

# INSIDE

Issue of Concern	2
Ask the Expert	3
Member Group profile	13
Thank you	14
Seeking stories	16

Focus on:

Unsung heroes



# the BEACON

Breast Cancer Network Australia's Magazine

Issue 78

Autumn 2017

ISSN 1834-5921

## Unsung heroes

This issue of *The Beacon* pays tribute to the unsung heroes – the people who often have the biggest impact, but receive the smallest reward – the people who make a difference.

BCNA's network is brimming with unsung heroes. From those who volunteer their time and skills, to those who go above and beyond in their role, and those who step up when the time is right.

I don't have to look far to find one of BCNA's unsung heroes. Here in our office in Melbourne, we are very fortunate to have the invaluable support of 30 dedicated office volunteers who provide logistical, practical and administrative support. We could not achieve what we do without the hard work of our volunteers who help us on a daily basis.

As this issue of *The Beacon* goes to print, I am looking forward to meeting many of our unsung heroes at our National Summit on the Sunshine Coast. Every two years, BCNA hosts a summit, bringing together key women



*Christine Nolan (second from left) with BCNA office volunteers Marg, Judy and Carol*

and, this year for the first time, men from around Australia to attend a two-day program. The theme of this year's summit is 'Making a difference'. Delegates will share knowledge and experiences and develop skills to support them in making a difference in the lives of people affected by breast cancer in their communities.

Summit delegates will include Community Liaisons, who speak about their personal experience with breast cancer and represent BCNA in their local communities, as well as our online network champions, and leaders of our peer support groups. Turn to page 13 to read about the great work of one of the support groups in our network.

As we head closer to May (one of the busiest months on BCNA's

calendar) we will see many generous supporters in our community swing into action. From Pink Lady events, to Pink Sports Days and Mini-Fields of Women, many people who themselves have been affected by breast cancer will give back to support the work that we do. Bakers Delight's annual Pink Bun campaign will run from Thursday 11 May to Wednesday 31 May this year. Around the country, hundreds of franchise owners and their staff will donate their ingredients and time to support the campaign, as they do every year. This year's Pink Bun campaign will feature a new way to support BCNA. See page 11 for more information.

As well as the unsung heroes who are enriching our community today, I'd also like to

acknowledge the unsung heroes of yesterday. BCNA was founded on the voices of women, and there have been many women and men throughout our almost two-decade history who have helped to ensure a better journey for all Australians affected by breast cancer.

From making the drug Herceptin available to women through government subsidies in 2001 and again, in 2006, to allowing women to access breast prostheses at minimal cost in 2009, there have been many times when our members have raised their voices and created a better journey for those who will follow.

This year, we are undertaking an exciting project that will shape our organisation and our advocacy efforts for many years to come. See page 4 for more information about the State of the Nation project and how you can have your voice heard.

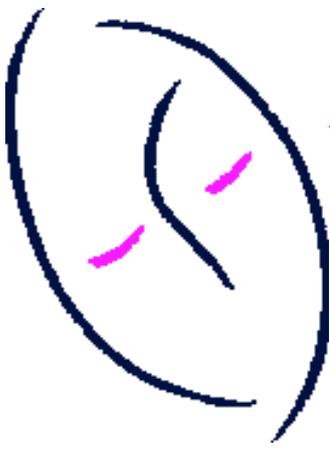
*Christine Nolan  
Chief Executive Officer*

### Subscribe to *The Beacon* online

Help reduce our postage costs by changing to an online subscription.

Visit [bcna.org.au/beamon](http://bcna.org.au/beamon), email [beamon@bcna.org.au](mailto:beamon@bcna.org.au) or phone 1800 500 258.





# Issue of Concern

## Is there a role for immunotherapy in breast cancer?

In the past few years, the rapidly advancing field of cancer immunology has produced several new methods of treating cancer, called immunotherapies or immune therapy.

Immune therapy is a treatment designed to boost the body's natural defences to fight cancer. This can be done by stimulating the immune system to work harder or smarter to attack cancer cells or by adding components, for example synthetic immune system proteins, to a person's immune system.

Scientists first thought of manipulating the body's immune system to attack cancer more than 100 years ago. Making the immune system do that, however, was filled with challenges and setbacks. Before safe and effective immunotherapy could be delivered to patients, the medical community had to build

a better understanding of both cancer biology and the immune system. As research on cancer immunotherapy grew, clinical trials of promising approaches followed one after another.

Many of the advances to date have been in the area of melanoma. For example, you may have heard of the drug Keytruda, an immunotherapy that is extending the lives of some people with advanced melanoma. Immunotherapy is also now being used to treat some other forms of cancer, including prostate, kidney and lung cancer.

Additional research is underway in the field of immunotherapy to:

- understand why immunotherapy is effective in some people but not in others who have the same cancer
- expand the use of immunotherapy to more

types of cancer, including breast cancer

- increase the effectiveness of immunotherapy by combining it with other types of cancer treatment, such as targeted therapy, chemotherapy and radiotherapy.

One of the advantages of immunotherapy over conventional systemic (whole body) treatments, such as chemotherapy, is that it has fewer side effects. This means it may be able to be given for longer periods of time or in combination with other types of treatment without adding toxic side effects. People may also be less likely to develop resistance to immunotherapy.

Historically breast cancer was thought to be less likely to respond to immunotherapy. However, breast cancer is now one of the major cancer types for which immune-based

cancer treatments are currently in development. Clinical trials underway around the world, including in Australia, are investigating the effectiveness of immunotherapy in different types of metastatic breast cancer, including triple negative and HER2-positive metastatic breast cancer. However, it will be several years before results of these trials will provide answers to the question of whether there is a role for immunotherapy in breast cancer and whether these treatments are superior to current treatments.

BCNA will continue to provide more information about the role of immunotherapy in breast cancer as results of clinical trials become available. Talk with your medical oncologist if you would like to learn about any clinical trials that may be relevant to you or you can visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

## New breast cancer drug – we need your help

You may have seen news in the media about a new breast cancer drug called palbociclib (Ibrance). Palbociclib is used to treat hormone receptor positive, HER2-negative metastatic (secondary) breast cancer.

An international clinical trial found that giving palbociclib in combination with the hormone therapy drug letrozole doubles the length of time before the

cancer spreads, from 10.2 months for women who took letrozole only to 20.2 months for women who took both drugs.

This is an exciting development for women with this type of metastatic breast cancer.

While palbociclib is already available in 52 other countries, it is not yet approved for sale in Australia, and so of course is

not listed on the PBS. Australian women who want to use it must currently buy it from overseas, at a cost of around \$10,000 per month.

Palbociclib is currently being considered for sale in Australia by decision makers. BCNA has an online petition to let the government know that this is an important new drug for women

with breast cancer and that it needs to be available in Australia and listed on the PBS quickly so that women who are eligible for it can have access to it.

Help support women living with metastatic breast cancer by adding your voice to our campaign. Visit our website, [bcna.org.au](http://bcna.org.au), and follow the link to the petition.

# Ask the Expert: Reconstruction decisions

Women who need to undergo a mastectomy face the difficult decision of whether to restore breast shape after surgery. The Beacon spoke to Associate Professor Kerry Sherman, Macquarie University, about BRECONDA, an interactive tool developed by Kerry and a team of researchers to help women make decisions about breast reconstruction.

## What is BRECONDA?

BRECONDA is a free, interactive decision-making tool that is now available on BCNA's website. BRECONDA guides women through a series of questions to help decide if a breast reconstruction is right for them. At Macquarie University, we developed the tool with an international team of researchers, clinicians and surgeons. The tool has been created to assist women diagnosed with early breast cancer and also women diagnosed with DCIS (ductal carcinoma in situ).

The decision about whether, and how, to undergo breast reconstruction surgery is difficult and women are often under pressure to make a decision quickly. Studies show that 20–30 per cent of Australian women feel regret following their decision about breast reconstruction. This is often because women are stressed at the time of making a decision and do not have enough information on the sorts of

things they need to think about before deciding.

We wanted to develop an online tool that could help women to make informed choices about breast reconstruction, to feel more confident when having discussions with their surgeon and to feel happier about their decisions.

BRECONDA gives detailed information online about the range of breast reconstruction surgical types available, what they feel and look like, and options for immediate or delayed breast reconstruction. This helps to build realistic expectations and a balanced view about breast reconstruction. BRECONDA is designed to lead you through the decision-making process at your own pace. The questions can be answered from the comfort of home and in your own time.

## How can BRECONDA help me?

The tool will help you learn about the breast reconstruction options available and the advantages and disadvantages of each option. A benefit of BRECONDA is that it offers interactive exercises that help you to clarify your personal values. For example, it can help you identify whether it is important for you to have natural-looking breasts, or whether it is more important to limit the amount of surgery you have. By helping you to identify your values and priorities,



Associate Professor  
Kerry Sherman

decisions about whether to have a reconstruction are guided by what is most important for you and your life.

BRECONDA includes stories from women who have been through this decision-making process. This can help you to weigh up the pros and cons of different options and also show you that you are not alone. Recognising that it can be challenging to make decisions when feeling stressed, BRECONDA also provides simple stress management strategies that can be very helpful.

Another benefit of BRECONDA is that it can help you to talk about your decision with the people you are close to. While BRECONDA is not intended to replace the advice of your breast surgeon, it can help you to have more informed and confident discussions with your treating team. This can also be of benefit for surgeons and specialists, by helping them to feel more informed about your individual needs.

## What if I don't want a breast reconstruction?

BRECONDA is designed to provide you with a balanced picture of the advantages and disadvantages of breast reconstruction and to make choices based on your own personal needs. Whether you choose to have a breast reconstruction or not, BRECONDA can help you in this journey. We have found through our research that women who use BRECONDA as a guide feel clearer and more certain when they make decisions about breast reconstruction. This helps women to feel more satisfied with outcomes, whatever path they decide to take.

## How can I access BRECONDA?

BRECONDA is available free of charge right across the country. You will need access to the internet and will be asked to create a log-in so your responses can be saved and you can come back to the tool later. Visit BCNA's website [bcna.org.au/resource/breconda](http://bcna.org.au/resource/breconda).

BRECONDA will be reviewed regularly by leading surgeons through Breast Surgeons of Australia and New Zealand to ensure it remains up-to-date with the latest research and knowledge. To help us keep BRECONDA a valuable and relevant tool, women who use the tool are encouraged to leave their feedback.

# Improving research, treatment and care

*I have found that researchers do listen to us and take our suggestions on board. The value of having a Consumer Representative involved in research should never be underestimated. – Kym, BCNA Consumer Representative*



*Kym, BCNA Consumer Representative*

Since 1999, BCNA has run the internationally recognised consumer representative program Seat at the Table (SATT).

The program aims to make sure the voices, needs and interests of Australians affected by breast cancer are taken into account wherever decisions are made about breast cancer research, treatment and care.

Through SATT, BCNA recruits, trains, appoints and supports people who have had a

diagnosis of breast cancer to become BCNA Consumer Representatives. There are currently 91 women throughout Australia in the program.

BCNA Consumer Representatives volunteer their time on a wide range of local, national and international projects. For

example, BCNA Consumer Representatives give advice and feedback to researchers who are working to develop new breast cancer treatments or to reduce the side effects of current treatments, such as fatigue or nausea.

BCNA Consumer Representatives also work with health professionals to develop new programs and services aimed at improving people's physical or emotional wellbeing. These may include programs aimed at increasing people's physical activity, programs to reduce people's fear that the cancer may return, or services for those diagnosed with breast cancer when their children are young.

Consumer Representatives also sit on a range of advisory committees. For example, two BCNA Consumer Representatives sat on a Cancer Australia working group that developed clinical guidelines for health professionals about how best to manage menopausal symptoms in younger women affected by breast cancer.

We wish to thank all BCNA Consumer Representatives for their significant and ongoing contribution to improving the outcomes of Australians affected by breast cancer.

You can find out more about Seat at the Table on our website, [bcna.org.au/satt](http://bcna.org.au/satt).

## State of the Nation project

BCNA turns 20 in 2018. We are already thinking about how we will celebrate that milestone and look forward to sharing our plans with you later in the year.

Ahead of that anniversary, however, we are undertaking an important project – State of the Nation.

State of the Nation is gathering information about the treatment and care Australians affected by breast cancer receive. We want to know where the gaps are and who is missing out. We'll compare the different states and territories to find out which

are doing well and which need to do better. We will use this information to put pressure on governments and health services to improve their services.

We will also be able to see just how far we have come in our 20 years of consumer advocacy.

The project will be led by the voices and experiences of our members. Thank you to those who have already completed our online Member Survey. If you did not complete the survey in February, then you still have a chance. Visit our website, [bcna.org.au](http://bcna.org.au).

State of the Nation will provide us with a very clear direction for our future advocacy campaigns, but we cannot do it without you. We need your help to ensure the system works best for everyone affected by breast cancer.

As Missy Higgins writes in her 'Hidden Ones' song:

*'Cause they made a choice  
Not to follow the leader  
But use one voice  
Shows ordinary people  
Can make a really loud noise  
When the hidden ones speak up*

How can you get involved in State of the Nation?

1. Complete the online survey at [bcna.org.au](http://bcna.org.au).
2. Look out for a BCNA information forum or consultation in your local area – we will be visiting various locations across the country.
3. Join the BCNA online network and join in the conversation.
4. Join our Review & Survey Group to participate in other research projects.

# The financial cost of breast cancer

Over the years, many women have spoken to us about the out-of-pocket costs related to their breast cancer diagnosis and the impact this had on them and their families.

BCNA has recently undertaken a major project to investigate the financial impact of breast cancer. We employed the consultancy firm Deloitte to survey members about their out-of-pocket costs related to their breast cancer, and we interviewed a number of women about their personal stories.

We were overwhelmed with the response to the survey, with almost 2,000 people participating. It indicated to

us what a huge issue this is for some of you.

Results of the survey showed that out-of-pocket costs can vary considerably, even for people who have similar treatments. Breast surgery, particularly breast reconstruction, had the highest out-of-pocket costs, with some women telling us they paid up to \$18,000 for their reconstruction. Women with private health insurance reported greater out-of-pocket costs than those who had their treatment in the public health system.

We were surprised to find that people living in rural areas had a similar amount of out-of-pocket

costs to those living in cities. The survey showed, however, that rural people tend to have less treatment – so are in fact paying more for less. The survey also showed that the financial impact on rural families is greater because their household income is often lower than that of city families – so their out-of-pocket costs represent a higher percentage of their household income.

The study also found that many people have:

- faced difficulties with their workplace
- relied on family and friends for financial assistance

- experienced problems getting payments through superannuation, income protection or other insurance
- experienced changes to their long-term financial plans and goals.

BCNA will use the findings of this project to continue to lobby governments and others to reduce the out-of-pocket costs related to breast cancer.

The project report will be launched later in the year and published on our website, [bcna.org.au](http://bcna.org.au).

BCNA thanks everyone who participated in the survey and interviews for this project.

## For benefit, not for profit

*The Beacon* sat down with Barry Frost and John Hurley from For Benefit Medicines (FBM) to learn more about what motivates these unsung heroes to give back to those with breast cancer.

Regular readers of *The Beacon* will know that FBM has an agreement with BCNA where 50 per cent of all profits made from the sale of two breast cancer drugs (Anastrozole FBM and Letrozole FBM) are donated to BCNA to help us support Australians affected by breast cancer. The remaining 50 per cent is donated to Breast Cancer Institute of Australia to fund research into breast cancer treatments and hopefully a cure.

Barry and John say it all began 20 years ago when they met through a local baseball club.



*John (left) and Barry presenting a cheque to BCNA Chair Kathryn Fagg (left) and BCNA CEO Christine Nolan*

During a post-game drink, they came up with the unique business model that later became FBM. Rather than profits from the sale of drugs being sent overseas to parent companies and shareholders, Barry and John asked themselves 'Why shouldn't the money instead

go to improving the health of Australians?'

Barry and John were motivated by their wish to make a genuine difference on a large scale, and were stimulated by the challenge of creating a profitable business that could give back as well as be an industry 'game

changer'. Barry also had a personal motivation, as someone close to him had been diagnosed with breast cancer.

Although breast cancer is the first disease to benefit from the FBM business model, their long-term vision stretches much further. In the future they hope to help those with leukemia, cystic fibrosis and multiple sclerosis, as well as perhaps adding another breast cancer drug to their brand.

Barry and John are modest when they say, 'This can't be successful without the patients and the doctors ... the patients are the real unsung heroes because they are the ones believing in us and supporting the idea ... if they get behind us then we can change the world!'

# Top breast cancer discoveries of 2016

The past 12 months have been an exciting time for breast cancer research around the world. We recently showcased our top 10 pick of cancer discoveries of 2016 on our website, [bcna.org.au](http://bcna.org.au). We shortlisted these discoveries for their contributions to treatment breakthroughs, breast cancer prevention and improvements in the quality of life of Australians diagnosed with breast cancer.

Here, we feature our top four picks from the past year. We are optimistic that the discoveries being made will provide hope to all those living with breast cancer and to the 17,586 women and 144 men expected to be diagnosed in 2017.

## 1. Blood test may help predict when a cancer is returning

New research shows that a blood test might accurately predict the return of cancer in people who have been previously treated for early-stage cancers. The blood test, also known as 'liquid biopsy', looks for cancer DNA in the bloodstream from cancer cells that have resisted treatment.

## 2. Scalp cooling systems can help reduce hair loss during chemotherapy

New research has shown that a scalp cooling system can reduce severe hair loss by 50 per cent in some women who are going through chemotherapy. Some oncology clinics offer women access to new scalp cooling

systems. These involve wearing a silicone cap, which slowly fills with a gel coolant and keeps your head cold during your treatment. This is promising news for many women facing hair loss, a distressing side effect of some forms of chemotherapy.

## 3. Research shows personalised exercise programs can help with treatment side effects in early breast cancer

An Edith Cowan University study has shown that personalised exercise programs can help reduce side effects of treatment in people with early breast cancer. The research shows that moderate-intensity, supervised exercise can increase energy levels, help reduce nausea and muscle loss, and may help some

people to recover faster. The findings were presented on the ABC's *Catalyst* program last year.

## 4. New treatment for hormone receptor positive, HER2-negative metastatic breast cancer

The PALOMA2 clinical trial has found the new breast cancer drug palbociclib (Ibrance) to be an effective new first-line treatment for hormone receptor positive, HER2-negative metastatic breast cancer when used in combination with the hormone therapy drug letrozole. See page 2 for more information.

For the full list of our top breast cancer discoveries of 2016, visit the latest news section of our website at [bcna.org.au](http://bcna.org.au).

# When breast cancer has spread

Hearing that your breast cancer has spread can be devastating. The emotional, practical and medical challenges that follow are different for every person and add to what is already a very challenging diagnosis.

BCNA's *Hope & Hurdles* information pack provides detailed information to help you cope with this diagnosis and to make decisions about your treatment, care and wellbeing. It includes information on treatments, managing side effects and looking after yourself emotionally. There is information specifically for those whose first diagnosis of breast



BCNA's *Hope & Hurdles* pack

cancer is metastatic breast cancer, for men diagnosed with metastatic breast cancer and for young women diagnosed with metastatic breast cancer.

*Hope & Hurdles* also includes practical tips and advice from others living with metastatic disease to help you live well.

A number of optional booklets are designed to provide information that is specific to your type of breast cancer. These include booklets on:

- the four main sites of metastases (bone, liver, lungs and brain)
- the three main subtypes of breast cancer (HER2-positive, hormone receptor positive and triple negative).

There is also a booklet with practical advice to help you plan ahead.

Booklets can be ordered with your *Hope & Hurdles* pack right from the start or later if/when you need them.

To order a copy of *Hope & Hurdles*, visit our website [bcna.org.au](http://bcna.org.au) or call us on 1800 500 258.

*What a brilliant read! Not only did I learn a few more things about my cancer, but my husband found it very interesting also. I think it hits the spot. Not too overwhelming and covers lots of medical questions that I know I have had in the past.*

– Sonia

# Someone to talk to

Our members often tell us that their breast cancer diagnosis made them feel isolated and alone. At these times, we know how valuable it can be to simply be able to pick up the phone and talk. The reassurance of a voice on the end of a telephone can go a long way.

In early March, we extended our Helpline hours to 9.00 pm (Australian Eastern Standard Time) on Tuesday and Thursday. So if you're at work or busy with children during the day, you can now connect with us outside of business hours.

BCNA's Helpline is available to support everyone affected by breast cancer, at any stage in their journey. Whether you've just been diagnosed or you're supporting someone

else through a diagnosis, the Helpline team can provide you with information about breast cancer and issues that may be concerning you.

The team can also talk to you about concerns that you may be experiencing because of your breast cancer diagnosis, and can refer you to supports available to assist you.

You can contact our Helpline team on 1800 500 258 between 9.00 am and 5.00 pm on Monday, Wednesday and Friday, and between 9.00 am and 9.00 pm on Tuesday and Thursday. Out of hours you can leave a voicemail and we'll call back when we're next open.

Calls are free from landline phones anywhere in Australia.



BCNA Helpline team

Callers using mobile phones pay a rate that is determined by their mobile service provider.

If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service and ask to call Breast

Cancer Network Australia on 1800 500 258. If you need an interpreter, phone 13 14 50.

Please note that BCNA's office will observe daylight saving time until Sunday 2 April.

# Fear that cancer may come back

*In the beginning, the support is there more; from the medical profession, friends are still attentive, family are there every moment and therefore you feel quite safe ... but now, years down the track, you are like everyone else; the only difference is you HAD cancer. I think that as time goes on we can feel quite alone and frightened without really realising it. – Robyn*

We know that many people who have had breast cancer worry that their cancer may one day

come back (recur). This is a very normal response to a cancer diagnosis.

Being fearful that your cancer might return can affect your quality of life, your relationships (including with your medical team), and the way you think about and plan for the future.

BCNA has developed a range of resources to help identify and manage fear of breast cancer recurrence. The range includes a series of short videos and a fact sheet with practical tips and coping strategies.

The videos feature information from a woman diagnosed with breast cancer about how she manages her fear of recurrence. There are also videos from an oncology social worker who supports people dealing with fear of recurrence issues, and a leading breast surgeon.

*It can feel very isolating. You go from having nurses that you're seeing regularly and people ringing to see how you are, and then it feels like everyone has gotten on with their life. – Carrie, oncology social worker*

The videos are available on our website, [bcna.org.au](http://bcna.org.au), and our YouTube channel. You can download or order a copy of the fact sheet from our website or by phoning BCNA on 1800 500 258. You can also connect with others who have experienced breast cancer and learn how they cope with fear of recurrence by joining our online network. Visit [onlinenetwork.bcna.org.au](http://onlinenetwork.bcna.org.au).

## Assurance at a time of uncertainty

I finished up at my job and had a week off before starting my new job. On the Monday, I went for my routine breast screen appointment, and after a biopsy later that week I was diagnosed with early breast cancer.

Due to my family history, it was decided that I would have a bilateral mastectomy. I called my new employer Healthcare Australia (HCA) and informed them of this and offered for them to give the job to someone else, as I could not start when arranged and my future was uncertain.

They did not hesitate in keeping the job for me, allowing me to come in before my surgery to start to learn the job. They helped me feel a little normal and provided great support.



*Dianne (centre) with her colleagues*

I then went off and had my surgery, and required two weeks longer off than expected. Again, I called HCA and offered for them to employ someone else and again they were great, telling me to take my time, get better and return when I could.

This support at such an emotional and uncertain time was brilliant. Given that I was an unknown entity to them and could provide no certainty about my future, their support of me, and ultimately, my family, was superb. At a time when nothing

else about my future was what it once was, my sense of self had taken a hard battering, and myself, my husband and two boys were experiencing emotional turmoil, knowing I had a job when I was ready was the only certainty.

I was lucky – no chemo, no radiotherapy – just the dreaded oestrogen blocking drugs. I am now working at HCA and loving it because I am surrounded by great people, which is no surprise given how well the place is managed from the top. Knowing my job was here was a key contributor to my recovery and return to a 'normal' life.

*Dianne, VIC*

## My long-distance lifeline

I was diagnosed with breast cancer at 37. That 7 cm lump changed my 2016, often for the worse, but in many ways, for the better.

At the time, my family life was chaotic, work was stressful and I struggled where my priorities should be focused. If this wasn't enough, along came cancer to test my strength and push me to the edge.

But, this story shouldn't be about me. It is about another amazingly strong woman, a nurse and a breast cancer survivor herself, who gave me love and support while I went



*Jessica (left) and Beth*

'down the rabbit hole' that was cancer treatment.

Beth is my husband's auntie. I hadn't had a lot of contact with her before my diagnosis because she lives interstate. As soon as she heard, she reached out to me.

Beth was with me from day one of my diagnosis, despite living over 2,000 km away in Hobart. She called me, listened to me through my tears, understood my fears and helped me make sense of all the information I was being bombarded with. She even shaved her head prior to us catching up after I started chemo! Beth was more than just someone to talk to who understood cancer – she understood me, and how cancer would inevitably change me.

Every day I received a beautiful text message from Beth – a thoughtful quote and message. I

received weekly cards of support and a care package of gifts at each milestone. These thoughtful gestures got me through, lifted my spirits and kept me fighting when all energy seemed lost.

If this was not enough, at the end of my treatment, Beth sent me a 2016 diary – each day filled with every message she had sent me, as well as a photobook of pictures I had sent her during my year.

Beth taught me that kindness and love means the most in my life – she has helped make me a better person for my family and loved ones.

*Jessica, QLD*

## A hero twice over

My father has done the job of being 'unsung hero' at least twice in his life. Firstly, with my mother who died of breast cancer back in 1982, and then myself nine years ago.

With his army boarding school upbringing in the colonies, he was not emotionally equipped for an experience requiring emotional stamina. However, that did not stop him from finding previously unknown personal resources. He dug deep and unstintingly offered the willingness and tenacity to stick out the hard yards and give support when it was needed.

My mother feared dying alone in the hospital and my dad knew the words she needed to hear, 'But you will have stamped on your forehead "Belongs to Jim".' Those words gave her the much-needed courage to face her mortality, knowing he was by her side.

When it was my turn, he sat in on the doctor's appointment as I got my diagnosis. After the doctor left the room, he held my hand and said, 'I haven't done this since you were a little girl!' He then happily paid for and joined me in having a very



*Zeb with her father Jim*

expensive double scotch at the nearest motel at 11.00 am.

My dad continued to be a source of support. He would drive from Phillip Island, where

he resides, to see his second wife, who had had a back operation in Melbourne, then to take me to surgery in Traralgon from my place in Foster.

He was also prepared to jump over the desk and grab the surgeon by the throat for taking so long to give the final results of the surgery. He continued his support through my radiation treatment over in Traralgon. All this was done without complaint, by a man who was 82 at the time. My dad, my now sung hero!

*Zeb, VIC*

## My light through the darkness

I was 36 when I was diagnosed. The news didn't surprise me, but my age and the timing in my life did surprise me.

Both my grandmothers had breast cancer, and when my mother had breast cancer when I was 30, I went and got gene tested. I came back negative for BRAC1 and BRAC2 and was told that I was back in the general population of statistics of getting breast cancer. So I went about my life thinking I would most likely get breast cancer, but after menopause like the general population.

At 35, I gave birth to the most beautiful and wonderful gift of my life – Skyler Jade. I breastfed her for eight months, enjoying

this most magnificent time, not even considering breast cancer as a possibility at that stage of my life.

Two weeks after I stopped breastfeeding, I not only felt, but also saw, a huge lump in my breast. Ductal adenocarcinoma, stage II, oestrogen receptor positive (ER+) with lymph node involvement.

I had four rounds of chemo and a bilateral nipple-sparing mastectomy with axillary clearance. I am currently going through 25 sessions of radiation. The one person that kept me going and made the biggest difference in my journey was my precious little girl.



*Julie and her daughter Skyler Jade*

I described her as my therapy, my medicine, during some very sick days with chemo. She was my reason for fighting. Although

it was challenging at times, she certainly made the days and long nights better, just with a smile or by watching her learn to walk, talk, play and cuddle. It was magic and light at a time of my life when some moments were dark.

I was desperate to protect her from what was happening to me and be as normal as possible around her, which many breast cancer survivors can relate to.

Having a strong reason to survive and protect gives the strongest reason to cope, stay positive and not allow cancer to win. Fight like a girl.

*Julie, NSW*

## At last, someone who understands

In April 2015, my world just crumbled. I was 66 years of age. After being treated since January for a breast abscess, being told the news I had breast cancer was absolutely devastating.

Having moved from New Zealand in 2012, my support network wasn't here. My husband and two adult children were here, but they didn't seem to understand at all why I was so upset. I felt trapped like a rabbit in headlights with nowhere to run.

There were many tears, and many sleepless, fearful, disbelieving nights. I felt I was spiralling downwards, all alone. I tried to tell my family, but they



*Diana*

just didn't understand my feeling of devastation of losing a breast. I found a wonderful surgeon

who agreed to put an implant in immediately, as I knew I would never cope with having nothing there.

I found it really difficult to come to terms with my new body shape. Thank goodness for the Sunshine Coast Breast Cancer Support Facebook group. When I asked if I could meet a woman who had been through what I had, as I wasn't coping mentally, they found me someone. I so needed to be able to talk to someone who wouldn't dismiss my feelings.

Oriana and I met over coffee. We talked, well, I mostly talked, and we even cried together. She has been my saviour. At last there

was someone who understood what I was going through, and could advise and empathise.

It was so gratifying to know how I was feeling was normal. After meeting Oriana, I felt so much better and calmer within. We now meet regularly and I thank her every time for being so patient and understanding with me and for being so supportive.

It has helped me enormously to speak to her face-to-face. I am still struggling with my image, but I am slowly coming to terms with it all. I just have to learn to love the new me.

*Diana, QLD*

## Pink Lady AFL Football Match

### Help turn the MCG Pink!

Following the success of last year's Pink Lady Match, BCNA will be partnering again with the AFL and the Melbourne Football Club to host a dedicated match to support Australians affected by breast cancer. The match will be held on Sunday 7 May at 3.20 pm when the Melbourne Football Club will take on traditional rivals, Hawthorn.

With the support of BCNA's Major Event Partner Red Energy, our aim is to turn the MCG pink and bring families together to pay tribute to Australians affected by breast cancer and to those loved ones who have lost their life to the disease.



There will be thousands of Pink Lady silhouettes planted in Yarra Park just outside the MCG, and all visitors to the match are welcome to write a personal message of support for someone affected by

breast cancer and display their message on a silhouette.

Regardless of which footy team you barrack for, you can support BCNA by purchasing a general admission ticket to the game,

coming along and sitting in our dedicated Pink Lady Bays, or alternatively purchasing a ticket to the Pink Lady Match Exquisite High Tea held in the Harrison Room at the MCG on the day.

General admission is \$25. Tickets to the Pink Lady Match Exquisite High Tea cost \$125 and include a ticket to the game. Purchase tickets online at [bcna.org.au](http://bcna.org.au).

All funds raised will go directly to support BCNA's programs and services.

Keep an eye on BCNA's website and Facebook page for further information and regular updates. We'd love to see you there!

# Help us give breast cancer the finger bun

Once again, this May all of the Bakers Delight bakeries around Australia will come together to host the annual Pink Bun campaign. In 2017, the campaign will run from Thursday 11 to Wednesday 31 May.

This year we celebrate 17 years of our partnership with Bakers Delight. During the campaign, 100 per cent of the sale of Pink Buns and Pink Lady silhouettes comes directly to BCNA.

The Pink Bun campaign not only raises funds to help us provide a better journey for all Australians affected by breast cancer, but also raises awareness of the support that is available in local communities for women and men and their families affected by breast cancer.

Jumping on the Pink Bun bandwagon and helping us

reach our \$1.5 million target is as easy as:

- regularly visiting your local Bakers Delight bakery during the campaign
- developing a craving for Pink Buns and purchasing them often
- telling all your family and friends to purchase Pink Buns too
- writing a message of support on a Pink Lady silhouette in the bakery
- putting a donation in the Pink Bun tin on the counter
- liking your local bakery on Facebook
- going into the bakery and thanking them at the end of the campaign.

You can also get your workplace, school, social or community group involved with a Pink Bun Party, such as a morning or afternoon tea. Register your Pink Bun Party at [bcna.org.au](http://bcna.org.au) or by calling 1800 500 258. We have everything you need to turn your party pink.

The Pink Bun campaign is a wonderful opportunity for you to be involved with both your local community and your local Bakers Delight bakery. Your generosity ensures we're here to support the 17,586 women and 144 men expected to be diagnosed with breast cancer this year.

To find your nearest Bakers Delight bakery, visit [bakersdelight.com.au/BakeryLocator](http://bakersdelight.com.au/BakeryLocator).

## A new way to support Pink Bun

We are very excited to reveal the new BCNA tote bag, hot off the production line! The bags will be available for \$5 from all Bakers Delight bakeries during the Pink Bun campaign.



## The importance of being 'normal'

I was having a pretty regular life. We were about to move cities for a 12-month contracting opportunity, but we were stopped dead in our tracks when, after a routine medical check-up, I was diagnosed with breast cancer in August 2013. It was only when six little words were uttered so routinely, clinically and confidently, 'You will lose all your hair,' that I realised the enormity of what faced me. My oncologist went on to explain my treatment, but I

didn't hear any of it. It wasn't the diagnosis or the prognosis that scared me, it was the thought of losing my precious hair.

I knew I could handle the treatment, but losing my hair, my identity, this would test me. I was going to be exposed. I felt so alone. I turned to Darrell, my hairdresser friend, who helped me put a plan in place. I had faith that he would know what to do. I wasn't going on this ride alone.

We made an appointment to go wig shopping and I entered

a whole new world of hair! All shapes, colours and styles. Then I spotted her – the perfect style. A blondish bob, right length and even with a touch of regrowth. I tried it on – a perfect fit. Yes! I had a wig.

Twenty days after my first chemo treatment, my hair started falling out. Darrell said it was time to take the first step – a super short cut. I went to his studio. One of my friends came for moral support. The next cut a few days

later was even shorter. This time Darrell came to my house.

The weeks and months stretched on. My treatment finished. Little tufts of fluff appeared on my head. Eventually more hair. It was different hair, but it was my hair.

Darrell's support throughout my journey meant the world to me. I am now loving my short, blonde, cropped look. I won't be going back to long hair and I never complain about a bad hair day!

Kerry, WA

# Fernwood rises to the challenge

Since 2015, BCNA has partnered with Fernwood Fitness to improve the health and wellbeing of women diagnosed with breast cancer. We are very excited to announce that this year Fernwood is making a long-term commitment to BCNA and all that we do by becoming a Major Partner.

In November, Fernwood Fitness clubs set out to raise \$100,000 for the second year running with the 100k for BCNA campaign. We were overwhelmed and delighted when they exceeded that target and raised an incredible \$128,000.

From 100 km treadmill challenges to bake-offs and raffles, it was fantastic to see Fernwood

members from all across the country come together to show their support for Australians affected by breast cancer.



Fernwood Penrith

Fernwood continues to offer all BCNA members a fabulous discount off Fernwood memberships, where you will not pay a joining fee and you will also receive 15 per cent off memberships.

To find a Fernwood Fitness club near you, visit [fernwoodfitness.com.au](http://fernwoodfitness.com.au) or call 1300 FERNWOOD (1300 33 76 96 63).



Fernwood Belconnen

## Revitalise with BCNA

We are very pleased that Revitalise with BCNA will continue in 2017. This six-week online health and wellbeing program is designed for women who have completed their active (in hospital) treatment for breast cancer.

You can access the program from your home and receive customised advice from breast cancer experts on goal setting, motivation, healthy eating, exercise, mindfulness and meditation. There are meal and exercise plans, shopping lists and ways to connect with other women doing the program.



Revitalise with BCNA costs \$87, which is donated directly to BCNA, and includes a free month's membership at your local Fernwood.

To sign up or find out more, visit [revitalise.bcna.org.au](http://revitalise.bcna.org.au).

## Mother's Day all wrapped up

Regular readers of *The Beacon* may remember that in November long-time BCNA partner Sussan proudly launched a beautiful new gift bag range in support of BCNA. The gift bags were a hit over the holiday season. With Mother's Day just around the corner (Sunday 14 May) we are delighted that the gift bags will continue to be sold in Sussan stores throughout the year. The gift bags are available in two sizes, with two stunning prints to choose from. The small bags are \$2 and large bags \$3.

For every gift bag sold, \$1 will be donated to BCNA. Visit [sussan.com.au](http://sussan.com.au) or call 1300 363 351 to find your nearest store.





# Profiling our Member Groups

## Metastatic Breast Cancer Telephone Support Group

Cancer Council NSW runs a telephone support group for women with metastatic (secondary) breast cancer. Cancer Support Consultant Gabrielle Asprey shares with *The Beacon* how this unique support group is connecting women with a shared experience.

Metastatic breast cancer is when cancer cells have spread from the original cancer site in the breast to more distant parts of the body. A diagnosis of metastatic breast cancer brings a range of unique emotional, medical and practical challenges.

Some women find that they can't get the support they need in their local support group, where they are often the only one living with metastatic breast cancer. Others can't attend a traditional face-to-face support group because they live in a remote area or have physical limitations due to their disease or treatment. In 2006, Cancer Council NSW began offering a telephone support group for young women (aged up to 55) with metastatic breast cancer. In early 2013, the group was opened up to include all women with metastatic breast cancer.

Our members are women from all walks of life and from all over Australia. The group 'meets' on the second and fourth Tuesdays of each month from 1.30 pm to 2.30 pm. Participation is flexible, so the group members can skip sessions when they need to.

There is no cost to participate and women can join the call from



*Group facilitators Gabrielle Asprey, Sally Carveth and Kim Pearce from Cancer Council NSW*

the comfort of their own home, or any location of their choosing. The telephone meetings are facilitated by qualified health professionals who are experienced in supporting people affected by cancer.

The group gives members a place to discuss topics that they wouldn't necessarily talk about with their family or friends, such as the ups and downs of scans and waiting for results, living on tenterhooks or dealing with uncertainty.

The facilitators and the group members place a great deal of importance on confidentiality of discussion. This means the women can openly talk of the trials, tribulations and positive aspects of living as well as they can. Being able to talk to others who really 'get' where you're at is incredibly beneficial.

Group members discuss the myriad of changes that occur over time when living with metastatic disease, like having to give up work, physical restrictions, finding out what's important to them in

life and how to live to the best of their ability.

As well as providing emotional support, the group also includes practical discussions, where women share knowledge and first-hand experience of things like palliative care and accessing superannuation early. Participants draw on the strengths and knowledge of other group members, share practical tips and learn new coping strategies.

Our aim for the group is to strengthen the members' capacity to help themselves and each other by reducing feelings of isolation and sharing coping strategies and problem-solving skills. By speaking with others who face similar challenges, the women are also able to enhance communication with their family members and friends.

If you would like more information, or to join the telephone support group, call Cancer Council on 13 11 20 or email [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au). You do not have to live in NSW to join the group.



## Connecting people

A key part of BCNA's mission is to connect Australians personally affected by breast cancer.

We welcome new Member Groups to our network. They now total 288.

New Member Groups:

- Geelong and Bellarine Breast of Friends Cancer Support Group, VIC
- Pink Persisters, VIC

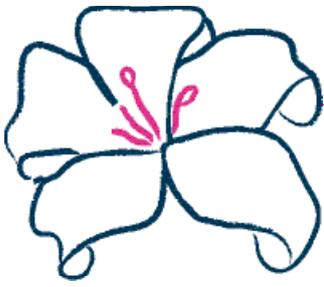
To find a support group in your state or territory, visit [bcna.org.au](http://bcna.org.au).

If you can't find a face-to-face support group in your area, considering joining our online network. Connect with hundreds of others talking about:

- what it's like to be newly diagnosed
- undergoing treatment
- breast reconstruction options
- living with metastatic breast cancer
- getting active and well again.

For more information, visit [bcna.org.au](http://bcna.org.au), or phone 1800 500 258.

*I cannot tell you how much positive information, comfort, relief, knowledge and peace of mind I have already gained from being a member of this site.  
– online network member*



# Thank you

Thousands of generous supporters across Australia donate their time and money to support BCNA. We would especially like to acknowledge significant contributions recently received from:

- 8 Days Café, VIC
- Alexandra O'Brien, VIC
- Blairgowrie Yacht Squadron, VIC
- BLC Cosmetics – Penelope Wood, NSW
- Carol Finley and Teresa Ellis, VIC
- Coburg Football Club – Mary-Anne Blair, VIC
- Corryong IGA Plus Liquor – Robyn McGowan, VIC
- Dandenong Eisteddfod of Dance – Sheila Daniells, VIC
- Elza Semsarian and Cynthia Hartman, NSW
- Geelong Touring Cyclists – Heather Christmas and Pam Morrow, VIC
- Intact Projects Pty Ltd – Nick Staniscia, VIC
- Ivoclar Vivadent Australia – Joanna Greenham, VIC
- Jog for Jugs Australia – Peta Burton

- Just 8's Car Club Sunshine Coast – Stuart Forsyth, QLD
- Lorelle McAndrew, QLD
- Lynda Wong, VIC
- Mataya Hodgetts, TAS
- Middy's Frankston, VIC – Leigh Masterson
- Narre Warren South P-12 College – Kelly Lackmann, VIC
- Pamela Schramm, QLD
- R15 Lifestyle Village – Jennifer Preston, VIC
- Sandringham Royals Baseball Club, VIC
- Sarah Kidd, VIC
- The Valley Private Hospital – Lee Alexander, VIC
- Thirteenth Beach Golf Links Ltd, VIC
- TJs Pirie Gourmet Meats – The Hairy Butcher – Tony Marshall, SA
- U Rod/Harley Owners Melbourne – Frank Andriuli, VIC
- Ultimate Finance Group/ Beaconsfield Cricket Club – Marty Oke, VIC
- UTas – Jett Karolewski, TAS
- Vapiano – Chris Bassett, QLD/ NSW/VIC

- Victorian Polo Club – Alfa Romeo Ladies' Day, VIC
- Vivien Brass, VIC

## Brave for BCNA team

- Alison Neilson, VIC
- Amanda Whitby, VIC
- Anita Parsons, NSW
- Arlene Garrity-Komp, VIC
- Belinda Macaulay, NSW
- Casey Churchill, NSW
- Colette Haymes, VIC
- David Jones, NSW
- Donna Shetty, QLD
- Jen Murray, VIC
- Jenny Haitidis, VIC
- Judith Thomson, VIC
- Karen Samuels, WA
- Kate Pallone, NSW
- Kerry Graham, NSW
- Leanne Jessop, QLD
- Linda Carrad, QLD
- Megan Kemp, WA
- Reagan Pabis, NSW
- Rebecca Danton, VIC
- Renee Pallone, NSW
- Sally McConachy, NSW

- Samantha Hogan, QLD
- Wendy Thom, VIC

## Memorials

We pay tribute to the lives of:

- Evelyn Swanson, QLD
- Glenda Terry, QLD
- Jody West, SA
- Kathleen Rooney, VIC
- Mary Atkinson, SA
- Melissa Parker, SA
- Sally Crisp, VIC
- Sandra Kenyon, VIC
- Suzanne Maguire, VIC

We are grateful for the donations we received in their memory.

## Celebrations

Thank you to those who celebrated a special occasion and asked for donations to BCNA in lieu of gifts:

- Barbara Hall, VIC
- Christie and Ron Vanderloo, SA
- Maddaiena Franfiosa, QLD
- Tina and Sunil Purba-Pajnoo, NSW

# A new partnership with Reflex

We are thrilled to welcome a new Major Partner to the BCNA family. Australian Paper has been supporting BCNA for more than 10 years, with more than \$1 million worth of paper donated so far.

This year, Australian Paper decided to do more to support BCNA through its brand Reflex. To launch the partnership, Australian Paper hopes to sell

1.5 million specially marked reams of Reflex Carbon Neutral Ultra White paper, with 10 cents from every ream donated to BCNA.

We hope the specially marked reams will not only raise money, but awareness of the support that BCNA provides. The packaging features the stories of four of our members – Heather, Helen, Julianne and Ryan.

We thank Australian Paper for their enthusiastic support and for again supplying all the paper for this edition. *The Beacon* is printed on Australian-made Revive 100 per cent recycled carbon neutral paper.

To find a Reflex stockist near you, visit [reflex.com.au](http://reflex.com.au) or call 1800 REFLEX (1800 733 539).



# Carman's Women's Fun Run



## Pink Lady Merchandise

*Show your support. Shop Pink in 2017!*



\$5

Five Pen Pack

\$30



Vanilla Soy Candle

\$15



Pink Lady Notebook

\$15



Pink Cap

\$15



Navy Visor

For more pink items visit [bcna.org.au](http://bcna.org.au) or call 1300 020 850



## Dates for your diary

**26 April** – Free BCNA information forum in Cairns. For more information and to register, visit [bcna.org.au](http://bcna.org.au) or call 1800 500 258. BCNA will host a number of forums around Australia throughout the year. Keep an eye on our website for details.

**7 May** – Pink Lady Match. Melbourne vs Hawthorn at 3.20 pm at the Melbourne Cricket Ground (MCG).

**11 May – 31 May** – Pink Bun campaign. Visit your local Bakers Delight bakery to show your support.

**September/October** – Pink Lady Luncheon series in Adelaide, Brisbane, Canberra, Melbourne and Sydney. Tickets go on sale later in the year.

**13 October** – Metastatic Breast Cancer Awareness Day.

### Challenges for you, your family and friends

BCNA is supported by fundraising participants in various fun runs. These events are a great opportunity to keep fit and healthy, achieve your personal best, challenge yourself or your friends, and raise money for BCNA. For more information, visit the websites listed below, email [fundraising@bcna.org.au](mailto:fundraising@bcna.org.au) or phone 1800 500 258.

**17 September** – Blackmores Sydney Running Festival. Sydney. [sydneyrunningfestival.com.au](http://sydneyrunningfestival.com.au).

**28-29 October** – Ride Daylesford. Cyclists will ride this inaugural event through the beautiful countryside of Hepburn, Macedon Ranges and Mt Alexander. Keep an eye on our website for details.

**3 December** – Carman's Women's Fun Run. Melbourne. [carmanswomensfunrun.com.au](http://carmanswomensfunrun.com.au).

### Trek all the way for BCNA!

Discover the secret south of New Zealand with BCNA. Arrive in Queenstown before heading off and trekking through Milford Sound, Mt Aspiring Hut and Ohau Range, while taking in the beautiful views, waterfalls, lakes and valleys that New Zealand has to offer.

The best part is knowing that with every step you take, you are supporting Australians affected by breast cancer.

#### Fast facts

**Dates:** 23 February 2018 – 4 March 2018

**Registration fee:** \$770 (non-refundable)

**Fundraising target:** \$4,000 (excludes travel)

**Travel cost:** \$3,950 (land only)

**Trip duration:** 10 days

**Challenge duration:** 6 days

**Challenge grade:** 3/5

**Accommodation:** Hotels and basic accommodation

**Minimum age:** 16

For more information or to register your interest visit [inspiredadventures.com.au/events/BCNA-NZ-Trek-2018](http://inspiredadventures.com.au/events/BCNA-NZ-Trek-2018)

## Seeking stories – breast cancer at any age

Facing breast cancer is never an easy thing, no matter what age you are. For the Spring 2017 issue of *The Beacon*, we'd like to know what it was like to be diagnosed at your age. What problems did you face? If you

were a young woman, perhaps you had to consider fertility. If you were an older woman, perhaps you lived on your own and would have liked more support. Stories should be about half a page long (200–300 words)

and can be posted to BCNA, 293 Camberwell Rd, Camberwell VIC 3124 or emailed to [beacon@bcna.org.au](mailto:beacon@bcna.org.au) by the end of June 2017. Please also include a high-resolution photo.

### BCNA Partners

Foundation Partner



Major Partners



## Join our mailing list

Would you like to be on the mailing list for *The Beacon* or *The Inside Story* (a supplement for people with metastatic breast cancer)? To subscribe, telephone 1800 500 258, email [beacon@bcna.org.au](mailto:beacon@bcna.org.au) or visit [bcna.org.au](http://bcna.org.au).



### the BEACON

BCNA  
293 Camberwell Road,  
Camberwell, Victoria 3124  
1800 500 258, (03) 9805 2500  
[beacon@bcna.org.au](mailto:beacon@bcna.org.au) or  
[bcna.org.au](http://bcna.org.au)

Layout: SUBStitution



The printing of *The Beacon* is kindly supported by Reflex and Australian Paper.



Printed on Australian-made REVIVE 100% recycled paper

