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Acknowledging those who helped us through

*This issue of **The Beacon** includes a section of contributions from many of our readers about those special people who helped them through the toughest of times during their breast cancer journey.*

I'm sure that, like me, you'll hear people say, 'I wanted to help, but just didn't know what to do'.

With this in mind, some years ago BCNA developed a brochure called *Helping a Friend or Colleague with Breast Cancer*, which included ideas and practical suggestions. Unfortunately, the word 'cancer' is still so scary for many people that it's simply easier for them to avoid us. Many of us have had friends move away and become distant as a result. This can be very hurtful.

On the other hand, others have risen to the occasion and many of these stories from our readers have warmed our hearts. Of course, not everyone is fortunate enough to have a circle of friends and family to lean on at such a challenging time. I can't begin to imagine what a lonely and terrifying time it would be to face the breast cancer journey alone.

This issue of **The Beacon** – our 35th – also marks an important step for us. We know that some



BCNA's State Representatives at the annual 'Think Tank'. As well as sharing ideas, they met up with 'Veronica' – our 5m high mascot.

women will, unfortunately, go on to develop secondary breast cancer. Others will have secondary breast cancer at the time of their initial diagnosis. For years, women in both these situations have told us how

isolating this can be, especially because this scenario is not always talked about openly. From this issue, we will produce a *Beacon* supplement – *The Inside Story* – which we are offering to any of our readers

who wish to receive it (just fill in the subscription insert to request a copy or telephone us). The supplement will include stories, articles, information about services and reports aimed specifically at informing and empowering women with secondaries. As always with BCNA, this new resource will focus on the woman and the information included will be accurate, up-to-date and informed by those living with the disease – real women in real situations, making the best of it.

On another matter, our State Representatives came together in February for a very productive two-day Think Tank. State Reps are a vital part of our network, which now embraces more than 17,000 members.

This issue also covers the latest in the Herceptin campaign and flags a potential call to action.

*Lyn Swinburne
Chief Executive Officer*



Breast
Cancer
Network
Australia



Ann, Kerri and Lexie sharing their experiences with the world

Young women gather from around the world

BCNA Consumer Representatives, **Ann Town** of Charmhaven, NSW, **Kerri Guy** of Melbourne and **Lexie Warren** of Brisbane attended the 6th Annual Conference for Younger Women Affected by Breast Cancer in Denver, Colorado, in February 2006.

The Conference, organised by US breast cancer groups, Young Survivors Coalition (www.youngsurvival.org) and Living Beyond Breast Cancer (www.lbbc.org), is the only international conference specifically addressing the needs and issues of younger women with breast cancer.

More than 800 delegates from around the world attended the conference, from as far afield as Australia, Africa, Canada, England, Argentina and Iceland, as well as 48 of the 50 states of the USA.

Ann, Kerri and Lexie received scholarships from the organisers to attend the conference.

The plenary sessions addressed medical advances in breast cancer in younger women and the workshops covered a diverse range of topics, including advocacy and psychosocial issues such as relationships, diet and nutrition, exercise, dealing with and relating to children, dating and intimacy issues, complementary therapies, genetic testing, clinical trials and a broad range of issues concerning advanced disease.

There was also a stream of workshops specifically for caregivers and partners and supporters of younger women with breast cancer.

The conference provided extensive networking opportunities at a number of receptions and the Saturday dinner, during which delegates were able to meet and share stories and experiences with other young women.

Ann, Kerri and Lexie were grateful for the opportunity to travel to and attend the Denver Conference and all agree that it was a wonderful opportunity to learn more about what is happening on an international level in the arena of breast cancer in younger women.

Lexie also travelled to Winnipeg, Canada, for a few days before the conference and visited the Manitoban Cancer Care 'Breast Cancer Centre of Hope' and attended its 'Younger and Wiser' educational program for younger women.

As a Dragons Abreast paddler with Brisbane DA team, 'Missabittatitti', Lexie attended a training session with Chemo Savvy, Winnipeg's Breast Cancer Dragon Boat team, to spread word of the 2007 World Regatta to be hosted by Dragons Abreast Australia at Lake Kawana on Queensland's Sunshine Coast in September 2007.

Breaking news on chemo drug

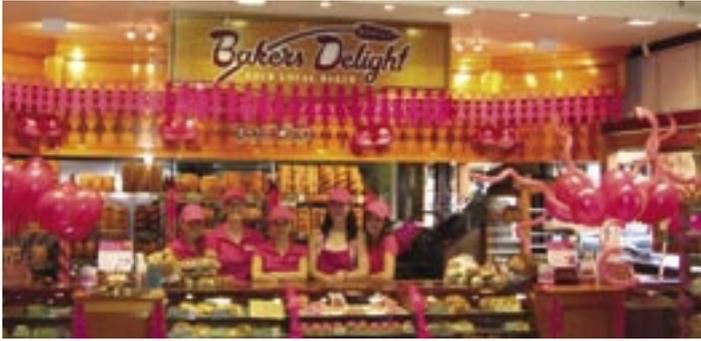
On 10 May, the Pharmaceutical Benefits Advisory Committee (PBAC) recommended a subsidy for the chemotherapy drug paclitaxel (sold as Taxol) for use in all node positive breast cancers. It is currently only subsidised by the PBS for use in node positive, oestrogen receptor **negative** breast cancer.

With this latest recommendation it is likely that the subsidy for Taxol for all node positive, oestrogen receptor **positive** patients will be available from 1 August 2006.

As with all drugs, Taxol can cause side effects and BCNA advises women to seek full information from their clinicians about the risks and benefits of the drug before deciding whether the drug is right for them.



Tasmanian State Rep Karen Forster was one of several BCNA members who carried the Queen's Baton in the lead-up to the Commonwealth Games.



Woodlands, WA



Murwillumbah, NSW

What's the sweetest part?

Bakers Delight's May promotion raises heaps of dough for BCNA

Bakers Delight bakeries have gone all out in their efforts to raise money for BCNA during this year's pink bun promotion.

From 18 April to 14 May, all proceeds from the sale of pink-iced finger buns were donated to BCNA. Aiming for a 'personal best' performance, bakeries hoped to raise \$250,000 – that's more than 200,000 pink buns!

At the time of going to press, we were still counting, but had already exceeded our target. BCNA, and families affected by breast cancer, are reaping huge rewards from their fundraising efforts.

This year breast cancer survivors have been actively involved in the promotion with BCNA women taking part in bakery events.

Isobel Harvie from Kyabram, Victoria, gathered a group of volunteers to staff an information kiosk at the Shepparton Marketplace shopping centre, right by the Bakers Delight

bakery. Franchisee **Heath Wyllie** baked extra pink finger buns while local women provided information about BCNA and our services. It's great to see our women and bakeries working together.

Thank you to Bakers Delight, its customers and all our volunteers for your amazing efforts to make this year's promotion the most successful yet.

The Pink Lady Award

We've been bowled over by the enthusiasm of the bakeries. Encouraged by the promise of

the inaugural 'Pink Lady Awards', bakeries across the country hosted wonderful pink events and promotions to get customers involved.

Thank you to all the bakeries that entered. Judging a winner was extremely difficult. However, after much deliberation, the winners are:

NSW

- Bakers Delight Murwillumbah
- Bakers Delight Nowra Mall
- Bakers Delight Parkes

Queensland

- Bakers Delight Newmarket
- Bakers Delight Windsor

South Australia

- Bakers Delight Gawler
- Bakers Delight Burnside
- Special Mention*
- Bakers Delight Welland

Tasmania

- Bakers Delight Glenorchy

Victoria

- Bakers Delight Lavington
- Bakers Delight Boronia Junction
- Bakers Delight Diamond Creek

Special Mention:

- Bakers Delight Balwyn
- Bakers Delight Drysdale
- Bakers Delight Kyabram

Western Australia

- Bakers Delight Perth City
- Bakers Delight Woodlands

Congratulations to everyone who took part in the awards. Winning bakeries will be presented with a special Pink Lady award by a BCNA representative.



Burnside, SA



BCNA gratefully acknowledges our partnership with Bakers Delight.





Issues of Concern ...

Herceptin: women are waiting and watching

Funding for Herceptin remains a key issue for BCNA. As women across the country struggle with how they might pay for this expensive drug, the approval process chugs along slowly.

Herceptin is not the wonder drug cure for breast cancer, but for some women diagnosed with breast cancer it does offer a chance of significantly reducing the risk of it recurring.

For BCNA, it is crucial that we see this new treatment option funded as quickly as possible through the Pharmaceutical Benefits Scheme (PBS), so that women, with their oncologists, can consider the full range of treatment options and choose the most suitable treatment.

While we wait for Herceptin to be subsidised, women around the country are facing undue pressures. They and their families are under pressure to find ways to fund this expensive treatment. Each day that passes before the drug is approved will see as many as eight Australian women diagnosed with HER2 positive primary breast cancer.

The story so far:

In **May last year** preliminary research data was released from three international trials showing that Herceptin could reduce the risk of breast cancer recurring for women with HER2 positive breast cancer.



Jill Suppree was the face, voice and heart of our 2001 Herceptin campaign.

Publication of the trial data in **October 2005** set the wheels in motion for access to funded Herceptin but, as we have seen, this is a very slow process. Roche began discussions with Australia's regulatory body, the Therapeutic Goods Administration (TGA), although little action could be expected until the pharmaceutical company made its formal application.

Roche made its application to the TGA late in **February** once final data from all the trial sites had been submitted and analysed. The application for Herceptin to be used in conjunction with chemotherapy following surgery for the treatment of HER2 positive early breast cancer was approved on **21 April**. More specifically, it is approved for use

in HER2 positive primary breast cancer where there is lymph node involvement or, if there is no lymph node involvement, where the tumour is greater than 20 mm.

Roche's application to the PBS is now being considered. If this process goes smoothly, it is expected that the recommendation for PBS listing could be made by **August 2006**. The final decision as to whether the drug is subsidised for Australian women will then rest with the Federal Government and must be approved at a Cabinet meeting, followed by an administrative process to formalise the PBS listing. In normal circumstances this would see the listing finalised in December.

We believe the government can, should and will accelerate this process. Once the PBS recommendation is finalised, we would expect the government to approve Herceptin for immediate subsidy.

Some of our longer-term members will remember the successful public campaign BCNA ran in 2001 to secure funding for Herceptin for women with secondary breast cancer. **Jill Suppree** was the face of that campaign. While we ultimately lost Jill to her breast cancer, her inspiration stays with us. We trust that there are still many Federal politicians who remember the power of women with breast cancer, multiplied by 10 with the support of family, multiplied by 100 with the support of their communities.

At this stage we believe funding for Herceptin can be achieved without a major campaign. However if anything changes we may need to call on you for help.

If we write to you further on this matter it will be a call to action. In the interim if you would like to receive regular email updates on the Herceptin issue, just email us at beacon@bcna.org.au.

The real cost of breast cancer

First, there is the diagnosis, the dreadful news. Then there is the turmoil that follows. It is the overturning of life as you know it, while somehow the world goes on around you as though nothing has happened.

On top of this difficult time, many, many callers to BCNA report the added burden of dealing with unexpected medical costs throughout their initial treatment and beyond.

'The first and second time I saw my specialist I was too embarrassed to ask how much this was all going to cost me. By the time I'd had sleepless nights worrying about it I knew I just had to ask on my next visit. I was so angry when he brushed me aside and said, "Let's worry about that after we've got this out". That is just not good enough. Surely I have a right to know how much it is going to cost me.'

A common theme in calls and emails is – 'I had no idea I would have to pay that much'.

These stories come from women treated in the private and public systems, living in the country and the city. Costs for women with early breast cancer can add up significantly over the years and for women with secondary breast cancer the costs are an even greater burden.

Breast cancer treatment is a complex jungle of services – and most 'trees' seem to have a cost attached. Some services are fully funded by the Federal Government through Medicare, others are part funded and still others draw no subsidy at all. In many cases the cost of a service will depend on where you receive it.

For women travelling from country areas for their treatment there are additional cost burdens. Patient assisted travel schemes (PATS), which can be known by different names in different states, can help with costs for petrol or airfares. However, the

eligibility and assistance available through PATS varies from state to state. It is important to ask what support might be available. In some cities, subsidised or free accommodation might be available near the treating hospital. Information about these services is available from the Cancer Council's Helpline.

Talking about costs is important. While some doctors are very good at explaining their own fees, they may not explain the fees of other services to which

they are referring you. Ask about pathology costs and the cost of the anaesthetist. Let your doctor know that you want or need to discuss the full costs. You can also tell your doctor if you can't afford those costs. Some doctors are prepared to negotiate their fees and might be able to request bulk-billing for your pathology tests and other services.

For most of us, unexpected bills are an additional stress that can affect our health.

Ideally, all costs should be outlined in a simple cost statement that highlights possible variations at different stages of the treatment. This statement would also explain which costs will be reimbursed by Medicare. It would clearly name the procedures, including item numbers, so that those with private health insurance can get a clear answer from their insurer about how much they will be reimbursed for that procedure.

Useful telephone numbers

Cancer Council's Helpline:
13 11 20

Medicare Safety Net Scheme:
1800 011 163

Pharmaceutical Benefits Scheme (PBS) Safety Net:
1800 020 613

Some hints

Ask, ask and ask again. You do have a right to know how much the service will cost.

Ask if there are any costs that will emerge later.

Ask if the service to which you are being referred is a public or private service. Is there another service you could go to that is either free or cheaper?

Keep notes about the financial discussions.

Don't be afraid to ring and ask why a cost was more than you

expected. (Let them know that your notes from your discussion on a particular day indicate the costs will be ...).

Keep track of your medical expenses. As part of the *My Journey Kit* BCNA has developed a Medical Treatment Expenses form. It also available from our website or by calling us on 1800 500 258.

Make sure you register for the Medicare Safety Net Scheme. Under this scheme, once you

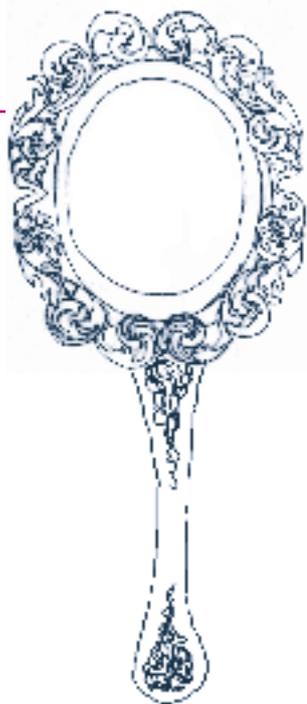
reach the safety net threshold for out-of-pocket expenses, additional expenses will attract an extra Medicare refund.

Ask your pharmacist for a Pharmaceutical Benefits Scheme (PBS) Safety Net Prescription Record Form to help keep track of your pharmaceutical costs.

You might like to put someone you trust in charge of your health costs (at least during your

initial treatment), so that they take responsibility for keeping these in order and following up reimbursements with Medicare and/or a private health insurer.

You may be entitled to a tax benefit on some of your out-of-pocket expenses at the end of the financial year – yet another reason to keep your records in order.



My Story

Coming to terms with hair loss

Heike sent us her story saying, 'Although I am not happy about becoming eligible to be sent **The Beacon**, I am very happy to be able to read about the various things that are happening around the country. I particularly like My Story – hearing about women in similar situations certainly made me feel a lot less alone.

So I had a bash at writing up my own story. The main thing I wanted to share was the photo.

I have read many stories about the impact hair loss has had on women undergoing chemotherapy and their families. I can now relate to many of them.

At first I read those stories with a detached interest – at that stage the 'lump' was only just diagnosed as being cancerous and I didn't think I was going to need anything as radical as chemotherapy. That would be just a tad over the top and melodramatic. That was just not going to be me.

A work colleague said she would shave her head as a sign of support if I lost my hair. I was deeply touched and convinced she would – but again that was not going to be me. Besides, she

was going to get married in a few months' time.

When told I was going to require chemotherapy, my first thoughts were 'I can't be responsible for a bald bride!' Some insistent pleading on my part and, well let's be honest, downright threats and I was able to persuade my colleague not to shave her head. A few months later she was indeed a very beautiful bride.

The time eventually came when my hair fell out in handfuls. It was not nice. I felt I was making more mess about the house than the dog during moulting season. Soon after came the day when I'd had enough and wanted it all off – rather than look at my hair thinning further and further.

Unbeknown to me, my husband

had bought some clippers for that day. He shaved the rest off while my children held my hands and gathered the cut hair. It was quite a family affair, with much nervous laughter as well as a few tears.

My husband then insisted on shaving his hair – I couldn't cope with that just then. He agreed to delay it for a day. I mean, I would have to wake up to seeing him bald every morning. I, at least, could simply avoid the mirrors!

Later that day I went on a practice 'excursion' to my friend down the road in preparation for going to work the next day. This friend had bought me a fantastic head wrap, made of lovely soft fabric and in beautiful blending colours of blues and greens. I was thrilled. This headwrap became

my 'work' headgear from then on.

This all happened over winter and the nights were cold, so my teenage daughter bought me a trendy brand-name beanie to keep me warm and look cool at the same time.

Over time I got used to my bald look. I didn't startle myself as I walked past mirrors and usually went about without headgear at home. Once I asked my daughter if that bothered her. 'No' she said, but admitted it bothered her more when I walked about wearing a T-shirt with no bra. I laughed.

During this time I went to a cancer fundraiser. It was a lot of fun and there were many volunteers providing pampering services. There I discovered how nice a head massage is.

Probably the most fun I had during my bald phase was when the kids decorated my head one Sunday morning. They had a lot of fun and I felt very special to have such loving messages and pictures drawn just for me – on me.

The photos remind me of a time when our family found fun and creative ways to support each other through an 'ordinary' time.

Now my hair is growing back, though sometimes I feel it is not fast enough. It is also growing back curly. After having had straight hair all my life, I now have another interesting hair experience to look forward to.



Heike says, 'Look what happens when you let the kids loose with makeup'.

Heike Billstein, NT

Who helped me through

We received many heart-warming examples of love and support in response to our request for stories from our readers. Friends, family members and complete strangers all featured, along with medical staff, and even an ex-husband. Some special sisters, husbands and partners were highly praised.

For many of those who responded their experience of support was overwhelming and they were very grateful. Women offered their stories in the hope that it might help – or inspire – someone else. There were some great ideas too – from rosters to gifts, from text messages to shopping lists.

However, not everyone finds adequate support and, for some, their already confronting experience of cancer is compounded by the distress of having to cope alone or with insufficient support.

We have included extracts of the stories here. Fuller versions have been added to our website. If you don't have web access and would like to read them, ring 1800 500 258 for a print-out or for copies of our brochure **Helping a Friend or Colleague with Breast Cancer**.

Sharyn Briggs

The people who helped me through most were the people who were consistent. What was important to me was that they just rang, consistently, to say, 'Hi, I was thinking of you. Hope you're going okay'. Even if it's a message left on a machine, or a note under the door, it means they are there for you, on your lonesome journey.

Rowena Morris

One friend dropped off or picked up my son from kindergarten. Another stocked my freezer with meals for my family so I didn't have to cook when I felt nauseated. Two other friends

would meet me weekly for a walk followed by coffee. **Probably the best help was the advice I got from a friend who is a psychologist.** She suggested I break my days up into morning, afternoon and evening; and then to set myself a goal, however small, to achieve.

Joyce Mulley

Through all this my husband has been there, doing dressings (after instruction), cleaning, washing, vacuuming, washing floors and in the early days trying to find meals that I would eat as I had no taste and only ate because I felt I had to.



Elizabeth Orchard and Kyi, Vic

Elizabeth Orchard

Di, my friend, neighbour and walking companion, became my saviour. From the day of diagnosis, she has been there. Di drove me to hospital for surgery; attended appointments with me; moved in to look after my dog Kyi while I was in hospital; cooked dinner every night throughout my chemo treatments; listened to my fears; and ignored my tears.

What can you do for a loved one? Just be there for them.

Helen Dillon

My darling sister Ruth moved in the day I came home from hospital and took over my job for a week. After a week my fabulous family and friends who live locally, took up where she left off. They continued to spoil me with delicious, cooked meals (filling my freezer to capacity), and an abundance of visits brimmed with love, support and laughter.



Michelle Mayo with her children, NSW

Michelle Mayo

A lovely lady who I didn't even know took it upon herself to send out a letter to all the kindy mums and the response was phenomenal. We now have meals cooked five times a week.

The best help are the friends willing to call and ask how I am

and be there when I need to talk. The biggest disappointment is those friends I thought close who have 'left me alone so as not to bother me'.

I've been very lucky in realising who my very close, dear friends are and how compassionate and helpful total strangers can be!



Sue Muenster, SA

Sue Muenster

The most important thing about all my wonderful friends is they kept me positive, treated me like normal and were always there.

Wendy F would call and collect the ironing, and give me a cuddle. Her husband, Michael, was great support to my husband – quite often they get forgotten, but he suffered just as much as I did. We came home after chemo and the lawns had been mowed. Yes, Michael did it. It was a 15-minute job, but my husband had been too busy looking after me and the business to care or notice the lawn.

Anne Abrahams

My husband accompanied me to medical appointments, scans, chemotherapy and radiotherapy sessions, supported my decision to have a double mastectomy and took over household duties. Once finding me crying in the shower, he dried me and put me to bed like a baby. My ex-husband and his family sent flowers and gifts. Other friends brought mild shampoo for my chemo scalp and mouthwash for ulcers. My daughter's little pupils made cards and gifts. My younger daughter's boyfriend brought flowers, hugged me each time he came and made me laugh.

Cathy Altmann

Heaps of people helped me. My church started a meals roster that was a wonderful help. I found my relationship with God shattered and remade and I screamed at him a fair bit! After the last lot of chemo, I had about five months of terrible fatigue. My husband, John, was

stretched to new levels then – he had to do everything for the kids morning and night, while still working. My kids had to cope with a Mum who had no energy to play. Matt's kisses at bedtime and Sophie's pictures from childcare meant so much to me. Mum was amazing.



Cathy Altmann, with her husband, John, children, Matthew and Sophie, and Inky the poodle, Vic

I became good friends with a kindred spirit in hospital. We talked daily, comparing notes – giving each other strength and courage.

Marilyn Synnes

My friend Heather was always level-headed and a good listener. She immediately swung into action, driving me to appointments, the GP, the surgeon, the hospital for other scans, shopping to stock up the fridge and freezer, and listening to the worries I did not want to dump onto my family.

Isabel Slater

I have a breast care nurse who was so kind and caring. She would drain my arm at any time of day and even opened up the hospital one Sunday lunchtime to drain my arm because I was in so much pain.



Isabel Slater, SA

Ann Worcester

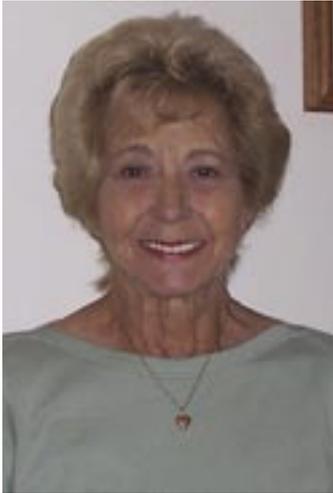
I had only been working for **my boss** a couple of months before my diagnosis, but she allowed me to hold my bookkeeping job all through my six weeks of treatment in Melbourne. I travelled home at weekends and did my work then. Our neighbour was a great help during this time, looking after our house, garden and dog. I hope they all realise how much they've helped.

Jann Walker

If I had a wish I could grant in real life, I would bestow on all women (and men) who live alone and discover that they have breast cancer – **a support team such as I had.**

I lived quite happily on my 1 ½ acres of house, lawns, trees and gardens, three kilometres out of a large country town. I had no family within a three-hour drive. The wonderful staff from the school where I worked made sure that after my operation someone was visiting me each day in hospital, which was in another town. Then they were meticulous about keeping in touch.

They organised a roster to water my large garden while I was away and in the middle of a Riverland summer that's a big job. I had timers on the taps, so one friend who drove past morning and night would turn on sprinklers knowing they would go off after two hours. Another would bring out books to mark, another to just take time to sit and read her own book. One would weed. Someone picked the tomatoes, sun-dried them and put them in oil for me. I don't think anything died – not even in the hanging baskets. They went beyond to fit all this in with their own busy lives and families.



Judi Connor, Qld

Judi Connor

Four days into my radiotherapy treatment for breast cancer, my husband dropped me off at a meeting, kissed me, told me he loved me and disappeared! I had to be an in-patient at the hospital to continue my treatment because I was not allowed to drive – some 47 kilometres return.

Somehow, with the love and help of my family, who all live in Sydney, my in-law family and great friends nearby, I got through it all. They telephoned me daily, offered all kinds of assistance – company, transport, meals, sending crosswords, letters and cards of good wishes and most of all, they were ‘there’ when I needed them most. They still are and I will be forever grateful.

Jan Tull

Karen is my best friend of 42 years. Her phone calls and text messages were my saviour. She has this way of making you laugh, with her great sense of humour. The day I went to choose my wig she was there. It turned out to be a day with lots of laughter.

Heather Purins

One of my friends rang and told me to give her a list of all the friends who were willing to help. She arranged a meeting and signed everyone up to a roster to drive, care, cook, do housework, etc. I hate to think how I would have gotten through it if not for this wonderful help.

It was lovely for my girls to see the love of friends around us in a time of crisis. They enjoyed having the revolving door that our front door became, with people coming at different times. Once I was over the worst with each cycle, it was also really nice for everyone to step back and allow the girls and me to have our space too. That was necessary for our sense of independence and dignity. The love never stopped, just the hands-on involvement.

Colleagues were equally encouraging. They told me I was an inspiration to them. Work was a tonic and a welcome distraction from the big things that were beyond my control. It was good to remind myself that I was not defined by this disease.

Helen Traves Smith

I had one group of friends who supported me in hospital during chemotherapy. Another group of friends prepared and froze meals. A third group of friends would phone me or just call in and their visits helped to keep me positive and emotionally stable.

My friends were there to help me celebrate life. We would go to the movies or out to dinner as we used to do.

It was a nice feeling to be the centre of attention!



Sharon Scoble, WA

Sharon Scoble

Cancer isn’t just about one person. It’s about all your family, friends, work colleagues. That someone special wasn’t just one person for me, everyone I love helped me get through the difficult times.

Jan Lees

From diagnosis to surgery I was well informed. I cannot praise the health professionals enough for their care and treatment.

The main thing that got me through was the absolute dedication of my dear sister Joan. A nurse herself, she was often on night shift the days she accompanied me to hospital for my treatments. She showed me what sisterly love is all about.

The key word that kept me going was ‘support’. The kids and my husband were great and my workplace also supported me and gave me the space to get better.



Donna and Robin Pumpa, NSW

Donna Pumpa

My son had a birthday while I was away and a lovely lady brought him a birthday cake. It was special for Daniel to at least have a cake even if his mum didn’t make it.

I was able to stay at supported accommodation in Sydney and **the other residents**

were a great support. Their friendship, laughter (there was a daily session of laughter), helpfulness and advice were amazing and definitely made my stay a lot less hard. Being able to talk openly about the cancers we each had and different treatments was very important. We supported, rather than pitied each other.



Kay Cook, Qld

Kay Cook

My older daughter lives out on the Downs two hours away from us with a busy farmer husband and six beautiful children, yet she still found time to put together a 'Joy Box' for my birthday and surprised me with it a few days before surgery. **It was a large colourful box filled with lots of presents and I could choose one at a time when I felt a bit down.** Each present had a message that made me laugh, cry, feel loved or keep going. My five-year-old grandson wanted me to open his first and I wore his necklace all the time. Some of the presents were:

- a funny hat for when I lost my hair – the message being 'to keep your head warm and your visitors smiling'
- a bag of marbles – 'If you ever feel like you're losing your marbles, here are some more.'
- a cheerleader's pom-poms – 'Give yourself a cheer when no one is around to cheer you on – you're doing great.'
- a can of beans – 'When you want to be "full of beans" open a can.'
- a box of tissues – 'For when the tears fall and the nose

Valda Daw

Mary cared for me in an unobtrusive way, she provided fresh fruit and cooked fresh vegetables when I didn't have the energy. She made me laugh, was bright company, kept me focused and encouraged me to have a good attitude, but mostly was there when the demons come out at night. I

shall always love her for caring for me so much that she put her own life on hold so that I could get well.

She never made me feel different or ill. We laughed a lot. She wore turbans on her head to keep me company and never fussed over me or let any negative people close to me.



Mary (left) was the source of support for Valda Daw (right), Vic

runs and the pain hurts so much.'

- 6 bulbs = 6 flowers = 6 Scott grandchildren who all love YOU.

My younger sister came twice and gave me a foot massage. It was just the most beautiful gift. She had a special electric foot spa and with oils and loving hands, it was great therapy.

Jen Johnston

The first person who lifted me out of my anxiety was **my boss**. I had only been in my job for six months. He phoned me to ask how my diagnosis had gone and said he wanted to raise a practical matter. I thought I was going to lose my job, but somewhere in the fog I heard him say, 'You are

not to worry about money'. I was to be paid sick leave for whatever time I needed.

I needed a mastectomy and opted for an immediate reconstruction, so the out-of-pocket expenses were enormous. One by one I paid the accounts but still did not receive an account from **my plastic surgeon**. At Medicare one day they said that the account had been settled – the surgeon waived my contribution.

Roni Jones

I have had five outstanding people by my side.

First, **my partner**, who has been to every appointment – and there have been plenty! He has made me laugh on my lowest days and tolerated my erratic, moody behaviour.

Second, **my mum**, who after my awful sickness from my first chemo made me pure ginger juice that blew my head off and then burnt ginger essence all around my home. The scent made me sicker!

Third, **my aunt**, who showed me, through from her own experience, that you do survive cancer and chemo.

Finally, fourth and fifth, **my oncologist and breast surgeon**, who always had a smile on their faces when I brought out my little black book filled with trivial questions I thought of at three in the morning. I never once felt like just another patient.



Julie Spokes, Vic

Julie Spokes

I received many cards and letters of hope while away for six weeks. It made me feel I was not alone and helped me through a very stressful time. Without the help of my wonderful family and friends, I couldn't have got through this. The support from counsellors and doctors has been great. The *My Journey Kit* was very helpful. It is comforting to know so many people care.



Dragons Abreast

The Queensland State Dragon Boat Titles held on 4 March at Kawana gave us an opportunity to flag the next breast cancer survivor dragon boat festival, Abreast in Australia 2007, to the local community.

We were delighted to have **Chris Cummins**, the State Member for Kawana, **Mark McArdle**, the Member for Caloundra and Councillor **Gordon Wallace** help with medal presentations for the Dragons Abreast races and watch the Flowers on the Water Ceremony. We were also joined by members of the Zonta Club of Caloundra and the Caloundra Rotary Club.

More than 23 international teams have registered their interest in attending the Abreast in Australia 2007 event, to be held on Kawana Lake near Caloundra in Queensland, 29–30 September.

There are 31 Dragons Abreast groups around Australia and we want every one to be with us, from Tasmania, Western Australia, Northern Territory and all the places in between, to welcome our Canadian, American, New Zealand and, hopefully, Italian, Polish, Singaporean and Chinese paddlers in this first Oceanic event.

Perhaps local communities can help raise money for participants' registrations, lend a bus for transport or just give a donation – which is tax deductible!

Two striking events recently have included the Pink Experience and Simply the Breast Yacht Race.



Dragons Abreast team Titty Titty Bang Bang from the Sunshine Coast with Chris Cummins, the State Member of Parliament for Kawana.

The Pink Experience was organised by Titivators Dragons Abreast in Coffs Harbour. On 10 March, under a starlit three-quarter moon, **Wendy Matthews** opened the evening by singing 'The Day You Went Away'. The song was dedicated to husbands who had lost their wives, children who had lost their mothers, siblings who had lost their sisters and to all the Angels Abreast women who have gone before them – it brought tears to the eyes of the 350-plus guests.

The star attraction was **Carlotta**, the infamous Les Girls drag queen, who entertained to perfection and incorporated the Titivators into her act. She brought the house down with her humour, love of the crowd and riotous girly/drag behaviour.

The inaugural Simply the Breast Yacht Race held in Darwin on 7 May proved to be extremely popular, with 55 yachts turning Darwin Harbour into a giant breast cancer awareness billboard.

Dragons Abreast featured on *Backyard Blitz* on 4 June – with a very surprised **Lee Millard** as the star of the show! This was a wonderful promotion for all our member groups!

For more about Dragons Abreast groups please visit the website www.dragonsabreast.com.au or call 1300 889 566 to talk to a representative in your state.

*Michelle Hanton,
National Co-ordinator,
Dragons Abreast Australia,
T: 0418 898 082 or
nationalcoordinator@
dragonsabreast.com.au*

Beacon survey results

BCNA recently conducted a survey of *The Beacon* readership. Approximately 1,000 surveys were randomly distributed with copies of the summer issue of *The Beacon*. Thanks to all who responded.

The survey started by asking people about themselves. Most respondents were 50 years or over and had experienced early breast cancer. Almost half of those surveyed had been diagnosed with breast cancer within the past two years.

We received an overwhelmingly positive response to *The Beacon*, with most people agreeing that it is informative; clear, concise and easy to understand; interesting and appealing in its design; with a good balance of information, news and events.

The sections people like reading the most were the personal stories and experiences of others, and up-to-date clinical, technical and research information. Survey respondents were very generous in providing us with comments.

While most comments were positive, there were some areas respondents thought could be improved. These comments will guide the future development of *The Beacon*.

Thank you to everyone who contributed to our readership survey. If you were not one of the randomly selected participants and have some comments about *The Beacon* to pass onto us, please feel free to let us know. We always love to hear from our members and readers.



Profiling our Member Groups

Caboolture Breast Cancer Support Group, Queensland

Located about 50 kilometres north of Brisbane, the group has evolved and expanded since its beginnings in 1999.

The group is not incorporated and has no official office bearers. **Jurina Demaine** is the treasurer, member database manager and writes the newsletter. She's also been the convenor since the district nurse was injured in an accident. **Sue Parker** and **Marina Haydon** coordinate fundraising, **Dianne Stoddart** arranges speakers for the monthly meetings, **Lynne Gavin** sets up the meeting room and takes care of the support group library and **Jayne Coe** sends meeting notices to the local newspapers. Another member, **Auriel Ainsworth**, recently surprised the group by making tablecloths, banners and aprons.

The group's newsletter is circulated to 183 members and monthly meetings regularly attract 20–30 people of all ages. In the future, the group would like a website.

In 2003 BCNA's Queensland State Representative, **Lyn Moore**, spoke to the group and suggested it hold a *Mini-Field*. This brought the group together as members forged strong bonds



Seven members of the Caboolture Breast Cancer Support Group attended the Field of Women – Live in 2005 at the MCG in May 2005.

and found themselves discovering new skills and loving it! The group held another *Mini-Field* in 2004 and prepared for one in 2005, but sadly it was washed out by torrential rains. Undaunted, the group plans to continue with a *Mini-Field* each year. Members also have a table at local events to promote breast cancer



awareness, display information and sell BCNA merchandise at every opportunity.

Using advocacy skills encouraged by BCNA Consumer Advocacy & Science Training in 2005, Jurina speaks on the Caboolture Community Radio 4OUR Morning Magazine program once a month and at local events.

Local media are supportive in promoting events and raising awareness in the community. The group keeps a scrapbook of media clippings and photographs.

The support group has built a wonderful relationship with some

local businesses and service clubs. One club applied for a grant on the group's behalf. A local business has charity sewing days to make turbans, bags and cushions that are then distributed by nurses to patients. The bags are full of information for the patients and can be used to hold their drainage bags.

Suggestions for starting a support group

Ask the local hospital, church and doctors' clinic for help and the local council for a list of local Members of Parliament. Find out about the Australian Government's 'Building Cancer Support Groups Grants'. Ask if your state cancer council has funds to assist support groups with administration costs.

Welcoming a new State Rep for Victoria: Pamela Williams

Pamela joined the world of breast cancer in January 2001 with a diagnosis that led to a lumpectomy followed by a partial mastectomy, six months of chemotherapy, six weeks of radiotherapy and the removal of her ovaries. She also undertook our Advocacy and Science Training Program that year.

Pamela found the first 18 months or so busy with treatment and follow-ups but she was surrounded by fantastically caring practitioners. Jo and Phillipa, her chemo nurses, were so skilled and caring she says they made chemotherapy quite bearable.

Within a couple of weeks of her diagnosis a local support group was set up by her breast care nurse and she considered herself extremely lucky to share the experience of treatment within a supportive group.

From around November 2001 Pamela's involvement in establishing a Dragons Abreast team in Victoria provided a distraction from treatment, and she continues to enjoy the company of the happy and 'well-balanced' paddlers. She also enjoys her involvement each year in a local *Mini-Field*.

She thinks one of the best things we can do is to offer encouragement, support and a sense of hope to women diagnosed with breast cancer. And she will be forever grateful for the opportunity to get to know so many fantastic women throughout her breast cancer experience and for the support she's received from BCNA.

Pamela joins existing Victorian State Rep **Gerda Evans**.



*Victoria's new State Rep,
Pamela Williams*

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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Seeking shelter

BCNA welcomes:

Member Groups

- Dragons Abreast Bendigo, Vic
- Avoca Breast Cancer Support Group, Vic
- Eltham Support Group for Women with Cancer, Vic
- Port Macquarie & Hastings Breast Cancer Support Group, NSW
- Breast Cancer Survivors, NSW
- Dubbo Breast Cancer Support Group, NSW
- Mudgee Cancer Support and Friends, NSW
- Central Coast Soiree, NSW

Associate Member Group

- Women on a Mission, Vic

This takes our tally to 160 – with 148 Members Groups and 12 Associate Member Groups. We now have more than 17,000 individual members.

*Look for
the miracles
hidden among
the common.*

The Pink Lady around town



Twenty breast cancer survivors lead the way down pit straight at the opening ceremony of the 2006 Australian Grand Prix. The Pink Lady was seen internationally by millions of viewers.



Pink was the theme when more than 200 BCNA members and friends joined the cast of Dusty: the Pop Diva for champagne and supper after a fundraising evening in Melbourne in February. Guests shown here with Dusty star Tamsin Carroll.



Kate Ceberano, BCNA's driver in the Grand Prix Celebrity Race, in front of her Pink Lady BMW.



Board member Terry Bracks and Lyn Swinburne address guests at the Grand Prix Ball.

You're not yet on our mailing list?

If you would like to receive *The Beacon* free, direct to your address, four times a year, telephone (03) 9805 2500 or 1800 500 258 (freecall), fax (03) 9805 2599, email beacon@bcna.org.au or fill in this coupon and send it to: Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.

Name:

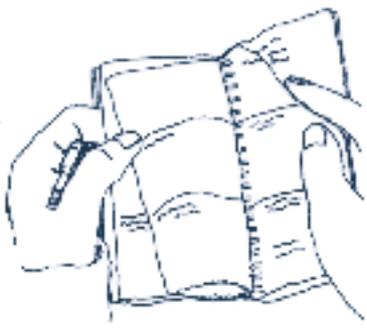
Address:

..... 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?



Upcoming Events

15 July: Breast cancer seminar and information day, 8.30 am – 3.30 pm, Mt Isa, Qld. Cost: \$10.00.

Contact: Karen Beetham, The Buffalo Club, phone (07) 4743 2365 or email mel.rutledge@buffs.com.au, or the Breast Cancer Association of Queensland, phone (07) 3839 6630 or email bcaq@bigpond.net.au.

5 August: Choices Medical Seminar all day at the Wesley Hospital, Brisbane. Speakers will present on a variety of subjects covering the breast cancer journey.

Contact: (07) 3232 7092.

19 August: Breast Cancer Action Group NSW's quarterly meeting, 2006 Information Update and Advocacy Forum, The Women's College, University of Sydney, 9.45 am – 3.30 pm.

Contact: BCAG NSW, PO Box 5016, Greenwich, NSW 2065, email info@bcagnsw.org.au or visit www.bcagnsw.org.au.

26 August – 1 September: Pink Ladies Golf Classic, Noosa Springs Resort.

Contact: Jacinta, phone (03) 9500 8954 or email jacintam@bigpond.net.au.

11–13 September: Member Group Summit, Sydney. BCNA is inviting one delegate from each Member Group to attend a summit. This will be an opportunity for Member Groups to develop a better understanding of our work and help us strengthen our national network. It will focus on sharing skills, ideas and information.

23 September: Rural and Regional Satellite Symposium, Westmead Hospital, Sydney, 9 am – 12.30 pm. This will be a community forum for people with cancer, their families and carers. It will be broadcast by satellite to 59 sites across Australia from Broome to Hobart.

Contact: Cancer Council, phone 13 11 20 for information about the venue nearest you.

22 October: Regional Field of Women, Wollongong.

23 October: Australia's Breast Cancer Day. Will include Mini-Fields across the country.

23 October: Bosom Buddies Alice Springs is participating in the 5 km walk in the 2006 Masters Games from 6 am. The intention is to promote breast cancer awareness and healthy living. Women over the age of 30 who may be in Alice Springs are invited to join them.

Contact: Liz, phone (08) 8952 6966 or Lesley, email reilly5@octa4.net.au.

Thank you for supporting BCNA

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 recent outstanding supporters and fundraising events:

- Melbourne Holden Dealer Association – Charity Golf Day
- Fenceliners
- NLC
- Belconnen Bowling Club
- Bell Charitable Trust
- Vivien Brass Pink Ladies Games Day
- Australian Fed Cup Tennis Foundation
- Westpac Matching Gifts Program

- John Johnstone
- Sue Davey
- Lucille and Mel Bridges
- Karingal Bowling Club
- Daniel Regan Male Fashion
- Maura Fay Productions
- *Dusty: The Pop Diva* in Melbourne
- Link Me
- Southern Metropolitan Region International Women's Day dinner, Department of Education and Training
- Adelaide Rowing Club.

Celebrations

Happy birthday to **Debbie Gutteridge, Jenni Lovel, Dani Mahemoff** and **Monique Ronai**, who celebrated their

birthdays and asked that money be donated to BCNA in lieu of gifts.

Best wishes to **Sophie Dewar** and **Brendan Freeman** who nominated BCNA to receive money in lieu of gifts on the occasion of their wedding.

In memory

We remember **Heather Wilson, Barbara Priestley, Michelle McLean, Elizabeth Gray** and **Giulia Arcuri** and are grateful to be the recipients of donations in their memory.

Farewell Fenceliners

Many of you will remember reading about the adventures of the Fenceliners, a BCNA Member Group. This group undertook some fantastic trips for breast cancer survivors, including cycling around Tasmania and canoeing down the Murray River.

Sadly, the group has called it a day. In winding up, it has sent a cheque for \$10,000 to BCNA to strengthen the voice of women with breast cancer in rural and remote Australia. We thank them for this gesture and wish all Fenceliners the best, especially their fearless leader, **Lorrie Ledwell**.

Website news

More than 18,000 people visited our website in April.

Our news panel on the side of the home page is a great way to find out the latest news. We've been tracking progress with Herceptin and updating information as it becomes available.

The 'State by State' pages are a good place to find out about state and territory activities. If we hear about lectures, studies and research opportunities you'll find information about them here.

The website is undergoing a small re-organisation to help users to find what they are looking for as easily as possible and because we are adding more information.

We welcome your feedback about any aspect of the website.

Regional Field of Women heads to Wollongong

The Illawarra Breast Cancer Support Group, a long-standing and active BCNA Member Group, will host the Regional *Field of Women* for 2006. Planning is underway.

Set on the coastline of NSW, Wollongong will be a great location for the next *Field of Women*, a visual and moving display of the impact that breast cancer has on the lives of Australians.

The *Field of Women* is made up of 11,800 pink silhouettes



representing the number of women diagnosed with breast cancer in Australia each year, 100 blue silhouettes representing the number of men diagnosed each

year and 2,800 white silhouettes representing those who die. The 2006 regional *Field of Women* will take place on Sunday 22 October.

We were delighted when the Illawarra group, ably co-ordinated by **Gloria Swift**, offered to host the *Field of Women* and we will be working with them to bring it and its message to more Australians.

Would you like to host a Mini-Field of Women in 2006?

Last year 81 *Mini-Fields of Women* (each displaying around 100 pink silhouettes) were planted throughout Australia to highlight the impact of breast cancer in local communities.

These *Mini-Fields*, together with our major *Field of Women* in Port Lincoln, SA, were held in October around Australia's Breast Cancer Day. This year we are aiming for 100 *Mini-Fields* to run in conjunction with our major *Field of Women* in Wollongong, NSW, on 22 October.

Mini-Fields are a very important way of communicating about the impact of breast cancer, promoting local breast cancer support groups and raising BCNA's profile and membership.

If you would like to host a *Mini-Field of Women* in your area,



we will send you an 'Event in a Box' which contains guidelines, promotional tips and suggestions on how to personalise your day, along with everything you will need on the day.

This year's *Mini-Fields* will focus on the support that families can provide and on promoting the *My Journey Kit*, our free

information kit for women newly diagnosed with breast cancer.

Each *Mini-Field* is unique so you can plan an event to suit your local community. The main aim is to provide an opportunity for people to dedicate a silhouette to those they know who have been affected by breast cancer and to highlight the impact of breast cancer.

If you would like to find out more about hosting a *Mini-Field*, please contact BCNA by telephone (free call) 1800 500 258 or email events@bcna.org.au.

For updates about *Mini-Fields* in your area check our website, www.bcna.org.au.



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Do you have a My Journey Kit?

It's free of charge to women newly diagnosed with breast cancer. Here's what one reader had to say:

'The *My Journey Kit* is an excellent production and covers all aspects of the breast cancer journey that patients experience. I often find myself diving into a section to re-read something or to search out some information regarding some part of treatment.'

In the two years that the *My Journey Kit* has been available 14,702 women have received their free copy. Ring 1300 78 55 62 for yours.



the BEACON

The Beacon is the magazine of Breast Cancer Network Australia.

Editor: Lyn Swinburne
Layout: Substitution

Your letters, articles, photos, comments and items for future issues are welcome. Send them to:

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