

Belarus Belgique Bălgariya Ceská Republika Danmark Deuts
Eesti España France Hellas Hrvatska Ireland Island Israel Ita
Kazakhstan Kirgiz Respublikası Kypros Latvija Leituva Lux
Makedonija Magyarország Malta Moldova Monaco Nederl

EUROPA DONNA

The European Breast Cancer Coalition

Mission

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.

Annual Report

2011

Deutschland Eesti España France
Israel Italia Kazakhstan Kirgiz R
Luxembourg Makedonija Magya
Nederland Norge Österreich Ö'z
Rossijshaja Federacija Sakartvelo Shqipëri Slovenija Slovensk
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Policy Officer

Karen Benn

Communications Officer

Barbara Klein

Admin/Events Officer

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Development Officer

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INTRODUCTION

2011 was a productive year for EUROPA DONNA as we continued to make significant progress in our advocacy mission in 46 member countries across Europe. The number of new countries using the *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* for lobbying and advocacy purposes in their countries is constantly increasing and ED advocates are having success in convincing their health ministries to begin providing these essential breast services – screening according to EU guidelines and specialist breast units. ED board members are actively engaged in our forum support project and we are seeing positive results in a number of inactive countries.

Our ED 10th Pan-European Conference, held in October, highlighted the “Challenges for the New Decade”. This conference is the only breast cancer conference in Europe directed primarily toward advocates and survivors, and over 220 participants gathered for it on the beautiful island of Malta. The conference was particularly important in outlining the challenges we face and brought together key stakeholders who can make a significant difference in enabling us to meet them. The EU Commissioner for Health and Consumer Policy, John Dalli, stated his unequivocal support for our efforts and initiatives and later followed up by announcing a €3.5 million allocation of funds to developing an accreditation protocol for breast units in Europe. The President of EUSOMA, as well as a breast care nurse, contributed their expert opinions on the situation today and where we need to make improvements in the future to ensure that women will receive high level services in specialist breast units. Another important challenge for the decade is improving advocacy and services for women with metastatic breast cancer. We emphasised our commitment to raising awareness and carrying out initiatives to ensure that this group is adequately served.

Our Breast Health Day campaign is now established with a majority of our member countries carrying out national activities, while our online campaign continued on Facebook, Twitter and YouTube. This year’s campaign featured a short mosaic video depicting women “Making Healthy Choices” and we again brought our campaign to the European Parliament with an Information Day on 12 October.

The incidence of breast cancer continues to increase, but recent data show a decrease in mortality from the disease in Europe. We know that early detection combined with appropriate treatment make a tremendous difference in improving outcome. Our strength and our ongoing challenge is to continue to find and train advocates to fight for the best services possible in their countries.



Susan Knox
Executive Director

EDUCATIONAL OPPORTUNITIES

10th EUROPA DONNA Pan-European Conference

Malta • 22-23 October 2011

European Breast Cancer Advocacy: Challenges for the New Decade

Our 10th Pan-European Conference was held in Malta on 22 and 23 October to reinforce our priorities and “Challenges for the New Decade”, the conference theme. More than 220 breast cancer advocates and specialists from 37 countries attended. It was a privilege to have the European Commissioner for Health and Consumer Policy, John Dalli, as key-note speaker to present the European Commission’s view of breast health services. This included the Commission’s commitment to establishing a European specialist breast unit accreditation scheme, which is one of our main priorities. Dr. Robin Wilson, President of the European Society of Breast Cancer Specialists (EUSOMA), also addressed this need and how to have specialist breast units implemented across Europe before the 2016 deadline stipulated in the European Parliament Resolution on Breast Cancer of 2006. Other experts gave presentations on specialist breast nursing, advances in radiotherapy and breast cancer treatment and trials. A special session was dedicated to metastatic breast cancer and presenting the results of our Forum survey on the topic. Other activities designed to provide support to our Fora included a presentation on capacity building, highlights of the Breast Health Day campaign across member countries and European policy endeavours. In addition, we were able to discuss our strategies in five workshops dedicated to social networking and blogs, attracting media attention, setting up young women’s groups, improving organisational management, and needs of women over 70. The conference was one of our most lively ever and advocates were able to return to their countries charged and motivated by the experience. Our biennial conference is unique in Europe in that it is the only conference

dedicated primarily to breast cancer advocates and survivors. A highlights report on the conference has been published and widely distributed.



EUROPA DONNA Annual Breast Cancer Advocacy Training Course

Milan, Italy • 11-13 November 2011

In 2011, 49 breast cancer advocates from 27 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 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).

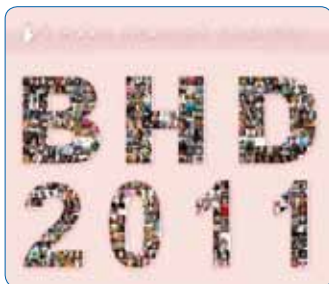
The course received excellent feedback in 2011 from participants who rated it as “very useful”.



KNOWLEDGE DISSEMINATION

Breast Health Day

Europe-wide • 15 October 2011



Our fourth annual Breast Health Day involved a public awareness campaign across Europe and beyond. It also aimed to reach MEPs through an Information Day at the parliament in Brussels. Held yearly to promote breast cancer prevention, this year's Breast Health Day was dedicated to the theme "Make Healthy Choices" 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; at an international meeting of experts at the Breast Cancer Prevention: Epigenome, Nutrition and Public Policy, held in Rennes, France in October; 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 the campaign website www.breasthealthday.org 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 video using a constantly changing mosaic design to show women engaging in a variety of healthy choices was the centrepiece of our 2011 campaign. It encouraged women to pursue a healthy lifestyle through physical activity and a healthy diet, and to join the Breast Health Day campaign online and in real life. It was made available on the Breast Health Day website and could be shared via social networks. To make it practical and useful for our member countries, and to make it easy to share worldwide, the video contained images only, with a final frame featuring this year's slogan "Make Healthy Choices" translated into 27 languages.



Breast Health Day Photo Mosaic: In the days leading up to 15 October, women were invited to become personally involved in the campaign by uploading their pictures through an application on the Breast Health Day website. Their pictures were then added to the mosaic appearing at the end of the video when it was relaunched for Breast Health Day.

Breast Cancer Facts Infographic: We gave a more upbeat look to the statistics on breast cancer incidence, survival, mortality and the influence of lifestyle factors by creating visual infographics for the Breast Health Day website.



Breast Health Day Poster and Leaflet: These promotional materials were available for download from the Breast Health Day website. The 8-page leaflet contains healthy hints and a checklist for making daily healthy choices.



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 177,990 with 163 followers, and our Breast Health Day YouTube channel had 5,134 global channel views. On Facebook we had 965 fans and 108,141 page visits after Breast Health Day.



KNOWLEDGE DISSEMINATION

Publications

Breast Health Day News

A 4-page report covered the 2011 Breast Health Day activities, ranging from those held at the European Parliament, all the campaign materials available and summaries of the activities held in our member countries across Europe.

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

In 2011 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 and updating the English, French and Italian versions. It has now 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 their lobbying efforts across all our member countries. It can be downloaded in all available languages directly from our website www.europadonna.org.

EUROPA DONNA News

Our annual newsletter was distributed widely in September and featured interviews with key opinion leaders, articles on living with metastatic 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.

EUROPA DONNA article in *The Breast*

In a “Viewpoints and debate” article published in *The Breast* (February 2011), our Executive Director, Susan Knox, gave the advocate’s perspective on mammography screening in keeping with the *EU Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. She reiterates that mammography screening is the best proven means of early detection of breast cancer available today, which, when followed by proper treatment provides the best chance of long-term survival. (See *The Breast* 2011; 20(1): 93-5.)



Websites

www.europadonna.org

We continue to update our website with our latest materials and our annual audited financial statements. We have also added an automatic translation feature to make it more accessible. The website includes links to our social networking pages on Facebook, Twitter and YouTube. Information about our upcoming advocacy events is also featured there.

www.breasthealthday.org

Our Breast Health Day website received 4934 visits from 95 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.

■ Breast Health Day Information Day at the European Parliament

On 12 October we were at the European Parliament in Brussels to ensure that MEPs and other policy makers knew about Breast Health Day and the importance of “Making Healthy Choices”. We handed out Breast Health Day leaflets and also distributed them to the mailboxes of the 736 MEPs. We aimed to reach MEPs with the message that healthy lifestyle choices can have a positive influence on breast cancer risk and remind them of the need to implement the 2010 Written Declaration and the European Parliament Resolutions on Breast Cancer of 2003 and 2006.

■ 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. Following a kick-off meeting of WP7 in Barcelona, Spain, an “Open Forum” meeting for all participants of EPAAC and all work packages was held in Madrid. Our Policy Officer, Karen Benn, co-chaired the session on how to improve the process and outcomes of care in cancer diagnosis and therapy.

■ AURORA Project Collaboration

EUROPA DONNA was asked by the European Commission’s DG SANCO to be an advisor to the EU-funded AURORA Cervical Screening Project. Our Policy Officer, Karen Benn, attended a 2-day meeting in Timisoara, Romania in September, where we contributed to the development of a training programme for cervical screening clinicians and advocates.

■ European Week Against Cancer (EWAC)

In May, we attended a 2-day conference in Brussels to mark the re-launch of the European Week Against Cancer (EWAC), as part of the EPAAC’s WP5 Prevention work package. The main purpose of EWAC is to communicate the messages of the European Code Against Cancer.

■ European Patients’ Forum Annual General Meeting and Conference

In April, our Policy Officer, Karen Benn, attended the European Patients’ Forum Annual General Meeting and capacity-building seminar. Seminar sessions covered research grants, cross-border healthcare and patient reporting on adverse reactions to pharmaceuticals.

■ Forum Against Cancer Europe Workshop

In March, our President, Bettina Borisch, spoke about the role of women in European advocacy at the 7th Forum Against Cancer Europe (FACE) workshop held in Brussels. The workshop focused on women involved in policy-making at the European level and those involved in patient support and advocacy.

Sponsor Meeting

We held our Fourth Sponsor Meeting in Stockholm on 24 September. Elizabeth Bergsten Nordström, Vice-President, and Susan Knox, Executive Director, attended and provided an overview on our progress on projects through 2011 and plans for 2012. 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.

Development Programme

In May, EUROPA DONNA submitted an operating grant proposal in response to the Executive Agency for Health and Consumers’ (EAHC) 2011 call for proposals under the second programme of Community action in the field of health (2008–2013). In December, the EAHC, acting under powers delegated by the Commission of the European Union, informed us that we had been evaluated positively and that EUROPA DONNA would be one of 16 recipients of a generous operating grant. The support of the European Union, in the framework of the Health Programme, will cover 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 addition, we continue to seek new sponsorship by contacting various foundations and organisations across Europe and the US.

COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2011 **EUROPA DONNA** served on the following committees:

Clinical Trials

- BIG Scientific Committee
- MINDACT Steering Committee
- ALLTO Steering Committee

During 2011 **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) WP7 Kick-off Meeting

Conferences

- European Patient Forum Rights and Needs of Older Patients and Annual General Meeting
- European Week Against Cancer (EWAC) Conference
- ECCO 16-ESMO 36 Multidisciplinary Congress
- Second International Symposium on Breast Cancer Prevention
- 10th EUROPA DONNA Pan-European Conference
- 34th Annual San Antonio Breast Cancer Symposium

Other Meetings

- EBCC-8 Organising Committee
- EBCC-8 Executive Scientific Committee
- Specialist Breast Unit Certification Meeting
- Skeletal Care Academy
- EMA Scientific Advisory Group meetings
- Forum Against Cancer Europe (FACE) Workshop
- International Experience Exchange for Patient Organizations, Frankfurt
- VZW-BCWG Breast Cancer Working Group
- ESTRO “Multidisciplinary Management of Breast Cancer” meeting
- Patient Advisory Boards
- European Breast Cancer Patient Advocates Meet Academia
- AURORA Cervical Screening Project

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 2011

ASSETS		LIABILITIES	
Net Fixed Assets (Plant machinery and equipment)	14,215	Reserve Fund	315,667
		Surplus and loss for the year	-56,991
Current Assets	595,349	Extraordinary reserve	372,658
Trade debtors	500	Creditors	293,897
Cash at bank and in hand	188,856	Amounts payable within 1 year	2,677
Reserve fund	405,993	Accrued charges and deferred income	291,220
TOTAL ASSETS	609,564	TOTAL LIABILITIES	609,564

Income and Expenditure Statement 2011

INCOME	
Turnover	547,571
Membership dues	16,000
Grants and donations	514,946
ED Pan-European conference registration	16,625
Financial Income	6,785
Interest current account	
Other financial income	3,352
Recovered items	3,433
TOTAL INCOME	554,356
OPERATING EXPENDITURES	
Services & Office Expenses	60,583
Administrative overhead	48,879
Fees (audit, legal, insurance)	11,704
Salaries (employees & related costs)	246,237
Activity Expenses	294,010
Publications, websites	28,400
Short Guide printing and translation	6,342
Advocacy Training Course	69,065
Board meetings	11,370
Other meetings	12,914
10th ED Pan-European Conference	103,581
Breast Health Day	60,638
Advocacy Leader Conference	1,700
Depreciation & Write-Offs	7,422
Office equipment	4,212
Loss Member Dues	500
Loss EAHC	2,710
Financial Charges (bank costs)	3,095
Surplus/Loss of the Period (transfer to/from reserves)	-56,991
TOTAL EXPENDITURES	554,356

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 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

VZW–Breast Cancer Working Group

€50,000–99,999

Boehringer Ingelheim • F. Hoffman-La Roche • GlaxoSmithKline • Novartis • Pfizer • Sanofi-Aventis

€20,000–49,999

Amgen Europe GmbH

Other Contributions

We would also like to express our appreciation to Cohn & Wolfe for the provision of Pro Bono services for Breast Health Day valued 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 EXECUTIVE BOARD AND NATIONAL REPRESENTATIVES

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