

EUROPA DONNA

The European Breast Cancer Coalition

Annual Report

EUROPA DONNA – The European Breast Cancer Coalition is an independent non-profit organisation whose members are affiliated groups from countries throughout Europe. The Coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and increased funding for research. EUROPA DONNA represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the EU.



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INTRODUCTION

Significant progress has been made on numerous key projects for breast cancer advocacy in Europe in 2012. The Joint Research Centre of the European Commission has designated a team to develop the accreditation scheme for breast cancer services. This follows many EUROPA DONNA advocacy initiatives promoting this scheme for the last few years. ED participated in an introductory meeting in June and will continue to contribute the patient perspective on this scheme throughout the various stages of the project. Our 2012 core programme has been supported by a grant from the Executive Agency for Health and Consumers (EAHC) of the European Union, thus enabling us to continue to provide education, information and support programmes to our 46 European member country groups. The European Breast Cancer Conference (EBCC) took place in Vienna in March; ED is a co-organiser of this important scientific conference with the European Society of Breast Cancer Specialists (EUSOMA) and the European Organisation for Research and Treatment of Cancer (EORTC). ED provides input into all areas of this conference, including programme development and advocacy participation in various sessions and lectures. This conference and our Advocacy Leader Conference, also held in 2012, were essential to ensuring that our advocates gain the knowledge and updated information needed to carry out their advocacy work nationally. Advocacy involvement in the health technology assessment (HTA) process will be important in the future and we have begun providing training for our groups concerning this important aspect of health care provision in many of our member countries. We are expanding our relationship and collaboration with Breast International Group (BIG) in a number of new and exciting research projects, again to ensure that the patient advocacy point of view is expressed and considered in relation to key projects for the future. To further our involvement in research issues nationally we developed a new booklet for advocates this year entitled *The Advocate's Guide to Understanding Breast Cancer Research*. In addition, we continue to pursue and promote improving advocacy for women with metastatic breast cancer; to this end, we have begun a new collaboration with the European School of Oncology to provide the European advocacy contribution to the Advanced Breast Cancer Second International Consensus Conference (ABC2) in 2013. Our Breast Health Day prevention programme continues to capture the attention of thousands of women around the world and to now be a focus for many of our national ED groups. Prevention has become an essential part of our programming and will become a pillar of our next strategic review, which was begun in the third quarter. Finally, preparations are under way for our 11th Pan-European Conference, which will take place on 19-20 October 2013 in Prague. Many of the key projects begun in 2012 will be reviewed at this important biennial advocacy conference.

While much has been achieved, the challenge remains to ensure that all women in Europe have access to best practice for screening, early diagnosis and treatment, as well as correct information concerning lifestyle factors that can prevent the disease.



Susan Knox
Executive Director

EDUCATIONAL OPPORTUNITIES

EUROPA DONNA Breast Cancer Advocacy Leader Conference

Milan, Italy • 22 September 2012

More than 50 National Representatives and delegates from 32 of our member countries gathered at our second Breast Cancer Advocacy Leader Conference in Milan on 22 September. Presentations featured the London School of Economics' Panos Kanavos, who gave a lively, informative talk on health technology assessment. Other sessions covered how to establish and run a non-profit organisation and tips for understanding breast cancer research. In workshops, participants shared ideas on advocating for the needs of women with metastatic breast cancer, understanding breast cancer research, managing and organising EUROPA DONNA fora, as well as key strategic approaches for our organisation. Topic-related reports have been published on the conference.



EUROPA DONNA Annual Breast Cancer Advocacy Training Course

Milan, Italy • 9-11 November 2012

In 2012, 58 breast cancer advocates from 33 of our member countries completed our two-and-a-half day Breast Cancer Advocacy Training Course, where they learned about the latest developments in breast cancer research and treatment, as well as advocacy techniques and communications skills that can be used to influence public health policy. The two-and-a-half-day course is divided into three modules. The first part (one day) covers an introduction to EUROPA DONNA and scientific topics, including basic biology and genetics of breast cancer, epidemiology, treatment and surgery options, clinical trials, diagnosis and early detection, mammography screening guidelines, specialist breast units and psychosocial factors. The second segment covers advocacy, lobbying and includes a special workshop on "Advocating for EU Guidelines" (half a day) and the third section consists of communication skills training (one full day). The course received excellent feedback in 2012 from participants who rated it as "very useful".



8th European Breast Cancer Conference

Vienna, Austria • 21-24 March 2012

In partnership with the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Breast Cancer Specialists (EUSOMA), we hosted the 8th European Breast Cancer Conference (EBCC-8) in Vienna, Austria from 21-24 March. More than 3,000 breast cancer specialists and advocates attended sessions on topics ranging from the latest treatment and diagnostic methods, to survivorship and the benefits of lifestyle interventions. Our Past President, Bettina Borisch, opened and closed the conference and reminded participants of the need for further advocacy for mammography screening and breast unit implementation. In a session on this topic, she also presented the results of our previous survey on specialist breast unit implementation. Many of our board members and national representatives also chaired sessions and presented on topics ranging from implementing the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, to healthy lifestyles and survivorship issues. Metastatic breast cancer was also the focus of one of our special EUROPA DONNA sessions. EBCC is unique in that it brings together all those concerned with breast cancer across Europe – researchers, scientists, physicians and advocates – to share best practice and the most recent advances in breast cancer research and clinical practice. Conference coverage is also provided in our 2012 newsletter.



KNOWLEDGE DISSEMINATION

Breast Health Day

Europe-wide • 15 October 2012



Our fifth annual Breast Health Day aimed to reach out to women of all ages across Europe and beyond to make them aware of the healthy lifestyle choices that can have a positive effect on their breast health. It also aimed to reach MEPs through an Information Day at the European Parliament in Brussels. Held yearly to promote breast cancer prevention, this year's Breast Health Day was dedicated to the theme "Make Good Choices for Your Breast Health" to emphasise that daily healthy lifestyle choices, such as being active, eating a well-balanced diet and maintaining a healthy weight, can protect women's future breast health. The event was also promoted throughout our member countries, featuring a broad range of colourful and active events, and through an extensive web-based campaign using the websites www.breasthealthday.org, www.europadonna.org and social networking sites such as Facebook, Twitter and YouTube. Activities across Europe are posted on www.breasthealthday.org, the campaign website, and have been published in our

Breast Health Day News summing up the campaign.



Breast Health Day Campaign Materials

Breast Health Day Video: An entertaining, animated video encouraged women to make a variety of healthy choices through physical activity and eating a healthy diet. It featured examples of less healthy behaviour and the healthy choices that can be used to replace them. The video is available on the Breast Health Day website and sharable via social networks. To ensure that women around the globe used the video, the final frame featured this year's slogan "For Your Breast Health" translated into 27 languages. It also contains a tag cloud of videos of healthy pledges sent from around the world.



The Breast Health Day Pledge: To foster active involvement in the Breast Health Day campaign, women were able to send in a personal pledge for their breast health through a web application on the Breast Health Day website and also share it through the social networks. A tag cloud on www.breasthealthday.org featured the pledges of those who joined the campaign and on 15 October the videos received were added to the final frame of the campaign video.



Webcasts on YouTube: Head of the Section of Nutrition and Metabolism at the International Agency for Research on Cancer Isabelle Romieu provided the latest epidemiological evidence on lifestyle factors and breast cancer prevention. The videos are webcasts of her presentation at the 8th European Breast Cancer Conference in March 2012 and cover the effects of alcohol, obesity, physical activity, the global burden of breast cancer and lifestyle recommendations.

Breast Cancer Facts Videographic: An animated video gave a lively presentation of breast cancer facts and statistics.



Breast Health Day Poster and Mini-diary: These promotional materials were available for download from the Breast Health Day website. The mini-diary is an 8-page booklet with healthy hints and a checklist for making daily healthy choices.

Banners and Website Badges: Three banners and badge sizes were available for people to add to their websites to promote the BHD message.

Social Networking Sites: Our EUROPA DONNA and Breast Health Day pages on Facebook, Twitter and YouTube had high traffic throughout the campaign. Many ED Fora joined in the social networking activities by making Breast Health Day posts and displaying the Breast Health Day banner. Our Twitter reach was 336,302 with 257 followers, and our Breast Health Day YouTube channel had 7,022 global channel views. On Facebook we had 1,563 fans and 70,778 page visits after Breast Health Day.



KNOWLEDGE DISSEMINATION

Publications

Breast Health Day News

A 4-page report covered the 2012 Breast Health Day activities, including those held at the European Parliament, all the campaign materials available and summaries of the activities held in our member countries across Europe.

The Advocate's Guide to Understanding Breast Cancer Research

Since EUROPA DONNA's advocacy work is grounded on evidence-based practice, this 20-page booklet is designed as an aid to understanding breast cancer research, whether presented in scientific papers or at conferences. It defines key epidemiological concepts, types of studies, statistical terms and calculations. It also explains some of the common figures and tables used to illustrate scientific findings. A self-assessment section for advocates to test their understanding of the concepts is provided at the end.

Clinical Trials and Breast Cancer

We published an update of our guide to clinical trials and breast cancer. The booklet describes the clinical trial process, the possible risks and benefits of participating in a clinical trial, how to find clinical trials and other helpful information women and advocates need to know about this topic.

EUROPA DONNA News

Our annual newsletter was distributed widely in September and featured coverage of the 8th European Breast Cancer Conference, interviews with key opinion leaders, articles on living with breast cancer, our advocacy activities at the European Parliament and support to our member Fora, as well as reports from our member countries, among other topics.

Highlights of the 10th EUROPA DONNA Pan-European Conference

Highlights of our Pan-European Conference held in Malta in October 2011 were widely distributed at conferences and meetings. The highlights cover presentations on the latest in diagnosis, treatment, metastatic breast cancer, breast nursing, breast unit accreditation, as well as the key-note address from the European Commissioner for Health and Consumer Policy, John Dalli, among other topics.

A Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis

In 2012 we continued our efforts to disseminate our *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* by translating it into Portuguese, Latvian and Norwegian. It has now also been printed in Dutch, English, French, German, Georgian, Greek, Italian, Polish, Russian, Spanish, Swedish and Turkish. The guide summarises the full EU guidelines document and describes, in language suitable for the lay public, best practice in mammography screening programmes and the requirements of a specialist breast unit. It has been well received by professionals and advocates and serves as the primary tool in lobbying efforts across all our member countries. It can be downloaded in all available languages directly from our website www.europadonna.org.

Who we Are EUROPA DONNA brochure

Early in the year, we published a four-page brochure describing our organisation, providing some European breast cancer statistics, our 10 goals, our priorities and advocacy initiatives, as well as member country contact information.

Websites

www.europadonna.org

We continue to update our website with our latest materials and our annual audited financial statements. The website includes links to our social networking pages on Facebook, Twitter and YouTube. Information about our upcoming advocacy events is also featured there. We are currently working on redesigning our website.

www.breasthealthday.org

Our Breast Health Day website received 4100 visits from 97 countries from the start of the campaign.



COLLABORATION AND NETWORKING

Parliamentary and Policy Activities

EUROPA DONNA remains active in seeing that politicians and members of the European Parliament (MEPs) understand the needs and issues of women with breast cancer.

▶ Meeting with the European Commission's Joint Research Centre on the accreditation of breast services

In June 2012 our Executive Director, Susan Knox, and Head of Policy/Public Affairs, Karen Benn, attended a meeting with the Joint Research Centre (JRC), the in-house science service arm of the European Commission, which provides science advice to EU policy. The meeting was to discuss the European Accreditation project for breast cancer services. As requested in EU legislation (Council conclusions on reducing the burden of cancer 10-06-2008), JRC plans to implement a voluntary accreditation scheme based on an EU protocol, which includes all stages of breast cancer care, from screening to follow-up, and which aims to put the patient at the centre of the process and to harmonise the quality of services delivered, independently of how they are organised.

▶ Breast Health Day Information Day at the European Parliament

On 10 October we held our annual Breast Health Day Information event at the European Parliament in collaboration with Nessa Childers, MEP. The aim was to spread the Breast Health Day message "Make Good Choices for your Breast Health" to parliamentarians and other policy-makers. At an information stand decorated with posters, representatives of our Head Office and ED Belgium distributed flyers to MEPs to raise awareness of the important steps that can be taken to prevent breast cancer later in life. One of the ultimate goals of this event is to have the European Parliament declare 15 October to be Breast Health Day.

▶ Breast Health Day presentation at the European Parliament conference on the role of physical activity in the fight against breast cancer

Dr. Birgit Carly from our Belgium forum presented the Breast Health Day campaign at the conference "Physical Activity: A Useful Tool in the Fight Against Breast Cancer in Europe". Held in French at the European Parliament in Brussels on 4 December 2012, the conference was organised by Sport and Citizenship within the framework of the European Union's Europe for Citizens Programme. The conference aimed to increase awareness among the European institutions of the benefits of physical activity in the population, and particularly in the fight against breast cancer, and to call upon European decision-makers to launch a wide-scale campaign on the topic. Since BHD is a fitting example of such a campaign, Dr. Carly was invited to give an overview of its history, the media outreach programme and the impressive activities undertaken in ED member countries.

▶ European Partnership for Action Against Cancer (EPAAC)

We are a collaborating partner in two of the European Commission's EPAAC Work Packages, WP5 Prevention and WP7 Healthcare. In June, our Executive Director, Susan Knox, gave a presentation about Breast Health Day to the Open

Forum meeting of EPAAC under the auspices of the WP5 Health Promotion and Prevention work package. The Open Forum is held annually and brings together all the partners in EPAAC. In September, Karen Benn attended the Advisory Council meeting of WP5 in Dublin. The aim of this meeting is to get an overview of European Cancer Leagues, EU and Irish priorities in cancer prevention and to provide advice for the organisation of the next European Week Against Cancer official conference taking place in Dublin in 2013.

▶ AURORA Project Collaboration

EUROPA DONNA was asked by the European Commission's DG SANCO to be an adviser to the AURORA Cervical Screening Project, which is an EU-funded cervical screening project working with hard-to-reach populations in countries where screening is not yet fully rolled out. Our Head of Policy/Public Affairs, Karen Benn, represents ED on this Advisory Board. She participated in a meeting in Tallinn by teleconference, giving input on the development of advocacy training modules for both practitioners and advocates.

▶ European Patient Forum Annual General Meeting and Conference

In April, our Head of Policy/Public Affairs, Karen Benn, attended the European Patient Forum (EPF)'s Annual General Meeting and seminar. The topic of the seminar was the EPF's strategic plan for the next 5 years and it gathered EPF members' input on its strategic direction via plenary sessions and workshops. Ms. Benn moderated two such workshops for EPF. She will also be part of a reference panel that EPF has formed to review its evaluation processes for its 2012 EU Operating Grant.

▶ Health Technology Assessment (HTA) workshop

An International Union Against Cancer and London School of Economics (UICC-LSE) Workshop for Cancer Patient Organisations was held in Montreal, Canada, at the end of August. Our Executive Director, Susan Knox, represented ED at this key meeting which outlined all the regulations and country involvement in HTA so far. The 2-day workshop was led by the LSE's Panos Kanavos. The meeting explored the ways in which HTA is conducted, the variations in the decision-making process country to country, and how advocates might have an impact on this in the future.

▶ Clinical/Commercial Payer Forum

Our Executive Director, Susan Knox, participated in the Clinical/Commercial Payer Forum held in Zurich, Switzerland, in May. She presented the patient perspective at a roundtable along with representatives of the European Organisation for Research and Treatment of Cancer (EORTC), the pharmaceutical industry and the European Network for Health Technology Assessment (EUnetHTA) to discuss future research schemes and funding/reimbursement issues. ED pointed out that we need to ensure that patient advocates are involved in the HTA process.

COLLABORATION AND NETWORKING

Development Programme

In 2012, EUROPA DONNA received its first operating grant from the European Union, in the framework of the Health Programme. The grant covered 60% of expenses associated with core activities of the organisation in 2012, such as our Advocacy Training Course, Information Programme, Forum Support and Advocacy Programme. In March 2012, we submitted a request for renewed funding for 2013 in response to the Executive Agency for Health and Consumers' (EAHC) 2012 call for proposals under the second programme of Community action in the field of health (2008-2013). In November, the EAHC, acting under powers delegated by the Commission of the European Union, informed us that we had once again been evaluated positively and that EUROPA DONNA would be one of 19 recipients of a generous operating grant in 2013.

Sponsor Meeting

We held our Fifth Sponsor Meeting in Vienna on 29 September. Elizabeth Bergsten Nordström, ED President, and Susan Knox, Executive Director, attended and provided an overview on our progress on projects through 2012 and plans for 2013. Representatives of our sponsoring organisations then had the opportunity to discuss these projects in detail and to ask about our involvement in other cancer-related programmes taking place on a European level. We emphasised our commitment to multiple sponsors and transparency as well as diversifying funding.

In addition, ED continues to seek new sponsorship by contacting various foundations and organisations across Europe and the United States.

COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2012 **EUROPA DONNA** served on the following committees:

- Clinical Trials**
 - ▶ BIG Scientific Committee
 - ▶ MINDACT Steering Committee
 - ▶ ALLTO Steering Committee

During 2012 **ED** participated in the following organisational activities:

- Policy**
 - ▶ European Parliament Information Day for Breast Health Day
 - ▶ European Patients' Forum
 - ▶ European Public Health Alliance
 - ▶ ECCO – Patient Advisory Council
 - ▶ European Partnership for Action Against Cancer (EPAAC) Open Forum
 - ▶ European Partnership for Action Against Cancer (EPAAC) WP5 Prevention Meeting

- Conferences**
 - ▶ EBCC8 March 2012
 - ▶ EUROPA DONNA Advocacy Leader Conference
 - ▶ EUROPA DONNA Breast Cancer Advocacy Training Course
 - ▶ ECCO 16-ESMO 36 Multidisciplinary Congress
 - ▶ 35th Annual San Antonio Breast Cancer Symposium
 - ▶ ECCO Oncopolicy forum October 2012

- Other Meetings**
 - ▶ EBCC-9 Organising Committee
 - ▶ EBCC-9 Executive Scientific Committee
 - ▶ Skeletal Care Academy
 - ▶ International Experience Exchange for Patient Organisations
 - ▶ VZW-BCWG Breast Cancer Working Group
 - ▶ AURORA Cervical Screening Project
 - ▶ Metastatic Patient Group Forum
 - ▶ POLE-ESO Programme for Oncology Leaders
 - ▶ International Capacity Building Alliance Workshop
 - ▶ EURAMA DONNA
 - ▶ Advocacy Committee for ABC2
 - ▶ UICC-LSE Workshop for Cancer Patient Organisations
 - ▶ Clinical/Commercial Payer Forum
 - ▶ Patient Advisory Boards

FINANCIALS

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 2012

ASSETS		LIABILITIES	
Net Fixed Assets (Plant machinery and equipment)	13,240	Reserve Fund	297,766
		Surplus and loss for the year	-17,901
Current Assets	829,753	Extraordinary reserve	315,667
Trade debtors	109,866	Creditors	545,227
Cash at bank and in hand	514,877	Amounts payable within 1 year	9,801
Reserve fund	205,000	Accrued charges and deferred income	535,426
TOTAL ASSETS	€ 842,993	TOTAL LIABILITIES	€ 842,993

Income and Expenditure Statement 2012

INCOME	
Turnover	609,615
Membership dues	14,000
Grants and donations	595,615
Financial Income	7,536
TOTAL INCOME	€ 617,151
OPERATING EXPENDITURES	
Services & Office Expenses	73,087
Administrative overhead	54,376
Fees (audit, legal, insurance)	18,711
Salaries (employees & related costs)	251,279
Activity Expenses	301,109
Publications, websites	84,186
Advocacy Training Course	71,026
Board meetings	12,463
Other meetings	3,946
10th ED Pan-European Conference	915
11th ED Pan-European Conference	69
European Breast Cancer Conference	42,016
Breast Health Day	48,511
Advocacy Leader Conference	37,977
Depreciation & Write-Offs	5,951
Office equipment	5,451
Loss of dues	500
Financial Charges (bank costs)	3,626
Surplus/Loss of the Period (transfer to/from reserves)	-17,901
TOTAL EXPENDITURES	€ 617,151

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. Finally, on behalf of the entire EUROPA DONNA breast cancer advocacy community, we would like to express our appreciation to the European Union in the framework of the Health Programme for its very generous 2012 grant in support of ED's Core Programming and 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 AND DONATIONS

EUROPA DONNA gratefully acknowledges the following for their generous support of our advocacy projects and activities:

Over €100,000

European Union, in the framework of the Health Programme

€50,000–99,999

F. Hoffman-La Roche • GlaxoSmithKline • Novartis • VZW–Breast Cancer Working Group

€20,000–49,999

Amgen Europe GmbH • Boehringer Ingelheim • Sanofi-Aventis

€10,000–20,000

BIG-Breast International Group

Other Contributions

We would also like to express our appreciation to Cohn & Wolfe for the provision of Pro Bono services for Breast Health Day evaluated at €28,000.

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

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www.youtube.com/BreastHealthDay

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