

# EDI News

Newsletter of the Irish Breast Cancer Campaign

NO. 11\_SUMMER/AUTUMN\_2010

[www.europadonnaireland.ie](http://www.europadonnaireland.ie)

## Vision

That women of all ages in Ireland will know what they can and should expect in terms of risk, diagnosis, treatment, recovery and support in order to improve early detection rates and survival rates.

## Christine Murphy-Whyte, Chairperson Europa Donna Ireland, Vice President EUROPA DONNA – The European Breast Cancer Coalition

**We in Europa Donna Ireland are deeply saddened at the loss of our Chairperson, Christine Murphy-Whyte, who died on 20 August, aged 58. The week before she passed away she was working on the final drafts of EDI News and it is truly shocking that it now carries this obituary.**

Christine had over 33 years full-time employment in the disability area, mostly at senior management level. She worked with and on behalf of people with disabilities in the fields of education/training and employment, disability services, advocacy, and national policy development and had extensive experience at both practitioner and management levels in the fields of research, training and development, standards, certification and quality assurance. Formerly Head of Policy and Public Affairs with the National Disability Authority, she took early retirement in 2005, following diagnosis and treatment for breast cancer.

Christine joined Europa Donna Ireland when its first national conference - Best Results for Women - Working Together for Best Breast Cancer Services Nationwide (2006) – was being planned. She brought to the project her fine administrative talents and her quick appreciation of advocacy, informed by her own experience of the disease, and she played a very significant part in the success of that conference. She was also central to the second national conference – Surviving Breast Cancer (2008). She became Chair of EDI and oversaw various publications, culminating in *9 Things*

*you should know about breast cancer*, for which EDI won the Crystal Clear Health Literacy Award earlier this year. This project was central to her determination that accessible information about breast cancer must be available to all women. Christine was a tireless campaigner for evidence-based, best practice health policy changes to ensure access for all women in Ireland to specialist breast centres and to screening for women between the ages of 50 and 69.

In Ireland she ably represented the patient voice on HIQA reports – The Report of the investigation into the circumstances surrounding the provision of care to Rebecca O'Malley...(2008), The Report of the investigation into...the Mid-Western Regional Hospital Ennis (2009) and The Report of the National Quality Review of symptomatic breast disease services in Ireland (2010).

In January 2007 she was elected to the Board of EUROPA DONNA – The European Breast Cancer Coalition. She was Vice President at the time of her death and made a very significant contribution to the work of EUROPA DONNA at European level. Susan Knox, Executive Director of EUROPA DONNA, says "She was a committed, dedicated advocate



who fought the disease with grace and fortitude until the very end. She has provided us with an example of what an advocate should and can be". Indeed she was a natural patient advocate – informed, articulate, passionate and very clear as to goals. Professor Niall O'Higgins has said "Everyone involved in one way or another with breast cancer is in her debt and will miss her greatly...She was a heroic figure. The impact of her work will endure."

Her loss is a great loss to breast cancer patient advocacy both here and in Europe. We will miss her enormously but will do our best to continue her work. Christine was working on plans for Breast Health Day (15 October) up to a few days before she died and we will dedicate that day to her. Her editorial for *EDI News* is on page 3.

Christine is survived by her husband, Michael, their three sons, Stephen, Darren and Jason, her mother Gisela, her brothers and sisters and extended family. We offer them our deepest sympathy and heartfelt condolences.

We are very grateful for the messages of support we have received from cancer organisations in Ireland and from EUROPA DONNA members around Europe.

Our Mission is to bring the voice of the woman with experience of breast cancer

- to raising awareness of the need for screening and access for all women to best quality specialist centres and
- to campaign for evidence-based, best practice health policy changes to ensure this happens.

## Committee 2010

<b>Chair</b>	Christine Murphy-Whyte
<b>Vice Chair</b>	Deirdre O'Connell
<b>Secretary</b>	Marie Ennis
<b>Treasurer</b>	Trudy Doyle
<b>Members</b>	Mary O'Brien Sarah Tierney Betty Watson Dympna Watson Eithne Weymes
<b>Information/Support Administrator</b>	Sarah Gillespie

## Thanks to

Dept of Health and Children, National Lottery, Cathy Kelly, Emma Hannigan, Trulife, GSK, Q4PR, Red Dog, Alice Griffin and Linda Walsh of DESSA, Novartis, Pfizer, Joanne Vance NWCI, Wendy Alla Tagle and Ellis J Quinlan and a special thanks to Judith Wojtowicz of Avon for pedometers and goodie bags on Breast Health Day 2009. We particularly want to thank Pippa Halley, formerly of Q4PR, for the excellent work she has done for us over the last few years. We will miss her but we wish her every success in her new position with the Fulbright Commission.

It is our policy to provide our publications, conferences and information sessions free of charge so we welcome donations to enable us to continue to make information about breast cancer accessible to all women in Ireland.

# 9 Things you should know about Breast Cancer

**Information on breast cancer can be very complex and the sheer volume available can be very confusing and daunting for many women. With 6 new cases of breast cancer diagnosed every day in Ireland, every woman young and old needs to be equipped with the most important basic facts about this disease.**



Thanks to the vision and persistence of Mary Harney, Minister for Health and Children and the leadership of Professor Tom Keane as Director of the National Cancer Control Programme, very significant progress has been made over the last two years in Ireland's breast cancer services. BreastCheck now has a presence in every county in Ireland. Breast disease services from around the country have been concentrated into the 8 Specialist Cancer Centres and these centres have been independently monitored by the Health Information and Quality Authority in relation to the National Quality Assurance Standards for Symptomatic Breast Disease Services.

We felt the time was right to get key messages out to women, because *the sooner breast cancer is found the better your chance of surviving it*. Women need to understand that these centres are the best places to diagnose and treat breast cancer. Our awareness raising leaflet distills crucial information into 9 illustrated points covering the risk of getting breast cancer, what one can do to reduce risk, what

to look out for, when and where to get checked out, as well as dispelling some commonly held myths.

In particular we wanted to get these messages out to women in disadvantaged areas/groups since the evidence suggests that they are less likely to access the screening and treatment benefits associated with earlier detection and increased survival.

With the support of National Lottery funding, the leaflet was distributed by An Post to over three-quarters of a million households throughout Ireland. We would have loved to distribute it to all households, but as a volunteer organisation dependent on donations, we had to prioritise remote rural regions, inner city and urban areas where women's and community groups and BreastCheck are actively raising awareness to get maximum impact.

**Christine Murphy-Whyte**



Emma Hannigan and Cathy Kelly

## New leaflet launched by Minister Harney

In October 2009 EDI launched a leaflet highlighting the 9 things every woman in Ireland should know about breast cancer. The project was funded by a National Lottery grant and, in all, 790,100 leaflets were distributed via An Post. It was the first mass distribution of a cancer leaflet to so many Irish households, with priority given to remote rural regions and urban areas where women's and community development groups and BreastCheck are actively increasing awareness. EDI's aim was to produce something that was accessible to everyone. In drafting the leaflet, EDI worked with women at grassroots level through the Disability Equality Specialist Support Agency (DESSA) and the National Women's Council. Feedback was generously received from the National Adult Literacy Agency (NALA) on a draft to ensure the plain English content. Subsequent drafts were tested with a wide cross section of women of all ages to assess the impact of the messages and their illustration

Officially launching the leaflet, Minister for Health and Children Mary Harney said: "This is an excellent idea that has been well executed. The leaflet is as leaflets should be: easy to understand and visually strong. I am delighted it will be getting out to so many households and it provides an excellent model for raising awareness about other cancers and serious diseases."

Speaking at the launch at the Chester Beatty Library, which was addressed by young women writers Cathy Kelly and Emma Hannigan, Christine Murphy-Whyte said: "Information

on breast cancer can be very complex and the sheer volume available can be very confusing and daunting for many women. However, with six people being diagnosed every day in Ireland, every woman - young and old - needs to be equipped with the most important basic facts about this disease.

"Our leaflet distills crucial information into 9 illustrated points which are easy to read and remember but accurate and vitally important," continued Ms Murphy Whyte. "They cover your risk of getting breast cancer and most importantly, what you can do to reduce your risk, what to look out for and when and where to get checked out, as well as dispelling some commonly held myths."

At the launch well known Irish author Cathy Kelly gave her support to the leaflet and urged women to read it, keep it and regularly revisit it. Author and recent Late Late Show star Emma Hannigan spoke about her own experience with breast cancer and the book she has written, *Designer Genes*. Feedback has been excellent, with requests for copies from GP practices, specialist breast units, cancer support centres, women's groups, clubs, community groups, etc. We have printed more copies and if you would like some, please contact us at [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie).

A special thanks is due to Mary Doherty, Katherine Brownridge and Debbie Cooke of Red Dog and Illustrator Steve Doogan for their work on the design of the leaflet and valuable assistance with the postal drop and to Pippa Halley of Q4PR for her work on the launch event. The contribution of women's groups who attended the NWC/EDI/DESSA Workshop in February 2009 and the subsequent work by the Clondalkin Women's Network were invaluable and absolutely central to the development of the leaflet.



Minister for Health and Children Mary Harney and Christine Murphy-Whyte

## EDI wins Health Literacy Award

In April 2010 we were delighted to win a Crystal Clear Health Literacy Award in the category Best Project in the Community or in a Social Setting for our leaflet, *9 things you should know about breast cancer*. Many thanks to all who contributed to its success.



Christine Murphy-Whyte with the award

# Breast Health Day 15 October 2010

## What are you doing for Breast Health Day 2010?

Breast Health Day 2010 will be on Friday 15<sup>th</sup> October with the theme:

### “Make healthy choices - breast health is up to you”



- » engaging in physical activity, +
- » keeping a normal body weight, +
- » eating a healthy diet
- » can help protect your breast health !

Breast Health Day will be going global this year with a digital/social media campaign. Keep an eye on our website and on [www.breasthealthday.org](http://www.breasthealthday.org) for up to date news and events. Ideas and suggestions for activities on and around the day are welcome and if you would like to organise a Breast Health Day 2010 event contact us at [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie) or 087 638 3609.

## Dragon Boat Racing comes to Ireland!

In June Europa Donna Ireland committee members Dympna Watson and Trudy Doyle took the plunge (*not literally*), and joined the Plurabelle Paddlers to attend a two day Dragon Boat Helm Course/training session in the University of Limerick Activity Centre, Killaloe, Co Clare. The Plurabelle Paddlers is a breast cancer support group with a difference. It's made up of a group of women in the Greater Dublin area who have the experience of breast cancer. The inspired Fiona Tiernan heard about Dragon Boating from a friend in Canada and with her incredible enthusiasm she has very successfully set up a dragon boat team (think Hawaii Five-0) to:

- » get fit
- » enjoy the mutual support of team mates
- » raise awareness about breast cancer.

We are all new to the sport and are inspired by the 150 or so breast cancer dragon boat teams worldwide.

On the day we were all of different levels of fitness and age but that didn't become an issue as we were all beginners when it came to paddling our canoes! Approximately 40 women attended and we were cheered along by a few men on the sidelines too. On the first day, Saturday, the weather was glorious and so after our initial safety training on dry land and with some apprehension but lots of enthusiasm, we took to the Shannon. In no time at all we all settled into the paddling routine, following our instructions from the trainee Helmswomen! Many of us were initially concerned about Lymphoedema issues and quite a few had compression sleeves on. Also there was a lot of talk among us at first as to which side of the canoe to sit on as this determines which of your arms gets most use but we quickly got into the rhythm of the paddling and in fact several ladies felt that they had a noticeable improvement in their arms the following morning.

Not everyone that attended on Saturday could stay for the Sunday training session so the numbers weren't as big and despite the change in the weather, for the worse, we took to the waters again. It was great to get the experience of canoeing in the hot sunshine and having to use lots of sunscreen on Saturday and then on Sunday going out in the rain and choppy waters. Overall it was excellent, exciting canoeing experience!



Dragon Boat launch at Killaloe

Also, Julie Doyle is the Team Coach. She has over 19 years experience of dragon boat racing and has raced all over the world. She has been at every World and European Championships since 1997 as part of the Great Britain Dragon Boat Team. Now based in Carlow, Julie, a level 4 coach, has trained numerous teams and individuals from the complete novice to those aspiring to be part of the national team. She was inspirational for us all.

The weekend was a great success and lots of breast cancer stories were exchanged and support given among the women. All in all, it was a challenging, sociable, energetic and very enjoyable weekend!

The Paddlers will be launching their own boats on the Grand Canal Basin during the second weekend in October. For more information see [www.plurabellepaddlers.com](http://www.plurabellepaddlers.com)

**Dympna Watson EDI Committee**

# National Quality Review of Specialist Breast Centres

Breast Cancer is Ireland's second most common cancer with about 2,500 cases diagnosed each year. The treatment of women with this disease in both our public and private hospitals has been a source of concern, since the summer of 2007 following a series of revelations of mis-diagnosis and system failures in diagnosis and treatment of breast cancer.

In June 2007 there were 33 hospitals providing services to women with symptoms of breast disease, many of which did not have the staff or facilities or practices to provide the standard of care required by best practice. Many were not seeing the volume of patients required to maintain standards nor meeting the timelines required for safe and accurate diagnosis as recommended by the National Standards for Symptomatic Breast Disease Services which were approved by the Board of HIQA and mandated by the Minister for Health and Children, Mary Harney in May 2007.

When media attention and public outrage erupted in the summer of 2007, EDI campaigned hard for the implementation of specialist cancer centres. In September of that year 13 hospitals were closed immediately with the remaining hospitals given a deadline for a phased transition to one of the designated 8 specialist cancer centres. At last we were on our way to making sure that the evidence-based best practices in the diagnosis and treatment of breast cancer services would be put in place serving the entire country.

When Professor Tom Keane took up his two year position as Director of the National Cancer Control Programme in November 2007, he prioritised breast cancer services. All designated cancer centres were expected to be fully established as specialist centres and meeting the Standards by the end of 2009. This significant change programme, required huge effort and cooperation of staff and management to ensure the transition of services from other hospitals, and the reconfiguration of staff, services and patients in the 8 centres, at a time when increases in referrals due to the controversies put substantial pressures on services.

The National Quality Review of Symptomatic Breast Disease Services published by HIQA in February 2010 is the

culmination of two and a half years of its interaction with the symptomatic breast disease services since the launch of the Standards. HIQA adopted a very comprehensive and flexible approach to monitoring compliance including giving feedback to the centres, which in turn led to improved performance. In addition, a service-user representative from EDI led discussion groups with a selection of patients on their experiences of the service they had received.

Importantly, HIQA concluded that all centres now have in place the fundamental requirements for safe, quality care, in particular, triple assessment, multi-disciplinary team meeting, core staffing and appropriate equipment. Centres have begun to introduce standardised data collection and management systems. Not surprisingly the 8 centres are at different stages of development and there is still progress to be made in achieving a level of consistency and embedding fully the requirements for safety and quality across the service nationally.

While a lot has been done, there is still a lot more to do. The National Standards need to be revised and updated to incorporate developments in clinical practice and patient centred care since the Standards were first published e.g. reconstruction surgery, familial history protocols, follow-up, psychological and social support, patient feedback, Lymphoedema. As ever, the patient perspective in drawing up Standards needs to be fully integrated into the process. Ongoing independent assessment of how centres are performing in relation to the Standards is a critical barometer of the quality and safety of our breast cancer services and a major reassurance to patients and their families. The same level of clarity and assurance cannot, however, be claimed for breast cancer patients in our private hospitals. Patients and their families need to be assured that the same requirements in relation to Standards apply and independent assessment / accreditation must be extended to our private hospitals.

Reports on each individual centre's Quality Review, together with the full National Report can be found on [www.hiqa.ie](http://www.hiqa.ie).

**Christine Murphy-Whyte**

# AGM 2010/Information Session



Marie Murphy and Charlotte Coleman Smith at 2010 AGM



Committee members at the AGM 2010

This year's AGM (15 May 2010) featured a full report from Chairwoman Christine Murphy Whyte on both EDI and ED activities, describing a very busy year for us and especially for her! We were particularly proud to display the Crystal Clear Health Literacy Award for the *9 Things* leaflet. We are also very pleased to welcome Eithne Weymes to the Committee.

The Information Session held following the AGM featured Marie Murphy, Exercise Specialist for the Simm/Mann UCLA Centre for Integrative Oncology, Los Angeles; Marie is also a 1988 Irish Olympian (Marathon), an IOC Sports Nutritionist, and Fitness Instructor for the Dr Susan Love Research Foundation. Marie's presentation was on using exercise to help lower our risk/recurrence of breast cancer along with discussing prevention of side-effects by applying progressive resistance training early following breast cancer surgery. She explained the concept of METS (Metabolic Equivalents), a measurement of the body's capacity to utilize oxygen, and

how we might bring our METS up to the recommended 15-20 MET hours a week.

Her presentation was followed by Charlotte Coleman Smith's talk on the Plurabelle Paddlers and their recently launched Dragon Boat Project, describing its progress and how women can get involved. Over 40 people attended the session, which could have gone on for another couple of hours, given the number of questions for the speakers and the lively discussion generated!

**More Information:** If you would like a copy of Marie Murphy's presentation please contact us at [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie) and we will email it to you. To keep up to date with the Plurabelle Paddlers and/or to join the project see [www.plurabellepaddlers.com](http://www.plurabellepaddlers.com) or phone 086 0363449.





## Fashion Targets Breast Cancer 2009/10

Now in its sixth year the Fashion Targets Breast Cancer campaign was a huge success. This year luxury department store Brown Thomas teamed up with celebrated New York designer Tory Burch to create a once off 'global exclusive' designer bag! The leopard skin print canvas tote which featured Tory's signature orange lining was a big hit with all this year, indeed, it sold out nationwide in two weeks and left many disappointed shoppers!!

New York based Tory is a busy mother of three but took time out of her hectic schedule to personally visit and endorse the campaign. Speaking about the campaign Tory commented, "Early detection is crucial in our fight against breast cancer, that, and the strength we gain from each other as women"



Tory Burch

Fashion Targets Breast Cancer, which was introduced to Ireland by Europa Donna Ireland, has gone from strength to strength in Ireland having raised well over half a million Euro through the sale of the bull's eye t-shirts and over the

last two years the hugely successful tote bags designed by Diane Von Furstenburg, Orla Kiely and Paul Smith. Plans for 2011 are already underway and no doubt Brown Thomas will have another sensational designer lined up. All the designers give of their time and designs free of charge. Unlike many other retailers Brown Thomas takes no monies whatsoever and all proceeds from the sale of the t-shirts and bags go to Action Breast Cancer and Europa Donna Ireland. All monies raised stay in Ireland and are used to raise awareness of breast cancer issues.

A big thank you to all who bought the bag, and supported this great campaign. Thank you also to Moira Murphy and all the great team in Brown Thomas, Clodagh Hogan and all in Kennedy PR and to Jim O Malley and his team at the Irish Cancer Society.

Sarah Tierney, EDI Committee

## A good bank! Biobanking in Ireland

In the context of cancer a biobank is a collection of small samples of tumour, normal tissue and blood taken from patients in the course of an operation. The tissue is left over after being used for diagnosis and is stored under stringent conditions for use in research. Patients are asked for consent and the tissue will be used by approved research groups who are working to find out how cancers develop, grow and spread. This work may lead to new tests and better treatments. The samples can also be used for comparative purposes when patients have a recurrence of their cancer.

In Ireland Professor Eoin Gaffney, St James's Hospital, is a co-founder of the Biobank Ireland Trust which is developing a network to make samples accessible to accredited researchers

around the country. Professor Gaffney invited Christine Murphy Whyte and Deirdre O'Connell to visit the biobank in St James's for an interesting and enlightening tour.

Funding has recently been made available for a National Breast Cancer Tissue Bio Resource, which will work in conjunction with the Biobank Ireland Trust. Indeed European networking is now on the cards. EDI is very supportive of this development which will benefit future patients and we would encourage everyone who is asked to consent to the collection of their tissue to do so.

For further information see [www.biobankireland.com](http://www.biobankireland.com)

# Gallery



Walk in Stephen's Green - Breast Health Day 2009



The Misses Tierney



At the walk in Stephen's Green



Harriette Lynch & Sarah Tierney getting ready for the walk in Stephen's Green



Breast Awareness Group Talk in Donegal



Christine, Ailis Ni Riain and Deirdre at 2009 AGM



Bray Cancer Support Centre sets out on walk on Breast Health Day 2009



Judith Wolfowicz, Avon presents Christine with a goodie bag.

# 9<sup>th</sup> Europa Donna Pan-European Conference

## Communication and Collaboration, Stockholm, 24-25 October 2009

EUROPA DONNA's 9th Pan-European conference in Stockholm was attended by a record 230 Coalition members - breast cancer advocates, nurses and other breast cancer specialists - to celebrate its theme "Communication and Collaboration". The attendance included a number of Irish delegates, with the usual strong delegation from the Bray Cancer Support Centre. It also marked the Coalition's 15th anniversary with a Presidents' Panel – in all five presidents who have witnessed the Coalition's growth to 44 member countries and its expanding influence across Europe.

In her introduction, Ellen Verschuur, EUROPA DONNA President, said, "The combined theme of this conference is in line with the core function of EUROPA DONNA, Communication and Collaboration, representing two essential tools in the world of advocacy. Communication and collaboration between the member countries is imperative because in this way there can be a mutual understanding of issues and needs. Communication also plays a very important role in the relationship between advocates and stakeholders of breast cancer care."

Dr Ailis Ni Riain, Director of Advocacy and Professional Competence at the Irish College of General Practitioners, covered the topic of follow-up after breast cancer, an important issue with so many women living longer after a breast cancer diagnosis. Other experts covered topics from



L -R Nicole Zernick (France), Stella Kyriakides (Cyprus), Susan Knox (Exec. Director ED) & Christine at Stockholm

screening to lifestyle factors and you can find more details on our website or by contacting us for the print version.

One of the workshops was dedicated to specialist breast unit implementation according to the European Guidelines. It was facilitated by Stella Kyriakides (Cyprus) former ED President and Christine Murphy-Whyte, ED Vice President.

As usual the Conference was very enjoyable, not only for the informative papers, but also for the chance to meet delegates from so many different countries. There was no shortage of discussion outside the formal sessions, as women exchanged information and experience. Many of the delegates praised the EDI leaflet, *9 things you should know about breast cancer*, and want to translate it! Communication and collaboration take many forms – not least in mass singing and dancing along to the ABBA tribute band who played at the conference dinner!

[www.europadonnaireland.ie](http://www.europadonnaireland.ie)

We have updated our website to incorporate the 9 *Things* leaflet, using the key messages to make it easier to find additional information and links to expert websites. Do please send us any comments and suggestions for what we might include on the site. If you would like your story included contact us at [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie).

The 10th Pan European EUROPA DONNA Conference will take place in Malta 22-23 October 2011

# The 7th European Breast Cancer Conference

Barcelona,  
24-27 March 2010

More than 5,000 doctors, researchers, nurses and advocates from 96 countries attended the 7<sup>th</sup> European Breast Cancer Conference (EBCC7). EUROPA DONNA – The European Breast Cancer Coalition (advocates), EORTC, The European Organisation for Research and Treatment of Cancer (researchers), EUSOMA, The European Society of Breast Cancer Specialists (doctors) jointly hosted the conference, where attendees heard the latest findings on best practice in mammography screening, imaging techniques, surgical and drug therapy, lifestyle and chemoprevention measures, and treating specific populations such as pregnant or older women.

The theme was Partnership in the fight against breast cancer and at the opening session EUROPA DONNA President Ellen Verschuur and Vice-President Christine Murphy-Whyte jointly presented the patient advocates' view of the importance of specialist breast units.

One of the EUROPA DONNA teaching lectures covered the implementation of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, and included a very informative and popular contribution from Professor Niall O'Higgins on the Irish experience. ED advocates from other countries thought we in Ireland were very lucky to have Professor O'Higgins and we know we are! Another ED teaching lecture was dedicated to prevention through healthy lifestyles. EUROPA DONNA Executive Director Susan Knox said the Breast Health Day campaign held on 15 October has been developed in response to important epidemiological studies concerning prevention. Dr



Christine & Prof Niall O'Higgins at Barcelona EBCC

Carlo La Vecchia, Head of Epidemiology at the Mario Negri Institute, explained that 10% or more of breast cancers could be avoided by widespread adoption of regular physical activity and even more by avoiding obesity and overweight. Limiting both alcohol consumption and the long-term use of hormone replacement therapy both reduce breast cancer risk significantly.

There were other interesting sessions on a number of topics. One of these covered therapy options for women diagnosed with breast cancer during pregnancy. The Metastatic Breast Cancer Task Force, which is aiming to create guidelines for this patient group, emphasised the importance of maintaining quality of life while attempting to extend survival. EUROPA DONNA daily wrap-up sessions, in which experts summarised earlier scientific sessions, were widely attended by advocates and scientists.

Held every two years, EBCC is the only conference of its kind to represent patient advocacy and major professional breast cancer organisations in one arena. *More information on the conference is available through the European Cancer Organisation (ECCO) at [www.ecco-org.eu](http://www.ecco-org.eu) and at [www.europadonna.org](http://www.europadonna.org). EUROPA DONNA news Summer/Autumn 2010 publishes highlights from EBCC-7 – contact us for a copy.*

**The next conference, EBCC-8, is to be held 21-24 March, 2012, in Vienna, Austria.**

## BreastCheck progress

We are very pleased that BreastCheck has continued to progress by finally extending the National Screening Programme nationwide. We will continue to campaign for extension of the screening age to 69 at least; this could be done without much additional cost and would be well worth doing in terms of lives saved. We are now one of the few countries with a national screening programme that stops at 64. The fact that it does is sending the wrong message to women as to risk and this came across very strongly in the feedback we received to our *9 Things* leaflet. Women who contacted us as a result of receiving the leaflet and women at various meetings we have attended have often expressed considerable anger at their lack of access to screening after the age of 64.

The fact remains that mammography screening is the best form of early detection of breast cancer available today and it does improve mortality. EUROPA DONNA's position remains unchanged that screening should be available for ages 50 to 69 and that more studies are needed to determine if screening should be available to the 40 to 49 year old age group and for those over 70. BreastCheck has issued a statement which deals with the extension and reduction of the screening age. You can find this on our website at [www.europadonnaireland.ie/content/policies](http://www.europadonnaireland.ie/content/policies)

In January 2010 EDI made a submission in collaboration with the NWCI and DESSA in answer to a BreastCheck call for **Successful Initiatives Targeting 'Hard to Reach' Marginalised Populations to uptake cancer screening.**

## Short Guide to EU Screening and Diagnosis Guidelines

In October 2007 EUROPA DONNA published a "*Short Guide to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*", with the financial support of the European Union. This short guide highlights the main points of the 4th edition of the *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*, published by the European Union in April 2006. The Short Guide is now available in English, French, Spanish, Turkish, Swedish, Italian, Polish, Greek, German, Georgian, Dutch and Russian at [www.europadonna.org](http://www.europadonna.org)

## Declaration on fight against breast cancer in the EU

Every year 331,392 women in the European Union are diagnosed with breast cancer and 89,674 women die of the disease. Mammography screening can reduce deaths from breast cancer by up to 35% in women between 50 and 69.

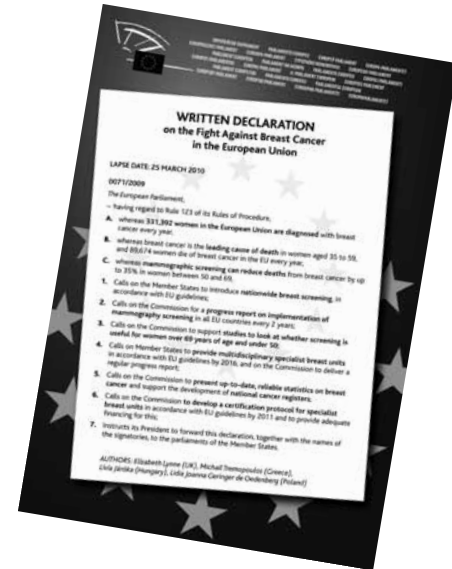
EUROPA DONNA has been working with MEPs to ensure that the new members are aware of the 2003 and 2006 Resolutions on Breast Cancer and the need to work toward their implementation. This Declaration, drafted with input from EUROPA DONNA, is a way of achieving that objective.

"This Declaration serves as a reminder to MEPs, new and old, of the need to implement the European Resolutions on Breast Cancer and the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis which we are striving to have implemented Europe-wide," said Susan Knox, EUROPA DONNA Executive Director.

The Declaration was put forward by four MEPs and backed by EUROPA DONNA – The European Breast Cancer Coalition. It calls for the implementation of measures across Europe to battle this disease which is the leading cause of death in European women aged 35 to 59. For the Declaration to be adopted a majority of MEPs had to sign it before 14 March 2010 and this was achieved with 369 MEPs signing up. We were delighted that all 12 Irish MEPs signed the Declaration and we would like to thank them and all our members and supporters who contacted them to ask them to do so.

The Declaration reiterates calls for nationwide breast screening and multidisciplinary specialist breast units in all member states in accordance with European guidelines.

See our website for the full text of the Declaration and the 2006 Resolution.



# LIVESTRONG Cancer Summit Dublin

**Dublin, 24 – 26 August 2009**

Christine and I were invited to attend the first LIVESTRONG Global Cancer Summit and joined 500 delegates from over 60 countries at the RDS. The invitation was extended following EDI's Commitment to Action submission which included the development of the leaflet *9 things you should know about breast cancer* and the organisation of Breast Health Day on 15 October 2009. The Global Cancer Summit was a truly global event and a large proportion of the delegates were from Africa, Asia and South and Central America, lending a perspective to the debate not found at events where most attendees are from the developed world. The aim of the Global Cancer Campaign is to build action on a worldwide scale to combat cancer – soon to be the leading cause of death worldwide – and to make cancer a global priority. The tone was set by Lance Armstrong in his introduction to the programme: "Together, through our collective action, we can empower cancer survivors and effect global change".

The panels for the various sessions comprised experts (medical, economic, etc.), government ministers (including Mary Harney TD), community activists and, of course, cancer survivors. Enjoyable social events in the evening afforded the chance to meet a wide range of delegates. One of the last sessions covered use of the new digital media, the strength of which was demonstrated by Lance Armstrong's experience, when a single Twitter message brought 1200 cyclists into the Phoenix Park to join him for a bike ride – much to his delight!

The Summit was very well organised and we are glad to say that one of our committee members, Marie Ennis, contributed by volunteering her very able services!

Deirdre O'Connell EDI Vice Chairwoman



Lance Armstrong at LIVESTRONG



Christine & Deirdre with Australian delegation at LIVESTRONG Summit

## Connect with EDI on Facebook and Twitter

Now there's a new way to keep up to date with EDI news and events. Thanks to Marie Ennis, EDI Committee

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## Contact Us

We welcome any comments and suggestions for future activities.  
Contact us at 01 496 0198  
or email us at [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie)

[www.europadonnaireland.ie](http://www.europadonnaireland.ie)



## Join Us, Support Us, Campaign for Change

Please complete (in BLOCK CAPITALS) and return this membership form to Europa Donna Ireland, P.O.Box 6602, Dublin 8. If you have any queries, ring 01 496 0198 or email [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie). You can also join up via our website [www.europadonnaireland.ie](http://www.europadonnaireland.ie)

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Are you interested in being actively involved in our campaign?

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