It is exciting to think that Australians whose lives have been touched by breast cancer now have a way to communicate on a national level.

Some people have wondered why another newsletter is necessary, but women with breast cancer have welcomed such a publication — a newsletter written by them, for them and for their families and friends.

We all recognise that other people, as well as the woman herself, are affected by the diagnosis of breast cancer. Their needs are often overlooked. There are important issues for families struggling to make the best of a difficult situation. Husbands, partners and children have needs which are barely recognised, let alone addressed.

This newsletter will provide a forum for the issues around breast cancer to be raised and shared.

Those involved with the HIV/AIDS lobby have achieved so much by presenting a loud and clear voice about the needs and issues of those affected by the disease. Drugs have been developed and made available through the insistence of those directly affected; services for those most in need have been established.

The disease has been 'personalised' to the Australian public by those who have spoken out about misinformation and prejudice.

In recent months, the media has raised the issue of inadequate funding for breast cancer compared with that for HIV/AIDS. We should applaud the effectiveness of the HIV/AIDS lobby and learn from their example.

Those affected by breast cancer need a national voice.

We need to communicate with each other across the country. We need to share information and experiences. We need to investigate the research being done, both in Australia and overseas.

We need to support one another and ensure that there is support available for each woman and for those close to her. We need to raise issues important to us, to educate ourselves and the community about breast cancer and its impact. We need to speak up when decisions are being made, so that services will best meet the needs of those affected by breast cancer.

The Beacon will be the chain linking us; it will be our voice.

So that our voice will be truly national, we need people like you to raise issues. Please send in your articles and stories, your questions and news.

It's important that we reach as many people as possible. Tell others about our Network and newsletter. Use your voice!

Lyn Swinburne
Network Co-ordinator

Why ‘The Beacon’?

After lots of brainstorming and think-tanking, the newsletter has been named The Beacon. In typically Australian fashion, some of us shortened the name of the newly formed Breast Cancer Network Australia to B.Ca.Net and so the sound of the word ‘beacon’ seemed to naturally follow. Importantly, we hope that this newsletter will reflect the symbolism of a beacon — enlightening and showing the way.
Australia’s Breast Cancer Day
- Snapshots around the nation

On October 27, women all over Australia painted the town pink as they marked Australia’s fourth Breast Cancer Day (ABCD).

As in past years, groups, individuals and state cancer organisations devised a wide range of ways to raise public awareness of the disease. Women got together on ABCD for breakfasts, brunches, coffee mornings, lunches, teas, cocktail parties and dinners.

They danced and sang, jumped from the sky, played bingo, held photographic exhibitions and strode along catwalks at fashion parades. They broadcast their message on the radio, and on national television, in newspapers and on the Internet. They raised money for research, encouraged and admonished other women to look after their own breast health, remembered, mourned and honoured those women who have lost their lives to this disease, and celebrated simply being alive and able to mark another ABCD together.

Plans are already under way for next year’s ABCD. The possibility exists to do something on a national scale as well as locally. See page 5 for details.

The ACT

Anna Wellings Booth reports from Canberra on a busy month in the capital. An exhibition of Heide Smith’s photographs of women with breast cancer was held at a cocktail party hosted by the University of Canberra Vice-Chancellor. Some 800 people attended a fashion parade organised by the support group, Bosom Buddies, and raised $10,000 for research.

Dr Rosie King was guest speaker at a brunch hosted by the ACT Cancer Society at the Hyatt hotel. Well-known for her work as a sex therapist, and a poised and gifted speaker, women found Dr King’s talk highly entertaining, while still delivering the important messages of the day.

For the second year, the ACT Cancer Society held an ecumenical service at Wesley Uniting Church. Anna says it was a moving and spiritual event honouring those who have died of the disease and giving hope to those who are living with it.

Tasmania

Norma Hudson wrote to tell us of their busy week. Norma, a member of the National Breast Cancer Centre (NBCC) Consumer Advisory Group, spoke at a luncheon attended by 90 women, to women at a local neighbourhood centre on Tasmania’s remote west coast, and gave several radio interviews on the importance of regular mammograms.

She also arranged a library display in Burnie, attended a Cancer Council breakfast, a ‘wine and nibbles’ afternoon tea in Devonport organised by fellow CAG member Joan Williams, and even found time to hold a ‘Mammograms — Myths and Facts’ seminar. Radiographers answered questions and showed women through the mobile BreastScreen van.

A letter campaign to all politicians, organised by Therese Mulford, resulted in a meeting being arranged between consumers and the Minister for Community Health Service’s adviser in December. They will be discussing the need to review programs and services for breast cancer across the state. At present, there is little equity in either access or service.

Jenny Littler held an afternoon tea at her home. Guests wandered around the garden, patronised the stall selling pink ribbons and enjoyed an old-fashioned spread of sandwiches and cream cakes. As Norma said, “We certainly had Breast Cancer Awareness covered over here in Tassie!”
In the Northern Territory, the day was marked by a luncheon at the local football stadium. A team of parachutists (three of them women) landed amid a fabulous array of pink flares and pink streamers. Moving speeches from breast cancer survivors followed lunch, and then the Grey Panthers, 12 perky women, ranging in age from early 50s to mid-80s, had everyone singing and clapping as they sang and line-danced.

The Breast Cancer Support Group organised a march through the streets of Darwin and along the beach. Members of the group, families and friends joined in and carried a large banner.

A Network member in Darwin says a great day was had by all — one that will truly be remembered as not only educational, but also extremely entertaining.

Television debuts were made by several Network members in Sydney, when they were invited to participate in the Midday with Kerri-Anne program on Channel 9. Joan Wilson and Sig Chan spoke of their own experiences, Dr Helen Zorbas from the NBCC reinforced the message of early detection, and Sally Crossing stressed the important role that husbands and partners can play in supporting women through treatment and recovery.

A ninita Keating was the guest speaker at a dinner to mark A BCD at Parliament House in Sydney, while Janette Howard was one of the Guests of Honour at a Pink Ribbon Breakfast at the A N A Hotel in Sydney.

In Port M acquarie, Network member Joan Van Every co-ordinated a morning tea, supported by the local M P, who reminded the audience that an increasing number of men are also facing breast cancer. Joan also seized the opportunity to publicise our new Network. Our goal, she said, is to reach every woman in the country, irrespective of geographical location, social and economic status, cultural and ethnic background.

Victoria marked A BCD with 120 brunches across the state, the emphasis this year being to get the message of early detection across to women in non-English speaking communities. Fifty of the brunches were organised by women of different ethnic groups.

Monash Health Promotion Network held a brunch and ‘Breast Bingo’. A formal bingo board was used, which lights up each number as it is called, and proper bingo sheets, but all similarities to the usual bingo game ended there. The usual ‘bingo lingo’ was replaced with breast health messages such as “24, let’s examine more”, “33, visit your GP”. No money changed hands, but local businesses supplied generous prizes.

On a more serious note, there are very few services available for women with recurrent or advanced breast cancer. This year, the Anti-Cancer Council arranged a forum especially for them. Guest speakers brought the 60 participants up to date with the latest treatment and research, while workshops explored a variety of topics, from relaxation and stress management, to sexuality, body image and intimacy. There was even a workshop on flower arranging for those who simply wanted to get away from breast cancer completely for an hour or two!

In South Australia, consumers organised an information night for medical office staff. A s Elizabeth Libregts says, these are the people who can most easily influence and educate doctors about breast cancer, as well as give invaluable information to individual women undergoing treatment.

The Anti-Cancer Foundation held a day and an evening information session for the general public, as well as arranging an open phone line, where consumers answered questions from callers. Many callers were younger women, concerned that they were not able to access the mammogram program. Consumers could reassure these women that they would not be turned away if they were 40+ and presented themselves to BreastScreen.

Barcaldine, a tiny town in western Queensland, has always prided itself on being ahead of the rest, so it was no surprise to anyone that they decided to celebrate A BCD two weeks early!

A s the mobile BreastScreen van was to be in town, local health workers organised a super ‘Look Good, Feel Good’ day for all women, writes Penny Button. The day consisted of a luncheon, with several inspirational guest speakers.

In Mackay and Brisbane, women were treated to fashion parades, where clothes were modelled by women who had all had breast cancer, several of them bilateral mastectomies. For many women present, the experience of breast cancer was something quite new, while those for whom it wasn’t such a recent event still benefited greatly from the positive messages of the parades.

Local businesses supported both events, and $3000 was raised for research and the local lymphoedema clinic in Mackay with a ‘cent sale’, again supported by local businesses with fabulous prizes.
It is hard for most of us to imagine what it must be like to live in a really remote area, where neighbours are a few hours’ drive away and school for your children comes via a crackling radio connection. Spare a thought for the special difficulties of women living in remote areas who are diagnosed with breast cancer.

Though there is some help available from the state health services, they are not always easy to access. Many rural women face considerable expense and long separation from their families when they undergo radiotherapy or chemotherapy.

For Network member, Chrissie Holt, who lives on a cattle station in Katherine, ‘town’ is a six-hour round trip away and any visit costs $200 in fuel alone. There are no radiotherapy facilities in the Northern Territory, so women must travel interstate, usually to Adelaide. Airfares and accommodation costs can be huge. Although the NT has a scheme designed to assist patients from remote areas to attend hospital called the Patients Assisted Travel Scheme (PATS), Chrissie was actually diagnosed and operated on in Brisbane while she was on holiday. This meant that she was not a typical claimant for PATS.

Rather than having to go through the constant explanations of why she was initially treated in Queensland, Chrissie and her family decided that it would be easier for her to go to Melbourne, where she had family support and could rest between treatments. A stem cell transplant, definitely not available in the Territory, she says. “Looking back, I think that year spent mostly in bed in Melbourne was probably the best way to handle my options. But, at the time, it was just one more disorienting and stressful thing to overcome. I felt as if I had stopped being a wife and mother, and had no place in life any more.

“The second, and I think much more important, disadvantage of isolation is the dreadful effect these massive disruptions cause to family life. Having your mother diagnosed with breast cancer is horrific for any child, but at least urban children can still see their mother, even if she is lop-sided and bald.

“I have three children, a girl and two boys. The year I was diagnosed, my daughter had just started a science course at Monash and my sons had just started boarding school in Adelaide. All bush families go through the misery of having to send their children away to school for their secondary and tertiary years, but for the kids starting a whole new life at school or university coupled with the fear of not knowing what is happening to their mother, and only seeing a very sick woman on school holidays, life is very difficult.

“My children coped wonderfully, but life was very hard for them that year. Malcolm, my husband, spent the year rushing between me and the station, and his life must have been a lonely hell; he suddenly had no wife and no children, and massive worries about my health and future, plus huge unanticipated financial costs.

“We're all back together now, settled and at peace, but I sometimes look back and wonder how we survived.”
World Conference on Breast Cancer Advocacy

The First World Conference on Breast Cancer Advocacy was held earlier this year in Brussels. More than 250 people from 43 countries attended, sharing ideas and identifying issues.

Six Australian women attended the conference, which was hosted by the National Breast Cancer Coalition (NBCC), a powerful and influential network of women in the United States.

The organisers have been inspired by the positive feedback resulting from the forum and will hold a Second World Conference on Breast Cancer Advocacy in March 1999. This will again be held in Brussels, because, the organisers say, it is an easily accessible location!

The NBCC will soon issue a call for papers to breast cancer activists around the world. They are interested in learning of ‘very specific, successful breast cancer advocacy efforts that have been employed in various regions and cultures’.

Women interested in attending in 1999 should begin planning now. More details of the 1999 conference in The Beacon next issue, or contact Lyn Swinburne on (03) 9660 6865.

Advocacy Training in Australia

The NBCC has developed a Consumer Advocacy and Science Training Program, in collaboration with members of their Consumer Advisory Group.

The program is modelled on Project LEAD, an initiative of the National Breast Cancer Coalition in the United States. This program has been very successful in increasing consumer advocacy relating to breast cancer issues.

The training program aims to empower women to fully participate at all levels where breast cancer decisions are made.

The courses run over four days and participants not only gain an understanding of the value of consumer participation, but also learn practical skills to enable them to successfully participate as a consumer representative on boards and committees.

They learn the basics of science and the biology of cancer, as well as practical skills in handling the media and getting the message across clearly.

One course participant said that what she found most beneficial was “gaining the confidence to actually go out and do something!”

“I have spoken at a recent fund raiser, and although I was still anxious, felt able to communicate my message succinctly without too much difficulty,” she said.

Three training programs have already been held, in Sydney, Melbourne and Brisbane.

The fourth will be held in Adelaide from March 11 to 14, 1998.

Another is being planned for the ACT later in the year.

The program is free of charge, but participants are responsible for their own travel, accommodation and evening meals.

The NBCC will try to cater for as many women as possible, but places are limited.

You should register your interest and find out more by contacting the National Breast Cancer Centre in Sydney.

Phone: (02) 9334 1700
Fax: (02) 9326 9329
E-mail: directorate@nbcc.org.au

The first graduates from the Sydney training program.

Join in the action

Women are becoming active in breast cancer advocacy issues all around the world, so now is surely the time for women in Australia to hold their own conferences. Dates have already been set for some state conferences, and plans are under way for a national consumer conference in Canberra to coincide with ABCD next year.

For more details phone:

SA - Elizabeth Libregts: (08) 8449 7761
NSW - Sunday, February 22:
Sally Crossing: (02) 9436 1775
Amanda Nickson: (02) 9334 1859
Victoria - Jenny James: (03) 9457 5977
In September 1969, at the age of 46, I found, by chance, a very small lump in my groin. The doctor gave me the ‘all clear’, but three weeks later I was back, having found a small lump in my right breast. Until a couple of days before surgery I was as sanguine as the rest of my team, but I suddenly felt sure my lump was malignant, even though the night before going into hospital I couldn’t even find it.

On waking from the anaesthetic, I knew immediately that I had cancer. Family and friends were very supportive and my main concern was coping with nausea, a side effect of pain-killers. Not even the old yachtsman’s trick of sipping brandy and hot water to stay on your feet when others turn green could help me!

A part from the nausea, my post-operative recovery was uneventful and four days later I was home. Just before the New Year, I began three weeks’ radiation therapy, driving myself to the hospital every day. My chest wall became both sensitive and sore, the skin of my treated area drying and cracking like post-flood black soil. At its worst, my chest wall was a curious mixture of what I called my ‘elephant’s hide’ and raw tissue. But, oh the joy of waking up one morning and realising that I was actually feeling better than on the previous day.

In 1969-70, most women knew about breast cancer, but it was not freely discussed. Most of my information came from my GP, surgeon and a radiographer friend. Family, friends and neighbours were wonderful — they treated me like a normal human being — there were no hushed voices, awkward silences or stilted conversations. I shocked some people, but reassured others with my open references to my encounter with breast cancer and resulting mastectomy. It certainly helped to have a corsetiere for a friend, who said, “Hurrah, another customer”. I enjoyed that sort of normality.

A doctor told me that I had an 85% chance of survival. I think that may have referred to five years only! My surgeon made sure I was well informed of the signs of a possible recurrence. This was before mammograms and ultrasounds.

Undoubtedly, I was one of the ‘lucky’ ones, but not all my experiences were positive, and I admit that life was a bit grim at times. As I have said, it was very important to me to be treated like a normal human being, intelligent and temporarily very sensitive to nuances. The negatives for me included:

- being forgotten and left waiting for long periods;
- rarely seeing the same hospital doctor more than once;
- having nowhere to hang my clothes while being examined; and
- having to wait a week or more for new or a change of medicine.

In 1969! Some of the main changes that I see now include:

- open discussions about breast cancer and its treatment;
- a great deal of information from a number of sources;
- support groups;
- cancer support volunteers;
- the range of treatment now available and, increasingly, genuine efforts to accommodate patient preferences;
- a dramatic improvement in the drugs available to help control pain and other unpleasant side effects of treatment; and
- new procedures which allow radiotherapy, for instance, to be spread over six weeks rather than three.

So, how has having had breast cancer affected my life? Outwardly very little. The mutilation of my body is forgotten once I’m dressed, and having cancer has never prevented my enjoying a full life. My interests seem to be broadening all the time.

I sincerely believe that cancer should be openly discussed, so that it does not become a source of fear and dread, due largely to ignorance and misunderstandings. I continue to speak freely about my personal experience of breast cancer. It is very important that both men and women know that one can have cancer and survive. Life is good.
Women in Action

Following the fence line

W hat is the most natural thing in the world to do if you’ve survived an encounter with breast cancer? Get on a motorbike and ride around Australia, of course. What else?

‘Following the Fence Line’ was the inspiration of Ramonda Te Mairaroa, herself a survivor of breast cancer. Ramonda wanted to raise community awareness about breast cancer, and at the same time provide adventures for women who have had the disease.

In April 1996, 10 women (most were middle-aged and had never been on a motor bike before) left Sydney on an around-Australia adventure, with another four women in two support vehicles. Their goal was to talk to as many women as possible about the importance of regular self-examination and mammograms.

The women visited towns and many small settlements, talking with community groups and individuals about breast cancer. They rode up through Queensland into the NT, across to WA, down the coast to Albany, over the Nullarbor into SA, and through Victoria to Canberra.

They covered 17,000 kilometres in 58 days, and raised enough money to cover the costs of the trip and also donate $12,000 to the Kathleen Cuningham Foundation for Breast Cancer Research.

Their epic ride was made into a documentary, shown on ABC television in October. Many people have asked the ABC for a repeat screening. It is a powerful film, documenting the women who rode, the people they met, the fun, the exhaustion, the trials and tribulations, the meetings, mastectomies, lumpectomies and reconstructions. It is a road movie with a difference – a fabulous record of the ride, as well as being informative about breast cancer!

Another adventure is being planned for early next year. Intrepid breast cancer survivors will paddle canoes 1000 kilometres down the Murray River, camping on the banks of the river and raising awareness about breast cancer as they go. Adventurous readers wanting an experience quite out of the ordinary may contact Ramonda for more information on (03) 9528 6321, or Maureen McGrath on (047) 587 214.

Melissa Jane Ades – “I am painting for my life”

Melissa Jane Ades was a fashion and fabric designer in Sydney when she was diagnosed with breast cancer in 1992, at the age of 32. Nine months and three operations later, she had a breast removed. She was forced to stop and reconsider her life.

Already living in Bali, where she found an easier pace of life, she dropped out of the fashion business and began to paint full-time.

“I feel I am painting for my life. It is important that I find meaning from the suffering and delve deep within that gaping hole to see who really is inside.”

The idea of the ‘Cancer Series’ began in 1995, when Melissa Jane woke one morning to find that her internal prosthesis had deflated. “I found myself having a personal crisis. I could only paint what I was feeling and this became imperative for my survival.”

In hospital having another reconstruction, she showed her paintings to other women, who responded with overwhelming emotion.

“I felt I had a responsibility to continue this work, in the hope of raising awareness about this issue. I realised that I was not the only one who felt less than whole after a mastectomy. None of us are whole; we are only flawed pieces of something larger. Breast cancer has affected my life dramatically. If sharing my experience, strength and hope through this series of paintings can create further awareness — this is our success.”

An exhibition of her work was held in Sydney to coincide with International Breast Cancer Awareness Week. Now she hopes to exhibit her work further afield. Some of the paintings are on the Internet (see page 8 for the address) or contact Nicky Ginsberg at Mary Place Gallery, Paddington, (02) 9363 3834.

Stamp of awareness

One of the highlights of ABCD this year was Australia Post’s release of a 45c stamp to help raise community awareness of breast cancer.

The stamp was launched in Canberra by Senator Jocelyn Newman, herself a survivor of breast cancer, and will circulate for the next four months.

Dr Linda Reaby, who was instrumental in lobbying for the stamp to be adopted by Australia Post, was presented with a plaque in appreciation of her efforts as a breast cancer advocate.

Feedback on the new stamp has been very positive and there has been huge media coverage. ‘Cleo’ magazine intends to run a feature on the stamp in its December issue.

In the United States, a bill is at present before Congress which would allow the US Post Office to add a surcharge of 8c to the price of a 32c stamp, with the extra revenue earned going directly into breast cancer research.

Though not without its critics, it will be interesting to see what happens to this idea. Advocates of the new stamp predict that $60 million a year could be raised, if just 10% of stamps are bought at the higher rate.

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USEFUL CONTACTS

The National Breast Cancer Centre (NBCC)
PO Box 572, Kings Cross, NSW 2011. Phone: (02) 9334 1700
Established in 1995, the mission of the NBCC is to reduce mortality from breast cancer and to improve the well-being of women diagnosed with the disease. Its role is to ensure that research findings are integrated into clinical practice, policy and information as quickly as possible. A list of N B C C resources is available from Sydney, or from the N B C C Co-ordinator in each state cancer organisation.

Breast Cancer Action Group (Vic)
PO Box 281 Fairfield, Victoria 3078. Phone: (03) 9882 7995
Started in 1994, the group holds bi-monthly meetings, frequently with guest speakers from the medical profession, and produces a bi-monthly newsletter.

Breast Cancer Action Group (NSW)
PO Box 5016 Greenwich, NSW 2065. Phone: (02) 9436 1755
A newly-formed advocacy group; if you are interested in becoming involved, contact Sally Cross (02) 9436 1755.

The Breast Cancer Book Service
PO Box 449 Heidelberg, Vic. 3084. Phone: (03) 9457 5977
Books by mail — on treatment, recovery, diet, lymphoedema, menopause issues, women's stories, complementary therapies etc. Free catalogue available on request.

Cancer information and support services
Phone: 13 11 20 in each state (1300 361 366 in Queensland)
A telephone counselling service is available around Australia to anyone diagnosed with cancer, and to their families and friends.

HAVE YOU TRIED THE INTERNET?

There is a great deal of information on it about breast cancer. Just search for ‘breast cancer’ or start your ‘surfing’ from the N B C C’s web pages.

The National Breast Cancer Centre, Sydney — www.nbcc.org.au
Information about breast cancer in Australia and plenty of links with other sites all over the world — information about conferences, treatment, research, clinical trials, women's stories and viewpoints. Add your comments to the bulletin board (user name nbcc, password Bbs).

Melissa Jane Ades — www.keig.com.au
Several of Melissa Jane's paintings can be seen on the Internet, including the painting, Grounded, featured on our cover.

Breast Cancer Information Clearing House, United States — www.nysernet.org/bcic/
A nother good place to start — links to medical sites, forthcoming international conferences, question and answer pages about cancer, etc. Usually there is free access to the Internet through your local library.

YOU'RE NOT YET ON OUR MAILING LIST?

Contact: Lyn Swinburne, phone (03) 9660 6865, fax (03) 9662 3881
Or fill in this coupon and send it to: Breast Cancer Network Australia,
PO Box 4082, Auburn South, Vic 3122

Name: .............................................................................................................
Address: ...........................................................................................................
........................................................................................................................
State: ............ Postcode: ............ Phone: (    ) ............................................

THE BEACON

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Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria 3122.

BREAST CANCER NETWORK AUSTRALIA

Why not shelter under our umbrella?

We would like to link a wide variety of women’s groups under the 'umbrella' of B.Can N et. If you are involved with a group — such as a support group, fund-raising group, advocacy group or community group, please consider linking up with us.

In future editions of The Beacon, we will publish lists of groups which have decided to shelter under the umbrella of the Breast Cancer Network Australia.

In the next issue ...

- Lymphoedema - an issue for women
- Spotlight on a group
- Ask the Doctor - your queries answered

... and much more