

# EUROPA DONNA

## The European Breast Cancer Coalition

2022 Newsletter



**EUROPA DONNA**  
Breast Cancer Advocacy  
Leader Conference  
*Building our Organisations for the Future*

Belgium,  
Bosnia and Herzegovina,  
Czech Republic,  
Denmark,  
Estonia,  
Finland,  
France,  
Germany,  
Greece,  
Hungary,  
Ireland,  
Italy,  
Latvia,  
Lithuania,  
Malta,  
Netherlands,  
Poland,  
Portugal,  
Romania,  
Slovakia,  
Slovenia,  
Spain,  
Sweden,  
Switzerland,  
UK, Ukraine,

### Highlights from the

- 13th European Breast Cancer Conference
- Europa Donna Breast Cancer Advocacy Leader Conference
- Europa Donna Webinar on Metastatic Breast Cancer Advocacy
- Europa Donna Virtual Roundtables

### European advocacy and policy 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 and breast cancer prevention
3. To emphasise the need for appropriate screening, early detection and diagnosis
4. To campaign for the provision of, and access to, multidisciplinary and specialised treatment and care for all disease stages
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 breast services
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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# Toward The New Normal

Marzia Zambon  
CEO Europa Donna



This past year, we finally returned to conferences in person. No longer heads and shoulders on a flat screen, but tridimensional physical interaction, the intensity of a responsive audience in a meeting room, the conversations during coffee breaks, the side meetings. Digital is here to stay, and the silver lining is that it is also a great opportunity for broader outreach and accessibility, though it will never replace the dynamism of live events.

In March we finally welcomed our Executive Board in Milan for a truly productive exchange of ideas, planning for 2022 and beyond. In June, our **Metastatic Breast Cancer Advocacy** conference was held online, and in September, 45 of our national leaders gathered in Milan, finally meeting up in person. The conference covered the progressing actions of **Europe's Beating Cancer Plan (EBCP)** and the latest update on the **European Commission Initiative on Breast Cancer (ECIBC)** as well as the incredible progress being made in genetics, genomics and personalised medicine.

And finally, shortly after our annual Advocacy Training Course, the 13<sup>th</sup> **European Breast Cancer Conference (EBCC13)** was held in person in Barcelona, Spain. It saw three full sessions run by Europa Donna, one of which focused on the importance of **primary prevention**. It is now a fact that improving lifestyle can prevent approximately 35% of breast cancer cases in Europe. Europa Donna has been advocating for primary prevention for a long time (we just celebrated our **15<sup>th</sup> Breast Health Day** on 15 October) and we look forward to sustaining and disseminating campaigns aimed at implementing the first pillar of the EBCP, which is prevention. The ED General Assembly held on 17 November elected three new members of our Executive Board, whom I warmly welcome.

Europa Donna engagement with EU policymakers is ongoing and growing: Our representatives are invited to speak at and attend awareness events by both the European Commission and the European Parliament. In October, during a **Transforming Breast Cancer Together (TBCT)** meeting at the Parliament, I had the opportunity

to call on EU parliamentarians to take action on the implementation of the EBCP and facilitate cancer prevention campaigns on a national level (see page 10).

Europa Donna is very actively involved in the **European Commission's Breast Cancer Guidelines and Quality Assurance** project: our Senior Policy Officer Susan Knox still serves on the ECIBC Guidelines Development Group, which has published a number of updates and new recommendations: see the [web hub](#). And I am proud to announce that, in October, I was invited to join the **ECIBC Quality Assurance Scheme** Development Group, and look forward to providing my contribution to designing a European certification system for breast cancer services.

**Europa Donna roundtables**, started during the pandemic, are an excellent opportunity for all our Fora to stay in touch on a regular basis, to share and to learn from each other by explaining how they achieved a successful result on a national level, such as obtaining national health system coverage of genomic tests or leading a pilot project to obtain legislation for flexible working solutions for women living with or after breast cancer. In 2022 we set up a roundtable educational programme covering the bases of breast cancer biology and epidemiology, artificial intelligence and screening, genetics and genomics. This is a very important topic that our advocates need to be knowledgeable about. Our recent publication, **The Advocate's Guide to Genomics, Genetics and Personalised Medicine in Breast Cancer** is available on our [website](#).

The ED roundtables are an excellent example of how we faced the pandemic and started our path toward the **"New Normal"**. They started as a *temporary solution* to counterbalance the absence of in-person meetings. Then we saw their additional value. Now they are here to stay, and we are to become busier and more productive than ever.

**2022 was a bustling year, filled with meetings and events held both digitally and in person**

## Europa Donna Breast Cancer Advocacy Leader Conference:

# Building our Organisations for the Future

24 September 2022

At the first in-person meeting since the pandemic, 45 leaders from 26 of Europa Donna's member countries gathered in Milan on 24 September where they received updates on the latest in breast cancer care and policy for now and in the future – from EU policy, prevention and screening to genetics and genomics and clinical trials. They also enjoyed networking opportunities to share experience, and to grow and fortify their organisations back home.

## Policy Update

To help launch the meeting there was a [video message](#) from MEP **Veronique Trillet-Lenoir**, rapporteur for a "[REPORT](#) on strengthening Europe in the fight against cancer", which was adopted in the European Parliament in February 2022 and aims to address health inequalities in the EU.

She also highlighted **Europe's Beating Cancer Plan (EBCP)** and its aims to improve prevention, screening, access to therapy, to support patients with advanced breast cancer, and to put breast cancer at the top of the research agenda. This includes safeguarding quality of life as well as the right to insurance coverage and loans.

ED CEO **Marzia Zambon** provided more details on the EBCP, which is spearheaded by **Stella Kyriakides**, EU Commissioner for Health and Food Safety and former ED President and a passionate breast cancer advocate. Marzia summed up some of the initiatives underway to address the EBCP's action areas of prevention, diagnosis, treatment, and quality of life. She outlined **10 flagship initiatives**, many with timelines in the next 3 years (for more details see the [EBCP fact sheet](#)). These include the **Knowledge Centre on Cancer**, launched in June 2021, and an EU supported **Cancer Screening Scheme** aiming to ensure that 90% of the EU population that qualifies for breast, cervical and colorectal cancer screening is offered screening by 2025. As part of the Plan, the 2003 **Council Recommendations on Cancer Screening** are to be updated. In **September 2022**, the European Commission issued its proposals for the update which aims to increase uptake of screening, to extend the breast cancer **screening age range from 45-75 years**, to ensure **equal access** to screening and adequate and timely diagnostic procedures, treatments, psychological support, and after-care, as well as systematic **monitoring** of screening programmes. This includes some €100 million in **funding** to roll out the recommendations and screening across various cancer types. The **European Commission Initiative on Breast Cancer (ECIBC)**



Marzia Zambon

addresses some of these essentials for breast cancer (see more on opposite page). The **HealthyLifestyle4All** initiative launched in September 2021 aims to link active lifestyles and health policies, much in line with ED's Breast Health Day initiative.

**Tit Albreht** from Centre for Health Care, National Institute of Public Health, Ljubljana, Slovenia outlined Joint Actions (JAs), which are EU funding instruments that aim to address specific EU health priorities. He described three JAs that have helped form the basis for the EBCP, one of which is **iPAAC (innovative Partnership for Action Against Cancer)**. Within iPAAC, **implementation and sustainability reports** were undertaken involving site visits to some member states. A [roadmap](#) was developed to support health administrators or anyone needing to implement cancer control activities, including the creation of "**one-pagers**", quick summaries on specific policy. As strengths of the EBCP he cited, among others, its commitment to **lifestyles** and to improving patients' lives, its clear action on **screening**, and its support of **comprehensive cancer centres (CCCs)**. As challenges he mentioned addressing **regional differences**, and the need for member states to **invest** in technology and expertise. He suggested it is important to bring together the different EU subregions, to find solutions for smaller member states, and to develop **sustainable approaches** to financing CCCs.



Tit Albreht

## Science Update

**Fabrice André**, Head of Research and Professor in the Department of Medical Oncology at Gustave Roussy Cancer Center in Paris, France, gave an enlightening talk on **genomics and precision medicine** in metastatic breast cancer. The concept is to use genomics to **identify genetic drivers** of tumour progression so that they can be targeted for treatment. They can also help identify patients who could experience **toxicity**, who would benefit or not from chemotherapy, and those whose cancer is developing **resistance**. Over time, more and more genetic alterations will be identified, some rare, and treatments may need to be designed for individuals. This will change the standard placebo-controlled approach to trials and require a new regulatory framework. Dr André added that it is important for academics to **share data** and generate databases to trace the natural history of a mutation for use as a control arm. He described a study of **artificial intelligence** for data analysis that



Fabrice André

## Europa Donna Breast Cancer Advocacy Leader Conference

tested the machine's ability to predict risk of recurrence and to learn: the machine learned in a few days what it had taken humans some 50 years. Genomics can also help **stratify patients** with a poor prognosis so that they can go straight into clinical trials. It can also be used to **identify cancer at its earliest stages**: a US company already commercialises a test of circulating DNA to identify cancer before it develops. All of this will put current protocols, standards, regulatory processes, and ethics committees to the test.

**Olivia Pagani**, from the Breast Cancer Programme and a coordinator at the European School of Oncology in Switzerland, joined virtually and described the **clinical research process** and how advocates can contribute to it. She noted that clinical research aims to test new

drugs and therapeutic approaches, new indications for old drugs, and new therapeutic combinations, and that the trial process takes many years. In contrast, the record-speed development of a **COVID-19 vaccine** shows what can be achieved with an invested interest from the public sector. She added that the real-life stage of drug testing, beyond drug approval, is key to gathering **long-term safety data**. Trials should include quality of life as a real cost/benefit measure, results should be reproducible in the real world, they should include ethnic minorities as well as older and sicker participants, and therapies should be available in all countries. Dr Pagani called for advocates to be, or continue to be, involved in **designing and conducting clinical research** and to promote relevant trials in their country.

## Update on the ECIBC

Three representatives from the **EU's Joint Research Centre (JRC)**, which is responsible for the ECIBC, were on hand for an interactive session on this initiative focused entirely on breast cancer. **Annett J. Roi**, the JRC Healthcare Quality Group Leader, gave an overview of the three main components of the ECIBC: the **European guidelines on breast cancer screening and diagnosis**, the **catalogue on international guidelines** on breast cancer treatment and rehabilitation, follow-up and survivorship and palliative care, and the **European quality assurance scheme (QAS) for breast cancer services**. She provided an update on the current status: the European breast cancer guidelines are undergoing their third round of updates and the QAS is expected to be ready for full implementation in 2023.

**Gian Paolo Morgano**, of the JRC, provided more specifics on the guidelines updates, which occur regularly and are posted on the [ECIBC web hub](#). The guidelines are developed according to a stringent **evidence-based methodology** and expert insight and include **76 recommendations**. He commended the helpful insight of ED's Executive Director Emeritus **Susan Knox** in this process. An update undertaken from December 2020 to

December 2021 resulted in **2 new recommendations** (on using artificial intelligence to support double-reading of mammograms, but not single-reading) and reaffirmed 7 recommendations (on digital breast tomosynthesis, decision aids, screening at age 45 to 49, and contrast-enhanced mammography). Details of these can be found on the [European guidelines](#) section of the ECIBC web hub.

**Luciana Neamtiu**, of the JRC, gave a status update on the **QAS**, which has established **86 quality and safety requirements for breast cancer services (BCS)**, the feasibility of which has now been tested in 8 BCS and a cancer registry. The BCS requirements include such criteria as a maximum 4-week period between pathology-supported diagnosis and treatment, and having a policy to routinely measure **patient-reported outcomes**. The scope of a BCS certification can include: 1) screening (and in some cases the process of diagnosis for screen detected lesions); 2) diagnosis to end of life care; 3) the entire care pathway. Detailed **manuals** have been created to help BCS implement services that meet certification standards with the aim of having BCS certified by an accredited certification body. Now that the positive feedback and clarifications identified in the **feasibility testing** have been implemented, the next step is a **pilot run** to check the auditing process. Based on feedback from this, the QAS will be improved, and the materials will be updated. Throughout this process, experts including patient advocates from ED, have been providing input. **Marzia Zambon** has been recently appointed to the QAS development group.

All the ECIBC materials are key tools for advocates to present EU-backed evidence-based recommendations for the full spectrum of cancer care. ED has created a [brochure](#) with key points on the ECIBC.

## Networking

In an afternoon of **networking sessions**, advocacy leaders were able to rotate through a series of **workshops** on three key topics: implementing EU Breast Cancer Policy at a national level; sponsorship and funding; and how to get involved in research and clinical trials.



Luciana Neamtiu, Gian Paolo Morgano and Annett J. Roi

ED Breast Cancer Advocacy Leader Conference



EBCC13



# 13th European Breast Cancer Conference

16-18 November 2022  
Barcelona, Spain

**Europa Donna – The European Breast Cancer Coalition** co-organised the 13<sup>th</sup> European Breast Cancer Conference (**EBCC13**), this two-yearly event that brings together scientists, researchers, clinicians, patients and patient advocates to further multidisciplinary collaboration for progress in breast cancer. The conference welcomed more than **1725 participants** from some 78 countries, including 1450 people attending in person. A recurring theme at the event was the potential for risk identification and stratification, whether in screening, prevention or therapy.

**Europa Donna** is an equal partner in organising and designing the sessions and topics to be covered with two scientific societies, the European Organisation for Research and Treatment of Cancer (**EORTC**) and the European Society of Breast Cancer Specialists (**EUSOMA**). This format ensures a truly multidisciplinary approach

and special attention to the perspective of patients, the real protagonists of breast cancer.

**Europa Donna President** and conference co-chair **Tanja Spanic** opened the conference and presented the **EBCC Arts and Humanities Prize** for “You are Not Alone — A Guidebook to Breast Cancer” — to **Nikol Pazderová** from the Czech Republic. In the book written in Czech, young breast cancer survivors share their experiences throughout the full breast cancer journey and provide their advice to help guide other women through this process. Europa Donna receives nominations for this prize, which was awarded for the 11th time at EBCC13.



Florita Poulakaki

## Europa Donna Sessions

### Survivorship

Each EBCC features specific sessions designed by Europa Donna on topics of interest to advocates and patients. In a session on survivorship, **Tit Albreht** from the National Institute of Public Health in Ljubljana, Slovenia, described **survivorship care plans** (SCPs). An SCP is a document that patients should receive after they complete their acute treatment (eg, radiotherapy or chemotherapy). It is based on the specific needs of the patient and outlines, for example, their treatment information and available supportive care services. SCPs are a key recommendation of an EU Joint Action on cancer policy and have become part of **Europe's Beating Cancer Plan** (EBCP); however, they will need member states to implement them. Dr Albreht said that **patient organisations** along with professional groups and others are vital to this implementation, which includes increasing awareness of SCPs. More on SCPs is available at [www.cancercontrol.eu](http://www.cancercontrol.eu) (see *Guide* section).

**Shoshana Rosenberg**, a cancer epidemiologist from Weill Cornell Medicine in the United States, described **lifestyle approaches** for the long term. Observational studies indicate that **physical activity** helps reduce breast cancer recurrence and mortality; randomised trials are ongoing. Other studies on physical activity show a **quality-of-life benefit** in women after chemo- or radiotherapy, and improved cognitive functioning in those on chemotherapy. **Yoga** helped to improve anxiety and depression. For many other approaches the

evidence is conflicting or shows no effect on recurrence or survival. A low-fat diet reduced recurrence in one study but did not affect overall survival in another. For **smoking**, however, current smokers had a greater risk of death than never-smokers. Obesity and smoking were both associated with decreased quality of life. A recent, large, pooled analysis on **alcohol consumption** showed no effect on overall recurrence or survival, although the recurrence risk was higher in postmenopausal women who drink regularly, and in women with oestrogen-receptor (ER)-negative breast cancer who drink occasionally. From the **patient's perspective**, a recent American Society of Clinical Oncology survey of cancer patients reported that only about 50% were asked about their eating or exercise habits at oncology clinic visits. In closing, Dr Rosenberg recommended the well-recognised approaches of **maintaining ideal weight**, achieving at least 3-5 hours of **moderate intensity physical activity** a week, **quitting smoking** and limiting **alcohol intake**. This is in line with Europa Donna's **Breast Health Day** prevention campaign, particularly for primary prevention.

**Elizabeth Bergsten-Nordstrom**, an ED Executive Board member, and two-time breast cancer survivor gave a perspective on the **real-life experience** of survivorship. She said that the real issues involve dealing with change because a woman's life is never the same after a cancer diagnosis. Each woman needs to find her own way forward, and each woman's needs will be different during and after treatment (eg, different ages and life stages). **Patient organisations** can support women through this and can provide insight that family members or friends may not be equipped to provide. Collaboration or communication between healthcare professionals and



Elizabeth Bergsten-Nordstrom,  
Shoshana Rosenberg and Tit Albreht

patient organisations is key to using different experiences to reach common goals. She added that cancer survivors or carers have valuable experience and can volunteer and make a difference in someone else's life, and have a positive effect on their own.

## Europe's Beating Cancer Plan (EBCP)

A session dedicated to the EBCP opened with a [video message](#) from MEP **Alessandra Moretti** where she said that EU countries are coming together to tackle health issues – as done with COVID-19 – and that working to create a “European health union” will help protect its citizens.

ED CEO **Marzia Zambon** gave an update on the current status of the EBCP, which calls for actions across all cancer stages, from prevention to survivorship (for more on EBCP, see page 2). She highlighted some of the main flagship activities. One is the **Cancer Inequalities Registry**, which aims to flag and address unequal access to screening, treatment and care, social services across and within EU member states. Europa Donna is a registered stakeholder in this initiative. The registry is a work in progress and cross-referencing of data is underway. It holds great potential for advocacy. The registry is hosted on the **Knowledge Centre on Cancer**, launched in June 2021. It is a platform hosting evidence-based cancer information, the European guidelines for cancer screening, diagnosis and care (both breast and colorectal). It also houses a **Cancer Information System**, including comparable cancer burden indicators on incidence, prevalence, survival and mortality, which may be used for the evaluation of cancer control measures by health policies. The **Prevention hub** houses data on cancer risk factors, and approaches to primary prevention. Marzia also noted that after 18 months of work, on 22 September 2022, the European Commission issued its proposed updates to the **Council Recommendations for Cancer Screening**, which dates back to 2003. This included expanding screening ages to 45 to 74 years. (ED Note: Following some debate, the Council of the EU adopted the new recommendations on 9 December, after EBCC13.)

**Gian Paolo Morgano**, of the EU's Joint Research Centre (JRC), which is responsible for the **European Commission Initiative on Breast Cancer** (ECIBC), gave an overview of the third round of guideline updates (for more on this see page 3). A new round of updates is to start in December 2022. He added that as it is important for the guidelines to be implemented in all countries, they must be applicable in all countries. Given that the guidelines are based on a costly and exhaustive review of the evidence base, the guidelines are also being picked up by countries outside the EU. He expressed gratitude for Europa Donna's dedication to disseminating information and **increasing awareness of the guidelines**.

**Annie Anderson**, from the University of Dundee in the UK, then described the ActWELL study on personalised

weight and physical activity, where radiographers in breast screening clinics gave women information about the study. It met an overwhelming response from women. The study showed that introducing **lifestyle advice at screening** is feasible, it may increase screening uptake, and increase awareness of breast cancer risk factors. Women in the study also lost weight, which can reduce risk for postmenopausal breast cancer.

## Impact of COVID-19 on Breast Cancer Patients

ED Vice-President **Fiorita Poulakaki**, who is also a breast surgeon and head of a breast clinic in Athens, Greece, gave an overview of the effect of the COVID-19 response on breast cancer, the data and challenges it posed. Various studies show that there was an increase in the use of neoadjuvant treatment (before surgery), but otherwise little change in breast cancer detection method, cancer stage at diagnosis, the type of surgical procedures performed, or tumour biology. However, the long-term effect may yet to be seen. Studies suggest that the **suspension of screening programmes** during the pandemic may lead to an increase in later stage detection of breast cancer and a rise in mortality. **Research must continue** in order to assess the outcomes and the impact in the long term.

**Silvia Almeida**, from the Champalimaud Foundation in Portugal, presented the findings of a BOUNCE Project study ([www.bounce-project.eu](http://www.bounce-project.eu)) showing that compared with pre-pandemic, exposure to the pandemic did not have a significant **psychological impact** on women with early breast cancer. Having a cancer diagnosis was the main concern. Of note, patients exposed to the pandemic seemed to have a **higher quality of life** than those not exposed. Reasons for this could be the protective effect of the lockdown measures, such as increased family time.

**Barbara Klein**, ED Communications Officer, covered the effect of the pandemic on **patient organisations**. She said the uncertainties and switching from in-person meetings to virtual taught the value of **flexibility**. It also helped keep the ED fora connected. A number of initiatives begun during the pandemic will continue, such as quarterly **forum virtual roundtables**, and a virtual rather than an in-person conference for women with **metastatic breast cancer** to facilitate their participation. In 2022, Europa Donna conducted a [survey on COVID-19](#) and the state of breast services. It indicated that while wait times for mammograms have generally returned to normal, **wait times** for breast services can be longer than those pre-pandemic. Women are returning without fear to **screening, treatment and follow-up** programmes. Barbara noted that a positive effect of the pandemic is that advocates are more connected than ever.



Gian Paolo Morgano, Antonella Moreo, Marzia Zambon and Annie Anderson



Barbara Klein, Fiorita Poulakaki and Silvia Almeida

## Reducing Breast Cancer Risk

### Innovations in Screening to Detect High Risk

The goal of determining the various degrees and facets of risk in breast cancer was a recurring topic throughout the conference, ranging from potential techniques to detect the risk and treatment approaches to target specific risk indicators.

In a session involving Europa Donna, **Andrea De Censi** from Galliera Hospital in Genova, Italy, presented his research showing a significantly **reduced breast cancer incidence** – and good tolerability – with 3 years of preventive treatment with low-dose tamoxifen (5 mg daily rather than 20 mg) vs placebo in women with hormone-sensitive or unknown breast intraepithelial neoplasia (ie, abnormal cells). These results spurred a change in various treatment guidelines which now recommend low-dose tamoxifen in high-risk cases. Dr DeCensi said that high risk may include women with, for example, a high-risk score, certain gene mutations, or with high mammographic density. He added that 10-year follow-up data from his study should be presented by the end of 2022.

**Inez Vaz Luis**, from Gustave Roussy Institute in France, showed the evidence for lifestyle measures in **primary breast cancer prevention**. As noted for secondary prevention above, physical activity and maintaining or losing weight are protective, while alcohol consumption increases risk. She mentioned measures to facilitate the update of healthy behaviours, including digital trackers such as step counters, availability of patient-friendly guidelines and individualised one-to-one programmes.

**Marzia Zambon** presented policy initiatives, primarily the EBCP and its **Cancer Prevention pillar**, driven by the over **40% of cancers that could be prevented** through healthful diets, physical activity, smoking cessation, reducing alcohol consumption and reducing environmental pollution. It is also part of the

**Knowledge Centre on Cancer** (see more on this on page 6). Some European Commission initiatives to raise nutrition awareness focus on clear **product labels**, for example. Promoting **access to sport**, there is the **HealthyLifestyle4All** campaign. Marzia added that it is important to raise awareness of the link between cancer and specific lifestyle factors, which also provides a **cost-effective control strategy**. She gave examples of specific successful initiatives in different countries such as a **heart logo** on healthy choices in supermarkets and restaurants in Finland. It is now a highly recognised brand and healthier meals are now served in restaurants. Europa Donna's **Breast Health Day** initiative is another fine example.

In a session on **screening innovations** to find those at highest risk, the goal for the future is to have technologies or methods to identify women at high risk of breast cancer so that screening can be tailored for high-risk groups. The session discussed imaging methods, artificial intelligence, genetic/genomic testing, and risk models. **Ritse Mann** from Radboud University Medical Centre in Nijmegen, The Netherlands, said that **validated novel screening methods** include tomosynthesis, ultrasound and breast magnetic resonance imaging (MRI). He said that these are all ready for implementation in screening but, given their sensitivity profiles, they would be best used in risk-based screening. He added that **contrast-enhanced techniques** are much better than anatomical techniques.

**Suzette Delalogue** from Gustave Roussy Institute in France discussed risk models and described **MyPeBS** (My Personal Breast Screening), an EU funded, ongoing clinical study comparing a personalised risk-based screening strategy (eg, additional screening with ultrasound or MRI in women with high or very high risk) with standard screening. It is also testing the methods to determine specific risk thresholds and has found that, for example, the 313SNP polygenic risk score is feasible, very accurate, inexpensive and rapid to implement.

Many scientific sessions were dedicated to **liquid biopsies** and the clinical potential of detecting circulating tumour cells and circulating tumour DNA in blood, for diagnosis, prognosis, monitoring effects of treatment, identifying resistance mutations, and as a target for treatment. Much research is ongoing, and this is an area to watch.

## Other Topics of Interest to Advocates

### De-escalating Therapy

In a talk on the use of genomic signatures for tailoring therapy in ER-positive/HER2-negative breast cancer, **Fatima Cardoso**, from the Champalimaud Clinical Center in Lisbon, Portugal, summarised the results of studies testing prognostic **genomic signatures**, the TAILORx, MINDACT and Rx-PONDER studies. They have all generally shown that in high clinical risk but low genomic risk disease, there was **no benefit of chemotherapy** in postmenopausal women and an approximate 5% benefit in premenopausal women. She concluded that in this breast cancer type, optimising endocrine-based therapy is probably better than using chemotherapy.

**Joseph Gligorov**, from the Sorbonne University in Paris, France, reviewed the data on the use of gene signatures to **tailor length of endocrine therapy**. He concluded that with one of the gene signatures it may be possible to identify a population that does not benefit from adjuvant endocrine therapy, among women with early-stage, low-grade ER-positive breast cancer. Based on the data to date, gene signatures may be best designated for de-escalation (ie, removing) therapies than for adding them. The most important decision criteria remain the customary pathological findings (eg, stage, grade and hormone status).

## Multidisciplinary Teams and Personalised Therapy

In a session on how to run multidisciplinary meetings, **Emiel Rutgers**, from the Netherlands Cancer Institute, reiterated that multidisciplinary management, which is the standard of care, should start from day one as it makes for personalised therapy at all levels. It reduces the number of operations, improves cosmetic outcomes, and increases patient satisfaction and outcomes. **Lesley Fallowfield**, from Brighton and Sussex Medical School in the UK, described the practicalities for effective multidisciplinary team (MDT) meetings and communication, including strong leadership, positive team dynamics, administrative support, information systems that are good quality and complete, adequate space, sufficient staff time and resources. She added that breast cancer is the prime example of MDT working.

## Breast Cancer, Fertility and Pregnancy

In a session on managing women who would like to become pregnant, **Matteo Lambertini**, from the University of Genova, Italy, said that all women of reproductive age with breast cancer should receive **counselling about their fertility** and cancer as early as possible, and that they should

all be considered at risk of developing treatment-related toxic effects to their reproductive system. Approaches to fertility preservation include cryopreservation of oocyte/embryo or ovarian tissue, and ovarian suppression therapy during chemotherapy. Studies indicate that **pregnancy after breast cancer is safe** as it does not have a detrimental effect on survival. It will be worth watching for the future findings of the POSITIVE study examining the safety of interrupting therapy to allow for conception and pregnancy. He noted that data are lacking on the effect of newer therapies on fertility.

ED President **Tanja Spanic** discussed patients' expectations and listed the unmet needs regarding fertility preservation at diagnosis: it is not offered to all, not covered in all countries, availability of donor egg cells is limited, and the "right to be forgotten" is needed for the medical certificate required for adoption. She described the international **Project 528** dedicated to defining the **unmet needs of young women** with breast cancer. It has launched a **global survey** to identify and understand the most pressing needs of young women diagnosed with breast cancer, their caregivers, and the healthcare providers that support them. It is available in 8 languages and so far has had 20,000 responses of the 50,000 target. Tanja also shared her personal experience with breast cancer treatment and the birth of her daughter more than 10 years after her diagnosis, emphasising that women need to be well informed about **fertility preservation** and the possibilities for motherhood that lie ahead.

## EBCC Manifesto Session

The EBCC13 Manifesto this year was dedicated to best practices for **contralateral prophylactic mastectomy**, given the concern about requests for this procedure from women with low breast cancer risk. The Manifesto has nine recommendations, many focused on effectively

communicating and informing patients about realistic risks. ED's **Tanja Spanic** and **Fiorita Poulakaki** were on the discussion panel. The full Manifesto and recommendations have since been published in the [European Journal of Cancer](#).

### Mark your Calendar

The next conference, EBCC14, is to be held on 20-22 March 2024 in Milan, Italy



Manifesto panel (Anne Bredart, Isabel Rubio, Fiorita Poulakaki, Jennifer Kelly, Douglas Easton, Emiel Rutgers and Tanja Spanic)

# Keeping Advocates Connected

## Europa Donna Metastatic Breast Cancer Webinar

**Europa Donna** held a virtual course on metastatic breast cancer (MBC) advocacy with 37 participants from 18 countries on 17 and 18 June, most of whom had personal experience with MBC. This was the third virtual conference since the Coalition began holding yearly MBC conferences and training in 2017 to address the unmet needs of women with MBC, which is an **advocacy priority** for the Coalition.

**Dr Fatima Cardoso**, from the Champalimaud Clinical Centre in Lisbon, Portugal and President of the ABC Global Alliance, outlined the complex topic of **treatment for MBC**. The treatment recommendations are anchored in the ABC guidelines provided by the ABC Global Alliance, in which Europa Donna is a member. She described the latest treatment approaches and research for three MBC subtypes: HER2-positive; triple negative; and oestrogen receptor-positive (ER+)/HER2 negative MBC. For advocacy purposes, Dr Cardoso recommended demanding **high-quality pathology** reports because they are crucial for high-quality treatment.

Discussing the important topic of **patient-doctor communication in MBC**, **Dr Gabriella Pravettoni**, from the European Institute of Oncology in Milan, Italy, said that it is important for clinicians to focus on cognition rather than emotion and help patients make decisions. She emphasised that patients with MBC have different personalities and needs and make decisions differently, and communication must be adjusted accordingly.

Covering the role of **exercise in reducing the side effects** of cancer treatment, **Dr Jana Müller**, from the National Center for Tumor Diseases in Heidelberg, Germany, told advocates that different forms of exercise can help reduce fatigue, joint pain and peripheral neuropathy. She noted that most studies have been performed in early breast cancer, but that the **PREFERABLE study** is underway to define the role of exercise in combatting **fatigue** in MBC. Europa Donna is a partner in this European Union-backed initiative.

Addressing the financial impact of MBC and inequalities among countries, **Dr Richard Sullivan**, from King's College London and Director of the Institute of Cancer Policy in the United Kingdom, said that any cost assessments in cancer need to balance many factors, including cost of treatment and loss of productivity due to illness or death. Across Europe, 60 to 70% of the breast cancer costs (drugs, etc) are paid privately, mostly out of pocket. For advocacy, he said cost-benefit research and data can **change political minds** and can be harnessed in advocacy campaigns.

The MBC advocates then participated in **workshops** related to overcoming the **stigma and taboos** of an MBC diagnosis and managing **side effects**. The second day of the course involved an advocacy skills training workshop, designed specifically for MBC advocates.

## Europa Donna Advocacy Training Course

On 4 to 6 November, Europa Donna held its **first in-person** European Advocacy Training Course since 2019. Intended to train new advocates with scientifically accurate and

up-to-date information, this was the **21<sup>st</sup> year** that the course took place and 45 advocates from 22 countries were in attendance in Milan. Course participants heard presentations from leading experts on the science of breast cancer, and on European guidelines and recent EU policy initiatives. Advocates then participated in a full day of intensive **communication skills** workshops to learn to effectively communicate with people of influence and spread advocacy messages in their countries.

## Europa Donna 2022 Survey on COVID-19 and the State of Breast Services in Europe

During the spring of 2022, ED performed a survey to provide a snapshot of the effect of COVID-19 on breast services in Europe from the perspective of **patient advocacy organisations**. This project follows a smaller survey carried out in September 2020. The survey addressed **17 questions** regarding screening, diagnosis, treatment and follow-up, clinical trials advocacy and policy. One conclusion was that the waiting times for screening have now returned to their pre-pandemic levels (for more on COVID-19 and breast cancer, see page 6). The full survey results have been published in a [comprehensive booklet](#).

## Online Roundtables for Europa Donna National Fora

Since moving online during the pandemic, Europa Donna has continued to hold regular virtual roundtables as an ongoing Forum support project. The first of **5 roundtables in 2022** covered **personalised treatment** and described technical terms and concepts an advocate should be familiar with regarding genetics and genomics. During the meeting, ED President **Tanja Spanic** stressed the importance of patients' personal preferences when discussing treatment as each person is unique. In April, the focus was **best practice advocacy examples** from the ED Fora. **Fiorita Poulakaki**, ED Vice President from Greece, explained the steps taken by the ED Greece forum to have **genetic testing** covered by the Greek National Health System; **Sema Erdem**, ED Board member from ED Turkey, talked about an ongoing collaboration with the European Oncology Nursing Society (EONS) to train **breast care nurses**, and **Rosanna D'Antona** spoke about ED Italy's pilot project aimed at obtaining legislation for **flexible working solutions** so that women living with or after breast cancer can continue working. In the June roundtable, **Fiorita Poulakaki** covered "**Screening in the Era of Personalised Medicine**" and then led an active discussion with participants. In October, **Prof Mireille Broeders**, from Radboud University in the Netherlands and PhD candidate **Jim Peeters** together described **artificial intelligence** and how it can be applied to personalised screening. They gave an update on the IMAGINE project which features in-depth analysis of mammography and pathology to optimise referral of possible invasive breast cancers at screening. In December, at the final roundtable of the year, Europa Donna released its plans for a new **MBC awareness campaign** to be launched in 2023.



# Collaborating in European Policy Throughout 2022 and Beyond



Europa Donna has been active throughout 2022 in ensuring the implementation of the European Union's **Europe's Beating Cancer Plan (EBCP)**. As part of this plan, in February, ED President **Tanja Spanic** participated in a hybrid event hosted by **Stella Kyriakides**, European Commissioner for Health and Food Safety and former Europa Donna President, to raise women's awareness of cancer. European Commission President **Ursula von der Leyen**, CNN's **Christiane Amanpour**, French Health Minister **Olivier Véran** and MEP **Veronique Trillet-Lenoir** all joined in this outstanding event. Tanja spoke about the importance of having standardised European guidelines for breast services and then participated in a panel discussion with **Dr Alberto Costa**, Special Adviser for EU Policy on Cancer, **Dr Nicole Concini**, President of the European Society of Gynaecological Oncology

(ESGO) and **Andreas Charalambous**, President of the European Cancer Organisation (ECO). For more on the EBCP see pages 2 and 6.

In view of advocating for the implementation of EBCP, the **Transforming Breast Cancer Together (TBCT)** initiative held an event in October at the European Parliament to launch a **Call to Action on Quality of Care**. ED CEO **Marzia Zambon** took part in the panel discussion along with other TBCT members, where she stressed the need for coordination, cooperation, implementation and a sense of urgency which should apply to the cancer pandemic. She also emphasised the important role that the EU plays in urging all member states to carry out awareness campaigns and lifestyle changes in their countries. During the event, **Stella Kyriakides** delivered a video message on **inequalities in breast cancer prevention** and care and confirmed the European Commission's commitment to the fight against cancer in the EU. TBCT's **Living a Normal Life campaign** to raise awareness around the realities of people living with primary, advanced, or metastatic breast cancer was first launched in May. TBCT is working on specific recommendations on how policies can improve the quality of life of breast cancer patients and help recognise the right to find, keep, return to work and/or care responsibilities.

**Europa Donna** has been advocating relentlessly for the development of a quality assurance scheme for breast cancer services as well as a new edition of **European guidelines** for quality assurance in breast cancer screening and diagnosis. ED representatives have collaborated in the **European Commission Initiative on Breast Cancer (ECIBC)**'s European guidelines on breast cancer screening and diagnosis, which are updated regularly. The ECIBC is also developing a **European quality assurance scheme (QAS)** defining a common set of both quality and safety requirements for breast cancer services. In September, **Marzia Zambon** was selected to be part of the ECIBC's Quality Assurance Scheme working group, as an individual patient advocate, and she has since attended the QAS meeting in October. ED, as an organisation, has been a stakeholder in the ECIBC initiative from its outset, and has actively contributed to the design, development and update of the European guidelines. For more on the current status of the ECIBC initiatives see pages 3 and 6.



February EBCP event: Andreas Charalambous, Stella Kyriakides, Jennifer Baker, Alberto Costa, Tanja Spanic and Nicole Concini



At the October TBCT event at the European Parliament

## Continuing Collaboration with Scientific Organisations

In October, **Tanja Spanic** spoke at the **European Society for Surgical Oncology (ESSO)** policy event, "Time for Change: Addressing the value of surgical oncology in the treatment and care of cancer". She discussed the need for cancer patients to be treated by **specialised surgical oncologists** at this event hosted by MEP **Cristian Busoi** at the European Parliament in Brussels. Designed in light of the implementation of the EBCP, this event

highlighted the crucial role of surgical oncology in cancer care to reduce the increasing cancer burden and to ensure a **patient-centred care system** in Europe.

In October, Tanja also took part in session 1 of the **European Cancer Organisation** Community 365 Roundtable Meeting on Cancer Care Needs in the Community Setting as well as a **BIG-EORTC** webinar on the topic of “The Unmet Needs of Older Patients with Breast Cancer”. Organised by Breast International Group (BIG) and the European Organisation for the Research and Treatment of Cancer (EORTC), this scientific webinar sought to stimulate greater awareness about the need to include more of the growing population of **older patients in clinical trials**.

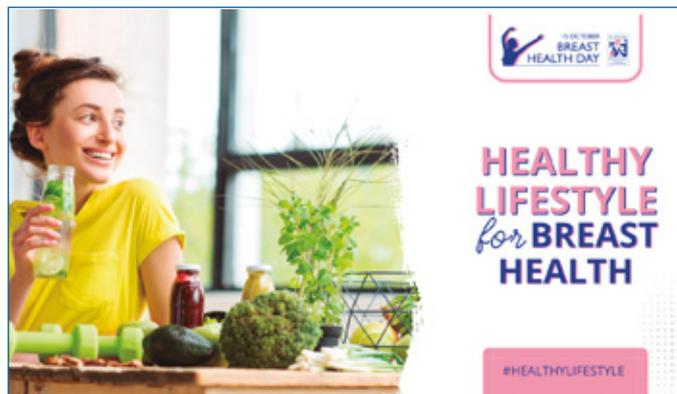
In early October, ED Past President and Executive Board member **Elizabeth Bergsten Nordström** participated in the 2022 EUSOBI (**European Society of Breast Imaging**) Annual meeting held in Malmö, Sweden. She took part in the session dedicated to “The Future of Screening” where she provided the patient perspective on “The Equity of Access to Screening”.

In September, ED Communications Officer **Barbara Klein** and ED Representatives from Spain and Sweden participated in Phase 1 of the **Oncoplastic Breast Consortium** OPBC 2022/EUBREAST/Toolbox2 Project online, on the topic “Uncertainties and Controversies in **Axillary Management**”. The OPBC was founded in March 2017 as global non-profit organisation and currently consists of 790 breast surgeons and 38 patient advocates, many of whom are ED members, from 92 countries.

In May, **Marzia Zambon** co-chaired the SPCC — **Sharing Progress in Cancer Care** online course on the topic “Precision Testing Early and Later: A Tool for Diagnosis and Better Treatment?” alongside **Anna Batistatou**, President of the Hellenic Society of Pathology. The course was held online with the participation of world-renowned experts and covered the potential of precision testing techniques, limits of use of these techniques, and regulatory issues. In March, ED Treasurer **Sema Erdem** took part in an SPCC webinar on “**Pain Management in Cancer Care**”. She provided the patient point-of-view and stressed the importance for women to communicate with their physician about any pain felt during treatment and the need for treatment by a multidisciplinary team.

Also in March, **Tanja Spanic** took part in the **European Alliance for Personalised Medicine** (EAPM) consensus panel on “Unmet medical needs”. Tanja pointed out the inequalities that still exist across Europe with regards to access to novel treatments, specialist breast centres, genetic/genomic testing and population-based mammography screening programmes.

In January, **Marzia Zambon** participated in the ABC Global Webinar “Protecting the Rights of Patients Around the World – The Role of Law.” The webinar focused on **the role of law in the provision of healthcare**, including the legal foundation of patient rights, and the influence of human rights law. During the webinar Marzia provided the European perspective thanks to ED’s experience in this field.



## 2022 Breast Health Day Campaign

On **15 October**, Europa Donna celebrated the **15th annual Breast Health Day** to disseminate information about breast health and to raise awareness of **prevention and early detection** of breast cancer among women and girls across Europe. This year, ED launched a [new video](#) showing the importance of making daily **#HealthyLifestyle** choices for your Breast Health. BHD was celebrated widely across ED member countries who held activities to mark the event.



# Strength in Numbers 2022

Europa Donna's 47 member countries are highly dedicated to breast cancer advocacy and hold multitudinous activities to further this cause. This section provides a sample of those activities.



## Albania

- Roundtable with patients
- Donation of bras and prostheses for breast cancer (BC) patients
- The "Race for the Cure" solidarity walk and run, in Shkodra and Lezha (2 of the most important cities in Albania)
- Small workshops with different companies and institutions to raise awareness about BC and metastatic breast cancer (MBC)
- For Breast Health Day (BHD), a solidarity walk and run and a canoe boat event, as well as discussing the importance of healthy lifestyle in the media
- A talk about healthy lifestyle and the importance of BHD and what it represents
- An event, "Donate Hair, Give Hope"

## Armenia

- In February, an awareness meeting with college students
- In March, a charitable concert and a marathon
- In April and May, online meetings and FAQs (frequently asked questions) with doctors
- In July and August, outdoor awareness meetings with citizens, talks and leaflet sharing
- In October, the annual conference "Towards Health", an awareness meeting with teachers in the Lori region, a Pink Marathon with famous people and a conference with family doctors to raise awareness about the importance of early detection
- In November, awareness meetings with teachers in the Kotayk and Ararat regions
- In December, New Year charitable and awareness markets

## Bulgaria

- Support for cancer patients, with a phone line, support consultations, training and a rehabilitation programme for women with BC
- Publication of literature and online campaigns
- For World Cancer Day and Pink October, educational fora and events
- Participation in developing a National Cancer Plan with a hybrid public consultation conference and a working group with the Ministry of Health
- A patient education online forum on bone health and BC
- Participation in scientific conferences and presentation of ED Bulgaria's activities
- Active collaboration with ED and ECPC (European Cancer Patient Coalition), surveys and webinars on advocacy and leadership
- 5 webinars for the European Week Against Cancer
- Inclusion of Bulgarian patients in international surveys

## Belgium

- The pink walk
- Collaborating with the EU-funded clinical study MyPeBS (My Personal Breast Screening)

- Running social media campaigns via Facebook
- Maintaining the ED Belgium website

## Croatia

- In February, a thematic session in the Croatian Parliament on the topic "Oncology Care in Pandemic Conditions" for World Cancer Day
- In March, Daffodil Day
- In June, a roundtable on "COVID-19 and Mental Health of Cancer Patients"
- In August, a humanitarian race for BC patients
- In October, Pink Ribbon Day
- For BHD, a conference for pregnant and breastfeeding women

## Cyprus

- A cocktail party for ED Cyprus's 20<sup>th</sup> anniversary
- Annual activities: co-organisation of a Cancer Day event, social media campaign, participation in conferences and seminars, and on boards
- Participation in the national screening programme steering committee
- Weekly posts on BC on social media
- Co-operation with the specialist breast unit (SBU) at Nicosia General Hospital
- Programmes for BC patients on psychology and physiotherapy
- Free prostheses and wigs
- A campaign, "The Right to be Forgotten" (eg, insurance coverage for cancer survivors) including a solidarity walk and run, a scientific conference, a meeting with the Minister of Health and MPs, insurance officials and participation in the House of Parliament Health Committee

## Czech Republic

- Help and support for Ukrainian women immigrants
- Monthly online activities: memory training; talks at a café on various topics
- In July, participation in the Expert Conference on Oncology in Brno, organised by the Ministry of Health under the Czech Presidency of the Council of the EU
- Activities (in cooperation with other organisations) for all cancer survivors: education, information, help with return to work, prevention, the right to be forgotten

## Denmark

- Key issue: improved visibility
- Working with key issues through ED Denmark channels via magazine, web, and social media
- In June, 3 debates at the Danish Democratic Festival (Folkemødet)
- Active media work
- Including the theme of "shared decision-making" in local committees and meetings
- Representation at cancer conferences through participation by nurses, doctors and researchers, and an exhibition stand

- Participation in external educational activities about advocacy, shared decision-making, influence on one's own treatment, among other topics

## Finland

- Rehabilitation course for families with MBC
- Holiday weeks with peer support for MBC patients and families affected by BC
- Continuing online activities such as support groups, webinars and yoga
- A member survey on the experiences of receiving a BC diagnosis and follow-up
- Participation in cancer research projects as patient advocates
- Dissemination of information on cancer research to patients and the public
- In September, the Nordic Congress on Breast Cancer for Nordic BC patient organisations

## France

- Renewal of the board of ED France and reflections on new strategies to be implemented
- In October, activities across France to raise awareness about BC
- In November, the annual conference at the senate, with the main topic "How to prevent the adverse effects of treatment and help the patients who suffer from them"
- A return to face-to-face meetings at the "Cafés Donna" after 2 years of virtual debates
- Development of a think tank, "Collectif 1310", with other associations to organise events for International MBC Day, raise awareness about MBC and improve patients' daily life

## Georgia

- In March, a campaign to support Ukrainian oncological patients, including collection of leftover cancer medications, fundraising and a contribution of 7000 boxes of chemotherapy drugs from a major Georgian pharmaceutical network
- A charity art exhibition by BC patients and ED Georgia supporters, to raise funds for medications for Ukrainian patients
- In July, a roundtable on cancer treatments with physicians, patients, government representatives and the mass media, where financing from the state and private sector were also discussed
- An information campaign on prevention of oncological diseases, aimed at early detection and diagnosis of cancer in women
- A pink marathon

## Greece

- Participation by ED board members in lectures and TV shows to raise awareness about BC, prevention and ED's mission and vision
- Courtesy beauty treatments for BC survivors
- Participation in the Economist Forum with the Ministry of Health and European Commissioner Stella Kyriakides
- Involvement in creating the National Breast Cancer Registry with the Ministry of Health
- Participation by the President of ED Greece in a European Parliament event
- A charity fashion show
- For BHD, national BC awareness and promotion campaigns, and participation in TV/radio broadcasts

- Coordinating participation in the ED Cyprus Conference
- Participation in the Athens Marathon
- Lectures throughout Greece raising BC awareness
- Online scientific lectures on MBC and scientific articles on Facebook and the ED Greece website

## Ireland

- Maintaining and expanding MBC Connect, a private Facebook page for women with MBC
- Participating in the National Cancer Control Programme Cancer Patient Advisory Committee, Psycho-Oncology Advisory Group and the Steering Group for Systemic Anti-Cancer Therapy Model of Care
- Events for MBC Awareness Day on 14 October (with the Marie Keating Foundation)

## Israel

- Support groups
- Online and face-to-face lectures
- "Yad Lehachlama" (Reach to Recovery): trained volunteer BC survivors supporting newly diagnosed women
- A digital campaign and information sheet on BRCA testing available through the public health system for Ashkenazi Jewish women
- A mobile mammography unit to improve equal access to early detection in all sectors of women across the country
- For BC awareness month, a press release and campaigns in print media and on social media, and a "Celebrating Life" workshop
- In October, online webinars and physical workshops on BC and MBC in Hebrew, Arabic and Russian

## Italy

- Launching a digital campaign on genomic testing
- A campaign to support psycho-oncological support in Italian SBUs
- On-demand courses for associations and patients on dealing with digital interaction with BC care
- A new delegation, ED Calabria
- A project, a webinar and a live Facebook event for patients with triple-negative BC
- Presentation of a manifesto to Italian parliament members on updating and increasing screening quality
- Presentation of the 3rd PWC analysis on social values
- A campaign on bone risk during hormone therapy, involving web seminars and media activity
- A 15-minute documentary on breast unit activities
- Inauguration of the ED Academy with classes on genomic testing
- Press conferences on return to work and ABC
- In October, an advertising campaign and a survey on MBC
- 4th edition of the Laudato Medico dedicated to ED founder Prof Umberto Veronesi

## Kyrgyzstan

- For World Cancer Day, organising a conference with the National Oncology Centre
- Regular meetings with BC patients and survivors for discussion, physical exercise, and provision of breast prostheses donated by an NGO and ED Luxembourg
- In May, end of the Talas region mobile mammography trailer programme with 1401 patients examined and 45 suspected BC cases detected
- Assistance during hospitalisation to women from remote areas with breast or cervical cancer

- Providing pension and benefit registration for BC patients with small children
- For Pink October, open days at the Republican Diagnostic Centre; a mobile mammography trailer promotional event; peer counselling groups at the National Oncology Centre; participation in mass-media programmes

## Latvia

- Psychosocial rehabilitation programmes for BC patients and their relatives
- Creation of ED Latvia's Psychosocial Rehabilitation Centre, which is planned to open in 2023 and will provide rehabilitation after cancer to at least 1,000 people a year
- Active defence of patients' interests regarding increased funding for oncological care and participation in the development of the Oncological Care Plan 2022-2024
- In October, the Pink Ribbon Campaign, training for the Volunteer Mentor Movement, mutual support group events and public lectures on life after cancer

## Lithuania

- A conference together with an MEP with the event being broadcast on the European News YouTube channel
- At the beginning of the year, starting the project "Genetic testing for mothers and daughters" with a partner
- During the Vilnius marathon, encouraging women to participate more actively in the breast screening programme
- October activities: Contact Annual Reporting Conference, and working with the National Cancer Institute Conference on hereditary breast cancer
- Finishing the National Project "Crowd Ideas" with breast implants now included in the compensation measures in Lithuania
- Continuing the "And Life Goes On" project with lectures by oncologists
- Continuing studies at the University of Women of Wonder
- Continued fundraising

## Luxembourg

- 20th annual BC Run "Broschkriibslaf", held in person for the first time since the pandemic
- In July, a conference "Together against Breast Cancer" for ED Luxembourg's 20<sup>th</sup> anniversary
- A photography project "Objectif Rose" to help BC patients reconnect with their bodies and reveal their beauty
- A flyer on breast self-examination in French and English for ED Luxembourg's website and October information stands
- Launch of a monthly BC support group at ED Luxembourg

## Malta

- Holding monthly members' meetings online due to COVID but with a gradual return to face-to-face meetings
- In June, a very successful in-person get-together and dinner with members
- The ED Malta annual general meeting with the setting-up of a new committee group
- In October, various Pink October activities

## Monaco

- Volunteer visits to cancer patients at Princesse Grace Hospital to provide information
- A "Wellbeing Centre" for BC patients, including a beautician, a nutritionist and yoga classes
- A healthy weekend excursion for patients
- Regular weekly walks for patients
- In October, the wearing of pink ribbons by members of the government and employees to show awareness, and a stand in partnership with a hospital to raise awareness about BC prevention
- The annual Pink Walk
- A meeting with a hotel about prevention and life after cancer
- Speeches by psychologists and specialists and interviews with patients
- In November, celebrating ED Monaco's 30<sup>th</sup> anniversary, with members of the royal family in attendance

## The Netherlands

- Improvement of patient information, implementing shared decision-making and encouraging precision medicine, with 3 new therapies submitted by The Netherlands
- Participating in international conferences
- An Instagram awareness-raising campaign on hereditary BC and early BC detection
- Promoting contact between patients through information meetings, sports activities and support groups
- For BHD, different sports activities, social media posts, and increasing research on exercise during treatment
- Improvement of MBC patient's journey: advocacy for access to new therapies, a brochure and fact sheet, 3 dedicated support groups
- In September, hosting an MBC meeting on developing future strategy with experts, MBC patients and stakeholders from the field
- The launch of ED Netherland's patient-driven research agenda naming 7 themes proposed by patients

## North Macedonia

- For October, a national BC campaign, including a social media press campaign, flyers on prevention, guidelines for newly diagnosed patients and BC patients' video statements
- Attending a government session on the national BC campaign, addressing the importance of prevention, early detection, screening and BC patients' needs
- Meetings with young BC patients
- Meetings with medical specialists and lawyers, including free examination/consultation and legal advice
- Online psychosocial support
- Preparing "Comfort care packages -- From me to you" from survivors to new patients
- Lectures on the importance of early BC detection and a healthy lifestyle
- The first "Pink Scarf Day", dedicated to Muslim women
- In December, a Pink Bazaar

## Norway

- Four national conferences with professional topics and networking including weekend gatherings for women under 45 and for women diagnosed with MBC

- Increasing awareness of MBC, including a documentary and statue
- Campaigns to ensure faster access to new publicly-funded medicine, such as PR and media coverage
- Support for research environments with funding from ED Norway
- Local activities including exercise groups, social gatherings and meetings on professional topics
- Supportive care visits/telephone calls
- Advocacy on cancer treatment topics, access to new medicines and care
- Continuing advocacy and fundraising after reaching a record high in funds raised during Pink October in 2021

## Poland

- A fundraising campaign with posters and leaflets on the activities of ED Poland
- Continued financial, material and organisational support for Ukrainian refugees
- Participation in urban and rural festivals, promoting a healthy lifestyle and preventive mammography examinations
- An interview with the Minister of Health on mammography screening for women aged 70-75
- The XXV Congress of the Delegates of the Polish Forum, including topics involving the 2023 work plan, and an appeal to the Minister of Health regarding screening for women aged 70-75
- A BHD campaign, with posters and brochures, media and social media activity, popular science conferences on BC, the “March to Health” and Zumba marathons

## Portugal

- A BC screening programme
- A Cancer Line to provide information and support
- Psychological support for patients and relatives
- Providing legal assistance
- 17 research grants for BC
- The Pink October campaign
- Medical expert support for cancer patients at medical boards
- Participation in the public consultation of the National Strategy to Combat Cancer
- 11th edition of the course “Physical Treatment of Oedema – Intervention of the Physiotherapist in Oncology – LEDUC Method”

## Romania

- Annual activities: 8th “Happy Run” (over 2700 participants), the “Brave Cut” Campaign (over 950 wigs donated) and a pink illumination event
- Supporting activities through an association to promote early detection of BC and other oncological or chronic diseases, with donation of prostheses and bras
- A mobile diagnostic campaign for breast and cervical cancer for women in rural areas
- An advocacy event at the Romanian parliament on the need for a National Cancer Plan, with participation of the Minister of Health, senators and MPs, doctors and the media; 98,000 pink ribbons were displayed in front of the parliament

- For BHD, donations via collaborations with a fitness app, and football and basketball players in pink shirts
- For MBC, a roundtable “Together for HER” on the importance of screening and new therapies

## Serbia

- Distribution of 600 pink gift packs to BC patients
- Online educational interviews on BC and COVID-19 vaccination
- Education about BC in Subotica
- Participating in a meeting on the psychological aspects of new treatment options for MBC
- An awareness-raising campaign on BC prevention, a healthy lifestyle and support possibilities for BC patients
- Participation in a new version of the “Guide to Diagnosis and Treatment of Breast Cancer” with the Serbian Ministry of Health
- For BHD, a demonstration and lectures about BC and fertility, and hereditary BC
- “The Race for the Cure”
- Participation in a lecture during the “59th Cancerological Week”
- A regional project on mammography screening in the Serbian Roma community, for women over 40

## Slovakia

- Education about proper life management, mammography screening and breast awareness training
- Tasting sessions of healthy foods with recipes
- Art exhibitions by BC survivors
- Sports activities
- Interactive discussions for the public
- Cooperation with the National Oncological Institute and the Ministry of Health in helping to prepare legislation, professional conferences, an awareness campaign for mammography screening in Slovakia and a presentation for the International Agency for Research on Cancer (IARC)
- Online activities at [www.ruzovastuzka.sk](http://www.ruzovastuzka.sk)
- Cooperation with other patient organisations
- For BHD, a press conference and 12 other activities
- Pink illumination of cities and satellite activities at screening centres

## Slovenia

- In October, over 60 local events with physical activity, promotion of a healthy lifestyle, awareness-raising about screening and early detection
- A visit to the national Parliament for a meeting with MPs and a speech by the President of ED Slovenia on the BC landscape and future for the country
- For BHD, an ED Slovenia stand in Ljubljana, raising awareness about healthy lifestyle and screening; presentation of breast self-examination using a silicone model
- In other cities, a pink festival, walks for health, healthy food, a cycling marathon, promotional stands to raise awareness, a cultural programme, and activities with cycling, hiking and exercise
- An active social media campaign

## Spain

- Webinars on digital accessibility, long-term survivorship needs, personalised medicine and other topics of interest to patients

- Launch of a survey "Needs of women with breast cancer. Beyond the disease"
- Advocacy activities and participation with the National Cancer Strategy Board in the update of the National Cancer Plan in line with Europe's Beating Cancer Plan
- Psychological support for women with BC and their families
- Physiotherapy for lymphoedema
- Fundraising for clinical trials
- Maintenance of the website and activity on Twitter and other social media

## Sweden

- Input in reviewing the national BC care programme
- National screening programme review in cooperation with The National Board of Health and Welfare
- Digital and physical rehabilitation for MBC patients
- A meeting with the Minister of Social Affairs on the unequal situation for treatment of MBC patients as the final activity in the project #givemetime
- Training courses for local peer supporters
- Education and workshops for elected officials in local branches
- For International Women's Day, a digital campaign on self-examination and early detection
- A webinar for all members about precision medicine
- In October, a BC report about individual and risk-based screening

## Switzerland

- Publishing news about BC, early detection, physical activity and nutrition on the simplythebreast.ch blog and on social media
- Start of a new Tavola Rosa support group in Chur
- Tavola Rosa meetings and excursions in Zurich, Bern and Chur
- BHD at the Bürenlauf
- For Pink October, an awareness campaign to teach women about breast self-examination
- Articles and interviews in newspapers and magazines

## Tajikistan

- Implementing the project on treatment access and palliative care based on a grant from Union for International Cancer Control (UICC)
- Courses and seminars for patient groups and primary care physicians
- Participation in the ED Advocacy Leader Conference
- Training in breast self-examination
- BC early detection campaigns in different regions, including among Afghan refugees
- Meetings with the government on state purchases of chemotherapy for BC patients and improving access to treatment
- Participation in a survey on access to radiotherapy for BC patients and a roundtable on radiotherapy
- A roundtable on improving access to treatments
- Distribution of breast prostheses

- For October and BHD, an early detection and screening campaign, seminars on nutrition, breastfeeding, and healthy lifestyle, free aqua aerobics classes for BC patients, an information session for young women
- Delivery of humanitarian aid (chemotherapy) to the National Cancer Centre

## Turkey

- A joint project with the European Oncology Nursing Society (EONS) on the breast care nurse training and curriculum for MBC patients
- Attendance at the Biannual BREASTANBUL Conference, including speakers from ED Turkey, preparation of BC patient track content, BC patient advocacy for both early BC and MBC
- BC cancer specialty training for oncology nurses
- Raising awareness and a BHD campaign on social media
- Addressing MBC patients' needs
- Organising safe transportation of BC patients from home to hospital for chemo- and radiotherapy

## United Kingdom

- Advising on a Cancer Research UK TV advert
- Virtual motivational presentation to new students at the University of Nottingham's Centre for Cancer Sciences
- Involvement in National Audit of BC in Older Patients to improve quality of hospital care and highlight concerns, and collaboration in a guide to the BC care pathway
- Assistance in a scheme with other organisations to provide personal support for cancer patients
- Organising an event on connecting technology with Imperial Women's Network discussing artificial intelligence in BC prognostics
- Collaborating with a health company campaign, "Check for Change"
- For International Women's Day, representation in a social club event and a talk at a luncheon for the charity ForcaAgainstCancer to raise BC awareness
- A talk at the Association of Breast Surgery conference on harmonisation of nursing titles and micropigmentation/medical tattooing
- Evaluating project applications for the Nottingham Breast Cancer Research Centre

## Uzbekistan

- In February, participation in the promotional and educational events of the Association of Oncologists of Uzbekistan
- In March, celebration of International Women's Day with BC survivors and advocates
- In October to promote BHD, social events in Tashkent involving BC patients and survivors
- Participation in the BREASTANBUL 2022 Conference in Turkey
- A series of online seminars on MBC for the BC survivors in the regions of Karakalpakstan and Khorezm

## ■ Europa Donna MBC Advocacy Webinar

16 June 2023

## ■ Europa Donna Pan-European Conference

Zagreb, Croatia, 28-29 October 2023

## ■ 22nd Annual Europa Donna Breast Cancer Advocacy Training Course

17-19 November 2023

## ■ Stay tuned for more upcoming Roundtable Webinars and Interactive Zoom Meetings with Fora

in 2023 which will continue to take place on a regular basis, covering many different topics and enhancing communication and exchange among member countries.

## WHAT'S NEW

### ■ Europa Donna Website

In April, Europa Donna launched a major update of its website which now covers the entire breast cancer pathway from prevention to diagnosis and metastatic breast cancer. You can still find all of the information related to our history, mission, work, policies, statements and publications in addition to new and updated information on screening and early detection, breast cancer treatment and genetics/genomics.

### ■ Publications

#### **The Advocate's Guide to Genomics, Genetics and Personalised Medicine in Breast Cancer**

This 8-page booklet outlines the role of genetic and genomics in breast cancer risk prediction, prognosis and treatment, a topic of utmost importance to achieve precision medicine in the near future.

#### **A Guide to the European Commission Initiative on Breast Cancer**

This 4-page leaflet describes the ECIBC, its foundation and projects. It includes highlights from the European Guidelines on Breast Cancer Screening and Diagnosis, descriptions of the European Quality Assurance Scheme for breast cancer services and the catalogue of international guidelines.

#### **Europa Donna 2022 Survey on COVID-19 and the State of Breast Services in Europe**

This 8-page report summarises the responses provided by 34 of ED's 47 member countries to its 17-question survey on the effects of the pandemic on access to breast care services.

### ■ Breast Health Day

In 2022, for its main prevention initiative, Breast Health Day, Europa Donna launched a new video campaign #HealthyLifestyle choices for your Breast Health. BHD was celebrated widely across ED member countries who held activities to mark the event.



### Keep up to date and connect with us

Website: [www.europadonna.org](http://www.europadonna.org)



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 [http://twitter.com/EuropaDonnaEUR](https://http://twitter.com/EuropaDonnaEUR)

 [www.youtube.com/EuropaDonnaChannel](https://www.youtube.com/EuropaDonnaChannel)



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. © 2023 EUROPA DONNA – The European Breast Cancer Coalition



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