

Guidelines for Best Practice – The Patient Advocate's Viewpoint

a report by

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Susan Knox, a breast cancer survivor, is Executive Director of EUROPA DONNA (ED), the European Breast Cancer Coalition, having previously held the position of Liaison Officer. Since joining ED, she has been responsible for organising three ED pan-European conferences, exhibits and meetings with members of the European Parliament, and all on-going lobbying and advocacy initiatives of ED, including the development of the European Parliamentary Group on Breast Cancer (EPGBC) for which ED acts as secretariat. She has developed the ED website, the EPGBC website and various publications concerning breast health for women. Over the last few years she has designed and developed the ED European breast cancer advocacy training course, which is being held annually. Ms Knox has extensive experience in the non-profit and for-profit sectors, holding various posts including Director of Therapeutic Activities and Assistant Executive Director at Menorah Home and Hospital for the Aged (a non-profit long-term care facility in Brooklyn, New York), and Vice President for Strategic Planning at Citibank in Milan. She holds a BA from Smith College and an MA from Columbia University.

In the EU (EU-25) there are 269,570 new cases of breast cancer and 87,700 deaths due to breast cancer per year. As the role of patient advocacy groups gains recognition and acceptance, they are increasingly being called upon to participate in a wide variety of activities from providing information and serving on clinical trial committees, to evaluating various aspects of patient care and lobbying politicians on service needs and patient rights.

EUROPA DONNA (ED), the European Breast Cancer Coalition, is actively engaged in trying to ensure that women in Europe have equal access to state-of-the-art breast services. To further this objective, much of its lobbying work and educational programmes in the last five years have been dedicated to disseminating information concerning European guidelines for best practice in both screening and treatment of breast cancer, to promoting acceptance of these standards and to demanding their implementation across all European countries.

The European Society of Mastology (EUSOMA) guidelines for specialist breast units were first published in the *European Journal of Cancer* in 2000. Since that time, ED has been lobbying for their acceptance and implementation, highlighting them at its conferences, advocacy training courses and meetings, and urging women advocates to return to their countries and demand that these services be provided. Speaking with one voice representing all ED's member countries it has lobbied vigorously at the European level for acceptance of these guidelines. So, too, with the European Mammography Screening Guidelines. ED is a member of the European Breast Cancer Screening Network (EBCN) and has collaborated with them over the last few years on various projects to support implementation of these guidelines, which are a main component of all ED's lobbying, education and information programmes. While some countries have started moving towards implementation, it is essential that more set up such programmes, and ED is involved in an on-going campaign to convince them; today only eight of the 25 EU countries have screening programmes in accordance with the guidelines and five others are nearing completion in rolling out such programmes.

ED instituted a breast cancer advocacy training course, which has been held annually since 2001. The training of advocates from all its member countries concerning guidelines is a key objective of the course, which is funded in part by a grant from the European Commission (EC). ED is training advocates, many of whom are breast cancer survivors, to return to their countries and lobby their governments and health ministries to implement these guidelines. ED worked diligently to see that both sets of guidelines were introduced at various meetings within the European Parliament, and has made them the focus of discussions with the European Parliamentary Group on Breast Cancer (EPGBC) (which was set up in 2001 with ED providing the secretariat). Many of the guideline requirements were then incorporated into the European Parliament Breast Cancer Resolution, which was passed in June 2003. It detailed targets and quality standards on everything from mortality rates to how mammograms are read, and it called on Member States to monitor and report back by 2006 on their progress, giving the EC the task of ensuring that countries do their utmost to comply.

The resolution sets a target of reducing breast cancer mortality by 25% by 2008, and reducing the disparities in five-year survival rates across Europe from 16% (EU-15) to 5% over the same time period. It also deals in some detail with areas such as screening, patients rights, treatment and training. It calls on all Member States to provide screening every two years for all women between the ages of 50 and 69, and lays down minimum quality standards, including monitoring of image quality and radiation doses. With regard to treatment, the resolution adopted by the European Parliament calls for patients to be treated by multidisciplinary teams of experienced surgeons, radiologists, oncologists, pathologists, nurses and radiographers who specialise in breast disease, and receive regular training to keep them up to speed with the latest developments. Member States are called upon to set up networks of specialist breast centres to deliver treatment, and ensure that patients also have access to oncopsychological counselling and physiotherapy and social services. This was a major milestone for breast cancer advocacy and the first time a resolution on a disease category was passed by Parliament.

The EPGBC is chaired by MEP Karin Joens and now meets several times a year. The newly constituted group with EU-25 decided that they needed to better understand the technical aspects of screening and the necessity for the guideline requirements; therefore two expert meetings have been held at Parliament to explain the mammography screening guidelines and their importance to women’s health. ED follows up on these meetings by posting reports on the EPGBC website and providing lobbying updates to further disseminate information concerning them. ED is now conducting a survey among all its member countries to see what progress is being made in getting the guidelines and the Parliament resolution implemented and what obstacles are being encountered. In October it will conduct a week-long exhibit concerning breast cancer in the EU-25 at Parliament to help further explain the need for implementation of guidelines across all member nations.

The education and dissemination process is long and complex, but ED has made a commitment to seeing that the guidelines are implemented. A revised set of guidelines are being reviewed by the EC this year. This again will help to stress the importance of their implementation nationally. Now it will be necessary to determine which units, hospitals, etc., across Europe meet the standards called for in the guidelines. This will require an accreditation process; such a process is currently being developed by EUSOMA. ED has a working committee that has participated in the revision of the guidelines and provided input on these procedures from the patient advocate’s perspective. Units wishing accreditation (which is voluntary) will be asked to fill out a questionnaire and

then request a site visit to determine whether they meet the standards called for in the guidelines. Site visits will be initiated and an ED advocate will be a member of the group that visits. It is a significant step forward for patient advocates, that ED is part of this team along with the surgeon, pathologist, radiologist, etc. When the accreditation process is in place, women will have a way to evaluate their options; they will know how to find specialist breast units and where they are located. Being able to access this information and ultimately gain access to this type of service is precisely what every woman who is diagnosed with breast cancer needs and wants.

What is taking place with regard to guideline development and implementation is the result of years of networking, partnership, collaboration and communication among the medical and scientific societies that ED advocates and public health officials. There is still a long way to go before the implementation of guidelines is achieved across all of Europe, but advocates can and do play a significant role in bringing projects of this type to fruition and making sure they receive the public and political attention they deserve. Advocates can bridge the gap between scientists and the general public, making evident to national governments, health departments and other public bodies what the real needs of patients are and why implementation of the guidelines is essential; implementation is not an option, it is an imperative. ED’s job is to see that the message gets across and is understood so that guidelines are implemented as quickly as is humanly possible. Delaying means a considerable and unnecessary loss of life to this devastating disease. ■

Founded in 1994, 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 care and increased funding for research. EUROPA DONNA represents the interests of European women to local and national authorities as well as to institutions of the EU. There are 37 member countries.

Ten goals of EUROPA DONNA

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 fully understand 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.