Celebrating the courage of long-term survivors

In the last issue, we featured an article from Eleanor McDonald, a breast cancer survivor of 27 years, and we asked other long-term survivors to contact us. Since then, we have been overwhelmed by the most marvellous stories of courage, persistence and survival. The really tricky bit has been trying to fit all these articles in The Beacon! We have, therefore, decided to leave out some of our usual features, in order to fit in as many of these inspiring stories as possible. Even so, we can only reproduce a smattering of stories. You will find many more on our BCNA website at www.bcna.org.au.

We thank you all for taking the trouble to record your wonderful journeys, for sharing them with us, and for giving us hope and inspiration.

– Lyn Swinburne

Second breast cancer conference for women

The weather might be cold, but our spirits will be warm! Be in Melbourne on August 27-29, 2004, for a not-to-be-missed chance to join with fellow breast cancer survivors from around Australia at BCNA’s second National Breast Cancer Conference for Women at the Melbourne Convention Centre.

We are thrilled to announce two major sponsors:
• Commonwealth Department of Health and Ageing; and
• BreastCare Victoria.

Make sure it’s in your 2004 diary and start planning NOW!

Look out for further details in the December issue of The Beacon.
**State Reports**

**VICTORIA**

There will be several Mini-Field of Women events from Saturday, October 25 until Monday, October 27.

The State Library Victoria on the corner of Swanston and La Trobe streets, Melbourne, is the setting for one event and we would love to see lots of local and rural people there on Monday, October 27, between 11am and 3pm.

This could also be a great opportunity to visit the reopened domed reading room at the library.

BreaCan, the drop-in resource centre in Melbourne, continues to offer support and information, and has a host of interesting speakers and activities coming up.

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

**THE ACT**

The first big Breast Cancer month event is on Sunday, October 26, with the season’s first Dragons A breast Regatta. Teams will compete for the Pink Lady Perpetual Trophy donated by Brendan Smyth, MLA.

Following the regatta, the Mini-Field of Women will be held. The venue for the field is Peace Park, adjacent to the National Library. The Silent Walk will begin at the Japanese Gardens behind the Hyatt Hotel at 1.30pm.

We are fortunate that Claire Dennis (daughter of Megan, a BCNA consumer representative) is using this task as her final assignment for her communications representative) is using this task as her final assignment for her communications course facilitated by Brendan Smyth, MLA.

We hope to bring the Warrior Women Exhibition to the ACT for Breast Cancer Week and the Masters’ Games.

A new exhibition of photographs of local women for Bosom Buddies by Brigitte Seiger will also be featured.

We particularly welcome women who will be competing at the Masters’ Games in all events to attend a Breast Cancer Forum on Friday, November 7, sponsored by the National Breast Cancer Centre and BCNA.

The keynote speaker will be Professor Don McKenzie from the University of British Columbia in Canada, who will address the topic of exercise following surgery.

If you are in Canberra at this time we’d love to hear from you. You might like to participate in the dragon boat breast cancer challenge race, on Saturday, November 8, if you are already registered for the Masters’ Games in other events.

Should you wish to receive a newsletter, or participate in the Games, contact: Elspeth Humphries, humphries44@ozemail.com.au, or Anna Wellings Booth, (02) 6247 8470 or wbfamily@ozemail.com.au

**SOUTH AUSTRALIA**

The women in Port Lincoln continue to be busy!

Sandra Sinclair and Maxine Barker travelled to Ceduna and Wudinna to talk to local women’s groups and regional doctors about their information kits for women who are newly diagnosed with breast cancer.

Sandra and Maxine also spoke about the Lending Library that has been set up through the Port Lincoln Caring Cancer Support Group. Both the information kits and the lending library are projects funded by BCNA’s Community Grants Program.

It was Adelaide’s turn recently for the public speaking course facilitated by Sue Watson and Gil Paulsen of BCNA. Jo Gemmell, Maxine Barker and Sylvia Thompson attended, along with ourselves.

Participants benefited from the information provided and the peer critique of their presentations. Some have already put their greater confidence and enhanced skills to work.

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

**NORTHERN TERRITORY**

August will see several of our members visiting Katherine for a catch-up with the local women, as well as participating in the Flying Fox Festival races on the world famous Katherine Gorge. This is a special event, as the traditional owners only allow dragon boats in the gorge once a year.

In September, Jill Burgoyne, our Alice Springs liaison will be participating in a national acceptability survey of the breast care nurse position. It is running under the auspices of Strengthening Support for Women with Breast Cancer in Rural and Remote Areas.

Members of Northern Territory Breast Cancer Voice (NTBCV) and the Cancer Council are working together on joint promotional efforts in October, with the aim of making this the best breast cancer awareness campaign the Territory has seen to date.

Activities planned include the Big Girls PJ Party, a Mini-Field of Women, various displays in shopping centres, a visit by the Caring for You team and a fundraising dinner.

For more details, or to become involved, contact either of us - we’d be delighted to hear from you!

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 Breast Cancer Directory of Treatment and Services for NSW Women is on-line and can be reached via www.bcagnsw.org.au or www.bc.org.au. Breast cancer specialists will be invited to update or enter their details on-line from now on.

BCAG NSW, through Cancer Voices NSW, has been active in shaping the...
Queensland workshop in September

Here’s your chance to hear the latest on breast cancer clinical trials and learn about the issues surrounding genetic research.

BCNA is sponsoring a workshop for women to be run by the Australasian Society of Breast Diseases at its conference on the Gold Coast.

The workshop will be held on Saturday, September 20 from 9.30am to 1.15pm. It will feature presentations from experts, as well as an opportunity to ask questions. The cost is $7, which includes refreshments.

To register, phone BCNA on 1800 500 258 or at the general meeting on September 17.

media and bravely spoke about their personal experiences with waiting times.

Contact: Veronica Macaulay-Cross, (07) 3269 8083 or vonphil@bigpond.net.au, or Lyn M ore (07) 3822 5468 or lyn.moo re@bigpond.com

Western Australia

Action On Breast Cancer WA (AOBC WA) held its annual general meeting in June.

Carol Bishop, the founder of AOBC WA, has resigned as Chair. Carol is an inspiration to women with breast cancer and will continue as a valuable committee member and a driving force on advocacy issues affecting women with breast cancer. Maria Waters is our newly elected chair.

AOBC WA is presently active in advocacy relating to the issue of radiotherapy delays in the treatment of breast cancer. The radiotherapy issue is becoming worse in WA, with waiting periods of 20+ weeks in the public sector. Clearly, this is unacceptable.

AOBC WA would like to hear from WA women who are experiencing these delays. Contact Maria via e-mail at alma.waters@bigpond.com (please state ‘Radiotherapy Delays’ in the subject line) or phone 0408 933 667.

Two specialist breast care nurses were funded by AOBC last year. Our members feel strongly that specialist breast care nurses are essential to the optimum care of women diagnosed with breast cancer, therefore AOBC is working towards continuing this sponsorship.

The women of AOBC WA would like to invite all those affected by breast cancer and the general WA community to join us at 11am on October 26 at the Perth Art and Cultural Centre for our Mini Field of Women.

One hundred silhouettes will be planted on the grassed area, adjacent the Art Gallery Café.

BCNA resources will be available, along with merchandise for sale.

Contact: Carol Bishop, (08) 9489 7312 or carol@cancerwa.asn.au, or Maria Waters (08) 9344 7362 or Alma.waters@bigpond.com

Queensland

Our Queensland BCNA fundraiser at Gail Wiltshire’s Twelfth Night Theatre was great fun! The comedy, Bedside Manners, with John Inman of Are You Being Served? and Jon English as the pirate king, gave us lots of laughs.

We have formed a Queensland Committee to support BCNA and to advocate on State-based issues.

Our first meeting, on June 14, at the Twelfth Night Theatre, Bowen Hills, was well attended, and included BCNA Board member, Dr Cherrell Hirst. At our second meeting, on July 26, radiation oncologist, Dr Liz Kenny, from the Royal Brisbane Hospital, spoke to us.

We are keen to form links via e-mail or mail with BCNA supporters in rural and regional areas. Anyone interested in attending or joining by e-mail/mail should contact us.

Recently, Lyn Moore and Veronica Macaulay-Cross, met with Queensland’s Minister for Health, Wendy Edmond, to lobby for the on-going funding of the newly appointed breast cancer nurses in public hospitals. They are currently in Cairns, Townsville, Mackay, Gold Coast, Toowoomba and Princess Alexandra Hospitals.

We also supported the Queensland Cancer Fund’s campaign about the unacceptable waiting times for radiation therapy by writing letters to politicians and raising the matter with the Minister.

Special thanks to Lyn Clarke of Mackay and Donna McPherson of Kenmore, who featured in television media and bravely spoke about their personal experiences with waiting times.

Contact: Veronica Macaulay-Cross, (07) 3269 8083 or vonphil@bigpond.net.au, or Lyn Moore (07) 3822 5468 or lyn.moo re@bigpond.com
In 2003, BCNA will ‘plant’ its largest number of Mini-Fields of Women around Australia. These community-based events are becoming increasingly meaningful to the groups involved, as they give people a chance to remember and honour those affected by breast cancer.

All the Mini-Field convenors have passionately embraced the role, ensuring that their Mini-Fields reflect their group and community. They would love to have as many people as possible attending their events. If you would like more information about a Mini-Field near you, check our website at www.bcna.org.au, where you will find details such as meeting times and venues.

Mini-Fields will occur in:
- ACT: City centre.
- Northern Territory: Darwin.
- Queensland: A yr, Boonah, Bulimba, Caboolture, Caloundra, Cleveland, Esk, Laidley, M oranbah, N oosa, Prosperine, Toowoomba, Toowong.
- South Australia: Berri, Henley Beach, Kingston SE, M t Gambier, Port Lincoln, Robe, Yorketown.
- Tasmania: Devonport, Launceston, W ynyard.
- Western Australia: Perth.

The locations of the 2003 Mini-Fields of Women.

Our wonderful corporate partners and friends at Bakers Delight will again be holding their promotional and fundraising block loaf initiative. In 2001 and 2002, this initiative raised an amazing total of $256,000 for BCNA, which has helped us fund a number of our projects for women and their families.

Many bakeries went all out last year. There were pink jelly beans, pink fairy floss and pink bread. A number of bakers even shaved their heads in support!

Bakeries have told us how excited they are about this year and we hope that it will be bigger than ever. Spread the word and encourage family and friends to visit their local Bakers Delight on Saturday, October 25.

Make sure you introduce yourself as a N etwork member and let them know what a fabulous job we think they are doing for us.

Congratulations
- Gloria Swift is the Illawarra’s inaugural N urse of the Year.
- Lynn Hill (a member of the SA Dragons A breast crew) has been named the A delaide Zonta Club’s 2003 W oman of the Year for her volunteer work.
Join us in Tassie for the 2003 Field of Women
Sunday October 26, Hobart

Every year our members travel great distances to pay tribute to the women and men who have been touched by breast cancer. If you have never witnessed a Field of Women why not come along and join us this year in Hobart?

Tasmania is ‘tickled pink’ to be the host of this distinct and moving event. Project officer Karen Forster says, “We would love to see you! Our pink lady silhouettes will be popping up all over Tasmania in the lead-up to the Field of Women”.

On the morning of the Field of Women there will be a free Breast Cancer Forum at The Old Woolstore, 1 Macquarie Street, Hobart, from 10.30am to 1.30pm.

The keynote speakers will include Professor Chris Ewan, Lyn Swinburne and Jocelyn Newman.

People will then gather at 1.30pm at Franklin Square to commence the Silent Walk at 2pm to the Hobart Cenotaph.

Breast cancer survivor, Raelene Boyle, will lead the walk to the Field of Women, where the launch will take place at 2.30pm.

For further information or to register for the Breast Cancer Forum, phone Karen Forster on (03) 6273 4422 or 0439 734 422.

Sponsor a Silhouette

Planting a silhouette with a personalised, sponsored message is an unforgettable experience.

Finding their silhouette each year has become a significant part of the pilgrimage for many people.

With this issue of The Beacon you will receive a Field of Women silhouette sponsorship form.

You can record your own silhouette message or pass the brochure on to someone who might want to record a message for you.

Pink Silhouettes on Ramsay Street!

Keep an eye out for our pink Field of Women silhouettes on the Channel 10 serial, Neighbours.

We can’t give too much away just yet, but there will be episodes involving a cast member with breast cancer, culminating in a Mini-Field of Women.

These episodes will be seen in Australia about December 15 and sometime during February in the UK.

The program’s producer, Peter Dodds, tells us that Neighbours is shown in more than 57 countries world-wide. This will be a wonderful way to promote not only our special event but the personal effect that breast cancer has on women and their families.

The Neighbours cast and crew members are also helping us through their involvement in a community service announcement to be seen on Channel 10 during October.

‘Must read’ books on breast cancer

In October, BCNA plans to launch our library list of ‘must read’ books. We developed the list based on input from many of our members, who suggested the books they had found most helpful during the journey with breast cancer.

We plan to send this list to every public library across Australia and ask them to stock these books for women and their families.

We will include a copy of this list in the next issue of The Beacon.

Ensuring insurance

The response to our survey in June about getting insurance coverage was wonderful. More than 800 responses have been received and your help is greatly appreciated.

We have started calling those readers who provided contact details, to discuss their difficulties in obtaining insurance, but the number of people means it may take some time to complete these calls.

The information we have obtained from members has greatly helped our work on insurance.

We will update you on with the results of the survey and our insurance investigations in future issues of The Beacon.
Bettina Woodburn

In early October 1973 I attended the Montmorency Country Women’s Association, where a speaker from the Anti-Cancer Council spoke about the warning signs of cancer. He concluded with, “Go home and find your lumps”. I had never thought about cancer, but there, in my left breast, was a pea-size lump that was unattached, moveable – just as had been described.

In my GP’s estimations, cancer was unlikely, as I looked so healthy. Hadn’t I just spent my youngest daughter’s second term at secondary school with her on a romp around Europe? My surgeon couldn’t take a biopsy, but arranged for a lumpectomy.

After the lump and a section of my left breast were cut out, I was stitched and plastered, and spent several days waiting for the pathology report that recommended removing the surrounds of the malignancy. Off I went for a radical mastectomy.

The morning my husband left me at the hospital there was the longest and most miserable of my life. I whimpered for hours about losing my femininity. How I needed a breast care nurse!

When I woke, I was propped up, the left side of my chest plastered, with a drainage tube leading to a bottle fixed to my bed. All of my breast, and sweat and lymph glands were gone.

I spent many miserable, lonely days, trying not to look at the site of the operation. I would listen to the trains outside and wanted to throw myself under them.

I returned to the ‘duties’ of wife, mother of four, house and garden, but I was shattered, in shock and felt that my life was ruined. I grieved for my lost part and felt sure I would die within a year. I wouldn’t buy clothes, as that would be a waste of money.

Gradually I accepted my misfortune and bought a special bra and prosthesis to replace the ball of cotton wool. One kind was a lambswool-covered triangular bag of rice or birdseed, with clips at the corners to attach to appropriate ones on the bra. Other oil-filled pink breast forms expanded in aeroplanes and threatened to burst. In time they were replaced by silicone exterior prostheses (I still hate anything tight around my chest and a bra-less day is a dream!).

My scars faded, my numb back became sensitive again. I put on a brave front, but hated myself.

The push-pull action of a double-ended kayak paddle was my greatest help towards normality.

During that time, I joined canoe clubs. I trained, raced and held records for the Barwon to Echuca, Yarramarra and the Barwon River long distance races. I did summer and winter triathlons, with kayaking instead of today’s swimming leg.

To match my new arm and shoulder muscles, I grew some in my legs by bicycling and I learnt about track and field veteran athletics. I held 15 Australian athletics records in the Veterans and Masters Games, and won medals in Rome (1985), Melbourne (1987) and A delaide (1989).

Forced to become self-reliant, I became confident, healthy, and fit - both physically and mentally.

Between the ages of 50 and 60 years, I gained three degrees and a diploma of education.

In 1998, I paddled my single touring kayak from Tocumwal to Mildura – 1000km along the Murray River – to raise awareness and money for breast cancer research.

For two seasons I have also been a member of a Dragons Abreast racing team at Melbourne’s Moomba Festival. Against national competition, I won the inaugural Get Up & Go Award in 2001.

I am now active in a retirement village with a bike path outside the fence for my ‘Eddie Merckx’ and me!

— Bettina Woodburn
Williamstown, Victoria

Joy Kelly

I found my lump in April 1980, at the age of 31, when I was five months pregnant with my third child.

On April 10, 1980, when six months pregnant, I had a radical mastectomy followed by 12 months of chemotherapy.

My beautiful daughter was born on August 8, 1980, while I was receiving chemotherapy and this year she will be 23. I will be 55 in November. I have had many ups and downs in my life, but I am a survivor.

In about 1983 I had a breast reconstruction and have had a silicone implant for about 20 years. So far, I have had no problems.

— Joy Kelly, ACT
I lost my husband at the age of 40 to melanoma. At the time our children were 14, 10 and eight years, and the road ahead looked daunting. However, with love and help from the children, we got through. My employment as a nurse was a source of stability.

Five years on, in 1978, and aged 45 years, I was diagnosed with breast cancer and had a radical mastectomy. I was devastated, but resumed nursing after three months of radiotherapy.

Due to the excessive surgery and the passing years, postural changes have appeared, but with specialised advice and guidance this is being attended to.

I am thankful for the 32 years since the surgery. I had prayed to be with my children and see them grow up. Life is full, and there are never enough hours in the day for commitments and relaxation.

— Heather Rutherford, East Bundaberg, Queensland

I am 75 years old and was diagnosed with breast cancer 40 years ago, resulting in a radical mastectomy. Halstead surgery was performed and it was more severe that anything carried out today.

In the past, I spent eight years working in a voluntary capacity with the Cancer Council. During that time I visited 400 mastectomy patients in hospital. I found this work most rewarding, as my years of survival gave inspiration and hope to many ladies.

— June Prior, Lane Cove, NSW

I was diagnosed with cancer in the right breast. I was 39 years old and married with two children (aged 9 and 7).

I had a radical mastectomy and a month later 15 sessions of radiotherapy at the Peter McCallum Hospital. Two years later, I had a simple mastectomy of the left breast.

In those days there was no such thing as reconstructive surgery, and the prostheses were filled with bird seed. What a change to today!

Since then, I have led an active life, playing lawn bowls four times a week. In February, I was diagnosed with radiation necrosis and spent 30 sessions in the Alfred Hospital’s hyperbaric unit before being operated on by a plastic surgeon.

Because of the radiation damage to my skin I have had to have skin grafts and a further 10 sessions in the hyperbaric unit.

Now I am looking forward to returning to my active lifestyle again and will be back on the bowling green as soon as I can.

— Gwen Jenkins, Victoria

I am 70 now and still golfing! My message for cancer sufferers is to keep the faith and a strong heart. I have kept it at bay for 25 years and have no intention of giving away my positive attitude to life just yet.

— Marlis Minns, SA

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— Marlis Minns, SA
29 years

Barbara Dowling

Mid-winter 1974 I was 51 years old and living on a beef cattle property in the bush.

Of my four children, my eldest son was planning a wedding, my only daughter was studying for her higher school certificate and my youngest son was also in high school.

By chance, I felt a small, hard lump in my left breast. My heart dropped. It will go away I assured myself, but all the time I kept putting my hand on the spot.

Ten days later, I saw a physician in the nearest town, a 1½ hour drive away.

A cyst? Better see the surgeon straight away. My heart dropped again.

“I am sure this is cancer,” the surgeon pronounced. I could barely talk to my husband. I could not ask a single question of the surgeon. I was in shock.

Everything happened so quickly. A lumpectomy was scheduled for Wednesday and the results were to be tested in another town. If malignant, I would have a radical mastectomy, which would include removing several lymph nodes, the next day. I don’t recall much discussion about this procedure.

This was probably one of the most horrific times I have experienced. I felt zonked out and tried to swallow lots of water. I didn’t know anyone who had been through this.

My desolation was complete when I asked the surgeon about a prosthesis. His reply was “I haven’t a clue”. Perhaps I could stuff my bras with panty hose was the suggestion! The physician said he would talk to his mother who lived in another State.

A sister at the hospital brought a prosthesis filled with bird seed that someone said might be suitable. That lady had a much larger boob than mine and it weighed a ton!

My lifesaver was a patient having some other treatment, who made me laugh with stories about her experiences using sanitary pads for filler. I got myself back into perspective and can honestly say I then began to feel more positive about my future.

At home, the isolation was not nice. A few weeks in hospital, I was as weak as a kitten and my husband was out in the paddocks most days.

Exercises and good friends seemed to work the magic. I restarted pottery classes, had art lessons, joined a group, got back into the cattle yards, restarted in the garden, learned to judge gardens and floral art, got involved in pony club. I never gave up the thought that life would improve.

Such an experience gives one a different prospective and in many ways I think one becomes a better person.

Since then, my husband, Ian, and I have travelled the world.

In my seventies, I learned to use a computer and wrote my memoirs, which I successfully self-published.

These days, I do tai chi regularly and still garden with a passion. On my 70th birthday I had a hot air balloon ride and last year, for my 79th birthday, I did a tandem sky dive. I wanted to be sure it happened in case I ‘fell off the twig’ before my 80th!

I am fortunate my family is close knit and my old boy is one in a million.

Early detection cannot be too heavily emphasised and now, with so much support and knowledge, and the skilled treatments available, the dreaded ‘C’ word can be faced with so much more certainty that it is not a death sentence.

The Beacon is indeed a beacon of positive light. Well done.

– Barbara Dowling, Dorrigo, NSW

23 years

Pauline Sutherland

When I was 48 years old, I found a lump in my breast.

Immediately, I went to the doctor, who sent me to hospital to have the lump removed. I asked them not to take my breast off, but the results weren’t good, so it had to come off. I was devastated.

But having a good husband and family helped me through the trauma of radiotherapy and chemotherapy.

Half way through chemotherapy, I felt I couldn’t go through any more, but the hospital staff were marvellous and talked me into having the rest of the treatment.

The nurse gave me a tablet to calm me, but it knocked me out and my husband had to come and get me.

I slept all the way home with my mouth wide open. My husband was driving and trying to push my mouth closed at the same time. What a sight we must have been!

I am now 71 years old and a grandmother of six, so it seems long ago.

I will always regret losing my breast, but you do the best you can, and keep positive and active.

– Pauline Sutherland,
Croydon North, Victoria
I live in a rural area, 65km from Young, NSW. I am a farmer’s wife, a mother and grandmother. Thirty-three years ago I had a radical mastectomy, at the age of 28 years. I was young, healthy and pursuing a teaching career.

After finding a lump the size of a walnut in my right breast I visited my GP. His diagnosis was “it’s just fatty tissue”, and I was dismissed.

The same day, without appointment or referral, I went to see a visiting surgeon who came to Young from Cowra. It was his consultation day and he operated in Young every week.

All the necessary phone calls were made to my GP and I was admitted to Young District Hospital the next day. I had a lumpectomy and remained in hospital for five days. When the results returned it was a big shock to hear the word ‘cancer’! (‘that sinking feeling’ and then the shakes).

The next day we went (stitches and all) to the Prince of Wales Hospital in Sydney. I had six weeks of radiotherapy, two doses each day.

We rented a flat at Coogee and made our stay a holiday. I must say we have had better ones since!

Returning home, I waited six weeks for the burns to heal. This period allowed my imagination to run riot. It was ‘mental hell’.

I then entered the Young District Hospital for my mastectomy and was treated as a VIP patient. My family and friends were able to visit at will. I was certainly looked after and cared for, but there was no welfare or support system.

I went home. What do you do with an empty bra? Some suggested to fill it with bird seed. No way!

My surgeon recommended a lambswool form, weighted with sand. The wool helped the healing and scaring and absorbed perspiration, and while it was comfortable, it did tend to go flat and ride over my shoulder.

Then I graduated to an oil filled-prosthesis (don’t stick the nappy pins in that side!), and finally, I got the silicone type.

Reconstruction was not ever discussed as an option.

Yes I am a survivor. I live and act as I did before the surgery. Breast cancer is something we can live beyond. We can live life as full and complete women. This surgery does not make us less of a woman.

I now have more of an understanding and compassion for others, because I know how much anxiety that ‘sinking feeling’ can cause. We can find good in every experience, if we just can see it through.

My husband was supportive and caring, and my family gave me all the encouragement I needed.

Two years after the surgery we adopted a lovely daughter and then later a loved son. I have never regretted the choice we made to adopt a family.

I have been blessed – I have a full life, a wonderful family and a future to look forward to.

I do enjoy reading The Beacon. There is so much support and encouragement now for fellow sufferers. I hope my story will help others to remember that ‘a quitter never wins and a winner never quits’.

– Janelle Campbell, Galong, NSW
In 1970, when I was 42, I found a thickening in my breast. It is important to highlight that breast cancer can appear in a variety of ways other than as a ‘lump’.

I underwent a mastectomy and had one lymph node removed. It proved to be clear of cancer, so no further treatment was required.

This was an incredibly difficult time for me. I knew nothing about breast cancer, as it was not openly talked about then as it is today. I did meet four other women with breast cancer, but they all went on to die, so I assumed this might be my fate.

I am confident that, had it happened today, I would have been able to save my breast. However, this physical loss was not a big deal for me at the time, as my husband assured me that he would not see me as disfigured in any way. In fact, I never felt that.

I did feel a wave of support from the many people who prayed for my good health, and my Christian faith helped me to get through this difficult time.

On a more practical level, I have found the 18-hour bra to be very comfortable because of its under padded shoulder straps.

My message to women diagnosed is You need courage and a great deal of support to get you through.

– Yvonne Bell, Melbourne, Victoria

My name is Shirley Isabel McIntyre. I am 77 years old and have been widowed for 11½ years.

In 1965, when I was 39, I felt a lump, the size of a pea on my sternum. My mother insisted I see my GP. He rang the specialist, who advised a frozen section and, depending on the diagnosis, a full mastectomy. The frozen section was positive.

I lost my right breast, but fortunately the cancer hadn’t entered the lymph glands. However, because the lump had been sitting on my sternum the specialist advised radiotherapy.

In 1995, the same GP, while conducting his yearly examination, found a lump deeper inside my left breast.

Thirty years later, I was off to the specialist again, where a needle biopsy, mammogram and ultrasound were performed. The result was positive.

In March 1995, at the same hospital, but with a different specialist and the same GP assisting, I lost my left breast.

I decided on a full mastectomy, as I had survived the first one.

This time I only had to wait a week for the positive result, whereas I had had to wait three weeks in 1965. I was put on Tamoxifen for five years.

My husband took me to the US in the 1970s to buy some decent breast forms, (I had been using bird seed) and for years I bought them by mail order from America. Today, I can buy natural forms from David Jones.

– Shirley McIntyre, Warrawee, NSW

My name is Gwen Coulter. I have been married for almost 52 years to a wonderful man, Lloyd. We have two daughters, who are 45 and 43 years, and seven grandchildren – four girls and three boys. We feel fortunate.

When I was 37 years old, I was soaking in the bath after a busy day when I felt a lump in my left breast.

I knew it shouldn’t be there, but as I was well, and it wasn’t sore, I convinced myself it was not serious.

The next morning, my husband, a retired pharmacist, was quick to tell me I would have to visit our doctor.

The doctor gave me a thorough check-up and felt it was an innocent little lump, but he said it would have to come out. How fortunate I am that he used the word ‘but’.

A couple of weeks later, when I went into hospital to have the lump removed, the news was bad. Two days later I had a radical mastectomy, followed by ray treatment.

I have never looked back and am involved in various organisations as a volunteer. My main role is with the Breast Cancer Support Service – I was trained in 1976 to give support to ladies diagnosed with breast cancer and have been involved with more than 700 ladies.

The hours I have spent on the phone and at the hospitals are my way of saying ‘thank you’. In September I will celebrate 35 years since I lost my left breast and I haven’t missed it a bit!

I hope and pray that many of the ladies I have supported, along with all those others who have been through breast cancer surgery, will live on and enjoy a happy and healthy life.

– Gwen Coulter, Orange, NSW
I discovered a lump in my left breast in mid-June 1970. My husband, who was away camping that weekend, was soon due for investigations about extreme oesophageal problems and knowing he would cancel this if I told him of my discovery, I kept my secret until plans were made for his surgery.

I waited about six weeks (and worried), until his surgery plans were made, before I went to my local doctor in Coleraine in early August. I was sent to our Hamilton specialist, who immediately expressed his fears; x-rays, mammograms, etc., followed.

We had four school-aged children aged 10½, 12, 13 and 14½ years living at home and travelling daily by buses at the time, plus our youngest daughter who was not yet 10 months old. We were on a farm 10 miles from the nearest town, but I did not, and still don’t, drive a car. We had very basic ‘mod-cons’ by today’s standards.

I had my 45th birthday in mid-August and I went to hospital in Hamilton on September 1, 1970. I was in the hospital for 11 days and this was followed by chemotherapy, radiotherapy, etc.

For about seven years, I received weekly injections of hormone therapy, until a new oncologist came to Hamilton hospital and on checking the records told my surgeon that the treatment was not necessary!

My surgeon was not happy about the suggested change, but agreed and kept a close check on me for a long time.

I now enjoy being a volunteer in a local nursing home for 3-5 hours every Tuesday.

I was diagnosed with breast cancer two days after my 50th birthday in March 2000. Treatment was a partial mastectomy and partial axillary clearance, followed by chemotherapy and radiotherapy. I lost all my hair and was off work for seven months.

However, I have a wonderful family and the best husband, who always has the answers to dissolve my fears. Since my recovery, I have regained my shoulder length hair and enjoy life to the fullest.

On the day I found out I had breast cancer, my daughter was able to attend university.

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33 years

Joan Rowe

My Journey update

Regular readers of The Beacon know we’ve been working hard on the My Journey Kit for more than a year.

We are delighted to report that the pilot kits are being tested by 80 women from around Australia who have recently been diagnosed with breast cancer. We are aiming to launch the kit nationally in April 2004.

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Jan van den Heuvel with her 3½-year-old granddaughter, Tahlia.
Support is available

I read your newsletter this week for the first time and thought it was informative, refreshing and real.

I was diagnosed with breast cancer 14 months ago and had a mastectomy. I was 26 weeks pregnant at the time with our fourth baby. Robert was born at 34 weeks and I began eight months of chemo/radiation the day after he was born.

Our other children were aged one, six and 11 so we had our hands full.

Our family live overseas and Shane works in Melbourne, a three hours round trip away, so I had to attend most medical visits with the babies, including my daily radiation treatments! Sleep didn’t happen as you’d expect with a newborn and a one-year-old.

So I have a tip I want to share with your readers.

My first enquiry was to Centrelink about childcare. Were we entitled to any help in these circumstances?

After a fraught meeting with a pleasant, but useless lady, myself and the babies left, having been told there was absolutely no help available. If I’d been on a pension card, or old and frail, the world would have been my oyster – cleaner, home help, childcare, meals on wheels. But we missed out because my husband earns more than the Centrelink limit – it did not matter that we had four children to keep on a single wage and were financially strapped.

After six months of hell, I found I was entitled to full-time/free childcare for both my babies. The lady at Centrelink didn’t know about it. It is called ‘in exceptional circumstances’ and is given for a 12-month period, while you assess your new situation.

The simplest way to access assistance is to find a council-run day care centre you want to use and then discuss it with them. They apply to Centrelink.

Imagine how different our family life would have been had the boys been there, even for just two days a week.

I do intend to put down some thoughts on my experience, particularly with the pregnancy element, but it’s a matter of finding the energy and time.

– Anne Marie Glanford, Drysdale, Victoria

Memory loss

It was with interest that I read your article about memory loss and chemotherapy.

I know that my concentration and memory definitely deteriorated during my chemotherapy. I finished chemotherapy mid last year and both have since improved.

When I asked my oncologist about memory problems during treatment, I was told that it can sometimes happen.

A friend recently had chemotherapy for bowel cancer and reported similar problems.

It is good that some research is being undertaken and that people are being made aware of this side effect.

– Eileen Bunney, Peregian Beach, Qld

New book release

Hey Jude – A Family’s Journey with Cancer is a new book by and about Judy Costello, a former Melbourne Dragons A breast paddler who died in April 2002.

It is made up of her diaries, with a commentary from her husband and three children.

The next issue of The Beacon will contain a review of the book. The book will be launched in October. To order your copy, phone BCNA on 1800 500 258

Celebrating a Dutch-Australian friendship

My name is Lieke and I am from Holland. I was diagnosed with breast cancer at age 26 in June 2001.

In October 2002, I flew to Sydney for the Field of Women, after an Australian friend of mine, Shannon, told me about it. She wanted to plant a lady for me as support, but I decided to fly over to be there with her. It was a wonderful experience. I was touched.

There are a lot of pictures on your site from October 27 in Sydney, do you think you can add one more? I’d love to see the picture of Shannon (left) and me (right) there as a surprise for her. I think our Dutch-Australian friendship is special.

– Lieke, Holland
Stress management for those with secondary breast cancer

Sydney women diagnosed with secondary breast cancer or ovarian cancer are invited to participate in a group stress management program based on Cognitive Behaviour Therapy. Participants will learn a number of coping strategies and discuss issues of concern.

The program is eight weekly sessions at the Health Psychology Unit, UTS, Royal North Shore Hospital, Sydney. It is a free program.

The session topics are: taking charge; beating the blues; managing anxiety; self-esteem; balanced lifestyle; dealing with anger; effective communication; and setting goals.

For information, phone (02) 9514 4309.

Warrior Women in Parliament

The Victorian tour of the Warrior Women exhibition culminated in a showing in the Queen’s Hall of the State Parliament House, launched by the Minister for Health, Bronwyn Pike. The newly completed Warrior Women CD-Rom was also launched on the night by Bernice Gerrand from the Australia Council for the Arts.

The Warrior Women CD features most of the moving imagery and text from the Warrior Women exhibition. It is presented in an attractive booklet that features black and white photos and writing created by women who have experienced breast cancer. In addition to the writing and the imagery, the CD features information, advice, animations, a list of resources and helpful contacts.

The CD costs $15 (incl. postage) and can be ordered by phoning BCNA on 1800 500 258 (free call).

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Forgotten member groups have taken inspiration from floral symbols.

FORGET ME NOTS

The Forget Me Nots is a support group for women who have been touched by breast cancer.

These women are of varying ages and stages of their disease, from those recently diagnosed and still undergoing treatment, to women who have been well for many years, to those whose disease has returned.

As a group, the women do not forget those who are unable to attend meetings, for whatever reason, they do not forget those who are going through difficult times and they do not forget those who are no longer with the group.

They care for each other, they support those in need, and they share the good times and the bad.

– Elischka Sageman, Rosanna, Vic.

DAFFODILS

The concept daffodil signifies cancer at the time the group was formed.

A bove the daffodils on our leaflet we have the words “we care how you feel”.

We give support to the cancer patient, knowing how they feel and, in doing that, hopefully making them stronger to then go home and tackle the needs of the family.

Daffodil bulbs regenerate each spring and with their beautiful blooms we likened it to the resurgence of a new, stronger and more understanding person.

– Noel Sumner, Richmond, Vic.

WARATAHS

The Waratah Breast Cancer Group was established in 1994 for women living in the East Gippsland and Wellington Shires of Victoria.

The flyer advertising our first meeting in February 1994 included a Roman goddess holding aloft a flower. This was later refined to a picture of the waratah bloom, when we gave ourselves the name Waratah Breast Cancer Group.

Later we were told of a waratah native to our area and we changed to this flower, the Gippsland Waratah, ‘Telopea Oreades’.

– Marlene Parsons, Gippsland, Vic.

WILDFRCHIDS

The Echuca-Moama Breast Cancer Support group is named Wild Orchids in honour of one of our members, Kaye Edwards, who we lost in April 2002.

For a long while, we had no name and our newsletter went out called No-name Newsletter.

We finally decided to call ourselves Wild Orchids in honour of Kaye, who had suggested it. The last time I spoke to her, I told her of our decision and that she would be with our women always through the name. We sent her a most beautiful bouquet of purple and yellow orchids.

Our name symbolises Kaye’s strength, courage and spirit. It also allows us to honour all those women who journey the road of breast cancer – and we are a little ‘wild’ and proud of it too!

– Judy Shepherdson, Echuca, Vic.

Inspired by flowers

Several BCNA member groups have taken inspiration from floral symbols.

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– Noel Sumner, Richmond, Vic.
Dragons Abreast report

Dragons Abreast Australia Inc.’s National Co-ordinator, Michelle Hanton, has much to report.

The most exciting news is that Don McKenzie from Vancouver, Canada, will be in Canberra in November for the Australian Masters Games. He is the man who founded the breast cancer survivor dragon boat movement and he will address the Breast Cancer Forum during the games.

In Darwin, the recent high point was the launch of Moontime, the dragon boat built for Dragons Abreast NT by prisoners of NT Correctional Services, with the assistance of local businesses, Ullrich Metals & Fingers Aluminium.

Madeleine Luck again generously provided the funds to bring Moontime to life.

The launch was at the Darwin Sailing Club and attracted 280 invited guests, including the NT Administrator, John Anictomatis, and his wife, Jeanette, Chief Minister Clare Martin and Lord Mayor Peter Adamson.

The Brisbane team’s season began again late in August, so that they would be ready to paddle at South Bank on the first Sunday of September.

All interested survivors and supporters are welcome to join training at the 18’ sailing club on the Bulimba reach of the river. Phone Janelle 0412 734 718 for more information.

Deb Martin and Sally Russell welcome members to join the new South Australia team in Adelaide. It will be for those interested in paddling socially in a non-competitive team.

A though the team won’t be on the water until the season begins, there will be informal get-togethers.

Phone Sally on (08) 8223 7106 (A H) or e-mail salrus@senet.com.au

Port Lincoln members hope to have a dragon boat feature as part of the Tunarama Festival. Anyone interested in joining in this event should contact Maxine Barker (08) 8682 6519.

The eager paddlers from Tasmania have received some grants enabling them to order a boat and they hope to be paddling the Derwent soon.

A membership drive is underway and Moira Connell wants to assure ‘would be’ paddlers that “we are all in the same boat, as none of us has seriously held a paddle!”

Sydney has an open day planned for September 13. For information, phone Margot Case on (02) 9542 1704.

The Sydney team has also welcomed Australia’s first ‘baby dragon’. Caroline Frommer, the first Sydney co-ordinator, recently gave birth to son Joshua.

In Newcastle, a fantastic bunch of girls are joining the paddlers at the Newcastle/Hunter Dragon Boat Club for a public/social paddle on Sunday mornings. It starts at 8.15 am on Throsby Creek, from the boat ramp at The Cowper Street Bridge, Carrington.

The atmosphere is fun and frivolous, and the cost is $5 – to cover insurance.

Phone Martine Boughton on 0418 626 790 or (02) 4961 3343.

WA would love to hear from people interested in taking up paddling, as Perth will be hosting the 2004 National Titles. Phone Yvette Libregts on (08) 9246 0739 and help fly the flag for WA!

Other reports have reached the BCNA desk and include news updates from Victoria and South Australia:

The Melbourne International Dragon Boat Festival will be on Sunday, March 14, 2004.


A dinner was organised to thank Pamela Williams for her invaluable role in establishing Dragons Abreast in Victoria and recognise her huge contribution as state co-ordinator for the past two years. Pru Menzies has now taken on this role, with valued support from several helpers. New members are welcome!

Phone Pru on (03) 9570 4896 (h) or (03)5996 2511(w), or e-mail prum@cclic.vic.gov.au

Lynn Hill reports that their Adelaide Club has welcomed its first male breast cancer survivor, Steve. Both he and his wife are paddling and the team is sure he will make a great contribution to breast cancer awareness.

Those who would like to have fun and get fit can join as a survivor or supporter in a social or a sports team. Phone Lynn Hill on (08) 8358 4117 or 0419 324 569, or e-mail aushill@hotmail.com, or Ginny Bullock at dragons@homenurses.com.
Messages for tomorrow’s doctors

In May, I made a presentation to 280 third-year medical students at Melbourne University. They were in the midst of a four-week lecture series about cancer and I was asked to speak about the patient’s perspective and a little about my work in breast cancer advocacy.

I thought a great deal about what to say, as this was a wonderful opportunity to make contact with our doctors of the future. I had an hour, so the challenge was to make some key points that would stay with the students long after the lecture.

They proved to be great listeners and asked many interesting and thoughtful questions at the end of the session. Professor Paul Waring, who had invited me to speak, later said the feedback from the session was very positive, and he has asked me to repeat the performance next year.

Following, is a list of key points I had printed onto a page to leave with the students. I thought they might be of interest to you. If you have some other suggestions, I would be pleased to consider them for next year.

— Lyn Swinburne

Introduction: The cancer world is a foreign experience for most people. You may be dealing with this on a regular basis, but this may be the first time your patients had had to face, not only this alien world, but their own mortality. You have the power to make an incredible difference merely through your approach to their management and care.

Point 1: Focus on the woman, not merely the tumour. Each patient will have individual needs and these may change with time. The woman’s social and psychological needs must be addressed, as well as the physical aspects.

Point 2: Consider your relationship as a partnership. Offer your expertise and experience to guide her, but encourage her to speak up, ask questions, raise concerns and make decisions.

Point 3: Work within a team. You cannot be everything to her, so make sure she is offered the services and contacts she needs to help her on the cancer journey.

Point 4: Offer useful information (oral and written), be prepared to repeat this and give her time to digest it. Don’t rush her!

Point 5: Show your patient that you care. Be kind. Let her know you are on her side. Sometimes relatively small gestures can mean the world. Offer hope at all times, but no false reassurances.

Point 6: Consumer advocates are powerful stakeholders in the breast cancer arena, capable of and passionate about influencing government, the media, scientific and medical worlds to improve outcomes for people affected by breast cancer.

You’re not yet on our mailing list?

Phone (03) 9805 2500 or 1800 500 258 (free call), or fax (03) 9805 2599, e-mail beacon@bcna.org.au or fill in this coupon and send it to:
Breast Cancer Network Australia, PO Box 4082, Auburn South, Vic 3122

Name: ...........................................................................................................
Address: ...........................................................................................................
.................................................................................................................. State: ............. Postcode: .............
Phone: ( ) ...........................................  E-mail: .........................................

Have you had a diagnosis of breast cancer? □ Yes □ No
September 6: Kids Space Indoor Play Centre BCNA fundraiser, 56 Keys Rd, Moorabbin, 7-10.30pm. Family ticket $25 (2 adults & 2 children), extra child $5 and adults $10.

Contact: Linda, (03) 9706 2280.

September 17: Tesselaar’s 2003 Tulip Festival. All funds raised on ‘Ladies Day’ to be donated to BCNA. Tesselaar Tulip Farm, 357 M onbulk Road, Silvan, Victoria.

Contact: (03) 9737 9811.

September 20: Consumer workshop at the 4th Scientific Meeting of the Australasian Society for Breast Disease, Marriott Resort, Surfers’ Paradise, 9.30am-1.15pm. Cost $7.

Contact: BCNA, 1800 500 258 (free call).

September 20: Breast Cancer Action Group general meeting, Level 7, Storey Hall, RMIT Melbourne, 7-9pm – Judy Shepherdson and M arlene Parsons on rural women’s issues.

Contact: Sue Lockwood, (03) 9878 0736.

September 21: Breast Cancer Action Group NSW meeting, YWCA Sydney – Diet and breast cancer: before and after; myths and certainties.

Contact: Sally Crossing, (02) 9436 1755.

October 1: Gympie ‘Bosom Buddies’ Support Group (meets first Wednesday of month).

Contact: Lou Beresford, (07) 5484 8913

October 4: Glitter Ball, Plaza Ballroom, Regent Theatre, Collins Street, Melbourne, 7pm. Tickets $150. A ll proceeds to BCNA’s My Journey project.

Contact: Leanne Bradford, (03) 9844 5446 or lee.bradford@bigpond.com

October 4: Tasmanian Breast Cancer Network meeting, Campbell Town Fire Station, 10am-3pm.

Contact: Karen Forster, (03) 6236 4422, or Joan Williams (03) 6424 5886.

October 6: Bundaberg B’rest Friends Support Group, CWA, 9.30am (meets 1st Monday of month).

Contact: Bev Cross, (07) 4155 6016.

October 6: Fit and Healthy Women’s Breakfast, Melbourne Sofitel Hotel, 7-9am. Cost $49.50. Proceeds to BCNA.

Contact: (03) 9572 3334 or info@fithealthy.com.au

October 8: Fit and Healthy Women’s Breakfast, Sydney Westin Hotel, 7-9am. Cost $49.50. Proceeds to BCNA.

Contact: (03) 9572 3334 or info@fithealthy.com.au

October 11: Bundaberg’s B’rest Friends Support Group (working girls) meeting, Signatures, 10am (meets 2nd Saturday of month).

Contact: Bev Cross, (07) 4155 6016.

October 17: Fit and Healthy Women’s Breakfast, Brisbane Hilton, 7-9am. Cost $49.50. Proceeds to BCNA.

Contact: (03) 9572 3334 or info@fithealthy.com.au

October 19: ‘Days of Spiritual Renewal & Encouragement – A Loving Way of Life’ with Stephanie Dowrick, Naamaroo Conference Centre, Chatswood West, NSW.

Contact: Alexandra Gorman, (02) 9958 4402.

October 24: Advanced Breast Cancer Forum, Park Hyatt, Melbourne, 9.30am-4pm.

Contact: Inner East BSEP, (03) 9276 3890 or s.galetakis@alfred.org.au

October 24: ACT Cancer Council’s Pink Ribbon Day Breakfast, Hotel Kurrajong, Barton, 7.30am.

Contact: Nicole Stone, Cancer Council, (02) 6262 2222.

October 25: Bakers Delight Field of Women promotion – Bakers Delight store will donate 50¢ to BCNA for every $2.60 loaf sold at any of its stores.

October 26: A nnual church service, St George’s Cathedral, Perth, midday. Speaker: M aria Walters.

October 26: Field of Women, Hobart Cenotaph, Tasmania.

Contact: Michelle Rule, 1800 500 258.

October 26: Dragon’s A breast Regatta Southern Cross Yacht Club, Canberra.

Contact: lan.on.askorich@bigpond.com.au

October 26: Sunshine Coast: ‘Bums on Bikes’ BCNA fundraiser – $50 for ½ hour coastal ride on Harley Davidson or $10 motor bike rides available.

Contact: Narelle, (07) 4152 7723.


October 27: NBCC’s Pink Ribbon breakfast, Westin Hotel, Sydney.

Contact: (02) 9036 3030.

October 27: ACT Cancer Council’s breakfast. Canberra.

Contact: 131 120.

October 27: Bosom Buddies Cocktail Party, Boat house by the Lake, 6-7.30pm, $35.

Contact: Pam Robertson, (02) 6281 0957 or pamrob@tpg.com.au

October 29: Young Women’s Network of QCF (Brisbane) – Practical Supports. Guest speaker: Kathy Kuipers.

Contact: 131 120.


Contact: (07) 3232 7596.

November 5-9: 9th A ustralian Masters Games (inc. Dragons A breast A ustralian Survivors Challenge and Flowers on the Water ceremony).

Contact: Elspeth, (02) 6239 6344 or visit www.dragonsabreast.com.au for full calendar of events.

November 7: NBCC/BCNA Breast Cancer Forum, Calvary Hospital, Canberra. Keynote speaker: Prof. Don McKenzie, U niversity of British Columbia, Vancouver.

Contact: Anna, (02) 6247 8470.

November 14: Pink Ladies Open Garden Day and Lunch (four gardens on Mornington Peninsula, Victoria).

Contact: BCNA, 1800 500 258.

November 20: Lymphoedema Victoria’s Christmas Lunch, Box Hill Golf Course, Melbourne, 12.30pm.

Contact: Maree O’Connor, (03) 9990 3778.

November 27: Breast Cancer Association of Queensland’s Annual Big Christmas Lunch, Hilton Hotel, Brisbane.

Contact: (07) 3839 6830.

December 7: Breast Cancer Action Group N SW A GM, YWCA Sydney – ‘Laughter is good medicine’.

Contact: Sally Crossing, (02) 9436 1755.