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Let's celebrate our achievements

*This year will be one that many of **The Beacon's** newest readers would rather forget – it will be forever engraved in their memories as the year they were diagnosed with breast cancer. Others will have celebrated important milestones this year, such as five and 10 years' survival.*

For BCNA, it has been a year packed full of opportunities and activities. We have now distributed more than 11,000 copies of our *My Journey Kit* to women in all States and Territories, and the feedback has made us proud of our efforts.

We have travelled the length and breadth of Australia this year, presenting State launches of the *My Journey Kit* and informing our members through State-based Forums.

We have met many gutsy and inspiring women on our travels – women who face enormous challenges daily, but who make the most of each day. This has reminded me that our network is just that – a connection of individuals, each with our own lives, dreams, plans and commitments. In the main, the thread joining us is our experience with breast cancer and the need to inform ourselves and to make sure the women, men and families affected by the disease get the best deal.



Members of the Port Lincoln organising group – Maxine Barker, Anne Baldissera, Sandra Sinclair, Pat Boylan, Mary Barnett, Beth Dunchue and Helen Hookings

My lasting and most powerful memory for 2005 will be standing on the MCG in May with almost 12,000 others in the incredibly moving *Field of Women – Live in 2005*. Sometimes, at my quietest moments, I can re-capture the extraordinary sentiments of the night, seeing all those expectant hot pink figures beforehand, the overwhelming sense of connectedness with the other women there, the way people weren't afraid to share their emotions so publicly and, more than anything, the combined drawing in of breath when I asked breast cancer survivors to raise their arms into the air. What a moment!

I applaud all of you who were proactive in your own way this year: the team in Port

Lincoln who presented our first regional *Field of Women*; the women and men who worked to present more than 80 *Mini-Fields of Women* across Australia; those who represented us on committees and projects throughout the year; those who participated in support groups and in assisting others; those who helped spread the word about BCNA or helped fundraise for us; our State Representatives and staff who have worked diligently ... and those just managing to get through each day.

Already, 2006 is showing signs of being an action-packed year, but I hope that, before you throw yourself back into the fray, you will have time to enjoy some peace and rest time over the holiday period, and that the

year ahead will give you great satisfaction and joy in whatever it is that you do.

*– Lyn Swinburne,
Chief Executive Officer*



Festive wishes

Warmest wishes to all readers of **The Beacon** for a happy holiday season. We wish you much happiness and good health in 2006.

BCNA travels from top to bottom

BCNA staff have been on the move again. Since the last issue of **The Beacon**, we have conducted member forums in Sydney, Alice Springs, Darwin and Launceston.

We are always delighted to get out and about and meet our members. The forums each had their own local flavour, yet there were consistent issues no matter where we travelled across this vast country. At each stop, we took the opportunity to promote our *My Journey Kit*.

In Sydney, a large crowd attended our forum. We were delighted that many of the women present were new to BCNA, having 'found' us after receiving their free *My Journey Kit*. We also held a media conference to further promote our *My Journey Kit*, in response to our concern that too many women in Sydney were not hearing about this fabulous resource. We were delighted with the media coverage of the event and noticed an immediate increase in requests for the *My Journey Kit* from NSW.

Our small gathering in Alice Springs was a great opportunity to renew long-standing connections, as well as meet new

members.

When diagnosed with breast cancer, most women leave Alice Springs for their treatment. Although surgery is available in Alice Springs, there is no access to radiotherapy in either Alice Springs or Darwin. This is tough for all women, but presents particular challenges for indigenous women across the Northern Territory.

Our Darwin Forum was addressed by **Dr Sid Selva** – the Territory's only oncologist. We were disappointed to hear that Sid will be leaving Darwin at the end of the year – possibly leaving the Territory with no oncologist. On our return, we wrote to relevant Territory Members of Parliament to express our concern.

The final leg of this year's State forums took us to Launceston. Although the weather was distinctly cooler than that in Darwin, the welcome was warm, with women travelling from all over the State to this 'sell out' session. We enjoyed a range of presentations and particularly thank **Dr Amanda Young** for her contribution. This forum



Mary Maloney, Shelley Sexton, Lyn Rigby, Terri Smith and Pauline Watson at the Tasmanian Forum

coincided with the launch of the Warrior Women Exhibition in Tasmania.

On the air waves

Stretching further afield, we ran a small forum in Dubbo, NSW. It was broadcast through the School of the Air to individuals and groups who logged in at student desks from farms and homes across outback NSW. BCNA's CEO, **Lyn Swinburne**, and Board member, **Raelene Boyle**, really enjoyed meeting

the women, both in Dubbo and over the airwaves. They were particularly impressed with the strength and courage of these women.

We are excited about the possibilities the School of the Air might provide in helping us reach women across Australia. We will explore these possibilities further next year.

Thanks to the School of the Air for helping make this happen.



Ted Egan, Administrator of the Northern Territory, held a reception with his partner, Nerys Evans, at Government House for supporters of BCNA



Terri Smith and Lyn Swinburne about to promote the work of BCNA

Field of Women goes regional

Wintry conditions, rain and winds, didn't dampen the spirits of the 100 volunteers – co-ordinated by **Helen Hookings, Maxine Barker** and the Port Lincoln Caring Cancer Support Group – who hosted the first regional planting of BCNA's Field of Women.

Pink, blue and white silhouettes, representing the latest breast cancer statistics, were planted along the shoreline of Port Lincoln, South Australia, eight hours' drive from Adelaide, to commemorate Australia's Breast Cancer Day.

The shoreline was marked into 24 squares; each of which was assigned for silhouette plantings by a local community group or survivor. The result was a stunning pink patchwork display of silhouettes which shone through the rain.

Local breast cancer survivor, **Amanda Proude**, spoke about her diagnosis three years ago at 33, and the journey she shared with her husband and two small children.

"Everyone's journey with cancer is different and the only way to deal with it was one step at a time. Piece by piece, one foot in front of the other, and just keep going," she said.

A routine screening was how Eyre Peninsula's Local Member for Flinders, **Liz Penfold**, was diagnosed. Ironically, she had lobbied to establish the mobile service some 10 years earlier. Liz urged all women to have regular screenings, to ensure the disease was detected as early as possible.

"They're frightening statistics, when you think that 11,500 women will be diagnosed and another 2700 will die this year alone," said Port Lincoln Caring Cancer Support Group's spokeswoman, Maxine Barker.

Entertainment was provided by **Chris Kenny**, a survivor of breast cancer, and members of the Sing Australia Group.



MP Liz Penfold, a local breast cancer survivor speaking at the Port Lincoln Field of Women



Field of Women in Port Lincoln

The local Dragons Abreast team, with Water Warriors, combined for the moving Flowers on the Water Ceremony and the crowd participated by throwing flowers from the foreshore.

To ensure this important annual exhibition continues, BCNA invites Member Groups to consider hosting the Major *Field of Women* in October 2006. Expressions of interest can be sent to kedwards@bcna.org.au with an announcement expected early next year.

BCNA would like to acknowledge the support of **Australian Air Express, Star Track Express** and **Naughton Transport** for their sponsorship of storage and transport for our silhouettes. We would also like to thank the **Port Lincoln Times** for allowing us to reproduce its photos.



The Silent Walk took place in Port Lincoln's torrential rain!



Alice Springs Bossom Buddies



Bacchus Marsh, Victoria

Mini-Fields of Women 2005

This October Mini-Fields of Women were displayed in 81 communities across Australia.

From Weipa near the tip of Cape York, to the grounds of Parliament House in Hobart, from Byron Bay in the east to Hillarys Boat Harbour in Western Australia, communities small and large gathered to honour Australians affected by breast cancer.

In Western Australia, sponsored Pink-on-Pedals cyclists broke through a string of pink lady silhouettes at the start of a 55km ride from Point Walter to the Mini-Field at Sorrento Quay. Toby

and David from Bakers Delight did a fabulous job driving the support vehicle.

A Silent Walk and speeches from local breast cancer survivors highlighted the fact that breast cancer has no barriers and that many of those affected lead full and productive lives. The Dragons Abreast team performed the moving Flowers on the Water ceremony.

In NSW, more than 200 people gathered on the waterfront in Port Macquarie for the local Mini-Field and to hear from speakers, including a 23-year survivor, the daughter of a male breast cancer

survivor, a woman who spoke of her brother's tragic battle with breast cancer and his wife who has recently been diagnosed with breast cancer. Each shared the story of their journey and those of their families. Pink ponchos from the *Field of Women – Live in 2005* at the MCG earlier this year were worn by participants to pay tribute to those affected by breast cancer.

The Mini-Field planted in Geelong, Victoria, was set around a labyrinth, to signify the twists and turns encountered on the breast cancer journey. People were invited to walk the labyrinth and

read the signposts along the path showing messages of inspiration, then follow the outer pathway to read the silhouette messages. The event received great support from local health professionals, and the guests speakers included local oncologists and social workers.

At Canberra Girls Grammar in the ACT, the rain dampened the ground, but not the spirits of those involved, in the first of what is hoped to be an annual Mini-Field at the school. BCNA State Representative, **Anna Wellings Booth**, addressed more than 250 students as part of the day's activities.



Robe, South Australia



The Geelong Dragon Boat Team's Mini-Field



Canberra Girls' Grammar School's Mini-Field.

Year 7 student, **Sarah Dobbie**, who had recently completed a project aimed at helping people affected by breast cancer said, "We must think of those who fight, remember those who have done their fighting and have support for the *Mini-Field of Women*".

As part of her project, Sarah put together a book of poems, quotes and support messages which now sits in the oncology ward at John James Memorial Hospital, to offer encouragement to breast cancer patients.

Hobart's *Mini-Field* was planted on the lawns of Parliament House and was part of a larger event that saw several organisations, such as the Breast Cancer Support Service, Dragons Abreast and local BCNA members, exhibit displays to raise public awareness about the impact of the disease.

The official planting ceremony featured guest speakers, **Janelle Hall**, a breast care nurse, and **Brian Gallagher**, a local male survivor, speaking about the impact of the disease on families and the wider community. Poems were read in tribute to those who have lost their lives to this disease.

Up north in Queensland, two *Mini-Fields* were held at St Clement's Anglican Church in conjunction with local church services. Willing helpers were ready to 'plant' the pink ladies on a beautiful morning at 5.30am. St Clement's Church is of an octagonal shape and the pink silhouettes were planted around the entire building, so that they could be seen by parishioners, no matter which direction they came to church. During both morning services, special prayers were offered and **Rev. Leisha Rule**, a 30-year breast cancer survivor, preached the sermon. After the sermon, members of the congregation lit candles in front of the altar and proceeded with a Silent Walk around the church.



Bakers Delight staff, Toby and David, supported the *Mini-Field* in Sorrento Quay, Western Australia

More than 200 people attended and experienced this symbolic and moving occasion. There was much celebration, as well as tears of remembrance and thanksgiving during the day. Special thanks to Bakers Delight at Windsor for supplying the morning tea after the 8.30am service.

The Redlands Breast Cancer Support Group brought its *Mini-Field* to life in Cleveland, Queensland, by inviting local women to stand in the shape of the pink lady silhouette, just like the *Field of Women – Live in 2005*, and honour those in their community affected by breast cancer.

In Bacchus Marsh, Victoria, the community gathered at the *Mini-Field* on the main street to plant their silhouettes.

In Robe, South Australia, the Kingston & Robe Women's Health Advisory Group had a magnificent day and planted their silhouettes among the roses as a fitting tribute.

In North Epping, NSW, Operation Pink Band hosted a *Mini-Field* family day that included face painting, head shaving and a pink stilt walker.



Senator Judith Adams

BCNA mentioned in Parliament

"BCNA has led the way in this country as a consumer advocacy organisation ... Through a sensible and determined approach, BCNA has earned the respect of key providers of breast cancer services across the country and ensured that breast cancer services continue to improve."

Senator Judith Adams,
October 12, 2005

BCNA was delighted to read a recent speech made by **Senator Judith Adams** during the October Federal Parliamentary sittings in Canberra.

A breast cancer survivor and former BCNA Consumer Representative, Senator Adams from WA spoke passionately and comprehensively about breast cancer and BCNA's programs, including the *Field of Women*, *My Journey Kit*, *A Seat at the Table*, lobbying and advocacy.

A transcript of her speech is available on the BCNA website – www.bcna.org.au – in the 'Latest News' section.

Thank you to our 2005 Mini-Field convenors

This year 81 *Mini-Fields* were held in the following communities:

ACT

Chifley – Pam Robertson
Deakin – Matthew Morrissey
Fraser – Bernadette Brady
Griffith – Denyse Gibbs
Tuggeranong – Jodie Stevens

NSW

Armidale – Vivienne Gregg
Byron Bay – Barb Pinter
Coffs Harbour – Lee Millard
Dorrigo – Margaret Corlis
Elderslie – Pauline Watson
Forbes – Christine Gorton
Galston – Glenys Barringham
Hunters Hill – Vanessa Loadsman
Kar-ing-gai – Megan James and Pam Bell

Macksville – Anne Pade
Merimbula – Jo-Anne Reid
North Epping – Jessica Ann Conaghan
Parkes – Deanne Tanswell
Port Macquarie – Kristine Lewis
South Grafton – Margaret O’Shea
Taree – Rachel Pitt
Tweed Heads – Jane Kelly
Wagga Wagga – Sue Munro
Warners Bay – Julie Owens
Woollahra – Susan Cohen

Northern Territory

Alice Springs – Wave Hayden
Darwin – Michelle Hanton

Queensland

Albany Creek – Leisha Rule
Auchenflower – Janine Porter-Steele
Burpengary – Jurina Bemaine
Cleveland – Wendy King
Condamine – Raqual Humphries
Dysart – Dale Redden
Goondiwindi – Bevis Gibson
Ipswich – Tanya Trost
Kilcoy – Cindy Kunde
Laidley – Jill Meuleman
Longreach – Mary Dempster
Proserpine – Marleen Ross



A young supporter at the Mini-Field in Stawell, Victoria

Toowoomba – Ruth Glanville
Weipa – Kerry Ayres

South Australia

Adelaide – Jill Borthwick
Balhannah – Jan Davies
Barmera – Jenny Boyd
Ceduna – Rebecca Kavanagh
Cummins – Anne Cummins
Grange – Jane Marsh
Jamestown – Susan Malchya
Mt Gambier – Tracy Bald
Port Augusta – Sally Edwards

Robe – Jenni Ling
Tumby Bay – Karyn Speed
Victor Harbour – Sandy Werchon
Whyalla – Verity Timms
Norrie Yorketown – Julie Tonkin

Tasmania

Devonport – Robyn Glen
Hobart – Karen Forster
Launceston – Queen Vic – Rachael French
– Holman Clinic – Julie Robinson
Wynyard – Anne Cameron

Victoria

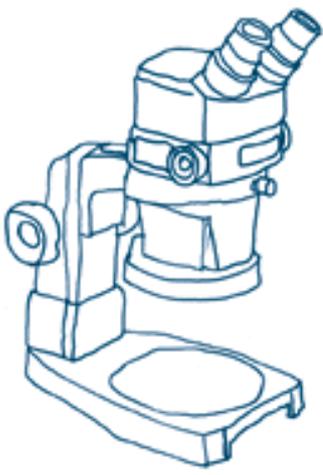
Ararat – Judy Gleeson
Bacchus Marsh – Lorraine Odges
Ballarat – Jeannette Vervaart
Brighton – Mary Gregory
Colac – Heather French
East Melbourne – Tina Griffiths
Geelong – Leanne Storer
Mount Eliza – Pamela Freeman
Numurkah – Kerry Patford
Ringwood East – Mandy Kavanagh
Shepparton – Kerry Patford
Silvan – Sheila Tesselaar
Stawell – Sue Boag
Traralgon – Judy Woods
Vermont South – Diane Cole
Williamstown – Carrie McKinnon

Western Australia

Esperance – Sharon Scoble
Geraldton – Kaye Street
Northam – Allison Fosbery
Perth – Maria Waters
Toodyay – Pamela Walsh



Mini-Field, Alice Springs



Research Update

NBCF's annual research update

In September, the National Breast Cancer Foundation (NBCF), which raises money for national research, held its annual research update in Sydney. The Hon. Ros Kelly, Chair of the NBCF Board of Trustees, opened the meeting. Eight researchers outlined the research they were undertaking or had completed using funds provided by the NBCF – and in some cases in co-operation with another agency or research fund.

BCNA Representatives from each State and Territory were funded by the NBCF to attend this session and to take the opportunity to ask questions of the scientists.

The session provided a terrific opportunity for researchers to meet with the women their research aims to help. The update demonstrated that it was not only possible but, in fact, crucial that researchers and women with breast cancer communicate.

BCNA advocates involvement by consumer representatives in the design and development of research projects. By involving consumers at the development stage, researchers can ensure that

their work will directly address the needs of those affected by breast cancer.

While some of the research presented is undertaken in the lab with test tubes (and in some cases mice), other research is addressing the 'people' aspects of breast cancer. The research presented ranged from developing the means to support ongoing research with tissue and cell banks, and the psychological and social impact of lymphoedema, through to developing an information tool about menopause for young women with breast cancer.

Other presentations included the KConFab study of family breast cancer, stem cells and breast cancer, the impact of exercise on wellbeing and survival after breast cancer, and an evidence-based review of complementary and alternative therapies.

The update was a useful session that outlined the important research underway. It reminded us that the cause of breast cancer is still unknown, although it is probably a combination

of genes and environment. It also highlighted the significant progress made over the past decade, most particularly in the area of understanding that breast cancer is a complex and diverse disease that requires individualised treatment.

The session demonstrated the importance of researching the possible causes of breast cancer, while also considering the impact of breast cancer and ways to make the journey a little easier for women diagnosed with the disease. While the research process is sometimes slow, it will ultimately influence outcomes for women in their breast cancer journeys. Perhaps one day it will even result in a cure or, better still, an end to breast cancer!

We congratulate the NBCF for taking this important step in reporting back to the community the results achieved through its continual fundraising efforts.

For more information, visit the NBCF website – www.nbcf.org.au – or phone 1800 000 118 for a copy of the *Annual Breast Cancer Research Update*.

Improving predictions

Scientists are always looking for ways to predict which breast cancers are more likely than others to re-occur after initial treatment. It helps to plan what extra treatment might be useful for a woman.

One of the usual methods is for surgeons to remove lymph nodes and have them tested for the presence of cancer cells.

Doctors at Stanford University in the US recently conducted a small study that investigated a new way of examining lymph nodes to determine the likelihood of breast cancer re-occurring.

Instead of just examining lymph nodes for the presence or absence of cancer cells, they looked at changes in the immune cells within the lymph nodes. Immune cells circulate in our body to fight the infections and illnesses we are exposed to.

The research findings suggest that changes in the immune cells of lymph nodes from people with breast cancer may help them predict which breast cancers have a higher likelihood of recurring. They believe that the finding of their small study may warrant a larger study to further investigate this issue.



Issues of concern ...

Progress in Herceptin funding

As discussed in the last issue of **The Beacon**, BCNA has continued to monitor the progress of Herceptin testing and highlighted the need for the Therapeutic Goods Administration (TGA) to fast track its approval, before subsidy approval by the Pharmaceutical Benefits Advisory Committee.

On October 20, the latest findings from the HERA trial were published in the *New England Journal of Medicine*, bringing good news for women whose early breast cancer is HER2 positive.

The new data showed a real benefit from Herceptin for this group – around 20% of women with early breast cancer – potentially reducing their risk of breast cancer recurring, and enhancing their life expectancy.

However, this good news is tempered by the knowledge that women who have already been diagnosed with HER2 positive breast cancer have a poorer prognosis and many cannot afford to pay for Herceptin.

On the day the findings were published, the Federal Health Minister, **Tony Abbott**, said the TGA would make approval of Herceptin a priority and encouraged Roche to submit its application for approval. Roche made its submission later that day.

However, the normal approval process takes about two years.



Elpis Barons from Melbourne is one of the many women who requires access to Herceptin

Can we afford to make women wait this long for an extra chance?

BCNA has heard and seen, first hand, the stories of women whose oncologists have advised them that Herceptin may be beneficial, but that it will come at enormous financial cost.

We have followed the journey of Scott Bradshaw, who has walked from Brisbane to Sydney to raise funds to pay for Herceptin for his wife, Leanne. In fact, BCNA Board member, **Raelene Boyle**, walked across the Sydney Harbour Bridge, as a display of BCNA's support. We have encouraged women to negotiate with their private health insurers for funds.

We have spoken with women and their husbands prepared to mortgage or sell their homes.

This drug may save women's lives. If the data continues to build as strongly as it has to date, that means some women with early breast cancer may avoid developing advanced disease. For these women and their families, prompt action by the TGA and subsequent approval for a subsidy by the Pharmaceutical Benefits Scheme cannot come too soon.

BCNA will do everything in its power to ensure that all women who need Herceptin can have affordable and equitable access to it. We will continue to raise the issues for women with breast cancer in the media, so that the community will understand and appreciate the need to move this agenda forward.

We will support clinicians in their endeavours on behalf of their patients. We will also advocate for optimal surveillance of women on Herceptin, in order to monitor their cardiac health.

We will continue our dialogue with those in power, to ensure we best represent women with breast cancer, no matter who they are or their personal circumstances.

40 women a day in 2011

Breast cancer's impact will increase with time, according to *Cancer Incidence Projections Australia 2002 to 2011*, a new report from the Australian Institute of Health and Welfare (AIHW).

According to AIHW's figures, the number of women diagnosed with breast cancer each year is projected to increase by around 26%, from 11,791 in 2001 to around 14,818 in 2011. This equates to approximately 40 women being diagnosed with breast cancer every day.

These figures are age-standardised, so they reflect Australia's trend towards an increasingly older population. Because cancer incidence increases with age, the incidence increases for the general population as it ages.

Consistent with the major message delivered by women at BCNA's National Conference in 2004, these figures highlight that breast cancer must stay on the public agenda. They clearly indicate that research, service provision and advocacy specifically addressing breast cancer must continue to be given the highest level of attention into the future.

The AIHW figures show that Government and the health system must remain focused. Women affected by breast cancer confront a multitude of medical, emotional, legal and financial challenges – our efforts must not only be maintained, but increased.

Response to Arimidex announcement

Excellent news – Arimidex is now subsidised on the Pharmaceutical Benefits Scheme (PBS) for all post-menopausal women with early stage breast cancer.

Arimidex is one of the aromatase inhibitors that can be used instead of tamoxifen.

There are some patients who, for a variety of reasons, cannot tolerate tamoxifen or for whom the risks outweigh any potential benefits.

BCNA's position has been that Arimidex should be available for those women who, for clinical

reasons identified in conjunction with their oncologist, should be taking Arimidex instead of tamoxifen.

With this in mind, BCNA wrote to the Pharmaceutical Benefits Advisory Committee (PBAC) in 2004, outlining our policy and seeking its agreement.

At its meeting in July 2005, the PBAC recommended that Arimidex be listed for the treatment of hormone-dependent breast cancer in post-menopausal women. Subsequently, in August, the Pharmaceutical Benefits

Pricing Authority accepted the pricing proposal of AstraZeneca, noting that Cabinet approval was required, as it exceeds the net \$10 million threshold.

BCNA subsequently wrote to the Federal Health Minister, **Tony Abbott**, asking that Cabinet expedite this approval by October, so that women would have easy access to Arimidex by December 1, 2005.

The Minister's announcement on October 21 is heartening news for BCNA members who will benefit from this decision.



Pink Bands for sale

Operation Pink Band

Operation Pink Band, the sale of bright pink wrist bands as a show of support for BCNA, has been a terrific success.

Since the campaign began in August, more than 50,000 pink bands have been sold. Members of Sydney's West Tigers NRL football team, the Manly Sea Eagles and the gang from TV's Better Home and Gardens are all supporters of the campaign.

BCNA sincerely thanks **Jessica and Peter Conaghan** from Sydney for their hard work and dedication in making this such a successful project.

Pink wrist bands are available from a variety of retailers nationally, including selected **Bakers Delight** bakeries, **Athlete's Foot** and **Events** fashion stores.

To find out more, visit www.pinkband.com.au or phone (02) 9869 0229.

Improved access to reconstructive surgery – long overdue in Queensland

On the eve of Australia's Breast Cancer Day, 24 October, Queensland's Premier, **Peter Beattie**, announced that an extra \$745,000 would be allocated each year to ensure that Queensland women have better access to breast cancer reconstructive surgery in public hospitals.

The State Government will also 're-prioritise' reconstructive breast surgery to reduce the waiting lists caused by its current categorisation as 'non-urgent Category 3 elective surgery'. This change is certainly overdue, given that women have spent nine years on previous waiting lists!

Mr Beattie said breast reconstruction could be better managed by including it in comprehensive breast surgery procedures and that, where clinically appropriate, doctors should be able to perform reconstructive surgery at the same time as a mastectomy.

BCNA State Representative, **Veronica Macaulay-Cross**, said the announcement was "great news and a step in the right direction".

"A few years ago, only one reconstruction was done in the public system in a whole year. I know of one young woman who returned to Adelaide so that she

could get a reconstruction in that public system," she said.

Premier Beattie's announcement reflects a key recommendation from last year's BCNA Conference, Still Making a Difference – "Recognition that reconstruction is a core component of care, not elective surgery, should be promoted".

As Veronica said, this is great news and Queensland women are encouraged to ask for a breast reconstruction if that is their choice and decision.

For more about this decision, visit <http://statements.cabinet.qld.gov.au/portfolio-display/tmp/1130205323.html>



BCNA gratefully acknowledges our partnership with Bakers Delight.



Media reports on breast cancer

As expected, there was a lot of media coverage about breast cancer in October. We thought you might be interested in seeing some recent items covered in the news.

A report in the *Weekend Australian* on October 1 discussed a new study in which researchers were better able to distinguish between early-stage breast cancers and non-cancerous lesions by combining standard ultrasound imaging and optical tomography. Improved diagnosis through this combination has the potential to reduce the incidence of unnecessary breast biopsies.

Brisbane's *Courier Mail* reported on the findings of a study by Cancer Research UK. The study indicated that advances in breast cancer screening and treatment should enable two-thirds of

women diagnosed today to still be alive in 20 years' time. Ten years ago, fewer than half the women diagnosed could expect to survive for two decades.

Australian Doctor reported that the Federal Government has added new item numbers to the Medicare Benefits Schedule, including cover for sentinel node biopsy for the surgical management of breast cancer. Until now, doctors were able to claim a rebate for the clearance or removal of lymph nodes in the armpit, but not for the more recently performed sentinel node biopsy.

According to the *Daily Telegraph*, women in the ACT must pay \$150 for a breast cancer check that is free in other States. The ACT BreastScreen program only provides free mammograms

to women over 50, whereas other States offer free screening mammograms to women over 40. The shortage of radiologists in Canberra has reportedly forced many 50-69 year olds to pay privately for a breast check. The ACT's waiting lists have topped six months, forcing some to give up and pay for private screening.

The *Adelaide Advertiser* reported on a new radiotherapy treatment for breast cancer in SA piloted by the Royal Adelaide Hospital Cancer Centre. The new procedure is performed under local anaesthetic with a small seed of radiation placed at the tumour site via a catheter. The treatment may reduce treatment times for radiotherapy from weeks to days.

Can I donate blood or organs following breast cancer?

At our Sydney forum, a member asked whether breast cancer survivors were able to donate blood and organs. We promised to check the latest advice and report back.

Here is current information from the Australian Red Cross Blood Service on the subject:

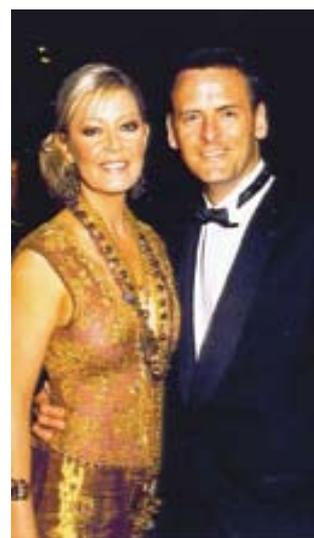
- All Australians are eligible to register their desire to donate their organs with the Australian Organ Donor Registry. It is strongly recommended that people also tell their family of their wishes regarding organ

donation. Family members will be consulted in the event that the possibility of organ donation becomes a reality.

- Some cancers, such as cancers of the blood and bone and melanoma, are absolute exclusions for subsequent organ donation. However, breast cancer is not one of these.
- Once a person who has had breast cancer has been cancer-free for at least five years they are potentially eligible to donate their organs.

- Unfortunately, once a person has had breast cancer, they become ineligible to donate blood for the rest of their life. This is as much to protect the donor as the recipient. As well as ensuring the safety of blood recipients, the Australian Red Cross Blood Service is careful to ensure it does not put donors at risk of ill health as a result of blood donation.

BCNA thanks **Nicky Webster** of LIFEGift, the Victorian Organ Donation Service, for her assistance with this article.



Leanne Bradford, chair of the Glitter Ball organising committee, enjoying the ball with her husband, Joe.

Glitter Charity Ball

The enchanting Regent Theatre Plaza Ballroom in Melbourne was the venue this year for the annual Glitter Charity Ball on October 1.

The event, co-ordinated and hosted by a small, but dynamic, team of passionate volunteers, raised funds for BCNA's *My Journey Kit*.

Now in its fourth year, the gala evening was attended by Olympic champions and BCNA supporters, **Lauren Hewitt** and **Kirstie Marshall**. Media personality, **Beverley O'Connor**, was this year's MC.

The silent and major auctions raised more than \$90,000 for BCNA. It will be used to fund the ongoing costs of producing the *My Journey Kit*.

Our thanks to **Leanne Bradford** and her energetic team for an outstanding achievement!



My Story

Bald can be beautiful

On January 31, I was diagnosed with breast cancer. A week later a lumpectomy was performed and 14 lymph nodes were removed from my armpit. A week after that I was back in hospital for a mastectomy. The physical and emotional roller coaster continued into chemotherapy, the first of my 'after' treatments.

I had the strongest, thickest mane of hair, so it was difficult when my oncologist told me I would lose it after a few weeks of treatment. A part of me refused to believe it. I did cut my hair to shoulder length as a precaution (alas, not short enough).

Meanwhile, husband Michael took on another challenge ...

Around the Bay in a Day for BCNA

Michael Swards raised more than \$12,000 for BCNA by completing Victoria's Around the Bay in a Day ride.

He was inspired to help us after his wife, Lisa, who was diagnosed with breast cancer earlier this year, received our *My Journey Kit*.

"My wife Lisa experienced a horrible eight months dealing with the shocking news that she had breast cancer," Michael said.



Lisa Swards with her children, Harrison and Isabella

After a week of chemotherapy, my husband, Michael, came home one evening with his head shaved. He had a thick head of hair, so it was quite a shock for me and the kids. For days our little girl kept saying, "Daddy has no hair".

Sure enough, after two chemotherapy sessions, my hair

began to come out in hand fulls.

Helpless, I stared at the clumps in my fingers and was extremely distressed by seeing my hair in every room of our home. After four dark, ungraceful and surreal days, my beloved hair was gone – my hairdresser came to my home and shaved the remnants.

"After an incredibly positive attitude from my wife, support from all our friends and family, and, of course, the medical arena, she is through the worst of it and we are looking forward to resuming a normal healthy life.

"I decided to enter the annual Bike Victoria Round the Bay 210km bike ride and therefore put myself through some pain of my own (although a fraction of what a cancer patient endures),

but, more importantly, to use the ride to raise money for a truly wonderful organisation, BCNA.

"BCNA was of considerable benefit to my wife and the many thousands of women annually who are diagnosed with breast cancer. BCNA offers an amazing support structure and immediate assistance from the time of the diagnosis and throughout the whole treatment period."

My six-year-old son, Harrison, hesitated slightly before he said, "You don't look as bad as I thought Mum". My two-year-old daughter, Isabella, said, "Mummy, you now look like Daddy". She then kissed my bald head and said, "I love you so much".

Perhaps bald can be beautiful ... in the eyes of a loved one.

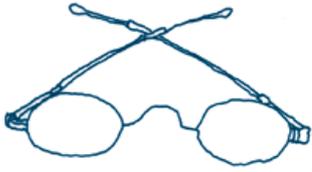
Over the weeks, Isabella has said on several occasions, "When I grow up I can shave my head too". In hindsight, Michael's selflessness has made my baldness easier for the children and perhaps me too.

A dear friend told me about a helpful and inspiring website – www.baldisbeautiful.org – for anyone coming to terms with their hair loss. It is the creation of a bold woman in New York, who has chosen to remain au naturel bald after her initial round of chemotherapy in 2003.

– Lisa Marie Swards, Victoria



Michael Swards



Book review

Healing Angels

by Arlene Nedeljkovic

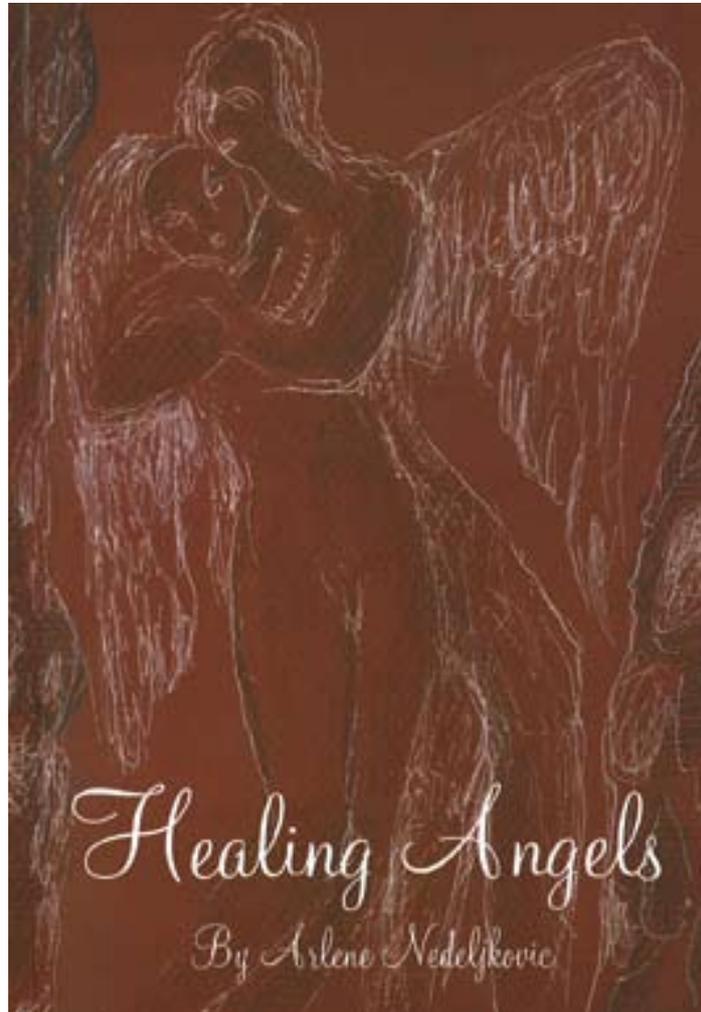
Available from the author at PO BOX 2289, Marion, WA 6020. for \$22.00, including postage. ISBN 0 646 44713 0

Healing Angels is a beautifully written book by painter and sculptress, **Arlene Nedeljkovic**, about her journey of healing after breast cancer surgery and treatment using her travels and change of lifestyle.

Healing Angels is different to the average book written by breast cancer survivors, as it does not dwell on diagnosis or go into detail about treatment. Instead, it concentrates on the relationship between a mother and daughter and their travels together through Europe visiting art museums, viewing paintings and drawings, and enjoying all the old architecture.

It is was a spiritual journey for both of them, but there were also some humorous moments, such as coping with the various public toilet systems in Italy, France and Spain. Arlene also had some 'hair-raising' moments with her wig while travelling, which many breast cancer survivors will relate to!

Her daughter, **Zivana**, a newly trained doctor, looked after her mother like she was a child, preparing special food and juices for her throughout the journey; but they occasionally broke away from their routine to sample the wonderful local cuisine.



Zivana has written an interesting preface for the book about a holistic approach to cancer treatment, which is followed by Arlene's drawings of falling and rising angels, which were inspired by Dante's *Divine Comedy*. Arlene's journey has followed Dante's path from hell to purgatory to paradise.

At the end of the book there are 13 pages of simple recipes designed to nurture the immune

system, and which Arlene and Zivana followed while travelling. There is also a useful two-page glossary.

This is a brilliant, uplifting story that would appeal to everyone, particularly those interested in the healing power of art and travel after breast cancer treatment.

– Marie Polla-Mounter,
Willung South, Victoria

A new way to spread the word

BCNA is delighted to have been named the Official Charity of the 2006 Formula 1 Australian Grand Prix.

The 11th Australian Grand Prix, to be held in Melbourne from March 30 to April 2, will attract a television audience of millions around the world. This should be another powerful way to raise awareness of breast cancer and reinforce our key messages.

Be sure to look out for the secret celebrity driver in the BMW Celebrity Challenge Race representing BCNA and driving – what else – a pink lady BMW!

Reader survey

Some of you will receive a reader survey with this issue of **The Beacon**.

We have developed the survey to get an idea of how well **The Beacon** is meeting your needs as a reader.

If you have not received the survey and would like to have a say, phone the BCNA office on 1800 500 258 and give us your address and we will post you one or download it from our website – www.bcna.org.au.

We always welcome feedback about **The Beacon**, so feel free to drop us a line, e-mail the office or phone us.

Changing Gears

In October, the east coast of Australia heard the thunder of 21 young breast cancer survivors on pink-themed Harley Davidson motorcycles as they revved up their engines for the final leg of the Changing Gears global motorcycle ride from Sydney to Brisbane.

Women in the United Kingdom, US and Australia participated in week-long rides for this event.

The ride, which aimed to challenge media stereotypes and raise awareness about breast cancer in young women, has already raised well over \$40,000 for BCNA, with money still coming in.

Among the women who participated were some still receiving treatment or not long out of treatment. Others were riding to commemorate friends or family members. BCNA's Northern Territory State Rep, **Pat Hancock**, from Darwin, drove one of the two support vehicles.

No BCNA event is ever complete without **Bakers Delight!**



Riders Pat Hancock (NT), Meredith Campbell (Qld) and Megan Dwyer (NSW) with BCNA State Rep, Pam Bell.

Through the generosity of the local Bakers Delight franchisees, the riders were treated to meals and snacks along the way. Bakers Delight's mascot Breadhead was also at the Coogee Beach launch to greet the crowd – he's always a great favourite with the littlies.

BCNA members and groups did a magnificent job of supporting the riders by hosting events en route to welcome them as they rode through their home towns, including a fabulous day at Steve

Irwin's Australia Zoo on the Sunshine Coast.

Raelene Boyle also got on two wheels for the event, joining the women for their final ride into Brisbane on the back of a Harley driven by Changing Gears and Amazon Heart founder, **Meredith Campbell**.

Thank you to Amazon Heart, all the Changing Gears participants, BCNA members and Bakers Delight for making this such a successful event.

Bakers Delight October promotion

As our major corporate partner, Bakers Delight are long-term supporters of BCNA.

Each October, to commemorate Breast Cancer Awareness Month, Bakers Delight bakeries nationally run fundraising activities to raise money for, and awareness of, BCNA.

This year was no exception. Throughout October, bakeries displayed BCNA donation tins, supported local *Mini-Field of*

Women activities and hosted fundraising events. We are delighted to report that Bakers Delight has raised more than \$1 million for BCNA over the past five years.

Our thanks to all Bakers Delight staff, franchisees and customers for their ongoing support.

When you next visit your local Bakers Delight bakery, remember to thank them for their support.



A Bakers Delight store used our silhouettes in a unique way to promote BCNA

Thank You

We appreciate the support given to us – in small and large ways – by so many people around Australia. We would especially like to acknowledge the help of the following outstanding supporters over the past three months:

- North Sydney Girls High School
- Kitchen Aid (Peter McInnes Pty Ltd)
- George Castan Family, Vic.
- Chemist Warehouse's Carseldine Team, Qld
- Roma's Ride (Elaine McTaggart), WA
- Bountiful Home, Croydon, Vic.
- Clover Cottage Luncheon (Barb McAuley and Sue Harrison), Vic.
- Tattersall's, Vic.
- Griffith Breast Cancer Support Group, NSW
- Del Shelvock at Yulara for the proceeds of fundraising
- Lee Naylor
- Pam McLaren
- Leanne Bradford and the Glitter Ball Committee
- Michael Sowards
- Harriet Moore, Prue Troedel, Jacinta Moore and the Pink Ladies Golf Classic
- Jacky Kyle
- Melissa Fulton and staff at Crowne Plaza, ACT
- Holly Gardner
- Meredith Campbell.

Thanks to all the readers who donated money in response to the letter that accompanied the previous issue of **The Beacon**. Special thanks also to those of you who gave such great feedback.



Dragons Abreast

Dragons Abreast Australia is extremely excited to announce that it has accepted the baton from Abreast In A Boat, Vancouver, Canada, to host the next 100% breast cancer survivor regatta in Australia.

It will be held at Kawana Lakes on the Sunshine Coast in September 2007.

The camaraderie engendered by such an event cannot be underestimated. For example, Canada's 10th anniversary celebration was attended by 65 survivor teams from the US, New Zealand, Canada, Poland, Italy and Australia — 1600 women all living with breast cancer. It was a celebration of life and a powerful statement. We were proud that 120 of our members were in attendance and flew the Aussie flag.

Our State representatives are



Dragons Abreast members, Barbara Williams, Rita Redden and Sue Sherratt

increasingly busy, as more regional areas seek to be a part of the magic of Dragons Abreast. We now have 29 member groups; nine more than we had in April.

Over the past few months, our members have participated in several different events, including the Ord River Marathon, the Australian Masters Games in

Adelaide and lots of other local regattas. Dragons Abreast ACT also hosted a successful regatta in Canberra during October.

For information on your nearest group, phone 1300 889 566.

*– Michelle Hanton,
National Co-ordinator,
Dragons Abreast Australia*

What's new on the BCNA website?

Our website is a good place to monitor developments in the Herceptin debate, to check out our media releases on issues of interest and to read what our politicians are saying publicly about breast cancer. You can also view photos of everything from our first regional *Field of Women* at Port Lincoln to the *Mini-Fields* that were held all over Australia in October. Our personal stories section is always popular.

As well as topical news and events, we regularly try to add more and more of the information we have available to the website.

There's an expanding 'A-Z' list of links in our 'Information' section to help people interested in looking for information on the site by topic. For instance, we have been building our list of book reviews and adding **The Beacon** articles and reviews from past issues by topic.

There are some new pages too. Under 'Information' are the sections 'About breast cancer' and 'Breast cancer organisations in Australia' which contain straightforward information and statistics.

Under 'About BCNA' there are pages for the component parts of

our network and a description of our activities.

For those interested in following our advocacy work and efforts to change the health system, our submissions are available to read or download. Recent additions include our submission to the Senate committee inquiry into services and treatment options for people with cancer. There are also those to other authorities, on such diverse issues as privacy and biotechnology.

Your ideas and feedback are welcome. You can visit our website at www.bcna.org.au.

Menopause the Musical – Brisbane

The Queensland BCNA Committee is hosting a fundraising night at Twelfth Night Theatre, Bowen Hills, on **Tuesday, February 21, 2006**, at 8pm of this musical, which has played to packed houses in Melbourne and Sydney.

Tickets are \$40 each. Pay by cash or cheque/money order (**made out to BCNA**). Purchase tickets **before January 10** to go in a draw for two free tickets to the night.

For tickets contact:

Lexie Warren on Mob 0410 553 550 or lexiewarren@bigpond.com

Veronica Macaulay-Cross on (07) 3269 8083, Mob 0419 745 694 or vonphil@bigpond.net.au

Lyn Moore on (07) 3822 5468, Mob 0407 143 689 or lyn.moore@bigpond.com

Encore Exercise Program

The YWCA will run the eight-week Encore Exercise Program for Women in Brisbane at the following times:

- January 31 to March 21, 2006, RBH Hydrotherapy Pool, Herston, 10.30am to 1pm.
- February 7 to March 28, 2006, Leichardt Pool, Ipswich, 12-2pm.
- February 16 to April 6, 2006, Elridge Swim School, Thornlands, 10.30am to 1pm.

To enrol or enquire, phone YWCA on (07) 3831 8727.



Letters to the Editor

While reading the most recent issue of **The Beacon**, I noted a question from **Hayley Johnston-Coutts** in Victoria.

Hayley raised the unusual problem of her own diagnosis at 25, followed by her mum's diagnosis with breast cancer in her late 50s. As the risk of breast cancer rises with age, it is unusual for a mother to be diagnosed after her daughter, but it does happen in some families.

Given that two family members have been affected by breast cancer, including one diagnosed before the age of 40, Hayley's relatives should be considered at potentially high risk of breast cancer. This history raises the possibility that there may be an inherited genetic fault that has caused some family members to be at a higher risk of breast and (possibly) ovarian cancers.

The family history needs to be assessed further. This can be done

via any of the Familial Cancer Clinics operating in most States of Australia. The family may be eligible for genetic testing.

The testing usually commences by taking blood from an affected family member. The genes BRCA1 and BRCA2 are then tested to determine whether there is a mutation that might cause breast/ovarian cancer in the family.

This testing is not perfect and cannot find all of the possible mutations, but in future there will almost certainly be other genes that we can test. Therefore, if Hayley has a genetic test and no mutation is found, it should be considered inconclusive.

If, however, a gene fault is found in either BRCA1 and BRCA2, then predictive testing can be done to determine the level of risk for Hayley's sisters, and in the long term, her daughter.

Although the family history has evolved in an unusual way, with

the daughter being affected before mother, this may still indicate a genetic predisposition. The family would gain a great deal of information and advice by attendance at a Familial Cancer Service.

– Judy Kirk,
Clinical Associate Professor,
Westmead Health, Sydney

Editor: Before undergoing genetic testing, BCNA believes a women must have thorough counselling, as the issue is complex and carries wide-reaching ramifications for the whole family.

Counselling and testing are offered at Familial Cancer Clinics in the ACT, NSW, Western Australia, Victoria, Queensland, South Australia and Tasmania. For more information and contact details for the clinics, visit www.nbcc.org.au/bestpractice/riskfactors. If you do not have access to the Internet, phone BCNA on 1800 500 258 and we will forward you a copy of the details.

The My Journey Kit is available, free of charge, to any Australian diagnosed with breast cancer in the past 12 months. To receive one, phone 1300 78 55 62.

Since its launch in May 2005, more than 11,000 My Journey Kits have been distributed.



Seeking shelter

BCNA welcomes the following new Member Groups:

- Breaststroke, Melrose Park, SA
- Manning Valley Breast Cancer Support Group, Taree, NSW
- Cancer Friendship Group, Forest Lake, Queensland
- Dragons Abreast North West Tasmania Inc., Devonport, Tasmania
- Southern Fleurieu Cancer Support Group, SA
- Jewish Women's Breast Cancer Network, NSW
- Broken Hill Breast Cancer Support Group, Broken Hill, NSW.

We are pleased to announce that BCNA now has 15,907 individual members and 148 Member Groups.

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:

..... State:..... Postcode:.....

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

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

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

Retiring State Representatives

BCNA is fortunate to have two committed and energetic State Representatives in each State or Territory. At the close of this year, two of BCNA's valued State Reps will stand down. **Maria Waters** (WA) and **Michelle Hanton** (NT) have both made enormous contributions in their time representing BCNA.

While they will no longer be State Reps, we will not lose touch. Maria will be a member of our Advanced Breast Cancer Working Party and we will hear from Michelle in her role as National Co-ordinator for Dragons Abreast.

It is always sad for us to say goodbye, but both women deserve a few minutes to themselves. We send warm (and pink) thanks to Michelle



BCNA sincerely wishes to thank Maria Waters and Michelle Hanton, our retiring State Representatives

and Maria. You have 'made a difference'. In the new year, we will welcome **Luisa Guiffre** (WA) and **Pat**

Hancock (NT) as our new State Reps. We will profile both our new representatives in the next issue of **The Beacon**.

BCNA's State Representatives

Our State Representatives, all breast cancer survivors, keep an ear to the ground for news across the country and make sure information is effectively distributed. They are also a local contact for women with specific enquiries or issues. You can read their latest reports on our website, www.bcna.org.au

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The Beacon is printed with the generous support of Mercedes Waratah Press.

This is not what I wanted for Christmas!

This is not what I wanted for Christmas

I got plenty of chocolate and jubes

This is not what I wanted for Christmas

The removal of one of my boobs

This is not what I wanted for Christmas

So Santa take note and instruction

If you want me to greet you with cheer next year

Make it a breast reconstruction.

— Rita Bevan, Victoria



the BEACON

The Beacon is the magazine of Breast Cancer Network Australia.

Editor: Lyn Swinburne,
Layout: Substitution

Your letters, articles, photos, comments and items for the next issue are welcome. Send them to

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