EUROPA DONNA
The European Breast Cancer Coalition

Newsletter > Autumn/Winter 2017

13th EUROPA DONNA
Pan-European Conference
October 28-29, 2017

Highlights of the 13th EUROPA DONNA Pan-European Conference

- Progress on the ECIBC – European Commission Initiative on Breast Cancer
- What women need to know about: research, imaging, surgery and radiotherapy
- Best practice for complementary medicine
- Survivorship: support and empowerment

Focus on Metastatic Breast Cancer – Messages from advocates at the 1st EUROPA DONNA Metastatic Breast Cancer Advocacy Conference

Annual advocacy activities in member countries
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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EUROPA DONNA continues to expand, and I would like to give a very warm welcome to our new country forum in Serbia.

2017 began with our annual Executive Board meeting, where we spent one and a half days planning and deciding on our upcoming projects, events and meetings. We welcomed two new Board Members, Sema Erdem (Turkey) and Biba Dodeva (Macedonia). During the year a lot of work has been done between the Board and the ED staff as we try to bring the voice of EUROPA DONNA, the advocacy organisation for breast cancer patients in Europe, to all the stakeholders making decisions on our behalf. And we can note that the ED voice is being heard, and is being listened to more and more.

In March, during the St Gallen Early Breast Cancer Congress in Vienna, Austria, I attended the EBC Council with ED Executive Director Susan Knox and former Board Member Nicole Zernik; there we discussed various strategic issues regarding the future of the European Breast Cancer Conference (EBCC), followed by further meetings and phone conferences. EBCC is an important event as ED is an equal partner in this conference alongside two scientific societies, the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA). Our partnership in this key scientific congress is important and we will work towards its continued success.

Also in Vienna, the Scientific Committee meeting of the Breast International Group (BIG) took place. Researchers from all over the world presented ongoing and new studies. ED is cooperating with this group as the only patient voice for breast cancer. Patient advocate input and opinion was sought on several new trials being undertaken and ED expressed interest in providing further input if invited early on in the trial development. This will include non-drug-related trials in early breast cancer, such as those investigating surgery, lifestyle, or quality of life. ED has asked to be included in the task force as patients are extremely interested in these areas.

In June, while in Milan, Italy, for the 1st ED Metastatic Breast Cancer Advocacy Conference, we held a Board meeting to brainstorm for the next Strategic Plan 2019-2023. Also in June, ED Vice-President Evi Papadopoulos was invited to give a presentation at the Patients and Advocacy Day during the 3rd St. Petersburg Oncology Forum. During her presentation, she gave a brief overview of the Coalition as well as how ED Cyprus implements policies and advocates for services including access to medicines at the local level. Evi also served as co-chair of ABC4 (the International Consensus Conference for Advanced Breast Cancer).

At our Sponsor Meeting during the European Society of Medical Oncology (ESMO) conference in September in Madrid, Spain, we met many of our sponsors, who were very interested in and appreciative of ED’s work.

In October, Sema Erdem was invited to speak at the European School of Oncology (ESO) meeting in Iran.

I have been invited to join the ESTRO PAG, the patient advocacy group of the European Society for Radiotherapy and Oncology.

“We the ED voice is being heard, and is being listened to more and more”

We held our 13th ED Pan-European Conference in Ljubljana, Slovenia, with more than 200 women from 40 countries. It was a wonderful conference and it was exciting to meet so many friends, old and new, women from around the world united by the same concerns and missions. At the opening, we remembered our founder, Umberto Veronesi, who inspired many women to establish ED country groups and to advocate for breast cancer care in Europe. We learned about policy, innovations in treatments, diagnosis and rehabilitation therapies. We gathered a lot of material to bring home to our local friends and advocates.

This will be my last editorial as my presidency finishes at the end of 2017. They were 3 years of hard, rewarding work – we have accomplished a lot since ED’s beginning, but there is still so much to be done. Let us continue joining efforts to reach the day that every woman will have the right and possibility to choose, together with the medical team, the best treatment for her, and the day that all women will be treated in a specialist breast unit.

Thanks to you all, to the Board and to Susan Knox and the Head Office staff for the support over these last three years. I will look forward to seeing you all at our ongoing events.
Advocacy in Action

EUROPA DONNA’s advocacy activities continue to increase both at the European and national level. The ECIBC (European Commission Initiative on Breast Cancer) is now progressing and guideline recommendations are already being posted at http://ecibc.jrc.ec.europa.eu/recommendations. Meetings of the Guideline Development Group on which I sit are taking place every 3 months so that all the recommendations and other guideline material can be completed over the next year. The Quality Assurance Scheme Development Group needs these in order to complete their work. ED Deputy CEO Karen Benn serves as a patient member of that group. The endeavours of both groups making up the ECIBC will ensure that the entire breast cancer pathway is encompassed from screening and diagnosis through treatment, follow-up, survivorship and palliative care. At the same time other organisations such as the SIOG (International Society of Geriatric Oncology) have asked us to work on their quality of life guidelines to provide the patient advocate perspective.

Much of our work this year has centred around advocacy for women with metastatic breast cancer (MBC). We have launched a new section of our website dedicated to MBC (http://mbc.europadonna.org). This was essential to further raise awareness of this issue, discuss the challenges, provide resources and an advocacy tool kit for use by women and advocates. This preceded the launch of our 1st ED MBC Advocacy Conference in June, which was attended by 68 advocates, including 28 who have metastatic disease. It was an inspirational and educational weekend sharing successful advocacy strategies and projects, as well as providing participants with communication skills training and information to help them with their advocacy work at home. Another new action regarding MBC advocacy was the first brainstorming meeting of the ABC Global Alliance, which took place at the St Gallen conference. This is a European School of Oncology (ESO) initiative where I am representing ED on the Interim Steering Committee. We have since agreed on a governance document, and the ABC Global Alliance charter describing the mission and goals of this new entity. Evi Papadopoulos, ED Vice-President, represented us as the co-chair of ABC4 and both of us attended the first meetings of the ABC Global Alliance. In addition, ED has been awarded a SPARC grant to continue our work on MBC advocacy, thus enabling us to provide an MBC advocacy course in 2018.

“We look forward to the combined efforts of all concerned, both at European and at local levels, to see that action on best practice begins now.”

Keeping breast cancer on the EU policy agenda is a key organisational objective. Toward that end ED representatives participated in various initiatives this year providing the breast cancer perspective on an “EU Strategy Against Women’s Cancers” to the Committee on Women’s Rights and Gender Equality (FEMM) of the European Parliament; giving a breast cancer advocacy presentation at the Council of Europe committee hearing on “Women and Breast Cancer”, and writing an article for the Government Gazette on our advocacy work and priorities.

We continue to be engaged in the breast cancer research agenda, attending Breast International Group (BIG) meetings and participating in the AURORA, OLYMPIA, and MINDACT steering committees. Several HORIZON 20/20 breast cancer projects have now received funding from the European Commission; ED has been invited to represent patients on an advisory committee as well as on an ethics committee. We have again provided the patient advocacy lecture for the ESO/University of Ulm course for breast specialists. In addition, Karen Benn gave a presentation in the session on health services research in cancer at the European Society of Medical Oncology (ESMO) congress and at the first International Forum on Cancer Patients Empowerment meeting in Milan, Italy.

Our Breast Health Day programme is now in its 10th year. A new video is produced each year showing members engaged in healthy activities and can be viewed at www.breasthealthday.org. This year, 24 of our national groups conducted special prevention and healthy lifestyle activities.

Our 13th ED Pan-European Conference focused on moving from “Policy to Breast Practice”. More than 200 advocates from 40 countries gathered in Ljubljana to be updated on best practice and gain insight on how to improve breast services in their home countries. This is now essential as we begin to disseminate the new guideline recommendations from the ECIBC. They are only valuable if we succeed in getting countries to act on them and implement them. Our country organisations are getting stronger and stronger so we look forward to the combined efforts of all concerned, both at European and at local levels, to see that action on best practice begins now.
The 13th EUROPA DONNA Pan-European Conference welcomed more than 200 breast cancer advocates from 40 countries to learn about progress in best practice for breast cancer care and to network with other advocates.

Tanja Spanic of ED Slovenia and ED President Roswitha Britz

Representatives of ED Armenia

Head Office staff Barbara Klein, Paige Robinson and Daniela Pirisi

Stella Kyriakides of ED Cyprus and Evi Papadopoulos, ED Vice-President

ED Board Members and ED Founding President Gloria Freilich

Mona Knotek-Roggenbauer and Olivia Pagani (ED Board members), Robert Mansel and Ruud Pijnappel

Representatives of ED Slovenia

Active advocates

Advocacy dinner
European Commissioner for Health Vytenis Andriukaitis spoke to advocates in a video address and emphasised that with the ageing European population, access to high-quality breast cancer screening is more important than ever. He mentioned three European Commission initiatives of particular importance to advocates: (1) The European Commission’s report on cancer screening presented in 2017 shows that concrete results have been achieved – with 25 member states having some form of population-based screening programme – but more efforts are needed. To address this need, (2) the Commission’s initiative on breast cancer – ECIBC – covers the whole cancer cycle, from screening and survivorship, to palliative care. (ED Executive Director Susan Knox and Deputy CEO Karen Benn sit as individual members on ECIBC committees.) “The time has now come to put in practice these guidelines, recommendations and best practice,” the Commissioner said. (3) A new Joint Action on Cancer is to begin with the aim of supporting member states in implementing concrete measures for prevention, innovative treatment, survivorship, pain control, and optimisation of resources for patient care. The Commissioner thanked the ED advocates for their dedication to improving breast cancer care and thanked EUROPA DONNA for its contribution to the ECIBC. The video address is available on the ED Facebook page: https://www.facebook.com/EuropaDonna

Elke Anklam, Director of the European Commission’s Joint Research Centre (JRC) Directorate F – Health Consumers and Reference Materials, outlined the structure and mission of the JRC, which is the body responsible for the ECIBC. For breast cancer care, the JRC’s specific functions involve harmonising cancer screening methods in the EU, coordinating and hosting cancer registries, and supporting the ECIBC. She said that within the ECIBC transparency is very important, and the country fact sheets and other comparative data can serve as an incentive for countries to provide high quality health care to their citizens.

Donata Lerda of the JRC and the Healthcare Quality Group Leader described the ECIBC activities and the progress to date. The ECIBC has three main steps or phases: 1) Developing evidence-based European Breast Guidelines for screening and diagnosis; 2) Creating a guidelines platform for treatment, rehabilitation, follow-up and palliative care; and 3) Implementing a European breast quality assurance (QA) scheme for breast cancer service accreditation. The guidelines are tailored for three profiles – individuals/patients, professionals and policymakers – and those for patients will be available in all EU languages on a web hub that can be updated as each recommendation evolves. Ms Lerda summarised the preliminary recommendations now posted on the age for screening (Yes for 45-74 years; No for 40-44 years) and imaging techniques. Screening in women of average risk can be performed with either mammography or tomosynthesis. In women with dense breasts, additional screening with ultrasound or magnetic resonance imaging (MRI) were not recommended, but mammography or tomosynthesis could be offered. Towards the end of 2017, recommendations are to be ready on screening.
Best Practice for Clinical Practice

- **Olivia Pagani**, Director of the Breast Unit of Southern Switzerland and an ED Board member, stressed that patient advocates should be involved in academic clinical trials from the beginning by participating in the steering committees and ethics committees. Among other areas, this could help improve the informed consent process for patients. She added that patients should be informed of clinical trials to participate in and that participants need to be notified about the results. Advocates should also help promote relevant clinical trials that should include patient-reported outcomes (PROs) that measure quality of life issues and real life cost and benefit of a treatment. Performing global trials reduces duplication of effort, while speeding up accrual and results. Advocates should help disseminate trial results and see that they are put into practice.

- **Ruud Pijnappel**, Professor of Radiology at UMC Utrecht and Chair of LRCB Dutch Expert Centre for Screening, described imaging techniques for screening in women with dense breasts saying that the degree of density is in the eye of the beholder (eg, radiologist), and dense breasts are not high risk per se, it is that dense tissue may mask tumours on mammogram. He outlined the evidence for supplemental imaging in dense breasts, evidence that backs the recommendations in the new ECIBC European Breast Guidelines: mammography remains the best detection method, not bettered by tomosynthesis (3D mammography), ultrasound (whether hand-held, 3D or automated), or contrast enhanced spectral mammography (CESM; with a higher radiation dose and use of IV contrast solution). He added that for magnetic resonance imaging (MRI) data are lacking and intervals, invitation tools, use of biopsy in diagnosis, Ki67 and conventional staging. In 2018, recommendations on biomarkers, communication and double reading, among other topics, are to be released. Also in 2018, a pilot programme of the QA scheme will assess its functioning and feasibility and the final QA scheme is to be available in 2019.

- **Robert Mansel**, Chair of the ECIBC’s Quality Assurance Scheme Development Group (QASDG) outlined the process for and importance of identifying quality indicators that are clinically relevant, relevant to patients and based on solid evidence. These are the indicators that will be measured to determine a breast unit or hospital’s level of quality. He added that there is a “clear message that the more you treat, the better it is”. In terms of how high to set the bar for quality, he said that it must be set high enough with “meaningful quality indicators that will improve women’s health.”

- **ED’s Deputy CEO Karen Benn**, who sits as an individual patient advocate on this group, said that the QA scheme is to address inequalities in breast care services, which has long been an ED priority. It is to be a voluntary scheme, developed jointly by the QASDG and JRC/ECIBC coordination team to address all processes in the treatment pathway using both accreditation (for testing activities) and certification (for the entire continuum of care). She added that patient advocates have an equal vote to clinicians on all aspects of the QA scheme. “We are equally and actively involved in all meetings and our experience as individual patient advocates is valued,” she added. The QA scheme is based on evidence that is linked to better outcomes, which she said will be key to advocating for them to be put into practice.

- **Tit Albreht**, from the National Institute of Public Health in Ljubljana, Slovenia and Co-ordinator of Joint Action Cancer Control (CanCon), discussed programme implementation and best practices. It is beneficial to be able to identify high-risk groups for screening (eg, women of a specific age), and higher risk profiles for breast cancer need to be identified. He pointed out that screening programmes and registries need to be linked to measure benefits. They can also help to identify access to screening by women of different socioeconomic groups or educational levels. Future approaches to screening will be stratified, as will treatment approaches. He stressed the importance of the patient voice: “Patient preference has to become much more important than in the past because the spectrum of choice is increasing.”

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**How does your country compare? Resources and Tools for Advocates**

ECIBC web hub (including preliminary diagnosis and screening guidelines)
http://ecibc.jrc.ec.europa.eu/recommendations

ECIBC country fact sheets (demographics, epidemiology, screening programme and quality assurance data)
http://ecibc.jrc.ec.europa.eu/ecibc-country-profiles

Cancer Screening in the European Union (2017). Report on the implementation of the Council Recommendation on cancer screening (covering screening programme implementation and performance, such as participation rates and cancer detection rates with specific, comparable data for each country)
an ongoing trial in breast density in the Netherlands expects to have results in 2018. He ended with a warning about misconceptions: \textit{thermography} is not a replacement for mammography screening.

\textbf{Robert Mansel}, Emeritus Professor of Surgery at Cardiff University School of Medicine in the UK, said that screening and early detection, as well as neoadjuvant treatment, have led to more breast-conserving surgery (BCS) than mastectomy due to reduced tumour size. Recurrence rates are low for BCS and radiotherapy (RT) in certified breast units, and the use of \textit{sentinel node} staging has led to a dramatic drop in axillary dissection and reduced lymphoedema in the last 10 years. Based on the START study, the use of a 40 Gy radiation dose over 3 weeks has now become standard over the historical regimen of 50 Gy over 5 weeks. For \textbf{breast reconstruction}, he said that delayed reconstruction has more favourable results with less readmission and greater patient satisfaction than immediate reconstruction. He added that RT should be given in cases of immediate reconstruction. In \textit{whole vs partial breast RT}, a Cochrane review slightly favours RT of the whole breast rather than just in the tumour vicinity. However, the UK \textbf{IMPORT LOW} trial in more than 2000 patients found that partial breast and \textbf{reduced dose RT} were not worse than standard whole breast RT in terms of local relapse; and adverse effects were similar or fewer. Prof Mansel added that it needs to be determined if the small gains in adverse effects are enough to abandon whole breast RT in patients with a good prognosis.

\section*{Supporting the Survivors: From CAM to Survivorship Programmes}

\textbf{Sanja Rozman}, medical doctor, psychotherapist and survivor, covered the use of \textbf{complementary medicine (CAM) and rehabilitation}, to address the physical, psychosocial and spiritual effects of cancer and its treatment. Rehabilitation offered as part of \textbf{interdisciplinary treatment} helps patients regain strength, independence, reduce stress, and can include \textbf{physical therapy} (individualized exercise training) or \textbf{manual therapy} (eg, massage, acupuncture and reflexology). CAM involves treatments used alongside standard medical treatments (while alternative medicine is in lieu of such treatment) and while they do not cure cancer they can help in recovery. The list of CAM is long and includes \textit{music therapy}, \textit{soy}, \textit{tai chi} or \textit{marijuana/cannabis}, to name a few. Medical cannabis (eg, as sprays, capsules or tablets) is used in some countries to control chemotherapy-associated nausea, or for treatment of pain. As some CAM, such as St John’s Wort or vitamins, can interfere with cancer treatments, Dr Rozman advised women to discuss their use with their doctor. She recommended advocating for access to standard treatment and for CAM therapies to be tested in a similarly rigorous fashion.

\textbf{Natalie Doyle}, from the Royal Marsden NHS Foundation Trust in the UK, said that as cancer is now recognised as a long-term condition, “patients” must be \textbf{partners in the care process}. She highlighted that it is about people, not about cancer alone, and that policy makers need to keep this at the forefront when designing \textbf{health care policies}. Advocates should remind policy makers about their purpose: \textbf{person-centred care} should be the pillar of all approaches. She added that the language used when talking about people with cancer can change perceptions (eg, use of the word “patient”). The care goal should be to help people live as well as they can. By 2020, everyone diagnosed with cancer in England and Wales is to receive the \textbf{Recovery Package}, including a \textit{holistic needs assessment}, a \textit{treatment summary} and an invitation to attend health and \textit{well-being events} for peer support, as well as a cancer care review undertaken by the primary care team. Dr Doyle said that people need to be asked what concerns them when they are diagnosed and what concerns them about treatments as they move forward: “What's the matter with you? Becomes: What matters to you?” Evidence suggests that person-centred care is not only better for the individual but more economical for service providers – which provides \textbf{grounds for advocacy}.

Macmillan Cancer Support in the UK has a number of publications with tips on person-centred care:

\textbf{Recovery Package Toolkit}
\texttt{www.learnzone.org.uk/recoverypackage}

\textbf{What to do after cancer treatment ends: 10 top tips}
\texttt{After Cancer Treatment: A Guide for Professionals}
\texttt{www.macmillan.org.uk}

Sanja Rozman and Sema Erdem (ED Board member)
Making our Voices Heard

MBC Advocates Speak Out

EUROPA DONNA has made metastatic breast cancer (MBC) a priority for its future advocacy activities as women with MBC face different challenges from those with earlier stages of breast cancer and many of their needs are unmet and not well understood. With this in mind, ED held its First Metastatic Breast Cancer Advocacy Conference in June. Here some of the advocates who attended that conference share some words of reflection and inspiration for others.

Sabine Spitz Austria
“I make MBC seen and heard with all its special needs! It matters to me as an MBC patient and advocate!”
I was diagnosed with MBC in February 2014. I used to work as a clinical psychologist and psychotherapist and now I am a full-time volunteer as vice-president of ED Austria, and as a patient advocate with EUPATI Austria. This has been very important for me, as it has given me back some normality. We all need a purpose in life. My life has changed a lot, but I am the proof that MBC can just be a chronic disease. You have a few handicaps because of the treatment but you can live quite a good life. I am the proof of it.

Elena Volkova Russia
“Don’t worry, be happy every moment your life.”
Two years ago I was diagnosed with MBC and all my dreams were crushed. The treatment was difficult, but this is not the end. I am an active person and love sport – swimming, cycling, running. I am going to run in a race, go sky diving and buy a motorcycle. I believe that everything in my life will be OK! Set goals! Be strong! Feel happiness in your heart and the whole universe will help you. Use every moment to make your life better! You can do it!

Marie Pandeloglou Australia
“I must have missed the memo that said that my breast cancer could come back…”
I share this burning fire in my belly to be the voice of women in Australia living with MBC, as I am. Something needs to be done and it needed to be done now. MBC can no longer be ignored – it is real, it needs awareness, research, funding and ultimately a cure.

Martine Krammer Austria
“‘Create your world, as you like to see it.’ This is what I practise each and every day – as every day is precious and you are precious.”
I was diagnosed with MBC in 2016, about 13 years after my first breast cancer diagnosis. After some arduous treatment I could hardly walk. I felt I had no power and energy to move out of this condition. Then I asked myself “Is this really me? Will I stay in this bad condition or do I want to change?” Inspired by the report of a 90 year old woman, I started practising yoga sessions each morning together with my small dog. It is amazing how quickly it works to get from an extremely weak body to a stronger one. Some words of encouragement: What was your favourite movement as a child? What brings you joy and happiness? Dancing, singing, acting, being in nature or playing music? Is there something you have wanted to try for a long time? If you do what your body really enjoys, the benefit can be huge. And most of all, you can gain back the feeling of trust in your body.

Meri Petrova Macedonia
“Cancer made me discover a better me, which I like the most.”

Daniela Travnik Macedonia
“To live with MBC is not easy but it’s possible. I’m here to prove it.”

Ger Byrne Ireland
I am a wife, a mother, a granny, a sister, a friend.
I am passionate about about life, people and my work.
I am a dragon boat paddler.
I am an optimist.
I am also an MBC patient, but it is not who I am.
Making our Voices Heard Across Europe

EUROPA DONNA’s First Metastatic Breast Cancer Advocacy Conference
ED held its first conference for metastatic breast cancer (MBC) advocates in Milan, Italy, in June where 68 women from 34 countries and 6 continents gathered to exchange ideas, experience and best practice. There were expert talks on science and advocacy, as well as communication/advocacy skills training and workshops on using personal stories to communicate effectively with the media and policy makers. Some advocates were filmed and video clips on their experience with MBC are now available on the new MBC section of the ED website (http://mbc.europadonna.org). A report on the conference will follow.

Working together on the ABC Global Alliance and the ABC4 Conference
ED Executive Director Susan Knox serves on the Interim Steering Committee of the ABC Global Alliance and attended several meetings in 2017 to develop the ABC Global Charter and the Terms of Reference document describing its mission and goals. The ABC Global Alliance, established by the European School of Oncology (ESO), is a multi-stakeholder platform for all those interested in collaborating on common projects relating to advanced breast cancer (ABC) around the world. The first meeting was held in November following the ABC4 Conference in Lisbon, Portugal. ED Vice-President Evi Papadopoulos was the co-chair of that conference, where ED also had a booth, and many advocates were in attendance.

Continuing collaboration with the ECIBC
Susan Knox and ED Deputy CEO Karen Benn have attended regular meetings for the European Commission Initiative on Breast Cancer (ECIBC), which aims to deliver a voluntary European quality assurance scheme for breast cancer services (QASDG) and to develop new European Breast Guidelines for Screening and Diagnosis. Susan Knox sits on the Guidelines Development Group (GDG) and Karen Benn is on the working group developing the quality assurance scheme. The GDG is devising a new set of about 90 evidence-based breast screening and diagnosis recommendations, the first group of which are now live on a web platform (http://ecibc.jrc.ec.europa.eu/recommendations). The rest will be developed in 2018 and the supporting data are to underpin the quality assurance scheme for breast care services. ED is a stakeholder in this initiative and will be disseminating information on it at all of its conferences going forward.

Bringing the advocacy voice to the EU Parliament and Council of Europe
Karen Benn has represented ED at various EU Parliament meetings throughout the year. At a public hearing of the European Parliament’s FEMM committee (the Committee on Women’s Rights and Gender Equality) entitled “EU Strategy Against Women’s Cancers”, she was an invited speaker and ED’s European initiatives were shared with the stakeholders present. The hearing provided input to the rapporteur Daniela Aiuto (MEP Italy) for the upcoming report on the subject on behalf of FEMM. In October at the Council of Europe, Elizabeth Bergsten Nordström, former ED President, gave a short presentation on employment and insurance issues faced by women with breast cancer; this was followed by an exchange of views with the Committee members.

Speaking at ESMO and IFCPE
Karen Benn was invited to speak at the European Society of Medical Oncology (ESMO) conference in September 2017 in a session on health services research. Her presentation was entitled “Health Services Research – What Cancer Patients, and Advocacy Organisations, Want”. She was also invited to present at the first International Forum on Cancer Patient’s Empowerment (IFCPE) in Milan in May 2017 in a session entitled “EU Action Plans – What’s Next for Cancer Patient Empowerment?”

Sharing patient advocacy strategies
Susan Knox is an invited lecturer in the ESO/University of Ulm Certificate in Competence in Breast Cancer postgraduate e-learning course for physicians with experience in the field of breast cancer. Her lecture entitled “Optimising Adjuvant Strategies: The Patient’s Perspective” takes an optimistic look at the many initiatives that can lead to living “a vibrant, intellectually fulfilling life after breast cancer” and the specific advocacy activities of ED over the years.

At the White Nights 3rd St. Petersburg Oncology Forum in Russia in June, Evi Papadopoulos gave a presentation during the Patients and Advocacy day. She gave a brief overview of the Coalition as well as how ED Cyprus implements policies and advocates for services including access to medicines at the local level. ED Board Member Sema Erdem was invited to speak at the ESO Breast Cancer Observatory 2017 held in Tehran, Iran, in October, where she introduced ED’s activities and emphasised the multidisciplinary team approach to breast cancer care.

Promoting women’s health through Breast Health Day
This ED event is held every year on 15 October 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. The 2017 campaign began months before BHD with a regular social media campaign with messages and images encouraging women to choose a “Healthy Lifestyle for Breast Health”. Via the social networks, people were asked to send in a picture of themselves doing something healthy; these were included in a video launched on 15 October. ED member countries spread the messages through their local campaigns. Detailed information is available on the ED website dedicated to this initiative (www.breasthealthday.org).
Albania

Highlights of 2016

- A “Donate Hair, Give Hope” campaign lasting several months
- An “Open Letter” on issues faced by women with breast cancer (BC), with many diplomats’ and foreign representatives’ signatures
- Creating a “Zen Room” for women with BC
- First training course for local organisations on advocacy for better health
- “Ride for Life”
- A volleyball team activity at the Sports University in Tirana
- Joining the first “Patient association coalition” which involves meetings and demonstrations concerning patients’ rights
- Obtaining media support for activities and attention to oncology issues

Activities for 2017

- The second phase of “Donate Hair, Give Hope”, providing wigs for women
- Publishing 2 ED Albania newsletters for free, with the daily newspaper Panorama
- Creating a website dedicated to women and cancer
- October activities
- Meetings with women with BC, a roundtable with patients, doctors and policy makers

Activities for 2017

- A charity concert “You Are Not Alone” for women with BC
- Street activities in 3 different towns, promoting early detection
- A “Conquerable Cancer” conference with doctors and patients
- Throughout July, swimming training for women with BC, and a small competition
- A bicycle ride around Yerevan
- In October, an “I Love You Mummy” walk of BC survivors with children, wearing pink T-shirts
- Free ultrasound for BC, trainings and meetings in regions
- Meetings in hospitals with patients and doctors

Austria

Highlights of 2016

- 3rd Austrian Breast Cancer Patients Congress
- Breast Health Day (BHD) campaign: “Day of Movement”
- Cooperation with Austrian Cancer Aid and Pink Ribbon
- Pink Dragons Austria paddling event
- Participation in conferences and public events

Activities for 2017

- 4th Austrian Breast Cancer Patients Congress
- Annual activities: advocacy and public relations, “Day of Movement” BHD campaign, cooperation with Austrian Cancer Aid and Pink Ribbon, Pink Paddling events and participation in conferences and public events

Belgium

Highlights of 2016

- Participation in the 10th European Breast Cancer Conference (EBCC10)
- Participation at the EORTC patient’s day
- Several conferences throughout the country: “Healthy Food and Moving: What a Pleasure!”
- Conference on implementation of specialist breast units (SBUs) and the need for breast nurses
Strength in Numbers

- Presentation at the symposium of the Belgian Society of Lymphology
- Attending the Breast Cancer Group Forum in Milan
- Participating in ED Advocacy Training course
- Attending the Breast Cancer Europe Roundtable by the International Centre for Parliamentary Studies
- Holding the ED Belgium General Assembly in France and meeting with ED France
- Promoting BHD
- Press communication for the reimbursement of breast reconstruction

Activities for 2017
- Conference on healthy lifestyles and implementation of SBUs
- Letter to the Belgian Minister of Health concerning the implementation and monitoring of SBUs
- Attending the ED Pan-European Conference

Bulgaria

Highlights of 2016
- Meetings with parliamentarians to present issues concerning BC in Bulgaria and ED activities
- Meeting with health professionals to promote best practices
- Participation in the activities of APOS, a patient organisation for different types of cancer
- Participation in 3 radio shows and in one TV talk show on the main topics of breast health, prevention and breast health in young women

Activities for 2017
- Aiming to participate in 3 radio shows and additional radio and TV programmes
- Activities in cooperation with other cancer organisations
- For BHD, participation in a national TV morning show, and promoting the BHD video on the ED Bulgaria Facebook page

Croatia

Highlights of 2016
- “Daffodil Day” event in 33 cities, including the main event in Zagreb city centre
- Attending EBCCT10 and the ED Advocacy Leader Conference Annual General Assembly (AGA)
- Fund-raising campaigns to purchase an intraoperative radiotherapy (IORT) device
- Advocacy activities for SBUs and on comprehensive cancer care and research
- Participating in national projects for the cancer strategy
- Media campaigns and lectures on BC and on healthy lifestyles, as well as BHD activities
- Pink Ribbon activities and walks
- Participating in the working group to establish Croatian guidelines for genetic testing for breast and ovarian cancer

Activities for 2017
- Fund-raising activities including a humanitarian run “Donate for Donna”; a movie screening “Mamma”; and a theatre performance “Comet”
- Participating in “Making the Cancer Partnership Work”, a joint action of cancer patient organisations in European Economic Community countries
- Raising awareness through lectures in schools and other target audiences
- Annual activities: Daffodil Day event; Pink Ribbon activities and walks; conference attendance (ED Pan-European Conference and MBC meeting)
- Updating ED Croatia leaflets

Cyprus

Highlights of 2016
- Annual activities: a summer party for women with BC, Pink Silhouette walk, BHD activities, pink illumination of Paphos
- Medieval castle, “Look Good, Feel Good” day activities, participation in conferences abroad, psychological support by an ED Cyprus psychologist, “Breast Friends” support programme, crafts workshops, Christmas and Easter family food packages, lectures in all towns, participation in solidarity runs
- Meetings with the Ministry of Health about implementing a SBU in Nicosia General Hospital
- Participation in the steering committee of the national screening programme
- Letter in memory of an ED Cyprus member
- Workshop on empathy, creativity and drama therapy
- Co-organising a Cancer Day event
- Co-organising a conference on home nursing with other organisations in Cyprus and Greece
- Membership in the Cyprus Patients’ Organisation that represents Cyprus at the European Patient Forum (EPF)
- Updating all ED Cyprus leaflets
- Participating in a charity event “i Fitness”, with all day Pilates, yoga and other fitness activities
- Musical charity event at the Presidential Palace

Activities for 2017
- Annual activities: Pink Silhouette walk, BHD activities, pink illumination of public buildings, conference participation, fund-raising fashion shows, Breast Friends programme, psychological support, lectures, solidarity runs, “Look Good, Feel Good” day activities, summer party for women, Cancer Day activities, national screening programme participation, being board members of Cyprus Patients’ Organisation
- Opening of the SBU in Nicosia General Hospital
- Longest knitted scarf event in memory of a member
- Sponsored seminar on lymphoedema
- Lectures on the relationship between the breast, body image and art, “The Preventive Power of Food” and “Bereavement and Loss in Children”
- Meeting with the national organisation of breast surgeons
- Translation of the oncoplastical breast reconstruction guidelines
- Participation in the Europe Day events

Czech Republic

Highlights of 2016
- Professional seminars for patients’ organisations on psychological support during and after treatment
- Annual Alliance of Women with BC conference
- Campaigns on importance of BC prevention – BHD (“We Are Swimming the Breast Stroke”, “Closely Watched Breasts”, a walking event, education at schools)
- Ongoing “Invisible Women” project focused on MBC
- Ongoing “Bellis Young & Cancer” project focused on young women

Activities for 2017
- Celebrating the 15th anniversary of the Alliance of Women with BC with local organisations
- Psychological workshops with professional training in self-support of patients due to lack of oncological psychologists
- Annual activities: Alliance of Women with BC Conference, BHD, education at schools, “Bellis Young & Cancer” and “Invisible Women” projects
- Closely Watched Breasts campaign: a “Breast Tent” in Hradec Královo and a travelling “Breast Wall” exhibition in local cafes in 30 towns

Estonia

Highlights of 2016
- Cancer patient group monthly meetings with presentations and counselling
- May Breast Health Awareness Month activities with full media coverage. The ED mammography bus promoted breast screening at the marathon for women
Creating a cycle of films under the main title “I Defeated Breast Cancer”

Activities for 2017
- Continuing the cancer patient group meetings
- Launching a new BC education campaign (“Pink Rules”) in May on co-operation with health education university students and patient volunteers
- Annual summer retreat for cancer patients
- National-wide Pink Ribbon campaign to coincide with BHD
- Advocating for the National Breast Screening Programme which will be extended to age 69 from the current 62 years

Finland

Highlights of 2016
- Producing a video on how to exercise to ease lymphoedema symptoms
- Training new peer support specialists
- Art therapy courses
- Recreational activities for women with MBC
- BHD event at the Helsinki City Centre, giving away “healthy bags” with fruit and information on breast health
- “Pink Bales” fund-raising campaign

Activities for 2017
- Producing a Q&A leaflet to help patients with shared decision-making at doctor's appointments
- Training new peer supporters and starting new groups
- Different theme weekends, recreational activities
- BHD activities
- Lectures providing information on BC and ED Finland in several cities

France

Highlights of 2016
- Introducing a new scientific board and steering committee
- Participating in various scientific committees and advisory boards (Unicancer, Institut Curie, Screening organisations, Cancer League)
- Advocacy for equal access to best care for all patients

Activities for 2017
- Monthly Café Donna in Paris, Lyon, Bordeaux, Nantes, Auxerre, Strasbourg
- Sailing and biking in Nantes
- Country trek and city trek in Lyon and Angers
- Dragon Boat with the Paris Dragon Ladies
- Pink October all across France
- And also music, theatre and more

Georgia

Highlights of 2016
- Completing the “Target For Life” information campaign for co-financing of BC treatment, with a further extension to include MBC
- BHD activities with students at medical faculties with TV campaigns, charity concerts, patients’ art exhibitions, advocacy activities and free examinations for women in regions
- Creating a cycle of films under the main title “I Defeated Breast Cancer”, featuring women with BC telling their stories, and aired on national TV

Activities for 2017
- Continuing the film cycle “I Defeated Breast Cancer”
- Bringing together the representatives of state institutions, medical doctors, mass media and NGOs in a roundtable to discuss solutions to patients’ problems
- For BHD 2017, a flash mob with students and a televised concert with participation of celebrities

Greece

Highlights of 2016
- Attending the ED Advocacy Training Course
- Participating in TV panels on BC
- Participating in the Parliamentary Committee on BC Issues to discuss such topics as access to diagnosis, treatment and reimbursement, and to collaborate in conducting a survey on BC therapy and general health services
- Meetings at the Ministry of Health on NGOs and their help in maintaining the national health care system
- Participation in the Centre for Disease Control Committee on Cancer Registries
- BHD activities
- Organising an educational event on BC prevention and treatment with the participation of renowned physicians and 250 attendees

Activities for 2017
- Participation in the Women for Oncology Cancer Conference
- Increasing membership by 500 people through a web-based registration process
- Developing a charity programme to offer free mammograms and genetic tests for women unable to afford the test
- Forming a committee with the Greek Oncologists
- Organisation to propose a reimbursement programme for genetic testing to the Ministry of Health, and providing scientific data on the topic
- Participating in the Athens marathon as an ED Greece team

Iceland

Highlights of 2016
- “Casting for Recovery,” a fishing activity, every year for women in rehabilitation after BC treatment
- Monthly “open meetings” on different discussion topics for women diagnosed with BC
- The biennial Nordic Congress on Breast Cancer, held for the first time in English, with more than 150 participants, and focusing on hereditary BC and living with BCA “Pink Forum” on late side effects of BC treatment, with lectures from women in Iceland and Denmark and professionals in association with the Icelandic cancer associations

Activities for 2017
- Annual activities: “Casting for Recovery”, monthly open meetings, “Pink Month” and BHD activities, and preparing for the next “Pink Forum”

Ireland

Highlights of 2016
- Attending EBCC10 and the ESO-ESMO Breast Cancer in Young Women Conference
- Increasing activity in patient involvement in research by contributing to 2 EU Horizon 2020 research proposals, one of which has reached the second round
- Participation of ED Ireland representatives on bodies including Patient Forum for the National Cancer Strategy and Radiographers Registration Board
- Launching “Connect MBC Network”, a private online forum for women living with MBC plus a public information platform, and co-hosting a seminar, “Metastatic Breast Cancer & You”
• BHD activities including Ireland’s largest university with events on campus to encourage students to pledge lifestyle changes for future breast health, and local awareness raising events at community centres across the country
• ED Ireland stands at a number of events and conferences

Activities for 2017
• Development of Connect MBC Network project
• BHD 2017
• Upgrade of ED Ireland website
• Campaign issues: improved MBC services; legislation for private hospitals; completion of national cancer strategy
• Expansion of national network of ED Ireland volunteers

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Israel

Highlights of 2016
• A press release on up-to-date BC incidence, survival and mortality rates in Israel
• Annual “Celebrating Life” seminars, including ones for young women with BC and women with MBC
• New public information booklets and advertisements
• Support groups for BC patients and their partners as well as for specific groups, eg, women with MBC
• Partnering with a cosmetic company in illuminating the Charles Bronfman Auditorium in Tel Aviv
• Premiere screening of the film Mama Mia, a tribute evening to raise MBC awareness
• “Sister in Pink” fund-raising event
• “Things Aren’t as Bad as They Seem”, a play by Aviva Rosen who has faced BC
• Collaboration with photographer and BC survivor Michal Bendek, who took semi-nude shots of 40 women for a social media campaign to raise awareness of early detection
• Disseminating ED materials via the website and Facebook

Activities for 2017
• A press release on national BC incidence, survival and mortality rates
• Continued posting of public service announcements, articles, personal stories and ED materials on the website and Facebook
• Annual seminars
• Support groups for BC patients and a special support group for their partners

Italy

Highlights of 2016
• Promotion of the SBU law with public events in Turin and Terni
• Implementation of BC screening in the south with events in Catanzaro
• Creating the second and third chapters of an interactive library: “Prevention” and “MBC”
• A training programme for associations working in the SBU: 3 levels with 1-day sessions each in 4 cities with 70 associations and 170 women in attendance

Activities for 2017
• Promotion of the SBU law with public events in Venice, Rome and Bari
• Implementation of BC screening in the south with events in Pescara
• Video with patients and medical associations asking public authorities to implement SBUs in all regions
• Meeting with parliamentarians to revive “Europa Donna Parlamento”
• 10 recommendations for SBU implementation presented to Health Ministry
• National training programme on MBC for associations working in the breast unit

Kyrgyzstan

Highlights of 2016
• A press lunch on opioid availability to cancer patients
• A charity event “I Can, You Can” with participation of MPs, the Ministry of Health, journalists and NGOs
• Awareness-raising activities on early diagnosis and prevention of BC, including meetings, presentations and discussions
• A 3-month social theatre advocacy project “You Are Not Alone”
• Visits from European Society of Oncology (ESO) and other experts to ED Kyrgyzstan’s Patient School

Activities for 2017
• Advocacy and technical assistance for the development of BC guidelines
• Facilitating good collaboration between ESO, the Ministry of Health and the National Oncology Centre for training of lab specialists, oncologists, radiographers and others
• Advocacy for availability and affordability of chemotherapy and hormone therapy
• Continuing BC awareness raising activities using different tools and approaches
• Celebrating BHD and Pink October activities
• Continuing work on palliative care development

Latvia

Highlights of 2016
• Psychosocial rehabilitation programmes for BC patients and relatives
• Publishing in the patient information newspaper “The Patient’s Voice” an article on “the BC screening programme: the best way to save lives”
• “The Tree of Life” video: “How to Change/Influence the World?” posted on YouTube
• In October, inspiring talks on “disease as a burden or a challenge and a new beginning”
• In October, “The Healthy Food Table” for everyone
• A charity campaign “Give Five” organised to support cancer survivors and their relatives and held during a week-long radio show to inspire people to have quality of life

Activities for 2017
• Holding 21 psychosocial rehabilitation programmes for cancer patients and their relatives
• Pink Latvia campaign in October with a photo exhibition “My Life, My Challenge: How to Live After Cancer?”
• Planning to create information booklets “My Mum Has Cancer, What Does it Mean?” and “Quality of Life After Cancer”
• In October, a press conference on BC awareness and reality

Lithuania

Highlights of 2016
• After a General Assembly, the ED Lithuania association name was changed to the National Association of Breast Diseases (NABD)
• Meeting with Minister of Health and subsequent correspondence
• For BHD, a press conference for patients and doctors on the theme “When did you last check your breasts?”
• In October, participation in events organised by other groups in various cities
• In December, organising an annual conference, “Will science meet our expectations?”, in collaboration with the National Cancer Institute and Vilnius University
• Creating a video on breast self-exam in Lithuanian
• Continuing “The Knot of Life” project with the Vilnius Academy of Art to support women with BC who have lost their hair due to chemotherapy, and involving the presentation of 2 unique publications about headwear at the
Activities for 2017
- Continuing advocacy activities
- Electing a new ED Lithuania president

Montenegro

Highlights of 2016
- "Serenity and Well-being" conference with workshops on yoga, mindfulness, reflexology and more
- Participation in the 24-hour Awareness Run “Relais for Life”
- Participation of 11 women in the “Breithorn” climb inspired by the film “Rope of Solidarity”
- Presentation of the results of the 2015 survey “Parcours de Femmes”
- In October, the “Broschtkriibslaf” annual run against BC
- In October, participation at the “Pink Shoe Day” in Leipzig, Germany, with 450 pairs of pink shoes collected in Luxembourg, one for every new diagnosis per year
- Cinema Spot “Breast Cancer: Aware-Share-Care”
- Participation in the ED Advocacy Leader Conference in Milan

Activities for 2017
- Celebrating 15 years of ED Luxembourg with a conference and photo competition
- Fashion show featuring lingerie and wigs
- Dialogue with hospitals following the results of the 2015 survey "Broschtkriibslaf" annual run

Macedonia

Highlights of 2016
- Organised the biggest campaign in Macedonia for BC awareness “Go Pink Walk and Race For the Cure”
- The 9th National Breast Cancer Conference in October
- Organising a project for “resocialisation” of women with BC
- BHD activities with a small demonstration of BC survivors
- An SOS line for the BC patients, family and friends
- Running psychosocial groups twice a month for women with BC

Activities for 2017
- Attending the ED Pan-European Conference in October and ED Advocacy Training in November
- The “Go Pink Walk and Race For the Cure” in autumn with a focus on MBC
- For BHD, holding a 1-day excursion and picnic at a famous national site

Malta

Highlights of 2016
- Elected a new committee
- Awareness walk and run
- Motorbike ride
- Public lecture “Who Cares for the Carer” inspired by Doris Fenech
- A seminar in Gozo
- BHD in Malta and Gozo
- Advocacy course for advocates
- Annual fund-raising gala

Activities for 2017
- Doris Fenech Memorial seminar about MBC
- Re-establishing the metastatic branch of ED Malta
- Awareness walks
- Fashion show
- BHD activities
- Annual public lecture
- Annual fund-raising gala
- Translation of an MBC book from English to Maltese

Monaco

Activities for 2016 and 2017
- Holding monthly “dance and write” workshops where women can work on their bodies, and on self-acceptance, while attaching words to how the body is feeling
- Organised a conference on “After Cancer”, the role of physical activity during treatments as well as afterwards, plus meditation for rehabilitation
- Organising a charity evening for the 25th anniversary of the association
- Maintaining regular communication with the Minister for Health, which led to bringing in a healer to the hospital to help with the side effects of radiotherapy for BC or other cancers
- Participating every year in “Pink Ribbons of Monaco”
- Providing free support daily to patients and their caregivers at the hospital and in a care centre

The Netherlands

Highlights of 2016
- Partnering with Dutch screening organisation and advocating for state of the art for the national screening programme
- Making “Monitor Breast Cancer” with criteria for optimal care available for all patients in 90 hospitals
- Implementing “B bewust, B awareness”; a web-based tool with 12 theme checklists to help patients make informed treatment choices, now in 20 hospitals
- Creating “B optimum” in cooperation with medical professionals to set 10 goals for optimal BC care
- Conference on BRCA and other hereditary BCs with 600 attendees
- Three magazines, one special edition to raise awareness of late effects of treatment
- Successful advocacy at the Dutch Institute of Healthcare (which advises the Minister of Health) for reimbursement of lipofilling

Activities for 2017
- Project comparing the treatment option tools for MBC to help patients choose a tailored treatment
- Working group about the late effects of treatment and to prevent overtreatment
- Implementing “B Optimum” by discussing it with medical professionals and other stakeholders
- Educating the 300 active members of “BVN Academy” to provide them with tools for patient advocacy
- One conference for new patients and one about MBC
- A special edition of “B” magazine about MBC

Norway

Highlights of 2016
- Increasing awareness of hereditary BC and MBC
- Continuing advocacy related to cancer treatment and care
- Weekend gatherings for women under 40, those diagnosed with metastatic cancer, with hereditary BC, and those diagnosed 3-5 years ago
- Supporting research environments
- Local activities including exercise groups, social gatherings and meetings on professional topics
- Supportive care visits and telephone calls

Activities for 2017
- A national conference featuring professional topics and networking
- Increasing awareness of supportive care after treatment
- Weekend gatherings for women under 45 and for women diagnosed with MBC
- Annual activities: supporting research environments; local activities such as exercise groups, social gatherings and meetings; supportive care; continuing advocacy for cancer treatment and care

EUROPA DONNA NEWS
Poland

Highlights of 2016

- Participating in EBCC10 and the ED Advocacy Leader Conference
- In April, the GA and a conference “Diagnosis and Treatment of Breast Cancer” in Piła
- In August, gathering of the regional ED Poland presidents in the Parliament in Warsaw
- For BHD: a conference and workshops, a “March to Health” and zumba marathon, a Pink Ribbon March; lectures about BC in schools and free mammography

Activities for 2017

- In May, BC lectures in schools and participation in SBU opening in Wrocław
- In June, GA in Nowy Sącz and a conference “Effective Treatment of Breast Cancer” and “Role of ED in improving the access to prevention and treatment of BC”
- For the BHD campaign, a press conference at the Parliament
- Participation in the ED Pan-European Conference and the Advocacy Training Course

Portugal

Highlights of 2016

- Petition “For Equity in Access to Screening, Diagnosis and Treatment of Women with BC” with 27,505 signatures was delivered to the Vice-President of the National Assembly on the World Day Against Cancer and resulted in the unanimous approval of 2 draft resolutions
- Campaign with a cosmetic company to raise funds and awareness for BC to enable the purchase of 3 direct digital mammography units
- Digital campaign for BHD
- “Pink Wave Movement” to encourage BC prevention and early diagnosis: pink wave on the street, at work, in the digital world, in transports, in buildings
- BC screening programme advocacy
- Psycho-oncology consultations aimed at women with MBC

Activities for 2017

- Continuation of activities: BC screening programme, psychooncology consultations for women with MBC, BHD digital campaign, “Pink Wave Movement”, fund-raising campaign

Romania

Highlights of 2016

- The 2nd “Happy Run” with 2500 participants, including 150 BC survivors
- Launch of the Coalition for Women’s Health, a partnership of patients, authorities, etc. to implement screening programmes and access to adequate treatment for breast and cervical cancers
- Mobile diagnostic unit campaign provided 1191 mammograms and 1681 Pap tests
- “Brave Cut”, offering natural hair wigs to cancer patients
- Pink illumination of the Romanian National Museum of Art

Activities for 2017

- Roundtable at the European Parliament and the Romanian Parliament to present the study “Female Oncologic Diseases in Romania” and advocate for prevention and early diagnosis of gynaecological and breast cancers
- Annual activities: 3rd “Happy Run”, mobile diagnostic unit campaign for breast and cervical cancer, pink illumination event

Russia

Highlights of 2016

- Initiated and provided support for the local BC programme launch in the Belgorod region
- Provided financial support for implementing mammography screening standardisation workshops for radiologists
- Held the first public forum in favour of local BC programme in Chuvash Republic
- Donated breast prostheses and bras to 115 underprivileged patients in 3 regions
- Published the first national “Breast Cancer Manual” for newly diagnosed women
- Supported rehabilitation groups in Kursk region
- Took part in international and national cancer conferences
- Managed the international internship for medical professionals at Munster University Hospital to promote learning from mammography screening experience in Germany
- Supported the opening of a BC screening reference centre in Kursk region
- Took part in ED Advocacy Leader Conference and Advocacy Training
- Managed public lectures “All About Breast Health for Women Workers” within the BHD and Pink Ribbon campaigns

Activities for 2016

- Organising a patient session within the BIG Breast Cancer Conference
- Organising the training programme for 23 cancer counsellors from 3 regions
- Providing grants for cancer counsellors to hold therapy groups for BC patients
- Providing information support for public cancer centres on mammography screening
- Organising a patient session within the 3rd White Night International Cancer Forum
- Establishing a Breast Cancer Support Centre #Together in Moscow
- Annual activities: donating breast prostheses and bras; participating in ED conferences;
- BHD 2017 and Pink October activities

Serbia

Highlights of 2016

- Establishing a Serbia BC Forum and negotiating membership in ED
- Strategic planning

Activities for 2017

- Official registration of the organisation Serbian Forum as ED Serbia
- Setting up the organisation (creating a website, email, social media sites)
- Regional meeting with ED National Representatives from Croatia and Slovenia
- Announcement of the ED existence in Serbia to authorities, professionals, BC NGOs, women’s organisations and the general public
- Fund-raising campaigns
- Working towards increasing membership (organisations, individuals, etc.)
- Establishing cooperation with relevant medical and government institutions
- Pink October activities (campaigns, public events)
- Attending ED events

Slovakia

Highlights of 2016

- Creation of a platform supporting the implementation of organised mammography screening (association of NGOs and professional organisations)
- BHD organised by this platform (3000 participants)
- Co-operation with the Ministry of Health in the preparation of mammography screening conditions
- Lectures for the public on the BC prevention and healthy lifestyle
- Training women waiting for BC screening
- Interviews with parliamentarians, ministries and EU parliamentarians on the need for mammography screening

Activities for 2017
- Expanding a platform supporting the implementation of organised mammography screening
- BHD in Bratislava
- Lectures, awards for mammography departments working according to European standards
- Public awareness campaigns on cancer prevention and healthy lifestyle (on TV, radio and other media)
- Cooperation with the Ministry of Health in the implementation of mammography screening
- Interviews with parliamentarians and EU parliamentarians

Slovenia

Highlights of 2016
- Publication of 4 issues of ED News (129,000 copies each)
- 39 lectures about BC throughout Slovenia
- Counselling: by telephone, personally, e-mail, visiting patients at hospital
- Support group for young BC patients
- 2-day seminar for ED members with more than 200 attendees
- "Running and Walking for Hope" in 4 cities
- Participation in ED Advocacy Leader Conference and in Advocacy Training
- Participation at ESMO, IEPPO, ESO Masterclass
- In October, a major campaign in 3 cities with the slogan "Lovely Day" and an “awareness dance”

Activities for 2017
- Annual activities: publishing 3 issues of ED News (101,000 copies), patient counselling (personal, via phone and email), lectures, “Running and Walking for Hope” in 4 cities
- Emphasis on psychosocial support and holistic rehabilitation
- 2-day seminar for ED members (physical activity and treatments)
- 2-day intensive seminar for active members on advocacy
- October activities: press conference, intergenerational connections between elementary schools and women with BC
- Photo exhibitions around Slovenia for awareness
- Hosting the ED Pan-European conference in October

Spain

Highlights of 2016
- Presenting a study on the information needs and health care expectations of BC patients
- ED Spain Universidad Menéndez Pelayo summer course for specialists and women with BC covering the challenge of maintaining sustainability of the public health system with a focus on clinical research and innovation
- On BHD, a press conference to present the Manifesto and an awareness campaign on early detection and for fund-raising
- Participating in the National Health System Cancer Strategy as a member of the follow-up and evaluation committee
- Psychological support for women with BC and their families
- Physiotherapy for lymphoedema

Activities for 2017
- In June, attending the ED MBC Advocacy Conference
- Summer course at Universidad Menéndez Pelayo with a focus on survivorship
- On BHD, a media campaign about early detection and to present the 2017 Manifesto
- Advocacy activities and participation in the National Cancer Strategy
- Support in developing an app to assist women undergoing chemotherapy

Sweden

Highlights of 2016
- As a result of an ED Sweden report on mammography submitted in 2015, the Parliament decided that mammography screening would be free starting in July 2016
- Based on an ED Sweden report, the Swedish Breast Cancer Group decided to join a UK trial for evidence to extend the age range for mammography screening in Sweden from 40-79 or 80 years of age (currently 40-74 years)
- Presentation of pilot programme as a result of seminars and articles about MBC patients being included in the BC registry

Activities for 2017
- Presenting a report on introduction of new drugs approved within EU at seminars during the political week in July with the aim of shortening introduction time and achieving equal access
- Increasing and the number of rehabilitation weeks for MBC patients, and financially supporting weekends for young women
- Meeting with the government on 2 occasions to discuss equal access and quality care
- Starting a new advocacy training programme in the autumn, as well as further training

Switzerland

Highlights of 2016
- Celebration of 10 years of ED Southern Switzerland
- Participating in the 30th Swiss women’s run in Bern
- European Ladies on the Road, biker event in Locarno in favour of ED Switzerland
- BHD media campaign in Southern Switzerland
- Keynote presentation at the BCY-3 (Breast cancer in young women) in Lugano
- Publishing translated documents from a MBC campaign on the website
- During October, Pink Illumination in Southern Switzerland
- Creating a new ED Switzerland flyer
- “Young Women with Breast Cancer” group activities
- Active participation in different conferences in Switzerland and abroad

Activities for 2016
- Workshops and seminars for patients
- Launch of an app for children “The magic tree”
- Literature contest
- Participation in the “Relay for Life”
- Regular meetings for patients
- Attendance at different conferences

Tajikistan

Highlights of 2016
- A BC advocacy information campaign
- Workshops and training on breast awareness in 3 regions, where in June, health centres also provided free breast exams for more than 1000 health workers and women, and to 5200 women in October
- Participating in EBCC
- Roundtable on treatment adherence
- Practical training with exercises for BC prevention at a fitness centre
- Monitoring and evaluation of activities carried out by primary care physicians (PCPs)
Participating in the annual International Women of Istanbul
• Working with refugees to create BC awareness and for
• Training for healthy lifestyle specialists on prevention and early detection
• Activities for BHD, International Children’s Day and Breastfeeding Week
• Meetings with women leaders on advocacy for women’s health and BC prevention

Activities for 2017
• A BC advocacy roundtable with representatives of the National Cancer Centre, USAID and other international organisations and patient groups
• Study assessing the situation of the provision of mammography equipment
• A BC prevention marathon
• “Healthy nutrition and physical activity for BC prevention” in 3 regions
• Meeting with parliament representatives about access to mammography screening
• Annual Pink Ribbon gala dinner and BHD activities
• Women’s health campaign with free breast exam performed in 14 cities
• A roundtable with National Cancer Centre representatives on developing the cancer registry
• Meetings with patient groups

Turkey
Highlights of 2016
• Acting as main stakeholder of the bi-annual Istanbul International Breast Cancer Conference (IIBCC) in charge of the patient advocacy programme and co-chairing the scientific programme
• Working on BC nurse training and speciality in collaboration with Marmara University BC nurses and coordinators
• Monthly training seminars on BC and femininity, BC and yoga, and women’s health topics
• Working with refugees to create BC awareness and for immigrant women to have an initial screening free of charge by a group of health care professionals at a breast unit
• Participating in ED Advocacy Training
• Participating in the annual International Women of Istanbul Christmas Bazaar with the traditional calendar, handicrafts and gift items provided by ED members

Activities for 2017
• Preparing for the next IIBCC in October 2018
• Continuing working on capacity building and fund-raising activities
• Working on extending and expanding ED Turkey coverage nationally and internationally by developing joint projects on the BC nursing speciality
• Working on European Patients Academy on Therapeutic Innovation (EUPATI) implementation in Turkey starting with a pilot project to be extended until 2018

Ukraine
Highlights of 2016
• Held the 5th School of Mammography 4-day training course with 48 Ukrainian breast radiologists in attendance
• Initiated and developed by ED Ukraine specialists, the concept of the new state programme “Reproductive Health of the Nation” for the period of 2017-2021, including a section on BC prevention, was approved by the Ministry of Health and the Health Committee of Ukrainian Parliament
• Participation as keynote speaker in “Pink Breakfast” special event for Pink October

Activities for 2017
• Organised rehabilitation programmes for BC survivors at a health resort
• Initiated and supported 9 sessions of a “Health School” educational programme as monthly meetings for BC survivors and various health care practitioners
• Regular support of BC hotline

Activities for 2017
• A joint press conference to announce the launch of a small grant programme to support 5 municipal oncological centres for implementation of early BC diagnosis and screening programmes
• BHD at the parliament featuring an information fair with banners, and distribution of BC information and pink ribbons to MPs
• Annual activities: comprehensive rehabilitation programme for BC survivors; production and distribution of information materials for women; 9 sessions of “Health School” designed for BC survivors

United Kingdom
Highlights of 2016
• Advised TV soap “EastEnders” on a MBC storyline
• Presentation to Soroptimists in London
• Lecture to pharmacy representatives about SBUs and breast nurses
• Distribution of ED materials at Pink Ribbon Magazine Breast Cancer Forum
• Stand at an educational meeting at Royal Marsden Hospital on new and controversial breast care management, led by eminent professors
• Exhibition stand at a hospital with breast health care leaflets promoting healthy living, visited by Prince Charles
• Breast Awareness Afternoon with Imperial College Healthcare, with information for women with learning disabilities, a talk on breast awareness and screening and interviews for TV news
• Attendance at Parliamentary Group on Breast Cancer reception, reporting on an inquiry into geographical inequalities, hosted by the shadow minister for public health and NHS national cancer director
• Britain Against Cancer Conference “Urgent Issues in Cancer Care”

Activities for 2017
• ED UK Annual Symposium “Breast Cancer: Living With and Beyond” on risk assessment and survivorship
• Talk to advocacy charity “Against Breast Cancer”, researching secondary BC challenges
• 10th Royal Marsden Meeting with a stand at a seminar on hot topics in BC
• BHD displays, awareness talks and presentations
• BC session with Imperial College Women’s Network

Uzbekistan
Highlights of 2016
• In January, a New Year celebration with BC survivors at the Tashkent City Oncology Clinic
• In March, an International Women’s Day tea party with oncologists and survivors
• In September, the ED Advocacy Leader Conference in Milan
• The Pink October charity gala

Activities for 2017
• In April, seminars for graduate oncology students on raising BC awareness at Tashkent Medical Academy
• Attending the ED Pan-European conference in Ljubljana
• “Pink October” celebrity with BC survivors at the Tashkent City Oncology Clinic
11th European Breast Cancer Conference – EBCC11
21-23 March 2018 – Barcelona, Spain

EUROPA DONNA is a co-organiser of the biennial European Breast Cancer Conference (EBCC) along with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA). ED actively participates in the development of the scientific programme whose global aim is to highlight the importance of teamwork and interactions between all professionals and specialties involved in breast cancer. EBCC11 will feature EUROPA DONNA Sessions on topics of particular interest to advocates such as the European Commission Initiative on Breast Cancer and advocacy for metastatic breast cancer, to name a few. Registration rates for advocates to attend EBCC11 are now considerably lower than in the past, so please register to participate as soon as possible.

For more information [http://www.ecco-org.eu/EBCC](http://www.ecco-org.eu/EBCC)

EUROPA DONNA Breast Cancer Advocacy Leader Conference
Building and Improving Our Organisations for the Future
29 September 2018 – Milan, Italy

First EUROPA DONNA MBC Advocacy Training Course
28-30 September 2018 – Milan, Italy

EUROPA DONNA has been awarded a grant through the Seeding Progress and Resources for the Cancer Community: Metastatic Breast Cancer Challenge (SPARC MBC Challenge) to provide this course in MBC advocacy.

18th Annual EUROPA DONNA Breast Cancer Advocacy Training Course
16-18 November 2018 – Milan, Italy

Website Section on Metastatic Breast Cancer Advocacy
EUROPA DONNA launched a new section of www.europadonna.org dedicated exclusively to advocacy for and with women living with metastatic breast cancer (MBC). It contains statistics on MBC, identifies challenges and areas for advocacy, and provides an advocacy tool kit. A special section includes the voices of women with MBC in videos and interviews describing their personal experience with MBC and breast cancer advocacy.

For more information [http://mbc.europadonna.org](http://mbc.europadonna.org)

What’s on in 2018

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

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. © 2017 EUROPA DONNA – The European Breast Cancer Coalition
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