Answering the advocates
on mammography screening
Lawrence von Karsa

on accreditation of specialist breast units
Luigi Cataliotti

on TRANSBIG
Martine Piccart

Young survivors show their strength at their first Working Group meeting

A young survivor gives her personal account

Member news

October European Parliament exhibition and reception

Don't miss the 7th EUROPA DONNA Pan-European Conference in Rome
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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personal political

President Stella Kyriakides

"Joining Voices–Meeting Needs". This theme, that of the EUROPA DONNA Pan-European Conference to be held this year in November, is uppermost in my mind as I sit to write this message.

As a Coalition, we work towards the implementation of the European Parliament Breast Cancer Resolution both at European and national levels, we work through information with our leaflets, booklets and website, through education with our advocacy course and our Pan European Conference. We work closely together with our partners to join our voices, to share the knowledge, to promote best practice, to help through the advancement of research towards finding the cure.

However, sometimes, in our efforts and daily work, we become absorbed in the everyday difficulties involved, we find ourselves rushing to meet deadlines and complete paperwork necessary for our projects and activities, and we almost seem to lose the personal, individual aspect we all have in our minds, that which binds us all together in such a unique and creative way. And, then, suddenly, a significant life event happens and it again brings the realisation and the focus back to the individual woman, the individual person.

One such recent significant life event was the loss in early March of a former member of the European Board, powerful advocate and friend, Josipa Horvatin from Croatia, who lost her life to breast cancer. Josipa worked with passion towards promoting our Pan European goals, both at a national and European level, letting neither differences in culture nor language act as barriers. Of course, Josipa will be greatly missed, yet I cannot but feel that knowing her, for many of us, was in itself a gift, and that her loss makes us only stronger as a EUROPA DONNA Family, and more determined in our work and efforts.

It is as I sat to write this greeting that the title theme of our Pan European Conference, the loss of one of our friends, the efforts all we make together with our partners, the different points of view often expressed, the bonds that are created through our Fora, the respect we have achieved at the tables where decisions are made, suddenly, it all became one and the same, became even more pertinent and even more meaningful.

This, we all know, is a joint effort. It inspires individuals and groups, it motivates many into action, it unites the voices of patients, relatives, friends, of the advocate and the clinician, the nurse and the scientist, and so many others all working tirelessly together to implement our mission.

To this effect, the last 6 months have seen EUROPA DONNA actively involved in a wide range of advocacy events. We have been working closely with all our partners on many different projects, with enthusiasm and commitment from all the members of the European Board, the executive director and the Head Office staff, and I thank everyone for their ongoing support.

Very recently was the first meeting of the EUROPA DONNA Working Group for Young Women with Breast Cancer. If I make a special reference to this project, it is because I believe that this will mark the beginning of a new, dynamic initiative that will further establish our Coalition as a front runner in meeting the needs of women with breast cancer by specifically addressing the needs of this group of women and separately addressing the issues that are of concern.

In ending I would like to thank all the national Fora that have given me the opportunity to visit their countries in the last few months. These have been valuable experiences, and allow a more realistic understanding and approach to the implementation of our goals, but also confirm that breast cancer knows no boundaries and can create none where personal and advocacy partnerships are concerned.

With these few words, let us look forward to another successful year of European breast cancer advocacy, that will see us hold an exhibition at Parliament in Brussels in October, and, celebrating life through our Conference in Rome in November. Join your voices with us there!

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Executive Director Susan Knox

Breast cancer advocacy in Europe continues to gain momentum and strength; for EUROPA DONNA this means meeting new challenges, and taking on new roles in the European arena vis-à-vis the European Commission, research organisations, and other scientific bodies with whom we collaborate. These new projects have required us to develop new skills, new strategies and new expertise. During the last year, we have worked on the design and development of the website for the European Parliamentary Group on Breast Cancer (EPGBC) at www.cpgbc.org, as well as the total restructuring of our own website at www.europadonna.org. We continue to hold our EUROPA DONNA breast cancer advocacy training courses on an annual basis and have been successful in receiving a commitment from the European Commission to provide a grant for the course for the next two years – 2005 and 2006.

We have held two meetings with the newly constituted EPGBC (EU-25), and will hold a third in June. This group is now actively engaged in learning what they need to know to campaign for implementation of the Breast Cancer Resolution in their home countries. This will be reinforced at our exhibition and reception “Breast Cancer in the EU-25” to be held in Brussels 17-21 October 2005. Our Lobbying for Best Practice Survey, which has been completed by our national representatives, will be helpful in communicating our message to the Parliament as well. We have worked diligently with our partner EUSOMA on the revised version of the guidelines for specialist breast units and on establishing a procedure for accreditation concerning them, one in which advocates have a direct role. This is a key concern for EUROPA DONNA, as we have been lobbying for these guidelines for many years and it is essential that an effective process be established so that we will truly be able to direct women to centres of excellence for treatment in the future.

Since our last meeting in October we have welcomed two new members, Slovakia and Latvia, so we now have 37 country members.

Our involvement in important research initiatives is also progressing. The TRANSBIG project is moving forward and EUROPA DONNA is working on dissemination of information concerning it at all the relevant meetings and events in which we participate. All Commission and NCI grants of this type now require a consumer advocate group as a partner, so we have been asked to participate in numerous applications.

During the last year we have presented the advocate’s point of view at meetings across Europe: ESMO, the Gastein Health Forum in Austria and UICC world conference in Dublin, to name a few. In June we held a meeting of our Working Group for Young Women with Breast Cancer, a real brainstorming initiative to determine how EUROPA DONNA can help meet the needs of this group of women across Europe. The efforts and skills of our dedicated Head Office staff, Karen Benn, Jill Byrnes and Daniela Pirisi, enable us to pursue and carry out a wide variety of projects successfully, and we are fortunate in having a committed and skilled Executive Board available to advise and work with us.

Our 7th EUROPA DONNA Pan-European Conference will be held in Rome 5-6 November 2005 (see inside back cover). We look forward to seeing all of you there – there are new members to meet, new projects to discuss, elections to be held and much more…. Ci vediamo a Roma – See you in Rome!!
EUROPA DONNA – The European Breast Cancer Coalition – now has an active voice in a number of projects covering the full spectrum of breast cancer care, from participating in guideline revision and breast unit accreditation to clinical trial committees. EUROPA DONNA has helped revise EUSOMA’s Requirements of a Specialist Breast Unit, particularly sections concerning patient support and communicating diagnosis and treatment. The revised guidelines are due to be published later this year by the European Commission. A longstanding advocacy target for EUROPA DONNA, the European guidelines are fundamental in realising the Coalition’s aim of ensuring that all women across Europe have access to high-quality breast cancer care.

Another step towards this end is the implementation of specialist breast unit accreditation with EUSOMA. As a member of the Advisory Committee and the Accreditation board, EUROPA DONNA will also be part of a team of four experts performing site visits to assess whether breast units meet the accreditation requirements. The next step will then be to make information on accredited units available to all women, so that they can seek state-of-the-art breast care in their countries.

As a partner in TRANSBIG, a translational research network of 39 institutions in 21 countries, EUROPA DONNA is a deciding force in clinical trials which could lead to improved breast cancer treatment options. EUROPA DONNA is a member of the TRANSBIG Steering Committee, the Legal/Ethics Committee and the Spreading of Excellence Committee. MINDACT is the first clinical trial to be conducted in the TRANSBIG network and aims to identify a group of women who may not need to undergo chemotherapy. The trial is to start recruiting this year.

Interviewing the experts

As these three initiatives are major initiatives for EUROPA DONNA and women around Europe, for this edition of Answering the Advocates, we sought to learn more about these projects by talking to the people in charge. Dr. Lawrence von Karsa, Co-ordinator of the European Breast Cancer Network (EBCN), shared his insight into the European guidelines, their revision and how to implement them across Europe. Also involved in revision of the guidelines, Prof. Luigi Cataliotti told us about adapting the Requirements of a Specialist Breast Unit and how units will be put to the test with the breast unit accreditation process, soon to be underway. He explained how creating a group of accredited units will facilitate data collection and research which could revolutionise breast cancer treatment. Along similar lines, Dr. Martine Piccart, co-ordinator of TRANSBIG, shared her ideas on this translational research network, its first trial and how such concerted efforts could greatly improve breast cancer treatment for women.
Dr. Lawrence von Karsa is co-ordinator of the European Breast Cancer Network, an organisation linking professionals involved in breast care, from scientists to screening programme organisers. The network aims to improve the quality, effectiveness and efficiency of breast cancer care by applying pan-European expertise in data collection and analysis, development of best practices, training of health professionals and certification of health care services. The EBCN, in which EUROPA DONNA also participates, is now involved in revising the European Guidelines for Quality Assurance in Mammography Screening and the 4th edition is due before the end of the year. Dr. von Karsa told EUROPA DONNA about the fundamentals of the guidelines and strategies for implementing them across Europe.

EUROPA DONNA: The European Guidelines for Quality Assurance in Mammography Screening are an important instrument to help EUROPA DONNA achieve its goal of bringing high-quality breast cancer care to all women across Europe. Why is it so important that these guidelines be followed?

Dr. Lawrence Von Karsa: The European Guidelines do not just apply to mammography, they apply to the entire screening process, including the follow-up diagnostics of women who show lesions on the mammogram and also the treatment of these lesions. The widespread implementation of these guidelines has therefore also led to a great increase in the quality of the breast cancer care for women who do not attend screening, because diagnostics and treatment also affects them.

ED: What role does the European Commission play in the guidelines?

LVK: The European Commission publishes the guidelines and co-finances their development, including expert meetings and consultations. It is among the 10 most distributed public health publications.

ED: What strategies can you suggest to convince national governments to implement screening programmes according to the guidelines?

LVK: Our experience shows that the most effective way to promote these best practice guidelines is to have an international meeting or workshop at which experts from various countries demonstrate in a very neutral way the tremendous impact that quality-assured, population-based screening has had on breast care in their countries; this tends to be very convincing. Furthermore, we try to show women the advantages and disadvantages so that they can decide for themselves. As a rule, most informed women recommend population-based screening. Therefore, the EBCN is developing guidelines on communication which emphasise objectivity.

“Pan-European training opportunities have played a key role in a number of countries which have implemented the guidelines”

ED: What obstacles do you see to the guideline implementation and how can they be overcome?

LVK: When setting up a population-based screening programme, the quality has to be very good at every step in this process. This is an enormous organisational task and experience shows that it is virtually impossible to have this kind of optimum quality in every place across an entire country. So usually one starts by developing a pilot programme in one or two regions and optimises the quality in these geographic regions. These become centres of excellence that the physicians, organisers and policymakers in other parts of the country can use as an example and for training purposes. In any one country there is only a limited number of experts who understand the organisational and scientific problems, such as the involvement of cancer registries in evaluation and monitoring. Without international co-operation setting up a programme can take quite a long time.

ED: How can programmes be set up across Europe?

LVK: Pan-European training opportunities have played a key role in a number of countries which have implemented the guidelines, for example for doctors who read the mammograms, radiographers who take the mammograms, surgeons who perform operations, and for staff involved in monitoring. This international exchange of expertise and experience is something that helps to overcome the lack of resources at the very beginning. It is unrealistic to expect every country to have all of these training resources. We have to share the burden.

ED: How does the EU expansion from 15 countries to 25 in 2004 affect the guidelines or their implementation?

LVK: The expansion of the EU has substantially increased the number of countries striving to implement quality-assured breast screening programmes. A few of the new member states such as Hungary and Cyprus have already established population-based screening programmes. The next step will be to bring the experts and programme planners and administrators in expe-
rienced countries together with those interested in implementing new programmes so that they can expediate programme implementa-
tion in the new member states and co-operate on further improve-
ments.

ED: What would you say are the greatest achievements affecting women with breast cancer this year?

LVK: A major development this year will be the publication of the fourth revised edition of the European Guidelines for Quality Assurance in Mammography Screening. The fourth edition of the guidelines will place more emphasis on the follow-up and the treatment of breast lesions, as well as on sympto-
matic diagnostics and monitoring.

ED: What stage are you at in their development and when do you expect these to be published? Will it be possible to consult them on a website?

LVK: I expect that the European Commission will be able to publish the document near the end of this year. The editorial board is currently working intensely on the final word-
ing. In the past, the guidelines have not been available on the Internet, but there may be a change in this policy in the near future.

ED: In your opinion, can guideline-based screening be implemented everywhere? How far are we from achieving this?

LVK: The European guidelines have been developed by European experts in a European context, but the underlying evidence and scientif-
ic principles are universally applicable. Some of the recommendations in the guidelines, such as involve-
ment of cancer registries in monitor-
ing and evaluation of screening activities will pose a challenge to any country which does not have such resources. Whereas regional or national breast screening pro-
grames have been implemented in most countries belonging to the EU before 2004, the opposite is the case in the new member states.

ED: What can EUROPA DONNA and its fora do to facilitate the process?

LVK: EUROPA DONNA's advocacy courses provide training in pro-
moting the implementation of evi-
dence-based guidelines and proce-
dures. This type of activity should continue and training advocates also from the new EU member states will strengthen the whole movement.

ED: Do you think that EUROPA DONNA's lobbying activities have been influential in improving breast cancer screening and care for women in Europe? If so, how?

LVK: Certainly EUROPA DONNA's lobbying activities and advocacy have helped to continue the activities of the cancer screening networks under the current public health programme of the European Commission. There was a danger 2-3 years ago that these very successful guideline development and best practice activities would cease. EUROPA DONNA helped to com-
municate the need for continuation of these efforts. This is something that should be recognised and appre-
ciated.

Another good example of con-
structive lobbying by EUROPA DONNA was the adoption in 2003 of a resolution of the European Parliament on a European pro-
grame to fight breast cancer. EUROPA DONNA should continue down this path to assure that these activities lead to fruition.

“The fourth edition of the guidelines will place more emphasis on the follow-up and the treatment of breast lesions, as well as on symptomatic diagnostics and monitoring”
Prof. Luigi Cataliotti is the President of EUSOMA, a society representing breast specialists in all disciplines covering all aspects of breast cancer. EUSOMA is now involved in revising its guidelines on quality assurance in the diagnosis of breast disease and its requirements of a specialist breast unit for publication in the new edition of the European Guidelines. Also underway is the implementation of a specialist breast unit accreditation process, which according to a set protocol involving site visits, will provide accreditation to breast units meeting the criteria established in the guidelines. As EUROPA DONNA plays an important role in the revision of the Breast Unit Guidelines and is part of the accreditation team, we met up with Prof. Cataliotti at his office at the Careggi Hospital in Florence, where he is Head of the Surgery Unit. He told us about the progress made in these projects and his hopes for what they could mean to women in the future.

EUROPA DONNA: You are involved in revising section for the new edition of the European Guidelines. What does this involve and where are you in this process?

Prof. Luigi Cataliotti: In the previous European Guidelines, the EUSOMA document on quality assurance in the diagnosis of breast disease was published in the annexes. For the new edition we were asked to put it as a full chapter. We were also requested to include the guidelines for the requirements of a specialist breast unit, the first EUSOMA guidelines, originally published in the European Journal of Cancer.

In the last year we have also been preparing the protocol for breast unit accreditation, in which EUROPA DONNA and EUREF are involved, and we thought it would be interesting to include this in the new edition of the European guidelines. We are now waiting the final decision of the editorial board.

Later, all these EUSOMA documents will be available on the EUSOMA website.

ED: What are the main points you have revised in the guidelines?

LC: Our changes to the requirements for a breast unit make them much clearer. Some specialists now are part of the core team, while in the first edition they weren’t.

EUROPA DONNA is playing a role in the accreditation process, in the guidelines and site visits.

ED: You have the specialist breast unit requirements and now you will begin to implement the accreditation process.

LC: The requirements of a specialist breast unit provide the definition of a breast unit. This accreditation process is how we will proceed to determine if the unit meets these requirements. It’s a voluntary process, because there is no law or regulation which says that EUSOMA has to do it, but it’s something that we offer to all units. From a methodological point of view, it’s a very rigorous process.

ED: EUROPA DONNA is playing a role in the accreditation process, in the guidelines and site visits.

LC: EUSOMA has already visited nine units for the experience and to confirm that we are moving in the right direction. But from now on we will visit these units with four different experts: a surgeon, a radiologist, a pathologist, and a EUROPA

We are also now preparing the guidelines for health professionals dealing with breast cancer in order to provide equal training for all of the members of the core team in a breast unit. In this way we will have guidelines on diagnosis, treatment and quality control. Moreover, we will have minimal requirements for a breast unit, the process to accredit a breast unit and how to train specialists working in this unit.

The next step will be to create a network to collect all the data on breast cancer from different units, in order to create a centralised database. This will harmonise diagnosis and treatment of breast cancer around Europe.

ED: At what stage are you in preparing the guidelines for the multidisciplinary team?

LC: About 1 year ago we created eight specialty groups, including surgeons, pathologists, nurses, etc in order to write the standards for the training of specialised health professionals dealing with breast cancer. Each of these groups has followed a set format and has written a chapter. Now we are editing all these chapters and in few months we will submit this paper to the European Journal of Cancer.

ED: EUROPA DONNA is playing a role in the accreditation process, in the guidelines and site visits, checking the quality of patient information and how well a patient is guided throughout her journey.

“EUROPA DONNA plays a fundamental role during the site visits, checking the quality of patient information and how well a patient is guided throughout her journey.”
DONNA representative. The process is co-ordinated by Prof. Roger Blamey, whose contribution has been essential to the development of the whole process. Prior to the site visit, units will have to fill in some questionnaires in which there are special questions prepared by EUROPA DONNA. This is the first time that a non-medical organisation takes part in such an important process.

ED: Have many breast units already expressed an interest in becoming accredited?

LC: We have received a lot of requests from Germany, as well as from Italy and the UK. We have about 20 requests so far. For the time being we have asked interested units to wait because we are finalising the details of the different steps of the process.

In the future the accreditation procedure will be available on the EUSOMA website. When we start the accreditation process we will ask people to help us spread this message, particularly EUROPA DONNA. This will help all patients in Europe find out exactly where they have to go to receive equal treatment.

It is interesting that the requests for accreditation are coming from the periphery; single units realise that it’s important to be accredited to work better.

ED: Of the nine units you have visited, are any able to become accredited?

LC: At the moment we are evaluating them. If a unit respects the guidelines and has all the necessary requirements, initial accreditation can be given. To be fully accredited the unit has to demonstrate in the next 5 years that it respects all the rules, collects all the data for quality control according to some quality indicators. I think this shows how rigorous the system is.

ED: EUSOMA will be responsible for cancer care and EUREF will cover the screening and diagnostic components. How will this co-operation work?

LC: We may encounter units covering all aspects of breast care, whether with a screening unit incorporated or associated, or without. EUSOMA will accredit the breast care components of a unit, while the screening component will be assessed separately by EUREF, which will also assess self-containing screening units and diagnostic units only.

ED: When will the site visits begin?

LC: As soon as possible, but only when all the steps have been finalised.

ED: Once a breast unit obtains initial accreditation, how will women know which units are accredited in their country?

LC: We plan to publish a list of units with initial accreditation on our website (www.eusoma.org).

ED: How important is the role of EUROPA DONNA and how can its fora help in this process?

LC: EUROPA DONNA plays a fundamental role during the site visits, checking the quality of patient information and how well a patient is guided throughout her journey. Moreover, EUROPA DONNA can help us to spread the message and to ask for quality control.

EUSOMA has no official role, but all this material is ready to be used even by the health authorities, if they want, and EUROPA DONNA can help us not only in the accreditation process, but also in finding political support for this initiative.
EUROPA DONNA: What were your aims when you created the Breast International Group in 1996?

Dr. Martine Piccart: At that time, breast cancer research in Europe was fragmented and I thought that if we combined all these forces, we could speed up the progress in breast cancer research. There were 22 groups doing adjuvant breast cancer trials in Europe. These groups were not talking to each other, so frequently similar ideas were being tested by different groups. At the same time, our American colleagues were better organised. They had created an intergroup, so they were already trying to synergise. I invited the chairs of all 22 groups to a meeting. It was quite tense because people were very surprised and a little bit anxious about this initiative. They didn’t clearly understand what this was all about at the beginning. Very quickly the atmosphere changed and it became very constructive. The meetings of BIG now take place three times a year. They are extremely constructive and successful. Very frequently there are about 45-60 people. We now have 35 groups worldwide under the BIG umbrella.

In terms of clinical trials, I think that we have made a lot of progress and we have a mechanism in place that works as efficiently as the one in the USA.

ED: Now you have begun the TRANSBIG research network for translational research. How do you expect that its activities will lead to improvements in breast cancer treatment for women?

MP: In 2000-2001 everybody began to realise that translational research was going to become key in the upcoming years. Until that point, it seemed like an exotic exercise. Now it’s clear that a trial that will not collect tumours and serum will soon not be worthwhile. I think we really need to concentrate forces on that aspect. So we thought that it would be wonderful if BIG had a sister network made up of laboratories and institutions committed to translational research, with a good track record in certain technologies.

If our hypothesis is correct, about 15% of women in the future will no longer receive adjuvant chemotherapy

From now on when we have an agreement to start a clinical trial, the TRANSBIG network will examine the trial and brainstorm about the key biological questions so that the translational research will be integrated from the beginning. What we want with translational research is to improve the tools that the clinician will have to make a much better selection of who needs treatment and which treatment works best for whom and needs to be given to whom.

ED: How is MINDACT different from other breast cancer trials? Where might this trial and its findings lead?

MP: MINDACT is the first large clinical trial that will have translational research as a key component of this study. The whole idea behind MINDACT is that we think that we have the technology to better identify women at low risk of relapse. Using this technology, if the assumption is correct, fewer women will be treated with adjuvant chemotherapy because we will be able to better select women at low risk of relapse. But of course, these are all assumptions. This is why we are going to run this MINDACT trial. We want to demonstrate that using this gene signature technology, we will do a better job than we do today. It is essential that the trial demonstrate that if a woman is identified as being low risk with the new technology, she is going to do very well even without chemotherapy and that very few of these women will relapse.

We have additional questions in the MINDACT trial that we want to address. It is a 6000 patient trial and, therefore, a large investment of time and energy. We will ask additional questions related, for example, to refining endocrine treatments and chemotherapy. But these are secondary questions. The really important issue is to demonstrate that we have a better tool for selecting women who do not need chemotherapy. This is why we are so excited about MINDACT; we feel that if our hypothesis is correct, about 15% of women in the future will no longer receive adjuvant chemotherapy because they simply don’t need it.

ED: Recruiting will begin in the last quarter of this year and then samples will be collected?

MP: It is going to be a very difficult trial that probably can only be conducted in Europe or certain parts of the world. We are going to require a frozen specimen of the tumour to
be secured and sent to Amsterdam, where the test will be done. A biopsy has to be done on all women participating in the trial, which is quite a challenge in terms of organisation. We need a special cooler to bring the specimens safely to Amsterdam.

We are going to follow these 6000 women for many years, but with a follow-up of approximately 5 years we should be able to say whether our hypothesis is correct: that the women managed according to the gene signature who are not given chemotherapy are really doing as well as we expect. We expect 3 years of recruitment, plus 2 years of additional follow-up, and then we could have a first look at the data.

ED: EUROPA DONNA will be involved in creating the consent forms for patients recruited in MINDACT. How important is this input?

I think that for very different and innovative trials such as MINDACT, the role of EUROPA DONNA is going to be very important. The trial in itself is complex. It involves a new technology and several randomisations. Women have to understand that the computer will assign them to a certain type of management and then possibly also to a certain type of endocrine treatment or chemotherapy. It is a lot of difficult information that women need to receive and understand. It’s going to be crucial that we can count on the help of patient advocacy groups to make sure that these informed consent forms are understandable and written in clear language and that they will also not be harmful to women and will be done carefully. This is an example of how collaborating with these groups is going to be really important.

ED: EUROPA DONNA is a member of various committees for TRANSBIG, as well as the BIG Scientific Committee. How valuable is the role of patient advocacy groups in clinical trials?

MP: I think that it is becoming more common, but it is certainly not as advanced as in the USA, where patient advocacy groups have been closely involved for several years, even in the design of the trials. Here, it is the beginning. MINDACT and TRANSBIG are going to be a wonderful experience to have this collaboration moving smoothly.

We are also hoping that advocacy groups will publicise the clinical trials to encourage women in the different countries to participate. I am optimistic because my experience with women with breast cancer has always been that they are really motivated to be part of trials because they always think of their daughters. They immediately think that if they participate and the trial is positive and identifies a better treatment, then this is going to benefit their daughters. I am optimistic that women will be keen to go into MINDACT, but I am a little more worried about physicians because they will have to devote energy to the launch and conducting of MINDACT.

ED: Are there any ways that EUROPA DONNA and its fora in 37 countries can be of further help in TRANSBIG or MINDACT?

MP: They can certainly help by advertising about the trial, by designing the informed consent form and maybe also designing a CD-ROM that could be used in the hospitals to show to patients. Finally, it would be wonderful if some women in the EUROPA DONNA community would consider doing some lobbying for us in the different countries to get more financial support: MINDACT represents a total cost of about 32 million euros of which 5 million still have to be found.
My name is Violet Aroyo. In September 1995, when I learned that I had breast cancer and both of my breasts had to be removed at age 34, I never asked myself why I got cancer. I had already lost my mother and my eldest aunt in 1991, my second aunt in 1992 due to breast cancer, and my third aunt was in the terminal phase at that time. I knew for sure that I’d also get it sometime in my life, so I was not surprised by this diagnosis.

When I heard that I had breast cancer, I tried not to think about death, or feel desperate. The most important thing for me was to start the treatment, do the best things necessary, and get healthy again. I had responsibilities, a two-and-a-half-year-old daughter, a husband and a job. It was important to get well soon and go on with my life.

“Breast cancer was not just my illness, it was a process which affected my whole family”

I had a really tough and painful time until I was diagnosed. Despite my family history, none of the doctors thought or wanted to think that I could have breast cancer because of my young age. After the diagnosis, I had to visit a lot of doctors to learn about the best treatment options for me. Finally, with the consensus of a few doctors, I had both breasts removed and there was no need for radiotherapy or chemotherapy. Because I had bilateral mastectomy, my recovery period was painful, but since I did not have chemo or radiotherapy, it was shorter.

As you all know, breast cancer was not just my illness, it was a process which affected my whole family. My husband and I decided the most proper way would be to get professional help for our daughter, and through the help of a professional counsellor we tried to explain to her about the illness, the operation and the post-surgical stage in the simplest way so that she could understand. My daughter tried to understand the situation as much as she could at that time, and as she grew older each year, she had new questions to ask to understand her mother’s illness. Maybe being open to her and informing her about the things that were happening caused her to think about cancer and illness at a young age, but at least she did not have uncertainties about what her mother had or what was being done to her.

My husband, my family and my friends supported me a lot in every way from my diagnosis to the end of my treatment. I especially believe that my husband’s support and tolerance in those days was a very important factor in my healing. Every woman needs such support at that time. I will be grateful to my husband all my life for all the support he gave and being with me during this period.

It is not possible to get over this illness alone. You need the support of your family members, close friends and also professionals, if necessary, during the treatment period. I believe someone should ask for this kind of support without any hesitation as soon as possible.

After getting breast cancer at age 34, I started to research what breast cancer is, whether it is possible to have an early diagnosis or not, the methods of treatment, and how to support women who had mastectomy.

As a result, I also had breast cancer, but I was able to get diagnosed early by my insistent efforts. Unfortunately, the women in my family who got breast cancer did not have such a chance. Therefore, I sometimes felt guilty because as a nurse I could not guide them. As time passed, I realised that even if I guided them, the best thing I could do would be to educate them about breast cancer and help it to be detected earlier. I was not able to do this for them because I did not have so much awareness and knowledge about breast cancer at that time. That’s why I started working actively with my friends setting up the Turkish Breast Cancer Foundation and Breast Diseases Coalition Forum, which then set up the forum of EUROPA DONNA Turkey.

“Now the priority is to create awareness about breast cancer among women by educating them and explaining the importance of early detection throughout Turkey. We face a lot of problems which we never considered during our activities. First, we want to continue our way with our government, overcoming bureaucracy, taking its support, but we have not been able to get very successful results despite all we have done. I personally think we have to educate people to make them more sensitive and aware of this subject.”

“After starting our activities in 1999, at first our results were small, but now we see that they get larger as time passes. Our biggest goal is gradually to reach women throughout Turkey and educate them to create awareness about breast cancer.”

Violet Aroyo
Email: violetaroyo@hotmail.com

After starting our activities in 1999, at first our results were small, but now we see that they get larger as time passes. Our biggest goal is gradually to reach women throughout Turkey and educate them to create awareness about breast cancer. Of course, the authorities have to be educated first.

My friends and I wish women to have breast cancer detected in its early stages and get them treated using easier methods so that they can get well soon.
In addition to coping with issues similar to those of other breast cancer survivors, young women with breast cancer have others to face, such as fertility, pregnancy, possibility of early menopause and higher mortality rates as well as heightened concerns about self-image, dating, partner communication and caring for small children.

The Working Group set forth some specific steps they believe will help young women facing these difficult issues. EUROPA DONNA will hold a special workshop dedicated to breast cancer in young women at the 7th EUROPA DONNA Pan-European Conference in Rome to follow up on the meeting and report back on the group’s findings. A full written report on the proceedings of the Working Group Meeting will be prepared and presented.
Drug approval is a long and complex process, requiring great attention to safety and efficacy, and, thus, it implies the involvement of all the possible stakeholders, from users to health care professionals.

**Drug approval in Europe**

Since 1995, when the European system for authorising medicinal products was introduced, providing for a centralised and a mutual recognition procedure, the regulatory approach of pharmaceutical products has been implemented by the EMEA, the European Agency for the Evaluation of Medicinal Products (http://www.emea.eu.int). Pharmaceutical companies may now submit single marketing authorisation application to the EMEA and the evaluation is carried out by European evaluators and experts through the CHMP, the Committee for Medicinal Products for Human Use. If the relevant Committee of the CHMP concludes that quality, safety and efficacy of the medicinal product is sufficiently proven, it adopts a positive opinion. This is sent to the Commission to be transformed into a single market authorisation, valid for all the European Union countries. The EMEA’s role is also to provide additional information for citizens and encourage the dialogue between health care professionals and better informed patients.

**The FDA and consumer representatives**

The FDA, Food and Drug Administration, is the Agency in the USA that (the modern era of the FDA dates to 1906!) works with similar procedures and with the same mission (http://www.fda.gov; Redmond K, The US and European Regulatory Systems: a comparison. The Journal of Ambulatory Care Management 27, 105, 2004). Several years ago, the FDA implemented a system to get consumers’ points of view by including consumer representatives on Agency Advisory Committees (http://www.fda.gov/oashi/patrep/patrep.htm #overview). The role of the consumer representatives is to represent the consumer perspective on issues and actions before the advisory committee, to serve as a liaison between the committee and interested consumers, associations, coalitions, and consumer organisations, and finally to facilitate dialogue with the advisory committees on scientific issues that affect consumers. Moreover, as documented below, a consumer representative must be able to analyse scientific data, understand research design, discuss benefits and risks, and evaluate the safety and efficacy of products under review. It is also essential that representatives have an affiliation with and/or active participation in consumer or community-based organisations.

**The EMEA and patients’ organisations**

Very recently in March 2005, an EMEA/CHMP working group with patients’ organisations was created with the following areas of interest: transparency and dissemination of information, product information, pharmacovigilance (the monitoring of the risk of adverse effects resulting from the use of the drugs), and interaction between the EMEA/CHMP and patients’ organisations (EMEA/149479/2004 Final). Therefore European patients’ organisations are encouraged to participate in order to take as much as possible the patients’ expectations into account.

This document represents another important step in order to continue in the direction of full collaboration between users and health care professionals, and to implement pragmatic actions to really involve consumers in the process of approval of new drugs. The EMEA document places great emphasis on information adapted to patients’ needs, and focuses on developing appropriate communications tools to increase the awareness of the correct use of medicinal products. Nevertheless, some issues are not considered; in particular, how and where consumers and consumers’ representatives may be involved in the entire process to decide on the approval of a new drug; how to improve the scientific background (scientific principles and basic statistics) and the level of expertise required for accurate comprehension of the scientific data; finally, how to identify the consumers among the different associations available.

What has been done by the FDA may be used as an example. In fact, the FDA proposes a simple document that describes the involvement modalities through 12 frequent questions/answers: “When a Patient Speaks…Patient Representatives to FDA Advisory Committees” (http://www.fda.gov/oashi/patrep/patrep.htm). Moreover, two programmes have been developed for cancer: “Cancer drug development patient consultant” and “Cancer patient representative program”. The first (http://www.fda.gov/oashi/cancer/pconback.html) incorporates the viewpoint of cancer advocates into the drug development process with the opportunity to participate in the drug regulatory process; the second develops a process for recruiting, assessing, and selecting patients’ representatives to serve as members of cancer-related advisory committees (http://www.fda.gov/oashi/cancer/cpat.html). This modality could also soon be transferred to a European level.

**EUROPA DONNA and making consumers’ voices heard**

Consumers and patients’ organisations, such as EUROPA DONNA - The European Breast Cancer Coalition, must be well informed about EMEA procedures to ensure the prompt availability of high-quality, safe, effective drugs. Moreover, each association, through an appropriate representative group – the EMEA/CHMP working group with patients organisations is at the moment the voice of four different generic and four different illness-specific patients organisations – must dynamically participate in the debate in order to consolidate the responsibility of patients and consumers in the process.

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EUROPA DONNA recently sent out a questionnaire to all its member countries to try and measure the response of each country’s government or health service to the European Parliament Breast Cancer Resolution passed in 2003 as well as to learn what progress has been made in implementing screening programmes according to the European Mammography Screening Guidelines and specialist breast units according to the EU-SOMA Guidelines. To see the full text of the Resolution go to www.epgbc.org.

The questionnaire we sent out asked our membership to respond in detail about their country’s response to the resolution itself and to its constituent elements. Those countries who are not members of the European Union were asked to answer the questionnaire in terms of the breast cancer services that their health systems currently provide.

The questionnaire had 28 questions in total and out of our Europe-wide membership of 37 countries, we got a reply rate of about 70%. EUROPA DONNA’s members made substantial efforts to respond to all of the questions and many of the countries also wrote comments about the individual questions asked. The responses are currently being collated and analysed and a full report will be available at the Parliamentary exhibit in Brussels in October 2005. From the results so far, we can already make the following observations:

- A few of the parliaments of our member countries have already agreed to implement the Resolution or, if they are a non-EU country, have agreed to provide the breast services called for in the Resolution.
- Some of the countries who replied say that their country’s health services already provide the items asked for in the Breast Cancer Resolution.
- 21, or 85%, of our groups say that they have contact with “a National Parliamentarian who is interested in breast health”. All except one of our groups have contact with either a local, regional or national politician and either a local, regional or national health service representative. This shows that EUROPA DONNA’s membership is very successful in its primary goal of …lilloying!
- Very few (3) of the countries have an all-party parliamentary group on breast cancer, but the vast majority do report that their countries now have some sort of Patients’ Rights legislation or regulation. Most of these measures have been passed recently.
EUROPA DONNA has been making its voice heard at various events around Europe this year, and many important events are yet to come. January and June saw EUROPA DONNA active in European Parliament at meetings of the European Parliamentary Breast Cancer Group. From Sarajevo to Berlin, from Athens to Anaheim, EUROPA DONNA advocates have participated in numerous important meetings this year; among them: ESMO in Vienna, the Gastein Health Forum in Austria, UICC world conference in Dublin, OECI in Greece, AACR in Anaheim, USA, and ASCO in Orlando, USA. The EUROPA DONNA Working Group for Young Women with Breast Cancer held its first meeting in June. EUROPA DONNA has also been active in the BIG and TRANSBIG trials and in the EUSOMA guidelines revision and implementation of breast unit accreditation. Still to come are the European Parliament exhibition and reception in Brussels in October, the 7th EUROPA DONNA Pan-European Conference in Rome in November, followed by this year’s Advocacy Training in Milan.
News from member countries

EUROPA DONNA’s membership now encompasses almost the entire continent of Europe. Here the Coalition’s member countries – 37 in total – share the activities that have kept them busy in the last year.

Belgium

In September 2004 EUROPA DONNA Belgium organised the very first EUROPA DONNA Belgium Awards. The aim was to honour five Belgian people or associations involved in exceptional projects or actions concerning breast cancer. ED Belgium insisted on the human dimension of the selected projects. HRH Princess Mathilde of Belgium was invited to present the awards together with the Belgian Minister of Health and other celebrities. Her participation stressed the fact that the fight against breast cancer is unquestionably of concern to Her Royal Highness. Her actions truly showed her support for our activities and commitments. On this occasion, we were also very honoured to have Stella Kyriakides, President of the EUROPA DONNA European Breast Cancer Coalition in our midst. The festivities took place at the Palace of Academies. Many politicians and medical doctors working in the field of breast cancer were present. For the occasion the building was illuminated in pink by the Estée Lauder Company. A few days later, we organised “Breast action” in cooperation with the Belgian Federation against Cancer and on different occasions we discussed, ably assisted by other experts in the field, crucial questions on breast clinics with a very interested audience. Two weeks after these events, ED Belgium was invited by a Belgian MP to take part in an exchange of ideas in order to prepare a resolution on breast clinics in Belgium. ED Belgium actively assisted her in her project and at the present time, the resolution is being presented to Parliament for discussion.

Bulgaria

ED Bulgaria has been established for a year and in co-operation with cancer patient organisations and friends (APOZ and friends), it has developed several programmes: everyday work with patients; extending structures; working with institutions; publishing and distribution; and participation in the European patients’ forum. A public debate on the problems of oncology was organised, in which different specialists participated, and emphasis was placed on the importance of prevention and timely diagnosis. We organised several informative sessions including visits to an oncology hospital, a Sunday party, a school of self-education to enable people to consult with competent specialists, and an art-therapy club to help women express their feelings about the disease through drawing. In addition, we have increased the level of activity in our organisation to attain European standards for patients’ rights, screening and early diagnosis, availability of up-to-date treatment for all and social adaptation. Stella Kyriakides’ visit to Sofia in September 2004 enabled her to meet the Vice-Minister of Health to discuss breast cancer problems, drug policies, and to remind the Ministry of the importance of establishing a national screening programme. She participated in a press conference and met the co-ordinators from ED Bulgaria and APOZ and friends. There are now 10 ED Bulgaria and APOZ and friends’ parallel structures throughout the country. Hardships faced this year have been caused by scarcity of drugs, despite the Ministry of Health increasing its oncology budget.

Croatia

ED Croatia remains involved in providing support to breast cancer patients, as well as attempting to expand links with medical specialists, the media, government institutions and individuals concerned about breast cancer. The Forum forged a relationship with a private hosiery producer, who agreed to place the Forum’s shower card promoting breast self-examination in each package of its hosiery. The Croatian Medical Association and Croatian Senologic society have begun the mobile mammography project. They are working very hard and are achieving very good results. They have visited many towns and have checked approximately 10,000
women ranging in ages from 40 to 70. Another very important role is that of the education of girls and women on breast awareness and of early detection in breast cancer. In April, we organised Daffodil Day in Zagreb and in 29 cities in Croatia. On this day we sold donated daffodils, thus raising money for the acquisition of apparatus and necessary instruments. We organised a Breast Awareness Walk under the name of Pink Ribbon Day on Saturday 2 October. Apart from the walk itself, we distributed some promotional and educational materials. In ED Croatia, we are almost all volunteers ready to dedicate our goodwill, free time and knowledge to realise these plans. The Forum has also been active on the international front.

Cyprus

The first 6 months of 2005 have found the ED Cyprus Forum very actively involved in the national screening programme through organisation of awareness events all over the island. January was a milestone for our Forum as ED Cyprus together with the Ministry of Health oversaw the launch of the first mobile mammography screening unit, which is already hard at work in distant towns. Promotion of the pan-European goals continues through Forum events such as lectures on surgery and best practice, and safeguarding of patients’ rights, while the Forum also organised and ran a specialised course for physiotherapists on the neurological problems often faced by women following breast surgery. On Women’s Day in March, our literature and awareness pins reached thousands of women, and we are currently advocating towards the implementation of the European Parliamentary Resolution on Breast Cancer. ED Cyprus recently issued the first comprehensive booklet on breast cancer in Greek and distributed over 500 ED Cyprus pink bags containing information about ED Cyprus for all women with breast cancer. ED Cyprus members now numbers 1,165.

Czech Republic

ED Czech Republic moved to new premises near the main entrance to the Thomayer Hospital in Prague. Prior to this move we were using facilities made available to us free of charge by the ARCUS-Onko Centrum. Our volunteers helped set up the new office and each afternoon distributed important information about cancer. We have a new website, www.europadonna.info, thanks to one of our members doing training lessons. Both she and another member participated actively in the first training sessions at a board meeting. Three members attended the March meeting in Hamburg of the Federation of European Cancer Societies and four European conferences about breast cancer. In November, the first meeting of the Organisation for Patients with Cancer in Middle and Eastern Europe was held in Warsaw, and a presentation was given on ED Czech Republic by Jana Filackova. The article was published in the Onkologicka Pece journal and in the ARCUS Bulletin, as well as on its website, www.arcus-oc.org. Information about ED is available from any oncological organisation, the Onkologicka Pece journal, nursing staff, the ARCUS Bulletin, and hospitals. ED Czech Republic is organising seminars in Ceska Lipa and Znojmo, and together with the ARCUS-Onko Centrum we distributed informative materials such as shower tags and leaflets about self-examination for breast cancer prevention.

Denmark

ED Denmark’s activities over the last year included the investigation of the standard of mammography equipment used in various private clinics and hospitals. We published three issues of our LMB Newsletter, discussing among other things a survey of women’s opinions on routine mammography examinations for breast cancer; the “apparent” centralisation of breast surgery which does not lead to proper centralisation with expert surgery; and a report on mammography equipment. A public debate was initiated with letters to newspapers on 23 March about centralisation, with the summer topic being reduced capacity, and we continued to participate in the public debate regarding the benefits of mammography. Our administration of the Pink Ribbon Fund is ongoing; it is a small fund trying to support joie de vivre, awarding grants to breast cancer patients on application. Eligibility requirements are breast cancer diagnosis within the last 3 years and an indication of use for the grant.

Estonia

ED Estonia has had a very busy year. In May, together with the Cancer Society we organised a Breast Cancer Awareness Week. A film, “Under the Glance of Mammography”, was produced and shown several times on two TV channels. A special breast cancer edition of the leading daily newspaper was issued, articles and interviews with patients and doctors appeared in magazines, and a week-long series of radio interviews with different specialists about breast cancer issues was held. A big achievement was the opening of the Information Office at the Out-patients’ Department of the Oncology Hospital in Tallinn. The room is equipped with two computers with Internet access, a video for watching films, books and medical brochures. Survivors are there in two shifts to give support to the newly diagnosed or simply to patients with any kind of problem. Assistance by a doctor or a social worker is available, and the office has become very popular among patients. At the ESMO Breast Cancer Symposium in October in Tallinn the issue of genetic counselling was raised at a Patient Advocacy Groups roundtable session. A team of doctors has been working on it and in 2005 genetic counselling for breast cancer patients and family members will become available. Lobbying for a National Cancer Plan continues. Once accepted by the government as a state programme, it will enable current mammography screening to be popula-
towards improvement of the system. and research are the main concerns. Screening, faster access to treatment breast cancer is the main interest. mentioned to set up an all-party group on by professionals involved in our missions. At the same time, we launched a booklet on “All the questions you always wanted to ask about screening” which was very well read and had a large audience. It is available online and can be downloaded in French from the website, www.europadonna.fr. Another action was important for us this year: better coverage of the French territory. We have increased the number of regional delegations with conferences in all of them held by professionals involved in our mission. Although we have not yet managed to set up an all-party group on breast cancer, we have been involved in study groups within the parliamentarian all-cancers group, where breast cancer is the main interest. Screening, faster access to treatment and research are the main concerns and we are working together towards improvement of the system.

France

As usual, ED Forum France has had a busy year! Nicole Zernik has become President of the French Forum, keeping in mind the excellent work done by her predecessor, Nicole Alby, in launching ED in France and the goal of developing it. Looking at the goals of ED, one of the priorities this year has been to finalise the implementation of the screening programme throughout the country. In order to do so, a number of regional screening organisations have ED members on their boards: this shows our input in the system. At the same time, we launched a booklet on “All the questions you always wanted to ask about screening” which was very well read and had a large audience. It is available online and can be downloaded in French from the website, www.europadonna.fr. Another action was important for us this year: better coverage of the French territory. We have increased the number of regional delegations with conferences in all of them held by professionals involved in our mission. Although we have not yet managed to set up an all-party group on breast cancer, we have been involved in study groups within the parliamentarian all-cancers group, where breast cancer is the main interest. Screening, faster access to treatment and research are the main concerns and we are working together towards improvement of the system.

Germany

ED Germany has continued its lobbying for European quality standards in early detection and treatment by setting up special events, participating in public fora, intensifying contacts with the media and by emphasising its position at the 4th European Breast Cancer Conference, held in Hamburg from 16-20 March 2004. European quality standards are still not a matter of course in Germany. In 2004, only 1% of women were offered mammography screening in accordance with EU guidelines in the context of three pilot projects. As the implementation of an area-wide screening envisaged for 2005 in Germany is further delayed, opponents of mammography screening take advantage of this situation to rekindle the debate against screening. Thus, ED Germany has focused its activities on providing information on mammography screening and on emphasising the immense advantages of early detection. We have also criticised the fact that not all German Bundesländer have cancer registries and have called upon them to collect such data on a uniform basis, as this is a precondition for the implementation of screening according to EU guidelines. We also underlined relentlessly the importance of setting up multidisciplinary breast units according to EU criteria. We are happy to say that despite women’s continuing uncertainty about mammography screening, the overall status of information when women are faced with the diagnosis of breast cancer seems to have increased through the dissemination of our leaflets and the regularly updated website. We are equally happy to announce the steady increase of members in our forum.

Greece

During 2004, ED Greece promoted the legal process for approval of its constitution and was introduced to Greek society through a variety of events in collaboration with the Society of Volunteers Against Cancer. A brilliant event organised by ED Greece in the Old Parliament of Greeks was attended by a number of high profile politicians, MPs, members of voluntary organisations and Forum members, and ED President, Stella Kyrtaikides, spoke regarding the coalition’s role in Europe. MPs committed their support to ED Greece’s efforts. Anna Benaki, the first woman Chairman of Parliament received an award. During Pink October, along with members of the Society of Volunteers Against Cancer and the Hellenic Association of Women with Breast Cancer, we established an information kiosk in Central Square, Athens, for 15 days, circulating printed material to the public about breast cancer awareness and early detection. We were represented in the mass media, as well as at events of other voluntary breast cancer organisations. We participated in panel discussions organised by the Greek Female Scouts, the Prefecture of Piraeus, and the National Workers’ Union of Greece. In April we participated in a meeting with representatives from the Ministry of Health, Ministry of Labour and other key health and labour organisations to discuss the rehabilitation and incorporation into the workforce of women with breast cancer. Jointly with the Hellenic Association of Women with Breast Cancer we initiated a survey of issues related to existing labour and social security conditions for women with breast cancer.

Hungary

The ED Hungary Forum selected a new national representative, Melinda Gyenie. She has already attended the advocacy training course in Milan, as well as various other breast cancer meetings in 2004. The Forum carried out a number of advocacy and awareness programmes over the last year, including: a week-long programme for volunteers; a patients’ forum held in a hospital; an Alliance Against Breast Cancer way of life camp; education of volunteer self-help group leaders; and “About us but only with us”; and patient-doctor meetings at the Parliament Café on Wednesday evenings in Budapest. In addition, various articles on breast cancer have been translated and distributed.

Iceland

It has been a good year for the Icelandic Forum. Together with our traditional meetings six times a year and supporting women newly diag-
nosed with breast cancer, we visited several places around the country, illustrating breast examination and encouraging women to participate in the breast screening programme. Last October we celebrated our 25th anniversary with approximately 300 guests and our guest of honour was Mrs. Vigdis Finnbogadóttir, breast cancer survivor and former president of Iceland. Last year, 167 women were diagnosed with breast cancer, and today there are 1,800 breast cancer survivors in Iceland. Our organisation has 640 members on the mailing list. The Pink Ribbon Campaign was held in October, in partnership with Estée Lauder local agents in Iceland, Artica, and the Icelandic Cancer Society, to promote breast awareness. Profits helped fund important projects for women, such as improving the educational environment in the Cancer Detection Centre and also making an educational video about the importance of breast examination and mammography. Equally important was the production of waterproof shower cards to act as reminders for mammography appointments and self-examination in the shower. A number of key buildings including Reykjavik Town Hall, hospitals, schools and churches, as well as the aptly named waterfall Bleiksarsfoss (The Pink River Waterfall) in Eskifjordur, were illuminated to mark the campaign. In 2005, the Icelandic President, Olafur Ragnar Grimsson, has consented to having the presidential residence, Bessastadir, illuminated this year and will turn on the lights with his wife, Dorrit Moussaieff.

Ireland

Two resolutions were passed at the 2004 AGM calling for: i) improvements in prosthetics services to provide nationwide equality of access and service; and ii) resourcing and staffing of genetic breast cancer services. A public meeting held in December on genetic services was attended by people from families with familial breast cancer. We wrote to the Minister for Health and Children on these issues and continue to campaign for our goals. The extension of BreastCheck, the national screening programme, to the whole country remains a live issue. The current date for completion is now 2007, however this is now in doubt due to lack of funding. ED Ireland was invited to speak at public meetings and press conferences on the issue and lobbied the Minister for Health and public representatives. Our views on screening are frequently sought by the media and we appeared on Prime Time, the major Irish current affairs TV programme. In January, we were part of the Cancer Care Alliance deputation to the Minister for Health, where screening and access to radiotherapy were the main issues. We attended various conferences and events and addressed national meetings. We welcomed Susan Knox, Executive Director ED, to the WCCO in Dublin in November. We continue to promote our agenda by influencing policy on breast cancer services through membership of organisations. The sixth issue of our newsletter, EDI News, was published, and fund-raising activities included Mini Marathons and the Fashion Targets Breast Cancer Programme; such projects also heighten awareness.

Israel

In October 2004, the Israel Cancer Association (ICA) marked Breast Cancer Awareness Month as part of the extensive media advocacy campaign, in Hebrew and in Russian, with an open hotline on a popular radio station and hundreds of educational pamphlets distributed nationwide. Thousands of questions relating to breast cancer were answered by the Telemida televi-

mation service staff operating around the clock. In addition, the Moshe Aviv Tower in Ramat Gan, the highest tower in the Middle East, was illuminated in pink, on the initiative of Estée Lauder in Israel and the ICA. The annual seminar, “Celebrating Life”, with 700 breast cancer patients participating, was also held with lectures delivered by leading experts in oncology and a question and answer panel. Also attending this seminar was a group of Palestinian women from Project COPE, who listened to the lectures through simultaneous translation. This project is the product of Israeli-Palestinian co-operation in association with the ICA, JDC-Israel, the Association for the Promotion of Women’s Health, Patient’s Friends Society Jerusalem, and the Augusta Victoria Hospital. A “fashion show in pink” was also held at the seminar, in tribute to women who have been diagnosed with breast cancer and have succeeded in beating the disease, to convey a message of optimism and hope. Actresses and Knesset members modelled along with breast cancer survivors who are currently “Yad Lehachlama” volunteers at ICA, assisting women who have just been diagnosed, proving that this battle can be won.

Italy

The Italian Forum has had a busy year with many initiatives undertaken both by the lobbying parliamentary group, EUROPA DONNA Parlamento, and by the advocacy group. An enquiry process was started by the Commission on Health and Hygiene of the Senate into breast cancer and tobacco-related illnesses. The Commission has had advice and presentations from Italian breast cancer experts, and visits to the most important centres for diagnosis and treatment of breast cancer were organised. Significant attention was given to ED and other national patients’ associations, taking note of women’s viewpoints and patients’ needs. The research will take a year and the results, due out before summer 2005, will be important to set out the future objectives of political health strategies in the fight against breast cancer. Another important initiative was the creation and production of a DVD, “The Breast: Knowing and Protecting”, which was promoted by the President of the Cabinet Office and by the Ministry of Equal Opportunities in collaboration with ED Italian Forum. Two million copies of the DVD, which contained information...
on the breast and early diagnosis, reconstruction and a wide ranging interview with Prof. Umberto Veronesi, were distributed with four national weekly magazines. Our activities continued throughout the year, providing information and training with the publication of a brochure on breast reconstruction, two issues of our magazine, “EUROPA DONNA Informa”, and the organisation of a course in Sicily on sexuality after breast cancer, an important issue affecting many women, especially the young.

**Lithuania**

ED Lithuania Forum is working closely with the Council of Representatives of Lithuania Patients’ Organisations (CRLPO). The main tasks and goals of this organisation are communication with social and state institutions, while solving questions about medical supplementation of patients, treatment and psychological and social adaptation; defending patients’ rights in different social and political arenas; representing patients at the governmental and institutional level; defending patients’ rights in the drafting of new legislation and participation in the preparation and confirmation of such legislation; organising cultural, educational, sporting and health events and other entertainment. On 1 January 2004, the CRLPO represented 16 organisations, with a total of 15,000 members. In November 2004, we joined the project “Consolidation of Influence of Lithuanian Patients’ Organisation during Integration into EU”. This project is ongoing and involves seminars, meetings and workshops. In 1996, the Republic of Lithuania passed the law on patients’ rights and compensation for the damage caused to their health. This law was updated and came into effect from January 2005, and it raised a lot of issues in Lithuania. We actively promote raising awareness about breast cancer and early breast cancer detection. We publicised our special campaigns for women in October and May to carry out breast examinations and free mammography screening. As yet, there is no national screening programme in Lithuania.

**Luxembourg**

ED Luxembourg has had a very successful year. Most of our events were held in October 2004, including two art exhibitions, one organised by ED Luxembourg and the other in collaboration with the Ministry of Health. On 16 October, we co-organised for the second consecutive year the “Race against Breast Cancer”, to partly finance the completion of the survey on breast cancer in Luxembourg, first results of which will be available at the end of 2005. Despite rain, over 750 people participated, either running or Nordic walking. People of all ages socialised afterwards and had a snack. The most exciting event was our art exhibition at a famous old art gallery in the historic part of Luxembourg City. The aim of this event was to bring together professional and hobby painters, women who discovered art while coping with breast cancer, and students, who through meetings with ED Luxembourg committee members, learned that living with cancer is possible. The students expressed their feelings through collages, models and photo collage. Writers and sculptors also participated. For us it was important to throw a different light on breast cancer and to stimulate the exchange of knowledge between concerned women, their families and friends. Many visitors came and we received very good media coverage. In November, we met the new Minister of Health and underlined the importance of every woman receiving the best possible individualised cancer treatment. Two newsletters were circulated during the year informing members and professionals about our work.

**Malta**

ED Malta’s representative, Helen Muscat, held a breast awareness course for 67 health professionals at St. James’ Hospital. The last lecture was given in early December by Gertrude Abela, Marianne Micallef and Esther Sant, using the knowledge gained from the advocacy training course. The feedback regarding the presentation was positive. The ED Malta group is also trying to lobby for the implementation of the European Parliament Resolution on Breast Cancer.

**Monaco**

Ecoute Cancer Réconfort, the Monaco chapter of ED, has had a very busy year. One of our association’s main activities is volunteer visits to cancer patients at the Centre Hospitalier Princesse Grace. Approximately 30 volunteers, cancer survivors or others, visit patients to lend support and aid. The association also helps cancer patients in administrative procedures so that they may obtain various social benefits. Each month, the Association holds a support get-together for cancer patients, survivors, family members, volunteers and hospital staff. These meetings are a pleasant way to provide support and activities to members. In December, the annual Christmas dinner and dance was organised at the Café de Paris. In addition to members, doctors and nurses from the Cancer Clinic enjoyed an excellent meal, a convivial atmosphere and a pleasant evening of dancing. A tombola was held and many prizes were awarded and donations made. These and other donations were used to buy new medical equipment at the hospital and to help patients in need.

**The Netherlands**

The ED Dutch Forum has had a productive year, developing its 2003 themes of quality of breast cancer care, inability to work and insurance, and hereditary breast cancer. We worked on further implementation of our booklet, *Quality criteria for diagnosis and treatment of breast cancer from the patient perspective*. During the second breast care symposium in October, organised in co-
operation with the Breast Care Nurses Society, results of a survey among these nurses revealed that 41% were familiar with the booklet’s quality criteria. Much remains to be done to familiarise all breast cancer nurses with the booklet. A survey by ED Dutch Forum to analyse national, contemporary breast cancer care was hindered by the inaccessibility of data. In cooperation with the Consumers’ Association and health insurers, we began establishing quality indicators for breast cancer care. Our members participated as expert members in the breakthrough breast carcinoma project, and also gave a presentation on how to advocate for hereditary breast cancer at the EBCC-4 in Hamburg. Breast cancer awareness month, October, was launched with a Pink Ribbon glossy magazine, an initiative of the former chief editor of Marie Claire, a breast cancer survivor. A publisher provided employees pro bono and almost 100,000 copies were sold thanks to media attention. In cooperation with the Dutch Cancer Foundation (KWF) and Estée Lauder, a gala evening was held, and a number of celebrities attending the evening were successfully recruited as ambassadors or advocates for the breast cancer cause.

**Norway**

The Norwegian Breast Cancer Association (BCA) has been reorganised and has been very active this year. Our main task has been to influence the Norwegian Health Department to generally offer breast screening every second year for women aged 45 years and upwards. The present age limit is 50-69 years. We have also worked with the authorities to centralise breast surgery. It is presently carried out at 15 hospitals all over Norway and, as is well known, centralisation will definitely increase the level of expertise. In addition, we have been working for a reduction in the waiting list for breast reconstructions—it is presently 2-3 years. At the end of May, a meeting with the BCA board is planned.

**Poland**

2004 was the year of the 10th Polish ED Anniversary. Thirteen hard-working associations have participated in our progress: Czestochowa, Debica, Gdańsk, Krotoszyn, Legionica, Łomża, Nowy Sacz, Poznań, Przemyśl, Rypk, Słupsk, Wrocław, Warszawa. There are about 300 Polish ED breast cancer advocates. By following the 10 ED goals, we have achieved a constant increase in breast cancer awareness among Polish women and subsequently the increased need for mammography screening. During these 10 years breast cancer mortality among Polish women decreased by 10%.

The most important activities in the year 2004 included: the participation of four Polish ED delegates in the EBCC-4 in Hamburg in March; the 4th Polish ED Board Assembly in Debica; and the 2nd General Assembly of the Polish ED Coalition Representatives in Warsaw in June 2004. The agenda of the meeting included topics such as ED official statements regarding sponsorship, HRT, the promotional campaign of the Coalition and the need for lobbying to persuade the Polish government to increase funds for prophylactic mammography screening. In addition, there was the participation of two Polish ED delegates in the ED Conference in Vienna in October 2004. The 10th Polish ED Anniversary took place on 26–27 November 2004 in Legionica. There was a documentary exhibition of the 10-year history of ED in Poland, various social events, and we were hosted in the Town Hall of Legionica by the City Mayor, Tadeusz Krukowski. Mrs Stella Kyriakides, President of EUROPA DONNA, was the most honoured guest. She enchanted us with her warmth, straightforwardness and her splendid lecture “Mission, Passion, Vision”. The 7th Annual Polish ED General Assembly took place in Krotoszyn on 23 April 2005 and initiatives for the upcoming year were agreed.

**Romania**

ED Romania through the Renasterea Foundation continued the awareness campaign of the Breast Cancer Prevention and Early Detection Programme in Romania. Our key goal was to provide appropriate information to Romanian women, stressing the importance of early detection through periodical examinations. Communication campaigns, using both the print and broadcast media, and other informative materials were developed, supported by the free telephone line (08008 300 300) dedicated to breast cancer issues. Our programme includes the Renasterea Social Diagnosis Centre, where women get free breast examinations and mammograms. Last year, over 5,000 women were examined, over 4,200 mammograms were performed and over 410 patients were sent for further investigation. For cancer patients and their families, we organised daily meetings with doctors of the Institute of Oncology and psychological support groups at the Renasterea Medical Information Centre. Starting this spring, further psychological support has been provided at the bedside. The Centre also provided booklets about prevention.

**Portugal**

In 2004, ED Portugal reorganised itself according to the guidelines of the EUROPA DONNA Breast Cancer Coalition and we had several meetings in order to restructure the Portuguese forum. We attended some meetings with Novartis Oncology and other associations and individuals. A one-day roundtable event was held in Coimbra in the centre of the country so that people from both the north and south could attend. Topics discussed included the multidisciplinary approach in breast cancer treatments, actions on prevention and other breast cancer issues. We are trying to approach the Portuguese Health Parliamentary Committee in order to publicise the 2003 European Breast Cancer Resolution and to eventually have it incorporated into the Portuguese health system. We are now under the umbrella of the Portuguese League against Cancer.
and treatment, as well as the opportunity to consult specialised journals and literature. ED Romania members participated in the EBCC-4 in Hamburg in March, the European Breast Cancer Advocacy Training Course in Milan in November and the General Assembly and Elections in Vienna in October. Two fund-raising events were held: 1 October was celebrated by the Illumination event and an art auction was held with the generous support of Romania’s most famous glass artist, Ioan Nemtoi. The ED Romania representative is lobbying the parliament and government to promote European legislation regarding access to mammography and screening.

Slovakia

We would like to give our thanks for the warm welcome of Slovak Republic into EUROPA DONNA in November 2004 and for the opportunity to take part in the Advocacy Training Course in Milan during the same month. It was a very informative and useful session full of positive energy and inspiration. We are proud to be a member of the EUROPA DONNA family. We have started our activities by establishing our organisation and its website, www.europadonna.sk, at the beginning of this year, and we look forward to sharing our further achievements in the next report.

Slovenia

ED Slovenia’s successful 2004 fund-raising campaign for the purchase of a mammography machine attracted numerous individuals and enterprises. Together with the health spa, Dobrna, we also organised an exhibition by painters, and the paintings were then sold at auction with the proceeds going to the purchase of the mammography machine. Around 1000 people, among them many public figures, took part in the “Run and Walk for Mammography” event we co-organised. Following our successful fund-raising, ED Slovenia has achieved a higher profile and our membership has increased to approximately 1,150. We made use of all available media opportunities to continue our efforts to raise breast cancer awareness among the Slovenian public. We also published four issues of Novice ED (News ED) and held lectures in various parts of Slovenia. We have at our disposal two SOS telephones and well-edited Internet pages, and we reply by email to numerous questions. We also took part in the organisation of a seminar for radiological engineers, “Does Mammography Hurt?”, as well as in the 4th International Mammographic School. Ms. Mojca Sencar was invited to ISQUA FORUM for the Policy Leaders and Decision Makers in Quality and Safety of Care in Amsterdam in October 2004 and she participated in the section Clinician/Consumer Partnership. Unfortunately, less success was had in influencing our health policies, as we still do not have any organised programme for mammography screening, nor any organised centres for breast diseases in accordance with European recommendations.

Sweden

The Swedish Breast Cancer Association (BRO) increased its activities in 2004. The successful fund-raising Pink Ribbon campaign was kicked off on National Breast Cancer Day on 1 October and focused on breast cancer awareness and the achievements necessary for increased research and better treatment. All health function-related politicians and Swedish MPs received a letter about breast cancer and the European Parliamentary Resolution. BRO gave out its award for excellent achievements in treatment, care or awareness for the first time, with Queen Silvia, patron of BRO, presenting the award. Much media attention was attracted through the information about breast cancer and the priorities distributed by advocates, resulting in coverage of breast cancer-related issues in both the print and broadcast media. A survey among BRO members about breast cancer treatment and care throughout Sweden had 2,000 out of 3,000 surveys returned, many with personal experiences attached. The Pink Ribbon campaign and the programmes of the local organisations attracted new members, and two new local organisations were founded aided by the BRO: BCF Svea in Alingsås and BCF Viktoria in Angelholm. Today, there are 32 local organisations with 8,700 members. The BRO established co-operation with several new partners, and collaboration with others, including the working party for the National Guidelines for Breast Cancer within The National Board of Health and Welfare, and the National Breast Cancer Care Programme of the Swedish Breast Cancer Group. We would like to express our gratitude and thanks for all the support during 2004.

Switzerland

ED Switzerland looks back at an eventful and dynamic first (full) year of existence with the aim of increasing breast cancer awareness. Our association participated actively at many meetings, conferences and events by giving presentations on ED Switzerland and relaying our scope of activities to gatherings of patients, specialists and politicians. Thanks to the contribution of our active members, regional member groups were started up in St. Gallen, Zurich, Bern and Geneva. In Zurich, a well-attended roundtable meeting was organised on “Mammography: Medicine and Politics” with the equal participation of (female) politicians, MDs and patients. In Bern, a “Breast” exhibition was launched with the help of the Bern Cancer League. In Genolier (Geneva/Lausanne region), we organised an event “United to fight against breast cancer”, specially devoted to patients, with our guest speaker, Deirdre O’Connell, explaining how ED has been “moving forward”. In building up political support for its objectives, ED Switzerland welcomed the breast cancer screening programme initiative in Fribourg. In Geneva, where such a programme has existed for a
number of years, we contacted prominent female politicians of different parties, who support the screening programme and informed them about ED Switzerland, resulting in different politicians becoming members and giving us support. We consolidated links with existing related networks, such as the Swiss Cancer League, both at national and local levels. A lot of effort went into establishing a multilingual website, which provides the opportunity to ask the experts questions.

**Turkey**

Our 2004 activities focused on educational seminars and conferences for awareness in breast cancer and breast health; fund raising; and international co-ordination. In May, we held two seminars on nutrition and stress management for breast cancer patients, and our President and an executive committee member spoke at the Sexually Related Diseases Congress in Istanbul. In October, one of our executive committee board members attended the ESMO conference in Vienna. In November, one of our members attended the European Breast Cancer Advocacy Training course in Milan, briefing us on her impressions afterwards. As a survivor herself, she gives lectures on breast cancer awareness and early detection and in spring she spoke to Ford factory workers and to lesser educated women at local council buildings in Istanbul. In November, we organised a “Breast Cancer and Lymphoedema Symposium” in Istanbul with the participation of three Israeli experts. Approximately 200 people were in attendance, including professionals, survivors and their family members. A workshop on the basics of lymphoedema treatment for 27 therapists met high enthusiasm. Also in November, we organised a fundraising stand at the annual International Women of Istanbul Christmas Bazaar, representing our national forum and ED. December saw the printing of our calendar with the paintings of our member, Iphigenia Savas. In spring 2005, we held three seminars on lymphoedema, stress management and gynaecological issues for breast cancer patients. All lecturers were well-known professionals. Our membership increased dramatically and we are continuing to work on it.

**Ukraine**

ED Ukraine created a national network, Advocacy against Cancer, comprising 22 national NGOs promoting training and helping national health care-related NGOs to initiate women’s rights advocacy, to launch medical prophylactics programmes, to provide modern diagnostic opportunities, treatment, rehabilitation and social support of breast cancer patients. Thanks to the support of international organisations (Project UCAN/USAID, EUROPA DONNA, Renaissance Foundation, Mary Kay Company), an advocacy training programme was provided and training was successfully completed by members of Advocacy against Cancer. Five issues of the advocacy network bulletin were distributed, which included information about the national breast cancer situation in Ukraine and shared the positive experiences of network members. Also included was information about contacts among the advocacy network members. Due to widespread distribution of the bulletins, the advocacy network attracted new members, and enquiries from state bodies, NGOs, the media, and the parliamentary Health Care Committee. ED Ukraine in co-operation with Kiev City Oncology Centre created and organised a rehabilitation programme for 44 breast cancer patients with financial support provided by the Kiev City government thanks to the advocacy campaign. The 15-day rehabilitation course in the wonderful, medicinal climate of Crimea in the Yalta Sanatorium had a positive influence on patients after surgery and chemotherapy. In 2005, ED Ukraine and Advocacy against Cancer plan to continue the advocacy campaign nationally to introduce rehabilitation as an obligatory after-care component for breast cancer patients.

**United Kingdom**

Over the past year, our Forum has gained increased recognition and following. In November, we held a panel discussion, “Tissue Banks: Are They Relevant to the Future of Breast Cancer Management?”, in our annual series “A European Overview of Breast Cancer” at the House of Commons, followed by a reception celebrating our 10th anniversary. The panel was chaired by Robert Carpenter, Lead Clinician for Breast Cancer and Associate Director Cancer Services, Barts and the London NHS Trust, who chairs the UK Forum’s Tissue Banks Project working party, and hosted by Patsy Calton MP, Co-Chair of the All Party Parliamentary Group on Breast Cancer. The distinguished panellists were Prof. Michael Baum, Dr Kirstine Knox, Prof. Ian Smith, Mrs Hazel Thornton and Dr Clive Wells. This very successful event stimulated interest, highlighted issues for further investigation, and identified the need for the facts to be brought to the attention of the wider public; a campaign addressing these is being initiated. As a member of the UK Breast Cancer Forum, we established or cemented relationships with other leading organisations and charities with an interest in breast cancer and contributed to meetings exploring areas of mutual interest. We were also represented at various UK conferences. In March, Chairman Eileen Jaffé participated in a small group meeting with the then Secretary of State for Health and the Shadow Health Secretaries to discuss breast cancer issues and question the Ministers. Topics included standardisation of treatment and care, prevention, making informed decisions, doctor-patient communication and waiting times.

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Strength in numbers
**Seventh EUROPA DONNA Pan-European Conference**

**European Breast Cancer Advocacy:**
*Joining Voices – Meeting Needs*

5 and 6 November 2005
Rome, Italy

Register online now at [www.europadonna.org](http://www.europadonna.org)

See advert on inside back cover for details.

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**European Breast Cancer Advocacy Training Course**

18–20 November 2005
Milan, Italy

EUROPA DONNA’s annual course will cover:

- The basic biology of cancer and genetics
- Diagnosis and treatment
- EUSOMA guidelines
- Mammography screening and guidelines
- Developing a lobbying campaign
- Communications skills training
- Formal presentations
- Handling the media
- Other key topics necessary for all advocates

For more information contact your national representative or [europadonna@mclink.it](mailto:europadonna@mclink.it)

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**European Parliament Exhibition and Reception**

Brussels, Belgium

Exhibition: 17–21 October 2005
Reception: 18 October 2005, 6:30 pm

A week-long exhibition entitled “Breast Cancer in the EU-25” will be held at European Parliament to increase awareness of the need to implement the Breast Cancer Resolution. The European Commissioner for Health and Consumer Protection, Markos Kyprianou, will speak at the reception on 18 October and brief remarks will be provided by EUROPA DONNA President, Stella Kyriakides, and Karin Joens, MEP, Chair of the European Parliamentary Group on Breast Cancer.

See [www.epgbc.org](http://www.epgbc.org) for more information and for a full report after the event.
EUROPA DONNA now has a new domain for the website – www.europadonna.org. Still under the Cancerworld umbrella, this new URL will make the site easier to find.

Head Office updates

Daniela Pirisi has returned from maternity leave and now holds the position of Administration/Events Officer, while Nadia Maycock has left to pursue her own business.

In-box

Do you have an opinion or news you wish to share?

Let us know

info@europadonna.net

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Don’t miss the

Seventh EUROPA DONNA Pan-European Conference

European Breast Cancer Advocacy: Joining Voices – Meeting Needs

Rome, Italy - 5 and 6 November 2005

Agenda highlights:

- Health priorities across the extended Europe
  Markos Kyprianou, European Commissioner for Health and Consumer Protection

- The way forward – breast cancer surgery
  Alberto Costa, Director, Breast Surgery Unit, Fondazione Salvatore Maugeri, Italy

- New advances – breast cancer systemic treatment and trials
  Olivia Pagani, Institute of Oncology of Southern Switzerland (IOSI)

- Helping women cope – role of complementary medicine in breast cancer
  Pat Hargadon, Breast Nurse, Ireland

- EUSOMA guidelines/accreditation of breast units – how to improve care for women with breast cancer
  Luigi Cataliotti, President of EUSOMA

- Screening needs in Europe: what the European Mammography Screening Guidelines mean for women
  Astrid Scharpantgen, European Breast Cancer Network, Luxembourg

- Joining our voices: implementing the 2003 European Parliament Breast Cancer Resolution
  Karin Jöns, MEP, Germany, EPGBC Chair

Also on the agenda are a panel discussion on the workings of a multi-disciplinary team, led by EUROPA DONNA Founding President, Gloria Freilich, and workshops on a number of topics.

Register online now at www.europadonna.org

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