

## Breastfriends Cardiff and Vale Breast Cancer Support Group

May 2019

### Flying High ... zip wire style!



**Barry  
Breastfriends  
Jayne Lambe (right)  
with  
breast care nurse  
Sharon Chapman (left)  
at The Wire  
Chepstow**

(see page 3)

### 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.

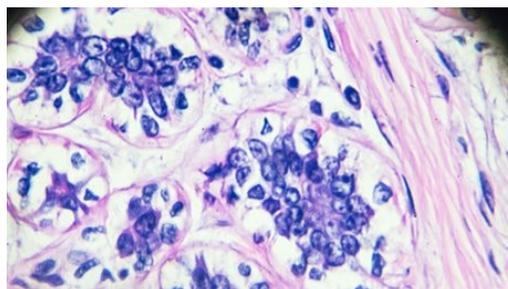
We know that walking into a room of strangers can be off putting, so please get in touch if you'd like a buddy for your first walk or meeting.

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

## New research into triple negative breast cancer

Researchers at Cardiff University have discovered a protein that drives the growth and spread of aggressive breast cancer.

The research is led by Professor Matt Smalley who is the Director of the European Cancer Stem Cell Research Institute. His team are investigating what drives an aggressive form of breast cancer called triple negative, which accounts for about 15% of cases of breast cancer.



Triple negative breast cancer does not have receptors for the hormones oestrogen and progesterone or the protein HER2. Consequently it is resistant to hormonal therapy like tamoxifen or anastrozole, or the targeted therapy drug Herceptin. It is more common in women under 40 and black women, and can be associated with a faulty BRCA1 gene.

Prof Smalley said "We looked at a protein called LYN, which is involved in keeping cells alive and allowing them to divide, and found that it was no longer properly controlled in aggressive breast cancer cells and could drive the cancer cell growth, spread and invasion."

In the subset of triple negative cancer cells associated with the BRCA1 gene mutation, the researchers found that LYN could be activated. This resulted in increased survival of the cancer cells due to the lack of BRCA1. Furthermore, when the researchers manipulated the function of LYN under experimental conditions the BRCA1 mutant cells died.

Prof Smalley added: "Thanks to Breast Cancer Now, who funded this research, we now understand the role LYN has in aggressive forms of cancer. We can now build on this and can start to think about developing targeted therapies."

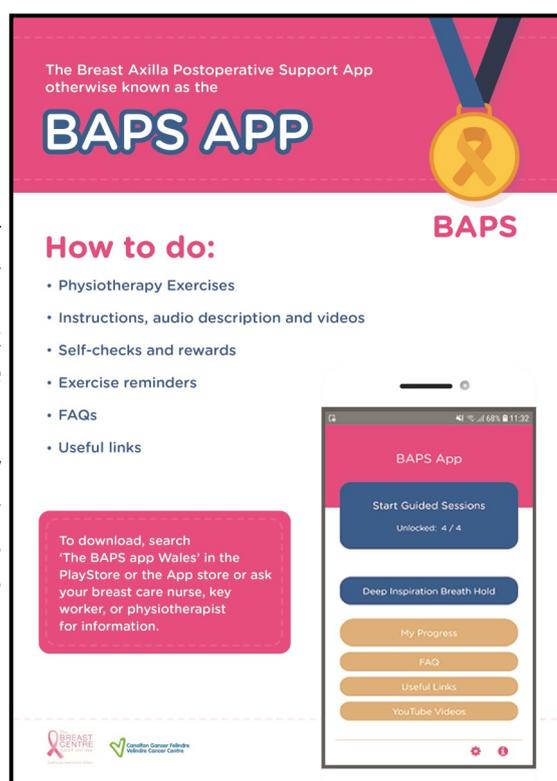
Future research will assess how to identify which patients have increased levels of LYN or a BRCA mutation and how to target LYN. This could lead to more specific and personalised therapies for women with aggressive breast cancer. **Giselle Jones**

## The BAPS APP

The app has been designed by physiotherapists, a breast cancer surgeon and some breast cancer survivors to encourage self-management, a sense of achievement and to improve overall wellbeing. It was designed following constructive feedback from patients about the information on post-operative exercise that is currently available in paper format.

Physiotherapy exercise is very important following breast and/or axillary (armpit) surgery to minimise the loss of shoulder movement and function on the operated side. The exercises are considered to prevent stiffness and to keep any scars mobile after surgery. The exercises will also help strengthen arm muscles, relieve and control pain and aid tissue healing.

**(Continued on page 3)**



## Flying High ... zip wire style!

(from Page 1)

Jayne Lambe from Barry was diagnosed with breast cancer in April 2016 at the age of 50 and underwent surgery at Llandough before having chemotherapy and radiotherapy at Velindre.

In January 2018, Jayne and her breast care nurse Sharon Chapman, undertook a hair-raising zip wire challenge to raise funds for Llandough Breast Centre.

'Llandough Breast Centre certainly saved my life' says Jayne 'and for that I'll be forever grateful. I wanted to give something back and the Zip Wire at Chepstow provided the perfect opportunity'.



'The Wire is based at the National Diving & Activity Centre, Chepstow and is one of the UK's longest Zip Wires. It is 700 metres long, 70 metres high and will reach speeds up to 40 miles per hour'.

'I was quite nervous in the lead up to the event but felt it was a small price to pay for my life and to help save others. Sharon went first and then it was my turn. I couldn't believe how exhilarating it was and how quickly it went. Too quickly in fact – I just wanted to do it all over again! Some of Sharon's colleagues came along to cheer us on and that made it extra special'.

Inspired by Jayne and husband Mark's fundraising efforts, her cousin David Sharpe, a security guard at Tesco, Barry, organised and raffled a pamper hamper at his store in aid of the breast centre.

Fundraising to date has raised £2,000 and Jayne is already thinking about what her next challenge will be. The money raised will provide patients at the breast centre with extras such as post-mastectomy bras, specialist physiotherapy input and complementary therapies.

Sue Youngman

## The BAPPS APP

(from Page 2)

During radiotherapy there is a requirement to remain in a position for a period of time, sometimes over 25 minutes. The aim of the app therefore, is to prevent delays in radiotherapy treatments due to restricted shoulder movement and to help to access earlier intervention when required.

The app enables patients to see how to do the exercises or read instructions or hear an audio description. It gives them an idea of how they are doing with the self-checks and rewards and there is a daily reminder alert that can be set up to remind patients to do the exercises. At certain points throughout the app there are triggers to contact key workers if things aren't progressing.

Thanks to: Patients who have contributed  
Donna Egbeare – Breast Surgeon C&VUHB  
Sioned Roberts & Kate Baker – Physiotherapy at Velindre Cancer Centre  
Bevan Commission  
Cardiff & Vale for supporting Health Hak  
Orchard team

**Kate Baker, Macmillan Deputy Head of Therapies/Clinical Lead Physiotherapist  
Velindre Cancer Centre**



# Dates for Your Diary



## 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.

### Moving Forward, Newport

10am - 1pm  
Tuesday 07 May—28 May 2019

### Moving Forward, Bridgend

9.30am- 12pm  
Friday, 05 July—26 July 2019

### Moving Forward, Cardiff Spire

**One day course**  
10am- 4pm  
Monday, 24 June 2019

### Family & Friends, Cardiff

5pm—7.30pm  
June 2019 (date tbc)

**Booking is essential for the above 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 please ring 0845 077 1893 or email [secondaryservices@breastcancercare.org.uk](mailto:secondaryservices@breastcancercare.org.uk)

**Friday, 17 May 2019, 12pm—5 pm,  
Health and Wellbeing Day  
Maggie's Centre, Whitchurch, Cardiff**

**Friday, 21 June 2019, 11am – 3pm,  
Speaker session—Art Therapy**

**Friday, 19 July 2019, 11am – 1pm, Meet up**

**Friday, 16 August 2019, 11am – 1pm, Meet up**



## Managing Menopausal Symptoms

A free 2.5 hour session on managing the menopausal symptoms that are all too often a side effect of breast cancer. The session is presented by Gail Williams, Oncology Nurse Specialist in breast cancer and takes place at Velindre Hospital.

For more information or to book onto a session, please call Helen Harris on 029 2031 6979

## Save the date!

### Breastfriends

### Body Image and Amoena bras

**Monday, 14 October 2019  
7pm - 9pm**

### ***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**

## Returning to work after a secondary diagnosis

I had had my primary breast cancer diagnosis in 2010. I had retired from nursing following my treatment owing to nerve damage in my hands and feet caused by chemotherapy and had found a new career working for Breast Cancer Care in 2014. I loved my job helping develop services for women and men affected by breast cancer. It was the best thing that happened to me following my initial diagnosis. I will never forget my husband John saying 'You are back'... meaning that being fulfilled by work I was a happier person at home. I had lost my identity when I finished nursing but found it again working for Breast Cancer Care.



In April 2018 I was told that unfortunately my breast cancer was now stage 4 and not curable. It felt like everything was finished for me. I was off sick to start treatment for pain control and to hopefully slow down and stabilize my metastatic disease. Telling parents, daughters, extended family, friends and colleagues was dreadful, I was numb, scared and unsure of any future. Initially just getting through each day was all I could do.

Once my treatment was underway, I started to think about returning to work. Initially it seemed impossible but just planning it in my head helped me cope with fears and anxieties. Family and friends initially were concerned that I would even consider a return (partly because of where I work and what that role involved). For me I just wanted to be back with my 'work family', part of a team making a difference.

Getting back to work was like climbing a mountain, slow, painful and frustrating at times but the joy of reaching that summit was the best feeling. Compromise, additional support and adaptation has been necessary. I do not have the health or stamina to work long hours. There are parts of my role that I am having to 'let go' because of my diagnosis. My physical abilities have changed and are likely to keep changing over the rest of my working life. The important thing is for me to keep communicating with my colleagues about how I am managing and seek help where necessary.

One thing I have learnt is that on the more difficult days it is not where I work that affects me. Those days are just hard. It is usually fatigue that is my main problem and I am still learning how to get the best work – life balance.

Splitting my working days so I have a recovery day in-between is one helpful thing that is so far working well. Working shorter days and, for home working, pacing my work to a couple of hours as and when I can give it my best seems to be working well at the moment. Having a cleaner a couple of hours a week has made a big difference. I never thought I would employ someone to clean but I now don't stress over the things I have no energy for. To be honest I wish I had had a cleaner when I worked full time and had a young family. It's a shame that illness can be the cause of doing something so helpful towards quality of life.

I still have so much to offer and am lucky that I have been able to return to work. I enjoy working and it gives me a purpose and a belief that, despite uncertainty about my future, I am not only defined by my diagnosis but the life experience, skills and knowledge I have. It is also a part of my life where I can make decisions and change and be in control.

So in conclusion, I am proof that life can return to some semblance of normality after a secondary diagnosis. It is not always easy but it is worth all the effort that I and my colleagues put in to making it work. It would not be possible without the support of my family, friends and my wonderful cleaner!

**Tracey Williams**

**A huge thank you to Tracey for sharing her inspirational story**

## Update from Breast Cancer Care and Breast Cancer Now

Baroness Delyth Morgan is the Chief Executive at Breast Cancer Now and Breast Cancer care from the 1<sup>st</sup> April 2019. She spent 10 years at Breakthrough Breast Cancer, as the charity’s first Chief Executive, from 1996, before which she worked at Shelter, Workplace Nurseries Campaign and Asthma UK.



After becoming a life peer she was appointed to Government in 2007, when she served as Children’s Minister for the Department of Children Schools and Families, Minister for Intellectual Property and Quality at the Department of Innovation, Universities and Skills and Government spokesperson for the Department of Work and Pensions in the House of Lords.

In 2011, Delyth returned to the field of breast cancer at the helm of Breast Cancer Campaign. Having jointly managed preparations for merger of two charities, Delyth was appointed Chief Executive of the newly merged charity, Breast Cancer Now – officially the UK’s largest breast cancer charity – which launched in June 2015.

Delyth now sits in the House of Lords as an independent peer. She is a Fellow of University College London and Honorary Fellow of the Institute of Cancer Research and Cardiff University. She is also Patron of Pancreatic Cancer UK and The Sheila McKechnie Foundation, and Honorary President of Cancer 52. In June 2015, she was appointed Chair of the National Cancer Research Institute (NCRI).

Delyth is of Welsh heritage. She divides her time between Cardigan in Wales and London and lives with her husband. She has one daughter, presently at university. In her spare time she enjoys walking, kayaking and listening to and playing live music.

### Mags Holloway Breast Cancer Care and Breast Cancer Now



In March, the then Breast Cancer Care won the prestigious 2019 Health Service Journal (HSJ) Partnership Award for “Best Not for Profit Working in Partnership with the NHS” with its Moving Forward Programme.

David Crosby, Director of Services & Engagement, says ‘We were delighted to collect the award on behalf of all Breast Cancer Care colleagues (including staff across the organisation who support our services in various ways), our Moving Forward Facilitators and volunteers who are vital to the delivery of Moving Forward, our trustees, our NHS partners and their healthcare professionals who we work with to deliver Moving Forward in over 90 NHS hospitals across the UK, and all the women and men who have benefitted from attending Moving Forward - nearly 11,000 to date’.

Saturday  
June 15th

### Lynn’s Garden Party Fairwater Cardiff

2pm—6pm

Tickets £7 to include a glass of fizz, nibbles and refreshments



Please contact Lynn on 07813202214  
lynnabel27@yahoo.co.uk

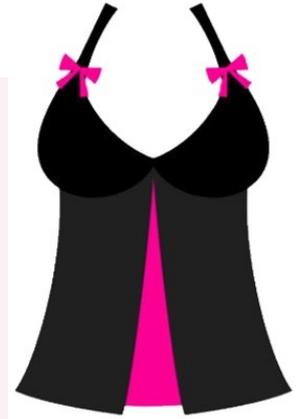
In aid of Breast Cancer Care and Breast Cancer Now  
Registered charity in England and Wales 1160558



## Keeping abreast of body changes

At our meeting on 8<sup>th</sup> March our guest was Jane O'Dwyer of Amoena, a company that manufactures breast forms, pocketed bras, swimwear and tops all suitable for women who have had surgery for breast cancer.

Jane brought with her a large selection of bras and other items and explained how important it is for a bra to be fitted properly, especially if lymphoedema, surgery scars or post radiotherapy skin irritation cause ordinary bras to rub or cut into the skin. She even had some examples of breast forms so we could feel for ourselves the different weights and shapes available. Before leaving Jane was able to measure some of us so we could then order from the catalogue. Ordering clothing online is always a bit hit and miss so having Jane to provide accurate measurements and being able to feel the fabrics was brilliant.



Although more shops are now stocking bras with pockets they don't carry extensive ranges and sizes so you don't have much of a choice of design, colour or fit. I still find it upsetting to walk through a lingerie department and see all the beautiful examples on display, all with matching briefs knowing that this isn't an option for me anymore.

This session brought back memories of my own experience post surgery 10 years ago. Following a period of treatment when every day seems to be about appointments, recovery and dealing with health issues you suddenly have the time to reflect on the impact of what has happened to you and the changes to your body shape and image.

Having had a double mastectomy – I had tumours in both breast so it wasn't a choice to go 'flat' – I remember going to the hospital to be fitted with my first pair of prosthesis. *'Oh, you're an easy customer'*, the nurse exclaimed, *'with most women I have to do a lot of fiddling about to get the right balance between the breast that is left and the one that is missing.'* For some reason I found a strange pride in not being too much of a bother to her. On my way out with my new boobs in a carrier bag I bumped into a woman I had gone through treatment with. *'I've got to see if they will replace my original one. I'd only had it a week'*, she told me *'my husband and I went camping last week and I lost it!'* She didn't elaborate and I didn't like to pry!

Apparently being 'flat' has other advantages. One woman I met told me that she has two pairs of boobs in different sizes. One 'everyday' pair and some bigger ones for special occasions when she wants to be a bit more curvy! Who knew!

Many people will tell you that having a sense of humour helps when faced with a serious health issue such as breast cancer and I do find putting my boobs in a box before I go to bed and have different one for swimming a bit bizarre. I'm grateful to have had such effective treatment and the support of many professionals and friends I have found through groups such as Breastfriends, however, it's not easy to deal with the impact of such radical surgery and sometimes being able to find something to laugh at helps. I just wouldn't want anyone to think that I was being flippant when I tell stories about me and my various sets of boobs, it's just how I cope with things.

**Jane Shatford**

**And finally .....**



**Don't forget our BreastFriends Strawberry Tea & AGM**

**Monday, July 1st, 7pm—9pm at Canolfan Beulah, Rhiwbina, CF14 6LX**

**With guest speaker Dr Annabel Borley, Consultant Oncologist, Velindre Cancer Centre**

**All Welcome!**

**We'd love to see you and please bring a friend**



# 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 10th May**  
Breast Cancer and diet  
Angela Cleaver

**Friday 14th June**  
Fatigue  
Helen Johns

**Monday July 1st 7pm—9pm**  
**Strawberry Tea and AGM**  
at Canolfan Beulah, Rhiwbina

**Friday 12th July**  
Coffee & Chat

**\*\* There is no August meeting \*\***

### 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 17th May**  
Coffee & Chat

**Friday 21st June**  
Coffee & Chat

**Friday 17th July**  
Coffee & Chat

**Friday 16th August**  
Coffee & Chat

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 10.30am. 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](mailto:info@breastfriendscandv.org.uk)

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If you have received this newsletter in the post, we are holding your details on our mailing list. If you do not want to receive further mailings from us, please let us know.