Answering the advocates
Marco Rosselli del Turco, EUSOMA’s new president, on the future of specialist breast units
Aron Goldhirsch, Director of the Department of Medicine, European Institute of Oncology, on the latest clinical trials

Another look at health economics
Living with breast cancer
Advocacy tools
News from member countries
Ten Goals of EUROPA DONNA

- 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 understand fully any proposed treatment options, including entry into clinical trials and their right to a second opinion
- To promote the advancement of breast cancer research

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EUROPA DONNA has already achieved a great amount since its foundation as the European Breast Cancer Coalition, 15 years ago – an initiative begun by the renowned surgeon Umberto Veronesi. He acknowledged the importance of the role of the patient advocate as a spokesperson for the interests of breast cancer patients. Starting with a small group of member countries, EUROPA DONNA has grown to become a professional organisation with 43 member countries! Albania and Kyrgyzstan have joined our Coalition in the last 6 months and I wish them both a warm welcome. I hope that their membership in EUROPA DONNA will be a source of inspiration in their advocacy for the best breast cancer services in Albania and Kyrgyzstan.

In the last 15 years, EUROPA DONNA has become a partner in numerous European and national organisations of health professionals and researchers dealing with the improvement of breast cancer services. Advocating for best practice is an ongoing effort and educating both the advocates and the caregivers is the way to achieve improvements. Attending conferences is an excellent way to keep informed about new treatments and the latest developments in breast cancer care. Several Board members attended the annual Breast Cancer Symposium in San Antonio, USA, in December 2008. The symposium includes special patient advocate mentor sessions where all the scientific updates are discussed in a patient-friendly manner.

Together with Board member Galina Maistruk, I attended the Interconference Breast Cancer Meeting (IBCM) held in the Parliament Building in Sarajevo, Bosnia and Herzegovina. The conference programme was set up for oncology professionals, breast cancer nurses and patient advocates. As a patient advocate, I had a role in the scientific programme and I acted as the patient expert in a tumour board roundtable discussion. It was an excellent opportunity to highlight the patient’s perspective on the treatment journey, both in primary and advanced disease.

The session chaired by Galina Maistruk, “Fundraising in countries with limited resources”, and the session chaired by myself, “Guideline implementation and advocating for breast health”, gave rise to lively discussions about the opportunities for (patient) advocates to influence breast cancer services in their own countries. The conclusion was that there are significant differences in the level of breast cancer services between countries. This large inequality in levels of services made me all the more aware that the advocacy needs and immediate priorities are different among member countries, depending on the level of breast cancer services and guidelines for these that already exist locally. To help in this regard, the Board decided to set up a Working Group on Forum Support this year with the aim of addressing individual Forum needs and assuring that all member countries take as much advantage as possible of the key advocacy programmes provided by EUROPA DONNA.

National Representative Day is also an excellent tool to provide member countries with information and an opportunity to exchange experiences on advocacy activities on a national level. The second National Representative Day will take place in Stockholm, prior to the biannual Pan European Conference entitled “Communication and Collaboration”. I would encourage all the National Representatives to take advantage of this opportunity to extend their knowledge about advocacy and to share the experiences in their countries.

As I emphasised above, communication is of great importance to advocates, and collaboration is equally important. The collaboration on the European level, between the member countries and EUROPA DONNA itself, the board and the staff, has helped us reach the point that the needs of patients during the breast cancer journey are far better met than they were 15 years ago. Thanks to all of you, especially to the Executive Director, Susan Knox, and the staff at the office in Milan.

Breast cancer has not been eradicated yet. Since many patients still do not have access to best practice in breast cancer services, EUROPA DONNA must continue its work toward making best practice available for all breast cancer patients.

Let us continue our efforts for best practice through collaboration and communication!

“EUROPA DONNA must continue its work toward making best practice available for all breast cancer patients”
Advocacy in Action

Executive Director Susan Knox

At the end of 2008 the EUROPA DONNA Head Office moved to its new and more spacious offices in Milan, Piazza Amendola 3. It is a pleasure to be in this new environment and any members who are in the Milan area are welcome to come to visit us. Our activities continue to grow and expand, starting with the launch of our Breast Health Day and National Representative Day on 15 October (please see www.breasthealthday.org for more details on this activity). Over 2,500 copies of our new Guide to Breast Health have been distributed during the year and copies can be obtained at Head Office. In addition, our first public service announcement was aired across Europe urging women to come to our website to find information contained in the Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

We continue to make progress on our key priorities. Advocating for implementation of specialist breast units is especially important, and we are working toward understanding better how to move this forward and what obstacles need to be overcome. In January we participated in the EUSOMA workshop held in Milan to study the woman’s perspective on and expectations of breast units. We continue our translation project to see that the Short Guide and information concerning this is accessible to women in our member countries. This year we will carry out a survey on breast unit implementation, will discuss it at a workshop during our upcoming Pan European Conference, and it will be the focus of several ED presentations next year at EBCC-7.

Among the important services provided by a breast unit is ensuring access to treatments that have been proven effective. For this reason we need to better understand how health economic decision making is carried out in all of our countries. ED continues to study this subject and participates in various types of initiatives addressing it (see page 11).

Implementation of our Strategic Plan continued with the initiation of a new development project to research and carry out grant applications to diversify our funding. A meeting for all of ED’s current sponsors will be held in September during ESMO-ECCO and is designed to update them on our various projects and annual work programme which they support.

In addition, we are expanding our commitment to support our national groups and add new members. Today we have 43 member countries as we have recently welcomed Albania and Kyrgyzstan to our Coalition. ED has published a new introductory brochure about our organisation to be distributed at various conferences as well as a membership kit that we will give to new members starting up or to those re-activating. Our EUROPA DONNA website www.europadonna.org has recently been re-established as a totally independent site outside Cancerworld.

This March we participated in the European Commission Stakeholder Meeting on Action against Cancer which is due to evolve into a European Partnership project on cancer later this year. Our involvement in several oncology groups provides us with current information on National Cancer Plan development as well as other research issues of concern to breast cancer patients. Several advisory groups are looking at the needs of metastatic breast cancer patients; we want to ensure that we are responding to the advocacy needs of all breast cancer patient groups and will begin discussing the needs of this group in more detail at our upcoming Pan European Conference.

Our plans for 2009 Breast Health Day are well under-way and will include a co-ordinated, multi-national media/public relations campaign designed to reach a wider European audience. It is essential that we work toward a public understanding that a significant percentage of breast cancer diagnoses can be prevented through a healthy lifestyle, especially regular exercise and avoidance of obesity. The 2009 campaign will include a central media event featuring celebrity testimonies as well as some messages and activities that can be accessed by Internet to encourage a healthier lifestyle.

Finally, we look forward to our 9th Pan European Conference in Stockholm on 24–25 October, where we will celebrate 15 years of EUROPA DONNA – 15 years of Communication and Collaboration with members and all those engaged in the fight against breast cancer. I look forward to seeing everyone there.
Collaboration between advocates and scientists: targeting women’s needs

EUSOMA

EUSOMA is the European Society of Breast Cancer Specialists. It has been very active in setting standards for specialist breast units across Europe to the extent that its Requirements of a Specialist Breast Unit, developed with input from EUROPA DONNA, are included in the fourth edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. The Society has also developed and is implementing a certification system for specialist breast units. EUSOMA holds workshops on various topics, from mammography screening to specialist breast units, in which EUROPA DONNA regularly participates. EUSOMA and EUROPA DONNA, in partnership with the European Organisation for Research and Treatment of Cancer (EORTC), also organise the biannual European Breast Cancer Conferences, which are unique in uniting scientists, researchers and advocates in the same setting.

BIG, TRANSBIG and IBCSG

These international breast cancer research groups have the common aim of promoting international collaboration in conducting trials that focus on the needs of women with breast cancer, on improving treatment, quality of life and survival. EUROPA DONNA has representatives on the Steering Committee, the Legal/Ethics Committee and the Spreading of Excellence Committee of TRANSBIG and the MINDACT trial. EUROPA DONNA Past President Ingrid Kössler is an elected member of the Foundation Council of IBCSG, and is the first advocate to represent EUROPA DONNA on the Council. IBCSG is dedicated to innovative clinical cancer research designed to improve the outcome of women with breast cancer. EUROPA DONNA encourages the participation of advocates in trial committees in order to ensure that women’s needs are addressed.

EUROPA DONNA has long recognised the importance of synergy between scientists, researchers and advocates and strives to ensure that the advocate’s voice reaches research circles. This is made possible in part through its work with the European Society of Breast Cancer Specialists (EUSOMA) and with international trial groups such as Breast International Group (BIG), the translational research consortium TRANSBIG and the International Breast Cancer Study Group (IBCSG). It is also part of three of the Coalition’s advocacy priorities today: mammography screening set up in accordance with EU guidelines, establishing specialist breast units in all countries as specified in the EU guidelines, and furthering breast cancer research. With this in mind, this year’s Answering the Advocates spoke to the new EUSOMA President, Dr. Marco Rosselli Del Turco, about progress with specialist breast unit implementation and other initiatives, and to the Director of the Department of Medicine at the European Institute of Oncology, Prof. Aron Goldhirsch, about ongoing trials, addressing women with special needs, such as those with metastatic breast cancer, and fostering participation in clinical trials.

Marco Rosselli Del Turco

Aron Goldhirsch
Answering the Advocates

EUSOMA and EUROPA DONNA: scientists and advocates striving for the same goals

Dr. Marco Rosselli Del Turco is the new President of EUSOMA. As a radiologist, he first became interested in breast cancer screening, early detection and prevention in the 1970s. Since then he has been very active in European breast cancer initiatives, including authoring the radiology chapter in the European guidelines, founding and serving as Vice-President of the European Reference Organisation for Quality Assured Breast Screening and Diagnostic Service (EUREF), and founding the European Group for Breast Cancer Screening. Dr. Rosselli Del Turco is also a regular speaker at the EUROPA DONNA Annual Advocacy Course. EUROPA DONNA's Answering the Advocates had the chance to talk to him about the common aims of our organisations and furthering the implementation of specialist breast units.

EUROPA DONNA: As the new President of EUSOMA, what are your priorities for the organisation?

Marco Rosselli Del Turco: Our aim is to try to improve the quality of life and of care for women with breast cancer. With this aim we are doing many things, such as developing guidelines and certification of breast units. Another aim is to promote the culture of expertise in breast cancer care.

ED: With these aims in mind, EUSOMA held a workshop to learn more about what women would like from a specialist breast unit and a multidisciplinary team. What were the general findings?

MRDT: We are trying to develop the “ideal” breast unit. We have spent a lot of time working on determining best practice in the field of surgery, diagnostics, therapy, etc., but we felt that there was not enough information about how to provide the best answers for women. So we held this workshop and invited doctors as well as nurses, psychologists and women with and without breast cancer.

What we learned in the workshop was that, first of all, women want the different specialists to speak the same language so that when they provide information it is clear and agreed between the different specialists. Women do not like to hear different specialists who may have different information or a different solution for the same problem. The second finding was that women asked for doctors to have more time to listen to their needs, and to take into consideration their problems. Women also want to have easier access to the different services, and for someone to be available to help them during their entire treatment. After the treatment, they would also like someone to take care of them and give them some indication of what they should expect in the follow-up. They also requested having a relative or friend with them to accompany them throughout the treatment and follow-up within the breast unit. These were the main results. We expect to write a document for publication within the year outlining women’s requests for the ideal breast unit.

ED: Did any women suggest the presence of a breast nurse?

MRDT: Yes. This is still under debate because the model of the breast nurse is well established in the UK, but in other countries there are not so many breast nurses. In Germany, a psycho-oncologist is present during all communication, taking notes of the treatment options. So doctors more than nurses do this job. I prefer not to get into a discussion, but I think that the nurse is the best model available. We probably have to define better who is the reference person for taking care of these needs. This could be a topic for a new workshop that EUSOMA could organise to specify the role of the breast nurse and how it should be adopted in the units.

ED: In order to determine what women/patients want and need from a specialist breast unit, have you or do you plan to undertake patient satisfaction surveys in the current units to study how these units are perceived by the users? Would you consider making the use of such
surveys a requirement for all units to undertake on an ongoing basis to ensure they meet patients’ needs? EUROPA DONNA could collaborate on this.

MRDT: A patient satisfaction survey is not yet a mandatory requirement for the certification of the breast unit, because standardised use of this tool and its interpretation is not so easy. We hope we can, in co-operation with EUROPA DONNA, adopt this requirement, provided we can provide a standardised and reliable methodology.

ED: Regarding breast units, the EUSOMA requirements of a specialist breast unit are included in the 4th edition of the European guidelines. Are there any new developments in guidelines for specialist breast units or even for breast cancer, perhaps based on information arising from your workshop?

MRDT: In future guidelines, I think that what should be better developed are the standards, the indicators we use to determine if the quality of care is good or not. We have already held a workshop on this topic, so we already have some material. The second point is in this field of patient support, we should better define the treatment follow-up, the nursing care, the rehabilitation, all the areas that are not sufficiently defined. This could be covered in the new edition of the guidelines.

ED: In the fifth edition, for example?

MRDT: In the fifth edition, but we do not know what will happen with this. Probably, yes, but we don’t have any information at the moment.

ED: Are you aware of any other guidelines that are underway?

MRDT: Yes, on specific issues. We are working on a document on the clinical indications for the use of MRI, and we are working for the optimal treatment for younger and older women. We are aware that younger and older women have specific issues that are still debated. There is probably some undertreatment of older women and at the same time overtreatment in women under 40 or 45. Women of this group and those older than 65 are the groups that we are currently working on.

ED: So you are working on special populations. Are you doing anything for women with metastatic breast cancer?

MRDT: Not at the moment.

ED: As for the implementation of breast units, EUSOMA has also established a certification system for breast units. What is the current status of this programme?

MRDT: At this point we have about 22 units which have already been initially certified. We have eight pending procedures. Most of them are in Germany, but also in Belgium, the Netherlands, Italy and Switzerland. I expect these activities to develop quite a lot.

We are now working on trying to better define the certification procedures so that they are as transparent as possible and also comply with the European recommendations. We are considering separating the certification process from the process of guideline development because the two should not be performed by the same body. We are working on the procedures because if we want to grow, we will have to better define the procedures to comply with the European requirements. We are working on that. I think it will be quite successful.

An interesting aspect is that all the units being certified have accepted to send their data on a regular basis. This way their data can be assessed and they can immediately see how they perform compared to the other units. These data can also be very useful for research.

ED: Could certification in any way help in the implementation of breast units across Europe? Or is this independent of certification?

MRDT: The certification will help in the development of breast units. If people know that they can be certified if they meet the requirements, then this will standardise how the different countries will set up the units. We hope that new breast units will try to comply with our requirements so that the quality will be high and homogeneous. We are trying to push for the highest quality of the breast units, but we also know that this may not be easy in all countries. We are trying to help by having at least common, basic quality requirements that can apply everywhere.

ED: This would be based on the European guidelines?

MRDT: On our guidelines and the European guidelines.

ED: Can you suggest any other ways to have the breast units implemented?

MRDT: This is EUROPA DONNA’s role.

ED: We need help.

MRDT: In this case, we are the ones who need help. We are not advocates. We are involved in the breast units from a medical or scientific context, but not with the public. I think that this is your role. We don’t want to overlap with your activities. We are very happy that you have always supported us in this and we hope that EUROPA DONNA will continue to do this in the future. You have already been successful, along with us, in obtaining the European Parliament Resolution which calls for the implementation of breast units in member states by 2016. I think it is EUROPA DONNA’s role now, with EUSOMA, to see that this is really applied and to undertake the initiatives which are necessary in the different countries to help make this happen.

We hope that new breast units will try to comply with our requirements so that the quality will be high and homogeneous”
ED: We can expand the multidisciplinary aspect to include advocates. As for the multidisciplinary approach to breast cancer care, do you think it is being widely accepted across Europe? Is it being adopted?

MRDT: I am quite pleased to see that many are applying it very well. This is the most difficult aspect, but those really working in the field of breast cancer know very well that this cannot be avoided. You must have a multidisciplinary approach.

ED: Ideally in the context of a specialist breast unit.

MRDT: Yes.

ED: Studies indicate that breast cancer survival is improving, due in part to early detection (see box on this page). Are you aware of any news with regard to breast cancer prevention?

MRDT: In this regard, I am not very satisfied because we know that mortality is decreasing due to early detection and improved treatment but that incidence is rising. We know this particularly for the middle age, between 50 and 69, and incidence is now probably even higher in older women. This is related largely to diet, lifestyle, exercise, etc., but I don’t think there is enough action on this.

We were very happy to learn that EUROPA DONNA has developed Breast Health Day on 15 October. I think we should move forward in that area. The problem is that we need more research in this field and, unfortunately, research is now driven by pharmaceutical companies; it is not independent, so they are not really interested in this area. Something must be done in the public health area that brings more investment to the field of prevention because we must have better knowledge to be able to convince people to improve their behaviour. We should work together on this, on the one hand, to inform the public about what should be taken into consideration, and on the other hand, to try to improve research. If you look, for example, at all the funds that have been received by different medical institutions in Europe through the EU 7th Framework Programme, the portion for prevention is very low compared to other aspects such as research and treatment.

ED: EUSOMA and EUROPA DONNA are in ongoing collaboration with the organisation of the European Breast Cancer Conferences. How else do you see that EUROPA DONNA and EUSOMA can work together?

MRDT: The most important is knowing that we have the same aims but that we are working in different fields. We should continue working on the scientific information, in developing the units, and you should continue with your work lobbying for the units and informing the general public. The aims are always the same. We know them very well. To work better, our actions should be better co-ordinated. If we know more about your programmes and you know more about ours, we can plan our activities without overlapping and create as much synergy as possible.

Primary prevention could also be an area for collaboration. In primary prevention you must approach the general public. EUROPA DONNA has a large role in that. There is still some scientific work to be done. This could be an initiative we could work on together. "Something must be done in the public health area that brings more investment to the field of prevention"

### Results of EURO Care-4 study show improvements in breast cancer survival

Recently published findings from the population-based EURO Care-4 study indicate that breast cancer survival is increasing in Europe. Over the period 1988–1999, five-year breast cancer survival increased from 74% to 83%, according to the analysis of 49 cancer registries in 18 European countries. The study suggested that this increase may be attributed to early diagnosis through screening and to improved treatment.

“In Slovenia, Czech Republic, Poland, England and Scotland, where survival was low in 1989, the survival increase (10% points or more) may be attributed to a wider availability of adequate treatments, as well as earlier diagnosis,” the study noted.

However, it also found that there were still significant survival differences between countries, ranging from 73% in Poland to 85% in Sweden in 1997–1999. The study did indicate, however, that as countries with initially low survival have improved over time, the gap among countries has become narrower.

The EURO Care study began in 1990 and is the largest international collaborative population-based study on the survival of cancer patients.

EURO Care-4 results were published in the European Journal of Cancer 2009, vol. 45. More on the EURO Care-4 results is also available at www.eurocare.it.
EUROPA DONNA: How has or could targeted treatment change the breast cancer experience for women?

Aron Goldhirsch: Breast cancer was the first type of cancer that was targeted in terms of tailoring the treatment to specific biological characteristics of the disease, knowing that if you have this type of target in the tumour you have a greater chance of response. In fact, hormonal therapy was the first targeted treatment which increased the probability of responding to the treatment. Since the oestrogen receptors were discovered in the 1960s, the target-finding has become increasingly more sophisticated. This has helped us to choose better the patients that have a higher chance of response to hormonal therapies.

Now we have other targets against which we have specific treatments. The most important is trastuzumab, a monoclonal antibody against the HER2 overexpressed protein, which allows a targeted treatment based on direct binding of the drug to the receptor and which enhances also an immunological anti-tumour effect. Its availability has dramatically changed the chance of response of the patient and the possibility of giving a patient a treatment which is also less toxic compared with therapies otherwise used for the type of disease in which HER2 protein is overexpressed. So, for efficacy and safety there has been a large benefit for the patients.

The targeted treatments have also evolved in the fields of breast surgery and radiation therapy. There is a significant evolution towards limiting the treatment of the tumour and of the tumour bed while attempting to spare normal tissue. Targeted treatment is a concept rather than only a prescription.

ED: Can any of these targeted treatments apply to the metastatic setting? EUROPA DONNA is concerned about meeting the needs of women with metastatic breast cancer (see box on page 9). Are there any new findings or new trials for this group of women?

AG: The metastatic setting is different from the adjuvant setting, the latter being aimed at definitive cure. Metastases to organs different from the breast and regional lymph nodes imply a chronic disease. The aim of treatment is to control symptoms of disease and allow a longer time of normal or similar to normal life, understanding that for almost all patients the disease will not disappear. Therefore, there are four features of this setting which should be taken into account. The first is that with all the means available today, the patient in fact has a good chance of living longer than in the past, sometimes very long, years and decades. The second feature is that you might use treatments in much more parsimony because you would need to change therapies when the disease progresses and there is a new “mutiny” of the metastatic disorder. Thirdly, you also do not need to perform an excess of specific imaging tests because doing many sophisticated imaging tests (like CT scans and PET scans) will not allow you to better adjust your treatment, and thus may have no real benefit for the patient. One should be aware of the fact that when there is one metastasis of breast cancer detected, there might be a multitude of metastases which are undetectable by current imaging means. There is a real impossibility to be precise by want-
There are many populations where there is very little research because they are not a good niche for business

ED: You are Co-Chairman of the Executive Committee of IBCSG which is an active participant in BIG. In your work through IBCSG are you able to do research that addresses these areas?

AG: Absolutely. We are trying to conduct research which takes into account “orphan” populations and which deals with treatments which are more user-friendly. There are a number of features here. Firstly, we try to convince the pharmaceutical companies that looking for niches of population and a treatment concept might be more useful than looking exclusively at the development of one drug. Secondly, we try to design trials to answer at least two questions rather than one only. The easiest trial design is usually related to a single question on efficacy of one drug compared with a standard treatment. Additional questions related to the schedule, duration and dose of a test drug increase the probability of obtaining answers related to the best use of a drug as well. A trial is a very expensive exercise, not just in monetary cost but in terms of personal investment, patients who are very generous in participatin-
allows putting progress for care and knowledge first rather than other market-related priorities.

Our group, the IBCSG, as well as the consortium of groups, the BIG, maintain this type of discussion as a very high priority in terms of the ethical approach to the field of clinical research. EUROPA DONNA might identify some political and financial targets in society, to help clinical research to be conducted according to such terms. I think that it is a very important message. We need a more patient-friendly and knowledge-friendly, rather than only a business-friendly regulation for clinical research.

ED: Are you aware of any studies underway for prevention of breast cancer?
AG: Prevention is a very interesting and important issue. Prevention involves a normal population free of disease. There are new areas of research in the field and also some new findings. At the St. Gallen conference this year, there was a presentation of lasofoxifene, a brother-compound of tamoxifen and raloxifene, shown to be effective in reducing the incidence of breast cancer in the trial participants. Information on vitamin D at pharmacological doses indicates that it might also be useful for prevention of breast cancer. Data on the so-called metabolic syndrome have led to an interesting hypothesis that an anti-diabetic drug, such as metformin, might be useful for preventing cancers. Investigations with this drug are underway.

ED: EUROPA DONNA is aware that some women are very interested in participating in clinical trials, yet might not have access to information about them. Can you suggest how they might find more information about accessing new trials?
AG: For women who are aware and want to keep an increased involvement in awareness, taking part in an interest group like EUROPA DONNA is very important. It is the role of EUROPA DONNA or other advocate groups to increase awareness about importance of clinical research. It can be best done by participating in the discussion of new trials, by participating in steering and ethics committees of research groups. This allows them to receive information while discussions on a given trial are ongoing, leading to a better understanding of all issues involved. Participation means also developing communication on new clinical research. Shared responsibility with clinical investigators leads ultimately to better conducting of research.

ED: EUROPA DONNA is fulfilling this role now by being involved in a number of steering and ethics committees and with different research groups.
AG: There already is a very interesting involvement. We always try to involve members of EUROPA DONNA in our activities through the steering committee and ethics committee, therefore exposing them to all the issues related to the development and conduct of trials. Such involvement in the scientific as well as the ethical and social aspects of research, might lead to improved support of clinical trials. A main role of EUROPA DONNA is indeed to bring the information on these subjects made as understandable as possible to every woman who needs it.

In the recent Bridge Survey, more than two-thirds of women with metastatic breast cancer (MBC) said they would like more public awareness of this disease. The survey results further confirm the needs identified and described in a consensus group report by the Metastatic Breast Cancer Advocacy Working Group, of which EUROPA DONNA is a member. EUROPA DONNA has recognised these needs and has also included metastatic breast cancer advocacy in its upcoming Pan European Conference programme.

The Bridge Survey involved 950 women with MBC in nine countries: the United Kingdom, France, Spain, Belgium, Poland, the United States, Argentina, Egypt and Mexico. It found that more than 50% of the women surveyed believe that MBC receives too little public attention, 44% are afraid to talk openly about their disease, 45% have difficulty finding information on MBC, and 51% said that the information they find is inadequate. They reported they would like to see more written materials on MBC, MBC support groups, educational public service announcements and conferences held for people with MBC, among other resources.

Almost 100% of women with early stage breast cancer in developed countries will eventually develop stage IV or metastatic breast cancer, while in developing countries, the majority of women with breast cancer have advanced stage or metastatic disease at diagnosis. Of the women surveyed, about two-thirds stated that despite the negative effects MBC has had on their lives, they are still able to enjoy life, and half of them consider themselves to be cancer survivors.
1991. I was diagnosed with cancer in my left breast. I underwent a lumpectomy and all the nodes were removed. It was ductal carcinoma in situ. I had radiation as adjuvant therapy.

Nine years later, I experienced a recurrence in the same breast and this time had a mastectomy. It’s not easy losing a breast; first of all for my husband, it was like a daily reminder of my cancer and he was so afraid to lose me. It also raised issues regarding sexual self-image and feminine identity, and even with a breast prosthesis, I feel so lopsided. But the only option for breast reconstruction was TRAM flap, which is quite heavy surgery. And then a little blond Tristan (the son of our son) was born. It was love at first sight! I decided that I had had enough surgery for a while.

Some 18 months later a small growth appeared, a pea-size lump, in my mastectomy scar. I was so shocked: the cancer was back. As feared, 6 months later I was diagnosed with metastatic cancer recurrence. When I asked if being cured of this kind of cancer could be a realistic goal, the answer was: probably not. I was told the average length of survival was 2–3 years. It may also vary considerably based on tumour behaviour. So I asked tons of questions. I tried to find as much information as possible, and thanks to EUROPA DONNA and the American Cancer Society I found answers to my questions.

So, okay, stage IV breast cancer it is. I said, “And now what’s next?” There is no next: it’s systemic recurrence! Am I going to die? It was frightening for both my husband and me. So I decided to change both oncologist and hospital so as to find the best treatment and do everything I could. I wasn’t ready to give up! At that moment keeping a diary, where you can be as honest as you want, was a very therapeutic way to release my anger, fears, frustrations and my innermost thoughts, and also clarify my observations, experiences and options.

Systemic therapy was recommended, so I got a port (imagine a Frankenstein sort of a bolt near your collarbone. I know it’s a bad joke). Chemotherapy, hormonal therapy, MRI, scans, PET scan, bad news, good news, new treatments, my mood changing moment to moment, dealing with fatigue, nausea, 13 pounds plus, a breast minus, kept me quite occupied.

I was very lucky to have “the best” of the oncologists (thanks to you, Prof. M. – I owe you). In addition to listening to you, doing everything I was supposed to be doing, having chiropractic, acupuncture, stress relieving treatments, dietary adjustment, I also exercise, I walk (thanks to you both, Monique and Laurence) and I try to keep that part of my health in good shape.

You know, metastatic cancer produces a roller coaster of emotions that can shake the foundations of your world. I was told it could be like living with a chronic disease. The goal of chemo or hormonal therapy was to help me live as well as possible for as long as possible. But sometimes, it’s like having an unpinned grenade in your palm; you always have to hold it tightly.

From the beginning, what helped me get through was the support and love of my husband, sons, daughters-in-law and most of all, you, my grandchildren...That strong backbone to hold me up whenever I was ready to fall down. Some friends were not able to handle the news of my illness (too long...?) and they drifted off. But with the “self-help group” I organised, I was surprised to discover new friends, some who have been through similar experiences. Most challenging was not falling into that sad place of self-pity. When I have these bad moments I have to accept them, acknowledge them and then get rid of them. I’m not the same person anymore. I discovered that a good life is not the same as an easy life. I have more of an appreciation for the present instead of feeling badly about losses or mistakes in the past, or anticipating what might happen in the future. There is no way to get around it; my only option is to get through it by helping other women with breast cancer along the way.

2009. Port still under my collarbone, 41 shots so far – once a month – of hormone therapy later, I’m still around! My husband, who sometimes feels helpless and powerless, Tristan, Anais and now, you, baby Prune, you all are what keeps me going.

Christiane S., Paris, France, with granddaughter Prune
EUROPA DONNA supports role for advocates in health economic decision making

Health economics and access to new treatments have been continuing priorities for EUROPA DONNA in 2009. At the The Prague Conference on Securing Europe’s Healthcare Future, held under the auspices of the Czech Presidency of the EU Council, EUROPA DONNA Executive Director Susan Knox was invited to present the advocate’s perspective and a response to the report “The Future of Health Technology Assessment in Europe” which was released at the meeting. She supported the proposal that all stakeholders, including patient groups, should be involved in the health technology assessments (HTAs) that influence health reimbursement decisions. She also suggested that countries should work toward unifying health assessment standards by creating guidelines.

“Guidelines can help in convincing health systems to adopt standards the EU has agreed upon. We have seen this in our work with the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. Advocates, when they are involved in the entire process, can then be instrumental in gaining implementation in the various countries,” she said.

The report which was presented by one if its authors, Dr. Panos Kanavos of the London School of Economics, supports the inclusion of patient groups in conducting HTAs: “Stakeholders (patient groups, medical sector, industry) should have the opportunity to actively participate in HTAs, submit evidence, as well as comment on draft reports and be able to access the rationale for the final decision.”

The full report analyses the health technology assessment methods available in Europe today, focusing on nine EU countries with national or regional HTA networks or systems: UK, Germany, France, Italy, Spain, the Netherlands, Sweden, Denmark and Finland. From this, the report considers the future of HTAs and how to improve international collaboration.

Many countries now have HTA systems to help them identify the most cost-effective treatments and how they rank with other available options. HTA systems most typically take into account safety, efficacy, cost, and cost-effectiveness of an intervention, as well as its societal, organisational, legal and ethical implications.

The report states that with the increasing use of HTAs, methods can be compared and best practice for HTA can be defined. It is important to have agreement on best practice since reimbursement of treatment approaches is now greatly dependent on HTA. With this in mind, Dr. Kanavos’s report identified 15 main principles that are important when conducting HTAs, some of which include using appropriate methods for assessing costs and benefits, monitoring the implementation of HTA findings, and appropriately communicating HTA findings to decision makers.

The report also proposes developing international standards for HTA methods, with the eventual step of having common decision making, similar to what now exists for drug licensing in the EU. The EUnetHTA project is now attempting to increase international HTA collaboration.

In her response, Ms Knox emphasised the main principles of particular concern to patient advocates: the importance of HTAs being unbiased, of their being undertaken independently of the body making, adopting, paying for and implementing the HTA decision, and being independent of affordability.

“This research provides the public and professionals with a much needed body of information about health technology assessment programmes as they are configured today, as well as pointing out the many gaps that need to be filled in order for such technology to ensure proper assessments will be used in health economic decision making across Europe. It will thus lead to the important goal of patients receiving and having access to all the most effective treatments and therapies that are available today,” she said.

The report was one of two reports presented at the meeting, which was part of a conference series that began in 2005 with the aim of providing policy makers with new research indicating practical solutions for health care sustainability.

The full report The Future of Health Technology Assessment in Europe, by Panos Kanavos, Ulf Persson and Michael Drummond, can be accessed on www.sustainhealthcare.org
Making our Voices Heard
Tools for Advocates

EUROPA DONNA’s Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis has now been translated into eight languages, French, German, Greek, Italian, Polish, Spanish, Swedish and Turkish, and translations into Dutch, Georgian, Russian and Slovenian are underway. Two of EUROPA DONNA’s main advocacy priorities are encompassed in these guidelines: establishing population-based mammography screening programmes and establishing specialist breast units in all countries set up according to the EU guidelines.

The advocate’s voice in scientific journals: reaching the scientific community
Breast cancer advocates have made great progress in communication with each other, policy makers and scientists, and in reaching consensus on key objectives such as those described in the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. It is essential that their views reach the scientists, researchers and health professionals who are so actively involved in fighting this disease on an ongoing basis and on a variety of topics.

Advocates have special insight to provide and, as confirmed at a recent editorial meeting of The Breast, are encouraged to submit articles for publication in the Viewpoints and Debate section of this journal. For more information please see http://www.elsevier.com/wps/find/journal-description.cws_home/623010/authorinstructions.

An article on health economic decision making by Susan Knox has been published in The Breast 2009, 18: 71-2.

Advocate’s voice at AACR
Scientist to Survivor meeting
ED Vice-President Christine Murphy-Whyte attended the 11th Scientist to Survivor Programme at the American Association of Cancer Research meeting in Denver, USA, on behalf of EUROPA DONNA. ED has sent a representative to this meeting for many years and it remains an important opportunity for advocates to gain insight into all aspects of cancer research. Twenty-seven survivors attended, including three from Europe.

In her impressions of the meeting, Christine pointed out “the phenomenal impact of the Genome Project, not only on what is researched, but how it is researched and the extraordinary accelerated pace of current cancer research.” Christine’s other impressions are posted on

As part of its information and education campaign EUROPA DONNA also seeks to improve awareness of breast cancer prevention and ensure that women diagnosed with the disease have access to information. Its Guide to Breast Health focuses on lifestyle factors, dealing with a diagnosis, clinical trials, advocacy and other key areas for women.
EUROPA DONNA
Advocates on the Move

October 2008
15 National Representative Day – Milan
15 Breast Health Day Media Launch Event – Milan

November 2008
7-9 Advocacy Training Course – Milan

December 2008
10-11 EU Open Health Forum, attended by Susan Knox and Ellen Verschuur – Brussels
11-14 31st Annual San Antonio Breast Cancer Symposium, attended by Ingrid Kössler, Sema Erdem, Simona Creazzola and Sanja Rozman – San Antonio, Texas

January 2009
9 EBCC-7 Executive Scientific Committee Meeting, attended by Ellen Verschuur and Christine Murphy-Whyte – Brussels
17-18 EUROPA DONNA Executive Board Meeting – Milan
21 Oncology Public Policy Advisory Board, attended by Susan, Knox – Brussels
21 EU Health Policy Forum Meeting, attended by Christine Murphy-Whyte – Brussels
26-27 EUSOMA Workshop “Breast Unit: The Woman’s Perspective”, attended by Susan Knox, Christine Murphy-Whyte, Sema Erdem – Milan

February 2009
17-18 Securing Europe’s Healthcare Future Conference/Czech Presidency, attended by Susan Knox – Prague
23 Cancerworld Video Conference, participants Susan Knox and Karen Benn – Milan

March 2009
10-11 Improving Patient Care by Sharing Skills and Expertise, attended by Susan, Knox – Warsaw
10 TRANSBIG/MINDACT Steering Committee Meeting, attended by Christine Murphy-Whyte – St. Gallen
11 BIG Scientific Meeting, attended by Christine Murphy-Whyte and Ingrid Kössler – St. Gallen
11 European Commission Meeting for Stakeholders on Action Against Cancer, attended by Susan Knox – Luxembourg
11-13 Primary Therapy of Early Breast Cancer: 11th International Conference, attended by Ingrid Kössler – St. Gallen
12 Patient Advisory Committee Meeting – ECCO 15/ESMO 34, attended by Ellen Verschuur – Brussels
13 VZW-Breast Cancer Working Group General Assembly, attended by Susan Knox, Ingrid Kössler and Nicole Zernik – St. Gallen
13 Editorial Board Meeting for The Breast, attended by Susan Knox – St. Gallen
18 Public Health Executive Agency of the European Union Information Day 2009, attended by Karen Benn – Luxembourg
19 Metastatic Breast Cancer Advisory Board Meeting, attended by Susan Knox – New York
26 European Patients’ Forum’s Annual General Meeting, attended by Karen Benn – Brussels

April 2009
18-22 American Association for Cancer Research Annual Meeting, attended by Christine Murphy-Whyte – Denver, Colorado
23-25 2nd Interconference Breast Cancer Meeting (IBCM), co-chaired by Galina Maistruk, with presentations by Galina Maistruk, Ellen Verschuur and Mojca Sencar – Sarajevo

May 2009
7-9 IMPAKT Breast Cancer Conference, attended by Astrid Schapartgen – Brussels
14 EU Health Policy Forum Meeting, attended by Ellen Verschuur – Brussels
14-15 Oncology Patient Advisory Meeting, attended by Susan Knox – Rome
19 Tapestry Network: Breast Cancer Working Group Meeting, attended by Susan Knox – Paris

June 2009
10-11 European Breast Cancer Advocates Summit, attended by Susan Knox, Ellen Verschuur, Sema Erdem and Sanja Rozman – Zurich
13 EUROPA DONNA Executive Board Meeting – Milan

July 2009
9 Tapestry Network: Breast Cancer Working Group Meeting, attended by Susan Knox – London

September 2009
20-24 ECCO 15/ESMO 34 Presentations by Ellen Verschuur, Ingrid Kössler, Sanja Rozman and Stella Kyriakides – Berlin
20 TRANSBIG Committees Ellen Verschuur and Susan Knox – Berlin
20 Breast International Group (BIG) Scientific Meeting Ellen Verschuur – Berlin
21 EUROPA DONNA Sponsor Meeting Ellen Verschuur and Susan Knox – Berlin
22 VZW-Breast Cancer Working Group General Assembly Susan Knox, Ellen Verschuur, Ingrid Kössler and Nicole Zernik – Berlin

October 2009
15 Breast Health Day Europe-wide
16 EU Health Policy Forum Meeting Ellen Verschuur – Brussels
23 National Representative Day Stockholm
24-25 9th EUROPA DONNA Pan European Conference Stockholm
At EUROPA DONNA’s first National Representative Day, 32 National Representatives and Delegates participated in the one-day training programme and information exchange, where they heard about the current policies of EUROPA DONNA regarding sponsorship, use of the EUROPA DONNA logo, and activities regarding promoting implementation of the EU guidelines. They were also quizzed on their familiarity with the EUROPA DONNA constitution using an interactive electronic voting system. Former Presidents moderated workshops in which each National Representative gave a brief overview of her Forum’s current projects, issues and needs, and delegates were able to share ideas and approaches to common obstacles. National Representative Day is designed to reinforce the unity of the EUROPA DONNA Fora and also provide support to the Fora.
Albania

The meeting “Cancer in Albania as seen by patients” was held on 16 April with the aim of informing the public about the reality of cancer in Albania, the chances of recovery, the different psychological and social issues of cancer patients and their experiences. We also aimed to inform about the insufficient medication, Oncology Service conditions, as well as about discrimination in the workplace. Sixty people, including physicians, social workers from the Oncology Services, psychologists, deputies from the University of Social Sciences, and representatives from ED Albania, participated in the meeting. A special participant was the First Lady of Albania, Mrs. Teuta Topi, who discussed special treatments and the legal implications of their use. Other presentations covered such topics as patients’ rights legislation, the meaning of life of cancer survivors and personal experiences, with the main subject being the poor quality of oncology services in this area. The meeting attracted much media attention. It also helped in establishing communication between ED Albania and Oncology Service employees, and in urging the public to learn more and to get more involved in cancer issues. A note of protest against the low budget, the lack of transparency of the Oncology Services, and their failure to consult with the interest groups was composed and signed, and is to be published in the press.

Austria

ED Austria carried out a number of activities in 2008. For our photo exhibition “Breast-Friends – Friendship for Life” (Bilder von Freundschaften fürs Leben), Austrian photographer Gabriela Koch shot portraits of 15 women with their breast-friends. The exhibition was shown in all eight Austrian counties and each opening ceremony involved an information event on the aims of EUROPA DONNA. We hope to have it nominated for the next Nathwani Prize. We also attended a Women’s Health Fair organised by the City of Vienna with the exhibition and information booth. Our advocates also attended EBCC-6 in Berlin, Breast Health Day in Milan and two attended the Advocacy Training Course. We give advice to women seeking information and guidance, such as which Austrian hospitals offer state of the art multidisciplinary treatment. We have been networking with Austrian institutions that are involved in breast health, and have issued press releases and had coverage of ED issues in magazines, newspapers and on television. We were a cooperating partner in the Austrian Pink Ribbon Tour 2008. In addition, we developed our website and had two DONNAS published. Every year the Austrian Society of Senology awards a piece of journalism and in 2008 all awardees were based on reports about the ED Breast-Friends initiative (see www.europadonna.at).

Belarus

EUROPA DONNA Belarus was founded in April 2008. In September and October 2008 we developed materials for breast cancer awareness, including a poster. These posters were displayed in the 30 busiest...
bus stations in Minsk. On four occasions, volunteer groups visited the Minsk oncology dispensary to support women and involve them in breast cancer advocacy movements. “HealthWise” – healthy life style materials – were also translated and prepared for lectures. We also held four educational breast cancer awareness lectures for 300 women. Tamara Serhzan, ED Belarus National Representative, attended Breast Health Day in Milan in September 2008 as well as the Advocacy Training Course in November 2008.

**Belgium**

ED Belgium was involved in a number of activities in 2008 and into 2009. In early October 2008 at the Belgian Breast Meeting, a symposium organised for medical staff, we presided over a session on long-term quality of life and made a presentation on the subject. On 9 October we participated in the Awareness Day Cancer and Prevention organised by the Cancer Support Group of the European Commission. On 10 and 17 October the biannual information day for the public “Action Sein” and “Actie Borst Kanker” was co-organised by the Belgian Foundation Against Cancer. On 12 October we participated in the Breast Cancer walk/run for fundraising for research in Brussels. On 15 October we also took part in the first National Representative Day and the first Breast Health Day in Milan. On 18 October our Annual General Assembly took place and we voted for a partially new board electing Rita De Coninck, Therese Mayer, Françoise Dache, Karine Serck and Vanessa Cipollini as new Belgian and European representatives, Treasurer, Secretary and President. On 22 November 2008 we participated in the Radiotherapy and Oncology congress. Throughout the year we have participated in several smaller medical congresses where we have made presentations on breast health, breast cancer prevention and on long-term quality of life. We also sent two new members to the Advocacy Training Course in Milan.

**Bulgaria**

In 2008 ED Bulgaria encountered problems with financing its activities. As a result, our activities concentrated on actions that did not require funding on our behalf but could contribute to promoting screening and increasing awareness. We undertook activities with members of Parliament and Ministry of Health representatives. The expertise of the members and supporters of ED Bulgaria helps give support to MPs in the discussion of bills and laws regarding public health. Due to the efforts of ED and other patient associations, a national screening programme is scheduled to start in 2009. The other main activities were promotional. Different members of ED Bulgaria participated in TV shows on various national TV stations. A lot of attention was placed on self-examination and raising the awareness of young women about the disease. We participated in different company events aimed at enhancing knowledge about cancer, such as a Health Day organised by a well-known bank. During the year, we also held informal meetings with patients. In many cases, we helped to solve personal problems and gave patients advice about specialist care.

**Cyprus**

The last six months of 2008 were very busy and saw development of our Forum. October, Breast Cancer Awareness Month, saw more advocating for the need to establish a breast unit based on the European guidelines. This was given much press and television coverage and, unfortunately, resistance from part of the medical profession. This did however lead to the rallying of men and women round the Forum and resulted in almost 1,000 people walking in our annual Pink Silhouette walk, held in Larnaca, where we also lit a public building pink. October to November saw the completion of our fourth advocacy course, and all presentations were well attended. The young women’s group is increasingly active and in order to help the women become as effective as possible and deal with their own experience, we also held a course run by a psychologist directed at specialised training of volunteers. We held meetings with the Ministry of Health, and continue to lobby for best practice for the breast cancer screening programme. ED Cyprus has seen the growth of its Breast Friends programme which provides women with prostheses and other support. Many women now contact us before surgery for advice on the guidelines and this we hope will raise awareness further. ED Cyprus volunteers have been very busy meeting requests for awareness about breast cancer.
cancer. We now have prepared a standard presentation based on the guidelines which we use as our advocacy tool.

**Denmark**

The former chairman of Landsforeningen mod Brystkraft (LmB), Lis Truels Jensen, had to resign as chairman because of advanced breast cancer. Sadly, our chairman and friend Lis Truels Jensen died in March this year. We all owe her much gratitude. Our new operating chairman is Karsten Skawbo-Jensen, who is also chairman of Patientforeningen Danmark. This association has the same objectives as ours with regard to a better quality of treatment, patients’ rights as well as information for patients. Furthermore, our chairman is candidate for the EU Parliament. In 2008, we were very active in the media. We were also politically active when we approached Minister of Health Jakob Axel Nielsen, as we had realised that the Cancer Register had not been effectively updated over the past years. The important clinical database Danish Breast Cancer Group (DBCG) lost some of its financial support due to structural reforms in the Danish health care system. We found this to be unacceptable, and we are still fighting politically for increased public financial funding. A new law was adopted about maximum waiting times for treatment of breast cancer patients. We have been quite vocal about the fact that not all hospitals have been able to comply with these rules.

**Estonia**

In 2008 the Estonian Forum continued its close co-operation with the Estonian Cancer Society. May is our Breast Awareness Month, which started with a press conference and the launch of the campaign “Don’t be Late”, advocating advantages of the early diagnosis of breast cancer. For that purpose a film was created by the Cancer Society in which members of our Forum took part. During May, the film was broadcast several times on TV. Articles about breast cancer and interviews with doctors and survivors were published in several newspapers and magazines. It is essential to promote breast awareness among all women and our aim is to reach every woman in the age-group. During this active campaign, the participation rate in the screening programme usually doubles. For the fourth year running, in August, a patients’ summer camp was held. It included lectures, sports activities, music and walks in the forest. Advocates from all parts of the country met there and exchanged their views and experiences. Two fundraising events took place in the autumn: a breast awareness run and a charity concert at a theater concert hall.

**Finland**

ED Finland’s activities have focused on peer support group meetings, 27 of which were held in the centre of Helsinki. Six were dedicated to a theme, ranging from young women, symptoms and medication, to therapy. Eight meetings were held for patients with recurrence. Information on the meetings was made available through our website and brochures delivered to hospitals, libraries and pharmacies. During 2008, 200 people participated in the meetings. Six new peer-support persons were trained during 2008 raising the count of trained persons to 15. Three camps were held in 2008, including fitness and art therapy camps and a camp on Iosaari Island. Fifty-eight women took part. A fitness training group and a water aerobics group gathered weekly. Our Truly Alive programme aimed to support the physical and psychological rehabilitation of breast cancer patients during and after the illness. Fifty participants from all over Finland met in four full-day seminars during the five-month programme. Given the positive feedback, we will continue this programme in 2010. Our Forum participated in events organised by the Parliament’s cancer network. We have also networked and developed co-operation with other cancer associations. The You May Have a Look exhibition portraying women with breast cancer was realized by photographer Leena Louhivaara in co-operation with our association. The three-week exhibition received over 2,000 visitors. Some of our members participated in the launch of Breast Health Day in Milan and the Rope for Solidarity event in Switzerland. Two members participated in Advocacy Training in November. The first issue of the association’s magazine was published in 2008 and was distributed mostly to hospitals and health centres. The association’s name has been changed to Rintasyöpäyhdystys Europa Donna Finland ry.

**France**

After numerous events celebrating our 10th anniversary last year, ED France has re-focused on its day-to-day activities and has increased its actions for breast cancer screening and the implementation of the European guidelines. Throughout France we have raised awareness through our presence in many cancer centres in an attempt to reach not only patients, but also health professionals, who are an important intermediary. The French translation of the “Short Guide” has been well distributed, mainly to politicians, and is the starting point for our discussions for better implementation of specialist breast units in all hospitals, as it describes the minimum standards for best practice and quality care. In early 2009, the second cancer plan was presented to President Sarkozy. EUROPA DONNA was audited and was asked to contribute. We mainly emphasised the importance for women to join the national screening programme and participate faithfully every two years, and the development of breast units in every cancer center. In March, we were offered a fantastic opportunity: a classical concert was arranged at the biggest concert hall in Paris in favor of ED. All singers generously provided their time and skills for an unforgettable event that raised not only funds but also awareness and provided better coverage for ED France.
In Georgia the problem of breast cancer is receiving much more attention than in the past. At ED Georgia we have carried out a number of activities in our attempt to fight breast cancer at the national level. The “Short Guide” has been translated into Georgian. With the collaboration of the South Ossetia administration, women refugees from the war in the South Ossetia region in August were invited for screening. We also participated in the Breast Cancer Experts Regional Meeting organised for professionals invited from different countries of the former Soviet Union. To spread ED’s mission and its 10 goals for improvement of breast cancer awareness and care throughout Europe, we are trying to promote breast cancer advocacy in counties with limited resources. The Breast Cancer Experts Regional Meeting also welcomed women from Armenia and Uzbekistan to become familiar with ED and share ED Georgia’s experience in breast cancer advocacy on the national level. On two popular Georgian TV channels the programmes “Life is Wonderful” and “Diary of a Journalist” were broadcast with the aim of removing the stigma of breast cancer. Our advocates were invited to discuss breast cancer issues from the survivors’ point of view. Our member Mrs Maya Sartania is one of 20 representatives chosen worldwide to participate in the Susan G. Komen for the Cure®. She will represent the Republic of Georgia at the Komen Parliament Café in Budapest. The “Alliance Against Breast Cancer” programme (“Walking Across the Chain Bridge”) was held on 5 October in Budapest. This was a public demonstration of healthy people and patients who collaborate and join NGOs, economic and government organisations, and mobilise the media and well-known individuals. We continued our “Equal Chance Against Breast Cancer” programme for its second year, which was organised for the very poor. There are 40 mammography screening stations all over the country that invite women aged 45–63 years. In 2008 the participation rate was 50%.

In 2008 various breast cancer awareness and advocacy activities were held. For the first time, ED Hellas organised a big social and advocacy gala at the King George Hotel in Athens in April 2008. Politicians of all parties were invited as well as health professionals, media and celebrities. Our aim was to successfully declare our 10 goals as a “life commitment”. A new leaflet was published and distributed with the support of a pharmaceutical company. In September 2008, ED Hellas participated in a large musical event which was held in the Athens Concert Hall. Many volunteer societies participated in that event. In October 2008, there was another large event held in “Pallas”, an old Athenian Theatre, by a medical magazine in order to honour ED Hellas and other breast cancer societies. Finally, ED Hellas participated in various seminars and conferences of other breast cancer societies. ED Hellas stressed the importance of advocacy, drew attention to the needs of cancer patients and emphasised the importance of opposing any socioeconomic and/or geographic inequalities.

In 2008 ED Hungary continued its distribution of two ED booklets in Hungarian. We distributed the Passport to Breast Health to healthy women and Clinical Trials and Breast Cancer to breast cancer patients. We held half-day meetings on complex treatment of breast cancer, nutrition, lymphoedema, movement and self-examination in 10 big cities. Several patient–doctor meetings (“About us but only with us”) were held at the Parliament Café in Budapest. The “Alliance Against Breast Cancer” programme (“Walking Across the Chain Bridge”) was held on 5 October in Budapest. This was a public demonstration of healthy people and patients who collaborate and join NGOs, economic and government organisations, and mobilise the media and well-known individuals. We continued our “Equal Chance Against Breast Cancer” programme for its second year, which was organised for the very poor. There are 40 mammography screening stations all over the country that invite women aged 45–63 years. In 2008 the participation rate was 50%.

Continuing its campaign for specialist breast units, ED Ireland invited key players to come together to outline plans and progress at its 2nd National Conference in Dublin, in September 2008. The Conference “Surviving Breast Cancer” was opened by Minister for Health and Children, Mary Harney, and attracted a lot of media attention and over 170 women, advocates and health professionals from all over the country. Prof. Tom Keane, Interim Director of the National Cancer Control Programme, told delegates he was prioritising breast cancer services in the implementation of the eight specialist cancer centres. Delegates were interested to hear the experiences of Judy Caldwell, founder of the British Columbian branch of the Canadian Breast Cancer Foundation and how advocates had contributed to developing services there. Breast Health Day was marked by a celebrity photo call emphasising exercise...
and healthy eating. Our presentations this year included one on Clinical Trials – The Patient Perspective. We now have the use of an office and have appointed a part-time administrator which will greatly assist us in our work. Our website has been expanded and developed and we hope it will streamline and improve communications with all our members and the public in general.

**Israel**

ED Israel organised seminars and conferences related to breast cancer. More than 800 breast cancer survivors participated in the 2008 “Celebrating Life” seminar. Additionally, hundreds of women participated in our seminars for young breast cancer patients and in a seminar for women at risk. We led a 2008 early detection TV awareness campaign emphasising the importance of having a mammogram once every two years. Mira Ziv, ED’s National Representative, initiated a discussion within the National Oncology Council about the European guidelines. Marking Breast Cancer Awareness Month, Jerusalem’s Bridge of Strings was lit up in pink, in collaboration with Estée Lauder. In addition, 500 women participated in the “Hila” March of the Galilee to promote breast cancer awareness. A network of 40 breast care nurses and social workers who serve as patient navigators is active throughout Israel. With our assistance, the new Reuben Foundation Comprehensive Breast Care Center was inaugurated at Linn Hospital, serving the northern region of Israel. Our Mobile Mammography Vehicle Unit attained additional significant achievements in the compliance rates of women from different sectors of the population. The film “Transparent Time” about a young dancer who coped with breast cancer and recovered, was aired on television.

**Italy**

In 2008, ED Italy participated in many activities, both advocacy initiatives as well as lobbying efforts of the group EUROPA DONNA Parliament. This included holding the 5th edition of the literary prize “Le Donne Raccontano – Women Recount”, a competition dedicated to all women who wish to communicate through writing the unique perspective of the feminine universe. The jury was composed of prominent members from publishing, journalism and the theatre. Hundreds of extraordinary and passionate pieces were received. For “Pink October” the Italian Forum together with ED Parliament and the Italian League for the Fight against Tumours (LILT) organised a seminar at the Italian Senate on “Breast Cancer: Mortality Zero Project”. Participants of the seminar included the President of ED Italy, Maria Giovanna Gatti; Prof. Umberto Veronesi, Senator and Scientific Director at the European Institute of Oncology; Prof. Alberto Luini, Director of the Division of Se-nology at the European Institute of Oncology; Prof. Francesco Schiutalli, President of LILT; and Dr. Patrizia Ravaiolli, Head of ED Parliament. In addition to the above activities, other initiatives for 2008 included: distribution of pink ribbons; providing ED bags for oncology patients; participation in the literature fair to speak about the disease, recovery and written works; collaboration with institutions and companies regarding ways to safeguard the rights of workers with cancer. All activities are described on www.europadonna-italia.eu.

**Kazakhstan**

ED Kazakhstan has managed to get support of the Parliament, and the National Programme for Awareness of Oncological Diseases has been accepted. We have run many working meetings, including a roundtable, conferences and scientific conferences with participation of doctors and patients. The national programme aims to preserve women’s health and to prevent breast cancer and cancers of the reproductive system. Within the limits of this programme we have launched two mobile diagnostic buses which are equipped with modern ultrasound equipment for breast and gynaecological examinations. Buses travel to companies and establishments in remote settlements and areas. The project began in March and plans to survey 10,000 to 12,000 women.

**Kyrgyzstan**

ED Kyrgyzstan was established in April 2009 under the umbrella of the non-profit organisation Ergene. The Chair of Ergene, Mrs Taalaiqul Sabyrbekova, will serve as National Representative and Mrs Saifuna Rysalieva will serve as National Delegate. Our advocacy activities are directed toward breast cancer issues on the governmental level (President’s administration, Ministry of Health of Kyrgyzstan). Our organisation also actively collaborates with local NGOs, the US Embassy, RPX (a US NGO) and USAID. ED Kyrgyzstan plans to advocate in the following areas: spreading of informative materials; organising of phone lines involving leading specialists; elaborating and implementing clinical guidelines on breast cancer at the primary health care level; spreading information on self-examination and clinical breast examination; and providing psycho-oncological palliative support.

**Latvia**

2008 has been quite busy for ED Latvia. Several very important projects were carried out and new ones have been started. The most important projects implemented or supported by ED Latvia in 2008 included the preparation of the newspaper Patient Voice designed for oncology patients and their relatives. Three issues were created. Several information campaigns were carried out for Breast Cancer Awareness Month in October 2008. We also worked with parliamentarians in developing the National Cancer Prevention Programme. A roundtable discussion was held on 4 February for Cancer Day. We have established a good network of journalists through our work with the mass media, including regular-
ly sending them press releases and other important information. We have also been working with other NGOs to find out how to improve our work. In 2009 we will continue to work toward our goals. We are establishing an oncology patient rehabilitation programme. The first rehabilitation camps for breast cancer survivors are to be held in June and others may follow in July or August. Our project “Let’s donate to the fight against cancer” is the first charity Internet shop in Latvia. We will also be carrying out different seminars and information campaigns in October 2009.

Lithuania

ED Lithuania had a busy year working with government institutions and the media. We discussed treatment availability, rehabilitation issues, and raised awareness through articles and interviews. We also had close contact with Lithuanian Parliament and were in touch with a member of European Parliament. We are working with the nurses and doctors of Vilnius University Oncological Institute. In co-operation with breast cancer survivors’ organisations, we held the international forum “Women Against Breast Cancer” and met with ED President Ingrid Kössler. In September, we held our first march against breast cancer, which also launched our fundraising campaign for the Pink Ribbon Society. In October we held our traditional scientifically-practical conference. Also in October an ED Lithuania member and a journalist participated in Breast Health Day in Milan, after which many articles were published in the biggest Lithuanian news portal. In December we backed the publishing of a breast cancer survivor’s book One Breast Story. Part of the proceeds from the sale of the book go to the core biopsy needles project for Lithuanian hospitals. Together with Vilnius International Women’s Association and a pharmaceutical company we raised more than 10,000 euros for this project, which will be implemented in 2009. During 2008 we organised three seminars for patients’ organisations. We published the brochure “Is it breast cancer?” and distributed it for free to all oncological hospitals, patients’ organisations and women’s health doctors. We also helped to establish another patients’ organisation in Kaunas.

Luxembourg

In 2008, ED Luxembourg organised several exhibitions with the paintings of breast cancer patients created during art therapy. This was organised in co-operation with an art therapist, and received large media interest. Another challenge was the organisation and initiation of a water gymnastic course for breast cancer survivors. We participated in conferences on palliative care and lymphatic drainage techniques with health care providers and the general public. In co-operation with different organisations, the film “Bilder, die bleiben”, about a breast cancer patient and her experience with the disease, was shown. A discussion followed. The exceptional exhibition “les Amazones s’exposent” portrayed the right to be different through photographs, paintings and sculptures. Approximately 500 people and many politicians visited the exhibition. During the month of October, the sixth run against breast cancer was held with 700 participants. Afterwards, a roundtable discussion, with specialists in charge of breast cancer patients, promoted physical activity during and after treatment in a health care setting. ED Luxembourg is a member of the working group, co-ordinated by the Ministry of Health, where discussions are held with health professionals to ensure that each woman, wherever she is treated, receives the same information and documentation. We also published three newsletters.

Malta

2008 was quite busy for ED Malta. A translation of the Passport to Breast Health was completed, printed and distributed to those who preferred to have it in Maltese. A major accomplishment for the group was the election of one of the breast care nurses as a member of the committee. Madam President Ms Gertrude Abela also volunteers at the breast clinic, and these two positions were instrumental for us to have better contact and availability with those who need our services. Throughout the year we also worked in collaboration with ABCF, Health Promotion and Dr. N. Delicata (director of the breast screening unit) on common issues like awareness, promoting healthy lifestyles and the setting up of the Breast Screening Unit. During October we held several activities to distribute promotional material and make contact with the public. Stands were set up during the Notte Bianca in Valletta and at Bay Street shopping centre in St. Julians on two different weekends. The highlight of the activities was the annual lecture when the Hon. Secretary for Health announced the distribution of free Herceptin® to all those who can benefit from its use. On several occasions, members of our group were invited to television and radio programmes to talk about ED Malta. By building a good relationship with journalists, coverage of our activities was ensured throughout the year. We also continued giving lectures and organising meetings and outings for our members.

Monaco

ED Monaco supports people affected by cancer, whether they are still in treatment, in remission or cured, as well as their family and people close to them. We now wish to go further than this. We have a major plan to establish a place in Monaco called “Getting Better” to provide people with a place to recharge and to facilitate their return to daily life, sometimes even between hospital stays. It will be a place to listen to meet, for well-being, where they can benefit from specific services and leisure workshops. Our volunteers will work to see that each person can envision a return to a normal daily life, with reinforcement and support.
Advocacy is a main activity of the Dutch Breast Cancer Association of which the ED Forum Netherlands is a part. In 2008 ED Netherlands made active contributions to the improvement of the quality of breast cancer care. We helped to further the development of breast cancer care monitoring, an innovative and unique tool which can reveal all aspects of the quality of breast cancer diagnosis and treatment. The project curriculum for general practitioners was evaluated after two pilot projects and showed that the doctors appreciated the curriculum and felt there was a need for education in the field of breast cancer care. Our members gave their input into a number of projects concerning the purchase of breast cancer services by health insurance companies. We also contributed to developing criteria for excellent care. The quality criteria for diagnosis and treatment from a patient’s perspective, which were published in 2003, served as a model for quality criteria for other patients’ organisations. The national guidelines for screening and diagnosis of breast cancer were compiled in one document and were edited in September 2008. We served on the feedback group updating national guidelines on mamma carcinoma. We also began a new project to create one document from the updated booklet on quality criteria for diagnosis and treatment from a patient’s perspective and a patient-friendly version of the national guidelines. Collaboration and support has been given to a pilot lawsuit concerning discrimination of women older than 75 who are not eligible to participate in the national screening programme. The court rejected this claim, but the court decision was appealed. Action was taken against a general practitioner who offered screening services which did not adhere to the guidelines. The inspector of health intervened and the general practitioner was ordered to stop the practice. Three of our members participated in an international workshop on metastatic breast cancer. Two staff members attended the Advocacy Course in Milan. Work and breast cancer is one of the issues on the agenda of ED Netherlands. Some members will focus on workplace awareness and will offer support in contacts with insurance doctors. The National Health Council has developed a protocol which insurance doctors must use when examining employees with breast cancer. Important issues and a translation of the ED electronic newsletter were published on our website.

Norway

In Norway there are two strong, well-organised associations working for cancer. The Norwegian Breast Cancer Association (FFB) is one of them and is a member of ED Norway, sharing the same goals. FFB is a patient association within the Norwegian Cancer Organisation. FFB has been holding many activities all over the country. We are now looking forward to the Pink Ribbon Campaign, jointly organised by FFB and the Norwegian Cancer Organisation every October. FFB has many volunteers who work for the Pink Ribbon Campaign. From April 2008 to March 2009 ED Norway also co-operated with Professional Nails “Women Support Women” to raise funds for breast cancer research in Norway. We have raised a lot of money with this nail polish, by offering it to family members, friends, members of FFB, and at information booths for our association. In Norway the public mammography screening programme is under evaluation. We are waiting for the results before continuing our lobbying activities for mammography screening starting from age 45.

Portugal

Following the steps we have taken in recent years, ED Portugal continued its information campaigns in the most remote locations in Portugal in 2008. Our main goal was to raise awareness where the need is greatest and where the European guidelines for prevention, detection or treatment are not yet applied to their best. ED Portugal also implemented several lobbying activities in order to promote to Parliamentarians the need for effective and real political changes. Since May 2008 we have increased our contacts with Parliamentarians and 2009 will clearly focus on that change. For a start, in direct co-operation with a group formed by the Portuguese Health Commission and led by Parliamentarian Sonia Fertuzinhos, ED Portugal will promote in June 2009 an awareness event directly at our National Assembly. For that event we also count on the help and participation of two other national NGOs that will uniquely convey several approaches to the breast cancer theme.
**Romania**

In 2008 we continued our project “Renasterea – Breast and Cervical Mobile Diagnostic”, a project that includes an effective national and local media campaign. The programme complies with the European guidelines for quality of specialist breast units, and benefits from the expertise of the medical team of Renasterea Breast Diseases Early Diagnostic Center. Every year we organise different campaigns in collaboration with the Romanian media. Our “Natural Born Beauties” event was a unique project for our country. Twenty-five famous women were photographed without make-up in order to emphasise women’s naturalness and to bring hope to those who have suffered from cancer. The photos were bought at a presentation and the funds were redirected to our programmes. On 1 October 2008, for the eighth time, we illuminated in pink a historical building in Bucharest, as a symbol of the fight against breast cancer. The Illumination of the Triumphant Arch of Bucharest this year aimed to raise awareness among Romanians with regards to breast cancer. The 1st October event brought together Mrs Fran Drescher, US Public Diplomacy Envoy, ambassadors, representatives of public authorities and non-governmental organisations, business people, political, cultural, media and sports personalities.

**Slovenia**

ED Slovenia has increased its membership to approximately 2,110 people. Together with the Ministry of Health and experts, we took part in designing the State programme for cancer control, passing the law on patients’ rights. We participated in launching an organised screening programme (DORA) which started in March 2008. The programme as a whole implements the European guidelines and the first results correspond to the requests and parameters of the guidelines. The programme is now limited to a smaller region of Slovenia. We expect it will be extended to the greater part of Slovenia by 2010. We are also actively promoting two other screening programmes for early cancer detection in cervix, uterine and colorectal cancer. We have established a section for patients under 40 years of age. We are strongly engaged in raising awareness of breast cancer, other types of cancer and in promoting healthy lifestyles through lectures, counselling (via telephone and in person), seminars, newsletters issued four times a year. We are connecting patients in order to make their coping with the distress, inflicted by the illness, and their rehabilitation easier through yoga, courses in ceramics, painting, foreign languages, running and walking for hope, outings, etc. We are active throughout the year. In October each year we try to present our activities to a broader circle of people. We cooperate closely with the media.

**Spain**

On 30 September 2008, a not-for-law proposal on psychological support for cancer patients and their families was approved by all parliamentary groups of the Commission of Health of the Spanish Parliament based on a proposal from the Asociación Española Contra el Cancer. Ana Fernández, of the Spanish Association Against Cancer and Executive Committee member of ED Spain, serves on the NHS Cancer Strategy Technical Committee of the Spanish Health Ministry. This committee is in charge of the follow-up and updating of the Cancer Strategy. She worked on the translation of our Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis and has been actively disseminating it to various groups and the Spanish Health Ministry. Ana will serve as ED’s representative on the National Organising Committee of EBCC-7.

**Sweden**

ED Sweden has increased its membership to approximately 2,110 people. Together with the Ministry of Health and experts, we took part in designing the State programme for cancer control, passing the law on patients’ rights. We participated in launching an organised screening programme (DORA) which started in March 2008. The programme as a whole implements the European guidelines and the first results correspond to the requests and parameters of the guidelines. The programme is now limited to a smaller region of Slovenia. We expect it will be extended to the greater part of Slovenia by 2010. We are also actively promoting two other screening programmes for early cancer detection in cervix, uterine and colorectal cancer. We have established a section for patients under 40 years of age. We are strongly engaged in raising awareness of breast cancer, other types of cancer and in promoting healthy lifestyles through lectures, counselling (via telephone and in person), seminars, newsletters issued four times a year. We are connecting patients in order to make their coping with the distress, inflicted by the illness, and their rehabilitation easier through yoga, courses in ceramics, painting, foreign languages, running and walking for hope, outings, etc. We are active throughout the year. In October each year we try to present our activities to a broader circle of people. We cooperate closely with the media.

**Switzerland**

ED Switzerland undertook several actions during 2008 that aimed to create awareness and lobby politicians. In September the “Climb for Solidarity” led 85 women and some men from 15 European countries to climb the over 4,000-metre peak of the Breithorn in Zermatt. This event was organised by the Swiss Forum of ED and the Zonta Club Morges-la-Côte and received support from the village of Zermatt. In the evening, a roundtable discussion including Swiss cantonal and national health politicians aimed to underline the unmet needs of women with breast cancer in our societies. In October a second event organised by the Berinese group of ED Switzerland dis-
played 1,500 bras (the number of women dying every year of breast cancer in Switzerland) in front of the Federal Parliament in Bern to ask for a nationwide breast cancer screening programme in Switzerland. In reality, their call for people to send in bras collected over 19,000 of them. As political achievements, we have to note that this year St. Gallen, as the first German speaking canton in Switzerland, started with the introduction of a screening programme. In the cantons Bern, Lucerne and Grisons, political movements were on their way to get the respective health ministries to move forward.

Turkey

It has been a year of advocacy in support of a nationwide mammography screening programme. We had a joint project with Breast Cancer Foundations Confederation of Turkey, “Mom and I Can Beat the Cancer”. We participated in awareness seminars for local women in 17 different cities in Turkey, where our Board members presented on breast cancer awareness. At the National Breast Cancer Congress, held in Istanbul, our participation and ED President Ingrid Kössler’s presentation on ED Breast Cancer Awareness was followed by a panel Q&A session. Dr. Serpil Ocal, ED Turkey Board member, lectured on breast cancer awareness in local municipalities in and around Istanbul. We participated in the Cancer Patients’ Platform Conference on problems faced by breast cancer patients, held in Ankara, and took part in ensuring the progress of the patients’ platform for 2009. We also supported the sales of the traditional calendar for 2008. We participated in the annual IWI Christmas Bazaar with the handicrafts and gift items provided by Board members. Songul Icoz, ED Turkey Board member, joined a Cancer Patients’ Seminar. Our Board members met with the head of the Health Commission of the Turkish Parliament to emphasise the need for appropriate screening and early detection of breast cancer and agreed to follow the progress of the EU guidelines in co-operation with the National Cancer Organisation. Our Board members translated the Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis into Turkish. A number of patient seminars were also held.

United Kingdom

The EUROPA DONNA UK Forum 2008 lecture in the series “A European Overview of Breast Cancer” was hosted by Dr. Ian Gibson, MP, Chair of the All Party Parliamentary Group on Cancer. The event featured a panel discussion on “Perspectives on Breast Cancer Detection, Management and Outcome” and speakers included Prof. Mike Richards, CBE, National Cancer Director for England, Dr. Edwige Bourstyn, MD, Breast Surgeon, Hôpital Saint Louis Paris, Stella Kyriakides, BA MED, MP Cyprus and Dr. Galina Maistruck, MD, Chief of Board Women’s Health and Family Planning, Kiev, Ukraine. The event attracted a distinguished audience of politicians, patients, doctors, nurses, advocates and researchers. The presentations highlighted the progress and challenges with breast cancer detection and management in the four countries. The ED UK Forum was involved in a number of Parliamentary events during the year, including a discussion session with the National Cancer Director for England at a meeting of the All Party Parliamentary Groups on Breast Cancer, Cancer and Men’s Health, a reception hosted jointly by the All Party Parliamentary Group on Breast Cancer, Breakthrough Breast Cancer and the NHS Breast Screening Programme which called for the swift and comprehensive roll out of digital mammography to help improve early detection of breast cancer.

Ukraine

As a result of a three-year advocacy campaign organised by local NGOs, including ED Ukraine, a draft of the new law on “Breast Cancer Screening, Treatment and Rehabilitation” was approved by Ukrainian Parliament in January 2009 in the first hearing. According to Parliamentary procedures, the Parliament’s Health Committee established a working group to review and update the draft of the law. The final version of the law will be adopted by MPs in June 2009. Three representatives of ED Ukraine (Galina Maistruck, Nadia Bedrychuk and Svetlana Malay) were included in the working group. They developed proposals for the law based on the European Parliament Resolution on Breast Cancer, the European guidelines and a number of documents on patients’ rights. In particular, we proposed launching the implementation of mammography screening as a national programme and to create breast units. We had a serious discussion with Ukrainian state bodies, including MOH since it presents breast cancer as a part of cancer problem in general. We used media resources, conversations and meetings with MPs to assure them of the priority of breast cancer issues for Ukrainian women. We organised two meetings with regional journalists and representatives of patients’ groups from different regions, which resulted in good media coverage and large support from regional NGOs and cancer centres. Our short-term advocacy objective is the final adoption and implementation of the law. As Ukraine has limited resources, we need to be sure that appropriate state funding will be provided to regional cancer centres.
EUROPA DONNA’s Head Office has moved to a larger office space located in a lovely garden courtyard of an historic building in Milan. The new address and telephone numbers are as follows:

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Breast Health Day
15 October 2009
The aim of the day is to disseminate information concerning breast health and to raise awareness of prevention and early detection of breast cancer among women and girls across Europe.

EUROPA DONNA National Representative Day
23 October 2009, Stockholm, Sweden

9th EUROPA DONNA Pan European Conference – Communication and Collaboration
(see announcement on opposite page)

8th Annual European Breast Cancer Advocacy Training Course
13–15 November 2009, Milan, Italy
Supported by the European Union, the 2.5-day course will cover various areas of importance to breast cancer advocates, including diagnosis and treatment of breast cancer, learning effective communication and public speaking skills, advocacy techniques and media training.

7th European Breast Cancer Conference (EBCC-7)
24–27 March 2010, Barcelona, Spain
Organised by EUROPA DONNA in partnership with EUSOMA and the EORTC, EBCC-7 will convene all stakeholders within the breast cancer field, including patient advocates, clinicians, health professionals and scientists.
Early registration closes 23 October 2009
Regular registration closes 22 February 2010

2nd IMPAKT Breast Cancer Conference
5–8 May 2010, Brussels, Belgium

Inbox Do you have an opinion or news you wish to share?
Let us know info@europadonna.org

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 regarding breast cancer to local and national authorities as well as to institutions of the European Union.

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Communication and collaboration are essential in helping EUROPA DONNA implement the EU Guidelines to ensure that all women in Europe have equal access to essential breast cancer services. At this year’s conference participants will hear outstanding speakers discuss a variety of topics of concern to breast cancer advocates.

**Agenda highlights**

- Mammography screening: past, present and future
- Specialist breast units: spreading information and implementation
- Targeted therapies and clinical trials today
- Breast cancer surgery and radiotherapy: overview of best practice
- Living with metastatic breast cancer: advocacy needs and issues
- Follow-up after breast cancer: what women want
- Lifestyle factors: what we know and what can be done
- Workshops on specialist breast unit implementation and organisational development
- 15th Anniversary President’s Panel

Join us to celebrate EUROPA DONNA’s 15th anniversary in the beautiful city of Stockholm. Experience interesting and inspiring events – communicate and collaborate with advocates from many countries across Europe.

Download the registration form now at [www.europadonna.org](http://www.europadonna.org)

Or contact EUROPA DONNA Head Office for details [conference@europadonna.org](mailto:conference@europadonna.org)
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