

HIGHLIGHTS OF THE

# 10<sup>th</sup> EUROPA DONNA PAN-EUROPEAN CONFERENCE

MALTA  
22 – 23 October 2011

## EUROPEAN BREAST CANCER ADVOCACY: CHALLENGES FOR THE NEW DECADE

### INSIDE

**Breast cancer services in Europe: the European Commission's perspective**  
*John Dalli, European Commissioner for Health and Consumer Policy* **2**

**Meeting the 2016 deadline: specialist breast unit implementation**  
*Robin Wilson, President of EUSOMA* **4**

**The specialist breast nursing curriculum: progress so far**  
*Manuela Eicher, University of Applied Science of Western Switzerland* **6**

**Latest technology and advances in radiotherapy**  
*Philip Poortmans, Radiation Oncologist, Institute Verbeeten, The Netherlands* **8**

**Update on breast cancer treatment and trials**  
*Olivia Pagani, Institute of Oncology of Southern Switzerland* **9**

**Metastatic breast cancer: advocacy issues and needs of patients**  
*Doris Fenech, breast nurse and advocate, and Karen Benn, ED Policy Officer* **10**

**Capacity building: starting up and raising funds**  
*Galina Maistruk, gynaecologist and NGO founder* **12**

**Highlights from Breast Health Day 2011**  
*Susan Knox, ED Executive Director* **13**

**European Policy Highlights 2011**  
*Karen Benn, ED Policy Officer* **13**

**Advocacy workshops** **14**

The 10<sup>th</sup> EUROPA DONNA Pan-European Conference, held in Malta on 22 and 23 October 2011, highlighted the priorities for the European Breast Cancer Coalition and its “Challenges for the New Decade”, the conference theme. One of the main challenges is the implementation of specialist breast units that comply with the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, and European accreditation of such units. The 220 breast cancer advocates and specialists from 37 countries in attendance had the privilege of hearing key-note speaker John Dalli, the European Commissioner for Health and Consumer Policy, express the Commission's commitment to working toward the creation of a European specialist breast unit accreditation scheme.

In opening the conference, Bettina Borisch, President of EUROPA DONNA, said, “When we talk about the 10<sup>th</sup> Pan-European conference, we talk about ideas of advocacy, of fighting to improve breast cancer education, information, appropriate screening, quality treatment and care for all women in Europe, independent of their socioeconomic status and where they live. This also means fighting for patient rights, social justice and equity, since inequalities still exist among EU countries, but also in countries themselves and even within cities.”

The biennial EUROPA DONNA Pan-European Conference is unique in Europe in that it is the only conference dedicated primarily to breast cancer advocates and survivors.



*Bettina Borisch, John Dalli and Susan Knox*





Commissioner John Dalli

*“Imagine if we could cut the incidence of cancer in Europe by one-third. This is why a great deal of European action is about helping people avoid certain cancers by making healthier choices”*

## Breast cancer services in Europe: the European Commission’s perspective

In an encouraging key-note address, John Dalli, European Commissioner for Health and Consumer Policy, gave his support to EUROPA DONNA’s advocacy activities and reiterated the Commission’s dedication to **prevention, early diagnosis and appropriate treatment of breast cancer**. He said that this is exemplified through the Commission’s publication of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, its commitment to producing future supplements to these guidelines, and through working toward the creation of a **European specialist breast unit accreditation scheme**. “Such a scheme would enable women to know what breast units meet European quality standards and help ensure access to equal quality of services to citizens of the European Union,” he said.

He emphasised that breast cancer remains a key challenge. It is the most frequent cancer among women across the EU, accounting for one in every three cancers. He added that there is much room for improvement in the screening and treatment of cancer, although progress has been made in fighting breast cancer in the past two decades.

### PREVENTION AND MAKING HEALTHY CHOICES

Commissioner Dalli said that to renew the Commission’s commitment to improving cancer prevention and control, it launched the **European Partnership for Action Against Cancer** (EPAAC) in 2009. The partnership aims to support member states in their efforts to reduce new cases of cancer by 15% by 2020 and to develop national cancer control plans by 2013. The Partnership provides a framework for sharing knowledge and disseminating good practice in cancer prevention, including healthy living and cancer screening. “I am very pleased that EUROPA DONNA participates as a collaborating partner in the European Partnership and very much welcome your contribution and expertise,” he said.

In the area of prevention, he stated that **one in three cancers is linked to lifestyle factors** and thus may be preventable. “Imagine if we could cut the incidence of cancer in Europe by one-third. This is why a great deal of European action is about helping people avoid certain cancers by making healthier choices,” he said. The **European Code Against Cancer** seeks to inform citizens of the lifestyle choices they can make to take control of their health. Commissioner Dalli said that these are the messages that EPAAC is spreading through various events, such as the **European Week Against Cancer**, which was launched this year and will be held the last week of May every year.

However, he added that although prevention can be effective, cancer also strikes the healthiest and the fittest: “Breast cancer afflicts so many women who have never smoked, not abused alcohol nor had problems with obesity. This makes early detection and regular screening particularly important to detect the disease early in the process and increase the chances of cure.”

### EARLY DETECTION OF BREAST CANCER THROUGH SCREENING

On the topic of cancer screening, Commissioner Dalli stated that EPAAC aims to help member states achieve by 2013 the targets for population coverage of screening for breast cancer, as well as for cervical and colorectal cancer, as set out in the **Council Recommendations on Cancer Screening**. This should contribute toward

**reducing the large inequalities** that exist across the EU in terms of organisation and coverage of screening and ultimately help decrease breast cancer mortality throughout the EU. He cited a study performed in Florence, Italy, showing a 25% reduction in breast cancer mortality after the introduction of a population-based breast cancer screening programme. Other studies in Sweden have demonstrated that women invited to attend breast cancer screening also had a **reduction in breast cancer mortality of 25%**. He added that this reduction in mortality could be even greater if all women invited to screening attend the screening programme: “This is where organisations such as EUROPA DONNA play an essential role through the advocacy activities to raise the awareness about the importance of getting screened.”

Commissioner Dalli added that in order to assist member states with the implementation of such cancer screening programmes, whereby the target population is invited personally to screening, the Commission produced European quality assurance guidelines on cancer screening for breast, cervical and colorectal cancer. The **breast cancer screening guidelines** were the first to be published. He said that the European Commission plans to produce supplements to these guidelines in 2012. He added that of the existing EU cancer screening guidelines, the breast screening guidelines are the most implemented across Europe and that the Commission will continue to encourage member states to implement the guidelines for everyone. He further congratulated EUROPA DONNA on the publication of its “very useful and user-friendly” *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, which is now available in 12 languages.

### ADEQUATE TREATMENT IN SPECIALIST BREAST UNITS: ACCREDITATION

While screening is the first step to detecting cancer, Commissioner Dalli emphasised that positive screening results must be complemented by adequate follow-up treatment. The Commission is therefore exploring ways to develop the voluntary **European accreditation scheme** for conformity assessment of specialist breast units and provision of breast cancer screening, diagnosis and management. Based on the European guidelines, such accreditation schemes should contribute to achieving the highest possible standards for the benefit of women with breast cancer. He added that the accreditation scheme should provide an effective tool to member states to improve the quality of their health services and to trigger the **certification of breast units** by a number of certification organisations accredited by a common European scheme. “I am persuaded that the accreditation scheme will further stimulate the EU-wide implementation of breast cancer screening programmes with appropriate follow-up, thereby also levelling out inequalities between countries in that area,” he said.

He concluded with a word of encouragement to EUROPA DONNA advocates in their endeavours to address breast cancer through organisations and institutions at national, regional and local levels and gave them his support.

*“I am persuaded that the accreditation scheme will further stimulate the EU-wide implementation of breast cancer screening programmes with appropriate follow-up, thereby also levelling out inequalities between countries in that area”*



Bettina Borisch, John Dalli and Gertrude Abela

### Take home messages

- The European Partnership for Action Against Cancer (EPAAC) aims to support EU member states in their efforts to reduce new cases of cancer by 15% by 2020 and to develop national cancer control plans by 2013. EUROPA DONNA is a collaborating partner in two work packages of EPAAC
- Population-based breast cancer screening programmes have been associated with a 25% reduction in breast cancer mortality
- European Council Recommendations on Cancer Screening set targets for population coverage of screening for breast cancer
- Preparation of supplements to the EU guidelines is planned for 2012
- The European Commission is developing a common European accreditation scheme for specialist breast units based on the EU guidelines



Robin Wilson

*“Specialist breast units have led to a decrease in mortality due to breast cancer, despite the increasing incidence of the disease”*

## Meeting the 2016 deadline: specialist breast unit implementation

Dr. Robin Wilson, President of the European Society of Breast Cancer Specialists (EUSOMA), told advocates and the European Commissioner for Health that progress must be made toward establishing **accreditation of specialist breast units** if we are to meet the 2016 deadline for implementation of such units across the EU. He added that the European guidelines need to be updated to a 5<sup>th</sup> edition in order for the process to work and that this must be funded accordingly. “I understand that the funding is available. All we need is to get it through to the right people and the right place. I am sure we can make great success with this and improve standards throughout Europe,” he said.

### THE REQUIREMENTS OF A SPECIALIST BREAST UNIT

The 2016 deadline refers to the date set in the **European Parliament Resolution on Breast Cancer** of 2006 for the provision of specialist breast units in accordance with the EU guidelines across the EU. The requirements of a specialist breast unit, as originally established by EUSOMA, are set out in these guidelines. Specialist breast units provide women with co-ordinated, multidisciplinary breast care services for screening and treatment if so required. Dr. Wilson explained that all units must work toward written protocols, and outcomes must be audited to monitor success. He added that specialist breast units have led to a decrease in mortality due to breast cancer, despite the increasing incidence of the disease.

#### General requirements of a specialist breast unit

- Critical mass and multidisciplinary team
- Clinical director
- Protocols
- Audit
- Multidisciplinary team clinical meetings
- Screening
- Communication and patient information
- Research and teaching

#### Multidisciplinary breast services

- Specialist breast surgery and oncoplastic surgery
- Specialist breast radiology (imaging)
- Specialist breast pathology
- Specialist clinical oncology
- Specialist radiation oncology
- Specialist breast nursing
- Other services: Specialist clinics, genetics, psychological support, etc.

## EUROPEAN VOLUNTARY BREAST UNIT ACCREDITATION

Dr. Wilson detailed the current effort to establish an EU accreditation process for specialist breast units, the main obstacle to which is funding. Such accreditation would provide women with a guidebook-like listing of certified units stating the services each breast unit provides and the outcomes. The current accreditation scheme involves a number of stakeholders and players. In an unfunded, joint activity through the European Cancer Network, the European Commission has accepted “**EA – European Accreditation**” as a competent stakeholder, thus giving it the authority to assess the quality of guidelines and protocols. The **International Agency for Research on Cancer (IARC)** has been designated as the co-ordinating centre for the writing of the accreditation guidelines. Dr. Wilson explained that for the last two years there has been a core team led by IARC and comprising representatives of EA, DG-SANCO and EUSOMA. DG-SANCO and DG-Enterprise, as part of the European Commission, are the organisations able to provide the funding for the exercise. The core team has produced a document which has been submitted to DG-SANCO for support. However, Dr. Wilson said that the lack of recent progress is due to the EU criteria for funding, whereby DG-SANCO provides 60% of funding and the EA stakeholder organisation, such as a hospital, must provide the remaining 40%. “That has become a bit of a problem and it is something that we do need to overcome if this is going to progress,” he stated.

## EUROPEAN CANCER CARE CERTIFICATION PROCESS

Dr. Wilson described the European Cancer Care Certification (ECCC) process that EUSOMA has meanwhile established, under which it has certified 27 breast units to date. The certifying organisation is a separate, non-profit organisation that provides the accreditation. Under the ECCC process, units seeking certification submit **detailed questionnaires** and must pass **site visits** by qualified inspectors. All data are entered into a common database. Certified units must **submit data** annually, which are analysed using a colour-coded grading system. This is accessible online and allows the units to see their own data and compare their results with those of other units. “This has proved a very effective way for units to improve their standards and their outcomes,” Dr. Wilson said. He added that the process adheres to the European Commission standards.

Summing up, he said that there is currently a 50% difference in breast cancer survival between the worst and the best countries in Europe. “We do need an accreditation platform on which each country can set up its own accreditation or certification process or borrow from other countries. The process that is needed at the moment for standardising this protocol is making very slow progress and I am worried about meeting the 2016 deadline if we carry on with the progress as it is at the moment, but it is something we can do and we can do quickly,” he said.

*“We do need an accreditation platform on which each country can set up its own accreditation or certification process or borrow from other countries”*



Robin Wilson, Bettina Borisch and Astrid Scharpantgen

## Take home messages

- The European Parliament Resolution on Breast Cancer of 2006 calls for the provision of specialist breast units in accordance with the EU guidelines across the EU by 2016
- Specialist breast units provide women with multidisciplinary breast care services for screening and treatment as set out in the EU guidelines. Such units are associated with reduced mortality due to breast cancer
- A European accreditation scheme will be funded by the European Commission and will include updating of the EU guidelines to the 5th edition
- EUSOMA has appointed European Cancer Care Certification to carry out voluntary certification of breast units. They have certified 27 units to date



Manuela Eicher

*“All over Europe we have a large variation in what breast nursing means. From the patients’ point of view, this is problematic”*

## The specialist breast nursing curriculum: progress so far

Dr. Manuela Eicher, from the University of Applied Science of Western Switzerland, outlined the **European Oncology Nursing Society (EONS) Post-Basic Curriculum for Breast Cancer Nursing**, which aims to set minimum standards for this discipline across Europe. There are currently vast differences between countries in the access to breast nurses and in their training. “All over Europe we have a large variation in what breast nursing means. From the patients’ point of view, this is problematic,” she said. The curriculum therefore aims to address this lack of standardisation.

### THE MULTIDISCIPLINARY TEAM

Dr. Eicher said that this comes at a time when medical needs are changing. Many acute diseases can now be considered chronic and the approach to their management needs to be adapted accordingly. She said that an important step in this direction is the creation of **specialist breast units with multidisciplinary teams that include a breast nurse** who can represent the needs of the patient.

#### The function of the breast care nurse

- To counsel and offer practical advice and emotional support to newly diagnosed patients at the time the diagnosis is given, so as to further explain treatment plans
- To be available on demand from patients in the primary breast cancer follow-up clinic and in the advanced breast clinic
- To be present to support women when the diagnosis is given that the disease has become advanced
- Two breast care nurses are needed per breast unit

*EUSOMA. Eur J Cancer 2000; 18: 2288-93*

Dr. Eicher added that breast care nurses are currently members of the multidisciplinary team in many EU countries. Their main role is to be able to assess specific symptoms and refer patients if required, to provide information and to co-ordinate patient care. In order to be able to do this, they require **special training** and must have specific competencies within the multidisciplinary team.

### TRAINING OF BREAST CARE NURSES

However, Dr. Eicher said that the **breast nursing concept varies widely** across Europe. The United Kingdom is considered the “gold standard” for training and establishing the role of breast care nurses, with at least 800 such nurses who are in many cases trained as clinical nurse specialists. In contrast, in some countries breast care nurses adopt the role after having completed no post-basic education or only very short internships, while other countries are unaware of the existence of the discipline. She added that the function of the breast care nurse can even vary greatly between hospitals or breast units within the same country.

## THE BREAST NURSING CURRICULUM

In response to this, Dr. Eicher said that the European Oncology Nursing Society (EONS) invited seven nurses from different EU countries to develop the **EONS Post-Basic Curriculum for Breast Cancer Nursing** in 2009. “We wanted to introduce a minimum standard that could be applicable all over Europe, even in countries where this model is not known,” she said. The curriculum has three main aims: **raising awareness** of the need for specially trained nurses in breast cancer care, **defining minimum standards** for the role of such nurses within the multidisciplinary team and minimum standards for their post-basic education and training.

The indicative content of the curriculum took the patients’ perspective as a starting point. As in some systems women may see many different doctors and specialists, Dr. Eicher said that **the breast nurse is the one person who follows a woman throughout the entire care process**. The nurses must therefore be able to counsel women on aspects of the diagnosis, on the treatments and long-term living after breast cancer, including such issues as fertility needs, body image changes, returning to work and coping with long-term effects, as well as with advanced breast cancer.

She said that breast nurses should therefore be **trained oncology nurses** before pursuing training in breast nursing. She added that the curriculum further defines the function of breast care nurses to empower them to take an active role in the multidisciplinary team meetings. “We want to encourage them to take on their role as an advocate of the patient and their families,” she said.

Dr. Eicher said that so far, there has been **progress in disseminating the curriculum** through publications in scientific journals (e.g., European Journal of Cancer 2011), a short form of the curriculum, and making it accessible on the EONS website. Translations in French and German are now available. The first organisations have requested certification of training programmes based on the curriculum.

In conclusion, she suggested performing a survey to evaluate how the curriculum is received and applied and if it remains relevant to the needs of centres across Europe. Ultimately, she said it would also need to be determined if training breast care nurses at such a high level impacts on the well-being of patients.

*“We wanted to introduce a minimum standard that could be applicable all over Europe, even in countries where this model is not known”*



Manuela Eicher and Sema Erdem

## Take home messages

- There is a wide gap in the application and training of breast care nurses across Europe
- Breast care nurses need to be equal members of multidisciplinary teams
- The EONS breast nursing curriculum builds a first basis for standardised application of the basic requirements for breast care nursing all over Europe
- The curriculum has been disseminated and the first organisations are now requesting certification of breast care nurse training
- A survey needs to be conducted to examine how the curriculum is received, implemented and practiced in each country where it is introduced
- The curriculum is available on [http://www.cancernurse.eu/education/post\\_basic\\_curriculum\\_in\\_cancer\\_nursing.html](http://www.cancernurse.eu/education/post_basic_curriculum_in_cancer_nursing.html)



Philip Poortmans

## Latest technology and advances in radiotherapy

In a very visual presentation, Dr. Philip Poortmans, a radiation oncologist from Institute Verbeeten in the Netherlands, said that new approaches, such as the use of computed tomography (CT), have revolutionised radiation therapy. Used in planning and during treatment delivery, this imaging technique allows for the delineation of the target volume and of the organs at risk, which helps target the dose so that there is less radiation to surrounding areas and organs. He added that it allows for the delivery of a homogenous dose, which reduces early as well as late side effects such as skin reactions and fibrosis.

Magnetic resonance imaging (MRI) has become the standard for monitoring effects of systemic therapy, particularly when given before surgery. He added that positron emission tomography (PET)/CT scans also show promise in monitoring treatment response in women with metastatic breast cancer.

### APPLICATIONS IN SURGERY

With regard to surgical techniques, Dr. Poortmans said that during removal of the tumour, surgeons no longer just remove the lump, but rather remove a segment according to how they plan to reconstruct the breast. This means that a **breast segment** containing the tumour is excised as far down as the thoracic wall, following which the remaining segments of the breast are mobilised and brought together. “This way you can remove quite a big lump and by reapproximating the residual breast tissue you still have a very cosmetically good outcome,” he said. A challenge for the radiation oncologist after this kind of more extensive surgery is to properly define the primary tumour bed for delivering a boost dose or, probably in the future, partial breast irradiation.

### PATIENT POSITIONING FOR RADIOTHERAPY

Dr. Poortmans added that for radiation therapy, the patient’s position is of prime importance. Imaging therefore needs to be done in the same position as required during radiation therapy, something which is not possible with mammography or MRI. In general, patients are treated in a **supine position** using a table wedge. This is the most stable, comfortable and reproducible position, although depending on the target volumes to be treated and the individual patients’ anatomy, an excessive part of the lungs and heart may sometimes be included in the radiation fields. To avoid this, alternative positioning is possible, such as radiation delivery to a woman in a **prone position** (face down) or lying on her side to lessen the radiation exposure to the heart and the lungs. Having her hold her breath during radiation of the left breast also can reduce the dose to the heart. Imaging is used during radiation therapy to ensure that the patient is correctly positioned for treatment and that there has been no movement between the different treatment fractions (i.e., administrations).

### SIMULTANEOUS INTEGRATED BOOST

Dr. Poortmans said that now it is possible to achieve a very homogeneous dose distribution of radiation therapy in three dimensions. At a national level across the Netherlands, the simultaneous integrated boost is now standard practice. It involves administering a **lower dose of radiation therapy** to the entire breast and a higher dose to the tumour site during all treatment fractions, instead of first delivering a series to the

entire breast followed by a boost series to the primary tumour bed. The overall number of treatment fractions can thereby be safely reduced from the former 30-35 fractions to the current 28 fractions. More recently, a **hypofractionated schedule** has been introduced and the number of fractions has been further reduced to 21, lowering the number of days – and therefore the burden – that the woman needs to go for radiation therapy.

He concluded that all of these advances have led to a substantial improvement in the control of the disease, survival and quality of life. He added, “Most of the patients have an intermediate risk and most of the systemic therapy is quite effective, not absolutely effective, but quite effective, meaning that the benefit of local treatment is currently at its highest. Maybe one day, if it comes, we will have systemic therapy that will be so effective that we do not need any local treatment anymore.”

### Take home messages

- ▶ Imaging techniques such as CT scan are an important component of radiation therapy, enabling the targeting of irradiation to the area that needs it
- ▶ The positioning of the patient during imaging for radiotherapy must reflect the position required for the delivery of radiation therapy. The position and technique chosen should also aim at reducing the exposure of organs such as the heart and lungs to irradiation
- ▶ With contemporary techniques delivering a conformal and homogeneous dose, the simultaneous integrated boost technique and the hypofractionated radiation therapy schedule allow for more concentrated dosing and thus require fewer radiation therapy sessions

## Update on breast cancer treatment and trials

Dr. Olivia Pagani, in charge of medical treatment at the Institute of Oncology and Breast Unit of Southern Switzerland and co-ordinating the Breast Unit in Castellanza, Italy, said that since one of the requirements of a specialist breast unit is to undertake clinical research, such units should be able to inform women about clinical trials that are ongoing or recruiting patients.

### PHARMACOPREVENTION

In her outline on the latest in breast cancer prevention, she said that tamoxifen remains the best option for prevention in pre- and post-menopausal women, although recent results with exemestane have also been promising in post-menopausal women.

### ADJUVANT TREATMENT

#### *Post-menopausal women*

In post-menopausal women with endocrine-positive tumours, she said that the dilemma remains as to whether tamoxifen or an aromatase inhibitor (ARI) is more **effective**, in what **sequence** and for **how long**. Tamoxifen has the practical advantage of being less expensive and available in most countries. Dr. Pagani cited a trial by the International Breast Cancer Study Group that investigated tamoxifen and the ARI letrozole and their sequence, which showed several effective possibilities according to the risk of relapse. She said that it is therefore suggested that intermediate-high-risk patients receive an ARI for at least the first 2-3 years, which is the period of greatest risk for relapse, before being possibly switched to tamoxifen for the remaining 2 years of treatment. "This is to reassure women who suffer from side effects from aromatase inhibitors, which are not trivial," she said. She added that an additional 5 years of tamoxifen should be offered to women with node-positive disease.

#### *Premenopausal women*

Dr. Pagani said that there are still many unknowns about the treatment of premenopausal women. While the addition of ovarian function suppression to tamoxifen is effective in women with high risk and endocrine-positive disease, the role of ARIs is still unclear. Chemotherapy is no longer thought to be always necessary in this group of women. She added that pregnancy after breast cancer is no longer a taboo: "We need to talk to women about **fertility**, about **sexuality**, about their future as women and mothers. This is a very important issue to give patients the strength and the courage to fight against the disease at the beginning of her diagnosis."

### HER2+ SETTING AND CHEMOTHERAPY

Dr. Pagani added that the latest news about new drugs is in the HER2+ setting. Recent results show that a combination of HER2-targeting drugs (pertuzumab + trastuzumab and trastuzumab + lapatinib) leads to significantly **better progression-free survival** than each drug administered alone in advanced breast cancer and better tumour shrinkage in the preoperative setting. Other new drugs that show promising data are TDM1, a combination of trastuzumab and chemotherapy. There are also three very promising cytotoxic drugs (i.e., nab-paclitaxel, eribulin and ixabepilone) that are approved and on the market, at least in some European countries.



Olivia Pagani

### METASTATIC BREAST CANCER

In metastatic disease, Dr. Pagani said that it is unknown if chemotherapy is always needed, if a single agent is better than a combination, and what duration is preferable. She added that clinical trials are difficult to run in this setting. "In metastatic breast cancer, as well as in adjuvant therapy, we have also to assess **quality of life** and what women are willing to tolerate to have a certain benefit," she said.

### PHARMACOECONOMICS

Dr. Pagani said that the great variation in price between some treatments may influence whether or not they are used. She added that the **increasing cost of clinical research** must also be taken into account. From 1995-2000, it cost drug companies \$1 billion to launch a new drug. In the subsequent 2-year period, this price had increased 50%. She said that this means that drug companies will be very selective about the trials they undertake. "As medical oncologists and researchers we have to be very careful and run clinical trials where the control of the data is in the hands of the investigators," she said.

### Take home messages

- In the adjuvant setting, post-menopausal women at intermediate/high risk of relapse can be given an ARI for 2-3 years followed by tamoxifen
- In premenopausal women, the role of ovarian suppression in all patients is unclear, and chemotherapy may not always be necessary
- In HER2+ disease combination treatments have shown more promise than single agents
- In metastatic disease, as in all disease, treatment needs to be weighed against quality of life
- The high cost of a drug may influence its availability, and the cost of clinical research has increased drastically



Karen Benn and Doris Fenech

*“Knowing that you are not alone in fighting this disease helps in coping with all the burdens of the disease and everyday life”*

*– Doris Fenech*

## Metastatic breast cancer: advocacy issues and needs of patients

*A full conference session was dedicated to metastatic breast cancer, one of EUROPA DONNA's priority areas.*

### *Needs of patients with metastatic breast cancer*

Doris Fenech, a breast nurse, a metastatic breast cancer (MBC) survivor and an advocate, bravely shared her personal experience with the disease and expounded the needs of women and their families. She said that soon after she was initially diagnosed with breast cancer she became involved in advocacy through a support group. Twelve years later she was diagnosed with bone metastasis, which three years of treatment later, had fortunately disappeared.

“From my experience with metastatic breast cancer, I can say that there are a number of things that need to improve,” she said. A **good patient-doctor relationship** is essential. She said that all treatment options need to be discussed, as do prognosis and outcomes, in understandable language. Women should be aware of possible side effects and should also be informed of symptoms of metastasis so that they can recognise them if they should occur. Nurses should always be present and the patient should have the option to attend the **multidisciplinary meeting** about her care.

Ms Fenech added that women should also have the support of physiotherapists to help prevent unnecessary pain. They should have **psychological support** since the stress and issues surrounding the disease can lead to depression. This should also be offered to family members, who may not always ask for such support. This can help in coping with other problems such as inability to work and financial concerns. Women should be granted an extended leave from their job if so required. It should also be kept in mind that some women may not have family and friends to support them.

She added that women should have the right to volunteer to be enrolled in **clinical trials** and be treated with respect. There is a general lack of information on MBC and reliable information needs to be made available online. She added that **statistics** on MBC are scarce: “We should start advocating our governments for this. This should be one of our priorities as EUROPA DONNA members in the coming years.”

In conclusion, Ms Fenech emphasised the importance of **support groups** for women with MBC: “Knowing that you are not alone in fighting this disease helps in coping with all the burdens of the disease and everyday life.”

### *Results of a EUROPA DONNA survey on metastatic breast cancer*

Karen Benn, EUROPA DONNA Policy Officer, presented the results of the Coalition's member survey on how the needs of women with metastatic breast cancer (MBC) are met in member countries. The survey arose from the EUROPA DONNA Executive Board's concern that more can be done to advocate for women with MBC. In order to do this better, ED Head Office administered a simple survey of 26 questions aiming to determine ED members' **knowledge of data, care, treatment and advocacy** for MBC and identify potential areas to address in the future.

Twenty-four ED member countries answered the questionnaire; 75% of these answered based on consultation with at least one woman with MBC. Ms Benn noted that the most used and preferred term was “metastatic breast cancer” followed by “advanced breast cancer.”

### Responding countries

Albania, Belgium, Croatia, Cyprus, Denmark, Estonia, Finland, France, Georgia, Iceland, Ireland, Israel, Italy, Kyrgyzstan, Luxembourg, Malta, Netherlands, Norway, Slovenia, Spain, Sweden, Turkey, Ukraine, United Kingdom

### CONTEXT AND DIAGNOSIS

Regarding MBC incidence, 60% of the responding countries said that data are available, and in 45% of these, the information comes from the National Cancer Registry. Nearly 50% said that women are given information about MBC during their primary breast cancer treatment or during follow-up, in the majority. Half said MBC is **detected by screening** and nearly all said it was **detected by symptoms** or during follow-up. Of these, one country reported that the diagnosis could be delivered by telephone, while in the rest it was delivered in person.

### TREATMENT AND CARE

Ms Benn stated that 40% of the ED member countries who responded reported having guidelines for MBC, while some of the remainder said that international or the American Society of Clinical Oncology guidelines are used. Sixteen countries claimed

that women with MBC could return to the **specialist breast unit** where they were initially treated. Eleven countries claimed that MBC patients have access to a “key worker.” However, several of these 11 said this was “their doctor” or “oncologist”. Since ED’s definition of a “key worker” is a “specialist breast cancer nurse or a team member with professional psychological training” not all of these 11 necessarily fit the definition.

### SUPPORT AND ADVOCACY

With regard to support for **family members** of those diagnosed, 14 countries said that the families receive support. Nearly all respondents, 22 of 24 countries, said that **patient organisations** support women with MBC. Just over 50% of countries said local patient organisations help with support and information on absence from work and home help. In 80%, women with MBC actively participate in local breast cancer support or advocacy group activities; 45% claimed local breast cancer groups adequately meet the needs of women with MBC for information and support, though several said that this was hard to judge.

Twenty countries agreed that there is a need to advocate for **special rights** for women with MBC with regard to information, treatment and counselling. All countries felt such needs and rights should be included in national guidelines on breast cancer treatment, and 21 countries said this should be included in the next edition of the **EU guidelines**.

Support at time of diagnosis	Yes	No
Women with MBC receive adequate support (including psychological support)	8 countries	12 countries
Women with MBC receive enough information at the time of diagnosis	8 countries	10 countries
Treatment starts in a timely manner	18 countries	6 countries (not always or don't know)
Women receive a written treatment plan	7 countries	—
Women are cared for by the same health professionals when they attend clinics	15 countries	—

### Take home messages on metastatic breast cancer

- ▶ All treatment options need to be discussed, as do prognosis and outcomes, in understandable language. A specialist breast care nurse should always be present
- ▶ Support should include a physiotherapist for the patient and a psychologist for the patient and her family
- ▶ There is a need to advocate for statistics on MBC to be collected by health systems
- ▶ In the EUROPA DONNA survey of its members, 50% of respondents said that women receive information about MBC during primary treatment or follow-up
- ▶ In 50% of countries, women with MBC did not receive adequate psychological support
- ▶ 83% agreed that there is a need to advocate for special rights for women with MBC, and 88% said this should be included in the next edition of the EU guidelines



Galina Maistruk and Nicole Zernik

*“You need to build a good long-term relationship with your donors and with individuals”*

## Capacity building: starting up and raising funds

In an inspiring presentation, Dr. Galina Maistruk, a gynaecologist and founder of a women’s NGO in Kiev, Ukraine, emphasised that starting up an organisation requires a long-term perspective and planning. “You need to build a good long-term relationship with your donors and with individuals,” she said.

One of the strengths of EUROPA DONNA comes from its realistic ten goals and its mission. She said that the EUROPA DONNA branding and logo are very well received and recognised: “It represents a collective voice.” She added that establishing a brand is very important and requires persistence.

### FINDING THE GAPS

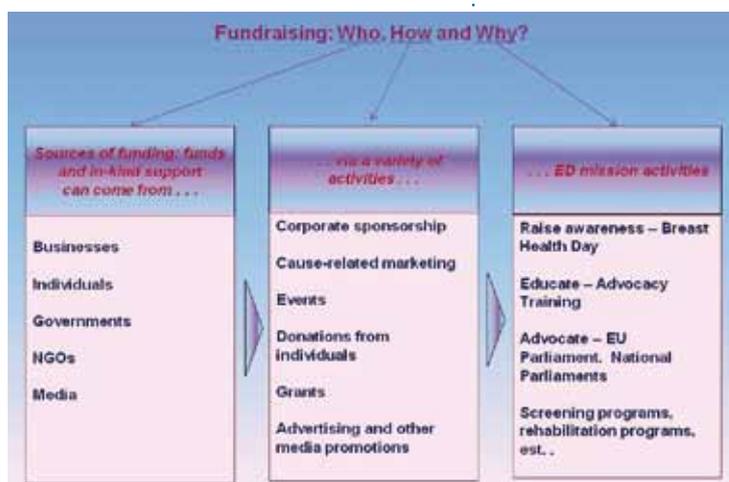
To start up an organisation, she said that each country must analyse its needs individually to determine the gaps and key challenges and what can be done to address them. A **full profile of the country** from different perspectives, such as that of professionals, local people and organisations, is needed to identify the gaps before planning can begin. She used EUROPA DONNA’s **Strategic Plan** as an example. An outside assessment was able to identify areas for change and development and led to a plan for future mission activities. “**Breast Health Day** is an excellent child of this strategic planning,” she said.

### SECURING FUNDING

Funding is a means to complete the mission activities. However, she said, “You will never get a penny if you don’t have a clear mission and activities.” The activities depend on the local situation, and the possibilities are endless, from web-based to sporting and cultural activities. It is very important to **assess the risks** of the activity (e.g., plan a walk at an appropriate time of year for the climate) and consult with logistics experts.

Dr. Maistruk added that **business donors** beyond the pharma industry can be targeted, such as those connected with women’s health, sports, airlines, etc. Donations from **individuals** are a key component of the foundation of an organisation. She added that some sponsors may not donate money but rather time, office space, print space or air time. Having **professional fundraisers** on board who are experienced, business-minded, creative, organised, persistent and ethical can make the difference.

“Fundraising is a never-ending process,” she said. “One of the most important fundraising rules is never to forget to say thank you.” She ended with a word of motivation for advocates: “When the results are successful, they make you so optimistic that you want to repeat the process again and again.”



### Take home messages: 5 steps to fundraising

1. Recruit a person with specific fundraising skills and assess the competitive landscape for breast cancer
2. Tailor activities to local tastes
3. Evaluate and prioritise specific fundraising options, assess risks
4. Plan and execute activities or campaigns
5. Track effectiveness and follow up with sponsors and donors

## Highlights from Breast Health Day 2011

In her overview of the Breast Health Day campaign, Susan Knox, Executive Director of EUROPA DONNA, said that a growing number of member countries – about 30 – held prevention-targeted activities on or around 15 October. “This campaign is a public health message that our countries can send out across Europe and across the world,” she said. The aim is to have the World Health Organisation declare 15 October as Breast Health Day globally.

Ms Knox described the 2011 campaign, which was focused on physical activity and nutrition, with the theme “**Make Healthy Choices**”. The campaign materials were designed to be accessible to all countries, in all languages, and featured a video of women making healthy choices. It ended with a screen shot of the “Make Healthy Choices” theme translated into 27 languages. Women could also submit their picture through [www.breasthealthday.org](http://www.breasthealthday.org) to have it added to the video. On the website, some new infographics brought a more upbeat and visual look to facts and statistics on breast cancer.

EUROPA DONNA promoted Breast Health Day at various meetings across Europe and at an Information Day at the European Parliament on 12 October 2011. Susan Knox also gave a presentation about the initiative at the **Second International Symposium on Breast Cancer Prevention**, which brought together epidemiologists and health policy makers from around the world. “These are people who work on the studies but are not so aware of how the studies are then turned into practical information that the public can use. They were very pleased that we are doing this,” she said. “Ongoing communication and collaboration is essential with IARC and research organisations to ensure all the evidence-based information is incorporated into our future campaigns.” She also emphasised the importance of connecting efforts to those of other disease areas with similar **healthy lifestyle campaigns**.

Ms Knox ended by giving an overview of the activities held for Breast Health Day across member countries.

During an earlier session, to put the physical activity theme to practice, advocates enthusiastically took part in a high-energy **Zumba** aerobics session, which helped get their circulation and ideas flowing.



## European Policy Highlights 2011

Karen Benn, EUROPA DONNA Policy Officer, gave an overview of the Coalition’s activities at a European level, a presence which has intensified since it was included as a priority in the ED Strategic Plan of 2007.

Since the adoption of the **European Parliament Resolutions on Breast Cancer** in 2003 and 2006, and the Written Declaration of 2010, ED continues to have contact with MEPs, particularly through **Breast Health Day Information Days**. Ms Benn noted that the European Health Commissioner’s participation in the conference and his statements backing the creation of an accreditation scheme for specialist breast units are encouraging and will be addressed with him in the near future.

### EU INITIATIVES

EUROPA DONNA is a collaborating partner in two Work Packages (WP5: Prevention and WP7: Healthcare) of the **European Partnership for Action Against Cancer (EPAAC)**, which is the main European Union-funded cancer programme. ED participated in initial consultation meetings with DG-SANCO, as well as a number of Work Package meetings. ED chaired a session of the 2011 EPAAC Open Forum and participated in the EPAAC launch at the European Commission.

ED has been invited to be on the advisory board of the EU-funded **AURORA** cervical screening project. ED’s presence was requested by DG-SANCO. “After all the hard work over the years, EUROPA DONNA has been recognised as having expertise which should be shared by other policy areas,” she noted.

### Other initiatives

- European Patient Forum meetings and seminars
- ECCO Oncopolicy meetings
- Noncommunicable Diseases Alliance meeting at the United Nations in New York

Dorota Czudowska, ED Poland National Representative, went on to share the experiences of a Polish delegation of 23 women on their visit with MEPs at the European Parliament.



Dorota Czudowska

## Advocacy workshops

A series of five workshops were held for advocates to share their ideas and know-how. The workshop leaders provided the main conclusions from their workshops.

### Getting involved in social networking and blogs

*Leaders: Barbara Klein (ED Head Office) and Marie Ennis O'Connor (Ireland)*

The workshop began with a presentation by Barbara Klein on EUROPA DONNA's use of social networking sites, such as Facebook and Twitter, for the Breast Health Day campaign and beyond. Of the 20 participants, 17 had Facebook accounts, while only three were on Twitter. Marie Ennis O'Connor also presented the ins and outs of blogging. A discussion followed and the following points were raised:

- ▶ Social networking is free, easy to learn, facilitates sharing information with a large number of people living in different locations
- ▶ ED fora would be interested in setting up a "Page" on Facebook, which is a public space, meant for businesses and organisations. A "group" is more like a private club
- ▶ Facebook often changes its policies and so the account settings need to be reviewed regularly
- ▶ Facebook is for people of all ages (studies show that 57% of users are women) and is a perfect tool for connecting with the world
- ▶ Fora can use the ED material from Head Office and share it via the social networks
- ▶ Blogs are more informal than websites, allow for more exchange with readers and can be created easily and for free (<http://wordpress.org>, [www.blogger.com](http://www.blogger.com), [www.tumblr.com](http://www.tumblr.com)). The Google search engine loves to pick them up



*Tanja Spanic and Mojca Miklavčič*



### Attracting media attention

*Leaders: Gertrude Abela and Coryse Borg (Malta)*

The workshop began with Coryse Borg explaining to the almost 30 participants how to build a good relationship with the editor of a newspaper and/or a publication. The following points were made:

- ▶ If you know the editor or any other feature writer, contact them personally first
- ▶ Be clear when you first contact the person concerned by e-mailing them your details and your organisation's aims and objectives
- ▶ To attract the editor's attention, write the article with a catchy headline
- ▶ Be sure to send pictures of the event
- ▶ The aim is to have articles and press releases reported upon correctly
- ▶ For TV stations the best way to make contact is by writing to the person in charge of the news

### Setting up young women's groups

*Leaders: Karen Benn (ED Head Office) and Mojca Miklavčič (Slovenia)*

Twenty-four women joined a stimulating and lively workshop for young women. Karen Benn presented ED past projects such as the Young Women's Working Group and described the grants and bursaries available to young women of ED to attend the Pan-European conference and EBCC. Mojca Miklavčič then detailed the experience of setting up a young women's group in Slovenia, its activities and approaches to networking. In the discussion that followed, it was agreed that finding ways to communicate with each other and to society about young women's needs remains a hurdle. Specifically, the following points were made:

- ▶ Local groups for young women with breast cancer are important due to the particular needs of these women
- ▶ Finding ways to network with each other that work is a challenge since many young women with breast cancer have particularly busy lives, with young children, jobs, etc.; as a result, much of the networking is virtual
- ▶ Ways to communicate the importance of breast cancer and breast health to society in general, and particularly targeting young women, need to be determined
- ▶ Young women with breast cancer need to know how to talk to children, especially young children, about their breast cancer; fertility issues are also important
- ▶ It is of crucial importance for the young women's group to have the support of, and a relationship with, the main ED group in the country (e.g., the young women's group in Slovenia has always had the full support of ED Slovenia and also has a permanent Board position within ED Slovenia)

## Improving organisational management

*Leader: Galina Maistruk (Ukraine)*

This workshop had 39 participants from 21 countries and began with countries describing the organisational set-up of their ED forum. They had the following characteristics in common:

- ▶ The majority are composed of volunteers and a group or network of organisations
- ▶ A small number of organisations have a permanent office and staff
- ▶ State funding is very limited
- ▶ The main source of funding comes from special fundraising events, grants and donations
- ▶ Funds are mostly used for mission activities, e.g., information, awareness, rehabilitation, advocacy and research

### Workshop recommendations:

- ▶ To conduct a survey regarding needs of ED member organisations
- ▶ To increase knowledge and capacity of organisations by developing a volunteer network
- ▶ To present the issues of psychosocial support and rehabilitation at an EU level
- ▶ For the ED Head Office and Board to use the practice of “site visits”

## Needs of women over 70

*Leader: Adriana Bonifacino (Italy)*

This workshop involved some 30 women from 20 countries and also included the input of speaker Dr. Philip Poortmans. It was agreed that many women diagnosed with breast cancer after age 70 have different needs than their younger counterparts. The following points were made:

- ▶ The best treatment must be decided upon based on the clinical need while taking into account quality of life
- ▶ As older women may be less versed in the use of the Internet, information must be provided by GPs, at specialist breast units and by patient organisations such as ED
- ▶ These women should have access to facilities for mammography screening
- ▶ Criteria for inclusion of women over 70 in clinical trials are needed and specific trials need to be performed in this group of women
- ▶ These women require social support groups for emotional and even economic support
- ▶ The cultural taboos older women may experience need to be addressed

## Country Presentations

Representatives from ED Cyprus, Kazakhstan and Sweden presented highlights of their advocacy activities.



*Evi Papadopoulou,  
Cyprus*



*Zhupar Bazarova,  
Kazakhstan*



*Elizabeth Bergsten  
Nordström, Sweden*

## Conference Photos





## About EUROPA DONNA

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

### Contact Information:

EUROPA DONNA – The European Breast Cancer Coalition  
Piazza Amendola, 3  
20149 Milan  
Italy  
Tel: +39 02 3659 2280  
Fax: +39 02 3659 2284  
Email: [info@europadonna.org](mailto:info@europadonna.org)  
Website: [www.europadonna.org](http://www.europadonna.org)

**Susan Knox**, Executive Director  
**Karen Benn**, Policy Officer  
**Barbara Klein**, Communications Officer  
**Daniela Pirisi**, Admin/Events Officer  
**Paige Robinson**, Development Officer

### Executive Board Officers 2011:

President: **Bettina Borisch** (Switzerland)  
Vice President: **Elizabeth Bergsten Nordström** (Sweden)  
Treasurer: **Sema Erdem** (Turkey)

### Executive Board Members 2011:

**Gertrude Abela** (Malta)  
**Mojca Miklavčič** (Slovenia)  
**Antonella Moreo** (Italy)  
**Astrid Scharpantgen** (Luxembourg)  
**Nicole Zernik** (France)

### Past President:

**Ellen Verschuur** (The Netherlands)

### Executive Board Officers 2012:

President: **Elizabeth Bergsten Nordström** (Sweden)  
Vice President: **Sema Erdem** (Turkey)  
Treasurer: **Gertrude Abela** (Malta)

### Executive Board Members 2012:

**Roswitha Britz** (Spain)  
**Mojca Miklavčič** (Slovenia)  
**Antonella Moreo** (Italy)  
**Ene Tomberg** (Estonia)  
**Nicole Zernik** (France)

### Past President:

**Bettina Borisch** (Switzerland)

### Member Countries:

Albania, Austria, Belarus, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Macedonia, Malta, Moldova, Monaco, The Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Ukraine, United Kingdom, Uzbekistan

EUROPA DONNA gratefully acknowledges



for their support



*This publication arises from the 2011 Work Plan of EUROPA DONNA which has received funding from the European Union, in the framework of the Health Programme. The Executive Agency is not responsible for any use that may be made of the information contained herein.*