Field of Women to go live in 2005

There is no more powerful way to highlight the impact of breast cancer on our community than to display a Field of Women with all those silhouettes like a pink carpet.

In 2005, we plan to present an even more compelling sight, by replacing our 11,500 silhouettes with 11,500 real women in pink! Can you imagine that vision?

I get goose bumps at the thought and hope that many readers will stand with me in the Field of Real Women on the Melbourne Cricket Ground on the evening of May 6. I'm confident such a powerful photo will be beamed around the world! You will find further details about the event on our website or by phoning us on 1800 500 258.

October saw many PINK events across the length and breadth of Australia. I'm sure many of you attended breakfasts and forums, paddled your dragon boats, enjoyed the company of other survivors, and were involved in the many and varied Mini-Fields held in communities in all States.

I attended a successful Mini-Field in Geelong and was so impressed by the energy and vitality of all involved. I also thought it was a wonderful way to bring together that community's various groups – local support groups, hospitals, doctors and nurses, Dragons Abreast, BreastScreen, as well as individuals and families – to mark Australia's Breast Cancer Day!

The end of another busy year is upon us and we hope that you will have felt supported, informed and inspired throughout 2004 by The Beacon.

I am in awe of the wonderful women and men who make up our network and am inspired by their stories of endurance, such as Frances Reynolds on page 8, a 50-year breast cancer survivor, and courage, as demonstrated by Jenny Donovan's trek to Everest on page 9.

I would like to take this opportunity to thank you all for your involvement and to wish you all the best for a happy Christmas, a restful holiday season, and a healthy and fulfilling year to follow.

I look forward to wonderful things happening in 2005!

Lyn Swinburne,
Chief Executive Officer
**Mini-Fields of Women 2004**

Many communities have come to know the pink lady symbol and all that it represents via 53 Mini-Fields of Women scattered across the country during the last week of October.

This year we had a focus on promoting the *My Journey* Kit, and it also provided an excellent opportunity for breast cancer survivors to speak of their ‘journeys’ with breast cancer.

This year’s Mini-Fields are a testament to the passion and dedication of our wonderful convenors and their committees.

Many Mini-Fields events were creative, fun and informative days attracting a range of individuals and families.

Some convenors chose to set up hospital and library displays, Mt Barker in SA had a pampering day for women, and others had Silent Walks and speeches.

In Queensland, the Kilcoy Ladies Group had 70 silhouettes sponsored at their Mini-Field, part of Kilcoy Hospital’s Open Day.

The women in Caboolture, Queensland, went to great lengths to publicise the Mini-Field which included an illuminated pink tree in the park, an Elvis impersonator and Bollywood dancers!

Campbell Town held its Mini-Field in the centre of Tasmania, with the Mayor speaking and the silhouettes were planted in the shape of Tasmania.

Murwillumbah in NSW had a Silent Walk down the main street to Knox Park.

There were also opportunities to make new friends, share experiences and support one another; while enjoying a morning tea from Bakers Delight and viewing the visual arts display from local women after their diagnosis.

Collie in WA had more than 300 people march in its Silent Walk and 101 sponsored silhouettes; they released pink helium balloons which looked fabulous.

Henley Beach in SA saw increased participants this year following the issuing of printed invitations and publicity through Adelaide’s daily newspaper and Cancer Council publications.

Again in SA, Kangarilla’s Mini-Field achieved an amazing result, with 137 silhouettes sponsored.

Geelong had a successful Mini-Field event displaying their silhouettes on the football oval.

Three large pink ladies accompanied their field and a huge banner hung between the goal posts.

This family day brought together many different support groups and local services and attracted a crowd of 300. Presentations from several speakers were followed by a minute of reflection to the haunting sound of the flute.

No matter how many or how few silhouettes were sponsored, each Mini-Field left its mark; the awareness and community spirit generated is priceless.

Rebecca Montgomery, 
Mini-Fields Project Manager 2004
Thank you to our Mini-Field convenors

Thanks to all our wonderful convenors, their committees and helpers:

**Victoria**
- Bacchus Marsh: Lorraine Ogdens
- Bairnsdale: Barbara Elderidge
- Geelong: Leanne Storer
- Greensborough: Kayleen O’Neil
- Kyabram: Isobel Harvie
- Melbourne City: Gerda Evans
- Ringwood: Helen Spicer
- Shepparton: Mandy Kavanagh
- Silvan: Kerry Patford
- St Kilda: Sheila Tesselar
- Wangaratta: Kerrin Elliott

**New South Wales**
- Armidale: Vivienne Gregg
- Byron Bay: Barb Pinter
- Camperdown, Sydney: Kate Orme/Catherine McGrath
- Forbes: Christine Gorton
- Gosford: Stephanie Foster
- Lismore: Nancy Jaeger
- Murwillumbah: Lyn Laws
- North Sydney: Felicity Brazel

**Tasmania**
- Campbell Town: Karen Forster
- Devonport: Robyn Glen
- Wynyard/Burnie: Anne Cameron

**Queensland**
- Boonah: Michelle West
- Bulimbah: Lyn Moore
- Bundaberg: Dianne Moller
- Caboolture: Jurina Demaine
- Cleveland: Wendy King
- Cooma: Jane Redmond
- Esk: Aileen Elliott
- Ingham: Kristene O’Brien
- Kilcoy: Cindy Kunde
- Laidley: Jill Meuleman
- Longreach: Heather Morton
- St George: Kerrie Lomman
- Toowoomba: Ruth Granville
- Toowong, Brisbane: Leisha Rule

**Western Australia**
- Albany: Veronica Hare
- Collie: Wendy Hingston/Megan McDermott
- Esperance: Sharon Scoble
- Geraldton: Kaye Street
- Perth: Maria Waters
- West Perth: Ros Worthington

**South Australia**
- Adelaide Hills: Kathy Rutledge
- Ceduna: Bernie Lowe
- Henley Beach: Deb Martin
- Kangarilla: Brenda McLennan
- Minlaton/Yorketown: Dianne Reade
- Mt Gambier: Janet Williams

**ACT**
- Canberra: Bernadette Brady
Minister announces breast cancer funding

In October, during the National Breast Cancer Centre's Pink Ribbon Breakfast in Sydney, the Federal Health Minister, Tony Abbott, announced increased funding for two National Breast Cancer initiatives.

Each year the Australian Department of Health and Ageing funds the National Breast Cancer Centre, in Sydney, to the tune of $2.1 million, with $100,000 of this for the Centre’s ovarian program. The Minister promised to increase the Centre’s funding by $750,000 a year over the next four years. This was pleasing news, as many of us were concerned that there might have been a general sense of diminishing commitment to the breast cancer cause.

The Minister also announced funding for BCNA’s My Journey Kit of $200,000 a year over another three years. This was music to our ears, as the project is extremely expensive to run. When you realise that there are potentially 30 women every day newly diagnosed with breast cancer, you will appreciate the cost involved.

We know from the feedback we receive from newly diagnosed women that the Kit is worth every cent it costs us to produce it. Of course, there are lots of other expenses involved on top, such as in promoting the Kit across the country.

Don’t forget that you can play a role in helping with this too. If you can display our posters or postcards on a notice board somewhere, we would be very happy to mail some out to you.

Please keep plugging the My Journey Kit hotline number – 1300 785 562 – to newly diagnosed women. It’s wonderful to be able to point these women in the right direction!

Also, make sure your doctor knows what an excellent resource this would be for patients. Posters displayed in medical rooms and hospitals would be a great help to us.

Fit & Healthy Breakfast

This year, the Fit & Healthy Business Women’s Breakfast was held at the splendid Park Hyatt, Melbourne.

Three-hundred and fifty business women (and men) embraced the early start to enjoy a cooked breakfast while listening to interesting and informative talks by Olympian, Jana Pittman, and Telstra Business Women of the Year finalist, Tanya Bensimon. Olympians, Cathy Freeman and Lauren Hewitt, and Oscar winner, Adam Elliott, were in the lively audience.

Lyn Talbot was a fabulous MC and BCNA CEO, Lyn Swinburne, made a speech about the My Journey Kit.

Dr Lee Naylor, again, did a fantastic job organising this popular and successful event.

The line up at the Fit & Healthy Breakfast: MC, Lyn Talbot; organiser, Dr Lee Naylor; BCNA Chair, Dr Patricia Edgar; BCNA CEO, Lyn Swinburne; Olympians, Lauren Hewitt, Jana Pittman and Cathy Freeman; and guest speaker, Tanya Bensimon.

New-look website

We’re excited to announce the launch of Breast Cancer Network Australia’s new-look website at www.bcna.org.au.

Additions to the site include a comprehensive search function, an on-line shop where you can purchase our ever-popular pink lady merchandise, as well as personal stories written by women with breast cancer.

Be sure to look out for the latest news and events happening in your State in the Around the Country section.

Happiness is a perfume you cannot pour on others without getting a few drops on yourself.

Emerson

Glitter Ball

For the third year running, the Glitter Ball has been a shimmering success.

On October 2, 450 formally dressed attendees walked the red carpet into the beautifully decorated Plaza Ballroom in Melbourne to part take in an evening of silent and major auctions, dancing to the Funky Xpress band and being sung to by mystery act, Kate Cebrano.

The total amount raised was $120,000 and this will go towards producing and distributing the My Journey Kit.

We would like to thank Lee Bradford and her committee for their dedication and hard work.
A Delightful promotion

Bakers Delight bakeries around Australia enthusiastically supported BCNA with their pink finger bun promotion in October.

The bakeries were supplied with a marketing kit containing pink silhouettes, pink balloons, pink posters and streamers and were encouraged to decorate their shops and workers in anything (you guessed it) pink.

Customers were invited to buy the $1 pink buns and to place the money in the BCNA money tins on the counters. The tins stayed on counters right through October.

Initial reports, as we go to press, indicate that this promotion has been a outstanding success.

It was great to see that many of the bakeries worked closely with our Mini-Fields this year. Some bakeries went to extraordinary lengths for us. Michael Kuilder and his fantastic staff at Bakers Delight Bankstown, NSW, led the way and raised more than $8000 all by themselves!

We would love our readers to personally thank the staff in their local Bakers Delight for supporting this promotion.

BCNA really has a fantastic partnership with Bakers Delight, which continues to financially support us, while improving public awareness about the affect of breast cancer.

Help spread the word

With this issue of The Beacon we have included a My Journey Kit postcard. We want to ensure that women know about the Kit as soon as possible after diagnosis and we need your help! Give the card to someone who should know about it. Is your surgeon routinely recommending the My Journey Kit? Perhaps you could pass it on to him/her with a word about how fantastic the Kit is.

A head turner

We know our pink lady symbol pops up in strange places, but this just about takes the cake!

The staff at Bakers Delight’s head office in Camberwell held a Pink Day for BCNA in October.

Josh Prior looked his usual self until he turned around and there, emblazoned on his shaved head, was our pink lady! Josh’s girlfriend (who is a hairdresser) had made sure no-one would question his devotion to BCNA.
Project LEAD in Madrid

From June, 20-25, Pam Bell and I attended Project LEAD (Leadership Education Advocacy and Development), an innovative science and advocacy training program for breast cancer activists, presented by the National Breast Cancer Coalition Fund (NBCCF).

The NBCCF is a grassroots US organisation and you can learn more about it by visiting www.stopbreastcancer.org.

The course was run in Madrid, Spain, the first time it has been offered outside the US.

NBCCF and a prestigious international faculty welcomed a group of 35 attendees from more than 25 countries to the intensive five-day program designed to help breast cancer activists effectively influence research and public policy in the wide range of forums where breast cancer research decisions are made.

The curriculum included lectures and study sessions on cell biology, the microbiology of cancer, genetics, the epidemiology of cancer and critical appraisal of research design.

Since 1995, Project LEAD has graduated more than 1000 trained activists.

Project LEAD Madrid was developed in response to requests by international advocates, and in consultation with international and US scientific organisations and advocacy groups from around the world.

The faculty for Project LEAD Madrid was drawn from international academic and research institutions, including the University of Hamburg, Germany; Guy’s and St Thomas Cancer Center, England; the University of Oslo, Norway; the Cochrane Collaboration, Spain; and Brown University, US.

This was a terrific opportunity to interact with women (most of them breast cancer survivors) from all over the world who all have a common vision to end breast cancer and, in the meantime, support survivors.

I spent the week absorbing as much information and speaking to as many women as I could. It was an intensive week – with lectures all day and reviewing the next day’s topics at night.

But it wasn’t all work. On our final night we had a celebratory evening, including a walking and bus tour of Madrid, and dinner with flamenco dancing, which was a lovely way to end a very full-on week!

Both Pam and I look forward to using the knowledge and tools from Project LEAD to help us promote effective breast cancer advocacy in Australia. We feel energised by the experience and I am keen to put what I’ve learnt into practice.

Maryanne Maher, NSW

Le Rêve’s dream offer

BCNA relies on donations from individuals and corporations to fund our programs and support our important work. We are, therefore, delighted when we receive an offer of on-going financial assistance, as it ensures a future for many of our programs.

Le Rêve Charity Foundation has committed to exactly that.

Le Rêve recently launched a range of Charity products and a percentage of every item sold will be donated directly to BCNA.

The Charity range is currently made up of Charity Lip Gloss, as well as two designer perfumes, Charity and Charity II.

During October 2004, Le Rêve hosted a National Party for Charity Day and hundreds of perfume parties were held nationally. A percentage of sales on the day were donated to BCNA and although we are still tallying up the final fundraising result, it looks to have been a huge success!

To learn more about Le Rêve Charity products phone the Le Rêve hotline on 1300 622 840 or visit its website www.lereve.com.au.
I couldn’t resist passing on to you this demonstration of what a wonderful partner you have in Bakers Delight!

Last week I was buying bread from one of its Richmond stores with my four-year-old. She had the job of handing over the money.

Just as she was about to give it to the young woman behind the counter, she noticed the BCNA collection tin and said, “Can I put it in there? Please?” I started to say no, she needed to give it to the woman to pay for our bread, but the young women interrupted to say, “Go ahead sweetheart, you put it in the tin”, and wouldn’t accept extra payment.

This was such a lovely gesture and, of course, the women working behind the counter could only do this if they felt secure in the knowledge that the company truly supports the cause.

Louise Davidson, Co-ordinator, Mother’s Day Classic, Melbourne

Thank you for publishing my letter in The Beacon. I felt the need to hear from other women who had been diagnosed with cancer in several of their lymph nodes and who were doing well.

I had so many phone calls as a result of my letter. I would like to thank all those who contacted me. I gained the confidence I needed to reinforce my thinking that I’m here for a long time yet.

Robyn Van Haren, Queensland

I am wondering whether you have ever done an article on BRCA 1 and 2? I have read newspaper articles in the past and get frustrated when I see that these genes can be passed on by a grandmother, mother, granddaughter, but they never mention whether it can be passed on by a male.

Noreen Rye, Victoria

Editor: It is important to note that mutations can certainly be carried through the male side of a family. In the past, we have done some articles on these mutations, but not for some time. If other readers would like, we could cover this topic in a future issue of The Beacon.

Congratulations to our BCNA members

- Judith Adams from Western Australia was elected a Senator during Federal Election in October.

  Judith, a member of BCNA’s Rural and Remote Working Party, has been a BCNA consumer representative on a number of committees and is a passionate advocate for women with breast cancer who live in remote Australia.

- BCNA’s Northern Territory State Rep, Michelle Hanton, was named the NT’s Telstra Business Woman of the Year.

  Michelle has worked diligently over the past five years to establish Dragons Abreast across Australia.

- BCNA Board member, Karen Hayes, was a finalist in the Victorian section of the Telstra Business Women of the Year Award.

Thank you

There are so many people who have worked hard to assist BCNA over the past months. We would like to thank everyone, including the following supporters, for their magnificent efforts:

- Bakers Delight for its October promotion, Turning a family’s world around;
- Australia Post for sponsoring the 2004 Mini-Fields;
- The Print Centre and Alf Puglia from Precision Forme Cutting for producing 5000 new pink silhouettes for us without cost;
- The Ninety Milers women’s networking group from East Gippsland for raising $5500 throughout the year;
- Lee Naylor – Fit & Healthy Breakfast;
- Lee Bradford and the Glitter Ball Committee and sponsors;
- Tesselaars Tulip Farm;
- Yates, which has raised funds via its pink dianthus seed packets;
- Le Réve’s fundraising nights;
- NLC’s Cox Plate Fundraiser; and
- All our wonderful volunteers, who have given so generously of their time in 2004.
My Story

Frances Reynolds

Once upon a time, in 1954, when I was breast feeding my six-month old baby, I felt a lump the size of a pea in my left breast.

At my next visit for a check-up with the obstetrician, I showed him and the lump was duly removed and sent to pathology. This was no fairy tale. At this time, breast cancer was not talked about and only occasionally mentioned in the press, but research was being undertaken in a small way by pathologists. Oncology departments did not exist as they do today!

I was told my cancer was at an early stage and seemed confined to the lump. I had two options: proceed to have a mastectomy or do nothing more. Since I was only 30 and did not feel or look ill, and had two children and a husband to look after, we decided to let things be and get on with our lives. This we did for the next 43 years.

The day after arriving home, I reported to the GP and then to St Vincent’s clinic. Since it felt like the first lump, I suggested to the doctor that perhaps I could just have it removed. There was talk of chemotherapy and radiotherapy. Research had really gone on since 1954.

I opted for just a lumpectomy and suggested that Royal Newcastle Hospital (RNH) be contacted for information regarding my first lump. RNH sent the information and the specimen so that St Vincent’s could make its own slide and diagnosis.

By 1997, I had a lump under the arm and a stay in hospital to have some nodes removed. During this time, I saw the oncologist and agreed to undergo six months of chemotherapy.

We were going to England at this time to visit our daughter and family who were living there and the chemotherapy was arranged around this visit. It all worked out well.

After chemo, it was suggested that I have radiotherapy. This was more concentrated – five days a week for six weeks.

“Was such a disruption to life really necessary?” I was thinking, but the doctor convinced me it was, and need not be a great disruption. I could arrange it around my activities, which were still tennis and now bridge and, on occasions, voluntary work.

This was managed with a little give and take.

That was seven years ago and now I report to the surgeon and oncologist once a year.

Today, with the aid of two cataract operations and a new aortic valve (four years ago), I am still playing tennis, travelling overseas and always eating an adequate diet (I was a dietitian).

By having faith in my doctors, hope within myself and love about me, I have been living happily ever after – 50 years after – my first lump.

Frances Reynolds, Victoria

50 years a survivor: Frances Reynolds in 1954 and in 2004.
Tackling something I’ve always wanted to do

Come on Mum, you’ve always wanted to walk in the Himalayas!

My daughter and I trekked with 12 others for 16 very long days. We flew from Kathmandu to Lukla and then walked all the way to the Mt Everest Base Camp.

The hiking distance was 78 kilometres, altitude range 3000m, and maximum altitude 5550m. As we walked, the air became thinner and I became slower and slower. Most days we walked 7-10 hours. The food was simple: rice, dahl, boiled eggs, garlic soup and lemon tea. We stayed in wooden huts and the stoves were heated by yak poo that was carefully collected. I loved the Nepalese and their happy faces. It was a privilege to walk with my daughter and to share the time together. It was a jolly hard walk and the head guide told me afterwards that he was sure that ‘Mums’, as he had nicknamed me, was NOT going to make it. I’m 54 and a very baroque/Boticelli shape (especially after all of those steroids as part of the chemotherapy treatment) and weigh a light 81kg or so. I did manage to leave my bottom on the track!

With all of those rocks we climbed as we went up and up and up, thank goodness for those walking sticks. The greatest danger was high altitude sickness and one woman was evacuated back down the mountain one night on the back of a sherpa. The actual day’s walk to the Mt Everest Base Camp was along the top of a glacier. It snowed lightly all day and the visibility was poor, but then a wonderful Nepalese Sherpa appeared out of the mist with lemon tea. It was very much appreciated. Since experiencing the life-changing circumstance of a lumpectomy with nodal involvement in December 1998 and a presumed recurrence in July 2000, I now aim to live in the present (a challenge at times), having hopefully let go of the past.

Both of my precious daughters have, in some way, introduced me to Buddhist philosophy and it is teaching me so much about how to be (and not be)!

Thank goodness, as those acute episodes of hospitalised care have truly woken me up to the fact that one minute we’re here going about our business and then the next we might not be. After the six-month chemotherapy regime, I was depressed and could hardly walk around the block. If someone had forecast that I could have completed this walk I would have probably told them they were nuts.

It doesn’t have to be the Himalayas but if there’s something you’ve always wanted to do, do it!

And don’t wait – things change all of the time.

I wish you peace.

Jenny Donovan, South Australia

Oh no not I, I will survive. Oh as long as I know how to love, I know I’ll stay alive. I’ve got all my life to live; I’ve got all my love to give, I’ll survive, I will survive, Hey, hey!

Gloria Gaynor
Global action: women use their voices

The power of women to effect change should never be underestimated. While women may have to work twice as hard, they are incredibly motivated and can move mountains. This powerful advocacy role has had a huge impact on breast cancer diagnosis, treatment and psychosocial issues around the world.

Dr Susan Love kicked off the session on international advocacy by reviewing how the breast cancer movement had started using the template created by AIDS advocacy. She once suggested (jokingly) that if women wanted to achieve change in breast cancer they needed to march topless on the White House. After the talk she was approached by several women who demanded to know when the march was going to start! The Breast Cancer Coalition came out of this passion and desire for change.

In the beginning, they needed collaboration, especially with scientists and politicians, and they needed funding. The Breast Cancer Coalition took its demands to the US Senate and lobbied for US$300 million more in funding for breast cancer research. And they got it!

One of the key factors in advocacy is that women need to collaborate as partners not pawns. We need to get the truth out there. We need to be telling not just the ‘sexy’ stories of survival but the other truths as well: that cancer does come back, that older women do get it. We need to ensure politicians are doing meaningful things, not just those that are media-friendly.

We must advocate for quality care: respect, choice, accountability. We need to demand easy to access information that women can understand. We need to focus on environmental issues as they are related to cancer and we need funding for better science.

Susan concluded by saying that we should not set our sights too low – we needed to aim for a world without breast cancer!

*****

Stella Kyriakides, a clinical psychologist from Cyprus, became involved in breast cancer advocacy after her first breast cancer diagnosis.

She and a group of other breast cancer survivors formed the first breast cancer movement in Cyprus, and Stella is the 2004 president of Europa Donna – the European Breast Cancer Coalition.

Stella stressed that the ‘personal is political’. After breast cancer, women have two choices: to become negative and insular, or to make the experience positive and use it to create change.

She says that the breast is a celebration of life. Breast cancer is traumatic because the breast itself is a symbol of fertility, of nurturing, belonging and giving.

Within the European Union (EU), every 2½ minutes a woman is diagnosed with breast cancer. Every 7½ minutes, a woman dies from the disease. Europa Donna has 34 member countries. It works by lobbying the European Parliament, the European Commission and Health Alliance to improve services throughout the EU.

Stella concluded by saying that we need to keep breast cancer on the agenda: we owe it to the generations that follow.

*****

Lyn Swinburne, BCNA’s CEO, began by reviewing the key strategies from the 1998 Canberra conference, Making a Difference, at which BCNA was officially launched.

One of those initiatives has only just come to fruition – the My Journey Kit. This free kit offers practical advice, includes a list of resources (books, tapes, websites, etc.) and actively encourages women to be their own advocates.

BCNA is also advocating a database of clinical trials which would be a valuable resource for women wishing to take part in trials and their physicians.

Lyn says that advocacy groups cannot claim all the credit for the progress that has been made. But, she says, “rallying the troops means that we have strength in numbers; we have a powerful and influential voice”. The successful Herceptin campaign is a model for what can be achieved.

BCNA is often cited as a model for consumer involvement and representation on a national and international level. It has a reputation for working in partnership with other groups, including doctors, scientists, government, politicians and the media. It is by working with their clinical allies that BCNA has its best shot at making improvements.

Lyn believes that BCNA’s success can also be measured by the fewer shocking stories coming from Australian women – there are still awful stories, but they are less frequent.

The BCNA action words – inform, empower, represent and link – are at the heart of Australian advocacy.

Sue Claridge, New Zealand
Book Reviews

Miss Lily’s Fabulous Pink Feather Boa
ISBN O 140559 02 7
A reader, Louise Davidson, alerted us to this charming children’s book after seeing all the women at the Tickled Pink Party in feather boas, in the previous issue of The Beacon.
The story is so perfectly in keeping with our own concept of the pink feather boa!
The book’s promotional paragraph reads, “Miss Lily’s fabulous pink feather boa is the most wonderful thing the last Potoroo has ever seen. When Miss Lily dances the tango, the last Potoroo can’t take her eyes off it. And when she wraps it around herself, she feels for the first time in her life, that she can do anything – and everything!”
Just as the feather boa empowers the last Potoroo, it has also surreptitiously become a special symbol for BCNA women. At our Conference Party, the women wrapped themselves in their feather boas and left their troubles at the door.
Those of you who were privileged to hear Veronica Macaulay-Cross speak in the final session of our Conference will appreciate the power of her pink boa as she confirmed that, even for women with advanced breast cancer, life can be fulfilling and wonderful.

Lyn Swinburne

Amazon Heart: Coping with Breast Cancer Warrior Princess Style
Amazon Heart covers the journeys of two young women, Megan and Meredith, as they cope with the experience of breast cancer and try to make sense of the impact of breast cancer on their lives.
We travel with them as they deal with their worst fears, gain acceptance of their plight and begin to realise their dreams; all with a pinch of good humour along the way.
Amazon Heart is about the importance of support, friendship, and honesty with yourself, during breast cancer treatment and the more independent phases of the recovery process.
Megan and Meredith meet via a common interest in sport and then find they also share the experience of breast cancer. The book is mainly a dialogue between the two via e-mail and live conversation as they develop a close friendship and provide emotional support for each other.
The book will appeal to anyone who would like to share the experience of breast cancer. It covers well the whole gamut of emotions and issues one may face during their treatment and the first few years beyond.
Breast cancer survivors will gain comfort from finding that they are not alone as Megan and Meredith bravely and honestly convey their most private feelings on every day practicalities to the ‘hard stuff’.
The book touches on the issues of diagnosis and treatment, self-image, getting fit again after treatment and participating in sport, work, travel, young families, relationships (heterosexual and lesbian), being a survivor, things not going to plan, and working beyond physical and emotional limitations. The book contains great and meaningful quotes.
At times, the conversational style of Amazon Heart seems contrived and repetitive, and is a little disjointed. The book touches on many important issues, but the conversational style did not always allow for development and expansion of these ideas.
The book is a personal account of coping with breast cancer, rather than a guide with substantiated facts; however it still teaches us about finding strength and courage within and what is possible after a diagnosis of breast cancer.

Marina McGlinn NSW
Tamoxifen alternative available

BCNA’s Policy Unit has been active throughout the year lobbying for a new group of drugs to be made available for women with early breast cancer.

These drugs are in a grouping called aromatase inhibitors and trial results show these to be a promising alternative, or even follow-on, to tamoxifen for some women with breast cancer.

The good news is that one of these, Anastrozole, also called Arimidex, has now been added to the PBS. The new listing means that women who are unable to take tamoxifen, for a variety of clinical reasons, will now have easy access to an effective alternative from December 1, 2004.

The actual wording for the PBS listing from December 1, 2004, is:

“Restricted Benefit: treatment of hormone-dependent early breast cancer in postmenopausal women in whom tamoxifen therapy is contraindicated; treatment of hormone-dependent early breast cancer in postmenopausal women who are intolerant of tamoxifen; and treatment of hormone-dependent advanced breast cancer in postmenopausal women.”

The estimated cost over four years is $24 million.

Victoria tries to solve prosthesis problem

At the 1998 Making a Difference Conference, an issue that was constantly raised was the need for easy access to external breast prostheses for women after breast cancer surgery.

Until recently, little has been done to fix the problem. However, a State-wide program recently launched in Victoria will hopefully convince other States the problem can be solved.

The Victorian Department of Health has joined forces with the Department of Community Services to establish a ‘ring-fenced’ pool of money solely for funding replacement prostheses.

No longer will Victorian women compete for funding in the pool alongside people needing wheelchairs, oxygen equipment and prosthetic limbs.

Importantly, the new system, the Victorian Breast Prosthesis Subsidy Program, begun on August 16, is being managed by one central body – Southern Health (based at Moorabbin Hospital).

 Hopefully, this will mean that the new system will be streamlined, responsive to individual women’s needs, regardless of where they live in Victoria, and will slash the waiting times for prostheses. The first prosthesis (or breast form) will still be available from the initial treating hospital, but subsequent units (the maximum subsidy is $300) will be funded centrally.

Women will be able to order and buy prostheses from their shop/supplier of choice, as long as they have approval from the program. An information line, operating Monday to Friday, 9am to 5pm, has been set up to answer any queries. The contact person is Linda Maddaford and she can be reached on (03) 9928 8627 or 1300 789 047 or l.maddaford@ southernhealth.org.au.

An excellent booklet has also been produced by BreastCare Victoria in conjunction with the new system. Upfront: About Breast Forms (Prostheses) is a comprehensive and user-friendly resource that includes information on the types of forms and bras, the care of the garments, fitting advice and the psychological issues following breast surgery.

The booklet is free from The Cancer Council Victoria by phone (03) 9635 5000 or on-line at www.cancervic.org.au/breastforms.

BCNA hopes that this new program will make life easier for Victorian women. We intend to follow the new process closely and lobby other States to follow Victoria’s leadership.

Genetic discrimination research

Researchers are recruiting participants for a national research project on genetic discrimination.

The Genetic Discrimination Project will investigate how a person’s genetic status is used in certain decision-making processes in Australia – particularly regarding employment and insurance.

Consumers can participate by completing a questionnaire that the researchers estimate may take 15 to 40 minutes to fill out. If you are interested in participating in the project you can phone the investigation team on 1800 554 000 (freecall).

Alternatively, the questionnaire and information sheet can be downloaded from the project’s website at www.gdproject.org.

There is provision within the questionnaire for you to include your personal details, so that the researchers can contact you for further information. However, as always, BCNA encourages you to read any information about the project and consider your decision carefully before providing this information.

Genetic discrimination research
Dragons Abreast

Alice Springs was treated to the full Dragons Abreast spectacular when we participated in the Henley on Todd Regatta.

September saw all Dragons Abreast Australia's group co-ordinators and state representatives meet in Brisbane for a one-day workshop.

The Dragons Abreast Australia – Territorial – calendar was launched on the October 1 by the Northern Territory's Chief Minister, Clare Martin, and is now on sale for $22. Ordering details are on our website.

We welcome aboard new member groups in Port Macquarie and Townsville, and a dragon baby into the Dragons Abreast Australia family.

Congratulations to Martine Hammond (nee Boughton) and her husband, Stevan, on the birth of their son, Calin.

Judi Sweatman in Adelaide reports that SA Dragons Abreast, incorporating SA Vipers as its supporters, started its race season with renewed vigour and Come and Try Dragon Boating sessions each Saturday in October.

They joined with Dragons Abreast Australia members to take Federal Health Minister, Tony Abbott, and local Liberal Member, Simon Birmingham, out to experience paddling on West Lakes.

Their other exciting news is the launch of two new dragon boats for the Torrens River.

The fifth International Dragon Boat Federation World Championships in Shanghai, China, was another opportunity to showcase our movement.

We were well represented in the Internationally Abreast teams – Hope, Spirit and Inspiration – and several members of Dragons Abreast Sydney formed part of Team Australia masters squad.

We spoke at the Shanghai Cancer Recovery Centre and were interviewed for a Dragon TV documentary. It was also wonderful to meet Chinese and Singaporean breast cancer survivor teams.

For further details, see our website at www.dragonsabreast.com.au.

I take this opportunity to wish each of you the ‘breast’ of health, and a merry Christmas and happy new year.

Michelle Hanton,
National Co-ordinator,
nationalcoordinator@dragonsabreast.com.au

Breast cancer survivors enjoy the camaraderies of Dragons Abreast.

Exercise boosts recovery from breast cancer

Preliminary results from a UK trial have shown clear benefits for women with breast cancer who undertake physical exercise, even if it’s only 30 minutes gentle exercise three times a week.

The study, by the University of Birmingham, found that exercise therapy and lifestyle counselling hastened recovery and improved the long-term physical and mental wellbeing of women recovering from breast cancer.

Researchers decided to look at this area as there was evidence that once treatment was completed, many women experience on-going physical side effects including weight gain, insomnia, fatigue, loss of muscle tone, reduced flexibility and loss of libido. These physical symptoms can lead to feelings of low self-esteem, depression, anxiety or lack of confidence.

The women in the eight-week trial were randomly divided into three groups. The first group took part in an exercise program designed to suit their physical ability. At each session, an exercise therapist also worked with the women to support and encourage them to include more physical activity in their lives.

The second group followed a body conditioning program, but were given no encouragement to do more physical activity, while the third group were offered only currently available standard treatment (no recommendations to exercise).

Initial results following the women at three intervals – eight weeks, three months and six months – showed that the first group displayed the most positive results, reporting lower depression, an increased satisfaction with their lives and a reduction in their weight.

These results will come as no surprise to groups such as Encore, the post-breast cancer surgery exercise program for women and our dragon boating readers, however it is important to point out that the benefits could be also gained from simple exercise regimes, including walking the dog.
ACT

Anna Wellings Booth has been to Vienna to represent BCNA at the ESMO Conference. Bernadette Brady organised an excellent Mini-Field, starting at the Canberra Centre with a Silent Walk to City Hill. Anna has been networking on the south coast and an group from Merimbula came to our Mini-Field and the Dragons Abreast regatta.

Bosom Buddies benefited from a fashion parade breakfast by Ondina and Escala Shoes. They also organised a floral emblem and held a dinner for 227 with a fashion parade by Maggie Shepherd.

Hadas Haileselassee spoke to a group at St John’s, Kippax. Bernadette spoke at the Crowne Plaza Australia’s Breast Cancer Day tea, while Elspeth attended the launch of the NBCF National Action Plan. They were both at the launch of the five-year report of Breast Cancer Treatment Group for the ACT. Pam Robertson presented a cheque from Bosom Buddies to help with the report’s publication.

Bernadette made sure there were pink ladies outside the Legislative Assembly! Bosom Buddies and Dragons Abreast will fund a pamphlet about the role of breast nurses.

Anna Wellings Booth, (02) 6247 8470 or wbfamily@homemail.com.au, and Elspeth Humphries, (02) 6239 6344 or humphries44@ozemail.com.au

NSW

As I write this, Pam Bell is paddling her way to success in a dragon boat overseas. We had several Mini-Fields in NSW this year and it was great to have people support BCNA in this moving tribute.

Early in October I was invited to be a guest speaker at one of Le Rêve’s charity functions in Sydney. Le Rêve is very passionate about raising money for BCNA. I also attended the NBCF’s research launch. There were some interesting speakers, topics and questions, and certainly lots of information to disseminate.

ENCORE in Sydney is holding a photographic exhibition of women who have had breast cancer. It started on October 28 at Boy Charlton Pool in the city. I attended the opening event. Pam and I still have a few post-conference actions to follow up on and we are working together to get better communications and information to our NSW member groups.

On that note, there was a woman I spoke to at the conference who lived just outside of Dubbo. I promised to follow up on a couple of things and, in the flurry of questions and paper, I misplaced your e-mail and telephone details. If you could drop me a line at mjames@globalswitch.com that would be terrific.

Pam Bell, (02) 9955 9313 or bellpc@bigpond.net.au, and Megan James, (02) 9440 0373 or mjames@globalswitch.com

Northern Territory

NT Breast Cancer Voice (NTBCV) arranged a public forum at Parliament House, to report on the BCNA Melbourne conference. It was well attended and the dinner on the lawn afterwards was enjoyed by all.

October began with the media launch of the Dragons Abreast Australia calendar by the Chief Minister, followed by the NT Telstra Business Women of the Year Awards, where Michelle Hanton was named as the overall Territory winner. The following day we were all at Government House for the annual NTBCV luncheon, graciously hosted by NTBCV’s Patron, Nerys Evans.

Susan and Michelle celebrated Australia’s Breast Cancer Day in Sydney with many other Aussie members of BCNA from around the country.

In Darwin, our members attended breakfasts hosted by the Business & Professional Women and Dr Rosie Muller, a fellow survivor.

Next year will see changes in the NT as Susan, who has been involved as a consumer advocate since the pre-BCNA days, will step down as State Rep. We have recommended that the second State Rep be recruited from Central Australia.

We wish you all a healthy 2005.

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

Queensland

Congratulations and thanks to all the women involved in holding Mini-Fields. Here in Brisbane and close environs, they were held at Bulimba, Cleveland, Caboolture and the Wesley Hospital’s Kim Walters Choices Program. Convenors, Lyn Moore, Wendy King, Jurina Demaine, Janine Porter-Steel and Leonie Young, said they were successful. Bakers Delight franchisees helped with generous morning teas.

Veronica Macaulay-Cross spoke at the Queensland Women in the Public Service Luncheon, which was attended by 180 people. The Queensland Cancer Fund held its popular Bras Afloat on the Brisbane River.

The Queensland Committee of BCNA is busily working to organise Warrior Women – a dramatic, insightful and evocative multi-media art exhibition, created by women who have had breast cancer. It will be held at the Brisbane Powerhouse, New Farm, from February 28 to March 14. The exhibition has already been displayed in Melbourne and Canberra and we are very exited about bringing it to Brisbane.

The My Journey Kit will have its official Queensland launched on March 1, at Powerhouse. We encourage as many people as possible to support the exhibition and the launch. Anyone wishing to help as a volunteer please contact us.

Veronica Macaulay-Cross, (07) 3269 8083 or vonphil@bigpond.net.au, and Lyn Moore, (07) 3822 5468 or lyn.moore@bigpond.com

We wish you a healthy 2005.

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

We wish you all a healthy 2005.
These reports are extracts of comprehensive quarterly reports written by our State Representatives. The complete reports can be found on our website – www.bcna.org.au. Our State Representatives are always happy to hear from readers or to promote activities within the State. Just give them a call!

South Australia

What a busy time it has been, with Mini-Fields happening in many parts of the State.

Mt Barker ran a Pampering Day in conjunction with its early in October and what a success it was.

Our Port Lincoln Friends didn’t hold one this year, but several ladies traveled to Adelaide to attend the one at Henley Square, which coincided with the finish of the Fence Liners walk of the Heysen Trail, enabling us to use Sue Lane from Queensland as one of the guest speakers.

We had the privilege of speaking at Encore early in October and hope this will be an on-going commitment with women just out of their treatments.

Jan travelled to Kangaroo Island for a Pink Breakfast on October 25 and was greeted with good country hospitality. Again, we are hoping for on-going contact.

The Public Forum 2004 on November 14, broadcast from the Oakbank Racecourse.

Best wishes for the future to Deb Martin from all SA.

Deb Martin, (08) 8241 1804 (home), and Jan Davies, (08) 8388 4825 (home) or jandavies@adam.com.au

Tasmania

On October 16, a large group of Tasmanian BCNA members gathered at Campbell Town, the geographical centre of Tasmania, to hold a Mini-Field and launch the My Journey Kit in Tasmania.

Campbell Town was chosen as the venue because it necessitated all the attendees having to make a journey to reach the small country town.

Kim Polley, the Mayor of the Northern Midlands Council, launched the My Journey Kit. Mayor Polley spoke about the Kit and how much she had learnt from reading it, including how much she was touched by the stories contained therein.

Local breast cancer survivor, businesswoman and poet, Helen Lindsay, read a wonderfully funny poem she had written about her own journey.

The day was beautiful and sunny, although cool, and many passing travellers stopped to look at the silhouettes and inquire about the significance of the Mini-Field, which was planted in the shape of Tasmania.

Karen Forster has been chosen to represent BCNA at the San Antonio Breast Cancer Conference in Texas during December.

Joan Williams, (03) 6424 5886 or gwilliams44@vtown.com.au, and Karen Forster, (03) 6273 4422 or dforster@vtown.com.au

Victoria

Our journeys with breast cancer are reflected well in Spring Carnival atmosphere and Spring weather in Victoria – sunshine, rain, wind, races, fashion, colour, parties and roses!

Then there are the joys and sorrow, highs and lows, gales and calm, bread and wine, pinks and perfumes, winners and losers, but always HOPE.

The range of activities and the numerous groups involved in functions for breast cancer awareness in October is confusing and overwhelming. BCNA’s Mini-Fields had to compete with many ‘pink ribbon’ activities in October.

However, the feedback we have received has been excellent, with families and friends grateful for the opportunity to show their support for a loved one with breast cancer, or their loss for someone who has died.

We are confident that these events provide an opportunity for practical information at a local level and a focus for acknowledging the impact of breast cancer on the lives of families and friends.

Thank you to everyone who helped with the Mini-Fields and to all those who generously donated.

And a special thank you to the Bakers Delight staff who promoted BCNA using the finger bun promotion in October.

Enjoy summer!

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

Western Australia

Action on Breast Cancer’s (AOBC) Annual General Meeting was held in August. The officers elected were: Maria Waters (Chair); Sue Hassett (Vice Chair); Jennifer Pettigrove (Treasurer); Jade Hart (Secretary/Fundraising Co-ordinator); Liz Milward (Database Manager); with Carol, Judith, Liz, Lorraine and Ann elected to the Committee.

We had one of this year’s AOBC Specialist Breast Care Nurse sponsorship recipients as a guest AGM speaker. Hearing Julie speak of her work with such enthusiasm and how much need there is for women to have access to specialist breast care nurses has confirmed our position to increase the number of sponsorships each year. Invitations from AOBC to country and metropolitan hospitals for expressions of interest from registered nurses have been circulated.

Thank you to all those involved across WA who displayed and held a Mini-Field. So many friendships have been forged and the support gained is invaluable.

As we fast approach the end of the year, I would like to take this opportunity to wish you all a safe and happy Christmas and welcome the new year with good health and happiness.

Maria Waters, (08) 9344 7362 or alma.waters@bigpond.com, and Carol Bishop, (08) 9205 1018 or carolbishop@inet.net.au

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Upcoming Events

February 28 – March 14: Warrior Women, multi-media exhibition by women with breast cancer, Brisbane Powerhouse, New Farm.  
Contact: Qld BCNA Reps, Veronica (07) 3269 8083 or vonphil@bigpond.net.au, or Lyn (07) 3822 5468 or lyn.moore@bigpond.com

March 1: Queensland launch of My Journey Kit and BCNA Public Forum, Brisbane Powerhouse, New Farm, 11am – 3pm.  
Contact: BCNA, 1800 500 258.

May 6 (evening): Field of REAL Women, MCG Melbourne.  
Contact: BCNA, 1800 500 258 or www.bcna.org.au

Contact: Terry Gilmer, wcbwbcoc@cogeco.net

There are other locally based events happening around Australia, but there too many to list here. Readers can learn about these by logging onto Upcoming Events on our website, www.bcna.org.au

 Miracle baby offers hope

Baby Tamara Touirat’s recent arrival was so important that her birth was announced in the medical journal, The Lancet.  
She was born in Brussels, after her mother’s ovarian tissue had been removed, frozen, stored and then replaced six years later, following her treatment for cancer.

Tamara’s mother, Ouarda, had five samples of her ovarian tissue removed, but not the whole ovary, because it is sometimes possible that the ovary will recover following chemotherapy. In Ouarda’s case, this did not happen and so doctors thawed and replanted the tissue that had been stored in liquid nitrogen.

This is a landmark case and one that should offer hope to young women with breast cancer about to undergo chemotherapy, who might want to have children down the track.

You’re not yet on our mailing list?
Phone (03) 9805 2500 or 1800 500 258 (free call), or fax (03) 9805 2599, e-mail beacon@bcna.org.au or fill in this coupon and send it to: Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.

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

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

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

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

In politics, if you want anything said, ask a man. If you want anything done, ask a woman.  
Margaret Thatcher