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.

WOMEN ACROSS EUROPE CAN GET ACCURATE UP TO DATE INFORMATION ABOUT BREAST CANCER AT www.europadonna.org

En kort vägledning till de europeiska rekommendationerna för kvalitativt och effektivt screening och diagnos av bröstcancer.

Breve Guida agli Orientamenti europei per la prevenzione, la screening e la diagnosi del tumore del seno.

Guide résumant les Recommandations européennes pour l’assurance de la qualité dans le diagnostic et le traitement du cancer du sein.

Guía resumen de las recomendaciones europeas para el control del cáncer mamario y el diagnóstico del cáncer de mama.

A Short Guide European Guidelines for quality assurance in breast cancer screening and diagnosis.

15 OCTOBER
BREAST HEALTH DAY
WOMEN of all ages need accurate breast health information to understand the influence lifestyle choices can have on their future health.

15 OCTOBER
Because healthy living today keeps us healthy tomorrow.

www.breasthealthday.com
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INTRODUCTION

Our ambitious work programme for 2008 helped in furthering the goals of EUROPA DONNA – to ensure that all women in Europe have access to state of the art early detection and treatment of breast cancer, to promote further research and ensure that all women are educated concerning breast health. We continue to pursue these through initiatives in three main areas: education, information and lobbying.

2008 was an exciting and productive year as we moved forward with the Strategic Review activities agreed by the board in January 2008. These efforts enabled us to make significant progress in strengthening EUROPA DONNA by raising awareness, ensuring more transparency, communicating our positioning more clearly, and providing more support to our National Fora. Three completely new initiatives were central to this year’s advocacy programme: the launch of Breast Health Day on 15 October, the introduction of National Representative Day, and the dissemination of a multi-lingual public service announcement across Europe to raise awareness of the EUROPA DONNA website and to direct women to our Short Guide to the EU Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

We welcomed two new members to our Coalition in 2008, Albania and Belarus, bringing our total number of member countries to 42.

Susan Knox
Executive Director
6th European Breast Cancer Conference
15–19 April 2008 – Berlin, Germany

As a partner with EUSOMA and EORTC we actively participated in the 6th European Breast Cancer Conference (EBCC-6) from 15–19 April 2008 in Berlin. The meeting had over 4,500 participants. About 85 EUROPA DONNA advocates attended and we provided input into over 15 different presentations as well as providing a stand and exhibition throughout the week. At the opening symposium we had the opportunity to present the advocacy perspective on health economic decision making. This is available on webcast, and an interview concerning it is also posted on our website, www.europadonna.org. Conference coverage is also provided in our 2008 newsletter. Our President, Ingrid Kössler, awarded the Nathwani Prize to Gabriele Schärer for her award-winning film “Busenfreundinnen/Affaires de Bain” and also presented our final messages at the end of the conference. This meeting 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.

The First EUROPA DONNA National Representative Day
15 October 2008 – Milan, Italy

The first National Representative Day was designed to reinforce the unity of EUROPA DONNA Fora and also provide support to the Fora. It consisted of a one-day training programme/two-way communication exchange. During the day our National Representatives heard about the current policies of EUROPA DONNA regarding sponsorship, branding guidelines such as the use of EUROPA DONNA logo, activities regarding promoting implementation of the EU guidelines. They were asked to respond to questions concerning the EUROPA DONNA constitution using an interactive electronic voting system. Our former Presidents moderated workshops in which each National Representative gave a brief overview of her Forum’s current projects, issues and needs. This programme was very well received and will be continued with refinements in the future.
EUROPA DONNA Annual Advocacy Training Course

7-9 November 2008 – Milan, Italy

In 2008, 45 advocates representing 23 countries attended EUROPA DONNA’s two-and-a-half day advocacy training course, supported by the European Union under a contract with the European Cancer Network (ECN). This is always an inspiring programme and feedback from attendees was excellent, with 98% saying that the course had met their expectations and that it was very useful. This year observers from Europa Uomo and the European Cancer Patient Coalition (ECPC) attended to see what aspects might be replicated for programmes for prostate cancer patients and cancer patients respectively.

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).

The First Annual Breast Health Day

15 October 2008 – Europe-wide

EUROPA DONNA launched this new public health education and awareness-raising campaign aimed at prevention and early detection of breast cancer. A media/press conference was held in Milan to initiate this campaign and featured experts discussing the facts and studies available today about prevention. Presentations of support were also made by the Head of Cabinet to the EU Commissioner for Health, and Directors of the European School of Oncology and the European Institute of Oncology. EUROPA DONNA National Representatives attended as well as 10–12 local and foreign journalists who covered this topic. The event was webcast live on our website and an archived version is available for six months. Other communications materials for this event included news releases, posters, booklets, a specially dedicated website, www.breasthealthday.org, and a Breast Health Day News publication. Breast Health Day will now become an annual event.
Publications

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

In 2008 we focused on the dissemination of our *Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. This guide 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 has now been translated into five languages, French, Italian, Spanish, Swedish and Turkish, and translations into Greek, German, Polish, Russian, Slovenian, Georgian and Dutch are now underway. It was distributed to all of the EBBC-6 conference participants and to all attendees in all of our conferences and advocacy training courses this year. It can be downloaded directly from our website [www.europadonna.org](http://www.europadonna.org).

EUROPA DONNA News

Our annual newsletter was distributed widely in September, and featured coverage of EBCC-6, interviews with key opinion leaders and reports from our Fora, among other topics.

Breast Health Day News

This new publication highlights the Breast Health Day launch event.

EUROPA DONNA Guide to Breast Health

Another new publication, the *EUROPA DONNA Guide to Breast Health*, provides information on breast cancer and lifestyle factors, prevention, mammography screening, clinical trials and advocacy, among other topics. It was distributed to the media and those attending the Breast Health Day event, and at various conferences and meetings in the last quarter.

EUROPA DONNA e-News

An electronic newsletter summarising our activities in 2008 has been sent to 2000 people.
Websites

**www.europadonna.org**

Our website manager Karen Benn has updated our website with new features as suggested in the Strategic Review. These include posting an annual report describing our activities and projects, posting our annual audited financial statements, acknowledging our sponsors, and revision of various sections to make them more transparent and easier to understand. Later in the year we launched a Web Forum accessible only to National Representatives where they can share opinions on subjects of common interest.

**www.breasthealthday.org**

In October we launched the Breast Health Day website on the occasion of the first Breast Health Day on 15 October. This website serves to provide ongoing access to all the events and information disseminated on Breast Health Day and to the National Fora activities related to this event. A webcast of all of the presentations from the media launch event is available on this website and [www.europadonna.org](http://www.europadonna.org) for six months.

Public Service Announcement

EUROPA DONNA’s first public service announcement (PSA)/media campaign was developed and aired free of charge in 41 countries across Europe. The announcement was translated into all our country languages. It directs women to consult the Coalition website ([www.europadonna.org](http://www.europadonna.org)) to access accurate information on breast cancer, particularly concerning the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. The announcement served to both raise awareness of EUROPA DONNA by directing women to our website and to make women aware of the existence of the EU guidelines. In addition, the PSA is posted on our website and was shown at various conferences and advocacy training meetings. Various networks such as CNN Europe, TV 5 Europe, Euronews and many national networks aired the PSA numerous times free of charge.
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. We now include a core group of MEPs in all our regular mailings and correspondence to ensure they are updated on new events such as Breast Health Day.

Activities this year were targeted to getting our message disseminated through the "Short Guide to the EU Guidelines" at the national level. Many countries picked up the challenge and have taken the Short Guides to their parliaments and conducted meetings and information sessions locally. Various press conferences, meetings with national health ministries and national parliamentarians took place (see national reports on www.europadonna.org).

EUROPA DONNA remains involved with other European level organisations that provide support to our objectives as well. We are a partner of the European Cancer Network (ECN), through which we receive support for our advocacy training course and are involved in the evolution of all screening efforts throughout Europe. The ECN is pursuing the development of EU guidelines for specialist breast unit certification at the European Parliament, an effort which EUROPA DONNA fully supports. Our President Elect Ellen Verschuur and Executive Director attended the Open Forum of the European Health Forum and had a chance to indicate our interest in this, both to the Commissioner for Health and to the Director of DG SANCO. The Commission will launch a cancer partnership project in 2009 and EUROPA DONNA has expressed its willingness and interest in participating.

Sponsorship of NGOs lobbying at the Parliament has been the subject of debate and discussion this spring. EUROPA DONNA took a direct and positive position in this regard by writing an article that was published in Parliament Magazine in June, followed by written position statements sent to individual parliamentarians, the European Patient Forum, the European Health Forum and all our partner organisations as well as various interviews with journalists on the subject.

Working Group on Scientific Enquiry

The EUROPA DONNA Board established this working group for 2008. Board Members Bettina Borisch, group co-chair with Astrid Scharpantgen, and Sema Erdem review the numerous requests EUROPA DONNA now receives to participate in research projects, especially those of the European Commission Research Framework. They have now developed a matrix system for the board to test in 2009. This will constitute a review mechanism for these types of projects to determine whether or not they adhere to EUROPA DONNA’s Strategic Plan and current priorities and that resources are available to carry out such projects.
Sponsor Meeting

In 2008 we held our first meeting for our sponsors at the European Society for Medical Oncology (ESMO) meeting in September. The purpose of this is to share with our sponsors our projects and programmes for the current year and to inform them of our plans for the future. Thirteen sponsor representatives attended and we received very positive feedback concerning this new initiative.

Development Programme

In 2008 we initiated a development project to diversify EUROPA DONNA’s funding and explore all the fund-raising possibilities that exist for the Coalition. This included hiring a Development Officer to research all foundation, corporate and other possible sources of funds and grants and to develop proposals to generate additional income.
COMMITTEE MEMBERSHIP AND ACTIVITIES

During 2008 EUROPA DONNA served on the Committees listed below.

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
- HERA
- HABITS

During 2008 ED participated in the following organisational activities:

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

Conferences
- EBCC-6
- EBCC-7
- ECCO Patient Seminar
- IBCM Sarajevo
- ESMO Patient Seminar
- VZW–BWG Breast Cancer Working Group

Other Meetings
- Metastatic Breast Cancer Advisory Board
- Cancerworld.org Website Meeting
- Slovenia EU Presidency Meeting on Cancer in Europe
- European Patient Forum Spring Conference
- HEAL
- Organisation of European Cancer Institutes Annual Meeting
- Roche Oncology Advisory Board
- European School of Oncology Patient Group Meeting
- Europe for Patients Campaign Meeting
- International Union Against Cancer (UICC) World Cancer Congress
- European Society of Medical Oncology Congress
- Patient Advisory Boards
- EU Open Health Forum
- EC Public Health Day
- San Antonio Breast Cancer Symposium
NEW OFFICE

In November EUROPA DONNA moved to a larger office space located in a lovely garden of an historic building in Milan.

It has three large offices for the five members of office staff, and an area for meetings.

The new address and telephone numbers are as follows:

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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.
EUROPA DONNA’s financial situation continues to be solid with a final year end income of €770,000 and expenses of €653,000. At year end, reserves of €861,000 were invested in our monetary fund for pending projects. It is important to note that half of the €400,000 received from VZW-BCWG (Breast Cancer Working Group) is specifically slated for projects in 2009. Thirty National Fora paid the annual dues of €500. Our annual financial report has been prepared by an independent auditor and is posted on our website.
SPONSORS

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

Over €100,000

€50,000–99,999
Novartis • F. Hoffman-La Roche, Ltd. • GlaxoSmithKline

€20,000–49,999
Pfizer • European Commission • AstraZeneca

Below €20,000
Schering-Plough • European School of Oncology • Eli Lilly Company • Krueger & Associates

Gifts In-Kind
CNN Europe • TV 5 Europe • Euronews • BNT – Bulgaria • Vitata – Belgium • OTV – Croatia
LTV – Cyprus • DR TV – Denmark • France 24 • Canal + – France • Commedie! – France • iTele – France
Jimmy – France • Lagardère – France • Planete – France • TMC Regie – France • TF1 – France
RTL2 – Germany • Info TV Channel – Romania

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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