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Focus on:
Unsung heroes



Our unsung heroes

There are so many people in our community quietly doing incredible things. I have met many extraordinary individuals who give of themselves without wanting recognition. They are unsung heroes, and this issue of *The Beacon* pays tribute to them.

There are millions of Australians who volunteer in a huge diversity of ways in our community. They might run or do volunteer work in the local sporting club, services club, youth group, environment club and many others; roles that are an essential part of the fabric of our local communities.

In the breast cancer sphere I have met health professionals who go above and beyond their required duties and dedicate a huge part of their time and lives to helping people with breast cancer. They include our forum speakers, breast care nurses, surgeons, oncologists, scientists, social workers, allied health professionals and palliative care workers.

The hundreds of people involved in breast cancer support groups around Australia are also great unsung heroes. These women volunteer their valuable time to support others facing the challenge of breast cancer.

There are more than 300 support groups registered with BCNA and each of them makes a real difference to their members. Our members who train to be Community Liaisons and Consumer Representatives are really busy doing great work on behalf of our entire membership, both in the media and on various committees. We also have around 40 volunteers, both women and men, here in our office in Camberwell. These volunteers provide an enormous amount of logistical, practical and administrative support. We simply could not function as we do without their help.

Then there are the wonderful people and organisations that raise money for us at Pink Lady events. This year we are expecting 250 events across Australia, all organised by people who at some point during their lives have been affected by breast cancer and now give back to support the work we do at BCNA.

I also want to acknowledge the staff and franchise owners at Bakers Delight who donate their ingredients and time to support the Pink Bun campaign. This year they raised more than \$1 million during the three-week campaign!



BCNA volunteers packing My Care Kits

There are also the staff in workplaces who donate funds to us and generous professionals who do pro bono work for BCNA. We are also fortunate to have great Board members who volunteer their time to ensure the ongoing success of our organisation.

Finally, there are all the amazing partners, friends, family, neighbours and colleagues who rally around to support someone who is affected by breast cancer. Everyone can make a difference. A simple act of kindness can sometimes have the most amazing impact. Stories from our members in this *Beacon* typify what many of you will have experienced. Sometimes we are surprised by those who come forward and offer a great depth of empathy and love.

I hope to meet some of our unsung heroes at our national conference Strength to Strength in Sydney this October. I look forward to seeing some of you in Sydney so that we can absorb the information and enjoy each other's company at our Pink Gala event on the harbour.

*Maxine Morand
Chief Executive Officer*

Breast
Cancer
Network
Australia



Breast cancer research helps other cancers too!

Research into breast cancer has benefited many women and their families through better treatments, improved survival rates and a clearer understanding of the disease.

What many people don't realise, however, is that the investment in breast cancer research has also, in some cases, resulted in benefits to people living with a range of other cancers, including prostate and stomach cancers.

Genetics

Research into the genetic drivers of breast cancer discovered that women with certain mutations, in particular to genes known as BRCA1 and BRCA2, are placed at a significantly increased risk of developing breast cancer.

It was then discovered that men with mutations in the BRCA1, and particularly the

BRCA2 gene, have an increased risk of **prostate cancer**. This is a major development in the understanding of prostate cancer.

Tamoxifen

Clinical research led to the development of tamoxifen as a highly effective treatment for a large proportion of women with a particular type of breast cancer known as oestrogen or progesterone receptor positive breast cancer. Tamoxifen has been used for more than 30 years to treat breast cancer in both women and men.

In the UK, tamoxifen is now also used to treat or prevent side effects of breast tenderness and swelling in some men with **prostate cancer**.

Herceptin

Herceptin is a targeted treatment for women with a particular type of breast cancer known as HER2-positive breast cancer. Herceptin has resulted in a significant increase in survival rates for these women.

In 2010, the US drug regulator approved Herceptin for use in HER2-positive metastatic **stomach cancer**. In addition, Herceptin is being tested in clinical trials for the treatment of **oesophageal cancers**, with very promising results to date.

Multidisciplinary teams

Research into the best models of treatment and care for women with breast cancer led to the development of multidisciplinary teams (MDTs).

MDTs bring together all the health professionals at a particular hospital or clinic who are involved in the care of women with breast cancer for regular, usually weekly, meetings. The health professionals involved in these meetings include medical oncologists, surgeons, breast care nurses, pathologists and radiation oncologists, to name a few.

At the MDT meetings, the health professionals will discuss each woman's case, review any mammograms, pathology results, or other tests, and develop a treatment plan based on the latest evidence and research. MDTs are widely used in breast cancer in Australia, although not all women with breast cancer will have their case discussed by an MDT.

MDTs are also now slowly being introduced for the care of people with **gynaecological, colorectal, lung and prostate** cancers.

As these examples highlight, research into breast cancer has often led the way for developments in other cancer areas. Ongoing investment in breast cancer research is critical, not only to continue to benefit women with breast cancer, but also those living with a wide range of other cancers.



A sparkling symbol of survival

BCNA's Survivor's Pin is especially designed for breast cancer survivors. It is instantly recognisable between our members as a symbol of love and support. Beautifully crafted with pink diamonds, it is available to purchase for \$20.

To view our entire range of merchandise, please refer to the merchandise brochure enclosed in this edition of *The Beacon* or visit our online store at www.bcna.org.au.

Ask the Expert

Dr Debra Wilson

Dr Debra Wilson is a general practitioner (GP) working in private practice in Melbourne. She is a member of the BCNA Reference Group that oversaw the update of Hope & Hurdles, our information resource for women with secondary breast cancer. The Beacon spoke to Debra about the role of GPs in caring for women with breast cancer.

Why is a GP an important person in a health care team?

GPs often get to know their patients quite well, so we can see them as a 'whole' person. We know the roles they play – as a mother, partner, daughter and worker. So, to some extent, we support them through all those different aspects of their lives. We get to know their children and their partners, which can help us to understand the type of support they may need.

A GP can help women with breast cancer in many ways.

Women are going to get the usual aches and pains and other illnesses during their breast cancer treatment. A GP can assess their symptoms and determine what needs to be done. We can also give advice on managing side effects, such as fatigue and nausea, and can bridge the gap if a woman runs out of medication prescribed by her specialist.

As a GP, women often talk to me about complementary medicines. Women make choices about what they use and at such

a delicate time. I have to strike a balance about allowing women to use medicines that make them feel better and are not causing harm.

GPs can refer women to allied health professionals such as physios and dieticians, and complementary therapies such as massage and acupuncture, which can give women another way to feel better. I also refer women to self-help groups in the community where they might be able to obtain support.

I use palliative care services to help support women with secondary breast cancer. I try to link women in early if they want more information. There are many services palliative care can provide. Sometimes women and their families reach a point where they are fearful of what death looks like. Introducing them to people who might be there to support them at that time can be really helpful.

Is providing emotional support a part of the GP's role?

This is a huge part of our role. Being able to share information in a safe way is very important. Sometimes women don't want to talk about their diagnosis or share their concerns with family or friends. Their GP is someone with whom they can have these conversations.

We can also refer women to a psychologist or counsellor when it's appropriate, for example, if they are having trouble



Debra Wilson

adjusting to their diagnosis or have anxiety or depression. Counselling can provide women with support and give them different ways of thinking.

Do you provide support to partners?

Some of the blokes are tricky. They often don't want to come to appointments: they don't want to be faced with their partner's diagnosis and they don't want to think about it. They just want to go to work and do their normal things. Men can be a bit forgotten, but they often won't present to doctors until things become a bit unstuck.

How can women find a good GP?

I'd suggest they ask a friend or someone they've met through a support group for a recommendation. It can be difficult sometimes to find a GP who can be part of your team, especially if you live in an area where there are a limited number of doctors.

I think it's really important for women to feel that they can be believed and heard. Often their voice can be suppressed during this time because they're at the mercy of the experts. It's really helpful to have a GP with whom you feel comfortable to ask questions.

Often women will preface a question to me with 'This is a really stupid question', but no question is too stupid. If you have a question, it is important you feel you can ask it and make some sense of what it might mean for you.

I think that the ability to be able to ask for information and feel you can be believed and not dismissed is an essential part of any relationship, but particularly your relationship with your GP.

Connecting women through our conference

Bringing women together is something BCNA does well, and we're thrilled that hundreds of women have already registered to attend our Strength to Strength national conference in Sydney on 25 and 26 October.

Highlights from the program include the following topics:

- Managing the fear of recurrence
- Family history of breast cancer: myth busting and facts
- Sexual wellbeing
- Relationships with partners, family and friends
- Menopause / hormone therapy
- Lifestyle factors and breast cancer outcomes



- New directions in breast cancer treatment
- Bone health.

As well as a number of renowned Australian breast cancer experts, we are excited that several international speakers have agreed to speak at the event, including Professor Dame Valerie Beral of Oxford University (UK) and Dr Thomas Buchholz and

Dr Fraser Symmans, both of the University of Texas (USA).

Not only will Strength to Strength be a chance for Australian women with breast cancer to hear world-leading authorities speak on breast cancer treatment and new research, but also a fantastic opportunity for women to meet other breast cancer survivors

who have gone through a similar experience.

As part of the conference, BCNA will be hosting a spectacular Pink Gala dinner on Sydney Harbour on the evening of Thursday 25 October. The three-course sit-down dinner will be a great opportunity to network and share stories with others. The dinner is part of the conference program and is included in the registration fee. BCNA has a history of throwing a great party – and this event will be no different!

Early bird registration has been extended until 30 September. To register, visit www.bcna.org.au > Events > BCNA conferences > National conference 2012.

A diagnosis of secondary breast cancer

While many women diagnosed with early breast cancer will go on to live long and healthy lives following their treatment, some will develop secondary breast cancer.

Secondary breast cancer, also referred to as advanced or metastatic breast cancer, is when cancer cells have spread from the breast to more distant parts of the body, such as the bones, liver or lungs.

Unfortunately, secondary breast cancer cannot be cured; however, it can be controlled, sometimes for many years.

I was diagnosed with secondary breast cancer eight years ago in 2004. It made me re-evaluate my life. I cut back my workload and took up some pleasurable

hobbies. I travel and have fun when I can and try to live each day in faith. – Susan

Women often want to understand why they have developed secondary breast cancer, especially if they have previously had treatment for early breast cancer. Unfortunately, even the best treatment for early breast cancer doesn't always remove every diseased cell. Most commonly, secondary breast cancer develops from cells that are left behind. Sometimes, cancer cells have already started to travel around the body when the cancer in the breast is found.

In 2007, BCNA launched *Hope & Hurdles*, our information resource for women with secondary

breast cancer. In September this year, we launched an updated and enhanced edition of *Hope & Hurdles*. It includes new information, such as a series of optional booklets to help women whose breast cancer has spread. More information on *Hope & Hurdles* is included in *The Inside Story*, our *Beacon*

supplement for women with secondary breast cancer.

If you have been diagnosed with secondary breast cancer and would like to receive a copy of *Hope & Hurdles* and/or *The Inside Story*, please phone us on 1800 500 258 and we can arrange this for you.



BCNA Consumer Representatives: unsung heroes

BCNA operates an internationally recognised consumer representative program called *Seat at the Table*. Operating since 2000, *Seat at the Table* recruits and trains women as Consumer Representatives. The program appoints and supports breast cancer survivors to work with scientists, researchers, and health service providers for many different types of studies and projects that aim to improve outcomes for women with breast cancer.

We currently have 75 trained Consumer Representatives who represent BCNA and women with breast cancer on local, national and international committees and in other activities. One of these women, Lee McKerracher, recently completed a 12-month appointment as a Consumer Representative on a committee organised by the Royal College of Pathologists of Australasia. The committee oversaw the development of fact sheets that explain the role and process of pathology testing to consumers. Lee said that initial drafts of the fact sheets were written with very technical language that a lay person would be unlikely to understand. Involving Consumer Representatives ensured that that the fact sheets were consumer-friendly and more likely to be of use to health consumers, including women with breast cancer.

The fact sheets are now available and can be downloaded from the Royal College of Pathologists of Australasia's website at www.rcpa.edu.au.

Gerda Evans is another busy BCNA Consumer Representative. For the past 14 years, she has represented women and their families on the kConFab Executive Committee. kConFab is a national organisation that seeks to understand the causes and consequences of a family history of breast cancer. The organisation has an extensive resource of tissue and blood samples donated by members of families with multiple cases of breast cancer, and makes those samples available to researchers investigating the familial and

genetic aspects of breast cancer. Gerda's role is to ensure that the voices of those families are heard and considered in all aspects of kConFab's work. Gerda says 'This has been both a challenging and rewarding role, working with researchers from many disciplines, all aiming to reduce the burden of cancer in families like my own'. Gerda, three of her sisters, an aunt and a cousin have all had breast cancer.

After her long and successful tenure with kConFab, Gerda will be stepping down from her role and passing the baton to another experienced BCNA Consumer Representative with a keen interest in this topic. BCNA thanks Gerda for her fantastic

contribution on behalf of women with breast cancer. BCNA Consumer Representatives are currently involved in many ongoing projects and research studies. These include topics such as sexual wellbeing, gestational breast cancer and survivorship issues. If you think you have the skills and confidence to represent women with breast cancer on project and research committees that can sometimes involve complex subject matter, you can register your interest in our 2013 Consumer Representative training by visiting our website www.bcna.org.au > About BCNA > Get involved > Speaking out.



Gerda with her sons at the Field of Women LIVE

Bone mineral density tests: a BCNA survey

Many women are aware that their bone density can decrease after menopause; however, some are surprised to learn that breast cancer treatments can also reduce bone density. These include tamoxifen and aromatase inhibitors (AIs) such as Arimidex, Aromasin and Femara.

If you are taking hormone treatment, you may need to have a DXA test to determine your bone mineral density level. During the test, an X-ray scan will be taken of particular bones, often your hip and spine. You may have a test early in your treatment to check your baseline level, and then further tests during your treatment to check if your level has changed. If your bone mineral density drops, your doctor may recommend some bone-strengthening treatment. There is currently no Medicare rebate specifically for women with breast cancer who need a DXA test, although some women may be eligible for a rebate for other reasons, such as having been diagnosed with osteoporosis or being over the age of 70. As some women need regular tests, BCNA knows the out-of-pocket costs can really add up.

We invited members of our *Review & Survey Group* to complete an online survey about bone mineral density testing, and 447 women participated.

Bone mineral density tests

A total of 290 women told us they had at least one DXA test in conjunction with their treatment (71% had taken an AI and 29% tamoxifen). 177 women (61%) had more than one test.

I had a test before starting treatment, then one at 12 months and three years.

Out-of-pocket costs

Of those surveyed, 114 women (39%) were bulk billed and did not incur any out-of-pocket costs for their last DXA test.

A total of 128 women (44%) incurred an out-of-pocket cost for their last test. Of these:

- 56 (44%) were charged \$100 or less
- 55 (43%) were charged between \$101–\$200
- 17 (13%) were charged more than \$200.

Many women told us that a rebate should be available for women who require a test in conjunction with their breast cancer treatment.

If low bone density is a result of breast cancer treatment, surely DXA tests should be covered by Medicare.

The survey results tell us that many women are prescribed DXA tests in conjunction with

their hormone treatment, and many of these women are incurring out-of-pocket costs. Some are incurring these costs regularly.

BCNA will meet with the Medical Oncology Group of Australia to discuss approaching the federal government for a Medicare rebate for women who need a DXA test in conjunction with their breast cancer treatment. We will also advocate for clinical guidelines to be developed to advise health professionals when to prescribe these tests.

To read the report about the survey findings, visit www.bcna.org.au or phone 1800 500 258 and we will send a copy to you.

If you are required to have a DXA test, you may like to call the imaging clinic before your test and ask what your out-of-pocket costs, if any, will be. Some clinics provide bulk billing for women who are eligible for a Medicare rebate, particularly if you have a health care, concession or pension card. If you are unhappy with the quote you receive, you can shop around for a clinic that will bulk bill you or charge a lower fee.

Help reveal the unsung heroes in your community

Do you know someone who is providing an exceptional service to those affected by breast cancer?

Let us know about the best products and services in your local community and include them in BCNA's Local Services Directory.

The Local Services Directory helps people find breast cancer-related support and services by location or type.

Services may include:

- specialist lymphoedema massage therapists
- counselling services that extend to families, as well as those who have been diagnosed with breast cancer
- breast care nurses and other health professionals
- wig and prosthesis suppliers.

The team at Savvy are great! They have been so supportive throughout my breast cancer journey. They make the experience fun, whether it's a shave, shampoo or help with a wig. I always leave in a much brighter mood after visiting the salon! – Kitty

All you need to do is go to BCNA's website www.bcna.org.au > Sharing and support > Find services in your area > Suggest a service

Please use your experience and local knowledge to help others.

A daughter's devotion

My unsung hero – my beautiful and ever supportive daughter Jenna – was just 17 years old and eight months pregnant when I was diagnosed with breast cancer in 2008.

We have always been close, but the strength, support and maturity she showed during this time were just amazing.

She attended every appointment, blood test and scan with me. She was with me at the hospital for 15 hours the day of my mastectomy. I became a very proud Nana two weeks later when baby Jayden was born. Jenna was with me again just two weeks later for further surgery to remove my lymph nodes – with Jayden by her side. Next came chemo and the many oncology appointments and blood tests that are required. Every one of these was



Kerry with her daughter Jenna and grandson Jayden

attended as a family. Chemo was particularly gruelling, with many visits to the emergency department and hospital stays, but Jenna was with me every step of the way. She would bring

Jayden and stay at the hospital with me all day every day and would then travel home, have a sleep and return the next morning. She also drove me to and from every test, treatment

and hospital stay and looked after the cooking, cleaning and a brand new baby as well as dealing with a separation from her partner.

It's now three years on and still Jenna and Jayden attend all my appointments with me. Jenna has managed all this, become a full-time university student and a wonderful mother, as well as an amazing daughter to me, and is still only 20 years old.

The support Jenna showed me and the maturity and patience she has done it with definitely makes her my hero. I will be forever grateful and appreciative of all she has done and amazed at her ability to cope so willingly with so much at such a young age.

Kerry, WA

A close-knit community

I was diagnosed with breast cancer in 2011. My family was small – just my three children who are my whole world. I was an only child. My parents had passed away, I had no partner and, after 23 years of working nightshift, my network of friends was virtually non-existent. My children are wonderful but I didn't want to burden them with my cancer. I felt isolated, terrified and alone.

Enter my heroes!

My dear neighbours, Barbara and Brian, were with me during chemo and would drive me to and from every session as well as to my many medical appointments. When my doctors told me that my treatments would take 12 months, Barbara hugged me tight and said she had the next year spare to look after me. She also managed to administer my stomach injections on the days following chemo. Barbara is a bowel cancer

survivor. She and Brian are constantly helping others. Next, but not least, my dear friend Tony, who I first met 25 years ago, attended each chemo and radiation session with me. He had travelled his own prostate cancer journey the previous year. His was a difficult time with little support, so he knew all too well the anguish I was facing. He ensured my journey wasn't a lonely one like his.

These people held my hands, wiped my tears, hugged me close, made me laugh and cheered me on. Without them my journey would have been so much worse. They are part of my new extended family and forever in my heart.

Amy, SA

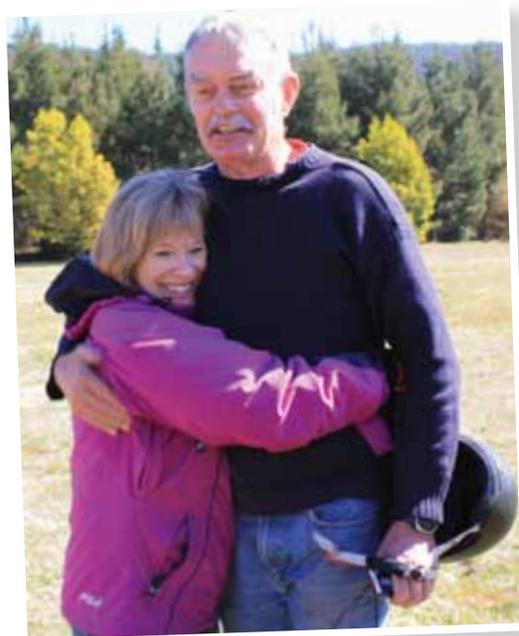
The love of a good man

For me, the real unsung hero is that person who is so close that I sometimes fail to recognise him for what he is. While close friends and family have been incredibly supportive and understanding, doing extraordinary things to assist in my recovery, the person who sees it all – tears, fears, anger, joy, and every emotion in between – is my husband Roger. In those dark moments when things aren't so bright and the mask is off, he's the person who 'cops it all'.

As I write this, he is my carer as I come to the end of six weeks on crutches, the result of a skiing accident on the first day of a skiing holiday in Canada. To add insult to injury, this was supposed to be the holiday that made up for cancelling a cruise around Cape Horn, which had

coincided with radiotherapy in 2011. Many of his dreams and expectations have had to change to accommodate my needs.

He is also the person who saw wisdom in my 'bright idea' to move to north-eastern Victoria from the northern beaches of Sydney, a move that meant early retirement and a total tree change. For me it meant leaving behind the hectic pace of city life for a more tranquil and peaceful life in the country; the chance to take control of my life and to make choices that would help to ensure a positive outcome to my diagnosis. This was a decision made out of self-interest, purely selfish in many ways, but my unsung hero saw it as a team decision, one that he has embraced with enthusiasm and total dedication.



Helen with her husband Roger

Gone are our pursuits of sailing and swimming, exchanged for bike riding, fishing, skiing, not to mention the chooks, veggie garden and a semi-rural lifestyle.

This total commitment to our relationship, my welfare and our life together makes my husband an unsung hero.

Helen, VIC

The greatest gift

Reaching the age of 68, I really thought I was too old to be diagnosed with breast cancer. However in 2006, I noticed a nipple change on my left breast. Over the next 18 months I was assured that nothing was wrong but then a lump developed in my left breast and I was diagnosed with breast cancer. From then on life became one round of continuous treatment. Treatment went without a hitch except for the physical drain on my body.

My husband of 45 years never once complained and drove me to every single appointment, sitting through each examination and time-consuming journey. Our youngest son flew up weekly from NSW to support me, and it was he in the end who secretly went to Brisbane airport one day to pick up my niece from the UK who had flown over to be with me for six weeks at the beginning of my chemotherapy.

That was above and beyond any sense of duty. She told me that I had given her unqualified love throughout her difficult childhood. I can never explain fully the depth of love and appreciation I have for her. I shall never forget her devotion.

These are the messages one needs to get out there; those unselfish acts given so freely without any fuss or theatrics. We are all part of the human race with its follies, shortfalls and



Barbara

misdeeds, but in the end one single act is so enduring that it overcomes all.

Barbara, QLD

Unfailing love and support

I was diagnosed with breast cancer at the age of 45, three years after a sea-change, which is how I found myself 1700 kilometres away from my family when I needed them most.

A week after my diagnosis, and one day before a radical mastectomy, my mum Bev arrived on my doorstep. Mum was no stranger to this sort of thing, having done exactly the same 11 years before, after my sister's breast cancer diagnosis. Mum dropped everything to be with Sonya, who sadly passed away in a very short period of time. This launched Mum into a support role for my brother-in-law, who was left to raise three young children alone.

She became a much-loved and integral part of their lives.

Mum had also taken on a similar role when her younger sister battled breast cancer for nearly 10 years, before finally succumbing. A week after my aunt's passing, Mum lost her mother to pancreatic cancer.

So, when we found out my news we feared the worst. Two years down the track, my treatment has finished and I have picked up where I left off, but in that time Mum has been with me through surgery, chemo, and radiation. She put her busy life on hold, including her active involvement with her community providing meals, babysitting, transport, and other services to people who are



Marianne with her mum Bev

sick or in need, and volunteering at a school for teenage mums, looking after their children while they attend class.

Mum doesn't see what she does as extraordinary; she'd say she's just doing what anybody else would do, but I know that's

not true. Mum has been a regular reader of *The Beacon* for many years and she will be reading this – Mum, I know how fantastic you are; now everyone else does too.

Marianne, QLD

Above and beyond the call of duty

Many people helped me along the way, especially my husband and daughter. However, special mention must be made of my school friends, my friends for almost 50 years. From the moment of diagnosis, flowers started to arrive to cheer me up. I live in Ballina, Sue W at Pottsville, one hour away and Lyn, Karen and Sue M are in Sydney. Sue W visited every weekend for the first couple of months. We laughed and cried together over coffee. She was also there with me, my husband and daughter to select the wig. Then, the four friends banded together and bought me five beautiful caps to wear when I was hairless. The

weekly phone calls, texts and emails were very special to me and always gave me a boost.

Twice during the year the girls flew up from Sydney, timed with my chemotherapy treatments

so that I was on a 'good' week. We spent one weekend in Byron Bay, laughing, crying, eating and talking. The other weekend was after chemotherapy and before radiation. This was spent in the Gold Coast hinterland. Here we walked, went on the paddle boats, played golf and relaxed. Although the five of us live apart, I thank my wonderful friends for their constant support during my journey last year.

We are now looking forward to our 55th birthday celebrations in Fiji in 2013.

Maryanne, NSW



Sue M, Lyn, Karen, Maryanne and Sue W

Doing the hard yards

I'd like to nominate my sister-in-law Annie as an unsung hero.

Annie is married to my brother, James, so in some ways it is not surprising that she helped me during my journey. However, her level of support, generosity, kindness and above all sense of humour, was critical in keeping me from falling into a great wallowing hole. Whereas many friends tried to avoid conversations with me about what I was going through, Annie did the hard yards by asking the difficult questions and then enabled me to see the funny side

of things, as there often is, even in challenging times.

Not only did she phone me almost daily for months (we live 400 km apart) but always took time from her busy schedule (as a PA for a big boss in a big company; and as a mother of two lovely girls) to come with me to post-op appointments in the city and one long stint in ER one night. She always welcomes me into their home, and allows it to be my 'home away from home' – a place to be me, and do what I need to do when I'm in the city, with no expectations. Although



Pam with Annie

we are so different in many ways, I feel a sense of connection that is stronger than friendship and

family. I will forever be grateful to Annie and her heroic help.

Pam, WA

Sharing the pain

When I was first diagnosed with breast cancer in June 2011, my 19-year-old son Cameron was at a loss as to how to help. One night he informed me that he was going to run the Melbourne Marathon in my honour. If he couldn't take away some of my pain, then he was going to inflict some on himself and so, in effect, 'share the pain'. At this stage he was running 3–6 km with a friend, to keep fit; running 42.2 km in three months seemed like an impossible task.

As I journeyed through the ups and downs of chemo, Cameron and his friend Luke trained. We often compared our aches and pains, with my joint pain matching their muscle soreness. They set up a Facebook page and a bank account to raise



Luke, Cameron and Nick

awareness of breast cancer and money for BCNA. They also pledged to shave their heads.

Before long, more friends signed up to run a variety of distances in the Melbourne Marathon, some committing to 10 km or the half.

At this stage my daughter Kirsty committed to the 10 km, never having run further than 3 km before.

Cameron's friends, Nick and Sam, both pledged their support. Both their mums are breast cancer

survivors. Sam couldn't run due to a knee injury, but he pledged to ride the course alongside the three others.

None of them had ever contemplated running a marathon before, but as my son said, 'I'd never had a reason to run one before'. I was on the phone to my husband as they covered the last kilometre and cried many tears of pride. This was surely the proudest mum moment of my life.

It goes to show you that breast cancer touches the hearts of more than just the women affected. With support of this kind, the breast cancer journey is made so much easier; the pain can in fact be shared.

Jackie, VIC

My young unsung heroes

Going through breast cancer brings its own rewards and surprises. And one of the most pleasant surprises I had was the love and kindness I received from my friends' children.

I hoped my friends would be there for me and I was extremely grateful when they were, but the love from younger generations was truly unexpected.

To say that I felt less than attractive as I lost my hair, my eyebrows and eyelashes, was an understatement. Add to it my juicy pink face and unfamiliar voice. So not only was I looking at a stranger in the mirror, I was also listening to one.

But somehow, the young ones not only coped with it, they also encouraged me and made sure our relationships became even richer as I went through cancer.

Felix turned 21 just weeks after my diagnosis and not only did his hugs increase, he showed an interest in the various stages of my treatment.

Matthew and Tobias, both in their thirties, stayed in touch throughout and kept me entertained with funny messages and entertaining cards from their families.

Sisters Sam and Kara, both in their twenties, were my fashion police and kept an eye on my berets and scarves. When I was visiting their mother the girls were always up for a cuppa and a chat and Kara even baked my favourite cake for me.

Lauren called when she heard my news and promised that she and her husband Matt would be there for me. They had one

toddler when I was diagnosed and a second child when I was going through chemo. The young children were a wonderful distraction for me and Lauren generously ensured that I had frequent play dates with their children.

My young friends may never know how their individual friendships affected me or how good it felt to be a part of their everyday lives. Together they brought love, kindness and the freshness of youth into my life. Their company made me feel normal and gave my sagging confidence the boost it needed.

Irene, VIC



Irene with Lauren's baby Eva

An unexpected hero

My unsung hero was the lady at the library. I had a mammogram on a Saturday morning and I could tell by the way the radiographer acted that something was wrong. Afterwards, I ripped off all the 'Do not open' stickers on the report and read the result. Bad news. I was 44. I went home and made some phone calls, finding out who was the best surgeon and so on, and then went to the library.

I found five or six books on breast cancer and when I was checking them out the librarian

asked if they were for me and if I was going to be having treatment. I said I didn't know

yet. She told me that if I needed treatment there would be times when I would feel so sick that I

wouldn't want to go on but that I must persevere. It would be worth it.

I told my sister this story and thought no more of it. Then, when I had the first round of chemo, I was so sick and so dehydrated that I thought I would die. I told my sister that I just couldn't do it again. She reminded me of what the librarian had said – that I must go on. So of course I did. The librarian will never know how much she helped me.

Prue, NSW



Prue

Introducing our Board

Over the next few issues of The Beacon we're profiling our Board members so you can get to know the people behind the Pink Lady. The Board is made up of 10 individuals who have been personally affected by breast cancer. They are leaders in their fields, and generously volunteer their expertise, inspiration and, importantly, compassion and understanding for those affected by breast cancer.

Marg O'Donnell is Chair of the Board, and has been a Board member since 2006.

Tell us about your experience of breast cancer.

I've experienced breast cancer twice – first in 2003 and then again last year. It was the same breast both times, with two small lumps that were not at all related. The two experiences were very different. The first was really just a blip in my life – a lumpectomy and radiotherapy and then I quickly moved on. The second time was quite different. As I'd already had a lumpectomy, this time I had to have the full works – a mastectomy and chemotherapy. One year on from my second diagnosis, I feel really fit and healthy.

How did you get involved with BCNA?

When I was first diagnosed in 2003 I had very little contact with or knowledge of BCNA. I think I may have received a bra but not the *My Journey Kit*. I was approached to join the BCNA Board in 2006. My first impression was that the

Board was a group of extremely impressive people who were voluntarily giving up their time for a great organisation. Once I spoke to Lyn Swinburne, I felt it would be good fit for me. My second experience with breast cancer only emphasised the need for the support and information BCNA provides and made me really proud to be involved with such an important organisation.

What inspires you to volunteer your time as a Board member?

I like what BCNA does. I'm semi-retired and while I still have some paid work, I felt it was important to also volunteer my time. It's very important to me to give back to the community. I also felt I was a good fit for BCNA and it matched my skill set as a former public servant and experienced public speaker.

Some interesting facts about you.

I used to be a hippy! For three years in the late 70s/early 80s my then husband and my two daughters (then toddlers) moved to the Sunshine Coast. We lived in a tent, were largely self-sufficient and had lots of animals – goats, chickens, sheep. I used to milk the goats each morning before heading off to work in nearby Nambour as a social worker. I loved it and look back on it as a really special time in my life.

What's your vision for the future of BCNA?

Firstly, my hope is that every woman in Australia who is diagnosed with breast cancer gets relevant and up-to-date information from BCNA; I also

want her friends and family to benefit from our support. Secondly, I want BCNA to further cement itself as a powerful advocacy agency that influences the government and has its respect. Thirdly, I would like to see BCNA do cutting-edge research on breast cancer survival, how to live with it, and how to avoid getting it again. Finally, I would like BCNA to set the standard for other non-government health organisations in Australia.



BCNA's founder Lyn Swinburne, CEO Maxine Morand and Chair of the Board Marg O'Donnell



Profiling our Member Groups

Brave Hearts making a difference

Brave Hearts on the Murray Inc. was established as an important part of the Albury Wodonga community with the successful release of the 2005 calendar – *Brave Hearts Faces of Love, Courage and Support*. Jenny Black and Fiona Jones share how this vibrant group has provided support for cancer survivors, raised community awareness of breast cancer and shown how to live well beyond breast cancer.

The Brave Hearts Dragon Boat building project brought together a passionate group of survivors to build their own dragon boat. We paddle in this boat to promote awareness, exercise, have fun and support each other.

Dragon boating is only one of our passions. A special project close to our hearts is our Celebration Garden. Our vision was to provide a beautiful place to commemorate those in our community we have lost to cancer, and also to celebrate those living strong after their diagnosis. The vision came to life with a magnificent tall bronzed sculpture of a woman pointing to the sun surrounded by rows of roses. We named her Isis. In Greek mythology she was the protector and patron of women and a powerful healer gifted with the ability to cure mind, body and spirit. She affirmed

women as great sources of strength, healing and inspiration for each other. The official opening of the garden was held on 13 November 2010 in conjunction with our *Mini Field of Women*.

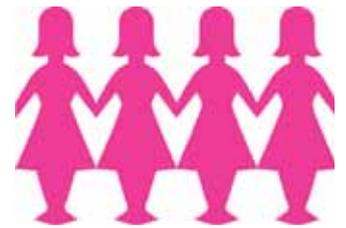
Our vision inspired Community Liaison, Mandy Forteach, to establish her own rose garden in Launceston (see *The Beacon*, Issue 57, Summer 2011).

In June of this year our group took part in a locally written and produced play entitled *The Symphony of Life* featuring well-known actor John Wood. The play highlighted the healing power of music and how belonging to a support group like Brave Hearts has a nurturing effect and helps form special relationships.

Through the generosity of our local community our group has been able to provide financial support to the local wig library,

Look Good Feel Better program, wellness clinics, oncology units and for relevant speakers to visit the town. We are particularly proud of our involvement in providing \$35,000 towards a new cancer carers' accommodation complex being built adjacent to the Albury Base Hospital.

Brave Hearts is truly a group supported by and for the local community. We are a group who want to make a real difference while proving there is life after a cancer diagnosis and that together we can overcome the hurdles along the way.



Linking together

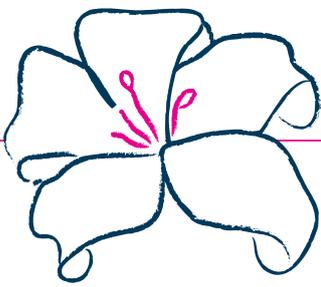
Over the past 13 years a key part of BCNA's mission has been to link Australians personally affected by breast cancer.

We welcome new Member Groups to our network. They now total 325.

New Member Groups:

- Albany Breast Cancer Group – Albany, WA
- Blossoms Breast Cancer Support Group – Sale, VIC
- BOOBS (Bunch of Open Minded Brave Sisters) – Cameron Park, NSW
- Border Breast Friends – Lavington, NSW
- Breast Cancer Support Group – Camperdown, NSW
- Breast Friends Support Group – East Melbourne, VIC
- Flamingo Belles – Wanguri, NT
- Grafton Night Time Breast Cancer Support Group – Grafton, NSW
- Holbrook Culcairn Cancer Support Group – Holbrook, NSW
- Mandurah Breast Cancer Support Group – Halls Head, WA
- Metastatic Breast Cancer Group – Randwick, NSW
- Pingelly Pink Ladies – Pingelly, WA
- Pink Finns Charity – Windsor, NSW
- Secondary Sisters – North Hobart, TAS
- Wagin Cancer Support & Palliative Care – Wagin, WA
- Women's Cancer Support Group – Emerald, QLD
- Women's Central Breast Cancer Support Group – Gwelup, WA
- Young Women's Breast Cancer Support Group – Randwick, NSW

To find Member Groups, including support groups, in your state or territory visit www.bcna.org.au > Sharing & support > Find a support group in your area.



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:

- Alison MacNeill, QLD
- Bakery Hill Friends Abreast, VIC
- Ballarat Clarendon College, VIC
- Bell Charitable Fund
- Bicheno Golf Club, TAS
- The Brasher Family Foundation, VIC
- Colleen Unger, QLD
- Christelle Coquet – Shades of Pink, VIC
- Chris Howlett and the Melbourne Piano Trio, VIC
- CWA Bunyip Night Owls Branch, VIC
- Debra Freeman, QLD
- Dunlop Flooring
- Elizabeth Hagen, QLD
- Emily Chang, NSW
- Ernst & Young Foundation

- First Class Hampers
- Friends in Pink, SA
- Gloucester High School, NSW
- Green Acres Golf Club, VIC
- Helen Douglas, WA
- Jacques Stap – Trip Around Australia
- Jellis Craig Run Melbourne team, VIC
- Lions Club of Goolwa, SA
- Lucy Anderson and the City of Eltham, VIC
- Lynn Brewster – Clover Cottage Luncheon, VIC
- Lauren Browne – Wallerawang Bowls Club, NSW
- Macksville High School, NSW
- Margaret Illman, SA
- Mary Crooke, TAS
- Michael Lucas, NSW
- Ming Tak Ng, NSW
- The Quill Club, VIC
- Patricia Ezy, NSW
- Petrina Burnett – Divas & Divos Concert, WA

- Peter McInnes Pty Ltd – KitchenAid
- PricewaterhouseCoopers
- Red Finch, Katie Woolway, VIC
- Robert Moerman, NSW
- Sandra Mitchell, ACT
- St Catherine's Primary School, VIC
- St Luke's Anglican School, QLD
- Sydney Women's Baseball League, NSW
- Theodoros Marinis, SA
- Toshiko Budgen, QLD
- Wanda Battel, VIC
- Woolworths Craigieburn Highlands, VIC
- Woolworths Plenty Valley, VIC

Thanks to the participants, fundraisers and organisers of: *SMH Half-Marathon*; *Sun-Herald City2Surf*; *Chevron City2Surf*; *The Age Run Melbourne*; *Gold Coast Airport Marathon*.

A special thank you to those who contributed during our once-a-year donation request in the Winter edition of *The Beacon*.

Memorials

We pay tribute to the lives of:

- Aninda Robertson
- Dorothy Lilian Gordon
- Heather Anne Earp
- Hilary Anne Manzin
- Monica Wilson
- Theodora Furfaro
- Ursula Irma Regelein
- Zelma Beatrice Smith

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:

- Maynell Grenfell
- Patricia Fielder
- Raymond Jelleff
- Verna Horsley
- Janet Betts
- Allison Fyfe

Workplace giving

With only 17% of our revenue from government, BCNA relies on community and corporate support to provide free services to Australians affected by breast cancer. Workplace Giving is a key program that contributes significantly to BCNA where employees donate regularly through their employer's payroll system.

Every employee's contribution adds up over time to make a real difference to our work.

Jon Saunders, General Manager Supply Chain at Collins Foods

Limited (CFL), has noted that many people donating regular small amounts can really make a significant impact:

'Since December 2008, Collins Foods Group (CFL) has encouraged our employees to support a charity that is important to them; we've found our employees really want to give back to those going through the breast cancer journey. Workplace Giving has been easy at our end as employees can make

contributions (pre-tax) directly through the CFL payroll system, and as a further incentive for employees to give, CFL matches all donations up to an annual cap of \$100,000.'

BCNA would like to thank the following organisations and their staff who take part in a Workplace Giving program:

- City of Boroondara, VIC
- Collins Foods Group
- Ernst & Young
- Konica Minolta

- Macquarie Group
- MLC
- NAB
- National Wealth Management
- UBS Australia
- UXC Australia
- Westpac
- Windsor Recruitment

If you would like more information on BCNA's Workplace Giving program, email fundraising@bcna.org.au or phone 1800 500 258.

Bringing *The Beacon* to you

There are many organisations that help BCNA to reduce our costs. They are our unsung heroes. One of these organisations is Australian Paper. Australian Paper donates the paper for every issue of *The Beacon* – saving us thousands of dollars every year. Australian Paper's CEO, Jim Henneberry, shares his thoughts about our partnership, and another cause that is close to his heart.

Australian Paper is proud to sponsor Breast Cancer Network Australia as it continues to provide crucial information and support for women with breast cancer and their families.

We are Australia's only manufacturer of paper and we understand our important role in helping BCNA share its message through *The Beacon*. We have donated paper to this cause for eight years and have continued to do so despite difficult economic times.

By supporting BCNA we are helping to raise awareness of breast cancer to Australians and also our employees by sharing *The Beacon* and holding an annual morning tea. In the past, this morning tea has provided some of our staff members the opportunity to connect with BCNA members and share their own personal and family experiences.

As part of our close relationship with BCNA we are also asking BCNA supporters to do something positive for the environment and Australian Paper by getting behind our recycled paper pledge at www.onpaper.com.au. We conducted a feasibility study into the construction of a \$90 million recycled paper plant at our Maryvale Mill in the Latrobe Valley, Victoria. This major investment would more than triple our current volume of recycled papers and divert up to 80,000 tonnes from landfill. It would also create and help secure local jobs. But to help get this project off the ground we



Jim Henneberry, CEO Australian Paper

need to demonstrate support from Australians to prove that recycled paper is wanted.

Help to secure our investment to BCNA and support

Australian manufacturing and jobs by signing our pledge at <http://www.onpaper.com.au/au-made-recycled-paper-pledge>.

Made with Love

Keep an eye out for a very special book that will be in Sussan stores this October to mark Breast Cancer Awareness Month.

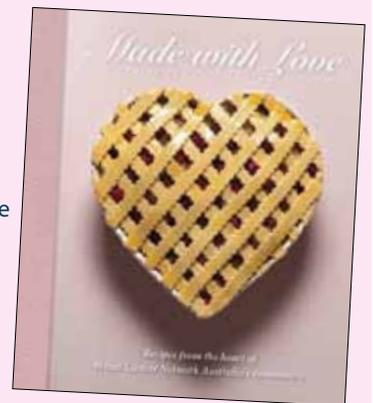
Inspired and authored by you, we have developed a beautiful hard cover recipe book called *Made with Love*. The book brings together hundreds of hand-picked recipes from BCNA women and celebrity chefs.

Each contributor has shared the background story to their meals, paying tribute to special times with family and friends. Some stories will make you cry; others will give you a giggle.

BCNA champion and celebrity chef Lyndey Milan has shared her favourite Greek recipe, and Raelene Boyle's rustic galette will be one to try.

The team at Sussan were inspired to start this project with us after hearing your stories about your friends filling your freezers with spag bol during treatment. We have featured recipes that are great to freeze and will be helpful for anyone wanting to help a friend in need.

These recipes – from the heart of BCNA's community – will be on sale in Sussan stores in October for \$34.95. BCNA receives \$15 from each copy sold.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Dates for your diary

Sunday 16 September Blackmores Sydney Running Festival, NSW. BCNA has been chosen as one of the supporter charities for this festival. If you would like to register to participate in this event and to fundraise for BCNA visit www.sydneyrunningfestival.com.au

Tuesday 2 October Free BCNA Gold Coast information forum. For more information and to register phone 1800 500 258. Places are limited so register early to avoid disappointment.

Tuesday 9 October Pink Lady Melbourne Luncheon. Great Hall, National Gallery of Victoria. Guest speakers: business leader Naomi Milgrom, Olympic legend Raelene Boyle, and BCNA CEO Maxine Morand. For more information and to book visit www.bcna.org.au/events or call 1800 500 258.

Friday 12 October Free BCNA Toowoomba information forum. For more information and to register phone 1800 500 258. Places are limited so register early to avoid disappointment.

Sunday 14 October Melbourne Marathon Festival, Melbourne. If you would like to register to participate in this event and to fundraise for BCNA visit www.melbournemarathon.com.au

Wednesday 17 October 6–7.30pm BreaCan presents a free session on Body Image, Self-Esteem and Sexuality After Cancer. Partners are welcome to attend. Queen Victoria Women's Centre, 210 Lonsdale Street, Melbourne. Bookings are essential. Phone 1300 781 500 or email breacan@breacan.org.au

25–26 October **Strength to Strength: BCNA National Conference 2012. Sydney Exhibition and Convention Centre, Darling Harbour, Sydney.** Registrations (\$250) close 22 October. Places are limited so register early to avoid disappointment. For more information visit www.bcna.org.au > Events > BCNA conferences > National Conference 2012 or phone 1800 500 258.

Sunday 28 October Pink Golf Day 2012. Held in partnership with the PGA of Australia, clubs are encouraged to get involved. Visit www.bcna.org.au > Events

Sunday 28 October Dragons Abreast Australia National Festival, Darling Harbour, following on from BCNA's conference. Enjoy a day out with your family, friends or work colleagues. Training is included. For more information or to register visit www.dragonsabreastfestival.com.au

17–18 November Profound Healing – Sustainable Wellbeing: The Gawler Foundation Annual Conference at the Sebel Albert Park, Melbourne. It features the latest research, evidence-based therapies, and practical tools for preventing and effectively managing cancer and chronic illness. Endorsed by Royal Australian College of General Practitioners (RACGP) and Royal College of Nursing Australia (RCNA). For program details and to book online visit www.gawler.org/conference or call 1300 651 211.

Sunday 2 December Sussan Women's Fun Run, VIC: 5 km and 10 km run or walk supporting BCNA. Catani Gardens, St Kilda, Melbourne. Cost: \$60 Adults, Junior \$50 (early bird entry fees available for entry before 3 October). For details and online entry visit www.supersprint.com.au

16–17 March 2013 'The Ongoing Journey' Tasmanian State Breast Cancer Conference 2013, Saturday 9.30 am to Sunday 1.30 pm, Hotel Grand Chancellor, Cameron Street, Launceston. Contact: email tasbreastcancerconference2013@gmail.com or mail: PO Box 8005, Trevallyn, TAS 7250.

Seeking stories – strength to strength

We are seeking stories for the Autumn 2013 issue of *The Beacon* about **strength to strength**. How have you grown over your breast cancer journey? What has helped to keep you strong?

Please email articles of 200–300 words (about half a page) to beacon@bcna.org.au by the end of December 2012.

We ask you to also include a high-resolution photo, or post your photo to us and we will scan and return it to you.

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 or visit www.bcna.org.au > Resources.



the BEACON

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If you wish to unsubscribe to *The Beacon* or *The Inside Story* please contact BCNA.

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