

Breastfriends Cardiff and Vale Breast Cancer Support Group

May 2018

From Roath Park to Hyde Park!



Jackie Rawlings, one of our regular Tuesday morning walkers is training for the 13.1 mile Walk the Night in London in July.

See page 5

Who are we?

Breastfriends, described by one of our members as a source of instant friendship, 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



The Institute of Cancer Research, London, is looking for people who have been affected by cancer to share their story.

About us

The Institute of Cancer Research (ICR) is one of the world's most influential cancer research organisations with an outstanding record of achievement dating back more than 100 years. Our mission is to make the discoveries that defeat cancer.

We are world leaders in identifying cancer genes, discovering cancer drugs and developing precision radiotherapy. Together with our hospital partner The Royal Marsden NHS Foundation Trust, we are rated in the top four centres for cancer research and treatment worldwide. The ICR has charitable status and relies on support from partner organisations, charities, donors and the general public.

We provided the first convincing evidence that DNA damage is the basic cause of cancer, and discovered many of the early chemotherapies. Today, we are world leaders at identifying cancer-related genes and discovering new therapies for personalised cancer treatment. Since 2005 we have discovered 20 drug candidates and progressed 9 into clinical trials.

Some recent advances in breast cancer at the ICR

Our researchers were responsible for one of the biggest ever discoveries in cancer genetics – the identification of the breast cancer gene *BRCA2*. Its discovery has enabled families with a history of the disease to be assessed for future risk, and has helped lay the groundwork for the development of novel therapies that target *BRCA*-associated cancers. Science carried out at ICR underpinned the development of PARP inhibitors such as olaparib, which the FDA has recently approved for advanced breast cancer in women who have inherited *BRCA1* or *BRCA2* mutations.



How you can help us

Your story might help us illustrate the importance of research into your cancer in written features that we publish on our website. Or you might be interviewed and appear in a video we are making about the ICR's latest research discovery. Your personal experience with cancer can be an inspiration to others and encourage further support for our research.

Before any media opportunity we would work with you to see if you feel comfortable doing the interview and ensure you are as prepared as possible. We will not give out your contact details without your consent and the Media Relations team will be on hand to support you every step of the way.

If you are interested in sharing your story with the ICR please visit icr.ac.uk/shareyourstory, or contact us at stories@icr.ac.uk.

Decisions, decisions, it's good to talk

From the second we are told we have breast cancer we are in the odd situation of our lives being ruled by treatments, but still having to make decisions.

When I had my mastectomy in 2001 My decision was to not have a reconstruction. My priority was to stay alive long enough to bring up my three children. It was difficult to see a future and I did not have the time or energy for a reconstruction.

Over time my feelings changed and I wanted a reconstruction. Talking it over with family, friends and Peer Support at Breast Cancer Care (as it was then) I made the decision to go for a reconstruction.

At Morriston Hospital I had several discussions about the type of reconstruction and the pros and cons of each. Eventually I was able to make an informed choice, I had a tram flap in 2009. A long time? Yes, but it was right for me. My self confidence improved and I could once again enjoy clothes.

Breast Cancer Care has been very important to me and I have used the call a nurse service several times. Also the Someone Like Me service* (as it is now) when I could talk to others who had been in my situation. There is now an email service as well to talk to others, many like this type of communication because you can take your time writing. Then you have a written reply to refer back to.

For several years I have been a volunteer for the Someone Like Me service, both telephone calls and emails. Often it is someone trying to make a decision. Some times people do not yet have all the information, so may need to gather it first. Then it takes time to take it all in. Everyone needs to be kind to themselves and allow time.

Making decisions can be so hard, being scared, tired and suffering from chemo brain makes it so much harder. Everything can seem confusing, and which information can we trust?

If we are lucky we have good family and friends to help us through and listen to us. When we tell others our thoughts we have to organise what we are saying so they will understand, in doing so we often see things more clearly for ourselves. Someone listening to us can make such a difference, especially if they can resist telling us what we should do! We need support in making a decision, not to have it made for us.

A huge positive effect is the support we get from our Breastfriends group. It is open, strong and fun. It has helped me in so many ways when making difficult decisions. It has a positive and supportive feel and is a place where we can discuss our worries, share good news and eat the best cake in Cardiff.

Yes we have to make decisions, but first we need all available information, then to be able to think things through and talk them over with those we trust.

Decision made.

Lynn Abel

* <https://www.breastcancercare.org.uk/information-support/support-you/someone-talk/someone-me>



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.

Cardiff

10am - 1pm

Wednesdays 02 May - 23 May 2018

Merthyr Tydfil

10am - 1pm

Mondays 04 June - 25 June 2018

Cardiff

10am - 1pm

Wednesdays 04 July - 25 July 2018

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

Please call 0345 077 1894 or e-mail 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

18 May 2018, 11am—3pm
Wills and Legal Considerations
Followed by lunch and meet up

15 June 2018, 11am— 3pm
Speaker to be confirmed
Followed by lunch and meet up

20 July 2018, 11am – 1pm, Meet up

19 August 2018, 11am—1pm, Meet up

Monday, 25 June 2018
7pm - 9pm

Strawberry Tea & AGM

Guest speaker

Dr Helen Passant



Friday, 19 October 2018
7pm - 9pm

Breastfriends Fashion Show

In association with
Calon Rhiwbeina

The Canolfan Centre
Rhiwbina, Cardiff CF14 6LX

All Welcome

Please join us and bring a friend - we'd love to see you!

From Roath Park to Hyde Park! (from page 1)

On July 14th, Jackie Rawlings will be joining thousands of others as men and women unite to take to the streets of London for the first ever Walk the Night challenge.

'I'm doing the half marathon which is 13.1 miles and the furthest I've walked since I was a child' says Jackie. 'The event will support people affected by Breast and Prostate Cancer and the more money and awareness we can raise the better'.

A lovely, sunny lady, Jackie joined our Tuesday morning Roath Park walks on the recommendation of a friend who had walked with us throughout her chemotherapy. 'I love getting out in the fresh air and feel so much better for it' says Jackie, 'plus it's great for bone strength'.



When Jackie underwent a mastectomy in January 2017, her daughter, Joanna started doing challenges to raise money for breast cancer charities. Joanna was Jackie's inspiration to sign up to Walk the Night and will be doing the walk with her.

Originally from Peterborough, Jackie and her husband, John, moved to a farm near Llanelli in 1985. Their farm was home not only to their two sons and two daughters but also to a number of long term foster children, most of whom are still in touch.

Jackie and John's life changed forever when John fell and hit his head while on holiday in France four years ago. The fall caused a bleed on the brain damaging the area that controls movement and John can now only move his right arm. John is now in full time residential care in Penarth and Jackie lives close by.

'Bad things happen in life' says Jackie 'and we just have to get on with it. Mentally John is still the person he always was and loves spending time with his family especially the grandchildren. We all make the most of the special time we spend together'.

Jackie still walks on a Tuesday morning but now does 3 or 4 laps of the lake before joining us for coffee. Over the next few months I'm looking forward to joining this inspirational lady on her training walks to help her build up her mileage and stamina so that her Walk the Night will be a walk in the park! **Sue Youngman**

Greetings from Cyprus



Hello to Breastfriends from Demetra's Pink Fighters at Afetiría house in Moniátis, 17 March 2018. The cancer charity PASYKAF provides 5-day 'moving forward' style programmes for cancer patients who have finished their treatment. Demetra, a wonderful specialist nurse, organised a fantastic day in the mountains including lunch and dancing in a tavern, singing!

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

News from Barry

It was a delight to be able to welcome Pam Allinson to the Barry group monthly meeting in January at the Barry Hospital.

Pam, since suffering a debilitating stroke, has been at Llandough Hospital but was recently transferred to the Barry Hospital for her long term care. This allowed her to come down from the ward and meet up with old friends. It is hoped Pam will be well enough to visit on a regular basis.



The group meet on the third Friday of every month and listens to guest speakers on a variety of cancer related topics. Meetings start at 2pm in the Mary Lennox meeting room and after light refreshments usually end at 4pm.

Welcome is extended to anyone going through treatment or awaiting diagnosis and family and friends affected by breast cancer. It is a warm friendly group who offer support to each other and always make new visitors welcome. Pam was a founder member of the group.

Rosina Butler



The Barry ladies enjoying a wet and windy Tuesday morning walk earlier this year.

See page 8 for walk details.

Farewell to one of a kind

At the end of last year we lost one of our lovely inspirational members, Josie Ireson.

Always elegant, Josie was a very special lady and a longstanding member of our Cardiff group. We'll miss her stories and her wicked sense of humour.

Diagnosed with breast cancer on her 75th birthday in 2004, Josie finished taking tamoxifen on her 80th and celebrated by taking a trip on the Orient Express with her sister and two brothers.

Back in 2014, I had the pleasure of interviewing Josie for the newsletter. We spent an unforgettable couple of hours together as she gave me some amazing material before adding it was for my ears only!

At the Celebration for her Life, Josie was described as a 'trailblazer' and 'a collector of friends' and I, for one, feel honoured to have been one of the friends she collected.

We'd like to say a huge thank you to Josie's family for asking that donations in memory of Josie be made to Breastfriends. We were all very touched by such a kind and thoughtful gesture, so very reminiscent of Josie herself.

Sue Youngman



My reality

I was 34 and had only been married for 3 months when I was diagnosed with triple negative inflammatory breast cancer.

'No Evidence of Disease' are the words you dream of hearing. When you think that the only outcome is dying, you've written letters to loved ones and chosen songs for your funeral, you don't think hearing those 4 words would ever be a reality. When you do hear them, you expect to feel a massive sense of relief, to want to celebrate and feel like the hell of cancer is finally over. Instead, I looked around me and wondered why my family and friends were more relieved and happy than I was.

The reality is, it isn't over in, in a way it's just beginning. During treatment I was living from appointment to appointment. My motivation and fight was to kill the cancer, I didn't know what I'd do once I'd got there, or how was going to come to terms with the things that cancer stole from me (my identity as a woman, as a wife, daughter, friend, Social Worker, my appearance, my confidence and the biggest thing - the prospect of not having children and a family). I still don't know if I'll ever come to terms with any of these things, and that instead it's about finding the new me.

Cancer forces you to make changes to your life and to find the positives and I was determined that Cancer wasn't going to stop me doing things. I planned things to look forward to at the end of treatment, things that kept me motivated to get to the end. A second Christmas, events with friends, a Take That concert, and, despite being riddled with anxiety, I went away to Snowdonia for our first anniversary.

Everyone thinks (I wrongly did before cancer) that getting a 'No Evidence of Disease' means that you're cured, and it doesn't. The reality is that we are at risk of recurrence and secondary cancers developing. So every cough, headache, aches and pains - the panic sets in and it is easy to convince yourself that its back and that it is going to get you this time.

Yes, I know that the future isn't promised to any of us, and that no one knows what's going to happen to them tomorrow, and if I hear "anyone of us may get run over by a bus tomorrow" again I may scream! Yes I could, and so could you, but the difference is I know what getting run over by that bus (cancer) feels like - I know how battered and bruised it made my body feel, the pain, sickness, fatigue, infections, allergic reactions, losing hair, eyebrows, eyelashes and nails. So, because I know the reality of that bus I'm more afraid of it and I think about it more.

We all assume we are going to live until we are old, and that we have time to do everything we want in life, but cancer makes us face the reality that life isn't always that kind. My sense of naivety that bad things only happen to other people has gone, and life now means accepting to live with fear and uncertainty.

This isn't how it is for everyone, it's just how it is for me, this is my reality.

Many thanks to Kim Shore for allowing us to share this excerpt of a piece she wrote for The Younger Breast Cancer Network in October 2017

Breastfriends Cardiff and Vale would like to say a huge thank you to Macmillan Cancer Support for its continued support and a grant of £1985 to help with leaflets and other publicity materials

**WE ARE
MACMILLAN.
CANCER SUPPORT**

And finally

Good Luck to Michael Williams and his uncle, also Michael Williams, who will be running the London Marathon for Breastfriends on April 22nd.

Love the outfit Michael!

<https://uk.virginmoneygiving.com/MichaelWilliams56>





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 11th May

Jo Fowler, Choir Leader, 'Sing with Us', Tenovus

Friday 8th June

Managing Menopausal Symptoms
With Gail Williams, Oncology Nurse Specialist

Monday 25th June

at Canolfan Beulah, Rhiwbina, CF14 6LX

Strawberry Tea and AGM

Guest Speaker
Dr Helen Passant

Friday 13th July

Coffee and Chat

**** Please note there is no afternoon meeting in August**

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 18th May

Coffee and Chat

Friday 15th June

Coffee and Chat

Friday 20th July

Coffee and Chat

Friday 17th August

Afternoon Tea at Whitmore + Jackson
Please contact Rosina on 01446 745269 for more information and to book

For more information on the Barry meetings please call Rosina on 01446 745269 or Linda on 01446 710516 / 07967 806073

Walk and talk with Breastfriends

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

Barry walks alternate between Barry Island and the Knap and start at 10am or 10.30am depending on the time of year—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 at 10.30 am** 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

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