



# The Beacon

Breast Cancer  
Network Australia  
newsletter

## Network's first National Summit a great success



*Leona Furstenburg and Anna Wellings Booth from the ACT were among those at the Network's first National Summit.*

**E**ighty-three breast cancer survivors from around Australia met at Swinburne University, Melbourne, on February 22 and 23 for Breast Cancer Network Australia's first **National Summit**.

The women included representatives from the Network's member groups, State Representatives and key breast cancer advocates. They came from as far afield as Perth, northern Queensland, the Northern Territory and southern Tasmania.

The energy levels were high and there was a buzz of expectancy as the Network's Chair, **Dr Patricia Edgar**, launched the summit.

The two days that followed were filled with presentations, workshops and discussions.

The Summit's major purpose was to tell women about the Network's key projects and plans for the future.

It also had another important purpose – to identify a liaison person in each of the member groups. This means we can continue to communicate and share information about the Network and its activities with women in all corners of Australia.

Highlights of the Summit were the launch of the **2002 BCNA Community Grants Program** by **Raelene Boyle** and a motivational speech by 30-year breast cancer survivor **Bettina Woodburn**, who recently won the Get Up and Go! Award for senior citizens.

Friday evening's celebration at the home of **Maureen and George Swinburne** enabled us to recognise the support of: **Freehills**, which provides pro-bono legal work; **Ernst & Young**, which provides pro-bono auditing; **PMP Print** which sponsors the printing of *The Beacon*; and **Joanne Naughton**, whose transport company carries the *Field of Women* silhouettes to a new place each year.

The Network Summit was exhausting, but exhilarating, and would not have been possible without the financial support of **Perpetual Trustees**.

The Summit's success was best summed up by the participant who said: "My head is spinning with so much new information. It's great to be a part of a group of women really doing something about breast cancer!".

Breast  
Cancer  
Network  
Australia



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*Delegates from all parts of Australia at the Network's first National Summit at Swinburne University, Melbourne.*

# State Reports



## NEW SOUTH WALES

The **Illawarra** women have been particularly energetic, forming a dragon boat team and running their annual AdCare Retreat at beautiful Stanwell Tops in March.

**Gloria Swift**, Oncology Nurse Consultant extraordinaire, is the Illawarra group's ringleader – what a woman! She tells me that their Young Women's Forum (see page 10) will have some interesting speakers, including **Doreen Akkerman** on sexuality issues and **Domini Stewart**, the author of *You Can Get Through This*.

**Jane Redmond** from Cooma – our rural mover and shaker – reports that five women have now been trained as breast care nurses for the **south-eastern region**, with others planning to undertake studies in the near future.

Armidale contact, **Vivienne Gregg** reports that the area's breast cancer support group, **Power Pals**, is again meeting on a regular basis. For more information, phone Vivienne on (02) 6772 2931.

The women of the Central Coast and the Newcastle-Hunter trained hard and competed at the National Dragon Boat Titles. They were there in full force on the Gold Coast, led by the charismatic **Martine Boughton-Briggs**.

Contact: Pam Bell, (02) 9955 9313 or [bellpc@bigpond.com](mailto:bellpc@bigpond.com)



## WESTERN AUSTRALIA

More than 350 women attended the Breast Cancer Research Alliance Advisory Group's inaugural breakfast. One of our members, **Maria Waters**, gave an impressive speech about her breast cancer journey.

*Action on Breast Cancer* (AOBC) members also attended the inaugural committee meeting which followed.

Interestingly, six of the nine participants were Network members.

An issue being followed up by AOBC is the availability of initial and replacement breast prostheses in WA. We plan to conduct a survey to identify and highlight the problems that women are experiencing.

Radiotherapy waiting times are also on

the agenda, and we are investigating the effect of these delays on women with breast cancer.

One other issue that has continually been brought to the attention of members is the lack of drug information leaflets for consumers when they are placed on a treatment.

If you have any comments or experience of these, or any other issues, please contact Carol Bishop.

Contact: Carol Bishop (08) 9489 7312 or [carol@cancerwa.asn.au](mailto:carol@cancerwa.asn.au) or Yvette Libregts on [amazons@iprimus.com.au](mailto:amazons@iprimus.com.au)



## QUEENSLAND

Congratulations to **Janelle Gamble** and her helpers for their work hosting Network members competing in the National Dragon Boat Titles on the Gold Coast.

**Margaret Petrie** from Mt Isa reports that a local lingerie retailer has trained to fit prostheses, which will greatly benefit local and rural women.

**Shirley Gilmore** from Ayr is working hard for the Queensland Cancer Fund's Nurse of the Year quest.

**Leonie Young** has returned from the US, where she completed Project LEAD, a science and advocacy training program run by the US National Breast Cancer Coalition.

**Jenny Morrison** met with the Queensland Health Rights Commission and is writing an article about the complaints process and the work of the Commissions across Australia.

The Breast Cancer Association of Queensland organised a fundraiser at the Beaudesert Horse Races on April 25, and an education seminar at Goondiwindi on May 26.

**Veronica Macaulay-Cross** was a guest speaker at the **Women in Super**

breakfast as part of the national conference of major superannuation funds on the Gold Coast in March.

This year, Brisbane's Women in Super held a Mothers' Day breakfast and plan to host a fun run next year, as they already do in Melbourne and Sydney.

As part of the national project, *Strengthening Support for Women with Breast Cancer*, Queensland is working on the selection process to appoint six new breast care nurses. It is hoped they will be operational by July 1, and work in the Gold Coast, Brisbane, Toowoomba, Mackay, Townsville and Cairns areas.

The positions are part-time for one year, but local districts are 'topping up' the positions in some cases.

An unrelated project about improving communication between the treating public hospital and the woman's GP, is in the evaluation stage. A reference committee meeting was held in May.

Contact: **Veronica Macaulay-Cross** (07) 3269 8083 or [@bigpond.com](mailto:wymara.bigpond.com)



## THE ACT

**Leona Furstenburg** and **Sandy Heaton** gave a presentation to Bosom Buddies about the **National Summit** in February.

There is great enthusiasm for the Community Grants Program and the Science and Advocacy Training program.

**Margaret Knott** and **Anna Wellings Booth** attended a meeting of the Breast Cancer Treatment Group, a multi-disciplinary group from the ACT and south-east NSW.

Local support group, **Bosom Buddies**, donated \$5000 to the group's Quality Assurance Project, while **Sally Rubenach** from the ACT Population Health Research Centre presented a draft discussion paper about breast cancer in the ACT.

The Cancer Council hosted a conference in Canberra, *Living With Cancer*, which focused on the concerns, rights and responsibilities of people living with cancer.

**Elsbeth Humphries** attended one of the workshops to discuss key issues, and develop recommendations to support and enhance survival.

These reports are extracts of more comprehensive quarterly reports written by our State representatives.

The complete reports can be found on our website, [www.bcna.org.au](http://www.bcna.org.au)

Our state representatives are always happy to hear from our readers or to promote activities within the state. Just give them a call!

Elsbeth also represents the Network on the Australasian Society for Breast Disease, which is planning a consumer workshop for its next scientific meeting in 2003.

Dragons Abreast (the ACT and regions) had a busy summer season. **Jan Skorich** maintains a wonderful website of our activities.

A group of us joined the Walk for Wigs in Kosciusko National Park in memory of **Lyn Hull**.

Contact: **Anna Wellings Booth** (02) 6247 8470 or [wbfamily@ozemail.com.au](mailto:wbfamily@ozemail.com.au) or **Elsbeth Humphries** (02) 6239 6344 or [humphries44@ozemail.com.au](mailto:humphries44@ozemail.com.au)



*The Network's Board met in Melbourne during March for a one-day workshop.  
Back row: Jocelyn Newman, Raelene Boyle, Debbie Goodin, Mary Wooldridge and Andrew Barling.  
Front row: Anna Wellings Booth, Lyn Swinburne, Patricia Edgar, Karen Hayes and Cherrell Hirst.*



## TASMANIA

A laser therapy information session and massage demonstration was held in Devonport on April 3. Organised by BCNA member **Gerry Rockliff** and involving staff from The Tasmanian Lymphoedema Centre at St Marys, the afternoon program attracted about 70 women, including lymphoedema sufferers and community health nurses.

Several of our members were also involved in the Breast Cancer Foundation's Research Priorities Consultative Interviews to ensure that the views of women personally affected by breast cancer were heard, along with those of doctors and scientists.

Contact: **Joan Williams** (03) 6421 7700 or [joan.williams@dchs.tas.gov.au](mailto:joan.williams@dchs.tas.gov.au) or **Karen Forster** (03) 6273 4422 or [kforster@vtown.com.au](mailto:kforster@vtown.com.au)



## NORTHERN TERRITORY

After the lovely break over Christmas our members got enthusiastically back to work!

January saw Darwin members of NT Breast Cancer Voice join forces with Dragons Abreast NT for the launch of their new dragon boat.

We are delighted to announce that we are now enjoying an excellent partnership with the Department of Correctional Services, which generously built and donated a double trailer for our boat, Sunshine.

Public information meetings were held in Alice Springs and Katherine in February. It was also a great opportunity to meet with local Cancer Council branches and breast nurse **Stephanie Gaynor**. The women from Alice Springs'

Zonta Club kindly organised the venue and a wonderful afternoon tea.

Alice Springs member **Jill Burgoyne** attended the Network Summit in February, along with the NT's State representatives.

We plan to undertake more social and educational efforts to promote breast cancer awareness in the Territory. We would love to hear from Territory women who would like to participate or wish to give us feedback.

The NT Breast Cancer Voice held its AGM and is delighted to announce continued membership growth, with enthusiastic new members joining the committee.

Contact: **Susan Tulley** (08) 8927 3327 or [tullynt@msn.com.au](mailto:tullynt@msn.com.au) or **Michelle Hanton** (08) 8941 8923 or [hanton@ozemail.com.au](mailto:hanton@ozemail.com.au)



## VICTORIA

Our motto 'Giving a Voice to Australians Affected by Breast Cancer' has certainly been acted out in Victoria during the past couple of months.

Regional Victoria has been hosting the 'Warrior Women' art exhibition and writing workshops. Several regional cities have organised functions in conjunction with the exhibition, offering opportunities for breast cancer awareness and updates. The workshops have identified some wonderful hidden talent and provided a means for expression, which surprised many participants.

Please read **Hayley Coutts'** story on our website – [www.bcna.org.au](http://www.bcna.org.au) (Projects. Dragons Abreast Vic.) – for a great description of what it is like to be part of

the Victorian dragon boat team. The site also has wonderful photographs.

New members are most welcome, so please phone **Pamela Williams** on (03) 9592 6352 or e-mail [nwilliams@arc.net.au](mailto:nwilliams@arc.net.au) for details.

BCNA and YMCA Victoria are working together to encourage exercise and activity opportunities for our members. Many YMCA centres have agreed to negotiate rates for BCNA members. If you are interested, please contact your local YMCA centre.

YMCA centres can be found on the web at [www.ymca.org.au](http://www.ymca.org.au) or in the phone book. Further details can be found on the BCNA website at [www.bcna.org.au](http://www.bcna.org.au)

The Victorian Educational Grants Program has funds available (from the Health Department's BreastCare Victoria) for Victorian women to attend workshops and conferences. Please phone **Gil Paulsen** on (03) 9805 2500 for an application form.

Contact: **Gerda Evans** (03) 9805 2500 or [gerda@bigpond.net.au](mailto:gerda@bigpond.net.au)



## SOUTH AUSTRALIA

Eight women from South Australia attended the Network's National Summit and six women participated in the Advocacy and Science Training Program in February.

Since the summit, **Lyndal Outram** has established a support group for younger women with breast cancer in Adelaide.

**Maxine Barker** and fellow support group members from Port Lincoln will be actively involved in the State's Strengthening Support for Women with Breast Cancer project.

# Finding shelter under our umbrella

**B**reast Cancer Network Australia now shelters these 83 groups under its umbrella.

## MEMBER GROUPS

### ACT

- Cancer Council ACT Breast Cancer Support Group
- Bosom Buddies
- ANZ Breast Cancer Trials Group's Consumer Advisory Panel
- Dragons Abreast, ACT & Region

### NSW

- B Friends Breast Cancer Support Group Batemans Bay to Bermagui
- Breast Cancer Action Group NSW
- Breast Cancer Survivors Coffs Harbour
- Illawara Young Women's Breast Cancer Support Group
- Warilla Breast Cancer Support Group
- Woollongong Breast Cancer Support Group
- Kiama Breast Cancer Support Group
- Inner Balance Women's Cancer Support Group, Albury
- Lymphoedema Support Group of NSW
- Moree Breast Cancer Support Group
- Parkes/Forbes Breast Cancer Support Group
- Wagga Wagga Breast Cancer Support Group
- Southern Area Health Service Breast Cancer Advisory Group
- Griffith Breast Cancer Support Group
- Breast Cancer Support Group, Penrith Women's Health Centre
- Goulburn & District Breast Cancer Support Group
- Young Women's Breast Cancer Support Group, Coffs Harbour

- Bankstown Women's Cancer Support Group
- Armidale & District Breast Cancer Support Group
- Dragons Abreast, Hunter & Region
- Dragons Abreast, Sydney Region
- Dragons Abreast, Illawarra

### NORTHERN TERRITORY

- NT Breast Cancer Voice
- Bosom Buddies, Alice Springs
- Dragons Abreast, NT

### QUEENSLAND

- Breast Cancer Support Group Beaudesert
- Breast Cancer Queensland
- Fenceliners
- Friends of the Wesley Breast Clinic
- Noosa and District Breast Cancer Support Group
- Calloundra Breast Cancer Support Circle
- Queensland Young Women's Network
- Laidley Breast Cancer Interest Group
- Burdeken Breast Cancer Support Group
- West End Group for women with advanced breast cancer, Brisbane
- Breast Cancer Support Group, Mt Isa
- B'r'est Friends, Bundaberg
- Mackay Breast Cancer Support Service
- Dragons Abreast, Queensland

### SOUTH AUSTRALIA

- Action for Breast Cancer SA Inc.
- Mount Gambier Breast Cancer Support Group
- Murray Mallee Breast Cancer Support Group
- Port Adelaide Breast Cancer Support Group

- Caring Cancer Support Group, Port Lincoln
- Riverland Breast Cancer Support Group 'Breast Friends'
- Royal Adelaide Hospital Breast Cancer Support Group
- Whyalla Breast Care Support Group
- SA Dragons Abreast

### TASMANIA

- Tasmanian Breast Cancer Network
- Tasmanian Breast Cancer Group

### VICTORIA

- Breast Cancer Action Group
- Cassia Women, Bendigo Breast Cancer Support Group
- Bone Marrow Donor Institute Inc. Breast Cancer Support Group
- Daffodils Breast Cancer Support Group
- Forget-Me-Nots Breast Cancer Support Group
- Japonica Women - Young Women Support Group, Bendigo
- Kyabram Cancer Support Group
- La Trobe Breast Cancer Support Group
- Lesbian Cancer Support Group
- Patient Support Program – MACS 20-40 Support Group
- North Western Breast Cancer Support Group
- Ringwood Luminaires – Lighting the Way
- The Young Ones
- Waratah Breast Cancer Support Group
- Geelong Breast Cancer Support Group
- Warrnambool & District Breast Cancer Support Group
- Ballarat Breast Cancer Support Group
- Ararat Breast Cancer Support Group
- Bayside Breast Cancer Support Group
- Seaside Support Group
- B.R.E.A.S.T. – Breast Reconstruction Education & Support Team, Geelong
- Southern Health Reference Group
- Dragons Abreast, Victoria

### WESTERN AUSTRALIA

- Action for Breast Cancer WA
- Dragons Abreast, WA – Cockburn Amazons

### ASSOCIATE MEMBER

### GROUPS

- Life Force Foundation
- Breastlink
- Encore Programme
- Otis Foundation
- Quest for Life Foundation

## Congratulations Gerda

We are delighted to announce that **Gerda Evans** is the Network's first 'Seat at the Table' appointee to an international organisation.

Gerda, the Network's Victorian State Representative, has been appointed as one of two consumer representatives to the steering committee



tee of the Cooperative Family Registry for Breast Cancer Studies.

As well as being the first Network representative to be appointed to an international committee, Gerda is also the first non-US community representative on this committee. She will serve for an initial two-year term.

Gerda's appointment involves monthly teleconferences and two face-to-face meetings in the US each year.

We know Gerda will be a wonderful representative for us all.





Latest graduates of the Network's Advocacy and Science Training Program.

# Advocacy and Science Training Program

**T**wenty-six enthusiastic and unique women from around Australia completed the Network's *National Breast Cancer Advocacy and Science Training Program* in Melbourne during February.

The women brought a variety of experiences and backgrounds to the three-day program. Some live in capital cities, while others live on the land, hours from a major town. Six of the women are living with metastatic disease, one works with Aboriginal women, and they vary in age from 22 to 65 years. What they have in common is a personal experience of breast cancer and a passion to improve things for women who will be diagnosed in future. They will do this by becoming consumer representatives for the Network.

Two women from New Zealand also participated, at their own expense, and hope to take the course back to their own women across the Tasman.

The purpose of the training was to provide women with the knowledge, skills and confidence needed to take a 'seat at the table' with decision makers such as health professionals, scientists and government.

It will be their job to make sure that the issues and needs of Australians affected by breast cancer are the focus of work by key national organisations such as the National Breast Cancer Centre, the National Breast Cancer Foundation and government bodies.

The training program is divided into three major areas:

- Day 1 Consumer representation and advocacy.
- Day 2 The science and basic biology of breast cancer.



Professor Sanchia Aranda presenting at one of the sessions of the training program.

Day 3 The structure of the health system and strategies for 'getting your message across'.

The training is expensive to run, but the Network received funding from the Commonwealth **Office of the Status of Women**, for which we are grateful. This funding meant women from interstate could travel to Melbourne.

Training is an essential part of our 'A Seat at the Table' program and a vital way of enabling women to do the best job they can as consumer representatives.

The Network hopes to train more women later this year. If you are interested, phone **Gil Paulsen** on 1800 500 258 or e-mail [gpaulsen@bcna.org.au](mailto:gpaulsen@bcna.org.au)

## Our latest Seats at the Table

The following women are the latest to be appointed as our representatives:

- Australasian Society for Breast Disease Executive Committee – **Elsbeth Humphries** (ACT).
- National Committee to develop guidelines and award scholarships for rural nurses to obtain education and training in the area of breast cancer (a committee of the National Breast Cancer Centre [NBCC]) – **Susan Tulley** (NT).
- Improving access to specialist breast nurses project team (NBCC) – **Pamela Williams** (Vic).
- Feasibility study of providing people with cancer with an audio-tape of their consultations with their oncologist (University of Sydney) – **Cyndi Kaplan** (NSW).
- Hobart seminar on clinical practice guidelines for the management of advanced breast cancer (NBCC) – **Karen Forster** (Tas).
- Women who assisted with pre-testing for the DCIS survey (NBCC) – **Joan Williams** (Tas); **Robyn Wicks, Jan Dowd and Shirley Harding** (NSW); **Maureen Dickson** (WA); **Megan Dennis** (ACT); **Sylvia Thompson and Bridget Mills** (SA); **Dianne Shore and Alexandria Cannon** (Qld); **Kirsten Pavlovic and Diana Whitehead** (NSW).
- New Treatments Project Team (NBCC) – **Maria Waters** (WA).
- Interviews for NBCC publications – **Judith Adams and Jennifer Pettigrove** (WA); **Edith Cooper** (Qld); **Sheree Stephenson and Pamela Williams** (Vic); and **Maxine Barker** (SA).



Hot pink rashies mean the Dragons Abreast teams are known wherever they go.



The dragons in action at the National Titles on Hinze Dam, Queensland.

## Dragons Abreast tackle the National Titles

So many exciting things have happened since our last report, it is difficult to know where to begin.

Victorian Dragons Abreast made a fabulous splash at the Melbourne International Dragon Boat Festival with two full boats of pink ladies.

They took out the prize for the best-presented team. Those hot pink rashies sure were a hit with the crowds!

Everyone knew about Dragons Abreast and the Network by the end of the day.

What a fabulous job **Pamela Williams** has done in Victoria.

The AusDBF Australian National Championships held on Hinze Dam in Queensland from April 18 to 20 was the highlight of what has been a fabulous year for Dragons Abreast.

Saturday was our major focus. It was the day of our own event – the Dragons Abreast National Challenge.

We were thrilled to welcome a male breast cancer survivor/paddler at the Nationals – **Otto**.

The NT won the coveted Dragons Abreast perpetual trophy at the 2001 championships in Darwin, so all the teams were out to wrest it from them.

Our teams were resplendent in everything pink. Apart from the luminous pink rashies, there were wigs, bunny ears, halos, boas and zinc.

The challengers paddled out to the starting pontoons, accompanied by several supporters in the rescue tinnies, including **Gayle Creed** from Bakers Delight and **Madeleine Luck**, a fantastic supporter of the Network.



The starter's hooter blasted and we were off. It was so close! While Queensland was watching for the NT team, the **SA Dragons Abreast** team shot past to cross the finish line in first place.

It was wonderful to see such a vibrant team of paddlers and full credit to captain, **Vicki Nottage**, for leading her team to victory.

The shouting and cheering from the shore soon gave way to silence as the four dragon boats came together for the **Flowers on the Water** ceremony.

One hundred pink carnations and one blue carnation (for our male breast cancer survivor paddler) were floated on the waters in memory of those we have lost to breast cancer.

While each of us was lost in our thoughts, **Barbara Morris** from the Central Coast sang 'Lean on Me' and many (including me) were reduced to tears. It was a beautiful moment – celebrating life and remembering those not so fortunate.

The other impressive moment was

when a wonderful young man called 'Ferret' from the Gold Coast Dragons gave **Gayle Creed** the gold medal he had won the day before.

Gayle has advanced breast cancer and is unable to paddle, but went out in the dingy to participate in the Flowers on the Water ceremony. When the dingy came back to shore, Ferret shyly held out his medal saying, "You have earned this more than me". He hopes the medal will give Gayle strength in her ongoing battle.

Support for Dragons Abreast in the dragon boating community is strong and encouraging – we are all winners just by being there, celebrating life and keeping the spirit alive.

Our sincere thanks to the AusDBF and the QDBF for organising such a wonderful regatta – the biggest nationals to date – allowing us to participate and for altering their schedules to allow for our special ceremony.

**Janelle Gamble**, Queensland Dragons Abreast and the members of the Brisbane River Dragons must also be congratulated for their work to host such a marvellous week of activities for all our paddlers.

For information about Dragons Abreast, e-mail me at [hanton@ozemail.com.au](mailto:hanton@ozemail.com.au) or check out our website for the latest photos and full state reports. Go to [www.bcn.org.au](http://www.bcn.org.au) and then click on 'Projects', which will lead you to Dragons Abreast.

– Michelle Hanton  
National Co-ordinator  
Dragons Abreast

# Field of Women 2002

## Sydney, Sunday, October 27

The Network's *Field of Women* celebrates its fifth anniversary in 2002 and continues to raise awareness about the extent of breast cancer in Australia.

The 12,500 silhouettes send an emotional and powerful message.

The pink silhouettes represent the 10,000 women diagnosed with breast cancer each year, while the white ones remind us that we lose too many women to this disease.

This year's *Field of Women* will be planted in Sydney and launched on **Sunday, October 27.**

**All NSW members should have this date marked in their diaries.**

We know there will be women from interstate and overseas joining us on this special occasion.

The 2002 Breast Cancer Forum will begin the day's activities (see below).

The Silent Walk will

begin at 2pm from a central point near Circular Quay. We expect 10,000 people to walk along Macquarie Street to the Domain for the launch ceremony.

Planning for our Sydney *Field of Women* is well under way.

The Organising Committee, chaired by **Megan James**, has come up with some great ideas for making the day a memorable one.

Our project manager, **Dianne Logan**, has been working hard from an office generously provided by *Bakers Delight* in Sydney.

Thanks again to *Bakers Delight*, whose support means so much to the Network.

*There is still much to be done and we need YOUR help. To play a role in this amazing day, phone Dianne Logan on (02) 8585 1808 or 0418 897 027, or send an e-mail to [dlogan@bcna.org.au](mailto:dlogan@bcna.org.au)*



## Plant a Mini-Field

To coincide with the Sydney *Field of Women*, *Mini-Fields* will be planted by the Network's State Representatives and member groups around Australia.

These *Mini-Fields* will consist of 100 silhouettes, to be planted in regional areas and cities where women are enthusiastic about presenting their own community event. In 2001, 50 *Mini-Fields* were planted in communities around Australia.

Applications for holding a *Mini-Field* in 2002 are now being taken.

**The deadline for approval is July 19.**

To date, *Mini-Fields* are planned for:

**ACT:** Lyneham  
**New South Wales:** Tenambit, Wagga Wagga, Armidale, Penrith, Goulburn, Griffith, Keiraville, Broken Hill.

**Northern Territory:** Darwin.

**Queensland:** Alexandra Hills, Ormiston, East Bundaberg, Ayr, Caloundra, Toowoomba East, Toowong, Laidley, Esk, Boonah, Aspley, Gympie, Theodore, Gladstone, Mackay.

**Victoria:** Ararat, Mildura, San Remo, Lara, Spring Gully, Mt Waverley, Warrnambool, Newborough, Ringwood East, Meadow Heights, Traralgon, Loch Sport, Bendigo, Melbourne

**South Australia:** Whyalla, Port Lincoln, Minlaton, Murray Bridge, Mount Gambier, Kingston, Robe.

**West Australia:** TBA.

**Tasmania:** Hobart.

*If you would like to participate in a Mini-Field, phone the Field of Women Co-ordinators, **Wendy McClusky** and **Ro Pitt** at our National Office on 1800 500 258 or visit our website – [www.bcna.org.au](http://www.bcna.org.au)*

## Breast cancer forum

You are invited to attend a half-day seminar of information and discussion for women with breast cancer, their families and friends in Sydney on October 27.

It will start with a plenary session, followed by three streams:

- issues for young women with breast cancer;
- metastatic breast cancer; and
- lifestyle issues.

The speakers will include

**Petrea King, Stephanie Dowrick, Dr Fran Boyle and Dr Debra Campbell.**

The forum will finish at 1pm, to allow participants, after lunch, to attend the Silent Walk to the 2002 *Field of Women* in the Domain.

Date: Sunday, October 27, 2002.

Time: 9am – 1pm.

Venue: Hotel Intercontinental, Macquarie Street, Sydney.

Cost: \$25 (includes morning tea and lunch).

**Bookings are essential**

*For further information, phone **Louise Kippist** on (02) 9926 6584 or **Mandy O'Reilly** (02) 9926 7810.*

## Telling my story to help other young women

**M**y story begins a few months before my 21st birthday. I was still breastfeeding my son, Taylor, and had felt a small, pea-like lump in my breast.

Having been told by my mum to be cautious about things like this, I went to my GP straight away. The GP thought it was a fibro-adenoma and harmless, but thankfully she was cautious and referred me to a radiologist and surgeon.

The radiologist told me everything looked safe and so did my surgeon.

Although it was a harmless lump, it was decided that it should be removed while it was still small, as it would continue growing and would have to be removed at some stage.

A month later, I was recuperating at home after surgery to remove the lump when I got a call from the surgeon's registrar.

Initially, I was impressed, thinking that they were calling me to see how I was recovering.

Much to my surprise, it was blurted out that my lump had cancer cells in it and I would need to see an oncologist.

This was a huge shock, particularly because I was never told that the lump would be tested for cancer.

I was at home by myself when I received the call, and had to wait a terrifying hour until my partner, Paul, came home.

At the time I was studying full-time in my final year of university, working part time as a gymnastics instructor, looking after my son, and trying to have a bit of a social life.

After my diagnosis, I deferred university for a year, but kept teaching gym.

My next worry was that the gym kids would be scared to be taught by me – thinking that cancer was catching. That was one reason why I didn't want to lose my hair during chemotherapy,



*Sheree Stephenson and her son, Taylor.*

as it was the only way that the kids would find out that I was sick.

Another reason for not wanting to lose my hair was that I felt it would make me look like a cancer victim and I would get nothing but pity – not what I wanted.

Another concern was the fact that I was still young and wanted the option of having more children.

I was offered a new procedure, whereby a section of my ovary would be removed and frozen in the hope that there would one day be a procedure that could remove the eggs for fertilisation.

I decided against this procedure, having had enough of hospitals and operations, and with one delightful child. If it is meant to be, perhaps I

### A new adventure

The Fenceliners next adventure will be a trail ride on horseback in 2003, so polish your elastic-sided boots and dust off your Driza-Bone!

For more information, contact Fenceliners' secretary, **Jan Dowd**, at 96 Boorea Street, Blaxland, NSW 2774, or visit our website – [www.fenceliners.com.au](http://www.fenceliners.com.au)

– Lorrie Ledwell, Fenceliners

will have another baby, but if I don't, it won't be the end of the world!

I ended up having two three-month stints of chemotherapy and seven weeks of radiation therapy. And my hair didn't fall out, much to my relief.

I was worn out by the end of all the treatments, and it took me a few months to fully recuperate.

The support of my parents was crucial to my treatment and recovery. My mum came into every chemotherapy treatment with me, while my dad looked after Taylor, so that Paul could continue to work full-time.

I am at a loss to understand why I got cancer. It worried me for a long time, but now I have accepted it as a freak occurrence. I have no family history of breast cancer. I don't smoke and neither do my parents. I have a good diet and breastfed for 15 months.

I am happy to say that the cancer has not recurred. I am also proud of my achievements since my experience with cancer – I got my university degree this year, have started my first full-time job, my son is a beautiful young boy, and I am a happy, healthy person. Not too bad for someone who had a pretty traumatic time two years ago!

One thing I would like to see come from my bad experience is for awareness to be brought into the community that young people do get breast cancer.

True, it is not common, but I implore everyone to tell all the young women they know – daughters, granddaughters, nieces and friends – that any breast lump should be checked immediately, and to keep annoying the doctors until they act on your request to have something done.

Don't take a doctor's word for granted. You might be young, but you can still have breast cancer – just look at me!

– Sheree Stephenson  
Mooroobark, Victoria

# Issues of Concern ...



## Does mammographic screening make a difference?

*Late last year there were many reports in newspapers and on TV questioning the effectiveness of mammographic screening for breast cancer.*

*Australia spends about \$60 million each year to provide free mammograms to women across the country, so it is important that we are confident that this money is making a positive difference.*

*In March, a group of experts gathered together by the World Health Organization (WHO) met in France to review the evidence at hand from around the world. Following is the media report they issued at the end of their deliberations on mammographic screening.*

One million women develop breast

cancer each year world-wide. Early detection and treatment are considered the most promising approach to reduce breast cancer mortality.

The first mammography screening trial was initiated in 1963. Since then, studies have been carried out in different countries. Most have reported reductions in breast cancer mortality and several countries have established breast cancer screening programs.

The consensus on the value of mammography screening has been challenged by Danish investigators associated with the Cochrane Collaboration, who argue that many of the studies were scientifically flawed

and concluded that there was no overall benefit from mammography.

The available evidence on breast cancer screening was evaluated in Lyon by a working group convened by the International Agency for Research on Cancer (IARC) of the WHO from March 5 to 12, 2002.

The group, consisting of 24 experts from 11 countries, concluded that trials have provided sufficient evidence for the efficacy of mammography screening of women between 50 and 69 years. The reduction in mortality from breast cancer among women who chose to participate in screening programs was estimated to be about 35%. For women aged 40-49 years, there is only limited evidence for a reduction in mortality.

The quality of the trials that were used to make these evaluations was carefully assessed. The working group found that many of the earlier criticisms were unsubstantiated, and the remaining deficiencies were judged not to invalidate the trials' findings.

The effectiveness of national screening programs varies due to differences in coverage of the female population, quality of mammography, treatment and other factors. Organised screening programs are more effective in reducing the rate of death from breast cancer than sporadic screening of selected groups of women.

## The *My Journey Kit* takes shape

Timely access to good information and support is crucial when faced with a breast cancer diagnosis.

Those of us who have been around the 'breast cancer world' for some time are aware of the vast amount of good information and support that is available to Australian women and their families, and sometimes we even know how to access it. However, that is often not the case for women who are newly diagnosed.

The Network is committed to developing a *My Journey Kit* that will

signpost sources of information and support for newly diagnosed women and their families across Australia, and aim to get it to them as quickly as possible after diagnosis.

The sources of information and support listed in the *My Journey Kit* will be largely drawn from the knowledge and experiences of our members – women who have used these services and understand what women are looking for.

The kit will aim to help women and their families access information about breast cancer and its treatment, as well

as resources for emotional, practical and financial support.

The *My Journey Kit* will also contain a section for storing tests results and keeping a personal diary.

One of the main challenges facing this project will be ensuring that women newly diagnosed with breast cancer receive the kit as soon as possible.

Project Manager, **Mary Harvey**, and an enthusiastic steering committee are working hard to make the *My Journey Kit* available nationally by the end of 2002.

# New Resources

## Community Grants

We were delighted with the number and standard of applications received for the first round of the Network's Community Grants Program.

There were some great ideas for projects and, as this newsletter goes to print, we are finalising details with the successful applicants.

Details of the successful projects will be available on our website. We also plan to include an outline of each in the next issue of *The Beacon*.

The closing date for the next and final round of grant applications is **Monday, July 29**. For a copy of the guidelines, visit our web site – [www.bcna.org.au](http://www.bcna.org.au) – or phone the National Office on 1800 500 258.

## Ladies golf classic

Join us for five days of friendly golf from August 11 to 16 on some of Queensland's best courses – Twin Waters, Coolum and Noosa Springs.

Golfers of all handicaps are welcome, so escape the winter and help the Network raise some money, by joining new friends and old for a few rounds of golf in the sunshine.

For a detailed itinerary and prices, phone **Jacinta Moore** on 0412 857 240 or e-mail [moorecreativetours@bigpond.com](mailto:moorecreativetours@bigpond.com)

## Weight risk

Two studies have added to the evidence that extra weight raises a woman's risk of developing breast cancer.

Gaining more than 17kg during pregnancy increased the chances of getting breast cancer after menopause by 40%, according to a Finnish study.

A US study found that women with insulin resistance, a frequent precursor of diabetes linked to being overweight, had higher odds of developing breast cancer.

In both cases, researchers suspected that extra kilograms mean extra hormones – estrogen and insulin – which spurred cell growth and might have set the stage for the overgrowth that characterised cancer.

## Language-based services

Do you know someone who has cancer but can't get the information they need in their preferred language?

In the past few months, the Cancer Councils of Victoria and NSW have independently launched services to meet the information and support needs of people from non-English speaking backgrounds.

These services provide information for people with cancer, their family and friends, or people seeking information about any cancer issue.

**The Cancer Council NSW** operates the *Multicultural Cancer Information Service*. Bilingual information consultants, with tertiary qualifications in nursing, social work or welfare, adult education and clinical psychology, serve the needs and understand the cultural sensitivities of the Arabic, Chinese, Greek and Italian-speaking communities.

To contact an information consultant in these languages, freecall:

Arabic	1300 301 625
Chinese	1300 300 935
Greek	1300 301 449
Italian	1300 301 431

**The Cancer Council Victoria's** service is called the *Multilingual Cancer Information Service* and operates a little differently to the NSW service.

Telephone support and cancer information is available in more than 80 languages. Callers can dial a specific number for recorded cancer information in their language. By selecting from their touch-dial phone, they can also talk to a nurse counsellor with an interpreter on line.

While this service is Victorian based, Tasmanian callers can access this service by calling **The Cancer Council Tasmania** on (03) 6233 2030, who will transfer the call to Victoria.

Victorians who wish to contact this service can call:

Arabic	(03) 9209 0160
Cantonese	(03) 9209 0161
Greek	(03) 9209 0162
Italian	(03) 9209 0164
Mandarin	(03) 9209 0164
Polish	(03) 9209 0165
Russian	(03) 9209 0166
Spanish	(03) 9209 0167
Vietnamese	(03) 9209 0168
All other languages	(03) 9209 0169

In all other states, information and support for people from non-English speaking backgrounds is provided through the Cancer Information Service of each state cancer council (phone 13 11 20). The Cancer Helpline staff will arrange a conference call with a trained interpreter through one of the many interpreter services.

## Young women and breast cancer forum

The Illawarra Young Women's Support Group is hosting a forum about the issues relevant to younger women who have had breast cancer.

While designed with the young in mind, this free forum is open to anyone who wishes to attend, regardless of age.

The forum will be held on July 27, at the Port Kembla Leagues Club, from 9:45am to 3:30pm.

A number of inspirational and informative speakers will cover topics such as: breast reconstruction; sexuality; treatment options and recovery; and coping with stress.

Accredited childcare facilities will be available.

Contact: Sr Gloria Swift, BCN and Oncology Nurse Consultant, phone (02) 4295 8219 or e-mail [SwiftG@iahs.nsw.gov.au](mailto:SwiftG@iahs.nsw.gov.au)

# Who packed your parachute?

**Charles Plumb** was a US Navy jet pilot in Vietnam. After 75 combat missions, his plane was destroyed by a surface-to-air missile.

He ejected and parachuted into enemy hands, which led to six years in a communist Vietnamese prison. He survived the ordeal and now lectures on the lessons he learned from that experience.

One day, Plumb and his wife were sitting in a restaurant when a man came up and said, "You're Plumb! You flew jet fighters in Vietnam from the aircraft carrier Kitty Hawk. You were shot down!"

"How in the world did you know that?" asked Plumb.

"I packed your parachute."

Plumb gasped in surprise and gratitude.

The man pumped his hand and said, "I guess it worked!"

"It sure did. If your chute hadn't worked, I wouldn't be here today."

Plumb couldn't sleep that night, thinking about the man.

"I kept wondering what he might have looked like in a Navy uniform: a white hat, a bib in the back, and bell-bottom trousers," he said.

"I wonder how many times I might have seen him and not even said 'Good morning, how are you?' because, you see, I was a fighter pilot and he was just a sailor"

Plumb thought of the many hours the sailor had spent at a long wooden table in the bowels of the ship, carefully weaving the shrouds and folding the

## Genetics interest group

Are you interested in joining a genetics special interest group?

I am keen to establish an e-mail reference group to alert Network members of breast cancer genetics research and issues.

If you are interested, e-mail me at [gerda@bigpond.net.au](mailto:gerda@bigpond.net.au)

– Gerda Evans, Victoria

silks of each chute; each time holding in his hands the fate of someone he didn't know.

He now asks his audience, "Who's packing your parachute?"

Everyone has someone who provides what they need to make it through the day.

Plumb also points out that many kinds of parachutes were needed when his plane was shot down over enemy territory – physical, mental, emotional and spiritual. He called on all these supports before reaching safety.

Sometimes we miss what is really important in the daily challenges that life gives us. We may fail to say hello, please, thank you or congratulations; to pay a compliment; or do something nice for no particular reason.

As you go through this week, month and year, you might want to recognise the people who pack your parachutes.

*This short story was sent to us by Network member, Sharyn Boyd-May, from Mildura, Victoria.*

## Letter to the Editor

I am not wishing to blow my own trumpet, but I reckon good news stories are the best boost. I am really proud to have won the Moira Shire Citizen of the Year Award on Australia Day.

If someone had told me 5½ years ago, when I was diagnosed with breast cancer, that I'd be standing up to receive this award, I would have been mighty happy!

– Bronwyn Taylor  
Yarrawonga, Victoria



## Sally to leave NBCC

**Sally Redman** is leaving her role as director of the National Breast Cancer Centre (NBCC), to take up a position involving research into public health for the NSW Government.

Sally has worked hard since the NBCC was established seven years ago to ensure the best outcomes for Australians affected by breast cancer. She has championed the psychosocial needs of women and their families, something apparent in the approach taken to the Centre's Clinical Practice Guidelines for doctors and women.

The Network would like to thank Sally for her dedication and support, and to wish her well in the future.

## THE BEACON

*The Beacon* is the newsletter of Breast Cancer Network Australia.  
Editor: Lyn Swinburne (03) 9805 2500  
Layout: Substitution  
Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria 3122.

### YOU'RE NOT YET ON OUR MAILING LIST?

Phone (03) 9805 2500 or 1800 500 258, or fax (03) 9805 2599,

e-mail [beacon@bcna.org.au](mailto:beacon@bcna.org.au) or fill in this coupon and send it to:

Breast Cancer Network Australia, PO Box 4082, Auburn South, Vic 3122

Name: .....

Address: .....

..... State: ..... Postcode: .....

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

Have you had a diagnosis of breast cancer?  Yes  No

## UPCOMING EVENTS

**June 20:** Arm issues after breast cancer, information session at the Peter MacCallum Cancer Institute, Melbourne, 11am – 1pm.

Contact: Tina Griffiths, (03) 9656 1111, Ext 1925.

**June 14-15:** NSW Breast Care Nurses Annual Conference.

Contact: Minh Arvin, e-mail [minh@canc.rpa.cs.nsw.gov.au](mailto:minh@canc.rpa.cs.nsw.gov.au) or fax (02) 9767 793.

**June 15:** BCAG (Vic) meeting, featuring a talk about osteoporosis by Bernadette Matthews, Storey Hall, RMIT University, Melbourne, 2.30-5pm.

Contact: Sue Lockwood, (03) 9878 0736.

**June 15:** Living Well – A forum for women with advanced breast cancer, Bendigo, Victoria.

Contact: The Cancer Council Victoria, 13 11 20.

**June 19:** Queensland Cancer Fund's Young Women's Network (Breast Cancer) meeting, including a talk about complementary therapies, Brisbane, 9.30-11am.

Contact: [www.qldcancer.com.au/ywn](http://www.qldcancer.com.au/ywn)

**June 22-28:** Warrior Women Exhibition, Dudley House, View Street, Bendigo.

Contact: Sue Smith (03) 8430 8419

**June 23:** BCAG (NSW) meeting, YWCA, Sydney, 2.30pm.

Contact: Sally Crossing, (02) 9437 1755.

**July 1:** Symptom control, palliative and supportive care, an information session at Peter MacCallum Cancer Institute, 5.30-7.30pm (program repeated July 18, 11am-1pm).

Contact: Co-ordinator, (03) 9656 1111.

**July 6 – August 11:** Warrior Women Exhibition, Mildura Arts Centre, 199 Cureton Avenue, Mildura.

Contact Sue Smith (03) 8430 8419

**July 10:** Male partners of women diagnosed with breast cancer – education and support program, Peter MacCallum Cancer Institute, Melbourne, 6-8pm (program repeated on September 11 and November 13).

Contact: Co-ordinator, (03) 9656 1111, page 1203.

**July 19:** Think Pink Ball, a fundraiser for Wesley Private Hospital's Breast Clinic, Carlton Crest, Brisbane.

Contact: (07) 3232 6179.

**July 27:** Illawarra Young Women's Forum, Port Kembla Leagues Club.

Contact: Gloria Swift, (02) 4295 8219.

**August 5:** Life and love after breast cancer, an information session at Peter MacCallum Cancer Institute, Melbourne, 5.30-7.30pm.

Contact: Tina Griffiths, (03) 9656 1111 Ext 1925.

**August 17:** BCAG (Victoria) meeting, featuring a talk *Am I responsible for causing my breast cancer?*, RMIT University, Melbourne, 2.30pm.

Contact: Sue Lockwood (03) 9878 0736.

**August 31:** BCAG (NSW) meeting, YWCA, Sydney, 2.30pm.

Contact: Sally Crossing, (02) 9437 1755.

**October 27:** Breast Cancer Forum, the Intercontinental Hotel, Sydney, 9am-1pm.

Contact: Louise Kippist, [lkippist@nslcc.bsns.org.au](mailto:lkippist@nslcc.bsns.org.au) or (02) 9926 6584

**October 27:** Major *Field of Women*, the Domain, Sydney (preceded by Silent Walk).

Contact: Dianne Logan, (02) 8585 1808. Watch for further details in the next issue of *The Beacon* or visit our website [www.bcna.org.au](http://www.bcna.org.au)

**October 27-28:** Mini-*Fields of Women* across Australia.

Contact: Wendy or Ro, 1800 500 258.

**October 28:** Australia's Breast Cancer Day.

**October 28:** Sydney's Annual Pink Ribbon Breakfast, Westin Hotel.

Contact: National Breast Cancer Centre, (02) 9036 3030.

**November 11:** Conference of the Queensland Cancer Fund's Oncology Nurses Group, Marriott Resort, Gold Coast.

Contact: (07) 3258 2263.

**December 5:** Breast Cancer Association of Queensland's Big Christmas Charity Lunch, Hilton Hotel, Brisbane.

Contact: (07) 3839 6630.

## Stick with it!

This issue of *The Beacon* includes one of our new bumper stickers, which we are giving to you with our compliments.

This is the latest way to spread the word about the Network, so we would like you to display the sticker in a prominent spot.

We are also keen to further develop the mailing list for *The Beacon*. The best way to do this is for each of YOU to tell others who might be interested – your surgeons and GPs might also pass on the word to their patients.

## New on the website

- **Allison Piper** is undergoing chemotherapy and radiotherapy in Melbourne. She has written a letter to her friends to help them understand the treatment she is having, why she is having it and to thank them for their support.
- **Jennifer Tolley** from South Australia has written an excellent article about minimising the risk of getting lymphoedema after breast cancer treatment. Called *Why Didn't Someone Tell Me?*, it highlights the need for women to know about the condition *before* it happens and offers suggestions for those who want to be proactive in minimising their risks.
- **Jane Murphy** talks about the ups and downs of the two years since her diagnosis at the age of 40 and of now moving forward. In that intervening time, Jayne's younger sister was also diagnosed with breast cancer and her brother with lymphoma. The family has since decided to participate in genetic testing.
- Read about **Bettina Woodburn's** *Get up and go!* award – it is sure to inspire.
- Reports from the Network's National Summit.
- Laughter is always the best medicine – **Audrey Guy** from the ACT shares some funny moments.

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