

## Breastfriends Cardiff and Vale Breast Cancer Support Group

September 2016

### Celebrating 10 years Elaine and Gaynor Trek Iceland



In July, seasoned trekkers and breast cancer survivors Elaine Nicholas (nearly 60) and Gaynor Sinton (64) flew to Iceland with 21 others to undertake a gruelling 3 day, 39 mile trek. They were celebrating their 10 year anniversaries since diagnosis and raised over £5,500 for Breast Cancer Care.

Full story on page 5

#### Who are we?

Breastfriends is a friendly support group for anyone who has had a diagnosis of breast cancer, whether it was last week, last month, last year or many years ago.

Breast cancer can be isolating and scary, but meeting others in a similar situation and sharing information and experiences can make a real difference.



#### Walk with us or talk with us

We meet once a month in Cardiff and once a month in Barry as well as meeting regularly for short walks in lovely surroundings. **See back page for more details.**

We know that walking into a room of strangers can be off putting, so please get in touch if you'd like a buddy for your first walk or meeting.

[www.breastfriendscandv.org.uk](http://www.breastfriendscandv.org.uk)

# Oncotype DX

## What is Oncotype DX?

Oncotype DX is a test that can help your specialist team decide if you would benefit from having chemotherapy as part of your treatment and how likely it is that your cancer will return in the future. You may also hear this test called a gene expression profiling test (GEP), a gene expression analysis test or a gene assay.

Whether you are offered chemotherapy depends on various features of the cancer such as its size, grade (how different the cells look under the microscope compared to normal cells and how quickly they are growing) and whether the lymph nodes under the arm are affected. Oncotype DX provides information in addition to these factors that might guide the decision about chemotherapy in some situations.

The test is carried out on breast tissue removed during surgery.

## Who may benefit from having an Oncotype DX test?

People recently diagnosed with primary invasive breast cancer (breast cancer that has not spread beyond the breast or the lymph nodes (glands) under the arm (axilla) may benefit from the test. The cancer should be:

- stage 1 or 2 (the size of the cancer and how far it has spread are known as the stage)
- lymph node negative (the lymph nodes under the arm are not affected)
- oestrogen receptor positive (ER+) (some breast cancers have receptors within the cell that bind to the female hormone oestrogen and stimulate the cancer to grow).
- HER2 negative breast cancer.

Sometimes the test may be considered for post-menopausal women recently diagnosed with lymph node positive and ER+ primary breast cancer.

If you've been given primary endocrine (hormone) therapy it may not be possible to do this test. Talk to your specialist team.

## How does it work?

The test analyses a group of 21 genes found in breast cancer and results are reported as a Recurrence Score ranked between 0 and 100.

This score indicates how likely the cancer is to return and whether chemotherapy (in addition to hormone therapy) will benefit the patient.

The lower the score, the less likely the cancer is to come back. The higher the score, the more likely the cancer is to come back. If the Recurrence Score falls between the lower and higher range, the benefit of having chemotherapy is less clear.

Your specialist team will discuss the test results with you and decide if there would be any additional benefit from chemotherapy in your situation.

## How is the test performed?

- Oncotype DX is carried out on a small amount of breast cancer tissue removed during surgery.
- The tissue sample is shipped to a licensed laboratory in California, USA where the test was developed.
- The analysis is converted into the Recurrence Score, a number between 0 and 100.
- Within 10–14 days, the results are sent to your specialist.

## Is the test available in the UK?

NICE (National Institute for Health and Care Excellence) has issued guidance for use of Oncotype DX in England and Wales as an option to help doctors decide whether to offer chemotherapy to people with early breast cancer who are in the categories above.

Some private healthcare companies will cover the cost of the test. You can also pay for the test yourself, it costs around £2,500.

## Justine's journey

Back in June, Sue Youngman and I completed the eleven-mile Rhondda walk in aid of Macmillan Cancer Support. Although it was longer than any of the walks I'd done since my treatment, it wasn't especially arduous. The route from the Treherbert rugby ground to the Rhondda Heritage Park was about as flat as you get in a region famous for its valleys and hills. Still, by about mile nine, I could definitely feel it. My leg muscles were starting to groan, my knees were creaking and my feet were looking forward to a pair of slippers.



It was about this point that it suddenly dawned on me that it hadn't even been a year since I'd finished my treatment for breast cancer. First the surgery, then the chemotherapy, followed by radiotherapy. 11 months after throwing my hospital gown into the basket for one last time I was walking 11 miles. This recollection made me realise just how far I'd come (and not just in terms of footsteps) which gave me the extra energy I needed to get through the last couple of miles.

**During my chemo treatment last year I'd managed to go on a few Best Foot Forward walks** around Bute Park with Breast Cancer Care. I felt sick and weak and I was oozing chemicals, but it was a relief to get out into the fresh air with people who understood what I was going through. Even after my treatment finished my legs were a bit unreliable. Walking downstairs in the morning suddenly became an ordeal and my legs felt achy for several months. Eventually, though, I started to feel more normal and I've been trying to build up my strength since then with the help of supportive Team Barbra walkers.

When I was going through treatment it felt like it was taking over my whole life and it was hard to picture myself at the end of it all. Eventually, though, I did feel ready to move forward and begin the journey into the rest of my life. **Justine Hankins**

## Team Barbra update

Justine is the latest in a growing number of women we've supported from end of treatment to their first challenge and the immense pleasure we take in this is up there with the **amazing £52,525 we've raised for Breast Cancer Care** over the last five years.



I remember first meeting Justine on the Best Foot Forward walks in Bute Park and especially remember the time she brought her toy black poodle, Shirley, with her, describing the cute little dog as her comfort blanket. As she got stronger, we did longer walks together with a 7.5 mile walk up to Castell Coch being the ultimate test before we did the 11 mile Macmillan walk.

Justine has recently joined our Breastfriends committee and is keen to support our Tuesday morning walks and share her experience to help others which is a great indictment.



The week before Justine's challenge, I trekked up Snowdon with my Lymphoedema sleeve and dear friend and fellow founder Team Barbra member, Eryl Jones-Utter. We took great delight in flirting with the young men we met on the way (as only women of our age can!) and raised over £1000 for Marie Curie.

Another lovely brave lady I first met through being a volunteer for Breast Cancer Care is Nicki Ellis from Barry. Nicki finished treatment in March this year and signed up for the Race for Life in July. She invited me to join her and we completed the 5K course in her fastest time yet. Well done Nicki and here's to the next one! **Sue Youngman**



**If you'd like to be our next success story then please get in touch!**

# Dates for Your Diary

## Breast Cancer Care Cymru Dates

### Moving Forward Courses

This free four week course (one morning per week) covers a range of topics to help you move forward after treatment. Expert speakers are happy to answer questions and there's time to share experiences with people in a similar situation to you.

#### Llantrisant

10am - 1pm

Thursdays 6 - 27 October 2016

#### Newport

10am – 1pm

Tuesdays 1 – 22 November 2016

#### Cardiff

10am—1pm

Wednesdays 23 November - 14 December 2016

### Information Sessions - Breast Cancer Care Office Cardiff

#### Understanding drugs for primary breast cancer

Friday 23 September 2016

10.30am - 12.30pm

#### Lingerie Evening

John Lewis, St David's 2 Cardiff

Friday 14 October 2016

5pm - 7.30pm

**Booking is essential for the above Breast Cancer Care Cymru events.**

Please call 0345 077 1894 or e-mail [cym@breastcancercare.org.uk](mailto:cym@breastcancercare.org.uk) for more info.

## Living with Secondary Breast Cancer

has been designed to give you the opportunity to meet other people living with a secondary diagnosis and get relevant information and support.



In Cardiff there are regular (usually monthly) meet-ups where you can chat and share experiences with others with a secondary diagnosis. Topics include pain management, fatigue, benefits, and side effects sessions – we also welcome suggestions for topics you would like to cover.

If anyone is interested in the Living with Secondary Breast Cancer service they can contact Breast Cancer Care Cymru on 0845 077 1893 or email [secondarieservices@breastcancercare.org.uk](mailto:secondarieservices@breastcancercare.org.uk)

**16 September 2016, 11am—3pm, Pain Management**  
**21 October 2016, 11am - 1pm, Meet up**  
**18 November 2016, 11am—3pm, Speaker tbc**  
**16 December 2016, 11am - 1pm, Meet up**

### Join us for a Conker Walk

Saturday October 8th, 2pm, Porthkerry Park, Barry

Adults £5 Children £3

Guided walks of two different distances

### Make a decorative plate

Dotty Pots, Penarth

Saturday November 19th

**Please contact  
Linda Harrington  
For more info**



[L.harrington5@btinternet.com](mailto:L.harrington5@btinternet.com)

## ***If you are over 70..... Message from South East Wales Breast Screening Centre***

'We will not invite you but you are still able to be screened if you wish. Please ask us for an appointment by getting in touch with your local Breast Test Wales screening centre. Screening is only available every three years.

**South East Wales Breast Screening Centre**

**18 Cathedral Road, Cardiff, CF11 9LJ, Telephone: (029) 2039 7222**

## Celebrating 10 years - Elaine and Gaynor Trek Iceland (from page 1)

In July seasoned trekkers Elaine Nicholas (nearly 60) and Gaynor Sinton (64) flew to Iceland with 21 other trekkers. After arriving at Keflavik airport they boarded their four wheel drive bus for the five hour journey to their first campsite.



'We arrived at the campsite about 9pm' says Elaine. 'We then had a lesson in putting up our tents and Gaynor and I managed without too much trouble. Dinner followed and then a bathe in the hot springs which was a very surreal but amazing experience. It was 1am, cold and still light as there is no darkness at all in Iceland at this time of year'.

'After just 4 hours sleep, we were up at 6.30am for breakfast. We then made our packed lunch, packed up our tents and camp and ready for our first day trekking at 8.30am'.

'We had a very difficult first day of the trek as weather conditions deteriorated' explains Gaynor. 'It was cold and wet with a driving wind. We did an 11 hour walk in just over 8 hours, not just because we were all super fit but because it was far too cold to hang around'.

'That night there was a terrific storm and a couple of the tents were blown down. The worst storm in 5 years. We opted to stay in the hut and that was a real challenge being cramped in a small room with 30 other people, having to climb a ladder to the top bunk and try to sleep amongst drying clothes, snoring, stale cooking and body smells. Not bad for two women of a certain age!'

'The scenery was amazing and when the weather cleared up the views were fabulous'.

'I was dreading the water crossings in icy cold water but it was exhilarating and the snow bridge we had to walk across one at a time ..... just in case it collapsed so no pressure'.

'We ended our stay in style enjoying a glass of Prosecco in the Blue Lagoon. I will have fond memories of bathing at midnight in hot springs in the first camp, eating lots of chocolate, sensational views, snow fields, waterfalls, and a great bunch of people all walking for a cause they are passionate about'.

'What an amazing experience Trek Iceland was' adds Elaine. 'It's one of the hardest things I've ever done. Battling the elements, the storm, endless miles of snow fields, vertical drops, lava deserts, climbing higher than Snowdon and wading through knee high water'.



**Well done Elaine and Gaynor. We are all so very proud of you!**

**Hear more about Elaine and Gaynor's amazing adventure at our**

**'Seize the Moment' Open Evening on Friday 23rd September, 7pm - 9pm  
at Canolfan Beulah, Rhiwbina, Cardiff, CF14 6LX**

**Refreshments, lush cake, great raffle. All Welcome. Bring a friend.**

## The lasting legacy of a lovely lady



Every second Friday in the month members of Breastfriends Cardiff & Vale meet in the Margaret Whittaker Lounge adjacent to Beulah United Reformed Church in Rhiwbina. This has been our home for over 14 years.

Until very recently however no one had actually asked who Margaret Whittaker was. Elinor, a regular attendee at our meeting, a member of the church and a close friend of Margaret's was happy to solve this little mystery for us.

Up until her death in 1991 Margaret had been an active member of the church and she loved singing in the choir. She never married and worked for many years for the Inland Revenue. When she retired, Margaret seized the opportunity to fulfil her dream of travelling the world. She visited Australia, Africa, Canada, New Zealand and USA. She had a little red book in which she listed all the things she wanted to do or see. One wish was to visit The Ashmoleum Museum in Oxford and see King Alfred's Medal, which she did with Elinor.

Upon her death she left her house to the church of which half was donated to help with the building of the café and lounge. For many people in the area the Margaret Whittaker Lounge, with its cosy atmosphere, has become a home from home. There are many touching stories of individuals popping in for a cup of tea, making friends and having a quiet chat when they feel lonely or at a loose end.

Margaret sounds like a lovely, caring person with just a dash of the explorer about her who cared for her community and left a legacy that is a sanctuary and a lifeline for many to this day. Breastfriends is just one of many groups that is happy to call the Margaret Whittaker Lounge 'home'. Thank you Margaret.

Jane Shatford



## Strawberry Tea & AGM

There was a full house and fantastic atmosphere at our annual Strawberry Tea and AGM in July where our great raffle together with Kaye's sumptuous cakes **raised over £230 for our funds**.

A huge thank you to our regular guest speakers, Dr Annabel Borley and Dr Helen Passant who gave interesting and informative talks on the latest in Breast Cancer Treatments & Myths.

Our chair, Maggie Hourihan, supported by our secretary, Jane Shatford, summarised the work of the group in 2015 and treasurer, Ruth Williams, provided an update on our accounts.

Judith Evans stepped down from the committee after over 14 years service. Maggie thanked her for all her hard work and help in making the group what it is today and we all wish her well.

Elaine Nicholas, Justine Hankins and Irene Bowen were voted onto the committee joining Maggie, Jane, Ruth, Kaye Mundy, Jane Reynolds, Margaret Warren and Sue Youngman.



There was a special mention and our very best wishes for Pam Allinson who, as a committee member, set up and run Barry Breastfriends and is currently in hospital.

Breastfriends has supported and helped many women over the years and it's touching to see how many come back year after year to support us.

**Thank you so much to everyone who made our evening such a success!**



# Pilates

*Have you had a breast cancer diagnosis?*

*Do you have reduced shoulder movement as a consequence of your treatment?*

*Would you like to attend a 6 week Pilates class to help improve this?*



**For further information,  
please contact: 02920 615888 Ext 6340  
email us: [Velindre.physiotherapy@wales.nhs.uk](mailto:Velindre.physiotherapy@wales.nhs.uk)**

## Fringe Benefits

Like many other people who have been through treatment for breast cancer it wasn't until my hair fell out as a result of the chemotherapy that I actually looked ill. In preparation for this I had bought all sorts of hats and scarves and had been fitted for a wig that a lot of people said looked better than my real hair – cheek! I did wear the wig when I was out and about but in the house I found it cooler to wear a scarf and quickly perfected the art creating twists and turbans. However, the one thing I hated about the scarves was that I missed my fringe which I felt would cover the fact that my eyebrows were also missing.

In desperation I turned to my old friend 'Google' and typed in 'fringe wig'. Following a sift through some very dubious sites I found what I was looking for. I could order a fringe that matched my own colouring and I could stick it literally anywhere as it was attached to a strip of Velcro that stuck to scarves or, on the other side, a strip of adhesive that would stick to anything. My sister and I had great fun making a false beard out of it!

The one thing I did learn through this is that it is amazing what is out there to make you feel 'more yourself' during treatment. You just need to be a bit creative!

**Jane Shatford**





# What's on at Breastfriends

## Join us at one of our meetings

### Cardiff Meetings

Our Cardiff group meets on these dates from **1pm-3pm** at the **Margaret Whittaker Lounge, Rhiwbina, Cardiff, CF14 6LX** unless otherwise stated

**Friday 9th September**

Osteoporosis

Dr Jane Turton, Research Associate, Llandough

**Friday 23rd September 7pm—9pm**

at Canolfan Centre, Rhiwbina, CF14 6LX

Elaine and Gaynor's Trek Iceland

**Friday 14th October**

Reflections on my changing body image 7 years on Breast Cancer Care model - Jane Shatford

**Friday 11th November**

Working with anxiety for a happy mind

Mary Madhavi, Yogamobility Cardiff

**Friday 9th December**

Christmas Party!

### Barry Meetings

Our Barry group meets on these dates from **2pm-4pm** at the **Mary Lennox Room, Barry Hospital, Colcot Road, Barry, CF62 8YH**

**Friday 16th September**

Coffee and Chat

**Friday 21st October**

Coffee and Chat

**Friday 18th November**

Coffee and Chat

**Friday 16th December**

Christmas lunch tba

**Friday 21st January, Friday 17 February etc**

Coffee and Chat

For more info please call Rosina on 01446 745269 or Linda on 01446 710516 / 07967 806073

## Walk and talk with Breastfriends

We meet at **10.30am every Tuesday (weather permitting)** for a short leisurely walk followed by coffee and maybe cake!

**Barry walks** alternate between Barry Island and the Knap

(Please contact Rosina on 01446 745269 or Linda on 01446 710516/07967 806073 for more info)

**Cardiff Walks** meet by the lighthouse in Roath Park for a walk around the lake

(Please contact Sue on 07773 500525 for more info)



## Contact Us

Phone: messages care of Breast Cancer Care Cymru on 0845 0771894

Please check our website for up-to-date information

Email: [info@breastfriendscandv.org.uk](mailto:info@breastfriendscandv.org.uk)

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