EUROPA DONNA
The European Breast Cancer Coalition

Annual Report

2015
INTRODUCTION

Europa Donna made significant progress on its key priorities this year, starting with the launch of the European Parliament Written Declaration “On the fight against breast cancer in the EU” in March; advocacy initiatives were on-going until its passage by a majority of MEPs in July. This paved the way for the ECIBC project which selected its group members and began its meetings in September. Europa Donna is a stakeholder in this project and participated in the Joint Research Centre meeting “Putting Science into Standards” and the plenary for the ECIBC “Improving breast cancer screening, diagnosis and care in Europe.” We continued our work on the breast cancer research agenda through our on-going collaboration with BIG attending scientific committee meetings and steering committee meetings of AURORA, MINDACT, and OLYMPIA. An ED representative was also invited to serve on the Ethics committee of the IBCSG. Numerous other collaborations continued this year with EURECCA, CANCON, ECCO, ESO, EUSOBI, EPF and the European Commission Expert Group on Cancer Control.

The highlight of our education programme was our 12th Pan European Conference which took place in October in Paris. It is the only conference conducted for breast cancer advocates, and included important updates on research, treatment, and survivorship programmes. Over 230 people attended from 32 countries. This was followed by our participation in the advocacy activities of ABC3 and the 15th year of our advocacy training course held in Milan. The Breast Health Day campaign is now in its 8th year, and the growth in country participation is significant with 25 countries now carrying out local campaigns in addition to those we conduct on social media. (see www.breasthealthday.org for more details).

Our position as a stakeholder representing patients in the ECIBC is a key role we will play over the next 30 months (see web hub at http://ecibc.jrc.ec.europa.eu/). The goal is to arrive at new EU Guidelines for Screening and Diagnosis as well as a Quality Assurance Scheme covering the entire spectrum of breast services with a methodology for monitoring and evaluation.

Europa Donna continues to represent patients and advocates in 47 European countries. In 2015 we worked with numerous organisations to improve breast services across Europe, and we will continue these collaborations in 2016 and beyond.
ED 2015 PROGRAMMES

PUBLIC AFFAIRS

- European Commission Expert Group on Cancer Control Meeting 3-4 March Luxembourg
  Susan Knox represents ED in this group that consists of professionals representing cancer organisations, research organisations, patient organisations, representatives of national health ministries and the European Commission. The JRC, Joint Research Centre of the European Commission, gave a presentation on the ECIBC - European Commission Initiative on Breast Cancer. Susan Knox responded with a prepared statement that had been previously approved by the ED Executive Board outlining our position on this project.

- European Patient Forum (EPF) Annual General Assembly and Conference
  ED President Roswitha Britz participated in the European Patient Forum (EPF) Annual General Assembly and conference and campaign launch on Patient Empowerment in Brussels on 19-21 March.

- Joint Research Centre (JRC) Survey
  The JRC of the European Commission is conducting a survey in collaboration with EBCC-10 chair, Fatima Cardoso, and Europa Donna. The scope of the survey is to map out the degree of implementation of Breast Units in Europe with reference to the 2006 Resolution of the European Parliament on breast cancer in the enlarged European Union. 21 ED national fora have agreed to complete the survey.

- Launch of Written Declaration on the Fight Against Breast Cancer in the EU
  Europa Donna worked with a group of MEPs who co-authored a new Written Declaration on the Fight Against Breast Cancer in spring 2015. Nessa Childers MEP, Ireland, is the lead author of the declaration, along with 10 other MEP co-authors. The Written Declaration calls on all Member States to implement Breast Units in Europe according to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis (4th ed.) and emphasises the needs of people with metastatic breast cancer (MBC).

  Europa Donna’s member countries were active in writing to MEPs urging them to sign and ED produced a pamphlet “10 Reasons to Sign the Written Declaration 0017/2015” to encourage this effort. Susan Knox and Karen Benn also travelled to the European Parliament in Strasbourg in the week of 18 May where they held an exhibition in support of the Written Declaration.


  To Read the Declaration in all EU languages: http://www.europarl.europa.eu/plenary/en/written-declarations.html

- CANCON
  On 12 May Karen Benn attended the second stakeholder forum of CANCON, the European Commission cancer control project, which was launched in 2014 and will last 3 years. The main themes of the forum were enhancing equity and patient empowerment in cancer control. On the morning of 13 May, Karen attended a meeting of work package 2, the dissemination work package, and in the afternoon there was the first policy conference of CANCON on cancer survivorship. This conference aimed to generate a policy dialogue on how we all can raise cancer survival and reduce cancer mortality by improving the quality of life of cancer patients and survivors.

- ESO Breast Cancer Screening conference
  On 18-19 June, Karen Benn attended the European School of Oncology (ESO) Breast Cancer Screening conference, where she presented the European Parliament Written Declaration “On the Fight Against Breast Cancer in the EU” and ED’s campaign to get this initiative passed. She also presented ED’s past work on EU initiatives in mammography screening programmes.

- 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. This European Union project is now under way and is being managed by the European Commission’s JRC; it is called ECIBC (European Commission Initiative on Breast Cancer) and is overseen by DG SANTE. The kick-off meeting of the Guidelines Development Group (GDG) took place 7-9 September and the kick-off meeting of the Quality Assurance Scheme Development Group (QASDG) was held 9-11 September. ED is a stakeholder and will be invited to make presentations and to participate in other meetings regarding the development of this project, which is expected to take about 30 months.

- Joint Research Centre (JRC) Putting the Science into Standards event
  ED’s Susan Knox and Karen Benn attended the European Commission conference “Putting the Science into Standards: Evidence-Based Quality Assurance – An Example for Breast Cancer,” hostad by EARTO (European Association of Research and Technology Organisations), CEN & CENELEC (European Committee for Standardization (CEN), the European Committee for Electrotechnical Standardization (CENELEC) , and the JRC; it was held in Ispra, Italy on 20-21 October.

- Plenary of the European Commission Initiative on Breast Cancer (ECIBC)
  “Improving breast cancer screening, diagnosis and care in Europe” Susan Knox presented the Patient’s Expectations on European Commission (breast) cancer policies in the opening session at the first plenary of the European Initiative on Breast Cancer (ECIBC) which took place in Baveno, Italy 9-11 December 2015.
ED 2015 PROGRAMMES

**RESEARCH**

- **BIG (Breast International Group) Scientific Meetings**
  Susan Knox and Roswitha Britz attended the BIG Scientific meeting at St. Gallen in Vienna on 18 March as well as in Vienna on 25 September during ECC2015. Patient advocate input and opinion was requested on several new trials being undertaken.

- **MINDACT and EURECCA**
  Susan Knox attended the MINDACT Steering Committee meeting that took place during the ECC2015 congress in Vienna on 25 September and Karen Benn attended the EURECCA meeting on 26 September.

**EDUCATION**

- **12th Pan European Conference**
  The 12th Pan European Conference took place 17-18 October in Paris, France. This year's conference focused on Time for Action on Equal Access and described the essential breast services that women should receive and provided some strategies to advocate for their implementation across all European countries. 230 advocates from 32 countries attended.

- **ECC2015**
  ED had a stand in the patient advocacy square at ECC2015 near many of our patient advocate colleagues. Roswitha Britz spoke at the ECCO/SIOG Joint Symposium on Geriatric Oncology, a Multidisciplinary Approach to Reinforce Positive Outcomes in Older Patients.

- **Sponsor Meeting at ECC2015**
  Susan Knox and Roswitha Britz conducted our annual sponsor meeting on 26 September; it was attended by 17 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 2015 and beyond.

- **ESO Advanced Breast Cancer Conference (ABC 3)**
  The Advanced Breast Cancer Third International Consensus Conference ABC 3 took place in Lisbon, Portugal on 5-7 November 2015. ABC 3 had a special programme for breast cancer advocates. Evi Papadopoulos, ED Vice-President, served on the Patient Advocacy Committee which developed these sessions.

- **EBCC 10**
  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 “Multidisciplinary Innovation in Breast Cancer Care” and will take place 9-11 March 2016.

- **Breast Health Day 2015 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 “Make Good Choices For Your Breast Health Every Day!” and featured a fun new animated video. For more details see: www.breasthealthday.org

- **EUSOBI Annual Meeting, London**
  Susan Knox gave a presentation at the EUSOBI (European Society of Breast Imaging) annual meeting which was held on 2 – 3 October in London.

- **AURORA Steering Committee meeting**
  Susan Knox attended the AURORA steering committee meeting on 20 March. AURORA is an important metastatic breast cancer initiative of BIG.

- **BIG (Breast International Group) Scientific Meetings**
  Susan Knox and Roswitha Britz attended the BIG Scientific meeting at St. Gallen in Vienna on 18 March as well as in Vienna on 25 September during ECC2015. Patient advocate input and opinion was requested on several new trials being undertaken.

- **MINDACT and EURECCA**
  Susan Knox attended the MINDACT Steering Committee meeting that took place during the ECC2015 congress in Vienna on 25 September and Karen Benn attended the EURECCA meeting on 26 September.
COMMITTEE MEMBERSHIP
AND ACTIVITIES

During 2015 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 2015 EUROPA DONNA participated in the following organisational activities:

Policy
- European Patients’ Forum
- European Parliament Meeting, Strasbourg
- European Parliament Exhibition
- ECCO
- European Commission Expert Group on Cancer Control
- CANCON
- Plenary meeting of the European Commission Initiative on Breast Cancer (ECIBC)

Conferences
- 12th Pan European Conference
- St. Gallen International Breast Cancer Conference
- European Patients’ Forum Conference
- ESO Breast Cancer Screening Conference
- ECC2015 Congress
- EUSOBI Annual Meeting
- Joint Research Centre (JRC) – Putting Science into Standards Event
- Advanced Breast Cancer Second International Consensus Conference (ABC 3)
- EUROPA DONNA Advocacy Training Course

Other Meetings
- EBCC-10 Organising Committee
- EBCC-10 Scientific Committee
- International Experience Exchange for Patient Organizations
- EBC Council - European Breast Cancer Council
- Breast Cancer Patient Group Forum
- Digital lab
- ABC 3 Advocacy Committee
- ESR -Patient Advisory Groups for Medical Imaging
- Editorial Board “The Breast”

Publications
- 2014 Annual Report
- Metastatic Breast Cancer: Focus for Advocacy
- Newsletter
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 2015

<table>
<thead>
<tr>
<th>ASSETS</th>
<th></th>
<th>LIABILITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net Fixed Assets</td>
<td>€ 6,496</td>
<td></td>
</tr>
<tr>
<td>(Plant machinery and equipment)</td>
<td></td>
<td>Reserve Fund</td>
</tr>
<tr>
<td>Current Assets</td>
<td>€ 468,482</td>
<td>- Surplus and loss for the year</td>
</tr>
<tr>
<td>- Cash at bank and in hand</td>
<td>468,482</td>
<td>- Extraordinary reserve</td>
</tr>
<tr>
<td>- Reserve fund</td>
<td>-</td>
<td><strong>TOTAL LIABILITIES</strong></td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td><strong>€ 474,978</strong></td>
<td><strong>Creditors</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>INCOME</strong></th>
<th><strong>LIABILITIES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Turnover</strong></td>
<td>€ 431,050</td>
</tr>
<tr>
<td>- Membership dues</td>
<td>14,750</td>
</tr>
<tr>
<td>- Grants and donations</td>
<td>416,300</td>
</tr>
<tr>
<td>- Extraordinary revenues</td>
<td>26,830</td>
</tr>
<tr>
<td><strong>Financial Income</strong></td>
<td>339</td>
</tr>
<tr>
<td>- other financial income</td>
<td>339</td>
</tr>
<tr>
<td><strong>12th Pan European Conf. Registration</strong></td>
<td>15,077</td>
</tr>
<tr>
<td><strong>TOTAL INCOME</strong></td>
<td><strong>€ 473,296</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>OPERATING CHARGES</strong></th>
<th><strong>TOTAL EXPENDITURES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Services &amp; Office Expenses</strong></td>
<td>€ 60,969</td>
</tr>
<tr>
<td>Administrative overhead</td>
<td>50,150</td>
</tr>
<tr>
<td>Fees (audit, legal, insurance)</td>
<td>10,819</td>
</tr>
<tr>
<td><strong>Salaries (employees &amp; related costs)</strong></td>
<td>277,133</td>
</tr>
<tr>
<td><strong>Activity Expenses</strong></td>
<td>216,244</td>
</tr>
<tr>
<td>- Publications, websites</td>
<td>19,499</td>
</tr>
<tr>
<td>- Advocacy Training Course 2015</td>
<td>58,691</td>
</tr>
<tr>
<td>- Board meetings</td>
<td>7,583</td>
</tr>
<tr>
<td>- Other meetings</td>
<td>4,213</td>
</tr>
<tr>
<td>- 12th ED Pan-European Conference</td>
<td>110,419</td>
</tr>
<tr>
<td>- EBCC-10</td>
<td>198</td>
</tr>
<tr>
<td>- Breast Health Day</td>
<td>13,444</td>
</tr>
<tr>
<td>- Public Affairs Activities</td>
<td>2,197</td>
</tr>
<tr>
<td><strong>Depreciation &amp; Write-Offs</strong></td>
<td>4,792</td>
</tr>
<tr>
<td>- Office equipment</td>
<td>4,446</td>
</tr>
<tr>
<td>- Loss</td>
<td>346</td>
</tr>
<tr>
<td><strong>Financial Charges</strong> (bank costs)</td>
<td><strong>€ 2,073</strong></td>
</tr>
<tr>
<td><strong>Surplus/Loss of the Period</strong> (transfer to/from reserves)</td>
<td>-87,915</td>
</tr>
<tr>
<td><strong>TOTAL EXPENDITURES</strong></td>
<td><strong>€ 473,296</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.

We would also like to express our appreciation to Cohn & Wolfe 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.
EUROPA DONNA National Representatives 2015

Albania
Diana Myrto
Email: albania-breastcancer@hotmail.com

Armenia
Nvard Kocharyan
Email: nvardkocharyan@gmail.com

Austria
Monika Kootek-Roggenbauer
Email: info@europadonna.at

Belarus
Polina Soldak
Email: polinosoldak@mail.ru

Belgium
Marjane De Vriendt
Email: info@europadonna.be

Bulgaria
Milka Nenova
Email: eudonnabg@abv.bg

Croatia
Vesna Rumljak
Email: vesnaramljak@yahoo.com

Cyprus
Stella Kyriakides
Email: info@europadonna.com.cy

Czech Republic
Marta Kostrová
Email: aliance@breastcancer.cz

Denmark
Felicity Pors
Email: felpors@gmail.com

Estonia
Maie Egipt
Email: maie.egipt@cancer.ee

Finland
Anu Niemi
Email: puheenjohtaja@europadonna.fi

France
Martine Castro
Email: martinecastro@gmail.com

Georgia
Nino Kartvelishvili
Email: nin_k@hotmail.com

Germany
TBC

Greece
Elizabeth Meier
Email: ezameier85@gmail.com

Hungary
Zsuzsanna Péter
Email: info@rakozvetseg.hu

Iceland
Hrefnia Ingólsdóttir
Email: hrefnia2908@simnet.is

Ireland
Tara Byrne
Email: info@europadonnaireland.ie

Israel
Miri Ziv
Email: miriziv@inter.net.il

Italy
Rosanna D’Antona
Email: segreteria@europadonna.it

Kazakhstan
Nargis Plokhih
Email: zdorovayaaz@gmail.com

Kyrgyzstan
Tauligul Subyrbekova
Email: sabyrbekova2011@gmail.com

Latvia
Gunita Berke
Email: europadonna@dzivibaskoks.lv

Lithuania
Juventa Sartatavičienė
Email: juventa.sartatavičiene@nvi.lt

Luxembourg
Murielle Fischbach
Email: murielle.fischbach@yahoo.de

Macedonia
Bíba Doneva
Email: info@borka.org.mk

Malta
Doris Fenech
Email: info@europadonna.malta.org.mt

Moldova
Ludmila Sofroni
Email: sofroni@yandex.ru

Monaco
Valérie Berlado
Email: valerieberlado@gmail.com

The Netherlands
Ellen Verschuur
Email: ad_en_eaj_verschuur@planet.nl

Norway
Inger Margrethe Holter
Email: post@breastcancerforeningen.no

Poland
Dorota Czudowska
Email: polskieforum@europadonna.org.pl

Portugal
Isilda Pego
Email: europadonna@ligacontracancer.pt

Romania
Mihela Geană
Email: fundatiarenastere@gmail.com

Russia
Oksana Moldovanova
Email: moldovanova@nwcf.ru

Serbia
Andjelka Mojic
Email: saimar@yubc.net

Slovenia
Moja Senčar
Email: europadonna@europadonna-zdruzenje.si

Spain
Carmen Boronat Jiménez
Email: cboronat@icab.es

Sweden
Elizabeth Bengsten Nordström
Email: elizabeth.bengsten-norstrom@bro.org.se

Switzerland
Donatella Corbat
Email: sekretariat@europadonna.ch

Tajikistan
Firuza Abdullaeva
Email: avento97@mail.ru

Turkey
Violet Aroyo
Email: violetaroyo@hotmail.com

Ukraine
Galina Maistruk
Email: maistruk@hr.org.ua

United Kingdom
Margaret Spittle
Email: education@europadonna.org.uk

Uzbekistan
Shakhnoza Umansova
Email: eduzbekistan@mail.ru

EUROPA DONNA – The European Breast Cancer Coalition
Piazza Amendola, 3
20149 Milan, Italy
Tel: +39 02 3659 2280
Fax: +39 02 3659 2284
Email: info@europadonna.org

Websites: www.europadonna.org
www.breasthealthday.org
www.facebook.com/EuropaDonna
http://twitter.com/BreastHealthDay
http://twitter.com/EuropaDonnaEUR
www.youtube.com/BreastHealthDay

©2016 EUROPA DONNA – The European Breast Cancer Coalition. All rights reserved.