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Focus on:

**Communities**



# the BEACON

Breast Cancer Network Australia's Magazine

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## Communities

Reflecting on the term 'community', I am reminded of an Irish proverb; 'It is in the shelter of each other that the people live.'

It can sometimes take an event like a breast cancer diagnosis, for a community to really show itself. For some people, their diagnosis highlights to them the support that is around them. For others, a breast cancer diagnosis brings with it a feeling of isolation. Not everyone wants to share their breast cancer journey with those around them. Unfortunately for some of those who do want to share, they find their friends or family fall away, perhaps because they don't know what to say or how to help.

BCNA is a true community. Since 1998 we have brought people together through their shared experience of breast cancer to build support for individuals, groups and communities. Our network has now grown to more than 110,000 members. Though I'm sure most of these members would never have put their hand up to join the community of people diagnosed with breast cancer, many great things have been born out of this network.

One of the many ways we bring people together is through our community information forums in rural, regional and metropolitan locations around Australia.

Following on from the success

of our Greek information forum in 2014, in July we partnered with community organisations to present our first information forums in Vietnamese. Held in Sunshine and Springvale in Victoria, a strong sense of community was very apparent at these two events.

In addition to our forums, our 290 Member Groups also offer the opportunity for our members to connect face-to-face. In this edition of *The Beacon* we share the story of one of our Member Groups that has supported people diagnosed with breast cancer in its community for 20 years.

Launched in 2010, our online network gives you the opportunity to connect with others no matter where you live or what the hour. Since its launch, the online network has grown to 15,000 members. In response to your feedback, there are big changes coming to online network, which we hope will strengthen our growing online community.

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*Christine Nolan (second from right) with (left to right) Don Edgar, BCNA Founding Chair Patricia Edgar and BCNA Founder Lyn Swinburne at the 2016 Pink Lady Match*

We will be soon be heading into the month of October – Breast Cancer Awareness Month. This is an important time to reflect on the impact of breast cancer on Australians.

We know that October can be difficult. The increased attention that breast cancer receives during this month can serve as an unwelcome reminder of something you'd rather forget.

However, I know that many of our members will see October as an opportunity to come together, from hosting a Mini-Field of Women, celebrating with support groups or running community-based events. Thank you to everyone running events and raising funds to support other Australians affected by breast cancer.

In the lead-up to Breast Cancer Awareness Month, this year BCNA will be hosting five Pink Lady luncheons across Australia – in

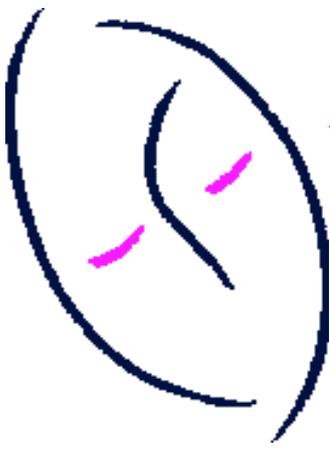
Canberra, Perth, Brisbane, Sydney and Melbourne. See the back cover to find out more.

We will also again recognise Secondary Breast Cancer Awareness Day on 13 October to raise awareness of the complex and specific needs of people with secondary breast cancer.

No matter where you are in your breast cancer journey, remember, it is not a journey that has to be taken alone. If you haven't already, I encourage you to reach out to the BCNA community – you will be warmly welcomed.

*Christine Nolan*  
Chief Executive Officer





# Issue of Concern

## I've been diagnosed with DCIS - what does it mean?

Every year, around 2,000 women in Australia are diagnosed with DCIS, or ductal carcinoma in situ. This can be a confusing diagnosis. Although it is technically not breast cancer, most women are recommended breast cancer treatments to remove the DCIS cells.

DCIS is a non-invasive, pre-cancerous condition that is usually diagnosed through a screening mammogram. Non-invasive cancers are those where the cancerous cells remain confined within the milk ducts or lobules and have not spread into the surrounding breast tissue.

Although it is a pre-cancerous condition, most women will be recommended treatment to remove the DCIS with the aim of preventing it from spreading into the breast tissue and becoming an invasive (early) breast cancer.

You may have seen debate in the media around whether all women need to be treated for DCIS. This has led to greater confusion for women trying to decide what is best for them.

Not all DCIS will progress to become invasive cancer. At this time, however, science is not able to tell us which women diagnosed with DCIS will go on to develop invasive breast cancer if the DCIS is left untreated, or what the timeframe for developing invasive disease might be.

There are clinical trials underway to see whether it is possible to identify which types of DCIS are most likely to develop into

invasive breast cancer. Two international trials, LORIS and LORD, are investigating whether a 'watch and wait' approach for low-grade DCIS is safe or whether it will lead to higher incidence of invasive breast cancers for these women. The results from these trials will help to determine the best treatment options for women with low-grade DCIS. At this time however, there are no national or international guidelines which recommend a 'watch and wait' management option for DCIS.

The Beacon spoke to Professor Bruce Mann, Director of Breast Cancer Services at the Royal Melbourne and Royal Women's Hospitals.

### Tell us about some of the current issues around treatment of DCIS.

The risk of death from breast cancer after DCIS is diagnosed and treated is very low, irrespective of the treatment chosen. Treatment decisions are complex, however. Part of this is because, even though only DCIS might have been found on the needle biopsy, it is quite common for invasive disease to be found in the breast during the surgery.

The chance of this happening is around 15–20 per cent and is due to a 'sampling error', where the original breast biopsy did not locate cancer cells but the surgery does find cancer alongside the DCIS. This is more likely where the DCIS is high-grade or where the



Professor Bruce Mann

abnormality on the mammogram is large or has particular features.

It is also known that a variable proportion of DCIS cases will go on to become invasive cancer if untreated – the proportion is higher for higher grade DCIS, and probably higher for younger women. The fact that not all cases that are diagnosed are destined to become invasive cancer means that there is a certain amount of 'over-diagnosis' (diagnosis of a condition that would not have caused harm in a person's lifetime). While a large majority of women accept this uncertainty and the possibility that treatment is actually unnecessary as an inevitable part of screening, some are uneasy about undergoing surgery that might not be absolutely necessary. We hope that clinical trials will in future provide answers in this area.

### What are the treatment options?

Assuming treatment is chosen, the options are generally between lumpectomy with or

without radiotherapy, and total mastectomy. The chance of dying from breast cancer appears to be the same for each of these options, but the chance of a local recurrence (i.e. more DCIS or an early breast cancer being found in the same breast on follow-up) is lower with more extensive treatment. Therefore there is a balance between accepting more intense treatments with increased short and longer term side effects, with a higher risk of local recurrence requiring further treatment at a later date. Personal preference is critical in making these decisions, and work is progressing towards decision aids to assist women in making a choice that is appropriate for them.

### What advice would you give?

For most women diagnosed with DCIS on needle biopsy there is no urgency about making decisions and undergoing treatment. The timeframe for DCIS to progress to invasive cancer is measured in months, if not years. Because of this, there is lots of time for women to find out more about their particular case and consider their individual philosophy before deciding. The exception to this is where the clinical picture looks very much like invasive cancer but the needle biopsy only shows DCIS. In such a case, most clinicians would encourage women to make a decision and proceed in a shorter timeframe.

# Ask the Expert: Family history

Many women with a family history of breast cancer are concerned about the risk for their sisters and daughters. The Beacon spoke to Professor Kelly-Anne Phillips, medical oncologist and Head of the Breast and Ovarian Cancer Risk Management Clinic at Melbourne's Peter MacCallum Cancer Centre, about breast cancer in the family.



Professor Kelly-Anne Phillips

## Which families are at increased risk of breast cancer?

Women who have a strong family history, which is two or more close relatives on the same side of the family who have had breast or ovarian cancer, may be at increased risk. All women should consider having their breast cancer risk formally assessed, but it is particularly important for women with a strong family history. You can talk to your GP or breast surgeon who can refer you to a family cancer centre for possible genetic testing if appropriate.

You can also use the 'Know your risk' tool on the Pink Hope website ([www.pinkhope.org.au](http://www.pinkhope.org.au)). The tool was developed in partnership between Pink Hope and Peter MacCallum Cancer Centre.

There are a number of factors other than family history that can also increase your risk. These include being diagnosed with lobular carcinoma in situ (LCIS) or atypical hyperplasia (a benign breast condition), having chest radiation for Hodgkin's disease at a young age, and/or factors that increase your lifetime exposure to female hormones, such as taking combined hormone replacement therapy (HRT) for more than five years.

## What is a BRCA gene mutation? Can people have a strong family history but not carry these mutations?

BRCA1 and BRCA2 are genes that normally help protect against breast cancer. Sometimes women can inherit an abnormal version of one of these genes, called a 'mutation', which puts them at higher than normal risk of developing breast cancer and some other cancers.

We find BRCA gene mutations in only about 20–30 per cent of families with a strong family history. In a lot of families, breast cancer is likely to be explained by combinations of lower risk gene

abnormalities. In the future, we are likely to be able to routinely test for these combinations.

## How can women at increased risk reduce their risk of breast cancer?

When I first started working in the field, there were not great options for women. We know that having both breasts surgically removed (bilateral risk-reducing mastectomy) significantly reduces risk, but it is a difficult decision and not the preferred option for many women.

The great news is that a number of clinical trials have now shown that there are medications women can take to reduce their risk, including tamoxifen. Tamoxifen is taken daily for five years, but the beneficial effect continues for at least 15 years after stopping it. If you wish to find out more, you could talk to your GP, breast surgeon or a genetic counsellor. Researchers at the Peter MacCallum Cancer Centre are currently studying other medications that may be useful for reducing risk and there are likely to be other clinical trials available for women in the future.

The Pharmaceutical Benefits Advisory Committee (PBAC) has recommended that Nolvadex (tamoxifen) be listed on the PBS for women at moderate or high risk of breast cancer. The Australian Government will need to approve the listing. We will keep you updated through our website.

## What are some of the emotional issues women may experience if they have not been diagnosed with breast cancer but have a strong family history?

Women with a strong family history obviously have a lot of experience of breast cancer in their family, which can impact how they think about and interpret their risk. Just watching a close family member go through the experience of cancer can cause long-lasting fear of the disease, even if the outcome is good. That fear motivates some women to be proactive about their risk and think about options to reduce it, but for other women the fear is paralysing and they prefer not to think about their risk or what they can do about it.

## What information and supports are available?

The NSW Centre for Genetics Education has some good resources ([www.genetics.edu.au](http://www.genetics.edu.au)). Pink Hope's 'Ask Our Genetic Counsellor' service ([www.pinkhope.org.au/get-support/genetic-counselling/ask-a-genetic-counsellor](http://www.pinkhope.org.au/get-support/genetic-counselling/ask-a-genetic-counsellor)) also allows people to email questions and a genetic counsellor will respond.

BCNA's *Family history* fact sheet provides information about family history and hereditary breast cancer, as well as a list of further resources and supports that are available.

BCNA's quarterly *Research Bulletin* provides summaries of the latest research related to family history and hereditary breast cancer. If you would like to sign up to receive our quarterly Research Bulletin, please email us at [policy@bcna.org.au](mailto:policy@bcna.org.au) with



'Subscribe to Research Bulletin' in the subject heading. Please give your full name, email address and postcode in the email text.

# Fertility after breast cancer

Many young women diagnosed with breast cancer have concerns about the impact of treatment on their fertility. Chemotherapy and hormone therapy can make it harder to get pregnant after treatment ends. If you are planning to become pregnant in the future, or even if you haven't given children much thought, it's best to consider your fertility options before you start treatment.

Making decisions about fertility treatment can be difficult and can put a lot of pressure on you and your partner, if you have one. Breast cancer treatment can interrupt plans to start or grow a family. There can be feelings of grief and loss if you think you may not be able to have a baby in the future.



Many women feel better about their choices after reviewing all the options and making a careful and considered decision, with the support of important people in their lives. Some women find that writing down their values, feelings and what

matters to them can help when making decisions about fertility treatment.

It is also very helpful to talk to your healthcare team to weigh up the pros and cons. There are a number of fertility treatment options available, including IVF, mature egg freezing, ovarian tissue freezing, ovarian suppression and medications. Your medical oncologist can talk to you about how your cancer treatment may affect your fertility.

A fertility specialist can explain which treatments may be best for you and help set up appointments. Although Medicare and private health insurance may cover some costs, there is sometimes an out-of-

pocket cost. Ask fertility clinics for pricing (including procedures, appointments, hospital stays and storage costs) and be sure to check the reimbursements available for each item.

*Fertility-related choices: a decision aid for younger women with early breast cancer* is a free booklet for young women who have recently been diagnosed with early breast cancer. It has information about cancer treatment and how it can affect fertility, and fertility preservation options to consider. There are also work sheets to help you think about these issues. The booklet is available to download or order from BCNA's website [www.bcna.org.au](http://www.bcna.org.au) or call us on 1800 500 258 and we will send a copy to you.

## BRCA clinical trial

About five per cent of people with breast cancer have an inherited abnormality, also known as a mutation, in the breast cancer genes, BRCA1 or BRCA2.

A clinical trial, OlympiA, aims to decrease recurrence risk of breast cancer for those with a BRCA1 or BRCA2 gene abnormality.

As part of OlympiA, people with HER-2 negative breast cancer will receive free genetic testing to see if they have an abnormality in the BRCA1 or BRCA2 gene. Those

who are found to have a gene mutation may be eligible for the main OlympiA trial.

While many people diagnosed with HER-2 negative breast cancer are successfully treated with currently available treatments, in some the breast cancer will recur and new treatments are needed.

OlympiA, is investigating whether taking olaparib tablets twice a day for 12 months can increase the chance of remaining free from breast cancer for those

with a BRCA1 or BRCA2 gene mutation. Women and men must enrol on the trial within three months of completing their standard breast cancer treatment (including surgery, chemotherapy and any radiotherapy).

The study is being coordinated in Australia by the Australia and New Zealand Breast Cancer Trials Group, the largest, independent, oncology clinical trials research group in Australia and New Zealand. It will enrol 1,500 participants from 23 countries,

including 15 Australian locations. Women and men with HER-2 negative breast cancer diagnosed in the past year and who are interested in participating in the OlympiA clinical trial should speak to their cancer specialist. More information about the study is available at [www.anzbcctg.org](http://www.anzbcctg.org) or the Australian New Zealand Clinical Trials Registry at [www.anzctr.org.au](http://www.anzctr.org.au).

# Hormone therapy: 10 years better than five

You may be aware of research we reported in 2012 which found that, for some women with hormone positive breast cancer, 10 years of the hormone therapy drug tamoxifen is better than five.

Doctors and researchers also wanted to know whether taking an aromatase inhibitor for 10 years would provide more benefit to women than five years, and have been conducting an international clinical trial with Femara (letrozole). Findings of the trial were released at the 2016 American Society of Clinical

Oncology (ASCO) Annual Meeting in June.

The trial included 1,918 women with hormone positive early breast cancer who had already received five years of hormone therapy treatment, either with tamoxifen or an aromatase inhibitor (anastrozole, letrozole or exemestane). The women were randomly assigned to receive either five years of Femara or five years of a placebo (a sugar pill that looked like Femara).

After about six years of follow-up, the trial has found that taking

Femara for 10 years instead of five further reduces the risk of breast cancer recurring (coming back) and of a new cancer being diagnosed in the opposite breast.

The researchers did note that women taking Femara experienced more bone-related side effects, such as bone pain and bone fractures, than women taking the placebo.

If you have been taking hormone therapy for five years, you may wish to talk to your medical oncologist about the findings of this research and whether taking

tamoxifen or an aromatase inhibitor for another five years is a suitable option for you.

*The hormone therapy drugs (tamoxifen and the aromatase inhibitors – anastrozole, letrozole and exemestane) are used to treat hormone receptor positive breast cancer. They have been found to be very effective in reducing the risk of breast cancer recurring as well as the risk of a new primary breast cancer in either the same or opposite breast.*

## Will my breast cancer come back?

*I'm 2½ years cancer free, but all of a sudden I'm finding it hard to deal with my fear of recurrence. I've never felt like this before. Every twinge or ache makes my mind race. – Melanie*

Feeling anxious and frightened about breast cancer returning is the most common fear for women who have had breast cancer. Research has estimated that between 55 per cent and 70 per cent of women experience fear of recurrence at some stage. For some women, this can affect their ability to enjoy life and make plans for the future.

Worry about cancer returning can be higher at different times, such as the anniversary of your

diagnosis or in the lead-up to your follow-up scans and appointments. Pain can also cause anxiety – is this a normal ache or is it cancer back? For some women, hearing about another person's cancer or that someone who has died from cancer can increase their fear about their own cancer coming back.

While fear of cancer returning may never go away completely, there are ways to manage it. Think about what triggers your anxiety and have a plan to cope. You might find it helpful to organise some activities to distract you in the lead-up to an anniversary or follow-up mammograms, or

plan a nice activity for after your doctor's appointment.

Concentrating on wellness can also help. A healthy diet and regular exercise have many benefits. Complementary therapies such as acupuncture, massage and guided meditation can help to reduce anxiety.

*I think we all have moments of anxiety and we all have different ways of dealing with it. I think about how I coped when I was first diagnosed. It is also necessary sometimes to talk to a psychologist. Even writing down your thoughts can help. – Ann*

It's also important to recognise when you might need

professional help. If your anxiety becomes overwhelming, doesn't go away or makes it difficult for you to undertake your normal daily activities, you may find it helpful to talk to your GP or a counsellor.

BCNA is developing a range of resources to help identify and manage fear of breast cancer recurrence. These will include an online video with advice from experienced health professionals and a fact sheet with practical tips and coping strategies.

You may also like to speak with other women in a similar situation through a local support group or by joining BCNA's online network at [www.bcna.org.au](http://www.bcna.org.au).

# For Benefit Medicines – new handy card available

In past editions of *The Beacon*, we have let you know about the exciting new funding initiative between BCNA and For Benefit Medicines (FBM), Australia's first not-for-profit pharmaceutical company.

FBM distributes generic versions of two hormone therapy drugs, anastrozole and letrozole. Under the agreement between BCNA and FBM, 50 per cent of all profits from the sale of these two drugs are donated to BCNA to 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 a cure.

Because it can sometimes be difficult to remember the names of drugs, FBM has produced a small business size card that you can slip into your wallet. This can be useful to have on hand if you wish to speak to your doctor or pharmacist about the FBM alternative and whether it might be suitable for you.

If you would like a card, please email [beacon@bcna.org.au](mailto:beacon@bcna.org.au) or call us on 1800 500 258 and we will send one out to you.

## How to Make a Difference



**If you are on Anastrozole or Letrozole, ask your doctor or pharmacist if you can have the FBM equivalent.**

**If your pharmacy doesn't have stock, they can get FBM products within a day or two. Phone ahead to check. Also ask them to order enough for the future.**

[www.forbenefitmedicines.com.au](http://www.forbenefitmedicines.com.au)

# Rural forums help women connect

*The forum helped me feel connected and 'not alone' in any aspect – so many people have the same feelings about diagnosis, treatment, aftercare and just getting on with life. It helps to see this.*

Each year, BCNA runs free information forums in rural areas across Australia for people living with breast cancer and those supporting them. The forums provide information about the medical, physical and emotional aspects of living well after a breast cancer diagnosis. Since 2008, BCNA has reached more than 5,000 rural women through our forums.

In 2015–16, we undertook research to examine the impact

of the rural forums on women who attend them. Women who attended one of three selected forums were invited to participate. They were asked to complete a survey immediately after the forum and a follow-up survey four to six weeks later. The surveys asked about women's breast cancer-related challenges over the previous 12 months and whether the forum provided useful information and support.

The research found that women's greatest challenges over the previous 12 months related to emotional issues (54 per cent), being active and well (53 per cent) and dealing with side effects (44 per cent). At least



70 per cent of women who had experienced a challenge indicated the forum had helped them with that challenge. In particular, 92 per cent indicated the forum helped with emotional issues. The majority rated the information presented at the forum as very or extremely useful.

The forums were also found to increase women's feelings of connection with others affected by breast cancer and their use of local services.

BCNA will use the outcomes of this research to help with the ongoing development of our rural forums program.

# Measuring the financial impact of breast cancer

An important issue for many women is the significant and often unexpected out-of-pocket costs that can occur when being diagnosed and treated for breast cancer. BCNA's 2013 Member Survey found that 76 per cent of the 1,231 participants had been affected by the financial pressure of breast cancer.

Costs are incurred in both direct and indirect ways. Not only are there gap payments for medical treatments and allied health care costs, such as physiotherapy and lymphoedema treatments, but there are indirect costs such as transport, parking,

accommodation, childcare and lost income. Where you live and whether you have private health insurance may also affect your out-of-pocket costs.

BCNA has identified the financial impact of breast cancer as a key research priority for 2016. We have contracted Deloitte Access Economics to assist us to estimate the out-of-pocket costs for women across five typical breast cancer pathways.

This project will provide us with an evidenced-based report that will clearly show the range of out-of-pocket costs associated

with breast cancer. We will use the report to lobby government and other key stakeholders to ensure Australians affected by breast cancer have access to the latest treatment and care on an affordable and fair basis.

An important part of this work will be to highlight some personal stories from women who have experienced firsthand the financial impact of breast cancer. If you are passionate about this issue and would like to be considered to share your story, please email [policy@bcna.org.au](mailto:policy@bcna.org.au) and we will be in touch with you.



Revitalise  
WITH BCNA

Past issues of *The Beacon* have let you know about Revitalise with BCNA, a six-week online health and wellbeing program specifically designed for women diagnosed with breast cancer. The program is aimed at helping women stay active and well after treatment for breast cancer.

Many health professionals and researchers that we speak to tell us about the increasing evidence of the benefits of exercise for people diagnosed with breast cancer. Research has shown that exercise can not only help reduce the side effects of treatment, but may also reduce the risk of recurrence.

*I thoroughly enjoyed the six weeks of the Revitalise program. The combination of online support through BCNA and being able to exercise at Fernwood through the four-week free membership really helped with my focus and staying on track. My energy levels increased and it helped with the fatigue after radiation treatment.*

– Johann

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

# Sexual wellbeing after breast cancer study

Women diagnosed with hormone positive breast cancer are increasingly being treated with tamoxifen or an aromatase inhibitor (anastrozole, letrozole or exemestane) for more than five years. This follows research that shows that, for some women, 10 years of hormone therapy may be better than five.

These treatments may affect women's sexual wellbeing. Side effects may include vaginal dryness, irritation, painful sex and urinary tract problems. These symptoms, which are more common among women taking an aromatase inhibitor, can be severe and lead to avoidance of sexual activity and reduced physical and emotional sexual

satisfaction, and may place additional stress on relationships. As a result, some women stop taking their hormone therapy drugs and so do not get the full benefit these drugs provide in reducing the risk of breast cancer coming back.

Low-dose vaginal oestrogen is sometimes recommended for women to help manage these side effects. However, a treatment that does not contain oestrogen would be highly preferable.

Researchers at Monash University are evaluating the effectiveness of a low-dose vaginal testosterone cream in women taking an aromatase inhibitor. This would provide an alternative to vaginal oestrogen.

The research will investigate the effect of the treatment on sexual satisfaction, including vaginal dryness and pain with intercourse, as well as the impact on vaginal health and urinary incontinence.

If you are taking an aromatase inhibitor and experiencing symptoms of vaginal dryness, itch or pain with sexual activity, you are invited to participate in this study. You will need to be able to visit the researchers' clinic in Melbourne three or four times over 26 weeks.

For more information, contact Dr Farwa Rizvi on (03) 9903 0374 or email [womens.health@monash.edu](mailto:womens.health@monash.edu).

# Connecting through a shared experience

I had always been rather cynical about gyms, even though I had never set foot inside one. Despite this, my daughter convinced me to join Carlton Fernwood in January 1999 at the time she was joining. I can't believe it's already 17 years ago. We commenced going to classes together, which was a lot of fun.

I was diagnosed with breast cancer in November 2011. Following my treatment of surgery, chemotherapy and radiation, it took me some time to get back into a routine of regular exercise. Towards the end of 2015, I read in *The Beacon* that BCNA had formed a partnership with Fernwood. I found this of great interest and began to wonder what Fernwood Carlton could do for women with breast cancer.



*Bernadette (right) and Janet*

I realised that there were probably quite a few members at my gym who had been affected by breast cancer and may be interested in sharing their stories and getting some support from each other. I had become very aware of and passionate about the advantages of exercise in assisting in recovery from breast cancer and also the

growing evidence around exercise reducing the risk of recurrence of breast cancer.

I contacted Janet Saltarelli, manager of Fernwood Carlton, offering my support to any members who had experienced breast cancer. Janet was very quick to respond and very enthusiastic to become involved. We met and came up with the plan

to hold an information session and a gentle exercise and stretch class.

Janet spent significant time promoting the event and organising the day, and several Fernwood staff members attended and were very supportive. It was also great to have some BCNA staff members present and involved in our information session. We had a very successful day, which was greatly enjoyed and appreciated by the women who attended.

Since the information day, I have run into some of the Fernwood members at the gym who attended and we have connected in a positive supportive way that would not have happened prior to this event.

*Bernadette, VIC*

# Discovering online support

For me, community is a sense of belonging, of connectedness with others. It doesn't have to be a physical or geographical space, but can simply be a group of people that share common goals and experiences.

Before I was diagnosed with breast cancer in 2012 I had avoided involvement in any social media, but during the long months of my treatment I came to realise that I needed to connect with others who would understand what I was going through, and so I tentatively ventured onto BCNA's online network.

For many months I was a quiet observer, occasionally commenting on posts that others put forward, always learning something new from other members, and appreciating the supportive environment that the forum offered.

However, as the time drew closer for my reconstruction in 2014, I became very anxious about what was ahead of me, and although I had been given some information about what to expect from my surgeon, I felt unsure about the decisions I was facing and wanted to hear directly from other women who had



*Jane*

been through the reconstruction experience. That first post opened up a whole new world. The support was immediate and this virtual, online community that

I was so nervous about joining became my lifeline throughout that time.

Four years later, I continue to be involved with the online network, offering support where I can to those who have been newly diagnosed, and acting as a facilitator for the network's breast reconstruction group. I have even taken to Facebook where I am also an active member of the Reclaim Your Curves breast reconstruction group. These communities, and the friendships developed, have become an important part of my life, and give me a great sense of belonging and direction.

*Jane, NSW*

## Community floats my boat

Nine months on from a breast cancer diagnosis and ensuing treatment, I find myself drifting in a wretched sea of nausea, night sweats and worse, fatigue. I'm blessed to have the support of my husband, family and friends, but there's another important well of strength I draw from: community.

I've been involved with my local neighbourhood house for the past 15 years and lately, in helping run a community newspaper. I'm also the member of a delightful group of volunteers who put together our village festival each year.

To me, community is about the joy of connecting with others, working on like-minded projects, sharing stories. Equally, it's about being part of something bigger than myself.

Community is a point of contact for people who want to teach or



*Cherie*

learn, or give back. It can also be a bridge to somewhere less lonely.

Community helped me become a published writer, giving me skills and opportunity. Consequently, I'm able to offer support to emerging writers in the same way. After months of hyper-focus on my lumpectomy, radiotherapy and a new drug regime, the

tight bands cancer had wrapped around my brain have loosened a little. It feels therapeutic to be immersed again, in the community I love.

At best a tonic, but even as a distraction, community involvement can be a relief from isolating thoughts. Because dealing with breast cancer can upset the mind of even the most capable women in normal circumstances.

Though it makes for an all too common story in our lives, there is nothing ordinary about breast cancer when it strikes you. Always energetic, I never pictured myself, at 53, in a boat this shaky. I need all available 'oars' in the water these days. I'm just grateful community is one of them.

*Cherie, VIC*

## Big changes are coming to the online network

In March 2015, we launched our new website, which included a new online network. Not all of you liked the new network and some asked why the change had happened.

Some of you told us that you've had difficulty using the new online network. We've listened to you. We heard the feedback online, on the phone and in person.

As a result, in September, the online network is moving to a new and different platform. We're creating an easy-to-use, mobile and tablet friendly community designed for your unique needs.

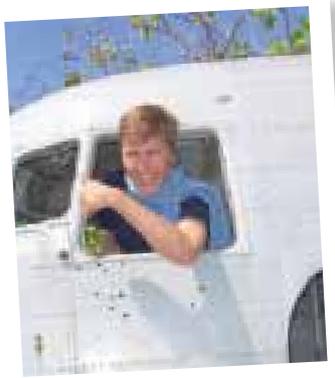
If you have any questions about the change, join the new online network group 'Community Shift' to find out more. We'll answer your questions and show you how the new network is coming along.

We value the online network and know that you are what makes our community great, not software. We hope you'll support us through this transition.

## Support isn't just face-to-face

During 2011–12, I faced the challenge and uncertainty of breast cancer, from my diagnosis of high-grade DCIS through to several surgeries (plus a few unforeseen complications). Right from the start, I felt disconnected from my close local community where I am a swim teacher and a surf lifesaver. I didn't want to share this big change in my life. It was just too personal.

I felt like I would have more control – and less stress – if I kept all of my breast cancer treatment (including mastectomy and



*Diane*

implant reconstruction) very private – at least until I'd fully recovered. So, for about 18

months, only my family and a few close friends knew.

Living in a regional area, I travelled interstate for my surgeries. It felt safer and more helpful for me to ask questions and get help via phone, email or online – with organisations such as BCNA, Cancer Connect and the Cancer Council helpline. I learnt to create a practical support network that I trusted and respected – that has now expanded to much more!

I have discovered new, and broader, communities of people

– through my local breast cancer support group, the BCNA online network and my BCNA Community Liaison work – that have thankfully become important parts of my life. I feel like the energy, empathy and openness I'm now sharing with others, as a person living with breast cancer, has reconnected me to my local community.

Being part of a 'community' is now more enriching, and more empowering, than I'd ever expected.

*Diane, NSW*

# The people that helped me through

My husband and I headed out into the quadrangle at BreastScreen to enjoy the midday sun, the garden and take a few deep breaths as we absorbed the events of the morning and awaited our turn for the biopsy to confirm diagnosis. It was late autumn and the air was crisp and the sky blue as ever.

It had been a busy morning at BreastScreen – how sad. There were a few of us becoming part of the statistics of breast cancer. By the time the message was delivered by the breast surgeon, we were prepared; upon arrival for appointment we'd been cut from the pack and introduced to a counsellor – the realisation that we were entering a challenging time of our lives and entering the world of the Pink Lady.

It is sometimes tough being a Pink Lady, the reality of 'How did this happen?' and 'Why me?'; but the support that is offered through the BCNA online network is immeasurable. You can be open, honest, annoyed, compassionate, or any form of emotion. Your fellow participants of the forum do not judge and are there to help you through, along with the amazing staff; they offer advice when you need direction.

Locally, I have always been a member of our local community and participated in different groups over the years. I'm a member of Country Women's Association, Gisborne Day Branch. As word filtered through of my journey, left breast mastectomy and sentinel node removal, along came the phone calls, cards,

visitors with beautiful flowers, cakes and meals; must say I have never seen so many cake forks in the washing up!

They've encouraged me to attend meetings and events when I am up to it. Recently I entered an item for judging at the art and craft exhibition for Central Highlands and received first prize. Well, how chuffed was I, the next show is the state exhibition.

As to volunteering, something out of left field, my real passion is the Victorian cemetery sector, a community that has also supported me throughout this journey. There are in excess of 3,500 volunteers that help run cemeteries across Victoria. I'm Honorary Secretary of our local trust – a role I have fulfilled for the past 11 years – and on the



Christine

Committee of Management for the sector for the past five years. My role is to represent and advocate on behalf of the industry and locally to help families through the process. A topic that is for another day.

I've just passed my first 12 months since diagnosis and it is onwards and upwards from here.

Christine, VIC

# A new perspective on an old tradition

I was diagnosed with ductal carcinoma in situ (DCIS) in October 2013. It was explained to me that DCIS is considered as stage 0 breast cancer. It was unknown whether the condition would eventually progress into cancer, but as the DCIS was found in two spots of my left breast and after seeking more than one opinion, I decided not to take a chance and to have a full mastectomy and breast reconstruction.

The diagnosis came as a shock, followed by fear and apprehension, as cancer robbed me of my father when I was seven years old, then one of my three brothers died of cancer at the age of 47.



Dalal

I am certainly fortunate that I did not have to go through chemotherapy or radiation therapy. Nevertheless, my operation was quite significant and the recovery took longer than I expected. I would say that even now I am still experiencing residual effects of the surgery.

Reflecting on my experience, I feel so blessed to have a supportive family and a caring community. I was overwhelmed by the kindness, warmth and generosity of my friends and colleagues within my Arabic-speaking community as well as my extended multicultural community.

I am of Lebanese background and have been in Australia for 40 years. Looking after the sick is somehow ingrained in our psyche. We have a word '*wajbat*' commonly used in the Lebanese community, and it refers to a set of duties to be performed on regular basis and which could range from visiting sick people,

or families and friends to extend condolences, congratulations, or to welcome relatives from overseas. Even to this day, some members of the Lebanese community dedicate regular time during their week to go and fulfil their *wajbat*.

I have not always appreciated such a tradition growing up, thinking it was too formal and perhaps sometimes executed for the wrong reason, but I have learnt to see this from a new perspective and value its intrinsic purpose and merit. It is a noble tradition enacted to remind us that to be human we need to be humane.

Dalal, VIC

## Fitness, friendship and fun

Every Saturday at 8.00 am, a group of pragmatic and determined women front up to Bradley Park under Sydney's Harbour Bridge for an hour of pretty hard-core exercise. We have all undergone various forms of treatment and surgery – many of us continued coming during our chemo cycles. It's a great way to stretch out leaden limbs and compare notes on everything from treatment updates to how to regrow your hair while maintaining a semblance of style! How did our little Sydney Breast Cancer Boot Camp come about? Sydney oncologist Lina Pugliano always wanted to do something more to support her breast cancer patients. So in 2015 she and personal trainer husband Rob started a small



*Sydney Breast Cancer Boot Camp*

informal exercise group open to her patients and anyone else interested. They generously give up their personal time each week at no charge to encourage and support us to help overcome complications of treatment.

Before too long, a core little group developed including not only women undergoing treatment, but lots more who had long finished. We bring ourselves, and a sense of fun, friendship and camaraderie to

each session. Friends, family members and even dogs are all encouraged to help promote continuity and commitment.

There's nothing like stretching out the muscles to encourage life back into leaden bodies. Exercise can also help mitigate some side effects of chemotherapy such as fatigue and nausea for some people.

Boot camp has become an informal support network for women at various stages of diagnosis and treatment. We are all so very grateful to Lina and Rob for going above and beyond the call of duty in supporting us all on our journey, so we in turn can continue to provide support for each other.

*Liz, NSW*

## Rallying my community for Sonia

On the 12-year anniversary of my diagnosis of breast cancer, I found myself enabling members of the Rotary Club of Tamar Sunrise to perform a gardening tidy-up for one of our secondary breast cancer sisters, Sonia.

Her plight became obvious to me during one of my regular weekly visits to her when she mentioned how her pre-winter garden looked so unloved and uncared for. Up until recently Sonia was able to delight in some weeding, planting and general garden time, which so many of us feel is of great benefit in so many ways.

Wearing my BCNA Community Liaison hat I contacted Danny, a member of this vibrant Rotary Club, to enquire if he had any ideas about how I could achieve a working bee sometime soon. He came up trumps with a keen team on a glorious sunny Saturday morning. The garden was completely tidied, 100 daffodil bulbs were planted, and the veggie patch was made to look respectable again.

Members of our local Launceston breast cancer support group arrived with freshly home baked scones, cakes, slices and savouries, so a terrific morning

tea was shared and much appreciated by all who attended. Sonia was overwhelmed and sincerely grateful for giving her a lovely aspect to look out on from her sunny verandah, and some peace of mind.

On my drive home I thought 'Wow, what a great community we live among,' but then this can happen anywhere if we get the word out about BCNA offering support in so many ways to Australians experiencing breast cancer. Our breast cancer community is part of a larger community no matter where we live, and access to others is made



*Mandy (right) and Sonia*

easier with the great support of BCNA.

This is, to me, the heart of community – the Pink Lady stands tall in so many hearts and I am proud to be part of it.

*Mandy, TAS*

# Improving outcomes in my community

I am an Aboriginal woman from Darwin, now living in Victoria and working as an Aboriginal Health Coordinator on the Mornington Peninsula. My primary role is to improve pathways and linkages between services that will significantly impact on quality of the lives of Aboriginal Victorians. I am concerned about the disadvantages my community faces compared with other Australians. The survival outcomes for Aboriginal and Torres Strait Islander people diagnosed with breast cancer are significantly lower than non-Aboriginal and Torres Strait Islander people. My journey began when I was diagnosed with breast cancer

in 2009. My cancer was picked up through self-examination, before a mammogram confirmed I had stage-three cancer. Despite having a very supportive partner, I felt scared and alone. I found BCNA when I attended my first chemo session. The resources were really useful and I found the organisation very supportive. Before I was diagnosed, I examined myself routinely and acted promptly, but I am aware this does not always happen in the Aboriginal community. Aboriginal women are less likely to participate in early breast cancer detection programs. This is something I want to change in my community and is why I joined BCNA as a volunteer



Debbie

Community Liaison. In 2015 I became an ambassador for BreastScreen Australia.

I have also had the opportunity to talk to small groups of Aboriginal women about early detection

and the resources available to them through BCNA. I felt privileged to be one of the faces of the Pink Bun Campaign in 2013.

I want to see Aboriginal women prioritise their health. Like most wives, mothers and grandmothers, we tend to put the needs of the family first. My dream would be to see a decrease in the prevalence of chronic disease in Aboriginal people and the life expectancy rates of Aboriginal people on a par with non-Aboriginal people.

Debbie, VIC

# Berlei launches a new breast cancer bra range

Berlei and BCNA have been working together for more than 11 years, and in that time we have distributed more than 120,000 free *My Care Kits*, aimed at supporting women during the 12 weeks post-surgery. The bras included in the kits may not be the most glamorous, but we know that they provide practical care for women directly after surgery. Post-surgery, many of you have told us that buying a mastectomy bra can be a challenge. Berlei has been working hard to find a solution for you.

We are delighted that in October, Berlei will release a range of sexy and beautiful bras, designed for women after breast cancer treatment. The design team used music icon Chrissy Amphlett as their inspiration. Chrissy died from breast cancer in 2013. When Berlei met with Chrissy's husband Charley, he told them how hard it was for Chrissy to find a bra post-surgery that made her feel sexy, while being practical. The range includes a mastectomy bra (illustrated above) that has been specially designed to meet our members' needs. To top it off,



Berlei will donate 100 per cent of the profits from the sale of the bra to BCNA. The bra costs \$64.95. We are so proud of our partnership with Berlei. They remain committed to supporting women with pioneering products for breast cancer survivors,

as well ongoing research and development into new fabrics and technologies. They want you to feel great, every day. The new BCNA range can only be purchased online through [www.berlei.com.au](http://www.berlei.com.au).



# Profiling our Member Groups

## Coffs Harbour Breast Cancer Buddies

*Coffs Harbour Breast Cancer Buddies shares its history and how it connects with the local community.*

Our Breast Cancer Buddies group celebrated its 20th anniversary in March this year, with past and present members sharing many memories and milestones. We also recognised the outstanding dedication and devotion of Ruth Cooper, a founding member and our group coordinator since 1997.

Following breast cancer treatment, Ruth moved to Coffs Harbour in 1995. She felt the need for a breast cancer support group here, as there was only one cancer support group (for all cancers) at that time. With help from Marilyn Pullen and a few others, a breast cancer support group was formed and sponsored as a community service by St John's Anglican Church.

Our group held its first meeting in 1996 and monthly meetings have continued ever since, offering support to people of all ages and at all stages of breast cancer diagnosis, treatment and survivorship.

Originally called Breast Cancer Survivors, we changed our name to Breast Cancer Buddies in 2009. Our aim has always been to support, encourage and listen to each other within a safe, friendly, and confidential environment, while gaining knowledge – and having fun! All who have had a diagnosis of breast cancer are welcome. Since 1996, more than 252 people (including one man)



*Photo: Trevor Veale / APN*

have been supported by our group.

Our regular meetings start with a cuppa at 10.00 am and finish at noon. There are opportunities to share, learn, laugh (and sometimes cry) and support each other. We also offer follow-up contact between meetings. Guest speakers keep us informed on topics such as managing stress, diet, exercise, treatment side effects and recovery strategies. We discuss a range of breast cancer issues openly, based on the needs of our members, and access relevant information, resources and research from BCNA and Cancer Council.

Over the years our members have participated in local BCNA Mini-Fields of Women, regional breast cancer forums, BCNA and Cancer Council conferences, YWCA Encore programs, Pink Bun campaigns, Daffodil Day, Relay for Life and Cancer Council Peer Support Programs.

We fundraise for Cancer Council and promote breast cancer awareness at our Australia's Biggest Morning Tea each May.

We also share in the annual information morning tea organised by our breast care nurse and her team of Cancer Connect volunteers.

Lee Millard-Newton, our amazing local breast cancer nurse and a breast cancer survivor herself, is always available to support our members and provide latest information on current services and treatments.

What makes Breast Cancer Buddies so worthwhile is summed up by Ruth, reflecting on her experiences over 20 years with our group; 'Often someone comes to the group feeling traumatised because of a diagnosis or treatment. It is wonderful to see the support that is offered and to see that person leave, with a smile, and new confidence from new supportive friends.'

As we fondly farewell Ruth, we warmly welcome our new group leader, Margaret Kelly. If you would like to join Coffs Harbour Breast Cancer Buddies please phone Margaret on (02) 6658 4074.



## 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 290.

New Member Group:

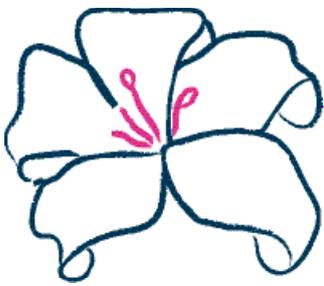
- National Council of Jewish Women (NCJW) Cancer Support Group, NSW

To find a support group in your state or territory, visit [www.bcna.org.au](http://www.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 secondary breast cancer
- getting active and well again.

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



# 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:

- AGC Networks Australia Ltd, NSW
- Aurizon
- Bell Charitable Fund
- Buderim Meadows Retirement Village – Sue Manning, QLD
- Camden Junior Rugby League, NSW
- Casey Cavaliers, VIC
- Clover Cottage – Lynn Brewster, VIC
- Collins Foods Group
- Dorothy Chambers, VIC
- Dunlop Flooring
- Gerard Early, ACT
- Golden Retriever Club of South Australia, SA
- Greenbushes Ratepayers and Residents Association Ltd – Pat Scallan, WA
- Hepburn Bath House & Spa, VIC
- Jack and Suellen Goard, ACT
- John Langford, VIC
- Jordan McCarthy, SA
- Julie Marinis, SA
- Julie Perna and Patricia Canteri, VIC
- Kendra Vince, TAS
- Knox Falcons Netball Club, VIC
- Knox Italian Community Club – Joe Furno, VIC
- Konica Minolta
- Lace Up for Lynne, SA
- Larry Sondheim, VIC
- Letitia Bullen, VIC
- Lynette Dawson, QLD
- Mehdi Qerim, VIC
- Mercedes-Benz Barloworld Motor Brighton, VIC
- Pink in the Tropics, QLD
- RACV Royal Pines, QLD
- Romsey Football Netball Club, VIC
- Sandringham & District Netball Association, VIC
- Sarah Aiello, VIC
- Susan Towns, QLD
- Viewbank Early Childhood Centre, VIC
- VS Sassoon

## Memorials

- Betty Lovegrove
- Branka Kuzmar
- Glenys Snelgar
- Heather Cook
- Julie Elizabeth Torbitt
- Margaret Horwood
- Sheree Jane Hooper
- Simone Braniska

## Celebrations

- Ann Scriven
- Janne Hardwick
- Pablo Larrosa

**NEW**

## Pink Lady Merchandise

**NEW \$15**

**Pink Lady Notabook**  
Features a soft touch cover adorned with a Pink Lady silhouette, lined pages and heavy blue page marker.

**Great Value! \$5**

**Five Pen Pack**  
Add these stylish ballpoint pens to your stationary collection.

To view more products and make a purchase please visit [bcnashop.org.au](http://bcnashop.org.au) or call 1800 628 628. *It's a real sign of support.*

# The power of partnerships

On Sunday 15 May, the MCG was awash with pink at the Pink Lady Match. The event celebrated the 10-year partnership between the AFL, Melbourne Football Club and BCNA.

The stands were a sea of pink, thanks to Major Event Partner Red Energy, who provided 7,000 pink caps for fans attending the match.

Tributes and messages of support were left by many at the Mini-Field of Women planted outside the ground.

Thank you to everyone who sat in the Pink Lady bays, attended the high tea, or participated in the walk of honour on the ground.



## New BCNA Major Donor and Bequests Manager



Abby Cormack is BCNA's newly appointed Major Donor and Bequests Manager.

A proud Kiwi, Abby comes to BCNA from Wellington, where she held a similar role at the Royal New Zealand Plunket Society. Plunket is New Zealand's largest provider of support services for the development, health and wellbeing of children under five.

Since starting at BCNA, Abby says she has been amazed to learn of the diverse range of resources and support that BCNA provides.

'I have been able to see how passionate the staff are here at BCNA and I to want to be part of that wonderful support network helping women, men and their families affected by breast cancer,' she says.

If you are considering making a significant donation or leaving a gift in your will to BCNA, or would like more information, please phone Abby on 0401 378 804 or email [acormack@bcna.org.au](mailto:acormack@bcna.org.au).

# Pink Lady luncheon series

On 24 August guests enjoyed an afternoon of fine dining and inspiring speakers in beautiful surroundings at our first Pink Lady luncheon of 2016 in Canberra. Four luncheons remain in the 2016 series, and we would love to see you there.

Tickets are \$165 per person (\$115 ticket price plus a \$50 tax deductible donation requested). Tables of 10 are available.

To buy tickets or find out more, visit the 'News & Events' section of our website at [www.bcna.org.au](http://www.bcna.org.au).



Melbourne Football Club Captain Daisy Pearce and Shane Crawford

**Perth – 8 September**, Crown. Special guest speaker: The Hon. Dame Quentin Bryce AD CVO, BCNA Patron

**Brisbane – 13 September**, Sofitel Brisbane Central. Special guest speaker: Rosemary Vilgan, 2013 Australian Business Woman of the Year and former QSuper CEO

**Sydney – 22 September**, Sofitel Wentworth. Special guest speaker: The Hon. Nick Greiner AC, former Premier and Treasurer of NSW and breast cancer survivor

**Melbourne – 4 October**, Crown Palladium. Special guest speaker: Christine Holgate, CEO of Blackmores and 2015 CEO of the Year

# Brave for BCNA to return in 2017

On Valentine's Day this year, 40 of our bravest supporters skydived across the country. In 2017, Brave for BCNA will be back again, bigger and better than ever!

Brave for BCNA will take place in Barwon Heads (VIC), Byron Bay (NSW), Wollongong (NSW) and Rockingham (WA) in February. There is no cost to take part, but each participant will have a fundraising target of \$2,500.

*If you'd told me a year ago I'd celebrate being five years clear of cancer by jumping out of a plane, I'd have told you you're mad! But WOW! What an opportunity and what an experience. I wasn't sure I'd love it, but I absolutely did and I will remember the day forever.*

*There are no words to describe dropping out of the sky – you just have to do it yourself to know.*

*It's the most exhilarating and liberating thing I've ever done. I must have watched my video 100 times with a big grin on my face, and giggled at the end every time. It was just such a special day.*  
– Nikki, Brave for BCNA 2016 participant

For more information, visit [www.bcna.org.au](http://www.bcna.org.au).

## Seeking stories – Unsung heroes

We are seeking stories for the Autumn 2017 issue of *The Beacon* about unsung heroes. Who helped you along the way? Who made a difference to your experience, and how? Was it someone unexpected? A stranger perhaps,

or maybe it was your breast care nurse, neighbour, colleague, local hospital staff, or a sales assistant in a wig library or lingerie shop. 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 December 2016. Please also include a high-resolution photo.

### BCNA Partners



## Join our mailing list

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



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