HIGHLIGHTS
REPORT FROM THE

7th EUROPA DONNA Pan-European Conference

5–6 November 2005 – Rome, Italy

Joining Voices – Meeting Needs

The 7th EUROPA DONNA Pan-European Conference "**Joining Voices – Meeting Needs**" united 210 breast cancer advocates from 38 countries to learn about the latest in breast cancer treatment and policy, particularly screening, guidelines and multidisciplinary breast units.

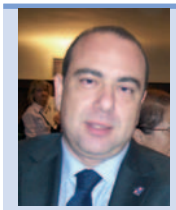
EUROPA DONNA President **Stella Kyriakides** urged the advocates to use their collective voice to implement the European Parliament Resolution on Breast Cancer and thereby improve breast cancer care for all women across Europe. The keynote speaker, the EU Commissioner for Health and Consumer Protection, **Markos Kyprianou**, confirmed this motion and set out the health priorities of the Commission, emphasising its dedication to effective mammography screening programmes as stipulated in the newly published 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

Introducing the medical aspects of breast cancer, a well-known face to advocates, **Dr. Alberto Costa**, Director of the Breast Surgery Unit at Fondazione Salvatore Maugeri in Italy, overviewed the evolution of breast cancer surgery and encouraged women to take an active role in their treatment decisions. **Olivia Pagani**, from the Institute of Oncology of Southern Switzerland, covered new advances in breast cancer treatment and trials for post- and premenopausal women, while **Pat Hargadon**, a breast nurse in Ireland, described the benefits of complementary medicine for women with breast cancer.

Moving on to policy, the President of the European Society of Mastology (EUSOMA), **Prof. Luigi Cataliotti**, discussed the recommendations for specialist breast units. **Astrid Scharpantgen**, co-ordinator of the national breast screening programme in Luxembourg, outlined the European guidelines for mammography screening and questions advocates should ask about the programmes in their countries. In her address, **Karin Jöns**, MEP and Head of EUROPA DONNA Germany, detailed the progress made since the adoption of the Resolution on Breast Cancer in 2003 and pinpointed areas for much needed advocacy work.

Other activities included a panel discussion involving six members of the Royal Free Hospital Breast Unit in London, UK, who demonstrated the workings of their multidisciplinary breast team. Advocates then joined their voices in six workshops on pertinent topics for lobbying, such as breast cancer in young women, setting up screening programmes and employment issues. The conference culminated with presentations on the EUROPA DONNA Forum survey, and the local activities in Belgium, Portugal and Turkey.

Held every two years, EUROPA DONNA's Pan-European Conference aims to bring together advocates from all European countries to provide them with the tools required to lobby for breast cancer care in accordance with the EU guidelines. It is the only European breast cancer conference that is dedicated to breast cancer survivors and advocates and provides them with a special arena where they can compare and discuss experiences and strategies.

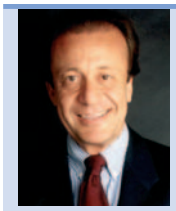


Health priorities across the extended Europe

Markos Kyprianou
EU Commissioner for Health and Consumer Protection

The European Commission has two main health priorities for the next 5 years: prevention and reducing inequalities between member states. Rising obesity rates, smoking and other lifestyle factors will have a future impact on disease incidence, including cancer. Life expectancy differs by more than 10 years among the EU member states, due in part to lifestyle factors and access to treatment. The divisions are based on geography as well as education, income and gender, and some can be alleviated through best practice exchanges and contacts with centres of reference.

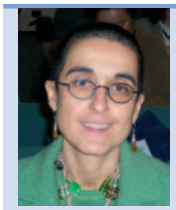
The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis have been revised to incorporate the 10 new member states and scientific progress. This fourth edition is the result of a Europe-wide review process co-ordinated by the European Breast Cancer Network (EBCN) with contributions from public health specialists and EUROPA DONNA. Also importantly, the 2003 Council Recommendation on Cancer Screening urges member states to organise national screening programmes for breast, cervical and colorectal cancer. Early detection of breast cancer through mammography screening is necessary: concerted, sustained efforts on a local, regional, national and European level are required to implement all of these recommendations.



The way forward: breast cancer surgery

Alberto Costa
Director, Breast Surgery Unit, Fondazione Salvatore Maugeri, Pavia, and Director, European School of Oncology, Milan, Italy

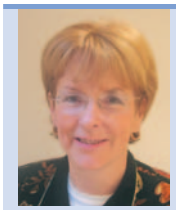
Breast cancer incidence is on the rise, due in part to the late age of childbearing and the decreased duration of breastfeeding. However, mortality from breast cancer is declining because of effective screening programmes, early diagnosis, awareness and treatment. Science involves asking questions and challenging existing concepts and practices. Advocacy should do the same. In the past 40 years, breast cancer surgery has evolved from mastectomy and enlarged mastectomy to breast-conserving surgery, sentinel node biopsy and limited irradiation. Breast tumours can be palpable, non-palpable, lobular or ductal, and their size, histotype, lymph node involvement, grading, hormone receptor status, proliferation index, vascular invasion and HER2 oncogene status all combine to create more than 50 different types of breast cancer. The treatment approach varies accordingly. Once used indiscriminately, chemotherapy is now known to be effective only in certain cases. It can also be given prior to surgery to control metastases, rather than only postsurgery. Clinical trials are investigating the effect of localised intra- or perioperative radiotherapy. Given the many types of breast cancer treatment, women should not hesitate to request a second medical opinion. Surgery alone cannot treat breast cancer; a multidisciplinary team incorporating all aspects of cancer treatment is the required approach.



Recent advances: breast cancer systemic treatment and trials

Olivia Pagani
Staff Oncologist, Department of Medical Oncology, Institute of Oncology of Southern Switzerland

Breast cancer treatment choice should be based on endocrine responsiveness, global risk evaluation, available data, the best therapeutic option and the woman's preference. Endocrine responsiveness is the main criterion for treatment choice. In postmenopausal women, the ideal sequence of treatment with tamoxifen and aromatase inhibitors is still being studied; however, the American Society of Clinical Oncology's 2004 recommendations for postmenopausal women with hormone receptor-positive disease include an aromatase inhibitor as initial therapy or after tamoxifen treatment. In HER2-positive women, the early results of both the HERA trial and two US trials showed a clear benefit in disease-free survival for trastuzumab (Herceptin®). However, the cardiotoxicity associated with trastuzumab and the optimal treatment duration require further study. In premenopausal women, the role of ovarian function suppression, chemotherapy, and pregnancy after breast cancer need to be investigated. Treatment of elderly women tends to be arbitrary due to the lack of studies in this population. These women should be encouraged to take part in trials. Other important studies are underway on micrometastases, preoperative systemic therapies, intraoperative radiation therapy and the impact of treatment on quality of life and cognitive function.

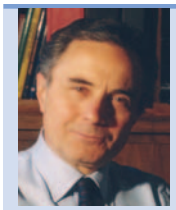


Helping women cope: the role of complementary medicine in breast cancer

Pat Hargadon
Breast Cancer Nurse Counsellor, ARC Cancer Support Centre, Dublin, Ireland

A diagnosis of breast cancer can often be a traumatic event in a woman's life, resulting in physical, psychological, social and spiritual distress. As well as dealing with the diagnosis and side effects of treatments, the woman may also be dealing with other issues such as relationship difficulties, work problems, financial concerns and living with uncertainty. Complementary medicine in the form of physical, psychological and pharmacological therapies can improve quality of life and help the woman diagnosed with cancer to cope by reducing harmful stress, increasing feel-

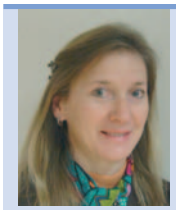
ings of personal empowerment, enhancing overall well-being and aiding symptomatic relief. Such therapies should be used in conjunction with conventional medical care and consequently are referred to as "complementary". Complementary therapies include massage, reflexology, relaxation, stress management, counselling, homeopathy and dietary interventions. In Ireland, the Department of Health has stated that complementary therapies used with conventional medical care can help improve the quality of life of patients with cancer, and should be an integral part of cancer care. Each European country should be committed to including complementary medicine in the care of women with breast cancer.



EUSOMA guidelines and accreditation of breast units: how to improve care for women with breast cancer

Luigi Cataliotti
Professor of General Surgery, University of Florence and President of EUSOMA

The Requirements of a Specialist Breast Unit, first published in 2000, have been updated and are to be included in the 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. Their aim is to make a high-quality specialist breast service available to all women in Europe, to define the standards, and to recommend a means of accreditation of breast units. The mandatory requirements for breast units include: being a sufficient size (*i.e.*, 150 primary breast cancer cases annually); having specially trained members of the core team, comprising a breast surgeon, radiologist, radiographer, pathologist, oncologist, patient support staff and a data manager; and offering associated services such as psychological support, reconstruction, physiotherapy, risk assessment, palliative care and a prosthesis fitting service. The unit must also have imaging and radiotherapy equipment and the facilities to safely deliver chemotherapy regimens. Performance and audit figures must be produced yearly. Breast units may stand alone or form part of a hospital with a multidisciplinary approach. An effective means of assessing quality standards and accrediting breast units is now under discussion.



Screening needs in Europe: what the European mammography screening guidelines mean for women

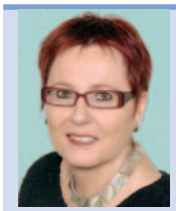
Astrid Scharpantgen
European Breast Cancer Network, Luxembourg

The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis set quality standards for epidemiology, physical and technical aspects of mammography screening, radiography and radiology, pathology, surgery, data collection and training. The revised edition of the guidelines includes new chapters on digital mammography, communication, pathology guidelines for open biopsy and resection specimens, specialist breast unit requirements and quality assurance in diagnosis. Currently the most effective means of reducing mortality from breast cancer, population-based mammography screening programmes also aim to provide high-quality service, to reduce excessive surgical procedures, and to improve women's breast awareness.

Advocates can ask the following questions about mammography screening in their countries:

- How many mammography facilities are there and do they meet the EU quality standards?
- How many registered radiologists and radiographers do the facilities have and are they specially trained?
- Are all mammograms read twice?
- Does all mammography equipment undergo technical control?

Advocates can use the guidelines to become better informed and prepared to ask questions to ensure that the screening programmes are effective, meet quality standards, and that they are accompanied by optimum treatment and care.



Joining our voices: implementing the 2003 European Parliament Resolution on Breast Cancer

Karin Jöns
MEP, EPGBC Chair and President EUROPA DONNA Germany

Since the unanimous vote in favour of the 2003 Breast Cancer Resolution, there has been the adoption of the Council Recommendation on Cancer Screening, and the reconvention of the European Parliamentary Group on Breast Cancer (EPGBC) in co-operation with EUROPA DONNA. With the Resolution, member states thereby agreed in principle to introduce mammography screening in accordance with EU guidelines in their own countries. The European Commission is to hold a mid-term review of all the demands made in the Resolution probably in 2007. EU Structural Funds can be used to invest in public health structures, particularly in the new member states. National governments designate funding for screening and should be targeted. Non-EU member states should also remain determined to implement nationwide screening. The revised edition of the EU guidelines now includes for the first time recommendations for specialist breast care units as requested in the European Parliament Resolution on Breast Cancer. The European Cancer Network should establish procedures for breast unit accreditation in close co-operation with EUSOMA, EUROPA DONNA and the support of the European Commission. Efforts to implement screening and set up breast units according to European guidelines must continue across Europe.

How the multidisciplinary breast team works: a panel discussion

Chaired by Gloria Freilich
EUROPA DONNA Founding President

The core team of the Royal Free Hospital Breast Unit in London, UK, discussed the cases of five women to demonstrate the workings of their multidisciplinary team. **Gloria Freilich**, EUROPA DONNA Founding President who chaired the session, introduced the requirements for breast units stipulated in the European guidelines and outlined the structure and function of the team which normally also included consultants in cytology, nuclear medicine and genetics, a clinical co-ordinator, junior members of the surgical and medical teams, medical students and the on-site breast cancer support charity, Cancerkin. The core team members present included **Tim Davidson**, Surgeon and Lead Clinician; **Brian Holloway**, Diagnostic Radiologist; **Nuala McDermott**, Pathologist; **Christopher Collis**, Clinical Oncologist; **Alison Jones**, Medical Oncologist; and **Tina Kelleher**, Clinical Nurse Specialist.

The importance of triple assessment in making a diagnosis, *i.e.*, clinical examination, radiology and cytology, was emphasised by Tim Davidson, who introduced each case for discussion. Cases presented ranged from benign diagnosis through to breast cancer at different stages and of different complexity, in both younger and older women. Each member of the core team then discussed his or her role in the diagnosis or treatment. The radiologist first used mammography or ultrasound scans to demonstrate imaging and grading of tumours. The pathologist discussed cytological findings and the case then passed to the surgeon who considered the rationale for his surgical recommendations. The pathologist was then in a position to provide her report based on the histology of the surgical specimen, which is key to decisions to be taken on further surgery or adjuvant treatment. The clinical oncologist and medical oncologist considered treatment options, including radiotherapy, endocrine therapy and chemotherapy, as appropriate to the case and the clinical nurse specialist discussed how the experience affected each woman, with reference to psychosocial and practical issues.

Santilal Parbhoo, Lead Consultant and Breast Surgeon at the Hospital of St John and St Elizabeth Breast Unit, then described the workings of the multidisciplinary breast team in the private sector.

Advocacy workshops

Advocates shared their opinions and experience in a practical session of six workshops on prime targets for lobbying. Some of the topics affect all women, while others were specific to a subset of women. "Breast cancer in young women" and "Advocacy and hereditary breast cancer" were two workshops in which the participants identified concerns specific to their group. As employment issues are a common concern for women with breast cancer, two workshops dedicated to this topic covered how effective lobbying can influence employment legislation. At two other workshops, "Lobbying for progress on the Breast Cancer Resolution" and "Setting up a screening programme", advocates were able to use the information provided in the conference presentations to discuss further steps to implement the Resolution.

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