



The Beacon

Breast Cancer
Network Australia
newsletter

Helping our friends and colleagues to help us



The Network welcomes Lyn Moore as Queensland's new State Representative. She will be working with Veronica Macaulay Cross.

Breast
Cancer
Network
Australia



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So often we hear from people feeling helpless and lost when a friend or family member has been diagnosed with breast cancer.

They can be shocked too, and want to help out, but often struggle to find the right words to say and the best ways to help.

We hope our latest brochure, *Helping a Friend or Colleague with Breast Cancer* (a copy of which is included with this issue), will be a useful resource for people in this situation.

Let's face it, everyone responds differently to the news of a diagnosis, and copes in different ways during treatment.

There are no hard and fast rules for finding the exact words to use, nor for identifying the best ways to help each person. However, there are some general strategies which are important, such as letting the friend know you are there for her, of taking your cue from her, and not merely avoiding the situation.

We conducted a survey of women from all parts of Australia who had experienced breast cancer. We asked them what had helped them, and what things did not help.

We put the brochure together with these ideas and also those sent to us in 2001 by Queensland Beacon reader, **Kathy Kuipers**.

Having a work colleague diagnosed can also present

challenges. We have found that most employers want to do the right thing but, again, are not sure how to approach the situation. Should they speak openly with her and about her diagnosis to her colleagues? Should they offer her leave from the position? Should they pretend nothing has happened?

Again, each situation is different. Some women appreciate the chance to work throughout treatment – they enjoy the stimulation and challenge of their work, and it affords them some degree of normalcy. Others want to stop working immediately, to concentrate on recovery, to ease tension, to spend quiet time at home.

What is clear is that there needs to be good communication between a woman and her employer. We hope our brochure will help.

We are keen to get *Helping a Friend or Colleague with Breast Cancer* out into the community.

The brochure is, of course, free and we will happily send multiple copies to our members who are prepared to distribute them widely.

Please let us know if you can help out with this by calling our freecall number, 1800 500 258.

Life should not be measured by the number of breaths you take, but by those times which take your breath away.

We thank the East Malvern Ladies Tennis Club for raising the money to pay for the development and printing of our new brochure.

– Lyn Swinburne

Plant a Mini-Field of Women in 2003

Is your group interested in raising awareness of breast cancer in your community, while remembering and supporting those touched by the disease?

If you or your group is interested in convening a *Mini-Field of Women* in October 2003, phone **Michelle Rule** or **Ro Pitt** on 1800 500 258.

For information about *Mini-Fields of Women*, visit the 'Projects' section of our website – www.bcna.org.au



The 2002 Mini-Field of Women in Traralgon, Victoria.



STATE REPORTS

With Christmas and the New Year, we decided to give our State Representatives a well-deserved break.

State Reports will be back in the next issue of *The Beacon*, which is due out in June.

As this issue goes to print, our State Representatives are gathering in Melbourne for the annual Think Tank.

This is an important two-day meeting where we, at the Network, consider the progress made against our targets in the previous year and set new priorities for the next 12 months.

The Think Tank is also a chance for the State Representatives to tell us about the issues concerning and interesting women with breast cancer and their families, across Australia.

THE BEACON

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Editor: Lyn Swinburne, 1800 500 258 (free call), (03) 9805 2500 or beacon@bcna.org.au
Layout: Substitution
Your comments and items for the next newsletter are welcome.
Send them to PO Box 4082, Auburn South, Victoria 3122.

Support for women with breast cancer in rural Queensland

Strengthening Support for Women with Breast Cancer is a Commonwealth-funded project to enable each State and Territory to improve the support services available to women with breast cancer.

Queensland's allocation is \$590,000 over four years, concluding on June 30, 2004. The project is being managed by Queensland Health.

Phase 1 of the Queensland project identified existing support services in the public and private sectors through a state-wide mapping exercise.

Zonal planning workshops were held in Brisbane and Cairns in August 2001, to bring together consumers, clinicians and those involved in the planning and co-ordination of support services to discuss gaps in services, identify priorities and discuss strategies to overcome these gaps.

Following the workshops, a project team was established in each zone to decide on priorities and strategies.

The project's Advisory Committee agreed to the recommendation to provide funding for the creation of one full-time equivalent breast care nurse position.

Based on this recommendation, six part-time specialist breast nurse positions were approved in selected

health services districts within the southern and northern zones.

These positions were approved for a 12-month trial. The aim is to improve the continuity of care and the provision of psychosocial support to women with breast cancer and their families.

The role of the specialist breast nurse is to support women during their primary treatment and to ensure they are linked to existing services in the public and community sectors for follow up psychosocial care.

Specialist breast nurses are now employed at Toowoomba, Cairns, Mackay and Townsville, on the Gold Coast and at the Princess Alexandra Hospital.

Following an orientation program, a monthly teleconference is held with the new specialist breast nurses.

In addition to the breast nurse positions, a project officer has been appointed and is based at the Royal Women's Hospital. They will improve access to information for women with breast cancer and facilitate the establishment of communication networks between health professionals.

For more information phone **Kay Murray** on (07) 3234 0903 or e-mail KMurray@health.qld.gov.au

Rural and remote breast cancer network marches on

Moves are under way to form an Australia-wide network to address the needs of rural woman with breast cancer.

Judy Shepherdson, who formed the Echuca-Moama Breast Cancer Support Group, Wild Orchids, 2½ years ago, is working with **Marlene Parsons**, the Warratah Women's Breast Cancer Support Group Co-ordinator from Gippsland.

This follows their successful application for a 2002 Community Grant from Breast Cancer Network Australia.

The funding is being used to develop a national rural/remote network called, *Project BREAST: Building rural equality and strengthening ties – Giving rural women a voice.*

A steering committee made up of women representing each State and Territory has been established.

The aim is to identify and address pertinent issues experienced by rural/remote women, and their specific needs, regardless of location, cultural and social differences.

Judy became aware of the problems facing country women when she moved to Echuca-Moama from Melbourne.

"Rural woman often have to travel long distances to access medical treatment and can be away from their families and friends for weeks," she says.



Judy Shepherdson and Marlene Parsons are working to create an Australia-wide network to address the needs of rural women with breast cancer.

"Accessing a doctor is harder in a country area and home visits are not an option for people living outside towns.

"Palliative care is limited, cross border issues present additional problems and support systems are lacking."

Judy and Marlene recognise the problems they have faced are small compared with those of the women living in more isolated parts of Australia.

For example, women with breast cancer in Alice Springs have to travel to Adelaide or Brisbane for treatment.

If you are interested in being involved in Project BREAST, phone Judy on (03) 5482 6602 or Marlene on (03) 5146 0470, or the Network on 1800 500 258 (free call).

Bumper sticker ideas for women

- Behind every successful woman is herself.
- Ginger Rogers did everything Fred Astaire did, but she did it backwards and in high heels.
- A woman is like a tea bag ... you don't know how strong she is until you put her in hot water.
- I have yet to hear a man ask for advice on how to combine marriage and a career.
- If you want breakfast in bed, sleep in the kitchen.

Zoladex and advanced breast cancer

The Network was contacted by a number of readers last year about Zoladex, a drug used to treat women with advanced breast cancer.

Many said they were receiving the drug monthly, but were aware that men with prostate cancer were able to have the drug every three months.

Following some investigation, we found out the reason why women are not having the drug every three months.

Research has shown that although the three-monthly dose is effective in treating other cancers, such as prostate, the drug is more effective in treating women with breast cancer when administered monthly.

More information is available on our website – www.bcna.org.au

Our pink silhouette reaches Ireland

In October, women in Ireland came together for their own breast cancer awareness day, and incorporated a pink silhouette all the way from our own *Field of Women*.

Network member, **Pat Hargadon** is seen here holding the silhouette among breast cancer survivors in Dublin.



BCNA Community Grants update

Meditate for Health

– Sheena Short, Tasmania

The meditation workshop was held in Hobart on February 22-23, with a follow up session on March 16.

Provision of prostheses

– Action on Breast Cancer WA

A report has been prepared for each State and Territory about the national provision of external breast prostheses. It recommends an improved funding scheme and the Network is now considering a plan of action.

Beginning the journey

– Illawarra Breast Cancer Support Group, NSW

This booklet of women's stories was launched at the Illawarra Young Women's Forum in July 2002.

Stories from inspirational women with advanced breast cancer

– BCNA's Advanced Breast Cancer Working Party

Stories from 10 women from across Australia with advanced breast cancer are being written and edited into a booklet.

Mothers and daughters seminar

St Vincent's Breast Centre – Breast Cancer Support Group, Queensland

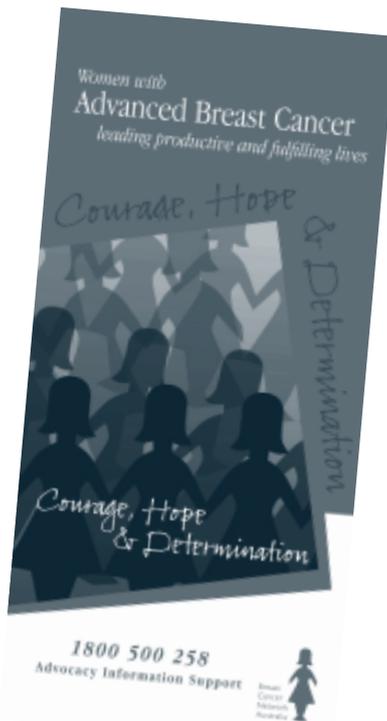
This seminar was held in Toowoomba in October 2002 and attracted more than 60 people. Speakers included the Network's Queensland representative, Lyn Moore, Dr Jane Turner, and genetic counsellor, Margaret Gleeson.

A video of the day has been produced for the Network.

Bags of Care Project

– Valkyrie Care Group, Victoria

A consultant has been employed to write the business plan and manual for the Bags of Care program.



The poster produced by the Network's Advanced Breast Cancer Working Party.

Promoting the message that women with advanced breast cancer can live full and productive lives

– BCNA's Advanced Breast Cancer Working Party

A banner was created and first used at the Field of Women in Sydney in October 2002. It, along with posters, will be used at a number of events and public forums to promote the message of women living creative, productive and full lives in spite of advanced breast cancer. The banner and posters can be borrowed from the Network.

Lending library and information kits for women

– Caring Cancer Support Group Port Lincoln, SA

Fifty information kits have been produced and distributed to women, local doctors, hospital and health care workers in the region. Another 50 are being produced and the library is being compiled after lots of research.

Information day for rural women affected by breast cancer

– Young Community Health Centre and Young & District Breast Cancer Support Group, NSW

This information day will be held on May 10. The committee is currently promoting the day and finalising the guest speakers.

Rural/remote women's working party

– Judy Shepherdson (NSW) and Marlene Parsons (Victoria)

A steering committee has been established to plan, develop and implement strategies to address issues faced by Australian rural women. They are working to connect rural women via e-mail. See article on page 3.

Young women's network

– Mary Macheras-Magias, Victoria

Mary has held two tele-conference calls and is recruiting women to write stories for the website. She is also recruiting young women for the e-mail link. See article on page 5.

Promotional posters

– NT Breast Cancer Voice

Two thousand posters have been produced to help Northern Territory Breast Cancer Voice promote its 'Voice' across the Territory. It will also continue to strive to improve services and conditions for all Territorians faced with a diagnosis of breast cancer.

My Story: Indigenous women's breast cancer video

– Indigenous Women's Cancer Group, North Queensland

Interviews are taking place with indigenous women in northern and north-west Queensland and the Torres Strait. These interviews will inform the video's 'storyboard'.

A voice for young women with breast cancer

The challenges faced by young women diagnosed with breast cancer are unique and varied.

Young women are generally planning for the future and breast cancer is not part of their plan. They are considering careers, study, relationships, family, and buying or renovating a home.

I was 33 years old when I was diagnosed with breast cancer. It was not my first brush with cancer. At the age of 29, I was diagnosed with thyroid cancer – a very treatable cancer.

My breast cancer diagnosis came at a time when life was 'back on track'. It was three years post-thyroid treatment and I had waited well beyond the recommended time to have a second baby. My husband and I had begun extending our house in preparation for more children.

My initial reaction to the news was one of shock. It felt like a cruel joke. After all, months earlier, when I first presented to my GP with the unusual swelling in my armpit, there was a feeling it was an ingrown hair.

Four years post diagnosis, I applied successfully for funds through Breast Cancer Network Australia's Community Grants Program to



– Mary Macheras-Magias, Victoria

conduct a project focusing on the needs of young women.

The idea for the project arose in 2002 during a workshop for young women at the Network's National Summit.

The project has three aspects:

- to develop a web page for young

Can you help?

The web page will include stories by young women about their experience with breast cancer. If you have a story please forward it to mmacherasmagias@optusnet.com.au

If you wish to be included in the e-mail link, contact me at the same e-mail address

– Mary Macheras-Magias, Victoria

women with breast cancer on the Network's website;

- to form an e-mail link between young women throughout Australia with information and updates regarding the project; and
- to develop initiatives that highlight, and address the unmet needs of young women with breast cancer and to develop strategies to improve the treatment and management of young women.

A working party of young women has been formed to help implement the last objective.

What are the issues pertinent to young women? Issues identified at the National Summit included:

- Fertility and chemically induced menopause – on-going health issues, such as, osteoporosis.
- Support and access to information.
- Improved access for rural/remote women and their families.
- Improving care – misdiagnosis.

If you have an experience regarding the issues identified or wish to add to the list, contact me direct via e-mail – mmacherasmagias@optusnet.com.au – or through the Network's office on phone 1800 500 258 (free call).

Letters to the Editor

My photo appeared in the last issue of *The Beacon*, along with that of my husband and three little boys at the Sydney Field of Women.

I was diagnosed at 28 years and was then single. When I asked my boyfriend, he said he didn't know if he would be able to cope or stick around. Well he did! We married and Dominic, aged 4, Alistair, aged almost 3 years, and Sebastian, 7 months – all solo breast-fed babies – have been the result.

I have just celebrated my 38th birthday and will be having a 10-year cancer free celebration in June.

We are now looking forward to celebrating 20 years, and 21st birthdays, graduations, weddings and grandchildren.

I am also involved with Dragons Abreast and naturally come with my own cheer squad.

– Louise Zammit, NSW

I lived in New Zealand for 49 years and was diagnosed with bilateral breast cancer in 1996. As my lymph glands were involved, I received chemotherapy (CMF) and extensive radiotherapy treatment to both breasts and axillae.

On reaching the five-year cancer-free period, I moved to WA to join my family.

During a routine mammography in August 2001, a vast area of tiny DCIS was found in my right breast. Last month, I had a mastectomy and breast reconstruction, and am impressed with the results.

I have to agree with Sandra Kunze, who wrote in the last issue of *The Beacon* about prostheses and the difficulties with costs, etc.

She also mentioned people with deflated self-esteem and I felt what she wrote was extremely valid. In NZ, the cost of wigs, prostheses, compression sleeves and special bras are covered by an annual government fund per patient after diagnosis and treatment.

We have just paid \$140 for a surgical bra here and I would like to help lobby for such costs to be covered for all women who experience the devastating effects of breast cancer. I do not feel it is appropriate to lump us into the same funding coffers as limb amputees.

– Melwa Telfer, Victoria Park, WA

Hair today, gone tomorrow and back again!

I woke my husband and told him of my fears. All of the unknown was overwhelming. I couldn't sleep and kept thinking of my beautiful thick dark hair. Only recently had I started to have the occasional colour put through it.

"Oh God is this really going to happen – my hair just falling out?" I thought. Then I had an idea.

I have always loved needle work and doll-making. I decided I would have all my hair cut off short, to save all I could before treatment started, and I would have a doll's wig made and then make a cloth doll or buy a porcelain one.

Suddenly, I felt so excited and in control again, as this was a real passion of mine – to create something beautiful with my hands.

In the morning, I told my husband my idea and he thought it was great. Nothing ever surprises him, I might add.

I phoned a friend who had been a doll maker and she gave me the wig maker's name. I phoned and explained I was facing chemotherapy and didn't want to waste my hair. I asked her if I could have some dolls' wigs made.

Another of my dear friends, a hairdresser (also a breast cancer survivor) came out of retirement to cut my hair off and lay it out on a tray.

Then there was the drum roll as I looked into a mirror to see my hair was now cut very short.

The next step was to take the hair to the wig maker's to have it stitched together into dolls' wigs.

The whole idea of losing my hair and wearing a wig was difficult to come to grips with. I couldn't and wouldn't say the word 'wig' and from day one, my wig was called 'Wendy'.

I attended a Look Good, Feel Better day between my first two chemo treatments and wore Wendy. I amazed myself and my friends when I took it off. I was beginning to accept things. I

Many women say the most distressing part of breast cancer treatment is the thought of losing their hair. While this may sound trivial, most women facing the prospect would certainly agree.

*This, indeed, was the case for Queensland woman, **Ronwynne Moffitt** (below), who has written to us with her own novel strategy for dealing with this distressing situation.*

Ronwynne's full account can be found on our website – www.bcna.org.au – but this extract begins just before she began her chemotherapy.

shared my story of having the dolls' wigs made and where to go if anyone wanted to do it too.

Look Good, Feel Better was wonderful. I learnt some excellent hints about makeup and how to cope with hair loss. Every day, when putting on my face, I thanked God that I could take part in such a worthwhile and supportive activity.

At my first treatment, I told my oncologist that I had been upset about having to lose my hair, but that I had

felt so much better after my 'hair brain' idea (pardon the pun).

He thought it was a brilliant idea and promised to share it with other patients.

The wonderful day arrived when the wigs were ready to be picked up. I was delighted with the results.

After discussing it with my daughter, we had decided on porcelain dolls, as they would last forever. I thought of the future, when I could say to my grandchildren – God willing – "This is grandma's hair, when she went through a very bad patch".

It was fun to go with my daughter and my doll-maker friend to buy the two dolls – one called Stephanie, the other Robert. Dressing the dolls was wonderful therapy for me when I was feeling up to doing something creative between treatments.

I gave a baby wig made from my extra hair to my hairdresser friend at Christmas and she dressed a baby doll, Charlotte, in heirloom fabrics.

The dolls were carried in a basket tucked in with a beautiful liberty patchwork quilt given to me by some quilting friends, with wishes for a speedy recovery.

This always caused great interest when taken with me to chemo. Robert, Stephanie and Charlotte have visited all my doctors, gone to treatments, stretch classes, the Connect Program and lots of other outings, including church. They have been a great source of interest and inspiration to everyone they have met.

As you can see, I am some way into my journey now, and it has been a fulfilling one. It was not by choice, but still it is one that I don't regret.

Everyone involved – my husband, family doctors, friends and fellow travellers – have given me tremendous support and encouragement, and for that I am truly grateful.

– Ronwynne Moffitt, Queensland



Ronwynne with her dolls, Stephanie, Charlotte and Robert, each of which have wigs made from hair she had cut off before chemotherapy.

Dragons Abreast report

The year is off to a flying start. The Chinese New Year races at Darling Harbour, Sydney, saw the biggest contingent yet – five boats of Dragons Abreast teams. Members from the ACT, Sydney, NSW's Central Coast, Newcastle, Illawarra and Brisbane participated and, for the first time, the *Flowers on the Water* remembrance ceremony was witnessed by huge crowds – a truly moving sight.

The entry fees and flowers were paid for by So Natural Foods.

Special thanks must go to **Melanie Cantwell** from Dragon Boat NSW for her support.

In the face of the devastating bush fires in Canberra, the women of Dragons Abreast ACT rallied together and took courage from each other.

On the Tuesday after the fire, **Anna Welling Booth** reported: "Jan Skorich did a wonderful thing this morning and brought some rose petals that were yellow ringed by red. We stopped near a willow tree in front of the National Library and thought about all those people who had lost their homes. The paddling timing this morning was terrible – everyone was preoccupied – but the boat was almost full. It was good to be together".

It is truly wonderful to know that members can bring each other strength in difficult times through participation in a team such as Dragons Abreast.

The girls in the ACT are now looking forward with determination and are keen to welcome as many paddlers as possible to the Australian Masters Games in November – in which dragon boat racing is an event.

Jan Skorich, whom many of you know as our capable webmaster, has officially taken over from Anna as co-ordinator for the ACT Dragons Abreast team.

Excitement is building about the Australian Dragon Boat Federation's National Titles being held from April 10 to 13 in Adelaide. Hosts, SA Dragons Abreast, have put



together a program for visiting paddlers. A number of States are sending teams and individual paddlers are joining composite teams. The highlight of the Nationals will be the annual Dragons Abreast Challenge, where Dragons Abreast teams compete against one another.

Dragons Abreast Sydney is moving ahead, thanks to the efforts of **Margot Case** and **Caroline Bommer**.

Dragons Abreast WA featured in a wonderful article in Australian Vital magazine – you can check this out on our website.

Victoria's Dragons Abreast are looking fabulous and their numbers

have grown amazingly since they first took to the waters last year.

NSW's Central Coast Dragons Abreast have doubled their numbers since having a dragon boat stationed locally. **Julie Woods** and **Louise Zammit** are doing a marvellous job of co-ordinating the team.

Dragons Abreast NT were recently pulled up by the water police for paddling too close to the two US war ships in Darwin Harbour. Luckily, the police decided a bunch of Pink Ladies posed no threat and allowed them to go with a warning.

The Inaugural South Pacific Breast Cancer Regatta on March 16-17 in Auckland has attracted 10 breast cancer survivor teams from around the world, including the US, Canada, Australia and New Zealand. This is the first time all four countries will have had full survivor crews together anywhere in the world!

Dragons Abreast Australia is taking 38 paddling members, plus a host of supporters, to fly the flag for the Network. We are looking forward to meeting Breast Cancer Network New Zealand members and competing at the Wellington regatta.

– *Michelle Hanton, Dragons Abreast Co-ordinator, phone (08) 8941 8923 or e-mail hanton@ozemail.com.au*

Back at work and loving it!

Recently **Jenny Richardson** wrote to us about her experience with breast cancer and reconstructive surgery. Her full story is on our website. She has since sent an update on her progress, including this experience on returning to work:

Being back at work is great and holds many surprises. I work at Centrelink in Burnie and, despite all the bad publicity, I just love it.

Last Friday, one of the counter staff came round and said, "There's a man at the counter who says he's just got out of prison and wants to know if you are back at work and recovered".

(At the moment, I'm away from front line counter work, because of the standing and frequent walking,

which is a bit difficult at present.)

Out I went and sure enough, a huge man in chains, rings, tattoos and leather smiled and said, "Welcome back ... I read about you in the paper the day before I went to jail and I promised myself I'd come and check on you when I got out. Great to see you beat it!"

Everyone was stunned – including me – but it was so lovely. I had only dealt with him a few times over the past couple of years, so it was amazing that he had been concerned and kind enough to come in.

This past year has given me a huge insight into where I stand and belong.

– *Jenny Richardson, Tasmania*

Introducing our member groups

Bosom Buddies make a difference in the ACT

Bosom Buddies is a support group for breast cancer survivors in the ACT and surrounding NSW.

Our first meeting of eight women was held in a private lounge room in January 1995, to offer support to a woman named Dianne throughout her chemotherapy and radiation treatment.

We had to borrow \$700 from her to bankroll the organisation and pay for postage!

With a membership now of more than 350, our major focus is on supporting local women and their families during their breast cancer journeys.

We have a mobile phone number published in the local white pages and people can call for assistance 24 hours a day, whether they are members or not.

Bosom Buddies provides fluffy ducks (a form of temporary prosthesis), underarm cushions and drainage bags (colourful shoulder bags to carry drainage bags) for all women who have undergone surgery.

Our volunteers are also available to visit women in hospital post-surgery and to attend weekly oncology clinics at the Canberra Hospital.

Some of our members serve as consumer representatives on local groups, such as the ACT & South East NSW Breast Cancer Treatment Group, the Consumers' Health Forum, the ACT and NSW Mammography Advisory and Quality Management Committee, and the ACT Lymphoedema Clinic Steering Committee.

Bosom Buddies, are currently supporting the *Caring For You* proposal submitted to the Health Minister in 2002 to obtain assistance for all women requiring mammary prostheses,



Members of the Bosom Buddies committee. Back: Sandy Heaton, Marilyn Ward, Norma Bradley and Pam Robertson. Front: Leona Furstenberg, Margaret Knott and Di Summerhynes.

irrespective of where they live.

We find the inequities and inconsistencies of the current plethora of state-based schemes totally unacceptable.

Our stated aims are support, education and advocacy, and any funds raised are directed towards breast cancer research or local support of a practical nature.

A breast awareness program was started in 1999 for girls in senior colleges, as well as various community groups.

An important event in the seven-year life of our organisation has been the annual 'Celebration of Life' fashion parade, where all the models are women who have experienced breast cancer.

Our major project for 2002 was funding a laser scanning machine at the Calvary Hospital Lymphoedema Clinic, at a cost of approximately \$22,000.

On Australia's Breast Cancer Day in 2002, we held a gala dinner and auction to raise funds and launch a young children's story book, *My Mummy has Breast Cancer* by **Kerry Glover**, which is available by contacting Bosom Buddies.

Guest speakers present at our general gatherings, which are held bi-monthly.

In addition, we have a number of smaller social groups that meet on a casual basis to take part in such activities as cinema, pitch and putt golf, young mothers and weekday lunch.

We trust our activities provide positive support and encourage a return to 'normal' life. Our main aim is to laugh and have fun!

Contact Bosom Buddies at
PO Box 4342 Kingston ACT 2604,
phone 0419 698 188 or Internet
www.bosombuddies.com.au



Meet our consumer representative – Margaret Tassell

I want to encourage other women to volunteer for the Network's *A Seat at the Table* program.

Although the work is challenging at times, it's rewarding to spin some of your pain into gold by improving the experiences and outcomes for other breast cancer patients.

My own diagnosis of one small, invasive lobular carcinoma came in 1996 at the age of 44 years.

Although my prognosis was good (and I have had no more problems), the diagnostic process was problematic and I had to make some difficult decisions.

I chose to have bilateral mastectomies, which turned out to be just as well, as there were multiple, undiagnosed tumours found through both breasts, despite the imaging.

Following this experience and mild lymphoedema, I became involved in consumer advocacy work, although I wouldn't have used that name.

At first, I worked alone, but soon joined with other women and The Cancer Council Tasmania.

Immediately after completing the Advocacy and Science Course in Hobart during September 1999, I put my hand up for a national consumer representative position about early detection with the National Breast Cancer Centre (NBCC).

My interest stemmed from a background in science, writing and editing, and my experience of problems with diagnosis.

At that time, the Network's *A Seat at the Table* program was just getting under way; in fact I was told that I was a 'guinea pig'!

The program now has well-planned procedures in place to select, guide and support consumer representatives.

Our project team worked to write national guidelines for doctors, concerning the use of mammography and ultrasound tests to assist with early diagnosis when a woman presents with a breast change.



Consumer representative
Margaret Tassell
from Tasmania.

The Breast Imaging Guidelines were launched in October 2002 and are primarily for radiologists, surgeons, GPs and oncologists. They concentrate on the why, when and how of referring a patient, reporting and interpreting the test results, and how the patient is informed about her results and treated.

I found it stimulating and rewarding to be involved with this team project, so much so that I agreed to come back for more!

Since January 2001, I have been a member of the New Technologies project team, which reviews new technologies for breast cancer diagnosis on a continuous basis, and posts informative summaries on the NBCC website, to assist both health professionals and the people affected by breast cancer.

– Margaret Tassell,
Launceston, Tasmania

Our latest Seats at the Table

As part of the Network's *A Seat at the Table* program, these women were recently appointed to represent us:

- National Breast Cancer Centre's Advanced Breast Cancer Guidelines Regional Seminars – **Tessa Mallos** (NSW), **Diane Shore** (Qld), **Maria Waters** (WA) and **Judy Shepherdson** (Vic.).
- 2002 Australia's Breast Cancer Day National Breakfast Panel – **Domini Stuart** (NSW).



Polly's still walking for breast cancer

Those of you who have been following **Polly Letofsky's** Global Walk for Breast Cancer since she left Australia in 2001 will be pleased to know that she has reached the UK. Here she is next to the English Channel.

She is a remarkable young woman and has many inspiring and hilarious experiences to share on her website at www.globalwalk.org

Congratulations

In December 2002, the Chair of our Board, **Dr Patricia Edgar**, received the Australian Film Industry's Longford Life Achievement Award – the highest accolade that can be bestowed on an individual in this field.

Patricia has been at the forefront of children's television in Australia for more than two decades.

Network member, **Judy Shepherdson**, was named Murray Shire's 'Citizen of The Year' at the 2003 Australia Day Ceremony in Moama, NSW.

Another Network member, **Maggie Stowers**, is the inaugural winner of the Victorian Nurse Campaign by The Cancer Council Victoria. Her prize is an around-the-world study grant.

Maggie is highly regarded by the many women with breast cancer whom she has helped in Melbourne's eastern suburbs.

Sydney's **Professor Martin Tattersall's** breast cancer work was acknowledged when he made an Officer of the Order of Australia in the Australia Day Honours List.

A beautiful haven in the bush

The Otis Foundation's respite units in Bendigo, Victoria, will open for bookings from March 2003.

The beautiful units, on land abutting the property of Breast Cancer Network Australia's Board member, **Andrew Barling**, are named St Jude and St Hannah. They are wonderful places to rest and draw strength, in order to face the challenges of living with breast cancer.

These units were originally the vision of Andrew's late wife, **Judy Burley**.

Nature often provided Judy with strength and rejuvenation during her time with breast cancer, and she and Andrew had a vision to provide a place of peace and natural beauty to share with others living with breast cancer (including their support persons).

The units are self-contained and are provided free of accommodation charges. They are available for either a week, Monday to Friday, or a weekend.

The units are made of rammed earth



The Otis Foundation's respite units will give people living with breast cancer a place to rest and draw strength.

with large, north-facing windows overlooking the bush of One Tree Hill National Park.

There is also a peaceful internal courtyard and a separate room for an independent carer, if required.

The Otis Foundation does not provide medical facilities or staff, but offers unique opportunities for women and men with breast cancer, or recovering from it, to benefit from a

period of time spent living close to nature, in a beautiful and tranquil place of retreat.

All linen and kitchen needs are supplied. Only food and personal items should be brought along.

To book, contact the units' manager, Liz Martin, on phone (03) 5439 3220, fax (03) 5439 3220, e-mail otisbookings@bigpond.com or visit www.otisfoundation.org.au

Check your superannuation benefits

Along with the physical and emotional trauma of a cancer diagnosis can come the added burden of income loss.

When I was diagnosed with metastatic breast cancer in the spine and ribs eight years after my first mastectomy, I was told that I would require time off work for treatment. Over the next three years I used up all my sick leave. I then thought that my only choice was to take leave without pay and return to work as soon as possible.

While I was off work, our workplace was visited by a representative from the superannuation organisation

which I had paid into for 20 years.

A colleague told me and I made an appointment. When I explained my situation, the representative told me that I might qualify for a Temporary Disability Benefit.

It was the first time I had even heard of this benefit.

I had to undergo several medical examinations and a visit to a psychologist, but it was worthwhile when the benefit was granted.

It meant I could have income from this benefit before my actual retirement age, without affecting my long-term superannuation payout.

As I neared retirement age, I was

offered a Permanent Disability Benefit or my normal superannuation options. It was wonderful to have this much choice.

Other people with cancer, particularly metastatic cancer, may well be eligible for this entitlement without realising that it is an option.

I only stumbled onto it by chance, so I hope that this good news may help others in similar situations.

The income from the Temporary Disability Benefit made a considerable difference to my life, and my family, in terms of financial comfort.

– Sandra Shively, San Remo, Victoria

BOOKS AND AUDIO

There's More to Life than My Right Breast

There's More to Life than My Right Breast by **Cyndi Kaplan-Freiman** is a combination of extracts from her own diary and interviews with other women.

It has easy-to-read chapters covering most aspects of diagnosis and treatment, as well as sections on relationships, recovery and healing. Types of breast cancer, the different stages and grades, and the various treatment options are all explained simply and clearly.

Each chapter has a really useful section called 'Lifesavers' that summarises the key points covered. For someone who had never been to hospital before, her tips on what to take would be handy.

Women learn from the stories of other women, so throughout the book women speak about their feelings of fear, depression and confusion, and the eventual acceptance of their situation.

Cyndi is not medically qualified, but seeks to help other women who have been recently diagnosed to anticipate some of the highs and lows along the way, and to deal with the decisions that need to be made. She achieves this objective well.

Some parts of the book are quite personal. Cyndi shares her thoughts on issues such as the initial shock, her need to seek reassurance and reconstruction. She also talks about faith, the power of the mind, the importance of humour and the people who inspired her to keep going.

Other women talk about the loss of a breast not changing who they are, but that cancer has given them the opportunity to think about what is important and to change the things they want to change.



Books that Cindy found helpful are also referred to throughout the book.

I found this an enjoyable book. It is factual and informative, while also giving an idea of how other women have coped with their journey. I would strongly recommend it to any women newly diagnosed with breast cancer.

There's More to Life than My Right Breast sells for \$25 a copy (plus \$3 for post and handling). To order a copy, phone (02) 9386 9110, fax (02) 9386 9112, e-mail cyndi@bigpond.net.au or

visit www.cyndikaplan.com.au

– *Alexandrea Cannon, Queensland*

Gems from Stephanie Dowrick

Many of you will know **Stephanie Dowrick** from her appearances on **Geraldine Doogue's** 'Health Matters' on ABC Radio.

Stephanie, herself a breast cancer survivor, also made a wonderful presentation to those attending the NSW Breast Cancer Forum before Sydney's *Field of Women* in October last year.

She is also an author, whose best-selling books have inspired and helped

many. We recommend Stephanie's book, *Forgiveness and Other Acts of Love*, which has sold more than 75,000 copies and her audio tape, *Guided Meditations: Grace and Courage*.

These and many other works by Stephanie can be found in good book shops or write to Wise Angels, 1-15 Barr Street, Balmain, NSW 2041.

CONSUMER GUIDE

Privacy and health guide

My Health, My Privacy, My Choice is a consumer's guide to privacy and health information produced by the Office of the Federal Privacy Commissioner.

For a copy, phone the office on 1300 363 992 or e-mail privacy@privacy.gov.au

EVENTS

Pink Ladies Gold Classic

The Pink Ladies Golf Classic will be held again from August 24 to 29.

The five-day golf getaway includes four of Queensland's Championship courses – Pelican Waters, Hyatt Coolum, Noosa Springs and Twin Waters.

Golfers of all handicaps and from all parts of Australia are welcome!

The women who participated in last year's golf tour had an absolute ball!

Contact: *Jacinta, Moore Creative Tours*, phone (03) 9500 8954 or e-mail moorecreativetours@bigpond.com.au

Thank you

- **Griffith Cycle Club** for donating \$500 to the *My Journey* project.
- **Bakers Delight** for raising \$7500 at its Christmas Ball in December. It also raised \$4451.60 at its Phillip Island conference and \$3385 at the South Australian conference.
- **Telstra Retail** for donating an **Ian Thorpe**-signed swimming cap for the Bakers Delight Victoria/Tasmania conference. It was auctioned and raised \$850.
- **East Malvern Ladies Tennis Club** for donating \$5500 to our National toll-free number, the Helping a Friend or Colleague brochure, and a digital camera.
- **Dean McLachlan** and **Wendy O'Sullivan** for asking their guests to make donations in lieu of wedding gifts on their special day.
- **Australian Air Express, Planpower** and the **Australian Olympic Committee** for donating funds to the Network instead of printing Christmas cards for their clients.
- **Harriet Moore** and her committee for raising \$3587 at the Open Garden Day on Victoria's Mornington Peninsula in November 2002.

UPCOMING EVENTS

March 16: Melbourne Dragon Boat Festival, from Jeffries Parade, on the Yarra River, between the Swanston and Swan Street bridges, 9am to 5pm.

Contact: Pamela Williams, (03) 9592 6352 or nwilliams@arc.net.au

March 29: Breast Cancer Action Group General Meeting 2.20-5pm, Storey Hall, RMIT, Melbourne. Annabel Pollard on 'Am I responsible for causing my own breast cancer? Balancing hope, guilt and optimism'.

Contact: Sue Lockwood, (03) 9878 0736.

March 31: Lymphodema presentation by Elizabeth Harrison, Wesley Breast Clinic, Brisbane. Bookings essential.

Contact: Phone (07) 3232 7596 for bookings.

April 11-13: Dragon Boat National Titles, Adelaide, SA.

Contact: Ginny Bullock, (08) 8358 4117.

April 23-27: 6th World Congress on Psycho-oncology, Alberta, Canada.

Contact: banffcongress@cancerboard.ab.ca

April 25: Breast Cancer Association of Queensland's Beaudesert Race Day.

Contact: (07) 3839 6630 or www.bcaq.net

April 28: Your Family – Living with Cancer, Wesley Breast Clinic, Brisbane.

Contact: Phone (07) 3232 7596 for bookings.

May 19-23: Illawarra Breast Cancer Support Group's Adcare Lifestyle Health Retreat.

Contact: Gloria Swift, (02) 4295 8219, 0414 422 463 or SwiftG@iahs.nsw.gov.au

May 24: Breast Cancer Association of Queensland's information session for women with breast cancer in western Queensland, Barcaldine.

Contact: Phone (07) 3839 6630.

June 26: Breast Cancer Action Group General Meeting, 7-9pm, Storey Hall, RMIT, Melbourne. Jacquie Chirgwin on 'Young women's issues'.

Contact: Sue Lockwood, (03) 9878 0736.

July 19-20 (also August 2-3 and August 30-31): Basic lymphoedema course for health professionals, Austin and Repatriation Medical Centre, Heidelberg, Victoria.

Contact: Gillian Buckley, (03) 92702422 or gmbuckley@optusnet.com.au

August 24-29: Pink Ladies Golf Classic on the Sunshine Coast, Queensland.

Contact: Jacinta Moore, (03) 9500 8954 or 0412 857 240.

August 28-31: World Dragon Boat Championships in Shanghai, China.

Contact: Michelle Hanton, (08) 8941 8923 or hanton@ozemail.com.au

September 20: Breast Cancer Action Group General Meeting, 2.30-5pm, Storey Hall, RMIT, Melbourne. Judy Shepherdson and Marlene Parsons on 'Rural women's issues'.

Contact: Sue Lockwood, (03) 9878 0736.

October 26: *The Field of Women, Hobart, Tasmania.*

Contact: Michelle Rule, 1800 500 258 (free call).

October 27: Australia's Breast Cancer Day.

November 8-9: Dragon boat racing at the Australian Masters Games, Canberra.

Contact: Michelle Hanton, (08) 8941 8923 or hanton@ozemail.com.au

November 19: Breast Cancer Action Group General Meeting, 7-9pm, Storey Hall, RMIT, Melbourne. Dr Craig Hassed on holistic care for women with breast cancer.

Contact: Sue Lockwood, (03) 9878 0736.

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, PO Box 4082, Auburn South, Vic 3122

Name:

Address:

..... State: Postcode:

Phone: () E-mail:

Have you had a diagnosis of breast cancer? Yes No



Seeking Shelter

The Network welcomes these new groups under its national umbrella:

- Merrygolds, Mildura, Victoria
- Cancer Carers and Patients Support (CCAPS), Mildura, Victoria
- Coorparoo Breast Cancer Support Group, Queensland
- Beleura Breast Cancer Support Group, Mornington Victoria

These four groups mean that Breast Cancer Network Australia now has 97 member groups and five associate member groups.

Endometrial cancer risk not proved

A 20-year study in the US has concluded that a family history of breast cancer does not put women at risk of developing endometrial cancer.

The study, by the National Cancer Institute, followed more than 37,500 women participating in a US national breast cancer screening program.

The follow-up study, which ran from 1979 to 1998, collected detailed information about the breast cancer history of the participants' relatives, including their age at diagnosis and whether cancer was found in one or both breasts.

Allowing for factors such as menopausal status, race and previous breast cancer diagnoses, there was no evidence to suggest that breast cancer in a first or second-degree relative was associated with an increased risk of endometrial cancer.



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