## Wednesday, 17 March 2004 17:15–17:45

POSTER HIGHLIGHT

# Advocacy and education

206 POSTER HIGHLIGHT

### The Field of Women: a powerful advocacy tool highlighting the impact of breast cancer within the community

L. Swinburne. *Breast Cancer Network Australia, Auburn South, Australia*

*The Field of Women* was first displayed in Canberra in 1998 to officially launch Breast Cancer Network Australia, now the peak national "consumer" breast cancer organisation in Australia.

The *Field of Women* is a traveling display, exhibited annually within a capital city and comprising silhouettes planted into the ground (figure 1).

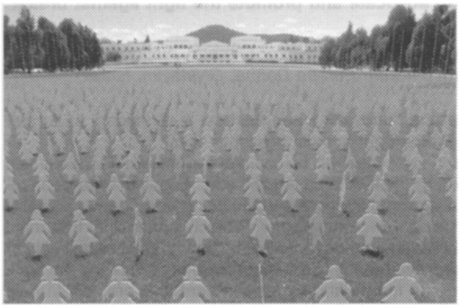
- 11,000 bright pink silhouettes represent the number of Australian women diagnosed with breast cancer annually
- 100 blue silhouettes represent the annual incidence for men, and
- 2700 white silhouettes represent the annual mortality statistics.

A Silent Walk also accompanies the annual event, with a major street closed off, allowing the public to participate and show support for the cause.

The annual event achieves a multitude of objectives:

- It is a powerful advocacy tool, as breast cancer issues are publicly raised
- The strong visual impact ensures media coverage
- It is an effective tool to promote important public health messages
- Politicians are keen to speak at the launch ceremony and pledge support
- Messages attached to the silhouettes highlight the impact of the disease on individuals and families
- Sponsorship of the messages raises funds for the organisation
- It provides an opportunity for organisations to work together

There is now substantial interest from international advocacy groups to conduct *Fields of Women* events within their respective countries; in fact this is fast becoming a global project. The presentation will further explore and describe the project, outlining key strategies for success and including a 4 minute video of a past *Field of Women* event held in Australia.



207 POSTER HIGHLIGHT

### Improving the organisation of breast cancer care increases quality of care while reducing costs

G.L. Beets[1], C.N.A. Frotscher[1], C.D. Dirksen[2], M.H. Hebly[1], M.F. von Meyenfeldt[1]. [1]*University Hospital of Maastricht, Surgery, Maastricht, The Netherlands;* [2]*University Hospital of Maastricht, Clinical Epidemiology and Medical Technology Assessment, Maastricht, The Netherlands*

**Background:** In the last decade new education and counselling programmes, diagnostic procedures and new surgical treatment options were introduced in breast cancer treatment. Between 1998 and October 2001 a breast care nurse, the core needle biopsies and the sentinel node procedure were introduced in our hospital. These changes facilitated a shorter hospital stay. In October 2001 both a patient centred breast cancer care programme and ambulatory surgery were introduced. In a prospective cohort study (Oct 2001–Sept 2002) the effect on hospital costs of the introduction of these changes was investigated. The results were compared to the standard of care provided in 1998.

**Material and methods:** For both the prospective cohort study and the retrospective study data were retrieved by the hospital registration system. This system registers every activity was registrated from the first hospital visit for breast pathology until 6 weeks after the last operation for breast cancer. These files were connected to the hospital cost files of 2001.

**Results:** In 1998 137 patients had 168 operations, while in 2001/2 234 operations were performed in 164 patients. The mean age of the population was 59.3 (sd 13.8) vs. 58.6 (sd 13.1) years. The mean duration of hospital stay for breast cancer was 6.9 days vs. 2.1 days. There was no difference in reported activities related to complications between the periods. The extra diagnostic procedures, e.g. ultrasonography, more core needle biopsies and the histopathological examinations, visit to the preassessment clinic anaesthesiology and more visits to the outpatient clinic for education and counselling caused an significant ($p<0.001$) increase in preoperative costs: €541.5 vs. €887.2. The large decrease of peroperative costs related to the reduction of hospitalisation largely overcompensated the costs related to the introduction of the sentinel node: €4347.7 vs. €3779.3 ($p<0.001$). Postoperative costs increased significantly ($p<0.001$), €265.4 vs. €487.5 because of a significant ($p<0.001$) increase in outpatient clinic visits. Total hospital costs were not significantly different between 1998 and 2001/2002 (€5146.6 vs. €5154.0).

**Conclusions:** The introduction of a patient centred breast cancer care program and ambulatory surgery did not lead to an increase of hospital costs while introducing new diagnostic and treatment procedures, extensive education and counselling. Thus, improved quality of care was established without increase of costs.

208 POSTER HIGHLIGHT

### Helping a friend or colleague with breast cancer: a resource developed by Australian women

L. Swinburne. *Breast Cancer Network Australia, Auburn South, Australia*

There have been many resources developed for women diagnosed with breast cancer and for members of their families. There is less support available for the close friends of these women and for the people with whom they share their workplace.

Many women from Breast Cancer Network Australia (BCNA) have noticed that the diagnosis of breast cancer has meant that some close friends have withdrawn from them. This can be hurtful at the time, but it is suspected that this has to do with feelings of powerlessness by the friend and of not knowing what to say or how to help.

Another group who has sought direction in dealing with this sensitive issue are work colleagues and managers. For this reason, BCNA has developed a printed resource entitled "Helping a Friend or Colleague with Breast Cancer". This has become our most sought after resource by far, with multiple copies being requested by Human Resources Managers, who have adopted the content as part of their HR Policies.

The resource is the result of national surveys and input from Australian women who have themselves experienced breast cancer. In the surveys, these women have listed strategies, both emotional and practical, which were most helpful to them, and importantly those which were not. As a result of the publication, BCNA spokeswomen are increasingly invited to make presentations to people in their workplaces to encourage the adoption of the strategies, which whilst compiled by women with breast cancer, are easily translatable to a range of life-threatening illnesses.

In this presentation, the development of the resource will be outlined and the resulting strategies listed. Copies of the resource will be available for participants.

209 POSTER HIGHLIGHT

### EUSOMA requirements about breast cancer units: results of a national survey in Spain

B. Merck[1], P. Cansado[2], A. Fernández-Frías[3], F. Ardoy[4], A. Rodríguez-Lescure[5], J.B. Ballester[6], I.T. Rubio[7], J.M. Ramos-Rincón[8], R. Calpena[9], M. Ramos-Boyero[10]. [1]*Hospital General Universitario de Elche, Surgery Department, Breast Unit, Alicante, Spain;* [2]*Hospital General Universitario de Elche, Surgery Department, Breast Unit, Alicante, Spain;* [3]*Hospital General Universitario de Elche, Surgery Department, Alicante, Spain;* [4]*Hospital General Universitario de Elche, Radiology Department, Alicante, Spain;* [5]*Hospital General Universitario de Elche, Medical Oncology Department, Breast Unit, Alicante, Spain;* [6]*Hospital de la Ribera, Surgery Department, Breast Unit, Alcira, Spain;* [7]*Instituto Oncológico Teknon, Surgery Department, Breast Unit, Barcelona, Spain;* [8]*Hospital General Universitario de Elche, Medicine Department, Alicante, Spain;* [9]*Hospital General Universitario de Elche, Surgery Department, Alicante, Spain;* [10]*Hospital Universitario de Salamanca, Surgery Department, Breast Unit, Salamanca, Spain*

**Introduction:** The First European Breast Cancer Conference statement demanded that "those responsible for organizing and funding breast cancer care ensure that all women have access to fully equipped multidisciplinary and multiprofessional breast clinics". After EUSOMA requirements were published, most European countries established a discussion through their scientific societies about a new model for breast cancer care. Due to the absence of data in our country, the Spanish Association of Surgeons (Breast Diseases Group) promoted a survey about breast cancer units in Spain.

**Methods:** The survey was sent to 241 general surgery departments of all kind of hospitals in Spain. The questionary included 56 questions about EUSOMA standards, clinical activity, acceptance of new techniques (especially sentinel node biopsy and oncoplastic procedures) and quality assurance measures.

**Results:** We received 164 (68%) answers. In most (131) of these hospitals breast cancer care was conducted by general surgeons, associated in 51 cases with gynecologists. Eighty hospitals had some basic structure of breast clinic. About 20 surgery departments treated 150 or more newly diagnosed breast cancer cases per year and another 20 about 100 cases yearly. Written protocols about diagnose and treatment were present in 119 hospitals. Referral criteria from the general practitioner were established in half of the cases and urgent referral was available.

When analyzing EUSOMA requirements there were dedicated breast surgeons in 80 hospitals, in 54 with postgraduate studies in breast diseases; 82 hospitals were provided with specialized radiologist and a specialized pathologist was present in 82, not always concordant; in 102 there was a medical oncology department in the same hospital or next to it. Radiotherapy was available in one third of the hospitals. A regular multidisciplinary session was held in 98 hospitals.

In regard to breast cancer surgical treatment, 50% of the patients underwent conservative procedures, and selective sentinel node biopsy was available in 47 hospitals. Breast surgical reconstruction was provided in 58% of cases by plastic surgeons and forty-one surgery departments undertook the reconstruction procedure by themselves.

When applying EUSOMA standards to breast clinics in Spanish hospitals, only 20 fulfill all requirements, considering the number of 150 newly diagnosed cases per year, the special training in breast cancer under supervision of a certified breast unit and the quality assurance measures.

**Discussion:** Nowadays there are only some breast units in Spain following all the EUSOMA requirements. Reducing the number of newly diagnosed breast cancer cases to a hundred per year would be probably more adjusted to the Spanish National Health System. Although Spanish Universities are teaching postgraduate programs in Mastology, breast cancer training should be adjusted to a common European standard.

**210** POSTER

## Counseling of breast cancer patients at primary therapy by breast cancer survivors: Experiences with a pilot project

R. Haidinger[2], M. Winkelmayer[1], B. Ruessmann[1], M. Kiechle[1], N. Harbeck[1]. [1]*Technical University of Munich, OB&GYN, Munich, Germany* [2]*Brustkrebs-muenchen e.V., Munich, Germany*

**Aim:** At primary therapy, patients are severely burdened by the recent diagnosis of breast cancer and their fears concerning this disease. Thus, they are hardly able to work together with the treating physicians as informed patients in order to develop an individualized treatment plan. In July 2002, we therefore started the pilot project "patients counsel patients" in collaboration with the patient support organization 'Brustkrebs-muenchen e.V". The aim of the project was to enable prompt contact with a breast cancer survivor right at the time of primary therapy and continuously thereafter.

**Method:** We started a regular counseling session twice a week giving our breast cancer patients the opportunity to talk to a breast cancer survivor on the ward. In order to evaluate the acceptance of this project, patients received an anonymous questionnaire comprising 18 questions. During the first year, we had a return rate of 75% (n=79).

**Results:** The key issues for our patients regarded individual therapy components such as surgery, chemotherapy, radiation therapy, together with follow-up care and potential alternative therapies. Most patients thought that gaining additional information was the most important advantage in being counseled by a survivor. In addition, the exchange of personal experiences and the opportunity to talk about personal fears were highly valued. All patients saw being counseled by a survivor as an asset in addition to the conversations with their doctors and would thus recommend this project to other breast cancer patients.

**In conclusion:** Our pilot project "patients counsel patients" was very positively received by our patients. During the initial stay in the clinic, breast cancer patients need to decide many different things almost immediately after hearing about their diagnosis. Thus, patients have a great need for information at this particular point in time. Counseling by the treating physicians and by psycho-oncologists can therefore be optimally enhanced by the opportunity to speak to a breast cancer survivor. We will therefore continue this project as part of our routine care and would be happy to share our experiences with other breast centers which are interested in initiating such a project.

**211** POSTER

## Survey of patient opinion on the retrospective use of their tissues for research

R. Blamey, K. Mullinger. *Nottingham City Hospital, Breast Institute, Nottingham, UK*

Translational research in breast cancer and many diseases is threatened by impending European and national legislation which will forbid the retrospective use of tissues and data without obtaining permission from the patients or relatives. Whilst in future prospective permission may be obtained, it will require years of follow up before any clinical correlations are available.

This survey sought opinion on this issue from the people most involved (ie) the patients.

The survey was carried out in our Primary Breast Cancer Follow up Clinic over a three month period; patients were diagnosed in the 1970s to 2002.

Questionnaires were handed out and returned to the clinic nurses. They were accompanied by a short explanatory letter stating that they were under no obligation to return the questionnaire.

**Results:**

1) a) 'The use of my tissues and data for research without my permission'
I approve 468, I disapprove 15
b) Do you feel strongly enough to wish your reply to be sent to the UK Secretary of State for Health:
(236 of the 468 did).
2) 'If I was the closest living relative of a patient who had died of breast cancer'
I would approve 394, disapprove 44, of the use of their tissues and data for research.

**Conclusion:** It is clear that the overwhelming proportion (97%) of patients treated with breast cancer support the retrospective use of their tissues and data for research and do not believe that their permission is required; many expressed strong views on this.

**212** POSTER

## Innovating means to advocate and promote the fight against breast cancer

M. Ziv. *Israel Cancer Association, Director General, National representative of Israel, Forum Europa Donna, Givatayim, Israel*

**Introductory sentence**: Innovating approaches are needed to further advocate and promote the fight against breast cancer.

**Brief description**: An overview will be given of the innovating means and approaches employed by the ICA to advance the fight against breast cancer on all possible fronts – promoting research, initiating and financing quality assurance of the National Mammography Project, enhancing treatment modalities and rehabilitation methods, promoting the rights of breast cancer patients and increasing awareness of the magnitude of supporting the fight, through enlistment of the media and by initiating creative projects to help break the code of silence and dispel myths surrounding the disease, in addition to underscoring the need to make concerted efforts to eradicate it.

**Summary & conclusion**: Using innovative approaches, the Israel Cancer Association successfully advances and achieves operative goals, which promote the fight against breast cancer and make it a top priority on the national agenda.