EUROPA DONNA
The European Breast Cancer Coalition

Annual Report

2017
OVERVIEW

In 2017 Europa Donna continued to make progress on various important advocacy challenges in Europe. We began our work on the next Strategic Plan which will be finalized in 2018 and continued to work on our current priorities, especially access and improved services for women with MBC (metastatic breast cancer).

In February we launched a new section of our website dedicated to advocating for and with women with MBC. It can be viewed at https://mbc.europadonna.org/ and includes sections on challenges, addressing issues, resource library, toolkit, and videos in which “advocates speak out.”

In June, we held our first MBC advocacy conference in Milan attended by 68 advocates including 28 women with MBC as well as numerous women who are leading MBC activities in their countries. It was also the first time that we opened registration to women outside of ED and outside of Europe. Women from 34 countries were present including Australia, Canada, Japan, and Africa. It was an inspiring weekend providing essential education on research and treatment as well as a new training module for communication and helping advocates to use and tell their personal stories to make a difference. A morning showcase event enabled advocates to share and disseminate the work done in their native countries.

We continued our work in this area sitting on the Interim Steering Committee of the ABC Global Alliance in 2017 where ED will continue as an engaged partner in the future. In addition, we have been granted a SPARC award to provide an MBC advocacy training course in 2018 so the momentum will continue.

In October our 13th Pan European Conference took place in Slovenia. Various aspects of the ECIBC-European Commission Initiative on Breast Cancer were highlighted by invited speakers; we were gratified that the EU Commissioner of Health, V. Andriukaitis sent a special video message emphasising the importance of this Commission initiative and ED’s key role in seeing that it gets implemented. In addition, our Founding President, Gloria Freilich, gave a moving tribute to our Founder, Umberto Veronesi who passed away in November 2016. The presentations of our fora were inspiring and the hospitality of our Slovenian advocates was superb.

As you can read here ED participated in many other events this year at the Council of Europe, at the European Parliament, at international conferences - all aimed at raising awareness of our continued challenges and improving breast cancer services. Progress has been made, but there are still significant inequalities among countries and a lot more work needs to be done to ensure equal access to quality breast services for all the women of Europe.

Susan Knox
CEO, Executive Director
**ED 2017 PROGRAMMES**

**PUBLIC AFFAIRS**

- **European Commission Initiative on Breast Cancer**
  ED has been advocating for the development of an accreditation scheme for breast cancer services as well as a new edition of the European Guidelines for quality assurance in breast cancer screening and diagnosis. The ECIBC (European Commission Initiative on Breast Cancer) is now under way and 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, September and November. ED as an organisation is also a stakeholder in this initiative.

  The first four Recommendations on Breast Cancer Screening are now available.

  For more information on ECIBC see their web hub at http://ecibc.jrc.ec.europa.eu/

- **Breast Cancer Awareness events at the Council of Europe**
  Elizabeth Bergsten Nordström, ED Past President gave a presentation on employment and insurance issues faced by women with breast cancer, during a joint hearing on 9 October in Strasbourg. The 2017 Breast Health Day leaflet and ED general brochures were distributed during Breast Cancer Awareness day on 10 October.

- **Bringing the Advocacy Voice to the EU Parliament**
  Karen Benn was an invited speaker at the European Parliament’s FEMM committee (the Committee on Women’s Rights and Gender Equality) meeting entitled “EU Strategy Against Women’s Cancers”. Her presentation described ED’s advocacy work and current priorities. The meeting was held on 16 October at the European Parliament.

**RESEARCH**

- **BIG (Breast International Group) Scientific Meetings**
  Susan Knox and Roswitha Britz attended the BIG Scientific meeting held at the St. Gallen Breast Cancer Conference in Vienna on 15 March, and Karen Benn and Roswitha attended a meeting in Madrid on 8 September during the ESMO 2017 Congress; there they heard updates 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 expressed interest in providing further input if invited early on in the trial development.

  A task force will be set up to study missed opportunities, and trials that could be run that aren’t currently being conducted. This will include non-drug related trials in early breast cancer, such as more about surgery, life style, or quality of life; ED is included in the task force as patients are extremely interested in these areas.

- **BIG OlympiA Steering Committee Meeting**
  This trial tests olaparib for patients with BRCA-mutated, high-risk HER2-negative early breast cancer. Karen Benn is a member of the trial’s steering committee and took part in the meeting during ASCO on 5 June.

- **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 7 March and both attended the meeting on 8 September.

- **MINDACT**
  Susan Knox sits on the Steering Committee of the MINDACT trial. The first results of the trial are now available. Karen Benn was interviewed on the patient perspective of the trial for the BIG 2016 annual report. ED members have been actively engaged in this trial since its inception in 2007.
ED 2017 PROGRAMMES

EDUCATION

• ECCO2017 European Cancer Congress
  ED’s Deputy CEO, Karen Benn, was invited to present the patient view at an Educational Session at ECCO2017, on the topic of PROs - patient reported outcomes. The session concentrated for the most part on the role of PROs in clinical trials but ED emphasised their importance also in evaluating health services because, when done well, they can capture what really matters to patients. ED also had a stand at the congress in the “patient advocacy square”.

• International Forum on Cancer Patients Empowerment
  The first International Forum on Cancer Patients Empowerment was held in Milan on 16-17 May at the Università degli Studi di Milano and was co-organized by the University and the Umberto Veronesi Foundation. ED Deputy CEO, Karen Benn, was invited to speak in the plenary session on EU Action Plans, What's Next For Patient Empowerment? The session focused on “One Policy - Common guidelines for the protection of human rights promoting optimal standards of health” and Karen described ED’s extensive work in influencing EU policy, thereby empowering both ED advocates and breast cancer patients in Europe in general.

• 1st EUROPA DONNA Metastatic Breast Cancer Advocacy Conference
  ED’s 1st Metastatic Breast Cancer Advocacy Conference brought together 68 metastatic breast cancer advocates from 34 countries, including women from among the Coalition’s 47 member countries as well as advocates from Australia, Canada, Japan, Kuwait, Mexico and Uganda in Milan on 9-11 June. The first MBC advocacy conference was created in order to exchange ideas, expertise and best practice in the weekend long event. Participants heard about the latest in MBC treatments and research from Fatima Cardoso, Director, Breast Unit of the Champalimaud Clinical Center, Lisbon, Portugal and Chair of ABC 4 as well as successful MBC advocacy strategies and best practices from advocates in Europe, Canada, UK, Italy and France. The advocacy skills training workshops, designed specifically for this event, provided participants with the tools necessary to communicate their messages effectively to the media and policy makers in their countries, using their personal stories. The event closed with a special advocacy showcase where campaign videos, brochures and other materials developed and produced by organisations participating in the conference and specifically related to MBC, were spotlighted.

• 13th Pan European Conference
  ED’s 13th Pan-European Conference brought together more than 200 breast cancer advocates from 40 countries in Ljubljana, Slovenia, on 28 and 29 October. European Commission representatives shared the first recommendations from the new European Breast Guidelines, developed as part of the European Commission Initiative on Breast Cancer (ECIBC), and outlined future steps for this initiative. Invited experts also presented what women need to know about breast cancer research, the latest in breast imaging, surgery and radiotherapy, and key survivorship issues.

• ESMO 2017 Congress
  Karen Benn, ED Deputy CEO, was invited to give a presentation on the patient advocacy perspective in a session on Health Services Research in cancer on Friday 8 September.

• Sponsor Meeting at ESMO 2017 Congress
  Susan Knox, Roswitha Britz and Karen Benn conducted our annual sponsor meeting on 9 September; it was attended by 20 representatives of ED’s current sponsors. Susan and Karen provided them with an overview of ED’s current activities as well as plans for 2018.

• Breast Health Day 2017 Campaign
  ED holds 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 a picture of themselves doing something “healthy” which were shared in a special video that was released on 15 October. For more details see: www.breasthealthday.org.

• ESO Advanced Breast Cancer Consensus Conference (ABC4)
  The Advanced Breast Cancer Consensus Conference ABC 4 took place in Lisbon, Portugal on 2-4 November 2017. Evi Papadopoulos, ED Vice-President, was Co-chair of the conference and Elizabeth Bergsten Nordström gave a presentation on “Impact on Legal and Professional Lives”. Evi and Olivia Pagani served on the Consensus panel. ED had a booth, and many advocates were in attendance.

• ABC Global Alliance
  ABC Global Alliance, established by the European School of Oncology (ESO), is a multi-stakeholder platform for all those interested in collaborating on common projects relating to advanced breast cancer (ABC) around the world. ED CEO Susan Knox served on the Interim Steering Committee of the Alliance and attended several meetings in 2017 to develop the ABC Global Charter and the Terms of Reference document describing its mission and goals. Susan gave a presentation on ED’s 1st Metastatic Breast Cancer Advocacy Conference at the 1st meeting of the ABC Global Alliance on 4 November in Lisbon.

• EUROPA DONNA Advocacy Training Course
  The ED European advocacy training course took place 17-19 November in Milan. This was the 17th year that the course has been held and 59 advocates from 31 countries attended. Advocates heard presentations both on the science of breast cancer, as well as on EU guidelines and recent 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 2017 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

During 2017 EUROPA DONNA participated in the following organisational activities:

- **Policy**
  - European Patients’ Forum
  - FEMM committee (Committee on Women’s Rights and Gender Equality) meeting on “EU Strategy Against Women’s Cancers”
  - ECCO – Patient Advisory Committee
  - Council of Europe breast cancer awareness events

- **Conferences**
  - 13th Pan European Conference
  - ECCO2017 European Cancer Congress
  - St. Gallen International Breast Cancer Conference
  - International Forum on Cancer Patients Empowerment
  - 1st EUROPA DONNA MBC Advocacy Conference
  - ESMO 2017 Congress
  - Advanced Breast Cancer International Consensus Conference (ABC 4)
  - ABC Global Alliance
  - EUROPA DONNA Advocacy Training Course

- **Other Meetings**
  - EBCC-11 Organising Committee
  - EBCC-11 Scientific Committee
  - ECIBC Working group meetings
  - ABC Global Alliance Interim Steering Committee
  - EBC Council - European Breast Cancer Council
  - ESO Breast Cancer Observatory
  - ABC 4 Advocacy Committee
  - ESO 3rd Patient Advocacy Masterclass Steering Committee

- **Publications**
  - 2016 Annual Report
  - BHD 2017 leaflet
  - 2017 Annual Newsletter
**FINANCIALS**

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 2017**

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<thead>
<tr>
<th>Assets</th>
<th>LIABILITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Fixed Assets</strong> (Plant machinery and equipment)</td>
<td><strong>Reserve Fund</strong></td>
</tr>
<tr>
<td>3,986</td>
<td>267,897</td>
</tr>
<tr>
<td><strong>Current Assets</strong></td>
<td><strong>- Surplus/loss for the year</strong></td>
</tr>
<tr>
<td>520,510</td>
<td>1,477</td>
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<tr>
<td>- Trade debtors</td>
<td><strong>- Extraordinary reserve</strong></td>
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<tr>
<td>27,414</td>
<td>266,420</td>
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<tr>
<td>- Cash at bank and in hand</td>
<td><strong>Creditors</strong></td>
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<tr>
<td>493,096</td>
<td>256,599</td>
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<tr>
<td>- Reserve fund</td>
<td><strong>- Amounts payable within one year</strong></td>
</tr>
<tr>
<td>-</td>
<td>15,635</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td><strong>- Accrued charges and deferred income</strong></td>
</tr>
<tr>
<td>€ 524,496</td>
<td>240,964</td>
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**LIABILITIES**

<table>
<thead>
<tr>
<th>Creditors</th>
<th>TOTAL LIABILITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>266,420</td>
<td><strong>€ 524,496</strong></td>
</tr>
<tr>
<td>267,897</td>
<td></td>
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**Income and Expenditure Statement 2017**

**INCOME**

<table>
<thead>
<tr>
<th>Income</th>
<th>581,891</th>
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</thead>
<tbody>
<tr>
<td><strong>Turnover</strong></td>
<td></td>
</tr>
<tr>
<td>570,721</td>
<td></td>
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<tr>
<td>- Membership dues</td>
<td>16,000</td>
</tr>
<tr>
<td>- Grants and donations</td>
<td>554,721</td>
</tr>
<tr>
<td>- 13th Pan European Conf. Registration</td>
<td>11,150</td>
</tr>
<tr>
<td><strong>Financial Income</strong></td>
<td>20</td>
</tr>
<tr>
<td>- Other financial income</td>
<td>20</td>
</tr>
<tr>
<td><strong>TOTAL INCOME</strong></td>
<td><strong>€ 581,891</strong></td>
</tr>
</tbody>
</table>

**OPERATING CHARGES**

<table>
<thead>
<tr>
<th>Charges</th>
<th>226,859</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Services &amp; Office Expenses</strong></td>
<td></td>
</tr>
<tr>
<td>58,394</td>
<td></td>
</tr>
<tr>
<td>Administrative overhead</td>
<td>47,751</td>
</tr>
<tr>
<td>Fees (audit, legal, insurance)</td>
<td>10,643</td>
</tr>
<tr>
<td><strong>Salaries (employees &amp; related costs)</strong></td>
<td>292,212</td>
</tr>
<tr>
<td><strong>Activity Expenses</strong></td>
<td></td>
</tr>
<tr>
<td>226,859</td>
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</tr>
<tr>
<td>- Publications, websites</td>
<td>17,030</td>
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<tr>
<td>- Advocacy Training Course 2017</td>
<td>58,014</td>
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<tr>
<td>- Board meetings</td>
<td>5,678</td>
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<tr>
<td>- Other meetings</td>
<td>5,111</td>
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<tr>
<td>- 13th ED Pan-European Conference</td>
<td>91,468</td>
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<td>- EBCC-11</td>
<td>1,050</td>
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<td>- 1st MBC Conference</td>
<td>48,252</td>
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<td>- Breast Health Day</td>
<td>256</td>
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<tr>
<td><strong>Depreciation &amp; Write-Offs</strong></td>
<td>1,717</td>
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<tr>
<td>- Office equipment</td>
<td>1,717</td>
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<tr>
<td><strong>Financial Charges (bank costs)</strong></td>
<td>1,232</td>
</tr>
<tr>
<td><strong>Surplus/Loss of the Period</strong> (transfer to/from reserves)</td>
<td>1,477</td>
</tr>
<tr>
<td><strong>TOTAL CHARGES</strong></td>
<td><strong>€ 581,891</strong></td>
</tr>
</tbody>
</table>
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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