



# Europa Donna E-News Highlights

## May - August 2023

### TBCT Policy Meetings



On **11 May**, the multi-stakeholder group Transforming Breast Cancer Together (TBCT), of which Europa Donna is a member, organised a virtual meeting with the members of the European Commission Cabinet of Health, including **Alberto Costa, Matthias Schuppe, Tove Ernst, and Philippe Roux**. A lively discussion involved all participants, during which European Commission representatives provided a detailed update on the progress of Europe's Beating Cancer Plan (EBCP) and on a number of actions that have been proposed to implement the plan. Most of the EBCP initiatives have already been launched, for instance the joint actions and the guidelines on cancer recommendations, imaging initiative, health data space potential activities, inequalities projects (No One Is Left Behind) with tools to help Member States with cancer inequalities registry (led by JRC and growing in a daily basis). Moreover, 28 projects are currently operational, and regularly updated. All relevant information will be made publicly available through a website that is currently being developed.

An upcoming EU targeted awareness campaign on cancer screening was announced with statistics on how Member States are performing, which will inform on current cancer screening programmes. The discussion then touched upon the Right to be Forgotten, on returning to work and job retention; on which a study will be launched soon. Europa Donna's Executive Director, **Marzia Zambon**, pointed out the importance of prevention as a pillar in the EBCP while **Dr. Fatima Cardoso** urged the Commission to take action on the issue of inequalities, that are greatly increasing, especially for advanced breast cancer patients.

The clock is ticking and it is now more urgent than ever to keep up the important work of the EBCP at a fast pace and in synergy with other entities, in particular with organisations representing patients. It is crucial that breast cancer remains high on the agenda of the European institutions now and during the next mandate.

On **12 June** TBCT held another virtual meeting with the Attaché of MEP **Radka Maxová** (S&D, Czechia). After explaining the purpose of this multistakeholder group and the importance of involving policy makers in its activities, Europa Donna's Policy and Research Officer **Martina Fontana** introduced the relevant policy asks of breast cancer patients and the Call to Action launched last September. Other important topics raised during the meeting were the perspective of Advanced Breast Cancer patients and the right to work and to have an active professional life for breast cancer patients. The conversation then led the group to ask what actions the European Parliament and the FEMM and SANT Committees could take to address issues and challenges on quality of life for patients and survivors with the hope to count on engagement and commitments from an increasing number of policymakers.





## ESMO Breast Cancer Conference 2023

Europa Donna's President, **Tanja Spanic**, presented on the topic of National Screening Programmes and chaired a session of the Patient Advocates Working Group at the 2023 edition of ESMO Breast, a congress for breast cancer researchers and clinicians with a specific interest in innovation in breast cancer care. The Conference took place **11–13 May** in Berlin, Germany. Tanja described her experience as “three incredible days of exceptional science, education, networking, friendship, mentorship and being mentored”. The Conference covered topics including recent developments in novel diagnostics, biomarkers and treatments in breast cancer; the role of antibody drug conjugates in HER2 non-overexpressing breast cancers; new strategies for HER2 positive, luminal and triple negative breast cancers; and special considerations for young patients with breast cancer.



## YCE Meeting at ED HQ



Youth Cancer Europe and 17 young advocates involved in the YCE driven EUCAYASNET EU-Health funded project paid us a visit at Europa Donna's headquarters in Milan, Italy on **17 June**. **Marzia Zambon and Martina Fontana** explained ED's historical value, from the advocacy steps taken in Europe by the first breast cancer advocates to the policy presence and involvement of the organization today.

The fresh, young perspective our guests provided with their questions and comments was priceless. We came away from the meeting with an even greater resolve to actively address the different needs of young people who are faced with breast cancer before reaching the “target” age of screening programmes.



## Europa Donna's May Roundtable

Our second spring 2023 roundtable took place on **24 May**, expanding on how Europa Donna's national groups can get involved in and boost our European MBC project, **the Cancer Currency Campaign**, which was subsequently launched on **14 June**. Approximately 35 people hailing from 19 European countries participated in an animated discussion about how to best spread information and educate the public on pressing metastatic breast cancer issues on a national and international level. 🙌



## Gothenburg Breast Cancer Meeting

In connection with the 400-year Gothenburg Anniversary, on **2 June**, Europa Donna was invited to deliver a presentation of its organization and work – with a special emphasis on its collaboration with member groups in 47 European countries.

The meeting was organized by the local breast cancer organization at Gothenburg, Sweden and sanctioned by the Swedish Breast Cancer Association, a member organisation of the Europa Donna Coalition. Europa Donna Board member **Elizabeth Bergsten Nordström** was delighted to represent the Coalition and deliver remarks on this auspicious occasion.





## MINDACT Steering Committee Meeting

**Susan Knox**, Europa Donna's Executive Director Emeritus and Senior Policy Advisor, attended the MINDACT steering committee meeting held virtually on **8 June**. MINDACT, an initiative of the Breast International Group (BIG), is a clinical trial that compares a genomic prognostic test with traditional clinical-pathological criteria for selecting candidates for adjuvant chemotherapy among women with breast cancer and 0 to 3 positive lymph nodes. It has found that using the gene signature, up to 46% of patients may be spared from unnecessary chemotherapy.



## Europa Donna Launches MBC Campaign

Metastatic breast cancer is incurable, and those living with it have been left to feel undervalued for too long. That's why we created **#TheCancerCurrency** - the most valuable currency in the world - to prove the immense worth of the lives of people who have MBC. You can see and share this campaign, launched on **14 June**, at [thecancercurrency.com](http://thecancercurrency.com).

Help us spread the word!



You can also take a look at a sampling of our first local media reactions on MBC advocate **Carla S. Whitbread's** inspiring story; Carla is one of the 5 advocates featured in The Cancer Currency campaign:

[Daily Mail online](#) 🖱️



## ABC Webinar



Europa Donna Board member **Elizabeth Bergsten Nordström** lent the patient advocate perspective on the topic of Optimal Management of older frail patients living with ABC/MBC at the ABC Webinar held on **15 June**, as part of the ABC Global Alliance web series: Tough Issues in Metastatic Breast Cancer.

Europa Donna is an active member in the ABC Global Alliance, an initiative aimed at improving and extending the lives of people with advanced breast cancer (ABC) around the world.





## ED MBC Advocacy Webinar



The 4th annual Europa Donna Metastatic Breast Cancer Advocacy webinar was held on **16 June** and featured advocates, patients and scientific experts among the 57 participants hailing from 27 countries, invited to share in updates and advocacy strategies in the field of MBC. Expert speakers leading the informative sessions and subsequent debates included **Dr. Fatima Cardoso, Dr. Alexander Eniu, Dr. Javier Cortes, Dr. Maria Die Trill and Barbara Wilson** from Working with Cancer UK.

The morning sessions were dedicated to the latest developments in research and treatment of MBC, also providing keys to emotionally cope with diagnoses, both for patients and caregivers. In the afternoon, we dove deeper into navigating the workplace with MBC and provided communication and advocacy tips and tricks to demand policy and legislative changes at a national level.

The webinar also helped launch The Cancer Currency campaign which features 5 ED advocates living with metastatic breast cancer, sharing their stories and struggles all with the joint message: we are still here, and we have a voice and value to give.



## ESTRO Consensus Meeting: Recommendations on Integration of Radiation Therapy with Targeted Treatments for Breast Cancer

On **16 and 17 June**, Europa Donna's President **Tanja Spanic** participated in the European Society for Radiotherapy and Oncology (ESTRO) consensus meeting on Recommendations on Integration of Radiation Therapy with Targeted Treatments for Breast Cancer, giving a talk on Patient Advocate Involvement in the Design and Conduct of Breast Cancer Clinical Trials. The purpose of the meeting was to provide preclinical and clinical evidence – and consensus-based guidelines on how to integrate targeted and other agents properly and safely with irradiation to improve the clinical care of patients affected by breast cancer who are candidates for these treatments.

Europa Donna has an on-going relationship with ESTRO, and ED advocates are often invited to give the patient's perspective during their meetings and courses, which are primarily intended for specialists and trainees in the field of radiation and clinical oncology, including doctors, physicists, radiation therapists, breast nurses, researchers and others who are interested in extending their knowledge of the management of breast cancer.



## International Patient Advocacy Symposium on Brain Metastases



The International Brain Tumor Alliance in collaboration with the American Brain Tumor Association organised the first ever International Patient Advocacy Symposium on Brain Metastases, which was held in Vienna from **24 to 26 June**. It included a series of scene-setting and perspective presentations delivered by patient advocacy experts representing breast, lung-, melanoma- and kidney-cancers. Europa Donna was represented by Board member **Ellen Verschuur**, who presented Europa Donna's work to date on MBC advocacy, including our bold new Cancer Currency MBC campaign that focuses on the question "What is a life with metastatic breast cancer worth?".

In her speech, Ellen recommended advance care planning: an on-going series of conversations between patients/family and caregivers/professionals covering palliative care, the real wishes of, including their expectations, desires, and the limits of treatment and care.

#### Take away messages:

- The best supportive care involves open communication with the ultimate goal of adding life to patients' days and not days to their lives.
- collaborative partners help address the unmet needs of patients with brain tumors
- there is a need to improve understanding of biology of brain metastases
- there is a need to create a central brain tumor registry



### Life Sciences Conference Organised by the Swedish Presidency of the EU Council

Europa Donna Board member **Elizabeth Bergsten Nordström** represented Europa Donna at a conference on **26-27 June** organized by the Swedish Presidency of the EU Council in Stockholm, on the cutting-edge topic of *Life Sciences: The era of personalised medicine*. Experts addressed ethical dilemmas and spoke about the need to examine how personalised medicines are currently regulated and clinical trials are designed, and to then enact changes to adapt to a new landscape and earn the public's confidence and trust in algorithm-modelled prevention and treatment techniques. Additional policy discussions on personalized medicine have already been scheduled under the upcoming Spanish and then Belgian EU presidencies during the coming 12 months.



### Europa Donna Advocates Attend WECAN Academy





Europa Donna Board member **Stella Mastora**, together with **Marzia Zambon** and **Martina Fontana** from Head Office attended the excellent WECAN – Workgroup of European Cancer Patient Advocacy Networks 2023 WECAN Academy in Frankfurt from **1 through 4 July**.

Throughout four days, they focused on sharpening their advocacy skills and sharing best practice with input from experts in various fields sharing their views on topics like evidence-based advocacy, stakeholder management, health economics and overall, how to stay on top of changing trends in cancer patient advocacy. We thank WECAN and look forward to continuing to advance patient advocacy and networking practices.



## European Commission Initiative on Breast Cancer Meetings

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 on **16 – 17 May** and **12 – 13 July**. Executive Director, **Marzia Zambon** serves on the Quality Assurance Scheme Development Group (QASDG).

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.

## Europa Donna Welcomes Two New Team Members!

We would like to introduce you to our two new team members at our headquarters office: **Laureline Bertrand**, Social Media Specialist and **Alianny Perez**, Communications Assistant. They join us as we pivot into a more active online presence, in an effort to better connect with you, our network, and advocate for our mission. Please join us in giving them a warm welcome to the Europa Donna family!





## New Publications of Interest:

### 1) Breast International Group (BIG) April 2023 Issue



#### *The POSITIVE Trial: Good News for Women with Breast Cancer who Want to have a Baby*

Europa Donna's President **Tanja Spanic** and former board member **Olivia Pagani** interviewed

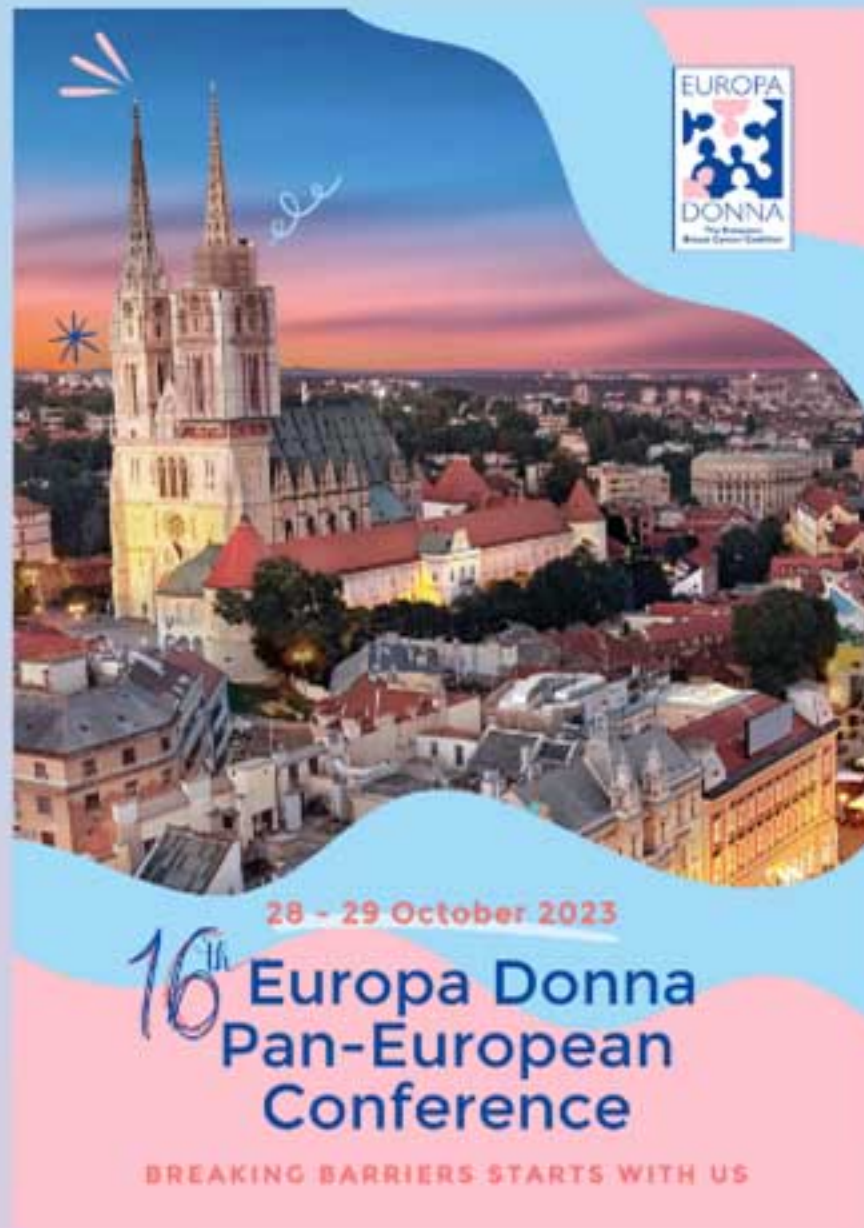
### 2) Publication of: *The Lucerne Toolbox 2 to Optimise Axillary Management for Early Breast Cancer: A multidisciplinary expert consensus*

The second Lucern toolbox is out on Science Direct! Europa Donna Vice President **Fiorita Poulakaki** is co-author and represented Europa Donna in the consensus.

[Link to article](#)



## Upcoming Events



Europa Donna is pleased to announce that the 16th annual EUROPA DONNA Pan European conference will take place **28-29 October 2023 in Zagreb, Croatia.**

Details on the conference available [here](#).





## 22nd Annual Europa Donna Breast Cancer Advocacy Training Course 17-19 November 2023 - Milan

In June, Europa Donna National Representatives and Delegates were sent information on nomination less seasoned advocates from their fora to attend this intensive 2 ½ day course.



A promotional poster for EBCC-14. The background is a gradient from blue to pink. On the left, the text reads: 'EBCC EUROPEAN BREAST CANCER CONFERENCE 14', 'SAVE THE DATE', 'Research &amp; Innovation in the Multidisciplinary Management of Breast Cancer', and '20-22 March 2024 Milan, Italy'. On the right, there is a circular collage of five images: a surgical team in an operating room, a woman smiling, a patient in a hospital bed, a woman in a lab coat, and a woman in a lab coat. The EBCC logo is in the top right corner.

### Save the Date! EBCC-14 in Milan, Italy

The dates for next year's EBCC-14 (European Breast Cancer Conference) are out: join us in Milan from **20-22 March 2024**! The conference, co-organised by ED, will focus on research and innovation in the multidisciplinary management of breast cancer.

More info at: <https://event.eortc.org/ebcc14/>

A Europa Donna Training Event will take place in Milan on **23 March 2024** following EBCC-14. Stay tuned for more information!