Uniting efforts: from EBCC-5 to the new EU guidelines

Answering the advocates
Nick Perry on the new EU guidelines
Peter Boyle on the IARC, European cancer initiatives and prevention

A special report on EBCC-5
The young women's group gains momentum
Member news
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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On the cover: images from the EBCC-5 programme cover (courtesy of VZW-BCWG) and the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis (©Gustav Klimt, “Guiditta II”, Musei Civici Veneziani, Galleria Internazionale d’Arte Moderna di Ca’ Pesaro, Venezia).
A little more than 40 years ago my mother was diagnosed with cancer. I was a teenager at that time but I can very clearly remember when and how she told me about it. She did not pronounce the word cancer. She said: “It is that disease you know.” At that time breast cancer was a shameful diagnosis and illness that you did not mention or only discussed in whispers behind closed doors. In Sweden where I live, the taboos surrounding breast cancer have now been lifted and the illness is discussed openly. A change has certainly occurred in the decades since my mother’s diagnosis. Sometimes it is only when you look back that you can see how far you have travelled. I am happy to see that this change, or rather revolution, has taken place in most countries around Europe. I am sure that this has happened thanks to the devoted and tireless work of thousands of advocates around Europe. However, this progress is only the beginning of what we must do.

Every 2 minutes a woman in Europe is diagnosed with breast cancer and every 6 minutes a woman dies from breast cancer. Breast cancer survivors are a remarkable resource because each of them has experienced diagnosis and treatment. Moreover, they have confronted their own mortality. Many of EUROPA DONNA’s members are survivors and others are family members and professionals who have joined us in the battle against breast cancer.

Together we can make a difference. From the Resolution on Breast Cancer adopted in June 2003 by the European Parliament we know that there were unacceptable disparities of up to 16% in the survival rates of breast cancer patients in the various member states, and that these were attributed to disparities in access to screening, diagnosis and treatment. The Resolution also states that every woman, irrespective of her place of residence, social status, occupation or education, should have access to high-quality screening for treatment and aftercare in the event of cancer. Now it is time to see the result of the Resolution, which calls on the Commission and the member states to report on the measures taken by the member states and, in the light of the progress achieved, to make a decision on further steps to be taken in the fight against breast cancer. Thousands of women across Europe are waiting for the results and, above all, are hoping for improvement.

Clearly the level of care is not good enough. Every woman affected by breast cancer should have access to quality treatment and care that is based on evidence and delivered in a respectful and timely manner. This still remains an important task for all the advocates in all the 39 national fora of EUROPA DONNA. Every year we have worked hard for our cause. Though we have experienced progress and innovations, and sometimes also setbacks, there is so much more to do. We cannot rest until we beat this cruel, heartbreaking disease. Let’s join together in powerful new efforts to do so.

My role and task as president is still new to me. The 5th European Breast Cancer Conference was my real test and also an overwhelming experience in the power of advocacy. EBCC is the only conference of its kind to represent advocacy groups and major breast cancer institutions together and to release a joint statement of demands. More than 100 advocates from EUROPA DONNA member countries gathered at the conference, and the General Assembly welcomed more participants than ever before. Thank you for trusting in me as the new president of EUROPA DONNA and let’s work even harder together. We cannot do it without you.

“We cannot rest until we beat this cruel, heartbreaking disease. Let’s join together in powerful new efforts to do so.”
Executive Director Susan Knox

Our range of activities continues to expand as we participate in more and more Europe-wide projects. Results of our survey and our October exhibition on breast cancer in the EU indicate that improvements in breast cancer services are occurring, and that advocacy and political lobbying are growing in our member countries. There are now 12 national screening programmes in place and five being rolled out; three countries provide specialist breast units for women and a majority of our member countries are involved in some type of political lobbying concerning breast cancer issues. All 25 EU countries are now members of EUROP A DONNA. Two new members, Finland and Georgia, have joined since our last newsletter, bringing the total number of member countries to 39.

The 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis was published in April and contains an important new chapter on the requirements for specialist breast units. EUROPA DONNA was a member of the working group and provided patient advocacy input for this important new chapter. Copies of the guidelines can be obtained from the EU bookshop (bookshop.europa.eu). Later this year, EUROPA DONNA will publish a “Woman’s Guide to the Guidelines” which will provide highlights of this document in lay language. This will enable advocates to better understand the content and what needs to be implemented and advocated for locally. Many of our efforts in 2006 will be directed toward disseminating this information and urging compliance across all member countries through activities at the Parliament, our website and educational initiatives. A new training module concerning these will also be included in our annual advocacy training course which is supported by the EC through the European Cancer Network (ECN). This course may serve as a model to be replicated or modified for use by groups representing other types of cancer, such as cervical and colorectal cancer.

The continued growth in each of our individual country organisations provides added resources and enables our coalition to carry out even more effective advocacy programmes across Europe. There are now five all-party groups on breast cancer in five of our member countries: Belgium, Italy, Latvia, Portugal and the UK. We have begun posting information concerning these on the EPGBC website (www.epgbc.org) so that these groups can liaise and share information with one another. The importance of tissue banking and new laws surrounding this is a topic of concern to all advocates; our UK Forum described the UK experience and their Forum’s impressive advocacy initiative in this regard at EBCC-5. This will also be pursued at the European level, first by using a web forum to collect information and opinions from all our countries. We will conduct a survey on hereditary breast cancer benefitting from expert advice from a member of our Netherlands forum, and we will continue to build the network of young women in EUROPA DONNA and strive to meet the special needs of this group.

The MINDACT trial, where we serve on three committees (Steering, Legal/Ethics and Spreading of Excellence), will begin recruitment this year and more information on this can be found on the Breast International Group (BIG) website (www.breastinternationalgroup.org/pages/transbig/transbig.html). The advocacy work involved in this has been rigorous, involving the review of documents, consent forms, patient materials, etc, and has enabled us to learn a great deal about trial design and development and the importance of the advocate’s role in this process. We continue to serve on the European Health Forum and the European Patients’ Forum, where policy development in areas concerning transparency and drug information are being addressed at this time. Our collaboration, partnership, and networking capabilities are our strength and continue to provide us with opportunities and ways to be more effective and gain improvements in breast care for women in Europe. The European Breast Cancer Conference, which is a partnership of three societies – EUROPA DONNA, EORTC and EUSOMA – remains an outstanding example. With the ECN, we will be working on the development of accreditation guidelines for specialist breast units, and with the International Agency for Research on Cancer (IARC), we are providing the patient advocate’s perspective in a new project aimed at co-ordinating cancer research in Europe, the EUROCAN+PLUS.

One collaboration leads to another. The advocate’s participation and contribution are now considered essential and important elements in the context of all breast cancer initiatives. This synergy makes all of our organisations stronger and better attuned to the needs of patients; it enables us to be better informed about breast cancer issues and brings us closer to our ultimate goals: to ensure that all women in Europe have equal access to state-of-the-art breast services and to finally eradicate this disease.
Answering the Advocates

Making connections: European guidelines, IARC and advocacy

The new European guidelines have been published and the European Cancer Network (ECN) which develops the guidelines – and in which EUROPA DONNA is a partner – is now part of the International Agency for Research on Cancer (IARC). As these are two major developments which are highly relevant to lobbying, EUROPA DONNA spoke to the two experts on these topics: guidelines editor Nick Perry and IARC Director Peter Boyle. With the breast cancer world more closely connected, EUROPA DONNA’s voice will be heard at many levels and its aim to see all women receive the best quality care will be within closer reach.

Nick Perry on the European guidelines

The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis are a cornerstone of EUROPA DONNA’s lobbying activities. First published by the European Commission in 1993, they set the standards of technical quality control and have benefitted millions of women inside and outside screening programmes. The revision of the new fourth edition was co-ordinated by the European Reference Organisation for Quality Assured Breast Screening and Diagnostic Services (EUREF) as part of the ECN, and includes some European Society of Mastology (EUSOMA) documents revised with input from EUROPA DONNA. Lobbying for and achieving implementation of the guidelines encompasses a majority of the Coalition’s ten goals. The foundation of EUROPA DONNA’s activities in the European Parliament – through the European Parliamentary Group on Breast Cancer and the 2003 Resolution on Breast Cancer – and in its 39 member countries lies in lobbying for adherence to the European guidelines.

Peter Boyle on the IARC and breast cancer prevention

At both a European and international level, as part of the World Health Organization, the IARC is involved in research, guidelines and prevention, all of which are main advocacy areas for EUROPA DONNA. The incorporation of the ECN into the IARC should increase awareness of the guidelines and may help them achieve international standing. The European Network of Cancer Registries, another key concern of EUROPA DONNA, is also part of IARC. As one of its main missions, the agency also investigates epidemiological trends and releases the statistics that are an essential tool for advocates.
EUROPA DONNA: Why was a new edition of the European guidelines necessary and what main changes have been made?

Nick Perry: Firstly, the European Parliament wanted to reaffirm and underline the importance of the guidelines. As well as including the physicistotechnical guidelines, in particular for digital mammography, it wanted to reinforce the need for specialist breast units. In a sense, that led to an overall strategy change which was to make the fourth edition not just about screening but also more about incorporating symptomatic care for symptomatic women.

All the chapters have been updated, and a EUSOMA document on quality assurance in the diagnosis of symptomatic disease has been included, having been reworked to emphasise the multidisciplinary aspects. We have also included a chapter on communication. All the updates and new content are more than sufficient to justify the fourth edition.

ED: Do you feel that advocates have added to this process?

NP: Yes. We have to look at how we achieve our objective of establishing a better, reliable service for women. We know from experience that professionals alone cannot do it, political support is also required. Even with this, we need women to be aware of the benefits of quality. So, we very much support the concept of educating women to know what to look for so that they can seek a better service and a quality product.

ED: As good quality breast units they should adhere to all the other aspects of the guidelines.

NP: Very much so. If you accept any one part of these guidelines, you should really take on board the whole concept. This is why we produced a 17-page summary document, published separately to the guidelines, despite the risk that people might just read the summary and not the whole document. We felt that the benefits would outweigh the risks, because professionals would know that they have to dig deeper. However, the summary document is useful for politicians, policy-makers and women’s groups as it summarises everything in key points. In particular, the very nature of the summary document underlines the importance of multidisciplinary teamwork, thereby ensuring that those using the document understand clearly not just the need for quality but also the need for all aspects of the multidisciplinary approach.

ED: EUROPA DONNA will be creating a woman’s guide to the guidelines. Do you think this will be helpful?

NP: I am so very pleased to hear this, because that will be a very digestible way to present the guidelines to women. I would say that that is completely the right thing to do. The most important people in this entire process are the women. The guidelines exist for the benefit of women, as well as for the benefit of the professionals in implementing a better service. However, ultimately the service is for women, and if they do not use it, then that effort has been wasted. We want to see a situation where women have access to good quality care and are not easily diverted to centres that offer low-quality care.

ED: Do the new guidelines aim to even out some of the disparities in services between countries?

NP: The prime goal of the European guide-
lines is to try to give member states a guide in order to bring their level of standards towards those of countries that have full national screening programmes or organised programmes. The aim is to try to disseminate the standards of excellence that can be, and have been, achieved. We were also conscious of not overdoing the requirements. Therefore, we have always had to strike a special balance between, on the one hand, standards we know are achievable in very expert units, and, on the other hand, not setting levels that are unachievable for member states that are attempting to develop their service. While never allowing standards to slip that affect mortality, we want to give targets that, as far as possible, are achievable and then improve on them.

ED: In the new guidelines, there are three categories of breast unit – diagnostic breast imaging unit, the diagnostic breast assessment unit and the specialist breast unit. Why were these categories included?

NP: This was done with particular regard to the accreditation/certification process. It is not sufficient to aim this process at large breast units that carry out all the functions such as screening and treatment, genetic counselling, palliative care, etc, because most women will actually go through much smaller clinics. Therefore we established a number of levels, starting with the basic diagnostic unit that performs mammograms and little else. We wanted to make sure that women attending these smaller units are also covered in terms of quality. We have covered small units doing mammography up to the major specialist breast units. We felt that this would be the best way to protect the majority of women.

ED: How did the certification process come about and where does it stand now?

NP: In the process of creating the guidelines, EUREF and EUSOMA saw the clear need to link efforts. This was not only for the requirements of a specialist breast unit, but also to begin to tackle the concept of certification of breast units. I think the European Parliament wants to progress this. Since this fourth edition has been made available to them they have stated that they want to develop the accreditation/certification protocol further. We will have a draft protocol ready for presentation to the European Parliament in October.

ED: The European Commission would like to have its own process of accreditation/certification.

NP: The European Commission must ensure that an accreditation/certification process is completely independent of any one organisation in order to be politically acceptable and applicable to different member states and in different environments. And while it is undoubtedly true that EUREF and EUSOMA would be in a particularly good position to carry out some of these certification visits, realistically we want to have protocols available that can be used by other appropriately qualified organisations to certify units.

ED: What can advocates do for this process of certification?

NP: As well as a huge role in helping in the development of guidelines, they can also help implement them, in particular by lobbying not only politically in their own member states for the concept of quality certification, but also with women’s groups so that women are aware of what is on offer. Ultimately, if certification is not present, women should question whether they really want to walk through that door.

ED: This could ultimately help to achieve the aims of the European Parliament Resolution on Breast Cancer, to even out the disparities between member states.

NP: Absolutely. I think that the European Parliament and certainly the European Commission have accepted in principle that an accreditation/certification system is a good way to carry this out. It is being done in a number of different spheres, and I think ultimately it will be seen to be essential. There is really no other way.

ED: What effect do you expect the new section on communication to have?

NP: One of the criticisms of breast screening has always been that you are doing it in a sort of force-feeding, evangelical way. Those of us in the programme feel very firmly that screening does offer a substantial benefit to the women who avail themselves of it. Yet we are very keen to see a fair reflection of what screening entails provided for women to enable them to make an informed choice.

Everyone has that right and we support that absolutely. Therefore, we felt that the section on communication was a very good step forward, as a way to start addressing these issues.

ED: Will there be another edition?

NP: We have put forward a proposal for a fifth edition and are hopeful that it will be supported by the Commission. In particular, we want to have a section on breast care nursing and also one on implementation of guidelines within member states, with regard to a practical approach on starting implementation. Those are two of the key issues.

ED: EUROPA DONNA has members in 39 different countries. Can you suggest ways for them to help with the implementation?

NP: They should take it to women’s groups. Respective governments will have had the importance of the guidelines made clear to them already. However, it is important to adapt the quality and the technical issues to the consumer, the women who are actually going to use the service. I think it is a wonderful, bridging scenario: you can then inform and educate women as to why the guidelines exist, not explaining the actual technical content but rather explaining why there is a technical content and what the benefits of this are for the women themselves. I think that is a great way forward.

“Ultimately, if certification is not present, women should question whether they really want to walk through that door.”
EUROPA DONNA: IARC now houses the European Cancer Network, which develops the European breast cancer screening guidelines. What does this collaboration mean for screening and prevention?

Peter Boyle: The basic idea is to try and improve the outcome of screening. Integrating the ECN into other IARC screening and cancer registration activities can only help to increase the influence of the guidelines to improve quality control in Europe. Given that IARC has worldwide responsibility, we would like to move towards improving quality control guidelines for screening worldwide. We have instituted collaborations with about 30 national cancer institute directors worldwide. There are six agreed themes, one of which is to improve quality control guidelines for screening throughout the world. The first targets are cervix, breast and colorectal cancers.

ED: Would the European guidelines be used as a basis for this?

PB: As a basis, yes. However, we have to take into account the local circumstances. The basic concept though is that mammography screening is just the first step in the global management of a woman who potentially has breast cancer. That has got to be the theme of everything we do. There must be quality control in everything associated with screening and we have to move away from the concept that opportunistic screening is as good as an organised screening programme. We need to concentrate on organised programmes, quality, and on the link between the mammogram and immediate access to therapy and care.

ED: The European Network of Cancer Registries aims to improve the quality of cancer data and make it comparable, among other things. What is the current status?

PB: I have funding to keep it going for 3 years. So it now has 3 years to get its grant funding organised. It went through a period where it was unable to attract grant funding for its continuation. Now we have funds to carry through. We need a lot of information to disseminate about cancer and cancer incidence in Europe, and the network should be the way to do that.

ED: The incidence of breast cancer is increasing.

PB: It’s rising, but we can’t say that this is worldwide, because only about 16% of the population is covered by cancer incidence data, and about 18-19% with mortality data. In northern European countries there are data on national incidence and mortality, and mortality is now coming down. So that’s...
progress. First we want to stop women dying of breast cancer, even if they have to live with breast cancer. As long as that doesn’t affect their life expectancy, it’s nearly a home run. We have to make a big impact on the quality of life. So it’s a whole package.

ED: What would you consider to be the greatest achievements in breast cancer?

PB: Just 30 years ago even, women with small breast cancer were having their breast completely removed in a terribly debilitating operation. To see how we are moving forward in breast cancer care, we must think of Umberto Veronesi, who was tremendously brave to cut around a small tumour and leave the breast when everyone else was removing the whole breast. There may be millions of women alive today with two breasts because of him. Look at his recent work on the sentinel node – he has revolutionised breast care for women.

ED: As the EUROPA DONNA founder, he has also contributed a lot to breast cancer advocacy.

PB: He has got vision.

Other important things have been done to move the scene forward. There is the pooled analysis in Oxford; the ABC meeting; St. Gallen; and the International Breast Cancer Study Group. These are big trials bringing top people together to come up with evidence-based approaches to therapy. I think it has been brilliant – every year we move the agenda forward and women benefit, families benefit. That is what it is all about.

ED: Are there any other IARC studies or initiatives underway or planned for breast cancer?

PB: Yes, you’re in luck. Today there is a meeting of some of the leading groups in the world involved in microarrays, to see if we can get a better focus on patients who will be good responders to particular types of therapy. We’ll be looking at the prospects of trying to accelerate this whole development and use of technology by, rather than just individual groups going on their own, having a pooled group. We’re very interested in the molecular pathology of breast cancer.

ED: As the IARC director, what is your agenda for the next 3 years?

PB: As epidemiologists, our great hope is that we can eliminate breast cancer and lung cancer. However, around the world there is no population with a truly low risk of breast cancer. Yet there is a ten-fold difference between the developed and the developing countries. In the high-resource western countries, women delay the first birth and have fewer births, and that is leading to an increase in the incidence of breast cancer. As a society, we can do nothing about that. To minimise the effect of that, we really have to stop women dying from breast cancer. Screening has a role to play in that, ensuring that each woman with breast cancer is treated in the most appropriate way. If we can diagnose every woman before the disease is metastatic and keep that disease in that state for the rest of her life, then we have success. But we have to do everything we can to stop women from getting breast cancer in the first place.

ED: How can EUROPA DONNA advocates help with this?

PB: For prevention, I think EUROPA DONNA has become very powerful and useful, together with the Coleman Foundation. It’s important to give out true messages, consistently. First of all, encourage every woman to breastfeed for the longest time possible, and encourage society to allow that to happen.

Secondly, we know of certain risk factors that do increase the risk of breast cancer. We have to challenge the long-term use of hormone replacement therapy (HRT). Oral contraceptives and HRT cause about 5% of cancer in a country such as France, and 2% of cancer deaths in women. Also, younger women are drinking more and more alcohol, and 60% of alcohol-related cancers in women in Europe are breast cancer. Women have got to know this. One drink per day is enough.

ED: Are these the messages EUROPA DONNA should use?

PB: For breast cancer, give messages that we are sure of and don’t deviate from them. HRT is an issue, alcohol consumption is an issue, breastfeeding has positive effects, avoidance of weight gain, and adding on some physical activity. We know about these.

Physical activity is a big area – we just know it’s good for you, but we don’t know how much. You should advocate brisk physical activity: one that makes you sweat or breathing. It’s difficult to quantify how much you need to do.

We have to think about the avoidable causes of cancer. That’s what we always try to capture in the European Code Against Cancer.

ED: Are there any other prevention measures that EUROPA DONNA can promote?

PB: There are certain places in Europe where the incidence of lung cancer in women is greater than the incidence of breast cancer. If we want to do anything about the 450 million tobacco-related deaths around the world before 2050 we have to stop current smokers from smoking. So, for EUROPA DONNA, I would suggest taking up smoking cessation advocacy for women and get women to ensure that their children don’t start smoking.

ED: How would you suggest the messages could be promoted?

PB: You could come up with five or six points about early detection, or prevention and screening, and then revise them every 2 years. If there is no change, then they would be good for another 2 years and that would be EUROPA DONNA’s position. Things like that increase credibility.

You could build this into your meetings, with perhaps a session or committees to talk about what statements you can make. Then you could have that report in the plenary session – “modifying EUROPA DONNA’s guidelines.” That could be very useful and powerful and receive a lot of publicity.

“We have to do everything we can to stop women from getting breast cancer in the first place”
Young women living with breast cancer are highly motivated advocates: they want to understand more about the condition, about its impact on their lives, and on their future. To do this they need information, knowledge and support for themselves as survivors and as advocates to share with other young women with similar concerns. Attending the 5th European Breast Cancer Conference (EBCC-5) in Nice offered just this opportunity. Young Women’s Working Group members Maricel Marin-Kuan and Irini Zannara eagerly agreed to attend the conference on behalf of their group. To encourage the group’s momentum, the EUROPA DONNA Board decided to ensure that at least one working group member could attend by sponsoring the costs for one individual. The group appointed Maricel to represent them at EBCC-5, and as Irini was sponsored by the Greek Forum of EUROPA DONNA, both young women were able to represent the group at the conference.

“It’s been important for us to share our personal experiences with breast cancer, and especially to learn about others’ experiences and find out more about our common struggle and expectations within different personal, cultural settings and health care systems.”

It was also a special opportunity for the women to catch up on recent events, share ideas and find answers to questions that affect them personally. The women first began to compare experiences as a group at the first working group meeting in June 2005 and then at a special workshop at the 7th Pan-European conference in Rome. At the moment, the group has six members from six different countries – France, Greece, Israel, Slovakia, Switzerland and Turkey. “It’s been important for us to share our personal experiences with breast cancer, and especially to learn about others’ experiences and find out more about our common struggle and expectations within different personal, cultural settings and health care systems,” the women commented in a report on the working group.

EBCC-5 was another setting for the women to become equipped with pertinent information for themselves and other women, and to meet other women in a similar situation. In order to expand their group and take steps towards advocacy, they need to understand how breast cancer affects young women. The disease itself can be different from that in older women, and younger women have other issues to face such as fertility, pregnancy, the possibility of early menopause and personal concerns, which can also affect all women with breast cancer, such as relationships with partners or with children.

Recognising these concerns and the lack of information for younger women, EUROPA DONNA encouraged the working group’s presence at EBCC-5 and also held a special EUROPA DONNA session on breast cancer in women under 40. It covered the unique concerns of young women and included special talks on fertility and pregnancy. The session drew a large crowd with hundreds in the room and many others watching from outside. Details on this session can be found on page 11.

Maricel and Irini also represented the working group at the EUROPA DONNA General Assembly at EBCC-5. They spoke of the importance of the group and of young women joining together and proposed ideas to increase awareness of breast cancer in younger women at a European level. These ideas included incorporating young women’s issues in the EUROPA DONNA Passport; creating a young women’s link on the EUROPA DONNA website; collecting the latest information on research, epidemiology and psychosocial aspects of the disease in younger women; producing a video; creating action groups; and advocacy training specifically aimed at young women. They also encouraged EUROPA DONNA Fora to put other young women in touch with the group.

In addition to the European events, the working group has also helped the young women to start or continue activities with their national associations. In Switzerland, Maricel has initiated a working group for women under 40 and the health professionals who care for them. As breast cancer in young women is not common and it can be a very isolating experience, the young women were grateful for the opportunity to participate in the conference and bring information and experiences to other young women and to their national representatives. “We hope that the small contribution we are providing with our experience and questions has an impact on the community and that other women can benefit from this.”

For more information contact the EUROPA DONNA Young Women’s Working Group Co-ordinator Karen Benn
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As co-organiser of the 5th European Breast Cancer Conference (EBCC-5), EUROPA DONNA is a main player in the European breast cancer arena. Organised jointly by EUROPA DONNA, the European Organisation for Research and Treatment of Cancer (EORTC) and the European Society of Mastology (EUSOMA), EBCC is the only conference of its kind to represent advocates, researchers and clinicians in the same setting.

Almost 5,000 European and international breast cancer specialists, from clinicians and surgeons to nurses and advocates, gathered at this unique conference in Nice to share ideas and present the latest research. Psychosocial and quality of life issues were given special priority. More than 100 EUROPA DONNA members were present to learn about recent developments in breast cancer and to meet with other advocates. EUROPA DONNA Past President Stella Kyriakides co-chaired the conference with Alberto Costa, breast surgeon and Director of the European School of Oncology. Dedicated to the theme “Making the difference”, the conference culminated with the release of the Nice manifesto containing recommendations for improved breast cancer care.

A full day was devoted to breast cancer screening, a principal advocacy issue. A wide variety of topics, from epidemiology to imaging and treatment were covered throughout the week. Special EUROPA DONNA teaching lectures and workshops were held on translational research; the involvement of advocates in the design of clinical trials; breast cancer in women under 40; management of high-risk families; the role of physical activity and weight in breast cancer; and complementary medicine. Many of these reflect EUROPA DONNA priorities, areas the Coalition feels warrant special attention and for which it has ongoing or planned initiatives. These topics are marked with an “ED priority” symbol in this report.

The Nice manifesto

- Improve the number and quality of European screening programmes
- Support breast cancer research
- Rethink the breast cancer staging system
- Define metastatic breast cancer guidelines
- Increase the number of breast care nurses
- Expand the breast unit accreditation process
- Give recognition to the essential role played by charities in independent breast cancer research

Making the difference through advocacy

Ingrid Kössler at the EUROPA DONNA stand

Alberto Costa and Stella Kyriakides
Guidelines for metastatic breast cancer in the making

Given the lack of internationally accepted recommendations on metastatic breast cancer, a European School of Oncology task force put 12 recommendations to a vote at EBCC-5. Stella Kyriakides was one of 12 panel members discussing the statements. The focus was on bringing patients to the forefront of the decision-making process and emphasising their psychosocial well-being and quality of life. Clinicians and advocates voted in favour of dedicating an entire session to guidelines at EBCC-6 in Berlin in 2008.

Bridging the gap with translational research

Translational research is the bridge between basic and clinical research. It examines the genes and proteins expressed in tumour samples to try to determine a woman’s prognosis and tailor her treatment accordingly. It also aims to avoid under- or over-treatment and to reduce treatment cost. At a EUROPA DONNA teaching lecture chaired by Past President Mary Buchanan, guest speaker Martine Piccart of Institut Jules Bordet in Brussels said that standard large clinical trials only provide data on average treatment effects. “There is increasing awareness that this traditional clinical trial strategy is neither efficient nor cost-effective: it leads to overtreatment of many patients in order to benefit just a few, and it contributes to increases in cancer drug costs that are not always justified,” she stated. Microarray profiling of invasive breast carcinomas has made it possible to classify tumours into five groups according to their gene identity card, which can then be used to monitor different responses to treatment. She added that collaboration is necessary to validate the gene signatures identified so that health authorities may agree to pay for treatments. “It may be time for governments to accept that they need to play a role in translational research,” she said. Strong collaboration between hospitals, with contribution from industry and academic institutions is needed. Such collaboration depends on the free circulation of tumour and blood samples across national borders, which can be facilitated or hindered by current or future legislation. The first trial of the translational research consortium TRANSBIG, MINDACT, is using gene signatures with the aim of identifying women who do not need chemotherapy. EUROPA DONNA is a partner of TRANSBIG and a member of the BIG scientific committee.

Children’s book wins the Nathwani prize

The third Nathwani prize for an outstanding contribution to improving the relationship between science and the arts was awarded to EUROPA DONNA Ireland’s Catherine Thornton for her book Why Mum? A Small Child Dealing With a Big Problem, describing her breast cancer through the eyes of her 7-year-old son. Ingrid Kössler, EUROPA DONNA President, and Stella Kyriakides presented the prize, which has been established to reward an individual who has made a difference through an artistic or humanistic activity, such as music, photography, artwork, film, drama, dance, literature or poetry.

New EU guidelines released

The new 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis emphasise the European Commission’s priorities of ensuring quality care for both non-symptomatic and symptomatic women, promoting specialist breast units and establishing the concept of accreditation. Nick Perry, editor of the guidelines, provided an overview of the new guidelines, which were developed through the co-operation of more than 200 professionals and patient advocates. The guidelines highlight the importance of specialist multidisciplinary breast units, incorporate recommendations for digital mammography, which has now been authorised in eight EU countries, and provide guidance on communication for breast cancer screening. Also new is a 17-page summary document for easier reference. Dr. Perry stated that a protocol draft on breast unit certification is to be presented to European Parliament in October 2006. The European Reference Organisation for Quality Assured Breast Screening and Diagnostic Services (EUREF), EUSOMA, the European Cancer Network (ECN) and the European Commission are to make combined guidelines on accreditation and certification. Also, the ECN has submitted an application to the EC for a fifth edition of the guidelines. For more on the guidelines, see the interview with Nick Perry on page 4.
Advocates have their say in clinical trial designs

Better co-operation between scientists and patient and advocacy groups could increase awareness and understanding of clinical trials and encourage women to enrol. In a EUROPA DONNA workshop, Deirdre O’Connell of the Irish Forum said that advocates help provide a link between researchers and prospective participants. “Patients have a right to information on clinical trials and should be informed about them by doctors,” she said. One of EUROPA DONNA’s ten goals is to ensure that all women understand fully any proposed treatment options, including entry into clinical trials. The Coalition keeps advocates on top of research developments at its annual Advocacy Training Course funded by the European Commission. It has published a booklet on clinical trials and breast cancer and it is represented on numerous trial scientific committees. An article by Deirdre O’Connell and Paola Mosconi, the workshop chair, was distributed to the participants. Entitled “An active role for patients in clinical research”, it is to be published in Drug Development Research.

Clinical trial participants want results

A related poster session revealed that 98% of participants in clinical trials on cancer want to know the trial results and that there is no standard method of conveying this information. Patients usually have to request the results from their doctor. Stella Kyriakides commented, “It is important that patients are not forgotten after they have participated in a study that ultimately improves cancer treatment for all patients.” A survey of more than 1,400 patients revealed that a majority prefer to receive the results by post.

Breast cancer in women under 40

Though young women account for a small proportion of women with breast cancer, a session dedicated to their needs attracted a more than capacity crowd. The EUROPA DONNA session was chaired by Ingrid Kössler, who informed the attendees about the EUROPA DONNA Young Women’s Working Group and the Coalition’s activities in this area. Tony Howell of Cancer Research UK presented data on the low (6% of all breast cancers), though rising, incidence of breast cancer in women under 40. Younger women have a poorer prognosis; different tumour biology; different treatment options; and different treatment side effects from older women. He concluded that it is still not known whether poor prognosis is related to age or to inadequate treatment, and that trials are ongoing regarding the optimal use of chemotherapy and endocrine therapies.

EUROPA DONNA Founding President Gloria Freilich said that critical concerns of younger women include survival, responsibilities, relationships, physical and psychological changes such as loss of fertility, early menopause, sexuality and body image. “For those in the 20-40 age group, the impact is shattering and affects every aspect of their lives and the lives of those around them,” she stated. Specialist nurses are key to skilled supportive care and doctors need to ensure that women understand their treatment options. She concluded with a summary of the main issues: the importance of doctor-patient communication; multidisciplinary services; good verbal and written information; guidance on the use of the Internet; professional supervision of support groups; and new technologies to improve communication.

Walter Jonat from the University of Kiel gave the gynaecologist’s perspective and said that doctors have the obligation to counsel a woman to help her become pregnant if she so desires. Chemotherapy can cause premature ovarian failure and compromise a woman’s ability to get pregnant. Some methods of fertility preservation are being investigated such as cryopreservation of eggs, embryos or ovarian tissue before chemotherapy. “Young patients need a bill of rights for fertility issues,” he stated.

Fedro Peccatori of the European Institute of Oncology in Milan added that although data are still lacking, pregnancy after breast cancer appears to be safe and should not be discouraged. In fact, a number of studies have shown that women who have a baby after breast cancer have a better prognosis. Various studies suggest that it is safer to wait 1-3 years after diagnosis or treatment before getting pregnant. He said that doctors have a duty to tell their patients that definitive data on pregnancy and breast cancer are still lacking, but they are favourable.

“Ingrid Kössler and Gloria Freilich“

“For those in the 20-40 age group, the impact is shattering and affects every aspect of their lives and the lives of those around them”
Tissue banking for the future: the UK sets legislation

Tissue banking for research can improve clinical care and standards, lead to new diagnoses and treatments and protect public health. In the UK, the Human Tissue Act 2004 regulates the removal, storage and use of human tissue: it aims to reinforce the public’s confidence in tissue donation and its fundamental principle is consent. In a session chaired by Eileen Jaffé, EUROPA DONNA UK Forum, Brian Clark of onCore UK said that the new legislation safeguards patients and their families while also fostering progress and research and inspiring public confidence. Though consent is a key element, certain types of research using “residual” tissue is permitted without consent as long as it is approved by a research ethics committee, and the donor remains anonymous. The legislation has established a Human Tissue Authority (HTA) that is developing guidelines and establishing licensing and inspection procedures.

The UK Forum plans to launch an awareness campaign on tissue banking for research to address patients’ concerns and the effect of the new legislation. On a European level, EUROPA DONNA plans to do research on this subject to determine what initiatives exist in all its member countries.

For more on the UK legislation: info.cancerresearchuk.org/publicpolicy/briefings/science/tissueact/

Intraoperative radiotherapy may minimise treatment

Nipple-sparing mastectomy involving intraoperative radiation of the nipple before breast reconstruction has so far shown good local control of the disease and acceptable cosmetic results. Umberto Veronesi, renowned breast surgeon and Scientific Director of the European Institute of Oncology, stated, “Minimum effective treatment will lead to better quality of life and will motivate women toward early detection and lead to a longer life.” He also presented preliminary results for intraoperative radiation during breast-conserving surgery. This technology avoids delays in administering radiation post-surgery and eliminates problems of accessing radiotherapy centres.

High risk and hereditary breast cancer

Understanding increased risk

There are a number of pertinent issues regarding genetic testing in high-risk women: the psychological impact on the woman, the effect on family relationships, the high cost of testing, and job and insurance discrimination. In a EUROPA DONNA teaching lecture chaired by German Forum President Karin Jöns, guest speaker Olivia Pagani of the Institute of Oncology of Southern Switzerland brought the issues down to the basics. She emphasised the importance of genetic counselling to correctly identify women at high risk so that they have access to prevention measures and early diagnosis. Counselling should involve a multidisciplinary team including a medical oncologist, a psychologist, a geneticist, a gynaecologist and a GP. EU and US guidelines on hereditary breast cancer are almost identical, recommending annual mammography or ultrasound in women aged 25-35 years and the availability of prophylactic mastectomy. Tamoxifen and aromatase inhibitors have been shown to be effective for prevention in oestrogen-receptor-positive breast cancer. However, BRCA1 tumours are often oestrogen-receptor-negative. Furthermore, both treatments are associated with side effects and more data on treatment approaches are needed.

Genetic counsellors in demand

Knowledge of hereditary diseases is growing and with it the need for genetic counsellors. In a EUROPA DONNA Session chaired by Board member Galina Maistruk, Brita Arver of the Karolinska University Hospital Solna in Stockholm presented the role of the onco-genetic counsellor at their hereditary breast cancer clinic. A study in Sweden is now evaluating the best method for early detection of a malignant breast tumour, whether self-examination, clinical examination, mammography or ultrasound, in 600 women who chose not to undergo prophylactic mastectomy. However, BRCA1 tumours are often oestrogen-receptor-negative. Furthermore, both treatments are associated with side effects and more data on treatment approaches are needed.

For more on the UK legislation: info.cancerresearchuk.org/publicpolicy/briefings/science/tissueact/
Avoid weight gain and engage in brisk physical activity every day. These were the key messages of the session dedicated to the role of physical activity and weight in breast cancer, chaired by EUROPA DONNA Board member Ellen Verschuur. Monica Castiglione of the University of Bern presented studies showing that weight and prognosis are linked. In the Nurses’ Health Study, weight gain was associated with higher rates of recurrence and mortality. In another study in BRCA mutation carriers, breast cancer occurred later in physically active women than in inactive women.

Peter Boyle, Director of the International Agency for Research on Cancer (IARC), added that being overweight is linked to a 12% increased risk of breast cancer and being obese to a 25% increased risk. Studies have consistently shown a modest risk increase in post-menopausal women with a high body weight. Regular physical activity reduces the risk of breast cancer independent of weight. However, it is not known how much activity is needed to have an effect. Dr. Boyle concluded that physical activity leads to a reduced risk in women of all ages and that avoidance of weight gain reduces the risk in post-menopausal women.

EUROPA DONNA Executive Director Susan Knox addressed the importance of identifying clear, accurate information on lifestyle factors to be distributed to women. The Coalition’s Passport to Breast Health includes lifestyle recommendations and is distributed to its 39 fora, many of which distribute the information to the public. The discussion led to the following main recommendations: avoid weight gain, undertake continuous physical activity, limit alcohol intake, and breastfeed after pregnancy.

For more on epidemiology and prevention, see the interview with Peter Boyle on page 6.

**Physical activity protects against breast cancer**

**“Being overweight is linked to a 12% increased risk of breast cancer and being obese to a 25% increased risk”**

Breast nurses improve efficiency of breast clinics

Breast nurses may help fill the gap in services for women undergoing breast cancer follow-up. Nicola Roche, a breast cancer surgeon from Royal Marsden Hospital in the UK, stated that women express a desire to have un hurried consultations, continuity with a health care professional, consistent information, and easy access to specialist services and tests. “It is my personal view that almost none of these needs are met with the conventional format of follow-up services,” she stated. More trials are needed, she concluded, and breast care nurses should publish articles on their experiences.

In response to the sharply increasing number of women contacting the breast clinic and their demand for better care and information, the Department of Surgery of Catharina Hospital in Eindhoven appointed a nurse practitioner to its outpatient breast clinic. Saskia Claassen, a nurse practitioner at the clinic, said that when the clinic evaluated its new design through a survey of 412 patients, the satisfaction rating was 8.4. The waiting time between the first visit with the GP and the final diagnosis was reduced from 12 days to 4 and the length of consultation time had increased to more than 30 minutes.

**“Breast care nurses should publish articles on their experiences”**

Ingrid Köessler presented the patient’s view of follow-up from a Swedish perspective. The Swedish Breast Cancer Association surveyed 1,200 members about their preferred place for follow-up and 89% of the respondents chose the breast care centre. However, the women reported that follow-up visits were rushed, investigations were not reassuring and there was a lack of continuity with oncologists in some cases. They also lacked the opportunity to ask questions, express emotional concerns or discuss their social situation. Follow-up therefore needs to change to better meet women’s needs. Ms Köessler concluded that research is needed to determine if nurse-led follow-up is as effective as conventional follow-up so that modifications can be made according to evidence-based information.

A survey on the scope of breast cancer nursing practice in Europe is being conducted by the European Oncology Nursing Society (EONS) and industry. Questionnaires were distributed to the participants in the session. Results are to be used to create initiatives to support the development of breast cancer nursing practice in Europe.
Complementary and alternative medicine (CAM) is in demand: 9-79% of patients use it. However, the diversity of CAM methods, products, patients, cancers and research methods makes evidence-based conclusions difficult. With this in mind, EUSOMA is soon to publish guidelines on CAM. In a EUROPA DONNA workshop chaired by Vice-President Nicole Zernik, Stéphane Lejeune of EORTC in Brussels said that CAM use is on the rise and that it is now more widely accepted. Patients turn to CAM to increase their feeling of well-being, decrease side effects of treatment, relieve stress, sustain hope and search for meaning. However, CAM products are not always of high quality, due to lack of standardisation of content, concentrations and risk of contamination.

Harold Burstein of Dana Farber Cancer Institute in Boston added that CAM has become the norm, not the exception. Yet most patients who use CAM do not tell their doctors. Some CAM can interact with chemotherapy and cause side effects such as abnormal liver function. Dr. Burstein concluded that doctor-patient dialogue is important to discourage dangerous ideas and dispel misconceptions.

EUROPA DONNA Board member Sanja Rozman provided the patient's perspective. Even though it is not proven scientifically and they have to pay for it, women use CAM because it supplies what is lacking in conventional medicine and it gives them a choice. As a doctor and a patient, she gave the following advice to women:

- Only use CAM as “complementary” treatment (i.e., in addition to traditional medicine)
- Talk about CAM with your doctor
- Ask for the CAM practitioner’s qualifications and about successes or failures
- Ask for the CAM practitioner’s opinion about medical treatment
- Get reliable information about the method to be used
- In the case of strange demands from the practitioner, be suspicious
- Ask in advance the price and what it encompasses
- In the case that symptoms worsen, consult your doctor

Michael Baum from University College Hospital in London concluded with an overview of the EUSOMA recommendations on CAM to be published in two companion papers in the *European Journal of Cancer*.

For more information on CAM:


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**Understanding terminology: a new breast cancer dictionary**

A new dictionary of breast cancer terminology for lay people is being created to help women understand the medical language used in the vast amount of information available, particularly on the Internet. It also aims to help doctors and patients understand each other better. In a preferred paper session, Radja Messai discussed the project conducted by French universities and the French League Against Cancer. They have identified over 1,300 concepts expressed by over 3,000 terms. The dictionary is being created in six EU languages.
News from member countries

EUROPA DONNA’s member countries now number 39 – including all 25 EU member states and almost the entire continent of Europe. Here each Forum shares its recent and future initiatives.

Austria

ED Austria has set up a website (www.europadonna.at) and a quarterly breast cancer magazine, DONNA. The first issue was sent out to clinics, hospitals, patient groups, etc, and 1,000 responses were received requesting future issues. The third issue will be presented at an ED event on 20 June 2006, DONNA’s official launch. Guests will include health professionals, the media, patient groups and other relevant parties. Austria’s Minister for Health and Women’s Affairs will attend, along with ED International Vice-President Nicole Zernik. A brochure on ED’s aims was produced, along with a questionnaire about information needs. Since October 2005, ED Austria has attended three exhibitions/events focused on women’s health care, and these materials have been distributed. In April, ED Austria attended the general symposia of the main patient group, “ARGE Austria – Women’s Self-Help after Breast Cancer”, and the Supportive Care Patient Summit in Amsterdam. We have linked our website with other relevant websites and other patient groups are invited to put a link to our website; we are currently working on an online forum and editorial department. Guidelines will also be available on the website, as well as in brochure format in late 2006. ED sponsored a guide book about how to help children when a parent is diagnosed with cancer. We have also supported and spread information about the Viennese Cancer-Liga “Cancer and Work” programme. Pink days are planned for October in co-operation with women’s health care centres throughout Austria. Two ED members will attend the ED Advocacy Training 2006 in Milan.

Belgium

ED Belgium looked back proudly at the very successful three-year presidency of Fabienne Liebens. As Birgit Carly, our European delegate, concluded in her presentation on ED Belgium at the 7th Pan-European Conference in Rome: “It is very important to have the right person at the right time.” In the sixth ED Belgium newsletter, our newly elected President, Nadine Cluydts, acknowledged the enormous engagement of the past president and considered 2005 a top year for ED Belgium. Members of the Board participated in advocacy training in Milan and international patient conferences in Milan and Paris. They presented a lecture at the scientific congress in Deauville and went to San Antonio, attended the reception “Breast Cancer in the EU-25” and the gala dinner on breast awareness at the European Parliament, as well as participating in the Advisory Committee of EBCC-5. As a result of our advocacy for the establishment of breast clinics, the voice of ED Belgium was heard by both the medical and political world. We agreed to present our priority dossier in the Belgian Senate, an action which in turn led to the start of new initiatives in the Senate. We continued to co-organise local information sessions on breast cancer; we joined a regional communication group on screening; and we were present at several initiatives of self-support groups and at the Euro-Regional Forum “Joy of Living”. We further participated in the Belgian National Scientific Consilium, “Breast Cancer”, and are contributing to the preparation of the Belgian Breast Meeting in the autumn of 2006.

Bulgaria

The activities of ED Bulgaria in 2005 were marked by two major events: the National Breast Cancer Patients’ Forum and the “Happening”. The Forum took place in October and was the first of its kind, with participants including representatives from the government, pharmaceutical companies and patients’ organisations. Many patients attended the event and had the opportunity to listen to lectures on the latest medical achievements. The event was highly successful and ED Bulgaria intends to continue with a successive event. In November 2005, ED organised an event aimed at raising the awareness of problems faced by cancer patients. It was organised jointly with the
Association of Cancer Patients (APOZ and Friends) and with the support of MM national television. The event was widely covered by the mass media and took place in Sofia’s Central Park. The slogan of the event, “It depends on you”, was publicised on all the advertising materials, flyers, scarves, key-rings and baseball caps, together with the logos of the two organisations. In addition to these two events, different representatives from ED Bulgaria took part in numerous TV talk shows and specialised programmes. The Forum continued the training of its co-ordinators in various cities. We organised an art club to help cancer patients to overcome psychological trauma caused by illness. Activities in 2006 will concentrate on the dialogue with the state authorities with the aim of implementing a screening programme for breast cancer.

Croatia

The beginning of 2005 was very sad for all of us as we lost our dear friend Josipa Horvatin and her precious advocacy. Josipa was founder of the Croatian Forum together with Prof. Ruža Sabol. She worked with passion as our general secretary and as a member of the European Board. Daffodil Day in April was organised in memory and in honour of all Josipa’s efforts towards promoting ED goals. Pink Ribbon Day was held on the first Saturday in October, and during the Breast Awareness Walk we were joined by the First Lady and the Deputy Prime Minister. These two important days were organised in Zagreb and in another 30 cities throughout Croatia. Representatives from all the media were involved. During the course of the year, many lectures were held and educational materials about breast awareness and the importance of early cancer detection were distributed. We enjoyed good collaboration with the Croatian Medical Association; the Croatian Senologic Society; the Croatian League against Cancer; and the University Hospital for Tumours. All members of ED Croatia are volunteers, ready to dedicate their good-will, free time and knowledge to accomplish ED’s plans. The main goal of all activities is to have permanent contact with local and national politicians and health services, and to lobby for the national screening programme for all women aged 50 to 69. We have been promised by the Health Minister that the programme will start in 2006. We have also underlined the importance of setting up multidisciplinary breast units according to EU criteria.

Cyprus

ED Cyprus organised two seminars for physiotherapists on late complications after mastectomy in 2005. Also, 350 pink silhouettes travelled all the way from Australia for the First Field of Women in Cyprus. A special event was hosted by the president’s wife at the presidential palace. Mrs Lyn Swinburne from the Australian Breast Cancer Network was a special guest. In October 2005 Nicosia municipality was lit up in pink; the first advocacy seminar of the Forum was held; 350,000 leaflets on breast cancer awareness were distributed through bakeries all over the island; awareness information was displayed on milk containers; a new leaflet was launched, “Helping a friend of a colleague”; pink ribbons appeared on three websites; and ED Cyprus members were featured in local magazines and on television. Board members had meetings with the Minister of Health regarding the screening programme, which is in its second successful year of operation. Letters were sent to all members of parliament to inform them of the importance of having breast clinics in Cyprus. We also met with insurance companies to discuss problems with insurance coverage for women with breast cancer. In 2006, the Forum celebrated its fourth anniversary with the children of the oncology ward at the children’s hospital. Women’s day was celebrated with a lecture on hormone therapy after the menopause and the same lecture is now being repeated in other towns. Two new leaflets, one telling children about breast cancer and another on self-examination, have been launched.

Czech Republic

The National Scientific Seminar with international participation was organised by ARCUS-Onko Centrum in cooperation with ED Czech Republic in November 2005 in Znojmo. This was ED Czech Republic’s most important event in 2005, and it was devoted to cancer prevention, treatment and follow-up care. It brought together more than 180 participants, cancer survivors and the general public. Our aims were to inform the participants about advances in cancer treatment; to inform patients about how to enrol in clinical trials; to educate patients about their rights; to enable the participants to create an informal patient–doctor dialogue; to inform the general public about patients’ organisations and their activities; to bring ED Czech Republic to the attention of the general public; and to present EU documents about the issues of health and cancer. The main objective was to inform the public how to effectively advocate for better quality health care and social services. Participants agreed on the following resolution: to join the National Cancer Programme declared by the Czech Oncological Society, to fully support the European Parliament Resolution on Breast Cancer, and to support ratification of the Framework Convention on Tobacco Control by the Czech Republic. In July 2005 we organised an educational seminar on breast self-examination techniques in our office in Prague. Our leading oncologist, Dr. Jitka Abrahamovou, explained the importance of regular breast examination and knowing the correct techniques for self-examination. The European Parliament resolution was translated into the Czech language and posted on our website. The document was presented at our seminars.

Denmark

The Danish ED Forum, the Danish Association against Breast Cancer, continues to pursue its aims for, among other things, centralisation of both the surgical and the medical treatment of breast cancer at a few large regional centres, by taking part in the public debate in the press and
on television. In 2006, the Association will celebrate its 10th anniversary, and is planning a public hearing in the autumn on the status of prevention and treatment of breast cancer in Denmark.

**Estonia**

The issue of genetic counselling for breast cancer patients and family members was raised at the ESMO Breast Cancer Symposium’s Patients’ Advocacy Roundtable in 2004. A team of doctors worked on it and it became available during the second half of 2005. In close co-operation with the Estonian Cancer Society, a Breast Awareness Week was held in May, including lectures, interviews on TV and radio channels, and articles in newspapers and magazines. A special edition entitled “Together Against Breast Cancer” was issued by a leading daily newspaper. An educational film, “Diagnosis +”, was produced and shown on TV. A new leaflet about breast cancer and breast self-examination was issued, and a brochure, “Knowledge of Breast Cancer”, was updated and redesigned. In November, breast cancer survivors participated in the TV talk-show “Meie” (“We”), that was dedicated to fighting against cancer. A festive Christmas fundraiser raising TV programme, “Christmas Tunnel”, raised more than 700,000 EEK (about €45,000) towards a new mobile mammography unit for the breast screening programme. A total of 20,101 women aged 43-59 attended screening tests in 2005, and 60 breast cancers were detected. The Information Office at the outpatient department of the oncology hospital in Tallinn opened in 2004 has become very popular and highly valued among patients. Regular lectures and workshops are held there each month. Finally, lobbying for a National Cancer Plan continues.

**Finland**

The first patient association for breast cancer in Finland was founded in May 2005. In September, the association was accepted as a member of EUROPA DONNA and this was announced in Brussels in October. The members of the board participated actively in ED’s advocacy training in Paris, Rome and Milan. The association also co-operated with Swedish breast cancer organisations, both in Helsinki and Stockholm, and got valuable information about how to start operations effectively. The main activities of the Finnish Breast Cancer Association were sharing information and arranging self-help group meetings among patients. Meetings were held twice a month. Web pages with general information were set up in October and included a discussion forum for patients to share information. A public lecture event was held together with Prostate-organization. In January, members of the association gathered together for a weekend of exercise and lectures about womanhood after breast cancer. In March, a four-part training programme for volunteer self-help group leaders was successfully concluded. The main goal of the Finnish Breast Cancer Association is to improve the quality of life of Finnish patients, advocate breast cancer issues in Finland and guarantee equality in screening and treatment. A future event is planned to be held in Helsinki to launch ED Finland to policy-makers and the general public. A booklet on breast cancer and ED will be printed in Finnish. Work on raising awareness about issues concerning breast cancer in Finland has begun, but there is still much to do.

**France**

Another year has gone by and ED France has been busy as always. 2005 has been a year of development for the French Forum: more members, more regional delegations and more volunteers throughout the country. Growing means keeping our website and printed material related to breast cancer up-to-date with information from conferences; it means continuing to convince and educate all women aged 50-74 to participate in the national screening programme. Many members of our Forum form part of their local screening organisations and are active in trying to increase the percentage of women participating in the programme, especially those who are considered less privileged, who are more difficult to reach, for social or religious reasons. Growing also means getting involved in new areas, such as political issues where the French Forum felt it had to take a position and fight for it. Being the biggest organisation involved in breast cancer in France, we have to represent and lobby for patients’ rights and their access to all new treatments while maintaining or improving their quality of life. Finally, we are, of course, still taking an active part in the Cancer Plan launched by President Chirac in 2003.

**Georgia**

ED Georgia has only recently been established and is presently trying to find some alternative to funding than a membership fee in order to start breast cancer advocacy activity in the country. However, this is very difficult. Nonetheless, we have planned a number of events and we have many ideas and global plans which depend on our financial status. We are translating two ED booklets, “Passport to Breast Health” and “Clinical Trials and Breast Cancer”, as well as ED membership application forms into Georgian to attract more members. We plan to make our website into a national forum and to make it more popular. To improve breast cancer education, we plan a symposium for health professionals and a breast cancer care workshop for breast cancer survivors. We aim to increase early breast cancer detection by providing modern equipment for breast cancer prevention centres in the high breast cancer risk regions of Georgia. A further aim involves participating in international clinical trials in order to establish a breast cancer research centre. We plan to encourage health professionals to translate and publish breast cancer guidelines. Other plans include organising a charity concert for breast cancer survivors and improving the health insurance system to protect breast cancer patients.
Strength
in numbers

Germany

During 2005 ED Germany focused its work on the distribution of information concerning the benefits of breast cancer screening. This was partly due to the annoying protest of screening sceptics in Germany right from the very beginning of the implementation of nation-wide screening programmes. This approach seemed to be even more important because regional administrations and women’s organisations again launched a campaign for breast self-examination. This is irritating as it leads to the impression that self-examination is a reasonable alternative to breast cancer screening. To reach the necessary 70% participation in the screening programme, ED Germany intensified its activities mainly in areas where screening started. Furthermore, ED Germany continued to criticise the slow implementation of screening in Germany, because even in 2007 there will still be regions without any screening facilities at all. Needless to say, ED Germany has always pointed out that offering best early detection is of little value without interdisciplinary treatment in qualified breast centres. Unfortunately, ED Germany had to criticise the German accreditation procedures of breast units by the German Cancer Association (DKG) as well as the initial accreditation procedures of EUSOMA for being insufficient and non-transparent. ED Germany constantly asked for consistent implementation of the EU guidelines for multidisciplinary breast units and pointed out that only 5% of breast cancer patients in Germany are operated on in hospitals meeting the required minimum number of 150 operations of primary carcinoma.

Greece

The year 2005 for ED Greece was a year of preparation and planning ahead. While waiting for the approval of our constitution, ED Greece was directed by a special board committee. During that time, we contacted several health officials and politicians and tried our best to pave the way for our future advocacy and lobbying activities. Members of our Forum participated in important meetings concerning breast cancer issues. To promote ED Greece, and during a campaign for breast cancer awareness and early detection, we used huge banners with photos of popular theatre actors and actresses with the slogan “Don’t shut your eyes to breast cancer”. The banners covered the walls of whole buildings in Syntagma Square, opposite the House of Parliament, in May and June. Continuing the effort, a new banner was put up on public buildings, banks, etc, in the main street of Athens in November and December, and this had a great effect on the public. We prepared the main issues for our projects for 2006.

Hungary

ED Hungary carried out a number of advocacy and awareness programmes over the last year. We produced two booklets, “Passport to Breast Health” and “Clinical Trials and Breast Cancer”. Several patient-doctor meetings were held monthly in Budapest. Topics included early diagnosis, participation in screening programmes, medical treatment of breast cancer, surgical intervention, etc. "BIG 98", a patient forum, was held in February at the National Institute of Oncology. We organised “EUROPA DONNA Day” in October, a Hungarian-international patients’ meeting on the situation of Hungarian cancer patients at home and in Europe, with participation from several mid-European countries. The programme included a plenary session by Ingrid Kössler, then ED Board member and another by Lynn Faulds Wood, chair of ECPC. There were presentations by local experts, a book presentation and signing, a roundtable panel discussion, a fashion show and exhibitions of paintings and medical supplies. The Alliance Against Breast Cancer programmes were held in several places nation-wide; these are public demonstrations of healthy people and patients in co-operation with NGOs, economic and government organisations, and they mobilise media and celebrities. A symposium preceded the “Walk across the Bridge” at the Hungarian Academy of Sciences in Budapest and at the culture centres in three different towns. The ED Hungary representative was invited in October by the government to visit different kinds of cancer organisations in the United States as part of a delegation of cabinet members.

Iceland

In 2005, ED Iceland mostly focused on advocating and opening discussions about breast cancer issues, with regard to diagnosis and treatment. As usual, we participated in Breast Care Awareness in October. The official residence of the President in Iceland was lit up in pink and the President, Mr. Olafur Ragnar Grimsson, and his wife, Mrs. Dorrit Moussief, honoured our group with a formal reception at their home. The President’s wife switched on the lights. We enjoyed even better media coverage than usual. The President also honoured our group at the Christmas meeting, handing over the funds raised during the month with support of Estée Lauder in Iceland. The President’s office used the photo of the residence in pink on the official Christmas card that was sent to sovereigns, groups and individuals throughout the world. Last but not least, the Icelandic Chef Association held a Pink Gala Dinner and honorary guests were the President and his wife. All funds raised went toward supporting breast cancer awareness. Two volunteers travelled to Milan to attend a workshop held by ED in November and now the ED advocates in Iceland are four: two breast cancer survivors and two oncology nurses. This year most of our efforts will go into preparing a seminar for the Reach to Recovery groups in Scandinavia, to be held in Iceland next September. Up to 200 women will attend this seminar where specialists will introduce the latest research in each field.

Ireland

ED Ireland, in co-operation with the Irish Cancer Society and Brown
Thomas, a major Irish fashion retailer, launched the Fashion Targets Breast Cancer Programme in May 2005. It was a great success, with Elle Macpherson as the face of the campaign, attracting much attention and raising awareness significantly. Most of the proceeds went to fund a programme for younger women run by Action Breast Cancer, a project of the Irish Cancer Society. We also cooperated with Action Breast Cancer on a survey which investigated women’s needs in relation to breast prostheses. The preliminary results were presented as a poster at EBCC-5. The campaign to have screening extended to the whole country continued and the programme is now on target to roll out to all of Ireland in 2007. If it does not, there will be a lot of awkward questions asked of government deputies canvassing for votes in the election which has to take place by June 2007! In 2005, the Minister for Health and Children, Mary Harney, set up the National Quality Assurance Group for Symptomatic Breast Disease Services and appointed Deirdre O’Connell, Chair ED Ireland, to the Group. The Group will work on developing an improved national approach to quality assurance in the management of breast disease and we feel that this appointment is recognition of our work in promoting best practice, both at national and European level. ED Ireland was delighted that one of its members, Catherine Thornton, won the Nathwani Prize at EBCC-5 for her book, Why Mum?.

**Israel**

During Breast Cancer Awareness Month, an extensive awareness campaign took place. Events included “The Shrine of the Book” in Jerusalem being illuminated in pink in a ceremony attended by the president’s wife, and a radio hotline with expert oncologists and surgeons. A seminar was held for young breast cancer patients, as well as the annual “Celebrating Life” seminar for breast cancer survivors. Breast screenings were carried out on Israeli MPs and staff. Throughout the rest of the year, the Israeli Cancer Association (ICA) national mammography screening programme continued to improve the early detection rates of breast cancer, and the mobile mammography unit continued to increase access and compliance rates in remote areas and from special sectors. The ICA updated and co-ordinated the nation-wide activity of the network of breast care nurses and social workers. The Nancy Reuben Comprehensive Breast Care Center was established. The Israeli Breast Cancer Coalition (IBRC) organised a conference to mark International Women’s Health Day. ED Israel presented an overview of the Breast Care Center in Israel at the National Advisory Council of Oncology and at the Israeli Society for Clinical Oncology and Radiation Therapy convention. Efforts were made to increase the government-funded medication package, and Herceptin will enter the 2006 package as an adjuvant treatment thanks to public pressure. The inaugural Anglo-Israeli Conference on Breast Cancer Genetics was held in collaboration with leading UK experts. Finally, ICA Reach to Recovery volunteers participated in a special challenging journey thanks to a donation from Mr. Henry Zimend, in memory of his wife, Anda.

**Italy**

For ED Italy 2005 was a year with many initiatives, both on the lobbying front, undertaken by the parliamentary group EUROPA DONNA Parlamento, and by the advocacy group. The projects involved three main areas: national health policy, early diagnosis, and work and women with breast cancer. With regard to the national health policy, the Inquiry on Breast Cancer and Tobacco, set up in April 2004 by the Commission on Hygiene and Health of the Italian Republic Senate at ED Italy’s request, was concluded. The proceedings have been published and were presented at a press conference in November 2005 in Rome. As for early diagnosis, one million copies of the DVD “The Breast: Knowing and Protecting – A Journey in Early Diagnosis” prepared by the President of the Cabinet Office and by the Ministry of Equal Opportunities were distributed in May with four national weeklies. With regard to work and women, the Ministry for Welfare prepared a leaflet with ED Italy, entitled “Breast Cancer and the Protection of Working Women”; to give working women and their employers knowledge of the laws reconciling work and treatment. The leaflet summarises the progress made by the legislation and national work contracts, e.g., part-time recognised by the Biaja Law and applicable rules for cancer patients. It also includes advice and testimonials, examples of good practice and privacy laws. Finally, Francesca Merzagora left the chair of the Italian Forum after nine years in October 2005. The President of the new national board is Anna Segatti, who is also President and Managing Director of Avon Cosmetics.

**Latvia**

ED Latvia has had a busy year. Recent activities include events held to celebrate Breast Cancer Awareness Month in October 2005, and the visit of Sanja Rozman from EUROPA DONNA. We used different forms of media to increase awareness about breast cancer, with approximately 60 articles appearing in 30 different media in October. We collected donations for free mammography screening, and we created and disseminated 50,000 educational brochures on breast cancer. We also organised the Pink Ribbon Movement support march on 29 October in Riga. We have been working with decision makers, and a series of meetings with politicians facilitated the creation of a parliamentary support group for breast cancer patients. Two of our members participated in ED training sessions about capacity building in advocacy in Milan. The Leader of ED Latvia participated in ED training in Rome. We held a “free mammography examination for early detection” event for women in November/December 2005. There have also been regular meetings of ED Latvia
Forum members. We aim to inform women in all regions of Latvia about the possibility of getting involved in activities to protect breast cancer patients’ rights. We are continuing our co-operation with other organisations and individuals in Latvia connected to the issue of women’s breast cancer. We continue to lobby the Ministry of Health and Parliament to improve the situation of breast cancer treatment. Finally, we aim to produce continuous publications to increase awareness of breast cancer.

**Lithuania**

ED Lithuania had a busy year working with the Health Ministry, convincing it to provide tests for the HER2 gene in the health care system. We are now trying to convince health care politicians to provide Herceptin, and have held meetings to discuss this as well as rehabilitation issues after breast cancer treatment. This year, new legislation on rehabilitation will come into force and we hope that the government will consider our suggestions. The influence of ED Lithuania and the Lithuanian National League of Breast Cancer has led to a national breast screening programme being introduced in 2006. We enjoy a very close relationship with the Lithuanian Parliament, which always supports initiatives run by ED Lithuania and the Lithuanian National League of Breast Cancer, and we work with the medical staff at the Vilnius University Oncological Institute. In October, we held Breast Cancer Awareness Month, organising a conference dedicated to the tenth anniversary of the Lithuanian breast cancer organisation movement. Many leading Lithuanian oncologists and politicians participated and there was a lot of media attention. We helped create an international awareness campaign, “Breast Friends”, which focuses on the need of every woman with breast cancer to have a Breast Friend to support her through diagnosis and treatment. We are also creating a website. An art camp will be held in summer for breast cancer survivors and newly diagnosed women. Our main aims for the future include organising a support system for newly diagnosed women in Lithuania.

**Luxembourg**

In 2005 ED Luxembourg members took part in many events, including an exhibition, “Brust – Lust Frust”, organised by a local council’s equality group, where ED members acted as artists but also as participants at an auction of bras transformed into objects of art. Our vice-president was the patient at a patient-doctor conference. Together with the coordinator of the national breast cancer screening programme run by the Ministry of Health, ED Luxembourg committee members spoke to student nurses about their experiences with breast cancer. A speech about breast prostheses was organised for doctors and nursing staff. Since autumn 2005 we have been running a successful monthly get-together for survivors wishing to meet others in an informal atmosphere. A painting group meets once a fortnight, under the guidance of an art therapist. The Race against Breast Cancer in October remains our largest and most successful event with 700 participants. The concept was a journey of solidarity, and so a tent village was built as a place to meet and obtain information. Stands covered all aspects of breast cancer, and after the race there was a roundtable discussion about breast cancer between survivors, politicians and specialists from different hospitals in Luxembourg. In November, ED Luxembourg helped to organise a conference entitled “Breast Cancer and Physiotherapy”. We published a brochure in French and German about radiotherapy for breast cancer to be distributed by radiotherapists to patients. Three newsletters were circulated to our members and professionals during the year. Finally, ED Luxembourg received good media coverage in 2005.

**Malta**

ED Malta holds monthly meetings and in June we had our annual general meeting. In 2005, members attended a three-day health fair, distributing books and leaflets; the European Parliament meeting; the Pan-European Conference in Rome; the 2nd Summit for Cancer Patients’ Advocacy Groups in Central and Eastern Europe in Warsaw; the ECCO 13 Patient Programme in Paris; EBBC-5 in Nice; an NGO programme in Gozo also attended by the Prime Minister; a meeting with the Minister and Director of Health; a seminar on bringing all the volunteer services under one umbrella; and advocacy training in Milan. Fund-raising included the purchase of collection boxes, with Air Malta sponsoring some of the cost; donation of a computer and a year’s Internet access from Lions Club Sliema; and an agreement with Avon Cosmetics, selling pink teddy bears. An awareness talk and a lecture on self-examination were given at a girls’ primary school. Our press conference to kick off October Month was well attended by the media and also by private radiographers, who announced that they would lower mammogram prices. October Month’s first lecture was attended by our Patron, Mrs Mary Fenech Adami, wife of the President of Malta. The Minister for Gozo opened the second lecture. We held two walks followed by a holy mass celebrated by the Bishop of Gozo. Regular meetings are being held to prepare October Month. Karin Joins MEP has accepted our invitation to address the opening lecture.

**The Netherlands**

The ED Dutch Forum focused on three particular themes: quality of breast cancer care from a patient perspective; (social) insurance in relation to breast cancer; and hereditary breast cancer. Two ED members, Ellen Verschuur and Tineke de Ronde, members of the expert team of the breakthrough Project Mamma Carcinoma, gave presentations at two conferences. The Project Mamma Carcinoma results were encouraging and a regional follow-up project will work further on the results; ED members have been
asked to participate. We participated in different commissions organised by the National Institute for Quality of Healthcare (CBO): the Decision Aid Breast Cancer commission, which aims to develop tools enabling breast cancer patients to make an informed choice about breast-conserving surgery or mastectomy. Two members participated in updating national breast cancer guidelines. We have contributed to the establishment of a working group as part of the national project Quality of Care. The working group, consisting of representatives of surgeons’ associations and patients, is developing external indicators for patient safety and efficacy of care. We also contributed to a survey organised by the national consumer organisation comparing the status of breast cancer care in hospitals. Despite the negative criticism which arose as a result, hospitals and the public are now aware that breast cancer care is far from being best practice. Member Ingrid Mulder also contributed to a working group on problems encountered by breast cancer patients when applying for social security payments; a report was published outlining the results. The second edition of the Pink Ribbon magazine was also published.

**Norway**

The main aim of the Norwegian Breast Cancer Association (FFB) is to influence the Norwegian Health Department to offer general breast screening every second year for women aged 45 years and over. The present age limit for breast screening is 50-69 years. Our 2005 Pink Ribbon Campaign attracted a lot of attention and was a good fund-raiser, and we hope that some of the attention and was a good fund-rais-

**Portugal**

The year 2005 was a turning point for ED Portugal. Despite the ongoing restructuring of the Portuguese Forum, we were able to attend various conferences and events and held several national meetings. We have remained in close contact with the Portuguese Health Parliamentary Committee and the Portuguese Educational Parliamentary Committee, in order to publicise the 2003 European Breast Cancer Resolution and to incorporate information regarding breast cancer prevention and treatment into the Portuguese educational programme. In October 2005, we promoted an awareness campaign at the Portuguese Parliament which was covered by the media and we appeared on prime-time television on almost every Portuguese TV channel.

**Romania**

In 2005, ED Romania in co-operation with the Renasterea Foundation particularly focused on raising public awareness about the importance of early detection of breast cancer. As part of the 2005 Summer Prevention Campaign, thousands of leaflets were distributed by volunteers with advice to protect families from skin cancer and about prevention and early detection of breast cancer. An important fund-raising event was the “Art for Life” gala, held in June at the residence of the Italian Ambassador. The main awareness event, the Illumination, held on October 1 in Bucharest and in five other cities in Romania, marked the beginning of Breast Cancer Awareness Month. The campaign involved press articles and advertisements published regularly in national and local newspapers and women’s magazines. Five TV spots encouraging women to take care of their health and have regular check-ups were produced and broadcast on nine national TV stations. The Free Access Telephone Line for information about breast cancer was also widely promoted. In December 2005, we participated in the International Women’s Association’s Christmas Bazaar, an important fund-raising opportunity, at which we distributed many informative materials to thousands of visitors. In March 2006, we organised a one-month media campaign, through the press, TV and radio stations, as well as through outdoor advertising in eight Romanian cities. Our National Representative, Mrs Mihaela Geoana, participated in high-rating TV and radio debates, talking about the benefits of early detection and the need to implement national mammography screening programmes in accordance with the European guidelines.
**Russia**

ED Russia’s main goals are to provide emotional support to the patient and other family and friends; to set up support groups and provide counselling; to communicate with doctors and other medical staff; to research medical aspects of the disease from books, the Internet or other resources; to serve as a point of contact for questions from family, friends and other people; and to care for the person at home, including sometimes learning new skills. ED Russia HOPE arranges free therapeutic physical training and our coaches work out unique sets of exercises for women after surgery, teaching them in the special halls in the regional health centres several times a week and at home. This also covers free entry to swimming pools where designated coaches teach women special water-based exercises. We operate a telephone hotline which is available from 8 a.m. to 10 p.m. throughout the week. We also work in close co-operation with breast cancer specialists who send patients and members of their families to ED Russia organisations. We organise annual conferences, the most recent of which was “Women of Russia against Breast Cancer” in April 2006 in St. Petersburg. The main lectures were given by Dr. Fedorov Andrey, a specialist in psychology and sexology, other nutrition and prosthetic specialists, and numerous health care professionals. The total number of breast cancer patients supported by ED Russia HOPE at our St. Petersburg branch is 550.

**Slovenia**

In 2005, ED Slovenia and citizens from all over Slovenia successfully raised the funds to purchase a mammography machine, which ED Slovenia bought in September 2005 and donated to the Oncological Institute in Ljubljana. By the end of 2005 the mammography machine had helped more than 100 women. We continued our lectures on breast cancer, healthy lifestyles and other cancer illnesses, and also appeared in both print and broadcast media to raise awareness of breast cancer, the importance of self-examination, and screening mammography after the age of 50. We have a well-edited website (www.europadonna-zdruzenje.si). We also offer support through two SOS telephones and we also arrange meetings with patients. Advice can also be sent by e-mail. Four issues of *Novice ED* (News ED) have been published as an insert to the magazine, *Naša tina* (Our Woman), with a circulation of 23,000. ED members receive a free copy. In September, together with the Slovenian Heart Foundation, we organised a running and walking benefit for a Rolloscope. In October we held a conference on equal chances for all patients and the availability of biological drugs. Health professionals, politicians and patients participated. ED Slovenia’s co-operation with the Cancer Patients’ Association of Slovenia and the Association of Slovenian Cancer Societies continues to intensify, and in March we jointly presented Fight against Cancer Week. In October, representatives of all three organisations were received by the Chairman of Parliament, Dr. Franca Cukjati. Herceptin was introduced in Slovenia in mid-2005 as part of adjuvant breast cancer treatment, for which much credit also goes to ED Slovenia.

**Switzerland**

In our second year of existence we extended our activities to other parts of the country and to other topics. We now have a central secretariat located in Bern. A main concern for ED Switzerland is mammography screening in an organised programme offered for the whole country. Today only five of 26 states have such a programme. Furthermore, in 2007 reimbursed mammography screening will be submitted for political decision. Our regional group in Eastern Switzerland created a whole party group pressing for the introduction of a programme in the state of St. Gallen. Our lobbying activities included the official handing over of 15,350 signatures asking for a nation-wide screening programme to a group of federal politicians at a joint press conference with the Swiss Cancer League. Both the Zurich and the Bern regional groups started to interact with their local politicians and organised several activities. Zurich regional group presented ED Switzerland at a big fair in the Zurich main station; Bern...
made interventions during the state elections. In the French-speaking part of the country, among other activities, we organised a public hearing with state politicians to ask them for their support of the Geneva screening programme which is in difficulty. Together with the ZONTA club Morges-La-Côte we organised an evening dedicated to women with two touching testimonials of women who had been through the experience of breast cancer. Activities for a regional group also began in the Italian-speaking part of Switzerland.

Turkey

In November, ED Turkey organised an event with breast cancer survivors and volunteers to help spread the word on breast cancer and advocacy. Our seminar series ran throughout the year, with seminars presented by experts to an audience of survivors and their families. Serpil Ocal, MD, survivor and member of our board, continues her conferences accompanied by a reporter from a local band, Clive and daughters Katherine and Libby, UK Forum Chairman Eileen Jaffé spoke of Patsy’s interest and involvement in ED and her active role as a breast cancer advocate both as a patient and parliamentarian. Prof. Cuzick’s predictions were both fascinating and optimistic. He anticipates that within the next 10 years, breast cancer will be approached in the same way as diabetes and heart disease are today. Regular assessment and precautionary medication will further early detection and help prevent the disease developing. “Barriers to effective tissue banking in Europe” at EBCC-5 was co-chaired by Mr Rob Carpenter, chair of the UK Forum’s tissue bank project working party, and Eileen Jaffé. Speakers were ED UK Executive Committee member Cathy Ratcliffe, Senior Development and Communication Manager, National Translational Cancer Research Network; Shirley Harrison, patient and member of ED and the Human Tissue Authority; Dr. Brian Clark Chief Executive, onCore UK – a national cancer biosample and information resource for cancer research.

Ukraine

ED Ukraine has had an active year. A national network, “Advocacy against Cancer”, was created and now spans 22 NGOs from 17 regions. The effective mechanisms established in the network mean that within two years the advocacy campaign has become visible at regional and national levels. An education programme for public activists was developed and put into effect. The 134 participants of the project completed the course on becoming a public activist with an in-depth study of the medical and social problems of breast cancer, as well as analysis of the current situation, organisational development, and looking for potential sources of financing to increase the potential of the regional NGOs. Co-operation and partnership mechanisms to organise joint events were worked out and implemented, and we partnered with Avon in our national “One Day Walking for Life” event in October. We produced and distributed high-quality educational materials to public organisations, NGOs, breast cancer patients and the public, in particular a reference book, “Breast Cancer Problem in Ukraine”, two issues of our “Advocacy against Cancer” bulletin, and two booklets (“What One Should Know about Breast Cancer” and “Way to Recovery”). Work started on special parliamentary committees in the Ukrainian Parliament, which includes representatives from the Cabinet of Ministers, the Ministry of Health Care, and the Ministry of Employment and Social Policy. Thanks to the initiative of ED Ukraine, the breast cancer issue in Ukraine has been included on the parliamentary agenda for a parliametary hearing in September 2006.

United Kingdom

“Prospects for prevention” were addressed by Prof. Jack Cuzick when he presented the lecture in the Forum’s annual series “A European Overview of Breast Cancer” on 27 October at the House of Commons’ Portcullis House. Host Dr. Ian Gibson MP, Chair of the All Party Parliamentary Group on Cancer, paid a touching tribute to the late Patsy Calton MP who had hosted the event in previous years and to whom the evening was dedicated. In welcoming the distinguished audience which included Patsy’s husband, Clive and daughters Katherine and Libby, UK Forum Chairman Eileen Jaffé spoke of Patsy’s interest and involvement in ED and her active role as a breast cancer advocate both as a patient and parliamentarian. Prof. Cuzick’s predictions were both fascinating and optimistic. He anticipates that within the next 10 years, breast cancer will be approached in the same way as diabetes and heart disease are today. Regular assessment and precautionary medication will further early detection and help prevent the disease developing. “Barriers to effective tissue banking in Europe” at EBCC-5 was co-chaired by Mr Rob Carpenter, chair of the UK Forum’s tissue bank project working party, and Eileen Jaffé. Speakers were ED UK Executive Committee member Cathy Ratcliffe, Senior Development and Communication Manager, National Translational Cancer Research Network; Shirley Harrison, patient and member of ED and the Human Tissue Authority; Dr. Brian Clark Chief Executive, onCore UK – a national cancer biosample and information resource for cancer research.
EUROPA DONNA has organised and participated in a number of high profile events across Europe since the last newsletter: the European Parliament Exhibition and Reception in October, the 7th Pan-European Conference in Rome, the European Breast Cancer Conference in Nice, and a meeting of the European Parliamentary Group on Breast Cancer (EPGBC) in Brussels in June. EUROPA DONNA advocates have taken part in other important meetings, including the European Cancer Conference in Paris. Still to come is a special EPGBC meeting at the European Parliament in October.
In April 2006, the European Commission published the 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

A full copy of these guidelines can be purchased through the EU Bookshop.

http://bookshop.europa.eu

European Breast Cancer Advocacy Training Course
10–12 November 2006 – Milan, Italy
EUROPA DONNA’s annual course will cover:
- The basic biology of cancer and genetics
- Diagnosis and treatment
- Mammography screening and guidelines
- Developing a lobbying campaign
- Communications skills training
- Formal presentations
- Handling the media
- Other key topics necessary for all advocates

8th EUROPA DONNA Pan-European Conference
27–28 October 2007 – Amsterdam, The Netherlands

For more information contact your national representative or europadonna@mclink.it

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

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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