Conference highlights from EBCC-8

Answering the advocates: Giuseppe Viale on pathology and patient care plus Julia Rowland on survivorship

A survivor tells us about the positive changes breast cancer has brought to her life

News on Breast Health Day and forum support

The year’s European policy activities

Reports from member countries
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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In-box
The EUROPA DONNA Executive Board began the year with a brainstorming session on the future of ED before our first board meeting in January. The purpose was to start thinking about a strategy for the next 3–5 years. **Strategy planning** is a way to keep any organisation up to speed with regard to its incentives. The ED brand needs to be seen and known for our organisation to be able to reach its goals.

One of the great challenges for ED is the vast difference between national health care systems and governmental financing of breast cancer services. With 46 national member fora, ED is aiming to achieve **best practice**. Ensuring the spread of such standards is a clear aim for advocacy work throughout our member fora. We discussed mentorship and forum support, and possible expansion beyond Europe. The latter issue arose from a discussion with Prof. Umberto Veronesi, in which he suggested that ED provide expertise to groups outside Europe. The Board will continue to look for opportunities to raise awareness of the importance of collaboration on a wider scale to get our messages across and make a difference in the fight against breast cancer.

I was invited to speak at the **International Congress of Breast Disease** in Paris in February, where the topic for ED was our view on specialist breast units. That was a very welcome opportunity as we had recently received a message from the European Commissioner for Health and Consumer Policy, John Dalli, who was also the keynote speaker at our 10th Pan-European Conference in Malta. ED had been urging the European Commission to move forward with a project to develop a **European protocol for specialist breast unit accreditation**. We have now been informed that €3.5 million has been allocated for this project, which is going to be carried out by the Joint Research Centre of the European Commission. To have quality assurance of EU standards for specialist breast units will mean that women will have access to accurate, up-to-date information about which units comply with these standards. This will be equally important as a tool for advocacy and for pushing for improvement.

The **8th European Breast Cancer Conference (EBCC-8)** in Vienna was a huge success from an advocacy/patient perspective with the organising committee having more input in the programme, roundtable discussions with advocates, science and industry, and a large number of advocates attending. The Lay Public Programme attracted the general public and many advocates, thanks to the Vienna Cancer Centre and our newly launched Austrian forum of ED. Each successive EBCC seems to show better involvement of advocates, which also means that we are getting messages across and our voices are being heard.

We are also involved in ongoing work for our **Forum Support Project** to help fora with different issues. Such issues can involve networking, and ED board members contacting and meeting people from inactive countries to get activities started again. The engagement of all our board members has been very important in solving the problems that are faced.

At our upcoming **ED Advocacy Leader Conference** in September, I really do hope to meet all of our National Representatives and National Delegates. There will be important information presented by a leading health economist on health technology assessment (HTA). HTA is a subject that I strongly believe that we as advocates need to be familiar with when seeking to achieve the best diagnosis and treatments for breast cancer. At the conference we will also use our new booklet on understanding and reading research reports. I look forward to meeting you all there and to taking advantage of the many opportunities to share inspiration and ideas about the future development of our Coalition.

“We are getting messages across and our voices are being heard”
Research remains a key priority for ED. This year we have entered into a new agreement with BIG (Breast International Group) to provide patient advocacy input into several projects: in addition to our participation on the MINDACT Steering and Legal/Ethics Committee, we will contribute to the informed consent forms for the BIG-North American Breast Group (NABG) Genomics Working Group and the BIG Headquarters (HQ) Biobanking Working Group. In September, we also provided the advocacy perspective on clinical trials at the new Programme for Oncology Leaders in Europe (POLE) Initiative, developed by the European School of Oncology (ESO), Bocconi University in Milan and Novartis Oncology Europe to educate the medical leaders of the future.

Ensuring that information is accurate and up to date is essential and remains one of our key goals. To this end, we have published a revised Clinical Trials and Breast Cancer booklet, a new brochure about ED, and have created a new booklet on understanding and reading research reports. The Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis is now available in 13 languages – Portuguese was a new addition this year, and all are available on our website. Furthermore, we have added an area to our website where country publications can be shared, as many of our national groups have developed materials that could be relevant for other countries.

Our Breast Health Day (BHD) campaign is now in its fifth year and many more countries and people are participating. A new and unique digital video supporting our healthy lifestyle messages is available on YouTube, Facebook and our website, along with updated material from the EBCC-8 presentation by Isabelle Romieu of the International Agency for Research on Cancer. We were invited to provide an overview on this key prevention programme at the European Partnership for Action Against Cancer (EPAAC) Open Forum held in Rome on 20 June and will hold our annual BHD Information Day at the European Parliament on 10 October.

As we complete our 5-year Strategic Plan in 2012, we are now embarking on a new strategic planning process that will be reviewed and agreed upon in 2013. We are making significant progress in an environment that is becoming more and more complex. Together with our partners and collaborators, our Coalition, now consisting of 46 member countries, is meeting the challenge and continues to make a difference in the fight against breast cancer.
As the only conference of its kind to bring together patient advocates and major breast cancer institutions in one arena, the 8th European Breast Cancer Conference (EBCC-8) held in Vienna, from 21–24 March welcomed more than 3,800 participants from 98 countries. EUROPA DONNA – The European Breast Cancer Coalition hosted the conference in partnership with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA). On various occasions the scientific organisers emphasised how the participation of EUROPA DONNA as a patient advocacy organisation lends to the uniqueness of EBCC, a conference that researchers are increasingly choosing as a venue to release new study findings.

Before a full house in the opening session, EUROPA DONNA Past President Bettina Borisch reiterated the message of hope conveyed in the book *The Year of the Pale Sunflower*, whose project leaders she presented with the EBCC Arts and Humanities Award. The book was the result of a project initiated by six women from EUROPA DONNA Switzerland, based on their experience of being diagnosed with breast cancer when their children were young. The award is given at every EBCC based upon nominations from EUROPA DONNA Fora.

Renowned breast surgeon Alberto Costa, who is the Director of the European School of Oncology and a long-time supporter of EUROPA DONNA’s advocacy activities, received the European Breast Cancer Science Award for his contribution to multidisciplinary breast cancer care and education. He gave an overview of his more than 30 years of experience as a breast surgeon and the positive changes that multidisciplinary teamwork has brought to breast cancer care. He encouraged women and advocates to insist that breast cancer surgery be performed according to the highest standards.

As the conference itself may be seen as a form of multidisciplinary teamwork, at the closing session, Prof. Borisch also reminded delegates of the need for further advocacy for mammography screening and specialist breast unit implementation: “We know that in breast units, team work is essential, but it is not easy. A European specialist breast unit accreditation scheme must be implemented so that patients know where they can go for optimum care.”

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

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**8th European Breast Cancer Conference**

**The Utmost in Multidisciplinary Working**

**21-24 March 2012, Vienna, Austria**

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**Among the headlines**

- A 20-year follow-up study shows national mammography screening programme saves lives
- Using ultrasound to guide surgery for palpable early-stage breast cancer helps in removing the entire tumour
- Outcomes are better when surgeons perform a higher number of breast surgeries
- Minimal alcohol consumption, avoiding obesity, eating a low-fat, high-fibre diet and avoiding sweet drinks could help to reduce breast cancer risk
- Overweight and obesity are associated with risk of breast cancer recurrence
- Physical activity and cognitive behavioural therapy help to decrease treatment-related menopausal symptoms
- Pregnancy may be protective after breast cancer
- Women with metastatic breast cancer should be treated by a multidisciplinary team within a specialist breast unit
**The News on screening and specialist breast units**

**A long-term look at screening**

Presenting the 20-year results (1990-2009) from the Dutch national breast cancer screening programme, Jacques Fracheboud from Erasmus University Medical Centre said that the programme has contributed to a decrease in breast cancer mortality, and that its benefits outweigh all the potential negative effects. In 1989, the programme began implementation for women aged 50-69; the age limit was extended to 75 starting in 1998; and the transition to digital mammography began in 2004. When compared with the pre-screening period, breast cancer mortality among women aged 50-75 had decreased by 31% in 2009. Overdiagnosis was limited, overall participation was 80%, and the total annual cost of the programme in 2009 was €51.7 million or €56.65 per examination.

From the same study group, H.J. de Koning recommended extending the upper age limit for screening to 75. He said that screening was associated with an 80% reduction in risk of dying from breast cancer in women aged 70-75.

Another Dutch study has shown that screening combined with adjuvant therapy reduced breast cancer deaths by more than 27%. Presenting the results of a model simulation, Rianne de Gelder from Erasmus University Medical Centre estimated that in 2008, adjuvant treatment reduced breast cancer deaths by almost 14%, while biennial screening in women aged 50-75 reduced this by almost 16%. The researchers also predicted that 10 additional screening rounds in women aged 40-49 could lead to a further mortality reduction of more than 5%.

**Special issues in specialist breast units**

Genetic counselling should be offered as an option to women in specialist breast units. Olivia Pagani of the breast unit in Southern Switzerland said that the decision to undergo genetic counselling must not be forced and that all options must be discussed. In a study at her centre, Dr. Pagani said that depression and anxiety were not increased in women going through the process. In fact, she cited a study showing that depression was greater in women declining the test than in those tested and found to be carriers or non-carriers of genetic mutations.

The First International Consensus Guidelines for Advanced Breast Cancer (ABC 1) based on the first conference by this name held in November 2011 (Breast 2012;21(3):242-52) indicate the unanimous expert consensus that metastatic breast cancer (MBC) must be managed by a multidisciplinary team. Olivia Pagani said that treating women with MBC in an advanced breast cancer unit has the advantage of being able to offer care of symptoms, quality of life and psychosocial support, as well as the potential disadvantage of causing a feeling of neglect or a sudden change in status. She said that an effort must be made to avoid marginalising women with MBC and to give them hope and strength.

Minimum standards for specialist breast nurses need to be implemented across Europe. Eva Gustafsson from Karolinska University Hospital in Sweden presented the European Oncology Nursing Society (EONS) Post-Basic Curriculum for Breast Cancer Nursing and said that collaboration between professional organisations, patient groups and politicians could help achieve these standards.

**Advocating for the needs of women with metastatic breast cancer**

EUROPA DONNA Executive Director Susan Knox chaired a special EUROPA DONNA session that aimed to specifically determine what aspects of MBC care need to be included in the upcoming 5th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. This is to ensure that women with MBC receive care within an appropriate specialist breast unit as specified in these guidelines and that their psychosocial needs are met. An informal ED survey and other studies have clearly identified that women with MBC are underserved in terms of being cared for in specialist breast units, by multidisciplinary teams including breast care nurses, having treatment guidelines, registry statistics, and are also underserved by support groups. In an EBCC-8 interview, Susan Knox said, “Women are living much longer now with this disease. This is important for the public to understand, but more than anything to understand that they have the same needs for outstanding, standardised state-of-the-art treatment as women with primary breast cancer.”
A glimpse at the latest scientific findings

Using ultrasound during surgery is better in the long run

In a late-breaking abstract session, Nicole Krekel of the University Medical Centre in Amsterdam, The Netherlands, showed that the use of ultrasound-guided surgery of palpable early-stage breast cancer led to a significant decrease in re-operations, mastectomies and extra radiotherapy, compared with palpation-guided surgery. The researchers found that when surgeons undertook breast-conserving surgery with the help of ultrasound, almost 97% of the tumours were removed with tumour-free margins, compared with just over 84% of those removed based on touch alone. A smaller amount of tissue was also removed when ultrasound was used.

Avoiding fragile bones

In a EUROPA DONNA Teaching Lecture on bone fragility in women treated with aromatase inhibitors (ARIs), Prisco Piscitelli from the University of Florence, Italy, discussed the importance of protecting bone health in women taking these drugs. Increased bone fragility and risk of bone fracture is one of the main side effects of ARIs. He said that before undertaking drug therapy to prevent bone loss, physical activity, calcium and vitamin D intake are recommended. As a co-author of a recent position paper by the European Society for Clinical and Economical aspects of Osteoporosis and Osteoarthritis (ESCEO), he outlined the target populations for treatment according to the ESCEO guidance. All women with osteoporosis, those aged 75 or older and those with a specific bone mineral density score should be medically treated throughout their ARI treatment (Rizzoli, R. Osteoporos Int 2012; Jan 20).

Breaking down the barriers

In a session entitled “Barriers to Effective Care,” François Taban of the Private Geneva Breast Cancer Network in Switzerland reported on a study showing that surgeon caseload is directly related to quality of care and specific mortality among patients with breast cancer. Using data from the Geneva Cancer Registry, his group compared 11 quality indicators in 595 women operated on by a surgeon with a high (10 or more cases/year) or a low caseload (< 10 cases per year). When the two groups were compared, women operated on by a high-caseload surgeon had a lower risk of dying of breast cancer. In the discussion, however, the definition of 10 cases per year as being a “high” caseload was put to question.

The session was chaired by EUROPA DONNA Past President Bettina Borisch, who also presented the advocacy perspective. She discussed some of the barriers to implementation of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis, citing structural and organisational hindrances, cultural barriers, bureaucracy and professional “tribalism”, to name a few.

New trastuzumab formulation may be more convenient

In what was named “best abstract” in the late-breaking abstract session, Christian Jackisch of Klinikum Offenbach in Germany presented phase III results establishing non-inferiority for subcutaneous trastuzumab versus the standard intravenous formulation of the drug. Although the implications remain to be determined, the findings suggest that there may be a more convenient, time- and resource-saving method of administering this drug that is the standard of care for women with HER2-positive breast cancer.

Pregnancy may be protective after breast cancer

Pregnancy after breast cancer has been shown not only to be safe, but to have a protective effect within the first 2 years of breast cancer diagnosis, although a clear trend was not demonstrated over time. In the first study to examine the safety of pregnancy after oestrogen receptor (ER)-positive breast cancer adjusted for selection bias, Hatem Azim of the Jules Bordet Institute in Belgium reported no differences in disease-free survival in pregnant women compared with non-pregnant women for both ER-positive and -negative disease. He concluded that pregnancy, which was formerly thought to be a risk for recurrence, should not be discouraged regardless of a woman’s oestrogen receptor status.

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News about
EUROPA DONNA advocacy priority areas

Preventing breast cancer through healthy lifestyles

In a well-attended, early morning EUROPA DONNA Teaching Lecture, Isabelle Romieu, Head of the Section of Nutrition and Metabolism at the International Agency for Research on Cancer, outlined the lifestyle factors that could help in preventing breast cancer. This is the focus of EUROPA DONNA’s annual Breast Health Day campaign, which was presented by Susan Knox, ED Executive Director. In her talk, Dr. Romieu said that research is now targeted at identifying the subgroups of breast cancer types that could benefit from certain lifestyle interventions. She reiterated that minimal alcohol consumption, avoiding obesity, eating a low-fat, high-fibre diet and avoiding sweet drinks could help to reduce breast cancer risk.

**Alcohol**
Dr. Romieu said that most studies show an increased risk of breast cancer of 3-9% for an additional drink per day (10 g), for all types of alcohol. The cumulative effect of drinking 3-6 drinks weekly is associated with a 15% increased risk, while binge drinking six or more drinks in a day has a 33% increased risk. Dr. Romieu said that the increased risk is mostly for oestrogen receptor positive tumours and that a potential mechanism behind this is the effect of alcohol on circulating oestrogens, among others.

**Nutrition**
Dr. Romieu explained that there may be a link between breast cancer and the insulin pathway. She presented recent nutrition-related findings from an 11-year follow-up of the EPIC study indicating that women with the highest carbohydrate intake had an increased breast cancer risk of 40%. The risk was reduced with high consumption of fibre from vegetables, and women with both a high-fibre and low-fat diet had an even lower risk. She added that although some studies have shown no clear evidence of a role of fatty acids on breast cancer, a meta-analysis indicated a possible protective effect of omega 3. A recent study in Mexico found this to be true among obese women. A French cohort of the EPIC study also showed an increased risk with the intake of trans fatty acids, which are found in processed foods. Another French cohort in the EPIC study found a protective effect of vitamin D. High dietary folate intake (≥ 1272 dietary folate equivalent/day), found in green leafy vegetables, was also associated with a 22% decrease in breast cancer when compared to women consuming ≤ 345 per day. Folate had a larger effect on oestrogen receptor negative breast cancer. A prudent dietary pattern, rich in fruits, vegetables, fish, low fat dairy and fibre, has also been shown to have a beneficial effect. In a 26-year follow-up of the Nurses’ Health Study, having a high vegetable, low carbohydrate diet was protective, particularly for oestrogen receptor positive disease, with a decrease of 29%.

**Weight**
Dr. Romieu added that overweight and obesity are a particular concern in postmenopausal women, in whom it leads to a 30-40% increased breast cancer risk. Gaining weight (10-30 kg) in adulthood doubles the risk, particularly in postmenopausal women with hormone receptor positive tumours. Research is also looking into whether the type of fat has an influence. In premenopausal women, while body mass index (i.e., global fat) is inversely related to premenopausal breast cancer risk, waist circumference and waist-to-hip ratio (i.e., abdominal fat) has a positive association.

**Physical activity**
Dr. Romieu cited further data from the EPIC study indicating that there is a decrease in oestrogen level with increasing amounts of physical activity. Moderate physical activity has been shown to reduce breast cancer risk by 15%; 2-3 hours per week is associated with a decrease of 9%, and more than 6 hours weekly with an 18% reduction.

**Window of exposure**
There is also research into the time of life at which women are exposed to the risk factors. Prior to puberty and just before a first pregnancy appear to be time of highest influence. Fat intake during adolescence has been associated with a 35% increase, and red meat consumption with a 34% increase in risk of premenopausal breast cancer.

When asked if she could make one recommendation, Dr. Romieu suggested avoiding sweet drinks.
Lifestyle in secondary prevention: a debate

Lifestyle was also the topic of a lively Oxford Debate, this time regarding breast cancer recurrence. Arguing in favour of the statement “This house believes that breast cancer oncologists must prescribe lifestyle changes more than drugs”, Anthony Howell of the University Hospital of South Manchester, UK, said that treatment should target the “host” not only the tumour, since the host feeds the tumour systemically. He showed how obesity can have detrimental effects for breast cancer at various phases: being obese at diagnosis can increase the risk of breast cancer recurrence; being obese is associated with a higher risk of breast cancer relapse; and mortality is higher in women who gain weight after surgery for breast cancer. He added that chemotherapy in itself can cause weight gain. In a breast cancer study in 34,000 women, losing 5% of their body weight proved beneficial in secondary prevention.

As a seconder to the argument, Wolfgang Janni of the University of Dusseldorf, Germany, gave data from the Nurses’ Health Study showing that physical activity, such as walking more than 3 hours weekly, was associated with reduced risk of recurrence and death. He cited observational data in more than 50,000 women showing that the higher their body mass index, the greater their risk of recurrence and death. In the Women’s Intervention Nutrition Study, women with breast cancer were randomised to a lower fat diet or a control group. It was found that by reducing fat intake, the women lost an average of 2.3 kg, and there was a trend in disease-free survival of 2.9%. This survival effect was greatest in women with hormone receptor negative tumours. He added that it is important not to just treat the cancer, but to treat the patient.

In moderating the debate session, Bettina Borisch, EUROPA DONNA Past President, said that people must make healthy choices when they are available to them: “Public health is the duty of societies to create conditions and make them sustainable so that they allow people to lead a healthy life.”

Physical activity and cognitive behavioural therapy lower adverse effects of treatment

Both physical exercise and cognitive behavioural therapy (CBT) have been found to decrease menopausal symptoms and increase sexuality and physical functioning in women experiencing treatment-induced menopause. Marc van Buerden of The Netherlands Cancer Institute reported the results of the first study to examine the efficacy of these two interventions in this population. The study included 422 women with an average age of 48, who were randomly assigned to receive CBT therapy alone, physical exercise alone or a combination of the two. The cognitive therapy involved 90-minute weekly group sessions for 6 weeks, including relaxation exercises. The physical activity programme involved a self-directed, 12-week programme of 2.5-3 hours per week. The beneficial effects of these treatments were still apparent 6 months later.

Overweight and obesity linked to increased recurrence

Women who are overweight or obese at the time of their breast cancer diagnosis are at greater risk of recurrence and shorter overall survival than women with a normal body mass index (BMI). Jennifer Ligibel from the Dana Farber Cancer Institute in the USA presented the 11-year follow-up results of the CALBG 9741 study of 1,909 women with node-positive breast cancer who had undergone weight-adjusted chemotherapy. They found that about two-thirds of the participants were overweight or obese and that BMI was related to survival. At 10 years, the recurrence-free survival of a woman with a normal BMI was 71%, compared with 65% for one who was obese.

The journey after breast cancer

In a first ever session dedicated to “survivorship”, Julia Rowland of the U.S. National Cancer Institute said that with the large number of breast cancer survivors, research and attention must be focused on the issues concerning this population. EUROPA DONNA members Mojca Miklavčič and Ingrid Kössler then gave moving accounts of their personal experience with survivorship and advocacy. For more on survivorship, see page 10 for the Answering the Advocates interview with Julia Rowland.

Networking roundtables

About 50 advocates, scientists and industry representatives participated in an evening networking activity aiming to ensure patients’ needs are better reflected in the development of new treatments in clinical studies. Participants sat at different tables to discuss the topics of patient information, drug availability, imaging and diagnosis, translational research and oral compliance.

Mark your calendars

EBCC-9
19-21 March, 2014
Glasgow, Scotland
Giuseppe Viale is Professor of Pathology at the University of Milan and the Director of the Pathology Department of the European Institute of Oncology in Milan, Italy. He has also been involved in numerous translational research groups and clinical trials, and is the pathologist responsible for the central review of the tumour samples in the MINDACT trial (Microarray In Node-negative and 1–3 node positive Disease may Avoid ChemoTherapy). Answering the Advocates met up with him at EBCC-8, where he said that such conferences and multidisciplinary working help pathologists to understand how relevant their work is to patients and their treatment.

**EUROPA DONNA: The pathology report is essential to a woman’s diagnosis and the treatment she might receive.**

**Giuseppe Viale:** The pathology report provides information for the choice of systemic treatments. At the beginning of this century we began a new approach to breast cancer. The pathology report now has to include not only the established, classic parameters, i.e., the tumour size, grade, type, etc., but must include information that will inform the systemic treatment, namely the two most important markers, oestrogen receptor (ER) and HER2, as well as the progesterone receptor. We also normally look for the expression of a marker of cell proliferation, Ki67 antigen. Our final pathology report for breast cancer will include these four biological parameters. There are some issues to overcome with Ki67, due to lack of reproducibility among labs. In my own clinical practice and for my oncologists, having these four parameters is considered very important.

**ED: Are these widely used across Europe?**

**GV:** If you exclude Ki67, these would be done in the majority of centres in Europe. Based on these markers, I am convinced that we are able to inform the systemic treatment. However, unfortunately, still many candidate patients for a treatment will not respond to it. We are treating patients with trastuzumab, for example, but only a certain percentage of those will respond. This is where we have to accept that traditional and established markers in pathology are not sufficient enough to identify the responding patients. This is where I hope that the new more sophisticated and comprehensive assays will be of help. What these new molecular assays indicate is that beyond the traditional markers, we must have a more comprehensive view of the different biological pathways which drive tumour progression, i.e., prognosis, and those which drive responsiveness to therapy, i.e., prediction. We are now quite convinced that these assays give us a more comprehensive view of what is happening within the tumour cell. From a biological point of view, these assays are very interesting, but they still need the clinical validation of their predictive power regarding responses to treatments.

**ED: They are still considered experimental.**

**GV:** It is experimental. All these molecular assays have been designed and validated as prognostic assays. What we want is predictive information. So in order to assess and to validate clinically whether these assays have predictive power, we have to wait for the results of the ongoing clinical trials, either with the Oncotype DX®, which is one assay, or MammaPrint®, which is the other. Both of these assays are tested in randomised clinical trials to see if they can be used as a predictive assay. Unfortunately, we have to wait for the results of these trials before adopting these assays as additional tests for predicting response to the different therapies. Some countries may have been a bit premature in adopting these assays for the selection of the therapy for patients without waiting for the results of the clinical trials. In my country and in many European countries, I know that we are still waiting for the clinical validation. The question will be how useful they are, in which setting, and then there are additional questions to be addressed. How many patients will ever be able to afford the cost of these assays?

**ED: How expensive are they?**

**GV:** Currently, in the US the Oncotype would cost about $4000 and MammaPrint would be similar, at about €2600. This is nothing compared with the cost of therapy and the value of a human life, of course. If you can use it to select the patients more accurately, and those that are expected to respond, you can spend less. It may even be worthwhile from an economic point of view to have these new tests at our disposal. This is another issue.
ED: You are the pathologist responsible for the review of the tumour samples collected in the MINDACT trial, which uses MammaPrint. How it is progressing?

GV: More than 6600 patients have been enrolled. The recruitment is over and in the next 2–3 years we will have this piece of information on whether MammaPrint is better able to identify patients who will be able to be spared chemotherapy, as compared to the traditional pathological assessment. I will be responsible for the central pathological evaluation of these cases. The patients have been randomised to receive treatment according to MammaPrint or the traditional clinical pathology. We will see whether more patients benefited from the treatment according to one procedure or the other. This will be very interesting.

ED: The MINDACT trial involved sending frozen tumour tissue to Amsterdam. With tissue banking, what should women be aware of? What are the benefits?

GV: The main message should be that we know that every individual piece of information, the prognostic or predictive value, is hidden within the tumour tissue. We have to consider tumour tissue as a kind of treasure. We have some established markers, but then we have a universe of potential markers that still needs to be unveiled. I think that patients and everyone should understand that tumour tissue is the most important resource available for research. Tissue banking, in my mind, should be mandatory in all clinical trials because once we have collected samples from all the enrolled patients we can use them for further information, for translational research. It is very important. The patient should be happy to know that a piece of her tumour may foster knowledge and may create the opportunity to truly find new markers that will be very important for future patients and maybe also for current patients.

ED: What are the legal and ethical issues involved in this?

GV: Unfortunately, there are plenty of legal and ethical implications, but we know how to deal with those things in order to ensure the best use of the tissue, in the interest of current and future patients. We have to avoid any commercial implications. Banking should be an academic activity as opposed to a commercial venture. This material should be available for research purposes with a solid scientific background. These banks should always have a scientific committee or governing body that will decide whether a research proposal is good enough to use tissue, because it is a finite resource. If you use it, it is gone. The responsibility of the scientific community is to use this treasure in the proper way. In the cancer centres around Europe I think there is a good attitude to banking biological material. There should be a kind of network in Europe for coordination of banks and there should be a common protocol for storage and handling.

ED: In what regard to training of pathologists, do you think most pathologists in Europe are aware of these issues and the new methods? How high is the bar?

GV: Firstly, across Europe we are running short of pathologists. Pathology has been less and less attractive for young, clever doctors in the last 20–30 years. This is ridiculous these days because at the same time pathology has become a very interesting and important branch of oncology. Now we have the situation where more is requested from the pathology department and we have ever fewer resources.

The second problem is that the pathologist has to be aware of the role of pathology in the treatment of patients. For myself, it was only when I started working in a truly multidisciplinary setting, where the oncologists, the surgeons, the radiologists were discussing cases and exchanging ideas, that I started to realise the implications of the pathology report for the treatment of patients. Pathologists working in such an environment can easily understand what they are doing and why. The issue is that if pathologists are not aware of their role in the overall setting, why should they care about new biological assays when they do not know what the clinical applications of these assays are? This is a pity because these new assays will only be truly useful when they are integrated with the old assays in a more comprehensive approach.

ED: Are there any other issues in pathology that advocates should be aware of?

GV: I think that the advocates should, where necessary, help in having pathologists be more involved in multidisciplinary teams and in clinical trials. The pathologist must be involved in the design of the clinical trial. This will facilitate enormously the conduct of the trial, the banking of the tissue, the quality assurance. This would be truly a step forward. The advocates on the executive committees and the steering committees of the clinical trials could require that the pathologist be included. Another area is to promote the participation of pathologists in multidisciplinary scientific meetings. This would be another way to foster the involvement of the pathologist.

ED: In the end it is to bring the pathologist a little closer to the patient.

GV: If the pathologist is not aware of the importance of what he is doing for the treatment of patients, why should he try to be more accurate, responsible and faster? He has to see why what he is doing is so important.

Interview at a glance

- The pathology report should include the markers oestrogen receptor (ER), HER2, progesterone receptor (PR) and Ki67 antigen
- Clinical trials are ongoing for two new biological assays, Oncotype DX® and MammaPrint®, to determine their ability to predict response to treatments
- Tissue banking should be mandatory in all clinical trials
- Tumour tissue is the most important resource available for cancer research and its use should be governed by a scientific committee
- Pathologists should be included in the design of clinical trials, as well as in multidisciplinary teams and conferences
 Survivorship: looking at life after treatment

Julia Rowland

Dr. Julia Rowland is Director of the Office of Cancer Survivorship at the US National Cancer Institute. Trained in psycho-oncology, she has served as a clinician and researcher and published widely on women’s reactions to breast cancer, as well as on the roles of coping and social support in adaptation to cancer. Answering the Advocates spoke with her at EBCC-8 about survivorship and how advocates can take up this call in Europe.

EUROPA DONNA: What is the concept of survivorship? Do you know if there are offices of cancer survivorship in Europe?
Julia Rowland: I am not aware of other countries that have a specific, government-sponsored office of cancer survivorship, although the concept is growing worldwide. More and more clinicians, scientists and researchers are examining survivors’ post-treatment health and function. With respect to the origin of the word “survivor”, the founders of the National Coalition for Cancer Survivorship, an advocacy organisation, argued that we should think of someone as a survivor from the day that they receive a cancer diagnosis and onward. Their intent was not to label a person, but to convey hope for a future, and also ensure that initial treatment decisions included attention to life after cancer. The term evolved in the US, but in some European languages, a parallel word for “survivor” may not exist.

When our office was created in 1996, we defined “survivorship” as issues related to the time period after treatment, since that was the neglected scientific area. The public advocated for the creation of the office, calling for better data on the late-occurring effects of cancer and how to address them. More and more people are living long term with a history of cancer. In the US alone, as of 2012, there are 12.8 million cancer survivors, including 2.8 million breast cancer survivors. World-wide there are over 27 million survivors. To promote national attention to survivorship, you need enough people living long term after cancer to attract public attention; then you need vocal and effective advocacy so that this becomes a priority topic for support!

ED: Are any survivorship statistics available through cancer registries?
JR: We can generally obtain 5-year prevalence estimates – the number of people who have been diagnosed in the previous 5 years – but it is much harder to get complete prevalence, or the total number of individuals in a country alive with a history of cancer. Cancer registries only ascertain the number of people who are alive or dead at a given point in time. They actually don’t contact patients directly, but obtain this information from other data sources. We are pursuing efforts to create a platform to track a representative sample of survivors in person and systematically capture quality of life data.

ED: What are some of the issues that survivors face? They may have long-term effects of treatment, for example.
JR: We have learned that it is not over when it is over. Everyone is usually delighted when treatment ends, but the transition to recovery can be surprisingly difficult. Breast cancer survivors often receive weeks of multimodal therapies, with many supportive staff involved. Yet at the end of treatment a woman may feel at sea; there may be no information given on what happens now and when she might be feeling better. These practical concerns must be addressed as women re-enter their life after cancer.

Then there are the late-occurring issues. Survivors understandably worry if the cancer will come back, or about a second malignancy. Survivors do have a higher risk of other malignancies. This may be due to an increased risk genetically or to the treatments, environment or lifestyle behaviour, or simply getting older. Another concern is morbidity related to the treatment, such as cardiovascular or bone problems. As we study survivors we have been sobered by the fact that cure comes with a cost. It is both a human cost, as well as a medical cost, and all aspects of a person’s life can be affected.

ED: Perhaps by looking at this population it will help to better tailor and monitor the effects of new treatments.
JR: Absolutely. It is important to continue to conduct long-term studies of survivors, particularly since the treatments keep changing. We have an obligation to look at the long-term impact of new drugs on women. At the same time, now that we know about some common problems, fatigue for example, we can work to identify women who are at higher risk of developing chronic fatigue following treatment. We are now getting to the point where...
we can do risk profiling and, when possible, tailor treatments to reduce the risk of problematic side effects.

**ED: Are there many studies in people over the age of 65?**

**JR:** Older individuals tend to be excluded from trials because of worries about their co-morbid functioning and their capacity to tolerate the interventions. The irony is that the majority of people diagnosed with cancer today are 65 and older. About 40% of US breast cancer survivors are age 65 and over. And yet we are not developing trials – or survivorship research – to study that population.

**ED: You mentioned recurrence. Are there figures? How realistic is the worry?**

**JR:** Fear of recurrence is probably the most common, persistent effect of a cancer diagnosis. Interestingly, degree of fear is not necessarily related to the actual risk. That is an important dialogue for women to have with their oncologist: what is my risk? One of the challenges to making risk estimates, however, is that our tumour registries worldwide do not capture recurrence. We have good data on second or multiple malignancies, but not on recurrence. We are also seeing more women living with metastatic breast cancer. That is why those recurrence figures would be nice to have. We want to know who was diagnosed with earlier stage disease and who has now progressed to metastatic disease but is living long term.

**ED: Is there a way to determine why they are living longer and which women?**

**JR:** We are beginning to use our data to identify the people who live beyond predicted limits, who we wouldn’t have expected to be here and who are still here. We can learn from this group of individuals as well as those who surprise us by succumbing rapidly. We expect there are factors unique to each of those pathways.

**ED: Do you think health systems are equipped for the sheer number of survivors?**

**JR:** Survivors’ health is a mounting global issue. With the ageing of the world’s population, there are going to be more and more people in the system with a cancer history. The question is who is going to take care of these individuals? We have data showing that survival outcomes, at least for breast cancer survivors, appear equal whether they are followed by an oncologist or a primary care physician. The issue then becomes how to transition care after treatment. The challenge of co-ordinating care has led to a focus in the US – and increasingly abroad – on what we call “survivorship care plans”. This document, given to a woman at treatment end, provides details about her cancer and its treatment, what her unique follow-up care should look like and who will be responsible for this.

**ED: What may be some of the work-related and financial concerns affecting survivors?**

**JR:** There is no question that having cancer exerts an enormous economic toll. The impact varies depending on where a woman is in her life course and her financial resources. What has been interesting in breast cancer, particularly, is that because we now have better drugs to help with the nausea, vomiting and fatigue, women are healthier and more functional during active treatment. Many women remain in the workplace, and for the majority that probably works. There can be enormous benefits to being in the workplace, but it is not optimal for everyone. The important message for women is that if you are concerned about your loss of capacity to work or cancer’s implications on your finances, this is something that should be talked about with your healthcare team.

**ED: Are there any other data that we should know about?**

**JR:** Two things. First, the physical activity data are very provocative. Women ask what they can do to stop the cancer from coming back. There is some very practical advice: keep moving! It is not just a matter of better function; we are finding a survival benefit for people who remain active. The data are still observational, but they are impressive. You can improve your quality of life, reduce morbidity and potentially lengthen your survival.

Second, because of a tendency to focus on medical areas, we often neglect some of the psychosocial needs of the woman and her family members. In the US, one of the national hospital accrediting programmes now requires that certified sites screen women for distress and refer them as needed for psychosocial care. These evolving certification criteria, we hope, are slowly leading toward a more whole-person approach to care.

**ED: In the US, advocates had a pivotal role in having your Office of Cancer Survivorship established. Can you suggest what can be done in Europe?**

**JR:** It is important for women to be advocates, not only for themselves, but for the people coming behind them. It was breast cancer survivors who successfully demanded that Congress put more money into research. Such grassroots efforts can be effective in any country. Advocacy can be very simple, from volunteering at a clinic, right up to service at the political level, influencing governmental funding and resource allocation nationally. When you have women, 50% of the population or more, coming forward voicing their concerns, people listen!

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**Interview at a glance**
- There is a need for data on issues affecting survivors
- More studies are needed in women age 65 and older
- Cancer registries world-wide do not collect data on recurrence
- Women with metastatic breast cancer are living longer
- Survival outcomes appear equal whether follow-up is provided by an oncologist or a primary cancer physician
- Women should receive a written “survivorship care plan” at the end of their active treatment
- Physical activity can improve quality of life, reduce morbidity and potentially lengthen survival

To find out more: Office of Cancer Survivorship

http://cancercontrol.cancer.gov/ocs/
Living with Breast Cancer

A life changing experience

Dymphna Watson, Ireland

At age 43 I was living what seemed a good life, working hard, keeping fit and travelling regularly. Then I experienced a year that was to test me on many levels; my mother passed away suddenly and then my cousin was diagnosed with a terminal cancer. So, when I was feeling exhausted myself I decided to go for a health check-up. To my shock, I too was fighting for my life and facing my own diagnosis of breast cancer. Suddenly I was thrown into a whole new world of doctors, hospitals, surgeries, chemotherapy and radiotherapy.

I soon realised that I was very fortunate to have access to good doctors and treatment and wonderful support from my family and friends. Following my treatment, I was again fortunate to be able to take some time and rethink my life. I decided to take the opportunity to retire early from my job and enjoy life at a different pace.

I had worked for 25 years with Aer Lingus, the Irish national airline, in their Revenue and Human Resources departments, culminating with my role as Employee Assistance Programme Manager. Leaving the security of that large organisation was another huge change in my life.

Looking back, I now realise that it was such a time of major loss and adjustment for me, with so many of the things that I took for granted not there anymore. My mother died, I had lost my health and I left my job. Physically I was changed and really struggling with fatigue. I couldn’t play my beloved basketball, which had been such a big part of me, and my social life was now so different. All of this had such an impact on my self-esteem. I felt my life was changed, in so many ways, forever. And, vain as it sounds, I also had to accept that my appearance was different and not for the better!

But gradually I started to have new and positive experiences. I now had the time to do some of the voluntary work I had always planned to do and I became involved with several non-profit organisations. I volunteered with ARC Cancer Support Centre, in Dublin for several years. Through my breast care nurse, I became aware of EUROPA DONNA Ireland – the Irish Breast Cancer Campaign. I was invited to join the executive committee of ED Ireland in 2005 and I currently serve as Chairperson.

I never imagined that I would be on television, radio or feature in newspapers, but it has simply become part of my life through my involvement with ED Ireland. In 2006, I promoted the Fashion Targets Breast Cancer campaign on behalf of ED Ireland and in that year, I also represented Ireland in the Avon “Walk around the World” breast cancer campaign in both Ireland and El Salvador.

In 2008, I worked as the co-ordinator of the Open House Event run by the Irish Architecture Foundation and since 2009, I have been home-visit volunteer with St Vincent de Paul. Sometimes I am amazed at how my life has changed since my breast cancer diagnosis. I have so many more interesting and positive aspects to my life and the people around me now than I had before. In particular, I feel privileged to have encountered many strong and determined women.

Two years ago I was intrigued to hear that a very determined lady called Fiona Tiernan was setting up a dragon boat team in Ireland, the Plurabelle Paddlers – a breast cancer support team. With my love of sport, I joined up and am now not just a “paddler” but I am a fully trained and qualified helm and coach! We have already hosted our first and highly successful International Regatta and we have also travelled to Kuala Lumpur, Malaysia, where we won silver and bronze medals! Recently we have launched a dragon boating programme for schools to encourage teenagers to be active and exercise. I have great fun being a coach for this programme.

It is amazing to think back that when told I had breast cancer, I thought my life was over. Yes, the life I had was changed forever, but I could never have envisioned the many good and positive changes and experiences that have been brought into my life!
Making Our Voices Heard
Tools for Advocates

Breast Health Day – 15 October

The 2012 Breast Health Day campaign will focus on the theme “Make good choices for your breast health” in order to remind women that engaging in physical activity, maintaining a normal body weight and eating a healthy diet can help protect their breast health. A special poster and animated video demonstrating healthy lifestyle choices versus unhealthy options will be available on www.breasthealthday.org and via the social networking sites YouTube, Facebook and Twitter. The video will feature the slogan “For Your Breast Health” which will be translated into all ED fora languages. Women will also be encouraged to make a Breast Health Day pledge, such as “On Breast Health Day I will ride my bicycle to work.” Other activities this year include providing the latest data on healthy lifestyles and breast cancer prevention from the International Agency for Research on Cancer. A summary of the 2011 campaign was published in Breast Health Day News available on www.europadonna.org.

Some 220 breast cancer advocates and specialists from 37 countries gathered in Malta in October for a very lively EUROPA DONNA 10th Pan-European Conference. The European Commissioner for Health and Consumer Policy, John Dalli, was the keynote speaker and expressed the Commission’s commitment to breast cancer prevention, detection and treatment through supporting updates of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis and an accreditation scheme for specialist breast units. Participants also heard from experts on specialist breast units, breast nursing, advances in treatment, metastatic breast cancer, capacity building and fund-raising. Topic-specific workshops gave advocates the opportunity to discuss and share strategies. A highlights report on the conference has been widely distributed and is available on www.europadonna.org.

Forum Support
One of EUROPA DONNA’s main priorities is to support the initiatives of member fora.

ED Advocacy Leader Conference
EUROPA DONNA National Representatives and National Delegates will gather in Milan, Italy, for the Coalition’s second Breast Cancer Advocacy Leader Conference, which aims to provide up-to-date information and share best practice with advocate leaders in ED member countries. On the agenda will be topics such as health technology assessment, reading and understanding research reports and advocating nationally for women with metastatic breast cancer.

Sharing of Member Country Publications
A new section on www.europadonna.org provides links to publications created by ED member countries to facilitate the sharing of materials between ED fora. Members are encouraged to use this space to share their publications for use and translation by other ED fora.

Supporting Active Membership
Members of the ED Executive Board have actively been engaged in a mentorship programme to address issues in member countries when they arise and to reach out to representatives of inactive member fora to offer them support and help them resolve problems they may be facing.
Reaching Policy Makers and the Public

In 2012, EUROPA DONNA has continued its advocacy efforts to reach European policy makers and women about its foremost priorities of implementing mammography screening programmes and specialist breast units according to the EU guidelines, as well as accreditation of such units, across Europe.

European advocacy continues yearlong

2012 set off on the right track, with European Commissioner for Health and Consumer Policy John Dalli expressing the Commission’s commitment to setting up a European specialist breast unit accreditation scheme. It has been confirmed that this project will be conducted by the Joint Research Center (JRC) on behalf of the European Commission. Commissioner Dalli was the keynote speaker at the 10th EUROPA DONNA Pan-European conference in October 2011.

In November 2011, ED’s Policy Officer Karen Benn represented the Coalition at a meeting of the European Partnership for Action Against Cancer (EPAAC)’s Work Package 5 (WP5) Health Promotion and Prevention, in which ED is a collaborating partner. This meeting was primarily to discuss the contents of the 2012 European Week Against Cancer (EWAC) meeting, held in Rome on May 29 and 30. In June 2012, ED Executive Director Susan Knox gave a presentation about Breast Health Day to the Open Forum meeting of EPAAC under the auspices of the WP5 Health Promotion and Prevention work package. The Open Forum is held annually and brings together all the partners in EPAAC.

Earlier in the year, in February, both Susan Knox and Karen Benn attended the farewell reception of Liz Lynne, MEP, who has been supportive of ED’s European advocacy initiatives, at the European Parliament, where Ms. Knox gave a short presentation. They also took the opportunity to meet with other MEPs who are involved with breast cancer issues and ED’s work.

In April, Karen Benn attended the European Patient Forum (EPF)’s annual general meeting and seminar; the topic of the seminar was EPF’s strategic plan for the next 5 years and it gathered EPF members’ input on its strategic direction via plenary sessions and workshops. Ms. Benn moderated two such workshops for EPF. She will also be part of a reference panel that EPF has formed to review its evaluation processes for its 2012 EU Operating Grant.

ED was invited to be on the Advisory Board of the AURORA project, which is an EU-funded cervical screening project working with hard-to-reach populations in countries where screening is not yet fully rolled out. Karen Benn represents ED on this Advisory Board and attended a meeting in Timisoara, Romania, last year. This year’s meeting was held in Tallinn and ED participated by teleconference, giving input on the development of advocacy training modules for both practitioners and advocates.

On 10 October, ED will hold its annual Breast Health Day Information Day at the European Parliament. Representatives will also attend the European Cancer Organisation (ECGO) Oncopolicy meeting the following day.

Adding the advocates’ voice to discussions on research and funding

At a Clinical/Commercial Payer Forum held in Zurich, Switzerland, in May, ED Executive Director Susan Knox presented the patient perspective at a roundtable along with representatives of the European Organisation for Research and Treatment of Cancer (EORTC) and the pharmaceutical industry to discuss future research and funding/reimbursement issues. The event brought together about 75 people, representing pharmaceutical companies, health technology assessment (HTA) organisations, EUNetHTA, payers, and the European Medicines Agency to share strategies that may be beneficial in the future, especially in view of the current economic environment.

Ms. Knox pointed out how important it is for all bodies concerned to involve patients at the beginning of any new initiatives or processes to ensure that they are informed and can evaluate new research or other strategies from the outset with total transparency on the part of all parties. The issue of rising costs of drug development and the possibility of new types of research and evaluations are of interest to patients and consumers. However, it is essential that the resources be made available to train advocates so that they can provide expert input into these discussions.

In addition, Ms. Knox is attending an HTA conference in Montreal, Canada, on 26-27 August. This topic is becoming part of the ED advocacy agenda as all countries need to understand the role of HTA in making treatments available. Panos Kanavos from the London School of Economics is keynote speaker addressing this topic at the ED Advocacy Leader Conference in September.

Prof. Umberto Veronesi and Susan Knox at an event in Rome in December 2011 honouring the renowned surgeon 30 years since the publication of the Milan trials on breast-conserving surgery versus mastectomy. Susan Knox thanked Prof. Veronesi on behalf of all the women in Europe for having made such an important contribution to women and breast cancer care.
EUROPA DONNA has 46 member countries, including all 27 EU member states. In this section ED Fora share their past and planned activities.

Albania

**Highlights of 2011**
- Involvement in a self-support programme for women with breast cancer
- In December, participation in a Christmas bazaar in Tirana, with proceeds going toward painting and decorating the chemotherapy room at the Mother Teresa Oncology Hospital, a project continuing until March 2012
- Celebration of Women’s Day at the oncology hospital

**Activities for 2012**
- A project supporting women at the oncology hospital in Tirana, providing daytime support and help with coping, with the professional input of psychologists, social workers and doctors
- A Breast Cancer Awareness pilot programme at high schools in Tirana to inform and train girls about breast cancer. If the project is successful, it is to be expanded long term to other schools in Albania
- A project to support nurses at the oncology hospital to help them deal with stress issues, planned for 2013

Belarus

**Highlights of 2011**
- Presentation of the Belarus Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) report in Geneva and inclusion of mammography as an agenda priority for Belarus
- Mammography legislation accepted by the Ministry of Health and launching of a pilot programme
- Mammography assessment performed by a World Health Organisation expert team
- Women’s groups’ acceptance of breast cancer as a priority for women’s health
- Website support
- Participation in Eurasia advocacy conference in Vilnius

**Activities for 2012**
- Roundtable for mammography standards development, including breast unit multidisciplinary team meetings
- Women’s groups training and community outreach for promotion of mammography screening
- Attending the ED Advocacy Leader Conference
- Website support

Strength in Numbers

**Austria**

**Highlights of 2011**
- Reorganisation, restructuring and relaunching of ED Austria
- Establishing a new team
- Organising the Lay Public Day at EBCC-8
- Development of a vision/mission statement

**Activities for 2012**
- Implementation of a new management board
- Holding a successful Lay Public Day at EBCC with more than 150 participants
- A pilot project on the discharge package at Vienna General Hospital
- PR activities on television, radio and in newspapers
- Relaunch of the website homepage
- Focus on management of hospital discharge, public awareness and psycho-oncology

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- Attending the ED Advocacy Leader Conference
- Website support
Belgium

Highlights of 2011
• Publication of two issues of the newsletter and updating the website
• In May, a training session on the state-organised screening practice update
• In September, a roundtable with the Minister of Health on the Belgian screening programme
• In October, Breast Health Day events and a seminar on breast cancer prevention
• In November, participation in the ED Pan-European Conference
• In December, the general assembly of ED Belgium with election of a new president and new board members

Activities for 2012
• In March, a roundtable with the Minister of Health to develop a screening programme for high-risk women, as well as participation in the 50th anniversary celebration of EORTC in Brussels and attending EBCC-8
• In April, participation at radio RTL
• In May, attending the 10th anniversary celebration of ED Luxembourg, as well as holding a “Walk to Run” event
• In October, a press conference on the Belgian law on breast units, as well as Breast Health Day events, co-organising the Belgian Breast Meeting, holding Action Sein and Borst Actie (Breast Action), and launching the magazine Pink Ribbon
• In November, a patient day, as well as a concert to promote hospital concerts for cancer patients

Croatia

Highlights of 2011
• Daffodil Day nation-wide
• Pink Ribbon Day nation-wide
• Breast Health Day nation-wide
• In October, a general assembly with three lectures (primary prevention, early detection, treatment guidelines)
• Participation in the 10th ED Pan-European Conference
• Participation in the Advocacy Training Course
• Promotion of the EU Declaration on Breast Cancer
• Lobbying on local and national political levels for breast units
• Printing and distribution of leaflets on medical and psychosocial rehabilitation

Activities for 2012
• Daffodil Day nation-wide
• Participation in EBCC-8
• Participation in the 5th Congress of the Croatian Senologic Society
• Participation in the ED Advocacy Leader Conference
• Pink Ribbon Day nation-wide
• Breast Health Day nation-wide
• Participation in the Advocacy Training Course
• Translation of the “Short Guide to the European Guidelines” into Croatian
• Meeting with the Ministry of Health

Czech Republic

Highlights of 2011
• Seminars on accounting, lymphoedema and social aspects, with 60 attendees
• Two public seminars on psychological support for oncology patients, with 60 attendees
• Prevention materials, self-examination leaflets
• “Pragomedica” medical fair and exhibition in Prague
• In May, a “You Can Also Do It” walk for patients
• In June, Avon Walk Against Breast Cancer, with 11,000 participants
• Purchase of 20 breast models and distribution to organisations
• Annual Patients’ Conference
• In October, a “We Swim the Breast Stroke” event in more than 13 locations, with 2,500 participants

Activities for 2012
• Educational seminars
• Annual conference
• Projects for patients’ organisations (e.g., “You Can Also Do It” and “Women to Women”)
• In June, Avon Walk Against Breast Cancer
• In October, “We Swim the Breast Stroke” event
• Distribution of educational materials
• Participation in oncological symposia and congresses
• Participation in EUROPA DONNA events
Denmark

Highlights of 2011
• Members’ meeting on sexuality and breast cancer
• Cancer and family members
• Employment rights for women with breast cancer, such as sick pay and sick leave

Activities for 2012
• A large conference on the latest in medical treatment and radiation therapy
• Follow-up on mammography screening programme for women 50-69 years of age

Estonia

Highlights of 2011
• Monthly meetings and lectures for advocates
• In May, annual Breast Cancer Awareness Month “Don’t Be Late”, with a press release, press conference, video clip and wide media coverage
• Run to promote healthy lifestyles
• In August, all-country patients’ annual summer camp at a seaside resort
• “Venus and Mars” charity concert
• In October, Breast Health Day activities

Activities for 2012
• Starting in January, a Health and Self-Help Project, including lectures, practical activities (painting lessons, knitting, etc.), two excursions to interesting country sites, theatre outings
• In May, Breast Cancer Awareness Month with a roundtable meeting with MEPs and health authority representatives about the screening programme, how to make it more effective and improve the attendance rate
• In June, a hike to a herb farm
• In July, patients’ summer camp at a lakeside resort
• In October, Breast Health Day and annual “Life and Love” charity concert
• In December, a patients’ Christmas party

Finland

Highlights of 2011
• Peer support activities, including 7 open meetings, 7 for young patients, 9 for patients with metastatic breast cancer in Helsinki, and 9 open meetings in Turku, plus 3 support group camp meetings
• Three public lectures
• Two issues of the magazine
• Co-operation with other patient organisations, hospital nurses, the Finnish Medical Association and the media
• Healthy lifestyle event in Helsinki
• Start-up for co-operation with the public health sector and Hospital District of Helsinki and Uusimaa
• Breast Health Day events in Helsinki and Turku

Activities for 2012
• Peer support activities in Helsinki, Turku, new activities in Tampere and 1-2 other locations
• Co-operation with other patient organisations, medical organisations (physicians, nurses and physiotherapists), the public health sector
• Four issues of the magazine
• Lobbying at the parliament, with a meeting with an MP in April and a meeting scheduled with the Ministry of Health
• Breast Health Day activities

France

Highlights of 2011
• Continued promotion of improving breast cancer screening, disseminating accurate information, supporting patients and advocating for specialist breast units
• Creation of a brochure on metastatic breast cancer by members of the ED France board and scientific committee with the help of patients, for distribution in oncologists’ offices and hospitals

Activities for 2012
• Assessment of activities and plans for the future with a view to creating a working plan to announce in the 2013 newsletter
• On 15 October, holding of the annual event at the French Senate

Georgia

Highlights of 2011
• Participation in a breast cancer conference organised by students and faculty at the State Medical University
• Holding of charity events, with the participation of breast cancer survivors
• Training sessions about self-examination and other related issues in Barisakho, a rural mountain region, including free breast exams
• A photography exhibition on surviving breast cancer and women who have been affected by the disease

Activities for 2012
• Articles about current problems in the country regarding breast cancer, its diagnosis and treatment facilities, and other issues, featured in two well-known magazines
• In February, placement of a donation box with the slogan “Save Women’s Lives” at the Tbilisi International Airport in order to collect donations for women who are in need and diagnosed with breast cancer
• Distribution of the booklet Breast Cancer is Not a Death Sentence to women patients at oncology hospitals
Greece

Highlights of 2011
• Encouraging breast health awareness
• Promotion of the EU guidelines to strengthen the importance of mammography screening and specialist breast units
• Active participation in the National Oncology Conference
• Participation in two meetings held by the Ministry of Health concerning the national cancer programme
• In June, taking part in National Cancer Survivors Day
• Awareness Rally for Breast Health Day

Activities for 2012
• Breast Health Day activities
• October activities including a meeting at the Greek parliament

Ireland

Highlights of 2011
• In April, an information stand at the Irish Breast Care Nurses Conference
• In May, the annual general meeting with a talk on specialist breast units and a Plurabelle Paddlers Dragon Boat Breast Cancer Support group update
• In September, stands at the Family Resource Centre’s National Seminar and the Irish Cancer Society national conference, as well as a talk at a local community centre and an article in Letterkenny Post newspaper
• In October, a talk on lymphoedema and another on Breast Health Day, with 20 groups around Ireland holding events for the day, including the ED Ireland lead walk and a trip on a dragon boat with the Plurabelle Paddlers

Activities for 2012
• A talk on pathology results and breast cancer
• Creation of an ED Ireland profile for Facebook and Twitter by a student group at a business school, with competitions for concert tickets
• Breast Health Day
• Involvement in review of the national screening programme
• Attendance at Ireland/Northern Ireland NCE – Cancer Consortium workshops
• Chairing several boards, on hospital pharmacy, radiographer registration and health technology assessment

Italy

Highlights of 2011
• Inclusion of data from ED Italy survey “Italians’ awareness of breast cancer” in a national survey requested by the Health and Hygiene Commission of the Italian Senate
• Enhancing relations with the ED Italia Parliament, with ED Italy counting on about 15 representatives between the Senate and Chamber
• Pursuing direct relations with regional institutions, particularly in Lombardy

Activities for 2012
• Meetings with the Health and Hygiene Commission of the Italian Senate and with the Superior Institute for Health, to encourage institutions to apply EUSOMA criteria regionally
• In June, an awareness event for the local population in Florence to involve authorities in Tuscany
• In September, attendance at a meeting organised by the Health Ministry with the main breast cancer associations
• In collaboration with the Italian Federation of General Practitioners and local patients’ associations, projects to raise GPs’ awareness of risk factors and to encourage local authorities to improve screening programmes

Israel

Highlights of 2011
• Pink illumination of Tel Aviv municipality
• Clips on “Onlife” portal with female opinion leaders encouraging women to “go get checked”
• Radio campaign to promote screening with a minute of airtime transmitted through the right-hand speaker, followed by the announcement: “That’s what losing one side feels like”

Activities for 2012
• Seminars for patients, survivors and their families, on metastatic disease and genetic mutation carriers
• An exhibition by graduates of a shoe and fashion accessories design school to promote breast cancer awareness
• A newspaper campaign, “Don’t turn your back on breast cancer” to increase screening awareness and promote prevention
• Breast Exam Day for MPs and parliament employees
• Providing assistance to purchase mammography screening equipment for an ultra-Orthodox hospital
• Training volunteer survivors to work with recently diagnosed patients

Activities for 2012
• Operation of a second mammography screening vehicle, based on previous success
• Ongoing activities such as seminars, support workshops, publication of information materials, and grants to promote breast cancer research
• Website updates, and forum questions answered by an expert
Kazakhstan

Activities for 2012
• Acting as goodwill ambassador for the Pink Silk Way to decrease the risk of breast cancer among women in Central Asia
• Working together with the Kazakhstan government for a national screening programme
• Having the National Programme for Oncological Care accepted and signed. The focus of the programme is implementation of screening for early diagnosis and provision of cancer therapy according to international standards
• Initiation of screening pilot projects to support women with breast cancer
• Participation in the ED Advocacy Leader Conference

Kyrgyzstan

Highlights of 2011
• Breast Cancer Patient’s School established, with more than 100 members
• Participation at exhibitions dedicated to International Women’s Day in March and a “Health, Sport and Beauty” exhibition in April
• The Breast Ultrasound Mobile Team examined 6147 women in pilot regions, detecting 12 breast cancer cases
• Development of several videos for Breast Cancer Awareness Month
• Creation of a handbook for women, “What do you need to know about breast cancer?”
• Pink October events
• A “Quality improvement of breast cancer diagnosis and treatment” workshop, with lectures by a US National Cancer Institute representative
• “Issues in Breast Cancer” symposium, with presentation of a model of breast cancer early detection and prevention

Activities for 2012
• In February, holding of a “For Life!” charity event
• Establishment of electronic registration system for cancer patients at the National Oncology Centre
• Awareness campaign “Life without Pain” to promote palliative care standards
• Pink October events

Latvia

Highlights of 2011
• For World Cancer Day, creation of a video to raise public awareness of the lack of breast prostheses, with 20,000 views on YouTube
• A project about NGO involvement in the decision-making process, run with EU support, and organisation of an international conference
• Three, one-week psychosocial rehabilitation camps in the summer, with about 60 participants
• Breast Health Day information activities

Activities for 2012
• Seminar cycle for GPs about psychosocial rehabilitation, with five seminars across Latvia to raise GPs’ awareness of the importance of rehabilitation
• Work with governmental institutions and co-operation with Health and Welfare ministries
• Involvement in international projects such as AURORA

Luxembourg

Highlights of 2011
• In July, a workshop co-ordinated by the Ministry of Health for breast cancer survivors and 35 doctors and nurses to discuss how to raise the quality of breast cancer care
• In October, a Breast Cancer Race, with more than 700 participants
• For Breast Health Day, an event at the Luxembourg Philharmonic to raise awareness of healthy lifestyles, as well as a film about a dragon boat event and a presentation on physical activity and breast cancer
• In December, participation in a meeting where the Ministry of Health presented the 2012-2015 roadmap for breast cancer care to hospital directors and those in charge of quality care

Activities for 2012
• In May, celebration of the 10th anniversary of ED Luxembourg, with an art exhibition “Toujours Femme”
• A “Breast Clinic Academic Day” with prominent international and national speakers and a Bossa Nova concert to end the celebrations
• In October, the 10th Breast Cancer Race
• A Breast Health Day event with an exhibition on the breast cancer treatment experience of foreign women living in Luxembourg, as well as a full week of courses on physical activity, culminating with a Zumba party and performances

Macedonia

Highlights of 2011
• Psychosocial support for patients by trained psychotherapists at the ED Macedonia office, twice weekly throughout the year
• An SOS line for psychosocial support of breast cancer patients, their friends and families
• Donation of wigs to breast cancer patients in need
• In May, “Go Pink” awareness-raising campaign
• 4th National Breast Cancer Conference
**Strength in Numbers**

- Breast Health Day activities
- In November, a “Pink Night” fund-raising campaign for new equipment for the university radiology and oncology clinic

**Activities for 2012**
- Donation of bras to women undergoing complete mastectomy and wigs to those undergoing chemotherapy
- Psychosocial support via the SOS line and within the ED Macedonia offices
- In May, “Go Pink” breast cancer awareness campaign

**Malta**

**Highlights of 2011**
- Hosting of the ED 10th Pan-European Conference
- Hilda Schembri Memorial public lecture on metastatic breast cancer
- Walk for awareness in Malta and Gozo
- Fashion show with the participation of breast cancer survivors
- Gala auction night
- Silhouette walk on Breast Health Day

**Activities for 2012**
- Quiz night
- Fashion show with the participation of breast cancer survivors
- Post-EBCC-8 seminar for health professionals
- Presentation of the book *The Year of the Pale Sunflower* to public libraries and the Health Minister
- Launch of a DVD on postoperative physiotherapy exercises for women

**Monaco**

**Highlights of 2011**
- In May, a charity lunch at the Monte Carlo Golf Club
- In December, a gala evening fund-raiser with a draw for prizes generously donated by shop owners, helping to fund ED Monaco’s activities
- A stand at the Christmas market on Quai Albert I displaying crafts made by patients and volunteers at the Wellness Centre

**Activities for 2012**
- On one Wednesday a month from February to June, a “tea time” in the “Espace Mieux Etre”
- In March, the annual general meeting, held prior to “tea time”
- Also in March, a song recital evening at the Princess Grace Theatre with proceeds going to ED Monaco
- In June, the traditional outing to “Cotton”
- In November, celebration of the 20-year anniversary of the organisation

**The Netherlands**

**Highlights of 2011**
- An advocacy training course for the first time for regional advocates
- The launch of the new magazine “B” for members of the Dutch Breast Cancer Society
- Quality criteria for breast cancer screening, diagnosis, treatment and aftercare from a patient perspective, designed for health care professionals and advocates
- “Monitor breast cancer care” used by most hospitals that deliver breast cancer services in order to improve services

**Activities for 2012**
- Further development of quality criteria for breast cancer services so the document can be used to further develop the “monitor breast cancer care” for all breast cancer service quality projects, including quality criteria for breast reconstruction, lymphoedema, improvement of quality in hospitals and collaboration with health insurance companies
- Surveillance of educational criteria, using the knowledge of breast cancer care combined with women’s experience
- Advocating for access to best practice care and diagnosis, e.g., access to new drugs
- Developing an opinion about waiting lists, and concentration of cancer care in special cancer hospitals

**Norway**

**Highlights of 2011**
- Local topic meetings, gatherings, physical activity events and trips by local associations, with almost 13,000 members
- A weekend gathering for women under 40
- A weekend gathering for health and relaxation with yoga/meditation
- A weekend gathering for women with advanced cancer and their partners
- A visitor service that has visited more than 900 newly operated women at 17 different hospitals
- Contact telephone helping about 170 women
- 1700 prostheses given to women postoperatively
- A Pink Ribbon event collecting more than €400,000 and raising awareness of breast cancer
- ED Pan-European Conference

**Activities for 2012**
- The right to breast reconstruction within 1 year of surgery as part of the treatment for Norwegian women
- More courses and conferences
- 20-year anniversary
- Attending the Nordic Breast Cancer Conference in Stockholm

**Poland**

**Highlights of 2011**
- In January-February, publication and promotion of the Polish version of the *EUROPA DONNA Guide to Breast Health*
- In March, the 14th Deputies’ Meeting and election of the board for a 4th term
• In April, participation in the National Conference “Breast Cancer”
• In May, a visit of an ED Poland representative at the European Parliament in Brussels
• In October, participation of 12 advocates in the ED Pan-European Conference
• In October, Pink Ribbon Marches in various cities and media coverage of Breast Health Day
• Lectures in schools on breast cancer prevention
• In November, participation in the Advocacy Training Course

Activities for 2012
• In March, participation at EBCC-8 and presentation of a poster
• In June, the 15th Deputies’ Meeting and a scientific conference on breast cancer prevention
• Publication of a Polish version of the Breast Health Day leaflet
• Participation in the ED Advocacy Leader Conference
• In October, a meeting with MPs at the Senate Health Commission on the Polish government implementing the EU call for specialist breast units
• Participation in the ED Advocacy Training Course

Romania

Highlights of 2011
• In March and October, two media campaigns to raise breast cancer awareness, with participation in highly rated TV and radio debates
• In April, the “Art for Life” gala fund-raising event under the patronage of the Norwegian ambassador to Romania
• In October, pink illumination of a historical building in Bucharest
• Presentations on television about women’s health, prevention and early detection of breast cancer
• Opening of a new medical centre, The Medical Center of Excellence, specialised in the early detection of breast and genital cancer
• Launching of the second mobile diagnostic unit, providing free mammograms and Pap smear tests to women in rural and pre-urban areas

Activities for 2012
• In March and October, awareness and communications campaigns
• Fund-raising events such as the “Art for Life” gala in June and the pink illumination in October
• Advocating for authorities, the media and the general public to support a national breast cancer screening programme, including ED Romania contributing to the protocol for the national cervical screening programme through the two mobile diagnostic units

Slovenia

Highlights of 2011
• Four issues of ED News, as well as Exercise is my Sun on the importance of regular physical activity during treatment
• 29 lectures throughout Slovenia on breast cancer, healthy lifestyles and self-examination
• Counselling by telephone, personally, e-mail and hospital visits
• Creation of a 2012 calendar with photos of young patients by a highly engaged young women’s section, and participation in “Rope of Solidarity” in Switzerland
• 2-day counselling for 190 participants on novel systemic treatments, radiation and sexual problems
• Creative literary web course “Pink palm”
• “Running and Walking for Hope” in three cities
• Yoga and two outings for breast cancer patients

Activities for 2012
• Publication of four issues of ED News
• Emphasis on psychosocial support and holistic rehabilitation
• Promoting guidelines on lymphoedema treatment
• Patient counselling
• Lectures throughout Slovenia
• 2-day seminar on the degree of likelihood of breast cancer in patients’ children
• “Running and Walking for Hope” in three cities
• October activities
• Outings for patients
• Occasional financial support to breast cancer patients with low or no incomes

Spain

Highlights of 2011
• Psychological support for women with breast cancer and their families
• Physiotherapy for lymphoedema
• Third University Menéndez Pelayo course, with more than 150 specialists and women with breast cancer attending, covering quality and sustainability of the national health system, safety and best practice and other topics
• In October, a press conference at the Ministry of Health, Social Policy and Equality to read the ED Spain Manifesto and present an awareness campaign on early detection
• Participation as experts in all meetings and initiatives organised by the Ministry of Health, especially in the National Cancer Strategy
• “Feel Good” campaign, including a booklet to help relieve chemotherapy-associated symptoms, with press conferences involving local partnerships
Strength in Numbers

Activities for 2012
• Study of long-term adverse effects in breast cancer patients, aiming to identify the information needs and expectations of patients in different stages of disease and survival, including a questionnaire on quality of life of long-term survivors
• In July, the University Menéndez Pelayo course
• In October, a media campaign and production of publicity material
• Awareness raising through the media on World Cancer Day and others

Sweden
Highlights of 2011
• In August, the Pink Walk “Rosa Steget” in Gothenburg
• In October, the National Breast Cancer Symposium in Stockholm
• Breast Health Day activities at Stockholm Central Station
• An annual award for excellent achievements in breast cancer treatment, care and awareness
• An award for the Swedish Breast Cancer Nurse of the year
• Research grants of approximately €473,000 given to clinical breast cancer research projects from the Swedish Breast Cancer Fund
• Recreational weekends for young women treated for breast cancer
• Pink Ribbon activities and awareness campaigns throughout the country during October

Activities for 2012
• In August, Pink Walk “Rosa Steget” in Gothenburg
• Breast Health Day activities
• Lobbying on both local and national political levels
• Recreational weekends for young women treated for breast cancer
• Pink Ribbon activities and awareness campaigns throughout the country during October

Switzerland
Highlights of 2011
• Introduction of mammography screening programmes in the cantons of Graubünden and Thurgau, making three German-speaking cantons, together with St Gallen, to have introduced early detection of breast cancer via an organised programme with quality assurance according to EU guidelines. The ED regional group Eastern Switzerland supports the programme and promotes information about the newly created early detection programmes
• In November, election of a new president of ED Switzerland, Donatella Corbat, from the regional group of Mid-Switzerland-Bern. A new board commences its activity in 2012

Activities for 2012
• EBCC Arts and Humanities Award to the “Cantiere di pensieri” group of young women from the regional group of Southern Switzerland for the project that led to the book The Year of the Pale Sunflower at EBCC-8 in Vienna
• Co-chairing of EBCC-8 by Prof B. Borisch, national delegate of Switzerland and Past President of ED Switzerland and ED

Tajikistan
Highlights of 2011
• Four roundtables on breast cancer advocacy with the participation of health professionals, communities, committees on women's issues, a youth committee, the Ministry of Health, city and oblast health departments
• 14 meetings on breast cancer advocacy
• Breast Health Day activities

Activities for 2012
• A Healthy Breast Week with four roundtables, practical training, 14 information campaigns, training in prevention, meetings with women community leaders and practical sessions on breast self-examination
• 16 breast cancer advocacy information campaigns
• 80 workshops on training women in breast self-examination
• 10 training sessions for medical personnel on improving clinical breast examination skills
• Organisation of three support groups for survivors
• Printing booklets and information materials
• Advocacy activities for Breast Health Day, International Children’s Day and Breast-feeding Week
• Monitoring and evaluation of activities carried out by primary health care physicians
• Meetings with women leaders on lobbying for women’s health and breast cancer prevention

Turkey
Highlights of 2011
• Participation in the annual National Communications General Assembly in Ankara, with more than 2 million attendees
• “Take Action & Tell Your Story” campaign on physical activity and breast health. The top three winners received awards through joint social activities with local celebrities
• In May, for Mother’s Day, a joint event with the Italian Hospital in Istanbul involving monthly awareness seminars
• Establishment of the ED Ankara branch
• A Breast Cancer Awareness choir at a Breast Health Day concert
• Participation in the annual International Women of Istanbul Christmas bazaar and donation of free mammograms through proceeds from sales
Activities for 2012
• Presentations on breast health around Turkey for the “Take Action and Tell Your Story” campaign
• Lectures on breast cancer awareness in and around Istanbul
• Patient seminars on hobbies, healthy lifestyles and family relations
• Planning of a nation-wide education programme for high school students and their mothers on breast awareness through the Ministry of Education, for implementation in 2012 and 2013. A pilot project will start with lectures in and around Istanbul in 2012

Ukraine
Highlights of 2011
• Partnering in the social programme “Together Against Breast Cancer”, including organising the 7th Annual Walk with the participation of numerous celebrities. A famous Ukrainian designer created a collection of pink accessories, which celebrities wore before the media. Proceeds went to ED Ukraine's annual School of Mammography
• A scientific conference on multidisciplinary breast cancer diagnosis and treatment, with more than 350 doctors participating. Conference materials were used as a basis for the training programme for family physicians and gynaecologists
• In April, a 4-day training seminar at the School of Mammography for 40 Ukrainian radiologists, with a curriculum prepared by international experts and which covered the EU guidelines
• Supporting rehabilitation programmes, with a special course for more than 100 patients with lymphoedema

Activities for 2012
• In April, the 3rd School of Mammography
• In October, a Forum of Breast Cancer Patients’ Organisations and a media campaign for Breast Health Day

United Kingdom
Highlights of 2011
• October Symposium on “Breast Cancer and Health Economics”, with Prof. Karol Sikora as the principal speaker and a capacity audience of medical professionals and advocates. Baroness Morgan's contribution emphasised the importance of respect for patients and their involvement in decision making
• In December, participation in the annual Britain Against Cancer Conference, where Health Secretary Andrew Lansley emphasised the need for improved public awareness, better cancer pathways and earlier diagnosis with quicker access to treatment, in view of the concern about proposed changes in the National Health Service

Activities for 2012
• In March, participation at a “Cancer Wellbeing” event promoting ED UK to cancer patients
• In May, a meeting with ED UK's Scientific Advisory Group to discuss breast cancer changes in the National Health Service and potential effects on professional practice and patients’ experience. This will provide topics for a large-scale public symposium in 2012
• In October, a stand at the Houses of Parliament to mark Breast Health Day

Uzbekistan
Highlights of 2011
• In April, a charity marathon “In the Name of Life”
• In May, training for 25 Tashkent breast care specialists on evidence-based epidemiology, diagnostics, treatment and prevention, delivered by experts from the US National Cancer Institute and Seattle Cancer Care Alliance
• From September-December, free breast cancer check-ups for socially vulnerable women in all regions
• In October, participation at the ED Pan-European Conference, holding of a charity gala dinner “Pink Party” and a charity concert with a performance by Eros Ramazzotti

Activities for 2012
• In March, attendance at EBCC-8, with an ED Uzbekistan poster presentation
• In April, a roundtable on psychosocial support
• In May, the first joint race organised by ED Uzbekistan, Susan G. Komen for the Cure and the National Breast Cancer Association
• In June, training sessions on psychosocial aspects of breast cancer in three pilot regions
• In September, participation in the ED Advocacy Leader Conference
• From September-December, free breast check-ups for socially vulnerable women in all regions
• In October, a charity gala dinner with a concert by a pop singer
Advocates from EUROPA DONNA’s 46 member countries have been busy networking and attending conferences across Europe, such as the ED Pan-European Conference and EBCC-8, in addition to their national activities and initiatives.
What’s new

EUROPA DONNA has published an updated version of its Clinical Trials and Breast Cancer booklet, available in print and in PDF on www.europadonna.org.

A Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis has now been printed in Portuguese and a Latvian translation is under way. These new editions and the French, German, Italian and Spanish versions have been updated to include information on the Written Declaration on the Fight Against Breast Cancer in the European Union (0071/2009). The Short Guide is now available in 13 languages (Dutch, English, French, Georgian, German, Greek, Italian, Polish, Portuguese, Russian, Spanish, Swedish and Turkish).

What’s on

ED Breast Cancer Advocacy Leader Conference
Building our Organisations for the Future
22 September 2012
The Coalition’s National Representatives and Delegates gather to share experiences, receive support and the latest evidence-based information necessary for their advocacy initiatives.

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 “Make good choices for your breast health” 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, as well as social networking sites such as Facebook, Twitter and YouTube, will encourage women across the globe to make responsible daily choices for their breast health.

For more information see www.breasthealthday.org

11th Annual EUROPA DONNA Breast Cancer Advocacy Training Course
9-11 November 2012 – Milan, Italy
Some highlights of EUROPA DONNA’s annual course:
• 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

11th EUROPA DONNA Pan-European Conference
19-20 October 2013 – Prague, Czech Republic

In box

Do you have an opinion or news you wish to share?
Let us know 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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