EUROPA DONNA
The European Breast Cancer Coalition

2018 Newsletter

Highlights from the
- 11th European Breast Cancer Conference
- 5th EUROPA DONNA Breast Cancer Advocacy Leader Conference
- 1st EUROPA DONNA Metastatic Breast Cancer Advocacy Training Course

European Advocacy Initiatives

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

In this issue

The Personal is Political .................................................. 1
President Evi Papadopoulos

Advocacy in Action ...................................................... 2
CEO/Executive Director Susan Knox

Highlights of the 11th European Breast Cancer Conference – EBCC11 ............................................. 3

Highlights of the 1st EUROPA DONNA Metastatic Breast Cancer Advocacy Training Course and the 5th EUROPA DONNA Breast Cancer Advocacy Leader Conference .................................................. 5

Making Our Voices Heard ................................................ 8

Strength in Numbers ...................................................... 9
News from member countries

What’s on ................................................................. 17

What’s new .............................................................. 17

In-box ........................................................................ 17
EUROPA DONNA dynamically began 2018 with the first Executive Board meeting in January; the 5 year Strategic Plan was presented and discussed and other initiatives and proposals to EUROPA DONNA were evaluated. This first meeting of each year is always important as plans are finalised for all upcoming events for the rest of the year as both participants and organisers.

March was marked by the bi-annual conference, the 11th European Breast Cancer Conference (EBCC11) in Barcelona, Spain; EUROPA DONNA members sit on the European Breast Cancer (EBC) Council, the Organising and Scientific Committees and make presentations at numerous sessions. Most importantly, EUROPA DONNA is an equal partner in the organisation of this conference, bringing the voice of patient advocates to the medical and scientific community with the EUROPA DONNA President serving as co-chair. As the co-chair this year, I had the honour of speaking at the press conference, presenting the Arts and Humanities Award, chairing sessions and sitting on panels with other medical professionals. A very successful conference, this EBCC gave us more tools to disseminate knowledge but also to advocate for the need for multidisciplinary breast cancer teams at local levels. The EUROPA DONNA sessions were well attended and the presentations covered a large variety of topics bringing our concerns and needs to the foreground, so that we can prepare action plans.

During our General Assembly (GA), EUROPA DONNA Executive Director Susan Knox presented the Coalition’s activities and plans as well as new prospects, and gave us an overview of scientific studies nearing completion. I was very happy to meet with many EUROPA DONNA advocates at EBCC11, and at our EUROPA DONNA sessions and our GA.

For the next EUROPA DONNA Pan-European conference to be held in October 2019, the Board considered a number of proposals submitted. We decided on Vienna as the next venue. We congratulate the Austrian Forum and EUROPA DONNA Vice-President Mona Knotek-Roggenbauer and look forward to a very successful conference there.

In June, we held a one-and-a-half-day Board meeting in Milan, and finalised the updated Strategic Plan. This indicates the way forward for EUROPA DONNA and touches upon issues such as participation in organising committees of conferences other than EBCC, commitment to the research agenda and Breast Health Day. We stressed the importance of the sustainability of our organisation to carry us into the future within an ever-changing environment.

Education is an important element of our advocacy efforts: so our first Metastatic Breast Cancer (MBC) Advocacy Training Course was held in September in conjunction with our 5th Advocacy Leader Conference. The training course was a continuation of the successful First MBC Conference in 2017 and the result of EUROPA DONNA receiving a SPARC grant administered by the Union for International Cancer Control for this MBC activity. Thirty-seven members from 26 countries attended this new training programme enabling them to network with other participants, share experiences and get practical guidance to start supporting women locally with MBC programmes.

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“Effective advocacy by EUROPA DONNA members has benefitted many women in so many countries. We will continue to work together to improve care for women across Europe.”

Finally, at our 18th Advocacy Training Course held in Milan in November, new patient advocates gained an overall knowledge on breast cancer science, best practice and issues. This course provides them with the tools to become active and effective advocates. It has been an exciting and rewarding year serving as EUROPA DONNA’s President and being involved in the progress made over these years and observing how effective advocacy by our members has benefitted many women in so many countries. We will continue to work together to improve care for women across Europe.

I look forward to seeing older and new members of EUROPA DONNA soon at upcoming meetings.
Our advocacy work this year has covered a wide array of projects including research, major breast cancer conferences and input into a number of European parliamentary initiatives on breast cancer. Our 20 year partnership with the European Society of Breast Cancer Specialists (EUSOMA) and the European Organisation for Research and Treatment of Cancer (EORTC) continues; over 2500 patient advocates, clinicians, researchers, and breast cancer health professionals came together to share information at a very successful multidisciplinary 11th European Breast Cancer Conference (EBCC11) in March in Barcelona, Spain (see page 3).

EUROPA DONNA remains a key stakeholder in the European Commission Initiative on Breast Cancer (ECIBC). The Guidelines Development Group, on which I serve as an individual, has published many of its recommendations. These, along with the background and justifications for each one, can be found on the web hub at https://ecibc.jrc.ec.europa.eu. ED has now published its own “Advocates Guide to the ECIBC” part 1, which we launched for the first time with European Commission representatives Ciarán Nicholl and Elena Parmelli at our Advocacy Leader Conference in September. EUROPA DONNA has a major responsibility, as Europe’s breast cancer advocacy organisation, to ensure that the new European Breast Guidelines are understood and implemented across Europe. This booklet gives our leaders the information they need to use when working toward this goal in their own countries. We also presented this new training tool at our Advocacy Training Course in November. In 2019, we will add part 2 on the quality assurance segment of this initiative. ED Deputy CEO Karen Benn serves as an individual patient representative on the Quality Assurance Scheme Development Group (QASDG).

ED continues its engagement in important research projects across Europe. Among them is the Breast International Group (BIG) Taskforce on Survivorship that is identifying and working to get support for quality of life research. ED also has representation on steering and advisory committees on 3 HORIZON 2020 projects: MESI-STRAT (Systems Medicine of Metabolic-Signaling networks: A New Concept for Breast Cancer Patient Stratification); BOUNCE (Predicting Effective Adaptation to Breast Cancer to Help Women to BOUNCE Back); and MyPeBS (My Personal Breast Screening project). ED is now a member of the Consortium of PREFERABLE (Project on Exercise for Prevention of Breast cancer; the back to work agenda and supported Together Transforming Breast Cancer 8) project, the back to work agenda and supported the white paper that underlines the rights women should have to return to work after breast cancer. We highlighted this issue at our Advocacy Leader Conference and it has become a priority in our new Strategic Plan for 2019-2023.

Numerous activities were undertaken together with members of the European Parliament, Council of Europe and European collaborators of EUROPA DONNA (see page 8). ED has contributed to the Transforming Breast Cancer Together project, the back to work agenda and supported the white paper that underlines the rights women should have to return to work after breast cancer. We highlighted this issue at our Advocacy Leader Conference and it has become a priority in our new Strategic Plan for 2019-2023.

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Karen Benn provided the patient advocacy perspective on genetic and family risk at EBCC and is one of the authors of the EBCC11 Manifesto “Genetic Risk Prediction Testing in Breast Cancer”. Incorporating BRCA and ovarian cancer advocacy content into our programming will also begin in 2019. There are advocacy groups in this area that we would like to welcome to our next Pan-European Conference to ensure that they are part of a European perspective on the genetic aspects of breast cancer.

Training is essential in furthering our advocacy agenda. Our Advocacy Training Course, now in its 18th year, enables us to continue to train advocates who can return to their countries to carry out advocacy work armed with evidence-based information and communication skills to help in this endeavour. This year we launched our 1st advocacy training course for women with metastatic breast cancer; this represents another important step to ensure that women with advanced disease gain access to the best treatments and appropriate support in their countries. There are still many disparities among countries and regions.

Today in Europe there are more than 562,000 new breast cancer cases each year and more than 150,000 deaths; 20-30% of these new breast cancers will become metastatic. We have made a lot of progress, but the challenges still remain enormous.

Advocacy in Action

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Today in Europe there are more than 562,000 new breast cancer cases each year and more than 150,000 deaths; 20-30% of these new breast cancers will become metastatic. We have made a lot of progress, but the challenges still remain enormous.
EUROPA DONNA advocates were among the more than 2500 participants at the 11th European Breast Cancer Conference (EBCC11) held in Barcelona, Spain from 21-23 March 2018. ED advocates chaired sessions and presented on topics ranging from European policy and breast care guidelines, to metastatic breast cancer (MBC) advocacy, and hereditary breast cancer. They also learned about the latest advances in imaging, diagnosis (including prognostics and gene sequencing) and treatment of the disease from leading experts.

EUROPA DONNA is a 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). It is the only breast cancer conference to include all the key collaborators in the breast cancer field and encourages interaction between clinicians, scientists and patient advocates. This report includes a summary of sessions of particular importance to EUROPA DONNA.

At the opening session, EUROPA DONNA President and conference co-chair Evi Papadopoulos presented the EBCC Arts and Humanities Prize to François Perri and Josefina Díaz Rubio for their photo project “Cicatrices — Scars ... My life in 1,096 days”. This book shows the many challenges of the whole breast cancer journey with personal pictures and the reflections of its author and highlights the need for high standards of comprehensive breast cancer care from screening onward.

**EBCC11 Webcasts**
https://www.ecco-org.eu/Events/EBCC11/Webcast

The EBCC11 Manifesto on Genetic Risk Prediction Testing in Breast Cancer

The EBCC11 Manifesto on Genetic Risk Prediction Testing in Breast Cancer seeks to address the growing direct-to-consumer sale of genetic tests for breast cancer. It stipulates that tests must be of high quality and information must be interpreted by appropriate healthcare professionals. Widely accepted by the EBCC11 audience, the Manifesto puts forward 7 specific demands to protect patients’ rights. ED Deputy CEO Karen Benn sat on the panel for this session and was an active participant in drafting the document that will be published in a medical journal.

Read the Manifesto
www.ecco-org.eu
**Advocacy Sessions at EBCC11**

**Update on the European Commission Initiative on Breast Cancer**

A special EUROPA DONNA session was dedicated to the European Commission Initiative on Breast Cancer (ECIBC), which is creating EU guidelines for breast cancer screening and diagnosis and a quality assurance scheme for the entire continuum of breast services. The first recommendations have now been launched on the ECIBC web hub. ED CEO Susan Knox, who sits as an individual on the Guidelines Development Group, chaired the session. Donata Lerda of the European Commission’s Joint Research Centre explained that the ECIBC web hub will be a “one-stop shop” for the European Breast Guidelines, the guidelines platform, and the quality assurance scheme. She noted that the recommendations are evidence-based with input from the highest level of expert opinion from the EU and beyond; national representatives from 35 countries are also involved. Robert Mansel, chair of the Quality Assurance Scheme Development Group (QASDG), said that their aim is to create a quality assurance scheme that can be used by all breast centres and monitored by individual health systems. The QASDG is identifying quality indicators that can be measured. Once the quality assurance scheme is finalised, the next step will be to pilot it in real-world breast centres. ED Deputy CEO Karen Benn sits as an individual on the QASDG and emphasised that patients have equal involvement with all other members in the quality assurance process. Susan Knox stressed the importance of this initiative for breast cancer advocacy for the future.

**ECIBC web hub** https://ecibc.jrc.ec.europa.eu

**Metastatic breast cancer: progress and promise**

In an ED Session on advocacy for MBC, oncologist Fatima Cardoso presented the progress on the new ABC Global Alliance, an initiative of the European School of Oncology. Evi Papadopoulos presented on living with MBC and patients’ needs, including the multidisciplinary care that has been shown to improve outcomes. Susan Knox outlined ED’s European initiatives in this area, such as its 1st MBC Advocacy Conference in June 2017, and its new MBC Advocacy Training Course in September 2018. ED France’s Nicole Zernik described MBC projects in her country, such as MBC leaflets and gatherings for patients. ED has a special website section dedicated to MBC.

**ED website** https://mbc.europadonna.org

**What genes can reveal: patients’ rights and genetic testing**

A recurring theme throughout EBCC11 was the advances made in identifying inherited genetic risk for breast cancer, as well as mutations in the tumours themselves. Karen Benn spoke about patients’ preferences and said that genetic counselling and testing should be provided by health systems for those with a strong family history of breast cancer. Individuals should receive personalised, individually tailored information on risks and benefits from a geneticist or genetics counsellor, who should also be a member of the multidisciplinary team, in a process that involves shared decision-making.

**The Digital Doctor: A new health care frontier**

The Internet and smart phones bring great potential for improving the patient experience. For example, they are being studied and used to monitor patient symptoms and adverse effects of treatment during clinical trials, and also during follow-up care. Marie Ennis O’Connor of ED Ireland gave a lively presentation “The Real Patient in the Virtual World”, where she said that the internet gives patients a more active role in their care. It also brings patients together in peer-to-peer exchanges and gives them a louder, common voice when trying to effect change. She added that doctors should direct patients toward reliable websites. The digital potential is vast, she said: “We are standing on the cusp of a new health care frontier.”
EUROPA DONNA’s 1st Metastatic Breast Cancer Advocacy Training Course and the 5th EUROPA DONNA Breast Cancer Advocacy Leader Conference

EUROPA DONNA dedicated a full weekend in September to the 5th Advocacy Leader Conference for its national leaders and the first Advocacy Training Course for women living with metastatic breast cancer (MBC). All advocates participated in sessions about some topics that are of great concern for both early and advanced breast cancer.

The basics of treatment and biosimilars
Olivia Pagani, Director of the Breast Unit of Southern Switzerland, described the treatment options for this complex disease: from endocrine therapy to anti-HER2 therapy and chemotherapy. She said that all patients with early-stage oestrogen-receptor negative, high-grade, or HER2 positive tumours should be offered chemotherapy as these patients will benefit the most. Patients with other tumour types should have individual evaluation of the risk and benefit of chemotherapy. In women with MBC, Dr Pagani said that endocrine therapy is the preferred choice for oestrogen-receptor positive MBC as it has fewer side effects than chemotherapy. Where chemotherapy is needed, the ABC guidelines call for it to be given one agent at a time because this approach is effective and has less toxicity than combination chemotherapy. Women with MBC may need to be on treatment for long periods of time, so tolerability is a key consideration.

In this new era of biosimilars, Dr Pagani outlined this topic for advocates using the case of trastuzumab. biosimilars are copies of biologic drugs (ie, a drug derived from living cells). For a biosimilar to receive regulatory approval it has to prove that it is equivalent to the originator. This means that the clinical trial process is shorter, which should make the biosimilars available more quickly and, most importantly, help to provide drugs that are about 30% less expensive than the originator. She added that like any drug, biosimilars need to undergo a process of long-term reporting of adverse events.

Getting patient groups involved in HTA
Tamás Bereczky, the Communications Officer for the European Patients’ Academy on Therapeutic Innovation (EUPATI), described the role of patient in health technology assessment (HTA). HTA is a multidisciplinary process involving a systematic evaluation of the benefits and risks of a health technology compared with the standard treatment in order to inform health care policy makers. He said that it is more than just an economic evaluation: the clinical effectiveness, safety and impact on quality of life (QoL) come first. He encouraged ED advocates to contact HTA bodies in their countries. An HTA Patient Group Submission Template is available to help with the procedures for communicating with HTA committees. Patients are crucial members in this process as they can provide insight on the pros and cons, side effects and impact on QoL of an existing or new treatment. In his advice to advocates he said that they need to be able to communicate effectively and follow procedures, show that they are informed, know the science and speak for the community, not as individuals. “Who else can critically appraise a treatment better than those who take it?” he asked.

For more information: www.eupati.eu

Returning to work after breast cancer
ED Deputy CEO Karen Benn gave an overview of the rights of breast cancer patients returning to work, indicating that return to work can provide stimulation and promote QoL, in addition to the financial considerations. She said that the EU Employment Equality Framework Directive of 2000 specifies that employers cannot discriminate against employees on the grounds of disability. Despite this legislation, there are vast differences between countries and, in some cases, employers still discriminate against cancer patients. She added that an EU draft report on “reintegration into work after illness” is currently being prepared by MEPs and should become a resolution. With regard to MBC, she added that there is a lack of data even on how many people it affects; however, a pilot project on MBC and work has been proposed by MEP Deirdre Clune (Ireland).

ED Board member and lawyer Elizabeth Bergsten Nordström then shared experience on work and insurance issues facing women in Sweden. She said that many women choose to look for other job opportunities. ED Vice President Mona Knotek-Roggenbauer presented the results of a survey on breast cancer survivors returning to work in Austria. At the conference, ED also launched a survey of its members with regard to work-related issues.

What advocates need to know about breast cancer registries
Ciarán Nicholl, Head of the Health in Society Unit in the Health, Consumers and Reference Materials Directorate, European Commission-Joint Research Centre, gave an overview of cancer information in Europe and its vast potential for learning about breast cancer and for fostering cancer prevention and control strategies. He said that while the cost of cancer registration is very low, the potential the data can unleash is very high. The JRC’s European Cancer Information System (https://ecis.jrc.ec.europa.eu) contains more than 33 million records of information on individual cancer cases and covers about half of the European population. These data originate from hospital-based registries and both specialised and general population-based breast cancer registries. He emphasised that high quality, harmonised data is a must and JRC initiatives to achieve this include: (1) the provision of Quality Checks Software to all registries free of charge, and (2) training events for cancer registries. He said in the near future the data will be geographically positioned and then they will overlay the data with, for example, environmental, socio-economic and other indicators. The ensuing cancer incidence and/or mortality spikes should yield new insights into cancer causality. Finally he encouraged advocates to also get involved in data collection policy meetings and to “spread the word” about the need for high quality cancer registries.

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EUROPA DONNA Breast Cancer Advocacy Leader Conference

National leaders from ED’s 47 member countries spent the afternoon session learning more about and discussing the European Commission Initiative on Breast Cancer (ECIBC) and funding strategies for their organisations, before sharing experiences in workshops. The interactive session on the ECIBC featured Ciarán Nicholl and Elena Parmelli of the European Commission’s Joint Research Centre (JRC), which is responsible for steering the ECIBC, with ED’s Susan Knox. It focused on ED’s new Advocates Guide to the ECIBC (part 1), which describes the ECIBC’s mission, and the methods its Guidelines Development Group is using to create new European Breast Guidelines for Screening and Diagnosis. The first Guideline recommendations from this group are now available on the ECIBC web hub (https://ecibc.jrc.ec.europa.eu/home). ED held this ECIBC training session so that ED’s national leaders could understand better the ECIBC and to review the new Guideline recommendations together.

Elizabeth Bergsten Nordström then discussed opportunities for funding, and explained that any sponsorship agreement has commitments on both sides and should be mutually beneficial. Tanja Spanic of ED Slovenia described how her forum has a wide variety of funding sources, including public funding, membership-related resources and private donations, pharma and funding from other companies. For non-pharma funding she recommended identifying a company, negotiating, preparing a unique project and making sure key messages are heard. To share experiences more effectively, advocates then gathered in 2 rounds of workshops on: good practice regarding sponsorship and funding, advocacy issues facing socially disadvantaged populations, work/insurance issues facing breast cancer survivors, and the patient advocate’s role in research.
The 1st EUROPA DONNA Metastatic Breast Cancer Advocacy Training Course

The afternoon session of ED’s 1st Metastatic Breast Cancer Advocacy Training Course was dedicated exclusively to MBC so that participants could learn more and share strategies to advocate with and for other women with this disease. The weekend-long course began with a gathering where 37 MBC advocates from 26 of the ED’s 47 member countries introduced themselves and gave a brief history of their personal fight against MBC and as advocates. During the course, MBC advocates also learned more about the EUROPA DONNA advocacy tools available to them, such as the website dedicated to MBC (https://mbc.europadonna.org), and the advocacy tool kit (https://mbc.europadonna.org/campaign-materials). Advocates also heard an inspiring presentation on living with MBC by ED’s President Evi Papadopolous who herself has been living with MBC for many years. It covered the different challenges, needs and priorities of women with MBC. Sabine Spitz of ED Austria, who is also living with MBC, described the activities of her Forum which are growing to include more MBC-related initiatives, from information and awareness campaigns to supportive care campaigns. Advocates then had an opportunity to share advocacy strategies from their countries, such as establishing 13 October as MBC day, an MBC postage stamp, online petitions, crowd-funding for projects and meetings with high-level politicians. ED’s Susan Knox also described the ABC Alliance, a multi-stakeholder platform for all those interested in collaborating in common projects relating to MBC. It runs webinars, has videos and is active on social media and in the European Parliament with, for example, an event scheduled on work issues for women with MBC. The course ended with a full day’s communication skills training and workshops so that advocates could learn to use their personal stories and other tools to advocate for increased attention to MBC. During the course, some advocates were filmed talking about their personal experiences and these videos will be made available on the MBC section of the ED website. EUROPA DONNA has made MBC one of its priorities, and the 1st EUROPA DONNA MBC Advocacy Training Course was supported, in part, by a UICC SPARC MBC Challenge grant.
Continuing collaboration with the ECIBC
ED CEO Susan Knox and ED Deputy CEO Karen Benn have attended regular meetings of the European Commission initiative on Breast Cancer (ECIBC); the ECIBC has begun to release recommendations from its European Breast Guidelines for screening and diagnosis and will be delivering a voluntary European quality assurance scheme for breast cancer services, underpinned by the guidelines. Susan Knox sits as an individual on the Guidelines Development Group (GDC) and Karen Benn is on the Quality Assurance Scheme Development Group (QASDG). ED has created a training booklet for advocates describing the ECIBC, the methodology used by the GDC and the recommendations it has released to date. As a stakeholder in this initiative, ED will be disseminating information on the ECIBC at all of its conferences going forward.

Bringing the advocacy voice to the EU Parliament
ED has been actively involved in supporting a number of current European Parliament initiatives which address the rights and needs of cancer patients in relation to work. One of these is a “pilot project” proposed by Deirdre Clune, MEP (Ireland), “Metastatic Cancer and the Workplace: Tackling the Lack of Data” and the second is the draft report “On Pathways for the Reintegration of Workers Recovering from Injury and Illness into Quality Employment” to which amendments have been added referring specifically to cancer patients by MEP Clune and Rory Palmer, MEP (UK). ED has also developed a survey on return to work and the situation as experienced by its members; the results of this survey were presented at an ABC Global Alliance event at the European Parliament in November.

As part of the Transforming Breast Cancer Together Initiative, MEPs Lieve Wierinck (Belgium), Elena Gentile (Italy) and Cristian Silviu Buşoi (Romania), along with EUROPA DONNA and other key organisations active in this area, have launched a Call for Change to transform breast cancer care in the EU. This includes nine policy recommendations which would significantly improve cancer treatment and care in the EU. It calls on EU institutions, EU Member States’ authorities and all relevant stakeholders to invest more in breast cancer prevention, treatment and care in order to ensure that breast cancer is screened, diagnosed and treated in its early stages.

Participating in ECCO Summit and ESMO
ED Board Member Sema Erdem represented ED at the BRESSO project meeting held during the European Cancer Organisation’s ECCO2018 European Cancer Summit in September and presented ED views on qualifications for specialist breast surgery. BRESSO is the Breast Surgical Oncology Project Team within the European Society of Surgical Oncology (ESSO). She emphasised the need for appropriately trained and experienced specialist breast surgeons working within specialist breast units. Sema also represents ED on the ECCO Patient Advisory Committee.

Susan Knox, Karen Benn and ED Vice-President Mona Knotek-Roggienbauer attended the European Society of Medical Oncology (ESMO) meeting and hosted the 11th Annual EUROPA DONNA Sponsor Meeting on 20 October to present the 2018 programme and plans for 2019.

Collaborating in European Commission Horizon 2020 projects
Ellen Verschuur represents ED as an Advisory Board member in the Metabolic Signaling STRATification — MESI-STRAT Research Project and attended the kick-off meeting in March in The Netherlands. The MESI-STRAT consortium explores the association between breast cancer metabolism and oncogenic signalling using systems medicine approaches to develop new models for patient stratification.

Karen Benn represents ED as a member of the external advisory panel to the Predicting Effective Adaptation to Breast Cancer to Help Women to BOUNCE Back project and attended the first meeting which took place in June in Crete. The BOUNCE project aims to research aspects that influence breast cancer patients’ resilience, and ability to return to normal/everyday life and work after breast cancer treatments. The project starts by modelling the factors that influence resilience. The BOUNCE Consortium includes experts from the field of oncology, computer modelling, psychology, and social medicine from 5 countries.

ED Board Member Paola Mosconi serves on the Independent Ethics and Data Monitoring Committee of the My Personal Breast Screening project – MyPEBS. The MyPEBS project is a randomised-controlled trial that will compare standard breast cancer with a screening strategy that takes account of a woman’s breast cancer risk. It was launched in January 2018 and is to run for 8 years in 7 participating countries.

PREFERABLE (Project on Exercise for Fatigue Eradication in Advanced Breast cancer to improve quality of life) is the most recently funded Horizon 2020 project in which ED is involved. ED is a member of the consortium that includes institutions from 6 European countries. PREFERABLE focuses on the role and benefits that structured and individualised exercise can have in the treatment of patients with breast cancer that has metastasised. This project will investigate if exercise can improve quality of life and survival of this patient group. EUROPA DONNA is very pleased to take part in this project as research is greatly needed to improve management of side effects from treatment and thereby improve patients’ quality of life.

Promoting breast health via 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. ED has launched a new website section dedicated to prevention (https://prevention.europadonna.org) in preparation for Breast Health Day (BHD) 2018. This year the campaign began with a steady social media campaign throughout the summer 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.
Albania

**Highlights of 2017**
- Distributing brochures and leaflets with information about breast cancer (BC) during International Kidney Day
- “Support Hope, Fight for Life” awareness raising activity, resulting in an “open letter” on issues faced by women with BC and signed by diplomats and foreign representatives
- In October, free mammography and informative meetings for women
- An information activity with participation from World Cup football aspirants
- Sports and games for Breast Health Day (BHD)
- An informative meeting at a high school
- “Donate Hair, Give Hope” campaign
- Hosting an oncology activity for patients and medical staff in the “Zen Room” for women with BC
- A “Café Donna” meeting to discuss improving goals and new plans and projects
- Advocating for access to trastuzumab treatment

**Activities in 2018**
- Publishing a newsletter distributed by Panorama newspaper
- “Café Donna” meetings with patients
- BHD and media activities
- In October, a “Buy a Coffee for a Woman with Breast Cancer” campaign

Austria

**Highlights of 2017**
- New edition of the ED Austria book Du bist nicht allein (You Are Not Alone)
- Reissuing the brochure “Initial Information About Breast Cancer”
- Panel discussions on future health in Austria
- 4th Austrian Breast Cancer Patients Congress
- Pink Paddling with Vienna Pink Dragons
- Participating in international congresses
- “Motivation on Movement” for BHD
- Social media activities and public relations
- An awareness film about metastatic breast cancer (MBC)
- Mona’s Blog

**Activities in 2018**
- Participation in stakeholder discussions on the future of oncological care in Austria
- 5th Austrian Breast Cancer Patients Congress
- Translation of the French MBC brochure
- New collaborations with other Austrian BC organisations
- Collaboration with breast care nurses
- Survey on the rocky path through the Austrian health system
- Final evaluation of the survey on work and cancer
- Social media, public relations and Mona’s blog
- Café Donna
- Pink Paddling
- For BHD, a flash mob (dancing in the city)
Belarus

Highlights of 2017
- Working with women’s groups in different regions
- Preparing women for the Eurasia Breast Cancer Advocacy Conference in Kiev in October
- Distributing MBC treatment materials for women’s advocacy groups
- Working with school teachers and teenagers to educate them about BC

Activities in 2018
- Participation in the Eurasian Screening Conference in May 2018
- Working with BC screening pilot programs and promoting ED BC screening standards
- Working with women’s advocacy groups in Minsk, Grodno and Gomel regions
- Updating the ED Belarus website

Belgium

Highlights of 2017
- In October, BHD activities, a BC campaign in conjunction with the French-speaking section of the Cancer Foundation
- Attending the ED Pan-European Conference
- In November, a BC campaign in conjunction with the Dutch-speaking section of the Cancer Foundation, and participation in the ED Advocacy Training Course
- In December, holding the General Assembly

Activities in 2018
- In March, participation in the 11th European Breast Cancer Conference (EBCC11), and the 3rd EORTC Cancer Survivorship Summit in Brussels
- In April, “Talk and Walk Pink” for awareness about BC prevention
- In May, a symposium on BC screening in Belgium for the Dutch and French communities held at a hospital in Brussels

Croatia

Highlights of 2017
- In February, a BC conference
- In March, Daffodil Day
- In June, the Women’s Race for ED Croatia
- In October, the 18th Pink Ribbon Day and BHD
- In November, a pink rugby match for ED Croatia and a MBC conference “Every Day is Precious”

Activities in 2018
- In May, nutrition workshops “Healthy Days” in shopping centres in Zagreb
- In September, the ED Zagreb Pink Run
- Annual activities: Daffodil Day event, Women’s Race for ED Croatia, Pink Ribbon Day, BHD, and the MBC conference

Cyprus

Highlights of 2017
- Annual activities: a summer party for women with BC, Pink Silhouette walk, BHD activities, pink illumination of various landmarks, “Look Good, Feel Good” day activities, participation in conferences abroad, psychological support by an ED Cyprus psychologist, “Bosom Friends” support programme, fund-raising fashion shows, lectures in all towns on BC awareness, participation in solidarity runs, participation in Europe Day events
- Monitoring the operation of the SBU in Nicosia General Hospital
- Participation in the steering committee of the national screening programme
- Co-organising a Cancer Day event
- Conference on “Breast Cancer Awareness” held every 2 years
- Board Membership in the Cyprus Patients’ Organisation that represents Cyprus at the European Patient Forum (EPF)
- 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 oncoplastic breast reconstruction guidelines

Activities in 2018
- Annual activities: Pink Silhouette walk, BHD activities, pink illumination of landmarks, conference participation, fund-raising fashion shows, Bosom Friends programme, psychological support, lectures, solidarity runs and dragon boat events, summer party, national screening programme participation, Christmas and Easter family food packages, being board members of Cyprus Patients’ Organisation, participation in the Europe Day events, updating ED Cyprus leaflets
- Free physiotherapy service offered by ED Cyprus physiotherapist specialising in lymphoedema
- Participation in the SBU ad hoc committee
- Press conference at the Presidential Palace announcing October activities
- Meetings with the Minister of Health on better BC services
- Meeting with policy makers for insurance schemes for women with BC

Czech Republic

Highlights of 2017
- “You Can Also Do It” celebration of the 15th anniversary of the organisation
- “It’s Not Only About Breasts” educational campaign at secondary schools about breast awareness and self-examination
- “Closely Watched Breasts”, a travelling “Breast Wall” exhibition in local cafés in 30 towns across the country
- “We are Swimming the Breast Stroke”, as part of BHD in 10 towns
- Annual conference
- Various projects, such as “Bellis” for young women with BC and “Invisible Women” for advocacy for MBC patients, with meetings held in the mountains

Activities in 2018
- “You Can Also Do It”, this time with pictures taken by a professional
- “Closely Watched Breasts Campaign” with a mobile exhibition of plaster breast casts, including advice on prevention and the importance of early diagnosis
- An educational activity on breast health for people with hearing impairment
- Pink October events organised by Bellis and Invisible Women projects, including charity fashion shows, recovery stays, swimming, and more
- Participation in conferences and training sessions organised by ED and other NGOs

Denmark

Highlights of 2017
- One seminar for women with MBC and 2 on late complications
- General Assembly and a thematic meeting with expert speakers
- ED Denmark award for doing something special for BC patients
- Issuing a magazine 3 times a year, a monthly digital newsletter, an annual report, updating the daily Facebook page and the website
- 3-4 annual meetings with other cancer patient groups and the National Cancer Organisation, participation in a national medical group on BC medicine
- Local activities including expert meetings with local medical staff and others, expert presentations on BC, and social activities
- Participating in ED conferences and training courses
- Helping to develop a “decision support tool” for professionals and patients to aid communication and patient decision-making
- Sewing by volunteers of about 3000 heart-shaped pillows for women having BC surgery

Activities in 2018
- Annual activities: seminars, expert meeting, ED Denmark award, publications and media activities, meetings with other cancer patient groups, local activities
• Launching a new logo
• Providing support to women whose mammogram results did not undergo a second reading as required by Danish law
• Participating in conferences including EBCC, ED conferences, a Danish “People Meeting” in Bornholm, a discussion meeting focusing on cancer survivors, and the Nordic Breast Cancer Conference
• A national campaign on “Healthy Lifestyle for Breast Health” using the ED BHD materials

**Estonia**

**Highlights of 2017**

• Successful advocacy for the National Breast Screening Programme to be extended from age 62 to 69 years
• Launching a new BC social media campaign “Pink Rules”
• Annual summer retreat for cancer patients
• Continuing cancer patient group meetings across the country
• Nation-wide Pink Ribbon campaign

**Activities in 2018**

• A special press conference on MBC in May resulting in articles published in all the major national newspapers, health magazines and broadcast on national TV
• Producing a new MBC video
• Taking the “Pink Rules” social media campaign to the 2018 national beauty convention
• Launching “Ignorance is Not Bliss”, a new breast health awareness campaign via social media and posters
• Cooperating with an agricultural supply company to make pink silo covers available this summer for purchase by local farmers with proceeds going to BC screening

**Finland**

**Highlights of 2017**

• Producing a leaflet with questions to ask during treatment
• BHD Activities: lecture “Tools for a Healthy Life” and creating a personal health recipe for how to adopt healthy new habits into everyday life
• Discussion groups in several cities
• Different theme weekends (art therapy, sport) and recreational activities
• “Pink Bales” fund-raising campaign

**Activities in 2018**

• Continuing MBC networking: a weekend for families including discussion groups for patients, partners and activities for children
• Wellness and peer support weekend for MBC patients
• Opening of a peer support phone-line
• Discussion groups and weekend retreats
• Lectures providing information on BC and ED Finland in several cities

**France**

**Highlights of 2017**

• Design and launch of the new ED France website
• Annual conference in Paris, “New Therapeutic Approach From Diagnosis to Treatment”
• Monthly Café Donna in Paris, Lyon, Bordeaux and Nantes
• Sports activities in regional offices
• Supporting Dragon Boat activities with the Paris Dragon Ladies
• Pink October across France
• Participating in various scientific committees and advisory boards (National Cancer Institute, scientific organisations, Cancer League)

**Activities in 2018**

• Celebrating the 20th anniversary of ED France in all the regional offices
• Action Plan in progress for MBC based on 5 pillars: awareness, information, access to best treatment, support and data collection

**Georgia**

**Highlights of 2017**

• Creating short films under one title “I Defeated Breast Cancer” in which BC survivors tell their stories to be aired on national TV
• Holding a joint roundtable with representatives of state institutions, medical doctors, mass media and NGO representatives to discuss ways to solve patients’ problems
• Working in Azerbaijan to disseminate information about ED
• Participating in a “Marathon for a Healthy Life” for BHD in Tbilisi and Batumi to increase BC awareness and prevention
• Attending the ED Advocacy Training Course

**Activities in 2018**

• Holding a press conference with participation of representatives of the Ministry of Health to stress the importance of government participation in funding for BC patients and future initiatives. It was aired on the national TV channel and other independent channels
• Attending EBCC11
• Holding an advocacy training course in Azerbaijan
• In cooperation with partners, offering free examinations for women living in the Gori region and visiting the region with physicians
• Awareness activities in cooperation with a hotel chain that served pink desserts and provided funding for ED Georgia initiatives
• Attending the ED Advocacy Leader Conference
• For BHD, taking part in a marathon, participating with physicians to offer free examinations of women of all ages, decorating the main square in Batumi with pink ribbons and holding an information campaign

**Greece**

**Highlights of 2017**

• Speaking at numerous medical conferences and cancer seminars
• Giving lectures in the Athens medical school training programme about ED Greece’s role in assisting clinical trial researchers in ensuring the protection of cancer patients’ rights
• Participating as an ED Greece team in the Athens marathon
• For BHD, an awareness campaign in the centre of Athens, with student volunteers handing out apples and Greek translations of the ED BHD leaflets. Breast nurses and 2 breast surgeons offered advice to women. The Red Cross also assisted
• Attending the ED Advocacy Training Course

**Activities in 2018**

• Meeting with MPs and the Minister of Health to discuss ED Greece’s help with the BC registry process, and to help the Greek Oncological Society receive reimbursement for BRCA genetic testing
• Drafted an official request to the President of the Greek Parliament for a BC parliamentary committee and a proposal for issues needing prioritisation. The document contained vital information on issues and solutions in other European countries
• Holding a board meeting and a General Assembly
• Attending the ED Advocacy Training Course

**Hungary**

**Highlights of 2017**

• Holding EUROPA DONNA Day in Martfű with more than 100 participants and culmination of the health programme with an awareness-raising walk

• Updating brochures: MBC, hormone therapy, family history
• New brochure on clinical trials for BC and biosimilars for patients
• In November, annual conference on progress on treatments and the management of BC over the last 20 years and gearing for the future
Strength in Numbers

- Introduced new country delegate and ED services in an ED Hungary official publication distributed to oncology centres across the country

Activities in 2018
- ED Day in Budapest
- ED programme with neighbouring countries
- The first nation-wide cultural meeting of cancer patients with 500 participants from 30 cities
- Creating and distributing thousands of copies of a publication describing the organisation and its objectives via the nation-wide network of 50 clubs and associations, as well as oncology centres and colleagues

Iceland

Highlights of 2017
- Monthly “open meetings” for women diagnosed with BC, for discussion and education about therapy, surgery, late side effects of chemotherapy, and benefits of healthy lifestyle
- “Casting for Recovery,” a fishing activity, for women in rehabilitation after BC treatment

Activities in 2018
- Forming part of a group of specialists invited by Ministry of Health in order to renew the BC screening programme
- Participating in the Nordic Breast Cancer Conference
- Participating in the ED Advocacy Leader Conference and in ED Advocacy Training
- Planning a seminar called “Moving Forward” for women who have finished BC treatment in cooperation with the university hospital and the Icelandic Cancer Society

Ireland

Highlights of 2017
- Participation in working groups, such as the Patient Forum National Cancer Strategy 2017-2028, National Cancer Control Programme’s psycho-oncology and survivorship groups
- Distribution of BHD information at University College Dublin and other locations
- Attendance at “Cancer Trials Ireland Stakeholders” meetings and “The Patient Voice in Cancer Research” meetings
- Consultation on research proposals
- MBC Day Communication issues and living with MBC
- Development of “MBConnect”, a private online forum for women with MBC
- Attendance at 1st ED MBC Conference and ABC in Lisbon
- ED Ireland stand at various conferences and meetings

Activities in 2018
- Celebrating 20th Anniversary of ED Ireland
- Annual activities: ongoing involvement in working groups and research groups
- MBC event in October
- Updating website
- Campaign for implementation of Cancer Strategy, especially in relation to psycho-oncology services

Israel

Highlights of 2017
- World Health Organisation 2012 statistics released: Israel leads in compliance and survival rates; compliance bridged between Jewish and Arab women
- Specialist breast units (SBU) established with ED Israel assistance; accreditation supported by Israel National Council of Oncology
- Support groups, public information booklets and advertising, social media campaigns
- Disseminating ED materials via the website and Facebook
- For BC awareness month: press release, annual seminar, public building illuminated in pink, pink lingerie collection, brass art exhibit, photos of women with BC and survivors, sailing and motorcycling events in collaboration with different companies, organisations and individuals

Activities in 2018
- A press release on BC in Israel
- Public service announcements, social media campaigns, annual seminars and support groups
- Awaiting implementation of SBU accreditation

Italy

Highlights of 2017
- Promotion of the SBU law with public events in Venice, Rome and Bari
- Implementation of BC screening in the south with events in Chieti, Abruzzo
- Two videos with patients and medical associations asking public authorities to implement SBUs in all regions
- Meeting with parliamentarians to request SBU implementation
- Training programme on MBC for associations
- National survey about women’s knowledge of SBUs

Activities in 2018
- Promotion of the SBU law with public events in Bologna and Milan
- Implementation of BC screening in the south with events in Bari
- Public event in the Senate asking for a National MBC Awareness Day
- Training programmes for associations on MBC and getting back to work after BC
- Information portal on BC diagnosis and treatments with links to Breast Units and Associations, a live chat and answers from specialists

Kyrgyzstan

Highlights of 2017
- Running breast health videos in Kyrgyz and Russian languages on 15 minibus routes
- Decorating a trolleybus with the pink ribbon theme and providing passengers with access to BC prevention information in Bishkek
- A lecture on breast and cervical cancer prevention for staff of the First National TV channel
- For Pink October, a “Plant a Tree – Change the World!” campaign where ED Kyrgyzstan staff together with BC patients and volunteers planted trees near the breast centre and Department for Children at the National Oncology Centre
- Participating in the ED BC Advocacy Training Course

Activities in 2018
- Visiting patients at the National Oncology Centre breast centre
- A roundtable on access to chemotherapy
- Lectures on palliative care for medical workers of Kochkor district of Naryn Oblast and Balykchy city
- Lectures by oncologist members of ED Kyrgyzstan followed by consultations with patients and their families on relevant issues
- Pink October events

Latvia

Highlights of 2017
- A “Pink Ribbon messengers” movement across Latvia with widespread distribution and exchange of pink ribbon stickers, including to the media, at the Parliament, the Cabinet and the Riga City Council

Activities in 2018
- A press release on BC in Latvia
- Public service announcements, social media campaigns, annual seminars and support groups
- Awaiting implementation of SBU accreditation
• A photo exhibition “We Are Here To Inspire You” in cooperation with “Dzivibas Koks” Liepaja Department to encourage those diagnosed to reassess their lives and improve their quality of life
• Psychosocial rehabilitation programmes throughout the year

Activities in 2018
• A conference on the multidisciplinary nature and importance of rehabilitation of cancer patients in promoting treatment and quality of life, the situation in Latvia, experience and perspectives
• A mentor campaign “You Are Not Alone, We Can Help You” with a 2-day mentor training session and public awareness
• Strengthening the regional support umbrella divisions and setting up new ones
• Creating a “Patient Rights Guide”
• Psychosocial rehabilitation programmes

Lithuania

Highlights of 2017
• Organising the annual conference in collaboration with the National Cancer Institute of Lithuania with a focus on disseminating information about breast reconstruction, quality of life after treatment, and living with MBC
• Participating in a debate with policymakers on breast implants for BC patients and the reimbursement process
• The “1825” promotional campaign, including video creation, and focusing on living with MBC
• An interview to the media and public on the use of cool caps during chemotherapy
• Participating in events organised by other BC groups
• Collaborating in the publication of the newspaper Oncologist Pages and the online medical news portal with news of scientific research on BC, diagnosis and treatment, living with BC and quality of life

Activities in 2018
• Organising a “Breast Day” in Vilnius in cooperation with the Oncological Association

Luxembourg

Highlights of 2017
• In January and February, dialogue with hospitals and decision-makers following the results of the 2015 survey
• In March, a fashion show of lingerie and wigs and participation at the 24-hour “Awareness Run Relay for Life”
• In June, celebrating 15 years ED Luxembourg with a conference and painting exhibition
• In September, a photo competition
• In October, “Broschtkriibslaf”, the annual run against BC, and an awareness event at a women’s tattoo convention
• In November, participation in the ED Advocacy Training Course in Milan, and a Zumba Marathon in Luxembourg

Activities in 2018
• Support for development of an e-learning platform on BC
• Annual Awareness and Education Conference and “Broschtkriibslaf”
• An “ED Luxembourg” postage stamp
• Training for physiotherapists
• Painting exhibition goes on tour

Malta

Highlights of 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

Activities in 2018
• Giving patients individual support and covering the cost of 12 counselling sessions with a psychologist
• Providing a €50 voucher for wig or scarves from a renowned hairstylist who in turn matches the discount
• Throughout September and October, awareness talks in factories, offices and schools
• The educational Hilda Schembri Memorial Lecture with this year’s theme “What About Me?” addressing patients’ families, with a patient and a patient’s daughter as speakers
• Joining forces with other NGOs in October to raise awareness and funds to buy the latest mobile biopsy machine
• A night walk
• For BHD, “Doctors in the City” where surgeons in walk-in mobile clinics provide check-ups
• Participating in the ED Advocacy Training Course

Monaco

Highlights of 2017
• In October, a conference provided by a gynaecologist specialising in gynaecological problems associated with cancer
• In November, celebrating 25 years of the organisation with a gala dinner in the presence of Prince Albert and Princess Stephanie
• In December, inviting patients to a Christmas dinner

Activities in 2018
• In January, being invited to the traditional galette des rois (three king’s cake) at a gathering with the Minister of Health
• In February, speaking at the biannual oncology congress held in Monaco
• In April, the General Assembly
• In June, participation of patients in a weekend seminar on self-esteem, an outing for patients on a sailboat, a luncheon for patients and members
Strength in Numbers

The Netherlands

Highlights of 2017
- Implementing “B Optimum” with 10 goals for optimal BC care by discussing it with medical professionals and other stakeholders
- One conference for new patients and one about MBC
- Setting up an expert group for patients with MBC
- A special edition of 8 magazine about MBC
- Implementing “Time Out Moments” and shared decision-making in hospitals
- Creation of an inventory with online support tools for patients
- Scientific research: setting up the BC research agenda

Activities in 2018
- Creating awareness of the need for shared decision-making
- Improving and organising care and after-care
- Opinions about the changes needed in the organisation of BC care
- Improving evaluation of research proposals
- Implementing information about online support tools
- Organising conferences and webinars for patients and patient advocates

Norway

Highlights of 2017
- A national conference for networking
- Continuing to create awareness about MBC
- Continuing advocacy on topics of cancer treatment and care
- Weekend gatherings for women under 45 and for women diagnosed with metastatic cancer
- Supporting research environments
- Local activities such as exercise groups, social gatherings and meetings on professional topics
- Supportive care visits and telephone calls

Activities in 2018
- Annual activities: weekend gatherings, supporting research, local activities, supportive care visits and telephone calls, peer support, advocacy on topics of cancer treatment and care, creating awareness about MBC
- Increasing awareness of supportive care after treatment, including family members

Poland

Highlights of 2017
- In June, General Assembly and conferences on effective treatment of BC and the role of ED in improving the access to BC prevention and treatment
- In October, BHD in 5 cities and in the Parliament with posters, brochures, lectures, scientific and press conferences, pink ribbon marches and a Zumba marathon
- In November, a conference about BC and a lecture on how to talk about BC with politicians, and participation in the ED Advocacy Training Course

Activities in 2018
- In the spring, participation in EBCC11 and fund-raising activities
- In July, a General Assembly in Legnica
- In September, participation in the ED BC Advocacy Leader Conference
- In October, BHD campaign
- In November, participation in the ED Advocacy Training Course

Portugal

Highlights of 2017
- Campaign to raise funds and awareness for BC to allow the purchase of 3 direct digital mammography units
- A BC research grant
- The participation of 3 Portuguese Olympic canoeing athletes in the BC awareness campaign in national and international competitions
- 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 transport systems, in buildings
- BC awareness campaign at all the Portuguese Football Championship matches, with BC survivors and key messages in the games
- BC screening programme advocacy
- Psycho-oncology consultations for women with MBC

Activities in 2018
- Extending the BC screening programme to Lisbon and Setubal
- Consultations for women with MBC
- BHD digital campaign
- “Pink Wave Movement”
- A fund-raising campaign

Romania

Highlights of 2017
- The third “Happy Run” with 2700 participants, including 100 BC survivors
- Roundtables at the European Parliament and the Romanian Parliament presenting the studies “Female Oncologic Diseases in Romania” and “The Costs and Burden of BC in Romania”, advocating for prevention and early diagnosis of gynaecological and breast cancer
- Mobile diagnostic unit campaign provided 590 mammograms and 1163 Pap tests
- “Brave Cut”, offering natural hair wigs to cancer patients
- Pink illumination of the Globalworth Tower and Sky Tower in Bucharest

Activities in 2018
- Annual activities: 4th “Happy Run” with 3000 participants, mobile diagnostic unit campaign providing 197 mammograms and 387 Pap tests, “Brave Cut” campaign, pink illumination event
- “Pink Touch – a Manicure for Life” breast self-exam and awareness campaign
- “Adolescence in Pink” BC prevention campaign in high schools

Russia

Highlights of 2017
- Running the patient session within the Big Breast Cancer Conference
- Carrying out an educational programme for 23 cancer counsellors
- Awarding grants for cancer counsellors in 3 regions
- Co-organising a patient session within the 3rd White Night International Cancer Forum
- Donating breast prostheses and bras for underprivileged patients at local cancer centres
- Taking part in a mammography screening pilot programme in Moscow
- Participating in ED conferences and courses
- For BHD, taking part in 2 business conferences for women to promote BC prevention and screening

Activities in 2018
- Launching the first ever in Russia Charity Breast Cancer Support Centre in Moscow where all BC support services are free of charge for survivors and their families
- Conference participation: EBCC11, the 4th White Night International Cancer Forum, ED conferences and courses
- Donating medical equipment
- A 2-day educational programme for radiologists on BC screening and diagnosis of bone diseases
- For BHD, public talks about BC prevention, distribution of information materials and launching a new Breast Cancer Navigator website
**Serbia**

**Highlights of 2017**
- Official registration of ED Serbia and setting up the organisation
- Promotion of ED Serbia at local and national levels
- Working towards increasing membership
- Establishing relationship/cooperation with relevant professional and government institutions
- Pink October activities (campaigns, public events)
- Attending national, regional and ED events

**Activities in 2018**
- Negotiation with authorities, including the Ministry of Health and a network of women parliamentarians and others in order to improve and carry out activities
- Identification of priority needs of women survivors
- Workshops and public discussion as part of Pink October activities
- Attending EBCC, ED Advocacy Leader Conference, ED MBC Advocacy Training Course, and ED Advocacy Training Course
- Advocacy initiatives (public, professionals, authorities) for improvement of BC prevention, diagnosis, treatment, rehabilitation, and psychological support

**Slovakia**

**Highlights of 2017**
- Creation of a platform supporting the implementation of organised mammography screening (association of NGOs and professional organisations)
- Co-operation with the Ministry of Health in the preparation of mammography screening conditions
- Lectures for the public on BC prevention and healthy lifestyles
- Training women waiting for BC screening
- “We Are Awesome IV” exhibition of paintings by survivors and their family members
- BHD events with 3500 participants

**Activities in 2018**
- Expanding a platform supporting the implementation of organised mammography screening
- Lectures, awards for mammography departments working according to European standards
- Public education on cancer prevention and healthy lifestyle (on TV, radio and other media)
- Cooperation with the Ministry of Health in the implementation of mammography screening
- “Go to Mammography, I Have Already Been” campaign
- BHD in Bratislava

**Slovenia**

**Highlights of 2017**
- Publication of 3 issues of ED News (100,000 copies)
- Patient counselling (personal, via phone and emails)
- Emphasis on psychosocial support and holistic rehabilitation
- 30 lectures throughout Slovenia
- 2-day seminar for members of ED Slovenia with 230 participants
- Intensive workshops for 14 volunteers about support for failing health “Running and Walking for Hope” in 6 locations
- October activities: press conference, visiting Parliament, humanitarian football match with the national team, humanitarian concert, dance performance, handball and basketball matches, fund-raising campaigns
- Hosting the ED Pan-European Conference

**Activities in 2018**
- Annual activities: publication of 4 issues of ED News (90,000 copies), patient counselling, “Running and Walking for Hope” in 6 locations, 2-day seminar for ED Slovenia members
- Emphasis on psychosocial support and holistic rehabilitation as active members of a working group at the Ministry of Health
- Physical activities – “Pink Challenge” including 12 hikes
- Support groups for relatives of BC patients and a weekend camp for children
- Discussion with experts about BC and ovarian cancer
- Main October activities: press conference, visiting Parliament, awareness campaign involving local municipalities

**Spain**

**Highlights of 2017**
- 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 in 2018**
- Summer course at Universidad Menéndez Pelayo with a focus on survivorship
- Advocacy activities and participation in the National Cancer Strategy
- Support in developing an app to assist women undergoing chemotherapy
- Participation as a support group in the Dragon Boat Race
- BHD campaign and presentation of the 2018 Manifesto

**Sweden**

**Highlights of 2017**
- Presenting a report on introduction of new drugs approved within the EU at seminars at the yearly political week with the aim of shortening introduction time and providing equal access. This led to debates in the media
- Increasing the number of rehabilitation weeks for MBC patients and weekends for young women, with expenses covered by ED Sweden
- Meeting with the government on 2 occasions about equal access and quality care
- Starting a new advocacy and peer support training programme
- Founding a quality assurance programme in pathology, with debates in the media

**Activities in 2018**
- Hosting 4 roundtables at the political week in July with a focus on unequal care and slow drug introduction for MBC patients
- Continuing the advocacy campaign for women with MBC
- Extending and covering expenses for MBC rehab weeks to include a partner week

**Switzerland**

**Highlights of 2017**
- Workshops and seminars for patients
- Launch of an app for children, “The magic tree”, in French and German
- Literature contest in Southern Switzerland
- Participation in the 24-hour race “Relay for Life”
- BHD in Southern Switzerland
- Regular meetings for patients
- Participation in a health fair
- Attendance at different conferences
Strength in Numbers

Activities in 2018
- Workshops and seminars for patients
- 32nd Swiss Women’s Run in Bern
- Regular “Tavola Rosa” meetings for patients
- Yoga event for young women with BC
- Co-operation in the publication of a guide for MBC patients
- Attendance at different conferences

Ukraine
Highlights of 2017
- Holding the third BHD event at the Ukrainian Parliament with parliamentarians and cabinet ministers taking part. ED Ukraine representatives and 10 women MPs raised awareness of the need for BC prevention and screening at an event for the media
- For Pink October, a nation-wide information campaign devoted to BC early diagnosis and prevention measures
- A 3-km “Pink Run” held in conjunction with the Kiev City Marathon, to raise funds for mammography equipment
- Regular support of BC hotline

Activities in 2018
- BHD campaign
- Advocacy and information event in the Ukrainian Parliament
- Pink Marathon 2018
- Press event in October

United Kingdom
Highlights of 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
- A stand addressing post-mastectomy radiotherapy and reconstruction at the seminar on hot topics at the 10th Royal Marsden Hospital BC Meeting
- BHD displays, awareness talks and presentations
- Nursing Matters: “Breast Cancer 2025 — Where Will We Be”, connecting experiences in BC
- Facebook and Twitter reach/re-tweets: 65,374
- Attendance at Britain Against Cancer Conference to discuss the future of cancer care

Activities in 2018
- Imperial College Women’s Network event on wellbeing in the workplace
- Prestigious Parliamentary Reception in the House of Lords, to raise ED UK profile among influential women in the City of London
- Promotional activities for BC survivor cycling Europe
- Stand on management of lymphoedema and menopausal symptoms at the 11th Royal Marsden Hospital BC Meeting

Uzbekistan
Highlights of 2017
- In March, International Women’s Day tea party with oncologists and survivors
- In April, seminars for graduate oncology students on raising BC awareness at Tashkent Medical Academy
- “Pink October” celebration with BC survivors at the Tashkent City Oncology Clinic
- New Year’s Eve celebration with BC survivors at the Tashkent City Oncology Clinic

Activities in 2018
- In April and May, psychological training sessions for BC survivors
- BC awareness campaigns in oncology clinics in Tashkent region
- In July, raising BC awareness among young girls in Ferghana region
- Pink October events throughout the month

Turkey
Highlights of 2017
- Starting a training programme for breast care nurses with Acibadem Hospital and Senaturk
- Attending more than 5 bazaars for fund-raising
- Starting a screening programme for immigrant women
- Working on the European Patients Academy on Therapeutic Innovation (EUPATI) implementation
- Collaborating on a Patients’ Rights Platform

Activities in 2018
- Monthly seminars
- Seminars and activities with the Patients’ Rights Platform
- In October, the bi-annual Istanbul International Breast Cancer Conference (IIBC)

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EUROPA DONNA News

What’s on in 2019

14th EUROPA DONNA Pan-European Conference
26-27 October 2019 – Vienna, Austria

2nd EUROPA DONNA MBC Advocacy Conference
7-8 June 2019 – Milan, Italy

18th Annual EUROPA DONNA Breast Cancer Advocacy Training Course
22-24 November 2019 – Milan, Italy

What’s new

EUROPA DONNA Advocates Guide to the ECIBC — European Commission Initiative on Breast Cancer — Part 1
ED has created a booklet describing the European Commission Initiative on Breast Cancer (ECIBC), and the methods used by its Guidelines Development Group to create the European Breast Guidelines. The booklet also outlines the first recommendations released by this group and EUROPA DONNA’s priorities for advocacy. The booklet is part 1 of the series and part 2 will follow in 2019 with a description of the ECIBC’s quality assurance scheme for breast cancer care.

New Prevention Section on the EUROPA DONNA Website
ED launched a new section of www.europadonna.org dedicated to breast cancer prevention and has incorporated the Breast Health Day website and materials into this section. The new prevention subsite includes information on primary and secondary prevention of breast cancer, early detection, and facts about lifestyle and breast cancer. The Prevention section is now home to all the campaign resources for Breast Health Day.

https://prevention.europadonna.org

In box

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

Let us know

info@europadonna.org

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

Views expressed in this newsletter do not necessarily reflect those of EUROPA DONNA. © 2018 EUROPA DONNA – The European Breast Cancer Coalition
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