

# EUROPA DONNA

News

summer / autumn 2010



## Conference

highlights from  
EBCC-7

Answering  
the advocates:  
**Isabel Rubio** on  
breast surgery and  
specialist breast units  
plus **Sibylle Loibl**  
on pregnancy and  
breast cancer

A survivor tells us  
about motherhood  
after breast cancer



EBCC  
European  
Breast Cancer  
Conference  
7

BARCELONA  
SPAIN

▶ Making progress at  
**European Parliament:**  
the Declaration on the Fight  
Against Breast Cancer in the EU

▶ The EUROPA DONNA  
**survey on EU Guideline  
Implementation**

▶ **Reports** from  
member countries



# 10 Goals

- To promote the dissemination and exchange of factual, up-to-date information on breast cancer throughout Europe
- To promote breast awareness
- To emphasise the need for appropriate screening and early detection
- To campaign for the provision of optimum treatment
- To ensure provision of quality supportive care throughout and after treatment
- To advocate appropriate training for health professionals
- To acknowledge good practice and promote its development
- To demand regular quality assessment of medical equipment
- To ensure that all women understand fully any proposed treatment options, including entry into clinical trials and their right to a second opinion
- To promote the advancement of breast cancer research

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# The Personal is Political

Throughout its history, EUROPA DONNA has been very successful in partnering with all stakeholders in the breast cancer community and has developed a strong patient voice. Starting with a few member countries, ED has grown to a coalition of 45 countries. Since our last newsletter we have welcomed two new members, Uzbekistan and Macedonia. I wish them both a very warm welcome and a fruitful collaboration with the other members of the EUROPA DONNA Coalition.

A strong patient voice is needed to get the message across and is the most important input for developing best practice in breast cancer care. The 7<sup>th</sup> European Breast Cancer Conference (EBCC-7), held in Barcelona from 24–27 March this year, is an excellent example of the development of the patient voice in the breast cancer community. The theme of EBCC-7 was “Leading Multidisciplinary Partnership Across Borders” in the fight against breast cancer. The core concept behind the EBCC meetings is a true partnership and collaboration between EUROPA DONNA, EUSOMA and EORTC – advocates, breast specialists, scientists and researchers in the field of breast cancer care working together as a team to overcome the obstacles in providing state-of-the-art breast services to the women in Europe and to ensure ongoing high quality research to find a cure for this disease.

The contribution of EUROPA DONNA to the EBCC-7 conference programme reflected the equal role that advocates share with the other partners, breast specialists, scientists and researchers. ED Vice-President Christine Murphy-Whyte and I showed a true partnership in presenting together a lecture entitled “Specialist Breast Units: The Patient Perspective” at the opening keynote session. The lecture offered an excellent opportunity to share the process of establishing specialist breast units in Ireland and the Netherlands, countries which Christine and I represent. There was a great contribution of other ED members as well, both as presenters and as advocates delivering comments and questions in the debates between presenters and the audience. I would like to thank all the advocates from ED member countries for their contribution to making the patient voice heard.

In April this year, I attended the spring convention of the European Oncology Nursing Society (EONS 7) in The Hague. My contribution was to present the patient perspective in the session “Long-term Effects of Cancer Treatment”. The long-term effect of breast cancer treatment is still a not very extensively explored field of study, so this topic should be given more attention in our advocacy for research.

Partnership between politicians and patient advocates also plays an essential role in addressing the political aspects in the fight for and access to best practice, especially on the European level. ED is very grateful to the four members of the European Parliament, Liz Lynne (UK), Michail Tremopoulos (Greece), Lívia Járóka (Hungary) and Lidia Joanna Geringer de Oedenberg (Poland), for their support of the breast cancer cause by launching the Written Declaration on the Fight Against



President **Ellen Verschuur**

Breast Cancer in the EU. Thanks to their support and the work in our member countries in contacting their European Parliament representatives, the Declaration was signed by 381 MEPs and adopted. I am very proud that EUROPA DONNA succeeded in keeping breast cancer issues on the European health agenda.

The last but not least important role of our partnership is in the relationships and interaction between our member countries. We need to build and maintain partnerships between the member countries to assure that we benefit mutually from each others' learning processes, skills and experiences. The upcoming EUROPA DONNA Breast Cancer Advocacy Leader Conference, to be held 25 September 2010, will be an outstanding opportunity to exchange experiences, ideas and best practices in the continuous fight for optimal breast cancer services and reducing inequalities in access on the national level.

There will also be Executive Board elections at our General Assembly on 25 September. Please think about nominating the National Delegate from your country for one of the open positions as it is a way of representing your country's unique perspective at the European level. Board Members must be fluent in English, but above all, should have either extensive advocacy experience or a scientific background in order to contribute to our European projects.

Looking at our still growing contribution to the breast cancer community, we have accomplished a great deal, but EUROPA DONNA's tasks are not finished yet, so let us continue to make the difference through building lasting partnerships.

# Advocacy in Action



Executive Director **Susan Knox**

EUROPA DONNA continues to advance important initiatives on behalf of the breast cancer community and to make progress in its three key areas of information, education and lobbying. We now have 45 country members in our Coalition and several more about to join. 2010 is also the third year of implementation of our **Strategic Plan** and many changes have already come about. In the last quarter of 2009 our policy officer, Karen Benn, represented us at the launch of the “**European Partnership for Action Against Cancer**” in Brussels and a joint exhibition with DG SANCO at the European Commission on 15 October. In November we voiced our position on the importance of an **accreditation protocol for specialist breast units** at the first MEP briefing and then worked with MEPs to draft a **Written Declaration on the Fight Against Breast Cancer in the EU** that was adopted by a majority of MEPs in March 2010. We now have firm backing from MEPs to continue to fight for implementation of the EU guidelines and have taken the first steps to ensure that all are aware of the important issues already agreed in the **Resolutions of 2003 and 2006**. We also had the opportunity to raise awareness further by presenting our advocacy programmes at the **European Health Forum** exhibition that was held 29–30 June. Plans are now under way to return to the Parliament to hold an **Information Day** on Breast Health Day in October 2010.

This year saw the launch of **Breast Health Day** as a global initiative and NGOs outside of Europe have been contacted and provided with materials to use locally.

Through participation in various international initiatives over the last year – NBBC meeting in Argentina, EBCC-7, global patient advocacy summit, international webinars and news article interviews – Breast Health Day has been introduced widely and we have been able to highlight the importance of lifestyle choices in preventing breast cancer, a subject still relatively unknown to the public. This will be reinforced and extended in 2010 through our campaign that will include a **webinar**, a **digital platform** using web widgets, a **video game** and involving **social networking sites** such as Facebook and Twitter as well as materials that can be downloaded directly from our newly transformed website dedicated to the event, [www.breasthealthday.org](http://www.breasthealthday.org).

Particularly during this time of economic uncertainty it is important for advocates to understand better the **health economic decision making** process in each country. ED will include an overview on this and Health Technology Assessment in our **2010 Advocacy Training Course** (12–14 November).

**Mammography screening** remains a priority for implementation across Europe, but media reports are often confused or inaccurate on this subject. We will provide an **ED statement**, and a lecture on this will be included in our **Advocacy Leader Conference** on 25 September. This conference is aimed at overcoming the inequalities among European countries with regard to breast services. I attended the **May European Cancer Network** meeting in Warsaw and presented a poster review of our advocacy efforts to get the EU guidelines implemented across Europe. It is significant that our *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* has been translated into 11 languages and is being used in many of our member countries, including seven non-EU countries. Three more translations are planned for 2010. This is solid proof of the significance of the guidelines and advocating for an agreed set of standards of service for all women.

The Board and Head Office are committed to supporting all our national member groups. To this end a **toolkit** was developed and sent to all members early this year. We want to help resolve issues and work with new representatives when designated to ensure that groups start off with all the best and most accurate information possible to be successful in their national efforts. The **Advocacy Leader Conference** on 25 September is an essential part of the two-way communication sharing process. It has been developed to enable ED leaders to gain the strategies and skills needed to help overcome barriers in getting the guidelines implemented; it is being supported with a grant from the **European Commission** because of their recognition of how important the country leader role is in making this happen at the national level. This is a great opportunity for our ED country leaders and I look forward to seeing all our National Representatives and National Delegates there.

# 7th European Breast Cancer Conference Leading multidisciplinary partnership Across Borders

24–27 MARCH 2010, BARCELONA, SPAIN



Alain Fourquet, Ellen Verschuur  
and José Baselga

*“The EU guidelines are a leading example of what can be achieved when organisations and individuals unite with a common purpose in the fight against breast cancer.”*

– Ellen Verschuur

Representing the voices of patient advocates, doctors, researchers and nurses, the 7<sup>th</sup> European Breast Cancer Conference (EBCC-7) in Barcelona, Spain from 24–27 March welcomed more than 5,000 participants from 96 countries. EUROPA DONNA – The European Breast Cancer Coalition, in partnership with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA) hosted the conference, which covered the latest findings on best practice in mammography screening, imaging techniques, surgical and drug therapy, lifestyle and chemoprevention measures, and treating specific populations such as pregnant women. Physicians and advocates alike attended the EUROPA DONNA teaching lectures and wrap-up sessions. This report summarises some of the key findings of interest to EUROPA DONNA advocates. For those wishing to re-visit the conference, many of the presentations are available on webcast on [www.ecco-org.eu](http://www.ecco-org.eu).

In one of the webcast sessions, keynote lecturers **Ellen Verschuur**, EUROPA DONNA President, and **Christine Murphy-Whyte**, EUROPA DONNA Vice-President, jointly presented the patient’s view of the need for specialist breast units. They outlined EUROPA DONNA’s advocacy initiatives to have these implemented, ranging from the European Parliament Resolutions on Breast Cancer, All Party Parliamentary groups, its *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, to the adoption of the European Parliament Written Declaration on the Fight Against Breast Cancer in the EU.



Ellen Verschuur and  
Christine Murphy-Whyte



Keynote symposia panel

## Specialist breast units as a key component of the European guidelines

As presented in the key note symposium, from the advocates’ perspective, the evidence-based best practice requirements and standards of a specialist breast unit can be summarised as follows:

- A multidisciplinary core team of specialists working together
- Clear quality standards for accurate diagnosis and optimal treatments
- Training of staff and regular auditing to ensure quality standards and care
- Person-centred care at all times as an integral part of care delivery

## The News about mammography screening and specialist breast units

### Implementing the EU guidelines

In a full session dedicated to implementing the EU guidelines, EUSOMA President **Marco Rosselli del Turco** described how the guideline editions have evolved to encompass the latest evidence and must be updated periodically to accommodate new advances. He added that the guidelines should now be expanded to include other aspects of breast cancer care such as medical treatment, follow-up and patient support. Above all, it must be verified that the guidelines are being implemented.



*Astrid Scharpantgen  
and Marco Rosselli del Turco*

In this regard, ED Board Member **Astrid Scharpantgen** presented the findings of the 2007 DG-SANCO-International Agency for Research on Cancer (IARC) survey of the 27 EU member states indicating that population-based mammography screening programmes were running or being established in 22 countries. She added that developing an accreditation scheme based on the EU guidelines could encourage improved performance and help women recognise where good service is provided.

**Susan Knox**, Executive Director of EUROPA DONNA, presented the findings of EUROPA DONNA's informal survey on the implementation of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* showing that most EU countries have some form of mammography screening. As many as half report having at least one specialist breast unit in their country, but in most no certification process exists to ensure that units meet EU guidelines. See page 14 for more on this survey. She said that having one standard document is important since health systems differ between countries and even between regions. EUROPA DONNA has taken care to accurately translate its Short Guide to these guidelines into eleven different languages to date, "so that we are speaking with one voice across Europe for these guidelines and these standards," she said.



*Susan Knox*

*“To get these guidelines implemented we need to be articulate in explaining why they are important to a lay audience of politicians and women in all of our countries.”*

– Susan Knox

### Moving forward with guideline implementation

- The European Oncology Nursing Society (EONS) has created a Breast Care Nursing Curriculum, which could help establish this discipline more widely
- The EUSOMA/SenoNetwork is educating professionals and certifying breast units
- The Declaration on the Fight Against Breast Cancer in the EU has been adopted and can be used to remind politicians of the need for screening and breast units according to the guidelines
- The European Commission's European Partnership for Action Against Cancer supports the EU member states in fighting cancer
- An EU breast unit accreditation protocol is being sought and is due to be co-ordinated by the International Agency for Research on Cancer

## Digital mammography: turning high-tech

Digital mammography is increasingly used in screening programmes across Europe. **Per Skaane** from Ullevaal University Hospital in Norway listed the potential benefits and drawbacks of digital versus screen-film in screening programmes, including:

### Pros of digital vs. screen-film

- Elimination of “technical failure” recalls
- Higher detection rate, according to recent studies (2007–2009), and higher detection in pre- and peri-menopausal women and of microcalcifications
- Reduced radiation dose
- Improved diagnostic accuracy in dense breasts
- Improved workflow and simplified storage, retrieval and transmission, plus potential for distant reading and consultations

### Cons of digital vs. screen-film

- Higher recall rates
- Lower detection rate in post-menopausal women in some studies; however, studies in Norway and Ireland, among others, indicate a higher detection rate
- Longer reading time required due in part to need for zooming
- Challenges in comparing digital and analogue systems, such as defining a positive test and interobserver variability

Dr. Skaane concluded that the performance of digital mammography is at least as good as screen-film and likely better, and as a result of this and other benefits, European countries with organised screening programmes are going digital.



Available on webcast

## Information technology meets mammography screening

A presentation by **Chris de Wolf**, Medical Director of the Fribourg breast screening programme in Switzerland, on the technical aspects of digital mammography use in screening, emphasised how digitalisation and integration of systems, while technically complex, facilitates the screening process. It allows access to previous mammograms and electronic reporting forms, distant reading, consulting expert opinions, teleconferencing to discuss cases, educational opportunities, automatic density measurements, quality control for radiographers, and eliminates the cost of printing images. It also requires an integrated software system and web-based applications for managing appointments.

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### Points to remember about screening and breast units

- The EU guidelines and the Short Guide to the guidelines allow us to spread a common message for breast care standards across Europe
- There are data in favour of screening in women up to age 75
- Digital mammography is the wave of the future and mammography screening programmes and specialist breast units will become increasingly high-tech
- New web-based systems enable benchmarking between breast units and provide opportunities for data collection
- Doctors should be given feedback from other professionals on their work

## Quality control of specialist breast units

**Antonio Ponti** of CPO–Piemonte Hospital in Italy and member of the EUSOMA Executive Committee described the web-based data system being adopted by all EUSOMA-certified breast units. It pools data from all the units and allows them to audit themselves to determine their ranking against benchmark centres. In addition to quality control, it provides access to data on a large number of patients and potential for research.

In a highly animated and interactive session, **Rob Tollenaar** from Leiden University Medical Centre in Belgium addressed the topic “How can you tell if your local breast unit is good?” He said that reliability of data and clear, standardised definitions are key, and that auditing should be undertaken using evidence-based guidelines, quality indicators and unit visits. Above all, he said, professionals should receive prompt feedback on their work.



Available on webcast

## Screening in women up to age 75

While the EU guidelines are for screening women aged 50–69, the new EU Declaration calls on the Commission to support studies to determine whether it is useful in younger and older women. **Harry J. de Koning** from Erasmus Medical Centre in the Netherlands reported that in his country, extending mammography screening programmes to women aged 70–75 led to a large drop in breast cancer mortality in this age group, and participation levels were high. Older women tend to have increasingly slower tumour growth and less severe disease. He recommended 75 years as an appropriate upper age limit for screening, with the same two-year screening interval.



Available on webcast

## News about EUROPA DONNA advocacy priority areas

### Preventing breast cancer through healthy lifestyles

In a teaching lecture on healthy lifestyles, **Susan Knox** presented the successes of the 15 October Breast Health Day campaign, which this year will extend to NGOs across the globe. For more on the campaign see page 25. **Carlo La Vecchia** of the Mario Negri Institute in Italy presented findings indicating that 15–20% of post-menopausal breast cancers could be avoided by controlling long-term use of hormone replacement therapy and by reducing overweight and obesity in post-menopause. He added that 10% or more of breast cancers could be avoided by widespread adoption of regular physical activity and about 5% through reduction of alcohol consumption.



*Carlo La Vecchia*



### Creating guidelines for metastatic breast cancer

The Metastatic Breast Cancer Task Force, which convenes at each EBCC, aims to create guidelines for this often forgotten group of women. The need to maintain quality of life while attempting to extend survival was emphasised. EUROPA DONNA Past President **Stella Kyriakides** said that patients need to be given straightforward information, receive guidance on searching the Internet, be allowed to make informed choices, and be able to have hope. **David Cameron** from St. James's University Hospital in the UK said that doctors need to understand what their patients want and how to communicate uncertainties while also providing reassurance. **Lesley Fallowfield** of the University of Sussex in the UK cited studies showing quality of life to be of equal importance to women as length of life. Earlier recommendations of the task force were published following a session at EBCC-6 (J Natl Cancer Inst 2009;101(17):1174-81).



### Psychosocial aspects of survivorship

**Stella Kyriakides**, in a session on life after breast cancer, said that services to provide follow-up psychosocial support need to be developed. Women need to be offered psychosocial support as part of the multidisciplinary team since almost half of women newly diagnosed experience psychological issues and emotional distress before treatment is started and have high anxiety levels after treatment. As **Lesley Fallowfield** stated in an earlier session, "The emotional well-being of the patient is an emergency, more so than the physical disease."



*Stella Kyriakides*



### Pharmaceutical prevention

In a debate session chaired by EUROPA DONNA Board Member **Bettina Borisch**, about two-thirds of the audience remained convinced that the future of breast cancer prevention will not be provided through drug therapy for certain risk factors, an approach currently used in cardiovascular disease prevention.



*Jack Cuzick, Ian Tannock, Bettina Borisch, David Cameron and Andrea Decensi*

### Breast cancer in pregnancy

A highly attended session discussed some cases of women diagnosed with breast cancer during pregnancy. Presentations by **Marie-Jeanne Vrancken Peeters** and **Sabine Linn** from the Netherlands Cancer Institute indicated that when the treatment is not compromised, prognosis of these women is similar to that for non-pregnant women. The session chair **Sibylle Loibl** of the German Breast Group and co-author of international consensus guidelines on breast cancer in pregnancy, noted that care should be as close as possible to standard recommendations and be provided by a multidisciplinary team that includes a gynaecologist and a paediatrician. For more on pregnancy in breast cancer see the Answering the Advocates interview with Sibylle Loibl on page 10.

## Breaking the barriers to research

Financial constraints were a recurring theme in a session on barriers to academic research. **Tanja Cufer** from Clinical Hospital Golnik in Slovenia stated that while funding has increased, it is still not optimal and there is an enormous gap in spending between countries. She suggested increasing partnerships between academia and industry and establishing common endpoints in the best interest of patients. Examples of successful partnerships she gave included the HERA and BIG-1-98 trials, in which EUROPA DONNA has been involved. Past President **Ingrid Kössler** cited a Swedish patient survey indicating that 70% of respondents were not informed about clinical trials. She said that while some women are hesitant to enrol, other women, such as those with metastatic disease, are given hope, and that women need to be informed about the options.



*Philip Poortmans, David Cameron, Emiel Rutgers, Ingrid Kössler, Tanja Cufer and Christos Sotiriou*

## Preliminary findings from the MINDACT trial

**Emiel Rutgers**, from the Netherlands Cancer Institute, presented the preliminary results of the pilot phase of the MINDACT trial, of which EUROPA DONNA is a member of the Steering Committee, indicating that this logistically complex trial is feasible. Based on the first 800 patients enrolled, it can be estimated that about 8% fewer women may require adjuvant chemotherapy in the future, as a result of patient selection using a low-risk genetic signature.

## Returning to work after breast cancer

**Tomas Rejda** from Amsterdam Medical Centre in the Netherlands stated that in his country, all patients have access to an occupational physician and suggested that one should be included in all multidisciplinary teamwork. He added that fatigue early on in treatment is the strongest negative predictor of returning to work, while patients who feel strong and want to return often do so. This is important in determining which patients require extra guidance. While evidence-based guidelines for work recovery have been published in the Netherlands, he called for the creation of international guidelines on the subject.

## Dutch singer/songwriter awarded the Nathwani Prize

ED President **Ellen Verschuur** awarded Dutch singer and songwriter **Ellen ten Damme** the Nathwani Prize for the documentary film shot during her breast cancer treatment. Nominations for the prize and the winner are chosen by EUROPA DONNA.



*Ellen ten Damme*

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## Points to remember about EUROPA DONNA advocacy priority areas

- Controlling use of HRT, reducing overweight and obesity, limiting alcohol consumption and increasing regular physical activity can all help to prevent breast cancer
- In metastatic breast cancer length of life and quality of life are both of utmost importance to women
- Emotional and psychosocial support need to be provided as a component of breast cancer diagnosis, treatment and follow-up
- Pregnant women with breast cancer should be treated as closely as possible to standard recommendations
- Academic research should have common endpoints in the best interest of patients, and women should be informed about clinical trial options
- Preliminary results of the MINDACT trial estimate that some women may be spared the need for adjuvant chemotherapy
- Women need occupational assessment to help them return to work after breast cancer, since factors such as feeling strong and positive about returning to work can improve these possibilities

Mark your calendars  
**EBCC-8**  
21–24 March, 2012  
Vienna, Austria

# Answering the Advocates

## What women want: specialised surgeons and specialist breast units



Isabel Rubio

Dr. Isabel Rubio is Head of Breast Surgical Oncology at the specialist breast unit at the Vall d'Hebron University Hospital in Barcelona, Spain. She completed her breast surgical training at MD Anderson Cancer Center in the USA. EUROPA DONNA spoke to her at EBCC-7, where she co-chaired the opening session on breast units. She told us she was initially drawn to breast surgery by the psychological aspects of breast cancer and the woman's need to decide on her own treatment.

### **EUROPA DONNA: How does your specialist breast unit work?**

**Isabel Rubio:** The breast unit was built two years ago and moved all the departments into one area. Women now have everything in the same friendly environment. We do mammography screening as well as diagnosis and treatment. The whole diagnostic process usually takes no longer than 24–48 hours.

We have our multidisciplinary team meeting every week. We discuss all the patients diagnosed or potentially diagnosed with breast cancer and decide on the treatment options and if there is a clinical trial she can participate in. I think that makes things easier for the patient, and the management of the patient is improved.

### **ED: EUROPA DONNA is advocating to have these units implemented across Europe. How was the unit established at your hospital?**

**IR:** Donations from patients helped build this breast unit. I think that Dr. Baselga's input and his willingness to have it implemented made this possible. The collaboration from the hospital itself and the breast cancer team showed that we were ready for it. We have worked for several years now as a breast unit, but we had been physically located in different areas of the hospital.

### **ED: So having a doctor strongly in favour of establishing units could be a way to help implement them in other countries?**

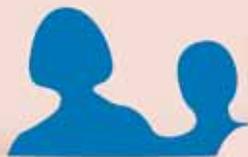
**IR:** Yes, doctors and advocates need to join forces. As advocates, I think that EUROPA DONNA is doing a great job because we need breast units. You need to have local advocates that know how people think in each country. Advocates probably also need the medical point of view. Studies show that women who are managed and treated in a breast unit do better. It is also important for patient advocates to inform the lay public because many people don't know where to go when they have breast cancer. The implementation of breast units not only needs to be worked on by the advocates, the medical community has to want or need them.

### **ED: Do you think it was significant that advocates presented on breast units at the opening session of EBCC?**

**IR:** Yes and it is where we need to go from here. That is the best way of getting things done. Advocates can put pressure on local and central governments. They have done it at a European level, so we should do it in our own countries.

When EUROPA DONNA talked about breast units at the opening ceremony, it was important that they mentioned the large amount of information a woman needs to absorb at diagnosis. We know as their doctors that when they leave the clinic, they only remember that they have cancer. The patients need time to think about all this. It is good that EUROPA DONNA talked about this. Patient advocates are important in this setting because as doctors we tell the patients that breast cancer is not a medical emergency, it is a mental emergency.

With any diagnosis of breast cancer it is important to have a treatment plan. In breast units the management of patients is discussed by the multidisciplinary team. That is the best thing you can do for your patients. Every patient is different and each cancer is different. It is also important for breast units to have support groups and psycho-oncologists to support the patient throughout the treatment.



**ED: EUROPA DONNA is advocating for an EU protocol for accreditation of breast units. Do you support this initiative and the concept that there should be some type of certification to ensure that EU standards are being met?**

**IR:** Accreditation of breast units is essential so you can ensure that the units are high quality. Women who are seeking hospitals can select the appropriate facility for their treatments based on this accreditation.

It is important for each part of the breast unit team to have its own quality control. Breast units need to have breast cancer specialists, enough cases to allow the specialists to maintain their expertise, have a multidisciplinary team, and provide all the services needed for the management of breast cancer patients. Each department needs to do its own studies to see its results.

**ED: There seems to be a lot of new technology and software to connect departments within a breast unit. Is this becoming a new aspect of running a breast unit?**

**IR:** About six months ago we started to record computerised medical history at our hospital. We try to have all the patients' records in the computer, radiology reports, mammograms. Data collection is an important component of the breast unit.

**ED: In order to specialise in breast surgery you went to the USA. Do surgeons want to specialise and how can we encourage them to specialise in breast surgery?**

**IR:** Surgeons need to realise that treating cancer patients is much different from doing general surgery. In the USA after the general surgery programme, there are surgical oncology fellowships that take another three years. In the last 5–10 years surgeons have started to become aware that they need to be more specialised. In cancer patients, sometimes the best treatment may not be surgery at first. There are so many advances in surgical oncology that it is difficult to keep up. That is why in breast units, surgeons need to do enough breast cancer cases a year to maintain and improve their expertise.

**ED: So there is hope that they will become more accepting of breast surgery as a specialisation?**

**IR:** Yes. This is also because people are demanding it. They want to be operated on by surgeons that are specialised.

**ED: The European guidelines specify that each surgeon must perform at least 50 new breast surgeries per year.**

**IR:** Yes, exactly. In the process of accreditation of breast units, one of the many requirements is that the surgeon does a minimum number of breast cancer surgeries per year. The answer is there.

**ED: Are there any new trends in breast surgery?**

**IR:** About 10–15 years ago, less than 10–15% of women undergoing mastectomy had immediate breast reconstruction. That was because the surgeon didn't offer it and/or the patient didn't ask for it. Nowadays,

if the patient needs a mastectomy and it is indicated, she needs to be offered immediate reconstruction.

The sentinel node biopsy is increasingly being applied with more indications, which will lead to a decrease in morbidity from axillary surgery. Breast surgeons are becoming more involved in clinical trials and understand the importance of women participating in them.

**ED: Are you aware of any new data that could be of interest to advocates?**

**IR:** Our patients are living longer because of new treatments. We need to be sure that the treatment has fewer side effects. For lymphoedema we are doing a clinical trial to see if we can find which lymph nodes drain the arm. If we can avoid removing them when we do an axillary node dissection, then we can decrease the risk of lymphoedema. So far our results suggest that in patients with one or two positive lymph nodes, we can probably spare that node and decrease the risk of lymphoedema. We are trying to lower the morbidity so that the patients can live their lives better.

I was impressed that women who attended the TRANSBIG workshop open to the public at EBCC were interested in clinical trials. I think that the mentality is changing. If we need to get results and we need to find out more about efficacy of treatment, we need clinical trials. Women know that this is how to get things done. That is because we give them information. We explain what a clinical trial is and how important participation is. These sessions involving the public are very useful for spreading information and I think they should be held at more meetings.

**ED: Do you think your patients might feel more comfortable with you because you are a woman?**

**IR:** I think that patients are more comfortable if you are a breast cancer specialist than if you are a woman or a man. It makes sense because you want someone to give you the best treatment, regardless of gender.

### Interview at a glance

- Studies show that women who are managed and treated in a breast unit do better
- Advocates and doctors need to work together to establish specialist breast units
- Every woman diagnosed with breast cancer needs an individualised treatment plan and to be given time to decide on her treatment
- Breast units should combine clinical work and research and use their research results to test the quality of their service
- Surgeons will need to specialise in order to be able to offer the best treatment
- New studies are investigating reducing the adverse effects of treatment

# Answering the Advocates

## Pregnancy and breast cancer are compatible



Sibylle Loibl

Dr. Sibylle Loibl is a member of the German Breast Group, Director of the Medicine and Research Department in Neu-Isenburg and Assistant Professor at Frankfurt University in Germany. She is also the lead author of the only international recommendations on treating breast cancer during pregnancy. EUROPA DONNA had the opportunity to speak to her at EBCC-7, where she chaired sessions and presented her research on this topic.

**EUROPA DONNA: At EBCC-7, you presented a poster on a European registry on breast cancer during pregnancy. What were your general findings?**

**Sibylle Loibl:** In September 2003, we decided to develop the first international guidelines on the treatment of breast cancer during pregnancy. These were published in early 2006 and are now being updated. At the same

time we launched a prospective registry in Germany, but due to lack of patients we expanded it to Europe and included retrospective cases. We now have more than 300 patients in the database. In parallel we are collecting tumour tissue and, where possible, also placenta tissue for further translational research. More information is posted on [www.germanbreastgroup.de](http://www.germanbreastgroup.de).

**ED: Have you managed to reach any conclusions about safety?**

**SL:** We haven't gone that deep into our data. What we do see is that in pregnant women the cancer is generally more aggressive. There are more undifferentiated tumours and more oestrogen-receptor-negative cases. The majority are node positive and we have about 34% HER2-positive patients. The patients are young, with a median age of 33 years, and are most likely candidates for chemotherapy. The children whose mother received chemotherapy during pregnancy had similar problems after delivery to those who did not. We have no long-term results yet, but are working on it.

**ED: What do your data or any other existing data indicate about treatment for women diagnosed during pregnancy?**

**SL:** Our data show that more and more women with breast cancer are being treated with chemotherapy during pregnancy and that this treatment is feasible without compromising the foetus. Some patients have told me that their doctors advise them not to have treatment until after delivery. This is wrong. It is very important for the patient to know that she can have treatment, surgery and/or chemotherapy, and if absolutely necessary, radiotherapy. We have no long-term data yet, but data from the USA, with a median follow-up of about 8 years, did not reveal any adverse findings. Chemotherapy has to first pass through the placenta to reach the foetus and, therefore, the foetus is exposed to a relatively insignificant amount.

Patients should go to centres that offer proper breast cancer treatment, have proper pre-natal and post-natal care and obstetrics units, and are able to treat patients in a multidisciplinary fashion. Patients should not be sent away and be told to wait until after delivery. They can be treated quite close to the standard guidelines. This is the message in the breast cancer in pregnancy guidelines: to treat them as close as possible to the standard treatment.

**ED: If you were pregnant and diagnosed with breast cancer would you have chemotherapy?**

**SL:** Yes, I would. You have to save the life of the mother. The child needs its mother. Both lives are important. Therefore proper treatment is important.

**ED: Would hormonal therapy, if necessary, begin after delivery?**

**SL:** Hormonal therapy should not be given during pregnancy because data show that tamoxifen can cause foetal defects. The same is true for trastuzumab. There should be no treatment with trastuzumab during pregnancy.



However, after delivery systemic treatment should be completed.

**ED: This brings us to young women diagnosed with breast cancer who want to have a child in the future.**

SL: They might face another problem: toxicity to the ovary. They might remain amenorrhoeic, or their ovaries might not function properly anymore due to the chemotherapy.

**ED: What would you recommend to preserve their fertility?**

SL: First of all, the women need to be aware of the problem and need appropriate fertility counselling. There are different options. The best option is freezing of the embryos or fertilised oocytes. Freezing the embryos, as is done in a normal in vitro fertilisation cycle, has been shown to be more effective. Freezing the ovarian tissue is not an option. The ZORO study by the German Breast Group has shown that a GnRH analogue before starting chemotherapy is not an option either.

**ED: To freeze embryos the women needs a partner.**

SL: Freezing mature but unfertilised oocytes is an option for women without a partner, but the chance of a successful pregnancy is much lower. Freezing parts of the ovarian cortex is not a real alternative in my opinion.

**ED: Is this safe in women who are oestrogen receptor positive?**

SL: Current literature shows this to be quite safe. There is a special regimen for breast cancer patients using an aromatase inhibitor for stimulation in combination with follicle-stimulating hormone, which is quite effective. The problem is that stimulation has to start during a certain time of the menstrual cycle, which might delay the start of the chemotherapy for several weeks.

**ED: That could be a concern for women needing to start treatment.**

SL: Yes. The main target population would be “middle-aged” young women. Very young women, under 30, probably need no ovarian protection because they regain their menstruation and ovarian function within a year of stopping chemotherapy. But in women older than 35 the ovaries are undergoing a dramatic change. These women would need counselling because they would undergo chemotherapy and perhaps endocrine treatment for five years. Then they would be in their forties and would probably have difficulties getting pregnant. The women and their partners must at least be informed about what could happen and what possibilities exist today.

**ED: If endocrine therapy is necessary, are there other options than the five-year treatment?**

SL: We always have to make an individual decision based on the risk of recurrence. If the hormone responsiveness of the tumour is very high, endocrine treatment would be advisable and we would suggest continuing treatment. If it is quite low or borderline, we would discuss the possibility of stopping treatment. Although

we have no data on that, a continuation of endocrine treatment after delivery for up to five years might be an option. Tamoxifen should be stopped for three months before trying to become pregnant.

**ED: In your experience, do women take these measures to preserve their fertility before treatment?**

SL: Unfortunately, most women do not. In Germany we have “Ferti Protect”, a network consisting of reproductive specialists who offer different options for fertility preservation in cancer patients. We try to collaborate with them.

**ED: Do you have any advice for EUROPA DONNA advocates and what they should tell women who want to become pregnant after breast cancer?**

SL: They should go ahead. I don't know why some doctors are reluctant and tell their patients they should not get pregnant. I have a lot of referrals from other centres and women ask me if they can become pregnant. Yes, they can. If we practice evidence-based medicine, we have to rely on the data. The data suggest that it is safe to have a baby after breast cancer, so doctors have to accept that.

**ED: It sounds like doctors need to be informed about this. Is there any way for EUROPA DONNA to do this?**

SL: You have to spread the guidelines. In Germany we have incorporated breast cancer during pregnancy and pregnancy after breast cancer into the guidelines by the AGO (Arbeitsgemeinschaft Gynäkologische Onkologie, [www.ago-online.org](http://www.ago-online.org)). We also developed the first patient guidelines last year and published a booklet on this topic. For a woman, it is a matter of finding the right doctor and finding the right advice about what to do.

### Interview at a glance

- Updated international recommendations are being prepared. For the current published recommendations, see S. Loibl et al. *Breast carcinoma during pregnancy. International recommendations from an expert meeting.* Cancer 2006;106(2): 237-46.
- Pregnant women with breast cancer should be treated as close as possible to the standard treatment in a centre offering breast cancer treatment, prenatal care and an obstetrics unit
- Endocrine therapy and trastuzumab should not be given during pregnancy
- Women wishing to become pregnant after breast cancer should have appropriate fertility counselling, particularly those 35 years and older
- Women under 30 probably do not need ovarian protection because they regain their menstruation and ovarian function

# Living with Breast Cancer

## Making a masterpiece after breast cancer



Irini Zannara, Greece

I was 32 years old when I discovered a lump in my breast and received the shocking diagnosis of “Breast Cancer”. Until then, I thought that cancer affects older people. I knew nothing about it.

At that time, my life was full of dreams about love, marriage, children, and dreams about a happy and prosperous future. And suddenly my life was full of fear, anxiety and uncertainty about the future.

When the doctor said the word CANCER, I completely froze and both time and dreams froze with me. I stood there like a child, unable to understand what I was told, ignorant, unable to think or ask anything. I just stood there waiting for the execution. I said to him, “Do whatever you have to do, just take it out of my body and make me well again! Let’s start immediately.”

A few months after my diagnosis, a friend introduced me to the Pan Hellenic Association of Women with Breast Cancer – Alma Zois, where I met other women dealing with breast cancer. I met 20-year survivors and received psychosocial support from the organisation’s psychologists and social workers. For the first time since my diagnosis I was offered a helping hand. Slowly but steadily all my questions regarding my illness were answered. *Why me? Why now? What’s next?* Before my diagnosis I thought I was strong and that I could deal with this on my own, but with peer support things were easier.

Two years later, I was trained under the Reach to Recovery International Programme and I became a volunteer who could offer emotional support to newly diagnosed young women. At the same time, I was introduced to the newly formed EUROPA DONNA Hellas and I started attending European conferences and meetings. I met other young survivors with whom I immediately felt a strong connection. We formed a Young Women’s Group to discuss our special issues.

During my chemotherapy, I ended a 2-year relationship, and a year later I met Theodore, who I married 3 years later.

After my diagnosis, I started dedicating time to myself, so I could do things that I truly loved, like painting, learning foreign languages and travelling. I have also added to my valuable list of experiences: a mastectomy, breast reconstruction, 6 months of chemotherapy, 2 years of menopause-inducing injections and almost 4 years of tamoxifen treatment. I had my job and a man in my life that wanted me exactly as I am.

I focused on the everyday activities and didn’t think having a baby was a must. With all my treatments, I was convinced that at the age of 37 my reproductive system would never work again. Pregnancy was not included in my dreams after breast cancer. Even if I couldn’t get pregnant, I would still be a very happy woman who achieved so many other things in my life. By that time, my husband and I even thought about adopting a child!

At a meeting of EUROPA DONNA’s Young Women’s Group in Milan I met the president of the Young Survival Coalition in the United States. She had given birth to a beautiful baby girl despite her chemotherapy. When I heard her story, my face lit up and I thought, “I still have a chance then!”

Upon my return to Greece, I did my research and was disappointed that due to lack of information at the time of my diagnosis I hadn’t taken any precautions to protect my fertility during chemotherapy. My gynaecologist answered my questions regarding my fertility vaguely and with uncertainty. Nobody could tell if I would be able to get pregnant.

Nine months after I had stopped all medications, the miracle happened! Suddenly, I got pregnant and all my doctors were thrilled: the oncologist, the breast surgeon, the gynaecologist and everybody at the Greek Association.

My gynaecologist said that it was a once in a lifetime opportunity to have a baby, so I was very careful not to miscarry. Everything went well and 6 years after my diagnosis I gave birth to my little baby girl, who I named Iris – Elpis, which means hope.

I did not breast-feed her in order to minimise the risk for the other breast. My doctor also said that I should not have another child because pregnancy would be too stressful for my body, and my health should be a priority.

This is my life and my decision to bring life into this world. I have learned that nobody’s life is given and guaranteed. So why worry about death in the future when we can live the present and create masterpieces in the process!



## EUROPA DONNA holds successful advocacy campaign at the European Parliament: Adoption of the Written Declaration on the Fight Against Breast Cancer in the EU

EUROPA DONNA has been actively advocating to keep breast cancer on the European Parliament agenda by promoting a Written Declaration on the Fight Against Breast Cancer in the EU (0071/2009). The Declaration was adopted on 25 March, with the signatures of a majority of MEPs – 381.

The purpose of the Declaration is to remind MEPs of the need to implement the Resolutions on Breast Cancer of 2003 and 2006, since a large number of MEPs have taken office since their adoption. It can now be used by EUROPA DONNA member countries to insist on this implementation.

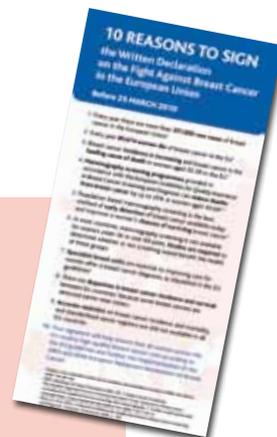
To ensure that MEPs are aware of the Declaration and to encourage them to sign it, EUROPA DONNA held a two-day information event at the European Parliament in Brussels in February as well as a similar event in Strasbourg. EUROPA DONNA President Ellen Verschuur, Executive Director Susan Knox and Policy Officer Karen Benn were on hand in Brussels to meet MEPs at a booth featuring three posters on the Declaration. They also distributed flyers stating “10 good reasons for MEPs to sign the Written Declaration” and copies of the *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. This campaign continued at the next plenary session of the European Parliament in Strasbourg. On the first day, Karen Benn attended and the next day ED Luxembourg National Representative Marie-Josée Weber-Hurt, along with ED Luxembourg member Nicole Poos, took over.

Many of EUROPA DONNA’s national organisations were also very involved in advocating for this Declaration. Those whose countries are EU member states wrote to their MEPs asking them to sign, and some National Representatives also instigated phone call campaigns where they rang each MEP individually asking for their support for the Declaration.

EUROPA DONNA helped draft the Declaration, which was launched by MEP Liz Lynne (UK) with co-signatories MEPs Michail Tremopoulos (Greece), Livia Járóka (Hungary) and Lidia Joanna Geringer de Oedenberg (Poland). As stipulated in the Declaration, now that it has been adopted, the EU President is called upon to forward the Declaration, together with the names of the signatories, to the parliaments of the Member States. It is also to be published in the Official Journal of the European Union.

### The Declaration calls for the following:

- Member States to introduce nationwide breast screening, in accordance with EU guidelines
- The Commission to create a progress report on implementation of mammography screening in all EU countries every 2 years
- The Commission to support studies to look at whether screening is useful for women over 69 years of age and under 50
- Member States to provide multidisciplinary specialist breast units in accordance with EU guidelines by 2016, and the Commission to deliver a regular progress report
- The Commission to present up-to-date, reliable statistics on breast cancer and support the development of national cancer registers
- The Commission to develop a certification protocol for specialist breast units in accordance with EU guidelines by 2011 and to provide adequate financing for this
- The EU President to forward this declaration, together with the names of the signatories, to the parliaments of the Member States



The full Declaration, in all EU languages, is available on

<http://www.europarl.europa.eu/activities/plenary/writtenDecl/wdFastAdopted.do?language=EN>



Karen Benn, Livia Járóka (MEP Hungary), Ellen Verschuur, Liz Lynne (MEP UK) and Susan Knox



Susan Knox, Ellen Verschuur, Lidia Joanna Geringer de Oedenberg (MEP Poland) and Karen Benn

## EUROPA DONNA member survey on Specialist Breast Units and implementing the 2006 EU guidelines

Overall results of EUROPA DONNA's 2009 member country survey "Implementation of Specialist Breast Units (SBUs) and Mammography Screening According to the EU Guidelines" indicate that the standard of services offered has improved and more countries now have SBUs that fulfil EU criteria, in comparison to data from a similar 2005 survey. Most countries' SBUs fell below the standard in availability of counselling and specialist breast nurses.

Completed surveys were received from 12 countries: Cyprus, Denmark, France, Georgia, Greece, Iceland, Ireland, Israel, Luxembourg, Netherlands, Poland and Slovenia.

### 2005 VS. 2009

A similar survey was distributed in 2005 and, although the response rate in 2009 was significantly lower, those answering seemed to be better informed. The aim was not only to compile the total results but to compare the results between the two years surveyed. Results for the nine countries that responded to both surveys, plus the three countries that responded in 2009 only were analysed.

### Survey results

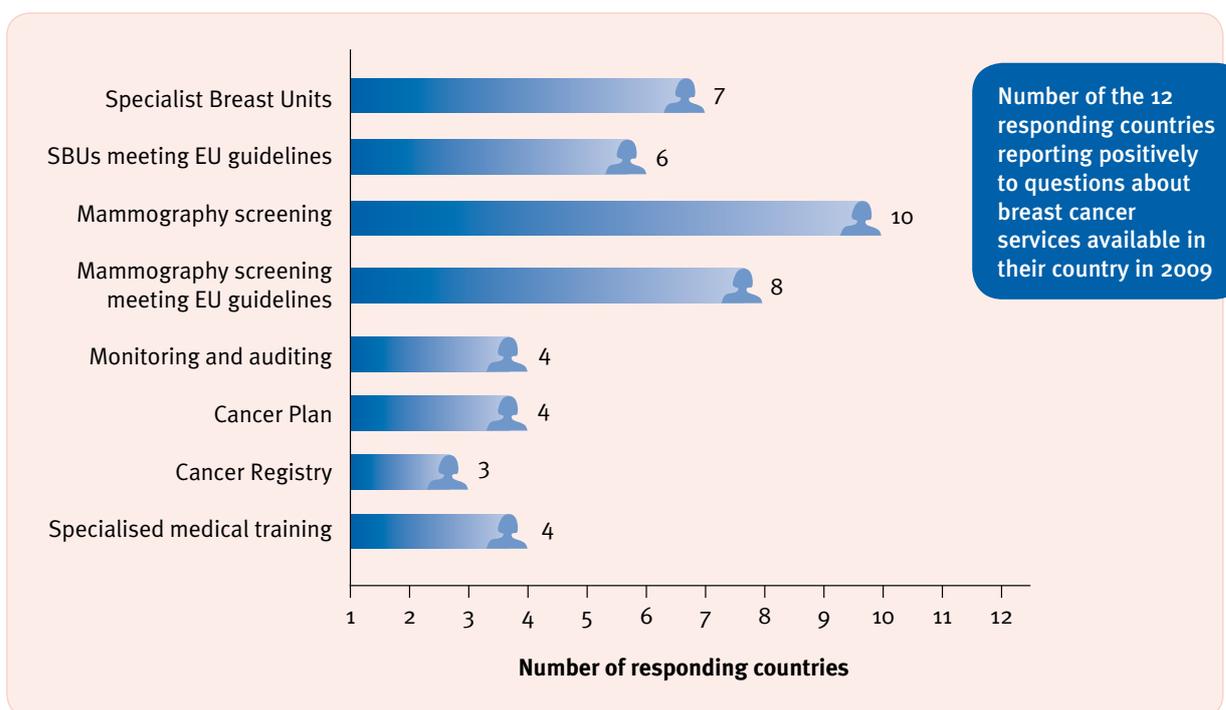
Overall, for 2009, 7 of the 12 responding countries reported having specialist breast units, and in 6 coun-

tries these were said to meet the EU guidelines on the most part; 4 indicated that the services were monitored; 1 country reported that it did not have specialist breast units but it did have multidisciplinary teams. With regard to population-based mammography screening, 10 countries reported having a programme, 8 of which confirmed that it met the EU guidelines. The age range for screening is 50–69 in 3 countries, 50–64 in 2, 40–69 in 2, 50–74 in 2 and 50–75 in one. Four countries indicated they have a medical specialisation leading to breast surgery and/or a breast specialisation; 4 said they have a National Cancer Plan and 3 have a cancer registry; 1 country reported having counselling; 1 country indicated it has an All Party Group on Cancer in general, and 4 reported that while they have no All Party Group they have contact with parliamentarians.

Of the nine countries that responded to both surveys, five expressed that there were positive changes from 2005 to 2009.

### Conclusion

In summary, of the 12 respondents in 2009, six reported having specialist breast units adhering, on the most part, to the EU guidelines, while seven had some form of specialist breast unit. This indicates that while headway has been made, advocacy is still required across all European countries.



EUROPA DONNA has 45 member countries, including all 27 EU Member States. In this section ED Fora share their past and planned activities.



## Strength in Numbers

### Albania

#### Highlights of 2009

- For Breast Health Day, discussion on the problems affecting early diagnosis, treatment, etc. of breast cancer
- Seminar organised by the Oncology Service at QSUT, ED Albania and the Public Health Institute on breast cancer issues ranging from epidemiology to screening
- In March, a “Do It For You...!” event held by the “Pro Jetes” Association in the framework of International Women’s Day and involving a mass meeting of women and girls in Shkodra
- In April a “Walking Together” breast cancer demonstration in Tirana
- In April the seminar “Cancer in the Eyes of Albanian Patients” to continue awareness activities of the issues such as psychosocial factors, access to medication and the effect on daily life and employment. It featured celebrity speakers, including the first lady and attracted much media attention
- In December an activity involving 70 patients, psychologists and volunteers to discuss real-life experiences

### Austria

#### Highlights of 2009

- A joint event with the Austrian Cancer Society for Pink Ribbon Day in Vienna
- Breast Friends Exhibition Tour, organised in co-operation with the Austrian Breast Cancer Study Group (ABSCG), travelled to each Austrian province

and was displayed in ABSCG-related hospitals and clinics

- A Breast Health Day seminar held for patients in conjunction with the exhibition, featuring presentations by local gynaecologists, surgeons, oncologists, psycho-oncologists, nursing personnel, health executives and ED Austria
- Showing of the exhibition with an ED information stand at “fem-vital”, Austria’s largest women’s health fair
- Two ED Austria Board Members attended the 9th ED Pan European Conference
- Maintenance of the Forum website and contacting sponsors

#### Activities for 2010

- Preparation of a brochure on early detection of breast cancer in co-operation with the Municipality of Vienna
- Two delegates are to attend the Advocacy Training Course in November

### Belarus

#### Highlights of 2009

- ED Belarus website launched, [www.europadonna.by](http://www.europadonna.by)
- Seven women’s group members trained in advocacy
- 60 articles on breast cancer selected and translated
- Printed 1,000 copies of educational materials for doctors and women’s groups
- Initiated project “beauty beads” for breast cancer awareness and mammography promotion



# Strength in Numbers

- Translated ED Short Guide to the EU guidelines into Russian and Byelorussian

## Activities for 2010

- A breast cancer conference for women's organisation in February
- Participation in June Breast Health Global Initiative summit in Chicago, with poster presentation of breast cancer early detection results
- Further development and support of the website
- Women's group further training in advocacy
- Continuation of "beauty beads" project with distribution of tools for breast cancer advocacy and explaining advantages of early detection
- Mass media advocacy training scheduled for August 2010
- Further Russian translations of materials for doctors and women's group

## Belgium

### Highlights of 2009

- Interparliamentary Breast Cancer Group meeting
- International Breast Cancer Meeting
- Symposium on Fertility and Sexuality after Cancer
- Together Against Breast Cancer Exhibition
- Cancer Support Group Day at the European Commission

### Activities for 2010

- Belgian Breast Meeting 2-day medical congress on breast cancer
- Symposium "Action Sein" providing a full day of information for the public
- Interparliamentary Breast Cancer Group meeting

## Bulgaria

### Highlights of 2009

- Problems were encountered with financing activities. Therefore, activities focused on actions not requiring funding but that could contribute to promoting screening and increasing awareness
- Meetings with members of parliament and Ministry of Health representatives, participation in the discussion of bills and laws regarding public health
- Promotional activities such as participation in TV shows on various national TV stations, and others to raise the awareness of young women about the disease and the need for regular self-examination for early detection
- Informal meetings with patients to help solve personal problems and provide advice about specialist care

### Activities for 2010

- Promoting the European guidelines and insisting on screening programme implementation
- Participation in the ongoing discussion on health reform

- Raising public awareness of the disease
- Information to young people about the disease and the possibilities of early detection

## Croatia

### Highlights of 2009

- Daffodil Day on the first Saturday in the spring
- Pink Ribbon Day on the first Saturday in October
- Project: "My First Mammography" for women aged 40-49 in 10 towns in Dalmatia
- Breast Health Day in Zagreb
- General Assembly in Zagreb on 12 December with the lecture "Rehabilitation of Patients with Breast Cancer"
- Participation in the 1st Croatian Congress of Psycho-Oncology and Liaison Psychiatry in Pula on 19-22 March
- Participation in the 5th International Symposium on Complementary Supportive Therapies in Lovran on 21-24 May

### Activities for 2010

- Daffodil Day and Pink Ribbon Day
- Project on psychosocial issues of women with breast cancer and their families (for medical teams)
- "My First Mammography" project in 10 towns in Istria in May
- Breast Health Day in Zagreb
- The 1st Croatian Symposium of Lymphology in Opatija on 18-20 November

## Cyprus

### Highlights of 2009

- Breast Health Day held outside parliament
- Advocacy events in all cities, numerous awareness events to reach women in many professions, meetings with political party leaders about the need to implement EU Resolutions, input given on the national cancer strategy
- Opening of second ED Cyprus house in Larnaca, increase in grass roots support
- Biggest pink silhouette walk held ever with more than 800 participants
- Young women's group further strengthened
- Held the first "Feel Good Look Good Day"
- New leaflet on sexuality and breast cancer

### Activities for 2010

- The reporting and support of screening according to the EU guidelines, and implementation of breast units with specific steps planned
- Further organisation of all services provided, training courses for new advocates
- Improvement of website
- Funding of new research on women's and patients' views on breast cancer services

- Celebrating 10 years of ED Cyprus in October and Breast Health Day
- Information events targeting young women

### Czech Republic

#### Highlights of 2009

- Video showing examinations – ultrasound, mammography, self-examination
- Main partner in Avon Walk Against Breast Cancer with over 7,000 participants
- Project “Women to Women” (distribution of vouchers for mammography examination for women whose examination is not reimbursed by health insurance)
- Brochure for newly diagnosed women with breast cancer (practical guide) and a press conference
- Series of seminars for member patients’ organisations on fundraising, patients’ rights, psychological aspects of work
- Leaflets distributed in large supermarkets
- Patients’ conference with presentations by specialists in oncology, radiology, patients’ representatives etc. and a press conference

#### Activities for 2010

- Public seminars for patients entitled “How to Communicate with Your Doctor”
- Brochure II
- Avon Walk Against Breast Cancer
- Women to Women Project
- Prevention materials: self-examination leaflets
- Preparing new project concentrating on stress release for doctors
- Interactive Q&A consulting on the website
- Patients’ conference
- Breast Health Day

### Denmark

#### Highlights of 2009

- Large conference at Christiansborg (the Danish Parliament) on 23 October 2009, with more than 200 participants, mostly women with breast cancer, as well as politicians and reporters. The Danish Minister of Health made the introductory speech about an agreement in which quicker diagnosis and early treatment were the goals

#### Activities for 2010

- Centralisation of specialities is being planned in order to ensure that treatment is only given where the greatest expertise is found
- Conferences on the latest research and rehabilitation
- Presentations by Prof. Nils Brüner and other researchers on tailor-made treatment; Dr. Niels Kroman, one of Denmark’s best surgeons; Rune Gärtner, PhD, on late side-effects after treatment; and Marianne Davidsen-Nielsen, psychotherapist and author, on the anxiety involved in breast cancer

- Talks on lymphoedema, on the importance of exercise and the possibilities for rehabilitation after discharge from hospital

### Estonia

#### Highlights of 2009

- Working in close co-operation with Estonian Cancer Society and North-Estonian Cancer Patients’ Organisation
- Promotion to increase participation in national screening programme established in 2002
- Press conference and media campaign “Don’t be Late” for Breast Awareness Month in May. Articles published in 15 newspapers and magazines, plus four TV and three radio broadcasts, and posters
- In June, Pink Ribbon campaign and charity event in a park in Tallinn followed by a walk through the city
- In February a new mobile mammography unit in southern part of Estonia
- In August a patients’ summer camp
- In September charity concerts in three towns and a breast awareness run in Tallinn
- Breast Health Day

#### Activities for 2010

- Promotion of healthy lifestyles and breast awareness
- In May a media campaign
- In June a breast cancer charity event
- In September a big charity concert
- Breast Health Day

### Finland

#### Highlights of 2009

- Organisation of a “road show” with lectures by breast cancer specialists (physicians, psychiatrists) in the five largest cities
- First launch of Breast Health Day in Finland
- Publication of two issues of the ED Finland magazine
- Members attended the parliament’s cancer group meetings and continued networking with other national cancer organisations
- 25% increase in use of Internet-based discussion forum
- Basic activities (weekly support group meetings, weekend camps)

#### Activities for 2010

- Opening of ED Finland’s own office in September
- Continued dialogue with national authorities and other interest groups
- Continuation of basic activities
- Special attention will be paid to young breast cancer patients and women with recurrence or metastatic breast cancer
- Launch of email box where women needing support can send their questions and thoughts. A trained person will reply within 48 hours



# Strength in Numbers

## France

### Highlights of 2009

- Unforgettable concert given in the largest concert hall in Paris. Internationally known singers and pianists contributed time and skill to enhance breast cancer awareness
- Yearly symposium at the Senate as a launch event for Pink October, dedicated to supportive care in breast cancer
- Usual Pink October activities in many hospitals and public places throughout France, emphasising the importance of participating in the nation-wide screening programme
- Promotion of Breast Health Day at Hôpital Européen Georges Pompidou

### Activities for 2010

- Continuation of previous activities and participating in parliamentary meetings on cancer
- Writing and publishing new brochures
- Working on the implementation of the 2nd Cancer Plan
- Planning of the Senate symposium on breast cancer in younger and elderly women, to be held on 4 October. Everyone is welcome

## Georgia

### Highlights of 2009

- “Short Guide to the EU Guidelines” translated and printed in Georgian
- Participation in the creation of Georgian Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis with the collaboration of Georgian Cancer Study Group, Georgian Society of Pathology and National Screening Centre and the support of United Nations Population Fund. The guidelines are awaiting approval

### Activities for 2010

- Distribution and promotion of EU guidelines implementation on the national level and creation of breast units
- Promotion and lobbying for approval of Georgian guidelines
- Promotion of ED’s mission in counties with limited resources to help them join ED
- Participation in Race For The Cure, to be held in Georgia by Susan G. Komen Foundation
- Breast Health Day events
- Increasing fundraising
- Continuing to hold meetings with politicians, diplomatic corps and journalists
- Promotion of breast cancer research

## Germany

### Highlights of 2009

- Participation in the Advocacy Training Course and reestablishing the ED Germany Forum

### Activities for 2010

- Participation of National Representative at EBCC-7
- Finding breast cancer survivors who want to be involved in ED activities
- Development of an ED Germany website
- Contacts with local and national politicians
- Co-operation with breast care units
- Co-operation with the MammaGroup in Nord-Rhein-Westfalen
- Distribution of ED information materials

## Greece

### Highlights of 2009

- Launched “Life Commitment” campaign in March
- Started “Advocacy Line” in September
- National Representative attended the 9<sup>th</sup> ED Pan European Conference in Stockholm
- On 15 October, holding of a conference in old parliament building, with pink figures decorating the inside and outside
- Two Board Members attended the Advocacy Training Course in November
- ED Hellas gala held in one of the biggest hotels in the centre of Athens in November

### Activities for 2010

- General assembly and elections in February
- A Women’s Day gala in March
- Participation of a team in the Gold Marathon in October
- Planning of other events for October

## Hungary

### Highlights of 2009

- Population-based breast cancer screening with a mean participation rate of 36%
- Awareness raising activities for the general public, including “Health Bridge” in Budapest and towns, conferences with local inhabitants and political decision makers on quality care of breast cancer patients, patients’ rights and representation, and ED goals
- Participation in a Susan G. Komen Foundation project to encourage screening among the gypsy minority and raise their health awareness
- Participation in congresses such as the Breast Cancer Consensus Conference, Budapest Annual NACP Congress and the 9<sup>th</sup> ED Pan European Conference

### Activities for 2010

- Establish a Europa Platform within NACP
- Distribute ED publications in Hungarian
- Ensure open fora to support detection of early breast cancer
- Introduce EU guidelines and support other ED initiatives
- Breast Health Day

## Iceland

### Highlights of 2009

- Celebrating the 30<sup>th</sup> Anniversary, including special decorations with 180 red roses representing women diagnosed with breast cancer each year and 40 white candles representing those who die from breast cancer each year
- Breast awareness in October and pink illumination of a prominent hotel in central Reykjavik
- Breast cancer seminar focusing on how cancer affects family life
- Honouring five people with a gold medal for their excellent contribution to helping women in the fight against breast cancer

### Activities for 2010

- A course for new volunteers in February in which 12 volunteers participated. The three main topics included: knowing breast cancer from A–Z, how to provide support and advocacy, and a presentation introducing ED
- Participation in the Icelandic Cancer Union's policy making
- A monthly open house with a mix of lectures, entertainment and refreshments. A culinary course promoting a cookbook with recipes of cancer-fighting food

## Ireland

### Highlights of 2009

- Development and design of public awareness-raising leaflet: "9 Things you Should Know about Breast Cancer"
- Successful application to National Lottery for funds for leaflet distribution
- Leaflet launched by Minister for Health on 5 October
- Postal drop to 790,000 households in remote rural regions and disadvantaged urban areas coinciding with Breast Health Day
- For Breast Health Day, exercise events hosted by 23 community groups, family resource and cancer support centres nation-wide
- ED Ireland service-user representative on national quality review of breast cancer centres by Health Information and Quality Authority
- Presentation to 600 members of Irish Country Women's Association

### Activities for 2010

- Launch of National Quality Review of Symptomatic Breast Disease Services in Ireland
- Further dissemination of "9 Things" leaflet
- Public meeting in May on using exercise to lower our risk/recurrence of breast cancer
- Building on 2009 Breast Health Day events

## Israel

### Highlights of 2009 and activities for 2010

- Seminars for breast cancer patients and their partners, young cancer patients and healthy women at risk held in October
- A vast public media campaign, including a report on Israel's ranking first place in Europe in mammography compliance rates, according to WHO statistics
- Launching of Hebrew edition of the ED mini-diary at sunset, while practicing tai chi
- Mobile mammography unit conducted screening tests for parliament workers and MPs at the Israeli Parliament
- Fun Day for breast cancer survivor volunteers who help new breast cancer patients in coping with the disease
- Initiation of a new breast care centre
- Continuing training courses for breast cancer medical teams as well as regional seminars in Arabic, Hebrew and Russian
- Rothschild Blvd. in Tel Aviv lit up in pink
- Unique breast cancer patient photo project

## Italy

### Highlights of 2009

- Meeting at the Italian Senate in April on prevention and early detection
- Stand at Torino International Book Fair in May and presentations by scientific experts on early detection of breast cancer
- Participation in various local TV and radio programmes to promote the importance of early detection and prevention, including healthy lifestyles
- General Assembly held in May and members participated in various international meetings during the year

### Activities for 2010

- Committee established in January with the aim of setting up and deciding on a strategy and 3-year plan by the end of the year

## Kazakhstan

### Highlights of 2009

- Screening programme "Women's Health: Early Diagnosis of Breast Cancer" March–November
- International advocacy forum on breast disease in Central Asia in October
- Four training seminars on early diagnosis of breast cancer
- Training for breast cancer patients throughout the year
- Delivery of the international nomination "Women's Health"
- Charitable photo exhibition "I'm with you"

# Strength in Numbers

## Activities for 2010

- Continuation of the screening programme from March–November
- Opening of the first children's cancer hospice in Kazakhstan
- International conference "Women's Health Issues"

## Kyrgyzstan

### Highlights of 2009

- Biennial Eastern Europe/Central Asia Breast Cancer Advocacy Summit in Bishkek in September (110 participants from USA, Eastern Europe, Central Asia and regions of the Kyrgyz Republic)
- Short (5 min) film "You Are Not Alone" on breast cancer (available on [www.ergene.org.kg](http://www.ergene.org.kg))
- Breast Cancer Awareness Day on 21 October (75 participants)
- Research on breast cancer awareness of population, involving 307 respondents
- Start of "Early Detection and Treatment of Breast Cancer in the Kyrgyz Republic" project financed by Swiss Confederation, 2009–2011

### Activities for 2010

- Breast Cancer Conference on 4 February for World Cancer Day (100 participants)
- Distribution of booklets on breast self-examination
- Holding of lectures on early detection of breast cancer among primary care physicians and the public
- Purchase of mobile ultrasound machine and visits to the regions within the "Early Detection and Treatment of Breast Cancer in the Kyrgyz Republic" project

## Latvia

### Highlights of 2009

- On World Cancer Day, roundtable discussion between representatives of ED Latvia, politicians and mass media
- Two psychosocial rehabilitation camps for breast cancer survivors held for the first time, in co-operation with the Latvian Cancer Society
- First charity "online shop" ([www.percunziedo.lv](http://www.percunziedo.lv)) where people can contribute by buying donated items
- A new tradition "Pink Ribbon Solidarity Walk" in October, with almost 200 participants
- Participation in new initiative by European Cancer Patient Coalition – European Partnership Action Against Cancer
- New information materials produced and distributed
- Fundraising activities

### Activities for 2010

- For World Cancer Day, an exclusive video "Support the Fight against CANCER" with patients sharing their stories (See [http://www.youtube.com/watch?v=\\_I3jYweCv68](http://www.youtube.com/watch?v=_I3jYweCv68))
- Awareness-raising "Walk through Latvia against Cancer"

- More psychosocial rehabilitation camps planned for summer
- "Pink Ribbon Solidarity Walk" in October
- Campaign for breast prostheses

## Luxembourg

### Highlights of 2009

- Film "As I was Wondering Where this Little Life of Mine was Leading Me" by Ellen Ten Damme followed by a Q&A session between 200 students and the actor
- 7<sup>th</sup> Race Against Breast Cancer with more than 600 participants, including politicians
- The English community held the first "pink evening" to promote breast health awareness and raise funds for local women undergoing treatment
- On 15 October the City Hall was lit up in pink and a silent walk with pink dolls was held in presence of the Minister of Health
- Courses such as aqua-gym, yoga, art therapy
- Providing of a bursary for three nurses, trained in Germany in breast care nursing

### Activities for 2010

- 8<sup>th</sup> Race Against Breast Cancer
- Think Pink Event and Breast Health Day
- Promoting art therapy in a hospital setting
- Publishing newsletters and brochures on topics such as radiotherapy and relaxation exercises

## Malta

### Highlights of 2009

- Weekend at a beauty parlour
- Walk For Health in March and Gozo Walk for Awareness in May
- Awareness talk given to the National Council of Women in October
- Awareness campaigns in shopping malls, with healthy meal preparation by a local chef and keep-fit sessions by a well-known instructor
- Awareness talk given to Caritas
- Annual Memorial Lecture
- Seminar for doctors and health professionals with the participation of well-known local and foreign specialists together with SOS Donna
- Participation in a health fair open to NGOs
- Awareness talk at one of the local councils
- Gala dinner
- Support of beauty parlour received with all proceeds going to ED Malta

### Activities for 2010

- Weekend at a beauty parlour
- Walk for Health and Gozo Walk for Awareness
- Seminar in Catania, Sicily together with SOS Donna in October
- Annual Memorial Lecture in October

## Monaco

### Highlights of 2009

- Opening of a “Better-being” living area for cancer patients, their friends and family. A number of services are graciously offered, such as that of an aesthetician, relaxation sessions, light exercises, special kinesiology for post breast surgery, gynaecological advice, all provided by professionals
- Leisure workshops at the living area, including activities such as watercolours, singing, card-playing, sewing and knitting, jewellery making, etc. to help people rejuvenate and return calmly to daily life

### Activities for 2010

- Continuing visits of patients undergoing chemotherapy in hospital by 16 volunteers
- Attending the Advocacy Leader Conference in Milan

## Netherlands

### Highlights of 2009 and activities for 2010

- Presentation at Cancer Genomics Plaza organised by Dutch Cancer Foundation, with a presentation on the patient view of tissue ownership after surgery
- A very successful third hereditary breast cancer conference covered the psychological and emotional effects of hereditary breast cancer, among other topics
- Printing and distribution of a poster and sending of the e-card for Breast Health Day
- Celebration of the 30th anniversary of the Dutch Breast Cancer Association, of which ED Netherlands is part, with a symposium including honorary guests Her Royal Highness Princess Maxima and the Minister of Health
- At the conference, the launch and demonstration of the Breast Cancer Care Monitor, a web-based tool giving insight into both the content of care and patient experiences. The Monitor shows all aspects of breast cancer care, from breast cancer outpatient department to complete diagnostics, a multidisciplinary breast cancer team, and possibility of offering immediate breast reconstructive surgery
- Translation of the “Short Guide to the EU Guidelines” into Dutch
- Permanent co-operation with the umbrella association of cancer patients on cancer-related issues such as access to new medicines, work, etc.

## Norway

### Highlights of 2009

- Active in local groups as part of Pink Ribbon Campaign with Norwegian Breast Cancer Society and the Norwegian Cancer Organisation
- Two advocates attended the Advocacy Training Course and returned home very inspired
- The National Representative attended the ED Pan European Conference in Stockholm

### Activities for 2010

- The National Representative attended EBCC-7
- General Assembly and election of new board in April

## Poland

### Highlights of 2009

- Media campaign and promotion of Breast Health Day
- Foundation of a new association of ED in Piła
- Participation on national TV programme about breast cancer and Breast Health Day
- “Marches for Health” and Breast Health Day events
- Meeting with MEPs at the Polish Embassy in Brussels to request European Parliament support for ED activities
- Visit of ED Poland Board Members to the Polish Parliament. Participation in the Health Commission at the Senate. Presentation of an appeal for improvement of breast cancer care
- Celebration of the 15th anniversary of ED Poland
- Promotional stands at scientific conferences. Lectures for women and students and fundraising for mammography examinations

### Activities for 2010

- Second edition of “Passport for Breast Health”
- Contacting Polish MEPs to support the EU Declaration
- Poster presentation on 15 years of ED in Poland at EBCC-7
- Polish version of the ED “Guide to Breast Health”
- Co-organising the international conference for nurses

## Portugal

### Highlights of 2009

- ESTRO Teaching Course for Oncologists where ED Portugal presented on breast units
- Fashion show at Portuguese Parliament for which national fashion designers created fashionable headwear. The event was made possible by the active co-operation of Dr. Sonia Fertuzinhos, parliamentarian and young breast cancer survivor
- Launch of a Facebook page reaching 1,113 members
- Participation at “Oncology Patient Advocacy Roundtable” at ECCO/ESMO
- Breast Day Health campaign promoted to Portuguese gymnasiums
- Breast cancer awareness presentation in Fafe in collaboration with Dr. Sonia Fertuzinhos
- Participation in ED 9<sup>th</sup> Pan European Conference
- Two members attended the Advocacy Training Course

### Activities for 2010

- Contacting all Portuguese MEPs with 60% responding to the request to sign the Declaration on breast cancer
- Participation in the Skeletal Care Academy congress in Paris
- Awareness presentation on breast cancer to young people



# Strength in Numbers

## Romania

### Highlights of 2009

- Organisation of three media campaigns (press, TV, radio and outdoor advertising in 13 Romanian localities), including participation in TV and radio debates
- Traditional “Art for Life” Gala in April under the patronage of the French Ambassador, with artists, journalists, diplomats, politicians, business people and physicians
- On 1 October, pink illumination of a historical building in Bucharest as well as the Oncological Institute of Bucharest, receiving wide TV coverage. Nine other cities took part in the initiative. Many high-profile people were involved
- An awareness event on 15 October, where pink bracelets were handed out
- Meetings with national and European parliamentarians resulting in 15 Romanian MEPs signing Written Declaration no. 71/2009
- Successful co-operation with the media through TV appearances
- Promotion of the Breast and Cervical Mobile Diagnostic Unit by the local TV stations and newspapers

## Slovenia

### Highlights of 2009

- Publication of quarterly “ED News”
- Publication of book “Nutrition and Cancer”
- 28 lectures country-wide on breast cancer, healthy lifestyles and self-examination training
- Counselling by telephone, personally, e-mail, visiting patients at hospital
- 2-day consultation for laypersons “Novelties in Breast Cancer Treatment”
- Numerous activities in October
- Awareness-raising campaign for secondary school students “Pink is not Just a Pose”
- Traditional “Running and Walking for Hope” in Ljubljana, Maribor and Dolenjske Toplice
- Hospital workshops: clay modelling, painting, jewellery, yoga
- Two outings for patients

### Activities for 2010

- Emphasis on psychosocial support and holistic rehabilitation
- Prevention and treatment of lymphoedema
- Counselling by phone, e-mail and personally
- Workshops for patients
- Seminar on follow-up in reconstruction
- Publication of ED News
- Running for hope
- Outings for patients
- CD on meditation: health and vitality

## Spain

### Highlights of 2009

- Participated in the Breast Health Day campaign with interviews and dissemination of press release
- Annual Breast Cancer Day to promote participation in breast cancer screening in Spain
- Distribution of materials for annual Breast Cancer Day

### Activities for 2010

- Served on the National Organising Committee for EBCC-7 in Barcelona
- Contacted Spanish MEPs and encouraged them to sign the EU Written Declaration
- Posted Declaration information on website
- Restructuring of ED Spain with new representation

## Sweden

### Highlights of 2009

- Pink Walk “Rosa Steget” on 15 August in Gothenburg
- Lobbying on local and national political level
- Co-hosting of the 9<sup>th</sup> ED Pan European Conference in Stockholm
- Holding numerous Pink Ribbon activities and awareness campaigns throughout the country during October in the 33 local organisations
- Annual award for excellent achievements in breast cancer treatment, care and awareness
- Award for the Swedish Breast Cancer Nurse of the year

### Activities for 2010

- Pink Walk “Rosa Steget” on 14 August in Gothenburg
- Survey of Sweden’s mammography and breast cancer units investigating to what extent they reach the targets recommended in the EU guidelines
- Survey of the 11,000 members treated for breast cancer, focusing on issues of quality of life, treatment and care
- Breast Health Day activities

## Switzerland

### Highlights of 2009

- Official launch of the ED “Short Guide to the EU Guidelines” in three of the four national languages, including a press conference at the Semper-Observatory in Zurich on 31 October
- Breast Health Day in Lausanne
- Acceptance and start of implementation of a mammography screening programme in the canton of St Gallen, making it the first German-speaking canton to adopt such a programme
- Acceptance at a political level of a screening programme in the canton of Graubünden

### Activities for 2010

- “Crossing Canton Borders” working group to join several cantons in order to introduce one single mammography screening programme in Ticino and Graubünden; St Gallen and Thurgau hopefully
- “How to Obtain Information on Breast Cancer Centres” working group
- Breast Health Day

## Turkey

### Highlights of 2009

- Lobbying in support of a nation-wide mammography screening programme with main goal of public awareness
- Participation in EBCC-7
- Presentations on breast cancer awareness and a panel discussion on doctor-patient communication at National Breast Cancer Congress in Istanbul
- Participation in Cancer Patients Platform Conference
- Supporting sales of traditional calendar
- Participation in the International Women of Istanbul Christmas Bazaar with gift items provided by Board Members, and donation of free mammography to visitors

### Activities for 2010

- Lectures on breast cancer awareness at Rotary Club meetings and in local municipalities in and around Istanbul
- Organisation of Mother’s Day Panel with participation of a medical oncologist, a breast surgeon and a radiation oncologist
- Meeting with the head of National Cancer Organisation to propose distributing Turkish “Short Guide to the EU Guidelines” to public health specialists
- Patient seminars on breast cancer and infertility, and patients’ rights

## Ukraine

### Highlights of 2009

- Global Illumination Initiative and awareness campaigns in October
- Illumination of the Ukrainian House in the Kiev city centre during the week of 20 October, the Ukrainian Day against Breast Cancer. Volunteers handed out leaflets
- Development of a website ([www.antirakinfo.org](http://www.antirakinfo.org)) providing information on breast cancer in Russian, implemented through a grant from Susan G. Komen Foundation. Information and awareness campaigns can increase the participation in screening and early breast cancer detection in Ukraine, where less than 2% of women over 40 have a yearly mammogram and 30% of the 16,000 women diagnosed every year are diagnosed too late. About 20% of women diagnosed with breast cancer die during the first year
- Fundraising programmes to increase access to modern mammography equipment. Thanks to such

programmes, two mobile mammography units are operating in the Cherkassy rural area and Autonomic Republic of Crimea

### Activities for 2010

- Planning of information campaign for October 2010

## United Kingdom

### Highlights of 2009

- The future of breast screening services in the UK and across Europe was the discussion topic at a symposium hosted by the UK Forum in January 2010. “Breast Screening: What of the Future?” included presentations from internationally renowned breast cancer experts. The event attracted a distinguished audience including the ED President, patients, doctors, nurses, advocates and researchers
- Involvement in a number of parliamentary events during the year including the Britain Against Cancer conference

### Activities for 2010

- To take forward the outcomes of the breast screening symposium discussions and to promote and support appropriate breast screening
- To support equality of access to optimal breast cancer treatments
- To engage the ED UK Forum membership through the Voice newsletter and email updates
- To support ED Head Office initiatives and to promote them in the UK as appropriate

## Uzbekistan

### Highlights of 2009

- Launching of activities by public association “Women’s Council”, with the creation of the group “In the Name of Life” for women with breast cancer
- Holding an international forum bringing together officials of state organisations, NGOs, business people and medical institutions. Specialists from USA, Europe and Asia participated
- Becoming the 44<sup>th</sup> member of EUROPA DONNA
- Social campaign aimed at screening, prevention and diagnosis as well as fundraising. It enabled 2,649 women nation-wide to consult leading breast care specialists, and 132 socially vulnerable women to receive chemotherapy. Information kits and brochures on breast self-exam were distributed and pink ribbon accessories were sold

### Activities for 2010

- Fundraising campaign to implement programme for prevention, early diagnosis, treatment of breast cancer and rehabilitation
- Charitable Forum-Marathon to raise funds for chemotherapy
- Tashkent International Breast Cancer Forum
- Gala concert dedicated to Breast Health Day



# Advocacy Album



EUROPA DONNA members from many of the Coalition's 45 member countries gathered in Barcelona at EBCC-7, where in addition to participating in scientific sessions, they shared experiences at the General Assembly, at a reception hosted by the Coalition and at the EUROPA DONNA stand.



# What's new

The new EUROPA DONNA Brochure was published and replaces the old pink membership brochure. The new brochure gives a brief background of ED's history, 10 goals and priorities. It also features a short description of the *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* and ED's *Guide to Breast Health*.

The *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* is now available in 11 languages (Dutch, French, Georgian, German, Greek, Italian, Polish, Russian, Spanish, Swedish and Turkish).

# What's on

## EUROPA DONNA Breast Cancer Advocacy Leader Conference\*

Reducing Health Inequalities and Fostering Healthy Ways of Life  
25 September 2010 – Milan, Italy

## Breast Health Day 15 October

The aim of the day is to disseminate information concerning breast health and to raise awareness of prevention and early detection of breast cancer among women and girls across the globe.

This year's campaign "Breast health is up to you" will remind women that engaging in physical activity, maintaining a normal body weight and eating a healthy diet can help protect their breast health. A digital campaign including a viral video and widget, as well as social networking sites such as Facebook and Twitter, will encourage women across the globe to make responsible daily choices for their breast health.

For more information see [www.breasthealthday.org](http://www.breasthealthday.org) 

\*This conference arises from the project "ED Breast Cancer Advocacy Leader Conference" which has received funding from the European Union, in the framework of the Public Health Programme.



## 9<sup>th</sup> Annual EUROPA DONNA Breast Cancer Advocacy Training Course

12–14 November 2010 – Milan, Italy

Some highlights of EUROPA DONNA's annual course include:

- Overview of ED mission, priorities and programmes
- Basic biology of breast cancer and genetics
- Epidemiology, prevention and risk factors
- Clinical trials
- Treatment of breast cancer
- Mammography screening guidelines and screening in Europe
- European guidelines on specialist breast units
- Psychosocial services for breast cancer
- Advocacy and lobbying techniques
- Media and communications skills training

## 3<sup>rd</sup> IMPAKT Breast Cancer Conference

5–7 May 2011 – Brussels, Belgium

## 10<sup>th</sup> EUROPA DONNA Pan European Conference

22–23 October 2011 – Malta

# In box

Do you have an opinion or news you wish to share?

Let us know

[info@europadonna.org](mailto:info@europadonna.org) 



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 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 European Union.

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