ELSEVIER

European Journal of Cancer 40 (2004) 1111–1116

European Journal of Cancer

www.ejconline.com

Current Perspective

Breast Cancer Advocacy across Europe through the work and development of EUROPA DONNA, the European Breast Cancer Coalition

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Received 28 January 2004; accepted 2 February 2004

Advocacy—the art of representing or promoting a cause or purpose on behalf of oneself or others—can include influencing policy, affecting legislation and changing attitudes. This is not an easy concept in some European countries and indeed the word 'advocacy' is not capable of direct translation into some languages. This is one of the challenges that EUROPA DONNA, the European Breast Cancer Coalition, has had to address to present its *raison d'être* during its short life as Europe's breast cancer advocacy organisation.

Advocacy by women advocating for women's health began in many countries during the second half of the twentieth century. Breast cancer advocacy as we know it has been around since the early 1990s but organisations by and for breast cancer patients and those close to them go back much further than that, starting in the United States. 'Reach to Recovery' [1] was founded in 1952 as a support group for women who had had mastectomies and continues today as an international organisation. In the 1970s organisations such as 'Y Me' and the Susan Komen Foundation [2] began to add a political dimension to the provision of breast cancer information and support, and around this time well-known women such as Betty Ford, Happy Rockefeller and Shirley Temple Black began to speak out about having the disease. This raised awareness, enabling public discussion, and as a result women increasingly felt able to identify themselves publicly as breast cancer patients and survivors. NABCO (The National Alliance of Breast Cancer Organisations) was founded in 1986 and The National Breast Cancer Coalition (NBCC) in 1991. The idea of campaigning politically for better services and for significantly more research to be carried out came in the wake of the effective advocacy activities of AIDS activists in the 1980s, and, in the United States, women began to adopt the same tactics in relation to breast cancer [3]. In European countries, too, small groups were forming to offer support and better services in all aspects of breast cancer. For example in the United Kingdom, the Women's Nationwide Cancer Control Campaign (WNCCC) was formed in 1965 and Breast Cancer Care (previously The Mastectomy Association) in 1968, in Sweden, The Swedish Association for Breast Cancer Societies (BRO) around 1975, and in Italy, ANDOS in 1976, to mention just four.

Also, in the early 1990s, Professor Umberto Veronesi, breast cancer surgeon in Milan, Italy, saw the power of women's advocacy for breast cancer in the United States, diverting $4m from the defence budget into breast cancer research. Professor Veronesi felt that the women of Europe should also have a say in their breast cancer journey and he set about exploring how to start this initiative. After one or two unsuccessful early approaches, he spoke to a group of women at a meeting in Venice. Following this it was planned to launch a new organisation at the European Society of Mastology (EUSOMA) [4] meeting in Paris in February 1993. Having heard of this possibility, several women working in the breast cancer field in Europe attended this meeting. They heard the proposal and offered to take up the challenge, but made it very clear that this had to be a women's organisation run by women. This was accepted and a small steering group was formed under the leadership of Gloria Freilich from the United Kingdom. Thus EUROPA DONNA (ED), the European Breast

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doi:10.1016/j.ejca.2004.02.007

Cancer Coalition, was formed, in the beginning as an educational arm of the European School of Oncology (ESO) [5] with the major support of the Director Alberto Costa, a support that has continued throughout ED's existence.

The rest is ED's well-documented history, the early milestones in which are:

- 1993 EUSOMA meeting in Paris
- 1994 1st ED Pan-European Conference
- 1995 2nd ED Pan-European Conference—election of first Board
- 1996 Constitution signed.

The emergence of breast cancer advocacy throughout Europe can be traced through the growth and development of ED, a coalition of affiliated groups from countries across the wider Europe. The organisation developed as its basis 10 goals:

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

So, ED started to lobby for best practice in all aspects of breast cancer across Europe, encouraging each individual country's forum to select one or two goals most pertinent to its situation and to work on these. The Executive Board, supported by the Head Office in Milan, worked hard to bring in other countries, and this progress has continued until currently we have 32 countries of the wider Europe in the Coalition (Fig. 1). This is the strength of ED's advocacy movement, each country acting nationally and autonomously but within the European framework, raising a united European advocacy voice.

EUROPA DONNA
32 Member Countries

- **Austria**
- **Belgium**
- **Croatia**
- **Cyprus**
- **Czech Republic**
- **Denmark**
- **Estonia**
- **France**
- **Germany**
- **Greece**

▪Hungary
▪Iceland
▪Ireland
▪Israel
▪Italy
▪Lithuania
▪Luxembourg
▪Monaco
▪The Netherlands
▪Norway

- **Poland**
- **Portugal**
- **Romania**
- **Russia**
- **Serbia and Montenegro**
- **Slovenia**
- **Spain**
- **Sweden**
- **Switzerland**
- **Turkey**
- **UK**
- **Ukraine**

Fig. 1. EUROPA DONNA: 32 member countries [7].

In 1997 a major development occurred with the establishment of a partnership with EUSOMA and EORTC (European Organisation for Research and Treatment of Cancer) [6], and led to all three partners hosting the first European Breast Cancer Conference in Florence in 1998 (EBCC 1). This robust partnership has developed through EBCC2 in Brussels in 2000, EBCC3 in Barcelona in 2002, and now into EBCC4 in Hamburg, in March 2004. The acknowledgement of ED as the advocacy arm has increased steadily with each Conference and ED is confirmed as the co-chair for all the EBC conferences. Our combined hosting of these Conferences is administered through FECS (Federation of European Cancer Societies), with and through whom we have developed relationships with other professional cancer organisations across the continent. These dynamic relationships and strong partnerships have added to the diversity of opinion expressed around the breast cancer meeting table, resulting in the effective promotion of our pan-European goals. To be effective advocates we must be well informed and we must be educated about breast cancer. We learn this up-to-date information from our colleagues in these societies, both within and without the conferences, and using our advocacy skills we can use this knowledge to lobby for action at government level, both nationally and on the European scene.

We began our early advocacy initiatives at national level by an introduction to the All Party Parliamentary Groups on Breast Cancer (APPGBC). One of the first such groups started in the United Kingdom during the 1990s. It was proving very successful so we proposed an initiative in 2000 to take parliamentarians from five other countries, each with a ED representative, to meet the APPGBC at the Westminster Parliament. Members of Parliament and members from Belgium, Estonia, Ireland, Italy and Slovenia had a very productive 2-day meeting.

The consequence of that first meeting was a meeting in the Senate in Rome in 2002 to meet the Italian APGBC and the ED members working with them.

Members of Parliament and members from four other countries, Croatia, France, Germany and Spain, were involved. ED's reception and acknowledgement there was very significant. These countries and others in our coalition are now working with their respective parliamentarians and this is raising awareness of breast cancer issues at national level. ED believes that a vital step in effective advocacy is to have parliamentarians and politicians 'on board'. They are the decision-makers at government level.

June 2000 saw ED's first advocacy foray at the European level when we held a reception in the European Parliament in Strasbourg. Over 100 Members of the European Parliament (MEP) attended and we successfully raised awareness of breast cancer issues throughout Europe. We invited our colleagues, the President of EUSOMA, Professor Luigi Cataliotti, and Dr Martine Piccart of EORTC to add their input, along with interested European parliamentarians and Commissioner Byrne, who was the Health Commissioner at that time. The combined weight of this advocacy initiative sent a powerful message to the European Parliament and the Commission on the needs of breast cancer patients and we have been building on this message ever since.

This initiative led our advocacy for breast cancer patients in several directions. First, there was the establishment of a Parliamentary Group on Breast Cancer at the European Parliament, led by Karin Joens, MEP, herself a breast cancer survivor and a great help to ED in planning our reception in Strasbourg. Karin is now President of ED Germany and currently one of our staunchest advocates. The European Parliamentary Group on Breast Cancer (EPGBC) is serviced by ED and we work closely with them. This partnership took us on to ED's first advocacy initiative of 2002, an exhibition of posters on breast cancer issues and actions across Europe by our colleagues and ourselves.

The newly formed EPGBC and ED, The European Breast Cancer Coalition, presented an inaugural exhibition 'Breast Cancer in Europe Today' at a reception at the European Parliament on 4 June 2002. Attended by over 200 participants, including parliamentarians and European Commission (EC) members, the 28-panel exhibition ran from 3 to 6 June in the Parliamentary building in Brussels. It marked the first European Union (EU) forum in which a dedicated exposition illustrated the current state of breast cancer throughout Europe. Stark figures on breast cancer incidence and mortality emerged at this exhibition, notably the statistic that in the EU a woman is diagnosed with breast cancer every 2.5 min and every 6.5 min a woman dies from breast cancer. These figures, presented in this way, raised more clearly and perhaps for the first time the reality of the magnitude of the 'epidemic' of breast cancer in Europe and gave ED a powerful platform for our advocacy.

Another outcome of our lobbying at the Parliament in Strasbourg was that ED gained one of the invited places on the EU Health Policy Forum, set up by the EU Commission for Health and Consumer Affairs (DG SANCO) and involving stakeholders across the health field. The Forum meets twice a year and ED is one of the 45 permanent members.

This in its turn led us to our participation in the newly formed European Patient's Forum, set up with the encouragement of the European Commission to represent the patients' voice by involving organisations concerned with patients with many long-term and chronic diseases, their carers and their representatives. ED's representative, Deirdre O'Connell has a seat on the Executive Board of this organisation, which is already an effective lobby group in the EU alongside other groups such as consumer groups, professional organisations and industry organisations.

These are two of the arenas where we continue our advocacy. Meanwhile, in the EC, ED was invited to join 250 cancer research and treatment specialists looking 'Towards Greater Coherence in European Cancer Research'. This opened a dialogue between scientific, industrial and health-care professionals as well as with patient advocacy organisations, and Executive Board member Paola Mosconi represented ED.

Following that, in October 2002, The European Parliamentary Committee on Women's Rights and Equal Opportunities held a public meeting in the European Parliament on breast cancer, led by Karin Joens MEP, to which ED was asked to contribute reports on advocacy and the patient's view. The focus on prevention, early diagnosis and the setting in place of multidisciplinary centres meant that continuing ED advocacy efforts were firmly planted at European parliamentary level. Amongst several experts in breast cancer screening, treatment and care, two ED members spoke, one a senior Specialist Breast Care Nurse from the United Kingdom., Sylvia Denton, President of the Royal College of Nursing, emphasising the vital role of the nurse in the multidisciplinary team, the other a patient advocate, Stella Kyriakides from Cyprus, Vice President of ED, giving the patient's view.

After this meeting, many of our representatives and Board members received a request from Karin Joens for information on various aspects of breast cancer in their countries and then a workshop was set up under STOA (Scientific and Technological Options Assessment) at the European Parliament to gather more information towards a report that was eventually to be presented and voted on in the European Parliament in plenary session.

This historic vote, the first to be presented in plenary on a specific disease, took place on 5 June 2003 in the EU Parliament in Strasbourg. ED Board members were present in support, having been instrumental in publicising the importance of the report through the country forums. The report was accepted by a large majority. The two key services mandated by the report were:

For all women across Europe, irrespective of her place of residence, social status or education:

- to have access to high-quality mammography screening at 2-year intervals for women between 50 and 69 years based on the European Screening guidelines

and

- to have access to a specialist breast centre staffed by a multidisciplinary team, set up according to the EUSOMA Guidelines.

The Parliament called on the Member States to implement these key issues so as to create by 2008 the conditions required for a 25% reduction in the breast cancer mortality rate in the EU and concurrently for a reduction to 5% in the disparity in the survival rates between the Member States. A progress report is to be available in 2006.

Immediately after the vote, ED gave a reception in the Parliament for MEPs to salute this occasion and to thank them for their support. At the reception ED pledged its support for the achievement of these targets and began appropriate advocacy initiatives forthwith.

The Report was circulated to all 32 country groups to raise awareness of it and its demands at national levels; in the few months since, monitoring of activities towards these ends has been constant. Every opportunity has been taken to raise these key issues, national representatives have been reminded and encouraged at every communication and Board members have included them in the many presentations they have made at meetings and conferences. These key issues of the Parliamentary Report on Breast Cancer are the corner stones of ED's current advocacy.

ED appreciated that it is essential that advocates have up-to-date knowledge of the science of breast cancer before they can lobby effectively, but also that it is equally essential to have the skills of lobbying and communication, and the paramount need for such training amongst its members became evident. So in 2001 in Milan a pilot training course in advocacy was inaugurated. The full programme in Communication Skills Training included:

- Getting your case heard
- Assertiveness
- Handling the media
- Verbal behaviour
- Developing probing and listening skills
- Formal presentations
- Body language
- Handling questions.

In the pilot course, ED members worked closely with the trainers by dividing into four groups. Two members from each forum presented challenges inherent to her particular country and experience, and shared possible effective solutions to what are often similar problems presented in different ways. The first programme was assessed and it was decided to lengthen the course and to increase the scientific input; the courses in 2002 and 2003 have reflected this.

In November 2003, physicians and researchers from Europe's top cancer institutions briefed the advocates on the current directions in breast cancer research and treatment. Over a period of a day and a half, experts from the Istituto Nazionale dei Tumori, the Mario Negri Institute, the European School of Oncology, the Centre for the Study and Prevention of Breast Cancer and others provided the 50 advocates with essential scientific background on the biology of breast cancer, the epidemiological aspects of the disease, clinical trials in progress, as well as the most current diagnostic and treatment methods. The third day was given over to the Communications Skills programme.

This year the course was funded by the EC and is now established as an annual event. It has proved equally popular with advocates and trainers, not only for its content but also for the opportunity for delegates from so many countries to share both their achievements and their difficulties, thus learning from one another and seeking ways to work effectively together. We hope in time to be able to open it widely across Europe.

Another recent ED advocacy activity involved radiographers from five countries of Eastern Europe who were brought to the Kodak facility in Genoa for training with specific reference to mammography. An ED member accompanied each group and the course was greatly appreciated by all involved. This again is a course we hope to repeat.

Lobbying government at all levels is vital for securing best practice in breast cancer, but working with other non-governmental organisations to add to this is also our aim. So we are pleased to have been invited to give the patient advocate's view at EPHA (the European Public Health Association) and EBCN (the European Breast Cancer Screening Network); on these bodies ED's Executive Director, Susan Knox, ably represents us. We have a seat at the table of B I G (Breast International Group) and this has led us onto the committees of three trials, HERA, Habits and IBIS ll. ED recognised early on the importance for patients, advocates and the lay public to have an understanding of clinical trials as the way forward in breast cancer.

We believe strongly that this information should be available long before they are asked to join a clinical

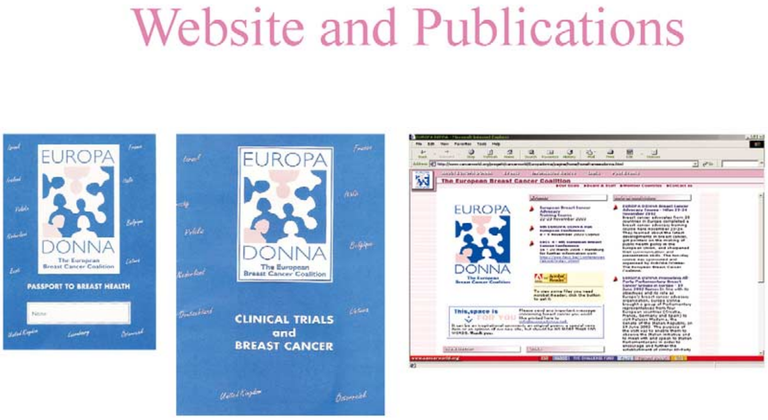

Fig. 2. Website and publications.

trial, which is often at the time when they are just coping with a diagnosis of breast cancer. So a brochure on clinical trials was developed and has proved an excellent *aide memoir* as has our 'Passport To Breast Health' originally presented at EBCC1 in Florence and upgraded since. ED's publications and website are shown in Fig. 2.

At local level each forum selects its priorities from the 10 goals and works towards implementation in a way that is appropriate to each country. ED ensures that local forums are kept informed of best practice and of the latest developments in breast cancer research and treatment. This is done through the advocacy course described above and through biennial pan-European conferences, as well as through continuing contact with the National Representative for each country. For example, the Conference held in Cyprus in November 2003—European Breast Cancer Advocacy: 'Uniting for Standards, Equality for All'—had the goal of developing a unified European voice speaking out for the right of women across Europe to have access to the best breast screening and breast care possible. The Conference was attended by 170 breast cancer advocates from 27 different European countries and focused on the need to utilise European standards and guidelines in the implementation of breast cancer services nationally. Contributions covered screening programmes, the development of specialist clinics, the role of all party parliamentary groups on breast cancer, as well as presentations on prevention, new treatment advances and risk factors. ED provides bursaries to ensure each forum can be represented.

We also ensure through the distribution of bursaries that members from each forum attend the European Breast Cancer Conferences, where they have further opportunities to learn about new developments and best practice, and to share with leading clinicians and scientists the needs of advocates across the whole field of breast cancer. As a result of this transfer of knowledge and skills, very many women are working hard every day to develop access to best-quality diagnostic and treatment services in their own countries.

Advocates see things differently and can therefore give professionals a new perspective on the doctor-patient relationship, to the benefit of everyone. Advocates have affected this relationship, and have put breast cancer on the political agenda by highlighting many aspects of the breast cancer journey. This has made all disciplines involved refocus, something that has become increasingly evident during these recent years of ED's advocacy We now see acceptance of our role in many spheres of breast cancer right across Europe. But we are not complacent and there is still much work to be done. Our intention in ED is to continue this work, to go on building on these relationships. Partnership and collaboration, trust and cooperation advance steadily; they are vital elements of this process and will go on being ED's aim.

As our Vice-President Stella Kyriakides said when she spoke in the European Parliament: 'This is not about my breast cancer—it is about everyone's breast cancer'.

Advocacy for breast cancer will be needed as long as breast cancer exists. As the European breast cancer advocacy organisation, ED will continue to play a full part in the battle against this disease, the commonest cause of malignancy amongst the women of Europe.

Acknowledgements

Susan Knox, Executive Director, EUROPA DONNA. The Staff of EUROPA DONNA at Head Office. National Fora of EUROPA DONNA, the European Breast Cancer Coalition [7].

Appendix

The Board of EUROPA DONNA, the European Breast Cancer Coalition, December 2003:

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References

1. http://cope.uicc.org/share
2. Braun S. The history of breast cancer advocacy. *The Breast Journal* 2003, **9**(Suppl. 2), s101–s103.
3. http://www.susanlove.md.org/living/k_htm
4. www.eusoma.org
5. www.cancerworld.org
6. www.eortc.be
7. EUROPA DONNA: the strength of its Heterogenicity. *European Journal of Cancer* 2004, **40**, this issue (doi: 10.1016/S0959-8049(03)00674-9).