

FIGHTING BREAST CANCER IN EUROPE

EUROPA DONNA – The European Breast Cancer Coalition (ED), 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 care 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 European Union. ED was founded in 1994 and now has 46 fora (national country organisations) across Europe. The strength of our organisation lies in uniting women of many countries, cultures, and backgrounds in fighting breast cancer and seeking common goals toward that end.

EUROPA DONNA ten goals:

1. To promote the dissemination and exchange of factual, up-to-date information on breast cancer throughout Europe.
2. To promote breast awareness.
3. To emphasise the need for appropriate screening and early detection.
4. To campaign for the provision of optimum treatment.
5. To ensure provision of quality supportive care throughout and after treatment.
6. To advocate appropriate training for health professionals.
7. To acknowledge good practice and promote its development.
8. To demand regular quality assessment of medical equipment.
9. To ensure that all women understand fully any proposed treatment options, including entry into clinical trials and their right to a second opinion.
10. To promote the advancement of breast cancer research.

EUROPA DONNA is an evidence based advocacy organisation and all our information and advocacy programmes are based on scientific evidence that has been agreed upon by European scientific experts in all the specialist fields. Since 2000 we have worked with the European Breast Cancer Network and EUSOMA – The European Society of Breast Specialists and these partnerships have resulted in the publication in 2006 by the European Commission of the “European Guidelines for quality assurance in breast cancer screening and diagnosis”. This document now forms the basis for much of our advocacy work as it outlines the breast cancer services that all women should have a right to receive. ED has published a “Short Guide” to these guidelines to enable women and the lay public to understand the main points contained in this scientific document. These can be downloaded from our website and have been translated into 14 languages in addition to English so far.

The Coalition, consisting of an elected board and representatives of all ED’s 46 member countries, have agreed on five main priorities for European breast cancer advocacy work today.

These are: establishing population based mammography screening programmes in all countries set up according to the EU Guidelines mentioned above, establishing specialist breast units in all countries set up according to these EU Guidelines, developing national breast cancer registries, furthering breast cancer research and breast cancer prevention.

The Head Office of the Coalition is located in Milan, Italy and is responsible for carrying out a variety of projects at the European level in the areas of education, information and lobbying. To enable us to advance these key objectives Europa Donna is the proud recipient of an operating grant from the European Union in the framework of the Health Programme for our 2013 core programme.

An important educational activity of our Coalition is our Europa Donna Pan-European Conference. This conference is held every two years and is the only conference in Europe that is conducted primarily for breast cancer advocates and survivors. The 11th Europa Donna Pan

European conference will be held in Prague, Czech Republic on 19–20 October 2013 and we expect at least 250 participants including National Representatives and members from our 46 member countries as well as people from various countries around the world. In 2013 the focus of the conference will be on key areas of extreme importance in today's changing economic environment- personalised medicine, the EU accreditation scheme for breast services, new study results on lifestyle factors, and important work being done on survivorship. We will aim to provide updated information on these areas and work on ensuring access to information and services for hard to reach populations and women with metastatic breast cancer. There are still vast differences in the breast services available in our different countries. While we have provided translations of the "Short Guide to the EU Guidelines" and other materials to help in disseminating information, we have seen that our national groups need support in overcoming obstacles in many of our countries. The current economic situation has made this even more difficult. This conference will provide speakers highlighting and reviewing the services that are available today and where advocacy is needed. Workshops will focus on practical topics that need to be addressed locally and in the majority of countries, by volunteers: how to overcome the obstacles in our countries to ensure proper access and provision of services, how to reach these populations that need to be represented – those who so badly need information and support. Our objective is to develop and refine skills and strategies, and provide help in meeting the challenges of today. Registrations and costs are maintained at a reasonable rate to ensure participation by as many people as possible. The Coalition provides bursaries to each national ED group to ensure that at least two representatives from each country are present.

EUROPA DONNA is also co-organiser with EUSOMA and the EORTC (European Organisation for Research and Treatment of Cancer) of the European Breast Cancer Conference which is held every two years. The next one will take place in Glasgow, Scotland, 19–21 March 2014.

An essential education programme provided by EUROPA DONNA is our annual European Breast Cancer Advocacy Training Course, a two and a half day training course that is conducted in Milan; here our members learn more about how to initiate and carry out advocacy programmes in their own countries as well as at the European level. Advocates learn about the science and best practice in treatment of breast cancer, the European Union Guidelines that have been developed, and how to communicate and lobby for these services at the local level. Finally, the Europa Donna Advocacy Leader Conference is a new training programme provided for the National Representatives of our member countries to discuss issues and topics of common concern and provide sessions for our country leaders to improve their local organisations and advocacy programmes.

In addition, ED is constantly engaged in influencing policy to bring about change at the European level. ED has campaigned and held numerous European Parliament Information meetings and exhibits resulting in two European Parliament Resolutions on breast cancer in 2003 and 2006 and the Written Declaration against breast cancer in the EU in 2010. These documents form the basis of much of our lobbying at national parliaments. Information on these activities as well as various publications, our annual newsletter and e news can be found on our website at www.europadonna.org.

ED's prevention programme, Breast Health Day, is held annually on 15 October and aims to raise awareness concerning prevention and early detection. Our Breast Health Guide and annual publications and campaign materials can be viewed at www.breasthealthday.org.

Promoting breast cancer research remains a key priority and we actively participate in some major scientific research programmes in Europe. We have representation on the Scientific Committee of BIG (Breast International Group) and serve as a partner in the MINDACT trial that is supported by the European Commission. ED actively serves on other trial committees, is a regular participant in training programmes for advocates concerning trials, and has published two booklets "Breast Cancer and Clinical Trials" and "The Advocate's Guide to Understanding Breast Cancer Research" to increase understanding of clinical trials among non-scientists.

EUROPA DONNA continues to make progress in furthering its goal to see that all women, regardless of educational background, geographical location or economic status, have access to accurate up to date information concerning breast cancer services and have equal access to state of the art services for early detection, diagnosis, treatment and follow up for this disease.

*Susan Knox
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