



20 years

1994 - 2014

20 years
of Advocating
for the women
of Europe.

Summer/Autumn 2014

NEWS

Highlights of the 9th European Breast Cancer Conference

Including

The EBCC9 Manifesto
on pathology

Highlights
of the scientific programme

And

EUROPA DONNA sessions,
from specialist breast units to prevention

A young survivor shares her story

Updates on European
advocacy initiatives
and Breast Health Day

Reports from member countries

EBCC
European
Breast Cancer
Conference 9

19-21 March 2014 | GLASGOW, SCOTLAND





10

Goals

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

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The Personal is Political



The 9th European Breast Cancer Conference (EBCC9) took place in March this year, but the work had already begun in November 2012 and continued throughout 2013 with meetings and teleconferences as set out at the first meeting. From that point on, discussions led to the programme and as the chair for this conference was the leading pathology professor **Giuseppe Viale**, the pathology theme was obvious. As a patient representative and advocate, I found this totally in line with my personal view. Every diagnosis begins with a good – and hopefully perfect – **pathology report**. This is the basis for the treatment to come. In addition, it was a pleasure working with “Beppe Viale”; he is not only the foremost expert in his field, but also is an excellent educator, always willing to discuss and explain material to advocates and non-scientists.

I also want to point out that the patient perspective at EBCC has been much more in focus during the last few years – due largely to the effectiveness of EUROPA DONNA’s advocacy work and, to some extent, as a consequence of competition. The European Breast Cancer Conference is the only conference where the patients are actually in partnership with the professionals in all aspects of the conference organisation. This is, of course, the correct approach, as the patient should be the focus – the research, treatment and medication are all about the patient. EBCC9 in Glasgow was about how to treat the patient and about the work of those brilliant health professionals that make us well and keep us alive.

In February, I had the privilege to participate in a meeting in the **European Parliament**, hosted by MEPs Emma McClarkin (UK), Anna Záborská (Slovakia) and Minadora Cliveti (Romania) about **metastatic breast cancer** (MBC) patients; the meeting highlighted their needs, especially having access to the most up-to-date treatments and to treatment provided within a **specialist breast unit** (SBU), with access to multidisciplinary teams. We now know that this gives the patient a 10-18% percent better prognosis. Hopefully this meeting will lead to a Declaration which will underline the rights of patients with MBC to treatment within a SBU where their special needs, including psychosocial needs, will be met.

Past President Ellen Verschuur and I have been working on an update of the **EUROPA DONNA Constitution**. In order to also take into account the historical aspects we held a meeting with all past Presidents prior to EBCC9. It was a highly interesting and important meeting and ensured that we are aware of the original ideas and thinking at the time of EUROPA DONNA’s creation.

This brings me to the September meeting – the **Advocacy Leader Conference** – where I very much look forward to meeting with our National Representatives. We will have an interesting programme with a focus on MBC, a topic that needs to be highlighted. Women



President
Elizabeth Bergsten Nordström

“Let us pull together and exert every effort to make MBC a subject for the European Parliament to address so that the message reaches all EU member countries and beyond”

with MBC are inspiring in the way that they face the challenges of their disease; they need all the assistance we can provide because our societies and health care systems do not currently do so. That is where advocacy can really make a difference. So let us pull together and exert every effort to make MBC a subject for the European Parliament to address so that the message reaches **all EU member countries** and beyond.

This is my last editorial as President of EUROPA DONNA. The time has really flown by, and when I think of all the things I wanted to do, I am aware that not all has been done; nonetheless I realise one does not have to be a president to get things done, so I am committed to continuing to further our advocacy goals. I look forward to meeting with all of you in the future and to continuing our important work to make every woman’s journey through breast cancer as smooth as possible and to ensure that it is a journey that every woman survives.





Advocacy in Action



Executive Director
Susan Knox

“Our 20th anniversary video points out the unique multi-cultural characteristics of our organisation, our strengths, our successes and the unmet needs that should be addressed in the future.”

2014 marks the **20th anniversary of the founding of EUROPA DONNA** and we took this opportunity to highlight the key advocacy initiatives of the past 20 years in an **8-minute video** that was released at the 9th European Breast Cancer Conference (**EBCC9**); it features Past Presidents of ED, past and current Executive Board members, and survivors from many countries pointing out the unique multi-cultural characteristics of our organisation, our strengths, our successes and the unmet needs that should be addressed in the future. It is posted on our website (www.europadonna.org) and on YouTube. In addition, we published a booklet entitled **20 Years of European Breast Cancer Advocacy**, which can also be accessed on our website. We held a 20th anniversary reception at the end of EBCC9, where the video was introduced and over 100 advocates came together to celebrate this important event in our history.

It is appropriate that 2014 also marks the beginning of our **2nd Strategic Plan Implementation** in which past priorities remain constant but several new ones have been added: prevention, survivorship, advocacy for women with metastatic breast cancer (MBC) and advocacy involvement in the research agenda. The **research training module** developed last year has now been refined and will be presented at our Advocacy Leader Conference to enlarge the number of ED advocates who will be able to serve on trial committees, both at a European and national level. We have also recently published a new booklet entitled *Exploring the Role of Advocates in Breast Cancer Research*, which will be distributed to advocates throughout the year.

We are collaborating in several **Breast International Group (BIG)** projects, including the Steering Committees of MINDACT and AURORA, as well as the Legal/Ethics Committee of AURORA. We now provide information on research and clinical trials via the **Research section** of our website and are enabling women to find out more about current treatments and guidelines by connecting them via our website to the key European conferences in which we are involved: EBCC, St Gallen, and ABC 1 and 2. Our position on screening was also described in an e-cancer interview conducted at EBCC and can be viewed at <http://ecancer.org>.

We are fortunate to be receiving an EU operating grant for 2014 and are continuing our work with the European Commission's Joint Research Center (JRC) on the **European Commission Initiative on Breast Cancer (ECIBC)**.

One of our new strategic priorities is meeting the needs of women with MBC. As part of this commitment, 20 women with MBC, invited by our country members, will attend our **Advocacy Leader Conference** in September. There we will highlight the content of the Advanced Breast Cancer ABC1 and 2 conferences and conduct workshops and networking sessions to help members develop strategies to improve services for women with MBC in their own countries.

Our **Breast Health Day** programme continues to gain momentum, both in our countries and in our digital Facebook/Twitter campaigns. We encourage people to participate both online and in person and “Take the first step for your breast health.”

Finally, the **resolution “Toward optimum breast cancer services across Europe”** has been adopted by the Committee on Social Affairs, Health and Sustainable Development of the **Council of Europe**, and will be voted on in the plenary in Strasbourg in October. The rapporteur is ED Cyprus President and MP Stella Kyriakides. We have provided input on this from the outset and will provide all the necessary support together with our member countries to see that this passes. It is an essential step toward ensuring improved breast services for all the women in all of the countries of Europe.

9th European Breast Cancer Conference

Keeping advocates informed about the latest research and scientists updated on advocacy issues



Giuseppe Viale, Elizabeth Bergsten Nordström and Alberto Costa

Almost 100 advocates from many of EUROPA DONNA – The European Breast Cancer Coalition’s 46 member countries were on-site at the 9th European Breast Cancer Conference (EBCC9) to learn the latest findings in breast cancer research, to provide the patient perspective and to network with other advocates and scientists. As co-organiser of EBCC in equal partnership with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA), EUROPA DONNA

organised and held sessions of interest to advocates and scientists alike. In all, the conference welcomed 3382 attendees from 96 countries. The recurring theme was the need for individualised care and treatment, and further progress in defining subgroups of patients. EUROPA DONNA President **Elizabeth Bergsten Nordström** was conference co-chair, and in the opening session reminded those present of the need to achieve equal high-quality standards in breast cancer care across all our countries. Later in the conference, she urged all those present to advocate for best practice: “We are striving to bring about the changes that you, the scientists, with all your excellent work, have put on the table to show that this is the future. Now go out and make the decision makers make it possible.”

EBCC
European
Breast Cancer
Conference
9

Making progress in pathology: EBCC9 Manifesto Session

This year’s conference reinstated the EBCC Manifesto, this time entitled “Optimal Pathology Should be Available in a Timely Manner to Every Breast Cancer Patient”, with a view to having a consensus document for use for future advocacy. In the EBCC9 Session held to release the Manifesto, ED President **Elizabeth Bergsten Nordström** presented the “voice of the patient.” She said that pathology is key to any breast cancer diagnosis and defining treatment, and must therefore be performed at the highest standards according to EU guidelines. She added that the pathology report must be documented in an understandable way for patients to make an informed decision about their treatment. Given reported variability in services, the Manifesto prepared by a European Breast Cancer Council working group, sets out essential, timely diagnostic and prognostic services, as well as organisational requirements for a breast cancer pathology service, including requirements for professionals, hospitals, departments and health systems. It also calls for a more patient-focused service that includes the pathologist as a multidisciplinary team

member who is visible to patients. It states a woman’s right to access all clinical information relevant to her case. The Manifesto is a position paper and is to be published in a scientific journal.

“The fact that this year we have introduced a Manifesto on pathology is of great importance to us because this is an area that women need to know more about. It is an area that is extremely important in terms of both the diagnosis and the treatment that a woman will receive. Having facts about that in a lay-person’s document, in a document that everyone can understand is going to be extremely important. It will be something that we are able to use and disseminate to all of our countries so that women can be more aware and knowledgeable about this area,” Susan Knox, EUROPA DONNA Executive Director, said in an interview at EBCC.

[Read the full Manifesto](#)

9th European Breast Cancer Conference



Highlights from the Scientific Programme

Genetic testing may improve the selection of women eligible for 10 years of hormonal therapy

Genetic analyses of results from postmenopausal women in the ATAC trial have shown that women with tumours that were HER2-negative but very oestrogen hormone sensitive had more than double the risk of their cancer recurring between 5 and 10 years after surgery and after having had 5 years of adjuvant hormonal therapy. Although further study is required, women with HER2-negative, high-oestrogen-signalling breast cancer may be candidates for adjuvant hormonal therapy being extended to 10 years. Prof. **Mitch Dowsett**, of The Royal Marsden NHS Foundation Trust, London, UK, presented his group's work, which involved using data from the OncotypeDx® 21-gene Recurrence Score that are not usually available from this test in order to analyse the genetic make-up and to predict the likelihood of cancer recurring within 10 years in these women. These findings may help in better tailoring of hormonal therapy beyond the first 5 years. The researchers are initiating new studies to examine the effect of extended hormonal therapy on preventing recurrence.

Radiotherapy after mastectomy is beneficial in women with involvement of a few lymph nodes

Women whose breast cancer has spread to 1-3 lymph nodes are less likely to have their disease recur or to die from it if they have radiotherapy after mastectomy. Dr. **Paul McGale**, of the Early Breast Cancer Trialists' Collaborative Group at the Clinical Trial Service Unit in Oxford, UK, presented results of an analysis of 3786 women from 14 randomised trials starting between 1964 and 1982. In the women with 1-3 positive nodes, radiotherapy to the chest wall and regional nodes reduced the recurrence rate by 31% and the breast cancer mortality by 20%. For women with 4 nodes involved these rates were 23% and 13% respectively. The benefit occurred regardless of whether or not the women were in trials where chemotherapy or hormonal therapy was given to all women. New trials could measure the effects of modern radiotherapy, chemotherapy and hormonal therapy in women with node involvement.

 Available on webcast

Highlights from EUROPA DONNA Sessions

Optimal intervals for screening and identifying risk

Researchers have found that the 3-year mammography screening interval in the UK is sufficient for women at low-average risk of breast cancer, but that about 30% of the population would benefit from more frequent screening. Prof. **Gareth Evans**, from the University of Manchester, UK, presented an analysis of the first 53,437 women who attended routine breast screening in Manchester and agreed to participate in the study. They asked the women about risk factors such as family history and lifestyle, and measured their breast density. In the women who developed breast cancer, there was a greater proportion of advanced cancers in women at higher risk, 32% compared to only 19% in women at average or below average risk. Those with the highest percentage of dense tissue were almost three times more likely to develop breast cancer in the next 10 years than women with the lowest density. Identifying the degree of risk of developing breast cancer in individual women could help in better target screening and prevention measures. The EU guidelines recommend screening every 2 years for women aged 50-69.

 Available on webcast



Robin Wilson, Susan Knox, Donata Lerda and Mojca Miklavčič

European Commission Initiative on Breast Cancer (ECIBC)

The European Commission Initiative on Breast Cancer (ECIBC) aims to set standards for breast services and specialist breast units (SBUs) across the EU and is coordinated by the European Commission's Joint Research Centre (JRC), in close collaboration with the Directorate General for Health and Consumers (DG SANCO). The JRC's **Donata Lerda** outlined the project and timelines, stating that the first step involves updating the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. A quality assurance scheme would then see

that they are implemented and audited. A separate set of guidelines will be created on treatment, rehabilitation and follow-up, based on existing guidelines. Member states will be encouraged to offer services in SBUs, as set out in the EU guidelines. Patient advocacy groups including EUROPA DONNA have been involved in the planning stages and will be involved throughout the whole process. "In the implementation as well it will be crucial for patient advocates and patients to be aware of what they have to expect and what to ask for from a quality assurance point of view," Ms Lerda said. The project website will host a list of certified centres, the guidelines and the specific data backing them, as well as a possible blog and feedback tool. She said that the project, including the guidelines, the pilot of the quality assurance scheme and a web hub, are to be completed by 2016.



Available on webcast

Specialist Breast Units

EUSOMA's **Robin Wilson** described EUSOMA's requirements of a specialist breast unit, which are included in the 4th edition of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* and in 2013 were updated, expanded and published in the *European Journal of Cancer* (2013;49:3579). SBUs provide co-ordinated screening, diagnosis and care throughout the entire process. Services can be integrated yet separate, including specialist clinics for women with metastatic disease, for example. In the new publication, he said that some recommendations have become requirements; for example there must be at least 2 of each core team member (eg, surgeons, radiologists, etc) and all specialists working within a breast unit must be specifically trained and dedicated to breast cancer care. Where in the past, nurses were recommended to attend the multidisciplinary meeting, now they must attend. Breast units must also be able to provide multidisciplinary treatment of women with advanced disease and offer a high level of palliative care services. Dr. Wilson said that the evidence is in favour of multidisciplinary team working. A large study performed in Scotland found that 5 years after the introduction of multidisciplinary care in specific health board areas, mortality from breast cancer was 18% lower in those areas than in the ones without the multidisciplinary care (Kesson, EM. *BMJ* 2012;344:e2718).



Available on webcast

Challenges in shared decision making: patient-doctor communication

EUROPA DONNA Board Member **Evi Papadopoulou** reminded participants that appropriately delivered



Lesley Fallowfield, N Foley, Evi Papadopoulou and Gertrude Abela

information is necessary from all specialities within the multidisciplinary team. She added that women want the doctor's undivided attention, and that women also need to give their doctors an accurate account of any side effects, psychological symptoms or the use of any complementary therapies. **Lesley Fallowfield**, University of Sussex, Falmer, Brighton, UK, who presented the psychologist's side of shared decision making, cited a systematic review on patients' preferences for participation in making decisions about their treatment, showing that patients wanted more participation than actually occurred in their case (Tariman JD. *Ann Oncol* 2010;21:1145). She added that in metastatic breast cancer, patient preference should dominate, but this is not always the case.



Available on webcast

Survivorship: what women need after breast cancer

Given the increasing number of women living with and beyond breast cancer, EUROPA DONNA held a special session on Survivorship. ED Board Member and oncologist **Olivia Pagani** discussed the many issues that women face after breast cancer, from self-image and sexuality to long-term effects of treatment. In women taking tamoxifen, she said bone health can be preserved through regular exercise, diet, calcium supplementation and vitamin D, or use of bisphosphonates. In younger women, Dr. Pagani cited a recent retrospective study showing that women who became pregnant 2 or more years after their breast cancer diagnosis had a comparable disease-free survival to their non-pregnant counterparts (Azim HA. *J Clin Oncol* 2013;31:73). **Manuela Eicher**, School of Health Fribourg, Switzerland, giving the breast care nurse perspective, cited a study showing that breast cancer survivors have a high degree of unmet supportive care needs compared to people with other cancer types (Boyes AW. *BMC Cancer* 2012;12:150). The most popular sources of information and support were informative brochures, psychologist consultation, information sessions and an informative website (Pauwels EE. *Psychooncology* 2013;22:125). A policy statement on multidisciplinary breast cancer care by the European Partnership for Action Against Cancer consensus group, in which EUROPA DONNA participated, states that a woman's follow-up phase should not begin without the multidisciplinary team elaborating a joint survivorship care plan with the patient (EPAAC. *Eur J Cancer* 2014;50:475). **Sanja Rozman** of ED Slovenia discussed rehabilitation and return to work, stating that for many survivors work is a financial and emotional necessity that helps them maintain their self-esteem and social support. She recommended that advocacy efforts should shift from increasing legal protection against cancer-based discrimination to helping survivors address their individual employment-related needs. In her presentation on patient support groups, **Stella Kyriakides** of ED Cyprus said that such groups serve as a safety net for many women, and studies show that women who participate report a feeling of wellbeing. She concluded saying, "Having access to a support group will allow women with breast cancer to reintegrate that experience into their lives so that they can move with it and beyond."



Available on webcast

9th European Breast Cancer Conference



Prevention and lifestyle

The 2014 EBCC Arts and Humanities Prize endorsed physical activity

In the EBCC9 opening ceremony, ED President Elizabeth Bergsten Nordström presented the European Breast Cancer Arts and Humanities Award to Irish ceramic artist Orla Kaminska for her mosaic created for the Plurabelle Paddlers, an Irish dragon boat team for breast cancer survivors. This underlines the Coalition's commitment to promoting physical activity in breast cancer prevention and remediation of adverse effects following treatment.

Obesity and diabetes increase risk of aggressive breast cancer

Dr. Philippe Autier and colleagues at the International Prevention Research Institute, Lyon, France performed a systematic analysis of studies on risk factors for breast cancer published since 2000. While reproductive factors, such as low number of births, are some of the main risk factors for developing breast cancer, they were found to have little influence on the risk of dying from the disease. However, pregnancy-associated breast cancer (ie, developing the disease within a year of childbirth), obesity and diabetes are risk factors for more aggressive disease, and increased risk of breast cancer death. He added that physical activity not only reduces breast cancer occurrence, it improves survival. Dr Autier suggested that chronic low-grade inflammation, which in turn decreases vitamin D levels, is the common denominator. In pregnancy-associated breast cancer, obesity and diabetes, systemic inflammation is increased, whereas physical activity reduces inflammation.

 Available on webcast

Regular physical activity at any age reduces breast cancer risk

Practising sport for more than an hour a day reduces the risk of developing breast cancer, a new study has confirmed. Compared with the least active women, those with the highest level of physical activity reduced their risk of breast cancer by 12%. Prof. Mathieu Boniol, of the International Prevention Research Institute, in Lyon, France, reported the results of a meta-analysis of 37 studies published between 1987 and 2013, representing over 4 million women. The effects were largely independent of body mass index and the age at which a woman starts being physically active.

Lifestyle choices and breast cancer: influencing recurrence

In a lively presentation, Anthony Howell, University of Manchester, UK, presented what is known and not known about lifestyle factors in preventing breast cancer recurrence, where the recurring message was "Don't worry about it." He said that data on fat and vegetable intake are conflicting



for prevention of recurrence. For alcohol consumption, a large epidemiological study showed that regular alcohol intake (>6 g/day) was not associated with risk of recurrence overall; however, there was a slight increase in postmenopausal women. Alcohol intake was not associated with mortality (Kwan ML. Cancer

Epidemiol Biomarkers Prev. 2013;22:32). Moving to weight, Prof. Howell cited a meta-analysis of 21 studies showing that obesity at diagnosis is associated with a 26% increase in risk of breast cancer death, whereas overall risk of death was increased by 20% (Niraula S et al. Breast Cancer Res Treat 2012;134:769). While all studies are not in agreement, many suggest that weight gain of more than 5 kg after diagnosis is associated with increased risk of relapse. A very recent study on the role of exercise in women on chemotherapy suggests it could have a beneficial effect on outcomes and warrants further study (Courneya KS. Med Sci Sports Exerc 2014;Mar 13). In another study, at least 2.5 hours of moderate physical activity per week reduced breast cancer mortality by up to 28% (Beasley JM. Breast Cancer Res Treat 2012;131:637). Prof. Howell said that in addition to having the right weight, diet and amount of physical activity, for prevention it is important to have the "right frame of mind". In her presentation, Susan Knox, EUROPA DONNA Executive Director, described the Coalition's wide-reaching Breast Health Day campaign, which promotes prevention based on data supporting a reduction in breast cancer risk through healthy lifestyles.

 Available on webcast

Breast cancer chemoprevention

Dr. Jack Cuzick, Wolfson Institute of Preventive Medicine, London, UK, said that while certain lifestyle measures could reduce breast cancer incidence by 25% across the whole population, identifying women at higher risk and an effective non-toxic prophylaxis could have a greater impact on breast cancer incidence. In the IBIS-II study in 3864 postmenopausal women with increased risk of breast cancer given anastrozole or placebo for 5 years, after a 7-year follow-up there was a 53% overall reduction in breast cancer incidence for anastrozole vs placebo (Cuzick J. Lancet 2014;383:1041). Other studies have shown that use of non-steroidal anti-inflammatory drugs, including aspirin and ibuprofen, reduces breast cancer risk (Takkouche B. J Natl Cancer Inst 2008;100:1439). Aspirin also reduced the risk of recurrence and breast cancer death (Holmes MD. J Clin Oncol 2010;28:1467). Women with diabetes who take metformin have been shown to have a decreased risk of breast cancer, and studies on this are ongoing (Chlebowski RT. J Clin Oncol 2012;30:2844).

 Available on webcast

For webcasts see: www.ecco-org.eu/Webcasts/EBCC9Webcasts.aspx

Living with Breast Cancer



Six years later

What does “six years later” mean to us? To a young, healthy person, probably not much. When you are 26, you think about getting 6 years older, what you will achieve in your career, your personal and family life and your education. At least I thought about those things at the time. I had no clue that I could be diagnosed with breast cancer.

I cannot say that my life was turned upside down or that a dark shadow came over me, but I found myself at a point where I did not know what I know now: how to go on. With great support from my husband, family and friends I gathered enough energy for THE fight. For some time I put neuroscience aside and breast cancer became my major area of study. In the last week of September 2008, I started chemo, which was followed by radical mastectomy and radiation therapy.

During therapies I finally took a lot of time for myself. Even though I was afraid of what I would do at home, I was not bored at all. I learned how to cook and studied healthy food; I made some handmade jewellery, Christmas greeting cards and painted a few glass bottles. I finally had enough time to arrange my stamp collection and read books that had been waiting for years.

Celebration of my 27th birthday was something special, although I did not want to celebrate it at all. Without making any announcement, everybody came who meant the whole world to me at that time. Our very close friends were great during the whole experience. We simply moved gatherings, drinks and parties to our home, including movie nights, cooking dinners and roasting of chestnuts. Every “coffee time” with my girlfriends started with a quick update of my treatments, side effects and upcoming treatments. After that, we caught up on all the new gossip and daily things. Now I know that I was living in my own movie at that time. A few months after everything had finished, they told me that they were very afraid of what would happen. But when they were around me, they did not show that fear at all. A great THANK YOU ALL for that! That was my power, my energy to continue the fight.

After chemo I lost my hair, after the operation I lost my breast, after radiation my skin was a mess... But why would I complain about that? The hair grew back; I got new breasts (I later had a mastectomy on the other side and reconstruction of both sides) and the skin eventually healed. But the change in me stayed. The experience made me stronger in different ways. It brought me lots of new and beautiful changes in priorities and putting myself in first place no matter what. Now I do things I like and I believe in. I live a full life and appreciate every single day! Now I even know how to say, “No, thank you” or “I can’t” or “I won’t” from time to time.

Cancer brought me lots of new friends, magnificent and warm people who are now indispensable in my



Tanja Spanic, Slovenia

everyday life. It brought me new challenges and tasks. One of my favourite activities at EUROPA DONNA Slovenia prior to assuming duties as secretary general was leading the Young Patients Group for women who were diagnosed under the age of 40. After my primary treatments, I joined the group and I saw all the problems that these women are facing... problems, difficulties and obstacles in their personal and professional lives. We are a very interesting group. Mostly we communicate via e-mail, but a few times a year we meet and discuss our problems. Sharing of our experiences really is priceless.

Living, moving on, going back to work or starting over, starting to do new things, making a warm, sweet home, getting a furry pet and having my loved ones next to me – somehow I did it; I did it with great support of my husband. Every new limitation became a challenge, and facing it with someone you love makes it much easier.

Where will I be and what will I do in six years? I do not know, I just know that I will still be here in this world!



Making our Voices Heard

Celebrating 20 years of EUROPA DONNA

20
years

1994 - 2014

2014 marks 20 years of EUROPA DONNA – The European Breast Cancer Coalition. To ensure that the celebration lasts beyond the special events held throughout the year, the Coalition is making the 20-year video created for the occasion available in short clips, or nuggets, on social media sites from June through December. The full video can be seen on www.europadonna.org and YouTube.

Taking steps for breast health

Breast Health Day – 15 October 2014



The slogan for this year's European and global breast cancer prevention campaign will be "Take Your First Step for Your Breast Health". The campaign materials feature cartoon girls, and the animated video will witness their transformation from

making poor lifestyle choices to healthy ones, such as eating nutritiously and exercising. Breast Health Day promotes prevention of breast cancer through healthy lifestyles in women and girls.

Promoting the rights of women with MBC at a European Parliament roundtable meeting

As an invited speaker at a roundtable meeting hosted by MEPs at the European Parliament in February, EUROPA DONNA called on MEPs to launch a Written Declaration after the May 2014 election that would reiterate the need to implement the 2003 and 2006 Resolutions on Breast Cancer and ensure that this includes the care and treatment of women with metastatic breast cancer (MBC). ED also asked that the new European Commission Initiative on Breast Cancer (ECIBC) being carried out by the European Commission's Joint Research Centre include specific reference and description of necessary services for MBC. ED also requested a follow-up meeting after the election.

Encouraging patient empowerment at the EPF annual conference and general meeting

EUROPA DONNA's Head of Policy and Public Affairs, Karen Benn, represented ED at the European Patients' Forum (EPF) annual conference and general meeting in May, where topics included the European elections, healthcare access and quality, and patient empowerment and youth. Through parallel sessions, EPF launched the first meetings of the Healthcare Access working group, and the Patient Empowerment working group; these two themes will form the backbone of the EPF Strategic Plan 2014-2020. A third session "Understanding youth and strengthening the involvement of the Youth Group in EPF" was also held.

Teaching at the 1st ESO Cancer Patient Advocacy Masterclass

EUROPA DONNA participated in the first European School of Oncology (ESO) Cancer Patient Advocacy Masterclass entitled "Working towards stronger and more effective advocacy in Europe", held in May in Baveno, Italy. The course, which included key leaders, CEOs and board members from 15 cancer patient organisations across Europe, covered important topics such as strategic planning, using evidence for advocacy, involving patients in research, long-term sustainability, and managing risks in NGOs. ED served on the Steering Committee and both Susan Knox, ED Executive Director, and Karen Benn, Head of Policy and Public Affairs, were faculty members for the course.

Championing a Resolution at the Council of Europe

The Council of Europe's Committee on Social Affairs, Health and Sustainable Development unanimously adopted the report entitled "Towards Optimum Breast Cancer Services Across Europe". Stella Kyriakides, Cypriot MP and President of EUROPA DONNA Cyprus, was the rapporteur and presented the report at a meeting of the committee on 12 May.

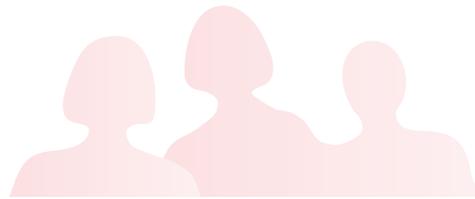
Collaborating in research through the EBCTCG

EUROPA DONNA President Elizabeth Bergsten Nordström serves as a patient advocate on the Early Breast Cancer Trialists' Collaborative Group (EBCTCG). At the June meeting, the group discussed an ongoing meta-analysis of treatment trials, as well as another research cycle involving statistical analysis and cross-referencing of data on systemic treatment to reveal undiscovered applications, combinations, and the like.

Partnering in CANCON, the EU's new Cancer Joint Action project

EUROPA DONNA's Head of Policy and Public Affairs, Karen Benn, attended the second group meeting of CANCON (CANcer CONtrol), the successor project to the European Partnership for Action Against Cancer (EPAAC). CANCON will run from 2014-2016. ED is a Collaborating Partner on three work packages of the CANCON project, focused on screening, survivorship and community cancer care.

Strength in Numbers



steering committee for screening programme and meetings for breast unit implementation

- Summer party for women with BC
- BHD activities
- Collaboration with other organisations for Cancer Day
- First Lady of Cyprus visit to ED Cyprus House in Nicosia
- The 6th year of the Breast Friends programme
- Group and individual meetings with ED Cyprus clinical psychologist

Activities for 2014

- Lectures with oncologists and surgeons
- Meetings with the president of Parliament about an oncology centre and with Ministry of Health and MPs regarding breast units
- Participation in the steering committee and follow-up of the screening programme
- Pink Silhouette walk
- Research on women's and patients' views on services
- Concert at the Presidential Palace
- Summer party for women with BC
- Meetings with ED Cyprus clinical psychologist
- Breast Friends programme
- Lecture on living with metastatic breast cancer (MBC) by Dr. Olivia Pagani

Czech Republic

Highlights of 2013

- The "You Can Do It, Too" event with a flight in a hot-air balloon to boost BC awareness
- Educational seminars on legal advice for patient organisations
- BHD and the "We are Swimming the Breast Stroke" national event
- Translation of the ED "Short Guide to the EU Guidelines"
- Hosting the ED Pan-European Conference in Prague

Activities for 2014

- Educational seminars for regional organisations on communicating with media, new laws for NGOs
- Translation of the MBC Annex to the "Short Guide to the EU Guidelines"
- Launching the support project for MBC patients
- Translation of the MBC guide published by ED France
- "Mamming Day Prague" event in cooperation with the breast unit to encourage participation in screening
- AVON Walk in Prague and for the first time also regionally
- "It's Not Only Breast" education of secondary school students for BC prevention
- "You Can Do It, Too" with a mini-golf competition
- Annual conference on MBC, multidisciplinary team, and new BC treatments

Denmark

Highlights of 2013

- A stand at the Healthy Lifestyle Fair in Aarhus
- In October, meeting on "How can long-term sequelae after breast surgery be treated?" and "Breast reconstruction during and after surgery for breast cancer"

Activities for 2014

- A gathering on the island of Bornholm in June
- A meeting on "The importance of early intervention on late sequelae and reconstruction after breast cancer surgery in Aabenraa" in September

Estonia

Highlights of 2013

- Monthly Forum meetings, lectures, excursions, and handicrafts
- Charity campaign in May with a video (<https://www.youtube.com/watch?v=0hbf-1sy4IY>)
- A "Run for Women" in May with about 14,000 runners
- Meeting members of Swedish BC organisation in Tallinn in May
- Annual summer camp for all cancer organisations in Estonia in August
- Annual BHD in October and Breast Awareness Month in May with press releases, TV and radio interviews, articles in print media

Activities for 2014

- Monthly Forum meetings
- "Run for Women" in May
- Annual summer camp for patient organisations at a seaside resort
- Campaign event in Tallinn with Femme.ee
- Annual Breast Awareness Month and BHD activities
- Charity concert in October
- Charity campaign with Prisma in May and in October

Finland

Highlights of 2013

- Successful continuation of activities, despite a challenging financial situation
- Launch of Helsinki University Hospital District TOIVO pilot project in March. ED Finland participated in planning and has a joint responsibility for peer support during the project
- Participation of two ED Finland members in the Finnish Cancer Association Delegation 2013-2015
- Establishing peer group activities in several cities, as well as for young and for chronic care patients
- Several awareness-building, cultural and wellness events
- Publishing four issues of ED Finland magazine
- Renewal of the ED Finland website

Activities for 2014

- Diversifying peer support activities to include various patient groups and geographic regions
- Expansion of activities to a national level
- Continued efforts for cooperation with regional cancer associations and membership in the Finnish Cancer Association
- Building cooperation with local and regional public sector organisations



France

Highlights of 2013

- Launch of two new delegations in Caen and Lille
- Opening of new “Café Donna” in different delegations. These are monthly meetings held in a cosy location, where women can gather and openly exchange their concerns over a cup of tea
- Participating in the third Cancer Plan
- Analysing ED France’s survey on patients’ and close relatives’ perception of their BC management
- Increase the physical activity options for patients

Activities for 2014

- Strengthening of delegation activities throughout France, with an additional delegation opening in Nantes
- Follow-up to the third Cancer Plan, announced by President Hollande, and meetings with Health Ministry and National Cancer Institute
- Implementation of initiatives to improve patient outcomes, as highlighted in the 2013 survey
- Annual Conference at the French Senate on “Innovations in all fields connected with breast cancer”

Georgia

Highlights of 2013

- TV bridge with Batumi and ED Georgia regional office to discuss simultaneous initiatives, informing the population of the Adjara region of BC issues through Facebook
- Free examinations in Tbilisi and Batumi in cooperation with medical doctors. ED advocates informed women of the importance of healthy lifestyles in reducing BC risk
- For BHD, a “Healthy Breast Dance” flash mob, live chain with coverage on three TV stations

Activities for 2014

- Free examinations and advocacy at the ED Georgia Batumi regional office in January
- In February, an ED Georgia celebrity member took part in a TV show
- In February, a charity evening “Tango Party” with BC patients modelling dresses by famous designers, with the funds going toward patients needing trastuzumab
- In March, a TV station invitation to speak on existing problems with BC in Georgia
- In May, an exhibition and presentation for MPs and wives of diplomats
- Meeting students and advocacy events in summer
- A charity concert in Batumi

Greece

Activities for 2013 and 2014

- Participating on television panels to discuss BC issues
- Presenting formal proposals to the Greek Parliament to form a Breast Cancer Advocacy Board, to be discussed in Parliament in 2014
- Meetings at the Ministry of Health about the role of NGOs in providing assistance, such as administrative and technical support and know-how, and also through advocacy programmes with the European Commission
- Participating in awareness events such a physical therapy congress where ED Greece spoke about rehabilitation for lymphoedema
- BHD activities in Athens with distribution of ED Greece “Self-Test guides” and guideline brochures

- Participation in medical conferences such as the Breast Cancer Seminar held by the University of Athens
- A booth at the “Money Show” exhibition in Athens to hand out brochures and inform attendees and participants of ED’s initiatives

Iceland

Highlights of 2013

- Co-hosting of a BC seminar. A breast care nurse spoke of her own recent diagnosis
- A BHD walk in downtown Reykjavik
- Attending the Advocacy Training course and the Pan-European Conference
- “The Casting for Recovery” programme, sending 12-15 women on a fishing trip to gain strength from each other in nature
- Meeting with the Health Minister and a Ministry of Health official to object to and discuss the abrupt end of subsidies of special bras for women who have had mastectomies

Activities for 2014

- Participation in the ED Advocacy Leader Conference and the Advocacy Training Course
- Continuing work to defend the rights and to empower women diagnosed with breast cancer
- Maintaining ties with fellow Nordic countries and seeking sponsorship from Icelandic corporations to be able to participate in the 2014 Nordic BC conference

Ireland

Highlights of 2013

- Fashion Targets Breast Cancer Campaign launch
- BHD Oireachtas (government) breakfast with members of parliament and senators
- Two ED Ireland teams entered in International Dragon Boat Regatta
- BHD events nationwide
- BHD “Breast Stroke for Breast Health” campaign
- Focus group sessions to review ED Ireland
- Funding for Dragon Boat Road Show
- ED Ireland talks nationwide
- ED Ireland stands at Irish Cancer Society (ICS) conference and ICS European Week Against Cancer
- Representation on Radiographers Registration Board, Oncofertility Consortium, and the Lymphoedema Prevention Group (National Cancer Control Programme)

Activities for 2014

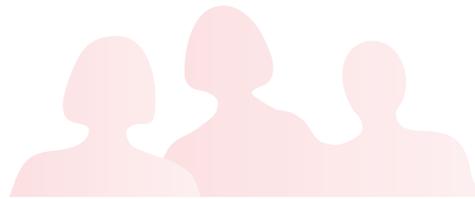
- Dragon Boat Road Show
- BHD activities
- Teams participating in the Dragon Boat Regatta
- Publication of the ED Ireland lymphoedema leaflet
- A public talk by Dr Susan O’Reilly, Director National Cancer Control Programme, Ireland

Israel

Highlights of 2013

- “Pink Dish Programme”
- A press conference with Ministry of Health and BC experts
- A hot-line in collaboration with *Yisrael Hayom*, the most circulated newspaper in Israel
- “Pink Postcard”
- Publishing a comic book *Hope and a Tear through the Lens*
- “Celebrating Life” seminar

Strength in Numbers



- Israel's first "Race in Heels"
- Activity week concluding BC Awareness Month on Ynet, Israel's leading website
- Campaigns and articles in the media
- A one-hour interview with the ED Israel National Representative on the most popular radio station
- Special issue of *Bio* health magazine dedicated to BC issues

Activities for 2014

- A press conference with Ministry of Health and BC experts
- New campaign to heighten awareness of gene mutation carriers
- "Pink Postcard"
- Campaigns and articles in the media
- "Celebrating Life" Seminar

Italy

Highlights of 2013

- Thanks to the commitment within the Oncological Commission, Lombardy approved the guidelines for the breast unit network
- Second meeting with the Associations of Southern Italy, with a new expanded edition of the dossier by associations supporting BC patients
- Dossier presented to the Ministry of Health
- Survey about life and needs of MBC patients presented in Milan and Lisbon

Activities for 2014

- For ED's 20th anniversary and the imminent launch of the breast unit law, three public events in Milan, Catania, Rome with national authorities, European delegates, scientists
- Three training sessions for ED Italy associations: interpersonal skills, health policy, fund-raising
- Survey about protection of women with BC by employers, conducted on workers and companies
- ED Italy delegations visit to the breast unit to make a guide from the women's point of view

Kyrgyzstan

Highlights of 2013

- Efforts to establish a breast health unit, including training a local medical team to use the digital mammography equipment, and adaptation of the EU guidelines in the Kyrgyz Republic
- BC patient support such as psychology consultations, rehabilitation and prevention of lymphoedema, provision of breast prostheses
- Pink October Events and fund-raising
- Organising mobile doctor team visits to regions
- Awareness-raising activities (TV and radio programmes, articles in newspapers and on websites, and printed materials on early detection and healthy lifestyles)

Activities for 2014

- "Movement Against Cancer in the Kyrgyz Republic" Forum in February
- Launching the "Mammography Examination Room" project

- Advocacy for improvement of laws for oncology patients
- Development of "Achyk Kitep", a book compiling issues of oncology patients
- Pink October Events and fund-raising

Latvia

Highlights of 2013

- For World Cancer Day, starting an online oncology-patient advisor where specialists talk about the latest in prevention, nutrition, exercise, etc.
- In summer, a psychosocial rehabilitation programme for survivors
- In October, "Colour Latvia Pink", emphasising breast health promotion
- In November, participating in the ED Advocacy Training Course

Activities for 2014

- Advocating for patients' interests through letters and meetings with government and parliamentary representatives about providing support during and after the treatment process
- Psychosocial rehabilitation programme for women after BC
- Creation of patient support groups throughout Latvia
- Participation in government working groups and projects, advocating for BC patients' interests
- BC screening update and informative activities, attracting the attention of men and calling for mammography through the screening programme

Luxembourg

Highlights of 2013

- A conference and workshop to present *The Year of the Pale Sunflower*, edited by young Swiss cancer survivors
- The 11th Breast Cancer Race with 1200 participants
- BHD in the centre of Luxembourg city, presenting 1000 bras collected in support of demanding best quality diagnostic and treatment services
- An exhibition "Hymne à la beauté"
- Distribution of pink ribbons and information in shops

Activities for 2014

- The 12th Breast Cancer Race on 4 October
- A conference "Breast Cancer, No Longer a Taboo" with presentations by photographers, speakers and performers
- A presentation of the film "Rope of Solidarity" produced in Switzerland, and emphasising the benefit of sports in cancer, especially BC
- A workshop for young women with the aim of creating an active support group for young women

Macedonia

Highlights of 2013

- The Go Pink 2013-Walk for the Cure with around 1500 "pink walkers"
- Participating in the Advocacy Training Course

- VIth National Breast Cancer Conference, with eminent guest speakers such as the Minister of Health and medical experts
- Attending the ED Pan-European Conference in Prague
- A BHD television show, featuring cooking demonstrations and key messages about early detection
- Running a help line
- Psychosocial groups for patients, visiting newly diagnosed patients in hospital and patients on chemotherapy
- "Pink Caravan", an educational tribute for BC held in 15 cities with more than 1500 women participating

Activities for 2014

- The Go Pink 2014-Walk for the Cure
- Participating in the Advocacy Training Course and the Advocacy Leader Conference
- BHD celebrations with a picnic in a renowned national site
- The VIIth National Breast Cancer Conference
- "Pink Night 2014"
- Running the help line and psychosocial groups
- "Pink Caravan" in other cities

Malta

Highlights of 2013

- "Updates in Breast Cancer" seminar for health care professionals
- Acquiring the first ED Malta premises
- Two nurses sent for training as breast care nurses at the Royal Marsden Hospital in the UK
- Breast surgeon sent for conference and exam as breast surgeon
- Awareness through an art exhibition
- Gala/auction dinner
- Fashion show with the participation of BC survivors
- Awareness walks in March and October
- A public lecture on BC
- Two awareness/informative activities in shopping centres

Activities for 2014

- MBC seminar for health care professionals
- Setting up of an MBC group
- Translation into English of the MBC book published by ED France
- Translation into Maltese of *The Year of the Pale Sunflower*, published by ED Switzerland
- 25th anniversary concert
- Art exhibition
- Awareness and donations through selfies on Facebook
- Three awareness walks

Monaco

Highlights of 2013

- In June, the traditional outing to "L'Hermitage"
- In July, H.E. the Minister of State visited the Wellness Centre, an important occasion for ED Monaco
- In October, an "evening of music" to support the association at Monaco's Variety Theatre
- In November, support of the hotel sector
- In December, a fund-raising Gala evening

Activities for 2014

- Launching a new more attractive website, with many reports and a photo gallery (www.ecoutecancerreconfort.org)

The Netherlands

Highlights of 2013

- A conference on hereditary BC, with much media coverage
- In June, the first conference for former BC patients in collaboration with Breast Cancer Research Group and Pink Ribbon
- Theme day for women with MBC

Activities for 2014

- Activities to optimise care, focusing on delay in access to care, psychological support and BC in the elderly
- Activities to empower patients in self-management by providing information on state of the art treatment options
- Editing of the magazine *B*, containing research results, stories of living with BC, interviews and information about treatment
- Development of e-health tools such as web-based questionnaires, a digital newsletter, further development of the "breast cancer care monitor"
- Organising a pre-survivor day for carriers of the hereditary BC and ovarian cancer genes, organising a patient conference on the latest research data, and a day for patients with MBC

Norway

Highlights of 2013

- Meetings on relevant topics, and physical activity events at the 60 local associations
- A weekend gathering for women under 40
- Two weekend gatherings focusing on health and relaxation (yoga/meditation)
- A weekend gathering for women with metastatic cancer and their partners
- A weekend gathering for women with the focus "Life After Breast Cancer"
- A weekend training course for volunteers in the visiting service, contact telephone and self-help groups
- A weekend training course for volunteers
- Visiting 992 newly operated women
- Receiving contacts from 170 women at the contact telephone
- Pink Ribbon Action in October collecting more than 2.4 million euros and increasing BC awareness

Activities for 2014

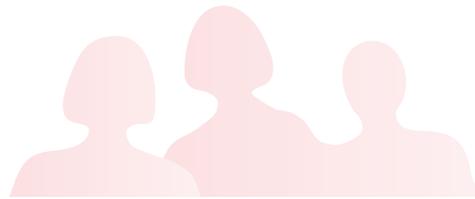
- Breast reconstruction
- Creating awareness of metastatic cancer
- Holistic patient care
- Awareness about hereditary BC
- Pink Ribbon Action in October

Poland

Highlights of 2013

- In March-April, administrative tasks associated with ED reports in the Ministry of Labour and Social Policy, Ministry of Health, etc.
- In June, XVI General Assembly of ED Poland
- In October, BHD activities in ED Poland organisations in Legnica, Dębica, Piła, Nowy Sącz and Przemyśl, plus Pink Ribbon Marches, oncology picnics, scientific and press conferences
- In autumn, a press conference about BHD and ED at the European Parliament

Strength in Numbers



- Participation in the Pan-European Conference in Prague, with a poster display and a basket full of apples

Activities for 2014

- In March, participation of the Polish delegation at EBCC9 in Glasgow
- In June, the XVII General Assembly of ED Poland
- In October, BHD activities
- In November, celebration of 20 years of ED Poland

Portugal

Highlights of 2013

- Writing an article for the newsletter, "More than two decades of activities for early diagnosis of breast cancer"
- In May, attending Parliament Health Days, including meeting the President of Parliament to discuss equal access to BC screening
- In October, a media and digital campaign for BHD
- In November, attending the Advocacy Training Course
- In November, the Advanced Breast Cancer 2 (ABC2) conference in Lisbon, meeting advocates and distributing leaflets at the ED stand

Activities for 2014

- Leaflets about BC prevention for the blind
- Free psycho-oncology consultations for women with MBC

Romania

Highlights of 2013

- Media campaigns for BC awareness with participation in TV and radio debates
- Initiating a draft legislation to allow all employed women to go for annual medical exams during the workday without the concern of being fired or punished
- Cooperating with the Ministry of Health in drawing up a national project for cancer screening
- Pink illumination of a historical building in Bucharest
- Invitations to the National Representative to speak on TV about prevention and early detection
- Continued promotion of the The Medical Centre of Excellence
- Fund-raising events to operate the mobile diagnostic units for breast and cervical cancer

Activities for 2014

- Awareness and communications campaigns and fund-raising events such as the "Art for Life" gala and the pink illumination
- Advocacy for a national screening programme for BC with plans to collaborate with the Ministry of Health by setting the regulations and providing mobile diagnostic units as with other cancer screening programmes

Russia

Highlights of 2013

- Awareness campaign in regions, including advocacy for free access to mammography

- Training for primary care physicians
- Conferences on prevention and early detection
- Training courses for radiologists
- Coordination of mammography screening pilot project in Kursk
- Fund-raising for research
- Donation of diagnostic equipment to 10 screening units

Activities for 2014

- Collaborating in publishing guidelines on radiology, and creating a web portal
- Creating and publishing a manual for newly diagnosed women
- Fund-raising for research
- Participation in ED conferences and meetings
- Creating a national database of clinics with free access to mammography and providing access online and via a free hot-line
- Participation in a panel discussion about women and cancer in the Russian Parliament
- Initiating a panel discussion about the need for a local screening programme in Moscow in the Moscow Public Chamber
- A conference on modern approaches to prevention, detection and treatment
- A rehabilitation group
- Coordination of the pilot mammography screening in Kursk

Slovakia

Highlights of 2013

- Lectures for students, mammography staff and the public with emphasis on keeping healthy
- Contributing to the St. Elisabeth Oncological Hospital magazine *Our Hospital*, collaborating in a series of "Healing Art" exhibitions at the hospital's prevention centre, and teaching women in hospital waiting rooms about early detection and prevention
- Television appearances
- Providing child-minding services for a single mother during her treatments
- Creation of brochures on BC prevention and early detection
- Participating at the ED Pan-European conference in Prague
- In cooperation with the Health Section of the Slovak Ministry of Health, WHO Slovakia and the Scientific Radiologic Society of Slovakia, an initiation of mammographic screening in Slovakia was issued
- Launch of the website www.europadonna.sk

Activities for 2014

- Continuing the same activities as in 2013
- Planning a meeting of NGOs interested in helping ED Slovakia establish breast cancer screening in Slovakia

Slovenia

Highlights of 2013

- Publication of four issues of *ED News*

- 30 lectures about BC, healthy lifestyles and self-examination
- Counselling by telephone, personally, e-mail, in the hospital
- Very active support group for young BC patients
- Two-day seminar for ED members
- October activities, with a focus on 15 October
- Participation in Festival – 3ŽO
- Running and Walking for Hope in five cities
- Publication of an MBC brochure
- Individual lymphoedema treatment for 30 patients
- Update of Breast Test application for smartphones and tablets

Activities for 2014

- Slovenian translation of the ED “Short Guide to the EU Guidelines”
- Publication of four issues of *ED News*
- Patient counselling and emphasis on psychosocial support and holistic rehabilitation
- Promoting guidelines on lymphoedema treatment
- Lectures throughout Slovenia
- A 2-day seminar for ED members: Psychosocial support
- Running and Walking for Hope in three cities
- October activities with a photo exhibition in shop windows, and on 15 October, a flash-mob event with patients and dancers
- Reprint of brochure *Nutrition and Cancer*

Spain

Highlights of 2013

- Physiological support for women with BC and their families
- Physiotherapy for lymphoedema
- Presentation of the study “Information Needs and Health Care Expectations in Breast Cancer Patients”
- ED Spain Universidad Menéndez Pelayo summer course attended by specialists and women with BC covering patient association efforts to face the challenge of maintaining sufficiency, sustainability and efficiency of the public health system
- On BHD, a press conference to present the Manifesto and campaigns to raise awareness of the importance of early detection
- Active involvement in the National Health System Cancer Strategy as a member of the follow-up and evaluation committee

Activities for 2014

- Summer course at Universidad Menéndez Pelayo on patient advocacy and sustainability of the public health system
- On BHD, a media campaign to raise awareness of early detection and to present the 2014 Manifesto
- Advocacy activities and participation in the National Cancer Strategy

Sweden

Highlights of 2013

- Peer support to women with BC and their families
- Yearly award for excellent achievements related to BC treatment
- Award for the Swedish Breast Cancer Nurse of the Year
- Rehabilitation for women with MBC and for young women
- BHD seminar on 15 October and Pink Ribbon activities throughout October
- Yearly meetings at the Parliament related to advocacy work

- Active membership in the Swedish Breast Cancer Group
- Participation in panel discussions and as speaker at the political week in Almedalen, Visby

Activities for 2014

- Participation in national project on cancer strategy
- Cooperation in advocacy with other cancer patient organisations
- Yearly awards to the health professional and the breast care nurse
- Nordic cooperation and participation in the Nordic Conference
- Pink Ribbon activities throughout Sweden during October
- Special awareness for women with MBC and their needs related to specialist breast units and multidisciplinary treatment
- Special awareness about the need for rehabilitation

Switzerland

Highlights of 2013

- Start of the mammography screening programme in the canton of Bern. ED is involved in information and communication.
- 24-hour “Walk for Life” with participation of survivors, physicians and relatives and a group walking 95 km from Lucerne to the Parliament building in Bern
- Presentation of the Italian website (Infoseno.org) on breast health and BC care by the regional group of Southern Switzerland
- Publication of a patient’s agenda by the regional Group of French Switzerland and launch of physical activities for women with BC
- BHD in different parts of Switzerland
- Participation and attendance in conferences in Switzerland and Europe

Activities for 2014

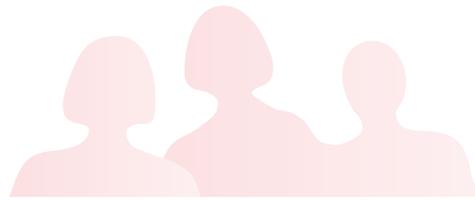
- Start of the mammography screening programme in Southern Switzerland with ED involvement in the information and communication planning
- Cooking course for women in chemotherapy
- Quality of life for survivors
- BHD
- Participation and attendance in various conferences

Tajikistan

Highlights of 2013

- Co-organising the international conference “Women’s Health. Breast cancer and cervical cancer advocacy” with the support of the Ministry of Health and in partnership with US and international organisations. It was widely attended, included 68 presentations, 8 by ED, and adopted a resolution.
- Four regional roundtables on BC advocacy and 12 meetings on BC advocacy
- A Healthy Breast Week with 6 roundtables, training sessions, and 16 information campaigns, with emphasis on healthy lifestyles
- Translating and printing the ED materials on healthy nutrition into Russian and Tajik
- Monitoring and evaluating activities carried out by primary care physicians
- BHD activities
- Participating in conferences and training sessions, such as Advocacy Training, the Eastern Europe/Central Asia Breast Cancer Advocacy, Education and Outreach

Strength in Numbers



Training Programme in Tbilisi, Georgia, and an expert meeting on cancer in Russia

Activities for 2014

- Attending EBCC9 in Glasgow
- Participating in the "Creative Fund-raising" Project by the National Screening Centre of Georgia
- Attending the ED Advocacy Leader Conference and the Advocacy Training course

Turkey

Highlights of 2013

- National awareness campaign through city high schools
- Participating in the 36th Intercontinental Istanbul Eurasia Marathon for BC awareness
- Establishing the Ankara Young BC Survivors and ED working groups.
- Participating in ABC2 and the ED Pan-European Conference
- Working on breast care nurse training with Marmara Universities' BC nurses and coordinators
- Monthly training seminars on BC and femininity, and BC and yoga
- BHD and Pink October activities
- Participating in the ED Advocacy Training Course
- Working with Caritas to raise BC awareness among immigrants
- Participating in the annual International Women of Istanbul Christmas Bazaar

Activities for 2014

- Being a stakeholder of the International Breast Cancer Congress to be held alongside the FIBA Ladies World Basketball Tournament
- Capacity-building and fund-raising activities
- Working with medical faculties on the breast care nurse curriculum and taking part in the development and implementation of courses on patient-doctor communication
- Developing joint projects with neighbouring countries

United Kingdom

Highlights of 2013

- A prestigious week-long stand in Houses of Parliament exhibiting ED publications and activities to MPs and the public
- A symposium on risk factors, prevention and lifestyle for healthcare professionals and BC charities, featuring top experts
- Attendance at All Party Parliamentary Group on Breast Cancer (APPGBC) to hear evidence on support for older women
- An exhibition stand at the "Champions for Change" educational event attended by 100 breast care and chemotherapy nurses
- ED UK representation at a launch of APPGBC's report *Age is But a Number*
- ED UK executive member Victoria Harmer was named Cancer Nurse of the Year by *Nursing Times* magazine

- Various presentations on breast awareness, diet and lifestyles and the NHS Screening Programme
- Attendance at Britain Against Cancer Conference, a government meeting addressing priorities for cancer care nationally

Activities for 2014

- Attendance at EBCC9, with contribution to ED and Scientific Sessions
- Annual Symposium at Medical Society of London "Past, Present and Future Perspectives of Radiotherapy and Chemotherapy"
- In October, talks and exhibition stands for BHD

Ukraine

Highlights of 2013

- Special BHD event in the Ukrainian Parliament, with participation and support of all political parties. Representatives of the Supreme Council Secretariat, Cabinet of Ministers and journalists were provided with updated information on BC, including display of posters and distribution of information materials. The ED National Representative and 8 women MPs discussed the importance of prevention and screening during the press briefing and individual interviews. All national media accredited in the Supreme Council took part in the event.
- A national conference "Breast Cancer Prevention: Information & Partnership" with 66 participants, including key Ukrainian oncologists, Ministry of Health representatives, World Health Organisation representatives, leading rehabilitation specialists, social workers, psychologists and BC organisation representatives, as well as national media representatives

Activities for 2014

- Mammography school for radiologists
- BHD in the Ukrainian Parliament

Uzbekistan

Highlights of 2013

- Regional football matches "In the Name of Life" to support women with BC
- A fund-raising gala concert dedicated to fighting BC and supporting BC survivors
- Psychological training for BC survivors in three regions in partnership with United Nations Population Fund
- A Pink Ribbon gala dinner in October
- Annual early diagnostics charity campaigns for women in all regions of Uzbekistan and the city of Tashkent

Activities for 2014

- Oncology hospital visits by ED Uzbekistan staff throughout Uzbekistan to support BC patients
- Annual Pink Ribbon gala dinner in October
- Psychological training for BC survivors and their families in three regions of Uzbekistan

What's new

EUROPA DONNA has published a booklet *20 years of European Breast Cancer Advocacy* and created a video to mark the celebration of the Coalition's 20th year. The booklet was distributed to all participants at EBCC9 in Glasgow, and the video was shown at a special reception to mark the event. Both are available 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 Croatian and Czech and a Slovenian translation is under way. The Short Guide is now available in 17 languages on www.europadonna.org.

Following the publication of the *Metastatic Breast Cancer Annex to the Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* in 2013, 2014 saw its translation into Portuguese and Czech. All brochures are available on www.europadonna.org.



In June 2013, EUROPA DONNA held a seminar for its Executive Board members to define precisely the role of its advocates in breast cancer research. Based on the seminar the booklet *Exploring the Role of Advocates in Breast Cancer Research* was produced and will be distributed in 2014.

What's on

EUROPA DONNA Breast Cancer Advocacy Leader Conference

Building and Improving Our Organisations for the Future
20 September 2014 – Milan, Italy

Breast Health Day

15 October

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

This year's campaign "Take Your First Step 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 

13th Annual EUROPA DONNA Breast Cancer Advocacy Training Course

14-16 November 2014 – 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

12th EUROPA DONNA Pan-European Conference

17-18 October 2015 – Paris, France

Inbox

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.

Views expressed in this newsletter do not necessarily reflect those of EUROPA DONNA. © 2014 EUROPA DONNA – The European Breast Cancer Coalition



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