

Belgique Bulgária Česká Republika Danmark Deutschland
Eesti España France Hellas Hrvatska Ireland, Island Israel Italia
Kazakhstan Kypros Latvija Leituva Luxembourg Magyarorszá
Malta Moldova Monaco Nederland Norge Österreich Polska

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

2009

France Hellas Hrvatska Ireland, Is
Kypros Latvija Leituva Luxemb
Moldova Monaco Nederland Norge
Romania Rossijshaja Federacija Sa
Srbija i Crna Gora Suisse Suomi Sverige Turkiye Ukraina
United Kingdom Belgique Bulgária Česká Republika Danmark
Deutschland Eesti España France Hellas Hrvatska Ireland Island
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Sagartvelo Slovenija Slovensko Srbija i Crna Gora Suisse Suom
Sverige Turkiye Ukraina
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Hellas Hrvatska Ireland,
Latvija Leituva Luxemb
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Admin/Events Officer

Daniela Pirisi

Development Officer

Paige Robinson

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INTRODUCTION

2009 marked the 15th anniversary of EUROPA DONNA and provided an opportunity to review past achievements and renew our commitment to the advocacy challenges ahead. EUROPA DONNA conducts **regular education programmes** for its members, and this remains a fundamental role of the Coalition that needs to grow and expand. Bringing our country members and leaders together to learn and share information enables each of them to return to be more effective leaders in their countries. Providing materials that can be used in each country is also a priority. In 2009 the “Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis” was translated into eight languages and made available on our website. Our **9th Pan-European Conference**, held in October, brought together more than 200 members. Our five Past Presidents provided highlights of our key accomplishments over the years, ranging from our role as a co-organiser of the **European Breast Cancer Conference** and our extensive work at the **European Parliament**, to the design of a five-year **Strategic Plan** for our organisation and ensuring that survivors play key roles as leaders within EUROPA DONNA.

Progress in implementing this Plan continues. The second **Breast Health Day** was held on 15 October and this year included an online campaign with e-cards that were sent to 5000 women in 58 countries. Our presence in Brussels has expanded as we worked together with several MEPs on the development of a **Declaration on the Fight Against Breast Cancer in the EU** and a campaign to have a majority of MEPs sign it. Finally, our board and staff remain committed to the **Forum Support Project**, to work toward solutions of the different problems and issues our groups face at the national level. A toolkit explaining various aspects of conducting a EUROPA DONNA forum was also developed to help in this process.

The strength of our organisation emanates from this constant exchange of information and ensuring that a unified approach to evidence-based advocacy exists at both the European and the national level.



Susan Knox
Executive Director

EDUCATIONAL OPPORTUNITIES

EUROPA DONNA 9th Pan-European Conference

Stockholm, Sweden • 24–25 October 2009

Our bi-annual Pan-European conference “Communication and Collaboration” was held in Stockholm in October and was the most attended in its history. More than 230 Coalition members, National Representatives, breast cancer advocates, nurses and other breast cancer specialists attended. In addition to the presentations by European breast cancer experts such as Dr. László Tabár and Dr. Alberto Costa, workshops were held on implementation of specialist breast units, organisational development and fundraising, and a networking meeting was dedicated to metastatic breast cancer. The conference concluded with a Presidents’ Panel with our five presidents to mark our 15-year anniversary. Our bi-annual conference is one of our main events since it brings together many of our advocates and reinforces the tools available to them and provides them an opportunity to share experiences with other advocates and representatives of the scientific community.



EUROPA DONNA National Representative Day

Stockholm, Sweden • 23 October 2009

On 23 October in Stockholm, National Representatives from 32 of our member countries shared the advocacy activities in their countries and, through workshops, brainstormed ideas for improved strength, cohesion and scope. This was the second annual National Representative Day, which is designed to reinforce the unity of EUROPA DONNA Fora and also provide support to the Fora. It is a one-day training programme/two-way communication exchange that is well regarded by National Representatives.



EUROPA DONNA Annual Breast Cancer Advocacy Training Course

Milan, Italy • 13-15 November 2009

In 2009, 47 breast cancer advocates representing 26 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. Our Advocacy Training Course, held every year, is funded in part by the European Union under a contract with the European Cancer Network (ECN). The course is divided into three modules. The first part of the course (one day) covers 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 EUROPA DONNA (half a day) and the third section consists of communication skills training (one day). It is extremely well received by the advocates who participate and is essential to enable them to return to their countries to advocate for best practice.



Breast Health Day

Europe-wide • 15 October 2009

Our second annual Breast Health Day involved a Europe-wide public awareness media campaign that had the support of the European Commission and spokesperson world tennis champion Arantxa Sánchez-Vicario. This advocacy activity is held yearly to promote breast cancer prevention and in 2009 promoted engaging in moderate exercise for at least 30-60 minutes every day for breast health. The event was promoted in our member countries, through a press conference in Brussels and an e-card sent via www.breasthealthday.org. Tracking of the e-cards sent on the world map showed that nearly 5000 people viewed the card world-wide. A mini-diary on how to become more active, a Breast Health Day poster and a video message from Arantxa Sánchez-Vicario all helped promote the event, which was picked up widely by media organisations across Europe. The e-card was sent to all our colleagues, friends and many MEPs interested in breast cancer issues.



Working Group on Forum Support

In 2009 the Executive Board established a Working Group on Forum Support to identify the countries that were inactive and/or in need of support. Thirteen countries were identified as inactive or in need of some type of support. Of the 13 countries, nine were contacted directly by either the Head Office or one of the Executive Board members from the working group. As a result, in two countries new groups were established and in two countries a new National Representative was identified. In several countries the contact enabled us to understand the issues and problems that they are facing; in most cases language remains a key concern. Three of the countries contacted have started attending our events and have become more involved. The Executive Board and staff will continue to work with all member countries to find solutions to unresolved problems.

KNOWLEDGE DISSEMINATION

Publications

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

In 2009 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 a further three languages. It has now been printed in French, German, Greek, Italian, Polish, Spanish, Swedish and Turkish. Translations into Georgian and Dutch will be printed in early 2010 and translations into Slovenian and Russian are also under way. 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.



■ 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 and health economic decision making, as well as reports from our Fora, among other topics.



■ EUROPA DONNA e-News

An electronic newsletter summarising our activities in 2009 has been sent to 2000 people.

■ EUROPA DONNA Brochure

A new updated four-page brochure was created in 2009 to distribute at conferences and meetings. It provides background on breast cancer as well as a description of EUROPA DONNA's 10 goals and main advocacy priorities.



■ Membership Toolkit

This toolkit was developed in 2009 to provide important background information and key documents for all our member groups.

Websites

www.europadonna.org

We have freshened up the look of our website and continue to include features as suggested in the Strategic Review, such as posting our annual audited financial statements. Information about upcoming EUROPA DONNA advocacy events is also featured there.

www.breasthealthday.org

The Breast Health Day website was launched in 2008 and provides ongoing access to all the events and information disseminated on Breast Health Day and to the National Fora activities related to this event. The video message from Arantxa Sánchez-Vicario, the e-card and the mini-diary can all be accessed through this website.

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 breast cancer patients.

■ European Parliament Written Declaration on the Fight Against Breast Cancer

We have been working with MEPs to ensure that the new MEPs are aware of the 2003 and 2006 European Parliament Resolutions on Breast Cancer and the need to work toward their implementation. In 2009, we worked with MEPs to draft a Written Declaration on the Fight Against Breast Cancer, which was released at the opening of the European Parliament Plenary Session in Strasbourg on 14 December 2009. We are holding a campaign in Brussels to encourage MEPs to sign the Declaration.

■ Joint Exhibition with DG SANCO at the European Commission

On 15 October 2009 we had a unique opportunity when DG SANCO invited us to join them at the main European Commission building at Berlaymont in Brussels for an exhibition to mark the launch of the new European Partnership Action Against Cancer. DG SANCO had a massive “cancer banner” on the front of the Commission building and we held a joint exhibition at the main entrance. As 15 October is also Breast Health Day, we used this opportunity to distribute materials specific to breast health as well as distributing our *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis* in several languages.

■ Launch of European Partnership for Action Against Cancer

On 29 September 2009 we attended the launch event for the European Partnership for Action Against Cancer. The European Commission is setting up a European Partnership for Action Against Cancer for the period 2009–2013 to support the EU Member States in their efforts to step up the fight against the increasing European burden of cancer. The intention of the Partnership is to put in place an EU-wide commitment for concrete action to prevent and treat cancer by engaging relevant stakeholders.

■ ESMO Policy Briefing for MEPs in Brussels

Our Executive Director Susan Knox attended the European Society for Medical Oncology (ESMO) Policy Briefing: “The Fight Against Cancer – Where Next?” at the European Parliament on 10 November 2009. She asked MEPs to continue supporting the two European Parliament Resolutions on Breast Cancer and the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. She also emphasised the need for an EU protocol for accreditation of specialist breast units.

Sponsor Meeting

We held our Second Sponsor Meeting at the European Cancer Organisation–European Society for Medical Oncology conference in Berlin in September. Ellen Verschuur, President, and Susan Knox, Executive Director, attended and provided an overview on our progress on projects through 2009 and plans for 2010. 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 in Europe today.

Development Programme

We continue to seek new sponsorship by contacting various foundations and organisations across Europe and the USA. More than 200 organisations have been researched and letters/grant applications sent to many. In 2009 a grant application was made to the European Commission to support a “Breast Cancer Advocacy Leader Conference” to be held in September 2010. This grant has received preliminary approval pending final negotiations in 2010.

COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2009 **EUROPA DONNA** served on the following committees:

Clinical Trials

- BIG Scientific Committee
- TRANSBIG Steering Committee
- TRANSBIG Legal/Ethics Committee
- TRANSBIG Spreading of Excellence Committee
- International Breast Cancer Study Group
- MINDACT Steering Committee
- ALLTO Steering Committee

During 2009 **ED** participated in the following organisational activities:

Policy

- European Health Forum
- European Patients Forum
- European Public Health Alliance
- ECCO – Patient advisory council

Conferences

- EBCC-7
- ECCO 15/ESMO 34 Congress
- ECCO Patient Seminar
- IBCM Sarajevo
- IMPAKT
- VZW–BCWG Breast Cancer Working Group

Other Meetings

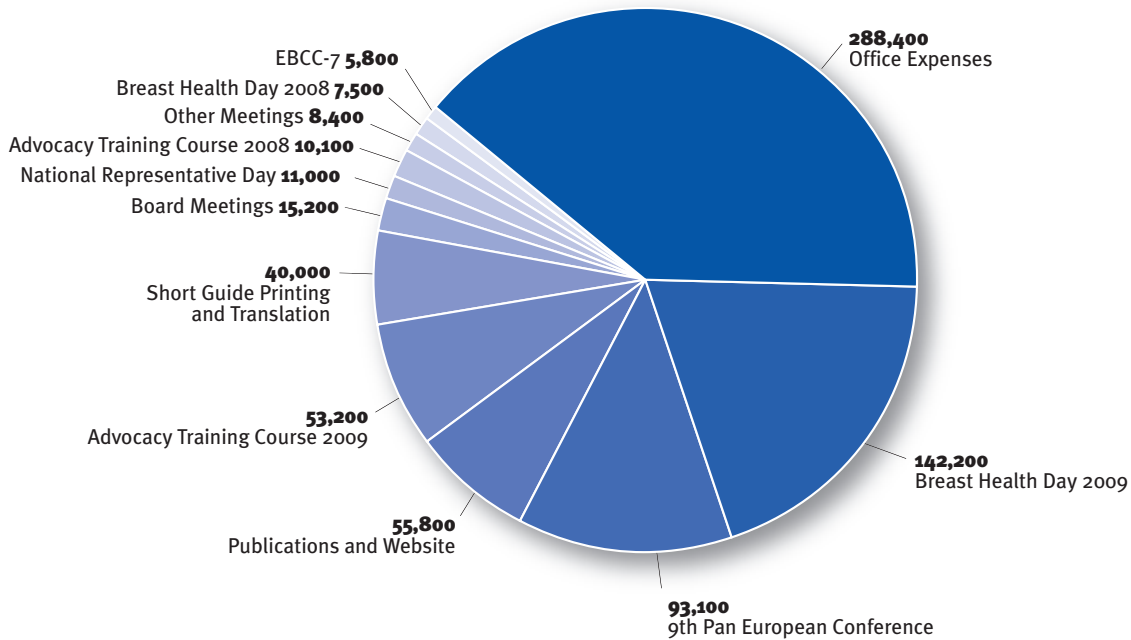
- Metastatic Breast Cancer Advisory Board
- EUSOMA Workshop
- AACR
- Tapestry Network–Breast Cancer Working Group
- European Breast Cancer Advocates Summit
- Roche Oncology Advisory Board
- Europe for Patients Campaign Meeting
- Patient Advisory Boards
- EU Health Policy Forum
- European Commission Public Health Day
- European Partnership for Action Against Cancer
- ESMO Policy Briefing for MEPs

FINANCIALS

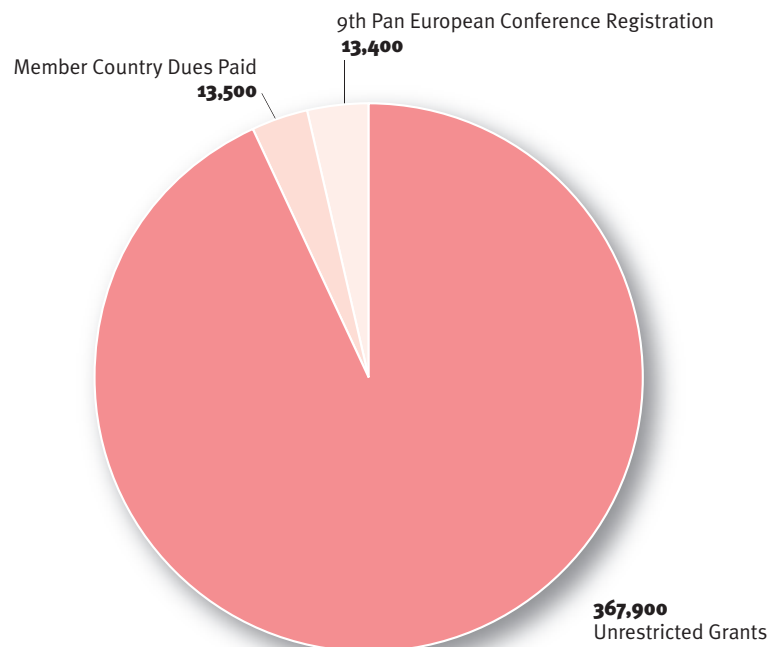
EUROPA DONNA continues to receive consistent financial support through unrestricted grants from sponsors. Income for the year totalled €394,900 and expenses were €730,800. Large projects such as Breast Health Day were funded by grants received in 2008 and held in an investment account until used. Twenty-seven National Fora paid their dues of €500. Our annual financial statement has been prepared by an independent auditor and is posted on our website at www.europadonna.org.

JANUARY – DECEMBER 2009

Expenses (Euros)



Income (Euros)



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.

SPONSORS

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

€50,000–99,999

Novartis • F. Hoffman-La Roche, Ltd. • GlaxoSmithKline • Merck Serono • Pfizer

€20,000–49,999

European Union WHO/ECN • Schering Plough

Below €20,000

Eli Lilly Company

Gifts In-Kind

Cohn & Wolfe – Pro Bono services for Breast Health Day evaluated at 32,000 euros

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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