

My Story	7
Member survey results	8
Letters to the Editor	10
New State Reps	12
Book review	13
Member Group profile	14
Thank you	15
Upcoming Events	16



Field of Women Live – it's on again!

The Field of Women Live event will be held at Sydney's Telstra Stadium (Homebush) on the evening of Saturday, August 11, immediately before the Sydney Swans versus St Kilda AFL match.

Those of us who stood together on the MCG in May 2005 will avow that this is a truly remarkable experience. If you can get to Sydney, we promise it will be an evening you will NEVER forget!

There will be 13,000 women in pink ponchos and 100 men in blue standing in the middle of the arena – a person for every woman and man to be diagnosed with breast cancer this year.



The spectacular the Field of Women – Live at the MCG in 2005.

All the details have not yet been finalised, but will be decided in the coming weeks. The best way to keep up with the latest news, including details about registering

for the event, is to watch our website at www.bcna.org.au.

We are committed to offering our members the opportunity to

register before we launch to the public, so we urge you to watch out for our exclusive BCNA members' early registration, probably early in May. Last time we had to close registrations early when we reached our target number. We don't want any of you to miss out this year.

Put the date into your diary! Help spread the word! Start planning!



Breast Cancer Network Australia

A family concern

This issue of The Beacon includes lots of articles focusing on the genetic/familial aspects of breast cancer.

This is such a complex and challenging area. For some of us it is an area where scientific discovery and knowledge has helped answer queries and solved puzzles; for others it has raised even more questions and made life and decisions more difficult.

It is important to note that only a small percentage of those of us

who are diagnosed with breast cancer have inherited a genetic mutation. Most women have no known risk factors for breast cancer, apart from being female.

For those of you who are concerned about your daughters or other members of your family, we hope this issue of **The Beacon** will help answer your questions and perhaps point you towards more information and assistance.

Lyn Swinburne, CEO



Gerda Evans (second from right), one of BCNA's state reps, with three family members. All four women were diagnosed with breast cancer within a few years of each other.

Having a family history of breast cancer

A strong family history of breast cancer increases the risk of developing the disease. A strong family history means having at least two affected close blood relatives on the same side of the family (mother's or father's) – often with the diagnosis occurring at a young age (before 50).

Importantly, most women who get breast cancer **do not** have a strong family history. Breast cancer affects one in eight women in Australia, and it is not unusual to find families with breast cancer in two or three relatives over the age of 50. Women can sometimes over-estimate their level of risk based on family breast cancer.

Some women have lived with the knowledge of their family histories for many years. Others begin to piece together their family history when they and/or their loved ones experience a diagnosis. Our women's stories include a range of experiences from mothers, sisters and daughters as they come to terms with the implications of their family history.

Women with strong family histories can attend family cancer clinics to find out more about their risk and ways to monitor

their health. Some choose to have genetic tests to see if they are carriers of inherited gene faults associated with the disease. Inherited gene faults, such as those occurring in BRCA1 and BRCA2, are estimated to account for only 5% to 10% of all breast cancer. Current testing cannot

always pick up gene faults in families, and for some women this leaves many questions unanswered.

Other women are unsure about taking such steps or are in the midst of the process. There are also women

who contribute blood and tissue samples to research programs to potentially help find a cure or prevention for breast cancer.

Family cancer clinics are publicly funded and their services are provided at no cost. They have specialists trained in genetics, including counsellors, doctors and nurses. Services include family history and risk assessment, as well as information and support regarding options such as genetic testing. To find a family cancer clinic, contact the Cancer Council Helpline on 13 11 20.

Below and on the following pages is a collection of stories from our readers about their experience of family breast cancer.

Importantly, most women who get breast cancer do not have a strong family history.

Know your history!

I was diagnosed with breast cancer in November 2005. I was 27 and knew of no previous family history. I noticed a lump in my right breast and immediately saw my doctor, who then sent me for tests. The results were not good.

I had a lumpectomy. They found cancer in my sentinel node, so they removed more lymph nodes which came back clear. I had chemotherapy followed by radiotherapy.

They told me that I did very well to find the tumour, as it was less than 1.5cm. I kept thinking, 'If I'd done a check the month before could I have found it earlier?' But with no family history, I didn't really think to be so aware.



Vanessa Burdett between her mother-in-law Theresa Burdett (left) and her mother Elaine Berryman (right).

While I was having chemotherapy, mum found a lump in her breast. She was 45 and had it checked out because of what I was going through. Yep, mum had breast cancer too. Here begins our family history!

Mum's just finished treatment. We've since found out that my grandmother died from ovarian cancer in her 40s. Mum was always told it was cervical. What a significant mistake! It's so

important to know your family history so that you can act on it.

We've also seen a genetic counsellor and discussed the option of a genetic test. I was booked in, but then decided against it because of the negative impact it could have on my two younger sisters (aged eight and 12). If a gene mutation was discovered, it might be difficult to get life insurance. Mum decided against it too. We may choose to have it done later on, but for now it's not our choice.

I thank my family and friends, medical team and the clinic staff for their love and support during my treatment.

Vanessa Burdett, ACT

Our family's curse

Breast cancer killed my maternal grandmother and two aunts before I ever knew them. Then at 71, my mother was diagnosed. She was treated but went on to develop metastatic breast cancer and died, aged 75 (March 2005).

Shortly before she died, my younger sister (who has regular breast screening like me) was diagnosed with ductal carcinoma in situ. Through her own persistence she was taken seriously, listened to and finally referred for genetic testing.

Our family's mutation on the BRCA2 gene was found. In April 2006, my test result came through: positive. I was devastated and have been on a roller coaster of anxiety and depression ever since.



Julie Adamson with her husband Greg.

I am 44 and have a wonderful family. I've decided to have my ovaries removed to reduce the risk of ovarian cancer associated with this gene defect. I'm planning to have my breasts removed and a reconstruction – the best way to ensure I'm here to be with my

loving husband and two beautiful children for as long as possible.

It is a scary journey and I still have a long way to go but I am hopeful that one day we will break this curse that has plagued the women in my family for far too long.

Julie Adamson, NSW

Dad's family history

Mum always said having four daughters made her feel like a queen and her four sons were the jewels in her crown.

Just before Christmas 1994 my oldest sister, Cathy, found a lump in her breast. We were all devastated by this news, but rallied around her for support. She had a lumpectomy and radiotherapy. Within 11 months the cancer moved to her bones, showing first in her ribs.

Cathy was wonderfully brave; she never complained even though she lived with pain. She fought hard, but in January 2001 left us. Mum and Dad felt the agonising pain of losing another daughter

(we lost Julie, aged 2, from Meningococcal disease).

We knew that dad's sister, Eileen, had experienced breast cancer. We found out that his grandmother and another sister had also been treated for breast cancer.

In August 2004, my sister, Fran, found a lump in her breast. This was nothing new, as she'd had cysts and non-malignant tumours for years. By October she sensed something different and went to the breast clinic. It was Melbourne Cup Day. Fran picked the winner in the sweep at work but lost in the 'Diagnosis Cup'.

Cancer! We broke the news to Mum and Dad.

One night in December 2004, when I was getting ready for bed, my left breast felt heavy and sore. I found a long tubular lump. I saw my doctor the next day. She organised a scan that afternoon and the diagnosis was confirmed.

Mum felt like she was losing her two remaining daughters. But Cathy hadn't given in and neither would we. Almost two years on, Fran and I are symptom free. If Julie had lived would she have had breast cancer? We have 12 young girls in the next generation. What will the future hold for them?

Rita Bevan, SA

Gene facts

Genes are always involved in cancer

The cells in our bodies constantly divide and reproduce. Cancer occurs if a cell becomes abnormal and reproduces out of control. Some genes are involved because they contain information to control cell division. If something goes wrong with these genes (and 'faults' occur) cell life is affected – the start of cancer.

We do not know why gene faults occur

Scientists can't say why gene faults happen, but they know they are more likely to occur as we get older.

BRCA1 and BRCA2

Two genes associated with breast cancer are BRCA1 and BRCA2 (pronounced brak-ka one and brak-ka two). Like the 25,000 or more different genes in our bodies, we all have two copies of these genes in every cell – one from each biological parent.

BRCA1 and BRCA2 protect against abnormal breast cell division. While either gene may develop faults over time, faulty copies of BRCA1 or BRCA2 can sometimes be present at conception (inherited from a biological parent).

Most breast cancer is due to gene faults occurring over time

Between 90% and 95% of breast cancer is 'sporadic', that is, due to gene faults that occur over a person's lifetime. These faults have not been inherited from a biological parent and cannot be passed down to biological children.

A mother's heartache ...

I'd been waiting, ever so vigilantly, having every lump checked and removed. Yes, this one was malignant. I had a mastectomy. I knew what lay ahead of me: my mum, her sister and her daughter had been on that same journey.

My surgeon referred me to a family cancer clinic, where our family was asked to participate in the KConFab research program. Blood samples were collected from family members scattered over Australia.

The risk of my cancer returning in my other breast was more than I could bear, so I had it removed and donated it to research.

Extensive genetic tests began over a three-year period. After counselling, I was told they had found a BRCA2 mutation. Other family members could now be tested. But did they want to know?

The heartache began. My darling daughters, my only brother and his daughter – all had the mutation. I felt overwhelming guilt.

Some family members do not want to know. They are involved

in the research, but that's it.

I've since had a hysterectomy and my ovaries removed. I pray that research will benefit my daughters and niece – and all women.

Rita Redden, NSW



Daughter and mother: Toni Dougan and her mother Rita Redden

... And a gift to her daughter

Since I I, I lived with the two words, breast cancer. I was very close to my nanna, who was diagnosed then and began her battle to live. She died two years later.

Some years later it was mum's turn. The lump was discovered early enough for her to recover relatively quickly, but she worried about the other breast and decided to have it removed. Mum is now the happiest and healthiest she's been in her life.

When mum donated her healthy breast to KConFab research my

journey began. After her genetic test results came through, the rest of the family was asked to participate. I decided I would.

I received counselling to alert me to the feelings I could encounter and the options available should I carry the mutation. More counselling, then the news that

Hereditary breast cancer accounts for just 5-10% of all breast cancer.

I, too, had the BRCA2 mutation. Only snippets of that meeting are in my memory. My husband attended with me and later filled in the blanks.

When I told mum, she cried. She said she was so sorry and felt so guilty.

But I feel that in donating her breast to research, mum gave me a wonderful opportunity to manage my future. These days, I'm not so afraid of the words, 'breast cancer'. Knowledge is power! Thanks mum.

Toni Dougan (Rita's daughter)



Helen Paine with her mother, Shiela, and niece, Kiara.

What about my daughters?

I am 42 years old and was diagnosed with breast cancer in November 2005. I had three operations in nine weeks. My right breast had two primary cancers. I decided to have both breasts removed and started chemotherapy which finished in June 2006.

My maternal grandmother died at 73 years of cancer (not known). One of her sisters died aged 42 of cancer of the uterus. Her other sister died of breast cancer aged 79. My grandmother's nephew died of cancer aged 49. One of my maternal grandfather's nephews died aged 25 of Hodgkin's disease. Another nephew of his died aged 41 of cancer.

I've spoken to my surgeon about having a genetic test, as I have three daughters, aged 17, 15 and 11. Then there's my mother, two sisters and eight nieces.

It scares me: should my daughters be tested? It will be their decision at the end of the day.

Helen Paine, Qld

Note: Cancer that is assumed to be due to family history is sometimes random and due to the high incidence of cancer. One in four Australian women is diagnosed with cancer by the age of 75.

An 'unknown' group

It's 2001 and I'm 39 with breast cancer. My mother's diagnosis was 10 years before. Is it a coincidence? It's a little hard to comprehend as I undergo lumpectomy, mastectomy, chemotherapy, radiotherapy, prophylactic mastectomy and double reconstruction.

Mum's words ring in my ears: 'There have been some aunts with breast cancer'. I sit her down and draw up a family tree: five women out of 18 across four generations.

I meet with genetic counsellors and test negative for BRCA1 and BRCA2. But we are a 'high-risk' family and of interest to research.

We join the KConFab research program.

Tissue is gathered – prophylactic mastectomy – some tissue is stored. Ovaries removed – tissue is stored. While we answer many questions for them and donate tissue there are, unfortunately, very few answers for our family in return. It's a two-edged sword.

Having a genetic risk is hard, but being in the 'unknown' genetic group is harder.

As we have an unknown gene mutation, sisters, aunts and daughters cannot be tested. How do they make decisions about their risk with so little information?

It is 2006 and five years have passed. I quietly celebrate this milestone. Two months later my non-identical twin sister is diagnosed. That makes it six out of 18 women.

I'm told that there'll be answers in the coming years. Even if our family's gene mutation is identified, the question remains: How do we prevent the breast cancer occurring?

Heather Drum, Vic

Editor's note: the Kathleen Cunningham Foundation Consortium for Research into Familial Aspects of Breast Cancer (kConFab) is a group of researchers and breast cancer families.

Detection not too late

Mum was diagnosed with breast cancer when I was 11. Her mother, aunt and cousins had all had breast cancer. Mum asked her surgeon if her breast cancer was hereditary. She was told at the time (late 1970s) that this was extremely unlikely.

Ten years ago, mum and I enrolled in a research program involving Jewish women of Ashkenazi (Eastern European) descent with a strong family history. The program involved genetic testing.

After questionnaires and counselling, we had the test. I was 30 at the time. Our results came back positive to the BRCA1 mutation.

I was referred to a breast surgeon for follow up and to discuss my options. I chose regular surveillance consisting of annual mammograms and six-monthly clinical breast examinations.



Kerri Guy

Over the next few years I had my family. It was during a mammogram after my second son's birth that we found a lump in my right breast. I thought it was mastitis as I had only just finished breast feeding. I was 35

years old – too young to have breast cancer! It turned out to be a 3.5cm tumour and quite aggressive.

I had a bilateral mastectomy with reconstruction. Lymph nodes were clear and the tumour was hormone negative. Chemotherapy followed.

Having the mutation also means a higher risk of ovarian cancer. For now, I've decided on routine ultrasounds and blood tests. I can opt for the removal of my ovaries later, maybe when I hit menopause.

I'm so thankful that I was tested for the gene. My breast cancer was picked up early due to surveillance which otherwise would not have commenced until I turned 40. By then, it would have been too late.

Kerri Guy, Vic

Sign up for an e-list

Would you like to receive email updates on any of the following issues?

- Young women
- Secondary breast cancer
- Rural and remote issues
- Family (inherited) breast cancer.

We call these e-bulletins. The e-bulletins provide updates on research, emerging treatments, media reports and targeted conferences. They will also ask for feedback from list members and maybe even a call for action.

E-bulletins will be sent to each list at least monthly.

To join the e-lists, email us at beacon@bcna.org.au, telling us which list(s) you want to subscribe to, and adding your full name and postcode.

More gene facts

The likelihood of inheriting a faulty copy of BRCA1 or BRCA2 is around one in 600 to 1,000 people. Those with an inherited predisposition to breast cancer are rare, but they make up an important group because of their higher risk for the disease.

A small amount of breast cancer is hereditary

Gene faults can sometimes be present at conception (in the first cell), inherited in the egg or sperm. Those inheriting faults in genes associated with breast cancer are said to have a 'predisposition' to the disease but are not certain to develop it.

Something we've all lived with

Cancer has been a part of my family for generations. I remember visiting my maternal grandmother in hospital when she had breast cancer. There was little known about the disease back then (it was the late 1960s) and treatment was very basic. My grandmother passed away, aged 60.

Shortly after turning 57, my mother Ros learned that she had a particularly aggressive breast cancer. She fought this with surgery, chemotherapy and radiotherapy. Ros also had surgery for bowel cancer. I was so proud of her. Would I have her strength if faced with cancer?

In 2004 Ros' breast cancer returned. Then my sister, Suzanne, discovered a lump in her breast that turned out to be an advanced tumour. Suzanne was 42 and Ros felt guilty that she had passed on this terrible disease.

In 2005, it was my turn. I was 44 and a mammogram revealed an intraductal papilloma. Pathology showed an unusual type of cancer called papillary carcinoma. The hardest person to tell was my mother.

Our family has experienced other forms of cancer. In 2004, Ros' brother was diagnosed with prostate cancer and her older

sister had bowel cancer. One of Ros' cousins died of breast cancer in her 50s and a nephew died of leukaemia at a very young age.

I've spoken to my surgeon about genetic counselling and have completed consent forms. I'm waiting to participate in the next stage. I have two daughters and a son and I want them to know about their genetic background so they can manage their health.

In February 2006 Ros passed away, aged 64. Cancer beat her body, but never beat her spirit.

Angela Wood, Vic

Three pink sisters

My sister, June, was the first to have her mastectomy in October 1990. She always stayed positive and happy, but went to heaven on October 22, 1993, just three days after her 50th birthday. My youngest sister, Noela, was next, with her mastectomy in December 2003. She is well and doing fine, keeping up with her first grandson. She'll turn 60

January this year. At 64, I've just had my mastectomy.

We are three pink sisters sharing everything life has to offer with love and laughter.

Betty Spinner, Qld

Right: Betty Spinner (standing) with her sister, Noela (sitting)



Women's stories – resources

We received an overwhelming response to our call for family breast cancer stories. This issue represents a small sample of those responses. All stories are available on our website www.bcna.org.au. You'll find a link on the homepage.

If you'd like to add your story, email beacon@bcna.org.au or post to BCNA, 293 Camberwell Road, Camberwell, Victoria 3124.

BCNA has a fact sheet on family history and hereditary breast cancer. It explains when family

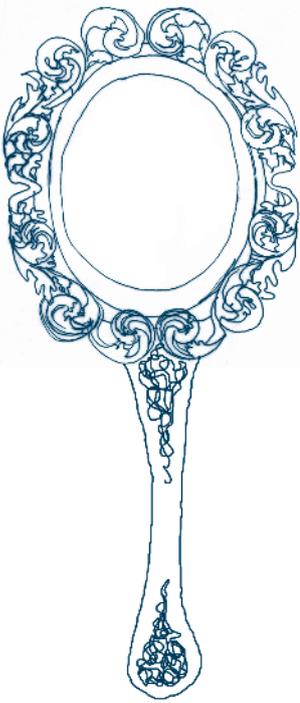
history becomes important in breast cancer risk and the options available if you have concerns. Visit www.bcna.org.au or telephone 1800 500 258 and we'll post a copy to you.

Hair and breath tests for breast cancer

You may have read about a couple of new tests that could be on the horizon for detecting breast cancer.

A research group in WA has been awarded almost \$100,000 by the National Breast Cancer Foundation to investigate whether a breath test that can detect cancer markers is sensitive enough to replace mammograms in population screening. While the thought of a simple breath test instead of a mammogram is deliciously enticing, it is important to note that the research is investigatory only. We're a long way away from trials and an evidence base for such a test.

Another story that has made it into the newspapers lately is a hair test for breast cancer. The test's developer is in the final stage of trialling it before steps are made for commercial availability, including an application for government funding. Although the hair test is a little closer to reality than the breath test, BCNA still suggests caution in supporting such a concept until the evidence is established. Current best-practice guidelines are to be breast aware, consult your doctor if you notice anything different about your breasts, and have regular mammograms.



My Story

A family's experience of breast cancer

My earliest memories of my maternal grandmother were travelling every weekend from Cheyenne, Wyoming, to the mountains of Colorado, so that my parents could help my grandfather take care of her. I remember playing quietly because 'grandma is sick'. It was 1959 and I was four.

I didn't know it then, but my grandmother was in the last stages of breast cancer. The cancer had spread so far by the time it was discovered that surgery was impossible.

I still remember the day of her funeral. My mother and father must have decided it was better for me to stay at my grandparents' house and play with a friend. I guess they wanted to spare me their tears.

My mother's journey with breast cancer began in 1992. By then I was living in Perth with my family. My mother, now in her late 60s, telephoned to say she'd found a lump in her left breast. After the requisite tests she was told it was cancer.

My mother had a lumpectomy and radiotherapy and seemed fine for a long time. Her doctor kept a close eye on her. In 1996, a routine blood test found an elevated 'marker', but a bone scan showed nothing. Months later they found metastases in her clavicle, followed quickly by tumours in her skull and spine.

In the midst of all this, my father had a stroke and passed away. This had a profound effect on my mother's outlook on life, but she maintained hope and underwent many radiotherapy treatments.

I was studying naturopathy at the time, and sent information to my mother as soon as it came to hand. My naturopathic studies helped me to see that while allopathic or traditional medicine

may not have all the answers, there is a lot we can do to help ourselves. My mother went to a naturopath and started taking natural supplements and herbs.

My mother's doctor had been urging her to undergo chemotherapy and in November 1997 she agreed, but after one infusion, she decided that chemotherapy did not do much to improve her 'quality of life'. The treatment ceased.

My family sold up and we returned to Colorado in January 1998 so that we could be with my mother. She felt good enough two weeks after we arrived to get up and bake a cake! My mother's last weeks were happy ones. She was

glad to have us near, but I know she could also feel her life ebbing away. We lost her in March.

I was always told that I had an increased risk of breast cancer because of my family history. My mother insisted that I start having mammograms as soon as I turned 40. However, I always thought that I'd be the one to break the cycle of breast cancer.

In March 2004, I was 48 and back in Perth. I found an olive-sized lump in my left breast. I wasn't at all worried, but I quickly made an appointment with my doctor. He immediately sent me for mammograms (I'd had one five months before and things were okay) and a biopsy.

I was hugely surprised to learn it was breast cancer. I couldn't believe it. I allowed myself 24 hours to grieve, then the battle was on. I had the lump removed, got a breast reconstruction and went home to heal. I was told the cancer hadn't spread. At first, I didn't want chemotherapy or radiation, but four months later I felt that chemotherapy would be a good idea. I got through six months of treatment, and I'm here today to tell my story.

I live with hope that I've beaten it.

Marnie Clark, Perth, WA



Marnie with her son Sean on his wedding day

Member survey results

In September last year we sent a survey to 18,101 members and your response was fantastic. A total of 12,597 responses were received – this represented a 70% response rate, with 5% of the total responses received online.

Who are our members?

- 90% have had breast cancer.
- 6% have a family member or friend who has had breast cancer.
- 1% have not had breast cancer but have a strong family of the disease.

Where do our members live?

Our members are drawn from all states and territories – with NSW and Victoria being the largest group. This is to be expected, as these are Australia's most-populated states. Of

the respondents, 58% live in major cities and more than a third (39%) in regional areas. Compared to national breast cancer incidence figures by remoteness classifications, we are doing particularly well reaching those in regional areas.

When were our members diagnosed?

While one respondent was diagnosed as far back as 1943, more than half (51%) of the respondents were diagnosed since 2004. Around 10% were initially diagnosed before 1995.

Secondary breast cancer

While the vast majority of our members have had early breast cancer – more than 1,000 members are living with secondary (metastatic) breast cancer.

How satisfied were you with your clinicians?

Respondents were generally satisfied with their clinicians – 94% were satisfied with their surgeon, 91% with their medical oncologist and 91% with their radiation oncologist. We were surprised that a smaller number (87%) indicated they were satisfied with their nurse. However, the level of satisfaction didn't vary with age. Over a 10-year period there was a consistent 3% increase in satisfaction with surgeons, medical oncologists and radiation oncologists. There was a 2% increase in the satisfaction with nurses. We are mindful that 10 years ago there were few breast care nurses available and even now many women don't get the services of a trained and dedicated breast care nurse.

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 about secondary breast cancer. It includes stories and information about resources, services and issues for women living with secondary breast cancer. It is mailed with *The Beacon* to those who nominate to receive it.

Name:

Address:

State: Postcode: Phone: ()

Email:

Have you had a diagnosis of breast cancer? Yes No

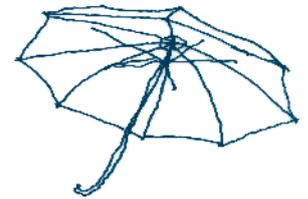
If yes, what year were you diagnosed? What year were you born?

Have you had a diagnosis of secondary breast cancer? Yes No

Surviving cancer

For most women the end of active treatment is not the end of their breast cancer journey. The spring issue of *The Beacon* (mailed in September) will focus on survivorship.

We are interested in your stories of how breast cancer has had an impact on your life, either positive or negative – whether it's financial, physical, emotional or otherwise. We would love to receive stories from readers to include in *The Beacon* or on our website. Stories (up to 500 words) should be mailed or emailed to BCNA by the end of June. Please send a photo.



Seeking shelter

BCNA welcomes:

Member Groups

- Illawarra Breast Cancer Support Group, Ulladulla, NSW
- Southern Peninsula Breast Cancer Survivors Group – Portsea to Mornington, Vic.

This takes our tally to 176, with 163 Members Groups and 13 Associate Member Groups. We now have more than 20,000 individual members.

'A wonderful and inspirational three days'

They came from all across Australia – Bicton, Western Australia, Smithfield, Queensland, and Hobart, Tasmania – 24 women gathered together for BCNA's annual Advocacy and Science Training Program last November.

The women shared their breast cancer experiences, and over three days heard from a range of speakers who shared valuable expertise on the science of cancer, breast cancer genetics, breast cancer treatments – surgery, chemotherapy,

radiation and supportive care. They explored consumer advocacy, and the 'ins and outs' of the health care system, influencing politicians and the 'Working with the media' session prepared them to confidently generate stories through their local media.

The women's comments reflect the program's success:

'I found it wonderful – useful info, empowering and I've made great new friends.'

'Well targeted – great speakers – well thought out topics and

structure to three days.'

'It was an enabling and empowering experience, intellectually and emotionally.'

'It is very rewarding and encouraging that we can help to make a change for the better.'

The women emerged as BCNA's new consumer representatives; the energy and enthusiasm generated throughout the three days will no doubt endure. Many have already undertaken local initiatives to raise the BCNA banner in their local areas.



Advocacy skills at the top

We know her as **Judith Adams**, breast cancer survivor, BCNA member, consumer representative and graduate of our Advocacy and Science Training Program. Australia knows her as Senator

Judith Adams, from WA, who has been leading recent charges on behalf of Australians with cancer. Judith is passionate about improving conditions and services. Her particular focuses

are establishing a national system for patient travel schemes and improving outcomes for women with lymphoedema. BCNA congratulates Judith on her excellent advocacy endeavours.



Suellen Williams from Alice Springs points out her contribution to the Calendar girls quilt

Calendar Girls Quilt

NT Rep **Suellen Williams** sent in this great photo and the story of this quilt. She writes:

The quilt was made as a message of hope and inspiration for others. It was sewn with the wonderful generosity and help of friends of the Alice Springs Quilting Club, Bosom Buddies, family and survivors of breast cancer. We each chose a month that was significant to each of us. For me it was February, when I found the breast lump, and I loved that in my month I was shown **The Beacon!**

The quilt hangs in the office of the breast care nurse. We were acknowledged with a photo in the local newspaper on the presentation of the quilt. The quilt was also in an exhibition in Melbourne in February.

The quilt kit was designed by Sally – 'In honour of the humble breast, whether you have two or one (or none)' – for Millamac Creations and Miss Sampsons's Drapery.



Letters to the Editor

Thank you for the work you are doing

Ed: We don't usually print letters of praise, but we were heartened to receive this letter. We were pleased to hear that our resources do what we intended them to do and thought others would identify with Leanne's sentiments.

Breast cancer changed my world and my family's and I was thrown into a life-changing event. What was one of the scariest times of my life also turned out to be the most amazing time for me to grow as a person.

In the first few weeks my dad suggested I get the *My Journey Kit* and what a wonderful Kit it was. Although my friends and family were there, I felt so connected to the women in your book. Also, your website became a great source of information and support, especially in the early hours when I woke and my mind was racing.

I have just finished my first year clear. My hopes and dreams for the future are simple. To watch my kids grow, see grandchildren, know that the fight against breast cancer is getting stronger. People such as yourselves enable this to happen.

Keep up the wonderful and amazing work you are doing and thank you BCNA for being part of my journey. I'm going back to bed now. It's 2am and the night sweats from menopause have

kept me awake, but I know it's a small price to pay for a second chance at life, which I wouldn't miss for a minute.

Leanne Edwards, NSW



Gail Woods

No such thing as an 'all clear'

I have recently heard about two breast cancer patients who, after five years without recurrence, have been 'given the all clear' and will no longer be consulting their

oncologist on a regular basis. I find this a little disturbing.

My breast cancer was initially diagnosed in 1988 as being 'as close to breast tissue as it's possible to be and still be malignant' – a weakling, slow-growing and non-aggressive. My treatment was surgery.

Fifteen years later I had undeniable symptoms of a major problem that took some months to diagnose. My breast cancer was back – in my bones and, more difficult, in my brain.

I know this a rare condition, but, I am advised, it is usually fatal. My treatment was whole brain radiation. My ongoing medication is hormone suppressants that drain me of energy. But I am alive three years later.

In 1988, getting breast cancer at the age of 36 was rare and long-term recurrence was never mentioned. My experience convinces me that an 'all clear' is a phase that should be taken out of use – at least until there is a recognised and effective cure.

My oncologist doesn't believe it to be a safe call and I am surprised that other oncologists do. I would like to see this practice stopped.

*Sincerely
Gail Woods, Vic*

Ed: We share your concern about the 'all clear' idea, but this is a difficult one. Many women are told that five years from diagnosis is the magic figure. While this is the period where the risk of any type of recurrence is greatest, unfortunately it is also true that some women do experience a recurrence many years later. The great news is that more women today are living longer after a diagnosis of breast cancer than before. Like you, we are concerned about the idea of an 'all clear'.

Victims – we are certainly NOT!

Thank you for the Spring issue of *The Beacon* which I enjoyed receiving but one of the things that did (and does) concern me was the article on page 7 with the newspaper cut-out paper story titled 'Cancer Victims plea for Subsidy'.

I lost a breast to cancer more than eight years ago and have supported and participated in many functions conducted to highlight the awareness of breast cancer in women and it always saddens me to hear us referred to as VICTIMS. The word victim sounds so negative to me; a person who has no control over what has happened to them or

Hope and Hurdles

We are developing a comprehensive information package for women with secondary breast cancer – those whose breast cancer has advanced to other parts in their bodies.

Hope and Hurdles, which is based on the *My Journey Kit*, is being based on the experiences

of many women living with secondaries.

The new resource will be available around mid year, but for more information about *Hope and Hurdles* order a copy of *The Inside Story* – our supplement to *The Beacon* for women with secondaries.

what they can do about their circumstances. That was not a message I would accept, then or now. Cancer does not give us a choice (if we have it, we have it), but we do have a choice about how we deal with it. We are not helpless and are still in charge of our lives. We ARE NOT victims in that regard. I refuse to allow anyone to call me a 'victim of cancer' as the term produces the wrong impression of me to the world.

I would love to see Breast Cancer Network Australia promote the 'non-use' of the term in its promotions and publications and to the world.

*Sincerely
Amanda Medcalf, ACT*

Ed: We heartily agree with Amanda that we are not victims!

Taking each day as it comes

Anita wrote after reading the 'My Story' in our Winter 2006 issue of **The Beacon**.

Like Heike I am not happy about being eligible to receive **The Beacon**, but am interested to read other women's stories.

My husband and I were diagnosed with cancers within a month of each other. His lung and mine breast. Right from then we coped with a very warped sense of humour, trying to out-do each other. I told family and friends about me, then followed with, 'But wait, there's more', and told them about my husband. The reaction was much the same: 'Both of you!' This, I am sure, prevented morbid tales and crushing sympathy. It is a condition, not a sentence.

The hardest time was waiting for results, and then phoning our daughters, who live on different



Getting on with life: Anita Renfry and her husband in the Northern Territory.

sides of Australia. They both wanted to rush home to be with us, but as we were coping and were well enough, we asked that they waited till the shock had worn off and to come when we could do things with them. Numerous phone calls kept them informed. Drawings from grandchildren kept us amused. Over the next two months, we will be visited by them, and a new grandchild. Life is good.

We don't dwell on 'Why me?', that doesn't answer or solve anything. We follow the doctors' advice: surgery, chemo and radiotherapy for me, and chemo for him. We take each day as it comes.

As I have a nursing background, many of my husband's friends thought I would know all about the treatments – I only worked in the gynaecology theatre.

We keep positive and we have each other. There are others a lot worse off than us – people that have to go in each day for dialysis or young children who are ill.

I have great faith. People care. Prayers have been given and answered.

Thank you to the women who have gone before, who conceived the idea of **The Beacon**.

Although pink is not my favourite colour, I will wear it in October. Thank you all.

Anita Renfry, Largs Bay, SA

20,000 members

Exciting news! Our network continues to expand, with more and more women finding out about BCNA and signing up for **The Beacon**. BCNA now has 20,000 members across the country.



Buy a finger bun and help BCNA

Vote for the best Bakers Delight store

This year's Pink Bun promotion is going to be bigger and better than ever and we need your help.

The stores will once again be 'pinked out' and every cent from the sale of the pink buns will come to BCNA.

Show your support between 3 and 16 May by:

- going to your local Bakers Delight store and thanking them for their fantastic support; and
- checking out the Bakers Delight stores in your area and voting on-line at www.bcna.org.au for the best pink store.

Bakers Delight's support of BCNA since 2000 has helped us to provide quality services to all our members.

Introducing three new State Reps

In 2007 BCNA welcomes three new State Reps – **Kerrie Griffin** in the ACT, **Sue Hassett** in WA, and **Pauline Watson** in Tasmania. We thank outgoing State Reps **Anna Wellings Booth, Veronica Macaulay-Cross, Ann Revell** and **Shelley Sexton** for their contribution to BCNA during their terms as BCNA State Reps.

Pauline Watson, Tas

Pauline was diagnosed with breast cancer in 1991 (with cancer in five of eight lymph nodes) and underwent chemotherapy and radiation therapy. In 1993 she developed metastatic cancer in the spine and was given a prognosis of two years. The rest is history – Pauline is still well and truly with us. She has been a member of the Tasmanian Breast Cancer Network since 1999 and founded the Launceston Breast Cancer Support Group in 2005. Pauline lives in Launceston with her husband and two sons.



Pauline Watson

Kerrie Griffin, ACT

Kerrie discovered a lump in her breast in 2001 when her girls were eight and 10 years old. She undertook BCNA's Advocacy and Science Training Program in 2004 after being inspired by the second National Conference. Kerrie belongs to Dragons Abreast ACT's Tickled Pink team and is the newsletter coordinator. She loves participating in the Dragons Abreast Australia's Chinese New Year regatta and the team is preparing for Abreast in Australia 2007.



Kerrie Griffin

Sue Hassett, WA

Sue was diagnosed in 1996 at the age of 48 and underwent chemotherapy and radiation therapy. She has been a member of Action on Breast Cancer since 1999, a volunteer with the Breast Cancer Support Service at The Cancer Council WA, a member of the BreastScreen consumer group, and is affiliated with the Breast Cancer Foundation WA. She attended BCNA's conference

in 2004 and the National Summit in Sydney in 2006. Sue is a mother of two and grandmother of three.



Sue Hassett

BCNA's voluntary State Representatives, all breast cancer survivors, keep an ear to the ground for news, distribute information, and can be a local contact for women.

ACT

Kerrie Griffin

T: (02) 6231 4344
taylorclan@iinet.net.au

Elsbeth Humphries

T: (02) 6239 6344
humphries44@ozemail.com.au

NSW

Pam Bell

T: (02) 9955 9313
bellpc@bigpond.net.au

Megan James

T: (02) 9440 0373
megs3008@yahoo.com.au

Northern Territory

Pat Hancock

T: (08) 8948 1333
pathancock_is@hotmail.com

Suellen Williams

T: (08) 8952 9018
suellenwilliams@ozemail.com.au

Queensland

Lyn Moore

T: (07) 3822 5468
lyn.moore@bigpond.com

South Australia

Alexandrea Cannon

T: (08) 8416 9428
impian@adam.com.au

Jan Davies

T: (08) 8388 4825
jandavies@adam.com.au

Tasmania

Karen Forster

T: (03) 6273 4422
kate4star@hotmail.com

Pauline Watson

T: (03) 6344 8968
M: 0408 448 959
watson_cr@yahoo.com.au

Victoria

Pamela Williams

T: (03) 9592 6352
pwil1957@yahoo.com.au

Gerda Evans

T: (03) 9805 2500
gerda@bigpond.net.au

WA

Luisa Giuffre

T: 0419 046 733
luisaa@bigpond.net.au

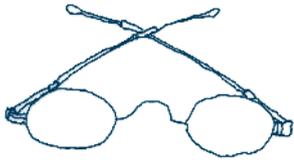
Sue Hassett

T: (08) 9276 6129
hassetts@iinet.net.au



BCNA gratefully acknowledges our partnership with Bakers Delight.





Book review

My Mum Has Breast Cancer – A Family's Cancer Journey

Story by Lisa & Harrison Sowards. Illustrated by Helen Grizinich & Harrison Sowards. ISBN 0646460536.

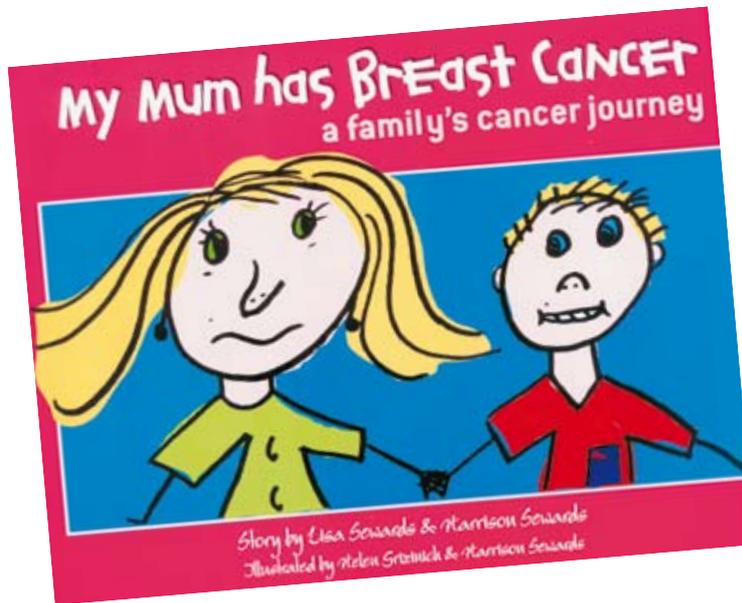
Format: illustrated children's picture storybook, paperback.
Number of pages: 24 pages.
Publication date: 2006.
RRP: \$16.95

To order: telephone (03) 9598 5111; email bookstreet@bigpond.com or buy online at www.leadingedgebooks.com.au

As this book was written by a mother and son, we asked another mother and another son to review it. We start with the thoughts of 13-year-old Jack Lidgett.

This is a journal, writing about a six-year-old kid named Harrison. It tells you about the year his mum went through breast cancer. There are lots of great pictures that Harrison drew which help describe his emotions.

I really enjoyed reading Harrison's story because I can really relate to what he and his family were going through. I remember when my Mum was going through breast cancer my brother and I were not sure what she was going to look like with no hair and wondered if we should still invite friends over but we, like Harrison, did not think she looked bad with no hair and most of the time she wore either a bandanna or a beanie anyway. I was 10 and Tom was 9. It is also a



very informative book, telling you what all the doctors are called and the treatments. It has pictures for the younger readers to also get an idea.

Anyone from the ages of 8+ would enjoy this book, especially young kids like Harrison who have had their parent or closely related family member go through breast cancer or any other cancer.

When I first read this book I thought it was very appealing because it is really well-illustrated and it shows the family's emotions and what they were going through.

Our family did a lot of things that they did, such as going on a holiday when Mum was sick.

When Mum first told us that she had breast cancer in 2004 I didn't really know what cancer was. Tom and I went to mum's chemo sessions, but Emma was 4 and too young to go.

Every year now I run a footy tipping competition to raise money for breast cancer awareness. This year I raised \$300.

Jack Lidgett – Aged 13



Jack Lidgett

I love the way this book looks at the difficult and always challenging breast cancer journey through the eyes of a child. It shows the very story that many mothers of young children have or are going through. The book is written so that all children can relate to it, the fantastic illustrations tell most of the story on their own. No matter the age of the child

reading it or being read it, this book would be applicable to all ages, as it has been written in a way that can be understood by the very young. Harrison Seward has been able to show us all the levels of understanding that young children have about this issue and that this should not be ignored.

I also loved the way the book showed the complete story and all the different stages of one woman, wife, daughter and, most importantly, mother's breast cancer diagnoses and the way it affects the whole family. Lisa and Harrison have been able to show us the world of breast cancer through the most innocent eyes of all, the young children of mothers who have been diagnosed.

On a personal note, I do wish I had had this book when I was diagnosed, more than five years ago. My son was only 2½ years old and having a lot of trouble understanding what was going on with his mother. We sat down and read this book together, only now do I understand how much he really understood and how many questions he was too scared to ask, even now after five years.

With the help of this book, we were able to talk about what had happened. He even had questions he didn't know he wanted to ask.

From one mother to another, 'thank you' for this book, not just because it helped me and my family, but because I know it will help others with their own journey.

Allison Piper



Profiling our Member Groups

Murray Mallee Breast Cancer Support Group

*The Murray Mallee Breast Cancer Support Group was formed in February 1998 by **Glenys Boseley and Rosalie Donovan.***

Glenys had just finished her radiotherapy treatment. During her treatment, Rosalie would ring Glenys on a weekly basis. They decided to get a group together.

The group is in Pinnaroo on the Victorian and South Australian border. Glenys and Rosalie chose the name, 'Murray Mallee', because there was no group that existed between the Victorian border and Murray Bridge, a distance of 150km. There was also no group between Murrayville and Mildura, a distance of 120km.

The group joined women from Murrayville in Victoria and Pinnaroo and Lameroo in South Australia. Lameroo has since formed its own group, which is part of the Mallee Health Service.

The local hospital was supportive of the venture, allowing the use of a room for meetings. The group was exactly what local women needed. One woman, for example, had undergone a mastectomy and had not talked about it for 17 years. She had no one to share her experiences with or relate to until the group formed.

The group meets regularly on the first Monday of each month and finds great comfort, support and camaraderie in members. Members occasionally go to the bakery after meetings for lunch. Those in the broader community have come to know them as 'the breast girls'.

A few years ago, the group made contact with the Mallee Women's Health Co-ordinator in Murray Bridge, some 150km away. She attended several meetings and over the years has established other important contacts for the group such as the Murray Bridge Breast Cancer Survivors' Group (featured in ***The Beacon* 36**

Spring 2006). These two groups now meet with other groups in the district twice yearly for lunches in different towns. True friendships across large distances have been forged.

The group was part of the *Field of Women* in Adelaide in 2001, planting a white silhouette in memory of one of its members. Glenys and Rosalie also attended the *Field of Women – Live* in Melbourne in 2005. Their participation gained local media coverage and the two women have been able to use the event to keep breast cancer at the forefront of people's minds. Glenys and Rosalie have given presentations at meetings of the

Country Women's Association and Women's Agricultural Bureau, dressed in their pink ponchos! Glenys has also given presentations at the regional Patchwork and Quilters meeting.

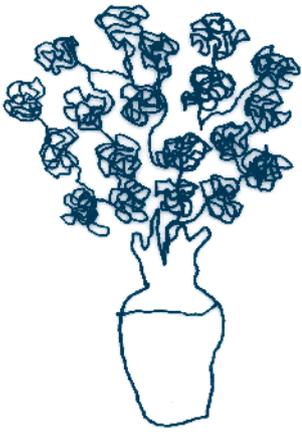
Glenys and Rosalie started the group with no resources, just a need to talk to others with similar experiences. Over the early years, they've gained skills in facilitating groups and have attended workshops such as 'Looking after the facilitators' at the Cancer Council South Australia in Adelaide. This has been invaluable in helping them to work through the pain of losing members to breast cancer.

Although the group is small in number (currently about five) members enjoy each other's company and look forward to the social gatherings with other groups in the district. Members take copies of ***The Beacon*** magazine when they travel and discuss them at the bigger gatherings.

'We are extremely grateful for the support we have received from each other and the wider community over the years and hope to keep our journey at the forefront of local issues for many years to come', says Glenys.



The Murray Mallee Breast Cancer Support Group: Rose Auricht, Anne Byrne, Jean Mickan, Rosalie Donovan, Pat Wilson, Dot Lawrence, Lyn Eisen and Glenys Boseley.



Thank you

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

- Sussan Group
- Manildra Group
- Bell Charitable Fund
- Rosebud Country Club
- Jesse Jones
- Gabby Romeo
- Pink Ladies Christmas Golf
- Peter Power Fitness Team
- Australia Post
- Ladies members of Kingswood Golf Club
- Griffith Breast Cancer Support Group
- Bakers Delight – Flinders Lane
- Pink on Pedals (WA)
- Heather Morton
- Annual Poker Run – Isobel Harvie



The Southern Cross Rodeo Circuit is supporting BCNA during its 2007 calendar of events hosted around the country. The organisation and supporting committees are promoting BCNA and the My Journey Kit to regional areas.

- Dianne Cameron
- Geelong JukeBox Rockers Inc
- Dragons Abreast ACT
- Carol Burt
- Nancy Trigona
- Mitre 10 Team Jude
- Australian Business Travel Association
- Nita Kino
- Steve McLean
- Bakers Delight – Glebe
- Australian Olympic Committee

In memory

We remember **Samantha Elder** and **Doris Fabian** and are grateful to be recipients of donations in their memory.



BCNA CEO, Lyn Swinburne (on the left), was presented with a \$65,000 cheque from the team at Sussan (Naomi Milgrom, Felicity McGahan, Anna Stevens and Robyn Batson) for money raised through the sale of BCNA merchandise in Sussan stores during October.



Bakers Delight Glebe has made a generous donation to BCNA. Franchisees Ravinder Singh and his wife Jasleen Lamba won the prestigious Gillespie Award at the recent Bakers Delight New Zealand Conference, which included a \$1000 prize. They donated the money to BCNA. Breast cancer survivor and BCNA member, Maryanne Maher visited the store to accept the donation and thank the Glebe team for their support.

Prosthesis and travel security

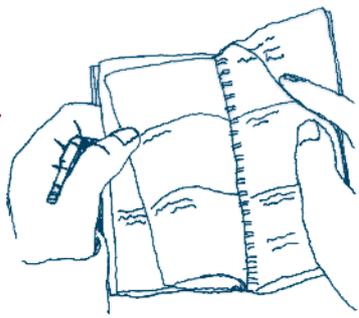
We recently met with the Office of Transport Security in response to concerns about new security measures for liquids, gels and aerosols for international travel.

As a result, we can reassure readers that prostheses are exempt from the new security provisions and do not need to be declared.

However, the new security provisions do increase the likelihood of random frisk searches. If you are chosen for a frisk search you can request that this be undertaken in a private room.

You are likely to hear more about this in the media as the new provisions will be introduced in Australia from 31 March.

For more information www.dotars.gov.au.



Upcoming Events

March 10: Lymphoedema Management – Today and Tomorrow. Practical program organised by the Lymphoedema Association of Queensland and Wesley Healthwise Centre. Evan & Mary Thompson Auditorium, Wesley Hospital, Coronation Drive, Auchenflower, 8.45am-4.00pm. Cost: \$10 (includes lunch and morning tea).

Ring Pam on (07) 3232 7666 for bookings (\$5 parking voucher available).

March 22: The Peter Meese Memorial Lecture 2007 – 'Not a breast cancer victim but a survivor: using a voice to bring about change'. Keynote speaker: Lyn Swinburne, Chapel, Cabrini Hospital, Malvern, Vic, 5pm. Cost: free.

Contact: (03) 9508 1375.

March 26: BCNA Forum for Young Women, Perth, 6-8.30pm.

Contact: 1800 500 250.

March 27: BCNA General Forum, Perth, 10.00am – 12.30pm.

Contact: 1800 500 250.

March 31: A free champagne breakfast for women newly diagnosed with breast cancer. Advice on style, makeup and wigs, as well as clothing fitting.

Network with others in the same boat. Lisboa Cafe and Bar, Westfield Woden, ACT, 8.30-10am.

Contact: (02) 6283 6000.

May 3-16: Bakers Delight Pink Bun promotion. Visit your local Bakers Delight during the campaign and buy a pink product in support of BCNA. All proceeds are donated to BCNA to continue our work.

June 17: 'Survivorship: Living Well with Breast Cancer', Hunter Breast Cancer Public Forum 2007. The principal focus will be the psychosocial issues associated with living with a breast cancer

Ongoing

In Brisbane, the Wesley Hospital's Kim Walters CHOICES Program runs varied, fun and comprehensive support activities in groups or one to one for women who have been diagnosed with breast cancer. The woman does not have to be a patient of the Wesley Hospital; the program is open to all women. Inquiries: (07) 3232 7064 or 1800 227 271

diagnosis. Western Suburbs Leagues Club, New Lambton.

Contact: Suzanne Mullen
(02) 4929 1118 or
0404 966 788.

June 30: Breast Cancer Association of Queensland's Rural Breast Cancer Seminar, Biloela (594km north-west of Brisbane).

Contact: Tracey (07) 3666 0614.

July 21: NSW Breast Cancer Action Group's Women for Women with Breast Cancer 2 Forum and 10th birthday celebration.

Contact: info@bcagnsw.org.au

August 11 (evening): Field of Women Live in Sydney, Telstra Stadium.

Contact: www.bcna.org.au

August 28-31: 'Partners Across the Lifespan', 9th Australian Palliative Care Conference, Melbourne Convention Centre.

Contact: apcc@iceaustralia.com,
(03) 9681 6288 or
www.iceaustralia.com/apcc2007.

September 28-30: Abreast in Australia (first international survivors' regatta), Coloundra, Queensland.

Contact: www.dragonsabreast.com.au



The Beacon is printed with the generous support of Vega Press and PaperlinX. Printed on Impress Gloss 115 gsm manufactured by Australian Paper's Wesley Vale Mill in Tasmania.



Decline in US breast cancer

It has been reported that annual rates of breast cancer in the US for 2002 to 2003 were 7% lower than expected. Experts concluded that the key contributing factor was a decline in the use of hormone replacement therapy (HRT) for menopausal symptoms. The decline in HRT use was the direct result of a study that linked its long-term use with breast cancer. Many women stopped using HRT when these study results were announced.

It's difficult to know whether we will see the same trend in Australia. It is possible that women in the US were more likely to have taken HRT long term than their Australian counterparts.

My Journey Kit reaches out

Just over 7,000 women who were newly diagnosed with breast cancer received our My Journey Kit during 2006. This brings the total number of kits freely distributed to women since May 2004 to just over 19,000.

As more and more women discover the My Journey Kit, they are telling their friends and family members about its value.

We rely heavily on our BCNA women to spread the word and help us ensure that every woman diagnosed with breast cancer

knows about the My Journey Kit. If you have an opportunity to help us continue promoting the My Journey Kit and would like some postcards, business-sized cards or small posters, please e-mail beacon@bcna.org.au or phone 1800 500 258.



the BEACON

Editor: Lyn Swinburne
Layout: Substitution

BCNA
293 Camberwell Road,
Camberwell, Victoria 3124
Freecall 1800 500 258,
(03) 9805 2500
beacon@bcna.org.au or
www.bcna.org.au