



The Beacon

Breast Cancer
Network Australia
newsletter



Breast cancer survivor, Megan James, and her organising committee are planning a huge event in Sydney for the 2002 Field of Women (See page 5).

Breast
Cancer
Network
Australia



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Women experiencing problems with prostheses

Easy access to an external breast prosthesis continues to be a major issue for women after mastectomy.

Those with private health insurance get no help unless they have 'Extras' coverage, and women in the public system miss out for a variety of reasons.

There are lengthy delays in funding, with women often waiting more than six months to get a prosthesis. What you get depends on where you live and varies from state to state, region to region and hospital to hospital.

For most women, this is an essential part of their recovery.

A well-fitted prosthesis can:

- assist with a woman's psychological recovery;
- allow her to re-enter her social and working life with confidence; and
- assist with realignment of a woman's body and carriage.

One of the key difficulties is that women find themselves at the end of the priority queue. The funding for breast prostheses is lumped in with other aids, including false limbs and wheelchairs, and is generally seen as a

low-priority issue by the people administering the fund.

The present system is clumsy and inequitable; it simply is not working.

But this is no new situation.

A key recommendation of the 1994 House of Representatives' Standing Committee on Community Affairs was that "as a matter of urgency the Medicare rebate schedule should be amended to include the provision of mammary prostheses".

Eight years down the track and nothing has changed!

Women have waited long enough for a better system. The Commonwealth Government tells us that this is the responsibility of the states, while the states say they are not given enough funding to cover the cost.

The Network is supporting a study to give us the full information and background we need to advocate for a better system (see page 6).

We intend to work hard to improve the current situation. We may need your help to get our message across. We'll keep you posted!

– Lyn Swinburne

Survival rates bring better news

The Federal Health Minister, Senator Kay Patterson launched Australia's Health 2002 in Canberra during June.

It reported that the five-year survival rates for breast cancer have risen from 72% to 84% in the past 10 years.

The Network is delighted to see such a significant improvement in the survival figures. We must point out, however, that incidence rates are still

steadily increasing and we must continue to work hard to ensure that the needs of Australians who are diagnosed are addressed.

Some people want to sit back and tick breast cancer off as having been 'done'. The survival trend is a positive sign, but further energy must be devoted to maintaining this trend.

– Lyn Swinburne

State Reports



SOUTH AUSTRALIA

Port Lincoln women are planning a *Mini-Field of Women* at the local Baptist Church on October 28 from 2pm. A wine tasting and an auction are planned for later that week. Then, on November 1, the play *Titbits* will be being performed. **Maxine Barker** and the other women of Port Lincoln are looking to make this a big week.

Mt Gambier's Breast Cancer Day luncheon will be held on October 28. This luncheon was first held in 2000 by two friends, **Kaye Holloway** and **Leanne Kosch**. Sadly, Leanne lost her battle with cancer in May 2001, but Kaye still runs the luncheon, which continues to raise large amounts of money.

Every three weeks there is a coffee morning for women in Mt Gambier who have been diagnosed with breast cancer. It has proved a great success and support for all those involved.

Vanessa Lambert raised the Network's profile during the SA Living Arts Festival between August 2 and 11. One exhibit, *The Bird of Freedom*, was filled with pink balloons, which people bought for \$2; the money raised came to the Network.

Contact: **Sally Russell** (08) 8223 7106 or salrus@senet.com.au or **Deb Martin** (08) 8241 1804 or d.martin@senet.com.au



TASMANIA

Tasmanian BCNA members wish to thank our inaugural state representative **Pat Mathew** for a job well done. Pat and Peter left on their long-awaited holiday early in August. We welcome **Karen Forster** as our new Tasmanian co-representative.

Sadly, we have also farewelled **Beth Batchelor**, who moved back to Melbourne at the end of July.

Network member **Gerry Rockliff** was selected by the Cancer Council Tasmania to participate in a communication skills *Train the Trainer* workshop in Melbourne during July.

Three Network members are participating in the Strengthening Support For Women With Breast Cancer project, as members of the project

reference group in Tasmania.

We are the only state without a Dragons Abreast Team, but get ready to don the pink Lycra in Hobart! New members from the south are pursuing the possibility of launching Tassie's first dragon boat team.

Several Network members will be attending a national convention presented by the Tasmanian Lymphoedema and Laser Centre on August 23-25 at St Mary's.

Contact: **Joan Williams** (03) 6424 5886 or jwilliams9@vtown.com.au or **Karen Forster** (03) 6273 4422 or dforster@vtown.com.au



THE ACT

It might have been mid-winter in Canberra, but that did not stop a hardy band of Networkers gathering at the lake's edge to scrape the ice off the dragon boat and get paddling.

The prostheses issue has featured in the *Canberra Times* on a number of occasions due to the work of the *Caring for You* girls.

The Lymphoedema Clinic at Calvary Hospital is up and running. An official opening will be held later in the year.

The Network was represented at a health professional's seminar to discuss the NBCC's Clinical Practice Guidelines for Advanced Breast Cancer and at the NBCF's series of interviews for research priorities.

Leona Furstenberg is forging ahead with plans for this year's *Mini-Field of Women*.

Bosom Buddies is organising its fundraising dinner and auction on Australia's Breast Cancer Day.

Elsbeth Humphries would be interested to receive ideas for the consumer workshop to be held at the

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

The complete reports can be found on our web site, 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!

Australasian Society for Breast Disease Conference in 2003.

Several ACT members are looking forward to participating in the Network's next Advocacy & Science Training Course in November.

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



QUEENSLAND

The Australian and New Zealand Breast Cancer Trials Group held its three-day annual scientific meeting at Sanctuary Cove on July 10-13.

Veronica Macaulay-Cross attended as a consumer representative of the Network and it gave her great hope for future care and treatment.

The Brisbane Theatre Night fundraiser for the Network at **Gail Wiltshire's** Twelfth Night Theatre on July 15 attracted 106 people. Not bad for a first attempt! Everyone enjoyed the West End comedy, *It Runs in the Family*.

Many thanks to Gail and her staff for their on-going support. Also, a big thanks to **Edith Cooper** for bringing a large group of friends, along with everyone else who supported the night.

Judy Irvine tells us that **Pauline Dwyer**, a reiki master, and **Fay Henderson** from the Gold Coast Dragons Abreast, spoke at recent meetings of the Caloundra Breast Cancer Support Group, which is also looking at forming a dragon boat team on the Sunshine Coast.

Astrid Raines is preparing for *Mini-Fields of Women* in Laidley, Boonah and Esk.

Kerry and Brian Zibell of Laidley Shire, are soon to take off around Australia in their bus, *Dragons Express*, which should include a visit to the Network office in Melbourne.

As part of the *Strengthening Support for Women with Breast Cancer Project*, seven new breast care nurses have been appointed to public hospitals across Queensland.

Edith Cooper, **Leonie Young** and **Veronica Macaulay-Cross** spoke to the nurses about issues from women's

perspectives, as part of their orientation and induction week.

Jenny Morrison and Veronica Macaulay-Cross were guests at the National Breast Cancer Foundation's (NBCF) dinner in Brisbane on July 25. On July 26, Veronica gave a presentation about consumer issues and priorities for breast cancer research to the NBCF Consultation Team.

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



WESTERN AUSTRALIA

State group, *Action on Breast Cancer* (AOBC WA) has been forging ahead in recent months, with some significant projects under way.

The group has received a **BCNA Community Grant** for a Prosthesis Investigation Report. The project came from initial reports concerning the availability and accessibility of breast prostheses in the public and private hospital systems. AOBC WA has employed a part-time researcher to investigate and report on this issue.

Two registered nurses have been selected for funding by AOBC to train as breast care nurses. The successful applicants will undertake the Breast Cancer Distance Learning Program at La Trobe University in Melbourne later this year. It is hoped that once the training is completed, two breast care nurse positions will be made available in the relevant Western Australian hospitals.

Radiotherapy delays have also been an issue in the west, with one of WA's major public hospitals stating that the current waiting time is 12-14 weeks (longer if the patient requires chemotherapy).

This year's *Field of Women* in Perth is sure to be an inspiring event, with plans now well underway. There will be the annual service for all dealing with breast cancer at St George's Cathedral, Perth, on October 27 from midday, with FOW silhouettes being displayed prominently on the grassed hill in front of the cathedral.

The silhouettes will be planted across the road at the beautiful Stirling Gardens on October 28. There will be a light breakfast at 7.30, with the opening at 9.30am.

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NORTHERN TERRITORY

The launch in Darwin of the Advanced Breast Cancer Guidelines on June 14 was well received. Those present were highly impressed by one of our local women, **Jan**, who spoke eloquently from a personal perspective.

The National Breast Cancer Centre (NBCC) public forum on June 15 drew more people than expected. We were delighted that **Sally Redman** was able to visit Darwin one last time before leaving the NBCC.

We are now busy organising events for October. These include the annual luncheon at Government House, the *Mini-Field of Women* to be held in the Great Hall and on the Speakers' Green at Parliament House on October 18 and the Australia's Breast Cancer Day Breakfast on October 28 at the Carlton Hotel Ballroom. We will also be hosting morning teas in conjunction with Bakers Delight. If you would like more information about any of the above please contact us.

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



NEW SOUTH WALES

The Illawarra group celebrated its 11th birthday in June, with more than 100 members attending to hear **Father David Catterall**, the Catholic priest diagnosed with breast cancer shortly before his ordination at the age of 27 years.

July saw the launch of *Beginning the Journey*, an account of group members' personal experiences with breast cancer.

The 'Don't Tell Gloria Committee' put the book together as a tribute to oncology nurse consultant, **Gloria Swift**, on the occasion of her 60th birthday.

Pam Bell launched the book at the *Young Women and Breast Cancer Forum* organised by the Young Ones sub-committee. It was chaired by **Martine Boughton-Biggs** from Newcastle.

Jan Newman says Griffith's small but hardworking group of six are planning a *Celebration of Life Dinner* for October 25 and a *Mini-Field of Women*. They are also organising donations for a Christmas raffle; last year's effort raised more than \$7500 for the Breast Cancer Institute.

Sally Crossing reports that BCAG

(NSW) launched of *The Directory of Breast Cancer Treatment and Services for NSW Women* in August. It is a comprehensive and much-needed publication that will be distributed to GPs state-wide.

Members of BCAG's Research Committee compiled a presentation to the National Breast Cancer Foundation about views on the direction of breast cancer research. The committee received excellent feedback about the scope of its paper.

BCAG continues to attract interesting guest speakers to its quarterly meetings in Sydney. Psychologist **Jacqueline Lim** recently spoke on the topic of 'Survivorship'. Medical oncologist **Professor Martin Tattersall** will be September's speaker.

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



VICTORIA

Congratulations to the Breast Cancer Action Group and Women's Health Victoria for successfully tendering for the three-year pilot project establishing a drop-in resource centre for Victorians with breast cancer.

We look forward to further news about its establishment.

In August, the Otis Foundation celebrated the official opening of two respite units near Bendigo, with a black-tie dinner and family day on **Andrew Barling's** beautiful property. The units will be available to women needing time out.

Congratulations to The Wild Orchids group of Moama/Echuca, which is being seen as a 'model' group to highlight rural issues.

There is also great enthusiasm from Warrnambool, with local support and publicity helping the local group's profile.

In October, The Young Ones will hold an afternoon tea and mini-auction to raise community awareness of the needs of younger women diagnosed with breast cancer.

Members will speak of their experience with breast cancer and promote the *Field of Women*.

To donate items to the auction or obtain more information, phone **Tanya Wilson** on (03) 9330 2785 or e-mail tanya_wilson@optusnet.com.au

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



Dr Fran Boyle accepted this year's Australian Medical Association award for contributions to women's health services from AMA President, Dr Kerry Phelps.

Women's health award

Each year an award is presented at the Australian Medical Association's (AMA) national conference to an Australian who has contributed to improving health care services in any field of women's health.

This year's award went to **Dr Fran Boyle** from Sydney for her work with the National Breast Cancer Centre.

The award was also an opportunity to recognise the work of the Medical Oncology Group, which has been advocating for women with breast cancer to have access to Herceptin. This advocacy work has been in partnership with the Network.

BCNA Community Grants

Round 1 of the Network's Community Grants program will fund these projects.

My Story: Indigenous Women's Breast Cancer Video Project

– Valerie Alberts, Indigenous Women's Cancer Group, North Queensland

A 'storyboard' will be developed about the experiences of 20 Indigenous women in northern Queensland who have been diagnosed with breast cancer.

This will become the basis of a video about breast cancer for Indigenous women in northern Queensland, north-west Queensland and the Torres Strait. It will detail treatment sites and the experiences of Indigenous women.

Network funding will also be used to develop the video's production plan. Funding from another source will cover the costs of the video's actual production and distribution.

Young Women's Network

– Mary Macheras-Magias, Victoria

Funding will be used to establish a:

- national networking group linking young women with breast cancer, including an e-mail newsletter;
- steering committee drawn from the

networking group to develop strategies to address concerns and issues for young women; and

- web page for young women linked to the Network's site.

Provision of Protheses Project

– Carol Bishop,

Action on Breast Cancer WA

Funding will be used to investigate and report on the provision of external breast prostheses for women from each state and territory. It will consider issues of cost, accessibility and availability.

The report will include recommendations for an improved funding system.

Promotional posters

– NT Breast Cancer Voice

Posters promoting the work of NT Breast Cancer Voice and BCNA will be developed and disseminated to people across the Northern Territory.

Beginning the Journey

– Illawarra Breast Cancer Support Group, NSW

A booklet recounting the stories of women and men who are members of the Illawarra Breast Cancer Support Group has been produced.

Herceptin program progresses well

Thanks to the efforts of people around Australia, and a commitment from the Federal Government, the drug Herceptin is available to women with advanced breast cancer.

A process, managed by the Health Insurance Commission (HIC), enables women to have free access to Herceptin via their oncologists.

In June, I attended a meeting in Canberra on the program's progress.

Since December 2001, 351 patients have been registered on Herceptin in Australia (excluding those on trials), including one man, five women under 30 years and two over 85 years.

The program is running relatively

smoothly, and I was impressed by the dedication and sensitivity of the HIC personnel.

One woman benefiting from the program is **Linda Wordie** from Echuca/Moama in Victoria. She writes:

"Cancer in the bones of my spine was causing me great pain. Because of this, I was struggling to cope with looking after the kids and managing the housework – and I soon learnt that kicking a footy with my two



Linda Wordie

teenage sons was not an option.

"This breast cancer was not just affecting me, but my kids as well – and as a single mum this was hard.

"I have been using Herceptin for seven months, and with the addition of pain killers I'm able to do some of the activities around the house that I previously couldn't do.

"I can continue to support my two growing teenagers and feel I'm able to focus on *their* needs and desires, as well as my own."

We are delighted that our efforts have made a difference to Linda and many other women.

– Lyn Swinburne

Join the pink pilgrimage!

The *Field of Women* will appear in **Sydney's Domain** on October 27 and 28.

For the first time, the city of Sydney will witness our tribute to all those Australians affected by breast cancer.

Please spread the word so that this *Field of Women* will dominate in Australia's largest city. Tell your family and friends and, if it is possible, we need *you* there!

Network members from all over have indicated that they will make the pilgrimage. Join our throng!

As well as spreading the word, we're looking for volunteers to help. We especially need Sydneysiders to hand out fliers at stations and shopping centres in the week before our event.

The *Field of Women* is the Network's powerful display of breast cancer's impact. The 10,000 pink silhouettes represent the number of Australian women who are diagnosed each year with breast cancer and another 2500 white silhouettes pay tribute to the women who lose their lives.

We also now have 100 blue silhouettes representing the number of

men diagnosed each year.

On Sunday, October 27, a *Silent Walk* from the **Customs House, Circular Quay, at 2.30pm**, will lead the public to the *Field of Women* in the heart of the Domain for the **launch ceremony at 3.15pm**.

The *Silent Walk* will be led by breast cancer survivor, **Raelene Boyle**, and women representing business, politics, media, arts and sport.

Thousands of Sydney-siders, **wearing pink**, are expected to join the walk, to show their support for the cause.

The Chairman of the Organising Committee is **Megan James**, herself a breast cancer survivor.

"It is a great opportunity to come together and recognise all of the women and their families affected by breast cancer," Megan says.

The *Field of Women* is possible thanks to the work of the Organising Committee and the generous support of our national sponsors – **Bakers Delight, New Idea, Australia Post, Puma**, as well as the **Royal Botanic Gardens & Domain Trust**.

– Wendy McClusky



Breast cancer forum

Coinciding with the *Field of Women* will be the Breast Cancer Forum at Sydney's **Hotel Intercontinental from 9am on October 27**.

The keynote speakers will be **Dr Fran Boyle, Stephanie Dowrick** and **Petrea King**.

Three special interest workshops will also be held:

- Metastatic Breast Cancer;
- Taking Back Control; and
- Young Women.

The cost is \$25, which includes morning tea and lunch.

For more information or to register, phone **Mandy O'Reilly** (02) 9926 7246 or **Louise Kippist** (02) 9926 6584.

Mini-Fields for 2002

Mini-Fields of Women, each made up of 100 silhouettes, will also be 'planted' in communities around Australia on October 27 and 28.

The *Mini-Fields* give local communities the opportunity to promote the Network, as well as raise awareness and money for breast cancer.

For more information about *Mini-Fields*, phone Ro or Wendy on 1800 500 258 or visit our website at www.bcna.org.au

So far, the following venues will be hosting *Mini-Fields*:

Canberra: ACT.

NSW: Wagga, Armidale, Griffith, Port Macquarie, Gloucester, Forbes, Tweed-Brunswick.

Northern Territory: Darwin.

Queensland: Redlands, Bundaberg, Toowoomba, Brisbane-Toowong, Laidley, Brisbane-Stafford, Gladstone, Mackay, Dysart.

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

Tasmania: Hobart-Glenorchy, Devonport.

Victoria: San Remo, Melbourne, Ararat, Bendigo, Waverley, Warrnambool, Traralgon, Hampton, Ringwood, Bayside, Ferntree Gully, Epping.

Western Australia: Perth.

Bakers Delight loaf promotion

Once again, the Network's wonderful corporate partners – Bakers Delight – will hold a promotion to coincide with the *Field of Women*.

This year every Bakers Delight bakery around Australia will donate 20¢ from every \$2.50 loaf during the week leading up to the major *Field of Women*. This promotion will run from October 21 to 28.

Each bakery will also be 'dressed' in pink; there will be balloons, pink silhouettes and pink flyers telling customers about the Network.

Bakers Delight has already produced



a great television commercial to be shown on Channel 9, so look out for it during that week.

Spread the word and let's try to get heaps of people into Bakers Delight stores during the promotion. Make sure you go in and introduce yourself as a Network member and let them know we appreciate their fantastic efforts.

Help Bakers Delight help us!

Issues of Concern ... Prostheses



Network to fund prostheses report

Through the Network's Community Grants Program, Action on Breast Cancer WA (AoBC) has obtained funding to research the process of accessing external breast prostheses, and financial assistance Australian women receive at time of surgery and in subsequent years.

AoBC has appointed **Céline Fournier** as the project officer. She recently finished a Master of Medical Science.

The *External Breast Prosthesis Project* began in July. It will investigate the



Céline Fournier

current provision, accessibility and cost of prostheses.

The research will include a survey of women's experiences.

A comprehensive report of the findings will be produced covering all states and territories.

– Carol Bishop

Caring for your needs with sensitivity

Two and a half years ago, **Shirley Fitzgerald** and **Roz Hill**, with the support of volunteers, started the breast cancer community awareness program *Caring For You*.

Shirley, an accredited fitter of bras and breast forms, had been fitting numerous brands of bras with breast prostheses for many years. Her work with breast cancer survivors has been recognised by the Australian Government with a Member of the Order of Australia (OAM).

Roz had a background in the operational side of engineering, designing and selling of bras.

It made sense to both women that, as survivors of breast cancer, they had a job to do – to ensure that women going through surgery knew the options available to them in bras after surgery, regardless of whether they were mastectomy bras or everyday pretty bras.

As the program has grown, so too has the number of volunteers, who range in age from 20 to 70 years. They are all breast cancer survivors and travel Australia with Shirley and Roz.

The *Caring For You* team can run workshops in any community with a need – metropolitan, rural, Outback.



Shirley Fitzgerald, Caring For You's co-founder

These workshops showcase the options available to women; the correct way to fit a bra and a prosthesis; the latest styles; and, when requested, fitting days.

This exercise has expanded into some hospitals, with the team conducting workshops for women nearing the end of their treatment. The *Caring For You* team then follow up a few weeks later and provide fittings in the hospital, in conjunction with the breast care nurse. This enables the women to buy at the retailer of their choice, already having

removed some of the trauma associated with the exercise.

A welcomed addition to the team in 2001 was a patron, **Associate Professor Linda Reaby** from the School of Nursing at Canberra University, herself a survivor of breast cancer.

Through Linda's involvement, the program now presents to trainee nurses, to help them relate to a survivor's needs following surgery and thereby be proactive in helping with the psychosocial issues involved.

Linda regularly says, "A prosthesis is only as good as the bra that it fits in, and a bra is only as good as the fitter that fits it".

When the team travels to an area where there is no bra and prostheses supplier, but there is a hospital and/or a community centre, they take between 1800 and 2000 bras of different sizes and styles. They also carry a large stock of sizes and styles of breast prostheses to fit any size or shape of woman.

The Berlei Group is *Caring For You's* major sponsor. It provides its service free-of-charge to the community, hospitals, health and medical centres.

For more information, phone *Caring For You* on 1800 771 577 or e-mail caringforyou@theberleigroup.com.au

Share the care pack

Are you a family carer? For help with information, referrals, support and resources, phone the Carer Resource Centre on 1800 242 636 for a free carer information pack.

In good form for a recovery

There they nestled. Like pale pink jellies freshly tipped out of their moulds. Prostheses.

Left breast prostheses. Scattered across my doona. On my bed.

There were at least 10 of varying shapes and sizes. I stood leaning against the wardrobe door, hands thrust in my pockets, hoping to give an air of studied nonchalance, while surveying the spectacle before me with interest and curiosity.

So, that's what a breast form looks like, I mused.

Naturally enough, I had wondered how I'd feel at this moment and was slightly embarrassed to acknowledge that in my 52 years, with 20-plus years spent working in a medical practice, I had never seen a prosthesis before.

Nor had I seen a woman's body after breast surgery. Not until now. I became conscious that I was rubbing my bare side, the one without a breast.

Today was to be memorable. I was going to choose a breast for myself from among those blobs of silicone.



*Judy Irvine,
Sunshine Coast,
Queensland*

The lady from the lingerie shop, who made house calls, suggested it was time to measure me for my new bra; then we could select the correct prosthesis for my shape and type of surgery.

I raised my arms and removed the loose T-shirt I had been wearing, exposing my soft pale breast and my newly acquired mastectomy scar. I was measured from every angle – or so it seemed – and was soon wearing a pretty bra with cups covered in lacy fabric.

The first prosthesis, a flesh-coloured oval, was heavier than it looked. Cool to touch and soft. When I ran my hands across the front, the gel rippled

and moved, like a natural breast.

Hang on! Was that a nipple mound in the centre? My finger circled it. Not bad as far as appearances go.

I tucked it into my bra and was delighted with my reflection when I faced the mirror – natural looking and comfortable on the new scar tissue.

As well as the various sizes, I learnt that the prosthesis came in shapes suitable for the left or right side, and partial to compensate for missing tissue after breast cancer surgery. One was adhesive, all were washable, adapted to body heat and came in two colours – tawny and flesh.

I do not wear my breast form to pretend I am the same woman I was before my surgery. I am not. Nor do I wear it so as to make believe nothing has happened to me. It did. I have battled breast cancer. However, the prosthesis does balance my body, helps prevent backache and my clothes hang properly when I'm wearing it.

I also exercise the choice to wear it or not, remembering that I have a right to claim and define my own body, and I am no less a woman without a breast.

– Judy Irvine, Queensland

Getting back into the 'swim' of things

I was diagnosed with breast cancer more than 3½ years ago, at the age of 38 years.

Within a couple of weeks, surgery revealed that the cancer was 'multi-focal' and four days later the surgeon removed my left breast.

I went through the procedure in a state of denial and did not consider the option of reconstruction.

During my hospital stay, a breast care nurse/counsellor visited me and gave me a material envelope and some wadding to wear in my bra when I left hospital.

I felt worse after her visit than I had beforehand, but she did give me useful information on where I could buy a prosthesis when the wound had healed. She said I could claim some of the cost from my medical insurer (once every three years).

I had a fitting at Myer in the city, where the staff were helpful.

After trying on all the mastectomy bras available and disliking the look of them, I settled for a silicone prosthesis in a 'matronly' bra that gave me a look reasonably close to what I was used to seeing beforehand.

My main difficulty was finding bathers that the prosthesis would fit into and I could swim in.

As an Aussie Masters swimmer, I wanted to continue with my sport, but found the mastectomy swimwear expensive and quite impractical.

Most bathers that held the prosthesis were too low cut and did not have 'sporting' backs to stop the suit from slipping off my shoulders. They also had wide armholes that made the scarring in my armpit clearly visible.

When I did find a pair that looked

okay and were designed for swimming (*and* a reasonable price), they wore out quickly and the prosthesis weight made them sag when wet.

In my experience, many swimwear sales staff (especially younger women) have no idea what mastectomy swimwear is and most shops don't stock them.

These days, I'm too busy enjoying life to think about putting myself (and my family) through the inconvenience of reconstructive surgery. The only time I think about my prosthesis is if it falls out when I'm bending over – usually when I'm doing the gardening!

I've become reconciled to my 'middle aged' look and wear a mastectomy bra when I'm working physically with other people.

– Janette Dickenson, Victoria

Letter to the Editor

After reading *The Beacon* for the first time, I wondered if I had missed something?

A friend had breast cancer 15 years ago, another 10 years ago and I had it last year. None of us call ourselves as breast cancer 'survivors'. As far as we are concerned, we had it, it's gone and if it comes back we'll cope.

I wonder whether the pioneer women referred to 'surviving' childbirth or did they just look on it as having kids, even though it had a high 'non-survival' rate for mothers and children?

With modern advances in breast cancer treatment, should we change our terminology?

– Audrey Guy

We have learnt that it is impossible to find a term that suits everyone. Many women are proud to call themselves survivors – Editor

Thank you

- Readers of *The Beacon* for donations so far totalling \$22,500 since the Winter 2002 issue.
- Staff from **Norwich Union, Portfolio Partners** and **Navigator** for participating in workplace giving, which means the Network receives funds from them each fortnight.
- **Australia Post** for double passes to 19 performances nationally of *Taming of the Shrew* by the Bell Shakespeare Theatre Company.
- **Senator Trish Crossin (NT)** and **Annette Ellis (ACT)** for raising the prostheses issue in Parliament.
- The Network members who completed questionnaires for the projects *Helping a Friend with Breast Cancer* and *Messages of Hope and Inspiration*.

Congratulations

- **Dianne Shore** from Mackay was selected by the Queensland Cancer Fund to attend August's Reach to Recovery Conference in Malaysia.
- **Vivien Cooper** from Whyalla, SA, is one of the 14 Australian rural remote nurses to gain a study scholarship from the NBCC.
- Breast Cancer Action Group (NSW), whose *Directory of Breast Cancer Services for NSW Women* was launched in August by the NSW Governor, **Prof. Marie Bashir**.

Adjusting to prostheses

In December 1999, I had bilateral mastectomies; the left one for a large tumour and the right one as a prophylactic measure.

I had naively thought I could have two breasts off and wake up with two reconstructed ones, but I was advised to have my adjuvant therapy first.

After finding out that 15 lymph nodes were involved, I thought I would soon be dead and it wouldn't be worth going through the extra surgery.

I received my *Program of Aids for Disabled People (PADP)* funding for my prosthesis within a few weeks, which apparently is pretty good.

I didn't wear the lightweight prostheses my breast care nurse gave me, as loose clothes did not make me look obviously flat-chested. However, the lack of breasts emphasised my pot belly and I was peeved when a woman in HBA asked if I was pregnant!

Six weeks after my surgery I went for a prosthesis fitting. I thought I was going to be okay, but got a bit weepy in the fitting room, and was glad my aunty was with me, as Mum was away.

My choice was Luxa Lites and several new bras with pockets in, which were ready for me to collect a week later. I was given \$600 through the PADP and only had to pay an extra \$60, plus the cost of the bras.

When I picked my daughter up from school that night, I proudly stood side on and asked if she could see anything different. She just grinned at me.

I have since purchased lightweight



Mary show us she is fit and well. She now paddles in the Victorian Dragons Abreast team.

prostheses to wear with bathers.

I found a book in my local library called *Living in the post-mastectomy body: learning to live in and love your body again* which had tips for adapting bathers and bras to fit prostheses.

Having heard of prostheses floating away in swimming pools, I bought a nice pair of bathers and sewed in pockets made of black lycra.

There are moments when I hate my prostheses, especially in the warmer weather, or when I want to go out somewhere special and it is hard to find something nice to wear.

I bought a ball gown recently for the first time in years and the woman in the shop was amused at my range of prostheses/wadding/bras.

In the US, specialist stores sell clothes for women who have had mastectomies. That's an idea with potential for someone locally.

I've seen a plastic surgeon again about reconstruction, but don't feel inclined to go through the expense and trauma of surgery. I am well and healthy, and don't want to compromise that in any way.

– Mary Bartlett, Victoria

An extended Encore

Avon is to continue sponsoring the YWCA's Encore program.

This means the program, which has been designed to help women who have experienced breast cancer to regain movement using gentle exercise, can continue.

Avon has a long-term commitment to Encore, allowing the YWCA to deliver the program to 20 locations around

Australia. There are also plans to expand into more regional areas.

More than a 1000 women each year use Encore to re-gain the mobility, strength and confidence they lost to breast cancer.

For information about the Encore program and locations, phone Claire Treadgold on 1800 305 150 or e-mail encore@ywca.org.au

Dragons Abreast Update

It's been chilly in the southern States, but that doesn't mean Dragons Abreast is hibernating!

The Victorian women are involved in a gym program to keep up their fitness levels.

In the ACT, they bravely scrape the ice off the boat and paddles every Saturday morning.

Everyone continues to paddle in NSW, with the Illawarra and Central Coast groups both looking forward to having boats permanently in their areas.

Tasmania, under the capable guidance of **Sheena Short**, continues to investigate options and hopes to see a team or two on the water in 2003.

Queensland members have become media stars, with interviews on ABC radio and in the local press.

The Northern Territory has been a hive of activity! We welcomed fellow paddler, **Valerie Kraus** from Philadelphia to Darwin while she was on a tour of Australia with her family.

The Inaugural Dragons Abreast Regatta on August 25 attracted 31 corporate teams. Photos and a full report are on the Network's web site – www.bcna.org.au – under the 'Projects' listing.

Alice Springs will host a Dragons



Abreast team in the Henley-on-Todd Regatta on September 21. This is very different race; it is literally run on a dry river bed.

Julie Woods is making the trek from the Central Coast of NSW for the race and Bosom Buddies Alice Springs is helping build a 'boat' for us!

Busting with Life from

Auckland will send nine members to the Masters Games on the Gold Coast in September. They will join with Dragons Abreast members to form a crew.

The Inaugural South Pacific Regatta, to be held in Auckland next March, will be a big event for us, with women from all States showing an eagerness to participate. Supporters are most welcome on the trip.

Tickets are on sale for our raffle at \$2 each. First prize is a fabulous pearl pendant donated by Paspaley Pearls valued at \$3925. Second prize is a queen size quilt – Rosebuds for Recovery – quilted and donated by the **King's School Quilters, Sydney**.

For further information on any of the above items, contact either your local co-ordinator or myself.

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



Dragons Abreast NT won the women's social races at the Sundragon Festival in Darwin during July (the 'dragon' on the end stepped in to replace his wife who was sick on the day).

New web sites

- Sharsheret is a new organisation in the US for young Jewish women with breast cancer. You can read more about it at www.sharsheret.org
- The redeveloped BreastCare Victoria website is now live at www.breastcare.health.vic.gov.au
- On July 1, the National Cancer Control Initiative (NCCI) launched the National Cancer Genetics Resource Directory on its web site – www.ncci.org.au



Leisha Rule wearing her Deacon's stole emblazoned with the Network's logo. She wears her stole most Sundays and plans to wear it when she preaches at the local Mini-Field in October.

Spreading the word

I was ordained a Deacon of the Anglican Church in the Diocese of Brisbane in November 2001.

I am the Network liaison person for the Wesley Hospital Breast Clinic in Brisbane and a volunteer with the Kim Walters Choices Program. I lead the evening groups for the *Stretch* support program at the Wesley Breast Clinic.

I also co-ordinate a cancer support group at Stafford in Brisbane. This support group is for those diagnosed with cancer, their families and supporters. It is the only one of its kind in the northern suburbs of Brisbane.

– *Leisha Rule, Queensland*

Introducing our members groups

Port Lincoln Caring Cancer Support Group

I live in Port Lincoln, South Australia, which is geographically isolated. In August 1996, when I was 48 years old, I was diagnosed with breast cancer.

For the next five months I had to live in Adelaide for my chemotherapy and radiotherapy treatment. During this time, I had to deal with a lot of decision-making issues that were challenging.

While being treated at the Royal Adelaide Hospital, I was cared for by a wonderful team – my bone marrow team, doctors, physiotherapist, social workers, a breast care nurse and nursing staff.

When I finished my treatment and returned home, I felt alone and isolated.

There was no support group in Port Lincoln and I was desperate to meet with other women and hear their stories. I also wanted to pass on my experiences and perhaps make another woman's journey less stressful.

With the help of a social worker, **Ronda Smith**, I set up a support group at my home in May 1997 and the group is still going strong six years later.

We are fortunate to have a social worker sit in on our meetings. This can prove invaluable when we need assistance with a difficult problem.

Introducing our member groups

The Network currently has 94 groups linked nationally.

These groups are diverse; many are support groups, many have advocacy as their main focus, some have hundreds of members and others have small numbers and meet informally.

Each group exists because it satisfies a need. We have decided to highlight one of our member groups in each issue of **The Beacon**.

The support group now meets for fellowship and coffee on the third Thursday of the month at the Port Lincoln Hospital. We enjoy a lot of laughter, but at the same time listen to



The Port Lincoln Caring Cancer Support Group is working to unite women in an isolated area.

the needs of our members, while also offering support and information. We have our sad times too, especially when we hear that one of our precious members has passed away.

Through the support group, we have become aware of issues that have caused a lot of unnecessary stress and anxiety. We have been advocating for many changes, such as improvements in the chemotherapy room and the possibility of having an oncology/breast care nurse in our hospital.

As we now have a consumer representative on our newly formed Breast Care Team at Port Lincoln Hospital, we can finally see changes of a positive nature.

Some of the activities we have been involved in are our own *Mini-Fields of Women*, of which we have had three. We are planning our next for October. During Australia's Breast Cancer week we will also have the play *Titbits* in Port Lincoln.

We are working on a information kit to be handed to newly diagnosed women in the area. We hope this will be in use by the end of 2002.

We are always pleased to receive the help, advice, and newsletters from the Network and we encourage new members to join.

*– Maxine Barker,
Port Lincoln, South Australia*

Our Latest Seats at the Table

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

- National Breast Cancer Centre's (NBCC) *Auditing and Identifying supportive care services* project team – **Sally Russell** (SA)
- NBCC's *Development of a brief summary card for general practitioners to support the implementation of the Psychosocial Clinical Practice Guidelines* project team – **Jenny Hall** (WA).
- Breast Care Nurse's Conference 2003 Abstracts Review Committee (Victorian based) – **Pam Williams** (Vic).
- Quality Use of Pathology Committee – **Rebecca James** (Vic).
- NBCC's *Informing oncology nurses about supportive care issues from the Psychosocial Clinical Practice Guidelines* project team – **Karen Forster** (Tasmania).
- International Advisory Committee for the US National Breast Cancer Coalition's project LEAD to be held in Europe in 2003 – **Lyn Swinburne** (Victoria).

Meet our consumer representative – Maria Waters

I have been married for 22 years, and my husband and I have two sons. In 1989, at the age of 34 years, I was diagnosed with breast cancer with lymph node involvement.

After a radical mastectomy, I went through six months of adjuvant chemotherapy.

Three years later, during a routine examination and tests, I was told the cancer had advanced to the liver. The prognosis was poor; my family was told I had 3-6 months to live.

After various treatments to outsmart the cancer, countless CT scans, bone scans, blood tests and participating in clinical trials, I became aware that my 13-year experience with breast cancer could be used in a positive way.

First, I became a Cancer Foundation volunteer, then a member of Action On Breast Cancer WA (AOBC).

This year, I attended the Network's Advocacy and Science Training Program. This confirmed that I was not only a breast cancer patient; I am a survivor who can contribute to the optimal treatment and care of those with breast cancer.

I am a consumer representative with the National Breast Cancer Centre's New Treatments Project.

Many new treatments have received publicity in the media. Reporting and the lack of evidence-based information sometimes results in confusion among



– Maria Waters, WA

women with breast cancer. Accurate and timely information about these new treatments is needed to avoid confusion among women in the community, health professionals, media and policy makers.

The aim of the project is to review these treatments, and develop and disseminate evidence-based fact sheets.

A consumer representative can contribute her personal experiences and knowledge, and those of her fellow survivors, to make a difference to the continuing care and improvement of services for those dealing with or caring for someone with breast cancer.

The Beacon is printed with the generous support of PMP Print.



Young women's project

Victoria's Western Breast Service Alliance Breast Services Enhancement Program is embarking on a project to improve the delivery of services to young women with breast cancer.

The team will be seeking the help of young women diagnosed with breast cancer within the past five years, before the age of 40 years, who live in Melbourne's western suburbs or were treated by one of these hospitals: Royal Melbourne; Royal Women's; Western Hospital Footscray; Sunshine Hospital; Williamstown Hospital; Frances Perry House; Freemasons; Melbourne Private; or Western Private.

Contact **Mary Bartlett**, on phone (03) 8345 7120 (Tues-Thurs) or mary.bartlett@wh.org.au, or **Sheila Hirst**, phone (03) 8345 6974 or sheila.hirst@wh.org.au

My Journey kit update

What will make the *My Journey* kit (which we are preparing for newly diagnosed women nationally) stand apart from other resources is that it will reflect the experiences of women who have experienced breast cancer.

To that end, we sent some members a questionnaire asking them to rate the helpfulness of various resources, and to suggest others they had found helpful.

We would like to extend a heartfelt thank you to those who completed and returned the questionnaires.

Your feedback highlighted many resources and a diverse range of views about what is or is not helpful. We are all different and will need different amounts and types of information to get us through difficult times.

Not all available resources will be listed in the *My Journey* kit (we don't want to overwhelm women when they're newly diagnosed). Additional resources will be listed on our website.

There will be another opportunity to let us know what you think about particular resources and to suggest additional, helpful resources through our website or by mail.

All aspects of the project continue to progress well. I have met with the national co-ordinators of *Strengthening Support for Women with Breast Cancer* to discuss how we can support each other's projects. Two sites have been selected to pilot the kit, hopefully in August or September.

– Mary Harvey,
My Journey Project Manager

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 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

September 6: *How Young People Heal: Facilitating Children's and Teenagers Grieving*, State Library of Victoria. Contact: (03) 9545 6377 or info@grief.org.au for details of seminars in other states.

September 7: Sexuality workshop for health professionals supporting people with long-term illness or disease, Burnie, Tasmania. Contact: Karen Campbell (03) 6430 6666.

September 9: BCAG (NSW) general meeting, YWCA, Sydney, 3pm. Contact: (02) 9436 1755.

September 11: Education and support program for male partners of women diagnosed with breast cancer, Peter MacCallum Hospital, Melbourne, 6pm (Repeated September 11 and November 13). Contact: Breast Cancer Nurse Co-ordinator (03) 9656 1111.

September 16: *Sexuality and Relationships*, Wesley Breast Clinic, Level 1, Sandford Jackson Building, Auchenflower, 6pm. Contact: (07) 3232 7596.

September 18: *Fertility – a personal perspective*, Queensland Cancer Fund, 7pm. Contact: (07) 3258 2264.

September 25: Estee Lauder Global Illumination to launch Breast Cancer Month, Park Hyatt, Sydney. Contact: NBCF (02) 9235 3444.

September 26: *Through the Looking Glass* by Wollongong High School of the Performing Arts for the Illawarra BC Support Group. Contact: Gloria Swift (02) 4295 8219.

October: Brunches for Breast Cancer – A series of brunches will be held across Victoria. Contact: Janelle Burgess (03) 9635 5251 or Janelle.burgess@cancervic.org.au for details of a brunch near you.

October 1: Premiere issue of *Pink Ribbon* magazine on sale at local newsagents.

October 8: Queensland Cancer Fund's CONNECT program for woman diagnosed with breast cancer (four-week program), 6pm. Contact: (07) 3258 2264.

October 18: Pink and Black Ball, Illawarra Yacht Club, for Illawarra BC Support Group. Contact: Gloria Swift (02) 4295 8219.

October 19: Best Breast Breakfast, Old Government House, Parramatta – hosted by BCAG (NSW) and NSW Breast Cancer Institute. Contact: (02) 9436 1755.

October 20: The Young Ones afternoon tea and mini-auction, Dorcas Gourmet Deli, South Melbourne (\$5 for afternoon tea and bidding number).

Contact: Tanya Wilson, (03) 9330 2785 or tanya_wilson@optusnet.com.au

October 22: Advocacy seminar, Health Care Consumer Association ACT, 12.30pm. Contact: Prue Borrmann, (02) 6290 1660 or hcca@tpg.com.au

October 23: *Impact of Breast Cancer on Families*, Queensland Cancer Fund, 9.30am. Contact: (07) 3258 2264.

October 24: Consumer forum on clinical trials in cancer, Sydney. Contact: Jennifer Denholm (02) 9380 9022 or jenny.denholm@cancer.org.au

October 27: *National Field of Women at the Domain, Sydney. To be preceded by a Silent Walk from Customs House at 2.30pm.* Contact: (02) 8585 1808 or www.bcna.org.au.

October 27: Annual service for all dealing with the issues of breast cancer, Saint George's Cathedral, Perth, 12pm.

October 27: Breast Cancer Forum, Intercontinental Hotel, Sydney, 9am. Contact: Louise Kippist, (02) 992 66584 or lkippist@nslcc.bsns.org.au

October 27-28: Mini-Fields of Women across Australia. Contact: Wendy or Ro, Breast Cancer Network Australia, 1800 500 258.

October 28: Australia's Breast Cancer Day.

October 28: Sydney's Annual Pink Ribbon Breakfast, Westin Hotel (\$55 each). Contact: National Breast Cancer Centre, (02) 9036 3030.

October 28: ABC Day Celebration of Life Luncheon, Wollongong Town Hall. Contact: Gloria Swift (02) 4295 8219.

October 28: Mt Gambier's Breast Cancer Day lunch, Women's & Children's Hospital. Contact: Janet Williams, (08) 8724 7901.

October 31: Young women and breast cancer – AOL live Internet chat with Dr Fran Boyle. Contact: Rebecca, BCNA, 1800 500 285 for details of how to link up or further information.

November 11: Queensland Cancer Fund's Oncology Nurses Conference, Gold Coast. Contact: (07) 3258 2263.

November 12: Indigenous health, Health Care Consumer Association ACT, 5pm. Contact: Prue Borrmann, (02) 6290 1660 or [e-mail hcca@tpg.com.au](mailto:hcca@tpg.com.au)

November 20: *Financial Planning*, Queensland Cancer Fund, 7pm. Contact: (07) 3258 2264.

December 5: Breast Cancer Association of Queensland's Christmas Charity Lunch, Hilton Hotel, Brisbane. Contact: (07) 3839 6630.



Seeking Shelter

The Network welcomes these new groups under its umbrella:

- The Wild Orchids, Echuca/Moama, Victoria/NSW
- Wimmera Breast Cancer Support Group, Horsham, Victoria
- LEAP – Young Women's Breast Cancer Support Group, Camberwell, Victoria
- Southern Breast Cancer Support Group, SA
- Hills Breast Cancer Support Group, SA
- Advanced Breast Cancer Support Group, SA
- Port Elliot Breast Cancer Support Group, SA
- Central Adelaide Breast Cancer Support Group, SA
- Tweed Brunswick Breast Cancer Support Group, NSW

Associate Member

- The Lymphoedema Association of Victoria, North Ringwood, Victoria

To make your group a link in our Network, phone 1800 500 258 or e-mail beacon@bcna.org.au

New on the web site

- *Be Thankful* – a poem by Jennifer Pettigrove.
- *Prostheses* – Dianne Wilson's story of having an internal prostheses fitted.
- *Prostheses* – Melanie Schubert's practical advice on prostheses and pockets sewn into bras.
- *Thank you* – Alison Piper's letter to her family and friends explaining what was happening, so that everyone would understand and be reassured.
- *Three personal pieces* – Full Frontal; The Art of Courage; and Post-operative Intimacy by Julie Richards.
- *My Journey* – Pat Jury from WA, tells of dealing with breast cancer alone.

See our new-look BCNA web site soon at www.bcna.org.au

THE BEACON

The Beacon is the newsletter of Breast Cancer Network Australia. Editor: Lyn Swinburne 1800 500 258
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Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria, 3122.

