

EBCC: Driving up standards in breast care

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The European Breast Cancer Conference set up by researchers, clinicians and advocates who wanted to co-ordinate their work and widen the fight against cancer to include the public and politicians. This year it took place under the shadow of the Clinical Trials Directive.

In 1998, three of Europe's leading organisations representing researchers, clinicians and women cancer advocates launched the biennial European Breast Cancer Conference (EBCC) to co-ordinate breast cancer research, educate primary care providers about breast cancer and sensitise politicians and women to the potential for progress.

These conferences are unusual in that they bring together, on an equal footing, researchers, clinical practitioners and women activists, and are oriented as much towards the public and politicians as towards professionals. Each EBCC issues a closing statement, which makes demands on national politicians, the EU and on clinicians and researchers.

They press for measures to improve the legal framework for research and treatment, the interchange between research and clinical practice and the management of services. They push ethical issues up the agenda, and introduce the patient view into debates.

The statements emanating from the biennial conferences carry great weight because of the authority of its three organising bodies:

- The Breast Cancer Co-operative Group of the European Organisation for Research and

Treatment of Cancer (EORTC) – an important driver of laboratory and clinical research in Europe.

- EUSOMA (the European Society of Mastology) – the organisation that sets standards in the management of breast diseases, and helps clinicians and centres to meet the standards to become specialist breast units.

- Europa Donna – the coalition of breast cancer groups throughout Europe that represents the concerns and interests of women.

Both EORTC and EUSOMA promote translational research, seeking to move laboratory discoveries quickly into clinical trials and to minimise the delay between the development of effective anti-cancer therapies and their use in patient treatment.

Europa Donna has proved a powerful lobby, pressing authorities and governments for improvements. It played a key role in securing a strong resolution in the European Parliament, in June 2003, aimed at reducing cancer mortality by 25% across Europe – the first policy ever passed by that body on a specific disease.

The EBCC formula emerged from lengthy discussions in the early 1990s around the possibility of

extending the former EORTC Breast Cancer Working Conference.

The plans were finalised in June 1995, at a meeting hosted by Umberto Veronesi and attended by representatives of the three organising groups and the Federation of European Cancer Societies. It was a success from the first and has since grown in size and diversity. In 1998, Florence attracted more than 3,000 delegates from 74 countries. The fourth EBCC in Hamburg this year welcomed 3,599 delegates from 82 countries.

FOCUS ON OPTIMAL CARE

Florence focused on the quality of treatment, demanding that all women should have access to multidisciplinary and multi-professional breast clinics. It also drew attention to the need for research to feed more quickly into clinical trials and treatments. By the time of the second EBCC in Brussels in 2000, the three societies had agreed guidelines defining the requirements for these dedicated breast units. The Brussels Statement called for all breast units to develop quality assurance programmes and to contribute to a common European database. It also called for mammogram screening to be implemented throughout Europe for women aged between 50 and 75, free at the point of delivery. The statement expressed early

concerns about the future of European research projects. The Brussels Statement called for informed consent to be routinely obtained from all breast cancer patients for the use of frozen tumour specimens. However, the EU, driven in part by public disquiet about medical abuses, was pursuing a different agenda.

RESEARCH CONCERNS TOP THE AGENDA

Fast forward two years to Barcelona in 2002, and the third EBCC recognised “pan-European concern about the future of clinical and translational research for cancer in general and breast cancer in particular”. The conference was presented with data about the steep increase in age-specific mortality from breast cancer between the war and the mid 1980s, followed by a significant fall in mortality between 1987 and 2000.

There was a consensus that around two-thirds of the reduction in breast cancer mortality could be attributed to improvements in treatment since the first trials of tamoxifen in older women and cytotoxic chemotherapy for pre-menopausal women.

The Barcelona Statement feared that European multi-centre trials, which were largely responsible for continuous incremental improvements in treatment, were under threat by “well meaning, but

Since its founding conference in Florence, 1998, the EBCC has gone from strength to strength. This year's gathering in Hamburg was attended by more than 3500 delegates from 82 countries





The 4th EBCC, in Hamburg, was chaired by Jacek Jassem, the dynamic head of Oncology and Radiotherapy at the Medical University of Gdansk. He is pictured here at the opening ceremony

misguided, bureaucratic challenges". Indeed, what the EU called 'good clinical practice' as applied to clinical trials, patient confidentiality and ethical issues would make trials difficult to conduct and prohibitively expensive.

Ethics Committees were tightening their interpretation of the Helsinki Declaration on ethical research to the point of threatening the recruitment of patients into trials. The statement said that unless Ethics Committees encouraged cancer research they would become obstacles to progress, "carrying equal responsibility for unnecessary loss of life in the future, as those clinical scientists who have abused the trust of the public in the past".

And so to the fourth conference in Hamburg in March this year, barely a month before the European Directive on Clinical Trials came into force. The Hamburg Statement – published in full on these pages – issued a clear warning: "Excessively rigid legislation, unjustifiable administrative restrictions and government budget cuts are threatening cancer research in general, and breast cancer research in particular." The EU directive was said to be especially damaging to research into surgery, imaging, radiation therapy and tailoring treatments.

There were calls for action. Karin Jöns, the European Parliament's standing rapporteur for breast cancer, who is herself a breast cancer sur-

vivor and President of the German Forum of Europa Donna, criticised the fact that only eight European countries currently offer nationwide mammography screening, and many of these are not in line with EU guidelines.

The need for screening was underlined by a controversy over self-examination. Professor Lars Holmberg, from the Uppsala Regional Oncologic Centre, Sweden, said that self-examination raised anxiety levels to no good effect and could be positively harmful.

He based his remarks on a Russian study, which found that women were reporting more benign lesions to their doctors without any reduction in cancer deaths.

FOCUS ON AGE

Age-related issues were a recurring theme. The Institut Gustave Roussy in Villejuif, France, reported that women who carry the highly aggressive BRCA breast cancer gene are at no greater risk of relapse after treatment. The gene is associated with cancer in young women, who are prone to recurrence. However, the risk factor appears to be age, rather than genetics.

Dr Suzette Delaloge, assistant professor at the Institut, called for more research into why younger women relapse. Younger women who survive breast cancer can suffer long-term physical and psychologi-

cal after-effects. Dr Lonneke van de Poll-Franse from the Comprehensive Cancer Centre South in Eindhoven, in The Netherlands, said that 22% of younger women were having problems with unusual tiredness even ten years later, compared with only 4% of older women.

In general, follow-up care is not reassuring. Ingrid Kössler, President of the Swedish Association of Breast Cancer Societies, reported on a questionnaire returned by 600 women following treatment for breast cancer, which revealed that follow-up examinations were often hurried, with no opportunity to ask questions, express emotional concerns or talk about a woman's social situation.

She called for research into follow-up by specialist nurses.

It is not only young women who need special

“We don't know enough about attitudes among physicians; we don't ask elderly patients what they want; and we don't do enough specific trials for them.”

Professor Silvio Monfardini, from the Division of Medical Oncology, Padova, Italy, agreed on the need for trials. “If this is not done we will discriminate against an already vulnerable group and deny us information on a very relevant part of the breast cancer population in Europe.”

Targeting treatment on specific age groups is a step towards individual packages of care, which is the direction signposted by research. Dr Alane Koki, Chief Scientific Officer of the French biotechnology company, Ipsogen, said that significant progress was being made towards identifying the genetic make-up of individual tumours, allowing treatment choices that are based on personalised information.

Ipsogen has developed a breast cancer profile chip for use in local pathology laboratories.



The consensus session, chaired by Alberto Costa, where delegates vote on which issues to prioritise in the closing statement

attention, but also the elderly. Professor Holmberg said that doctors were not trying hard enough to find suitable treatments for women aged 75 or older, who make up a quarter of breast cancer patients and who have a worse prognosis than younger patients.

WIDENING THE FIGHT

The next EBCC, in Nice in 2006, will be chaired by Alberto Costa, a breast surgeon from Pavia, Italy, and Director of the Milan-based European School of Oncology. At previous EBCCs he moderated the drafting sessions that developed the influential conference statements.

Dr Costa has a number of plans for Nice. He will invite experienced breast care nurses, to spread the concept of specialist breast care nursing beyond Northern Europe.

Dr Costa also hopes that some of the big cancer charities in Europe will attend, creating a forum for discussion on how to fund multi-centre, multi-national trials on breast cancer at a European level.

He said: “If we can include some of the major cancer charities in the Nice EBCC, it will strengthen links between those who raise money and the researchers and clinicians who need the funding to target treatment more precisely. If this led towards some national cancer charities combining resources to fund a major European cancer trial, that would be a fantastic step forward.”

The Florence, Brussels and Barcelona Statements can be found on the Eusoma web site at www.eusoma.org (go to Guidelines and Publications, EUSOMA Statements)