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/ 2013

# EDI News

Newsletter of the  
Irish Breast Cancer Campaign

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

## Vision

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



## Welcome to the latest newsletter from Europa Donna Ireland

The EDI committee has been continuing to work hard on your behalf with the EDI mission and vision and I would like to especially take this opportunity to welcome three new board members, Anne Keating, Ciara O'Donnell and Tara Byrne. They joined us this year and bring new skills and experiences to EDI. I would also like to thank Eithne Weymes for all her work with us over the last number of years and who has now stepped down from the board.

In our last edition we talked about our continuing to campaign for the extension of the national breast cancer screening programme to age 69 as we firmly believe that the ending of breast cancer screening at age 64 is sending out the wrong message regarding the risk of breast cancer. The latest news regarding this is that while all involved parties are in agreement with us on this issue, and a review took place in which EDI was involved, as yet the funding has not been found to extend the BreastCheck screening to age 69. Therefore we will continue with this campaign to ensure that it happens. We are concerned that spending cuts might adversely affect the current excellent services provided by the eight Specialist Breast Centres and will be looking out for any such developments.

Also, EDI is calling for an increase in accessible Lymphoedema services in Ireland for breast cancer patients. While there have been some improvements in this area we realise that there is also a lack of awareness about Lymphoedema in general and the ongoing risk of occurrence following a breast cancer diagnosis. We have highlighted this issue with the women TDs and Senators at an Oireachtas Lunch held to celebrate Breast Health Day 2012.

On a very positive note it is great to see new developments such as the Breast Pain App, especially aimed at younger women, which was launched by the National Cancer Control Programme this year and the BCY1-Breast Cancer in Younger Women Conference held in Dublin in November 2012. We also welcome the establishment of two more Breast Cancer Dragon Boat Team Support Groups in Clonmel and Waterford of which you can read more about in this newsletter.

Also EDI recognises the importance of providing current and factual information and therefore we will continue to send two new members to annual Advocacy Training in Milan and ensure ongoing training and attendance at relevant conferences for the EDI committee.

I'd like to take this opportunity to thank those of you who got involved with us on Breast Health Day last October and look forward to even greater participation on 15th October this year. We want to remind girls and women in Ireland about the importance of lifestyle factors that can influence their future breast health and help prevent breast cancer and also the role of early detection in fighting breast cancer. This year's theme is "Make Good Choices For Your Breast Health" and the campaign will continue to build on last year and remind women that engaging in physical activity, maintaining a normal body weight and eating a healthy diet can help protect their breast health. So please join the Breast Health Day 2013 campaign.

Finally, I would like to assure you of our continued commitment in 2013 to campaigning for better breast cancer services nationwide, and urge you to commit to making healthy lifestyle choices to protect your future breast health and help prevent breast cancer in Ireland.

Dymrna Watson

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.

<b>Chairwoman</b>	<b>Dympna Watson</b>
<b>Vice Chairwoman</b>	<b>Anne Keating</b>
<b>Treasurer</b>	<b>Trudy Doyle</b>
<b>Secretary</b>	<b>Tara Byrne</b>
<b>Social Media</b>	<b>Marie Ennis</b>
<b>Members</b>	<b>Mary Stokes</b>
	<b>Ciara O'Donnell</b>
	<b>Betty Watson</b>
	<b>Deirdre O'Connell</b>



# AGM 2013

The 2013 AGM of EDI was held on June 15th and was followed by a public information session. This year Mr Constantino Fiuza Castineira, Consultant Breast Surgeon, Waterford Regional Hospital, gave a most interesting talk titled *Are we walking the right path?* The talk took a practical and holistic look at cancer thereby suggesting we approach it from the intellectual, physical, emotional and spiritual aspects of our lives too which transpired to be a fascinating, frank and open talk that generated lively discussion.



Dympna Watson and Trudy Doyle



Constantino Fiuza Castineira and Dympna Watson



Members at the AGM



Anne Keating, Marie Ennis, Dympna Watson, Ciara O'Donnell, Mary Stokes

## Thank You to

Q4PR, Red Dog, Sruleen Women's Group, Eilis Quinlan and Wendy Aita-Tagle, Plurabelle Paddlers, St Andrew's Resource Centre, Covidien, Maura Tierney, Sarah Tierney, Michael Murphy and family, Julie Doyle, Irish Dragon Boat Association, Constantino Fiuza Castineira, Tina McGrath, Vanessa Reid, Mary Mitchell O'Connor TD, Alice Griffin and Linda Howe of DESSA.

# Breast Health Day 2012

**EUROPA DONNA – The European Breast Cancer Coalition established Breast Health Day on 15 October as an annual event to remind girls and women in Europe about the importance of lifestyle factors that can influence their future breast health and help prevent breast cancer and about the role of early detection in fighting breast cancer. A growing body of evidence shows the link between healthy lifestyle choices and a lower risk of developing breast cancer.**

The 2012 campaign featured an entertaining animated video encouraging women to make a variety of healthy choices and women around the world got personally involved in the campaign through a web application on the Breast Health Day website. The campaign theme was “Make good choices for your breast health” – all about engaging in physical activity, maintaining a normal body weight and eating a healthy diet. Europa Donna groups all over Europe organized appropriate events.

## In Ireland we organised

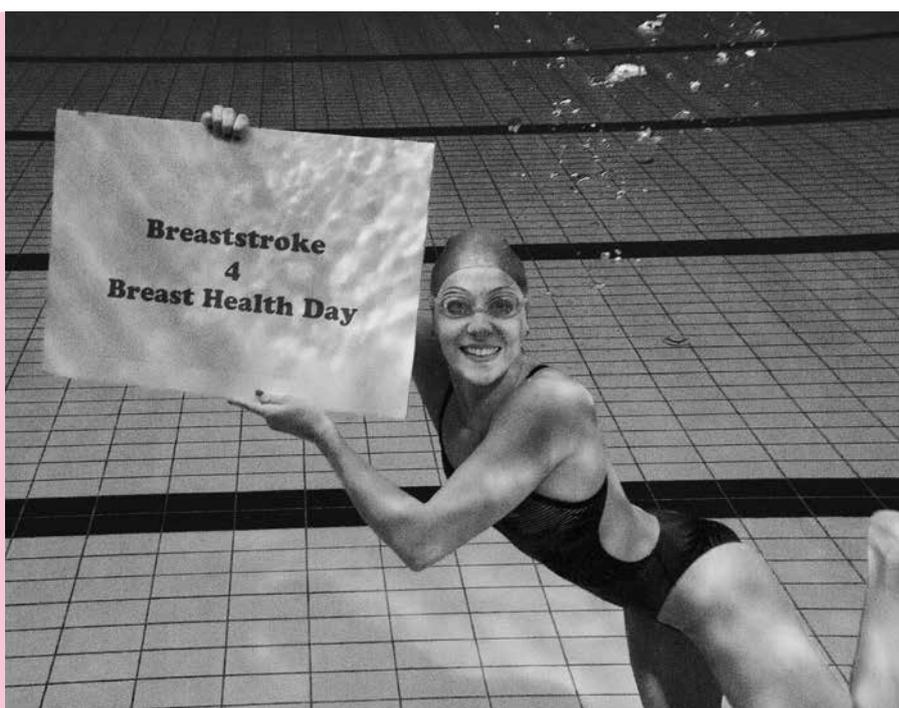
- A lunch at the Oireachtas hosted by Deputy Mary Mitchell O’Connor to mark BHD for women TDs and Senators
- A Breast Stroke for BHD event in conjunction with Swim Ireland at local swimming pools to increase awareness of breast health
- A call to local organisations nationwide to hold their own events for BHD. Walks and information events were organised around the country, as well as a continuous dance event, yoga and meditation. In County Tipperary, women were encouraged to register for Breast Check, while in Dublin, BHD was promoted at weekly meetings of the Personal Development, Stitch and

Bitch Women’s Group. On Thomas Street in Dublin our 9 Things leaflet was handed out along with free fruit by the Robert Emmet Community Development Project.

## EDI held two open talks in Dublin

- Vanessa Reid (Physical trainer/instructor) on **Breast Cancer and Exercise** and
- Marie Ennis (EDI committee and prize winning breast cancer blogger) on **How to be Your Own Health Advocate**.

**Breast Health Day 2013 will be celebrated again on and around 15 October. This year’s theme is: Make Good Choices For Your Breast Health. Keep an eye on our website and on [www.breasthealthday.org](http://www.breasthealthday.org).**



Breast Stroke for Breast Health Day



# Racing the Dragon!

## What is Dragon Boat Racing?

Dragon Boat racing is an ancient Chinese sport dating back over 2000 years. Today, it is an established worldwide sport in which 50 million plus people participate annually from across 76 nations.

## Dragon Boat Racing – what's the connection?

Breast cancer survivor's dragon boating is an international movement inspired by the research of Canadian sports medicine specialist Don McKenzie. Survivors of breast cancer join together to paddle dragon boats to the benefit of their physical health and social wellbeing. In 1996 Professor McKenzie started a dragon boat team for women with a history of breast cancer, which the women named 'Abreast in a Boat'. He believed that this activity would benefit breast cancer survivors as it provided strenuous upper body activity in an aesthetically pleasing and socially supportive environment.

Dr. McKenzie believed that by following a special exercise and dragon boating training programme, people could avoid or manage lymphoedema and enjoy active full lives. The initial training group was monitored, no new cases of lymphoedema occurred and none of the existing cases became worse.

As of June 2013 there were 130 Breast Cancer dragon boat clubs from 9 countries registered as members of the International Breast Cancer Paddlers' Commission (IBPC).



## Dragon Boat Racing in Ireland – the story so far....

The Irish Dragon Boat Association (IDBA) was formally established in 2010 and is the national governing body of the sport of dragon boat racing in Ireland. Julie Doyle is the chairperson and comes with 20 plus years experience as a professional dragon boat racer for Great Britain and also many years experience as an official serving on dragon boating committees and officiating at events across the world.

The Plurabelle Paddlers is Ireland's first breast cancer dragon boat team, established in April 2010 by its chief founder Fiona Tiernan who enlisted the help initially of just Marian O'Dea and Julie Doyle to get momentum going. Following a lot of support from friends, family, businesses and members the club launched its own two boats on the water in the Grand Canal Basin in October 2010 - pink and blue boats called Anna and Livia.

In less than three years the Plurabelle Paddlers has recruited 50 plus active members and has secured medals at international and domestic events from as far away as Malaysia to as close as their home ground of the Grand Canal Basin.

The IDBA, Plurabelle Paddlers and Europa Donna Ireland have worked together to promote and encourage the development of other dragon boat breast cancer support teams throughout Ireland. The results are now clearly visible with three new teams in place in the last 12 months.

In 2012, the Cork Dragons entered the race and were followed in 2013 by the Suir Dragon Paddlers from Clonmel and the Waterford Dragon Warriors.

### Cork Dragons, Cork

The Cork Dragons are almost a year on the water. They have received tremendous support from ARC Cancer Support, HSE, Prince Clinic and many local businesses such as Meitheal Mara and Get Ireland Active.

### Suir Dragon Paddlers - Clonmel, Co. Tipperary

They are now on the water as they received their new boat at the end of March. The club is lucky to have Constantino (Tino) Fiuza Castineira, Consultant Breast Cancer surgeon, Waterford Regional Hospital who has worked tirelessly to get the club on the water. C.A.R.E. Cancer Support Centre, Clonmel has been a great support too by providing funding for the equipment.

### Waterford Dragon Warriors, Waterford

Marcella Sweeney has experienced breast cancer and this change in her life motivated her to develop a dragon boat breast cancer support group for herself and others like her in the Waterford area. Marcella has recruited almost 20 members and now has the funds to purchase equipment so we expect to see the Waterford Dragons on the water by the end of 2013.

### Why Join Up?

People do not join because they want to dwell on their cancer experience but rather because they want to be part of an energetic group (a strong underlying support network that is there when needed) who are ultimately striving to live life. In addition paddling helps to control lymphoedema, which is another very important reward of the commitment to paddling.

The paddling team is looking to constantly improve and draw on new experiences and meet new people from across Ireland and the world. It would appear that members involved in the paddling teams have taken a decision to move on and learn to live within the world of cancer rather than by the world of cancer.

And now that we've whet your appetite for a taste of something different why don't you check out:

[www.dragonboat.ie](http://www.dragonboat.ie)  
[www.plurabellepaddlers.com](http://www.plurabellepaddlers.com)  
[www.corkdragons.com](http://www.corkdragons.com)  
[www.suirdragonpaddlers.com](http://www.suirdragonpaddlers.com)  
[www.facebook.com/waterforddragonwarriors](http://www.facebook.com/waterforddragonwarriors)

Tara Byrne

## Getting out and about

### Doctors 2.0 & You Conference, Cité Internationale Universitaire de Paris

In June 2013, Marie Ennis, EDI Board member, was an invited speaker at the Cité Internationale Universitaire de Paris for the Doctors 2.0 & You conference.

This annual event, which addresses the role of new technology in healthcare from healthcare social media best practice to innovative web 2.0 tools and mobile apps, brings together doctors, patients and healthcare innovators to share and learn from each other.



### Flinders University Centre for Innovation in Cancer Survivorship Conference.

EDI Board Member, Marie Ennis was invited to speak at the inaugural Cancer Survivorship Conference at the Centre for Innovation in Cancer, Flinders University which was held 1-3 February in Adelaide, South Australia. The conference was a unique event which brought together clinicians, researchers and survivors to address the issues facing cancer survivors and the priorities for survivorship care and research. Speakers from around the world shared their insights into the most exciting developments in the field of cancer survivorship. The wide range of topics discussed ranged from the clinical perspective on cancer survivorship, the challenges facing survivors, dealing with fear of recurrence, the psycho-social and physical effects of cancer and the impact of cancer on caregivers. It was a great opportunity to meet with and talk to experts in the field of survivorship and for survivors to share their perspective on what really matters to us.

### 2nd Eurama Donna conference EURAMA DONNA «ALL TOGETHER AGAINST BREAST CANCER» Moscow 20-21 September 2012

Deirdre O'Connell was asked by the EUROPA DONNA Board to make a presentation on **ED: breast cancer advocacy in action** to the session of this conference aimed at breast cancer survivors. The European-Asian Society for Breast Disease was founded with the aim of sharing the experience accumulated in Western countries with other parts of the world. There has been a steady increase in breast cancer incidence in most Eastern countries, where the disease was underestimated only 30 years ago.

## BCY1 Breast Cancer in Younger Women Dublin 8-10 November 2012

EDI was very pleased to bring our stand to this conference, organised by the European School of Oncology in collaboration with UCD and the Irish Cancer Society. We were even more pleased that the opening session was dedicated to Christine Murphy Whyte, our Chairwoman, who sadly passed away in 2010. Professor James Geraghty welcomed her family and friends as he opened the conference with a tribute to Christine and to her advocacy work with Europa Donna.

Breast cancer in younger women is poorly understood and under-researched so little evidence-based data is available about the optimal management of young women. For example while young women are more likely to be diagnosed with aggressive forms of breast cancer and have a worse prognosis than their older counterparts, it is not clear why this happens. The conference identified areas for future research, as well as reporting on existing work, and covered epidemiology, molecular biology, genetics, pathology, surgery, radiotherapy, systemic therapy and fertility preservation in young women with breast cancer. It also looked at the unique psycho social needs of younger women and survivorship issues. Gloria Freilich (ED UK and a founder member of EUROPA DONNA) gave the woman's perspective on familial and hereditary breast cancer. Marie



Marie Ennis and Deirdre O'Connell at the EDI stand

Ennis, EDI Committee member, had an abstract accepted for the conference: **Beyond statistics: How blogs provide a new framework for examining the quality of life experienced by younger breast cancer survivors after treatment.**

Approximately 300 medical professionals and patient advocates from over 47 countries attended, including members of ED from other European countries. A significant number of the medical professionals were from developing countries and they, in particular, were interested in EDI patient information.

BCY2 – 2nd Breast Cancer in Young Women Conference will take place in Tel Aviv, Israel, from 5 November to 7 November 2014.

[www.eso.net/events-2.html?e=BCY2\\_-2nd\\_Breast\\_Cancer\\_in\\_Young\\_Women\\_Conference](http://www.eso.net/events-2.html?e=BCY2_-2nd_Breast_Cancer_in_Young_Women_Conference)

## Forthcoming events

**Breast Health Day 15 October 2013** For details of the 2013 BHD see the EDI website and [www.breasthealthday.org](http://www.breasthealthday.org)

**11th ED Pan European Conference "Ensuring quality services and equal access" Prague 19-20 October 2013** The theme of the conference will be the essential breast services that women should receive and will provide strategies to advocate for their implementation across all European countries. EDI will have several delegates in Prague. [www.europadonna.org](http://www.europadonna.org)

**Advanced Breast Cancer Second International Consensus Conference (ABC2) Lisbon, Portugal, 7-9 November 2013.** An EDI delegate will be attending this conference, which will have a specific additional program for patient advocates. <http://www.abc-lisbon.org/>

**9th European Breast Cancer Conference (EBCC-9) Glasgow, 19-21 March 2014** <http://www.ecco-org.eu/Events/EBCC9.aspx>



# Why Specialist Breast Units are the place to go

The 8 Specialist Breast Centres are meeting their targets and provide an excellent service based on the best evidence based standards. From its foundation in 1998 Europa Donna Ireland campaigned for these centres and was very supportive of their implementation, which was completed in 2009. All the evidence is that they are working very well.

Recent research by the National Cancer Registry shows that almost one-fifth of Irish women having breast-conserving surgery in 2002-2008 needed one or more additional operations. Almost  $\frac{2}{3}$  of these went on to have a total removal of the breast (mastectomy). Although very little comparable information is available from other countries, the rate of re-operation in Ireland is not unusual, although the proportion needing mastectomy was high.

Older women, and those whose cancer was diagnosed through screening, were less likely to have a second operation. **The most important finding was that women who had their first surgery in a hospital treating a large number of breast cancer patients were less likely to have a second operation. Similarly, women treated by a surgeon with a high breast cancer caseload were less likely to have a second operation, or to have a mastectomy if they had a second operation.**

The study did not show why there was a lower rate of re-operation in larger hospitals; this may have been due to many factors, including better selection of women for breast-conserving surgery, greater surgical skill or closer adherence to treatment guidelines. Whatever the reason, this research further emphasises the fact that that women who have breast surgery in specialised hospitals and by specialised surgeons are less likely to need a second operation.

Specialist Breast Centres are part of the public health system and women referred by their GPs are diagnosed and treated promptly on the basis of need, not on whether they have private health insurance. We would advise any woman with a worrying symptom to insist on being referred to one of these centres.

Women in many countries envy us our system. EUROPA DONNA – The European Breast Cancer Coalition has been working to ensure that women across Europe will be able to access breast services that meet the standards described in the “EU Guidelines for quality assurance in breast cancer diagnosis and screening” and to that end has been pressing for an EU wide accreditation protocol for breast services. This project is finally coming to fruition and EUROPA DONNA is providing the patient advocate perspective and recommendations.

## EDI on Boards and Working Groups

We are pleased to report that Dympna Watson, as Chairperson of Europa Donna Ireland, is currently serving as a patient representative on the following boards:

- Radiographer’s Registration Board
- Irish Oncofertility Consortium

Deirdre O’Connell serves as a patient representative on the NCCP Cancer Survivorship Group

## Cancer in Ireland 2013: Annual report of the National Cancer Registry

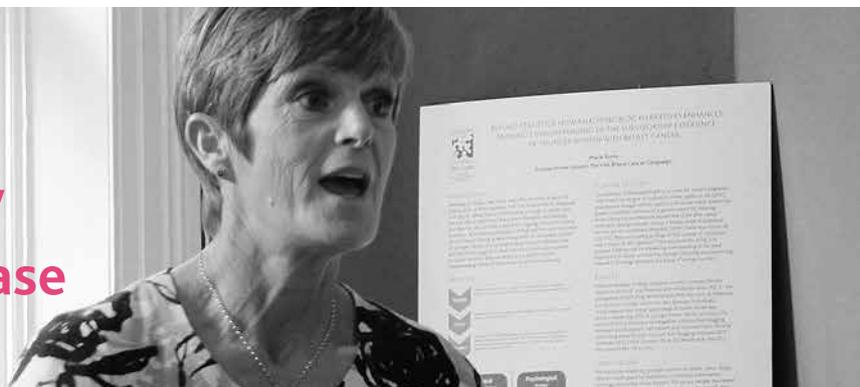
Some **breast cancer information** in the latest report from the National Cancer Registry:

- Average incidence 2008-2010 **2789**
- Mortality 2010 **659**
- Incidence **6th** highest of 27 EU countries – **12.5%** higher than EU average
- Mortality **3rd** highest after Belgium and Denmark – **22%** higher than EU overall
- **But** mortality/incidence ratios same as EU overall – 2 deaths for every 10 women diagnosed
- Incidence increased since 1994 but mortality rates have declined significantly (4 deaths for every 10 cases in 1994)

The Report is available to download at [www.ncri.ie](http://www.ncri.ie)

## The Murphy (METs) Programme: Reducing Your Risk/ Recurrence of Disease

By Marie Murphy



### Introduction

Exercise has been shown to improve cardiovascular fitness, muscle strength, body composition, anxiety, fatigue, depression, self-esteem, and health related quality of life in cancer survivors. Recent research has also demonstrated that it can reduce your risk of cancer recurrence, particularly for breast and bowel cancers.

### Cardiovascular Training

To reap all the benefits cardiovascular exercise (walking, cycling, swimming etc.) can provide, you need to be sure that your fitness routine is providing you with the right number of METS. METS are the rate at which our bodies use oxygen (metabolic equivalents). If you accumulate >15 METs every week, then you get significant benefits in terms of fighting cancer. Studies have shown as little as 9 MET/Hrs of physical activity over a seven day period increases survival rate for breast and bowel cancers. Your fitness level has a direct impact on how many METS you expend per minute. So let's say it takes you 16 minutes to walk a mile, your pace is 3.75 miles per hour, which corresponds to 4.3 METs per hour. If you walk 3 ½ hours over a seven day period you accumulated 15 METs for your week.

### Resistance Training

Resistance training is moving to the forefront as a major behavioural lifestyle activity for improving your health, preventing disease, and reducing the risk for premature death.

Upper-limb dysfunction is a commonly reported side effect of treatment for breast cancer and may include decreased shoulder range of motion

(ROM – the range through which a joint can be moved) strength, pain and lymphedema. Historically, there were concerns that breast cancer survivors with lymphedema should not engage in resistance training. There are now multiple trials that have demonstrated that such physical activity is not only safe, but actually reduces the incidence and severity of lymphedema. A resistance training programme that incorporates the 10 major muscles of the upper & lower body completes 15-20 repetitions for each exercise and repeats the routine twice weekly has been shown to have the greatest benefits.

### Nutrition

A good cancer diet is similar to a cancer prevention diet. The main differences are that people undergoing chemotherapy may have higher nutritional needs and poor appetites. It is very important to eat the most nutritious foods you can get. A diet that is high in vegetables, fruits, whole grains, beans, fish, and low in fat, high in fibre is cancer protective. Cancer treatments may decrease appetite and lower the ability to digest food which may interfere with your body's ability to absorb and use nutrients. Focus should be placed on getting enough calories to keep up your strength and eating as healthy a

diet as possible to boost your immune system to help deal with possible nutritional deficiencies. Think of our Irish Flag – plenty of green, white and orange fruits & vegetables. Make sure that your diet contains plenty of low-fat protein, such as cold-water fish (salmon, sardines, and mackerel), beans, and white meat (chicken or turkey). Protein rebuilds muscle and tissue which is particularly important when your body has undergone chemotherapy, surgery and radiation.

Good fat such as olive oil and omega 3 oils including flax seed oil and fish oil are important, while processed fats and oils, such as Trans and hydrogenated fats in margarines and fats used for baking should be avoided.

For more information please go to- [www.mbsfitness.com](http://www.mbsfitness.com) or email

### Marie's guidelines:

Carbohydrates: >5 grams/kg/day  
Protein: 1.2 – 1.7 grams/kg/day  
Fat: <1.5 grams/kg/day  
Water: 2 L. women, 3 L. men

[murphyprogramme@gmail.com](mailto:murphyprogramme@gmail.com) injury.

*The Murphy (MET's) Programme: The Irish Experience of Delivering Physical Activity for Cancer Survivors* has since been published and acknowledged by the American Institute of Cancer Research (AICR) 2012.

# Advocacy Training Course 2012

58 breast cancer advocates from 33 of EUROPA DONNA's 46 member countries in Europe completed a breast cancer advocacy training course in Milan from November 9-11 2012. Irish delegates, Laura Hennessy and Ciara O'Donnell, learned about the latest developments in breast cancer research and treatment as well as advocacy techniques that can be used to influence public health policy. EUROPA DONNA – the European Breast Cancer Coalition put together an intensive agenda covering two and a half days designed to increase our understanding and sharpen our communication and presentation skills.

Physicians and researchers from Europe's top cancer institutions briefed us on the current directions in breast cancer research and treatment. Over a period of a day and a half, experts provided us advocates with essential scientific background on the biology of breast cancer, the epidemiological aspects of the disease, clinical trials in progress, as well as the most current diagnostic and treatment methods.

Dr Giuseppe Curigliano described the latest research in breast cancer in his lecture on Clinical Trials. Adriana Bonifacino provided an overview of breast cancer treatments, while Bettina Borisch gave us an excellent overview of the biology of breast cancer. Perhaps equally important as treatment and research, however, is early diagnosis of breast cancer, which relies on thorough and effective screening as set out in European screening guidelines, as well as coordinated care after diagnosis. Psycho-social and psychological

services as part of an aftercare plan was also emphasized by Stella Kyriakides, Psychologist and past President of EUROPA DONNA. She encouraged us to lobby for a Europe wide programme to support breast cancer patients and survivors with the challenges of adjusting mentally to a cancer diagnosis and also the ability to create a full life after treatment has been completed. EUROPA DONNA is actively lobbying at European as well as at national levels for Specialist Breast Units, as called for in the European Parliament's Breast Cancer Resolutions of June 2003 and October 2006, and for the implementation of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis.

The purpose of this course is to ensure that breast cancer advocates in Europe have the most up to date information they need and develop the appropriate skills to use that information effectively in their countries. Armed with the latest information about research and treatment, these breast cancer advocates returned to their respective countries to pursue their own national – as well as European – agendas. They will continue their work to ensure that adequate funding and proper attention is given to providing the best available breast cancer screening and treatment to all European women.

The next **European Breast Cancer Advocacy Training Course** will take place in **November 2013, in Milan, Italy**, and two EDI members will be attending.

**Ciara O'Donnell**

## FTBC 2013 - Think. Look. Check.

In April 2013 Brown Thomas, EDI and the Irish Cancer Society collaborated in the Fashion Targets Breast Cancer™ Ireland Campaign for 2013, marking its 8th year. This year, the iconic FTBC target T-shirt was modelled by Super Model Karolina Kurkova. As usual, Sarah Tierney ably represented EDI in planning the campaign.

This year, the FTBC Campaign asked women to *Think, Look, Check*, and be breast aware. To date, the Fashion Targets Breast Cancer™ campaign has gone from strength to strength in Ireland, having raised just over €650,000, initially through the sale of the bull's eye target T-shirts and the hugely successful tote bags designed by Diane von Furstenberg, Orla Kiely, Paul Smith and Tory Burch. Proceeds from the Fashion Targets Breast Cancer campaign have contributed to the Irish Cancer Society's Action Breast Cancer programme which delivers vital information and support services to women with breast cancer and to the education and information activities of EDI.

The FTBC Campaign T-Shirts are available to buy at Brown Thomas shops nationwide and from the Irish Cancer Society online shop at [www.irishcancer.ie](http://www.irishcancer.ie)



# Breast Cancer Advocacy Leader Conference 2012

**EUROPA DONNA – The European Breast Cancer Coalition’s Breast Cancer Advocacy Leader Conference brought together more than 50 national representatives and delegates from 32 of the Coalition’s 46 member countries in Milan on 22 September. This was attended by Dympna Watson and Marie Ennis EDI. In workshops, participants shared ideas on how to advocate for the needs of women with metastatic breast cancer, understanding breast cancer research, managing and organising EUROPA DONNA fora, as well as key strategic approaches to ensure the continued success and sustainability of the Coalition’s advocacy activities Europe-wide.**

Financial sustainability – *This Time of Current Health Care Systems* – was one of the main themes of the keynote lecture by Dr. Panos Kanavos of the London School of Economics. The question of whether health care systems are seen as a *cost* to a society and not as an *investment* in the future of it was posed. “You need to be prepared to advocate for specific needs. It is going to be impossible in the future to fund everything in a sustainable and comprehensive way. The age of universal coverage and access is, in a sense, all but over,” Dr. Kanavos said in a lively presentation that put health care policy into the context of today’s economic situation. He described the role of health technology assessment (HTA), which seeks to assess the degree of clinical and cost-effectiveness of a new technology, such as a diagnostic method or a new drug, in comparison to the current standard of care. He added that patient groups must understand HTA and its

implications for health care policy so that they can advocate for health systems to enable selective coverage of new technologies. He encouraged patient groups to pool resources, to identify the health technologies required and to make factual submissions to HTA bodies and regulators. “You are not only cancer patients advocating for a particular type of cancer; you are individuals with an important opinion about where the health care system is going in the next 5 to 10 or 20 years,” he said.

In her introduction, Susan Knox, Executive Director of EUROPA DONNA, said, “Health technology assessment is a very important topic for advocacy today, particularly in view of the difficult situations that many of our member countries are facing. Advocates will need to understand more about the methodologies that are used by governments across Europe to determine whether they or members of the public receive treatment and pharmaceutical products.”

In a subsequent presentation, Ms. Knox went on to describe the key components of establishing and running non-profit organisations, particularly EUROPA DONNA fora. She highlighted the need for an annual work plan to ensure that the activities are addressing the needs of the target population, as well as outside auditing and increased transparency and accountability.

Prof. Bettina Borisch, EUROPA DONNA Past President and Professor at the University of Geneva, Switzerland, gave an informative training session on tips for understanding breast cancer

research. This was based on EUROPA DONNA’s new booklet *The Advocate’s Guide to Understanding Breast Cancer Research*, which was released at the conference.

Advocates had numerous opportunities to share ideas and work with representatives of countries with similar concerns in a variety of workshops on the following topics:

- The current situation of EUROPA DONNA fora, issues to resolve and barriers to overcome
- How to provide support and advocacy for metastatic breast cancer patients locally and nationally
- Understanding the main concepts of reading breast cancer research
- Strengths and weaknesses of the Coalition as a whole and areas for future development

“This Breast Cancer Advocacy Leader Conference dedicated to ‘Building our Organisations for the Future’ has provided a prime opportunity for our national representatives and delegates to work together and share ideas so that they can better advocate for optimum breast care services in their countries. Feedback from our members on our Coalition as a whole will also help to make us stronger and ready to face the challenges of the future,” said Elizabeth Bergsten Nordström, President of EUROPA DONNA.

## NCCP Breast pain App

In April of this year the National Cancer Control Programme launched a Breast Pain App designed to help women understand the nature of their breast pain in consultation with their GP. It describes simple measures a woman can take to manage this pain and provides a diary that can be filled in daily, or as appropriate, to record the level and type of pain. In this way the pattern of the pain can be graphically viewed and understood.

Breast pain (mastalgia) is a common complaint which can be very worrying for women but, on its own, is not usually a symptom of cancer. However, as with all breast symptoms, it should be checked with a woman's GP. The level of breast pain is different for each woman and can range from mild discomfort to severe.

The App empowers women to capture and record their pain experience over a three month time span and establish any predictable patterns that emerge. If appropriate, the woman can return to her GP after completing the diary.

There are two main types of breast pain:

**Cyclical:** this is the most common type of breast pain. It usually occurs a few days before the period and it goes away when the period begins. It is due to monthly normal changes in hormones. This is more common in younger women. It tends to occur in both breasts and women describe it as pain and tenderness that extends into the armpit. For the majority no treatment is required and it resolves with the onset of menopause.

**Non-cyclical:** this is not related to the period and it is most common among women in their forties to fifties. It can occur in one breast. It can be due to an injury or to muscle / joint pain in the chest wall. Sometimes no cause for this type of pain is found.

The App describes simple measures a woman can take to manage her breast pain including taking exercise, being a healthy weight, reducing caffeine intake before the period, wearing a good fitting bra and taking simple analgesia (pain relief medication) when the pain is worst. Sometimes evening primrose oil can help. It explains to women how to be 'breast aware' and also highlights the other types of breast problems that require urgent medical attention.

The App can be downloaded from the Apple / Android markets by searching for NCCP Breast Pain App.

## Would you like to make a donation to EDI?

We would very much appreciate your financial support.

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I hereby authorise the above Bank to pay the annual fee to Europa Donna Ireland account in:

Bank of Ireland, 85 James's St., Dublin 8, Ireland. Account no: 19488683 Sort code: 900877  
IBAN: IE07 BOFI 9095 9919 4886 83 BIC: BOFIE2D

Starting from (date) \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Ref no: (office use) \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Europa Donna Ireland, PO Box 6602, Dublin 8, Ireland. Registered Charity: CHY 16312

## Contact Us

We welcome any comments and suggestions for future activities.

Contact us at 01 496 0198

PO Box 6602, Dublin 8

or email us at [info@europadonnaireland.ie](mailto:info@europadonnaireland.ie)



See our website at:

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

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**Please note:** We will not be using your personal information for anything beyond our regular updates. If at any time you wish your name to be removed from our database please don't hesitate to let us know.