OVERVIEW

In 2018 Europa Donna continued its ambitious advocacy program on behalf of European women participating in numerous conferences, policy meetings and educational events across Europe and the world. EBCC 11 was held in Barcelona in March and is the only major conference jointly organised by clinicians, scientists and advocates- EUSOMA, EORTC, and Europa Donna. Over 2500 participants including advocates from 36 countries attended to hear the most up to date information on research and treatment of breast cancer. Europa Donna also held its first MBC advocacy training course in September and received a SPARC grant from the UICC in support of this unique activity helping advocates with MBC gain the skills to raise awareness and improve services for women with MBC in their own countries. Our Vice President Mona Knotek-Roggenbauer then represented us at the UICC World Cancer Congress in Kuala Lumpur, describing our educational activities for women with MBC so that they can be replicated across the world. We continued to raise awareness of issues facing women with MBC at the European Parliament where Karen Benn provided an overview of problems and discrimination that women with MBC encounter in returning to work across Europe. ED also carried out a survey on this topic at the MBC advocacy training course and published a summary of the findings later in the year.

ED continues to be active in providing the patient advocate perspective in a variety of research projects across Europe for BIG and in HORIZON 2020 breast cancer projects that have been funded. Our input into consensus statements, and other publications has also been deemed important by numerous professional organisations such as ESTRO, BRESSO, EUSOBI etc during the course of the year.

Work continues on the European Commission Initiative on Breast Cancer- ECIBC and many of the recommendations on screening have now been published on their webhub at http://ecibc.jrc.ec.europa.eu. This year Europa Donna published a booklet called “Europa Donna Advocates Guide to the ECIBC”. We introduced this with members of the European Commission at our Advocacy Leader Conference in September. The guide will be used at all of our educational conferences and courses as it is essential that women and advocates understand what they need to be advocating for in their countries. 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. ED has a key role to play in seeing that this happens and considers it a priority for advocacy work now and in the future.
ED 2018 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 meetings held in February, April, June, September and November. EUROPA DONNA is a stakeholder providing the patient advocate perspective and recommendations to the JRC concerning this project. The first Recommendations on Breast Cancer Screening are now available. For more information on ECIBC see their web hub at http://ecibc.jrc.ec.europa.eu/

- **ABC Global Alliance meeting at EU Parliament**
  ED Deputy CEO Karen Benn attended the ABC Global Alliance meeting at the European Parliament on 7 November where she spoke about employment/return to work issues facing breast cancer patients. The I have cancer but I want to work. Working rights of cancer patients event was hosted by MEP Lieve Wierinck, and is an initiative of the Advanced Breast Cancer (ABC) Global Alliance. Members of the ABC Global Alliance highlighted to policy-makers that the financial burden of breast cancer includes not only the direct cost of treatments, but also the indirect cost from loss of productivity when people living with advanced diseases, who are able and willing to continue working, are unable to do so because of a lack of understanding about their disease or because of direct or indirect discrimination.

- **Transforming Breast Cancer Together**
  MEPs Lieve Wierinck (ALDE), Elena Gentile (S&D) and Cristian Silviu Buşoi (EPP), representing the three main political groups in the European Parliament, together with key organisations active in this area, have launched a Call for Change to transform breast cancer care in the EU. EUROPA DONNA is participating in this initiative and supports the “Call for Change” along with ECPC, ESO and other stakeholders. Throughout the year, ED participated in teleconferences and listed both the ED Advocacy Leader Conference and annual Advocacy Training Course in their calendar of events for the year. The Call for Change issues nine policy recommendations which would significantly improve breast cancer treatment and care in the EU.

- **Breast Cancer Awareness events at the Council of Europe**
  Stella Kyriakides, who is MP for Cyprus and ED Past President held a Breast Cancer Awareness Day on 8 October at the Council of Europe in Strasbourg. The Breast Health Day leaflet and brochures about ED’s work were handed out during the event.

RESEARCH

- **BIG (Breast International Group) Scientific Meetings**
  Susan Knox and Roswitha Britz attended a BIG Scientific meeting held during EBCC 11 in Barcelona on 20 March; Karen Benn attended a BIG meeting during the ESMO 2018 Congress; at these meetings updates were presented from all the BIG collaborators on the progress of on-going trials and studies. Patient advocate input and opinion was sought on several new trials being undertaken and ED is also now part of the BIG Survivorship task force that has been set up to look at potential/possible survivorship studies.

- **BIG OLYMPIA Steering Committee Meeting**
  This trial tests Olaparib in patients with early stage BRCA-mutated, high-risk HER2-negative breast cancer. Karen Benn is a member of the Breast International Group (BIG)’s Olympia trial steering committee and took part in meetings during ASCO.

- **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 and Karen attended the meeting at ESMO in 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). EUROPA DONNA is the patient advocacy representative on the following four Horizon 2020 projects that have been funded: Advisory Board member in the “MEdabolic 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 – MyPBEs” and PREFERABLE – “Project on Exercise for Fatigue Eradication in Advanced Breast Cancer to improve quality of life”.

EDUCATION

- **3rd ESO Masterclass in Cancer Patient Advocacy**
  The 3rd ESO cancer patient advocacy masterclass was held in Lisbon 23-25 February. Karen Benn served on the Steering committee which developed the agenda for this year’s masterclass. The ESO masterclass aims to provide European cancer patient advocacy leaders with the opportunity to learn how to build more sustainable and effective EU cancer organisations, increase their understanding of key cancer policy issues and hone their advocacy and leadership skills. 53 cancer patient advocate leaders representing 24 cancer networks attended the ESO masterclass, along with 13 faculty (some from outside the cancer patient community), 8 observers and one journalist.
ED 2018 PROGRAMMES

EDUCATION

EBCC 11
More than 100 advocates from most of EUROPA DONNA – The European Breast Cancer Coalition’s 47 member countries were in Barcelona for the 11th European Breast Cancer Conference (EBCC11) to hear about the latest scientific findings in breast cancer, progress with European policy on implementing breast services, and to present the patient’s perspective. 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). This year’s scientific programme was divided into the steps of the patient journey. EUROPA DONNA President and conference co-chair Evi Papadopoulos presented the EBCC Arts and Humanities Prize to François Perri and Josefina Díaz Rubio for their photo project “Cicatrices — Scars ... My life in 1,096 days.” The book “…shows the many challenges of the whole breast cancer journey” with personal pictures and the reflections of its author and highlights the need for high standards of comprehensive breast cancer care from screening onward.

ECCO 2018 European Cancer Summit
EUROPA DONNA Board Member Sema Erdem represents ED on the ECCO Patient Advisory Committee and attended the ECCO 2018 European Cancer Summit. She also attended the BRESSO project meeting held during the European Cancer Organisation’s ECCO 2018 European Cancer Summit on 7 September in Vienna where she presented ED views on qualifications for specialist breast surgery. BRESSO is the Breast Surgical Oncology Project Team within the European Society of Surgical Oncology (ESSO). She emphasised the need for appropriately trained and experienced specialist breast surgeons working within specialist breast units.

1st Metastatic Breast Cancer Advocacy Training Course
EUROPA DONNA held its first MBC Advocacy Training Course 28-30 September in Milan. The course was designed especially for women living with MBC to share strategies to advocate, with and for, women with MBC. The course brought together 37 MBC advocates from 26 of the Coalition’s 47 member countries. Participants were selected based on their advocacy experience in their countries. In the weekend long event, participants heard about the latest in breast cancer treatments and research, including biosimilars from Olivia Pagani, Director of the Breast Unit of Southern Switzerland, and a member of the ED Executive Board, as well as health technology assessment, work and insurance-related issues, and breast cancer registries. They participated in a session on successful MBC advocacy strategies and best practice and concluded the weekend with advocacy skills training workshops, designed specifically for this event, providing participants with the tools necessary to communicate their messages effectively to the media and policy makers in their countries, using their personal stories. The 1st EUROPA DONNA MBC Advocacy Training Course was supported, in part, by a UICC SPARC MBC Challenge Grant.

EUROPA DONNA Breast Cancer Advocacy Leader Conference
EUROPA DONNA’s 5th Breast Cancer Advocacy Leader Conference brought together 44 national representatives and delegates from 32 of the Coalition’s 47 member countries in Milan on 29 September. The meeting was held in conjunction with the 1st ED MBC Advocacy Training course. Attendees firstly heard about breast cancer treatments and research, health technology assessment, work and insurance-related issues, and breast cancer registries, which are topics of great concern for both early and advanced breast cancer advocates. ED National representatives and delegates then spent the afternoon session learning more about, and discussing, the European Commission Initiative on Breast Cancer (ECIBC) and funding strategies for their organisations, before sharing experiences in workshops.

2018 World Cancer Congress
EUROPA DONNA Vice President Mona Knotek-Roggenbauer attended the UICC World Cancer Congress in Kuala Lumpur and presented ED’s 1st EUROPA DONNA MBC Advocacy Training course, addressing the topic of “best practices and effective collaborative approaches” at the Patient Group Pavilion. She was also chosen to deliver an e-poster presentation on the same topic at the conference. ED received a UICC SPARC MBC Challenge Grant in support of the training course which was held 28-30 September.

ESMO 2018 Congress
EUROPA DONNA Board member Tanja Spanic co-chaired a session on “Life after Cancer” at the ESMO 2018 Congress. EUROPA DONNA had a stand in the Society Village during the congress. Tanja is also on the ESMO Patient Advocates Working Group.

Europa Donna Sponsor Meeting at ESMO 2018 Congress
ED’s annual Sponsor meeting was held at ESMO on 20 October, hosted by ED Vice-President Mona Knotek-Roggenbauer, Susan Knox, Karen Benn; it was attended by 22 representatives of ED’s current sponsors. Susan and Karen provided them with an overview of EUROPA DONNA’s current activities, as well as ED’s plans for 2019. This was followed by a lively Q&A session.

Breast Health Day 2018 Campaign
EUROPA DONNA celebrated the 11th 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. In preparation, ED launched a new website section dedicated to prevention. This year’s campaign encouraged women and girls to choose a “Healthy Lifestyle for Breast Health!” and asked them to send in pictures of themselves doing something healthy, which were then shared in a video released on 15 October. For more details see: https://prevention.europadonna.org/

EUROPA DONNA Advocacy Training Course
The EUROPA DONNA European advocacy training course took place on 16-18 November in Milan. This was the 18th year that the course has been held and 59 advocates from 32 countries attended. Advocates heard presentations both 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 2018 EUROPA DONNA served on the following committees:

Research and Clinical Trials
- BIG Scientific Committee
- 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, MyPEBS, MESI-STRAT

During 2018 EUROPA DONNA participated in the following organisational activities:

Policy
- European Patients’ Forum
- ABC Global Alliance meeting at EU Parliament
- Council of Europe breast cancer awareness events
- Transforming Breast Cancer Together Initiative

Conferences
- EBCC-11
- ECCO 2018 European Cancer Summit
- EUROPA DONNA Advocacy Leader Conference
- 1st EUROPA DONNA MBC Advocacy Training Course
- ESMO 2018 Congress
- 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
- ABC 5 Advocacy Committee
- ESO 3rd Patient Advocacy Masterclass Steering Committee
- BOUNCE Horizon 2020 meeting
- Bresso Working Group-Organisation/Structure
- ABC Global Alliance meeting

Publications
- 2017 Annual Report
- Breast Health Day leaflet
- EUROPA DONNA Advocates Guide to the ECIBC
- 2018 Annual Newsletter
- Highlights from ED’s 1st MBC Advocacy Training Course
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 2018**

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>€ 518,836</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Fixed Assets</strong> (Plant machinery and equipment)</td>
<td>2,929</td>
</tr>
<tr>
<td><strong>Current Assets</strong></td>
<td>515,907</td>
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<tr>
<td>- Trade debtors</td>
<td>85,683</td>
</tr>
<tr>
<td>- Cash at bank and in hand</td>
<td>371,592</td>
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<tr>
<td>- Accrued Income</td>
<td>58,632</td>
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<tr>
<td>- Reserve fund</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>€ 518,836</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reserve Fund</strong></td>
<td>277,723</td>
</tr>
<tr>
<td>- Surplus and loss for the year</td>
<td>9,826</td>
</tr>
<tr>
<td>- Extraordinary reserve</td>
<td>267,897</td>
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<tr>
<td><strong>Creditors</strong></td>
<td>241,113</td>
</tr>
<tr>
<td>- Amounts payable within one year</td>
<td>51,632</td>
</tr>
<tr>
<td>- Accrued charges and deferred income</td>
<td>189,481</td>
</tr>
<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td>€ 518,836</td>
</tr>
</tbody>
</table>

**Income and Expenditure Statement 2018**

**INCOME**

<table>
<thead>
<tr>
<th>Turnover</th>
<th>587,798</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Membership dues</td>
<td>17,006</td>
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<tr>
<td>- Grants and donations</td>
<td>570,792</td>
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<tr>
<td><strong>Financial Income</strong></td>
<td>30</td>
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<tr>
<td>- Other financial income</td>
<td>30</td>
</tr>
<tr>
<td><strong>TOTAL INCOME</strong></td>
<td>€ 587,828</td>
</tr>
</tbody>
</table>

**OPERATING EXPENDITURES**

<table>
<thead>
<tr>
<th>Services &amp; Office Expenses</th>
<th>64,842</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrative overhead</td>
<td>53,512</td>
</tr>
<tr>
<td>Fees (audit, legal, insurance)</td>
<td>11,330</td>
</tr>
<tr>
<td><strong>Salaries (employees &amp; related costs)</strong></td>
<td>295,572</td>
</tr>
<tr>
<td><strong>Activity Expenses</strong></td>
<td>215,306</td>
</tr>
<tr>
<td>- Publications, Website</td>
<td>30,650</td>
</tr>
<tr>
<td>- Advocacy Training Course 2018</td>
<td>61,325</td>
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<tr>
<td>- Board meetings</td>
<td>11,995</td>
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<tr>
<td>- Other meetings</td>
<td>4,981</td>
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<tr>
<td>- 13th ED Pan-European Conference</td>
<td>625</td>
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<tr>
<td>- EBCC-11</td>
<td>29,955</td>
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<tr>
<td>- 1st MBC Advocacy Training Course</td>
<td>45,582</td>
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<tr>
<td>- Advocacy Leader Conference</td>
<td>30,193</td>
</tr>
<tr>
<td><strong>Depreciation &amp; Write-Offs</strong></td>
<td>1,057</td>
</tr>
<tr>
<td>- Office equipment</td>
<td>1,057</td>
</tr>
<tr>
<td><strong>Financial Charges</strong></td>
<td>1,225</td>
</tr>
<tr>
<td>- Bank costs</td>
<td>1,084</td>
</tr>
<tr>
<td>- Other finance costs</td>
<td>141</td>
</tr>
<tr>
<td><strong>Surplus/Loss of the Period (transfer to/from reserves)</strong></td>
<td>9,826</td>
</tr>
<tr>
<td><strong>TOTAL EXPENDITURES</strong></td>
<td>€ 587,828</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

EUROPA DONNA 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 EUROPA DONNA 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.

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