Isolated but not alone

Like the majority of Australians I have never lived in a regional or rural environment. From time to time over the years, I have thought about escaping to a pretty seaside town or moving to the country with a few acres. I love Melbourne and the things that come with living in a big city, and am lucky that includes access to a range of treatment and support services after my breast cancer diagnosis.

We know women living in rural and remote areas face very different challenges. The grant we receive from Cancer Australia Isolated but not alone has helped BCNA address the relative disadvantages, through improving access to information, encouraging supportive relationships and developing the capacity of rural and Indigenous women to take leadership and supportive roles in their communities.

This year BCNA has hosted free community forums across Australia, including in Port Lincoln, Sale, Ballarat, Cairns, Tamworth and Albury-Wodonga. We also connect women through our online network, offer quality information online, and provide support to women from rural and remote areas to attend events such as our Summit in Sydney.

Read more about the experiences of our rural and remote members who have shared their stories in this issue of The Beacon. Despite the challenges, there is a great sense of community, support and general resilience.

In November I represented BCNA members at the European Society of Oncology conference on Advanced Breast Cancer in Lisbon, which meets to set international guidelines regarding the treatment of advanced or secondary breast cancer. It was fantastic to participate in the organising committee for the patient advocate program and to witness the global dedication to improving outcomes in all measures for the complex and diverse challenges faces by women with secondary breast cancer. (See more on our website www.bcna.org.au)

As the year draws to a close we are busy planning our activities for 2014. Our membership continues to grow and we want to ensure we work as hard and effectively as possible to support the needs of Australians affected by breast cancer.

On behalf of everyone at BCNA my best wishes to you all for Christmas and the New Year.

Maxine Morand
Chief Executive Officer

Maxine Morand and Raelene Boyle in Ceduna with BCNA members.
Leaving home, family and friends is shattering. Being alone in a place you are not familiar with is so hard. It makes the breast cancer journey all the more difficult. – Judy

We know that for women diagnosed with breast cancer, living in a regional or rural area can create additional challenges. In particular, women living in these areas can be a long way from medical specialists and treatment centres, which are often located in cities and larger regional centres. Local services can be limited, which means that women have fewer treatment options or have to travel, often hundreds of kilometres, for treatment.

Living in a remote area limits your choice and has an enormous influence on your emotional wellbeing. – Mary

When access to treatment is limited, some women choose not to have the treatment that is recommended to them in order to avoid travel. For example, we know that some women decide to have a mastectomy instead of lumpectomy to avoid having to be away from home for up to six weeks for radiotherapy treatment.

What other option did I have? Travel to Adelaide and spend up to six months receiving chemotherapy and radiotherapy, staying in government accommodation, or remain at home with the support of family? Also, if I went to Adelaide, my husband would accompany me and have to take time off work without pay. – Mary

Recent Australian research has shown that travelling for treatment is the greatest disadvantage for those living in regional and rural areas, leading to financial hardship, inconvenience and social isolation.

In addition to the cost of travel, accommodation and living expenses while away, you may have to take time off work and pay for child care if you have young children. These costs further contribute to the substantial financial burden of breast cancer.

Patient travel schemes provide financial assistance to help meet the cost of travel and accommodation; however, the amounts paid are often inadequate and women can wait many weeks for reimbursement. As the schemes are run by each state and territory government, financial assistance differs by location.

Ask whether there is a welfare officer or social worker who can help you access support. – Marion, breast care nurse

While some women are able to have family with them during travel, this is not always possible. For women travelling alone, being away from their usual support network for long periods can leave them feeling isolated.

Phone, Skype, email and Facebook are just a few ways that women can keep in touch. There are also programs to help women keep in touch. Cancer Australia’s ‘Stay in touch’ program provides laptops with internet access to women and their families (visit www.canceraustralia.gov.au and type ‘stay in touch’ in the search field).

In Queensland and metropolitan Sydney, an organisation called Mummy’s Wish provides iPads to women with young children under the age of 12 (visit www.mummyswish.org.au > What we do > Our services).

If you and/or your partner are having trouble keeping up with the day-to-day running of your home, a breast care nurse, hospital social worker, GP, or the Cancer Council Helpline (13 11 20) may be able suggest financial and practical assistance available in your area. Your local council may also offer services that could help you, such as cleaning and grocery shopping.

Having experienced the isolation of being away during radiotherapy, it’s important to use the wonderful support around you – social workers, breast care nurses and doctors. – Wendy

Don’t be afraid to ask those around you for help. Family and friends often want to help but don’t know how. Be specific about what you need – cooking, shopping, or kids taken to sport. We often hear stories about the benefits of living in a small community, where others are happy to pitch in.

Being in a small community and the wonderful support from family and friends helped me get back to doing most things. – Elaine

Living in a small community can make it difficult to connect with other women diagnosed with breast cancer. BCNA’s online network connects women with others to share their experiences, regardless of where they live. Many women have used the network to ‘meet’ others in their area, only to forge strong friendships in person. To join, visit www.bcn.org.au > Online network.

Local breast cancer support groups are an excellent way to meet people and share experiences. To see if there is a group in your area, visit www.bcn.org.au > Find services & support near you.

BCNA’s ‘Financial and practical assistance’ fact sheet includes information about the benefits and services that may be available to you and your family. Download a copy from www.bcn.org.au > News > Resources > Fact sheets and booklets.
Ask the Expert

Heather Rogers

Heather Rogers is a breast care nurse in Cairns, north Queensland. Heather spoke to The Beacon about her role as a breast care nurse in a regional centre.

What types of support do breast care nurses provide to women?
Ideally we are connected to women when they are diagnosed, and we then see them through their treatment and beyond. Women are welcome to see us any time, even years after treatment is over.

We provide emotional and practical support to women and their families. We provide as much accurate information as possible to help women make decisions about their treatment. We tell women about the My Journey Kit and if needed, order a My Care Kit for them, which includes a free Berlei post-surgery bra. We can explain the treatments to women, and help them manage side effects of treatment such as nausea and fatigue caused by chemotherapy, and burns caused by radiotherapy.

Providing emotional support to women is an important part of my role. I talk things through with them, and can refer them to a social worker or psychologist if needed. I also refer women to other support services, such as a physiotherapist, if required.

Partners and family often need information and support during the breast cancer journey. I can provide them with support, or refer them to local support services.

What do you think is the most important part of your role?
There are many! Letting women know we are available to support them. We are also advocates for women. Women fall onto this ‘treatment treadmill’ and are exposed to jargon they don’t understand. We can attend their appointments with them and help them understand what is being said to them. We build a rapport with women that helps them feel secure. Women can come to us if they have questions or are uncertain about what is happening to them.

What are the main challenges for women in regional and rural areas?
The main challenge is travelling for treatment. Even though women may be reimbursed for travel and accommodation costs, there is still a huge out-of-pocket cost.

Women don’t have their regular support network while they are away receiving treatment. They can chat to family on Skype, but we know that it is not the same.

We know that there is sometimes a lack of support for women in their local communities. Women have a lot of contact with us during their active treatment. After treatment, family and friends think that women are ‘better’ but, of course, we know they face different challenges. During this time, support can be lacking and women can struggle.

BCNA’s online network is invaluable to help women connect with others at this time.

If you could give a woman one piece of advice, what would it be?
One is difficult! I always tell women to listen to their bodies. If you feel worn out, rest. If you feel pain, take painkillers.

How do you switch off at home?
I have had to work at it. I have learned to leave work behind and, at the end of the day, I turn my phone off and go for a run or walk. And I drink a little wine!

How can women find out if there is a breast care nurse in their area?
The McGrath Foundation’s website includes a directory of breast care nurses around Australia, not just McGrath nurses. Visit www.mcgrathfoundation.com.au.

Women who do not have a breast care nurse in their area are welcome to call the breast care nurse at the nearest hospital. Otherwise, they can seek support from a social worker or GP. They can also call the Cancer Council Helpline which is staffed by oncology nurses (13 11 20).

If you need to be away from home for radiotherapy treatment, you may be able to access Cancer Australia’s Stay in Touch program which is offered at a number of sites around the country. The program provides ‘buddy’ laptops and internet access so that families can keep in touch. For more information, visit www.canceraustralia.gov.au and type ‘Stay in touch’ in the search field.
The role of the rural GP

Women living in rural and regional areas sometimes find it difficult to visit their medical specialists when they need additional support and care. It may be difficult to travel a long distance to see your specialist, or to schedule an appointment when both you and the specialist are available.

In some cases, you may like to consider visiting your local GP. Women with breast cancer see their GP for a wide variety of reasons, throughout active treatment and beyond.

Your GP may be able to help you in the following ways:

- Discuss any side effects of your treatment and give you strategies and advice for managing them. For example, you may like to ask for help to manage side effects such as joint stiffness, vaginal dryness or hot flushes.
- Discuss and assess your emotional needs. Some GPs have specialist training in mental health and are experienced at providing psychological treatment. Your GP can also refer you for counselling by a trained specialist, such as a psychologist, social worker, counsellor or psychiatrist. Talk to your GP about whether you are eligible for treatment under a Mental Health Care Plan. This gives you access to up to 10 Medicare-subsidised appointments with a specialist.
- Develop a Chronic Disease Management Plan (CDMP). If a CDMP is suited to you, you may be able to receive up to five Medicare-subsidised appointments per year with allied health professionals, such as a physiotherapist, dietitian or lymphoedema practitioner. You may like to ask your GP about whether you are eligible for a CDMP.
- Arrange for referrals to specialised doctors if needed. Your GP will be able to tell you if you need to see your medical oncologist or another specialist for any reason.

Some women are concerned about their privacy in small rural and regional areas. You may see your GP in social situations or know members of his or her family. It is important to remember that GPs are obliged by their professional rules to keep your health information private.

New BCNA resources

Women often tell us that they feel shock, fear and uncertainty when diagnosed with breast cancer. We know that partners of women can also experience similar feelings.

BCNA has produced a new booklet, ‘I wish I could fix it’: Supporting your partner through breast cancer, which aims to help partners of women diagnosed with breast cancer within the last 12 months. The booklet includes information on breast cancer and its treatments, how partners can support the woman diagnosed, and practical tips to deal with some of the common challenges that they themselves may face. The booklet also includes information resources and counselling services available to partners.

If you have been diagnosed with breast cancer in the last 12 months and think your partner would like a copy of the booklet, you can view or download a copy at www.bcna.org.au > News > Resources > Fact sheets and booklets.

BCNA has also developed a series of videos where women with breast cancer share their experiences following their diagnosis. The videos include New diagnosis of breast cancer, Getting through treatment for breast cancer, Support following a diagnosis of breast cancer, Breast cancer and the family, Communicating with your family and friends, and Managing the expenses of breast cancer. To watch the videos, visit www.bcna.org.au.

While breast cancer in men is rare, we know that around 125 men are diagnosed with breast cancer in Australia each year. BCNA is developing a fact sheet for men diagnosed with breast cancer. The fact sheet will include information on breast cancer treatment and care, and practical tips to help them cope with common challenges that men with breast cancer face. The fact sheet will be available in 2014. Keep an eye on our website for it.
Tamoxifen benefits BRCA mutation carriers

Many women with hormone positive breast cancer will have received treatment with the hormone therapy drug tamoxifen.

As we reported in the last issue of The Beacon, clinical trials have shown that taking tamoxifen for five or up to 10 years can significantly reduce the risk of breast cancer recurring. Tamoxifen is also used to reduce the risk of breast cancer in women who have a strong family history of the disease.

New research led by Melbourne Medical Oncologist Professor Kelly-Anne Phillips has found that tamoxifen can also reduce the risk of breast cancer in women who are at high risk due to an inherited BRCA1 or BRCA2 gene mutation.

The international study recruited 2,500 women from Australia, Europe and North America who had an inherited BRCA1 or BRCA2 gene mutation and who had been diagnosed with breast cancer, and treated them with tamoxifen. The study found that their risk of developing a new breast cancer was halved. These findings give women who carry a BRCA1 or BRCA2 mutation a new option to consider in the management of their health. Until now, their options have been very limited – they could have surgery to remove their breasts and/or ovaries (as Angelina Jolie chose to do earlier this year), or they could have regular screening and monitoring so that if they developed breast cancer it was found early. Taking tamoxifen daily is now an option for these women to reduce their risk of developing breast cancer.

If someone you know has a BRCA1 or BRCA2 gene mutation and is interested in discussing ways to reduce her risk of developing breast cancer, she should talk to her GP or a counsellor at a Family Cancer Clinic. A list of Family Cancer Clinics can be found on the Cancer Council Australia website at www.cancer.org.au > About cancer > Causes of cancer > Family cancers.

Tribute Field of Women

Fifteen years ago, BCNA was launched with 10,000 silhouettes planted on the lawn of Parliament House, representing the number of women diagnosed with breast cancer in 1998.

In October, we planted 15,000 pink silhouettes in Sydney to represent the women diagnosed in 2013. Alongside them stood 2,700 white silhouettes for the women who will lose their lives to breast cancer this year, and 125 blue, representing the men diagnosed with breast cancer.

New messages of hope and inspiration were planted among the thousands of original silhouettes still carrying their poignant tributes from the past.

The event brought together our CEO Maxine Morand, founder Lyn Swinburne and Board members Megan James and Fran Boyle, along with support groups, members, family, friends and the general public.
Book reviews

Breast cancer: Taking control

by Professor John Boyages.
paperback, 367 pages,
RRP: $39.99 (+ $13 p&h)

The instant you hear the word ‘cancer’ lots of things run through your mind. Why, how, what next, what about my kids and family, what does that mean? Most of us turn to the internet to find answers to these questions, but the internet can be a dangerous place.

I have learned one thing along my journey, and that is every diagnosis of breast cancer is different. Everyone’s disease, treatment options, side effects and prognosis are different.

Breast cancer: Taking control is easy to read, either cover-to-cover or by the 20 control points ranging from shock and gaining control, to maintaining control. The author frequently lists appropriate websites to gain further information and includes relevant stories.

He uses a rose garden with a weed analogy to describe breast cancer, surgery and treatment options, and statistics. Relevant images and easy-to-follow charts and diagrams are used throughout the book. I was particularly impressed with the way he explained what the statistics really mean.

For those who like to make informed decisions, this book will help during each critical decision. The author, Professor John Boyages, has more than 25 years’ experience in the diagnosis and treatment of breast cancer. He answers many of the common questions including ‘How do I tell my children?’; ‘What will I do about my breast?’; ‘What are my options for Breast Reconstruction?’; ‘What does my Pathology Report really mean?’; ‘Do I need additional tests?’. There is a great section at the back of the book that lists relevant and important questions you should ask your treatment team. I wish I had this list at the start of my journey. So much information is thrown at you – it can get very confusing.

I would definitely recommend this book to patients, their family and partners.

Daniella Pager,
BCNA Review & Survey Group

One piece of advice

by Yvonne Hughes.
published by SOS Print, 2013
paperback, 128 pages,
RRP: $24.95; ebook $14.95

I thoroughly enjoyed reading this book. I found it incredibly easy to read – its format was simple, down to earth, brief, well organised and practical. It doesn’t discuss in detail different types of cancer, various treatments, or deciding what treatments you should consider. She simply says your doctors know best – go with their advice and don’t consider shortcuts. At diagnosis you have enough to worry about without having to decide on the best treatment yourself.

The book includes advice about accepting help when offered, whether it is to spread the word about diagnosis, clean the house, cook food, attend chemo sessions and appointments, look after children, etc. The author stresses you should always take any offers of help without embarrassment. People want to help you in any way possible. Other tips include how to deal with side effects of everything from surgery to nausea to lymphoedema to radiation burns. Plus countless other practical suggestions for everything from pre-chemo haircuts, to using a port instead of veins, temporary disabled parking permits, special underwear for different problems, radiation soaks and more.

I found this book uplifting and would recommend it to newly diagnosed women and those already undergoing treatment.

I still benefited from reading it two years after my diagnosis. It would also be useful for supporters of women with breast cancer with its handy tips on what not to say or expect at this time, and the little things that can make such a difference.

Cheryl Norman,
BCNA Review & Survey Group

For a limited time, BCNA members can save $18 on the award-winning book Breast cancer: Taking control by John Boyages. To take advantage of this special offer, visit www.breastcancertakingcontrol.com.au and enter the promotion code BCN at the checkout to pay $34.99 (including delivery).

Throughout December 2013, BCNA members receive a 20% discount when purchasing a copy of One piece of advice. Yvonne is also generously donating $1 from every book sold to BCNA. Order a copy online by visiting www.onepieceofadvice.com.au and entering the promotional code BCNA20 at the checkout.
The costs of isolation

Living in a remote area is something that is natural to me, as I have done so for most of my life. I currently live in (and grew up in) Katherine in the NT, 310 km south of Darwin. This year everything was great for my husband, our two young children and me until May when I was diagnosed with breast cancer. This was the first time in all my years living in the outback that I felt isolated.

My biggest challenge was having to travel to Darwin for all my treatment. Even for my diagnosis I had to travel to Darwin. My husband and I were too distraught to make the drive home and it was to become the first of many nights away from our children.

Overnight and day trips to Darwin are done without the children, but any longer and I insist that they come too which means a very increased price for accommodation. Having my children around gives me strength and helps them comprehend my treatment, rather than mummy just going away and coming home sick.

I’m currently having chemotherapy treatment. Every three weeks my husband takes two days off work so we can go to Darwin for my treatment. The three to four hour drive home afterwards is horrible. I’m lucky my mum is able to care for my children while I go for treatment. At the end of the year, I will have to relocate to Darwin for my six weeks of radiotherapy; this is taking some planning not to disrupt our lives too much.

Besides the travel and cost of going to Darwin for treatment, I am truly blessed to live in this town. I have been completely overwhelmed by the support of numerous people who have helped us in so many ways.

Anne-Maree, NT

You are not alone

In 2002 my husband and I moved to a beautiful coastal town after having retired. I decided to continue travelling to Melbourne once a year for my routine mammograms. We were settling in really well when I was diagnosed with breast cancer.

I had a lumpectomy in Melbourne and returned for annual check-ups. We continued to enjoy life until early 2011 when my husband was diagnosed with a terminal illness and was hospitalised on and off in Melbourne as well as Traralgon. I travelled often to see him and then at a routine mammogram was diagnosed again with breast cancer.

I had treatment again in Melbourne but the cancer this time was more aggressive and I needed chemotherapy and Herceptin every three weeks for a year as well as radiotherapy.

Travelling this time was extremely difficult as I didn’t have anyone to drive me. However, I learned that the Victorian Patient Transport Assistance Scheme could help me. I contacted them and to my relief was able to arrange transport. I was picked up by volunteer drivers and driven to Melbourne. They waited for me to finish my treatment and then drove me back home. They are such lovely kind people who give of their time freely.

When my husband passed away in January 2012, I found it very hard to continue with my treatment, but with support from my friends and family I was able to carry on.

I think I am very lucky to have such wonderful people I can turn to at any time.

Carmen, VIC
Ready, willing and able

Living in Bungawalbin, smack in the middle of nowhere, can make cancer treatment a bit of a challenge at times. Getting to my fifth chemo session, for example, was always going to be tricky. We were flooded in for an unprecedented third time this year, and I was obsessively checking the Bureau of Meteorology website in between bemoaning my fate on social media. Would the water recede in time?

Thank heavens for Facebook; a friend put up the phone number of the SES in response to my wails, with assurances that they solved these problems all the time. I made the call, and to my surprise it was pretty much a matter of ‘when would you like a chopper and where?’

Truly, it was that easy. Heaven bless Woodburn SES. And so on Wednesday morning I turned up at a neighbour’s place just as the helicopter landed. I’d been feeling pretty shocking, but when we took off ... wow! In my next life, I am so a helicopter pilot! Cancer? What cancer? I was overwhelmed by the joy of the experience.

And the pilot didn’t just push me out at Lismore Airport and take off again. He landed at the private terminal, saw that nobody was waiting for me and took off again for the main terminal. The co-pilot then escorted me all the way to the terminal doors to make sure someone was there to meet me, and assured me that if we needed a lift back all I had to do was call. In the end, I booked a return trip a few days later, and that was just as wonderful.

So ladies, don’t be afraid to ask for help if you’re stranded. Not only is the SES ready, willing and able – it might just make you feel a whole lot better about life.

Candy, NSW

A secret passion

We know the dramas involved with breast cancer and associated treatments can be quite a journey, and ‘journey’ takes on more of a literal meaning when you live in a rural or remote area. Since my diagnosis three years ago, there have been numerous trips backwards and forwards over hundreds of kilometres to different hospitals and medical specialists – an endless list of scans, tests and treatment. The one thing that has lifted my spirits and made me so very happy is where we live –

I wouldn’t swap it for quids. A pen-friend from the BCNA online network encouraged me to join the local brass band. It came about because I revealed a secret passion for music. I told her, ‘I couldn’t do that – I can’t read music, let alone blow a brass instrument!’ but my friend told me to go for it, so I did – and guess what? I am now reading music and playing with the band in public. It has brought me such happiness!

I have BCNA to thank too – it was the BCNA online network that introduced me to some amazing people. Through the tyranny of distance, I have found new friendships and a new life. Such support really helps when you have miles between ‘us and them’. After the chemo, etc., you find that the support drops off – especially if you live out in a rural area, but my ‘bestest’ BCNA buddy showed me there is always a wonderful new door to open somewhere, and it doesn’t matter how far you live from the big smoke – you are never alone.

Josephine, VIC
Flying for treatment

I live in Carnarvon, WA, where my husband and I run a banana plantation. It’s around a five-hour drive to Geraldton and a 10-hour drive to Perth. In 2008, less than a year after the birth of my youngest child, I was diagnosed with breast cancer and had a mastectomy, followed by six months of chemo. Immediately after surgery, luckily my mum was able to help out, but she lives a 15-hour drive away and was also caring for her own mother, so she looked after my baby at her home for a few months as I could not lift him in and out of the cot. Good old country hospitality kicked in for her, especially as more often than not some kind, thoughtful person delivered home-cooked meals to her and Dad. We also often had fruit and veg and home-cooked meals delivered.

I was delighted that halfway through my chemo the Patient Assisted Travel Scheme (PATS) changed its ruling regarding cancer patients and we were then allowed to fly without question; a real bonus, as the family didn’t have to drive me and could get on with their lives while I was having treatment and I could get home sooner before the side effects kicked in. Now the treatment is over I have found the courage to drive myself to Geraldton for my follow-up appointments, as the airline has cut back on the days they stop over in Geraldton.

I love living in the country and the kids love the freedom.

Debbie, WA

Thank you Red Cross volunteers!

‘Most people start to cry about now,’ bellowed my breast surgeon, after delivering the news that I had breast cancer. Perhaps I was in shock or perhaps I had no more tears to shed, because I already knew what the lump inevitably meant. One thing I did not immediately recognise however was the vast distances I would have to travel, week in, week out, to receive treatments over the next 14 months.

My husband and I are graziers in the south-east of South Australia and have two young children, so getting to and from Adelaide was going to be a huge challenge.

For the first three months of chemotherapy my husband diligently drove me the four-hour trip to St Andrews Medical Clinic and back home again.

But as we edged closer towards the end of the year and my treatments became weekly, we were relieved to discover the Red Cross Transport Service.

Naracoorte Red Cross volunteers Margaret and Bev drove me to my appointments, waited for the duration of my treatment, and then drove me back home. Instead of dreading the long journey and subsequent treatments, I actually looked forward to my day trips with the girls, which continued for nearly 12 months.

Overall, my experience of living in a rural area and dealing with cancer has been positive, and I have found if you try and keep an open and positive mind, there is an abundance of support for women with breast cancer.

Georgie, SA
Coffee and a chat really helps

I am 72 years of age and live in a small country town in eastern Victoria. I was diagnosed with breast cancer in 2010 and went on to have a mastectomy. I was one of the most fortunate ladies and thankfully ‘boob gone’ equals ‘cancer gone’. I decided to start a support group in our small township, by inviting ladies who have ever been diagnosed with breast cancer to join together for a coffee and chat once a month. With the group strongly supported by our local McGrath Breast Care Nurse, the very wonderful, capable and caring Di Gibbs, we have been able to offer comfort, companionship, understanding and some laughter and interesting activities to ladies in the surrounding area. Our aim is to have a guest speaker or an activity each month. The nearest support group is 20 km away, so our informal group has been quite a success story. There are now more than 16 women who attend whenever possible. We try not to offer advice, as that is the role of the breast care nurse and qualified practitioners, but we listen to each other’s tales of funny events or sometimes sad and trying times. Some days we don’t talk about breast cancer at all and this can be a welcome relief too.

Jeanette, VIC

A long way from family

I live in a large regional town and was diagnosed with breast cancer at the end of 2008. I had surgery, followed by treatment, at the local hospital. My mother was in a nursing home, and during the 18 weeks of chemotherapy, I continued to spend as much time as possible with her. I then had to travel to a major hospital 300 kilometres away for a planning appointment for radiation treatment. For that visit I stayed in a nearby motel. Finding more long-term accommodation was the next priority. Luckily, the hospital had suitable accommodation, but this could only be confirmed a week before treatment was due to start because of the high demand. During my radiation treatment, my mother passed away. Her funeral had to be scheduled around my treatment. To this day, I am still angry that breast cancer treatment took me so far away from my mother during the last weeks of her life. Radiation treatment is now available at our local regional hospital, which is a great achievement for the local community, but it is too late for my mother and me.

Bev, NSW
Getting back to the farm

At 60 and from a working cattle farm in north-east Victoria, I was diagnosed with breast cancer in 2012. Within a day I saw a breast cancer surgeon in Melbourne (two-and-a-half hours from home) and a mastectomy was scheduled for the following week. Four weeks later I was able to return to the farm. During that time, my husband Tony was only able to visit me twice, as ours is a working farm. After some problems best managed by staying in hospital in Melbourne, I recovered well and was able to return to the farm and my beloved cattle dogs and husband. I have done six months of chemo and have just finished my six-and-a-half weeks of radiation in Melbourne, again necessitating staying away from home during the week and only returning for the weekends. The travelling has been tiring and the journey a challenge. I am thankful the treatment has now finished and look forward to resuming life to some extent as normal as it can be. When you face an unexpected challenge like this, your friends and family shine through as enormous support through tough times. My toughest hurdle was coping with being so far from home. Supportive friends helped me cope and I am hopeful that I am now on the road to full recovery.

Judy, VIC

Community support made all the difference

We live in Charleville in south-west Queensland, 650 km from the nearest city of Toowoomba. When we moved there in 2008, it was the off year for the rural BreastScreen bus visit. I was due for a mammogram but thought I would wait until the bus visited in 2009. I was only 47 and we have no history of any cancer in my family so I figured it would be okay. However, my partner of 20 years insisted on driving to Toowoomba so I could keep to the scheduled visits. Just as well, because a lump was found in my right breast. This meant having to return to Toowoomba for two operations and then four weeks of radiation treatment. This was hard physically, mentally and financially. Initially, we had to stay in motels until we found a granny flat. As we were away from work we had to find ways to fill our time, as the treatment is only half an hour out of your day. We then had to return every three months for check-ups over the next year. We developed a distinct dislike for the Warrego Highway!

When we returned home we didn’t cook for a week as our friends rallied and provided meals for us. One friend even offered to do the housework. A small country town may be far away from health services, and it was tough going at the time, but the community support was fantastic.

Narelle, QLD

Grateful for all of the support

I live approximately five hours’ drive from Sydney. I was diagnosed with breast cancer in Sydney and chose to have my surgery there. Fortunately, I was able to stay with my daughter and her family. Chemotherapy was completed an hour’s drive away from my home and then it was back to Sydney for radiation. I found the cost of travel and accommodation, as well as being away from family and friends, very draining. Juggling work and leave entitlements was another problem as I am employed full time. However, I did have oodles of sick leave (thank goodness), although now I have none, so I have had to eat into my long service and annual leave.

I am very fortunate to have a wonderful and supportive circle of friends and family who looked after my animals and home in my absence. I received fabulous care from diagnosis through to treatment and follow-up – the breast care nurses still contact me after 18 months. I am very thankful to all involved in my journey including pilots, flight attendants and safe drivers on the road. Now it is just follow-up appointments, which means more travel, plus a Sydney physiotherapist for lymphoedema treatment, which is not available in my local area. My journey continues.

Julie, NSW
Introducing our Board members

BCNA’s Board is made up of 11 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. Here we profile two of our Board members so you can get to know the people behind the Pink Lady.

Megan James

How did you get involved with BCNA?

After being diagnosed initially in 1996, I was very frustrated at the lack of information and support for younger women. My oncologist suggested I participate in some science and advocacy training with the then National Breast Cancer Centre. It was during this training I met BCNA founder Lyn Swinburne and the rest is history!

I started volunteering for BCNA and chaired the organising committee for the first silent walk and Field of Women in the Domain in 2002.

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

For me it is a natural progression to now be involved in the Board. I’ve been with BCNA in all sorts of capacities since its inception so carry a lot of history and am compelled to keep working for all those women out there. The Board is a fantastic bunch of people, with a great cross-section of experience. What inspires me: it’s simple ... the women.

What changes still need to happen for people affected by breast cancer?

We just need to keep working and making it better. Reflecting on what has been done is quite inspiring. We’ve achieved a lot. We also need to continue to make this all easier for women in remote and regional areas, and to stay engaged with our member groups with current information.

Kathryn Fagg

How did you get involved with BCNA?

I first became aware of BCNA through my good friend, Andrea Hull, who is on the Board. At her invitation, I attended one of Raelene’s big birthday bashes a couple of years ago. It was a great evening, and I was really inspired by what BCNA does. Then, lo and behold, I was diagnosed with inflammatory breast cancer (IBC) mid last year. Andrea, and Lyn Swinburne, provided huge support during my treatment, which started with chemo. I am one of the fortunate people where Herceptin made a very big difference to my prognosis – so I’m deeply grateful for BCNA’s advocacy efforts.

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

When I was asked if I would become a Board member, I was very positive. I greatly admire BCNA’s work, and Andrea had told me how terrific she found both the organisation and Board. In addition, since I began treatment, I kept saying, ‘someone needs to fix the system’. Given my professional life has been about fixing problems, I realised that I needed to put my hand up and see if I could make a difference. Serving on the BCNA Board is a good way of doing so.

What changes still need to happen for people affected by breast cancer?

I was the beneficiary of fantastic medical treatment – and I would really like all Australians to be able to access that same level of treatment, regardless of where they live and their financial resources. I would like to see the whole process made easier and more holistic. And, of course, I hope the researchers can develop more targeted treatments that will reduce the need for tough regimes such as chemo.
Profiling our Member Groups

Young Women’s Support Group – Tamworth

Nichole Parry-Leahy from the Young Women’s Support Group in Tamworth represented the group at BCNA’s National Summit in August this year. Here she shares how her group supports others and what she gained from attending the Summit.

I joined the Young Women’s Support Group in Tamworth after my breast cancer diagnosis in October 2007. The group has 10 members aged from 37 to 60 years old.

The group has provided invaluable support to me and has given me the opportunity to give back and support others through their breast cancer journey. I know I can only do the best I can as a group leader and at the end of the day for me, if I have helped one woman by just being a support/friend who understands what she is going through, then that’s all that matters.

Attending BCNA’s National Summit gave me the chance to hear from some of Australia’s breast cancer experts on the latest in treatment, care and peer support. We also had an invaluable opportunity to network, share our experiences, and learn from each other.

The theme for BCNA’s National Summit was Support, Connect, and Grow, which pretty much sums up what we did. I love networking and catching up with friends and BCNA staff. I found that getting to know other group leaders who run a similar style of group made me feel like I was on the right track. We don’t fundraise as a group. When I started talking to some of the other women at National Summit I discovered that ours is not the only group with the sole purpose to support each other, and that that was okay.

The National Summit also focused on practical issues and aimed to help us run sustainable support groups. Session topics included living with the effects of breast cancer, running vibrant and effective support groups, and building resilient and effective community leaders.

I found the breakout sessions on breast reconstruction particularly helpful. I had opted for a lumpectomy so didn’t fully understand the challenges and choices that other women were making. I wanted to learn more about reconstructions so I actually had a better idea what other women were going through.

While Tamworth is a regional area, I feel lucky that we have a couple of options when it comes to treatment. Though some women opt to see a specialist in Sydney, the majority of women have surgery and chemotherapy here in Tamworth. When it comes to radiotherapy we have still had to travel three hours to Newcastle or five hours to Sydney. A new radiotherapy unit has recently opened in Tamworth and I hope this may now help to reduce the travel required.

In addition to regular meetings, the group gets involved in the famous Tamworth Country Music Festival each year to raise awareness of breast cancer and the support available through the group and BCNA. We hold a BCNA information stand and have had a BCNA float in the cavalcade the past couple of years.

Nichole (far right) with presenter Dr Kerryn Phelps and fellow Summit attendees.

Linking together

Over the past 15 years a key part of BCNA’s mission has been to link together Australians personally affected by breast cancer.

We currently have 305 Member Groups around Australia. To find one in your state or territory visit www.bcn.org.au > Sharing & support > Find a support group in your area.

If you can’t find a face-to-face support group in your area, consider joining our online network and connecting with one of our online support groups. We have more than 130 topic-based groups, including:

• Breast reconstruction
• Young women
• Triple negative breast cancer
• Inflammatory breast cancer
• Recipes you can taste
• Supporting a parent
• Partner support.

For more information, visit www.bcn.org.au > Network, 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:

- 8 Days Café – Jason Ennels and Ruairaidh Gunn, Vic
- AFL Victoria Country/SEDA Echuca Regional Primary School Girls Football Day – Mitchell McLellan, Vic
- Amelia Alliston, NSW
- Ballarat Clarendon College Players for Pink, Vic
- Beth Taylor and Peta Croft, WA
- Bride of the Year – Gwen Barr & Robyn Handel, NSW
- Canowindra Golf Club – Margaret Grant, NSW
- Deb & Pearl’s Pink Party – Deb Murray and Sandra Parker, Vic
- Donna Ann Moore, Vic
- Edith Shaw, QLd
- Faith Holbourn, SA
- Geelong Cycling Club – Heather Christmas, Vic
- Hastings Deering – Donna Miller, QLD
- Hampton Art Exhibition for Kids – Isabella Sewards and Owen Bowditch
- Home Hill Winery – Prue Cripps, TAS
- Innisfail Breast Cancer Support Group, QLD
- Jill Newton, Vic
- Joan Egel, SA
- Jog for Jugs – Peta Burton, QLD and WA
- Kym Frost & Committee, Vic
- Lynn & Carly Brewster, Vic
- Margaret Stevens, QLD
- Mary Reader, QLD
- Mathoura Girls’ Night Out, NSW
- Melissa McMillan, Vic
- Michelle Boxall, Vic
- Mount Hotham Alpine Resort – Belinda Trembath, Vic
- Narelle Breen, Vic
- National Council of Jewish Women of Australia – NSW & WA
- Pennant Hills Crafty Ladies – Robyn Handel, NSW
- Perisher & Thredbo Resorts – Helen Blackmore-Lee, NSW
- Pink in the Tropics, QLD
- Rainbow Beach Surf Lifesaving Club – Maree Van Oirschot, QLD
- RAWR (Raising Awareness With Rock), QLD
- Red Finch Boutique – Sarah Woolway, Vic
- Rio Tinto Wickham, Cape Lambert & surrounds – Taryn Higgins, WA
- Rotary Club of Jindalee – Mark Toil, QLD
- Seafood Central Shopping Centre – Sam DiCicco, SA
- Shed the Red – Rhiannon Dansey, QLD
- Shirley Gilmore, QLD
- Shirley O’Brien, NSW
- Springvale RSL – Barbara Richards, Vic
- Sue Harding, NSW
- Swap for a Cause – Jenni Eyles, SA
- Tasmanian Breast Cancer Network
- The Inner Wheel Club of Gayndah – Annemaree McGilvery, QLD
- Thirteenth Beach Ladies Christmas Golf Day – Lois Marriott and committee, Vic
- Victorian Pink Ribbon Ride – Terry Caffery, Vic
- Wentworth Community – Shirley O’Brien, NSW
- Willowbank Raceway – Terri Sander, QLD
- Women of Woodside – Ali Walmsley, WA
- Yvonne Hargreaves, Vic

We would like to acknowledge the Honan family and the Manildra Foundation for their generous donation and for supporting BCNA since 2006.

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

- Gerard Spence
- Julia Segal
- Noel Van Den Berg
- Peta Rix

Special Pink Ladies
To mark BCNA’s 15-year anniversary, Showcase Jewellers has designed a special sterling silver Pink Lady pin and pendant, each featuring a pink Swarovski zirconia. You can purchase these two very special items for $34.95 each, with $10 from every purchase coming directly to BCNA. To purchase you can go to www.bcna.org.au > Store > Merchandise.

Memorials
We pay tribute to the lives of:

- Alison Blackburn
- Amanda Rynne
- Annette McDonald
- Kaye Kay
- Annie Veal
- Janette Hoggett
- Jedda Berry
- Joan Cooney
- Diane Shears
- Kitty Barron
- Maureen Meikle
- Joanne Johnson
- Mary O’Loughlin
- Jennifer Weeks
- Sue McRae

We are grateful for the donations we received in their memory.
A gift to you from Berlei

Berlei gratefully acknowledges our partnership with Bakers Delight.

BCNA gratefully acknowledges our partnership with Bakers Delight.

We’re thrilled to announce a new benefit for BCNA members from our long-term supporting sponsor, Berlei.

Berlei has been proudly supporting BCNA since 2005, mainly through our My Care Kit program, which has delivered 80,000 post-surgery bras and soft forms to women affected by breast cancer.

Berlei is now generously offering our members a 40% discount* off the recommended retail price (RRP) of any products purchased online at www.berlei.com.au until 31 January 2014.

Berlei does not have your contact details, so to receive the discount, register and create an account on its website. Once you’ve selected your items, enter the promotional code BEACON40% at the checkout. Please note this discount does not apply for purchases made in store.

To check out the range or make a purchase, please visit www.berlei.com.au.

*Terms & Conditions

40% off for members only. Available until 31 January 2014. This offer may not be used in conjunction with any other offers and may be subject to special terms and conditions, including cancellation. % off applies to RRP of full priced items. % off not in addition to other discount or multi buy offers. Not available on gift cards. Not applicable on charity items. The coupon code must be entered at the cart for the discount to apply. Coupon expires 11:59pm 31/01/14. Discount only available to customers who are logged in with a registered Berlei account. While stocks last. Coupon code: BEACON40%.

Online network supports more than 10,000 members

We might not live close, but we are here! Only a couple of clicks away! – Jacky, inner regional Australia

Since it was first launched in 2010, BCNA’s online network has grown to now reach more than 10,000 members – all connecting, sharing experiences and supporting each other at any time of the day or night.

It’s an easy way to connect with other people who have ‘walked in your shoes’ from the privacy of your own home and without the constraints of time and distance.

The online network is particularly useful for women living in rural and remote areas, and for those who feel more comfortable sharing their thoughts and experiences in a secure online environment.

It’s a great way to find support not only during your active treatment but through the ups and downs of side effects, going back to work, dealing with anxiety and depression, fear of recurrence, reconstruction, and living well after breast cancer.

I have been overwhelmed with the help and loving support I have received since I was diagnosed. This online network helps so much as well, as everyone here understands the challenges involved. – Janet, BCNA online network member

Joining the online network is easy. Visit BCNA’s website www.bcna.org.au and click on the green ‘Join our network’ button at the top right of the screen.

BCNA’s online network allows you to:

• set up a personal profile
• share your story and maintain a blog
• search for and find others with similar experiences
• create and join online interest and support groups
• control your privacy settings and what information you share.

Visit www.bcna.org.au > Network for more information or phone 1800 500 258.
Pink Lady highlights

We are always thrilled to see our Pink Lady out and about! From a single BCNA member taking a silhouette on a memorable trip to groups coming together to pay tribute and raise awareness. A special thank you to everyone who hosted a Mini-Field of Women in local communities this year.

Seeking stories – When treatment is not the only obstacle

We are seeking stories for the Winter 2014 issue of The Beacon about some of the sorts of challenges you faced during your journey. Perhaps your cultural background, gender, age, sexuality or rare type of cancer impacted on your experience? The stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell 3124 or emailed to beacon@bcna.org.au by the end of March 2014. Please also include a high-resolution photo.

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.