The world of cancer is, for most of us, an alien place: unknown territory for which many of us are inexperienced and ill-equipped. The breast cancer landscape is full of concepts and words we have never before encountered and we do our best to make sense of it all and to position ourselves for the best outcome.

As a community, we are certainly at a loss to express our feelings about a disease which comes unannounced and which shakes our own sense of mortality and steadiness in life. With the passing in 2008 of well-known women such as Jane McGrath and Kerryn McCann, much was written and spoken in the media about these brave women ‘losing their battles’ with breast cancer.

Although I understood that people speaking in this way were well-meaning, expressions such as this are often misplaced. They infer that if they’d fought harder and not given up, then they’d be alive today. Anyone who knew Jane and Kerryn would realise that there is nothing further from the truth. Both women had much to live for – husbands, family and friends who loved them, dreams to fulfil and small children to nurture and see grow up. The truth is that these women’s types of breast cancer were particularly aggressive and that the treatments were ultimately unsuccessful.

There were a number of articles in the media, especially after Kerryn’s death, that took up the issue of language and cancer. A young Melbourne woman, Tamar Paluch, wrote a beautiful piece that was published in The Age newspaper, called ‘Living with cancer is much more than a win/loss equation’. She wrote about her own mother’s upset response to certain terms, including the notion ‘all clear’, citing an old clipping from her fridge about Kerryn McCann headlined ‘Runner beats breast cancer’. You can read Tamar’s piece on our website at www.bcna.org.au > stories > Family & Friends

The truth is we are all living with some degree of uncertainty and we know unfortunately that, with breast cancer, the concept of ‘all clear’ simply does not exist, even though many of us will experience the disease as a one-off set-back.

The theme of this issue of The Beacon is ‘I never thought I would … if I hadn’t had breast cancer’. Women have once again shared their inspiring stories about living life not as victims but as survivors.

I have to say we have been thrilled by the response to our new ‘Survivor’s Pin’ – clearly this struck a chord with many of you, and our sparkly pin will be a sign to all that we have at some time been diagnosed with breast cancer, however we choose to refer to ourselves.

Lyn Swinburne
Chief Executive Officer

If you would like to buy our new sparkling ‘Survivor’s Pin’ visit our website www.bcna.org.au > Visit our shop or call us on 1800 500 258 (freecall).
Over the past few years, BCNA’s Forums have brought women together to hear about the latest in breast cancer treatment and care, meet BCNA representatives and, most importantly, gather and share a cuppa with other women with breast cancer in their local area.

In 2009 we will be presenting BCNA Forums in all states and territories, and supporting some major breast cancer events for women, organised by local groups.

In February 300 women in Sydney heard Associate Professor Michael Bilous and Associate Professor Fran Boyle presented the reasons behind those breast cancer pathology tests and how they help oncologists choose treatment options for women. Stephanie Dowrick motivated the audience to take practical steps to build and nurture their emotional selves after breast cancer.

You can read more about the Sydney Forum on our website, www.bcna.org.au > Events > BCNA Forums.

On 25 March we visit Bendigo, Victoria where our Forum will again feature guest presenters on the latest in breast cancer treatment, and on living well after a breast cancer diagnosis.

BCNA is supporting the Tasmanian Breast Cancer Network’s conference for women in Launceston, on 28 and 29 March. Contact Pauline Watson on 03 6344 8968 or watson_cr@yahoo.com to register.

In April women will come together at our Canberra Forum which will focus on life after breast cancer.

The theme of the forums is ‘Love and Breast Cancer – its impact on women, their families & friends’. See the ‘Upcoming Events’ section on page 16 for registration details.

We could not organise and present these forums without assistance from our Community Liaisons and women from our Member Groups, who help with promotions, setting up on the day, welcoming women and a host of other general leg work involved in presenting these events. Their involvement highlights that BCNA truly is an extensive network of dedicated women.

At this stage, we are planning Forums in all other states and territories throughout the rest of 2009. We will update our website www.bcna.org.au > events > BCNA Forums as destinations, dates and venues are confirmed, and they will also be listed in future issues of The Beacon.

MRI rebate

The Minister for Health and Ageing Nicola Roxon’s announcement of a new Medicare rebate for MRI (Magnetic Resonance Imaging) screening from February this year is great news for women at high risk of developing breast cancer.

To be eligible women must be under the age of 50 and have a strong family history of breast cancer, or carry a known genetic mutation such as BRCA1 or BRCA2. The rebate does not apply to women who have already been diagnosed with breast cancer.

Women who meet these criteria are usually advised to have an annual MRI scan as part of their regular screening program. This is because MRI can be more effective in detecting early signs of breast cancer in younger women who tend to have dense breast tissue, often making it difficult for doctors to read a mammogram.

To claim the rebate women need a referral for an MRI scan from a breast cancer specialist. In addition, the MRI must be conducted by a Medicare-eligible provider. It is therefore advisable to check the provider’s Medicare eligibility before making an appointment for a scan.

Further information about the MRI rebate, including the full eligibility criteria, is available on BCNA’s website at www.bcna.org.au > Information > A-Z > MRI rebate, or phone us on 1800 500 258 (freecall) and we will post a copy to you.
Issue of concern

I never thought I would have to pay for my mammogram after breast cancer

‘It seems wrong that women who have had a diagnosis of breast cancer and have had to cope with all the associated costs, should then have to pay for their mammograms, while those blessed with not having the disease get theirs free.’

Many women may be surprised to find that, after completing their treatment for breast cancer, they often have to pay for their follow-up mammograms. Previously many of these women were eligible for free mammograms under the BreastScreen program.

‘Friends and family could not believe that I was further out-of-pocket (for mammograms) after experiencing all the expenses last year and what with the ongoing cost of medication now.’

In response to women’s concerns, BCNA invited 250 women with breast cancer to complete an online survey. We asked women about the out-of-pocket costs related to their mammograms and invited them to comment on the impact of these costs. We received completed surveys from 160 women. Most of the respondents were women with early breast cancer. There was a good spread of women from across Australia.

This is what we found:

**Cost of mammograms**

Most of the women surveyed were having annual follow-up mammograms after their breast cancer treatment. Sixty-three per cent of women having mammograms contributed to the cost. There was great variation in the charges. While some women paid under $50, and one woman paid $400, the cost to most women was between $50 and $150.

**Cost of ultrasounds**

The trend was similar for the 67% of women having ultrasounds. Sixty-four per cent of these women incurred out-of-pocket costs. The cost to most women was between $51 and $200.

**MRI (Magnetic Resonance Imaging)**

Twenty-one women reported having breast or full-body MRI scans after their breast cancer treatment, usually in response to a particular concern, or because of their age. Around 39% of women having MRIs were between the ages of 31 and 50 years. While MRI is not usually part of regular follow-up care, it highlighted that some women do incur this additional cost – sometimes up to $700.

Women’s comments confirmed the strong feelings that had been previously expressed to BCNA. Around a third of respondents stated that tests, with a particular focus on mammograms, should be available at no cost.

‘… consideration must be given to making these services (ongoing tests after breast cancer) totally rebatable or free of charge.’

Overall, many women felt that the costs of these tests added to the already substantial burden of breast cancer.

‘Add the cost of hormone therapy and other medication… follow up visits with surgeons, GPs, day charges in hospital, mammograms and ultrasounds, and you have a very high ongoing cost …’

Some raised their concern that the costs of the tests may be prohibitive.

‘I am very pleased that this issue is being addressed. It is quite expensive to have the essential annual follow-up mammograms/ultrasounds – I worry that some women may not have them for that reason.’

It was found that women in rural areas and younger women were particularly affected by the costs of these tests.

‘The costs of a mammogram for the under 50s in some cases is prohibitive, especially in the country where you have to travel a 100 kilometres – so a day off work, organising the children for after-school care, then the cost of petrol and the procedure. It should be free …’

**Where to from here?**

BCNA has written to the Federal Government, the National Breast & Ovarian Centre and other key agencies to inform them of the results, with a view to improving outcomes for women around this issue. We will keep our members informed on progress through updates on our website and in The Beacon magazine.

To read the research report The out of pocket cost of follow-up care: Mammogram, ultrasound and MRI, visit www.bcna.org.au > Policy and advocacy > Research reports and surveys, or phone us on 1800 500 258 (freecall) and we will send you a copy.

We would like to thank all the women who participated in this survey. If you would like to get involved in future research surveys you can join our Review & Survey Group. Visit www.bcna.org.au > Policy & Advocacy > Seat at the Table > Get involved or phone us on 1800 500 258 (freecall) for more information.
Kathryn Watts and Clare John are breast care nurses at Sydney’s Mater Hospital for Cancer Care and Research. They support women before, during and after their breast cancer surgery. Kathryn and Clare spoke about some of the changes that women make in their lives after breast cancer.

Kathryn: All women are heroes in their own way. Everyone deals with things differently. A few women go into meltdown on hearing the word ‘cancer’. A few weeks after the surgery, they might come around and talk about it. Over time, they get there.

For some women, having breast cancer raises unresolved issues. Some have been angry or defensive. It’s our job to listen. It’s important that women feel they can tell you anything. Even if women are struggling, they often keep going with their jobs, keep taking kids to sport, or looking after elderly parents for example. There are a lot of quiet achievers out there.

Clare: In the first year after a diagnosis, for the most part, women are adjusting to the effects of treatment. They may experience fatigue and side effects from hormonal treatment for example. Often at this time they are really getting used to the ‘new normal’. They may find it hard to find positives in the breast cancer experience. Once things settle down, we often hear that women have made positive changes in their lives. They may change their diet, or join a gym or a group such as Dragons Abreast. Some find that they become closer to family or to a colleague who turned out to be very supportive during the course of their treatment. In general, women may look to decrease stress in their lives, and increase their overall quality of life. Sometimes having breast cancer is a wake-up call to make a major change in one’s life, such as to leave a stressful job or an unsupportive relationship. A few women have gone on to do volunteer work in the cancer sector. Many women start to put themselves first, instead of prioritising everyone else’s needs.

Kathryn: There are also the women who have the drive to do things in a more public way, like fundraising for example. One woman we know has put her energy into marathons. She plans to run in a multi-marathon across the Simpson Desert in September this year, with a view to raising $250,000. She is only one year out of treatment, and her enthusiasm is contagious.

Another young woman has written a book, to be published this year, for kids whose mums have early breast cancer. She now has secondaries, and is writing a book for kids about that.

And yet another has changed her diet radically. She hasn’t had a soft drink or a coffee in three and a half years. Her perseverance is amazing. We still can’t believe that she hasn’t had a chocolate in all that time!

Clare: It is our experience that, in the long run, having breast cancer seems to give women coping strategies to help deal with other things that might arise in their lives. The majority of women make some great changes, and go on to live long, fulfilling lives. This is the most rewarding part of our job.

When women gathered at the first BCNA National Breast Cancer Conference in Canberra in 1998, they placed breast care nurses at the very top of the list of important issues for women diagnosed with breast cancer. Since then, more and more women have been supported by dedicated breast care nurses, such as Kathryn and Clare (see above), at a crucial time in their breast cancer journeys.

The McGrath Foundation now champions the creation and appointment of new breast care nurse positions across the country and we are proud to support them in their efforts. Thanks to funding recently provided by the Australian Government, the McGrath Foundation is looking to appoint new breast care nurses in another 44 communities across the country within the next 12 months. Most of the appointments will be in rural and regional locations, where many women have previously missed out on this valuable and essential support.

New McGrath breast care nurses in 44 communities

For more information and to see which Australian communities will have a new McGrath breast care nurse in the coming months, visit www.mcgrathfoundation.com.au/nurses. We will update you as the new positions are filled in upcoming issues of The Beacon.
Flamin’ Dragons

I was diagnosed with breast cancer in March 2004 and after a lumpectomy and radiotherapy settled back into my life in Port Macquarie. Towards the end of that year I heard from a friend that she was going to try paddling with Dragons Abreast. I thought I would like to try this but at 70, and walking with a crutch, wondered if it would be possible, but when my surgeon gave me the OK I went along and was totally hooked. I’m not a good look getting into the boat but, once in, I thoroughly enjoy paddling on the river. I’ll never be a brilliant paddler but the joy of being in a happy boat is one of the best experiences in life.

Although I don’t compete anymore I have competed in regattas on the Wyong, Georges and Clarence Rivers and at the Olympic Rowing Centre in Penrith. My sons were open-mouthed at the sight of me drenched with perspiration after racing! I also competed in Abreast in Australia, in Caloundra, Queensland, last year. It was a huge thrill to be part of a regatta for breast cancer survivors with over 2300 women from various countries attending.

My club, Flamin’ Dragons Abreast, had less than a boatload (20) when I joined but the club now has almost 82 members, both survivors and supporters. I never thought I would be paddling on the river in a dragon boat at my age, much less be president of the club. I have met the most wonderful women along this journey: they are the happiest, bravest, kindest good friends to me and I have had many, many wonderful times with them and their partners. We support each other when needed and I am indebted to breast cancer for making it all possible.

Jan Barnard
Port Macquarie, NSW

Moon bear rescue

I was diagnosed with breast cancer in February 2004 when I was working full-time as a primary school teacher. After a mastectomy I became ill with depression and retired from teaching. This was a huge life change and led me to choose two activities which I never thought I would be involved in.

First I joined a Dragons Abreast team. As part of this team I have travelled to international regattas in Singapore and Caloundra and numerous times to Sydney, Grafton, Port Macquarie and Taree for local regattas. Paddling in a local dragon boat team is fun, exciting and hard work and I love it. Through this sport I have also met many inspiring, joyful and loving friends who have enriched my life.

I also retrained as a vet nurse so that I could work with animals and this enabled me to experience the most rewarding time of my life. In July 2008 I travelled to the Moon Bear Rescue Centre near Chengdu in China established by the Animals Asia Foundation. For 16 weeks I worked mainly as the small animal carer looking after cats and dogs, many of whom were victims of the 2008 earthquake. What a joy it was to restore these delightful animals to good health, animals who were often disabled or had been neglected but who took joy in simple pleasures and had boundless love to share.

Every day as I walked my dogs around the sanctuary I also saw the Moon bears enjoying their freedom – eating, playing, swimming and snoozing. After years of cruel treatment on bear ‘bile’ farms, trapped in tiny cages, they are now free to enjoy life in peaceful natural surroundings.

Anne Ditton
Forster, NSW
Becoming a Fenceliner

I am fond of telling people that breast cancer isn’t the worst thing that’s ever happened to me, not that I could see that when I was diagnosed in 1996 and undergoing radiation and chemo.

Four years later I read in our local paper about a group of survivors doing a 1000km bike ride around Tasmania with a group called Fenceliners. I knew the trip was for me.

I trained hard on my new bike and set off to join them in March 2001 and it’s the best adventure I’ve ever had. I learned more about breast cancer, met some wonderful survivors and made life-long friends, plus saw Tasmania and got fit. Undulating became a swearword. There are a few hills down in Tassie!

After the trip I joined the Fenceliners’ committee and helped organise the fourth adventure – a 500km walk of the Hans Heysen trail in South Australia in 2003.

During our trip we talked to different groups at night about who we were and why we did these adventures. We wanted to prove that having had breast cancer was not a death sentence. I’m sure we got the message across many times. After all, we were living proof of survivors not sufferers. Both trips were filled with fun and laughter and I’m grateful I had breast cancer so I could join them. It’s just one hell of an entrance fee!

Sue Lane
Browns Plains, Queensland

Talking about expensive treatments

‘Doctors shouldn’t make judgements on whether or not women, rich or poor, can afford a drug – we should all be given the opportunity to use the drug rather than shutting the door and making assumptions.’

Many of our readers know how expensive medications for women with breast cancer can be. Drugs such as Herceptin and Tykerb cost thousands of dollars before they were made available at no cost through the government’s Pharmaceutical Benefits Scheme (PBS).

Research has shown that many oncologists worry about talking to women about expensive treatment options. They are often concerned about causing distress to a woman and her family if it turns out that she cannot afford to pay for the treatment.

We decided it was important to find out whether women who have had breast cancer actually want their oncologists to tell them about costly drugs, and if so, how they would like that communicated, or if they would rather not know about them.

BCNA worked with researchers from the University of Sydney to develop a survey to ask women this question.

Forty-seven women from across Australia participated in the survey. Just over half the participants had secondary breast cancer.

Ninety-six per cent of the women involved in the survey told us that they would want to discuss an expensive drug with their oncologist, even if they were unlikely to be able to afford it.

We also asked women what style of communication they would like their oncologist to use. Eighty-seven per cent said that they preferred their oncologist to take an honest and direct approach when discussing expensive drugs.

‘My doctor is very upfront about things. He’s not warm and fuzzy, but he’s very consistent and that is very reassuring.’

Women told us that taking an upfront approach could include asking how much information they want, and what kind of information they want.

‘In an ideal world it would be great if your doctor found out how much you wanted to know before diving in.’

Eighty-nine per cent of women said that they were comfortable discussing their financial situation with their oncologist, with some women noting that they had discussed far more personal issues with their doctors.

These findings are being used by others in communication skills training for breast cancer clinicians. We will continue to seek opportunities to promote the outcomes to women and their doctors.
February 2008 marked the fourth anniversary of my breast cancer treatment and my first article in the Medical Journal of Australia (MJA).

Breast cancer has given me a challenging and exciting chapter in my life, which has seen me stretch my own abilities with a host of new life experiences. Never for a moment could I have foreseen the evolution of events that followed that devastating diagnosis; and it has all been good. I owe my life to early detection and modern medicine and I wanted to find a way to say thank you. I volunteered to be in the Sentinel Node versus Axillary Clearance (SNAC) clinical trial but I knew I could do more.

When I gained weight I looked to natural remedies. I researched what was available to see what would work for me, only to be disappointed. As a computer professional and scientist, I soon became aware of the lack of patient-friendly and evidence-based information on complementary and alternative medicine (CAM), so I used my skills to create an advertising-free, health information website that is now number four in the world in its field. Then, focusing on weight management, I identified more than 1000 government-approved, but ineffective, products. This detailed research, which I presented in my persona of ‘The Jelly Bean Lady’, led to television, radio and published articles including the MJA report that I had collaborated on with other scientists. Because of our work, new guidelines for weight loss products have now been written.

I know that I can still do more. With the growth in usage of CAM and with access to a worldwide range of CAM research, I would like to continue focusing on ways to improve the wellbeing of cancer patients through integrative medicine. I have already been invited to participate as an informed consumer in several research projects. My next chapter has begun.

Loretta Marron
Burpengary, Queensland

I was diagnosed with breast cancer in 2002. It was the long stay, during treatment, that I had at Jacaranda House, attached to the San Hospital at Wahroonga that gave me time to rethink where I was going in my life.

I did try returning to work part-time, but realised that too many bits of my mind and spirit had been jangled by the experience. I couldn’t return to where I’d been.

When I had a second ‘scare’ – luckily a false alarm – I decided to reorganise what I was doing and how I was living.

The local Breast Cancer Support Group was wonderful – not all gloom, doom and medical in content – but a safe, interesting and supportive group of women of all ages and stages of their ‘journey’. I look forward to our monthly meetings, which help me not only to catch up but to move on.

However, the most rewarding thing I have done is take up singing, in the safety of a choir. A friend told me she was going ‘Singing in Paradise’ and asked if I wanted to go. I said ‘I can’t read music, don’t think I can sing and have never been in a choir since primary school’. Despite this I went to Fiji for a week as part of an a cappella choir and was hooked.

That was in November 2007. It was so good I went back in May 2008 and have also joined ‘Sing Australia’.

So, my priorities now are to be as happy as I can be, not in the hedonistic sense but to seize the day – carpe diem. For too long I felt the glass was half empty, not half full and I defy anyone to feel depressed when they are singing in a choir. The heart and soul are too bound up in the song to deviate sideways.

Marika Privett
Port Macquarie, NSW

Loretta the Jelly Bean Lady.
An artist’s muse

I never thought I would be an artist’s muse. I could never have imagined that at 48 and as an avoider of communal changing rooms, I would sit naked in an artist’s studio.

Shortly after having a wide local excision for breast cancer I enrolled in a life drawing class. ‘I wouldn’t mind being a model sometime’ I half joked to John, my art teacher, ‘I’m an interesting colour at the moment with two prominent red scars and blue dyed skin’. Later I was far from sure that this was something I could see through.

However, I had recently been half-naked with complete strangers, had my breasts squashed by mammogram plates, lain under the gel of an ultrasound probe, had a piece of breast tissue cored out for biopsy, and radioactive isotopes injected around my nipple. Finally my breast had been cut open from nipple to chest wall. It was all very necessary, all very medical.

This, I reasoned, was about restoring balance into my life, bringing slowness, softness and gentleness. This was about curves and contours, beauty and light. This was transcending the merely medical and was about triumph and life.

So I took off my clothes, and was just me. A woman, comfortable in my altered body, looked at for proportion and colour, for light and shadow, for the wonder of life. This was my way of weighing art against science and leaving me whole.

After that first time I returned every week to the studio. This continued through chemotherapy, hair loss and radiotherapy. Some of the paintings were beautiful, some very confronting. All were truthful. John was dealing with his own on-going journey with a rare genetic cancer and what resulted was something about both of us, expressed in paint and charcoal. An exhibition is planned entitled ‘Muses — Inspiration and Intimacies’. A year after my diagnosis I am feeling well, confident and hopeful about the future.

Being an artist’s muse was an intrinsic and tangible part of my recovery from the physical and emotional challenges of breast cancer and treatment. I cannot finish this without acknowledging my exceptional husband Paul, who has shared my medical and artistic journey with me, slightly bemused, but always with love.

Sarah Holmes
Canberra, ACT

Tree change

On a good day, during a long course of treatment, I was pottering around my inner suburban garden. We had tradesmen in the house and one of them observed me from the verandah as he enjoyed his morning cuppa. Something in what I was doing prompted him to ask, ‘You a country girl are ya?’. Without thinking, I answered, ‘Only in my dreams’.

I had breast cancer in 2000 and another primary cancer in 2002, so there were years of treatment and illness. Yet here I am in 2008, living in the country, joyously tending a large food garden, revelling in the physical work, followed around by a beautiful flock of purebred chooks, enjoying the peace.

Somehow cancer gave me the breathing space to reassess, to articulate the ‘dream’ and gradually bring it to reality. It’s not that I set out consciously with a plan but rather cancer called ‘STOP!’ and then recovery allowed me to go on in a new direction. Change became possible in the present, rather than in a distant future idea, once my ‘normal’ life was interrupted.

I sometimes ask myself whether I would be here if I hadn’t had cancer. I don’t have the answer to that question, just the knowledge that here is where I want to be.

Judy Margolis
Portarlington, Victoria
Having had two benign lumps removed from my left breast I wasn’t too worried when I found a lump in my right breast. So when I saw my doctor after my mammogram the last thing I expected to hear was ‘Sorry Jane this is a nasty one’.

My appointments with the breast surgeon were a blur, especially when she told me I would need to have a mastectomy. I do, however, remember saying to her ‘I don’t have time for this’. With the support of my fantastic family and friends I have not let this horrible disease slow me down.

In September 2008 I walked the Kokoda Track, which is something I never thought I could do. However, having had breast cancer, I now go through life with the attitude ‘live life like there is no tomorrow’ and I am very thankful that there is!

Kokoda was physically very hard but the most amazing experience and one which I will never forget. The people I went with were terrific, everyone supported each other and the local PNG people are very caring; I couldn’t have done the track without my porter Buddy. We walked 96km in seven days, eight nights.

I’m proud of my group and feel honoured to have shared a very emotional journey with them. I now feel I can conquer the world!

Jane Ashcroft
Red Hill South, Victoria

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**Becoming a storyteller**

In 2004, while working as the director of a child care centre, I was diagnosed with breast cancer.

Following a mastectomy and chemo, I returned to work. I found that there were few appropriate resources to help my preschoolers understand the issues related to cancer. So began a new journey for me. I wrote a picture book based on my own story and the book *Safina and the Hat Tree* was published in 2004. It is currently listed as a useful resource and tool by BCNA and the NSW Cancer Council to help young children in their understanding of cancer. Writing this book was enormously fulfilling, as I always had a desire to write a children’s book, but I would never have thought that it would be one related to a personal journey.

Since writing the book, I have stopped working as a director and commenced storytelling; doing performances in preschools using stories, song and dance, masks, puppets and hats and sharing magic time with these young children! I continued on this career path until January 2008 when I was diagnosed with cancer in the other breast. Throughout the year, following a mastectomy and treatment, I have rekindled my creativity, working together with a dear friend creating a storytelling quilt to help me express and reflect on the emotions of this current journey. Again, I would never have believed that one day I would work on a project involving fabric, threads, design, colour and drawing skills I did not know I had!

I believe my cancer journeys have allowed me to explore a creative self which had been lying dormant for many years. I continue to be creative in writing stories for my grandchildren and engaging them in storytelling performances, and hope in the near future to be able to return to storytelling professionally.

Cynthia Hartman
Thirroul, NSW
I never thought I’d fall in love again

My husband Maurice and I met through work and married in 2000. There is not much surprise in our life and everything is just normal. As we don’t have kids most of our fights were related to ridiculous things; for example I complained that he has never shown enough passion towards me in public. Sometimes when we walk our dog together, he tends to walk in front of me and I walk behind.

Also, I hate to see Maurice always wearing shabby clothes, even when attending important occasions. One time when we rushed to a friend’s party, I realised he was wearing an old t-shirt that had a stain on it. So I had to drag him to the nearest shop to buy a new shirt. That night all I heard was him whingeing about my wasting money on unnecessary things and that it was really making him uncomfortable to dress formally.

To me Maurice is a stubborn person who likes to follow his own rules. He doesn’t like to get his hair cut, he doesn’t like to attend parties and he doesn’t like to meet new friends. A few times we got into serious arguments because of our differing opinions. I cried so much and wanted to leave him. I seriously doubted if our marriage could last forever. He was such a different person and all we seemed to do was argue.

Last Wednesday I had a mastectomy after I was diagnosed with invasive breast cancer. I woke up feeling so weak but the first thing I saw was Maurice wearing very formal clothes, jumping up and down with tears, and kissing me everywhere in front of the nurses, saying ‘Honey, I love you, I love you, I love you!’... the Doctor said you are okay and I am going to be good, I went to have a hair cut for you’. I burst out laughing.

So if you asked me when I really decided that I will spend the rest of my life with this man, love him dearly, deeply for the rest of my life, until death do us apart, it was at 8.30pm on the 3rd of December, 2008.

Stephanie Hsu
Epping, NSW

Becoming a hospital chaplain

I never thought I would be a Pentecostal hospital chaplain. If my life had not changed after breast cancer, I certainly would not be visiting patients in hospital. I had never envisaged doing this with my life.

I now meet many wonderful, brave people suffering all kinds of medical conditions. The work is very rewarding to me personally as from time to time I meet the whole family, relatives, the husband or friends. I meet so many caring people as well as nurses tending to their patients. My husband is also a hospital chaplain at the same hospital; he visits the men and I visit the women.

The other passion I have had for almost 20 years was to re-visit Italy, as our first visit was a long time ago and quite short. After collecting information about Italy for years, we decided it was time to go. We went in the spring last year for nine weeks. We booked a 500-year-old cottage in a hill town in Umbria for a month. The entire trip was wonderful and we met many interesting people.

Joan Brown
West Beach, South Australia
My story

I never thought I would …

On my 35th birthday in September 1979 I never thought I would be diagnosed with breast cancer, however a month later I was. My children were aged 8 and 10.

At the time I thought I would never see my two daughters grow into wonderful mothers. They now each have three children. I take great pleasure in watching their development and being involved in the nurturing of five granddaughters and one grandson.

I also thought I would never complete a further nine years of study, finally achieving a Bachelor of Business in 1986. I am still working as a self-employed accountant.

I never thought I would get to see more of our wonderful country but my husband and I have undertaken extensive travel. We have driven more than 150,000km around Australia and New Zealand. These trips allow me to indulge three passions—planning the trips, photography and collecting books on Australian history and Australian travellers’ tales. I have written and illustrated a book based on our travels for our grandchildren.

Some of the other things I thought I would never do but now have:

- drive the infamous Gibb River road
- do a sunrise walk to the summit of Mt Kosciuszko
- be a passenger on several mail runs in the outback
- climb the sand dune called Big Red in the Simpson Desert
- be shown sacred Aboriginal tribal lands by an elder in the Pilbara
- spend time inside the enclosure with cheetahs at the National Zoo in Canberra.

As I approach my 30th anniversary on this journey, I can say that I never thought I would see my 65th birthday. To celebrate I am planning two trips. The first will be 30 days driving around Tasmania and the second will be 30 days driving around Australia taking in all the mainland states.

Barbara Satterley
Lockleys, South Australia

I never thought I would …

• fly in an open Tiger Moth plane
• drive the infamous Gibb River road
• do a sunrise walk to the summit of Mt Kosciuszko
• be a passenger on several mail runs in the outback
• climb the sand dune called Big Red in the Simpson Desert
• be shown sacred Aboriginal tribal lands by an elder in the Pilbara
• spend time inside the enclosure with cheetahs at the National Zoo in Canberra.

More stories

You can visit our website at www.bcna.org.au > Stories to read more personal stories from women and men about how breast cancer has affected their lives.

Also visit www.bcna.org.au > Stories > Seeking stories to see what types of stories we would like to receive for future issues of The Beacon.
In Part 1 ‘Put your diagnosis into perspective’ Kerslake discusses many commonly held misconceptions, including the origin of cancers. His theory is that since it is not known how or why the cancers form, it is therefore much more important for people to focus on their recovery. This struck a chord with me, as did his statement that the cancer patient has not helped create the cancer. These are both statements that we know to be true, but it is comforting to have them repeated!

As this book was written by a survivor, I feel that it is most suited to people who are in recovery, or who are post-treatment and are looking for a bit of reassurance and help in moving forward. It is designed to be a handbook that you can refer to when needed and not necessarily read cover to cover.

I do not entirely agree with all his methods and ideas, but acknowledge that they have certainly worked for him, and therefore other readers may be able to relate them to their own circumstances and benefit from them.

It is a concisely written book and provokes much thought. I recommend this book because of its positive uplifting content and ‘you can do it’ attitude.

Marlene Fiebiger
Goolwa, South Australia

Polly’s ability to ‘go with the flow’ and the opportunities the Lions’ Club of Australia gave Polly by opening up a new world of friendships and camaraderie from others around the world, were admirable.

Polly is an inspirational person who has been able to bring the ‘breast cancer crusade’ to places where it had usually been a subject that was not openly discussed, an encouraging sign for women across the world that this subject should be heard.

The DVD is a thoroughly enjoyable walk that enabled me to travel, albeit through Polly’s eyes, to places in the world that I would never have been able to visit. I hope Polly’s friendships made on this journey stay with her forever.

Marie Craw
Werribee, Victoria

The DVD is available for $24.95, plus postage, from our website at www.bcna.org.au > Visit our shop.
The Hills Cancer Support Group, in Mount Barker, South Australia, has been running for three years and places a strong emphasis on supporting its members through friendship and laughter.

‘We are a fun group,’ says group coordinator Mary Haimes. ‘We support one another in times of need, but know the importance of letting our hair down and having some fun.’

The group meets monthly at Mount Barker Hospital. Most are breast cancer survivors, but the group caters for people with all cancers, including one brave man.

‘Our volunteer facilitator, Bette Barrow, helps to make the group so successful,’ Mary said. Bette is a former palliative care nurse and organises a guest speaker for the group every three or four months.

‘One of the most helpful was a grief counsellor,’ Mary said. ‘Our group has lost three members and the counsellor helped us with strategies to cope during the final stages of a person’s life and afterwards.’

Another valuable speaker was a physiotherapist, who talked about osteoporosis and gave the women some useful tips to help them better manage their daily household tasks.

In between meetings, the group organises social activities including lunches, coffee mornings and movies. They hold an annual Melbourne Cup Luncheon, wearing ‘mad hats’ and enjoying each other’s company.

The group also enjoys pampering days run by the Adelaide Hills Community Nursing Service. The group works quite closely with the Service and in 2008 combined with them to host a Mini-Field of Women. ‘We will definitely do that again in 2009,’ Mary said. ‘We also make sure new members know about the My Journey Kit and Hope & Hurdles Pack.’

Over the past two years, several group members have attended a five day retreat at Yorke Peninsula, organised by the Peninsula Palliative Care Service. ‘This is a week of fun and information, and an opportunity to let our hair down,’ Mary said. ‘Last year we performed plays and even an Abba routine.’ The nine members who attended were so thrilled that they have convinced more to attend in 2009.

Joy Ayres, Rosemary Ingles, Mary Haimes and Iby Horton (front) join in the mad hatter fun at the Hills Cancer Support Group Melbourne Cup Luncheon.

Profiling our Member Groups

The Hills Cancer Support Group

Linking together

Over the past 10 years one of BCNA’s key priorities has been to link together Australians personally affected by breast cancer.

The 208 breast cancer groups around Australia that have come under the BCNA umbrella as our Member Groups are essential in linking women together.

We welcome the following new BCNA Member Groups:

• Bega Valley Pink Links Breast Cancer Support Group, NSW
• Bendigo Cancer Support Group, Vic.
• Dragons Abreast Wagga Wagga Inc, NSW
• Livin’ Laughin’ and Lovin’ It group, Townsville, Qld
• Mayflies (secondary cancer support group), Wodonga, Vic.
• Stanthorpe Cancer Support Group, Qld
• Young Women’s Network Group – Toowoomba, Qld

You can visit our website to find a Member Group, including support groups, in your state or territory at www.bcna.org.au > About BCNA > Member groups.

BCNA also has 32,000 individual members across Australia.

Our members are women, men, their family members and friends who have been affected by breast cancer and subscribe to our Beacon magazine.
Thank you

We appreciate the financial support given to us by individuals, clubs, organisations and companies around Australia. We would especially like to acknowledge the help of the following recent outstanding supporters:

- ACT Dragons Abreast
- Athletics Australia
- Ballarat and Clarendon College, Victoria
- The Berlei Group
- Berwick Balcarra Social Club
- Robert Boysow
- Braces ‘n’ Faces Orthodontics – Paul Buchholz
- City of Casey, Victoria
- Collins Food Group
- Effective Freight Management
- G-Force Recruitment – People At Work
- Hope Young and Ina Fuhlbohm
- Juriina Demaine
- Chris Kelly
- Kingswood Golf Club, Victoria
- Jodi, Michele and Laura Kirkby
- Laidley Hospital, Queensland – Lorraine Prole
- Le Reve Pty Ltd
- Lion Nathan
- Manildra Group – The Honan family
- The Michael and Andrew Buxton Foundation
- Montmorency Secondary College, Victoria
- nabCapital – National Australia Bank
- Pink Lady Golf Day – Committee, Victoria
- Pymble Ladies College, NSW
- Roadhouse Café – Cheryl Davis
- Roost Homewares
- Rubegg 4 Hair – Sandy Banks
- Roth Charitable Foundation
- Sacred Heart Primary School, Kew, Victoria
- WA Institute of Fashion and Textiles, Swan TAFE
- Weipa Bowls Club, Queensland
- WA Institute of Fashion and Textiles, Swan TAFE
- Weipa Bowls Club, Queensland

Memorials

We pay tribute to the lives of:

- Anthony Avery
- Heather Growse
- Janice Burke
- Jane Parks
- Karyn Warren
- Kerryn McCann
- Linda Evans
- Linda Wordie
- Lorna Gibson
- Marlene Dixon

We are grateful for the donations we received in their memory.

Celebrations

Thank you to those who celebrated a special occasion and asked for donations to BCNA in lieu of presents. Congratulations to Carly Nairn and Simon Bryant on their recent wedding.

On Saturday 10 January 2009, the inaugural Pink Lady Fundraising Day was held at Kembla Grange Racecourse. Bakers Delight bakeries across Wollongong hosted the day and more than $15,000 was raised for BCNA. Thank you to all who supported the day.
Pink buns are on their way

The Pink Bun campaign for 2009 is fast approaching. From 23 April to 13 May 2009 Bakers Delight bakeries around Australia will turn pink. This campaign gives Bakers Delight the opportunity to continue its generous support of Breast Cancer Network Australia (BCNA).

The campaign aims to:
- raise much-needed funds
- raise awareness of the support available to those who are affected by breast cancer.

“It is great to know that 100% of all the pink bun money goes to BCNA. They must sell an awful lot of buns.” – Joan NSW

How can you help?
- Develop an appetite for pink buns and visit your local Bakers Delight bakery to buy a pink bun or two. Visit our website www.bcna.org.au to find your local bakery.
- You can also vote for your favourite Bakers Delight bakery in the Pink Bun awards at www.bcna.org.au

The Bakers Delight staff love to meet women who have used BCNA’s free resources, such as the My Journey Kit and The Beacon. We are able to provide these resources free to women and their families thanks to the generous support of Bakers Delight and our other sponsors.

‘Bakers Delight is extremely proud of its long association and unique partnership with BCNA … The Bakers Delight annual “Pink Bun” fundraising campaign provides our bakeries and their staff with the sense of satisfaction knowing that every dollar raised goes towards BCNA’s work.’ – Roger and Lesley Gillespie, Co-Founders and Directors of Bakers Delight

Bakers Delight bakeries have supported BCNA since 2000 and in that time have raised more than $2.7 million. We are overwhelmed by their enthusiasm in making a real difference locally and nationally for those personally affected by breast cancer.

Spread the word in 2009

During 2008 we sent out our free My Journey Kit to just under 9,000 women newly diagnosed with breast cancer. With approximately 13,000 women diagnosed every year, we need your help to reach even more women in 2009.

In this issue of The Beacon you will find a My Journey Kit promotional flyer, which includes ordering details. You might like to keep it handy, to show or give it to a friend, family member, a doctor – or anyone who would benefit from knowing the My Journey Kit is available.

In 2008 we launched our Virtual Field of Women website (www.fieldofwomen.org.au). People can send a message of support to someone who has been diagnosed with breast cancer, while making a $20 donation to BCNA.

All donations help us to continue providing our free resources such as the My Journey Kit and The Beacon. For more information or more promotional flyers email beacon@bcna.org.au or call us on 1800 500 258 (freecall).

BCNA gratefully acknowledges our partnership with Bakers Delight.
Upcoming Events

March 25: BCNA’s forum in Bendigo, Victoria, will feature guest speakers, with the theme Living Beyond Breast Cancer. For more details visit our website www.bcna.org.au > Events > BCNA forums or call us on 1800 500 258 (freecall).

March 28 – 29: The Tasmania Breast Cancer Conference for women will be held at the Hotel Grand Chancellor, Launceston, from 12 noon Saturday to 1pm Sunday. The conference is free for women to attend, though registration is essential. For more information about the program and to register contact Pauline Watson 03 6344 8968 or watson_cr@yahoo.com or visit www.bcna.org.au > State by State > Tasmania > Tas events.

April: BCNA will present a forum for women in Canberra in April. For more details about the forum visit our website www.bcna.org.au > Events > BCNA forums or call us on 1800 500 258 (freecall).

April 23 – May 13: Bakers Delight Pink Bun campaign where 100% of the money raised comes to BCNA. See page 15 to read about how you can help make this campaign the best so far.

May 10: The National Breast Cancer Foundation will be holding their Mothers Day Classic, in all capital cities as well as Parramatta, Geelong and the Gold Coast. To register visit www.mothersdayclassic.org

May 13 – 15: The UICC 15th International Reach to Recovery Breast Cancer Support Conference will bring women from across the world to Brisbane. Visit www.reachtorecovery2009.org for more information on this three day event, including registration options.

May 24: The UICC 15th International Reach to Recovery Breast Cancer Support Conference will bring women from across the world to Brisbane. Visit www.reachtorecovery2009.org for more information on this three day event, including registration options.

May 24: The Hunter Breast Cancer Public Forum 2009 – Love and Breast Cancer – its impact on women, their families and friends will be presented by The Hunter Breast Cancer Education and Support Committee and will be supported by BCNA. Contact Suzanne Mullen on 0404 966 788 or suzanne.mullen@bigpond.com for further information and to register.

Visit our website www.bcna.org.au > Events for information about recent and upcoming events held by or for BCNA. You can also visit www.bcna.org.au > State by state for information about events taking place in your state or territory.

Would you like to be on the mailing list for The Beacon or The Inside Story?

Telephone 1800 500 258 (freecall), email beacon@bcna.org.au or fill in this coupon and send it to: Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.

Yes, please send me: ☐ The Beacon, BCNA’s free quarterly magazine
☐ The Inside Story, a four-page supplement on living with secondary breast cancer, mailed with The Beacon to those who request it.

Name: ...........................................................................................................................................................................................................

Address: ........................................................................................................................................................................................................

State: .................................................. Postcode: ............... Phone: (     ) ......................................................................................

Email: ...........................................................................................................................................................................................................

Have you had a diagnosis of breast cancer? ☐ Yes ☐ No
If yes, what year were you diagnosed? .................................................. What year were you born? ..............................................

Have you had a diagnosis of secondary breast cancer? ☐ Yes ☐ No
If yes, in what year.................................