patients.

Method: A questionnaire circulated via hospitals to participating UK patients in autumn 2004 asked if they would like to be notified of trial results when available, and if so, how they would like results conveyed. Advantages and disadvantages of each method of conveying results were explained. A similar survey of participating HCPs was conducted simultaneously.

Results: 1431 (34.7% of UK trial population) patients returned questionnaires. 30 (2.1%) patients did not want trial results. Of 1395 (97.5%) patients who wanted results, 554 (39.7%) wanted to be told or given them by a hospital doctor or nurse; 664 (47.7%) wanted the trials office to post results to their home, 177 (12.7%) wanted to request results by telephone when available. 6 (0.4%) patients did not answer this question. 176 HCPs from 89 UK centres returned questionnaires. 169/176 (96%) HCPs wanted results written in lay terms for patients. 144/176 (81.8%) thought patients should receive results via their hospital. Of these, 75 (52.1%) preferred the hospital to send results by post rather than give them face to face.

598 (41.8%) patients thought next of kin of deceased patients should be told results, 543 (37.9%) did not, and 290 (20.3%) did not answer this question. If the deceased patient had not wanted results, responses to this question were 519 (36.3%), 309 (21.6%) and 603 (42.1%) respectively. 47 (26.7%) HCPs thought next of kin of deceased patients should receive results; 118 (67.0%) thought they should not; 11 (6.3%) did not respond. Where the patient had not wanted results, responses were 27 (15.3%), 16 (9.1%) and 133 (75.6%) respectively. Patient responses by UK region and age group will be presented.

Conclusion: Posting trial results directly to patients' homes was preferred by patients, although 2% of patients do not want them at all. Most HCPs want to disseminate trial results to patients, a method moderately well supported by patients. Mixed responses to questions concerning giving results to relatives of patients who have died suggests an ethical dilemma.

143 Poster

Public meetings as a tool to inform and educate the general public about topical issues in breast cancer

J.B. Bristol, S. Scarrott. *The Breast Cancer Multidisciplinary Team. Cheltenham General Hospital, Breast Care Department, Cheltenham, United Kingdom*

Aims: This study aimed to estimate the value of public meetings in assisting the spread of accurate and topical information to the local population about controversial aspects of breast cancer care.

Introduction: Despite the plethora of information from increasing numbers of sources, various aspects of breast cancer and its management are often poorly understood by patients and other non-professionals. Announcements in the media of new developments and "breakthroughs" relating to breast cancer leads to a large and rapid rise in the number of enquiries from patients and their carers, along with a considerable rise in their anxiety levels. The nature of the anxieties depend on the issue at the time, but chiefly surround concerns about the applicability of the latest therapy(ies) to the individual, and in the UK at least, fear that appropriate treatments might be denied because of insufficient funding being available, or inadequate expertise in the local cancer centre or unit. Apart from exposing the lack of accurate information, the enquiries generated impose a large and sudden strain upon the resources of the Breast Care Departments which have to deal with them.