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# the BEACON

Breast Cancer Network Australia's Magazine Issue 30 Autumn 2005

## 11,500 pink ladies *live* on the MCG – can we do it?

*We have been working really hard to get things in place for our Field of Women – Live in 2005, to be held on the evening of Friday, May 6, before the Melbourne versus Adelaide AFL game on the Melbourne Cricket Ground.*

Wherever we go, we are met with enthusiasm; whoever we approach has offered help and support. The excitement is mounting!

But can we really make this happen? Is it possible to recruit 11,500 women to stand on the MCG, dressed in pink, to bring the annual Australian breast cancer statistics to life?

It is a huge number of women, but what a powerful sight it would be and what an amazing experience to stand in the formation with other women committed to our cause.

We are asking each 'pink lady' in the Field to pay a \$25 registration fee, which will provide you with free entry to the game, a pink poncho and a carry bag.

### **WE NEED YOUR HELP!**

The live Field will remain just a concept unless our members spread the word and get friends, family and workmates to sign up.

To get to this stage has been

incredibly challenging, but we have done it. Permission has been granted by all the relevant bodies and **Ruth Sowden** has been recruited as our Project Manager.

Sponsors include Australia Post, Bakers Delight, KAZ and her industrie.

We will be doing all sorts of things to promote the event, but it simply won't happen without the energy and commitment of our readers, especially those in Victoria.

Having said that, we have been overwhelmed by phone calls from interstate readers who

are coming in a group, have booked their fares and tell us they wouldn't miss it for the world!

To learn more about the event, for regular updates, to register and to find out how best you can help make it happen, visit our special website at [www.fieldofwomen.org.au](http://www.fieldofwomen.org.au). In the meantime, you will find further details on the sheet inserted in your copy of *The Beacon*.

Don't miss being a part of this once-in-a-lifetime-event!

*Lyn Swinburne*  
Chief Executive Officer



*BCNA Board Member, Raelene Boyle, in our very first Field of Women in 1998. Raelene is committed to being one of the 11,500 women bringing the Field of Women silhouettes to life on the MCG on May 6, 2005.*

Breast  
Cancer  
Network  
Australia



# BCNA and Berlei to offer the My Care Kit to newly diagnosed women

*In January, BCNA teamed up with Berlei, a Pacific Brands company, to run the My Care Kit program to aid women following breast cancer surgery.*

The My Care Kit is available **free of charge** to women in Australia who undergo surgery for breast cancer. It contains a Berlei post-surgery bra and a soft form insert (if required) in a bright pink carry bag.

Berlei has specifically designed the bra to be worn during the first seven to 12 weeks after surgery, so it has extra hooks and eyes in the back to allow for swelling.

The fabric has been chosen for its softness and special attention has been paid to the position and sewing of the seams. It has fabric pockets inside the bra cups to hold a soft form insert in place (if required) and can be worn during any radiation treatment. The insert comes in various sizes and is easily customised to the individual woman.

This exciting new program is another invaluable opportunity for BCNA to communicate with women at a vital time in their breast cancer journey – the very beginning. It will enable us to tell them about such things as **The Beacon** and to make sure they have received the My Journey Kit.

This service has already been available to newly diagnosed women for three years, as part of Berlei's Caring for You program. The initial approach has



been via a breast care or community nurse, who fits the women and order the kits, which are then passed on to the women in their care.

Berlei has made an ongoing commitment to supply BCNA with the kits and money to further develop the program, so as to reach many more newly diagnosed women.

In the short term, we intend to run the service along the same lines as Berlei has done – with breast care nurses ordering the kits from us via e-mail.

We know, though, that some women, especially those in rural Australia, still do not have access to a breast care nurse. With this in mind, we will use the first six months to monitor demand and our own processes for getting the kits out to women, and speak with nurses and women in order to expand and streamline the program.

Patients undergoing surgery for breast cancer are encouraged to speak to their breast care nurse about the My Care Kit.

To enrol in the program, breast care health professionals can send an e-mail containing their name, hospital, address, telephone number and e-mail to [mycarekit@bcna.com.au](mailto:mycarekit@bcna.com.au).

We thank Berlei for its continued commitment to women with breast cancer via the My Care Kit Program.



*Melbourne volunteers, Cheryl Cookson and Rhonda Galbraith, pack the My Care Kits to be sent out to newly diagnosed women.*

# Our partnership with Bakers Delight is five years old

It is now five years since we first forged the incredibly successful partnership between Bakers Delight and Breast Cancer Network Australia. Long-term readers of *The Beacon* will have read about all the amazing things Bakers Delight have done for us over these years.

The list is truly impressive.

Bakers Delight:

- supply us with fully equipped offices in Melbourne (totally rent-free);
- provide our computers and IT support (at no cost to us at all);
- raise substantial funds via activities in their bakeries – the figure over five years is more than \$500,000;
- spread the word about BCNA on their paper bags and posters;
- decorate their bakeries (and often their staff) in pink each October;
- offer us advice and access to their networks and contacts;
- Bakers Delight staff are often volunteers at our events, e.g. the registration desk at our recent National Conference;
- provide products for morning teas – many of our member groups have been helped at this level; and
- so much more.

Our partnership has won awards (finalists in the Prime



*Bakers Delight founder, Roger Gillespie, and BCNA founder, Lyn Swinburne, celebrate a wonderful five-year partnership.*

Minister's Community Business Partnerships in 2001 and winner of the national award in our category in 2004) and is held up as a wonderful model of how partnerships should operate.

It works because Bakers Delight's support for us is totally genuine. They believe passionately that our work is

important and worthwhile and helps the members of the community in which they operate.

We thank Bakers Delight – and everyone connected with the organisation – for their total support over the past five years. You have helped us achieve so much!



*The 2004 Mini-Field in Toowoomba, Queensland*

## Mini-Fields in 2005

The 2005 *Mini-Fields* will be held in October, so you might like to give some thought to organising your own *Mini-Field*.

Some people choose to organise a public event that involves the whole local community. In other instances, private companies organise a *Mini-Field* on the balcony for their employees or schools organise them for their students. A great example of that in 2004 was the *Mini-Field* at St Laurence's College in Brisbane – an all boys school.

For more information on how to organise your own *Mini-Field*, be sure to go to our new-look website, [www.bcna.org.au](http://www.bcna.org.au), or register your interest with Molly Stacey on (03) 9805 2558 or 1800 500 258, or [mstacey@bcna.org.au](mailto:mstacey@bcna.org.au).

For those of you who organised a *Mini-Field* last year, look out for your photos on the website.



# Issues of Concern ...

## Latest news on tamoxifen alternatives

In the last issue of **The Beacon**, we wrote that BCNA's policy unit had been actively lobbying for new breast cancer drugs, aromatase inhibitors, to be made available to women with early breast cancer.

One of these drugs, Arimidex (the pharmaceutical name is anastrozole), was given a restricted listing on the Pharmaceutical Benefits Scheme (PBS) on December 1, 2004. That means it can be prescribed for oestrogen receptor positive, post-menopausal women for whom tamoxifen is not suitable. Since then, new results from the drug's five-year trial have been released. These show that anastrozole can provide even greater protection than

### Stop press

The results from the trial of another aromatase inhibitor, letrozole, released in late January, add to the growing evidence that these drugs may be useful in the treatment of some women with early breast cancer.

tamoxifen against breast cancer returning, by reducing the risk of recurrence by more than half as much again.

Other results showed that women who had taken tamoxifen for two to three years and then changed to anastrozole also had a lower risk of their cancer returning than if they continued on tamoxifen alone for five years.

We believe it is important that women discuss all of their treatment options with their surgeon or oncologist.

Despite the fact that the women on the trial taking anastrozole reported improvements in quality of life and a reduction in some of the side effects associated with tamoxifen, such as hot flushes and deep vein thrombosis (DVT), the women taking anastrozole in the trial experienced more fractures and joint pain than women taking tamoxifen.

Also, it should be noted that there is no evidence yet about the long-term effects of aromatase inhibitors.

We know that thousands of our readers are currently taking tamoxifen and that this will be

an area of interest and concern to you. In our next issue, we will pose some questions on the subject to a medical oncologist from BCNA's Medical and Scientific Reference Group.

If you have a question about aromatase inhibitors you would like to put to our medical oncologist, please e-mail it to our policy officer, **Alison Boughey**, at [beacon@bcna.org.au](mailto:beacon@bcna.org.au). We will pass the most frequently asked questions to our medical oncologist and publish the answers in the next issue of **The Beacon**.

BCNA believes women should be able to access aromatase inhibitors on the PBS when their clinician, in consultation with the woman, considers these to be the most appropriate treatment.

## Good news for lymphoedema sufferers

Since July 1, 2004, patients with a chronic condition, such as lymphoedema, requiring complex care have been able to claim Medicare rebates for up to five allied health visits a year.

To be eligible, the patient's GP must be managing their condition under an Enhanced Primary Care (EPC) multi-disciplinary care plan.

That means the GP and at least two other health professionals are involved in making and

implementing a plan for managing the medical condition. The two other team members might include a physiotherapist, occupational therapist or other allied health practitioner, a breast care nurse or another medical practitioner, such as an oncologist.

The allied health provider must be registered with the Health Insurance Commission (HIC).

The Medicare rebate for these allied health professional items is

\$44.95 and can either be claimed back from Medicare after you have paid your practitioner or, if the practitioner is willing to accept the rebate as full payment for the service, they can claim it directly from Medicare themselves.

For this to happen, the patient must sign a form, similar to the one you sign if you are bulk-billed by your GP. Each claim must also be accompanied by a copy of the EPC referral form.

If you have private health insurance, you need to decide whether you will use Medicare or your private ancillary cover to pay for these services, as you cannot use your private cover to pay for any gap between the Medicare rebate and the fee the practitioner charges.

For more information about this initiative, visit the HIC website at [http://www.hic.gov.au/providers/incentives\\_allowances/medicare\\_initiatives.htm](http://www.hic.gov.au/providers/incentives_allowances/medicare_initiatives.htm).



# My Story

## Claire Tedeschi

*My story doesn't exactly have a beginning and it certainly doesn't have an end.*

It doesn't have a beginning because I don't know where my breast cancer came from. Perhaps I'll never know, perhaps I don't want to know, but at the moment it feels like I've drifted into a scary movie somewhere after the opening scene.

And clearly my story doesn't have an end because, at 42, diagnosed just three months ago, I am in no position to predict the future.

People tell me how important it is to be positive and in many important ways I am.

But I can't always be positive in terms of thinking I'll be fine because that doesn't seem realistic. I'll do everything I can to maximise my chances, but in reality, I just don't know what the future holds.

The most valuable piece of advice I've received so far was from my older brother. He keeps reminding me that we all live with uncertainty, it's just that I'll be more aware of it from now on.

The fact is, since I was diagnosed with breast cancer, I've become more aware of a whole lot of things like:

- Losing a breast doesn't feel like the end of the world.
- I am brave.
- It is misguided to respond to people when they tell you they have cancer with a 'shock-horror' approach that will make them feel they're as good as dead.
- Learning from the experiences of others can give you ideas about dealing with cancer, but you still have to work out the best way for you.
- Cancer gives me a certain licence to be upfront with

people about what I need. I have been ruthless about surrounding myself with people who make me feel strong and keeping at a distance people who make me feel weak.

Not bad for only three months; imagine how wise I'll be if I get to live a long life. It's one of the positive aspects to this journey and there are a few. I've heard people talk about them before and hoped I'd never get the chance to experience them firsthand.

Now that I am, I'd like to make a couple of observations about what I see as clear positives.

First, you're able to recognise the source of courage you've seen in other people facing serious illness – an acceptance that life is made of many parts.

It's an experience that sharpens your senses like nothing else. Beautiful things are more beautiful, simple pleasures more pleasurable.

I look at myself in the mirror more kindly, not spending nearly so much time scrutinising the flaws, more admiring the courage that I've discovered in me that makes me better looking somehow.

I'm told by people that, after my treatment is over, I will also get much better at living for the moment.

I'm still a little resistant to giving away that forward-looking anchor. I've always hated the idea of being taken by surprise, so when visitors are expected, I always wait by the window. I feel like I'm going to want to keep watch in case the disease returns.

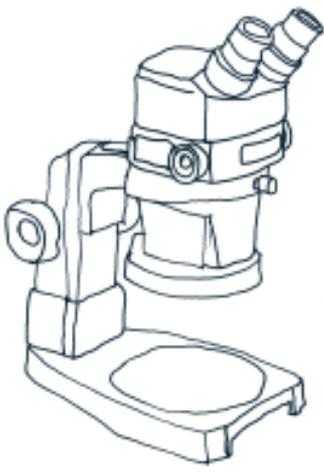
But that's no way of living.

The other experience I'm only just ready for is being part of what looks from the outside like a formidable network of women, constituted around an experience of such intensity that it overrides differences in background and lifestyle.

Telling an early chapter of my story is my way of starting to forge that link.

*Claire Tedeschi, Canberra*





# Clinical Update

The power of the Still Making a Difference Conference was exemplified in the Clinical Update Plenary session. Our Conference, held in Melbourne in August 2004, brought together 600 breast cancer survivors to hear progress reports from leading doctors, health professionals and advocates, and to use our own voices to raise issues and identify recommendations. This report is adapted, with our thanks, from UPFRONT, the newsletter of Breast Cancer Network New Zealand.

## Breast cancer treatment in the 21st Century

Sue Claridge, Breast Cancer Network New Zealand

Dr Susan Love introduced her talk on hormones by saying "Medicine is a work in progress! We never really know the truth; where we are is just the best guess at the moment." She could well have been introducing the plenary session *Clinical Update: then, now, next ...* in which four breast cancer specialists provided us with news of the latest advances.

### Psychosocial update

Dr Helen Zorbas  
National Breast Cancer Centre,  
Sydney, NSW

Perhaps the greatest and most rapid advances in breast cancer treatment and care have been in the psychosocial



field. Dr Helen Zorbas reported that 10 years ago psychosocial care was virtually non-existent. Psychosocial morbidity – for example, depression – is very high among cancer patients and it was identified as a priority for action in the 1990s. Australia's National Breast Cancer Centre guidelines, which were developed in 1999, have become

a template for psychosocial care in other cancers.

Themes addressed in the guidelines include: sexuality and body image (and difficult to discuss issues, such as negotiating new relationships and how to tell people about cancer); fertility and pregnancy; anxiety regarding the lack of information and a woman's ability to make informed decisions; fatigue; and issues of survivorship.

Dr Zorbas said that younger women were at a higher risk of depression and anxiety and that there were considerable issues regarding a woman's partner and/or children to be faced. These concern the desire to protect family and friends versus the need for them to be informed. Other big areas that need to be addressed from the psycho-social perspective are same sex relationships and the supporters of women with breast cancer.

There is a need for women to be referred to appropriate psychosocial clinicians during their treatment and afterwards. Additionally, many surgeons find it difficult to deal with the hard transition that some women must make from curative to palliative care.

### Radiotherapy update

Dr Liz Kenny, QLD

Recent research has shown that breast-conserving surgery combined with radiotherapy



is as good as radical mastectomy and axillary clearance in women with early breast cancer.

The use of radiation leads to a profound reduction in the recurrence of breast cancer and an increase in survival rates.

A new radiotherapy technique uses only partial irradiation of the breast, as opposed to irradiating the whole breast. This technique treats only a very limited breast volume and the overall treatment time is considerably reduced, from six weeks to between one and five days.

Partial Breast Irradiation (PBI) is still experimental, however, and the long-term impact of large doses of radiation or doses administered twice a day are unknown.

Another development is intensively modulated radiotherapy (IMRT), which compensates for the irregular

shape of the breast and evens out the dosage over the whole breast.

It is hoped these advances will reduce the side effects of radiotherapy.

### Adjuvant therapy update

Dr Fran Boyle, NSW

Dr Fran Boyle started by setting out the questions that medical oncologists ask themselves when considering systemic therapy for breast cancer:



- When is it time to watch and wait?
- When is it time to use simple oral drugs?
- When is it time to use more powerful drugs and combinations?

A new tool, Adjuvantonline.com, allows oncologists to assess what treatment is most appropriate for a patient. Prognostic factors (e.g. age, general health, tumour size and grade, lymph node involvement, HER2 positivity and oestrogen receptor status) can be entered into the program to

help health professionals estimate the risks.

Dr Boyle went on to discuss the benefits and risks of the various forms of adjuvant therapy, concentrating on tamoxifen, aromatase inhibitors, such as arimidex and letrozole, and combination chemotherapy.

She concluded by saying that while it was difficult to talk about prognosis, women needed to know the facts. She emphasised the importance of being hopeful about the future and the outcomes of drug therapy.

Research has shown that the majority of women are prepared to suffer side effects for a limited increase in survival times: 70% of women think that chemotherapy is worth it for a 5% increase in survival, while 80% of women on tamoxifen believe it is worthwhile for a 5% increase in survival.

## Still Making a Difference report

Reports from Australia's Second National Breast Cancer Conference for Women are now available.

The summary that documents all the recommendations from the Conference will be sent directly to those who attended, as well as to key organisations, government departments and politicians.

To limit costs, we will have produced a smaller number of the full Conference Report. At 80 pages, this is a large reference document.

Both documents are available on our website, [www.bcna.org.au](http://www.bcna.org.au), or by telephoning 1800 500 258.

## Surgery update

Dr Melissa Bochner, SA

Fifty years ago there was no mammography and no pre-operative diagnosis. A cancer diagnosis came following the disabling and mutilating Halsted radical mastectomy – nothing less than an amputation of the breast.

The emphasis is now on breast conservation surgery and mastectomy rates are as low as 30%. Research has shown that lumpectomy plus radiotherapy is as good as mastectomy for long-term survival.

Lumpectomy or mastectomy, coupled with axillary clearance – the removal of lymph nodes from



the arm on the same side – has become the accepted standard of surgical treatment for breast cancer. However, axillary clearance is not without its risks and side effects. The sentinel node biopsy is a huge advance, which has reduced the need for axillary surgery and the Sentinel Node versus Axillary Clearance (SNAC) trials have been very important in assessing the safety and efficacy of this technique.

Multi-disciplinary care is becoming the norm in breast cancer treatment and Dr Bochner said that the breast surgeon played an important role in a woman's care, walking some of the journey with her. The focus of future surgical advances will be on a better quality of life, better cosmetic appearance, better and greater use of minimal surgery, and lower morbidity from surgery.

## Put the glass down

A lecturer was discussing stress management with his students.

He raised a glass of water and asked the audience, "How heavy do you think this glass of water is?"

The students' answers ranged from 20g to 500g.

"It does not matter on the absolute weight. It depends on how long you hold it," he said.

"If I hold it for a minute, it is okay.

"If I hold it for an hour, I will have an ache in my right arm.

"If I hold it for a day, you will have to call an ambulance.

"It is the exact same weight, but the longer I hold it, the heavier it becomes.

"If we carry our burdens all the time, sooner or later, we will not be able to carry on, the burden becoming increasingly heavier.

"What you have to do is to put the glass down and rest for a while before holding it up again."

We have to put down our burden periodically, so that we can be refreshed and are able to carry on.

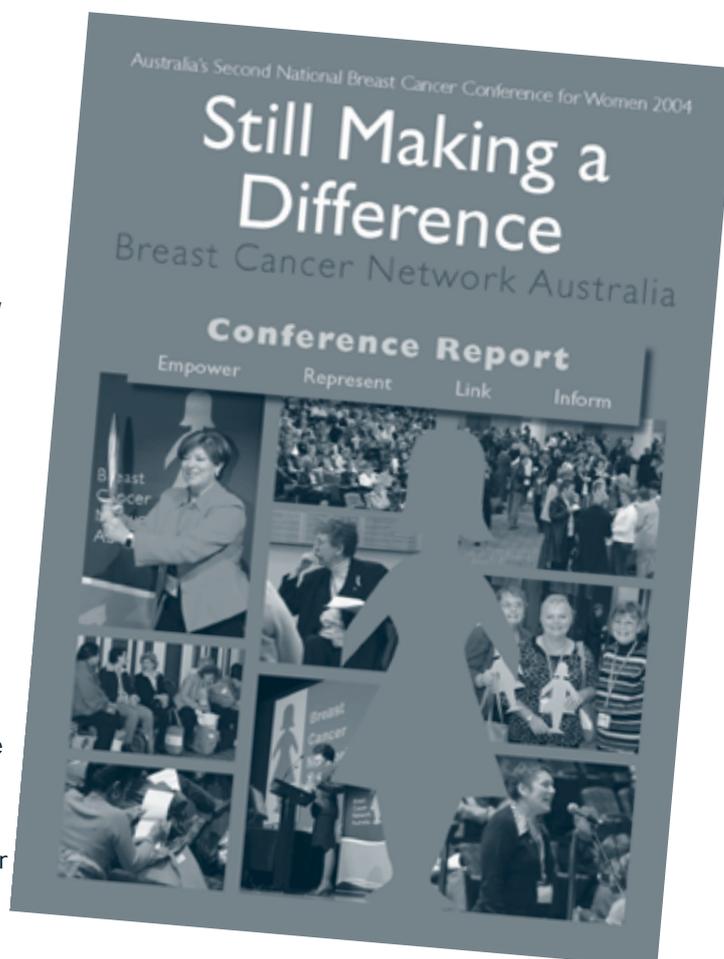
So before you return home from work tonight, put the burden of work down. Don't carry it back home. You can pick it up tomorrow.

Whatever burdens you now have on your shoulders, let it down for a moment if you can.

Pick it up again later when you have rested ...

Rest and relax.

Life is short, enjoy it!



# Dr Susan Love: The hormones are jumping

*Gillian Woods and Sue Claridge from New Zealand summarised Dr Susan Love's address to the Still Making a Difference Conference.*

**Dr Susan Love** needs little introduction to most of us. Among her numerous achievements, probably her best known is as the author of several books, particularly her *Breast Book* and *Menopause and Hormone Book*.

Susan is an entertaining and charismatic speaker. Her passion for women's health comes through clearly, as does her conviction that breast cancer can not only be cured but, ultimately, prevented. She speaks with great humour and in terms that even the less medically minded can understand.

She is a staunch advocate for women and our ability to change the world.

At the Conference, she spoke about the role of hormones, strongly rebutting the view that menopause was a disease, or failure on the part of women's bodies to do what they were designed to do. Rather, she said our "hormonal program" was natural and in-built.

"Post-menopausal women run the world!" she argued.

Susan presented an alternative view that women have children, then go beyond reproduction, and achieve power. Post-menopausal women are the ones with time to take on leadership roles.

She said that lifestyle factors were important for health and



*Dr Susan Love's address to the Still Making a Difference Conference was a passionate one.*

happiness. But while we should be looking at exercise, diet, weight and smoking, we should also *have fun*.

"Eat your vegetables" Susan said. But that said, she has also reasoned that chocolate is a vegetable because it comes from the cacao bean.

Susan offered delegates practical advice about breast cancer. For instance, diagnosis is no longer an emergency. Breast cancer starts 8-10 years before diagnosis; there is time to consider the options.

She pointed out that cancer cells in the breast are not going to kill you – it is when they get to other organs that they become a problem. She recommended women take time to decide what to do, remembering that cancer in the breast could be removed and treated.

All breast cancer starts in the lining of the milk ducts, even lobular cancer, and Susan has found that abnormal cells can be detected in the fluid from the ducts.

To do this, she uses a technique called a Ductal Lavage, in which a fine catheter is inserted through the nipple into the duct. Saline is used to wash the duct and remove a sample in which abnormal cells may be detected. This technique has been approved in the US for use with high-risk women.

However, only a third of women with abnormal cells go on to develop breast cancer. Susan said we needed to find a cancer marker in the fluid.

If we can diagnose breast cancer from ductal fluid, Susan believes it might lead to local treatment via the ducts, offering hope for a path to eradicate breast cancer – find the abnormal cells and treat briefly with chemotherapy in the ducts, end of story.

## Health and wellbeing study

If you live in Victoria and your first diagnosis of breast cancer was after June 1, 2004, you are eligible to join a new study investigating the wellbeing and ongoing health needs of women after breast cancer treatment.

Researchers at Monash University are inviting all recently diagnosed women to take part in the study, which involves completing a questionnaire once a year for five years.

The aim is to investigate the effect of breast cancer on women's lives and highlight the issues that are important for their wellbeing after treatment.

As this is a questionnaire study only, taking part will not affect your individual treatment, but will provide information that may be used to improve the health and wellbeing of *all* women after breast cancer.

To take part or to find out more, phone 1800 034 348 or visit [www.afterbreastcancerstudy.org.au](http://www.afterbreastcancerstudy.org.au).

## Genetics website

The Victorian Family Cancer Genetics Service, funded by the Department of Human Services, has launched a website that will provide valuable information to many Victorians who have questions about cancer and genetics. The site is hosted by The Cancer Council Victoria at [www.cancervic.org.au/familycancer](http://www.cancervic.org.au/familycancer).



Ron Dewhurst, Raelene Boyle, Katie Dewhurst and Judy Wild at the Friends of the Network launch.

## Friends of the Network

*Friends of the Network is a new group for significant financial supporters of BCNA.*

To become a Friend of the Network, an individual, couple or family donates \$1000 for a year.

We know a \$1000 donation is beyond many people, but there are some who can and want to support such an initiative.

Brochures outlining the program and the benefits to benefactors are available from BCNA's Relationships Manager, **Kerrie Edwards**, by phoning (03) 9805 2537 or e-mailing [kedwards@bcna.org.au](mailto:kedwards@bcna.org.au).

Our target for this financial year (up to June 30, 2005) is to secure 100 Friends of the Network.

The Network was launched in Melbourne last October at the home of BCNA's Board member, **Ron Dewhurst**.

To date, we have received \$45,000 in Friends of the Network donations. BCNA's website lists our Friends of the Network members.

### Friends of the Network at January 1, 2005

- Anonymous
- Antony and Julie Avery
- Andrew Barling
- Paul and Robyn Brasher
- Sam and Tania Brougham
- Leon and Diana Buchanan
- Melissa De Campo
- George Castan Family
- Sir Peter Derham
- Peter Dixon
- Jo Fisher
- Michael Gibson
- Peter Grayson
- John and Jo Hatherley
- Robert Heathcote
- Janet Holmes à Court
- Tim and Sue James
- Anna Kasman
- Mark and Judith Kellett
- Terry Little
- Ian and Jane Mandie
- Stephen and Amanda Mandie
- Tim and Sue Margetts
- Sir Laurence Muir
- David and Liz Nettlefold
- Parncutt Family Foundation
- Bill Prappas
- Martin and Maria Ryan
- Graeme and Ina Sampieri
- David and Ros Smorgon
- Peter and Kate Spargo
- Tom and Lyn Swinburne
- Norman Tilling
- Steve and Sarah Vizard
- Mary Wooldridge



## Seeking shelter

BCNA welcomes

- Cowra Breast Cancer Support Group (NSW);
- Breast Cancer Peer Support (Central Coast, NSW); and
- Gloucester Breast Cancer Support Group (NSW).

under its national umbrella.

This brings our total to 118 member groups and 6 associate member groups.

If your group is not a member of BCNA, you can find out more about the benefits of free group membership by calling 1800 500 258.

## Making connections

BreaCan, Melbourne's information and support service for people with breast cancer, is introducing *Making Connections*, an eight-week support program for women with advanced breast cancer. The first program begins in March.

For more information, phone **Josie Scott** on (03) 9664 9336 or e-mail [breacon@whv.org.au](mailto:breacon@whv.org.au).



# Letters to the Editor



I am looking for the answer to a question that has been 'bugging' me for a few months.

In February 2004, I was diagnosed with cancer in my right breast. I had a mastectomy, am now on Tamoxifen and everything seems fine.

Fine, that is, except for my question. As I meet more people who have had breast cancer, and as I read more about it, etc, it struck me that a large percentage of breast cancer seems to affect the right breast.

Have any studies been done into this? Are there any statistics you could provide? Am I just imagining it?

I've just come from a group of women who have all had breast cancer and I asked, 'Lefty or righty?' The result was 90% righties.

Hopefully you can put me out of my misery with some facts and figures.

*Melanie Glasson, Albany, WA*

*Editor: We asked our BCNA Medical and Scientific Reference Group and were told that the incidence is 50% left and 50% right breast.*

I would like to use your magazine as a forum to express my appreciation for the 'Look Good Feel Better' workshop I attended at Taree Hospital.

The volunteer beauticians and

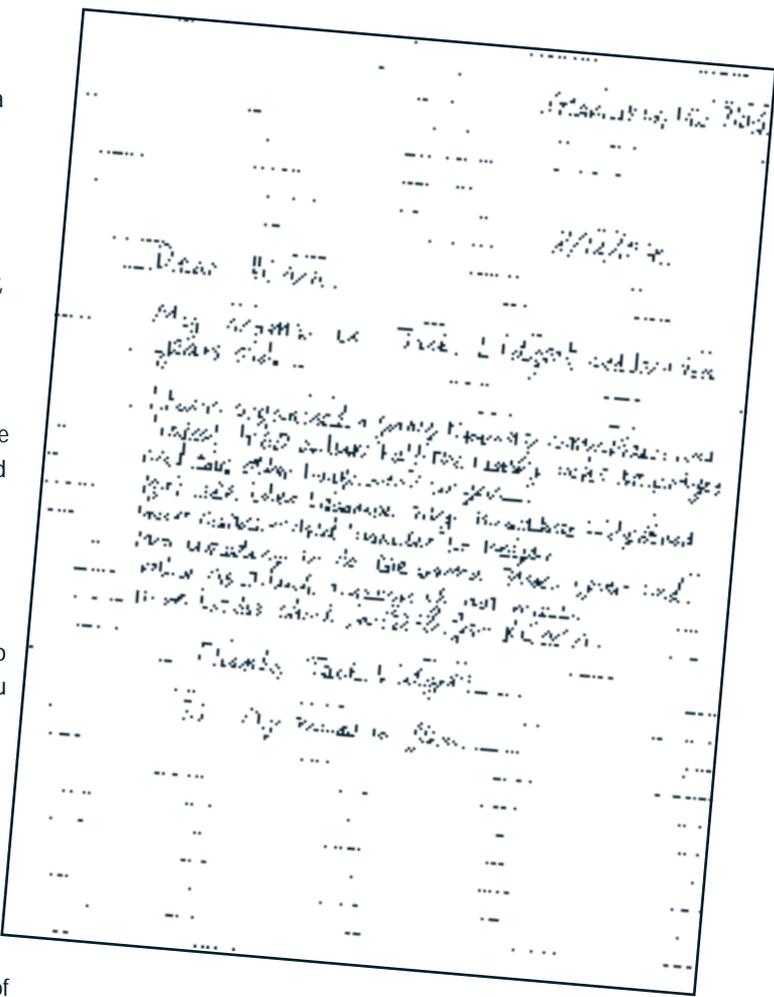
hairdressers who conducted the course made me feel very comfortable and gave us lots of tips to assist in making ourselves up. It was a great boost when I was feeling so low and looking so ordinary. I still had my last chemo treatment to go.

A special thank you must go to the cosmetic companies who donated all the items. We received every variety of make-up and cosmetics all suited to our colours and skin types.

Keep up the good work. The workshop is a terrific concept. It lifts your spirits considerably and it makes you feel very special and feminine to receive such wonderful gifts and to be able to apply them in the company of women with similar experiences is comforting.

*Heather Kelly, Forster, NSW*

*Editor: We plan to profile 'Look Good Feel Better' in the June issue of The Beacon.*



## Thank you

Many groups and individuals support BCNA in a range of ways. We would particularly like to acknowledge the help of these supporters:

- Reece Australia Ltd
- Aviva Guiding Star Committee
- Lions International 201 Q2
- The Maura Fay Group
- Gale Insurance Brokers
- Australian Olympic Committee
- Brambles Industries Limited
- Australian Federation Cup Tennis Foundation Inc.
- East Malvern Tennis Club
- Bicheno Golf Club Associates, Tas.
- Kingswood Golf Club, Vic.
- Ladies Committee at Kingston Heath Golf Club, Vic.
- Mona Vale Swingers, NSW
- Yarra Bend Ladies' Golf Club, Vic.
- The Valley Private Hospital
- Community Services & Health Staff, Warrane Campus, TAFE Tasmania
- Our Lady of Good Counsel, Deepdene, Vic.
- MLC, Kew, Vic.
- Carol Farmer's 60th birthday
- Graeme Hayes' 50th birthday
- Tim Gill's 50th birthday
- Edwina Winter's Christmas lunch



# Book Reviews

## Safina and the Hat Tree

By Cynthia Hartman, illustrated by Hayley O'Brien, published by Nomota, 2004.  
ISBN 0 646 43541 8

The children's book, *Safina and the Hat Tree*, is written by **Cynthia Hartman** from Illawarra, NSW, and is about one woman's journey through the trials and tribulations of her experience with cancer.

Coming from a long line of storytellers and a rich multicultural background, Cynthia is an accomplished author who relates to young children, being a mother of three and with a 14-year career working in early childhood centres.

The book is aimed at preschool to early primary school children and relays a positive message with simple eye-catching illustrations.

Considering the seriousness of the disease, the story centres on the varying emotions of a school teacher, which are represented by her collection of unique and colourful hats.

The hats are a continuing metaphor throughout the story, emphasising the need for young people to understand that even when people get sick they are still the same person.

The transition from healthy to sick to recovery is brief and enables children to relate by reaching their level of understanding.

With simplicity and humour, Cynthia has captured the essence of the situation and



expresses the importance of the support networks around her.

Throughout her difficult experiences, she involves her students, so that they can understand, firsthand, the illness and treatment of this disease.

However, because some children may have lost a loved one to cancer, there is a need to address this possibility, so that they can understand all the implications of the illness.

Although the topic of the story is complex, the book conveys a simple and brief message that the children can understand.

I do recommend this book for preschool and early primary school ages, as it engaged my own children's interest.

*Melany Bussey, Queensland*

## Welcome to the Amazon Club

By Jane Bissell, published by Longacre Press, 2004.  
ISBN 1 877135 93 3

**Jane Bissell** was a 45-year-old writer with a successful career, who was about to embark on an overseas trip, but was stopped in her tracks when she learnt she had breast cancer.

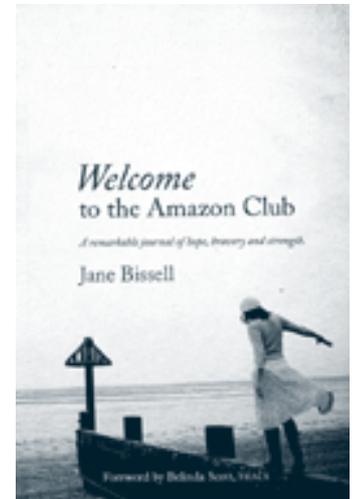
*Welcome to the Amazon Club* is about how Jane's good friend responds to the news.

Amazon women were brave, fearless warriors, who had their breasts removed in order to shoot their arrows more effectively. They were known for their protective loyalty towards each other and would bravely fight on, even when wounded in battle.

Jane meets her challenges face on and reveals her vulnerabilities in this open and completely honest account.

I particularly like the way she doesn't pretend to be a superwoman and we see her highs and lows 'warts and all'. She struggles to come to terms with her physical weakness and limitations and concludes, 'I listen to my body these days'. She also relates this back to the stress in her life before the cancer diagnosis. Her counsellor subsequently advises, 'You need to be a human *being* rather than a human *doing*'.

Jane provides simple and easy to understand explanations of medical terms and procedures as she encounters them. She receives excellent support from



her medical team, family, friends and support group. I certainly gained an appreciation of the importance of a strong network of support and its valuable contribution to recovery.

Despite the loyal support that Jane has, I felt the loneliness of her darkest moments following her treatment and was reminded that the power to cope through such trying times ultimately comes from within.

There are several pearls of wisdom imparted by various people (Amazon women) who Jane encounters on her journey.

The main message I took from the book was that cancer can, paradoxically, create a window of opportunity to 'stop and smell the roses'. Jane's touching and candid account of her diagnosis, treatment and recovery left me with a sense of hope and renewed appreciation of the 'here and now' for what it is.

*Melanie Adams, Victoria*



# Profiling our member groups

## Support Group for Women with Advanced Breast Cancer, West End, Queensland

*I commence this story by saying I am a very experienced breast cancer survivor – experienced with breast cancer that is.*

In 1996, at the age of 40, I was diagnosed with primary breast cancer. In 1999 I was diagnosed with metastatic breast cancer – the breast cancer had moved into my lungs and bones.

Although this is difficult to deal with, I continue to respond to timely and ongoing treatment and have good family support.

During my journey with breast cancer, I have found that support groups help me live a happy and purposeful life. I've become a 'groupie'!

Luckily for me, in late 1999, I heard about a support group for women with recurrent/advanced breast cancer and have been attending regularly ever since.

What are the benefits of a support group? I have heard women say they don't want to sit around discussing breast cancer and being reminded of it all the time. In my experience this is way off the mark.

In our support group, there is a partnership between the professional facilitation provided by the psychotherapists and the peer support provided by members.

While our group meetings are underpinned by the special psychosocial training of the



*Veronica Macaulay-Cross (far right) with members of Queensland's Support Group for Women with Advanced Breast Cancer.*

professional facilitators, they do not have a personal experience of breast cancer. That said, they have learnt a lot about it over the past five years. The members of the group bring their shared experience of life, breast cancer and treatments.

However, this peer support doesn't just happen – we have to work at it. We attend regularly, so that trust and friendship builds. If we can't attend, we send an apology. Confidentiality and privacy are respected.

We talk about everything and anything, not just breast cancer, and have lots of laughs! The group is based on supportive-expressive group therapy. We aim to be inclusive of all comers and strive to be good listeners.

This group has become a friendship circle of women.

Often when women are diagnosed with breast cancer, they say some of their friends don't seem to understand and give them a wide berth, so it is good to be with women who have experienced a diagnosis. They have a better understanding.

That doesn't mean we give up our other friends, we just make some new, special friends. Being together helps us adjust to our situation and 'normalise' our experience. We don't feel so 'different'.

A few years ago, the professional facilitators sourced funding for teleconferencing equipment, so that women in rural and regional areas could join our group meetings by phone. This is an innovative method of delivery and adds a wonderful dimension to our group.

Thanks to the efforts of our facilitators, the group is free to all. For the past three years, it has been funded by Queensland Health, which recently agreed to fund us for another two years.

We hold regular get-togethers for coffee and a chat after our meetings. We also have social activities, such as a BBQ at someone's place, when we can bring along our partners, family and friends. This is particularly helpful for them, as they can mix, in an informal atmosphere, with other families who have been affected by breast cancer. We also telephone, e-mail, write and even text message each other and have a lot of contact between meetings.

In summing up, the group is not just about *me*, but about *we*.

We want the group to be there for future women diagnosed with breast cancer. For the group to be sustainable, members need to attend on a regular basis and contribute to the peer support. Of course, there is no onus on any member and we all just do what we can, when we can; and there are so many laughs along the way!

*Veronica Macaulay-Cross  
BCNA Queensland State Rep*



# Dragons Abreast

We are delighted to welcome aboard new member groups in **Merimbula, Port Macquarie and north-west Tasmania.**

The enthusiastic support we receive continues to raise breast cancer awareness around Australia and beyond. This is the essence of why we exist – to ensure that breast cancer remains in the public arena by giving a ‘face’ to the statistics, while enjoying the benefits of belonging to a national group of dynamic and enthusiastic people enjoying activities on and off the water.

Amid pomp and ceremony the dreams of **Maxine Barker** and **Tracie King** to bring dragon boats to **Port Lincoln** and **Geelong** have been realised with the launch of their very own dragon boats.

Australia Day saw members of our **Warriors Abreast** team in **Adelaide** travel to **Port Lincoln** to join in the festivities of Tunarama. In Darwin, the **NT** pink ladies fielded three teams for the races at Cullen Bay, with many members enjoying their first-ever regatta!

Chinese New Year was celebrated in great style in **Sydney** with nine Dragons Abreast boats registering. More than 190 members from across **NSW, Queensland, the NT, the ACT** and **Victoria** came together to participate at Darling Harbour. **Cynthia Kuiper** is to be congratulated for introducing the QUACKS race to the festivities – a race where the **breast cancer specialists**



*Vivienne Gregg (NSW), Judy Smith (NT) and Penny Birtles (ACT) enjoyed every moment in Shanghai for the fifth International Dragon Boat Federation World Championships.*

were challenged by their patients – full results and articles are on the Dragons Abreast website.

**Jan Skorich** and the **ACT** members look forward to welcoming everyone to Canberra for the **Xanadu Wines AusDBF Australian National Titles** in April. A number of Dragons Abreast Australia workshops are being organised in conjunction with the nationals and there will also be a welcome dinner on Friday night.

More than 120 members and supporters have signed up to attend the **Abreast In A Boat**

**Regatta in Vancouver, Canada**, this June. We have registered four full boats of breast cancer survivors from Australia.

Some members will also be continuing on to **Berlin** to participate in the first **IDBF World CorCom Games** at the end of July. If anyone is interested in this event, please contact us, as space is still available on our team.

– **Michelle Hanton**,  
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[www.dragonsabreast.com.au](http://www.dragonsabreast.com.au)



*Members of Dragons Abreast Geelong in their new boat.*

## Well done

- On Australia Day, BCNA Board Member, **Raelene Boyle**, was named Maroochy Shire Citizen of the Year in Queensland, and much-loved Victorian breast care nurse, **Loretta Lilford**, received the Kyabram Citizen of the Year award.
- To the breast cancer survivors who completed the 500km trek on the Heysen Trail, SA, from Kapunda down south to Cape Jervis in October. **Sue Bowen, Chris Caughley**, and **Pam Robertson** were a part of the Fenceliners' latest adventure.



*Breast care nurse, Loretta Lilford.*

**Twenty years from now you will be more disappointed by the things you didn't do than by the ones you did.**

– **Mark Twain**



# State Reports

BCNA has two State Representatives in each State and Territory. Our State Reps each serve for two years, but have the option of renominating at the end of their term. In 2005, we are delighted to welcome four new State Representatives to our ranks.

## BCNA's new State Representatives



### Suellen Williams – Northern Territory

Suellen is our first Alice Springs-based NT representative.

Suellen was living with her husband in Alice Springs and their two children, aged just two and four years, when she found a lump in her breast on her 43rd birthday.

She chose to have her treatment in Brisbane because her family were there. The alternative was to go to Adelaide. Her father was also sick with cancer in Brisbane at the time.

Her first trip to Brisbane was alone, but she returned for treatment with her husband and children. That time she stayed for 4-5 weeks which included surgery and her first round of chemotherapy. She flew backwards and forwards for a further six cycles – all the while juggling childcare, her health and her feelings.

Suellen has used meditation to help her through her breast cancer experience and, while she doesn't follow any particular regime, she draws on what she has learnt on a regular basis.

Previously, Suellen worked in Aboriginal mental health and this role took her to remote Aboriginal communities. In addition to being a State Rep, Suellen is a member of our Young Women's Working Party.

Her first child has now started school and her youngest preschool.



### Ann Revell – Western Australia

Ann was diagnosed with breast cancer in February 2000, at the age of 51 years. Although two weeks into a new job, the support of family and friends allowed her to continue working during chemotherapy and radiotherapy treatments.

In 2002, Ann met **Carol Bishop**, BCNA's retiring WA State Rep and chair of WA's Action on Breast Cancer (AoBC). She soon found herself an active member of both groups and drawn into advocacy. Two years on, her involvement has increased (along with her confidence).

As a member of the Community Advisory Council of WA's largest teaching hospital, Ann's special responsibility is to improve the services to the hospital's cancer patients. She is also a member of a wide range of community groups (environmental, social and spiritual).

Ann is excited by the prospect of being a BCNA WA State representative, along with **Maria Waters**, although she is aware that Carol is a hard act to follow.

Ann reports she has a wonderful husband, Martin, who is always supportive of her endeavours; a terrific daughter, Caron, son-in-law, Craig, and three gorgeous grandchildren, Ben, Belinda and Hayley.



### Shelley Sexton – Tasmania

Shelley joins BCNA as our new Tasmanian representative. Based in Launceston, she comes to BCNA with substantial community and professional experience.

While she has lived in Tasmania for more than 30 years, Shelley was originally from New Zealand.

She has three adult sons and four grandchildren.

Shelley was diagnosed with breast cancer in November 2000. She had an initial lumpectomy as a day patient, further surgery to remove 16 nodes and subsequent radiation therapy. Shelley has had lymphoedema for two years.

Although now working as a registered nurse (with a particular expertise in advanced dementia), Shelley's early working life took her from an accident and emergency department in NZ to a Solomon Islands village.

As a nurse, Shelley particularly understands the impact of illness on family members as well as the patient. She notes that it is important to allow people to talk about their experience and ensure they have access to appropriate resources.



### Alexandrea Cannon – South Australia

Alexandrea was 39 years old and living in Brisbane when she was diagnosed with breast cancer in January 2000.

Like all women, she was shocked and distressed when told she had breast cancer, but worked her way through treatment and is almost up for her five-year tamoxifen review.

Alexandrea and her partner moved back to Adelaide two years ago, after 10 years in Brisbane.

Alexandrea brings a wide range of skills to her new role. She works as human resources manager (SA/NT) for Coca-Cola Amatil, and is an adviser to the Power State Credit Union Board and State President of the Australian Human Resources Institute.

Last year, Alexandra represented BCNA at a public forum run by the National Breast Cancer Centre to raise awareness of the importance of early detection. As well as telling her personal story as part of the forum, she responded to media requests to promote the forum.

## Live a life that matters

*This message was sent to us by e-mail from one of our members.*

Ready or not, someday it will all come to an end.

There will be no more sunrises, no minutes, hours or days.

All the things you collected, whether treasured or forgotten, will pass to someone else.

Your wealth, fame and temporal power will shrivel to irrelevance.

It will not matter what you owned or what you were owed.

Your grudges, resentments, frustrations, and jealousies will finally disappear.

So, too, your hopes, ambitions, plans and to-do lists will expire.

The wins and losses that once seemed so important will fade away.

It won't matter where you come from, or on what side of the tracks you lived, at the end.

It won't matter whether you were beautiful or brilliant.

Even your gender and skill colour will be irrelevant.

So what will matter?

How will the value of your days be measured?

What will matter is not what you bought, but what you built; not what you got, but what you gave.

What will matter is not your success, but your significance.

What will matter is not what you learned, but what you taught.

What will matter is every act of integrity, compassion, courage or sacrifice that enriched, empowered or encouraged others to emulate your example.

What will matter is not your competence, but your character.

What will matter is not how many people you knew, but how many will feel a lasting loss when you're gone.

What will matter is not your memories, but the memories that live in those who loved you.

What will matter is how long you will be remembered, by whom and for what.

Living a life that matters doesn't happen by accident.

It's not a matter of circumstance but of choice.

Choose to live a life that matters.



# Upcoming Events

**March 3-15:** WarriorWomen – a mixed media exhibition exploring the experience of breast cancer at the Brisbane Powerhouse.

Contact: Veronica Macaulay-Cross, 0419 745 694 or Lyn Moore, 0407 143 689, or visit [www.brisbanepowerhouse.org](http://www.brisbanepowerhouse.org).

**March 7:** BCNA's Brisbane Launch of the *My Journey* Kit at 11am, followed by a Members' Forum at 1pm, Brisbane Powerhouse (To coincide with WarriorWomen Exhibition).

Contact: 1800 500 258.

**May 6 (evening):** *Field of Women – Live in 2005* at the MCG (before the Melbourne vs Adelaide Football match). Registration \$25 through [www.fieldofwomen.org.au](http://www.fieldofwomen.org.au)

**May 21:** Think Pink Masked Ball, Palladium, Crown Casino, Melbourne. All proceeds go to The Cancer Council Victoria.

Contact: Lisa Cavalaro, (03) 9635 5584 or visit [www.cancervic.org.au/thinkpink](http://www.cancervic.org.au/thinkpink).

**June 8-12:** World Breast Cancer Organisation's 4th World Conference on Breast Cancer, in Halifax, Nova Scotia, Canada.

Contact: Terry Gilmer, [wbcwbcocogeco.net](mailto:wbcwbcocogeco.net) or visit [www.wbco.ca](http://www.wbco.ca).

**July 6-9:** ANZ Breast Cancer Trials Group's 27th Annual Scientific Meeting, Hyatt Regency, Perth, WA

Contact: [www.anzbctg.org](http://www.anzbctg.org).

## Launceston support group

The Tasmanian Breast Cancer Networks Launceston Support Group meets at the Kings Meadows Community Health Centre, McHugh Street, Kings Meadows on the first Tuesday

each month on alternating mornings and evenings:

- Evenings 7.30pm (February, April, June, August, October)
- Mornings 10am (March, May, July, September, November).

For more details, telephone Pauline on 6344 8968 or Margaret on 6331 2280.

## You're not yet on our mailing list?

Phone (03) 9805 2500 or 1800 500 258 (free call), or fax (03) 9805 2599, e-mail [beacon@bcna.org.au](mailto: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: ( )..... E-mail: .....

Have you had a diagnosis of breast cancer?  Yes  No



*The Beacon* is printed with the generous support of Mercedes Waratah Press, Alladice Graphic Arts and Dalton Fine Paper.

**5995 My Journey Kits have been distributed by BCNA to newly diagnosed women in the nine months since the kit's launch in May 2004.**



## the BEACON

*The Beacon* is the magazine of Breast Cancer Network Australia.

Editor: Lyn Swinburne, free call 1800 500 258, (03) 9805 2500 or [beacon@bcna.org.au](mailto:beacon@bcna.org.au)

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Your comments and items for the next issue are welcome.

Send them to BCNA 293 Camberwell Road, Camberwell, Victoria 3124