OVERVIEW

Europa Donna continued its progress on key breast cancer advocacy initiatives in 2016. Many ED advocates participated in and contributed to the 10th EBBC conference held in March in Amsterdam. Over 100 advocates attended and the central theme was one of our core goals: implementing specialist breast units in all countries. ED is a co-organiser of this conference with the EORTC and EUSOMA and also served on the committee writing a “Manifesto” on this topic due to be published shortly in the EJC.

ED continues to move forward with its prevention and awareness raising programme - Breast Health Day, and has added lifestyle information to our website www.breasthealthday.org that can be important for women to help avoid a breast cancer recurrence. More than 30 countries are now participating in this campaign either through social media or local activities. Sessions at EBCC also reinforced the importance of physical exercise and maintaining a normal body weight in preventing breast cancer as well as the value of physical exercise in overcoming side effects from breast cancer treatment.

Europa Donna actively participated in the 2nd ESO Masterclass for cancer patient advocacy organisations contributing to sessions on advocacy at European institutions as well as developing effective training programmes for patient advocates from many different countries and backgrounds.

A key priority for Europa Donna is the development of advocacy strategies to address the needs and issues facing women with Metastatic Breast Cancer. We held our 2nd workshop for women with MBC at our Advocacy Leader Conference in September. From MBC advocates’ interventions and the feedback from a survey they completed, we have finalised our strategic direction and begun projects aimed at this important area.

In October ED organised a special meeting at the European Parliament to update parliamentarians on this key issue as well as on other priorities that were addressed in the Written Declaration of 2015. Central to this is the completion and implementation of the ECIBC. The two working groups of this initiative continue to make progress and the first recommendations from the Guidelines Development Group have been posted on their web hub at http://ecibc.jrc.ec.europa.eu/.

We completed the 16th year of our advocacy training course in November; while it is heartening to know that progress is being made, we are also made starkly aware of the on-going need to train new advocates to work toward improving breast cancer services across Europe for the future.
ED 2016 PROGRAMMES

PUBLIC AFFAIRS

- European Commission Expert Group on Cancer Control Meetings
  Susan Knox, ED CEO, represents ED on the European Commission Expert Group that consists of professionals representing cancer organisations, research organisations, patient organisations, representatives of national health ministries and the European Commission. In 2016, she attended two meetings in Luxembourg, 25-26 February and 19-20 October. Both meetings provided updates on the CANCON Joint Action project and focused on screening and early detection with the International Agency for Research on Cancer (IARC) presenting the second implementation report of the 2003 Council Recommendation on cancer screening at the October meeting.

- European Commission Initiative on Breast Cancer- Joint Research Centre (JRC)
  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 European Union’s ECIBC (European Commission Initiative on Breast Cancer) is now underway and is being coordinated by the European Commission’s Joint Research Centre under the auspices of the Directorate General for Health and Food Safety (DG Santé); ED’s CEO Susan Knox and Deputy CEO/Head of Policy Karen Benn are members of of the Guidelines Development Group (GDG) and the Quality Assurance Scheme Development Group (QASDG) respectively and attended the meetings held in March, June and November. ED as an organisation is also a stakeholder in this initiative.
  For more information on ECIBC see their web hub at http://ecibc.jrc.ec.europa.eu/

- Plenary of the European Commission Initiative on Breast Cancer (ECIBC)
  The second plenary of the European Initiative on Breast Cancer (ECIBC); “When Science and Policy Collaborate for Health” was held in Villa Ponti, Varese from 24-25 November. The plenary was attended by over 150 participants from 27 countries out of the 35 participating in the initiative. This year’s plenary focused on the transfer of science into policy. Key points were the launch of the first four recommendations of the European guidelines for breast cancer screening and diagnosis (European Breast Guidelines) and the exchange and collection of feedback from countries on the possible implementation of the European breast guidelines and the voluntary “European Quality Assurance Scheme for Breast Cancer Services” (European QA scheme). ED’s Deputy CEO Karen Benn, attended along with ED President Roswitha Britz, who also participated in a panel discussion as well as the country table for Spain. Former ED Presidents, Elizabeth Bergsten Nordström and Ellen Verschuur were also in attendance.

- European Parliament Meeting on progress with issues raised in the 2015 Written Declaration “On the Fight Against Breast Cancer in the EU”
  On October 18 Nessa Childers MEP (Ireland) hosted a meeting at the European Parliament to update MEPs on the progress made with the items called for in 2015’s successful Written Declaration “On the Fight Against Breast Cancer in the EU” and EUROPA DONNA - the European Breast Cancer Coalition was invited to co-organise the event. Guest speakers included Donata Lerd, from the JRC, who is leading the European Commission Initiative on Breast Cancer (ECIBC); Luigi Cataliotti, of Senonetwork and BCCert, a breast cancer surgeon and expert on multidisciplinary care; Olivia Pagani, a vastly experienced breast oncologist and European Board Member of EUROPA DONNA; Roswitha Britz President, EUROPA DONNA and Karen Benn Deputy CEO, EUROPA DONNA.

- CANCON Stakeholder Forum
  Karen Benn, ED Deputy CEO, attended the CANCON Stakeholder Forum in Rome on 15 September. CANCON is a European-wide effort which focuses on promoting quality in cancer control and aims at harmonising the way our healthcare systems fight cancer, by providing coherent recommendations to update the national cancer plans. The CANCON recommendations encompass several aspects of cancer care, from prevention and screening to survivorship, and are collected in a “European Guide on Quality in Comprehensive Cancer Control”. The Stakeholder Forum updated the attendees on progress with the CANCON work packages and presented some external perspectives on it, including from professional organisations and patient organisations.

RESEARCH

- BIG (Breast International Group) Scientific Meetings
  Susan Knox and Roswitha Britz attended the BIG Scientific meeting held in Amsterdam 9 March during the EBCC 10 Conference as well as in Copenhagen on 7 October during the ESMO 2016 Congress; there they heard updates from all the BIG collaborators on the progress of on-going trials and studies.

- BIG OLYMPIA Steering Committee Meeting
  This trial tests Olaparib for patients with 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 attended meetings during ASCO in Chicago on 5 June and in December 2016.

- AURORA Steering Committee Meeting
  This trial aims to help scientists understand the molecular aberrations in Metastatic Breast Cancer. Susan Knox and Karen Benn are members of the AURORA steering committee and Susan attended the steering committee meeting on 10 March. AURORA is an important metastatic breast cancer initiative of BIG.

- MINDACT
  This trial (now concluded) used microarray technology to better determine which women really need adjuvant chemotherapy. Susan Knox serves on the MINDACT steering committee. The results of the trial were published in the New England Journal of Medicine 2016;375(22):2199-2201.
ED 2016 PROGRAMMES

EDUATION

• EBCC 10
  More than 100 advocates from most of EUROPA DONNA – The European Breast Cancer Coalition’s 47 member countries were in Amsterdam for the 10th European Breast Cancer Conference (EBCC10) to learn 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 Roswitha Britz presented the EBCC Arts and Humanities Prize to the Norwegian Breast Cancer Society and the Norwegian Cancer Society for their film “To Mommy”, about a 27 year old mother living with advanced breast cancer. This echoes the Coalition’s commitment to increasing awareness of the needs of women with metastatic breast cancer, as well as those of younger women.

• MBC Global Advocacy Alliance Webinar
  On 16 May, Susan Knox gave a presentation on EUROPA DONNA’s MBC advocacy work, as an example of best practice in MBC advocacy, for the 1st MBC Global Alliance webinar that was co-sponsored by the European School of Oncology and the National MBC Alliance in the United States. Thirty people from 15 countries all over the world were in attendance, including ED Vice President Evi Papadopoulos and members of ED Ireland.

• 2nd ESO Masterclass in Cancer Patient Advocacy
  The 2nd ESO cancer patient advocacy masterclass was held in Milan 24-26 June. Susan Knox served on the Steering Committee and also coordinated and conducted a “Leadership” workshop session on the topic of moving to the next level - managing organisations through growth and change. Karen Benn gave a presentation on ED’s effective advocacy work at the European Parliament through the years in a session on ‘Cancer patients’ influence on EU policy: from the first EU Breast Cancer Resolution (2003) to the ECIBC Leaders from 26 different patient advocacy organisations attended.

• EUROPA DONNA Breast Cancer Advocacy Leader Conference
  EUROPA DONNA’s 4th Breast Cancer Advocacy Leader Conference brought together more than 65 national representatives and delegates as well as advocacy leaders with metastatic disease from 35 of the coalition’s 47 member countries in Milan on 24 September. Donata Lerdà from the Joint Research Centre (JRC) gave an overview of the European Commission Initiative on Breast Cancer (ECIBC) and the roles of the Guideline Development Group and the Quality Assurance Scheme Development Group. Karen Benn, ED Deputy CEO, spoke about the role of European Resolutions and Declarations in getting us to where we are today. Participants also received an update on new research results relating to MBC and were presented a case study on “Implementing Specialist Breast Units” nationally from Italy. MBC advocates from 15 countries participated in a special session where they heard about various advocacy initiatives related to MBC, including blogging, and a new MBC section of the EUROPA DONNA website that will be launched soon.

• ESMO 2016 Congress
  Karen Benn, ED Deputy CEO, gave a presentation on patients’ preferences at an ESMO special symposium entitled “Treatment options in patients with early breast cancer and BRCA mutation or family history of cancer” on Sunday, 9 October.

• Sponsor Meeting at ESMO 2016 Congress
  Susan Knox, Roswitha Britz, and Karen Benn conducted our annual sponsor meeting on 8 October; it was attended by 19 representatives of ED’s current sponsors. Susan provided them with an overview of ED’s current activities as well as a summary of our Strategic Plan for 2017 and beyond.

• Breast Health Day 2016 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 your Breast Health!” and featured a fun new animated video. In addition, women were encouraged to send in pictures of themselves doing something “healthy” which were then included in a special video that was released on 15 October. Over 70 pictures were received from women across the globe. For more details see: www.breasthealthday.org

• International Society of Geriatric Oncology (SIOG) Conference
  The 2016 edition of the SIOG Annual Conference took place in Milan, Italy from November 17-19. This year’s conference programme revolved around the theme “Geriatric oncology: a multidisciplinary approach in a global environment”. ED CEO, Susan Knox was invited to give the patient’s perspective on living with cancer on a daily basis in the session on Quality of life in the geriatric population: why, what and how? She also participated in the panel in the Debate session: Clinical research in geriatric oncology: adaptation or revolution? giving the patient advocate perspective.

• EUROPA DONNA Advocacy Training Course
  The ED European advocacy training course took place 18-20 November in Milan. This was the 16th year that the course has been held and 57 advocates from 30 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.

• EBCC 11
  ED is a co-organiser of the biennial European Breast Cancer Conference (EBCC) along with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA). ED actively participates in the development of the scientific programme for each conference. The title of the conference is “Together, a Major Step Forward” and ED Vice President, Evi Papadopoulos will serve as Co-Chair for the conference that will take place 21-23 March 2018 in Barcelona.

• The International Consortium for Health Outcomes Measurement (ICHOM) Initiative
  Karen Benn, ED Deputy CEO, served on the ICHOM committee as one of the authors of “A Standard Set of Value-Based Patient-Centered Outcomes for Breast Cancer” published online in JAMA Oncology on December 29, 2016.
COMMITTEE MEMBERSHIP
AND ACTIVITIES

During 2016 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)
- OLYMPIA Clinical Trial Steering Committee
- LIVE TRIAL Steering Committee

During 2016 EUROPA DONNA participated in the following organisational activities:

Policy
- European Patients’ Forum
- European Parliament Update Meeting: Written Declaration 2015
- ECCO – Patient Advisory Committee
- European Commission Expert Group on Cancer Control
- CANCON Stakeholder Forum
- Plenary meeting of the European Commission Initiative on Breast Cancer (ECIBC)

Conferences
- EBCC 10
- ESO 2nd Masterclass in Cancer Patient Advocacy
- ESMO 2016 Congress
- International Society of Geriatric Oncology (SIOG) Meeting
- EUROPA DONNA Advocacy Leader Conference
- EUROPA DONNA Advocacy Training Course

Other Meetings
- EBCC-11 Organising Committee
- EBCC-11 Scientific Committee
- ECIBC Working Group Meetings
- PICTURE Project Meeting
- MBC Global Advocacy Alliance Webinars
- EBC Council - European Breast Cancer Council
- Breast Cancer Patient Group Forum
- ABC 4 Advocacy Committee
- Editorial Board “The Breast”

Publications
- 2015 Annual Report
- ED General Brochure
- MBC Annex translation in German
- 2016 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 2016**

<table>
<thead>
<tr>
<th>ASSETS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Fixed Assets</strong> (Plant machinery and equipment)</td>
<td>3,360</td>
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<tr>
<td><strong>Current Assets</strong></td>
<td>503,768</td>
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<tr>
<td>- Cash at bank and in hand</td>
<td>503,768</td>
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<tr>
<td>- Reserve fund</td>
<td>-</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>€ 507,128</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES</th>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Reserve Fund</strong></td>
<td>267,420</td>
</tr>
<tr>
<td>- Surplus and loss for the year</td>
<td>-47,642</td>
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<tr>
<td>- Extraordinary reserve</td>
<td>315,062</td>
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<tr>
<td><strong>Creditors</strong></td>
<td></td>
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<tr>
<td>- Accrued charges and deferred income</td>
<td>239,708</td>
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<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td>€ 507,128</td>
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</tbody>
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**Income and Expenditure Statement 2016**

**INCOME**

<table>
<thead>
<tr>
<th>Turnover</th>
<th>476,102</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Membership dues</td>
<td>14,250</td>
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<tr>
<td>- Grants and donations</td>
<td>461,852</td>
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</tbody>
</table>

**Financial Income**

- Other financial income                      19

**TOTAL INCOME**

€ 476,121

**OPERATING EXPENDITURES**

<table>
<thead>
<tr>
<th>Services &amp; Office Expenses</th>
<th>57,439</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrative overhead</td>
<td>47,063</td>
</tr>
<tr>
<td>Fees (audit, legal, insurance)</td>
<td>10,376</td>
</tr>
</tbody>
</table>

**Salaries (employees & related costs)**

281,679

**Activity Expenses**

- Publications, websites                     22,344
- Advocacy Training Course 2016              59,431
- Board meetings                             5,674
- Other meetings                             2,194
- 13th ED Pan-European Conference            5,188
- EBCC-10                                    36,041
- EBCC-11                                    40
- 1st MBC Conference                         3,264
- Advocacy Leader Conference 2016            43,143
- Breast Health Day                          971
- Public Affairs Activities                  1,370

**Depreciation & Write-Offs**

- Office equipment                           3,136

**Financial Charges** (bank costs)

1,849

**Surplus/Loss of the Period** (transfer to/from reserves)

-47,642

**TOTAL EXPENDITURES**

€ 476,121
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.

Other Contributions
We would also like to express our appreciation to Cohn & Wolfe and Tiwi Srl for the provision of pro bono services for Breast Health Day.

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.