As well as all the other difficulties we face when we’re diagnosed with breast cancer, women in rural and remote Australia encounter unique challenges due to distance from treatment centres. Often this means missing out on the full range of treatment options or having to travel for many hours to get the treatment needed.

Separation from families and supports is another common experience, as is stress associated with costs of travel and accommodation. Travelling to big cities for treatment can be daunting, especially when women aren’t sure of how or where to find the practical help or support they need.

Lorraine wrote to us saying: ‘I’m lucky to receive great information through BCNA, but a downside is that it makes me realise how little we have in rural areas compared to major centres or big cities. For example, there is no Dragons Abreast group here – there is no water! There is no encore program either. We have a local public pool but it is not heated or open during the winter months.’

When I’ve travelled to places away from major cities and regional centres, I’m always struck by the sometimes overwhelming difficulties faced by these women following a diagnosis. I am also struck by their courage and determination to make the best of things. As if facing a horrendous drought isn’t enough!

On the other hand, sometimes the support offered in a small country town is far greater than that found in some suburbs of big cities, where people might not even know their next-door neighbours.

In this Beacon, we have included some of the pieces sent in to us from women living off the beaten track. They help us to understand what the issues are and what might be needed to help these women. For BCNA, the important thing is that when we’re advocating for better services and care, this means for ALL Australians. We must keep our rural ‘sisters’ and their families top of mind when we work for improvements.

Lyn Swinburne
Chief Executive Officer

At the Field of Women in Wollongong – Melanie Griffiths, Narelle Gardner and Melissa Hopkins from Bowral in the Southern Highlands of NSW, who were diagnosed within months of each other

We wish all readers a happy, safe and healthy Christmas and New Year.
From Darwin in the top end down to Bicheno in Tasmania and across to Karratha, 1,557 km north of Perth in WA, a record number of Mini-Fields of Women were held in communities across Australia.

The 2006 theme was Our Journey, raising awareness of the journey that affects not only the women, but their families, friends and communities.

Schools and children were involved in a number of Mini-Fields. Girls at Danebank Anglican School for Girls, Hurstville, NSW held their Mini-Field to remember and honour parents and teachers who have survived breast cancer and those who have died.

The Four Cee’s Group (Cancer, Chicks, Coffee, Chat) in Eltham, Victoria, involved the walking school bus in its Mini-Field and the Tiddleywinks Playgroup held a family picnic with children’s activities along with its Mini-Field.

A number of men held Mini-Fields this year too. Michael White held a large community Mini-Field at the Campbelltown Sports Stadium in NSW and Arthur Kunde worked closely with Jo Weller on the Kilcoy Mini-Field in Queensland.

Mini-Fields were held by old and new supporters. Mini-Field veteran Jurina Demaine and the Caboolture Breast Cancer Support Group in Queensland held their fourth Mini-Field of Women at the Burpengary Community Hall, which included performances by local bands. The
West Wyalong Ladies Cancer Support Group in NSW held their very first Mini-Field at McCann Park.

Mini-Fields were also held in a number of capital cities across Australia with Women’s Network Australia incorporating Mini-Fields into their corporate member luncheons in Melbourne, Sydney and Brisbane.

Pulteney Grammar School held their event in Adelaide while St Mary’s College and the Royal Hobart Hospital held Mini-Fields in Hobart.

NT’s Mini-Field was held on the lawns of the Royal Darwin Hospital.

Dragon Boaters in the nation’s capital again held their Mini-Field on the banks of Lake Burley Griffin at Commonwealth Place.

2006 saw Mini-Fields in rural and remote areas of Australia. Kalbarri in WA demonstrated tai chi and held a parade of bras modelled by brave women representing every generation from teenagers to women in their 70s.

Mount Isa and Weipa in Queensland, Dubbo in NSW and Oodnadatta in SA were among

Continues over page
Breast Cancer Network Australia

the remote locations and regional towns to hold Mini-Fields.

Val Weir and Karen Martin in the NSW town of Young joined forces to hold a Mini-Field in the town centre with the Bakers Delight bakery providing morning tea and lots of support for the event.

Our thanks to Australia Post and Bakers Delight. Their generous support has helped to make this our most successful year yet!

The pink lady in Cyprus

Our pink lady symbol is being incorporated into advocacy and awareness efforts on the other side of the world.

Cyprus held its first Field of Women last year. In its recent second Field, pink ladies stood proudly on the Byzantine Wall that surrounds old Nicosia. They remained there for a week, with special permission from Nicosia’s Archaeology Department.

In conjunction with the Field, Members of the Cyprus House of Representatives held a ceremony on the steps of the Town Hall and then joined women for a Silent Walk to the Byzantine Wall. The walk was led by Stella Kyriakides, President of our sister group Europa Donna Cyprus, who is now a Member of Parliament.

It’s exciting to know our much-loved symbol also has special meaning so far from Australia.

A big thank you to all the Mini-Field convenors and their organising committees

The list of people to thank is now too big to print in the Beacon. We would love you to visit our website www.bcna.org.au to see more great photos, to experience the extraordinary variety of events that took place in 2006, and to acknowledge the people who made these events happen in communities across Australia.

A list of Mini-Field locations and convenors is also available by contacting the national office.
More than 1,000 people came to support the 2006 Regional Field of Women in Wollongong on Sunday 22 October.

In a moving tribute to those in their local community who had been affected by breast cancer, the NSW coastal town planted a total of 14,800 silhouettes. The Field of Women is a very visual way of bringing breast cancer statistics to life. The 12,000 pink silhouettes represent the number of women in Australia diagnosed this year; the 100 blue silhouettes the number of men; and the 2,700 white silhouettes the number of people who die each year from the disease.

The event began with a walk through the town centre, which arrived at WIN stadium to a wonderful array of local musical talent and messages from breast cancer survivors. The significance of the event was felt by everyone who read the powerful messages of remembrance and support on the silhouettes.

The Organising Committee did a fabulous job involving many local community groups. We heard many stories of courage and survival.

Here are just a few photos taken by Ron Townsend at the Field. More photos are on our website www.bcna.org.au.
Breast Cancer Network Australia

Rural and remote issues around Australia

We need your ideas!
Calling all readers in rural and remote areas: we need your tips! BCNA is putting together a tip sheet for women travelling to major centres for treatment. Tell us what worked for you or what practical things could have made life easier. Email your thoughts to beacon@bcna.org.au or post to 293 Camberwell Road, Camberwell, Victoria 3124.

Members of BCNA’s Rural and Remote Working Party collected stories from women around Australia for this Beacon. These stories offer insight into the lives of rural and remote women with breast cancer and some of the issues facing them.

Facing significant issues in the West

Kalbarri is on the Murchison River mouth in the mid-west of Western Australia, 600 km north of Perth. It is a beautiful place to live but not such a beautiful feeling when lengthy medical treatment means travelling to Perth and living away from family, work or business.

Most women are able to make treatment choices, but some might choose not to have all the recommended medical treatment because they can’t spare the time away.

Women with their own businesses find it financially difficult – even impossible – to leave Kalbarri for any length of time. Others find it difficult to leave family behind for treatment, and some find it even harder to take them along. I know women who have decided not to have treatment, such as radiotherapy, for these reasons.

My husband was able to look after our business when I stayed in Perth. I also made the most of things by visiting places, going to the movies and lunching with friends. But some women who travel to Perth aren’t accustomed to city driving, and may not have friends or relatives to help them. The experience for them is not as positive.

There are many benefits in living in a small and remote community. Being diagnosed with breast cancer means being as resourceful and resilient as you can.

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Mt Isa seminar

More than 40 women, including BCNA’s Queensland State Representative Veronica Macaulay-Cross, attended the Breast Cancer Association of Queensland’s annual rural breast cancer seminar in the mining town of Mt Isa in July. Both Townsville and Alice Springs are about 10 hours’ drive from Mt Isa.

Patients travel to Townsville for radiotherapy, however chemotherapy can be given at Mt Isa’s well-equipped base hospital. The tyranny of distance adds extra challenges to women already confronted by a breast cancer diagnosis.

Rural issues attract TV attention

The story of Chrissey Newton, a long-term breast cancer survivor, and her family was included in the Four Corners ‘Far from Care’ program. Screened on the ABC in June, the program explored the personal side of country Australians who are far from care. The transcript is available at www.abc.net.au/4corners.

‘Diagnosis meant several trips away from my family. I had to find someone to look after the kids and my husband, and to help around the property – and with the dogs and the cattle – all in the middle of a drought.’

Cathy

Join our Rural and Remote Working Party

The Rural and Remote Working Party is made up of two Representatives from each state and territory. We are now seeking women from Western Australia, Queensland and South Australia to become involved. Please contact Terri Smith, Rural and Remote Working Party coordinator, on 1800 500 258 or email beacon@bcna.org.au.

Some of the Members of the Rural and Remote Working Party: Vivienne Gregg, NSW; Anna Wellings Booth, ACT; Pauline Venn, Vic; Marlene Parsons, Vic; Lesley Reilly, NT with Jane Redmond, NSW

Margaret Burges, Kalbarri, WA
Details make a difference

In 2000, I underwent seven weeks of radiotherapy in Melbourne. I moved there for the treatment, something I had done once before during my first breast cancer treatment. My two young boys stayed with their Nan and Pa near our home in eastern Victoria.

The care I received was exemplary but there was that persistent image of being in a bunker far beneath the ground. The waiting room was small; its walls lined with uncomfortable chairs.

The new Cancer Care Centre at Latrobe Regional Hospital in eastern Victoria was opened mid-year. Here, patients spend their time in a large waiting room, bathed in natural light, with local artwork hanging on the walls. Large, comfortable chairs are positioned in clusters around the room and a wet area provides coffee and tea facilities. There is a patient’s retreat for privacy when needed.

We cannot change the treatment regimes that are necessary in helping us fight this disease; but by providing high quality rural-based services we can make the journey a little easier.

Marlene Parsons, Loch Sport, Vic

Rural health professionals get together

I coordinate a group of health professionals in the greater southern area of New South Wales. Our area extends from Canberra, north to Goulburn and Crookwell and west to Young and on to the Riverina area of Wagga Wagga and Albury. It extends south from Bateman’s Bay to Bega and into the Monaro area, including Bombala and the Snowy Mountains.

Our group is an invaluable forum for networking, involving people with an interest in breast cancer care and coordination of services. We are an advocacy group that seeks to be an information and advisory resource for programs and services. We try to make sure that national guidelines for the treatment and care of women with breast cancer are followed by health professionals throughout our region.

Annie Flint, Batemans Bay, NSW

Local initiatives highlight useful strategies

Earlier this year BCNA Consumer Representative Helen Collyer attended a National Workshop that reviewed the impact of the Strengthening Support for Women with Breast Cancer (SSWBC) program.

Funding had enabled developments that focused on coordination of care, access to support services, access to information for both women and health professionals, professional development needs of health workers, and continuity of care. Approaches varied considerably across the states and territories. The local initiatives highlight a range of useful strategies for improving services. It is clear that there is still a long way to go but that the work from the SSWBC does provide some building blocks for better rural care.


Waiting in north-west Tasmania

I have heard many stories from women in north-west Tasmania – both positive and not so good. Lynne, from Burnie, knew that early diagnosis for breast cancer was vital and yet she had to wait six weeks for her mammogram and ultrasound.

Lorraine, from Ulverstone, enjoyed her stay at the hospital in Launceston for radiotherapy. She met three other women with breast cancer and missed their company when she returned home. They are now firm friends.

Waiting times at hospitals and clinics are a source of dread when you have to travel long distances for treatment, especially when you feel that services should be available locally. Rural communities raise millions for medical equipment but that often doesn’t translate into services nearby. Surgeons and other specialists can leave rural facilities for bigger centres, and this has a tremendous impact on patients with whom they have strong relationships.

Anne Cameron, Wynyard, Tas

“We need a physiotherapist in the public health system for the management and treatment of lymphoedema. We also need funding for breast care nurses in our region.”

Anne

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“We need a physiotherapist in the public health system for the management and treatment of lymphoedema. We also need funding for breast care nurses in our region.”

Anne
I had been a resident of Alice Springs for around 30 years when my secure world was rocked by a diagnosis of breast cancer in late 2004. Pathology results from my mastectomy returned as HER2-positive early breast cancer. The promising news from trials of the drug Herceptin offered new hope – but at enormous cost.

I went public about my breast cancer in mid-2005 in support of other women faced with the same dilemma.

As a result, I found I had wide community support behind me, whether it was someone inquiring about my health or assisting financially towards costs of Herceptin treatment. If I was living in a larger city, instead of an isolated town in central Australia, I doubt I would have had the same degree of support, which has made the journey easier.

Raelene Treis, Alice Springs, NT

Warming up for their walk in the 2006 Alice Springs Masters Games: At front: Jeannie Lewis, Liz Locke and Noel Harris, and bringing up the rear, Lesley Reilly (partly hidden), Sheree Zaleski and Wave Hayden

The region of Alice Springs covers over a million square kilometres and has a population of 54,000: half in Alice Springs, the remainder widely dispersed in small towns, remote communities and on cattle stations. People often travel many hundreds of kilometres on rough dirt roads to reach Alice Springs.

Our oncologist visits about every three months. When there are delays with appointments our Aboriginal patients may have to return to their communities on the single available transport option, and so miss out.

We treasure our committed health care professionals but face ongoing problems with recruitment and retention. We have the highest turnover rate in the country.

We are 1,500 kilometres away from both Darwin and Adelaide. In many respects, the Centre has a stronger health care relationship with Adelaide services than with Darwin. Adelaide has Greenhill Lodge, a very well-run accommodation facility. Many women stay there during their radiotherapy or other treatment. There is a proposal to build a radiation oncology unit in Darwin, and while this will be a blessing for cancer patients in northern Australia, it may have implications for patients in Alice Springs. If women from the Centre have to travel for treatment, it is important that they can choose where to go.

Lesley Reilly, Alice Springs, NT

Support from local community

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Raelene Treis, Alice Springs, NT

Raelene Treis (on left) with Margie Brown

‘One woman decided to have a radical mastectomy (when a lumpectomy was recommended) because her husband had his ribs broken by a steer and she couldn’t leave him to manage on his own if she had to have further treatment. Two weeks later, with drains still in, she was on the back of a truck lifting hay bales to feed stock!’

Jane

Unexpected highlight

Travelling to Wagga from Hay for radiation treatment was a highlight of my breast cancer journey.

I treated it as an adventure rather than thinking about it in a negative way – although at the end of the day I may be out of pocket after sightseeing and shopping in a big city!

I sometimes forgot that I was sick; my mind was mostly occupied with good things around me like staying in great accommodation with great hospitality – and developing friendships with people I met along the way.

I would spend only a few minutes at the hospital for treatment, and would look forward for my walk around the city, taking in the scenery and even catching a bus to see the suburbs. I will always treasure that time.

Maggi Ford, Hay, NSW
More than 140 breast cancer survivors representing our Member Groups, State Representatives and Working Parties attended BCNA’s Summit 2006 in Sydney from 11 to 13 September. Delegates came from every state and territory in Australia. It was a significant undertaking that proved to be an exciting and worthwhile event. The Summit ran over three information-packed days giving delegates an opportunity to learn more about BCNA’s work and to share ideas, laughs and tears. Highlights included the Consumer Representatives session, where Marie Polla-Mounter, Vivienne Gregg and Kerri Guy demonstrated how they influence decision making and ensure consumer voices are heard. Also powerful and moving was the session on living with secondary breast cancer, with personal accounts by Maria Waters and Veronica Macaulay-Cross.

The experts panel session was extremely well-received by delegates eager to know the latest in treatment and care. This panel included Dr Fran Boyle, Professor Kate White, Associate Professor Judy Kirk and Dr Katrina Moore, and covered topics from multidisciplinary care to psychosocial support. It was an inspiring and memorable few days for all who attended!

BCNA and the Country Women’s Association of Victoria are working together to promote the My Journey Kit. At the Country Women’s Association of Victoria’s quarterly State Council Meeting in September many of the 70 group presidents were keen to promote the Kit.

BCNA looks forward to working closely with CWAs in all states and territories to spread the reach of the My Journey Kit into rural and regional areas across Australia. More than 18,000 My Journey Kits have now been distributed since its launch in May 2004.

Participants at our successful National Summit in Sydney

Research update

BCNA Consumer Representatives were among the 80 breast cancer survivors who attended the National Breast Cancer Foundation’s (NBCF) 5th Annual Breast Cancer Research Update in Sydney in September to hear about the latest in NBCF-funded research.

What’s new in breast cancer research? Attendees heard about innovations in treatment research involving parts of the immune system and dendritic cells. We also heard about viruses, like the common cold, which have the potential to destroy cancer cells.

While some of these developments are far off, others may be closer. In the short term, for example, we are likely to see improvements in computer-aided detection of tumours. In the medium-to-longer term, there may be research advances in what are called the ‘bio-markers’ of breast cancer (blood and genetics) with breakthrough drugs for increasing numbers of identified genetic predispositions.

‘I found the variety of the different research programs presented today to be extraordinarily,’ said one woman who attended. ‘Researchers are working on such diverse areas but are united in wanting to understand breast cancer and how to find better treatments. As a survivor, it is enormously reassuring to know that this is going on.’

Louisa Shepherd, BCNA’s My Journey Kit coordinator, with CWA’s Victorian State President Noela Macleod and group presidents
I am an inquisitive person by nature, so it was little surprise that I signed up for my first mammogram when the mobile unit visited Omeo in December 2004 – the year I turned 40.

A lump was detected and could be felt in my right breast. Twelve days later I was called to the Latrobe Valley hospital. My home in Benambra is four hours’ car travel from the hospital. The hospital – in recognition of the distance from home and the early appointment time – provided motel accommodation the night before. I was grateful for this gesture and was amused by its location. The motel was behind the Traralgon Funeral Directors!

I was not so amused when I received a breast cancer diagnosis that would require surgery, chemotherapy and radiotherapy – the latter being in Melbourne. I drove home alone with Gretchen Wilson’s song ‘We are here for the party’ playing on repeat on my car stereo.

Things really started to sink in once back in the sanctuary of my beloved mountains and in the privacy of my home. I have a life-threatening disease, but it is treatable. I need to have all this treatment to offer the best chance of beating it. But where is the best place to do this? And – most significantly as a sole parent – what about the care of my child who needs me to cope and manage his high-functioning autism?

I made the decision to receive all my treatment in Melbourne because it offered the least amount of disruption to my son’s life. It was also a complete treatment package, something that could not be found in Gippsland at the time.

Accommodation was the next hurdle. The hospital could offer accommodation for me alone, but would not take my son. I do have family in Melbourne, but I preferred to be independent. A social worker put me onto a Lions Club house that aided country travellers. However, six weeks was the maximum duration there, and I needed a stable environment so my son could attend school and after-school care at times.

A friend offered me his house in a semi-rural location. Having wide open spaces meant a lot to me. The only catch was I had to vacate every Wednesday night and every second weekend to allow access visits with my daughter. This presented a few problems when my health was bad during chemotherapy, and I had to find somewhere else to go every second weekend.

I took advantage of the generosity of the Otis Foundation on two occasions for weekend accommodation and visited with friends on others. Occasionally I would return home for the weekend, but with six hours’ travelling time each way this took its toll. The most important thing was that my son and I remained together.

Once home it hit me hard that there is a real shortage of city accommodation that allows families from rural and remote areas to remain together. It’s hard to know what’s available, let alone what’s suitable. How can we put together what’s out there? How can we make sure women in rural areas know so they can plan their treatment trips? These questions need a coordinated response. I am a member of BCNA’s Rural and Remote Working Party and am passionate about, and committed to, keeping this issue on the agenda so that things can be better for women travelling for treatment.

Editor’s note: The Otis Foundation’s bushland retreat – two furnished self-contained units, on land in the Mandurang Valley near Bendigo in central Victoria – is a place of sanctuary at no cost for those living with breast cancer. Telephone (03) 5439 3220.
First, what’s an aromatase inhibitor?

Aromatase inhibitors are a hormone therapy for postmenopausal women with hormone-receptor-positive breast cancer. Aromatase inhibitors can be used instead of tamoxifen — or sometimes as an alternative after a period of time on tamoxifen. While tamoxifen can lead to side effects like hot flushes, vaginal discharge and vaginal bleeding, aromatase inhibitors show fewer of these side effects but can cause bone mineral loss.

You might have heard of these aromatase inhibitors currently used in Australia:
- anastrozole (Arimidex)
- letrozole (Femara)
- exemestane (Aromasin).

Guidelines now out

The National Breast Cancer Centre has released clinical practice guidelines for the use of aromatase inhibitors. Importantly, the guidelines summarise evidence drawn from research around the world that has tested the effectiveness of this group of drugs. Sue Timbs represented BCNA as the Consumer Representative on the committee that developed the guidelines.

Recommendations

The new guidelines recommend that most postmenopausal women with hormone-receptor-positive breast cancer take aromatase inhibitors.

- At high risk of recurrence: An aromatase inhibitor rather than tamoxifen
- At high risk who have been taking tamoxifen for two to three years: A switch from tamoxifen to an aromatase inhibitor
- At low risk of recurrence: Continued use of tamoxifen unless it causes considerable side effects

New drugs approved for subsidy

From 1 December Femara (letrozole) and Aromasin (exemestane) will be subsidised through the PBS for use in early breast cancer. From 1 October access to Taxotere (docetaxel) through the PBS has been extended to include women with node-positive breast cancer and women with HER2-positive early breast cancer. Taxotere had previously only been subsidised for women with secondary breast cancer.

Arimidex (anastrozole) is already funded. It's good to see these breast cancer drugs funded through the PBS. An increased range of funded drugs means that women have more treatment options.

BCNA gratefully acknowledges our partnership with Bakers Delight.
Herceptin now funded

After our long campaign for Herceptin funding for women with HER2-positive early breast cancer, we were delighted to see the PBS subsidy implemented on 1 October. While Herceptin is no miracle cure it is an important treatment option for some women.

The long hard fight was well vindicated by the emails and letters we received from women around the country when they learned that, at last, the drug would be available to them.

Comments included:

‘On behalf of my family (which includes six sisters) and myself, we thank you all at BCNA from the bottoms of our hearts, for your help and commitment to this cause. It is such a relief that this campaign has finally achieved a fantastic outcome, not only for me, but for other women (and men) who may follow this journey.’

‘Hooley dooley, you guys are amazing. There is no substitute for patience, sheer guts and determination! Congratulations to all of the team!’

‘I can’t tell you how much I appreciated being kept informed with your emails about funding for this drug. Your email yesterday was great news and a good way for me to hear it first. Many thanks for your efforts to date and I can assure you this decision will make a big difference to me and I am sure, many other women and their families.’

‘Well that has just made our day! We were “looking forward” to shelling out $4,000 on Thursday for the loading dose of Herceptin, so now will treat ourselves to something nice.’

‘God bless you – if you hadn’t sent that I wouldn’t have known. I was going back to my oncologist at the end of October and would have missed out.’

We thank the many people who worked to help secure funding and all the women who shared their stories.

One more step

Roche has proposed an extension to the PBS listing to include the option of Herceptin treatment for women following their chemotherapy. Currently women starting Herceptin will only receive the PBS funding subsidy when Herceptin is taken at the same time as their chemotherapy. Some women had hoped to have the choice of subsequent rather than concurrent treatment. The proposed extension will benefit both these women and some women who may have missed out because of timing. BCNA supports greater treatment choices for anyone dealing with breast cancer.

SNAC2 trial – now recruiting

Some readers will remember the SNAC trial that tested removing the sentinel node (rather than lots of underarm lymph nodes) as the way to determine if breast cancer has spread to the underarm. The sentinel node procedure has fewer side effects. As a result of the trial, sentinel node biopsy is becoming more accepted for smaller single tumours, however axillary clearance (underarm lymph nodes removal) is the current standard operation, particularly for women with larger or multiple tumours.

Women with tumours over three centimetres, or with more than one tumour, were not eligible to participate in the SNAC trial. SNAC2 – a further trial – will consider whether the sentinel node process is as effective as axillary clearance for those women with larger or multiple tumours. This trial is seeking participation from newly diagnosed women with breast cancer, who have not yet had their surgery. SNAC2 will better inform women and surgeons about the risks and benefits of sentinel node biopsy in a wider range of breast cancers. For more information contact the SNAC2 Trial Coordinator on (02) 9562 5049.

Although the world is full of suffering, it is full also of the overcoming of it.

— Helen Keller
Heartsongs in the Key of C

Heartsongs in the Key of C: Women Writing About Breast Cancer, hard cover, 267 pages, 0 9775529 0 0, $24.95, published by Kate Carey Productions.

Available through bookshops (some may have to order it in), through www.everycloud.com or by emailing katecarey@overthefencepress.com.au.

Heartsongs in the Key of C is a book of stories, poetry and descriptions of important moments in the personal journeys of a group of women. Each author has experienced breast cancer either personally or they have shared the journey with someone close. This book is 259 pages of pure gold. Collated in a writing project that spanned four years, the pieces are a product of nine workshops from around rural Victoria plus one in Melbourne. They were attended by 94 extraordinary women. The project was managed and nurtured by Marlene Parsons and Sharyn Dickeson and the workshops facilitated by Christine Gillespie. Together with their many other supporters they must be congratulated.

The book is illustrated by Judy Horacek’s ‘The pond of tears’ and divided into sections arranged around six frames. These illustrations roughly follow the breast cancer journey from a first discovery in ‘Last summer I cried’ to ‘Strange and beautiful things grow’ which explores a phase of new beginnings. The reader is taken through a journey of diagnosis and treatment, through friendship and loneliness, to the end of life, but not the end of living. Evocative smells in hospitals in one story contrast with the perfumes of far north Queensland in another. The cold of winter, of fear and tears, give way to the warmth of summer and hope and laughter.

Perhaps it is best if I describe how I read Heartsongs. I started to read it one Saturday morning. I read hungrily, marching from one piece to the next, taking breathers in between each section. But I was always eager to return. The last pieces I read would follow me through the shopping, the housework or the gardening. I became caught up in their moments, sometimes crying, sometimes laughing, sometimes completely enthralled by their words. Each woman’s story pressed me onto the next, until by the end of the day I had finished. Then, the next day I started reading again. This time I savoured the moments, getting to know each of the women more intimately. The biographies of each contributor found at the end of the book gave meaning and context to their writing.

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Heartsongs is a powerful book. It is inspirational and a fitting memory for those who did not make it to see the book published, as well as a tribute to the lives of all the women involved. This book is essential reading for all clinicians who care for women with breast cancer as Heartsongs gives feedback on their care that comes from their heart. I felt privileged to read it.

Reviewed by Nicola Bruce

A Pocketful of Sequins

BCNA has been working in partnership with the National Breast Cancer Centre and the National Breast Cancer Foundation on a great book. A Pocketful of Sequins is an inspirational book of more than 90 quotes and thoughts from breast cancer survivors and their families. They are accompanied by beautiful illustrations.

RRP $19.95. For more information or to purchase online, visit www.pocketfulofsequins.com.au.

Terrific survey response

Thank you, thank you, thank you to the more than 12,500 members who have returned their surveys. Researchers told us to expect a return rate of around 30%. We expected better than that and we weren’t disappointed. Almost 70% of the 18,000 surveys have been returned. Given this response, and the many comments, it will take us some time to work our way through them. If you asked a question in your response, please be patient.

If you haven’t returned your survey as yet – it is not too late! Watch out for a survey report in the next Beacon.
NT Breast Cancer Voice is a survivor advocacy group that grew out of BCNA’s Making a Difference conference in 1998. The group has around 300 survivors on its mailing list and is based in Darwin. Run by a small committee with Susan Tulley as President, the group aims to ensure that the voices of Territorians affected by breast cancer are heard.

The group has identified many challenges including the Territory’s large geographical area and the diversity of its people. There are more than 120 culturally and linguistically diverse groups in the Territory. Indigenous people make up 28% of the population. What works in one area or group is often inappropriate for another.

NT Breast Cancer Voice works hard to represent all those affected by breast cancer.

“We are concerned with issues for those living outside the major centres of Darwin and Alice Springs,” says Pat Hancock, Vice-President. “We have made a conscious effort to be as inclusive as possible of women from regional centres.”

With their limited resources, the group produces newsletters and provides funding for women outside of Darwin to attend forums in Darwin and other states. An initiative of the group is its Outreach Program, established in 2005. Members had become aware of several Indigenous women being treated in Darwin for breast cancer – travelling huge distances along the way. For many, the need to seek treatment in Darwin is daunting. Yet, to have to travel to Adelaide or another capital city for radiotherapy – as is presently the case – can be worse. Often, women opt for a mastectomy to avoid this.

In August 2005, four committee members travelled to the remote communities of eastern Arnhem Land where, as Pat explains, ‘We met with, listened to, and talked with local women.’ Meetings and consultations were held at Nhulunbuy, Yirrkala on the Gove Peninsula, and Alyangula and Angurugu which are both on Groote Eylandt. Darwin is in NT’s north-west, while the Gove Peninsula is far north-east. Groote Eylandt is in the Gulf of Carpentaria.

Women talked about travelling long distances to Darwin for diagnostic mammograms; and having to return a week later for ultrasounds and fine needle aspirations rather than being able to have all necessary procedures in the one trip. An Indigenous breast cancer survivor at Yirrkala spoke of traditional bush medicine and her fears of radiotherapy and chemotherapy. She stressed the importance of early detection and appropriate treatments for breast cancer.

NT Breast Cancer Voice plans to continue to reach out to geographically isolated women to dispel the myths of breast cancer, encourage early detection and increase their capacity to take control of their illness.

“Our strength lies in our determination, as breast cancer survivors, to turn our different experiences into positive outcomes for others,” says Pat.


Members of NT Breast Cancer Voice meet with women at Yirrkala in eastern Arnhem Land
Thank you

We appreciate the financial support given to us by individuals, clubs, organisations and companies around Australia. We would especially like to acknowledge the help of the following outstanding supporters:

- Michael Seward and team: Adam Begg, Gordon Dixon, James Dixon, Mark Robertson, Alan Holt, Rob Dowling, George Malliaros
- Pink Ladies Golf Classic
- Tattersall’s
- Ritchies Supermarkets
- Jodie Strong
- KAZ
- Fenceliners
- Medical Industry Association of Australia
- Hebees Inc
- Tesselaar Tulip Festival
- Shoalhaven Breast Cancer Support Group
- CTE Pty Ltd
- Australian Institute of Management, Victoria & Tasmania
- CitiPower and Powercor Australia
- Ballarat & Clarendon College Girls 1st XVIII
- Lynn Brewster
- Bountiful Home
- Lois Mifsud
- Medicare Greensborough
- Past and Present Police Women’s Association of Victoria
- Symbion Pharmacy Services

The Pink Ladies Golf Classic held at the Sunshine Coast in August. It was again a successful event, raising more than $13,000 for BCNA in its fifth year. Special thanks to Harriet and Jacinta Moore and Prue Troedel.

Celebrations

Congratulations to Di and Rob Maxwell who celebrated their wedding anniversary and asked that money be donated to BCNA in lieu of gifts.

Hayley Coutts, breast cancer survivor and BCNA representative (far right), visited her local Ritchies store in Pakenham in the lead-up to Australia’s Breast Cancer Day to accept a cheque on behalf of BCNA for more than $10,000.

Ritchies donates 1% of the money spent by customers to their nominated charity. BCNA sends a big thank you to Ritchies’ customers in Victoria and NSW who have nominated BCNA when they shop. If you would like to be part of this, ask for your free Community Benefit Card at your local Ritchies store.

In memory

We remember Kathleen Mary Alexander; Gillian Barton, Kathryn Dwyer, Susan Eichler, Nada Lukac, Anna Mazzurco, Grace Mazzurco and Kath Stewart and are grateful to be recipients of donations in their memory.

Michael Sowards and his team of Pink Lady riders completed the Around the Bay in a Day event raising more than $25,000 for BCNA. This is the second year that Michael has raised funds for us through the event.
State Reps in action

BCNA’s voluntary State Representatives, all breast cancer survivors, keep an ear to the ground for news, distribute information, and are a local contact for women with specific enquiries or issues.

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Startimg out early: NSW State Rep Megan James’ son Dylan caught with a silhouette

Would you like to be on the mailing list for The Beacon or The Inside Story?

Telephone 1800 500 258 (freecall), email beacon@bcna.org.au or fill in this coupon and send it to: Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.

Yes, please send me:
☐ The Beacon, BCNA’s free quarterly magazine
☐ The Inside Story, a four-page supplement about secondary breast cancer. It includes stories and information about resources, services and issues for women living with secondary breast cancer. It is mailed with The Beacon to those who nominate to receive it.

Name:...............................................................................................................................................................................................

Address: ...............................................................................................................................................................................................

State: ............................................. Postcode: ............... Phone: (   ) ..........................................................

Email: ...............................................................................................................................................................................................

Have you had a diagnosis of breast cancer? ☐ Yes ☐ No

If yes, what year were you diagnosed? ......................... What year were you born? .........................

Have you had a diagnosis of secondary breast cancer? ☐ Yes ☐ No

Lyn still leading BCNA

Lyn Swinburne received a flurry of calls and messages from readers following the announcement of her retirement from the Board of the National Breast Cancer Centre (acknowledged in its insert in the last Beacon). Several people thought she was hanging up her BCNA (pink) boots. This is certainly not the case. The team at BCNA hope Lyn will be fearlessly leading BCNA for some years yet.