10th EUROPA DONNA Pan-European Conference
22 and 23 October – Malta

Answering the advocates: Isabelle Romieu on reducing the risk of breast cancer
Olivia Pagani on treatment and specialist breast units

A survivor tells us about overcoming advanced breast cancer

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Reaching policy makers and the public
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Goals

➔ To promote the dissemination and exchange of factual, up-to-date information on breast cancer throughout Europe
➔ To promote breast awareness
➔ To emphasise the need for appropriate screening and early detection
➔ To campaign for the provision of optimum treatment
➔ To ensure provision of quality supportive care throughout and after treatment
➔ To advocate appropriate training for health professionals
➔ To acknowledge good practice and promote its development
➔ To demand regular quality assessment of medical equipment
➔ To ensure that all women 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
My Presidency began with the preparation of the scientific programme for the upcoming European Breast Cancer Conference (EBCC) in Vienna in 2012. We worked together with our partners, EORTC and EUSOMA, on developing an innovative programme that will include a Clinical Science Symposium on “Barriers to effective care”, where we will discuss why specialist breast units are difficult to implement.

In March, the Forum against Cancer Europe (FACE) invited me to talk about “Women against cancer – women as cancer advocates”. The meeting was held at the European Parliament and led by Sidonia Jedrzejewska, MEP from Poland. This meeting gave me the opportunity to underline the importance of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis and European breast unit accreditation/certification and remind those present that new MEPs should also continue to support the 2003 and 2006 Resolutions on Breast Cancer.

The European Society for Therapeutic Radiology and Oncology (ESTRO) held a teaching course in Lugano, Switzerland and I had the opportunity to present EUROPA DONNA’s priorities and programmes to the members. It was appreciated that I integrated the several health professional and patient advocate perspectives in one vision about the improvement of the breast cancer situation all over Europe. The following day, again in Lugano, I gave a presentation to the Italian-speaking community of doctors, nurses and patients about EUROPA DONNA and advocacy using also the work of the local forum of EUROPA DONNA Switzerland in the Italian-speaking part of Switzerland as an example.

In February, I was invited to visit the Cyprus Forum; there I met with advocate friends, visited the screening programme, and observed the advancement of a specialist breast unit in Nicosia. Finally, I gave a formal presentation at the Bank of Cyprus to patients together with Fatima Cardoso from Portugal. I hope to meet with other fora during my one-year presidency.

In June, I facilitated a patients’ workshop in Vienna and gave a presentation on teamwork in breast cancer care as seen from the advocates’ perspective. The multidisciplinary team has been shown to improve quality of care and to improve patient satisfaction, so it is essential that we advocate for this service to be available to patients. This meeting brought together some of us from different fora and a number from Austria to help prepare for the EBCC congress in Vienna in 2012.

I am looking forward to our 10th Pan-European Conference knowing that our friends from the Malta Forum have wonderful plans for us and that it will be a beautiful conference. This is our main meeting and very important for the exchange of ideas among advocates around Europe. I hope to see many of you in Malta!

In November, the inaugural Advanced Breast Cancer First Consensus Conference will take place in Lisbon, organised mainly by Fatima Cardoso and Alberto Costa. I will serve on the panel of this meeting and hope to put forward several of the topics that are important to and will address the needs of women with metastatic breast cancer.

Finally, let me conclude by saying that I am happy to serve as the EUROPA DONNA President for this one-year term and I hope that I will be able to make a contribution in my capacity as a doctor, but moreover as a public health professional, as a teacher and finally as a woman.
Breast cancer advocacy activities continue to expand and knowledge of best practice is spreading across the map of Europe. Forty-six European countries are now members of EUROPA DONNA. Our main priority is to see that all women have access to high quality breast services, so reducing and overcoming inequalities among all our member countries remains a major challenge. To this end our 25 September 2010 Breast Cancer Advocacy Leader Conference, supported by the European Commission, provided all our country leaders with information and techniques to use in improving services in their countries.

Our Breast Health Day campaign for prevention of breast cancer on 15 October seeks to raise awareness among women of all ages concerning lifestyle factors that have an impact on breast cancer risk. To ensure we reach younger women, ED launched Facebook, Twitter and YouTube campaigns as well as an interactive video. We reinforced this by taking our messages to the European Parliament, distributing pamphlets and hosting a healthy reception with MEP Liz Lynne in October. In December we met with advocates from all over the globe at the San Antonio Breast Cancer Symposium and had a chance to get some of our South American colleagues directly involved in our prevention activities. Our 25 September 2010 Breast Cancer Advocacy Leader Conference, supported by the European Commission, provided all our country leaders with information and techniques to use in improving services in their countries.

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IARC and breast cancer prevention

EUROPA DONNA has always anchored its advocacy work on evidence-based findings. The evidence clearly shows that lives can be saved by preventing breast cancer through healthy lifestyles and detecting it early through high-quality mammography screening. Treatment in specialist breast units as described in the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis improves quality of care and also helps to save lives. The European Parliament Resolutions on Breast Cancer and the Declaration on the Fight Against Breast Cancer in the European Union (0071/2009) call for the implementation of such specialist breast units across the EU by 2016. This and access to new treatments, key priorities for EUROPA DONNA advocacy, should help to ensure that all women have equally high levels of breast care across the continent. They are thus the subject of this year’s interviews for Answering the Advocates.

EUROPA DONNA relies on research and guidance from the International Agency for Research on Cancer (IARC). In keeping with the Breast Health Day campaign, which aims to raise awareness among women and girls that healthy lifestyles can influence their breast health, we approached IARC’s Dr. Isabelle Romieu about the scientific data on breast cancer prevention. There is mounting evidence from IARC’s EPIC study and others indicating that the Breast Health Day campaign is extremely relevant. Physical activity, controlling weight and alcohol consumption, diet and avoiding smoking, as well as the time of exposure, are all associated with breast cancer risk and prevention.

IARC and breast cancer prevention

http://epic.iarc.fr/

The latest in breast cancer treatment and specialist breast units

Since advocates need to remain informed about the latest treatments and trends in breast cancer therapy, for this year’s Answering the Advocates we also spoke to Dr. Olivia Pagani, a medical oncologist. Not only is she head of medical treatment, she is also Clinical Director of the specialist breast unit in Castellanza, Italy. Breast cancer treatment provided in a specialist breast unit by a multidisciplinary team is fundamental for quality. Certification of breast units is also key to ensuring quality of care and is a main priority for EUROPA DONNA.

Isabelle Romieu
Head of the Section of Nutrition and Metabolism and Head of Nutritional Epidemiology, IARC

Olivia Pagani
Clinical Director and Head of Medical Treatment, Specialist Breast Unit, Castellanza, Italy and Head of Medical Treatment, Institute of Oncology of Southern Switzerland
Taking control of breast cancer risk through healthy living

Isabelle Romieu

Dr. Isabelle Romieu is Head of the Section of Nutrition and Metabolism and Head of Nutritional Epidemiology at the International Agency for Research on Cancer (IARC). One of the main focuses of her current and past research is breast cancer, determining its risks and trying to reduce them. In an interview with EUROPA DONNA, she told us how she is a great believer in breast cancer prevention. Her current project aims to better understand the little-known risk factors for premenopausal breast cancer.

EUROPA DONNA: IARC’s European Prospective Investigation into Cancer and Nutrition (EPIC) study is investigating various lifestyle factors and cancer risk. What are the main findings for breast cancer?

Isabelle Romieu: The EPIC study was performed in 10 countries and 23 centres in Europe and has followed close to 500,000 subjects over 13 to 19 years. We are looking at different outcomes including breast cancer. The conclusion of EPIC for breast cancer, as reported in other studies, is an increased risk associated with alcohol consumption. In terms of dietary factors, there have not been very strong findings. Trans-fatty acids, which are highly present in industrial foods, have been related to an increase in breast cancer. In addition, recent results suggest that intake of foods with a high sugar content, which is increasing in the population, could increase the risk of postmenopausal breast cancer.

ED: There has also been a link between carbohydrates and breast cancer.
IR: Other studies have looked at this and have also found that refined carbohydrates, like the sugar which is quickly absorbed, were related to a risk in postmenopausal breast cancer. This effect could be mediated through the insulin pathway and could also explain the association between metabolic syndrome and breast cancer.

ED: So there is an association with diabetes?
IR: A number of studies now show a link between diabetes and breast cancer. There are several interplaying factors associated with breast cancer risk and the insulin pathway, through insulin growth factor I, could play an important role. Other mechanisms linked to obesity, over-synthesis of oestrogen and chronic inflammation, also appear to be very important factors in breast cancer.

ED: Could this explain why overweight and gaining weight after menopause is more related to breast cancer risk than in premenopause?
IR: The relationship is very clear in postmenopausal women. Women with more body fat tend to synthesise more oestrogen and have a higher risk of breast cancer. In premenopausal breast cancer there appears to be an inverse effect. Most studies have found some kind of protective effect of body mass index or no effect at all. However, data are lacking to better understand the role of body composition in this cancer.

Currently several studies are trying to understand what type of body composition might be worse in terms of breast cancer and in particular if abdominal obesity is more related to this cancer.

ED: There was a finding that weight loss plays a role regardless of physical activity. Is there a relation?
IR: Physical activity is related to body composition and regular physical activity will increase your lean body mass and decrease your fat mass. It also acts on metabolic factors. Physical activity increases insulin sensitivity and decreases circulating hormonal levels and acts also through these mechanisms to decrease the risk for breast cancer. Physical activity is one factor we really need to focus on. We need to encourage people to increase their physical activity. There is accumulating evidence that physical activity at any age will have beneficial effects on decreasing the risk for breast cancer and also on increasing survival.
Data have shown that weight gain between the age of 20 years and menopause was related to an increased risk for breast cancer in postmenopausal women. In relation to weight loss among obese women, there are few data, but results suggest that sustained weight loss (over 5 years) could have a beneficial impact.

ED: Of all the modifiable factors, which ones would be associated with the highest risk in breast cancer?
IR: The two risk factors for which we have the most evidence, as has been stressed in the World Research Cancer Fund reports, are alcohol consumption and body mass and obesity.

In terms of diet, a recent meta-analysis shows what we call a “prudent dietary pattern”, based on fruit, vegetables, fibre, a low-fat diet and fish, with low consumption of meat, and low alcohol consumption appears to have a protective effect on breast cancer.

ED: So diet does have an effect.
IR: Yes. Based on the meta-analysis I just mentioned, it is clear that we have to take all those factors into account. A global dietary pattern approach is a way to decrease breast cancer incidence related to diet. However, when you look at individual foods, the relation is not so clear. Sometimes it is difficult to separate the effects.

We are also looking at the effects of some specific nutrients. There is some work on vitamin D, which has been in the focus for many cancers, not only breast cancer. There might be a protective effect of vitamin D, which comes from diet and from sun exposure. A small amount of sun exposure is certainly a good idea.

The EPIC analysis is now looking at nutrient-gene interactions in breast cancer, because nutrients might modify the effects of genes and have some epigenetic effect. We know that folate acts on gene methylation. Some studies show that if you have a low folate status you are more at risk of breast cancer. With increased folate intake you might reduce your risk. We also know that alcohol drinkers have a lower folate status.

ED: For alcohol, we have been recommending no more than one glass a day for women.
IR: Yes, that is 10 g. No more than one drink a day is a good recommendation. This is for all types of alcohol.

In terms of risk, the EPIC study has shown a 3% increase for one drink per day (10 g/day). The Nurses’ Health Study had very similar results. But other studies have reported an increased risk of up to 10%. For the risk of breast cancer the content of alcohol seems to be the most important. Studies have also been looking at different windows of exposure that could be investigated. Recent alcohol intake was more linked to breast cancer. Yes, that is 10 g. No more than one drink a day is a good recommendation. This is for all types of alcohol.

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ED: Are there any other factors that can increase risk?
IR: We are also studying breast density measured on mammograms to determine the factors associated with a higher density. High breast density is a strong predictor of breast cancer. If we can catch susceptible women early on, we might have a more preventive effect by assessing specific risk factors and making recommendations.

We are also looking at specific phenotypes of breast cancer, not just pre- and postmenopausal but also some subgroups of breast cancer, in particular related to receptor status. This way we can better understand the mechanisms of those cancers and have a stronger idea of the specific risk factors for specific tumours.

ED: Since, in fact, there are many different types of breast cancer.
IR: Exactly. When you pool everything together that is where you lack specificity and it is more difficult to distinguish the risk factors.

One interesting thing to stress is the importance of the timing of exposure during one’s lifetime that might be more relevant for the risk of breast cancer. Basically, there are four periods that we think are the most important: foetal life, where what is happening in the foetus might condition some gene expression and some epigenetic changes that might condition the risk of breast cancer later on. There is adolescence, prior to puberty, because the breast cells might be more susceptible. Prior to the first pregnancy is also a period that might be more risky. We know that with pregnancy there is a maturation of cells. So when you have less differentiated cells they are more susceptible to mutation. There is also probably the moment of lactation; we know that longer lactation has a protective effect against breast cancer.

ED: Those are all stages during a woman’s younger years, which is part of the focus for our Breast Health Day campaign.
IR: It is great to target younger women. There are certainly some habits you get in youth and keep in later life. If you start with good lifestyle habits, you can keep them up all your life. Some data from the Nurses’ Health Study also show that adolescent diet is related to premenopausal breast cancer. They looked at meat and fat intake and showed that it was related to premenopausal breast cancer. Those are interesting results because it shows that we need to address the problem of breast cancer really early on.

ED: In the Women’s Health Initiative, some recent analysis has shown that smoking increases the risk of breast cancer. Data to date had not established this association. Are there new ideas in this area?

“We need to address the problem of breast cancer really early on”
IR: You are right. There has been a lot of discussion since the results had been essentially null until now. In the EPIC study, results were generally null. We are reanalysing the data with a larger number of cases than the previous analysis to explore the association further. Results from the Women’s Health Initiative study show an increased risk among smokers, past smokers and recent smokers. That has also been confirmed in the Nurses’ Health Study. The Women’s Health Initiative has also mentioned findings about passive smoking. This is interesting with regard to legislation against tobacco. Until now, there had not been results about the effect of passive smoking on breast cancer. Their research suggests that very heavy exposure to passive smoking might be related to breast cancer as well.

ED: Moving on to statistics, we rely greatly on statistics to support our advocacy work. How can women and advocates recognise a well-performed study in breast cancer?

IR: That is a tough question. I would say that first you need to see where the study is published. In scientific journals, there is some quality ranking. A more reputable journal like the New England Journal of Medicine, just to name one, would indicate that the results are reliable. It has a very strong peer review. If you have an obscure study in an obscure journal, you should be more cautious. I know that EUROPA DONNA looks to WHO and IARC. IARC is doing a review of evidence on different risk factors and has a very stringent review of the literature. The monograph collection at IARC is a great series.

If you are not an epidemiologist, it is very difficult. Basically, you need to look to the type or design of the study. A cohort or an intervention study is more reliable and has more weight in terms of causality. Also a study should include a large number of people. A study on 10 people might be a biased selection and would have much less weight. Confounding factors need to be taken into account when looking at risk factors. You should also never look at a single estimate. There is always a confidence interval around a figure. If it is 9%, it can vary between 7% and 12%, for example. Usually good papers report findings this way.

The advantage of a prospective cohort study is that you are actually measuring your exposure factor prior to the development of the cancer. You measure it at baseline or during the follow-up, and you follow people and see who develops cancer and who does not. Then you can compare to see if the risk factors are relevant to the cancer. Another type of study is a case control study where you select the cases and ask them about their prior exposure. People might respond in a certain way when they already know their diagnosis. That would give less weight to the findings. Usually we put more weight on cohort studies. Another important point is the consistency of results across studies and summary estimates obtained in meta-analyses are very important because they combine results across studies to give an overall effect which is less population specific and more robust.

ED: We as advocates need the statistics and also help disseminate findings to the public. How important is the role of advocacy to epidemiologists?

IR: I think your role is extremely important. We do this research in order to transmit a message to people who might be susceptible to this disease. Sometimes we may not be so successful in translating those scientific findings for the public. I think your role is crucial. This includes awareness of the population about those risks and also translation of the scientific-sounding findings to women so that they can take preventive action. I think we need to work closely together.

ED: What would be your main message for women?

IR: The message that we could give now is to have very moderate alcohol consumption, no smoking, a prudent diet, regular physical activity and avoid weight gain, even in early age. By controlling those factors we can considerably decrease the risk of breast cancer as well as other chronic diseases. Even moderate physical activity has a beneficial effect. It is so beneficial, even psychologically, by improving the way people are feeling. They lose weight and feel more confident. There is never no risk, but you can certainly decrease your risk through healthy lifestyles.

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**Interview at a glance**

- There is an established association between breast cancer and:
  - Moderate physical activity
  - “Prudent” diet pattern
  - Alcohol consumption (no more than 1 glass a day)
  - Body mass and obesity

- Some studies suggest a role for:
  - Vitamin D
  - Folate
  - Phyto-oestrogen (e.g., soy)
  - Polyphenols (e.g., in fruit, vegetables, tea, chocolate)
  - Carbohydrates
  - Trans-fatty acids
  - Smoking
  - Sleep deprivation

- There are four periods of exposure to risk factors that may be important: foetal life, prior to puberty, prior to first pregnancy and lactation

- Studies are examining the link between body type and breast cancer, nutrients and genes, specific types of breast cancer and specific risk factors

- Cohort studies would be the most reliable study type for breast cancer risk factors

- To reduce breast cancer risk women should have low alcohol intake, never smoke, have a prudent diet, get regular physical activity and avoid gaining weight

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Targeting treatment and certifying specialist breast units

Olivia Pagani

Dr. Olivia Pagani is Clinical Director of the breast unit in Castellanza, Italy, and is also responsible for breast cancer medical treatment at the Institute of Oncology of Southern Switzerland and within the regional breast unit. Both units have been certified by the European Cancer Care Certification, a process which she is highly in favour of. As an oncologist involved in large global trials, she was able to tell EUROPA DONNA about the latest treatments and findings for breast cancer. Dr. Pagani is also part of a multidisciplinary team put together by the European Society of Breast Cancer Specialists (EUSOMA) to set up treatment guidelines for young women with breast cancer.

ED: What are the main factors to consider when treating a woman with breast cancer?
OP: These factors were highlighted in detail at the last St Gallen meeting in March. Since 1995, we have been trying to select treatments according to breast cancer subtypes. We are progressing quite well from the idea that we had to consider stage, i.e., tumour size, lymph node involvement and so on, moving from that quantitative aspect to a qualitative aspect, defined by the biology of the tumour. At the last St Gallen meeting an effort was made to move forward and to say that when deciding on adjuvant treatment, you need to take into account the biological picture of the tumour. This means the hormonal receptor status (oestrogen and progesterone), proliferation, which is one of the most important features, HER2 presence or absence and all the possible combinations. Defining tumour subtypes by normal pathological immunohistochemistry (which mimics genetic testing) means that every country – this is very important – has the availability and technology to define breast cancer in the correct way. You do not need sophisticated and costly technology to be able to define breast cancer properly.

ED: Is St Gallen setting the standards for this testing?
OP: Only the general picture. The paper should be available soon in the Annals of Oncology. This will set and define breast cancer subtypes. According to these subtypes the adjuvant treatment would be better selected. We are moving from quantity to quality. These are international treatment guidelines, but the treatment decision has to be made according to the individual patient’s situation, the doctor’s evaluation and the patient’s preference.

ED: Are there any new treatments for breast cancer available or on the horizon that advocates should know about?
OP: There are always new treatments on the horizon. Especially as far as targeted therapies are concerned, new compounds are quite close to approval and introduction into clinical practice. In my opinion, the future of targeting for HER2 is combination and not single agent therapy. All the current and new emerging data point in this direction, which is combining drugs that act on the HER2 target in different ways. We are not there yet, but the data presented in San Antonio are very promising for the combination of lapatinib and trastuzumab (neoALTTO) and trastuzumab and pertuzumab (NeoSphere) in the neoadjuvant setting. The accrual in the adjuvant ALTTO trial is finished, so I bet this will be the future.

The combination of trastuzumab and pertuzumab, another very promising anti-HER2 agent, will take a little longer. The adjuvant trial is just starting. In general, it is increasingly evident that the biological targets are the key. The problem remains with very aggressive and fortunately not very common, so-called triple negative breast cancer (oestrogen, progesterone and HER2 negative), where we do not have any specific target or targeted therapy. Basic and clinical research aims to find possible drugs for this tough subset, which represents 15-20% of all breast cancers. Possible drugs are the PARP (poly ADP ribose polymerase) inhibitors, which are very smart drugs. However, it is not yet clear if they are specific for this subset of patients or if they are just indicated in the
BRCA1 and 2 mutated breast cancer, which are even smaller subsets of breast cancer.

In the vast majority of endocrine-responsive breast cancer, there are very few new drugs on the horizon right now. However, there are some new drugs that do not target the hormonal receptors but rather some other pathways interacting with the endocrine stimulation. These new drugs are still far from approval and from being available in the clinic, but there is a lot of research as usual in this field.

**ED: None of these are in clinical use yet.**

**OP:** Not in the adjuvant setting. A very important issue for advocates is that there is a gap between the research results available and the possibility of having the drugs in the clinic. This gap is filled in by all the regulatory bureaucratic steps which are needed and which differ in speed according to different countries. Advocates should be part of this process as well as they are already part of the discussion of many global clinical trials. It is very important for them to be involved also in the availability of drugs in routine clinical practice. There are still many differences from country to country, and also within Europe. In each country, one of the tasks for advocates should be, as soon as there is sound scientific evidence, to contribute to making these drugs available for every woman everywhere, covered by the health systems.

**ED: An example would be the MINDACT trial, but in this case the aim was to identify a subset of women who would not need adjuvant chemotherapy.**

**OP:** The MINDACT trial is enrolling very well and enrollment will be closed very soon. It is a European led trial. The American trial that is addressing the same question (TailorX), in a slightly different way, has closed accrual. We should have the results relatively soon.

**ED: What options are there for advanced breast cancer? What are the drugs in clinical use?**

**OP:** Treatment depends on tumour biology also in metastatic breast cancer. In endocrine responsive disease there is a list of anti-endocrine agents. Some can be used in the metastatic setting but not yet in the adjuvant setting (i.e., fulvestrant). If you are HER2-positive you can use trastuzumab and lapatinib in the advanced setting. If you are triple negative, you use the chemotherapy alone. Bevacizumab is an option in advanced triple negative breast cancer.

**ED: Some recent follow-up data from the HERA study show that using trastuzumab after chemotherapy can reduce recurrence in women with early stage HER2-positive tumours. Can you comment on these findings and the treatment options for reducing recurrence?**

**OP:** We have two options in the adjuvant setting. One is the HERA trial model, where trastuzumab is given after chemotherapy. Then there are the American studies, at least three of them, which gave chemotherapy (paclitaxel) together with trastuzumab after an anthracycline regimen. With this approach trastuzumab is given earlier than in the HERA trial. This approach is more effective, but it is slightly more cardiotoxic. According to the risk of the patient, the age and concomitant diseases, you have both options available in current clinical practice.

**ED: You mentioned the cardiotoxicity of that combination, and many treatments have long-term side effects. Can anything be done to avoid them?**

**OP:** Yes. It depends on if we are dealing with early breast cancer or advanced breast cancer. Specific drugs have specific side effects and one of the issues in modern breast cancer care is to try to identify the best solution for the individual patient, also by taking into account concomitant diseases, age and the drug toxicity profile. In the adjuvant setting, some side effects are specific to anti-endocrine therapy, which is long-term, and some are more specific to chemotherapy, which is short-term. We now have many possibilities to reduce side effects. For example, nausea and vomiting are no longer the problem they used to be. Now you can have cardiotoxicity with targeted treatments. You have to take this into account, check cardiac function and follow patients very carefully. These effects can occur during and after therapy.

Cardiotoxicity due to trastuzumab is very rare if you select patients correctly. Transient cardiotoxicity occurs in up to 4%, while severe, chronic cardiotoxicity is up to 1.5%. The impact of anti-HER2-targeted treatment on prognosis is so high. The efficacy, the way it prevents relapse, is so significant that the balance is absolutely in favour of its use.

**ED: As an oncologist, do you think that being a woman has any effect on the way patients or colleagues might see you?**

**OP:** This would be up to patients. I may be biased, but I think that being a woman and working in breast cancer makes a difference. I dealt with all solid tumours for many years and now I only deal with breast cancer. I think I can say that breast cancer patients are a different population because they are women and breast cancer is quite a peculiar cancer because it has to do with femininity, sexuality, self-image. If you are young, it has to do with your being a mother or not being a mother. It has so many different aspects involved that make this kind of tumour different. In general, being a medical oncologist and a woman makes things easier for me and probably easier for women as well, but I think you should ask patients about that.

**“EUROPA DONNA is the right advocacy group to have a political, advocacy role to make certified breast units available all over Europe”**
ED: Moving on to specialist breast units, as you are aware, EUROPA DONNA is advocating strongly to have these implemented all across Europe. How important is this?
OP: It is very important. I think it is the next step: after screening and the optimal diagnosis, women deserve the optimal treatment. Multidisciplinary teamwork is the first requirement, but is not the only one. Someone has to check that your approach is effective and that the results of the multidisciplinary team are good enough. That is the role of EUSOMA.

ED: Your breast unit in Castellanza has been through EUSOMA's certification process, which has now been moved to an independent body called the European Cancer Care Certification (CCC). What was your impression?
OP: I think that quality assessment is essential. Doctors are not used to being checked, but I think that it is crucial for improving our work. That's why working in a multidisciplinary team is so important. You listen to everyone's ideas. Then the certification board tells you that you are proceeding correctly, but maybe you have to improve a certain aspect. Having an external body that is unbiased and independent is the key to maintain and increase quality over time.

ED: So you felt that the CCC process was very well run? Do you think it should be an EU or IARC-approved process?
OP: Yes, it was well run. I think there has to be a process like EUSOMA's. Otherwise everyone would set and follow personal rules. I think there ought to be certification guidelines which are for all European countries. A woman in Switzerland has to be treated and have the same quality treatment as in Germany, Italy or Spain. This is fundamental. I think that EUROPA DONNA has to be involved and has a critical role. It is a very well-organised and recognised organisation. It is the right advocacy group to have a political, advocacy role to make certified breast units available all over Europe.

ED: How can women know if their unit meets the quality standards?
OP: There is also the SenoNetwork, a network of units that have a multidisciplinary approach. Not all of them have been certified. They provide information on how many cancers they treat and their services. Although certification is essential, the SenoNetwork is the first step where women can check which units in their country provide at least the list of services.

ED: EUROPA DONNA does not recommend or provide specific information about breast cancer treatments. However, are there places, or websites, where women can go to find out about new treatments or clinical trials?
OP: This is quite a problem. EUROPA DONNA in Southern Switzerland has a multidisciplinary team made up of advocates, patients, surgeons, medical oncologists, etc., building a website in Italian where breast cancer patients can have updated scientific information in an accessible way. The web can be very dangerous. You can find lots of information, and not all of it is reliable. Sometimes it is in very difficult language, so it may not be the best way for women to become informed. We are creating a website which would be certified. There are certification processes for websites as well. A first step could be to only consult websites that are certified.

ED: What role can advocates play in improving breast care services for women?
OP: I recognise that it is not very easy because it is quite time- and emotionally consuming, but the best way is for breast cancer patients to become advocates everywhere at the local level. That way they can check locally that the breast care services that other women receive are optimal. This is important but also difficult for patients. As consumers, we have the duty to check what we buy. To a certain extent, breast cancer patients are consumers of services and are the best people to check the level of the service locally. From the European level, we have to reach the local level because it is the only way to change things.

ED: Hands on.
OP: Yes. It is a big responsibility. It is difficult for a woman with breast cancer to take this responsibility because sometimes she wants to forget what happened. It is the responsibility for doctors to ensure quality. I think it is a responsibility for patients to check the quality of the services they receive, not just for themselves, but for all the women that will be diagnosed.

Interview at a glance
- The 2011 St Gallen meeting focused on tumour subtypes identified by standard pathology to guide adjuvant treatment decision making (Annals of Oncology 2011)
- Promising studies are showing that anti-HER2 treatment is more effective in combination than as a single agent in the neoadjuvant and advanced setting
- Advocates need to be involved on the boards of clinical trials and in the drug approval process to ensure that drugs are made available and reimbursed everywhere in a reasonable amount of time
- Two models have been shown effective for reducing recurrence in HER2-positive breast cancer in the adjuvant setting: chemotherapy followed by trastuzumab or overlapping chemotherapy and trastuzumab, the latter being slightly more effective but also more cardiotoxic
- Specialist breast unit certification provided by an unbiased external body such as European Cancer Care Certification is essential to ensuring quality (www.cancercarecert.biostatistica.net)
- Women with breast cancer are the most suited to monitor and review the quality of local breast care services
It all started about 17 years ago (1994) when I was pregnant with my second daughter. Six weeks before my delivery date I noticed a lump in my left breast. Both a mammogram and a trucut biopsy during my pregnancy and another biopsy after the delivery showed that there were no signs of malignancy.

During the months that followed, I was still worried about this breast lump and the accompanying pain in my left arm. At my insistence I had another biopsy 2 years later, which then showed malignancy. I was only 37 years old when I went for a mastectomy, at which point it was found that the malignancy had already reached four of the axillary lymph nodes. At a time when I was supposed to be full of life and energy, raising my two young girls and working as a nurse, my life had been shattered by the diagnosis of breast cancer. I felt that my body had failed me and I had failed my family.

Worse still, I had to have chemotherapy and premature menopause was induced by ablation of the ovaries and anti-hormonal treatment. I got very sick and thought I was going to die. Then my hair started to fall out and, despite getting a lot of support from family and friends, I also suffered from mild depression.

Weeks and months passed and my hair started to grow back again and slowly my life returned to normal. When most of the physical and mental pain started to subside, I felt the need to do something to help other women affected by breast cancer. My concern was for those women who did not have family and friends to support them or who were not able to understand much about the illness. I started by appearing on a TV programme, where I was asked to talk about my experience with breast cancer. Later I joined the Breast Care Support Group where I continued offering support and raising awareness. Another reason for being active in raising awareness is to ensure that my two daughters are more knowledgeable.

After a few years I decided to go for reconstructive surgery. I had been looking forward to the day when I would not need to use a prosthesis, but I was disappointed. My reconstruction was not successful due to rejection of the prosthetic implant.

More time passed and in 2004 the Breast Care Support Group became affiliated with EUROPA DONNA. During this time, I was serving as a committee member. Being part of the support group has helped me to continue with my mission to offer support and awareness and also for my well-being. In 2008 I was elected Vice-President of the group and National Representative of EUROPA DONNA Malta. This post has increased my opportunities to meet women from across Europe with whom I can share ideas and learn more.

Unfortunately my experience with breast cancer did not stop there, since after 12 years of being disease free I was diagnosed with bone metastasis. I felt my life had been shattered once again. My biggest concern was the stress I was causing my family, who were again very supportive.

Being a person who adapts well to new situations, I managed to continue coping with my very hectic life while also following the treatment for the metastasis. After two years of treatment I had to undergo more testing, but I was in for a surprise. I was certain that the doctor was going to give me bad news but I was astonished to hear that the metastatic spot had disappeared. I couldn’t believe my ears and I cried with joy and relief.

The whole experience has made me a stronger person and by sharing my story I want to bring hope to all those who read it. I am also giving more priority to support and awareness. Going through all these ordeals in my life has made me appreciate every moment. My experience with breast cancer has brought me opportunities which I would not otherwise have had. I want to thank all my family and friends who have helped me along my bumpy journey with breast cancer.

“I was astonished to hear that the metastatic spot had disappeared”
EUROPA DONNA held a successful first Breast Cancer Advocacy Leader Conference for its national representatives to help them network and gain more tools for advocacy. The conference was divided into two main sessions: overcoming the obstacles to implementing the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis and breast cancer prevention through promoting healthy ways of life, using our Breast Health Day campaign as a model. The conference and a Proceedings Highlights document, which has been distributed widely by e-mail and is now available on www.europadonna.org, were co-funded by the European Union in the framework of the Public Health Programme.

Austrian Advocates Meeting
Bettina Borisch, ED President, Susan Knox and some ED Board members met with Austrian advocates in Vienna in June in preparation for the 8th European Breast Cancer Conference which will be held in Vienna 21-24 March 2012. EUROPA DONNA co-organises this bi-annual conference with EORTC and EUSOMA. A local event involving advocates is planned for EBCC-8.

ED Cyprus screening programme visit
Bettina Borisch, ED President, visited the Cyprus Forum, where she gave a talk to the public and scientists on “Barriers to effective care”. She visited the screening programme and later the histopathology lab at the General Hospital of Nicosia. The medical community is aware of the involvement of a team of well-trained advocates.

ED Czech Republic National Patient Conference
Susan Knox, ED Executive Director, spoke at the ED Czech Republic National Patient Conference and at their press conference in Prague. The forum is advocating for a continuation of the increasing screening coverage provided in the national screening programme and for better support of treated women and their families. They are carrying out national advocacy training and are promoting the implementation of the EU guidelines.

ED Italy press conference
In September 2010, during her ED Presidency, Ellen Verschuur spoke at a press conference organised by ED Italy to highlight its new advocacy agenda. ED Executive Director Susan Knox also attended. The Italian Forum announced its plan to present its agenda at the Italian Parliament and to participate in a meeting of the senate.

Forum Support
One of EUROPA DONNA’s main priorities is to support the initiatives of member fora.

The 2011 Breast Health Day campaign will focus on the theme “Make Healthy Choices”, a slogan which will be translated into all fora languages for use in the 2011 Breast Health Day video. The video will feature a mosaic of women engaged in making healthy choices and will be available on www.breasthealthday.org and via the social networking sites YouTube, Facebook and Twitter. Other activities this year include optimising the Facebook and Twitter pages, updating the poster and leaflet and creating a new poster reflecting the video campaign. A summary of the 2010 campaign was published in Breast Health Day News available on www.europadonna.org.

Keep informed on www.breasthealthday.org
http://www.facebook.com/EuropaDonna
http://twitter.com/BreastHealthDay
http://www.youtube.com/BreastHealthDay
In 2011, EUROPA DONNA has continued its advocacy efforts to reach European policy makers and women about its foremost priorities of establishing specialist breast units and mammography screening programmes according to the EU guidelines across Europe.

**ED gives advocacy perspective on mammography screening in The Breast**

In a “Viewpoints and debate” article published in *The Breast* (February 2011), EUROPA DONNA Executive Director Susan Knox provides an evidence-based argument backing the reasons for the Coalition’s support of mammography screening performed in keeping with the EU guidelines: the studies show that it improves mortality.

She reiterates that EUROPA DONNA remains firm in its position that mammography screening is the best means of early detection of breast cancer available today, which, when followed by proper treatment provides the best chance of long-term survival. For mammography screening programmes to be effective, they must be carried out in accordance with the EU guidelines and communicated properly to the public.


**Establishing specialist breast unit certification**

EUROPA DONNA participated in a meeting with members of EUSOMA regarding the issue of specialist breast unit certification, since both organisations are striving to ensure that all breast units that are implemented meet quality standards. The European Parliament Resolution on Breast Cancer (B6/0528/2006) calls on Member States to ensure nation-wide provision of multidisciplinary breast units in accordance with the EU guidelines by 2016.

While the European Commission has confirmed to EUROPA DONNA that a European certification procedure will proceed and will be led by IARC, this project has so far not been initiated. In the meantime, EUSOMA has developed an advanced and detailed certification process, which is now run by an external body established by EUSOMA and called Cancer Care Certification. EUSOMA is seeking ED’s support of this system, which is administered according to 10 quality indicators EUSOMA established following an extensive expert review (Eur J Cancer 2010; 46: 2344-56).

ED considers breast unit implementation and ensuring that units meet EU guideline standards a key priority; ED has therefore agreed to study the methodology used in the EUSOMA process. Karen Benn, ED Policy Officer, observed a site visit at the specialist breast unit in Castellanza, Italy. Based on her report, the Executive Board will decide the next steps in ED’s involvement in this important initiative.
### October 2010

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<tr>
<td>8-12</td>
<td>ESMO 35th Annual Conference</td>
<td>Milan</td>
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<td>8</td>
<td>BIG Scientific Meeting, attended by Susan Knox</td>
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<td>8</td>
<td>TRANSBIG Committees, attended by Susan Knox</td>
<td>Milan</td>
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<tr>
<td>9</td>
<td>Patient Advocacy/Ethics Track Committee meeting, attended by Ellen Verschuur</td>
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<td>9-10</td>
<td>8th ESMO Patient Seminar</td>
<td>Milan</td>
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<tr>
<td>12-14</td>
<td>Breast Health Day/Information Day EU Parliament, attended by Susan Knox, Ellen Verschuur, Karen Benn and Barbara Klein</td>
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<td>13</td>
<td>VZW General Assembly teleconference, attended by Susan Knox</td>
<td>Milan</td>
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<td>15</td>
<td>Breast Health Day</td>
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### November 2010

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<tr>
<td>2-3</td>
<td>Czech Republic National Patient's Conference, attended by Susan Knox</td>
<td>Prague</td>
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<td>12-14</td>
<td>ED Advocacy Training Course</td>
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<tr>
<td>16-17</td>
<td>Metastatic Breast Cancer Meeting: Helping To Put Patients First, attended by Susan Knox</td>
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### December 2010

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<tr>
<td>8-12</td>
<td>33rd Annual San Antonio Breast Cancer Symposium – San Antonio, USA</td>
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<td>8</td>
<td>Breast Cancer Dialogue Series, attended by Susan Knox</td>
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### January 2011

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<tr>
<td>12</td>
<td>EBCC-8 Executive Scientific Meeting, attended by Bettina Borisch and Elizabeth Nordström</td>
<td>Brussels</td>
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<tr>
<td>22-23</td>
<td>Executive Board Meeting</td>
<td>Milan</td>
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<tr>
<td>25</td>
<td>EUSOMA-EUROPA DONNA Specialist Breast Unit information meeting, attended by Susan Knox and Karen Benn</td>
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### February 2011

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<th>Event Description</th>
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<tr>
<td>2-5</td>
<td>Project Lead International, attended by Elizabeth Nordström and Sema Erdem</td>
<td>Cancun, Mexico</td>
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<td>4</td>
<td>EBCC-8 Executive Scientific teleconference, participation by Bettina Borisch</td>
<td>Brussels</td>
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<td>8</td>
<td>ECCO Advisory Council Meeting, attended by Bettina Borisch</td>
<td>Brussels</td>
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<td>25</td>
<td>Skeletal Care Academy 2011, attended by Nicole Zernik</td>
<td>Madrid</td>
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<td>24-26</td>
<td>ED Cyprus event Breast Cancer Today, attended by Bettina Borisch</td>
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### March 2011

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<tr>
<td>4</td>
<td>EMA Scientific Advisory Group meeting, attended by Ellen Verschuur</td>
<td>London</td>
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<tr>
<td>15</td>
<td>FACE Workshop on Women Against Cancer, attended by Bettina Borisch</td>
<td>Brussels</td>
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<tr>
<td>17</td>
<td>VZW-BCWG meeting, attended by Ellen Verschuur, Susan Knox, Elizabeth Nordström and Ingrid Kössler</td>
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### April 2011

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<tr>
<td>1-2</td>
<td>4th Breast Cancer University (BCU 4), attended by Nicole Zernik</td>
<td>Frankfurt</td>
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<td>2-5</td>
<td>ESTRO “Multidisciplinary Management of Breast Cancer”, attended by Bettina Borisch</td>
<td>Lugano</td>
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<td>12-13</td>
<td>European Patients’ Forum Annual General Meeting, attended by Karen Benn</td>
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### May 2011

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<tr>
<td>3</td>
<td>EMA Scientific Advisory Group meeting, attended by Ellen Verschuur</td>
<td>London</td>
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<td>3-5</td>
<td>IMPAKT 3</td>
<td>Brussels</td>
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<tr>
<td>12-13</td>
<td>European Partnership for Action Against Cancer (EPAAC) WP7 kick-off meeting, attended by Karen Benn</td>
<td>Barcelona</td>
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<td>18</td>
<td>Europe Patient Advocacy Executive Council, attended by Susan Knox</td>
<td>Zug</td>
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<tr>
<td>26-27</td>
<td>European Week Against Cancer meeting, attended by Bettina Borisch and Karen Benn</td>
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### June 2011

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<tr>
<td>14-15</td>
<td>European Partnership for Action Against Cancer (EPAAC) Open Forum, attended by Karen Benn</td>
<td>Madrid</td>
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<tr>
<td>17-18</td>
<td>European Breast Cancer Patient Advocates Meet Academia, attended by Susan Knox, Bettina Borisch, Sema Erdem, Elizabeth Nordström, Ellen Verschuur, Mojca Sencar, Barbara Klein</td>
<td>Vienna</td>
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<td>19</td>
<td>Executive Board Meeting</td>
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### September 2011

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<tr>
<td>1-2</td>
<td>Global Patient Advocacy Advisory Board</td>
<td>Frankfurt</td>
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<tr>
<td>23-27</td>
<td>ECCO 16 - 36th ESMO Multidisciplinary Congress Participation of Elizabeth Nordström in debate in Patient Track</td>
<td>Stockholm</td>
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<td>23</td>
<td>BIG Scientific Meeting</td>
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<td>24</td>
<td>Sponsor Meeting</td>
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### October 2011

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<tr>
<td>15</td>
<td>Breast Health Day Europe-wide</td>
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<tr>
<td>22-23</td>
<td>10th Pan European Conference</td>
<td>Malta</td>
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Advocates from many of EUROPA DONNA’s 46 member countries have been busy networking across Europe, from specific ED Fora events, to European advocacy meetings and the ED Breast Cancer Advocacy Leader Conference.
EUROPA DONNA has 46 member countries, including all 27 EU member states. In this section ED Fora share their past and planned activities.

**Albania**

**Highlights of 2010**
- In October, a “Let’s Walk Together” event, with the slogan “breast cancer kills less if detected early”. The first lady, foreign ambassadors, patients and others participated. Brochures, umbrellas, hats and calendars were distributed, all with the symbol of the fight against breast cancer.
- In November, a competition between journalists brought out the essence of cancer and survival. The winners received prizes.
- In September, for Miss Globe, young women from around the world visited the oncology hospital, where they met with patients, had pictures taken with them and gave out presents. During the show, they all appeared in a commercial on breast cancer awareness. Part of the show was dedicated to breast cancer and ED Albania presented a “Miss Health” prize. The commercial aired on national television.

**Activities for 2011**
- In October, breast cancer awareness activities in schools and in other institutions.

**Austria**

**Activities for 2011**
- Sylvia Eisenburger is serving on the National Organising Committee for the 8th European Breast Cancer Conference in Vienna. Local events are being planned for Austrian citizens after the conference ends.
- In June, a workshop was chaired by ED President Bettina Borisch for Austrian advocates in Vienna.

**Belarus**

**Highlights of 2010**
- A grassroots advocacy conference for the Women’s League and Association of Working Women.
- Distribution of the ED “Short Guide to the European Guidelines” to women’s advocacy NGOs.
- Advocacy strategy development with focus on opportunistic mammography screening.
- Presentation of Belarus achievements in the early detection of breast cancer at the Breast Health Global Initiative Meeting in Chicago, USA.
- Participation in ED Breast Cancer Advocacy Leader Conference.
- Training two Belarusian journalists at the Advocacy Training Course.
- In December, the Ministry of Health issued the order to start pilot mammography screening.

**Activities for 2011**
- Presentation of the CEDAW report and breast cancer issues at a United Nations session in Geneva.
**Belgium**

**Highlights of 2010**
- Publication of two issues of the newsletter and updating of the website
- In September, the opening of the new Atossa breast clinic
- In October, presentation of results of the study “Women’s knowledge of risk factors for breast cancer” in the presence of Princess Mathilde
- In October, the Belgian Breast Meeting
- In October, “Action Sein” (Breast Action)
- In November, “Actie BorstKanker” (Action Breast Cancer)
- In December, a concert to promote well-being in hospitals
- Participation in the Advocacy Training Course

**Activities for 2011**
- Publication of two issues of the newsletter and updating of the website
- In February, ED Belgium seminar on organisation and strategies
- In May, training session on state-organised screening practice update
- In October, seminar on breast cancer with information on prevention

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**Croatia**

**Highlights of 2010**
- On the first Saturday of spring, Daffodil Day nationwide
- Participation in EBCC-7 in Barcelona
- On the first Saturday in October, the Pink Ribbon Day nation-wide with the project “My First Mamography” for women aged 40-49 in 10 towns
- The “Psychosocial Issues of Breast Cancer, Women and Their Families” project organised for medical teams and held in county centres
- Participation in the ED Breast Cancer Advocacy Leader Conference
- Breast Health Day events
- Meeting with the Prime Minister and lobbying for breast units according to the EU guidelines
- Participation in the Advocacy Training Course

**Activities for 2011**
- Seminars on accounting, lymphoedema and social aspects with 60 attendees
- Two public seminars on psychological support for oncology patients with about 60 attendees
- Prevention materials – self-examination leaflets
- “Pragomedica” medical fair and exhibition in Prague
- In May, a “You Can Also Do It” walk for patients
- In June, Avon walk
• Purchase of 20 breast models with distribution to the organisations
• Patients’ conference
• In October, Breast Cancer Month activities
• Updating website with news

Denmark
Highlights of 2010
• On Breast Health Day, a lecture on lymphoedema and treatment by well-known physiotherapist Kirsten Tørsløff
• Participation in PhD response of Dr. Rune Gärtner “Early Recovery and Chronic Sequelae after Treatment for Breast Cancer”

Activities for 2011
• An evening for members and other interested parties with lectures on sexuality after breast cancer
• Another evening with lectures on the breast cancer patient and her relatives
• In October, General Assembly

Estonia
Highlights of 2010
• In May, annual Breast Awareness Month “Don’t Be Late” with a press conference and media campaign, receiving coverage in newspapers, on TV and through radio interviews with doctors
• Pink Ribbon campaign to enhance breast cancer awareness
• Patients’ summer camp at a seaside resort
• A charity concert, the “Elvis Presley Story”, with the best singers singing his classic songs. The concert house was lit up in pink
• Breast Health Day activities

Activities for 2011
• In May, Annual Breast Awareness Month
• Annual patients’ summer camp
• Activities to involve female MPs in the fight against breast cancer
• In October, Breast Health Day activities with promotion of healthy lifestyles, including fitness lessons for girls, preparation and tasting of healthy food at the atrium of a large shopping centre, as well as a charity concert

Finland
Highlights of 2010
• A new office in Helsinki which is open twice a week and is staffed by a volunteer
• Operations now established in two cities (Helsinki and Turku)
• For the first time, organisation of a special well-being day for patients with advanced breast cancer

Activities for 2011
• Holding of the usual activities such as patient meetings, lectures, Breast Health Day in October, achieving visibility in the media, such as in magazines and on television

France
Highlights of 2010
• Usual Pink October activities throughout France in order to continue emphasising the importance of participating in the breast cancer screening programme with the following message: “Participate in order to take care of your health”
• Participating in Parliamentary meetings on cancer in order to keep it on the agenda
• Helping to implement breast units
• Membership in different think tanks on breast cancer and pain, breast cancer and nutrition, how to cope with breast cancer, breast cancer and those close to you, bone health

Activities for 2011
• In addition to the same activities as in 2010, creation of a new brochure on metastatic breast cancer
• Breast Health Day event to be held during a meeting organised by the French Cancer League
• On 3 October, yearly symposium at the Senate on the importance of the follow-up procedure, why it should be done, for whom and when

Georgia
Highlights of 2010
• Publication of three books, What to do During Chemotherapy, Physical Exercises after Surgery, and Psychological Support for Breast Cancer Survivors
• In March, a conference for patients and support groups

Activities for 2011
• Field events outside of Tbilisi, in the regions of Rustavi, Batumi, Kutaisi and Ozurgeti, where women participated in various activities, such as lectures and short training sessions. Participants were given small presents
• A small charity concert, where survivors participated by singing and dancing. The event also featured reading poems and inspirational stories
• A “Race for the Cure” marathon, with active participation from a large part of society and celebrities
• A small meeting with students, where they received information regarding breast cancer and the importance of awareness

Germany
Highlights of 2010
• Creating a group for breast cancer patients so they can meet each other monthly and share their stories
• Guiding this group and organising lectures
• Starting weekly visits to breast cancer patients in hospital
• Co-operating with the hospital to have the breast unit certified  
**Activities for 2011**  
• Certification of the breast unit  
• Organising activities for breast cancer patients in partnership with the doctors and nurses of the breast unit  
• Breast Health Day activities  
• Attending the 10th ED Pan-European Conference

**Greece**

**Highlights of 2010**  
• In March, a Women’s Day event to make ED Hellas more known to Greek women  
• In October, a Breast Health Day TV spot, an Internet campaign and distribution of materials in Athens  
• On 15 October, a reception at the Old Parliament of Greece, plus activities at Greek Parliament and the Ministry of Health, including a meeting with the Prime Minister and the Minister of Health  
• On 15 October, meeting with the President of the Greek Parliament, who committed to discussing the creation of a special breast cancer committee in the Greek Parliament  
• On 23 October, a prevention and detection day organised with Metropolitan Hospital  
• On 31 October, participation in the 28th Classic Marathon of Athens  
• In November, participation in the Advocacy Training Course

**Activities for 2011**  
• On 14 February, an event to celebrate the new year  
• For Women’s Day, an event in Kastoria for prevention and early detection  
• Meeting with the Health Minister  
• In April, representation at the Greek Oncology Symposium

**Hungary**

**Highlights of 2010**  
• Participation with leading civil associations against breast cancer in several programmes, such as Bridge Walks in Győr and Budapest and Health Days in several small settlements and in cities  
• In September, attending the ED Breast Cancer Advocacy Leader Conference in Milan  
• On 15 October, holding of a nation-wide meeting for breast cancer patients and civil support groups. The attendees were informed about ED goals and activities, about patients’ needs in Hungary and about the importance of healthy lifestyles  
• In November, participation in the Advocacy Training Course

**Activities for 2011**  
• Ensuring running costs are covered, as a main priority  
• Supporting our office network where cancer patients can obtain support and assistance

**Iceland**

**Highlights of 2010**  
• In October, holding of a public seminar on breast cancer in co-operation with local cancer societies to discuss the topics “Stress and breast cancer”, “The importance of physical activity and nutrition” and “Maintaining gold standards in breast cancer treatment”  
• In October, participation in the “Pink Party”, with more than 2,000 women to raise awareness of breast cancer  
• A prominent school was bathed in pink light  
• Selling of reflective pink ribbons to raise funds for activities  
• Monthly meetings to educate and inform women on e.g., developments in oncoplastic surgery and how to maintain good health  
• Participation in the chairman’s meeting and the general meeting of the Icelandic Cancer Society

**Activities for 2011**  
• Sending of a formal letter of objection to hospital authorities to protest cutbacks in service to breast cancer patients  
• In response to patients’ requests, helping to raise funds to improve the environment for patients at the main hospital

**Ireland**

**Highlights of 2010**  
• Publication of National Quality Review of Symptomatic Breast Disease Services in Ireland (ED Ireland provided service-user representative)  
• ED Ireland service-user representative on National Cancer Control Programme Working Group on Follow-up  
• Information stand at conferences organised by Irish Cancer Society, Irish Breast Care Nurses Association, Older Women’s Network, Mater Breast Cancer Conference  
• In March, Fashion Targets Breast Cancer  
• In May, annual general meeting followed by public information session on “Using exercise to reduce our risk/recurrence of breast cancer”  
• In September, presentation to Irish Council of Trade Unions health group  
• In October, presentations to women’s organisations in Dublin, Limerick and Monaghan  
• For Breast Health Day, free exercise classes, lunch for women parliamentarians, Anna Livia walk in Dublin, exercise activities by groups around Ireland

**Activities for 2011**  
• “Specialist Breast Unit and Fertility” leaflets updated  
• In March, ED Ireland Committee Strategic planning exercise
• Meetings planned with community organisations around Ireland
• Fashion Targets Breast Cancer
• In May, annual general meeting and information session
• Breast Health Day activities
• Attendance at 10th ED Pan-European Conference

### Israel

**Highlights of 2010**
- National media campaign for Breast Cancer Awareness Month
- “Light Up Pink” 2010 featuring illumination of Jaffa port
- Seminars for young women with breast cancer, women with metastatic disease and healthy women at risk
- The annual “Celebrating Life” seminar with over 800 women and their partners in attendance
- Fashion event and public auction
- “Hila” March in the Galilee to increase awareness
- ED Breast Health Day Mini Diary booklet published in Hebrew and presented on Israeli TV
- Breast examinations at the Israeli parliament for all employees

**Activities for 2011**
- The Mammography Vehicle is scheduled for an upgrade and will continue to travel across the country to perform hundreds of examinations each year
- An annual breast cancer conference for hundreds of family physicians and health care professionals
- Additional seminars scheduled throughout Israel
- A breast cancer media campaign for Breast Cancer Awareness Month and other special events
- Publishing the ED Breast Health Day Mini Diary in Hebrew
- “Light Up Pink” 2011

### Kazakhstan

**Highlights of 2010**
- Implementation of the National Programme for Awareness of Breast Cancer
- Holding Breast Health Day activities in Almaty
- A round table with participation of members of parliament to discuss advocacy questions about breast cancer
- Implementation of the breast cancer screening programme, with 17,500 women participating

**Activities for 2011**
- In June, the National Strategic Programme on preservation of female reproductive health, together with the Parliament and Ministry of Health
- In June, opening of the first children’s hospice
- In October, a Charity Ball for women with breast cancer
- On 9 October, a cycling-walking event to mark the Day of Palliative Medical Care

### Kyrgyzstan

**Highlights of 2010**
- Breast Cancer Conference for World Cancer Day with 100 participants
- Development of a training programme on early detection using the Clinical Breast Examination Guidelines and for inclusion in the curriculum of Kyrgyz State Medical Institute for Continuing Education
- Purchase of mobile ultrasound machine and visits to the regions within the “Early Detection and Prevention of Breast Cancer in the Kyrgyz Republic” project
- Pink October events
- Opening of the first immunohistochemical laboratory

**Activities for 2011**
- Establishment of Breast Cancer Patient School
- Participation at exhibition among local NGOs, dedicated to International Women’s Day
- In April, participation at a Health, Sport and Beauty exhibition, to spread information on prevention and early detection
- Visits to pilot regions for breast ultrasound project
- Development of film on prevention
- Research on awareness of breast cancer prevention, involving 220 respondents
- As a result of the pilot project, development of a model on early detection and prevention, which will be given to the Ministry of Health to adapt for the health system
Latvia

**Highlights of 2010**
- For World Cancer Day, making of a social video about fighting cancer with participation of real patients and distribution through social networks
- Psychosocial rehabilitation camps for cancer patients during summer with two 5-day camps based on the psychosocial rehabilitation programme developed by ED Latvia
- Pink Ribbon Solidarity Day in October in the framework of Breast Cancer Awareness Month
- Several charity and information campaigns
- Work with legislative authorities of Latvia

**Activities for 2011**
- For World Cancer Day, a social video about lack of breast prostheses in Latvia
- In February, international conference “Effective Patient Organisation Participation in Decision Making Process”
- Seminar cycle for GPs about psychosocial rehabilitation camps for cancer patients
- Pink Ribbon Solidarity Day in October
- Work on “Aurora” project for cervical cancer
- Several charity and information campaigns
- Work with legislative authorities of Latvia

Luxembourg

**Highlights of 2010**
- In October, the 8th Race Against Breast Cancer, with 600 participants, including the Ministry of Health
- In October, pink illumination of the the Grand Theatre in Luxembourg in the presence of an MP and over 250 participants. Sports groups working with breast cancer survivors presented their activities with a performance by a young girls’ gymnastic group. More than 5,000 pink ribbons were distributed
- In a hospital setting awarding of a bursary to a nurse to run art therapy sessions with patients
- Publication and promotion of a book on a woman’s account of her experience with breast cancer
- Publication and distribution of newsletters and a leaflet

**Activities for 2011**
- On 1 October, 9th Race Against Breast Cancer in the Abbey of Neumünster
- On 14 October, Breast Health Day with the illumination of the Philharmonie
- On a national level, ED Luxembourg will be invited by the Ministry of Health to discuss with the medical community tools to ensure that women have the best breast cancer services

Macedonia

**Highlights of 2010**
- Participation as new ED member in the ED Breast Cancer Advocacy Leader Conference and at the Advocacy Training Course
- “The Go Pink” campaign received an award for the most successful philanthropic campaign in the country
- Lectures given around the country

**Activities for 2011**
- Meetings with the Minister of Health and ministry representatives, and with the general manager of the health insurance fund. ED Macedonia’s proposal for training new staff in radiology by European experts was accepted, and ED helped to organise the training sessions
- Presentation of the ED Macedonia programme to women parliamentarians, who gave their support and wish to be involved in all future campaigns
- Continued co-operation with the University Clinic for Radiotherapy and Oncology
- Training for women who work at the EU delegation in Skopje and collaboration with EU representatives
- Third annual Go Pink campaign walk, including participation from the diplomatic corps and companies, followed by a concert
- 4th National Conference on Breast Cancer
- Lectures around the country
- Breast Health Day activities, including printing of brochures
- 10th ED Pan-European Conference

Malta

**Highlights of 2010**
- Mass for members, family and friends on the feast of St Agatha
- Weekend at a Beauty Parlour with all profit donated to ED Malta
- Walks for Health and Awareness in Malta and Gozo
- Barbecue with another breast cancer group
- Seminar for Health Professionals in Catania along with a Sicilian women’s association
- Awareness activity for all the family over two weekends at shopping centres in Malta and Gozo
- Annual public memorial lecture, with guest speaker Stella Kyriakides from Cyprus
- Distribution of Breast Health Day Mini Diary at Malta’s main Hospital. Women MPs and other dignitaries were present
- Week at a department store where breast awareness material was distributed

**Activities for 2011**
- Advocating for better prostheses and the implementation of a certified breast unit
- Sponsoring the decoration and furnishing of a new unit where women go for prosthesis fitting
- Silhouette walk to mark Breast Health Day
- 10th ED Pan-European Conference

Monaco

**Highlights of 2010**
- In November, celebration of a mass for the ill and the deceased
• In November, a stand for 3 days at the retailers’ market at the Fontvieille marquee
• A “No Finish Line” walk from Saturday afternoon until Sunday morning with many people walking for ED Monaco
• In December, a gala evening

Activities for 2011
• In May, a charity lunch at the golf club in Monte Carlo to support ED Monaco
• Additional activities throughout the year

Netherlands

Highlights of 2010
• In October, at the first “1000 Breast Fair”, the Dutch translation of the ED “Guide to Breast Health” was presented and more than 1,000 were distributed. Ellen ten Damme, a Dutch pop singer and breast cancer survivor, received the first copy
• “Crossing Borders in Breast Cancer” screening symposium to mark the 20th anniversary of breast cancer screening in the Netherlands, with an afternoon workshop on best practice in screening led by Ellen Verschuur
• Writing of an updated booklet on breast cancer care and quality criteria from the patient’s perspective

Activities for 2011
• In co-operation with the National Federation of Cancer Patient Organisations, development of guidelines to help doctors better understand the physical and psychological issues breast cancer patients face on returning to work
• Presentations on the importance of implementing the quality monitor for breast cancer care. All hospitals offering breast services use the monitor to have insight into the quality of their services
• Providing the patient’s perspective on a number of committees, at symposia and conferences

Norway

Highlights of 2010
• Participation in the ED Breast Cancer Advocacy Leader Conference
• Attendance of two ED Norway Board Members at the ED Advocacy Training Course
• After several years of work, ED Norway managed to have the arm sleeves for lymphoedema covered by the health authorities
• Activities to raise awareness and funds all over Norway in the 63 local groups as part of Pink Ribbon Campaign in October
• Funding of several research projects at hospitals and universities
• Training course for breast cancer survivors who volunteer as visitors at hospitals and give out the contact telephone number for breast cancer patients

Activities for 2011
• Translation of the “Short Guide to the European Guidelines” into Norwegian
• Participation in the ED Pan-European Conference
• Attendance at the Advocacy Training Course
• Launching of a new website
• Working to shorten the wait for breast reconstruction
• Working for breast care units in Norwegian hospitals

Poland

Highlights of 2010
• Promotion of EU Declaration on Breast Cancer
• In March, XII Convention of Delegates of ED Poland with presentation of activities to president and politicians on the Przemysl City Council
• Organising mammography examinations and training sessions for women in rural areas
• Poster presentation on ED Poland at EBCC-7
• Lectures about breast cancer and other cancers
• Lectures about ED advocacy for breast units at scientific conferences in four cities
• Co-organising two scientific conferences
• Participation in ED Breast Cancer Advocacy Leader Conference and the Advocacy Training Course
• Exhibition of paintings by an artist and breast cancer survivor
• In October, Marches for Health, Pink Ribbon Marches in four cities, and a Breast Health Day media campaign
• Publishing second edition of ED “Passport to Breast Health” and a Polish version of the Breast Health Day Mini Diary

Activities for 2011
• Gathering for breast cancer survivors for the feast of St Agatha
• In March, XIV Convention of Delegates
• In April, ED stand at the VII conference “Diagnosis and Treatment of Breast Cancer”
• In April, signing of the resolution of the Polish Cancer Patient Coalition to improve access to all modern medical advances
• In April, visiting of the European Parliament on invitation of a Polish MP

Portugal

Highlights of 2010
• In January, maintaining constant contact with MEPs and 70% signed EU Declaration 0071/2009
• In March, participation in the Skeletal Care Academy meeting with some Portuguese doctors and nurses
• In April, launching of first awareness meeting aimed at young women (15–18 years) at a school in Leiria
• In September, a presentation at the ESO Course “Breast Cancer in Young Women”
• In October, a regional campaign in southern Portugal to promote Breast Health Day. At two gym clubs
free sign-up fees were granted to any accredited ED Portugal member. Given the positive feedback, an attempt will be made for national coverage in 2011.

Activities for 2011
• In January, publication of an article in Woman’s Practice magazine on the urge for new breast units and an adequate and updated national database on breast cancer
• In February, participation in a round table on metastatic breast cancer
• In September, in agreement with the Portuguese League Against Cancer, a joint meeting is planned with all breast cancer-related groups in order to achieve a national understanding on common priorities.

Romania
Highlights of 2010
• Three media campaigns with participation in TV and radio debates
• In May, the “Art for Life” gala under the patronage of the Chinese ambassador
• In October, pink illumination of a historical building in Bucharest, and the illumination of the Romanian Palace of Parliament. The event was broadcast live on TV and nine other cities took part
• For Breast Health Day, organisation of an event in Bucharest, where pink bracelets and brochures were given to all the women guests
• Meetings with MPs and MEPs on the fight against breast cancer
• Media promotion of the breast and cervical mobile diagnostic unit that offers free mammograms and Pap smears to women in rural and pre-urban areas. In January, the ED Romania President was awarded the “Pearl of Wisdom” for the results achieved with this mobile unit at the European Parliament in Brussels

Activities for 2011
• Inauguration of two medical centres: the second mobile unit for breast and cervical diagnosis and “Renasterea Medical Center of Excellence” in Bucharest specialised in breast and cervical cancer diagnosis, supported by a grant through the EEA Financial Mechanism
• Awareness campaigns and participation in the 10th ED Pan-European Conference

Slovenia
Highlights of 2010
• Publication of four issues of ED News, 200,000 copies of the brochure “Act in Time”, and 50,000 copies of a CD about relaxation
• 23 lectures throughout Slovenia on breast cancer, healthy lifestyle and self-examination training
• Counselling by telephone, personally, e-mail, visiting patients at hospital
• 2-day patient counselling on new findings in breast cancer treatment with 160 participants

October activities
• Awareness campaign for secondary school pupils “Pink is Not Just a Pose”
• “Running and Walking for Hope” in three cities
• Workshops for hospitals on pottery, painting, yoga
• Two outings for patients
• Co-operation with specialists and health politicians

Activities for 2011
• Publication of four issues of ED News, “Exercise is my Sun” on the importance of regular physical activity also during the treatment, reprinting of the brochures “Food and Cancer”, “Breast Reconstruction”
• Emphasis on psychosocial support and holistic rehabilitation
• Promoting guidelines on lymphoedema treatment
• Patient counselling
• Lectures throughout Slovenia
• Seminar on patients’ sexual problems
• “Running and Walking for Hope” in Ljubljana, Maribor and Dolenjske Toplice
• Outings for patients

Spain
Highlights of 2010
• Psychological support for women with breast cancer and their families
• Physiotherapy for lymphoedema
• Awareness campaigns (conferences, meetings, publications) about early detection to encourage participation in screening
• Course and meeting with more than 150 specialists and women on the topics women and health; social cohesion and equal rights to the public health system; the doctor-patient relationship; sustainability of the national health system
• Breast Health Day, including a press conference to present “Manifesto 2010”, distribution of information materials during local activities
• Co-operation with companies and groups specialising in breast cancer research to co-finance research projects
• Participation in all meetings and initiatives convened by the Ministry of Health

Activities for 2011
• Psychological support for women with breast cancer and their families and physiotherapy for lymphoedema
• Awareness campaigns to increase participation in screening
• Course on health policies; the National Health System; quality, equity and cohesion
• Breast Health Day campaign based on the Manifesto
• Co-operation with companies and research groups to co-finance research projects, and meetings with the Ministry of Health
• Study about the side effects of drugs after cancer treatment
Sweden

**Highlights of 2010**
- In August, Pink Walk “Rosa Steget” in Gothenburg
- Survey directed to Sweden’s mammography and breast cancer units investigating to what extent they reach the targets pointed out in the EU guidelines
- The annual award for excellent achievements in breast cancer treatment, care and awareness
- Award for the Swedish Breast Cancer Nurse of the year
- Research grants given to clinical breast cancer research projects from the Swedish Breast Cancer Fund

**Activities for 2011**
- In August, Pink Walk “Rosa Steget” in Gothenburg
- Breast Health Day Activities in Stockholm
- Lobbying on both a local and national political level
- Recreational weekends for young women treated for breast cancer
- Pink Ribbon activities and awareness campaigns throughout the country during October

Switzerland

**Highlights of 2010**
- Launching the first quality-assured mammography screening programme in a German-speaking canton, St Gallen
- Becoming an official member of the Swiss Patients’ Coalition
- Social networking by putting ED Switzerland on Facebook
- Breast Health Day
- Launching an independent central secretariat for ED

**Activities for 2011**
- Helping to introduce a screening programme in Ticino, the Italian-speaking canton
- Lobbying for screening programmes to be introduced in Glaris, Graubünden and Thurgau
- Taking part in the breast unit concept of the Swiss Cancer League and Swiss Society of Senology

Turkey

**Highlights of 2010**
- In March, participation in EBCC-7
- In April, participation and presentation on breast cancer awareness, followed by a panel discussion on patient-doctor communication at the National Breast Cancer Congress
- Launching of the campaign “Take Action and Tell Your Story” to highlight the impact of physical activity on breast health
- In October, sharing of pink ribbons and pink illumination of the Tower of Leander historical monument

**Activities for 2011**
- Participation in the annual International Women of Istanbul Christmas bazaar with handicrafts and gift items provided by ED members. Donation of free mammography to visitors and support for the sales of the traditional 2011 calendar
- Presentations by ED Turkey members and physicians on breast health and physical activity at the “Take Action and Tell Your Story” event
- Lectures on breast cancer awareness throughout the municipalities in and around Istanbul
- Patient seminars by local experts on breast cancer and nutrition; physical activity and health; avoiding obesity and weight gain; patchwork as a team-building activity; family relations and the breast

United Kingdom

**Highlights of 2010**
- Holding of a symposium “Breast Screening: What of the Future?” with eminent speakers Prof. László Tabár, Prof. Valerie Beral and Prof. Michael Baum, which produced a fascinating and lively debate
- Participation in the ED Breast Cancer Advocacy Leader Conference
- Participation in the Advocacy Training Course with production of reports which have been widely circulated among members

**Activities for 2011**
- In October, holding of the next meeting entitled “Breast Cancer and Health Economics” featuring more eminent speakers

Uzbekistan

**Highlights of 2010**
- In May, the charity pink-ribbon marathon “In the Name of Life!” with 5,000 participants and proceeds going to purchase medication for women with breast cancer
- In May, the Tashkent International Breast Cancer Forum, bringing together specialists and representatives of major international organisations, such as WHO and UNESCO, state bodies and pharmaceutical companies from various countries
- In October, the “Campaign 14” charity auction hosted by Tashkent’s National Centre of Arts to raise funds to support 14 women with breast cancer (one for each of the 14 regions of Uzbekistan)
- From October to December, free diagnostics campaigns and medical check-ups for women

**Activities for 2011**
- In April, the Annual Marathon “In the Name of Life!” with more than 10,000 participants
- In May, training of 25 breast cancer specialists at a session on evidence-based medicine by US experts from the National Cancer Institute and Seattle Cancer Alliance
- In October, the Second Congress of Oncologists of Uzbekistan including the hosting of a satellite symposium on breast cancer issues
A Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis has now been updated in English, French and Italian to include information on the Written Declaration on the Fight Against Breast Cancer in the European Union (0071/2009) that was passed in March 2010. The new versions can be downloaded from www.europadonna.org.

Our Short Guide is now available in 12 languages (Dutch, English, French, Georgian, German, Greek, Italian, Polish, Russian, Spanish, Swedish and Turkish).

The EUROPA DONNA Guide to Breast Health has now been updated to include information on the Written Declaration on the Fight Against Breast Cancer in the European Union (0071/2009) that was passed in March 2010. The new versions can be downloaded from www.europadonna.org.

Breast Health Day
15 October

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 the globe. This year’s campaign “Make Healthy Choices” will remind women that engaging in physical activity, maintaining a normal body weight and eating a healthy diet can help protect their breast health. A digital campaign including a viral video, as well as social networking sites such as Facebook and Twitter, will encourage women across the globe to make responsible daily choices for their breast health.

For more information see www.breasthealthday.org

10th EUROPA DONNA
Pan-European Conference
European Breast Cancer Advocacy: Challenges for the New Decade
22-23 October 2011 – Malta
(See announcement on opposite page)
EUROPEAN BREAST CANCER ADVOCACY: Challenges for the New Decade

Malta – 22 and 23 October 2011

Challenges For the New Decade are many and this year’s conference will describe the key advocacy priorities and provide some strategies and insight into how they can be met. Participants will hear the perspective of the European Commission, as well as leaders in specialist breast unit implementation, breast care nursing, radiotherapy and clinical trials provide updates and their views on how to meet the decade’s challenges. In addition, advocates will hear experts discuss important aspects of capacity building and organisational development that are so essential for our groups to move forward and continue to make progress on advocacy initiatives.

Agenda highlights
- Breast cancer services in Europe: the European Commission’s perspective
- Meeting the 2016 deadline: specialist breast unit implementation
- The specialist breast nursing curriculum: progress so far
- Latest technology and advances in radiotherapy
- Update on treatment and trials
- Metastatic breast cancer: Advocacy issues and needs of patients; results of the EUROPA DONNA survey
- Capacity building and organisational management
- Workshops on: getting involved in social networking and blogs, attracting media attention, increasing transparency and professionalism, needs of women over 70, setting up young women’s groups

Join us on the beautiful island of Malta, a spectacular setting in which to meet and network with advocates from many countries to gain inspiration and skills to meet the Challenges for the New Decade.

You can register online at www.europadonna.org
Or contact EUROPA DONNA Head Office for details conference@europadonna.org