



Breast Friends York

Newsletter – Edition 5

Registered Charity No: 1175926

BREAST FRIENDS YORK CELEBRATES ITS 5TH BIRTHDAY

We have had a busy time since our last newsletter so there's lots to tell you all, the most exciting of which is that we are turning 5 this month. It's been 5 years of fun, friendship, support and dedication from our members and has resulted in a growth that we really don't like to see but really demonstrates the need for ongoing support following a breast cancer diagnosis. We are celebrating by having dinner together which is open to any member of Breast Friends York via booking on our private Facebook group or by emailing us.

Spring, as we all know, symbolises new growth, so it is hardly surprising that two of the biggest UK breast cancer charities, **Breast Cancer Care** and **Breast Cancer Now**, have chosen April as the month in which to join together to make one super charity which supports, informs, fundraises, researches and raises awareness in relation to breast cancer. For the time being they will operate under the name Breast Cancer Care, but a new name will be announced in the coming months.

At Breast Friends York, we too like working together with other charities, so last October we joined forces with our local Breast Cancer Now fundraisers to put on an afternoon tea. The event was a sell-out and many of our supporters fetched out their favourite frocks and joined us and the York Breast Cancer Now team to enjoy cakes, sandwiches and those all-important scones, as well as all you could drink tea and the odd bit of cheeky fizz.



Along with a fabulous raffle, we raised a total of £917.49 and splitting the funds equally, we had just over £450 each. We know Breast Cancer Now will be spending theirs on life saving research into breast cancer treatments and ours will be spent on life-affirming and supportive experiences for our group living with and beyond breast cancer treatment.

We would like to thank Bedern Hall for hosting us and catering the event, Breast Cancer Now York fundraising team for partnering with us, and of course those of you that supported us at this event and beyond.



OUT & ABOUT



This year BFY will be having a stall at **York Pride** on **Saturday 8th June** – see <https://yorkpride.org.uk> for more details. Come and pay us a visit and say hello!

We will also have a stall, along with the BFY Supportive Sewers, at the **Fossgate Festival** on **Sunday 2nd June, Sunday 7th July and Sunday 4th August**. Craft items will be available to buy, helping raise vital funds for our wonderful sewing group who make the pillows and drain bags that are given out at the hospital.

<https://www.visit-york.org/whats-on/fossgate-festival-p825791>

Supportive Sewers



Making pillows and drain bags

UPCOMING EVENTS

MAY 2019

Supportive Sewers Pillow and Drain Bag Workshop*

**Tuesday 7th
12.45pm-4.30pm**

The Viking Loom,
Wigginton Road, York
YO32 2RH

Sewers and non-sewers welcome to join our friendly group. We make heart shaped pillows and drain bags for use after surgery.

Evening Meeting*

**Tuesday 14th
7pm-9pm**

Pig&Pastry
Bishophorpe Road,
York YO23 1NA

Come and join us at the Pig & Pastry for free coffee, cake and chat.

Luncheon Club*

**Tuesday 28th
12-2.30pm**

Toby Carvery Hopgrove,
Malton Road, York YO32 9TE

A chance to sit back and socialise with others who have shared similar experiences. Lunch is free. Just bring yourself and lots to talk about, it doesn't have to be breast cancer-related at all.

Newcomers are welcome but please do tell us if you are coming in advance so we can ensure we book a table big enough.

JUNE 2019

Living With and Beyond Cancer Event

**Monday 3rd
11am-3.00pm**

York Hospital
Main Reception

This event is being hosted by York Teaching Hospital NHS Foundation Trust and is free to attend.

BFY will be manning an information stand alongside other local charities and organisations.

Supportive Sewers Pillow and Drain Bag Workshop*

**Tuesday 4th
12.45pm-4.30pm**

The Viking Loom,
Wigginton Road, York
YO32 2RH

Evening Meeting*

**Tuesday 11th
7pm-9pm**

Pig&Pastry
Bishophorpe Road, York
YO23 1NA

Luncheon Club*

**Tuesday 25th
12-2.30pm**

Toby Carvery Hopgrove,
Malton Road, York YO32 9TE

A chance to sit back and socialise with others who have shared similar experiences. Lunch is free. Just bring yourself and lots to talk about, it doesn't have to be breast cancer-related at all.

Newcomers are welcome but please do tell us if you are coming in advance so we can ensure we book a table big enough.

JULY 2019

Supportive Sewers Pillow and Drain Bag Workshop*

**Tuesday 2nd
12.45pm-4.30pm**

The Viking Loom,
Wigginton Road, York
YO32 2RH

Sewers and non-sewers welcome to join our friendly group. We make heart shaped pillows and drain bags for use after surgery.

Evening Meeting*

**Tuesday 9th
7pm-9pm**

Pig&Pastry
Bishophorpe Road, York
YO23 1NA

Hula Hoop/Aerial Skills Class**

**Thursday 18th
8.15pm-9.30pm**

**These classes are held at Jenny's home and therefore there is a limit on numbers. Please contact us for details.

Luncheon Club*

**Tuesday 30th
12-2.30pm**

Toby Carvery Hopgrove,
Malton Road, York YO32 9TE

A chance to sit back and socialise with others who have shared similar experiences. Lunch is free. Just bring yourself and lots to talk about, it doesn't have to be breast cancer-related at all.

Newcomers are welcome but please do tell us if you are coming in advance so we can ensure we book a table big enough.

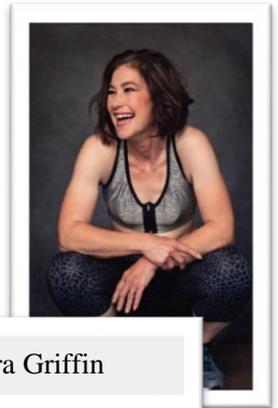
**Newcomers are welcome but numbers are needed in advance so please call or email if you wish to attend any of these events.*

07516 066599 info@yorkbreastfriends.org

MEMBERS' STORIES

Barbara Griffin, our Secretary, talks about turning 50 and feeling like her old self.

Diagnosed with breast cancer in August 2014, I had a mastectomy with immediate reconstruction, followed by 6 rounds of chemo and Herceptin (an injection every 3 weeks for a year). I was lucky to find Breast Friends York right at the beginning of my cancer journey, just before my mastectomy. Breast Friends York has helped me enormously in this whole new world of appointments, treatments, medical terminology, etc. Being a medical secretary at the time didn't make it any less scary! I am now 4½ years down the line and feeling fit and healthy. I take Tamoxifen tablets and have annual mammograms to check the remaining breast.



Barbara Griffin



Last year I turned 50 and rather than being sad about 'getting old' as I hear lots of people comment when they have a birthday coming up, I was determined to celebrate, as without the surgery and treatment I received I might not be here now. Despite never being a confident runner or wanting to join a running club, I joined GoodGym York (a running group that runs to complete community tasks across the city) in January 2017 as it started up. I reached the milestone of completing 50 good deeds in January last year and got to wear the wonderful 'cape of good deeds' – I really did feel like a superhero! This got me thinking and so I planned other various 50-related challenges throughout the year and started off by collecting 50 hugs from friends (all photographed), which was great fun. I went to 50

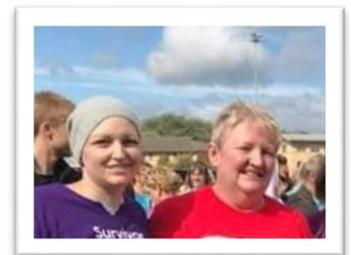
parkruns (running and volunteering) and visited 50 different cafes (easy peasy!). One of my big challenges was completing 50km (walking and running) in 24 hours at the Relay for Life York event in September. With the support of the Breast Friends York team, despite awful weather and very little sleep, I reached my target with the whole team joining me for my last lap.

One of my 50th birthday presents was a Lovely Lady photo shoot with the wonderful Andrea Denniss of Pink Lily Photography. As exercise and running are a big part of who I am, I just had to have a photo of me in my running gear. I had some more glamorous shots taken as well, including some with my wedding dress (now almost 28 years old), which I was super happy to be able to fit into again. It was lovely to have my hair and makeup done professionally and to feel more like my old pre-cancer self – better actually! I'm looking ahead to my 51st birthday this year and I will definitely be celebrating again!



RELAY FOR LIFE 2019

Have you heard of Relay for Life? 2018 was the first year that this event was held in York and I must admit it was the first time I had ever heard about it. The basic idea is you form teams and the teams fundraise all year round, ending with a 24-hour relay. Last year there were 21 teams and together we raised an amazing £55,000! It was a rather wet, but fantastic event with a lot of fun and a great team spirit.



Relay for Life 2019 is on 3rd & 4th August. So far we have 18 teams signed up, all busy fundraising and we have already banked £30,309.00 between us. The team I am part of is my daughter Rachael's team. It mainly comprises members of RSPCA and Dog's Trust staff and so is called Dog Squad!! As many of you will know Rachael has a brain tumour and so raising funds for research is close to our hearts. We are all working hard and our little team has raised £1650.00 so far. If anyone would like to get involved and/or join our team please contact me for more details; you will be sure to receive a warm welcome: sallyharris160861@gmail.com You can donate to our team via the Cancer Research Relay for Life 2019 website - just search for Dog Squad. Thank you, Sally H.

PRAISE OUR PARTNERS

In this section we want to highlight and give thanks to those companies, organisations and people who have supported us with their time, generosity, kindness and general support of our cause.

Cancer Care Centre, York Hospital

York is very well known for its secret treasures buried below its buildings, unearthed in carparks and hidden in our snickleways, but did you know that the most precious of treasures is hidden in plain sight at York Teaching Hospital. Nestled between the Magnolia centre and the Children's Centre, set back from the road is the **Cancer Care Centre**. Funded, hosted and run by a combination of York Teaching Hospital, Macmillan and York Against Cancer, the Cancer Care Centre is a free to use space and resource which is, in my opinion, seriously under-utilised. It is manned by some really lovely staff who have a real commitment to making the cancer rollercoaster ride a little less nauseating for all cancer patients. There is a seating area which can be used by anyone who has had a cancer diagnosis, their families and loved ones, for meeting up for a chat, waiting for the bus in comfort or having a cuppa and a biscuit before attending an appointment or having tests. There is an extensive information resource here and it is also home to a hair loss department where advice is available on all things hair loss such as a wig cutting/styling service and a hat and headwear shop. It is also here that cancer patients can sign up for free Look Good Feel Better sessions, 6 complementary therapy sessions, register for an oncopsychology appointment and apply for a short break in one of the York Against Cancer holiday apartments in Whitby or Filey. Most of these things need to be referred by your Cancer Specialist Nurse, in our case the Breast Care Nurses, so have a word with the staff in the Cancer Care Centre or your BCN to get the wheels in motion. If you've not already been in, pop in and say hello; tell them that we sent you and enjoy the peaceful surroundings.



SUPPORT FOR WOMEN TAKING HORMONE TREATMENTS

Rachel Bruce, our Vice Chair, attended some workshops about new support for women taking hormone treatment.

Many people assume that after surgery, chemotherapy and radiotherapy are over our medical treatments are finished. However, for many women with hormone receptive cancer there can be years of hormone treatments such as Tamoxifen or aromatase inhibitors (Anastrozole, Exemestane and Letrozole.) These have often been given for 5 years although the guidelines for Tamoxifen are now to take it for 10 years. Common side effects are menopausal symptoms such as hot flushes, night sweats, vaginal dryness, reduced libido and mood changes. Other women may experience brain fog, joint and muscle pain, nausea and fatigue.



Many women find these side effects have a negative effect on their quality of life and therefore stop taking the tablets. This is often done without talking to a GP or Consultant. Women can feel embarrassed about talking about these symptoms, feel that they will be pressured into staying on them or feel guilty that they are stopping a treatment that reduces their risk of cancer returning. In order to try and change this, Yorkshire Cancer Research are trying to find out how many women stop taking the treatments, why they do so and how they can be supported into continuing.

The first workshop was held in York and a group of us got together with a researcher to talk about our experiences of taking hormone treatment. It was quite emotional at times. Many of these side effects can have a big effect on our self-esteem, relationships and sex lives. Many people didn't feel supported or that these side effects are taken seriously by the medical professionals.

The second workshop was held in Leeds. A range of patients, breast care nurses, psychologists and surgeons came together to look at what can be done to support women. The idea is that a psychological intervention will be delivered to increase resilience and help women deal with the side effects. The intervention was introduced as ACT (Acceptance and Commitment Therapy) which aims to teach people acceptance, mindfulness and behaviour-change strategies to increase psychological flexibility. It can't lessen the side effects but might help people approach them differently, so they can continue the treatment. We discussed in groups what we would like from an intervention. The researchers are now going to take all of our ideas and see how they can turn them into an intervention that can be delivered to women soon after they have started to take their hormone treatment. Hopefully it will help them to have strategies that will help them keep taking the tablets. If it proves to be successful, the aim is that the project will be delivered across the country.

MY EXPERIENCE

Radiotherapy

I can't lie, being told I needed radiotherapy scared me, it was the fear of the unknown. However, the staff are brilliant. Even though they do this from dawn to dusk, they never forget that it is new and daunting for you, and do their utmost to relax you. The good thing is that you get to go and look around the unit a week or so before you have your treatment. The room is quite sparse, very clinical, with a huge machine and you are tattooed with three very small dots/guide marks, leaving no margin of error for when you start the treatment. You are shown how they would like you to position yourself and answer any questions.



On the day of your treatment you are asked to undress to the waist and put on a gown. You are allowed to take your own if you prefer. The bed of the machine is cold as you lie on a hard surface. The machine likes to be cool apparently, which is no problem for those of us who have been plunged into menopause. A target shaped light appears on your chest; the staff may well have been bread makers in a previous life, as they gently pummel and knead you into the exact position, with your hands holding on to a bar so as not to tire your arm. You are told to lie lovely and still, and I liked the idea of 'lying lovely.' The staff leave you in the room with music playing. At this point I closed my eyes, concentrated on the music, and pretended to be somewhere else. The machine does all the work, grunting, groaning and whirring as it moves around you. The staff scurry in and out for a second and third kneading, but apart from the chill, that is literally all you feel.

From being called through to undress, to leaving, only takes about fifteen minutes. If someone drops you off to park the car, the chances are you'll be done and in the queue for Costa by the time they come in. I highly recommend a coffee afterwards. There were a couple of bake sales when I went, well worth a look, and you deserve the calories. I was very lucky to cadge a lift on most days, the car park is free with your appointment card. I went on the train a couple of times, and there are several busses from outside the station to take you to the hospital door. You can also get a minibus, arranged through patient transport at the hospital, but this can mean that you wait for others, or they wait for you to finish, adding extra time in the hospital. If you have a late appointment, followed by an early one the next day, you can stay over in the hospital, not on a ward, but in a hotel style room at the top of the hospital. The rooms are basic, but have a TV, kettle and microwave. You check in and out as you would in a hotel. This is a brilliant, free service.

After all your sessions you get to ring the bell, heralding the end of treatment. I found this strangely cathartic. I was quite tired by week three but that could be down to travelling every day after a period of not doing very much. My routine when I got in was to have a warm bath, then apply lashings of body cream to the zapped area. We are told not to buy anything new, just use what your skin is used to.

Now that I'm through it, I can honestly say that, as with a lot of things, the thought is worse than the deed. I applied my new mantra, which is, if I can get through chemo, I can get through anything. Actually, the two don't even compare..... *Sara M.*

NEWS

Live Well York, an information and advice community website for adults and families, has officially been launched!

Check out their Health & Wellbeing section -

<https://www.livewellyork.co.uk/s4s/WhereILive/Council?pageId=4230>



FRIENDS OF BREAST FRIENDS YORK

We have not done all of this alone. We have had the help and support of some amazingly kind and generous people and organisations, without whom we would not be able to exist.

On this page we would like to thank you for being our ‘friends’. Our thanks go out to:

- ❖ York Against Cancer
- ❖ Breast Care Nurses at the Magnolia Centre
- ❖ The Viking Loom, Wigginton Road, York
- ❖ The Cancer Care Centre, York Hospital
- ❖ The Pig&Pastry, Bishopthorpe Road, York
- ❖ Jill Long from the Yorkshire Cancer Patient Forum
- ❖ York Breast Cancer Now
- ❖ Trafalgar Bay, York
- ❖ York Press
- ❖ Sue Cooper at Nicola Jane
- ❖ Jenny at High Hoops
- ❖ Yorkshire Cancer Research
- ❖ Marks & Spencer, Pavement, York
- ❖ Macmillan Cancer Support
- ❖ Marriott Hotel, Tadcaster Road, York

Also, we would like to thank the following individuals and organisations who have supported us:

- ❖ Mel (running coach) Tel: 07930 366077 melaniejelkan@hotmail.com
- ❖ Nancy Passmore for her kind donation.

SUPPORT US



Fancy a challenge? Are you great at cycling, running, climbing or something a little more daring?

Sign up to Localgiving and pledge your donations to us or to simply make a donation go to:

localgiving.com/breastfriendsyork



Do you shop online?
Do it through easyfundraising.org.uk and raise a free donation for us every time you shop online.
No cost, no catch.

easyfundraising.org.uk/causes/breastfriendsyork

CONTACT US

For more information or an informal chat please don't hesitate to contact us:

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