

EDI News

Newsletter of the Irish Breast Cancer Campaign

NO. 9_WINTER/SPRING_2007/2008

www.europadonnaireland.ie

Friends and Fellow-Advocates!

In many ways 2007 was a defining year for breast cancer services in Ireland and for Europa Donna Ireland.

Following a very positive and constructive meeting with Minister Harney in January, EDI applied for Lottery Funds for an extensive Information and Training Programme to support the development of breast cancer advocates in Ireland. On the eve of our AGM in May, we received word that we had been successful.

May also saw the formal launch of the National Quality Assurance Standards for Symptomatic Breast Disease Services which Deirdre O'Connell, our then chairperson, had been actively involved in developing with Professor Niall O' Higgins and his team. Despite the Minister's call for a plan to implement these important national standards by July 2007, there was no sign of a plan coming from the HSE. What we got instead, over the summer was a shocking and disturbing series of revelations of misdiagnosis and poor practices in breast cancer diagnosis, that upset and unnerved women across the country. For the women directly involved, a nightmare was unfolding, sparking a number of independent investigations.

EDI campaigned strongly throughout the summer for the need to concentrate resources and staffing in specialist breast centres, which could be independently accredited by HIQA (Health Information and Quality Authority) against the National Quality Assurance Standards. At the end of September, the HSE formally announced the designation of 8 Cancer

Control Centres - to include breast cancer.

EDI's target now is to keep up the pressure for the planned and phased transition of specific breast cancer services from the remaining hospitals into the 8 designated centres. We very much welcomed the appointment of Professor Tom Keane in November and were pleased to have had the opportunity to meet with him in December to discuss areas of mutual interest.

Look out in Spring 2008 for our re-vamped website which we hope will make it easier and offer lots of ways for women, with an interest / experience of breast cancer, to volunteer some of their time to contribute to our important work.

We all volunteer our time and I can't let this opportunity pass without warmly acknowledging the supreme achievement Deirdre O'Connell has made in the past decade in leading Europa Donna Ireland. Many women in Ireland who have more recently been on the breast cancer journey owe her and her fellow EDI founders and advocates an enormous debt of gratitude.

We hope you enjoy our new look newsletter and welcome your comments and suggestions. We look forward to seeing as many of you as possible at our second National Conference which will take place in the Alexander Hotel, Dublin on Saturday 27th September, 2008.

Christine Murphy-Whyte

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.

“

I can't let this opportunity pass without warmly acknowledging the supreme achievement Deirdre O'Connell has made in the past decade in leading Europa Donna Ireland. Many women in Ireland who have more recently been on the breast cancer journey owe her and her fellow EDI founders and advocates an enormous debt of gratitude.

”



Deirdre O'Connell

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.

AGM 2007 and Information Session

The 2007 AGM was held on 12 May in Buswell's Hotel and was followed by a well attended Information Session – Your New 'Normal': Moving On After Breast Cancer Treatment. Dr Janice Walshe, consultant medical oncologist at AMNCH Tallaght, spoke on "Issues with breast cancer follow-up and surveillance". Mary Scarff, Psychotherapist and Stress Management Therapist, talked about "Understanding the communication and inner wisdom of your body through the integration of body-mind and soul, which enhances well being".

A new committee was elected at the AGM and officers were elected at the first committee meeting.

The members are

Chair	Christine Murphy Whyte
Vice Chair	Deirdre O'Connell
Secretary	Marie Ennis
Treasurer	Dympna Watson
Members	Frances Fitzgerald Maeve Pomeroy Alison Sainsbury Sarah Tierney Betty Watson



The Committee was delighted with Marie Ennis's marriage in late December. Congratulations and every good wish for the future to Marie and Billy.

Our Thanks to...

Professor Niall O'Higgins, The National Lottery, Mary Harney T.D., Minister for Health and Children, Mary Doherty of Red Dog, Q4 Public Relations, The Cross Group, Trulife, Eilis Quinlan, Jennifer McDonald, St Andrew's Resource Centre, Dr Gill Gormley, Dr Declan Keane, Marie Lavin, Mary Murray, Dr Janice Walshe

Specialist Breast Centres

2007 was a significant year in the development of quality breast cancer care in Ireland. In May the National Quality Assurance Standards for Symptomatic Breast Disease Services were launched by Minister for Health and Children, Mary Harney. The standards were drawn up by a group chaired by Professor Niall O'Higgins and which included Deirdre O'Connell, Vice Chairwoman of Europa Donna Ireland. As Professor O'Higgins says in the introduction:

“

This report relates to the general requirements for patient care in the setting of the breast centre and the physical and administrative facilities that should be in place to facilitate patients and services. It also defines measures of high quality for each specialty involved in breast cancer care. ”

The document can be downloaded from the HIQA site at www.hiqa.ie. Based on the standards HIQA is carrying out a review of breast centres and Deirdre O'Connell is part of the Breast Services Advisory Group working with HIQA on the review.

During 2007 EDI published a leaflet, Specialist Breast Centres. The leaflet describes these centres and the reasons why women should go to them as well as explaining procedures at the centres. See our website or contact us for copies.

In September 2007 the HSE announced the location of the 8 designated centres as follows:

- Beaumont Hospital
- Mater Misericordiae Hospital
- St James's Hospital
- St Vincent's University Hospital
- Cork University Hospital
- Waterford Regional Hospital
- Limerick Regional Hospital
- University College Hospital Galway (with additional outreach service delivery in Letterkenny)

8

In November we sent a letter to all TDs and Senators enclosing the Specialist Breast Centre leaflet and received many supportive replies.

While initial diagnosis and surgery will take place in these centres, chemotherapy will be administered on a more local basis. We know that issues relating to travel are of great concern to women in some areas of the country but we are convinced that women have a much

better chance of an accurate diagnosis and a good treatment plan leading to a much better chance of survival if they are diagnosed and their treatment is planned in such centres. We are glad that the issue of travel is being addressed and that funds have been made available for this.

We have called for information to be available to women on the transition plan as soon as possible and for transparency in relation to the decisions made as to location.

We welcome the appointment of Professor Tom Keane as Director of Cancer Services and had a meeting with him in December. We will be keeping in touch with him on progress.

Breast Cancer Misdiagnoses

2007 was characterised, by revelations that a number of women had been given an incorrect all clear as regards breast cancer. The first case came to light in May when Rebecca O'Malley from Tipperary went public with the facts about the 14-month delay in her diagnosis because of a misreading of her biopsy. The Health Information and Quality Authority (HIQA) was requested by the HSE to conduct an independent investigation into the circumstances surrounding the provision of care to Rebecca O'Malley. EDI welcomes the inclusion of patient representatives on the investigation team, which included EDI Chair, Christine Murphy-Whyte. We also congratulate Rebecca O'Malley on her bravery in giving up her privacy in order to highlight issues of such importance to women.

In August another Tipperary woman was found to have had her treatment delayed for 18 months due to incorrect biopsies and HIQA set up another investigation. A review of the work of a locum pathologist, Dr Antoine Geagea, is being carried out by a UK laboratory in connection with this investigation.

In August a review was undertaken by Dr Ann O'Doherty of more than 3,000 mammograms carried out at the Midland Regional Hospital in Portlaoise, after a consultant radiologist at the hospital was put on administrative leave. Nine women were found to have been wrongly given the all-clear and were subsequently found to have had breast cancer.

An inquiry was also initiated into the management of breast cancer patients at Barrington's Hospital in Limerick and this hospital has since ceased to treat breast cancer.

In November, John O'Brien of the HSE Hospitals Office announced at a meeting of the Joint Oireachtas Committee Meeting for Health and Children that breast ultrasounds from Portlaoise were also being reviewed and that 97 women were being recalled for further tests. This came as a surprise to everyone – Minister Harney, Brendan Drumm and, worst of all, the women themselves. There was much entirely justified criticism of the way in which the HSE handled this terrible situation and a review of this was commissioned. On 5 March, 2008 the four reports dealing with Portlaoise were published. In a statement on that day, Christine Murphy-Whyte said:

“

This whole sorry chain of events has caused enormous worry among women and a significant loss of trust in the existing services. Europa Donna Ireland has made it clear in various statements that we see the implementation of the national quality assurance standards as absolutely crucial to the improved diagnosis of women. There will always be some errors but multidisciplinary specialist centres will provide a structure where errors will be minimised. ”

Advocating for Best Breast Cancer Services Nationwide

In March 2007, EDI submitted a proposal to the National Lottery, for start-up funds for the first year of a 5 year strategy to establish EDI as *the* breast cancer patient advocacy organisation mobilising support for best quality, breast cancer services in Ireland. The good news that we had secured the funding came through in May.

With the Lottery funds, EDI is planning to host a series of information seminars/events to establish the degree of interest and support for breast cancer patient advocacy throughout the country. By building up and developing our membership base, EDI aims to develop informed advocates nationwide through advocacy training, using the model developed by EUROPA DONNA – The European Breast Cancer Coalition, which has been run successfully over a number of years and receives funding from the European Commission.

What Every Woman In The West Of Ireland Needs To Know About Breast Cancer

As part of its advocacy programme EDI organised a well attended public meeting in Galway on 25 September 2007, addressing the needs of women in relation to breast cancer. The guest speaker was Professor Michael Kerin, University College Hospital Galway, who spoke on quality breast cancer services and new developments in breast cancer treatment and care. Dymrna Watson and Deirdre O'Connell gave a presentation on the aims and work of EUROPA DONNA and Europa Donna Ireland.

New Website

EDI is developing a new website with part of the National Lottery funds received and this should be ready to launch by the end of April 2008. We have retained 54 Degrees Internet Consultancy to do this work for us. The new site will enable us to use technology to communicate much more effectively with members, with politicians and with decision makers and will be a valuable advocacy tool, as well as a source of useful and accurate information.

EDI plans 2nd National Conference

EDI's second National Conference will take place in the Alexander Hotel, Dublin on Saturday **27th September 2008**. A keynote speaker will be Professor Tom Keane, the Acting Director of Cancer Services; Professor Niall O'Higgins and Dr Tracey Cooper of HIQA will also be speakers. **KEEP THE DATE!!!**

Breast Cancer and Fertility: EDI Launches New Booklet

In October 2007 Minister for Health and Children, Mary Harney, launched *Breast Cancer and Fertility*, a booklet designed to help younger women diagnosed with breast cancer by providing them with up-to-date information on issues such as fertility and pregnancy after cancer treatment. The booklet has been welcomed by breast care nurses who regularly deal with the issues raised in it, as well as by women. As Marie Ennis says in her introduction: 'Dealing with fertility issues on top of a diagnosis of breast cancer can feel overwhelming. Sometimes just the fact of knowing that you investigated all of your options and you did what you could at the time is very helpful to your recovery emotionally and psychologically'. The booklet is a very good example of how the personal experience of a woman with breast cancer can identify a real need and how an advocacy organisation can work with nursing and medical experts to fill that need.

EDI Committee member Marie Ennis took the initiative of bringing together the following to develop the booklet: Dr Gill Gormley, Dr Declan Keane, Marie Lavin, Mary Murray and Dr Janice Walshe. If you would like a copy or copies of the booklet, please contact us.



Tina McGrath and baby Killian with Mary Harney, Minister for Health and Children



From left : Marie Ennis, Dr Janice Walshe, Dr Gill Gormley, Minister Mary Harney, Marie Lavin



Fashion Targets Breast Cancer 2007

In 2007 super model Erin O'Connor donated her time to launch the FTBC 2007 t-shirt. All services are donated free of charge so that the two benefitting charities, Europa Donna Ireland and Action Breast Cancer get the maximum amount of funds. T-shirts are sold through the Brown Thomas group of stores nationwide and are also available to purchase on the ABC website.

Monies donated to Action Breast Cancer have been used for the development of services for younger women with breast cancer, Europa Donna Ireland has used the money for the publication of a patient information booklet: *Breast Cancer and Fertility*.

Plans for this year are well underway and the end of April will see the launch of a yellow canvas tote designed by Diane von Furstenberg - the must-have item for Summer 2008. The bag will be available from Brown Thomas and BT2 stores.

Professor O'Higgins to be medical advisor to EDI

Professor Niall O'Higgins, now retired from St Vincent's University Hospital and UCD, has agreed to become medical advisor to EDI. Professor O'Higgins has played a hugely important role in the development of breast cancer services in Ireland and continues to do so. He has always been very supportive of EDI and we are delighted that he has now agreed to formalise his association with us.

BreastCheck - rollout

Europa Donna Ireland welcomed the long overdue rollout of BreastCheck to the West and South of the country which took place in December 2007. It will be another two years before

all eligible women in those areas are offered mammograms but at least a start has been made. We would urge all women who receive an invitation to take it up. Some women may not be on the BreastCheck register, which is compiled from information supplied by the Department of Social and Family Affairs, General Medical Services, and private health insurance providers. If you are between 50 and 64 and you want to check if you are on the register you can check on the BreastCheck website at www.nbsp.ie or by phoning 1800 45 45 55. If you are not on the register you can have yourself added. The programme is rolled out area by area, so if women where you live have been getting invitations and you have not, you should definitely check. BreastCheck is acknowledged as a world class service and early diagnosis means that treatment is easier with much better chance of a recovery. Northern Ireland has had a 20% reduction in deaths from breast cancer over 10 years and much of this improvement has been put down to screening.

Europa Donna Ireland wants to see the programme extended to women up to the age of 70 as soon as possible. This is in accordance with recommendations in *A Strategy for Cancer Control in Ireland* and European Commission recommendations.

"European Breast Cancer Advocacy: Ensuring Progress on Best Practice"

8TH EUROPA DONNA PAN-EUROPEAN CONFERENCE, Amsterdam, 27-28 October 2007



Betty Watson and Dympna Watson at Amsterdam



Christine Murphy-Whyte with Robert Carpenter, St Bartholemew's Hospital

The 8th EUROPA DONNA Pan-European Conference

"European Breast Cancer Advocacy: Ensuring Progress on Best Practice" brought together more than 200 advocates from the Coalition's 40 member countries in Amsterdam on 27-28 October, 2007. The focus was on continuing to lobby for the implementation of the European Guidelines for Quality Assurance in Breast Cancer Screening and



Diagnosis. In a special webcast session, Dr. Nick Perry, editor of the EU guidelines, emphasised the importance of the guidelines in lobbying for best practice. EUROPA DONNA – The European Breast Cancer Coalition has published a 32 page booklet which summarises the over 400-page *European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis*. The Short Guide can be downloaded from www.europadonna.org. Copies of the guide are also available through the ED Head Office and it is being translated into several languages. Delegates also heard about the latest in diagnosis and treatment of breast cancer, ongoing clinical trials, health economics and access to new treatments, the needs of younger and older women with breast cancer, implementing specialist breast units, lifestyle factors and complementary medicine.

In her opening address, EUROPA DONNA President Ingrid Kössler stressed the importance of the Coalition's extensive membership of 40 countries and this opportunity for advocates to network and share strategies to achieve equal access to high-quality breast services for all women.



From left to right: Joan Walsh, Alison Sainsbury and Daniela Pirisi (ED Head Office)

“ With more than 330,000 women diagnosed with breast cancer across the European Union, we must continue to combine efforts to ensure that breast services in countries across the continent adhere to the EU guidelines.”

A sizeable number from Ireland attended the conference, including delegates from both Europa Donna Ireland and from the Bray Cancer Support Centre. All agreed that it was an informative and enjoyable event.

General Assembly

On the last day of the conference ED held a General Assembly which discussed proposals for the development of ED arising from a major strategic planning exercise. A spare vacancy on the Board was filled by Sema Erdem from Europa Donna Turkey. We are delighted to say that our Chair, Christine Murphy-Whyte, was elected at a subsequent Board meeting to be Treasurer of ED. Ingrid Kössler (Sweden) continues as President and Ellen Verschuur-van der Voort (The Netherlands) was elected as Vice-President.



EUROPA DONNA Board

EUROPA DONNA Information Days at the European Parliament

On 17 October 2007 an Information Day was organised by ED at the European Parliament in Brussels. Ingrid Kössler, ED President, Susan Knox, Executive Director, and Karen Benn, Training Co-ordinator, attended on behalf of ED to distribute various information materials and talk with Parliamentarians about advocacy initiatives in Europe. Throughout the day ED publications were distributed.



European Parliament

EUROPA DONNA's European Breast Cancer Advocacy Training Course



Christine Murphy-Whyte (left) and Sara McDevitt at the Advocacy course

A highlight of the ED calendar is the annual course which attracts breast cancer survivors from all over Europe to Milan to meet and learn about breast cancer advocacy. This course receives funding from the European Union via a project managed by the European Cancer Network. Last year's course attracted 42 women from 23 of the 40 ED member countries. Ireland's two delegates were EDI members: Christine Murphy-Whyte from Dublin and Sara McDevitt from Cork.

Each year this course gets very high ratings from those who attended and the 2007 course was equally enthusiastically received. Topics participants wanted to hear even more about included:

- Lobbying methods, including practical examples
- Psycho-Social aspects.

Support was also expressed for increasing the amount of interactive communications training and workshop participation.

This year's course will take place on the weekend of 7-9th November, 2008, in Milan. Delegates are sponsored by ED to attend and the good news is that this year EDI has two vacancies so applicants, preferably breast cancer survivors, should register their interest in attending by contacting: edi@iol.ie or 01 4960198.

EBCC-6 Together We Will Make the Difference

The 6th European Breast Cancer Conference takes place in Berlin from 15 to 19 April 2008. All the latest on breast cancer will be covered at this unique conference. About 6000 delegates are expected to attend this conference where interaction between clinicians and patients is encouraged.

Christine Murphy-Whyte, Chairwoman of EDI, will be making a presentation on 'What breast cancer survivors want to know about lifestyle after breast cancer'.

Join us... see overleaf

Contact Us

We welcome any comments and suggestions for future activities.

Contact us at 01 496 0198 or email us at edi@iol.ie

www.europadonnaireland.ie



Working for better
breast cancer
services nationwide



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.

Name: _____

Address: _____

Tel: _____

email: _____

I enclose annual membership fee €15 Cash Cheque Standing Order

Bank Branch: _____ Account name: _____

Account no: _____ Sort code: _____

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, starting

from _____ (date)

Account no: 19488683 Sort code: 900877 Ref no: (office use)

Signature: _____ Date: _____

Are you interested in being actively involved in our campaign? Yes No