



EUROPA DONNA

The European Breast Cancer Coalition

Annual Report

2022

EUROPA DONNA Executive Board 2022

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OVERVIEW

2022 set a “New Normal” pace for all of EUROPA DONNA – The European Breast Cancer Coalition programmes and activities: we finally went back to in person events, meetings, courses, and conferences, an energizing and refreshing experience. We all kept a strong tie with digital meetings and events, so the New Normal is rather fast and intense, with TC slots booked 6 months in advance, packed calendars and emails flowing in, but, with the New Normal, along came the good old very much missed in person events.

The Annual Report details the Policy events Europa Donna was involved in, the progress being made in the ECIBC European Breast Cancer Guidelines and Quality Assurance Scheme, Europa Donna's involvement in international research projects and clinical trials, our cooperation with other patient organisations and multistakeholder groups and initiatives to make sure breast cancer remains high on policy makers' agendas.

Please also visit our new [website](#), make sure you are signed up to receive our Newsletters, and check out our 2022 publications (open source on our website under publications), including a very clear and comprehensive [advocate's guide](#) to genetics, genomics and personalized medicine in breast cancer.

I would like to now turn the focus to our Educational events:

Our **Forum Roundtable** webinar programme very successfully carried on throughout the year, including best practice advocacy examples and educational sessions, such as “One Size Doesn't Fit All” providing an overview of what an advocate should know about genetics, genomics and personalized treatment, etc. In October, we had the honor to host Prof. Mireille Broeders who spoke to our advocates about Artificial Intelligence and personalized breast cancer screening.

The other conference we kept in a digital format was our – now yearly - **MBC Advocacy Conference**. Thirty-seven participants from 18 European countries connected to listen to Dr. Fatima Cardoso speaking about the latest treatment approaches and research for three specific MBC subtypes, to Dr. Gabriella Pravettoni covering the patient-doctor communication issue, Dr. Jana Müller speaking about the importance of exercise in reducing side effects of cancer treatment, and finally Prof. Richard Sullivan addressing the financial impact of MBC and inequalities among countries.

The thirteenth edition of **EBCC** - The European Breast Cancer Conference finally took place as an in-person event, with Europa Donna once again co-organizing the event as equal partner with EORTC and EUSOMA. The Conference was held in Barcelona and welcomed almost 1800 attendees from 78 countries. As you know, this every two-year event brings together scientists, researchers, clinicians, patients and patient advocates to ensure a truly multidisciplinary approach in breast cancer. The ED Coalition General Assembly was also held in Barcelona, finally in person, and three new members of our Executive Board were elected to serve for the next three years.

Our biennial **Breast Cancer Advocacy Leader Conference**, also finally in person, took place on 24 September in Milan, with 45 leaders from 26 European of countries. Speakers included MEP Veronique Trillet-Lenoir, highlighting the need to address inequalities in breast cancer, Prof. Tit Albrecht of the National Institute of Public Health, who spoke about the implementation of the outputs of the cancer control Joint Actions in EU Member States, Prof. Fabrice André of Gustave Roussy Cancer Center, who shined a light on the new frontiers of genomics and personalized treatment, and finally Dr. Olivia Pagani who highlighted the importance of patient representatives being involved in research and clinical trials.

Finally, we held our annual **Advocacy Training Course** in Milan from 4 to 6 November. This course is intended to train new advocates from all of our member countries, providing all the information a breast cancer patient advocate should be aware of from all perspectives, including biology and science, existing European breast cancer programmes and guidelines and communication and advocacy skills in order to learn to effectively communicate with people of influence and spread advocacy messages in their countries. The 2022 edition of our Advocacy Training Course trained 45 new advocates from 22 of our member countries.

We are currently planning our **16th Pan European Conference** which will be held from 27th to 29th October 2023. A great programme with incredible speakers forecasts a very successful Conference which will finally see us all together. So, stay tuned, and I look forward to seeing all of you in Zagreb, Croatia for this very special Europa Donna event.

Marzia Zambon
CEO, Executive Director

ED 2022 PROGRAMMES

PUBLIC AFFAIRS

European Commission Initiative on Breast Cancer

ED 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 collaborate 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 finalizing its European Quality Assurance Scheme (QAS) defining a common set of quality and safety requirements and developing a European certification mechanism for breast cancer services. ED's Executive Director Emeritus Susan Knox is a member of the Guidelines Development Group (GDG) and attended meetings in June and December 2022. In September, ED's Executive Director Marzia Zambon was selected to be part of the ECIBC's Quality Assurance Scheme development group, as an individual patient advocate, and she attended her first QAS meeting on 3 October, which took place online. Europa Donna as an organization 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.

Europe's Beating Cancer Plan

Europa Donna was active throughout 2022 in ensuring the implementation of the European Union's Europe's Beating Cancer Plan (EBCP). As part of this effort, on 2 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 standardized 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 Concin, President of the European Society of Gynecological Oncology (ESGO) and Andreas Charalambous, President of the European Cancer Organisation (ECO).

On 26 October, Tanja Spanic spoke on the need for cancer patients to be treated by specialised surgical oncologists at a policy event held by the European Society for Surgical Oncology (ESSO) titled "Time for Change: Addressing the value of surgical oncology in the treatment and care of cancer", hosted by MEP Cristian Busoi at the European Parliament in Brussels. Designed in light of the implementation of the EBCP, this event provided a platform for highlighting 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. It brought together EU policy leaders and key stakeholders, as well as representatives from the surgical oncology community.

Transforming Breast Cancer Together

ED participates in the Transforming Breast Cancer Together (TBCT) initiative, which was established when influential policy makers and organisations strongly committed to breast cancer began to collaborate in 2017. In view of advocating for the implementation of EBCP, the Transforming Breast Cancer Together initiative held an event on 12 October at the European Parliament to launch a Call to Action on Quality of Care. ED Executive Director 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 and Dr. Fatima Cardoso, Chair of ABC Global Alliance, shared a video message highlighting the key policy asks. TBCT's Living a Normal Life campaign to raise awareness around the realities of people living with primary, advanced, or metastatic breast cancer (MBC) was first launched on 9 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. As part of this campaign, TBCT Chair and Member of European Parliament Frances Fitzgerald held an intimate conversation with breast cancer survivor Yamina Krossa about the challenges to return to work during and after cancer.

EU Science Hub

Ahead of World Cancer Day on 4 February, Executive Director Emeritus Susan Knox shared her story and Europa Donna's work to improve breast care services on the European Commission's EU Science Hub to highlight the need for better breast cancer screening, diagnosis & treatment. She noted that the ECIBC "will only have an impact if it gets implemented, so we will continue working on this objective. It is a key priority for all of our advocacy work today because it is essential to achieving our advocacy goals - to ensuring that women have access to the best, most up to date quality assured breast services from screening and early detection to diagnosis, treatment and appropriate follow up for breast cancer".

ED 2022 PROGRAMMES

RESEARCH

► 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. The full survey results have been published in a comprehensive [booklet](#) that is available on the Europa Donna website.

► EBCC-13 Manifesto

ED is a co-organiser of the biennial European Breast Cancer Conference (EBCC) along with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA). ED actively participates in the development of the scientific programme for each conference. ED President Tanja Spanic Co-Chaired the conference that took place 16 – 18 November 2022 in Barcelona, and Tanja and ED Vice President Fiorita Poulakaki served on the Manifesto Committee. The EBCC Manifesto sets out key principles and recommendations on how to maximise the impact of multidisciplinary breast cancer care. This edition focused on “How to control the ‘epidemic’ of contralateral prophylactic mastectomy (CPM)”. As part of the research, ED conducted a survey among its members in 2021; the results helped to formulate the manifesto and paper was published in December 2022. The EBCC Manifesto is available on the Europa Donna [website](#).

► Europa Donna Involvement in Research

Europa Donna actively promotes the advancement of breast cancer research and seeks to ensure that all women fully understand any proposed treatment options, including entry into clinical trials and their right to a second opinion. As part of our commitment, we regularly take part in advisory and scientific research committees. In 2022, ED representatives took part in numerous research projects. ED Executive Director Marzia Zambon and Board President Tanja Spanic represented ED in BIG (Breast International Group) Scientific Committee meetings. Europa Donna’s Executive Director Emeritus Susan Knox was active on the Steering Committees for the BIG MINDACT and AURORA

Trials and Tanja Spanic was on the Steering Committees for the POSITIVE and EUBREAST Trials. Board member Elizabeth Bergsten Nordström and Tanja Spanic sat on the Steering Committee of the EBCTCG Early Breast Cancer Trialists Collaborative Group, and Elizabeth was on the Ethics Committee of the IBCSG International Breast Cancer Study Group. Moreover, ED is the patient advocacy representative on the following Horizon projects that have been funded and continued/started their work in 2022: ED Board member Ellen Verschuur is an Advisory Board member in the “MEtabolic Signaling STRATification-MESI-STRAT” Research Project; former ED Board member Paola Mosconi is the ED Representative on the Ethics and Data Monitoring Committee of the MyPEBS (My Personal Breast Screening) Trial; Marzia Zambon is the ED Representative on the PREFERABLE (Project on Exercise for Fatigue Eradication in Advanced Breast cancer to improve quality of life) Trial; ED Board member Antonella Moreo sits on the Scientific Advisory Board of INSPIRE (INnovative tools for Safety Pharmacology for Integrated cardiovascular safety assessment to REduce adverse events and late-stage drug attrition) and she is on the External Advisory Board for CARDIOCARE - (An Interdisciplinary Approach for the Management of the Elderly Multimorbid Patient with Breast Cancer Therapy Induced Cardiac Toxicity). Furthermore, Marzia Zambon sits on the External Advisory Board for the IMI (Innovative Medicines Initiative) project OPTIMA (Optimal treatment for patients with solid tumours in Europe through Artificial Intelligence).

With regard to Horizon EU projects, Ellen Verschuur was on the External Advisory Board of both the 4D PICTURE Project (Design-based Data-Driven Decision-support Tools: Producing Improved Cancer Outcomes Through User-centred Research) and the ARTILLARY Project. Moreover, Marzia Zambon and Europa Donna’s Policy and Research Officer Martina Fontana represent Europa Donna on the newly funded SmartCARE Project, led by ECO (European Cancer Organisation).

Finally, Marzia Zambon represents ED on the Organisation for Economic Co-operation and Development (OECD) Patient-Reported Indicator Survey (PaRIS) Breast Cancer patient-reported outcome measures (PROMs) Working Group; this initiative aims at developing and implementing standardised patient-oriented measures of health-care performance.

EDUCATION HIGHLIGHTS

► Europa Donna Forum Roundtables

On 23 February, Europa Donna held its first Forum Roundtable of the year, led by ED President Tanja Spanic, in collaboration with ED Vice-President, Fiorita Poulakaki. Twenty-six advocates were present, representing 17 countries. The meeting, titled “One Size Doesn’t Fit All”, covered the topic of personalised treatment and gave an overview of what technical terms and concepts an advocate should be familiar with regarding genetics and genomics. During the meeting Tanja stressed the importance of

thinking about patients’ personal preferences when discussing treatment as each person is unique.

ED held a second Forum Roundtable on 6 April, in which three Best Practice advocacy examples from our ED Fora were presented. Fiorita Poulakaki explained the steps taken by the ED Greece forum to get genetic testing covered by the Greek National Health System; Sema Erdem, ED Board member from ED Turkey, talked about an on-going collaboration with the European Oncology Nursing Society (EONS) to train breast cancer nurses,

ED 2022 PROGRAMMES

and Rosanna D'Antona spoke about ED Italy's pilot project aimed at obtaining legislation for flexible working solutions in order to allow women living with or after breast cancer to continue working. Twenty-seven Europa Donna advocates participated in the discussion.

Another Forum Roundtable took place on 1 June, where Fiorita Poulakaki gave an overview of Screening in the Era of Personalised Medicine and then led a very active discussion with participants. Advocates from 16 ED member countries joined us to learn about this important topic.

ED's October Forum Roundtable was dedicated to "Artificial Intelligence: Opportunities for personalized breast cancer screening". The webinar, which took place on 19 October, was chaired by ED Board Member Ellen Verschuur hosting Prof. Mireille Broeders, Professor of Personalized Cancer Screening at Radboud University and her PHD student Jim Peeters. Together the two speakers gave attendees a clear and very interesting overview of what AI is and how it can be applied to personalized screening and provided an update on the IMAGINE research project which features in depth analysis of mammography and pathology to optimize referral of possible invasive breast cancers at screening; Ellen Verschuur is a patient representative in the IMAGINE project. On 1 December we held our final Forum Roundtable of the year with 35 advocates from 19 countries taking part. During the meeting, we revealed our plans for ED's exciting new Metastatic Breast Cancer Awareness campaign that will be launched in mid-2023.

► Major Update of Europa Donna Website

On 27 April ED 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 on the site in addition to new and updated information on Screening and Early Detection, Breast Cancer Treatment and Genetics/Genomics.

► Europa Donna Metastatic Breast Cancer Advocacy Webinar

On 17 and 18 June, ED held a webinar on metastatic breast cancer (MBC) advocacy for women to learn more and share strategies to advocate with and for other women with this disease. Thirty-seven participants from 18 European countries connected. In three comprehensive talks, Dr. Fatima Cardoso, Director of the Breast Unit in Champalimaud Clinical Centre in Lisbon and President of the ABC Global Alliance, described the latest treatment approaches and research for three specific MBC subtypes: HER2-positive; triple negative; and oestrogen receptor-positive (ER+)/HER2 negative MBC. For advocacy purposes, she recommended demanding high-quality pathology reports because they are crucial for high-quality treatment. Discussing patient-doctor communication, Dr. Gabriella Pravettoni, Director of the Psycho-oncology Division at the European Institute of Oncology in Milan, outlined the main communication issues surrounding MBC. Covering the role of exercise in reducing the side effects of cancer treatment, Dr. Jana Müller, an exercise oncology researcher from the National Center for Tumor

Diseases in Heidelberg, Germany, stressed the importance of remaining physically active during treatment. Dr. Müller noted that most studies have been performed in patients without metastatic disease, but that the PREFERABLE study is under way 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, Professor of Cancer and Global Health at King's College London and Director of the Institute of Cancer Policy and co-Director of the Conflict and Health Research Group in London, United Kingdom, gave an overview of the vast disparities in health care access and provision among countries and within them. The MBC advocates in attendance had a chance to participate in one of two workshops to discuss their experience and advocacy strategies related to overcoming the stigma and taboos of an MBC diagnosis and managing side effects. The second day of the course consisted of an advocacy skills training workshop, designed specifically for this MBC event.

► ESMO/Europa Donna Sponsor meeting

On 9–12 September ED President Tanja Spanic, Executive Board members Ellen Verschuur and Biba Schrepfler, CEO Marzia Zambon and Communications Officer Barbara Klein represented Europa Donna at ESMO2022 (European Society for Medical Oncology) in Paris, our first major in-person meeting since the start of COVID-19. Marzia and Tanja held the first in-person ED's Sponsor meeting in two years, and our representatives were involved in many activities, including the PREFERABLE research project meeting, a WECAN meeting and EAPM's High Level Policy Seminar. ED also had a stand in the Virtual Society Village.

► Europa Donna Breast Cancer Advocacy Leader Conference: Building our Organisations for the Future

Our biennial Breast Cancer Advocacy Leader Conference took place on 24 September in Milan, with 45 leaders from 26 of the Coalition's member countries participating in our first in-person meeting since the outbreak of the pandemic. Attendees watched a video message from French MEP Veronique Trillet-Lenoir highlighting the need to address inequalities in breast cancer and introducing the Europe's Beating Cancer Plan (EBCP)'s goals. The EBCP was later covered in more detail by ED Executive Director Marzia Zambon and Prof. Tit Albreht of the National Institute of Public Health, Slovenia, who presented on implementation of the outputs of the cancer control Joint Actions in EU Member States, followed by Prof. Fabrice André of Gustave Roussy Cancer Center, France, who spoke on genetics, genomics and personalized treatment, and then Dr. Olivia Pagani of the European School of Oncology, who discussed why and how patient advocates should seek involvement in research and clinical trials. The afternoon session was dedicated to further explanation of the European Commission Initiative on Breast Cancer (ECIBC), presented by representatives of the European Commission Joint Research Centre. Following that, in a session of workshops participants exchanged ideas on fundraising, implementing EU breast cancer policy at the national level, and participating in research and clinical trials.

ED 2022 PROGRAMMES

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.

MBC Campaign

Europa Donna is working on the launch of a new MBC awareness campaign aimed at the European public, especially women; it is designed to spread up-to-date information on MBC, reach out to international policy makers and simultaneously provide our national groups with materials they can adapt and use to run their own campaigns in their languages at the national level.

ED Advocacy Training Course

On 4 to 6 November, Europa Donna held our first in-person European Advocacy Training Course since 2019. Intended to train new advocates, this was the 21st year that the course took place and 45 advocates from 22 countries were in attendance. Course participants heard presentations from leading experts on the science of breast cancer, on EU breast cancer guidelines and the most recent EU health 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 Highlights from EBCC-13

Europa Donna co-organised the 13th European Breast Cancer Conference (EBCC-13), which welcomed more than 1725 participants from 78 countries, including 1450 people attending in person in Barcelona, Spain, from 16-18 November. This two-yearly event brings together scientists, researchers, clinicians, patients and patient advocates to further multidisciplinary collaboration for progress in breast cancer. A recurring theme at the conference was the potential for risk identification and stratification, whether in screening, prevention or therapy.

The Europa Donna Coalition 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). Topics of importance to advocates included Europe's Beating Cancer Plan, survivorship, the impact of COVID-19 on patients with breast cancer, pregnancy after breast cancer, reducing breast cancer risk, screening innovations and liquid biopsies.

Europa Donna President and conference co-chair Tanja Spanic presented the Arts and Humanities prize to Nikola Pazderová of the Czech Republic for the book: *A Guidebook to Breast Cancer*. Conceived as a guide for women diagnosed with breast cancer and describing the entire pathway through women's stories and experiences with the disease, the book includes beautiful illustrations and advice from experts. The book was initially presented at the annual conference of Europa Donna Czech Republic and it is given as a gift to all newly diagnosed women.

EDUCATION HIGHLIGHTS

ABC Global Alliance Events

ED Executive Director Marzia Zambon provided the European patients' perspective in the ABC Global Alliance Webinar on "Protecting the Rights of Patients around the World – the role of law" on 31 January. 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 and was led by Dr. Fatima Cardoso and Hayley Jones, Director of the McCabe Centre for Law & Cancer in Australia.

On 10 November Marzia was invited to speak about Europa Donna Programmes and Engagement with the MBC Community at the ABC Global Alliance General Assembly, and she discussed ED's key advocacy, education, information and research initiatives in this critically important area. Europa Donna is an active member in the ABC Global Alliance, which is aimed at improving and extending the lives of people with advanced breast cancer (ABC) around the world. Europa Donna also participates in its biennial Advanced Breast Cancer Conference, where guidelines for this disease stage are regularly updated.

SPCC Events

On 2 March, ED Treasurer Sema Erdem took part in a webinar on "Pain Management in Cancer Care" organized by SPCC - Sharing Progress in Cancer Care. This was the second webinar in the SPCC series based on the needs of daily clinical practice. Sema provided the patient point-of-view and stressed the importance of communicating with your physician any pain you feel during treatment and the importance of being treated by a Multidisciplinary Team. Carla Ida Ripamonti from IRCCS Foundation, National Cancer Institute, Milan presented on "What Are the Various Pains: Post-Surgical To 'Intractable' Pain in Metastatic Disease". The presentations were followed by a Q&A session led by Marie Fallon from the Edinburgh Cancer Research UK Centre.

On 20-21 May, ED Executive Director Marzia Zambon Co-Chaired the SPCC online course on the topic of *Precision Testing Early and Later: A Tool for Diagnosis and Better Treatment?* along with Anna Batistatou, Professor of Pathology, Head of Faculty of Medicine, University of Ioannina, and 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 their use, and regulatory issues. Attendees included oncologists, pathologists, HPCs, patient advocates, professionals working in cancer institutes and healthcare public authorities.

▶ **EAPM Consensus Panel**

On 15 March, ED President Tanja Spanic took part in the European Alliance for Personalised Medicine's (EAPM) Consensus Panel Series on "Pharmaceutical Legislation: The need for pragmatism – and how to make it happen". Tanja participated in the Consensus Panel on "Unmet medical need", giving the perspective from the breast cancer community. During the session, she pointed out the inequalities that still exist across Europe with regard to access to novel treatments, specialist breast centres, genetic/genomic testing and population-based mammography screening programmes. The consensus panels were organized in light of the upcoming revision of EU pharmaceuticals legislation and drawing upon lessons from the COVID-19

▶ **OPBC/EUBREAST 2022 Delphi and Consensus Conference**

On 1 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 of Uncertainties and Controversies in Axillary Management. The OPBC was founded in March 2017 as a global non-profit organization and currently consists of 790 breast surgeons and 38 patient advocates, many of whom are ED members, from 92 countries. The aim of the consensus conference was to identify and prioritize uncertainties and controversies based on their importance in contemporary axillary management of patients with breast cancer and to propose concrete strategies to address them. Following the conference, a report will be prepared and submitted to a peer-reviewed journal and the recorded conference will be available on the OPBC website shortly after acceptance.

▶ **2022 EUSOBI Annual Meeting**

ED Board member Elizabeth Bergsten Nordström participated in the 2022 EUSOBI (European Society of Breast Imaging) annual meeting held in Malmö, Sweden from 29 September to 1 October. Elizabeth participated in the session dedicated to "The Future of Screening" where she provided the patient perspective on "The Equity of Access to Screening".

▶ **Community 365 Roundtable Meeting**

On 3 October, ED President Tanja Spanic took part in session 1 of the European Cancer Organisation Community 365 Roundtable Meeting on Cancer Care Needs in the Community Setting. The session on "Living with Cancer: the metastatic breast cancer case study"

was co-chaired by Dr. Fatima Cardoso, Director, Breast Unit, Champalimaud Clinical Center; and President, ABC Global Alliance and Matthijs Van-Meerveld, Head of Global Public Affairs for Breast Cancer, Sanofi. Tanja participated in the discussion along with Taylor Puhl, Manager, Health Policy & Insights, Economist Impact and Barbara Wilson, Founder and Director, Working with Cancer.

▶ **BIG-EORTC Webinar**

To celebrate breast cancer awareness month, Europa Donna's President Tanja Spanic took part in the BIG-EORTC webinar on 19 October, 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. Presenters provided facts and figures, focused on the importance of geriatric assessment, recommended screening tools and highlighted examples of recent research being conducted in elderly patients.

▶ **The Economist's 8th Annual World Cancer Series**

ED President Tanja Spanic participated in The Economist's World Cancer Series: Europe 2022 on 10 November in the Panel Discussion on Equity and Access Across Europe. The panel aimed to analyse the current European landscape surrounding genomic testing and use in treatment. During the discussion, Tanja stressed the importance of equal access to and the true affordability of genomic testing and personalised medicine for better outcomes for breast cancer patients.

▶ **EUBREAST Pre-Pectoral Registry Launch Online Event**

On 22 November, ED President Tanja Spanic spoke in an EUBREAST Roundtable discussion on the topic of *Patients Come First: Quality-of-life* issues regarding the International Prospective REgistry on Pre-pectoral REconstruction (I-PREPARE) trial, an international prospective cohort study that aims at comparatively evaluating data on different surgical techniques of pre-pectoral breast reconstruction with or without radiation. She talked about the importance of positive body image in the long-term following breast cancer treatment and advised not overwhelming patients with too many questions when developing questionnaires in trial studies.

COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2022 **EUROPA DONNA** served on the following committees:

- ▶ BIG Scientific Committee
- ▶ MINDACT Steering Committee
- ▶ AURORA Steering Committee
- ▶ POSITIVE Trial Steering Committee
- ▶ Early Breast Cancer Trialists' Collaborative Group (EBCTCG)
- ▶ OLYMPIA Clinical Trial Steering Committee
- ▶ Horizon 20/20 Projects: CardioCare, INSPIRE, MyPEBS, MESI-STRAT, PREFERABLE
- ▶ Horizon Europe Project: 4D Picture, ARTILLERY, SmartCARE
- ▶ IMI Project: OPTIMA External Advisory Board, Cancer Outcomes through UserCentred Research
- ▶ IBCSG Ethics Committee
- ▶ EBCTCG Steering Committee
- ▶ OECD PaRIS PROMS Working Group
- ▶ PARIS Breast Cancer PROMS Working Group
- ▶ EBCTCG Early Breast Cancer Trialists Collaborative Group
- ▶ Ethics Committee of IBCSG- International Breast Cancer Study Group

During 2022 **EUROPA DONNA** participated in the following organisational activities:

- Policy**
- ▶ European Patients' Forum
 - ▶ Europe's Beating Cancer Plan
 - ▶ Transforming Breast Cancer Together Initiative
 - ▶ ECIBC (ED is a stakeholder)

- Conferences**
- ▶ Europa Donna MBC Advocacy webinar
 - ▶ Europa Donna Advocacy Leader Conference
 - ▶ Europa Donna Advocacy Training Course
 - ▶ EBCC-13
 - ▶ ESMO 2022 Hybrid Congress
 - ▶ EPF Congress
 - ▶ Oncoplastic Breast Consortium (OPBC) Consensus Conference 2022
 - ▶ BCY6 International Consensus Symposium

- Other Meetings**
- ▶ Europa Donna Roundtables (virtual) with Europa Donna members
 - ▶ EBCC-13 Manifesto, Organising and Steering Committees
 - ▶ ABC Global Alliance Webinar on Protecting Patient Rights
 - ▶ ABC Global Alliance Webinar on Pregnancy and MBC
 - ▶ SPCC Precision Pain Management in Breast Cancer webinar
 - ▶ SPCC online course on Precision Testing
 - ▶ ESSO Surgical Oncology event
 - ▶ EAPM Consensus Panel Series on Pharmaceutical Legislation
 - ▶ EUSOBI annual meeting
 - ▶ BIG/EORTC Webinar on Older Patients with Breast Cancer
 - ▶ Economist Cancer Series
 - ▶ EUBREAST Pre-Pectoral Registry Launch Online event
 - ▶ EUSOMA B3 Lesions Final meeting

- Publications/Videos**
- ▶ 2021 Annual Report
 - ▶ Breast Health Day leaflet
 - ▶ Breast Health Day Video
 - ▶ 2022 Annual Newsletter
 - ▶ ED General Brochure
 - ▶ Highlights from ED's MBC Advocacy Webinar
 - ▶ Four editions of ED Electronic News
 - ▶ One Early Breast Cancer Advocates Speak Out Video
 - ▶ The Advocate's Guide to Genomics, Genetics and Personalised Medicine in Breast Cancer
 - ▶ ECIBC – European Commission Initiative on Breast Cancer booklet 2022

FINANCIALS

Our annual financial statement has been prepared by an independent auditor and is posted on our [website](#)

2022

BALANCE SHEET

ASSETS

Net Fixed Assets		13.087
- Plant machinery and equipment	13.087	
Current Assets		1.103.340
- Trade debtors	314	
- Cash at bank and in hand	1.095.117	
- Accrued Income	7.909	
TOTAL ASSETS		€ 1.116.426

LIABILITIES

Reserve Fund		974.732
- Surplus and loss for the year	294.910	
- Extraordinary Reserve	679.822	
Creditors		32.724
- Amounts payable within one year	32.724	
Accrued charges and deferred income		108.970
- Withholding taxes	19.045	
- Accrued charges	28.987	
- Owed as Severance	60.939	
TOTAL LIABILITIES		€ 1.116.426

INCOME & EXPENDITURE STATEMENT

INCOME		
Turnover		762.724
- Membership dues	15.466	
- Grants and donations	747.259	
- Meeting registrations	-	
- Reimbursements	-	
Financial Income		
Other financial income	608	608
TOTAL INCOME		€ 763.332
OPERATING CHARGES		
Services & Office Expenses		53.068
- Administrative overhead	44.917	
- Fees (audit, legal, insurance)	8.151	
Salaries (employees & related costs)	228.314	228.314
Activity Expenses		180.982
- Publications, websites	35.492	
- Other meetings	1.800	
- ECIBC	2.250	
- Breast health day	2.604	
- Board meetings	7.227	
- MBC advocacy webinar	11.886	
- MCB campaign & materials	12.302	
- ECBB-13	21.553	
- Advocacy leader conference	31.408	
- Advocacy training course	52.459	
Depreciation & Write-Offs		4.186
- Office equipment	4.186	
Financial Charges		1.873
- Bank costs	1.352	
- Other financial costs	520	
Surplus/Loss of the Period		294.910
- Transfer to/from reserves	294.910	
TOTAL CHARGES		€ 763.332

ACKNOWLEDGEMENTS

ED wishes to acknowledge and express appreciation for the ongoing support of our Executive Board, our faculty members and scientific advisors for their generous contribution of time and effort on behalf of breast cancer advocacy. We would also like to commend our individual National Fora for their continuing commitment to our common advocacy goals, especially the implementation of the EU guidelines. The strength of our organisation emanates from our National Fora whose ongoing work and efforts are outstanding and become more impressive each year.

On behalf of the entire ED breast cancer advocacy community, we would like to express our appreciation to all of our sponsors who have provided us with unrestricted educational grants to carry out our advocacy work on behalf of all of the women of Europe.

GRANTS FROM NON-PROFIT ORGANISATIONS



GRANTS FROM CORPORATIONS

€ 50,000 - 100,000



€ 20,000 - 49,999



€ 5,000 - 19,999



OTHER FOUNDING

We gratefully acknowledge a Pfizer-SPCC multi-year grant in support of our project, "Europa Donna Advocacy for Quality of Care Improvement in Patients with MBC"

To safeguard the totally independent and autonomous voice of ED on breast cancer issues, we are guided by our Sponsorship Policy in all matters concerning financial support of our work.

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