Many of us would say that once you hear the words, ‘You have breast cancer’, your brain can barely take in any more details.

At BCNA, we believe that women should be informed of all the treatment options available to them.

However, it can be a challenge to take in all the information presented to you when you’re in shock. As a result, we have suggested that complex information be presented in stages and further reinforced in written form.

Another, newer, challenge is now facing some newly diagnosed patients.

Recently published research results have shown that the drug Herceptin can significantly enhance the chances of survival for women with a certain type of tumour – Her2 positive breast cancer.

Around 20% of women diagnosed with breast cancer have this type of tumour.

While this is exciting news, the high cost of Herceptin creates an enormous dilemma for these women and for their doctors.

At present, Herceptin is incredibly expensive at around $60,000 a year.*

Oncologists are torn by this situation. Should they tell their patients that a treatment exists which may ultimately save their lives, but will cost such a large amount of money up front?

The situation is far more complex than this, so this issue of The Beacon explores it further. It contains information about Herceptin and what the latest trials indicate – potential risks and benefits – as well as what we are doing on behalf of women with breast cancer.

– Lyn Swinburne, Chief Executive Officer

* Herceptin is subsidised for women with advanced (Her2 positive) breast cancer.
Use of Herceptin in early breast cancer

As highlighted in our front page story, trial results have pointed to promising outcomes from the use of Herceptin to reduce the risk of recurrence following early breast cancer for women with Her2 positive breast cancer.

BCNA has reviewed the research and discussed the preliminary results with key clinicians, including Associate Professor Richard Bell, a medical oncologist and member of our Medical and Scientific Reference Group, as well as with Roche, the manufacturer of Herceptin.

The current situation:
Herceptin is not subsidised for women with early breast cancer and costs are likely to be between $50,000-70,000 per woman, per year.

While it is difficult to predict when Herceptin might be subsidised for use in early breast cancer, the process is likely to take years rather than months.

Roche has informed us that it will not receive the formal study data until at least early next year. At that stage, it will prepare an application to the Therapeutic Goods Administration (TGA).

The approval process can take up to one year. Once TGA approval is gained, a further application is required to the Pharmaceutical Benefits Advisory Committee to gain subsidy for Herceptin under the Pharmaceutical Benefits Scheme.

BCNA will continue to monitor progress around Herceptin and do whatever we can to speed up the subsidy process.

If you are interested in this issue, you might want to keep an eye on our website for updates.

In the interim, BCNA is keen to ensure that oncologists are explaining the Herceptin treatment option to women with Her2 positive tumours, so that they can make their own (extremely difficult) decision about whether they are prepared to take and pay for Herceptin themselves.

While this is a difficult choice, we believe it is important that women, rather than their health professionals, make the final decision about their treatment.

Good, clear and comprehensive information from their health professionals will help women make these tough decisions.

Sue Lockwood’s article about Herceptin published in the Breast Cancer Action Group’s May newsletter provides a good summary of the information emerging from three international trials. We thank her for her permission to reproduce it here.

Herceptin clinical trials

Three clinical trials using Herceptin for women with early breast cancer have reported their results recently.

The trials were set up to see whether Herceptin could reduce the risk of breast cancer coming back (a recurrence) in that group of women who have early breast cancer with Her2 positive tumours.

Herceptin was known to slow down the disease in women with advanced breast cancer, but no-one knew whether the drug would be useful for women with early breast cancer.

HERA trial
The HERA trial was designed to see whether Herceptin improved outcomes for women with early breast cancer.

This large clinical trial involved more than 5000 women treated in 478 hospitals and 38 countries. Women from Australia participated in this trial.

The trial looked at three groups of women with early breast cancer. Some women had:
1. The current best treatment of a combination of surgery, chemotherapy and sometimes radiotherapy.
2. The current best treatment, plus one year of Herceptin.
3. The current best treatment, plus two years of Herceptin.

The ideas being tested in this trial were:
• treatment with Herceptin may reduce the risk of a recurrence
• two years of treatment may be better than one year of treatment.
Herceptin treatment carries a small risk of side effects to the heart – a weakening of the heart muscle that requires medical treatment (cardiac toxicity). This trial looked at all the side effects.

To protect patients who participate in large clinical trials such as HERA, an independent data monitoring committee (IDMC) was set up. It was made up of oncologists, cardiologists, a statistician and a patient representative.

In May 2005, after most women had been followed up for at least one year, the results were released for the observation and one-year group at a major conference in the US.

Of the 5090 participants, the number of women:
- taking Herceptin who had a recurrence of some sort - 127
- not taking Herceptin who had a recurrence of some sort - 220.

There are a number of different ways women could have a recurrence, e.g. a local recurrence, metastases, cancer in the other breast or death.

Another way of looking at this is, at an average time of one year, for women:
- taking Herceptin - 7.5 % of women had a recurrence
- not taking Herceptin - 12.7% of women had a recurrence.

The number of recorded deaths, from any cause, for women:
- taking Herceptin - 29
- not taking Herceptin - 37.

For side effects:
- There were more side effects in the women who took Herceptin compared with those who were being observed. Eight per cent of women taking Herceptin withdrew from the trial. Most withdrew because of potential changes to their heart function. The women were monitored closely and they withdrew from the trial if it looked as if their heart could become affected.
- There were more women with side effects which affected their heart function with Herceptin, but no women died from the effects on their hearts and it appears that the effects were relatively minor. This needs to be explored further.

Overall, more women benefited from treatment with Herceptin than had negative side-effects.

On average, women have been followed up for about one year. Currently there is no information available about whether two years of treatment with Herceptin was better than one year. This may change as time goes on and so further follow-up is important.

Women on the trial who did not receive Herceptin will be offered this drug. More details are to be released on this, hopefully soon.

**US Herceptin trials**

There were also two trials carried out in the US to look at the value of Herceptin when combined with another chemotherapy drug, paclitaxel, for women with early breast cancer.

The results of these two trials were combined when they were reported.

It has been known for some time that Herceptin works well with taxane chemotherapy drugs. Paclitaxel is a taxane, otherwise known as Taxol.

In this trial, all the women had doxorubicin (an anthracycline) and cyclophosphamide before having Herceptin and paclitaxel.

The two groups compared were women taking:
- doxorubicin and cyclophosphamide, followed by paclitaxel
- doxorubicin and cyclophosphamide, followed by paclitaxel and Herceptin.

Two different doses of paclitaxel were also compared.

The major focus was the difference between those women who had Herceptin and those who did not. Most of these women were followed for at least two years.

The results show that of the:
- 1629 women taking paclitaxel, 261 had some form of recurrence
- 1627 women taking paclitaxel and Herceptin, 134 had some form of recurrence.

In other words, for women taking:
- paclitaxel alone - 15.5% had a recurrence after two years
- paclitaxel and Herceptin - 8% had a recurrence after two years.

As with the HERA trial, the form of recurrence could vary from a local recurrence to metastases.

For deaths from any cause:
- 92 women died in the group taking paclitaxel alone
- 62 women died in the group taking paclitaxel and Herceptin.

The major problem was with the side effects on the heart. In women taking:
- paclitaxel alone, there were 794 cases of heart problems, with three serious cases and one death
- paclitaxel and Herceptin, there were 830 cases of heart problems, with 30 serious cases and no deaths.

In this trial, 19.9% of paclitaxel and Herceptin patients had to discontinue Herceptin because of cardiac effects. The problems with heart disease were a major issue for this trial and women need to be followed up with care in the future.

This trial also showed signs that the long-term risk of developing metastases was reduced. This also needs more follow up to be sure of the final outcomes.

If you want more details of both these trials, the results (in the form of a short summary or abstract) are accessible on the ASCO website, www.asco.org. The HERA results are on the HERA website, www.heratrial.com.

- Sue Lockwood

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BCNA gratefully acknowledges our partnership with Bakers Delight.
Influencing tomorrow’s doctors today

BCNA member, Pam Williams, recently spoke to third-year medical students at the University of Melbourne.

Pam joined 13 other Consumer Representatives to highlight the issues women face when diagnosed with breast cancer.

Student doctors see patients a number of times during their training, but they don’t often have the opportunity to hear about patients’ experiences of care, both good and bad, when they are no longer patients.

“We were able to remind them about the importance of having access to information, access to a team of health professionals, good communication skills and using clinical practice guidelines to treat breast cancer,” Pam says.

“We were also keen to remind them about the importance of addressing women’s psycho-social needs, not just their physical needs.”

Probably the most powerful message our representatives communicated was that every individual’s breast cancer journey is unique. While there are common experiences, no woman’s experience of being diagnosed and treated for breast cancer should be dismissed.

“It was a real opportunity to encourage open communication between clinicians and consumers. One student said he had learned that it was important to use language carefully, so that it could not be interpreted in other ways,” Pam says.

The students agreed the women’s presentations were valuable. As a result, the University plans to involve our Consumer Representatives in future years.

Consumer Representatives have also talked to breast care nurses, breast cancer specialists and allied health workers in most States and Territories. This work is helping to fulfil recommendations about consumer involvement and improving doctor-patient communication from our 2004 Still Making a Difference Conference.

“This was one of the most worthwhile experiences in which I have participated. From my times as a lecturer, I know how important it is for students to have someone speak with them about real experiences,” says course co-ordinator, Justine Tse.

Pam was diagnosed with breast cancer in 1997 and became a BCNA Consumer Representative after completing our Advocacy and Science Training Program in 2001.

Our silhouettes raise the profile of breast cancer overseas

Those of you who attended our National Conference in August 2004 will recall hearing from Stella Kyriakides, President of our European sister organisation, Europa Donna.

Stella is an amazing woman and a powerful breast cancer advocate in her native Cyprus.

When Stella heard I’d been invited to speak at international meetings in Europe during June, she asked me to extend my trip to make a presentation to her community.

Ideas flew between us via e-mail, until I landed in Cyprus in mid-June to help Stella present a Field of Women in Nicosia.

Three hundred and twenty women are diagnosed with breast cancer every year in Cyprus, so we sent 320 of our beloved pink silhouettes in advance.

It was a wonderfully successful event, attracting enormous coverage in the Cypriot media – including the front page of the three major newspapers!

The event was held at the Presidential Palace and the speakers included Mrs Papadopoulou, the wife of the Cypriot President, the Australian High Commissioner, Garth Hunt and Stella and myself.

The 320 silhouettes remained on a roundabout outside the Palace for a week (three minor accidents were reported!).

For me, it was a wonderful opportunity to meet other breast cancer survivors and to be reminded that, even though we live so far apart, many of our issues are the same.

It was also moving to see our pink symbols having such an impact so far from home.

Leading the Silent Walk in Nicosia.

- Lyn Swinburne
Field of Women begins its regional tour

October 2005 will see BCNA’s now famous Field of Women exhibited for the first time in a regional centre. Port Lincoln, on South Australia’s Eyre Peninsula, 650km west of Adelaide, will host the first-ever regional display of the Major Field of Women.

Now that the Field of Women has been seen in all the State capital cities, and was capped off with the Field of Women – Live in 2005 at the MCG earlier this year, we hoped to start a regional tour of Australia to give more people the opportunity to see the vast and moving field of pink, white and blue silhouettes.

As a result, we were delighted to hear of the enthusiastic response from BCNA members in Port Lincoln.

The Port Lincoln Field of Women will be co-ordinated and managed by Maxine Barker, Helen Hookings and members of the Port Lincoln Caring Cancer Support Group.

The Field will draw attention to the raft of issues faced by women in rural and remote parts of Australia when confronted with a diagnosis of cancer, and will raise the profile of the local group.

Exhibiting the Field also ensures that many more people will read the silhouette messages that are sponsored in support or memory of individual women and men affected by breast cancer.

As many of you are aware, our Field of Women has been planted each year since 1998 to highlight the breast cancer statistics, and to give survivors, carers and the community across Australia the opportunity to participate in a public display of support.

For six years, 11,500 (originally 10,000) pink lady silhouettes have been planted in a prominent public place somewhere in this country to represent the number of women in Australia diagnosed with breast cancer each year. One hundred blue silhouettes represent the number of men diagnosed each year and 2700 white silhouettes represent the number of people who die each year from this disease.

The Field of Women has special meaning for us and we hope it will continue to be displayed, with the help of our Member Groups, each year in regional areas around Australia.

For more information about this year’s event, contact Maxine Barker, Port Lincoln Caring Cancer Support Group, mbarker@epc.net.au or telephone (08) 8682 6519.

Mini-Fields spring up near you

This October, Mini-Fields of Women will be planted across Australia in many different locations and communities.

Each Mini-Field will display 100 pink silhouettes, each one of which can be sponsored in honour of someone affected by breast cancer.

Mini-Fields are as varied as the groups and individuals who host them. In Western Australia, the Esperance Breast Cancer Support Group will host a bra art exhibition in conjunction with its Mini-Field. At Hillary’s Boat Harbour, BCNA Member Group Action for Breast Cancer WA, will plant its Mini-Field at the end of a coastal bike ride that includes more than 50 cyclists.

Again this year, the My Journey theme will highlight the experience of breast cancer and help to create awareness in the community about the disease and the availability of the My Journey Kit.

The locations and contacts for each Field are listed on the insert in this issue of The Beacon. For further details, contact your local Mini-Field convenor or check our website for updates.
Government reviews cancer care

In the last issue of The Beacon, we reported that BCNA's Lyn Swinburne and Sue Timbs had appeared before the Senate Community Affairs Committee's inquiry into services and treatment options for persons with cancer.

In June, the committee released its report, compiled from evidence submitted by a range of individuals and organisations, including consumers, clinicians and policy makers.

The report reflects the committee’s interest in how quality cancer care can be provided to all Australians, regardless of where they live, what their cultural background is or where they receive their health care.

There is a great deal of consistency between the committee’s recommendations and those arising from BCNA’s 2004 Still Making a Difference Conference.

In areas such as multi-disciplinary care, complementary medicines, the provision of information, psycho-social support, the travel and accommodation needs of rural patients, breast care nurses and implementation of clinical practice guidelines, the recommendations are highly consistent with BCNA’s conference positions.

The committee also emphasised the importance of consumer involvement in all aspects of cancer service delivery reform and highlighted that cancer care should be patient rather than disease focused.

A number of individual cancer patients reported to the committee about the fragmented, ad hoc availability of support during their cancer treatment. The report states in regard to this, however, that, “One notable exception was in the case of breast cancer where the amount of information and support services was recognised and praised”.

The report includes quotes from famous people such as cyclist, Lance Armstrong as well as moving stories, such as the one from Hannah McGlade, a member of an Indigenous extended family caring for a dying boy. It is a compassionate and comprehensive document that reflects the human face of cancer care in Australia.

The report and other documents relating to the committee’s work can be accessed at www.aph.gov.au/senate_ca.

Chemo has long-term benefits

Increasingly reliable evidence is now available regarding the risks and long-term benefits of various breast cancer treatments. A recent analysis has shown that the benefits of both chemotherapy and hormonal therapy in terms of reduced mortality rates after breast cancer are not just short term, but continue for at least 15 years.

This latest five-yearly analysis of every breast cancer trial around the world that has been running for more than five years was published in The Lancet earlier this year.

The analysis involved almost 150,000 women in 200 randomised trials, many with long-term follow-up.

As new treatments are developed and older treatments are used in better ways, it is hoped that even greater improvements in long-term survival after breast cancer will be seen.

You can read a full review of this article on BCNA’s website or download the full article from The Lancet website www.thelancet.com/journals/lancet/article/PIIS0140673605665440/fulltext.

Thank you

BCNA would especially like to acknowledge the help of the following supporters over the past three months:

- Melissa Hale and Jacqui Blumfield
- The Ninety Milers
- Merlivic Schrank Pty Ltd
- Green Acres Golf Club
- Carey Baptist Grammar School, Kew
- Peninsula Country Golf Club
- Freehills Community
- Jenny Thorn
- Jessica and Peter Conaghan, and the team at Operation Pinkband
- Georgie Lanyon, Aviva
- Madeleine Luck.

Thanks to all those readers who donated money to support the free distribution of this newsletter to our members. Special thanks also to those of you who gave such great feedback.
Want the Warrior Women exhibition at your place?

Warrior Women is a mixed media exhibition that explores the experience of breast cancer.

It has been touring on and off over the past four years and more than 15,000 people have visited and been deeply moved by this powerful insight into the social and emotional impact of breast cancer.

Sadly, the cost of storing and maintaining the exhibition makes it difficult to keep it touring indefinitely. As a result, the exhibition's organisers, led by breast cancer survivor, Sue Smith are putting out a final call for anyone interested in having the exhibition visit their area.

The costs associated with having it for a one or two-week period depends on the location, but can range from $5000 to $15,000.

Organisations that have raised the funds to transport and host the exhibition include: the Dragons Abreast Team Canberra; BCNA Queensland; the Peninsula Health Service; and the Queen Victoria Museum and Gallery, Launceston.

If there is no further interest in touring the show, the organisers plan to contact the original Warrior Women and offer them the choice of having their artwork returned or donating individual pieces to an organisation or service for permanent display.

If any organisation is interested in having the Warrior Women tour, or in pieces for permanent display once the exhibition's touring is concluded, contact Sue Smith over the next couple of months by phone (03) 8430 8419 or e-mail start1@iprimus.com.au.

A place of healing in the high country

Women with breast cancer can now visit the NSW high country for a much-needed break, free of charge.

ACT State Representative, Elspeth Humphries, is offering Creekside, a lodge at Thredbo, NSW, for this purpose.

Creekside is available during the week from November to May and can be booked through the Otis Foundation.

Since the Otis Foundation opened its first retreat in the Mandurang Valley near Bendigo, Victoria, more than two years ago, more than 150 women have experienced the peace the retreat offers. Guests have travelled from as far as NSW, Queensland and South Australia.

The units are a place women can go without the burden of paying for accommodation.

The Otis Foundation is committed to funding these retreats so that others can continue to find that same strength and renewal.

The concept, inspired by the original vision of Judy Burley, has continued to gain momentum with Elspeth Humphries offering Creekside, another place of natural beauty.

“The Snowy Mountains are special to me. I am surrounded by the vast and timeless elements of earth, fire, air and water. The mountains refresh me in mind and spirit and I would like to share that with women who are learning to live with breast cancer,” Elspeth says.

The retreats have no resident staff, but the peace and quiet will sweep over guests as they have the chance to just contemplate.

The natural beauty of both sites provides a haven where healing can take place, and where a partner or support person can also take the time to revisit the simple pleasures of life.

For information and bookings, phone (03) 5439 3220, e-mail otisbookings@bigpond.com or visit www.otisfoundation.org.au.

An image from the Warrior Women exhibition.
SA forum a big success

What a treat it was to see almost 300 women from various parts of South Australia gathered together at our Members’ Forum in Adelaide.

Local breast surgeon, Melissa Bochner, gave an excellent overview of current advances in breast cancer treatment.

The standard of questions to Melissa from our members demonstrated that many breast cancer survivors have a keen understanding of the disease and want even more information.

BCNA’s CEO, Lyn Swinburne, provided an overview of our key strategic focus for advocacy work – as directed by the outcomes of our 2004 Still Making a Difference Conference.

Terri Smith, BCNA’s National Programs Manager, outlined our current wide range of activities.

Raelene Boyle spoke personally and passionately about her experiences, both as an Olympian and a breast cancer survivor.

“I used to be an elite runner, now I’m happy to be a part of a different elite group, that is, the many thousands of women in Australia who have experienced breast cancer,” she said.

The questions and comments from the floor provided a great opportunity for everyone present to hear about the issues currently faced by breast cancer survivors, both in Adelaide and rural SA.

The forum was also a chance for BCNA members to meet Alexandrea Cannon and Jan Davies, our two SA State Representatives.

We were particularly pleased to have women joining us from rural SA. It was also a great thrill for us to welcome many new members – women who have been diagnosed in recent times and have joined BCNA after receiving the My Journey Kit.

BCNA will continue its State-based launches and forums with visits in August to Sydney and Dubbo, NSW, as well as Alice Springs and Darwin, Northern Territory, in September. Our last visit for the year will be to Launceston, Tasmania, in October.

Honoured

We are delighted to note that three of our members were nominated in this year’s Queen’s Birthday Honours List:

- Jocelyn Newman – BCNA Board Member and a Board Member of the National Breast Cancer Centre
- Sally Crossing – Chair of the Breast Cancer Action Group NSW
- Lynne Crookes – Chair of the Sydney Breast Cancer Foundation.

We send our congratulations to these three women, each of whom is a breast cancer survivor who has achieved an enormous amount on behalf of the community through hard work, dedication and passion.

We would also like to acknowledge Onella Stagoll, the Director of BreastScreen Victoria, who received an honour for her work in developing Victorian breast screening services.
ANZ breast cancer trials

BCNA’s Policy Officer, Alison Boughey, along with BCNA Consumer Representatives, Pam Williams and Angela Verde, attended the Australian New Zealand Breast Cancer Trials Group (ANZBCTG) Annual Scientific Meeting in Perth during July.

The ANZBCTG is a group of Australian and New Zealand breast cancer researchers with links to researchers internationally. The group participates in large international studies into treatments for breast cancer.

The annual scientific meeting is an opportunity for members of the group, as well as other interested people, to come together to discuss the research that is being done into breast cancer.

Researchers are currently working hard to develop treatments specifically designed to treat each individual’s breast cancer in the most effective way. Their goal is to try to identify which women will get the most benefit out of particular treatments, in order to avoid offering treatments that have potentially dangerous or uncomfortable side effects to women for whom they will have little benefit.

Happy 100th birthday, Alison Ford.

Inspirational at 100

Following an article in The Age in the lead-up to the Field of Women – Live in 2005, we received an e-mail from Bill Ford about his mother.

Alison Jean Ford, now aged 100, lives at the Strathdon Nursing Home, Forest Hills.

Bill wrote:

“My mother had a double mastectomy and hysterectomy over a relatively short period of time in the late 1940s, when the treatment was more brutal than it is today. But now, apart from general frailty and some mental confusion, the only medication she is on relates to indigestion. She has been an inspiration to many people over the years, for her strength of will to survive.

“She was too frail to be a participant in the Field of Women at the MCG, but I thought it a good opportunity to tell you a little of her story.”

Quilting to my heart’s content

Earlier in the year, Linda Stillman spoke to her Country Women’s Association group about her diagnosis with breast cancer.

As part of her treatment, Linda stayed in Launceston during the week for eight weeks to receive radiotherapy, taking a break from building a house.

We wanted to share the positives from that time as she saw them.

- I learned cancer is just an illness, not a bad word
- I learned that I was considerably braver than I thought I was
- I learned my family loves me very much
- I learned that my dear husband really does need me
- I had eight weeks of indulging myself with sewing and quilting
- I learned that I could never get bored with quilting
- I had an eight-week holiday in Launceston and had only myself to look after – something I have never experienced.

As Linda summed it up, “All in all, not a bad result!”
My Story

Patricia Pollard, 82 years

Cancer has no respect for age or size. The day I was diagnosed, there was a photo on the front page of the Perth newspaper of a toddler with cancer in one of his eyes.

I had a lumpectomy on November 17, 2004, after a mammogram found cancer in my breast.

I recovered enough to enjoy Christmas with my family, although my period in hospital and recovery is now hard to recall.

I do remember that I was well cared for by all the staff and my family and recuperated at home in the little village where I live in a unit on my own.

My health now is good and I have just enjoyed a holiday in Sydney staying with my son and his four daughters. I also spent time with one of my friends from my days in the WAAF during World War II. We were wireless telegraphists in Perth.

Since my diagnosis, I have stopped Swimming Club, where I participated three times each week. Maybe I will return to this when the weather is warmer, but I am still attending my handicraft group and meet with my WAAF friends at Anzac House each month. I also love the garden and babysit for my daughter who lives nearby.

Breast cancer has not caused me too many problems, apart from a bit of a reaction to tamoxifen and a rash around the surgery area which responded to treatment.

When I was discharged from the air force after the war, I discovered that I had tuberculosis and was ordered to rest in bed in a sanatorium for two years. I eventually recovered but lost my first child, aged six months.

Later I had to support my other two children, Christina and Peter, and I trained as a midwife.

These experiences have given me the character to cope with my latest problem and my advice to the readers of The Beacon is ‘Don’t be fearful – what will be, will be!’

- Patricia Pollard, W.A

Bakers Delight raises some serious dough for BCNA

Bakers Delight staff around Australia are celebrating one of their greatest fundraising efforts in the company’s 25-year history, raising more than $260,000 for BCNA during its recent fundraising campaign.

As our major partner since 2000, Bakers Delight has raised more than $1 million for BCNA, both through the sale of specially baked pink iced products and in-store donations by local shoppers.

“It’s fantastic for Bakers Delight to be able to contribute to such a worthwhile cause that directly affects so many Australians,” says Lesley Gillespie, co-founder of Bakers Delight.

Be sure to encourage your friends and family to visit their local Bakers Delight store throughout October.

All bakeries will be displaying collection tins to show their support of breast cancer awareness month and BCNA, and some bakeries will be selling BCNA pink wristbands.

Bakers Delight at Griffith, NSW, really extended themselves to raise money.
Melissa Hale, 21 years

I was diagnosed with breast cancer in 2004 when I was 21. I was very fit, never smoked, rarely drank, ate well and had little family history. It was never going to happen to me.

My mum had recently beaten bowel cancer and she was my inspiration to know that I could beat it too. I was scared, angry, upset but always confident.

I found that my attitude was my strongest medicine. When I heard the words, ‘You have cancer’ and was told I would have to have treatment my reply was, ‘Bring it on’. I was young, had a good job, lots of people who loved me and wanted to help me. I didn’t have time to have cancer so I had to get rid of it as soon as possible.

I never once thought that I might die, which in hindsight was naive. I had an aggressive 5cm tumour and was going to need surgery, chemotherapy, radiotherapy, then chemotherapy again.

There are so many different issues that young people with cancer have to face. I had an operation to remove part of my ovary and at least 50 injections so that one day I still might be able to have children. I’m still to have genetic testing and to find out about possibly having both breasts removed.

I could also no longer live a normal 21-year-old life; I had to grow up, and fast. While everyone else continued with life, it felt like mine was on hold, which was why I went back to university to complete my teaching degree. It was hard, but I tried to live as normally as possible.

I had the most amazing support team, lead by my wonderful family, fantastic friends and amazing boyfriend. My doctors, nurses and radiotherapists were also incredible; their help and support made it a lot easier to get through.

To help keep my mind off my illness, my friend Jacqui and I ran an event called, ‘Just Beat It’ to raise funds and awareness of breast cancer. It was a cocktail party that attracted 500 people and raised $28,000 for BCNA.

It was a fantastic night and a great event for me to focus my energy on while I was recovering.

This was a win-win situation for all involved. I highly recommend, not only being proactive in beating your own cancer, but being active in raising funds or awareness so that people in the future won’t have to suffer like you have.

My message is keep strong, be positive, proactive and have confidence in your ability. Don’t be afraid to ask for help, the more love and support that you accept, the easier your journey will be.

– Melissa Hale, Victoria

Thank you Georgia

Georgia Martin found out about the Field of Women – Live in 2005 at the MCG in May through her local newspaper. She couldn’t attend, as she lives in Nandaly in north-west Victoria, so Georgia rang us to see if there was something she could do over the weekend at her local football game. She sold a full box of badges within an hour and raised $320.50 for BCNA. Her team is the Nandaly Tigers. Thanks Georgia.
Facing the Mirror with Cancer: A guide to using makeup to make a difference
by Lori Ovitz with Joanne Kabak

This book is published overseas and your local bookstore will probably have to order it in. The online book store everycloud has stock. Contact www.everycloud.com or phone (07) 3341 7550.

I am not one for makeup and went unwillingly to a Look Good ... Feel Better workshop during my chemotherapy. I was surprised there to discover helpful hints for dealing with hair loss (including eyebrows and eyelashes) by makeup, in addition to hats, scarves, earrings and other devices.

Lori Ovitz’s Facing the Mirror with Cancer had a similar impact on me. The book is well produced and filled with great photographs of women looking beautiful during chemotherapy - women without hair, women with great shaped heads, women with earrings, women using makeup to camouflage the short-comings caused by chemotherapy or just to make them look better.

Just reading the book is enough to make one feel good, but it is also filled with lots of practical hints for using makeup during cancer treatments.

After a general introduction refocusing one’s thoughts on makeup and skin care, the book has detailed sections on how to apply different types of makeup effectively, both in general, but particularly to make one look and feel good during cancer treatments, particularly chemotherapy.

These chapters move through every possible application of makeup, before offering useful information about finishing touches, such as wearing of wigs and care of nails during chemotherapy. There is also a small section for men.

As someone who rarely uses makeup, I would have loved to have this book to refer to after my Look Good ... Feel Better workshop, as I was struggling to remember the things I had been shown.

Women who have this book as a reference tool will be able to turn to it, confident that they will get some good tips on using makeup to look good and feel better during their treatment.

- Ann Holmes, Victoria

A new face in policy
After two years in the role, Sue Timbs recently resigned from her position as BCNA’s Policy Manager, to take up a government appointment as Chair of an independent panel.

We congratulate Sue and wish her well, and are glad to report that she will continue her involvement with BCNA as a Consumer Representative.

Leigh Hillman has now joined the BCNA team as National Policy Manager. Leigh comes to us with considerable experience in policy development and implementation.

A great deal of her employment experience has been in the Northern Territory, where she worked extensively in community and government agencies. For 3½ years, Leigh was executive director of NT’s Council on the Ageing.

In January, she was awarded an Order of Australia medal for her commitment to the Balinese community following the Kuta bombing in October 2002.
Profiling our member groups

Nambucca Valley Breast Cancer Support Group

Nambucca Valley Breast Cancer Support Group was formed in 2002 by its current co-ordinator, Anne Pade, and has about 20 members of all ages.

Nambucca Valley is a rural area near Coffs Harbour, NSW. The group meets at Cooper Cottage, on the premises of the Macksville Health Campus.

For two years, the group has organised a fashion parade, compered by the local breast care nurse, where breast cancer survivors model, raise awareness and show the community their zest for life.

The money raised is used to help locals buy prostheses and pressure sleeves, and to travel to the city for treatment.

The group sells BCNA merchandise and finds that its ‘I’m a survivor’ badges are a great way of introducing themselves to others who may want to start a conversation.

Members are currently excited about holding a Mini-Field of Women on Sunday, October 23, in the grounds of the Macksville Hospital.

The daughter of one of the group’s members took part in the Field of Women - Live in 2005 and rang her mum from the MCG.

Last year, co-ordinator Anne with seven others from Dorrigo, Sawtell, Coffs Harbour and Woolgoolga attended the Still Making a Difference Conference. They found it a fantastic experience.

The local papers publish notices of monthly meetings, cover the fashion parades and are generally supportive. This great coverage has raised awareness in their local community.

The group has brochures in all the local doctors’ surgeries, pharmacies and the hospital, and volunteers visit patients in the hospital.

Group members have been thanked for being ‘seen’ and prepared to share their story. Anne receives many phone calls from people wanting to talk but wishing to remain anonymous and not necessarily come to meetings.

Most group members receive and appreciate The Beacon, and look forward to finding out what is going on, hearing others’ stories and learning about new types of treatments.

The group finds Lee Millard, their nearby (half an hour’s drive away) breast care nurse, an absolute delight and always there to help and assist.

The support group is a great example of a small community bonding together to help survivors and their families.
Our State Representatives, all breast cancer survivors, keep an ear to the ground for news across the country and make sure information is effectively distributed. They are also a local contact for women with specific enquiries or issues. You can read their latest reports on our website www.bcna.org.au.

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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 or fill in this coupon and send it to: Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.

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

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

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Phone: (     )................................................. E-mail:........................................................ ...........................................................

Have you had a diagnosis of breast cancer? □ Yes □ No.

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

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**ACT State Representative**, Elspeth Humphries, who is making Creekside available to women with breast cancer, see story on page 7.

**BCNA welcomes**:

- Shoalhaven Breast Cancer Support Group, Nowra, NSW
- KI Cancer Support Group, Kangaroo Island, SA
- Breast Buddies, Gladstone, Queensland
- Tumby Bay Cancer Support Group, Tumby Bay, SA.

New Associate Member Groups:

- Amazon Heart (national, based in Queensland)
- Brownes Cancer Support Centre, Nedlands, Perth.

BCNA now has more than 130 Member Groups and 14,000 individuals linked under its umbrella.

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When women get together in numbers their strength compounds and is seen and felt by themselves and others.

- Hazel Hawke
Recently my beautiful Mum (aged late 50s) was diagnosed with breast cancer. This occurred almost 12 years after my first diagnosis, at age 25, and my second diagnosis five years ago, at age 32.

While I am aware that daughters are often diagnosed after their mum’s journey, is it unusual for mums to be diagnosed after their daughters?

Mum and I have been diagnosed with different tumours; hers was 100% hormone receptor positive, with some lymph node involvement, while my first tumour was lobular, with no lymph node involvement, and my second was in the ducts.

The doctors tell me that my two tumours are totally unrelated and it is unlikely that Mum’s and mine are related either.

As you can imagine, my sisters are ‘spinning’, however I have more concerns for my daughter, who now has two maternal relatives with the disease.

Have other readers had a similar experience and, if so, did they undergo genetic counselling? Is this likely to be genetic or just an unfortunate coincidence?

I look forward to your response.

– Hayley Johnston-Coutts, Victoria

Editor: BCNA has heard from several younger members whose mothers have this year also been diagnosed with breast cancer. We’ll direct Hayley’s query to Professor Judy Kirk, a member of BCNA’s Medical and Scientific Reference Group, and publish the response in the next issue of The Beacon.

I was one of the people who entered their story on your website telling of my experience with breast cancer and treatment. I still get strangers telling me it gave them a good laugh, which I find a humbling experience.

I would like to suggest a ‘down the track’ follow-up section. Being diagnosed with breast cancer isn’t the end of life – for many of us it has proved to be merely the beginning of a new one we never dreamt of. I went back to work with a whole new attitude towards life and decided what I was doing was a load of rubbish. I resigned, got a new, much more rewarding job, left that for an even better part-time job and have now been accepted to do more study – a PhD.

Without breast cancer I would have still been in the same rut. I’m sure I’m not the only one with this experience.

Please give us the opportunity to let other people know how ‘life changing for the better’ breast cancer can be.

– Audrey Guy, ACT

Editor: Thanks Audrey. It’s always inspiring to hear such positive stories. This issue of The Beacon reveals a wide range of experiences with breast cancer. We plan to keep adding to the stories on the website, in an attempt to reflect the range and depth of people’s experience with breast cancer.
Breast Cancer Network Australia

Upcoming Events

**September 15:** BCNA Members’ Meeting, Alice Springs.
Contact: 1800 500 258 (free call).

**September 17:** BCNA Member’s Forum, Darwin, 10am-12.30pm, followed by lunch.
Contact: 1800 500 258 (free call).

**September 24:** Exploring trust in the relationship between consumers and oncologists, 9-10.30am.
The Australasian Society for Breast Disease, in partnership with BCNA, invites people with a personal experience of cancer to attend this consumer workshop at the Marriott Hotel, Surfers Paradise. The workshop is free and limited to 80 participants.
Consumers are also welcome to attend two of the Conference’s scientific sessions: ‘Survivorship in breast cancer/patient outcomes’ (11am-12.30pm) and ‘Breast cancer in society’ (1.30-3pm).
To register call BCNA on 1800 500 258.
For more information phone Veronica Macaulay-Cross, BCNA’s Queensland State Rep, on (07) 3269 8083.

**September 25:** Breast Cancer Action Group NSW’s General Meeting with speakers, 3pm, YWCA, 5-11 Wentworth Avenue, Sydney.
Contact: info@bcagnsw.org.au.

**October 1:** Glitter Charity Ball, BCNA fundraising gala dinner, Plaza Ballroom, Regent Theatre, Melbourne. Cost: $150. RSVP ASAP.
Contact: Leanne Bradford, (03) 9844 5446, 0419 404 495, lee.bradford@bigpond.com or www.glitterball.org.

**October 5:** Celebrate Ladies Day at the 51st annual Tesselara Tulip Festival, 10am to 5pm, 357 Monbulk Road, Silvan, Victoria (Melways Map 123 B5). Cost: $14.50 Adults, $12 concession and $9.50 groups of 10 or more. Part proceeds to BCNA.
Contact: (03) 9737 7722.

**October 6 to November 2:** Bakers Delight Promotion, Bakers Delight stores nationally.

**October 8:** BCNA Members’ Forum, Launceston.
Contact: 1800 500 258 (free call).

**October 18:** Fit and Healthy Business Women’s Breakfast, includes full cooked breakfast and sponsor gifts, 7-9am, Ballroom, Park Hyatt Hotel, Melbourne. Raffle proceeds to BCNA. Cost: $49.50. RSVP ASAP.

**October 22:** BCNA SA fundraiser at the Burnside Town Hall Ballroom at 8pm. BYO drinks and nibbles, supper provided. Triple BBB Big Band, Silent Auction, Prizes. Tickets are $20.
Contact: Jan Davies, BCNA SA State Rep on (08) 8388 4825.

**October 23:** Annual service for all who are affected by breast cancer, 3pm, St George’s Cathedral, Perth. Everyone is welcome to this ecumenical service of reflection and hope.

**October 23-28:** Changing Gears, 21 young breast cancer survivors riding Harley Davidson motor bikes from Sydney to Brisbane. Proceeds to BCNA.
Contact: Meredith Campbell, 0412 653 202, meredith@amazon-heart.com, www.changinggears.org or PO Box 1204, Toombul, Queensland 4012.

A thought

I often think that people we have loved and who have loved us, not only make us more human, but they become part of us and we carry them around all the time, whether we see them or not. And in some way we are a sum total of those who have loved us and those to whom we have given ourselves.

– Source unknown