

# EUROPA DONNA

The European Breast Cancer Coalition

# Annual Report

# 2020



## EUROPA DONNA Executive Board 2020

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## EUROPA DONNA Head Office Staff

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### Deputy CEO/Head of Policy and Public Affairs

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### External Affairs Director

Marzia Zambon

### Communications Officer

Barbara Klein

### Admin/Events Officer

Daniela Pirisi

### Development/Training Officer

Paige Robinson

# OVERVIEW

2020 has been a disruptive and transformational year due to the COVID-19 pandemic. We began the year providing our input into the new Europe's Beating Cancer Plan launched in Brussels on 4 February by the European Commissioner for Health and Food Safety and former President of Europa Donna, Stella Kyriakides. By early March most of Europe was in various stages of lockdown and all of us were learning how to WFH - Work from Home, which is now the new normal. As the year progressed, we learned how to transform our advocacy programmes into primarily virtual activities using Zoom and various platforms to hold all types of meetings.

Our new President Tanja Spanic was elected at our first virtual Executive Board meeting in April. Marzia Zambon joined our staff in March conducting external affairs and working with all of our European colleagues on breast cancer policy in the Transforming Breast Cancer Together (TBCT) initiative. We met with sponsors, providing the advocacy perspective at numerous international meetings, and in October the 12th European Breast Cancer Conference (EBCC-12), in which we are a partner with EUSOMA and EORTC, was held virtually for the first time. While meeting and networking in person is essential for our members, these online meetings did provide an opportunity for many to participate who might not otherwise have been able to travel for both financial and health reasons. It also enables speakers to participate in more meetings as little or no travel time is required.

We held our first MBC webinar that included presentations, workshops and training sessions online at the end of October and participated in numerous policy meetings, BIG research and trial meetings AURORA and MINDACT, all online. Communications Officer Barbara Klein and Marzia conducted Zoom meetings and gathered input from our members on how COVID-19 changed the delivery of breast cancer screening and treatment. This led to an ED survey which was followed by a report on breast cancer services in Europe that we submitted to the Commission in the late summer, and to a year-end report on the impact of COVID-19 on patients and advocates from our member countries (see <https://www.europadonna.org/publications/ed-publications/>).

ED Board and staff co-authored seven articles including a new curriculum for BRESO, the Manifesto emanating from EBCC-12, and an important policy initiative from TBCT. All of these can be found on the Europa Donna website at: <https://www.europadonna.org/publications/europadonna-articles/>

It was also a year of tremendous loss to our organization and to me personally. Gloria Freilich, our Founding President who hired me in 1998, died in January and Karen Benn, our Deputy CEO with whom I worked closely in the Head Office since 2002, died of metastatic breast cancer in September.

This will be my last annual report as I will retire early in 2021 after 23 years as Executive Director. It has been an exciting and rewarding journey from the days when Europa Donna was first imagined by Umberto Veronesi - from being a small group of 12 country members to becoming Europe's breast cancer advocacy organization with groups in 47 member countries- from the time when no one thought patients should have a seat at the table to now being invited to sit at every table, to participate in every programme and every project related to breast cancer in Europe. Marzia Zambon will take my place and I know we all wish her much success in this position and in forwarding the advocacy goals of Europa Donna on behalf of the women of Europe in the future.

Above all it has been an extraordinarily rewarding experience to have worked with so many incredibly gifted and committed advocates from so many countries over the years. Thank you for taking this journey with me and for your contributions to improving breast services for women in Europe. I am stepping down but will continue to contribute in a voluntary role as Senior Policy Advisor.

We plan to hold our 15th Pan European Conference in person next October and I look forward to seeing all of you in Zagreb, Croatia for this very special advocacy event.



**Susan Knox**  
CEO, Executive Director

# ED 2020 PROGRAMMES

## PUBLIC AFFAIRS

### ▶ The European Commission and Europe's Beating Cancer Plan

ED's CEO Susan Knox attended the event to launch Europe's Beating Cancer Plan at the European Parliament in Brussels, Belgium on 4 February, World Cancer Day. The plan, an ambitious initiative tasked by European Commission President Ursula Von der Leyen to Stella Kyriakides, European Commissioner for Health and Food Safety and former Europa Donna President, proposes actions at every stage of the disease: prevention, diagnosis, treatment and survivorship. Following the event, ED provided its initial submission to the Consultation that was launched by the Commission as well as contributing to the one submitted by the Transforming Breast Cancer Together (TBCT) initiative, to which ED belongs.

On 28 May, the European Commission held a webinar on the topic of Cancer and COVID-19: Current and future challenges. ED External Affairs Director Marzia Zambon and Events and Administration Officer Daniela Pirisi participated.

On 26 October ED Communications Officer Barbara Klein participated in a Virtual Coffee Morning for Breast Cancer hosted by MEP Frances Fitzgerald (Ireland) and MEP Cindy Franssen (Belgium).

For more information on Europe's Beating Cancer Plan: <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan>

### ▶ Transforming Breast Cancer Together

Europa Donna 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. Susan Knox participated in the first face-to-face meeting at the Parliament on 5 February chaired by MEP Frances Fitzgerald (Ireland) and presented the key priorities for EU countries regarding breast cancer services. Later that day the group met with Health Commissioner Stella Kyriakides to present the various issues that need to be addressed and to understand how the group can work with her to improve breast services across Europe.

On 15 May, the TBCT group held a virtual meeting with Matthias Schuppe, Cancer Team Leader, DG SANTE of the European Commission, in which ED External Affairs Director Marzia Zambon participated. Mr. Schuppe reaffirmed the Commission's commitment to cancer as a key priority despite the COVID-19 pandemic. Annette Roi, Project Leader for the European Commission Initiative on Breast Cancer (ECIBC) of the European Commission's Joint Research Centre, informed the group that the recommendations would be finalised together with the implementation of the Quality Assurance Scheme.

During the TBCT awareness event "Europe's Beating Cancer Plan: Bridging the Gap in Breast Cancer Care" held on 15 October, Marzia Zambon spoke about the state of breast services in European countries.

### ▶ European Commission Initiative on Breast Cancer

ED has been advocating for the EU to develop a European

accreditation scheme for breast cancer services. In 2012, the European Commission Initiative on Breast Cancer (ECIBC) was launched; it is coordinated by the European Commission's Joint Research Centre (JRC) under the auspices of the Directorate General for Health and Food Safety (DG Santé). ECIBC is supported by two working groups composed of breast cancer experts, including patient advocates. ED's CEO Susan Knox is a member of the Guidelines Development Group (GDG) and attended the meeting held on 15 and 16 January. She also participated in an online review of the guidelines throughout the year, especially providing input into lay-person versions of guidelines. The online information has been updated and can be seen at <https://healthcare-quality.jrc.ec.europa.eu/>. In addition, the ECIBC published a new booklet outlining its work that was presented at EBCC-12; it can be accessed here: <https://www.europadonna.org/wp-content/uploads/ECIBC-at-a-glance-booklet.pdf>

Susan Knox further contributed the patient perspective in the ECIBC article *Development and use of health outcome descriptors: a guideline development case study*, published in June. ED is a stakeholder providing the patient advocate perspective and recommendations to the JRC concerning this project.

### ▶ European Breast Surgical Oncology (BRESO) Certification Curriculum

The BRESO Certification Curriculum – Theoretical and Practical Knowledge Curriculum was published in the European Journal of Surgical Oncology on 23 June, a document which comprehensively describes the knowledge and skills expected of a fully trained breast surgeon practicing in the European Union and the European Economic Area (EEA). Developed by a panel of experts from across Europe and validated by professional breast surgery societies in Europe, the curriculum forms part of a range of factors that contribute to the delivery of high-quality cancer care. In 2020, the BRESO founding members also launched their new website, <https://breastsurgeoncertification.com/>.

ED CEO Susan Knox served as the patient advocate representative on the BRESO organisational/management structure working group during the development in 2019 and 2020 which led to the launch of the curriculum and website.

On 3 September ED Communications Officer Barbara Klein participated in the BRESO webinar in which she gave the patient's perspective on the need for certified breast surgeons.

### ▶ The European Code of Cancer Practice (The Code)

ED's Executive Board member Sema Erdem, who serves as Co-Chair of the Patient Advisory Committee of the European Cancer Organisation, spoke about *Key Right #2: Information* at the launch of the new European Code of Cancer Practice on 23 September. The Code initiative will empower European citizens and cancer patients with 10 key overarching cancer patient rights, signposting what cancer patients in Europe should expect from their healthcare system. For more information on The Code, see <https://www.europecancer.org/2-standard/66-european-code-of-cancer-practice>.

## RESEARCH

### ▶ ED Survey on the Current State of Breast Services in Europe

In view of Europa Donna's contribution to the European Commission's Europe's Beating Cancer Plan launched on 4 February, ED undertook and effort to provide the Commissioner for Health and Food Safety, Stella Kyriakides, and Cancer Team Leader, Matthias Schuppe, with an update report on the current state of breast services from the patient's perspective throughout our 47 member countries. Fifty-two questions were posed in the survey, divided into five sections: your country and breast cancer care; mammography screening and diagnosis; Specialist Breast Units; Metastatic Breast Cancer; and miscellaneous, including Covid-19/cancer care. The resulting report was published in September and is available on Europa Donna's website.

### ▶ EORTC and BIG Webinar: De-Escalation of Breast Cancer Treatments for Lay Audience

Executive Board member Elizabeth Bergsten Nordström provided

the patient's perspective on the importance of giving patients the right information about de-escalation risks in the webinar held by the European Organisation for Research and Treatment of Cancer (EORTC) and the Breast International Group (BIG) on 14 October. The purpose of the webinar was to raise awareness about breast cancer and the importance of international academic research. The speakers were breast cancer experts and representatives from cancer research and patient organisations.

### ▶ BIG OlympiA Steering Committee Meeting

The BIG OlympiA trial tests Olaparib in patients with early stage BRCA-mutated, high-risk HER2-negative breast cancer. Tanja Spanic, ED President, is a member of BIG's OlympiA trial steering committee and took part in a meeting before ASCO in May and in September.

### ▶ AURORA Steering Committee Meeting

This programme aims to help scientists understand the molecular aberrations in metastatic breast cancer. Susan Knox is a member of



# ED 2020 PROGRAMMES

the AURORA Steering Committee and attended a virtual meeting on 21 October.

## ▶ HORIZON 2020

Horizon 2020 is the EU Research and Innovation programme with nearly €80 billion of funding available over 7 years (2014 to 2020). ED is the patient advocacy representative on the following five Horizon 2020 projects that have been funded: Advisory Board member in the “MEtabolic SIngnaling STRATification- MESI-

STRAT” Research Project, External Advisory Panel member for the “Predicting Effective Adaptation to Breast Cancer to Help Women to BOUNCE Back” project, Independent Ethics and Data Monitoring Committee member of the “My Personal Breast Screening project – MyPeBS,” PREFERABLE – “Project on Exercise for Fatigue Eradication in Advanced Breast Cancer to improve quality of life” and INSPIRE - INnovative tools for Safety Pharmacology for Integrated cardiovascular safety assessment to REDuce adverse events and late stage drug attrition.

## EDUCATION

## ▶ Digital Roundtables with National Representatives

During the second half of April through mid-May, ED External Affairs Director Marzia Zambon and Communications Officer Barbara Klein held a series of digital roundtable discussions with 20 ED National fora leaders to discuss how COVID-19 was affecting breast cancer patients in their countries. In many countries, screening programmes had been postponed and some patients were finding it challenging to continue their treatment. In spite of this, ED fora were pushing forward with their advocacy work by making phone calls, organising virtual meetings and using social media to communicate with patients and provide support.

In December, two follow-up meetings were held with 17 fora leaders. ED fora are working hard to communicate to the public that it is safe to attend screening and that women should not put it off. In many countries breast cancer patients are experiencing adverse psychological effects due to the pandemic, so ED fora are running online programmes to combat depression, self-isolation, fear and anxiety. Overall, our national groups have been able to continue modified programmes virtually throughout 2020.

## ▶ Webinar: Cancer Care in Times of COVID-19: Challenges and rapid response learnings

On 7 May, Europa Donna Georgia organised a webinar on *Cancer Care in Times of COVID-19: Challenges and rapid response learnings*. ED External Affairs Director Marzia Zambon spoke about ED's role in the Transforming Breast Cancer Together initiative and our contribution to the TBCT paper on the “Impact of COVID-19 on Breast Cancer Patients.” She also spoke about the actions ED has taken during this time, including our weekly digital roundtable discussions with our local groups and providing reliable resources for breast cancer patients.

## ▶ Metastatic Breast Cancer Advocacy Webinar

ED held its first metastatic breast cancer (MBC) webinar to provide information and share advocacy strategies with women who have this disease. Thirty-three participants from 18 of the Coalition's member countries connected on this course, held virtually on 30 and 31 October. In the morning session, advocates introduced themselves in an interactive session that was followed by an update on Treatment and Current Research for MBC given by Fatima Cardoso, Director Breast Unit, Champalimaud Clinical Center Lisbon, Portugal, and President of the ABC Global Alliance. In the afternoon, advocates heard about the Effects of Physical Exercise on Cancer Treatment-Related Side-Effects and the PREFERABLE Exercise Trial for MBC from Dr. Anne May of Julius Center, University Medical Center Utrecht; the MBC Fortemente Project from Rosanna D'Antona, President of Europa Donna Italy; and Living and Working with Cancer from Isabelle Lebrocquy, Founder of oPuce.

## ▶ ECCO Advancing Requirements for Quality Breast #CancerCare Virtual Event

ED Board member and Treasurer Sema Erdem gave a presentation on the patient perspective regarding quality cancer care for breast cancer patients on 25 May during the ECCO Advancing Requirements for Quality Breast Cancer Care Virtual event. ED External Affairs Director Marzia Zambon and Communications Officer Barbara Klein also participated in the virtual event.

## ▶ Breast Health Day 2020 Campaign

ED celebrated the 13th annual Breast Health Day on 15 October 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's campaign encouraged women and girls to choose a “Healthy Lifestyle for Breast Health!” and encouraged them to send in pictures of themselves doing something healthy which were shared in a video released on 15 October. For more details see: <https://prevention.europadonna.org/>

## ▶ EBCC 12

More than 100 ED advocates from 34 countries joined the 2500 registered participants at the 12th European Breast Cancer Conference Virtual (EBCC-12), held online on 2 and 3 October. ED advocates chaired sessions and presented on topics ranging from European policy and breast care guidelines to COVID-19, issues faced by young women with breast cancer, follow-up and survivorship issues, as well as on new developments in MBC. Among the presentations on the latest data, the theme of the patient was ever-present, included patient-reported outcomes, and factors affecting quality of life. Europa Donna is a co-organiser of EBCC in equal partnership with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA). It is the only breast cancer conference to include all the key collaborators in the breast cancer field and encourages interaction between clinicians, scientists and patient advocates.

At the opening session, Europa Donna President and conference co-chair Tanja Spanic presented the EBCC Arts and Humanities Prize for the Finnish film “Daily Living Although” animated story by Sari Nyman. Nominated by ED Finland, the film was made using a clay foam figure to portray the emotional and physical turmoil she felt after her diagnosis and treatment for MBC.

## ▶ European Cancer Summit 2020

The virtual European Cancer Summit 2020 titled “Working Together Against Cancer: Breaking Down Barriers and Saving Lives” on 18 and 19 November brought together leading oncology experts, patient advocates, politicians and policy-makers to discuss the main issues impacting cancer policy for the benefit of cancer patients, healthcare professionals and all people across Europe.

ED Board member Sema Erdem is Co-Chair of the Patient Advisory Committee of the European Cancer Organisation. On 18 November she participated in the session “How to Implement Quality Cancer Care in Europe: From good intentions to patient benefit” where she spoke about ED's recent survey of patient advocate leaders on the Current State of Breast Cancer Services in Europe. ED External Affairs Director Marzia Zambon and Communications Officer Barbara Klein participated in the two-day summit.

## ▶ Webinar with IncontraDonna

On 12 December, ED External Affairs Director Marzia Zambon participated in Incontriamoci sul Ring-Pink Ring, an event organized by Italian breast cancer NGO IncontraDonna, providing a snapshot of the current COVID-19 situation and its impact on breast cancer services throughout Europe from the perspective of breast cancer patients and survivors. She underlined that many European women are delaying check-ups and follow-up medical appointments to spring 2021, apparently driven by strong feelings of anxiety and fear of infection. This phenomenon has been reported by many Europa Donna national organisations which are trying to encourage women not to delay screening and to trust the safe paths organized by their national health systems.

# IN MEMORIAM



EUROPA DONNA mourns the loss of Karen Benn, our Deputy CEO, who died of MBC in September 2020. Karen was a dedicated advocate working relentlessly to further Europa Donna's advocacy goals for more than 18 years. Her intelligence, grace and communication skills enabled her to make an enormous contribution to Europa Donna carrying out projects in a wide variety of areas, from policy at the European Parliament to research

projects with BIG and the European Commission, from ECIBC to managing our Advocacy Training course for many years. Her acumen, her wit, and her dedication to breast cancer advocacy are greatly missed, but never forgotten. Her life and career serve as an example of what an advocate can be and what an advocate can accomplish on behalf of others. We will continue to learn from her example- to carry out and improve our advocacy programmes wherever we are in Europe. That is what she would want and that is what we shall do.



EUROPA DONNA gratefully remembers its Founding President, Gloria Freilich, who passed away in January 2020. From 1993 to 1995 she chaired the international working party on setting up our Coalition and was subsequently elected as EUROPA DONNA – The European Breast Cancer Coalition's first President, a role in which she served for three years. Gloria was also a founding member of EBCC

and was a member of its governing body from 1996 to 2005, and co-chaired EBCC-1 (Florence, 1998) and EBCC-2 (Brussels, 2000). She maintained close ties to Europa Donna throughout the rest of her life, and was often present at our Pan-European conferences. Gloria was a unique and inspiring woman who made a tremendous contribution to breast cancer advocacy in Europe and to our organisation. Her commitment and dedication to the Coalition's goals were extraordinary and lasting. She is missed by us all.

## COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2020 EUROPA DONNA served on the following committees:

### Research and Clinical Trials

- ▶ BIG Scientific Committee
- ▶ BIG Survivorship Task Force
- ▶ MINDACT Steering Committee
- ▶ AURORA Steering Committee
- ▶ Early Breast Cancer Trialists' Collaborative Group (EBCTCG)
- ▶ International Breast Cancer Study Group (IBCSG)
- ▶ OLYMPIA Clinical Trial Steering Committee
- ▶ Horizon 20/20 Projects: BOUNCE, INSPIRE, MyPeBS, MESI-STRAT, PREFERABLE

During 2020 EUROPA DONNA participated in the following organisational activities:

### Policy

- ▶ European Patients' Forum
- ▶ Launch of Europe's Beating Cancer Plan
- ▶ Transforming Breast Cancer Together Initiative

### Conferences

- ▶ EBCC-12
- ▶ EUROPA DONNA MBC Advocacy webinar
- ▶ ECCO2020 European Cancer Summit

### Other Meetings

- ▶ EBCC-12 Organising Committee
- ▶ ECIBC Working Group meetings
- ▶ EBC Council - European Breast Cancer Council
- ▶ EPF AGM & Leadership Meeting
- ▶ BRESO Organisational/Management Structure Working Group webinar

### Publications

- ▶ 2019 Annual Report
- ▶ Breast Health Day leaflet
- ▶ 2020 Annual Newsletter
- ▶ 25 Years of Breast Cancer Advocacy Brochure
- ▶ Highlights from ED's MBC Advocacy Webinar
- ▶ ED Breast Cancer Survey Report 2020
- ▶ Addressing the Challenges of Breast Cancer During the COVID-19 Pandemic in Europe

# FINANCIAL

Our annual financial statement has been prepared by an independent auditor and is posted on our website at [www.europadonna.org](http://www.europadonna.org).

## BALANCE SHEET AS OF 31 DECEMBER 2020

ASSETS		LIABILITIES	
<b>Net Fixed Assets</b> (Plant machinery and equipment)	<b>3,241</b>	<b>Reserve Fund</b>	<b>403,469</b>
<b>Current Assets</b>	<b>627,440</b>	- Surplus/loss for the year	114,476
- Trade debtors	1,334	- Extraordinary reserve	288,993
- Cash at bank and in hand	612,261	<b>Creditors</b>	<b>15,433</b>
- Accrued Income	13,845	- Amounts payable within one year	15,433
- Reserve fund	-	- Accrued charges and deferred income	<b>211,779</b>
<b>TOTAL ASSETS</b>	<b>€ 630,681</b>	<b>TOTAL LIABILITIES</b>	<b>€ 630,681</b>

## INCOME AND EXPENDITURE STATEMENT 2020

INCOME	
<b>Turnover</b>	<b>526,066</b>
- Membership dues	14,500
- Grants and donations	510,934
- Reimbursements	632
<b>Financial Income</b>	<b>41</b>
Other financial income	41
<b>TOTAL INCOME</b>	<b>€ 526,107</b>

OPERATING EXPENDITURES	
<b>Services &amp; Office Expenses</b>	<b>55,976</b>
- Administrative overhead	48,182
- Fees (audit, legal, insurance)	7,794
<b>Salaries (employees &amp; related costs)</b>	<b>300,125</b>
<b>Activity Expenses</b>	<b>50,479</b>
- Publications, Websites	12,945
- 1st MBC Advocacy Webinar	13,865
- 14th ED Pan-European Conference 2019	1,836
- 3rd MBC Advocacy Conference 2020	8,388
- Board meetings	6,791
- EBCC-12	4,793
- Other meetings	1,861
<b>Depreciation &amp; Write-Offs</b>	<b>948</b>
- Office equipment	948
<b>Financial Charges</b>	<b>4,103</b>
- Bank costs	593
- Other financial costs	3,510
<b>Surplus/Loss of the Period (transfer to/from reserves)</b>	<b>114,476</b>
<b>TOTAL EXPENDITURES</b>	<b>€ 526,106</b>

# 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 FUNDING

We would like to express our appreciation to Diego Apostolo, Partner, Studio Notarile De Vivo–Tacchini–Cecala & Associati, for the provision of pro-bono legal services in 2020.



**EUROPA DONNA** – The European Breast Cancer Coalition has received funding for its role in the project from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825677

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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[www.facebook.com/EuropaDonna](https://www.facebook.com/EuropaDonna)

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

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

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

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