EUROPA DONNA (ED) – The European Breast Cancer Coalition’s continuous lobbying in the European and national parliaments for high-quality breast cancer care for all women showed results with three major events in October:

- The adoption of a new European Parliament Resolution on Breast Cancer in the Enlarged European Union in Strasbourg on 25 October. It reconfirms the demands of the first resolution on breast cancer of 2003, and incorporates new demands, such as job protection and European directives for breast care nurses.


- A meeting on All-Party Parliamentary Groups on Breast Cancer held at the Belgian Senate on 18 October. National MPs and advocates worked to further the establishment of all-party groups in other countries.

These activities and others held throughout the year, such as the June European Parliamentary Group on Breast Cancer (EPGBC) meeting on the EU guidelines, and the relentless efforts made in the Coalition’s 40 member countries, will help to achieve ED’s top priorities across Europe:

- Implementation of the European Parliament Resolution on Breast Cancer in the Enlarged European Union
- Establishment of national mammography screening programmes and specialist breast units that adhere to the EU guidelines
- Development of certification guidelines for breast units
- Creation of national breast cancer registries
- Advancement of research
New European Parliament Resolution on Breast Cancer makes demands across the EU-25

Strasbourg, 24–25 October 2006

The European Parliament adopted a new Resolution on Breast Cancer in the Enlarged European Union in October 2006 reaffirming its commitment to ensuring access to quality breast care in all the member states. It reasserts the demands made in the first resolution of 2003 and adds new demands, such as the creation of a charter for the protection of rights of breast cancer patients.

The motion for a resolution was made by MEP Karin Jöns, President of the EPGBC and ED Germany. ED Vice-President Nicole Zernik, Executive Director Susan Knox, and members of ED France attended the plenary debate on the resolution in Strasbourg.

Though progress has been made since the adoption of the 2003 resolution, Ms Jöns said: “Fourteen years after the publication of EU guidelines on mammography screening, only 11 of 25 member states provide nationwide screening, although it does not always meet EU quality standards. With this form of early detection alone, we could save the lives of about 31,000 women a year in the EU.”

The new resolution demands the provision of specialist breast units across all EU member states by 2016 with a progress report on the status of implementation every two years. Commissioner for Health and Consumer Protection Markos Kyprianou also assured that by 2007 the Commission would produce a report on mortality statistics and the implementation of screening.

During the debate on the resolution, the Commissioner for Employment, Social Affairs and Equal Opportunities Vladimír Špidla emphasised the need for a charter for the protection of the rights of breast cancer patients in the workplace.

The new resolution incorporates the 10 EU member states that joined the union since the adoption of the first resolution. It reiterates the need to introduce nationwide mammography screening for women aged 50–69 at two-year intervals according to EU guidelines and encourages improved information policies to increase participation rates.

Prior to the debate, ED provided each Parliamentarian with a pink and blue card stating, “EUROPA DONNA – The European Breast Cancer Coalition thanks you for supporting the Resolution on Breast Cancer in the Enlarged European Union”.

ED President Ingrid Kössler affirmed, “The European Parliament’s adoption of the new resolution confirms its dedication to improving standards of care for breast cancer patients. It will also help the ED Fora work with their governments to ensure that breast cancer services meet the EU standards.”

Some key demands of the new resolution

- For the Commission to provide reliable data on the situation of women with breast cancer and to highlight the need for national cancer registries in the member states.
- To enable the creation of EU guidelines for breast care nurses and for certification of specialist breast units.
- To increase support for research projects for breast cancer in the areas of prevention and causative factors, biomarker testing, and therapies with minimal side effects, and to promote independent scientific research on breast cancer.
- To draw up a charter for the protection of rights of breast cancer patients in the workplace, so that women can be assured of their jobs during breast cancer treatment and their appropriate reintegration into the workforce afterward.
- To provide special information on the needs of young women with breast cancer.
- To set up information and advice centres on hereditary breast cancer, and for the Commission to present a progress report on this every two years.
- To enable the creation of EU guidelines for breast care nurses and for certification of specialist breast units.
- To provide special information on the needs of young women with breast cancer.
- To increase support for research projects for breast cancer in the areas of prevention and causative factors, biomarker testing, and therapies with minimal side effects, and to promote independent scientific research on breast cancer.
- To draw up a charter for the protection of rights of breast cancer patients in the workplace, so that women can be assured of their jobs during breast cancer treatment and their appropriate reintegration into the workforce afterward.
- To provide special information on the needs of young women with breast cancer.
- To set up information and advice centres on hereditary breast cancer, and for the Commission to present a progress report on this every two years.
- For the Commission to make the EU guidelines available for downloading from the Internet.

The resolution can be downloaded from www.europarl.europa.eu

More information on the European Parliament resolutions is available on www.epgbc.org
European Parliament workshop to define EU standards for breast care nursing

Brussels, 17 October 2006

The European Commission has agreed to include standards for breast care nursing in the next edition of the EU guidelines. As a first step toward this goal, the Workshop on the Need for European Guidelines on Breast Care Nursing was held in the European Parliament on 17 October. ED advocates and Board Members attended, along with over 100 participants, including breast care nurses, MEPs and breast cancer experts. The current EU guidelines now call for a minimum of two breast care nurses per specialist breast unit; however, a wide variety of practices for breast care nursing exist across Europe and need to be unified.

The workshop was organised by MEP Karin Jöns, President of ED Germany and the EPGBC, Presidents of the Committee on Women’s Rights and Gender Equality, and of the Committee on the Environment, Public Health and Food Safety in co-operation with the European Cancer Network (ECN).

Presentations were made on breast nurse specialists in seven countries (UK, Switzerland, Germany, the Netherlands, Slovenia, Poland and Slovakia), covering the different systems for training breast nurses, continuing education practices, and the standards and responsibilities of the nurses in each country.

Commitment from the Commission

Andrzej Rys, Director of Public Health and Risk Assessment in the Directorate General Health and Consumer Protection, reaffirmed the inclusion of standards for breast care nurses in the next edition of the EU guidelines and encouraged the use of European Social Funds to provide training of nurses. Dr. Rys applauded the work of ED with its 40 member countries. “We need to make progress on all levels – local, national, European – as EUROPA DONNA is doing and bring it to all levels so that women can have equal access to care,” he said. There is a need to work together, he added, since “the 270,000 women diagnosed with breast cancer each year are counting on it.”

The European guidelines

Dr. Nicholas Perry, EU guidelines editor, said that political backing is needed to implement the EU guidelines, something that has now been achieved through the EPGBC and the involvement of MEPs in breast cancer issues. The fourth edition of the guidelines incorporates diagnosis in addition to screening, because future editions will aim to include treatment and management of breast cancer, since screening and treatment go hand in hand. The next edition will also include standards for breast care nursing and a European policy for certification of specialist breast units. The need for breast nurses as part of the multidisciplinary team has been confirmed repeatedly by physicians, outcome studies, patients and consumer satisfaction surveys. “The need for EU guidelines for breast care nursing is essential,” Dr. Perry said.

Breast care nursing across Europe

The United Kingdom

As a result of successful lobbying, breast care nurses are now key members of the multidisciplinary team in the UK. Maria Noblett of the Royal College of Nursing in London said that to be considered a specialist breast unit, units must have breast care nurses. Nurses facilitate informed choice and decision-making, provide practical advice for prostheses and clothing, as well as psychological support. They must be experts in breast cancer treatment and be trained in oncology and psychological counselling.

Switzerland

Women needing breast cancer care in Switzerland can be treated mainly in general cancer units, in some breast care units and in smaller non-specialised institutions. Agnes Glaus of Tumorzentrum ZeTuP in St. Gallen explained that while there is no national policy regarding standards and responsibilities, a standardised breast care nursing role is being developed in some units. In a survey of women treated in the Inselspital Bern breast unit, the women viewed the breast care nurse as the second most important source of information next to the physician and the second most important source of emotional support next to family or friends. Training standards for nurse counsellors are being negotiated.

Germany

In Germany, there is no standard curriculum for educating breast care nurses. Doris Scholt of Klinikum Links der Weser in Bremen and Sara Marquard of Universitätsklinikum Witten-Herdecke described the curriculum development at their centres. A further education course in breast care nursing was begun in April 2006 and results of an evaluation are expected at the beginning of 2007. Course participants include registered nurses or midwives working in the area of breast cancer.
The Netherlands
The breast care nurse is an integrated part of the multidisciplinary team in the outpatient breast clinic in the Netherlands. Saskia Claassen said that as a breast nurse in Eindhoven, she provides care for women from diagnosis through treatment, including psychological support. Since adding breast care nurses to the team, the waiting times for appointments and outpatient visits required by breast cancer patients have decreased. A survey of 412 patients with regard to the new system showed a satisfaction rating of 8.4 out of 10.

Slovenia
Guidelines for breast care nursing in breast units have been developed in Slovenia in 2006. Katarina Lokar of the Oncological Institute of Ljubljana described the requirements: a postgraduate education in breast care nursing; continued training in the field at least every three years; one breast nurse for every 75 newly diagnosed cases; and one breast nurse for every 75 newly diagnosed cases. These aims to train nurses in oncology nursing, including psychological training, with a practical placement in an oncology department. She added that at her hospital, nurses are involved throughout the diagnosis, treatment and rehabilitation process and provide psychological support.

Poland
There are currently no uniform, mandatory standards for breast care nurses in Poland. Alina Flejszer of the National Cancer Institute in Warsaw explained that there is a bachelor’s degree in nursing and a nursing Master’s degree. These aim to train nurses in oncology nursing, including psychological training, with a practical placement in an oncology department. She added that at her hospital, nurses are involved throughout the diagnosis, treatment and rehabilitation process and provide psychological support.

Slovakia
Only three institutes have a breast cancer speciality in Slovakia and only the private sector offers employees screening opportunities. Jana Boroniová of Trnava added that there is a lack of qualified radiologists and mammography equipment, and long waiting times. While there is no specific specialisation for breast care nurses, oncology nurses work with breast cancer patients, and there are nursing guidelines to follow after surgery for malignant disease.

At the reception
Achieving equal services
The presentations indicated that there is a clear disparity in breast care nursing services and training across countries. Dr. Lawrence von Karsa, EU guidelines co-editor and leader of the International Agency for Research on Cancer (IARC)-co-ordinated European Cancer Network (ECN), reminded those present that the EU guidelines form the benchmark that countries should aim to achieve and against which progress should be determined. He encouraged the pooling of ideas and resources through the ECN.

ED President Ingrid Kössler echoed the need to share information and work together, which is the basis of the Coalition. In her presentation she pointed out that ED’s activities, such as congresses, publications and parliamentary meetings at a European and local level, show how countries can combine efforts and achieve results for women. She added: “One of ED’s main objectives is lobbying for the implementation of the EU guidelines in all of the Coalition’s member countries and this workshop at the European Parliament should raise awareness of the importance of establishing standards for breast care nursing.”

Brussels, 7 June 2006
EUROPA DONNA reasserted its dedication to ensuring that parliamentarians understand the EU guidelines at an EPGBC meeting at the European Parliament in June. Published in April 2006, the fourth edition contains an important new chapter on specialist breast units, which is based on updated EUSOMA requirements revised with input from ED.

Guest speaker Dr. Margrit Reichel, Head of the Mammography Screening Reference Centre in Wiesbaden, Germany and contributor to the EU guidelines, reminded the MEPs present that mammography screening in accordance with the EU guidelines is a more effective method of early detection of small tumours than clinical examination or self-examination.

Dr. Lawrence von Karsa, leader of the IARC-co-ordinated ECN, stated that no woman should receive a breast cancer diagnosis, undergo surgery or treatment without prior discussion of her case at a multidisciplinary meeting. He added that advocacy leads to communication between countries, and advocates and health professionals should inform their governments of the need to implement screening programmes adhering to the guidelines.

ED Executive Director Susan Knox said the Coalition’s 40 member countries – including all 25 EU member states – are actively lobbying for implementation of the guidelines. She encouraged MEPs to contact the Coalition members in their countries to work together toward this goal.

Creation of All-Party Parliamentary Groups on Breast Cancer

Brussels, 18 October 2006

Given EUROPA DONNA’s mission to represent the concerns and interests of European women to local and national authorities and governments, the Coalition actively encourages the establishment of all-party groups on breast cancer at national levels across Europe. It has now held three all-party group meetings, the most recent of which took place in the Belgian Senate in October 2006. All-party group meetings, which bring together existing all-party groups, national MPs and ED advocates, have helped to spur the creation of new groups so that breast cancer issues are considered in national policy and legislation.

At the first all-party group meeting in the UK in 2000, MPs from Belgium, Estonia, Ireland, Italy and Slovenia and ED advocates, learned about the existing UK all-party group and its activities. An Italian group was formed as a result. A second meeting in 2002, brought MPs from Croatia, France, Germany and Spain to the senate in Rome to meet the newly formed Italian group. In the last two years, Belgium, Portugal and Latvia have followed suit, bringing the current total of all-party groups to five.

The recent third meeting was held in the Belgian Senate, where representatives of the five existing groups and MPs or their representatives from Cyprus, Hungary and Sweden and ED advocates shared their experiences. Senator François Roelants du Vivier and Magda de Meyer, MP, of the Belgian Interparliamentary Group on Breast Cancer, hosted the meeting. Sen. Roelants du Vivier, Ms de Meyer, who also moderated the meeting, and Birgit Carly, Board Member of ED Belgium, presented the history of their group and what it has managed to achieve.

The Belgian experience

After determined lobbying efforts by ED Belgium, the Belgian Interparliamentary Group on Breast Cancer was formed in October 2005. Beginning with the UK meeting in 2000, ED Belgium began to pursue political contacts, including meetings with the Minister for Health in 2001 that led to the implementation of a national screening programme. In order to overcome some political hurdles along the way, they hosted an award ceremony for contributions to breast cancer. The Belgian MP Magda de Meyer then proposed the creation of a Belgian parliamentary resolution based on the European Parliament Resolution on Breast Cancer. From this, Sen. Roelants du Vivier tabled a bill to establish standards for breast clinics, which has since been proposed as a Royal Decree. If passed, this would mean the inclusion of the European guidelines in Belgian legislation for breast units.

The Belgian interparliamentary group is one of the largest all-party groups in the Belgian Parliament with more than 60 member parliamentarians. It meets four times a year and its main objective is to work beyond political boundaries to co-ordinate initiatives in the area of breast cancer. Every year in Belgium almost 8,000 new cases of breast cancer are detected and 22 new cases are diagnosed every day.

Initiatives and aims

➔ In October 2005, with the help of ED Belgium and the Foundation Against Cancer, the group held a symposium on clinical research, screening, psycho-oncology and breast clinics in the Belgian Senate.

➔ The group recently succeeded in having Herceptin® included in the national health reimbursement scheme.

➔ It is working to include the EU guidelines in Belgian legislation for breast units.

➔ It aims to boost the rate of participation in mammography screening from the current 55% to the required 70% for a successful programme.

➔ It is working to expand screening programmes to include younger and older women.

The UK experience

The All-Party Parliamentary Group on Breast Cancer was established in 1996-97, when Breakthrough Breast Cancer, a major UK charity, acted as its secretariat and organised some publicity events, such as a photo call at which 70 MPs wore pink ribbons. The group aims to raise issues of concern with government and other policy makers; to provide a forum for MPs and peers of all political parties to discuss breast cancer-related issues; and to take action on behalf of people with breast cancer. As well as organising occasional meetings with eminent speakers, the group publishes the Breast Cancer Bulletin newsletter and encourages its supporters to contribute to parliamentary debates and questions.
**Initiatives and achievements of 2005-06**

- The UK group has been campaigning to improve access to medicine and treatments, such as Herceptin® and HER2 testing. A fast-track system has been established to assess whether potentially life-saving drugs should be made available on the National Health Service.
- It lobbies to improve access to breast screening services and to encourage women over 70 to participate. In 2004, it succeeded in improving uptake of invitations and extending the screening programme to women up to the age of 70.
- The Breakthrough Patsy Calton Award has been established to honour former joint Chair of the UK all-party group, Patsy Calton, who died from breast cancer in June 2005. The annual award recognises exceptional achievements by parliamentarians in campaigning for improvements in breast cancer research, services and the patient experience.
- A Q&A session allowed parliamentarians to ask the National Cancer Director questions about breast cancer on behalf of their constituents.

### Five-year goals

- Promotion of a healthy lifestyle, e.g., breastfeeding.
- Establishment of breast units according to the EU guidelines and the integration of all units.
- National Health Service coverage for reconstruction.
- Evaluation of the need to lower the age for screening.
- Increased investment in research.

### The Portuguese experience

One of the newer groups, the Portuguese All-Party Parliamentary Group on Breast Cancer was formed in October 2005. With the collective effort of parliamentarians and ED Portugal, the group has already made some achievements in the areas of prevention, awareness and legislation.

### Activities and achievements

- More women now have access to free mammography and ultrasound services. Improved services for low-access areas have been addressed through agreements signed by the government and through the use of local mobile units.
- In accordance with the National Education Commission, secondary education biology syllabuses now include references to cancer. In July 2006 the group and ED Portugal met to make plans to introduce information on breast cancer physiology and treatment to the syllabus.
- Several years ago, the Portuguese government passed a law allowing people with disabilities significant benefits when acquiring a mortgage for their residence. However, banks usually demand that women with breast cancer have life insurance, which is almost impossible to acquire. With the passing of a law (36/2006) in August 2006, this type of financial discrimination is now an offence, and the insurance companies are obliged to cover the risk despite any pre-existing illness.

### The Italian experience

Formed in 2001, EUROPA DONNA Parliament is a working group comprising the Italian Forum of ED and Italian women MPs. Its aim is to maintain contact with institutional representatives, local health authorities, scientific directors, etc. In Italy, the breast care services women receive vary widely between regions, cities and even hospitals. Based on survey results, EUROPA DONNA Parliament pinpointed six main areas requiring attention:

1. Increased funds for research.
2. Increased awareness of prevention through information campaigns.
3. Promotion of early diagnosis through equal access to screening.
4. Improved treatment through investment in centres of excellence and greater co-ordination between the public and private health care sectors.
5. Increased attention to quality of life and access to reconstruction and psychological support.
6. Improved access to the workplace for women with breast cancer. A decree passed in 2003 allows such women to apply for a reduction to part-time hours.

### The Latvian experience

The newest group, the Saeima Support Group for Prevention and Treatment of Breast Cancer was established in Latvia in December 2005. Through the joint efforts of parliamentarians, physicians and media representatives, it aims to ensure that women receive better and more accessible breast cancer prevention and treatment. In her presentation, Latvian MP Ingrida Circene noted that despite its limited membership, the group has brought to light breast cancer issues in the parliament and has initiated discussions about a national cancer strategy.

In Latvia, the number of cases of breast cancer is on the rise. Of the cases reported, 30.1% are in the advanced stage (stages III and IV); in almost 82% of all cases this is due to a delayed consultation with a doctor. In 2005, health care spending was 3.38% of the GDP and about 3 euros per cancer patient, the lowest among EU countries. For a woman diagnosed with breast cancer in Latvia, her chance of recovery is 35% lower than that of a woman with the same diagnosis in Sweden.
Aims
➔ The Latvian group aims to bring effective cancer treatment in Latvia up to the level of other European countries.
➔ It encourages women to take responsibility for having regular medical check-ups and to request a breast examination.
➔ It urges the government to more actively disseminate information about prevention programmes.
➔ The group has initiated discussion in the parliament regarding the national oncology strategy.

Spreading the word to MPs
As the meeting aimed to motivate members of parliament to create all-party groups in countries where they are not yet in place, MPs or their representatives from three EU countries described the breast cancer situation in their countries.

Cyprus
Stella Kyriakides, Past President of ED and a newly elected MP in Cyprus, said that Cyprus is moving toward forming an all-party group for breast cancer. ED Cyprus has had some very successful lobbying campaigns involving politicians and the government. Through its work with the Ministry of Health, a pilot mammography screening programme was established. Part of the parliamentary agenda will now be to question its adherence to the EU guidelines. ED Cyprus also pressured for the creation of a cancer registry. Treatment and diagnosis for all cancer patients is now available at no cost to the patient, including Herceptin® treatment.

Sweden
With its 30 years of experience with mammography screening programmes, Sweden has witnessed an increase in the five-year survival rate from breast cancer from 63% in 1970 to about 80% in 2004. Screening is now recommended for women aged 40-75 years, although not all the counties have expanded their programme. MP Barbro Westerholm explained that a new all-party group may now be considered for breast cancer issues in general; 48% of parliamentarians in Sweden are women. There is a need for a national cancer plan that would:
➔ Speed up the approval of new medicines.
➔ Investigate the different treatment approaches in various counties.

Hungary
While an all-party group has not yet been established in Hungary, the country has shown that it has political will with regard to breast cancer. A nationwide mammography screening programme targeting women aged 45–65 was established in 2001. A representative for MP Zsuzsanna Dér said that emphasis is being placed on professional training for radiologists, mammographers, pathologists, cytologists, surgeons and oncologists. There are also awareness campaigns to make breast screening part of the “health culture”. In 2003, the National Public Health Programme was established based on a parliamentary decision.

On a European level: EPGBC
The EPGBC is a prime example of ED advocates working with politicians to set policy and standards for breast care across the EU-25. MEP Karin Jöns, the EPGBC Chair, emphasised the need to implement the European Parliament Resolution on Breast Cancer in the Enlarged European Union by 2016. European Structural Funds and Social Funds can be used to set up screening programmes and provide training for the multidisciplinary team.

The EPGBC and ED have included a national all-party breast cancer group section on www.epgbc.org.

Moving forward
ED is the common link between the all-party breast cancer groups in each country. Its efforts to ensure that all groups have up-to-date information on breast cancer can help the groups make a difference. Politicians must be approached in each country, and particular pressure can be made during pre-election times. ED Executive Director Susan Knox said, “ED is ready and willing to set up a meeting next year in another country and hopes that one of the current groups or a new group will want to host such a meeting. In this way we can continue the dialogue among parliamentarians on breast cancer issues and encourage the formation of new national all-party parliamentary groups on breast cancer.”

Susan Knox, Adriana Bonifacino and Stella Kyriakides

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

Advocacy targets
- Advise national governments of the European Commission’s review in 2007 of member states’ progress in implementing mammography screening programmes and in decreasing mortality rates due to breast cancer
- Encourage national members of parliament to establish all-party parliamentary groups on breast cancer
- Lobby national governments for implementation of specialist breast units in accordance with the fourth edition of the EU guidelines
- Advocate the inclusion of the woman’s perspective in the future creation of EU guidelines for breast care nurses and for specialist breast unit certification
- Pressure national governments to keep cancer registries in accordance with the EU guidelines

Advocacy training 2006
Supported by a grant from the European Commission, EUROPA DONNA’s 5th annual European Breast Cancer Advocacy Training course in Milan on 10-12 November welcomed 53 advocates from 29 of the 40 member countries. The 2.5-day course covered various areas of importance to breast cancer advocates, including diagnosis and treatment of breast cancer, learning effective communication and public speaking skills, lobbying techniques and media training. Presentations were delivered by leading European experts on subjects such as the basic biology of breast cancer and genetics, epidemiology, prevention and risk factors, and EU guidelines for mammography screening and specialist breast units.

www.epgbc.org
The joint EPGBC-EUROPA DONNA website is dedicated to European policy for breast cancer and the initiatives taken to ensure its implementation. The website covers the European Parliament resolutions on breast cancer, the EU guidelines and meetings of the EPGBC. It now also includes a special section on national all-party parliamentary groups on breast cancer.

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

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

For further information contact:
EUROPA DONNA
The European Breast Cancer Coalition
Via G. Previati, 12
20149 Milan, Italy
Tel.: +39 02 8907 9660
Fax.: +39 02 8907 9664
Email: europadonna@mclink.it
www.europadonna.org
(Member of Cancerworld)