Highlights of the

9th EUROPA DONNA Pan-European Conference

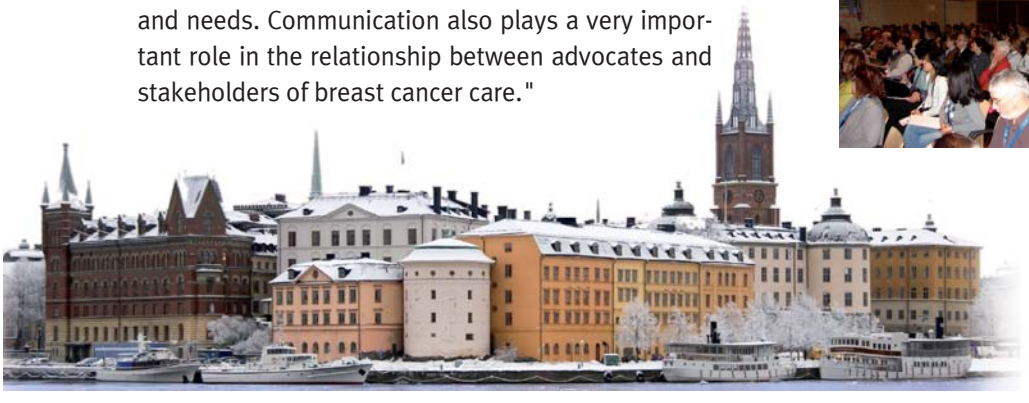
European Breast Cancer Advocacy:

Communication and Collaboration

With 15 years as Europe's breast cancer advocacy organisation, five presidents, nine Pan-European conferences and 44 member countries, EUROPA DONNA has grown in size, experience and influence as a result of constant communication and collaboration. Dedicated to this very theme, the 9th EUROPA DONNA Pan-European Conference was held on 24–25 October in Stockholm, Sweden, a country with decades of experience in breast cancer screening and high-quality breast care. The conference was the most attended in the history of the Coalition, welcoming more than 230 members, national representatives, breast cancer advocates, nurses and other breast cancer specialists. At a 15th Anniversary Presidents' Panel session, the Coalition's five presidents led delegates on a journey through EUROPA DONNA's many achievements and suggested a course for the future.

In her opening address, EUROPA DONNA President Ellen Verschuur said, "The combined theme of this conference is in line with the core function of EUROPA DONNA, Communication and Collaboration, representing two essential tools in the world of advocacy. Communication and collaboration between the member countries is imperative because only in this way there can be a mutual understanding of issues and needs. Communication also plays a very important role in the relationship between advocates and stakeholders of breast cancer care."

INSIDE



Stockholm, Sweden • 24–25 October 2009

Mammography screening: a revolution in breast cancer

László Tabár

In an enthusiastic key-note address, world-renowned authority and pioneer of mammography screening, Dr. László Tabár, Professor of Radiology at the University of Uppsala School of Medicine, emphasised that breast cancer is primarily a surgical disease, if it is detected early enough (i.e., when it is in situ and invasive but smaller than 14 mm in size). "It is not how we treat the breast cancer patient but when: early or late in its natural history determines the long-term outcome of the breast cancer patient," he said. He added that mammography screening has brought about a revolution by detecting many breast cancers while they are still non-palpable and in these cases overtreatment must be avoided: treatment guidelines of non-palpable screening-detected breast cancers should not be based on the results of trials with palpable, clinically detected tumours. "The punishment (of treatment) should fit the crime, i.e., stage at the time of treatment," he said.

The evidence from population-based breast cancer screening trials

Dr. Tabár has been one of the leaders of the Swedish Two-County Trial, which is a randomized controlled mammography screening study that started in 1977. The first results were published in 1985, showing that women who were invited to screening (i.e., those who attended combined with those who were invited but did not attend) had a 31% decrease in breast cancer mortality, compared with the control group, i.e., women who were not offered screening. The figure today, 25 years after the first publication of the results, is 39%. This led to the implementation of nation-wide mammography screening programmes in Sweden and other European countries, Australia and Canada. The results of the ongoing nation-wide service screening in Sweden were published in 2006, when the researchers compared breast cancer death among women who attended mammogra-

This is the first generation in the history of medicine that can really make a significant decrease in mortality from breast cancer or a significant change in the outcome of breast cancer patients.

Evidence from screening studies

- An extension of the Two-Country trial published in 2006 evaluated incidence-based breast cancer mortality in 542,187 women before screening implementation and 566,423 after implementation. There was a significant 43% reduction in incidence-based breast cancer mortality among screened women relative to that for women before the screening implementation. The authors estimated that 472 women needed to be screened to save one life (Cancer Epidemiol, Biomarkers Prev 2006, 15: 45).
- A Dutch study examined the relative contribution of adjuvant systemic treatment from 1975–1997 in the Netherlands on mortality from breast cancer compared to early detection. The authors estimated that the reduction in mortality due to screening was 28–30%, while the reduction attributed to adjuvant therapy would be 7% (Br J Cancer 2004, 91: 242).

phy screening during a 13-year period with breast cancer death during a 13-year period before screening was initiated. The results showed that 43% fewer women died of breast cancer during the screening period among those who attended screening regularly. Dr. Tabár concluded that the mammography screening trials have clearly shown that detecting and removing breast cancer early has a lifesaving effect, and also reduces the need for adjuvant treatment regimens. "I am so happy to belong to this generation of physicians," he said. "This is the first generation in the history of medicine that can really make a significant decrease in mortality from breast cancer or a significant change in the outcome of breast cancer patients."

The mammographic appearance of breast cancer as a prognostic tool

In screen-detected invasive breast cancers that are smaller than 14 mm, the mammogram can also be used to identify breast cancer subtype with excellent or poor prognosis. Dr. Tabár cited results of his group showing that women with "casting type calcifications" on the mammogram, had poorer long-term survival than women with other types of mammographic tumour appearance. He suggests integrating mammographic tumour features into the current TNM (tumor, node, metastasis) staging system so that poor-prognosis tumours can be identified, and thus could receive targeted treatment, while those with good prognosis can avoid overtreatment. He also cited very recent studies (Tot, T. et al. 2009) identifying multifocal breast cancers as having a higher risk of lymph node metastasis and an almost four-fold higher fatality rate than unifocal cancers.

Advances in imaging

Dr. Tabár described a new three-dimensional, automated, reconstructed ultrasound method now being studied in a randomized, prospective trial. This new method allows visualisation of the breast in 2-mm thick slices. For this technique the woman lies face up, a plate is placed on the breast and the probe takes a 3-D image that can be divided into layers from the skin down to the chest wall. He added that the technique is automated, i.e., not user-dependent (unlike the current hand-held ultrasound devices), it allows the detection of tumours hidden in the dense breast tissues, and therefore could be an effective screening tool for women with dense breasts when combined with mammography.

Take home message

- There is unequivocal evidence that breast cancer screening can prevent death from this disease
- Breast cancer is localised to the breast at the beginning, not a systemic disease. Breast cancer is a progressive disease, which can be arrested through early detection and treatment
- Treatment guidelines for non-palpable cancers detected at screening should not be based on results of trials with palpable, clinically detected cancers
- Mammography can identify tumour features that can be used as independent predictors of prognosis

Advocating for implementation of specialist breast units

Alberto Costa

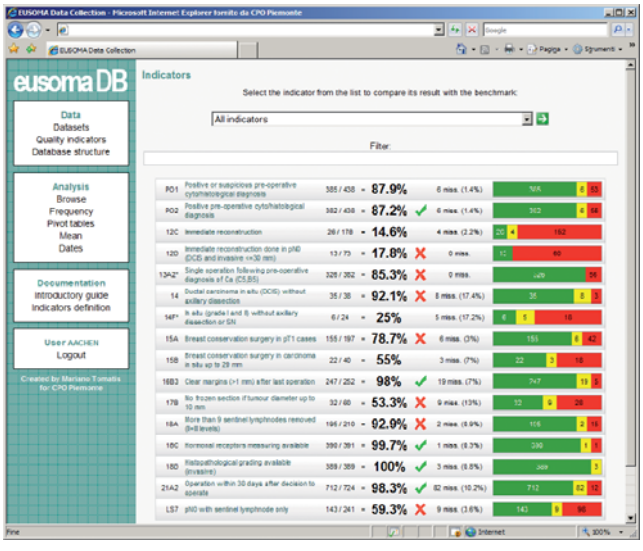
On behalf of Dr. Marco Rosselli del Turco, European Society of Breast Cancer Specialists (EUSOMA) President, Dr. Alberto Costa, Director of the European School of Oncology in Milan, presented the requirements of specialist breast units and the need to advocate for their implementation: the "European Parliament Resolution on Breast Cancer 2006" calls for their provision across Member States by 2016. He outlined the main prerequisites of specialist breast units as stipulated in the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, which are based on the EUSOMA breast unit requirements. Such breast units incorporate coordination between all the speciality breast health services a woman may need, provided in a multidisciplinary fashion.

Some of the main specialist breast unit requirements

- A single integrated unit working in multidisciplinary fashion (over 95% of cases have to be discussed at a multidisciplinary team meeting). This does not have to be within a single geographical entity, but should be close enough to enable multidisciplinary working
- A minimum of 150 new breast cancer cases treated per year
- Care by breast specialists in all the required disciplines (from genetics and prevention, to treatment and patient support)
- Dedicated staff in all disciplines (from screening and genetic counselling to treatment and patient support)
- Data collection and medical auditing

Quality and certification

Dr. Costa said that each specialist breast unit should comply with clear quality indicators for its diagnostic and treatment services, which can be measured through certification of breast units. He described the EUSOMA breast unit certification process which involves site visits, centralising of data and evaluation with suggestions for improvement. To date, initial certification has been granted to 28 European units. The EUSOMA database is used to score the services and practice of different breast units by determining the proportion of patients treated using a certain approach in a unit and compares the resulting percentage with the standards. This identifies each unit's strengths and weaknesses.



EUSOMA database showing results for quality indicators.

Implementation and collaboration

Dr. Costa said that implementation of breast units can be achieved by creating national or regional breast cancer resolutions, by fostering breast unit certification, and through

advocacy. He suggested co-operation between EUSOMA and EUROPA DONNA in creating a European observatory for breast unit implementation, developing a patient satisfaction survey and launching new campaigns for breast cancer prevention.

Forum input: workshop on specialist breast unit implementation

A special workshop provided advocates with the opportunity to share experiences in establishing specialist breast units in their own countries. In her introduction, Stella Kyriakides of EUROPA DONNA Cyprus and a EUROPA DONNA Past President, pointed out that women have the right to high-quality breast care in a specialist breast unit as stipulated in the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* and the European Parliament Resolutions on Breast Cancer. Christine Murphy-Whyte, EUROPA DONNA Vice-President, presented the Irish experience in which high-profile cases of misdiagnosis and an active response by EUROPA DONNA advocates led to an acceleration of the concentration of breast cancer services in specialist breast centres across Ireland. Eight specialist centres were designated and a number of smaller centres were closed as a result. The newly established Health Information and Quality Authority was charged with monitoring standards in the designated centres. Ms. Murphy-Whyte said that much was made possible due to the appointment of an outside expert to lead the National Cancer Control Programme, coordinate hospitals, clinicians, policy makers and advocates and drive the implementation of specialist cancer centres in Ireland.

Take home message

- Specialist breast units involve multidisciplinary assessment and co-ordination
- The European Resolution on Breast Cancer of 2006 calls for their implementation across the EU by 2016
- Implementation can be achieved through national resolutions, certification and advocacy
- Quality can be ensured through certification and benchmarking
- The requirements of a specialist breast unit are provided in the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* and in EUROPA DONNA's Short Guide to these guidelines

How to advocate for implementation of specialist breast units

- Use the EUROPA DONNA *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis,* now available in eight languages, to reach policy makers
- The evidence for specialist breast units is irrefutable. Put that evidence into the national context and use, where available, comparative data from other European countries on incidence and mortality rates. Use comparative statistics, such as indicating the numbers of women who would unnecessarily die prematurely from breast cancer
- Get media attention. Be precise and concise when speaking to the media and to the public in general
- Have a respected "clinical champion" on board, a clinician or policy maker who promotes the work of specialist breast units and has good contacts with all stakeholders
- Inform women and advise them to attend units which follow the EU guidelines, in cases where there are a wide variety of centres available
- Be able to offer alternatives in response to possible resistance to breast units (e.g., provide alternative accommodation when travel is an issue; direct media attention to the positive to ensure best practice; emphasise the cost benefits of concentrating resources and staffing in specialist units as opposed to dispersing them thinly across numerous centres)
- Use the EUROPA DONNA network to transfer experience from one country to another and help guide advocacy initiatives

The many facets of breast cancer and its surgical treatment

Alberto Costa and Ellen Verschuur

Dr. Alberto Costa, Director of the European School of Oncology in Milan, said that despite the enormous biological and technological progress in breast cancer medicine, surgery still plays a central role. It is essential for breast surgeons to understand the disease and not just the technicalities of the surgical procedures. He explained that breast cancer has at least 200 different profiles and minimum effective treatment must suit each type of cancer and each woman. The breast cancer profile is defined by a combination of the following eight parameters:

1. Size
2. Histotype (30% less malignant)
3. Lymph node status
4. Grading (1–3)
5. Hormone receptor status (oestrogen and progesterone receptors)
6. Proliferation index (Ki-67)
7. Vascular invasion
8. HER 2 (– , + , ++ , +++)

Breast cancer can be palpable or non-palpable, in situ, infiltrating, lobular or ductal. Dr. Costa added that without mammography screening, women usually detected the cancers themselves. "Now in areas where screening is available we can have up to one-third of diagnoses without any palpable lesions because the diagnosis is made by the radiologist," he said. Microcalcifications should never be underestimated, he added, and when suspicious they should be assessed by means of a core biopsy or other suitable diagnostic procedures.

In the case of breast-conserving surgery for non-palpable invasive or non-invasive lesions, radioguided occult lesion localization (ROLL) – a technique inspired by the sentinel node procedure – can be used. A radioactive substance is injected and the surgeon uses stereotactic or ultrasound guidance to locate and remove the affected area. As radiotherapy is indicated after breast-conserving surgery, partial breast irradiation undertaken during surgery is under investigation and preliminary results may be released soon. Dr. Costa said that subcutaneous mastectomy, when performed well, may confer better cosmetic results than breast-conserving surgery in cases of diffuse carcinoma in situ, in small breasts and for risk reduction. Nipple-sparing mastectomies can also be performed, he said, since the nipple is rarely affected. Dr. Costa added that the widespread awareness among women of the possibility of breast-conserving surgery is a powerful incentive for early detection.

Breast Cancer Surgery:

- Is rarely urgent
- Requires general anaesthesia
- May become bilateral
- Can benefit from plastic surgery
- Is almost always irreversible

Take home message

- Breast cancer is a very heterogeneous disease
- Patients should always receive a copy of the pathology report within one week of surgery. They should be given the results, sitting in a quiet room, if possible in the presence of a breast nurse
- Women should never be afraid to ask for a second opinion
- Women must demand competent surgeons

Targeting treatment and clinical trials

Jonas Bergh

Dr. Jonas Bergh, Scientific Director, Karolinska Oncology at the Karolinska Institute in Stockholm, emphasised the importance of understanding tumour biology so that treatment and trials are targeted accordingly. He added that the best type of cancer treatment depends on the characteristics of the woman, the cancer and the cells, and that for a targeted drug to work, the target and receptors must be present in the cell. "Unfortunately, most of the studies today are run in a way that they don't take biopsies, they don't measure the targets and the worst of all, the target may not be stable during tumour progression." HER2/neu status can change between a primary and a metastatic tumour in 10–20% of cases. He added that study patients must be correctly selected so that the treatments will work.

First generation

The need for this selection was demonstrated with the discovery of endocrine therapies such as tamoxifen, the first targeted treatment. As part of the "old" therapy arsenal, he explained, it has been shown that in women with the most common type of breast cancer, i.e., middle-aged women with an endocrine responsive tumour, who are given a combination of chemotherapy and tamoxifen for five years, the risk of dying within 15 years is halved. "This is very likely the most effective cancer drug so far innovated, if you look at the numbers of women cured, but it does not work in women who do not express the oestrogen receptors," he said. He added that for 15 years the scientific community debated the usefulness of measuring these receptors, a lesson which can be transferred to the new targeted drug discoveries today.

Another hormonal treatment, fulvestrant, entirely blocks the oestrogen receptors, but for unknown reasons, it is not more effective than tamoxifen. The aromatase inhibitors are part of a newer generation of targeted drugs, but they do not lead to an overall survival gain, he said.

Second generation

Women who have tumours overexpressing the HER2/neu oncogene, which occurs in 20–30% of breast cancers, have shortened overall survival. However, in these patients, administering trastuzumab plus chemotherapy following surgery has been shown to improve survival and decrease recurrence. Lapatinib, which inhibits both HER1 and HER2, has not been shown to have a survival gain, and hence has received only conditional approval in Europe until firmer data are available.

Latest generation

Many new HER-family interacting drugs and vascular endothelial growth factor inhibitors are now in development. The vascular disrupting agent bevacizumab has been shown to prolong time to disease progression in single studies, combined with chemotherapy, but there is no impact on overall survival.

Uptake of new treatments

Prof. Bergh concluded by citing a recent study on the uptake of new drugs reporting that it has increased in the EU13 countries, with the greatest use being in France. He added, however, the high cost of the new targeted drugs underlines the importance of identifying the patients who will potentially benefit from them so that they will receive the treatment. The report *A Review of Breast Cancer Care and Outcomes in 18 Countries in Europe, Asia, and Latin America,* dated October 2009, can be accessed on http://www.comparatorreports.se.

Take home message

- The first generation of targeted drugs was endocrine therapy, and tamoxifen remains an effective treatment in women with endocrine responsive tumours
- The second generation of targeted drugs was trastuzumab, which improves outcome in breast cancer patients with HER2/neu overexpression
- Angiogenetic compounds are among the latest generation of treatments: bevacizumab prolongs disease-free survival but not overall survival
- Understanding biology and selecting the correct patient for the correct drug are of utmost importance
- The high cost of treatment remains a caveat

Follow-up after breast cancer

Ailís Ní Riain

Ailís Ní Riain, Director of Advocacy and Professional Competence at the Irish College of General Practitioners in Dublin, said that follow-up is an important issue since more women are living longer after breast cancer: the current 20-year survival rate is greater than the five-year survival rate was 30 years ago.

She said that current protocols on follow-up vary widely in terms of setting, components, frequency and duration, and few are evidence based. Specialist follow-up aims to detect and treat local recurrence, to deal with adverse effects of treatment and to provide psychosocial support. However, she said, at least 70% of local recurrences are detected by the women themselves, the wide range of treatments may require access to a range of specialist services, and a holistic approach to psychosocial support is needed throughout the cancer journey. According to the UK NICE guidelines, regular clinical examination and annual mammography are sufficient, but she added, this is not widely adopted in practice.

She said that the current situation indicates that hospital-based follow-up is not particularly effective and other options should be considered, such as care provided by primary care physicians (GPs) or specialist nurses. Dr. Ní Riain added that many women believe that GP follow-up is the most appropriate, but express concerns about the expertise of the GPs. However, GPs may be more likely to ask about psychosocial issues and emotional well-being, whereas oncologists may be less prepared to assess emotional health. She cited another very recent study of the role of specialist nurse-led follow-up in which this model was acceptable to two-thirds of patients, there were no differences in outcomes and no women wished to return to routine follow-up in the clinic.

She added that follow-up care performed by trained primary care physicians working in an organised practice setting had comparable effectiveness to that delivered by hospital-based specialists in terms of quality of life and time to detection of distant metastases. In conclusion, she said that follow-up programmes based on regular physical examination and yearly mammography alone are as effective as more intensive approaches in terms of timeliness of recurrence detection, overall survival and quality of life.

Quantitative research on GP follow-up outcomes shows:

- Two-thirds of women were willing to have follow-up with a GP
- No differences in outcomes between GP and hospital-based follow-up
- No delay in diagnosis of recurrences with GP follow-up
- No differences in quality of life
- Higher level of satisfaction with GP care

Take home message

- There is no set, evidence-based protocol for breast cancer follow-up
- There is an increasing number of women living with breast cancer, who may require follow-up
- Primary care physicians or specialist nurses have been suggested as alternatives to hospital-based follow-up, with high acceptance by women and good outcomes
- When a woman finishes primary treatment, she should have a concluding consultation addressing the need for follow-up and what it entails

Metastatic breast cancer: needs and issues

Dora Wheeler

EUROPA DONNA Executive Director Susan Knox introduced the presentation on metastatic breast cancer (MBC) by citing figures from the BRIDGE study: 51% of the women with MBC surveyed reported that current sources of information did not meet their needs and 45% reported having difficulty finding information. "It is clear that as Europe's breast cancer advocacy organisation, EUROPA DONNA needs to begin to address these concerns because it is so often these women who cannot attend events such as this conference to represent themselves," she said.

Dora Wheeler, a senior campaigns officer from Breast Cancer Care in the UK, presented the findings and accomplishments of the group's Secondary Breast Cancer Task Force, which included a User Advisory Group of women with MBC. They identified priority areas based on surveys of women living with breast cancer, regular meetings with the User Advisory Group and expert consensus. Many women reported a lack of information, and only 18 (12%) breast care nurses surveyed in the UK said that care of patients with MBC was incorporated in their work.

Main issues identified, action taken and the result

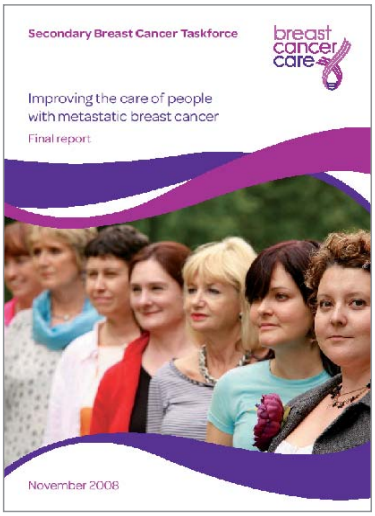
Issue: Lack of data on women with MBC
Action: Surveyed cancer registries, wrote a policy briefing and met with policy makers
Result: Collection of metastatic cancer data is now compulsory in England

Issue: Access to a key worker
Action: Surveyed breast care nurses, developed core competencies, wrote a policy briefing
Result: Publication of the *Guide for Commissioners. Meeting the Nursing Needs of Metastatic Breast Cancer Patients*

Issue: Lack of information
Action: Created a secondary breast cancer resource pack which contains: a booklet on the impact of coping with a diagnosis, a DVD on four women's stories of living with MBC, a patient record book and a standards of care leaflet
Result: Aim is this pack is given out at point of diagnosis by breast care nurses

Issue: Access to support services
Action: Determined that 50% of MBC patients were not offered any information on where to find emotional and psychosocial support services. A recommendation was made:
"Patients with a metastatic breast cancer diagnosis should have their physical, psychological, social, spiritual and financial support needs assessed regularly by a healthcare professional in their clinical team who has appropriate assessment skills."
Result: In February 2009, NICE produced specific guidance on MBC and this recommendation was included

Issue: Role of primary care in being aware of signs and symptoms of secondary breast cancer and management of patients
Action: Summary of good practice guidelines for MBC and palliative care
Result: Creation of a new patient information booklet *What next after follow up?* and the booklet *Metastatic Breast Cancer. A Supportive Tool for Primary Care Teams*



At the end of the two-year period the task force published a final report and recommendations, which now require implementation. The current focus is now on empowering women with MBC, for which they have created a new patient information booklet: *Standards of Care for People with Secondary Breast Cancer. Taking Action Together: A Guide to Improving Your Own Care and the Care of Others*. "Our challenge is acknowledging and addressing the complex needs of these women as they navigate the health and social care services while living with secondary breast cancer and I hope that our campaigning work in the UK will go some way towards improving the standard of care for these women and women like them living with metastatic breast cancer across the UK," Ms Wheeler said.

Take home message

- Women with MBC can feel neglected in terms of treatment care and support, particularly when they compare it with that received at their primary diagnosis
- Data should be collected on the incidence of secondary breast cancer and survival to allow for accurate planning of treatment and support services, and to investigate possible changes in prognosis due to advances in breast cancer treatment
- Women living with MBC must have direct involvement in creating tools to address their needs
- Every patient with an MBC diagnosis should have access to a clinical nurse specialist who has the skills and knowledge to manage MBC. The gold standard would be the inclusion of a metastatic breast care nurse within every breast care team.

Forum input: MBC networking meeting

A metastatic breast cancer networking meeting facilitated by Dora Wheeler and Susan Knox and attended by 24 people from 13 countries, including two women with MBC, was held later in the conference. The following main points were made:

- Women with MBC must be the ones to identify the needs of this population. This can be done by a small group of women with MBC working together and/or by distributing a survey designed for this purpose
- Less developed countries indicated that 70% of breast cancer patients have MBC on initial diagnosis and there are no treatments or palliative care available to them
- The leaflets produced by Breast Cancer Care in the UK can be adapted and translated and are available on www.breastcancercare.org.uk/secondarytaskforce
- EUROPA DONNA's booklet *Clinical Trials and Breast Cancer* may be of use in MBC and adding a specific section to the EUROPA DONNA website was suggested
- On a European level EUROPA DONNA could advocate adding MBC-related issues to the EU guidelines, such as the need for ongoing support and care from breast care nurses, and access to current treatment. The fact that women diagnosed with MBC are often outside the system and do not have access to ongoing services, even where specialist breast units are available, needs to be addressed

Dora Wheeler and Susan Knox

Lifestyle factors, physical activity and avoiding breast cancer

Bettina Borisch and Astrid Scharpantgen

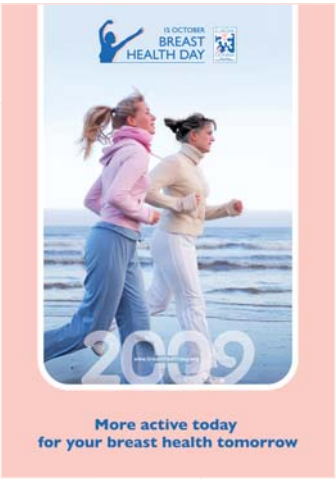
In a joint presentation, EUROPA DONNA Board members Bettina Borisch, from the Institute of Social and Preventive Medicine at the University of Geneva, and Astrid Scharpantgen, Coordinator of the Mammography Programme for the Ministry of Health in Luxembourg, said that studies show that 40% of cancer deaths can be prevented world-wide.

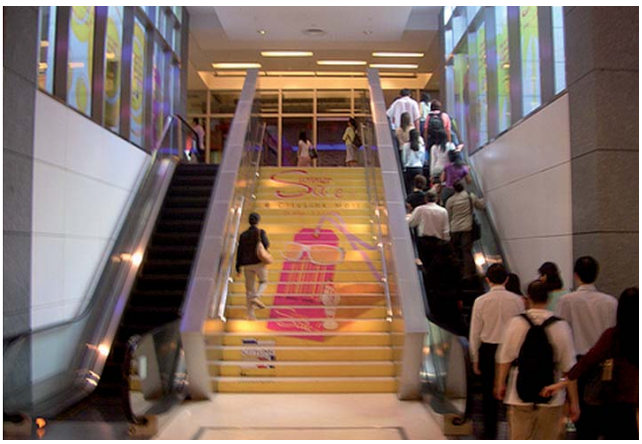
They cited the results of the EPIC study which examined the effect of never smoking, having a body mass index (BMI) below 30, being physically active for more than 3.5 hours/week and having a healthy diet. Of the 23,153 people studied, it was found that the 9% who followed all four lifestyle recommendations had a 36% lower risk of cancer. The role of physical activity in breast cancer prevention – the focus of this year's Breast Health Day – has been demonstrated in various observational studies, although having a healthy lifestyle will not guarantee that a woman will remain cancer-free.

Never forget: you can always start to be active. There are studies showing that if you start when you're 80 you will still improve your physical competence and this is very good news. We should do advocacy at the individual and society level.

Some Breast Health Day activities carried out by EUROPA DONNA Fora that create awareness and get people moving

- Events (running, climbing, cycling)
- Pink Silhouette March
- March for Health
- Race for the Cure
- Collaboration with fitness clubs, schools, hospitals





Your health is your choice

Prof. Borisch described the biological mechanisms in the link between fatty tissue and cancer development. She said that fatty tissue is an important source of chronic inflammation, which is linked to cancer risk. Fatty tissue also produces hormones which add to cancer risk, whereas exercise reduces oestrogen production. She added that while genetics accounts for 10–15% of breast cancer cases, 30–40% of them can be attributed to lifestyle factors.

Ms. Scharpantgen explained how exercise can also help to reduce the risk of secondary breast cancer. An NHS study in the UK showed a 50% decrease in risk of recurrence in stage III breast cancer in women who have metabolic equivalent task (MET) hours of more than 9 per week (e.g., walking for 4.5 hours per week).

With today's urban, sedentary lifestyles, they suggested taking the active choice when it is offered, i.e., using the stairs rather than the escalator or lift. However, since barriers to being physically active are present in our cities, buildings and work places, they suggested advocating at a community level to convince authorities to offer a heathier living environment. The Breast Health Day campaign offers the perfect opportunity to raise awareness of the need for active lifestyles. Prof. Borisch concluded, "Never forget: you can always start to be active. There are studies showing that if you start when you're 80 you will still improve your physical competence and this is very good news. We should do advocacy at the individual and society level."

For more information on lifestyle factors and prevention, see the Breast Health Day Mini-Diary and the *EUROPA DONNA Guide to Breast Health*. For more on Breast Health Day, see www.breasthealthday.org.

Take home message

- Lifestyle factors, particularly physical activity, have been shown to have a role in primary and secondary prevention of breast cancer
- 30–40% of breast cancer cases can be attributed to lifestyle factors
- Awareness of the role of physical activity in breast health must be promoted, as in the Breast Health Day campaign
- Advocacy at a community level is needed to improve the options for leading an active life
- It is never too late to start exercising

Forum input: workshop on organisational development and fundraising

This workshop emphasised the importance of "Communication and Collaboration" between Fora, where more established Fora could share experience with those that are less established. Setting up a forum was likened to a two-tier pyramid, with the bottom tier representing a structure for organisational development and the top tier representing EUROPA DONNA's 10 goals, which are often attainable through fundraising activities.

The foundation is the most important aspect of the pyramid and it must be solid. It can consist of, and be continually developed through, a network of committed people (members and volunteers are a good source), communication (via telephone, post, e-mail, websites, podcasts, etc) and resources (including, but not limited to money, time, human resources, office resources, tickets to events, food and other donations of products/services).

To create a fundraising strategy it was determined that first, there must be a demand in the country for the event or fundraising project. Second, it is important to understand the process, and follow the steps required in order to have a successful fundraising event which include: i) registering the funds which are being used; ii) producing, marketing and distributing the product; and iii) having a clear idea where the proceeds will go. The most important aspect to remember before planning an event is the budget, and this is an essential element to consider in the initial planning stages.

Since the contractual and financial aspects of establishing a non-profit organisation and fundraising initiatives can be complex, it was suggested that EUROPA DONNA could develop meetings to provide support to Fora. Holding a EUROPA DONNA walk on a set day throughout member countries was also suggested.

Possible fundraising strategies

- Using the Pink Ribbon concept, personalising it and having it registered or trademarked
- Donations (personal or structured, i.e., companies donating a percentage of profits of a certain product)
- Grants: businesses, government, embassies, charities and government agencies
- Fundraising charities
- Social marketing
- Direct sales (pink ribbons, pins, scarves)
- Tax deductions
- Events (concerts, pink bra/T-shirt walks, fashion shows, dinners, lotteries, golf tournament)

EUROPA DONNA 15th Anniversary Presidents' Panel: a journey through the years

Gloria Freilich, Mary Buchanan, Stella Kyriakides, Ingrid Kössler and Ellen Verschuur

A journey through EUROPA DONNA's history as Europe's breast cancer advocacy organisation was provided by the Coalition's five presidents, Gloria Freilich (Founding President; 1995–1999), Mary Buchanan (2000–2003), Stella Kyriakides (2004–2005), Ingrid Kössler (2006–2008) and Ellen Verschuur (current President). The Coalition's milestones were reviewed, such as its inclusion as an equal partner in the European Breast Cancer Conferences, its work at a European Parliamentary level with the adoption of the Breast Cancer Resolutions and the publication of the EU guidelines, the creation of All-Party Parliamentary groups, and its Strategic Plan, and plans for the future were proposed. Ellen Verschuur added, "I want to stress that EUROPA DONNA has strength in numbers. We have 44 country members, which means we are representing 55,000 individuals and organisations. I think that that is something to reckon with."

15 years of advocacy and accomplishments

EUROPA DONNA grew out of a concept presented by renowned breast surgeon Prof. Umberto Veronesi at the European Society of Mastology (EUSOMA) Congress in Paris in 1993. The EUROPA DONNA Constitution was later developed and signed. From its original member countries, the Coalition has now grown to 44. Over the last 15 years, a wide variety and number of activities have been held in each member country across Europe and a large number have been launched at a European level. Below is a list of the main European activities.

- Bi-annual EUROPA DONNA Pan-European Conferences
- Bi-annual European Breast Cancer Conferences (EBCC), in which EUROPA DONNA shares equal partnership with European Society of Breast Cancer Specialists (EUSOMA) and the European Organisation for the Research and Treatment of Cancer (EORTC)
- All-Party Parliamentary Groups
- Formation of the European Parliamentary Group on Breast Cancer (EPGBC) for which EUROPA DONNA acted as the secretariat
- European Parliament receptions, exhibitions and workshops with MEPs and the European Commissioner for Health
- Annual Advocacy Training Course with the support of the European Commission
- Adoption of the first and second European Parliament Resolutions on Breast Cancer in the European Union
- The Strategic Review by the Boston Consulting Group and the adoption of the EUROPA DONNA Strategic Plan
- Publication of the *EUROPA DONNA Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*
- National Representative Day
- Breast Health Day campaign – 15 October

2009 onward: challenges ahead

- Achieving membership of all countries in the WHO European region
- Development of an EU protocol for certification of specialist breast units
- Ensuring support and development of current members
- Unifying EUROPA DONNA branding across member countries
- Creating more partnerships and alliances with other patient organisations
- Continuing to address women with special needs
- Extending Breast Health Day beyond Europe

15 years of Collaboration and Communication

EUROPA DONNA – The European Breast Cancer Coalition – is an independent non-profit organisation whose members are affiliated groups from countries throughout Europe. The Coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and increased funding for research. ED represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the EU.

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