

EUROPA DONNA

The European Breast Cancer Coalition

Annual Report

2020



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OVERVIEW

2019 marked the 25th anniversary of the founding of Europa Donna and culminated in an inspiring 25 year celebration at our 14th Pan-European Conference in Vienna in October: more than 200 advocates from 44 countries attended and highlights included an opening presentation by Alberto Costa, MD, CEO of the European School of Oncology and Editor of Cancerworld describing the early days and founding of ED in 1994 with Gloria Freilich, our Founding President.

This event provided an opportunity to review our results over the years and progress on carrying out our 3 strategic plans and advocacy work on behalf of the women of Europe - expanding membership to 47 countries, training advocates at 19 annual Advocacy Training Courses, working with scientists on the European Breast Cancer Conference (EBCC) and clinical trials, setting standards with the European Parliament through 2 EU Resolutions and 2 Written Declarations. We have made significant progress in our key priorities that include: screening and early detection through raising awareness of EU guidelines; prevention through Breast Health Day; breast cancer in young women through working groups; and training of advocates through metastatic breast cancer (MBC) advocacy training courses etc. We have also begun addressing back to work issues for women with breast cancer and issues of concern to women with high genetic risk. A new brochure was also produced outlining our 25 years of advocacy progress.

Throughout the year we have continued our activities as a stakeholder in the European Commission Initiative on Breast Cancer - ECIBC and many of the recommendations on screening have now been published on their website at <https://healthcare-quality.jrc.ec.europa.eu/>. The ECIBC defines the entire pathway of breast services from diagnosis through treatment and follow up but it will only be valuable if it gets implemented across Europe. We are training advocates on this at all of our courses and conferences as well as developing educational aids for advocates to use to better understand these guidelines. ED continues to be active in providing the patient advocate perspective in a variety of research projects across Europe for BIG and in new HORIZON 2020 breast cancer projects that have been funded.

Finally, we engaged in numerous activities on breast cancer policy at the EU level this year through our participation in a multi stakeholder group 'Transforming Breast Cancer Together'. We provided the European breast cancer patient advocacy perspective at several meetings at the Parliament and in several new publications (see page 3).

As we conclude 25 years as Europe's breast cancer advocacy organisation, I would like to commend all of our members in 47 countries, as well as our friends, collaborators and sponsors for their commitment and dedication to our goals that have resulted in enormous progress and improvement in breast services for the women of Europe.



Susan Knox
CEO, Executive Director

2019 PROGRAMMES

PUBLIC AFFAIRS

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. The ECIBC is being 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 and Deputy CEO/Head of Policy Karen Benn are members of the Guidelines Development Group (GDG) and the Quality Assurance Scheme Development Group (QASDG) respectively and attended the joint meeting held in May. ED is a stakeholder providing the patient advocate perspective and recommendations to the JRC concerning this project.

The Recommendations on Breast Cancer Screening are now available.

For more information on ECIBC see their website at <https://healthcare-quality.jrc.ec.europa.eu/>

Transforming Breast Cancer Together

Meetings of the 'Transforming Breast Cancer Together' Group are held monthly and are conducted by MEP Lieve Wierinck, Belgium; ED has been participating in this initiative since 2018. The group held its first face-to-face meeting on 23 January at the European

Parliament and ED's CEO, Susan Knox, participated in the meeting where an overview of the 2018 activities and brainstorming for 2019 were discussed. On 26 March there was a special meeting conducted by MEP Lieve Wierinck with the European Commission DG Santé representatives Stefan Schreck- Head of Unit C1 "Health Programme and Chronic Diseases" and Paolo Guglielmetti- Policy Officer DG Santé Unit C1, in charge of the cancer dossier within the unit. Susan participated in this meeting where current cancer initiatives of DG Santé and of the TBCT group were exchanged.

On 16 October, ED President Mona Elzayat spoke at the European Parliament event 'Transforming Breast Cancer Together: The Next 5 Years to Reimagine the Future of Breast Cancer Care in the EU' in Brussels. Mona spoke about Europa Donna's policy initiatives over the years and the need to work together to get the Parliament resolutions of 2003 and 2006 as well as the Written Declarations of 2010 and 2015 implemented. She also stressed the need for mammography screening to be set up according to EU Guidelines and for the implementation of specialist breast units for all women diagnosed with breast cancer.

In 2019, ED contributed to the White Paper on "A New Collaborative Initiative To Improve Breast Cancer Prevention, Diagnosis And Care Across Europe", which was published by the Transforming Breast Cancer Initiative as well as the EU elections manifesto "Seizing the Opportunities for Breast Cancer Patients," which ED worked on disseminating.

RESEARCH

BIG (Breast International Group) Scientific Meetings

ED President Mona Elzayat attended the BIG Scientific meetings at the St.Gallen Breast Cancer conference in Vienna on 20 March and 27 September at the ESMO Congress. At the meetings, she heard updates from all the BIG collaborators on the progress of on-going trials and studies. ED is also now part of the BIG Survivorship task force that has been set up to study missed opportunities, and potential future trials, on the topic.

BIG OLYMPIA Steering Committee Meeting

This trial tests Olaparib in patients with early stage BRCA-mutated, high-risk HER2-negative breast cancer. Tanja Spanic, ED Vice-President, is a member of the Breast International Group (BIG)'s OlympiA trial steering committee and took part in meetings during San Antonio.

AURORA Steering Committee Meeting

This programme aims to help scientists understand the molecular aberrations in metastatic breast cancer. Susan Knox and Karen

Benn are members of the AURORA Steering Committee; Susan attended the steering committee meeting on 21 March at the St. Gallen Breast Cancer conference in Vienna and the meeting at ESMO in September.

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 Signaling 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

"Toolbox" Consensus Conference: A consensus and toolbox to improve breast conservation rates and to guide axillary management after preoperative systemic therapy (PST)

ED CEO Susan Knox, ED President Mona Elzayat, and ED Vice-President Tanja Spanic attended and were panelists in the consensus meeting in Lucerne on 8 February. The aims of the meeting were to improve breast conservation rates and to guide axillary management after preoperative systemic therapy. The meeting was convened and conducted by Peter Dubsky and more than 30 prominent breast cancer professionals from all disciplines attended.

ESMO Breast Cancer Congress

The first annual ESMO Breast Cancer Congress was held in Berlin 2-4 May. ED hosted two special sessions during the congress and also had a stand in the non-for-profit society area. ED Deputy CEO Karen Benn, ED Vice-President Tanja Spanic and ED Executive Board members Elizabeth Bergsten Nordström and Ellen Verschuur

spoke in the session on Patient Advocates' Role in Research and Karen Benn chaired the special session that covered the European Commission Initiative on Breast Cancer as well as Advocacy for Special Groups: what is needed where. ED President Mona Elzayat spoke about ensuring access for women with MBC and Tanja Spanic spoke about ensuring access and support for young women with breast cancer.

ENVISION Conference

ED President Mona Elzayat gave an introductory presentation on "The European Breast Cancer Advocacy Perspective on Screening, and New Vision for the Future" at the ENVISION conference that took place on 26-28 June in Innsbruck, Austria. ENVISION brought together six European consortia involved in risk stratification for the prevention and early diagnosis of breast cancer and the conference aimed to pool knowledge and join forces in order to identify specific actions required by the European breast cancer prevention and screening community for the development and implementation of risk-based breast cancer prevention and screening programmes.

2nd EUROPA DONNA Metastatic Breast Cancer Conference

ED held its second Advocacy Conference designed especially for women living with metastatic breast cancer (MBC), to learn more and share strategies to advocate with and for other women with this disease. The conference brought together 35 MBC advocates from 27 of the Coalition's 47 member countries in Milan, Italy on 7-8 June. Participants were selected based on their advocacy experience in their countries. In the weekend long event, participants heard about the latest in breast cancer therapies and research from Olivia Pagani, Breast Cancer Specialist at the Breast Unit of Southern Switzerland and a member of the ED Executive Board, as well as psycho-social support: what patients need, benefits of physical activity for women with MBC, nutrition and MBC and activity trackers and physical activity apps for MBC. They also participated in a panel session on advocacy for several topics of importance to people with MBC which concluded the conference.

ECCO2019 European Cancer Summit

ED Board Member Sema Erdem represents ED on the ECCO Patient Advisory Committee and participated in the European Cancer Organisation's ECCO2019 European Cancer Summit 12-14 September in Brussels.

Oncoplastic Breast Consortium Consensus Conference

ED President Mona Elzayat, CEO Susan Knox and Communications Officer Barbara Klein attended the Oncoplastic Breast Consortium (OPBC) Consensus Conference held in Basel, Switzerland on 12 September. The conference participants consisted of the official OPBC coordinators, OPBC panelists, as well as selected OPBC trainees, and OPBC patient advocates. During the conference, the panel voted on the 15 most important knowledge gaps in oncoplastic breast surgery selected during two Delphi rounds prior to the conference. The knowledge gaps that passed with a consensus were then voted on again after a concise strategy proposal to address each of the knowledge gaps was presented. Following the meeting the paper «Knowledge Gaps in Oncoplastic Breast Surgery» was accepted by The Lancet Oncology.

ESMO 2019 Congress

ED Vice President Tanja Spanic co-chaired a session on "Fertility and pregnancy of cancer patients during and after treatment" and spoke about "What are my options after diagnosis?" at the ESMO 2019 Congress held 27 September - 1 October in Barcelona. ED had a stand in the Society Village during the congress. Tanja is ED's representative on the ESMO Patient Advocates Working Group.

Europa Donna Sponsor Meeting at ESMO 2019 Congress

ED's annual Sponsor meeting was held at ESMO on 28 September, hosted by ED President Mona Elzayat, Susan Knox, and Barbara Klein; it was attended by 21 representatives of ED's current sponsors. Susan and Barbara provided them with an overview of ED's current activities, as well as ED's plans for 2020. This was followed by a lively Q&A session.

Breast Health Day 2019 Campaign

ED celebrated the 12th 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/> In addition, ED CEO Susan Knox participated in ED Finland's "Together for Breast Health" event in Helsinki on 15 October. Susan gave a keynote presentation on advocating for screening and early detection including the new European Commission Initiative on Breast Cancer.

14th Pan European Conference

EUROPA DONNA – The European Breast Cancer Coalition celebrated 25 years of breast cancer advocacy with more than 200 advocates from 44 countries at its 14th Pan-European Conference held in Vienna on 26-27 October. Advocates celebrated the progress made over the years and focused on the priorities for the future: achieving equal access to high-quality services for early and metastatic breast cancer (MBC) that adhere to European guidelines across Europe, giving increased attention to survivorship, return to work issues, and people with high genetic risk.

Alberto Costa, MD, CEO of European School of Oncology and Editor of Cancerworld who was instrumental in the founding of EUROPA DONNA, described the formation of the organisation and its early years. EUROPA DONNA CEO Susan Knox then presented highlights of programmes implemented over the years. Annett Roi from the European Commission's Joint Research Centre spoke about the European Commission Initiative on Breast Cancer (ECIBC).

Etienne Brain, a medical oncologist from Hospital René Huguenin, Institute Curie in France, described current treatments and research for early and advanced breast cancer. Christian Singer, Professor of Clinical-Translational Gynaecological Oncology and Head of the Centre for Breast Health at the Medical University of Vienna, Austria, gave an overview of genetic mutations that increase the risk for breast and ovarian cancer.

Isabel Rubio, Surgical Oncologist, Director of the Breast Surgical Unit at Clínica Universidad de Navarra in Madrid, Spain, described the state of the art of breast surgery and the importance of certification for breast surgeons to address the variability in breast surgery training across Europe. She described the BRESO Breast Cancer Surgery Certification project for breast surgery certification that was founded in 2019. EUROPA DONNA is a co-founder of this project with six other European organisations.

Pascal Baltzer, Associate Professor of Radiology, Medical University of Vienna, described the latest techniques in breast imaging, particularly for difficult-to-detect tumours in dense breast tissue. Barbara Wilson, Founder and Director of Working with Cancer in the UK covered "Work after breast cancer" and stressed the need to support women in their return to work, managing expectations and educating employers. Richard Crevenna, Head of the Department of Physical Medicine, Rehabilitation and Occupational Medicine at the Medical University of Vienna, covered oncological rehabilitation and techniques that can help address the short and long-term side effects of breast cancer and its treatment. Advocates were then able to discuss the individual and country-specific issues in workshops on these topics (ie, survivorship strategies, return to work, high genetic risk and ECIBC implementation), as well as on issues for women with MBC, and for young women with breast cancer.

On the second day of the conference, there was an overview of EUROPA DONNA's successful breast cancer prevention campaign, Breast Health Day, and presentations from ED Fora from Denmark and North Macedonia on their current activities. The conference ended with a celebratory 25-year song and a photo exhibition of ED's advocacy work for the last 25 years.

Advanced Breast Cancer Fifth ESO-ESMO International Consensus Conference (ABC5)

The Advanced Breast Cancer Fifth ESO-ESMO International Consensus Conference (ABC5) took place in Lisbon, Portugal, on 14-16 November. ED Deputy CEO Karen Benn took part in the Breast Cancer Advocacy Committee and Mona Elzayat, ED President, and ED Board Member Olivia Pagani served on the Consensus panel. ED had a booth, and many advocates were in attendance.

EUROPA DONNA Advocacy Training Course

The ED European Advocacy Training course took place on 22-24 November in Milan. This was the 19th year that the course has been held and 54 advocates from 30 countries attended. Advocates heard presentations on the science of breast cancer as well as on EU guidelines and recent EU policy initiatives. They then had the opportunity to participate in a one-day communication skills training programme to prepare them to disseminate and effectively communicate their advocacy messages to women in their countries.

COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2019 **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 2020 Projects: BOUNCE, INSPIRE, MyPEBS, MESI-STRAT, PREFERABLE

During 2019 **EUROPA DONNA** participated in the following organisational activities:

Policy

- ▶ European Patients' Forum
- ▶ Transforming Breast Cancer Together Initiative

Conferences

- ▶ 14th Pan European Conference
- ▶ St. Gallen International Breast Cancer Conference
- ▶ 2nd EUROPA DONNA MBC Advocacy Conference
- ▶ ECCO2019 European Cancer Summit
- ▶ ESMO Breast Cancer Congress
- ▶ ESMO 2019 Congress
- ▶ Advanced Breast Cancer International Consensus Conference (ABC 5)
- ▶ EUROPA DONNA Advocacy Training Course

Other Meetings

- ▶ EBCC-12 Organising Committee
- ▶ EBCC-12 Scientific Committee
- ▶ ECIBC Working Group meetings
- ▶ EBC Council - European Breast Cancer Council
- ▶ PREFERABLE Horizon 2020 meeting
- ▶ Toolbox Consensus Meeting to improve breast conservation and guide axillary management
- ▶ EUSOMA Workshop on the management of elderly women w/breast cancer
- ▶ EPF AGM & Leadership Meeting
- ▶ ENVISION Conference
- ▶ ABC 5 Advocacy Committee
- ▶ WECAN Programme Committee Meeting for ESO-WECAN Patient Advocacy Masterclass
- ▶ BRESO Organisational/Management Structure Working Group
- ▶ Oncoplastic Breast Consortium (OPBC) Consensus Conference
- ▶ ABC Global Alliance meeting

Publications

- ▶ 2018 Annual Report
- ▶ Breast Health Day leaflet
- ▶ ECIBC Recommendations from the European Breast Cancer Guidelines
- ▶ 2019 Annual Newsletter
- ▶ 25 Years of Breast Cancer Advocacy Brochure
- ▶ Highlights from ED's 2nd MBC Advocacy Conference

FINANCIAL

Our annual financial statement has been prepared by an independent auditor and is posted on our website at www.europadonna.org.

BALANCE SHEET AS OF 31 DECEMBER 2019

ASSETS		LIABILITIES	
Net Fixed Assets (Plant machinery and equipment)	3,398	Reserve Fund	288,993
Current Assets	511,312	- Surplus/loss for the year	11,270
- Trade debtors	4,857	- Extraordinary reserve	277,723
- Cash at bank and in hand	494,511	Creditors	4,743
- Accrued Income	11,944	- Amounts payable within one year	4,743
- Reserve fund	-	- Accrued charges and deferred income	220,974
TOTAL ASSETS	€ 514,710	TOTAL LIABILITIES	€ 514,710

INCOME AND EXPENDITURE STATEMENT 2019

INCOME	
Turnover	612,961
- Membership dues	16,235
- Grants and donations	576,039
- 14th Pan European Conf. Registration	17,696
- Reimbursements	2,992
Financial Income	
Other financial income	1,711
TOTAL INCOME	€ 614,673

OPERATING EXPENDITURES

Services & Office Expenses	63,077
- Administrative overhead	53,789
- Fees (audit, legal, insurance)	9,288
Salaries (employees & related costs)	290,048
Activity Expenses	246,082
- Publications, Websites	20,805
- Advocacy Training Course 2019	61,321
- Board meetings	6,333
- Other meetings	7,725
- 14th ED Pan-European Conference	120,487
- EBCC-12	118
- 2nd MBC Advocacy Conference	29,292
Depreciation & Write-Offs	959
- Office equipment	959
Financial Charges	3,237
- Bank costs	861
- Other financial costs	2,376
Surplus/Loss of the Period (transfer to/from reserves)	11.270
TOTAL EXPENDITURES	€ 614,673

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



€ 1 - 4,999



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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