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the BEACON

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Our focus on young women

Welcome to our final issue of **The Beacon** for 2007!

Inside we offer you a snapshot of some of the many initiatives and events held by Breast Cancer Network Australia members during October, which is Breast Cancer Month around the world.

The theme of this issue is **Young Women and breast cancer**.

One might ask 'How young is young?' When I was diagnosed in 1993 at 40 years of age and with two little children, I certainly felt very young.

Earlier this year, when I met the vibrant and gorgeous **Nikki Dwyer**, who at 22 was my own daughter Eliza's age, I realised that there is 'young' and there is 'very young'. From a medical management perspective, women with breast cancer who are pre-menopausal are considered 'young'. This life stage is extremely relevant to what is considered and offered as treatment by a woman's medical team.

While we don't want to get caught up in arguments about definition, it is important to acknowledge that very young women, whose cases may be relatively rare, face added issues and we must work to make sure they are cared for in the best possible way.



Nikki Dwyer

Facing breast cancer is never an easy thing, no matter what age you are. Many women of all ages can face issues related to body image, relationship concerns and an uncertain future. How challenging it must be to have the added issues of future fertility concerns or even a diagnosis during pregnancy. How tough it must be for those who have yet to find a life partner or those who are only beginning careers and entering the workforce.

How difficult it must be for parents to cope with a young daughter's diagnosis.

Breast Cancer Network Australia is committed to ensuring that everyone diagnosed with breast cancer is on the receiving end of the very best information, treatment, care and support available. We hope that women will feel empowered by good quality information and will be strengthened by the experiences

of others. By raising the real issues faced by real women, we hope to make things better for us all.

The women's articles in this issue are a poignant reflection of the challenges faced by young women with breast cancer across Australia. We will continue to work to ensure that these young women's issues and identified needs are heard by government, as well as doctors and scientists. Making sure that programs and services are tailored to individual needs as much as possible, will go a long way towards making a very difficult time a little bit easier.

Lyn Swinburne
Chief Executive Officer



We wish all our readers a happy, safe and healthy festive season and new year.

Pink Ladies across the country

More than 130 Mini-Field of Women events featured across Australia during October, with community groups banding together to show their ongoing commitment to women and families affected by breast cancer.

In September, Pink Ladies appeared on the snow fields at Thredbo, NSW, where Channel Ten conducted its weather report among the silhouettes, with breast cancer survivor **Jane Redmond**.

Woollahra Golf Club in Rose Bay, NSW, asked local businesses to 'sponsor a hole' and more than 60 golfers raised in excess of \$10,500.

Sisters **Jazz Tyrri-Smart** and **Cad Tyrri** turned Shorncliffe's Upper Moora Park in Brisbane pink as a tribute to **Veronica Macaulay-Cross**. 'We thought the best way to honour her memory was to keep raising awareness by supporting and remembering friends and family with breast cancer' Jazz said.

Emma Fulwood, Sue Humphrys and supporters turned South Australia's Kangaroo Island pink. Businesses and schools took on a pink tinge, the Pink Lady silhouettes adorned Cape Jervis and pink balloons were released during an emotional ceremony.

Kerrie Griffin organised the Pink Lady silhouettes for 10 public libraries in the ACT. The Pink Ladies also featured at the Dragons Abreast ACT Regatta.

Breast cancer survivor **Anne Cameron** and her team of supporters ran *Mini-Fields* in Burnie and Wynyard, Tasmania.

In Western Australia, the Pink Lady silhouettes overlooked the beautiful bay of Esperance, where **Sharon Scoble** and her team from the Esperance Breast Cancer Support Group placed 100 silhouettes in front of the Jetty Café.

Queensland's Member for Aspley and breast cancer survivor, **Bonny Barry** MP,

held a *Mini-Field* at Marchant Park in Brisbane, and Premier **Anna Bligh** attended to show her support for the local women.

Jillian Lawrow invited **Julia Gillard** MP and Senator the Hon. **Kay Patterson** to her *Mini-Field* at Victoria's Werribee Football Ground. The ceremony ended with a rousing rendition of *Up There Pink Lady*.

Thanks to **Senior Constable Kath McCabe** from the Victoria Police Breast Cancer Support Group, the lawns of the Police Academy in Melbourne glowed with the bright Pink Lady silhouettes. A lone piper played *Amazing Grace*, and the police chaplain conveyed to all a message of hope and support.

Cohana's Carole Heap was keen to lift the spirits of her community in northern Victoria. A 300-strong crowd witnessed the heart-shaped silhouette planting at the Barham Riverside Park. Carole said, 'Our community

is not only trying to survive breast cancer, but we are also battling the drought. The human spirit is strong and this day attests to that'.

In the Northern Territory, **Natalie King** planted Pink Ladies in front of SkyCity, one of Darwin's most popular locations.

PaperlinX, which supplies the paper for **The Beacon**, organised 10 *Mini-Field* events in its offices across Australia. **Bakers Delight** pitched in with delicious buns for the events. Thanks to all the bakeries across the country who supported *Mini-Field* events in their communities with delicious treats.

We are grateful to all the convenors across Australia who worked tirelessly to raise awareness and funds through this year's *Mini-Field* events. To see the extent of the activities and communities involved visit our website at www.bcna.org.au



Julie Kelly and Jane Kelly take a moment to reflect in Tweed Heads, NSW (courtesy of Daily News).



Jane Chapman and helpers pinked up the park in Beaconsfield, Tasmania.



Sheilagh Kentish, Karen George and Faye Quinlan held a Mini-Field of Women at Victoria's Ballarat North Sports Club (courtesy Ballarat Courier).



Anne Steele, the first Tasmanian woman to swim the English Channel, spoke on the lawns of Parliament House at the Mini-Field of Women in South Hobart.



Katrina Richardson among silhouettes at the Crown Plaza in Lovedale, NSW (courtesy Newcastle Herald).



The striking silhouettes in the snow at Thredbo, NSW, made Channel Ten's weather report with Tim Bailey.



Natrasska Chiron sits among the silhouettes planted by the Calvary Health Centre, ACT (courtesy Canberra Times).



Betty Stubbins was a guest at the Mini-Field of Women run by the Ingham Health Service in Queensland.



Donna and Melissa Pumpa and Kate White among silhouettes at O'Reilly Park in Nyngan, NSW (courtesy Nyngan Observer).



Jane Redmond nestles among the silhouettes in Cooma, NSW.



Senior Constable Kath McCabe on the lawns of the Victorian Police Academy.



Carole Heap and helpers rouse up the town of Barham, NSW.



One of the many silhouettes planted at the Mini-Field of Women in Kilcoy, Queensland.



The Mini-Field of Women at Hilarys Harbour in Western Australia.



Proud supporters of Mini-Field events 2007

2,800 Pink Ladies inspire paddlers from around world

More than 2000 breast cancer survivors from the United States, Canada and New Zealand joined their Australian sisters at the Dragons Abreast Australia International Regatta in Caloundra, Queensland, in September.

A spectacular Field of Women of 2,800 Pink Lady silhouettes, representing the number of women in Queensland diagnosed with breast cancer each year, stood proudly on the banks of

Lake Kawana, providing extra incentive for paddlers to reach the finish line. Despite an event full of activity, many paused to read the personal tributes on the silhouettes.

More than 20 locals and onlookers volunteered their time to plant and support the Field of Women. BCNA could not have done it without them, especially **Judy Irvine, Roma Jones** and the **Caloundra Breast**

Cancer Support Circle. We would also like to thank **Lyn Moore, Elspeth Humphries, Gerda Evans** and **Anna Wellings Booth.** Finally, thanks to **Naughtons Transport** for transporting and storing our Pink Lady silhouettes to events across Australia.



Judy Irvine and her granddaughters enjoy a break to read the messages on the Pink Lady silhouettes at Caloundra, Queensland.



Lyn Swinburne, with Berlei Ambassador Sophie Fawcner and Julie Malandin, General Manager The Berlei Group, at the Pink Lady bra launch in Sydney.

Berlei Pink Lady bra

Berlei has been sponsoring BCNA's My Care Kit program since 2004.

To celebrate Australia's Breast Cancer Month, Berlei extended its support to BCNA by introducing a Pink Lady bra range into Myer, David Jones and leading retail outlets.

Berlei donated \$5 from the sale of every Pink Lady bra, raising more than \$100,000 for our programs.

BCNA key rings are back

Back by popular demand, you can buy the key rings for \$5 each at our virtual shop at www.bcna.org.au or by phoning 1800 500 258.



BCNA gratefully acknowledges our partnership with Bakers Delight.





Issues of Concern

Fertility after breast cancer – what are the options?

'We had decided to try for a baby that year, and then we were told that chemo could decrease my fertility ... and even then we would not be able to even consider trying for 3–5 years after the treatment had finished.'

*Kylie Rowe (31)
Bogangar, NSW*

For women of child-bearing age diagnosed with breast cancer, making decisions about treatment options can be complex enough, but the possible impact on future fertility presents another range of issues. The impact of treatment on a woman's fertility depends on her age, the type of treatment she has and how it affects her ovaries. For example, some chemotherapy can result in premature menopause, which may be temporary or permanent.

Considering all the options that may protect or preserve fertility before starting treatment can help women make informed choices about the future. What are the options and do they work?

'Brad and I have a lot to look forward to, especially the 14 children we have in the freezer!'

*Joanna Mason (27)
West Footscray, Victoria*

Mature egg freezing involves stimulating the ovaries with hormones to produce eggs that are then frozen and stored until required. **Embryo freezing** also involves hormonal stimulation, but the eggs are fertilised before freezing. The embryos can then



The booklet, *Can I still have children? Fertility options for young women having chemotherapy and radiotherapy*, is available from the Melbourne IVF website at www.mivf.com.au/downloads/FPSbooklet.pdf

The contact details in the booklet are for Melbourne, but the Fertility Society of Australia website at www.fsa.au.com has contact details for clinics in all States and Territories.

be stored until required and on average around 80% survive.

Dr **Kate Stern** is Director of Research at Melbourne IVF and Medical Coordinator of the Fertility Preservation Service. She said: 'The effectiveness of egg freezing depends on how many eggs are frozen initially, how many survive the thawing process and the quality of the eggs after thawing. If 10 eggs have been frozen, we can expect that they will help make about two or three embryos for transfer when required. The pregnancy rates with embryos created from frozen eggs are expected to be about the same as thawed embryos. Egg freezing may be useful for young women who are single or not in a committed relationship, while freezing embryos offers good hope for women who are in relationships'.

However, mature egg and embryo freezing may not be appropriate

for all young women. 'We have some concern about hormone stimulation in young women with oestrogen-receptor positive tumours. Although there are some medications that we use to try and protect the breast from the hormones, there are no large studies confirming the safety of this practice. Each patient's situation needs to be considered individually when planning options,' Dr Stern said.

Other relatively new fertility options include **ovarian tissue freezing** and **auto-grafting of ovarian tissue**. These procedures involve freezing a sample of ovarian tissue from a woman before she starts her chemotherapy and grafting it back onto the ovary after treatment is complete, in the hope that the ovary may start to function again some months later. This is a very new procedure, with only four babies born to date. 'This

technique does hold promise as a means of restoring ovarian function in women who have developed permanent ovarian failure as a result of their chemotherapy, but it still cannot be considered to be a routine practice,' Dr Stern said.

Drugs such as Zoladex can provide a further option for protecting the ovaries during chemotherapy, with studies showing it can reduce the possibility of permanent ovarian failure by up to 40%. However, the studies undertaken to date have been fairly small and further substantial research is required. In addition, Zoladex is expensive, at a cost of more than \$320 a month.

For women who have no further ovarian function, the widely practised and quite successful option of using eggs from another woman to make an embryo may be an alternative. Although it is laden with additional practical and emotional complexities, surrogacy might suit some couples.

Each woman's case is different, so any young women considering pregnancy after breast cancer treatment would benefit from discussing the issues with their cancer treatment team and a fertility specialist before their treatment commences.

To find an accredited fertility clinic visit the Fertility Society of Australia's website at www.fsa.au.com under 'RTAC' on the left-hand side menu, then go to 'Accredited Units' on the bottom right-hand side.

Up Close and Personal

The Young Action on Breast Cancer (YABC) committee worked tirelessly to present the first national conference for young women with breast cancer, entitled Up Close and Personal. The Melbourne event drew more than 180 women together where they connected and shared their personal and often inspiring experiences of living with breast cancer.

Presentations and discussions focused on a range of issues including fertility issues, pregnancy during and after treatment, isolation, relationships with family, partners and friends, and supporting children. Performances by the YABC Divas brought to life many of the everyday challenges familiar to many young women in the audience.

As it turned out the conference was timed perfectly for this issue of *The Beacon*. There's no better way to hear about the important issues for young women with



The Young Action on Breast Cancer (YABC) committee left to right: Rita Marigliani, Young Ones coordinator; Ann Maree Scott, YABC organising committee member; Mary Macheras-Magias, YABC Chairperson and organising member; Jo Smith, organising committee member; Kerri Guy, organising committee member; Donna Gordon, YABC committee member.

breast cancer than to be immersed with them for a whole weekend. BCNA is collating a conference report which will be available from our website.

Transcripts, presentations and photos from the conference will be available on the YABC website www.yabc2007conference.org

It's more than physical

'I have found it to be not only a physical but a psychological trauma.'

Madaleine Byers (37)
Yangebup, Western Australia

Research suggests that up to 20-30% of younger women may experience psychological distress after being diagnosed and treated for breast cancer, and up to 50% may experience depression after they have finished their treatment. A feeling of isolation and sense of grief associated with loss of fertility, loss of body image, loss of autonomy and increased dependence can play a

part in these feelings. For many young women, especially if single, having to depend on parents and families to provide care and financial support, following years of independent living, changes the traditional developmental pathway and can contribute to depressed feelings.

Many women find support services helpful – peer support groups, or individual or family counselling. Maintaining a healthy diet has been proven to be effective for some young women, while others say exercising during

and after treatment helps them mentally as well as physically. Relaxation or meditation can be beneficial as can treating yourself to a massage, facial or even a new piece of fabulous jewellery!

Whatever the strategy, research suggests that as quality of life improves, negative feelings may begin to diminish. However, if negative or depressed feelings persist, it is best to have a chat to your GP or cancer treatment team, or phone the Cancer Helpline on 13 11 20.

Conception after treatment

'It suddenly dawned on me that we have a baby and that we are parents ... After being diagnosed with breast cancer ... we were not sure if we would ever be lucky enough to have a baby.'

Megan James (42)
Pymble, NSW

Ovaries can spontaneously function again following treatment for breast cancer, and some young women do go on to have successful pregnancies with no problems. Standard medical advice suggests waiting at least two years following completion of treatment, before attempting to conceive. Two years, however, can seem like a long time, especially if you are in your late 30s or early 40s.

Recent research from Western Australia found that women diagnosed with early stage breast cancer may not need to wait two years before attempting pregnancy. It is important to note that pregnancy within two years of completing cancer treatment is still relatively rare, and therefore, very little research has been conducted in this area. The researchers also highlighted the importance of discussing any pregnancy plans with your cancer treatment team.

Resources for young women

Our website includes a list of useful resources and support groups for young women. Visit www.bcna.org.au > Newly diagnosed > Young women or phone us on 1800 500 258 and we will send you the list.

No hair and a massive belly

In April 2006, aged 32, newly married, a newly qualified paediatrician, I had just been diagnosed with breast cancer. I was 12 weeks pregnant with my first child.

Fortunately the tumour was small, and I was node negative, but the tumour was also hormone sensitive, and so I was given the choice: terminate or chemo. Easy. What is hair compared to a baby? Clinging to the advice that it should be safe, I began the second trimester of my pregnancy. Breast conserving surgery followed by four cycles of chemotherapy, all to buy time until a planned early elective caesarean so that I could have radiotherapy without too much delay.

People ask me whether my experience has changed the way I practise medicine. While I always felt I was empathetic and kind, I now understand the anguish of the unknown, the torment of not knowing what one's future holds, the sense of despair when faced with one's own mortality, the overwhelming 'noise' that fills one's head when discussing a personal diagnosis of cancer, the sense of helplessness and dependency one feels when placing your trust – your life and fate – in the hands of others, and the fear above all for the life of one's unborn child. So, yes, I guess I am changed, and I believe for the better. One can hardly go through the treatment of breast cancer, or any cancer, and remain unchanged.

I sailed through the chemo without a hitch. However, nothing prepared me for the fatigue of pregnancy combined with chemotherapy; even my baby felt it and would barely move



Kylie Blackwell with her husband Brendan and son Thomas Jack.

during our low-count weeks. As for body image – no hair and a massive belly are not good for one's ego and resulted in the necessary purchase of several glamorous blonde wigs and hours of shopping.

Hospitalised at 31 weeks with premature ruptured membranes, I went into labour at 33 weeks resulting in an emergency caesarean. Thomas Jack was born a healthy 1.8 kg with a head full of hair, and no complications.

Six months on, he is enormous and never stops moving, smiling or babbling. He still comes to my appointments as he always did – my chemo buddy. Thomas helped me through every dark day by his

wriggling and kicking, through the sight of my constantly expanding belly, and the knowledge that all I was doing, I was doing for him.

I am still amazed by the reactions of others when I tell my story, the pity I hear in their voices and see in their faces. Yes, it was horrible, but it was also the best year of my life. Firstly, it gave me my beautiful son. Secondly, I have discovered the true meaning of love and friendship, from both family and friends. I have grown as an individual, discovered a strength that I never knew I had, and I have seen the best in those that I love.

*Kylie Blackwell (32)
Canterbury, Victoria*

Breast cancer while pregnant

'I had surgery immediately after diagnosis, while I was still pregnant. My daughter was delivered by caesarean five weeks later and I began chemotherapy when she was two weeks old.'

*Belinda Ryan (34)
Sydney, NSW*

Although a diagnosis of breast cancer during pregnancy is rare, accounting for only 2% of all breast cancer cases world-wide, it poses complex decisions for women in this situation.

Depending on the type of cancer, treatment options for pregnant women vary considerably. As radiotherapy is often not recommended while pregnant due to the risk to the unborn baby, some pregnant women choose to have a mastectomy rather than breast preservation surgery. Where chemotherapy is required, some women may wait until after the birth of their child.

Recent studies have shown that more women are undertaking chemotherapy during the second and third trimesters of their pregnancy, as it is considered safe for the baby. Research conducted in the US by the M.D. Anderson Cancer Center has found no adverse effects on children exposed to chemotherapy in the uterus. It is acknowledged, however, that further research is needed in this area.

What about the kids?

'The scariest thing for me was coming to terms with the fact that I would need chemotherapy and I would have to sit my two sons down and tell them "mum has cancer" and needed "special medicine to make her better"...my oldest son was almost 10 years old, so I couldn't lie or pretend to him. As expected, he was devastated and cried for the longest time. My youngest, who is only 6, went about playing his Nintendo Wii!'

*Maria Sardea (33)
Maribyrnong, Victoria*

What, how, or even whether to tell children about a diagnosis of breast cancer adds yet another level of stress to many young women experiencing cancer. Even though it can be difficult, there is strong evidence that shows that being open and honest with children is the best way to help them cope with a parent's illness, and reduce their anxiety. Children respond to a parent's illness in a variety of ways, and how they respond can depend on their age, gender, and developmental level.

At the *Up Close and Personal* conference, **Lisa Sowards** spoke about her experience of introducing breast cancer to her eight-year-old son, Harrison and her daughter, Isabella, who was only two at the time. 'From the very beginning I kept a journal, which Harrison also contributed to – with drawings and stories of what we were going through as a family'. This practical and therapeutic activity resulted in a book for primary school aged children, *My Mum has Breast Cancer*, written and illustrated by Harrison with Lisa's guidance.



Lisa Sowards and her children, Harrison and Isabella, play 'dress-ups' during Lisa's treatment.

Through her conference presentation, Lisa identified strategies that can assist when introducing children to breast cancer. With school-aged children, it can help to talk to their teacher, and also to ask the principal to inform the wider teaching staff. Lisa described how a notice board in the staff room of her son's school included photos of children who were going through challenging times, so all teachers were aware.

Some women in the conference audience had given Lisa and Harrison's book to their children's teachers to read to the class. They said it helped the children understand what breast cancer was, and why some mums have bald heads.

Other strategies can include telling children what to expect during treatment, for example how you may lose your hair

during chemotherapy, in language or ways that children can understand, so there are no surprises. Lisa described how her husband Michael shaved his head so Isabella wouldn't be frightened when mum lost her hair. Involving children as much as they want can also help to demystify the illness, and could include a visit to the chemo clinic to see that mum is going to a place that's not so scary.

'My daughter would like to be a hairdresser when she is older, so I let her cut my hair once it started falling out. She wanted to help and I think this was her way of dealing with it. My son also had a cut of my hair. It was a fun time for them – depressing for me, but it helped having the kids involved during this time.'

*Vannessa Estigarribia (37)
Narre Warren, Victoria*

Further strategies for talking with children as well as teenagers are included in the resource *When a parent has cancer: how to talk to your kids* available through the state and territory Cancer Councils.

The teenage years can often be emotionally turbulent and a parent's diagnosis of breast cancer can add to this turmoil. Teenagers are likely to have a more sophisticated understanding of cancer, and may want more detailed information about the illness, although may not be prepared to ask outright. The website www.myparentscancer.com.au provides straightforward advice to help teenagers work through their feelings, when their parent is going through breast cancer. The site includes contributions from many teenagers and is also useful for parents.

Friendships and other relationships outside the family are also often very important to teenagers. CanTeen offers a range of camps and programs for teenagers whose parents are diagnosed with cancer, where 'they can simply be young people, away from the daily pressures of living with cancer at home'. You can visit www.CanTeen.org.au or contact the national office on (02) 9262 1022.

My Mum has Breast Cancer: a family's cancer journey, by Lisa and Harrison Sowards (2006) is available at all good bookstores. RRP: \$16.95.

Plenty of time to find Mr Right

I was 36, living in Darwin and single when I was diagnosed with breast cancer. My life in Darwin came to a sudden grinding halt. I knew I would need my family around me, so I flew to Queensland to be with them. It was nine months before I got back to Darwin.

For me, the biggest impact of breast cancer was the likelihood that I might not be able to have children. I already had the anxiety of single women in their late 30s, wondering if it would ever happen for me. Now, the prospect of five years of treatment with Tamoxifen seemed to shut the door on that possibility. Funnily, the up-side of this was a big sense of relief that I no longer needed to hurry up and find the right guy! While I had debilitating hot flushes initially on Tamoxifen, my oncologist prescribed an antidepressant that

happens to reduce hot flushes. It was a godsend, and improved my quality of life enormously.

The surprising thing was that the best discoveries of my life happened as a result of breast cancer. The first of these was the incredible love and support I experienced, from my family and friends, acquaintances, and other breast cancer survivors. The kindness with which I was showered was absolutely overwhelming. It taught me a huge lesson. Why had I ever felt lonely before? I just hadn't realised this wonderful network was all around me. It is something that I will never forget now.

I was put in touch with the Young Women's Network – a breast cancer support group for young women on the Sunshine Coast. It was so good to meet and talk with other women my age going through a similar journey. When



Rosie Muller at India Falls, Kakadu, Northern Territory.

I returned to Darwin I joined Dragons Abreast, and have been so inspired by the beautiful, gutsy women who paddle under this banner around the country.

During my treatment, I learnt Buddhist meditation, and started on a whole new spiritual journey. Breast cancer and Buddhism between them have cured me

of most of my small worries and anxieties. I'm now four years down the track, and while it hasn't always been easy, so many aspects of my life have changed for the better as a result of this journey. The very positive gifts that have come out of it will always be with me.

*Rosie Muller (36)
Currimundi, Queensland*

Rebuilding the house of cards

Upon my arriving home from an 18-month 'trip of a lifetime' around Europe, I found a job, a new place to live and got back with an old boyfriend, who I had thought about the entire time I was away. Life was perfect. It was summer and I couldn't have scripted it better myself.

I went to my local GP to get a breast lump checked out, which I'd noticed a few months earlier while in London. I was assured it was nothing to worry about, but was sent for an ultrasound 'just in case'.

Within weeks my world, as I knew it, ceased to exist. I had an aggressive grade three tumour



Skye Santos

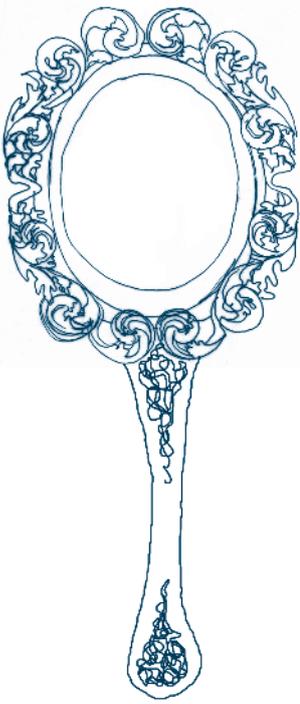
and after two surgeries, I was set to embark on four months of chemotherapy and six weeks of radiation.

My carefully built house of cards came crashing down around me. Not only did I have a cancer diagnosis at 29, I lost my job, was evicted from my flat and the boyfriend left as it was 'too difficult' for him.

Starting chemotherapy was the toughest time of my life. It was scary and I felt just awful. After a period I got used to the cycles and was able to feel okay most of the time. I set about getting my life back. I was fortunate enough to move in with some supportive friends, bought myself some treats and started looking for work again, and realised not only did I have a life worth living, but what a fantastic life it would be!

I am now out of the dark and into the ever-increasingly bright light. Cancer truly does give you that all important perspective on life. Each day brings a beauty to it that I might have otherwise missed. Sunsets have never been more beautiful, birds singing never sounded sweeter. It has also given me a strength that I never knew existed, and a confidence that I can tackle anything life throws at me. As for love ... he'd have to be a pretty special guy to fit into my life now, as it is full to bursting. I'm doing all the things I love in life, and I wouldn't change it for the world.

*Skye Santos (29)
West Melbourne, Victoria*



My Story

From final breastfeed to early menopause

When I was first diagnosed with breast cancer, I couldn't understand why it should be any different for a young woman to be diagnosed with breast cancer than an older woman. It sure is something that none of us deserve to go through at any stage of our life. Now that I am nearing the end of my treatment (having undergone two surgeries, chemotherapy and radiotherapy) I do realise that there have been certain things that have related particularly to me, as a young woman, that a woman at a later stage of her life wouldn't necessarily be concerned with.

My initial fear was that I still wanted to have another baby. Could this still happen? A fraction of a second later I thought of my 15-month-old, Sam, who was still enjoying being breastfed, and my four-year-old, Bailey, who had just begun kindy. What if I was to die? How would they cope without their mother? Simultaneously, I was thinking 'I want to see my kids grow up'. The next stage for me was what to say to the boys, particularly Bailey, if anything at all. How would I tell him and make it mean something to a four-year-old?

I think choosing which surgery to have was more painful than surgery itself! Lumpectomy, mastectomy, double mastectomy, reconstructive surgery – so many decisions to make – and what to cook for dinner?!

I had to stop breastfeeding and drain my breasts before I could have surgery. It turned out that that was to be the last time I ever breastfed. I met with a fertility specialist. He said there was no reason why I shouldn't freeze an embryo. My oncologist's opinion, however, was different. I had to make a decision immediately and I had to think not only of my own

future but that of my husband and children.

I wanted my children's routines to stay as normal as possible throughout my stays in hospital, months of sickness from chemotherapy and absences from home due to the long drive to and from radiotherapy. I had to rely on my mum, husband, mother-in-law, friends and neighbours to help out. Of course they were all happy to help but it's hard to let go of life as you know it.

At times the drugs made me angry or depressed. I lacked

energy and motivation. I wanted to go on as normal, I wanted to have tea parties in the cubbyhouse, hit the ball to the dog, drop Bailey at kindy, be on the parent roster, pick up a few groceries from the supermarket, get out of bed to see to Sammy when he woke up crying at night, make play dough and cook muffins with the kids. How hard could those little things be and why did they matter so much? I felt frustrated. I know that no-one else expected these things of me. But I did.

It hasn't been all bad. Even early menopause hasn't fazed me in light of all things good in my life. I must say I had to laugh when one of Sam's first words was 'Bumhead', directed at me. My husband responded by saying, 'Well, have you looked in the mirror lately?' I also cherish the family portrait Bailey drew with Mummy and Daddy – both bald.

I've been reminded of how precious my family and friends are; how good it feels to be given love, care and concern from total strangers; how my children bring me such happiness; how we are only on Earth for such a short time and that it can easily be cut even shorter; how good it feels not to wake up nauseous; and how good chocolate tastes once again!



Lee Sieracki with her two sons, Sam and Bailey.

Lee Sieracki (38)
Singleton, Western Australia



Reviews

When the woman you love has early breast cancer

When the woman you love has early breast cancer, you feel ... Angry? Helpless? Afraid? Frustrated? Guilty? Worried that you are going to lose her?

All of these, in fact. When the woman I love was diagnosed with early breast cancer last year, I experienced these, and more. True, we shared these feelings – well, I can only imagine what she went through, even though I felt that the battle with breast cancer was something that we shared. But it would have so helped me if I could have known that how I was feeling was pretty much what lots of other men also feel.

Listening to the National Breast Cancer Centre's CD *When the Woman You Love Has Early Breast Cancer*, I can now appreciate something of what I missed out on – the sharing of feelings and emotions that we men are usually so bad at. This excellent CD features the voices of some of the men who have experienced what it is to be the partner of someone who is going through the turmoil of breast cancer. It covers the initial diagnosis, the surgery, the ensuing treatment, chemo, radio, nausea, sickness, hospitals, moods, what to do about the children, whether she can have children, the housework, the issues with body image, early menopause, sexuality ... the works.

The men's voices are complemented by those of some of the women, who discuss how they see the role that their men performed, or – in some cases –



The CD When the woman you love has early breast cancer is available free through the National Breast Cancer Centre. It can be ordered via their website at www.nbcc.org.au/resources or via phone 1800 624 973.

should have performed. Experts in the area, oncologists, psychiatrists, who have seen and treated many women and sometimes men, provide their perspective, sometimes not pulling their punches. As one commented, breast cancer doesn't arrive in a vacuum – too often the strains on a relationship caused by all the usual things – money, kids, family, working hours, even simple incompatibility – are there *as well*. Not surprisingly, she concluded, the 'Disney' ending to this sometimes eludes us.

It is so powerful, and comforting, to hear other men express what you have thought yourself to be the case. Yes, we feel fear; we feel frustration as people who think we should be 'Mr Fix-Its', with solutions to everything; we feel anger of the 'why me?' or at least 'why her?' variety; we also feel great compassion for the women we love, and to hear this said by so many men, clearly from a range of backgrounds and a range of characters, is a great help. I only wish I had heard it last year as my wife went through her treatment.

This CD provides comfort, as well as a yard-stick by which we men can measure our emotions. We can listen to the experiences of other men and know that we are not alone, and for this reason I can strongly recommend it to others who are going through those testing times, with the women they love.

*Jon Ritchie
Melbourne, Victoria*



Choosing Happiness: Life & Soul Essentials

*By Stephanie Dowrick.
Sydney: Allen & Unwin, 2005
(paperback 2006) 481 pages.
RRP: \$35.00.*

Stephanie Dowrick, psychotherapist, author of books on personal and social development, and breast cancer survivor, began writing *Choosing Happiness* after meeting an interested reader at her gospel choir in Sydney. As a result of this collaboration between writer and reader, the author was inspired to write a book that could be read in parts, or dipped into when

required with a wide choice of entry points. The seven chapters range from 'Trust who you are' to 'Think and act positively'. Each chapter lists the essentials at the beginning and then gives a page or two to elaborate on each essential with descriptions of skills and strategies.

This book would offer useful insights and assist personal reflection for people, especially after treatment and learning to live life after cancer. For a person living with cancer or recovering from treatment, the pressure for positive thinking can be overwhelming, so the final chapter can give some useful strategies to achieve this elusive state of mind.

The author's way of writing is intimate, reassuring, and seeps with loving kindness. She is an inspirational writer, even to those jaded by self help books! I would recommend this book to others needing emotional nourishment and seeking happiness in any measure.

*Eke Woldring
Harbord, NSW*

*Stephanie Dowrick recently presented at BCNA's Harnessing Hope, Overcoming Hurdles forums for women with secondary breast cancer in Adelaide and Brisbane. Read more about her involvement at these special events in **The Inside Story** – our supplement to **The Beacon** for women with secondary breast cancer. You can view the latest edition on our website, order a copy via beacon@bcna.org.au or phone us on 1800 500 258.*

Women together in Albury and on the Gold Coast

Members of the **Albury-Wodonga Breast Cancer Support Group** helped to promote and support BCNA's forum in their region in August, where approximately 120 women and men gathered at Wodonga's Butter Factory Theatre. People had travelled from the surrounding regional towns including Benalla, Myrtleford, Wangaratta, Corryong, Corowa and Wagga Wagga to attend the forum.

The audience heard from BCNA Board member **Raelene Boyle** and BCNA's **Lyn Swinburne** and **Julie Hassard**. Local medical oncologist, Dr **Craig Underwood** presented the new and emerging treatment and care options for breast cancer. He highlighted the challenges associated with accessing cancer



Gold Coast forum – Kareann McCarthy and her mum Colleen Rowe

treatment and support services across state borders.

Brave Hearts, the local Dragons Abreast team, invited Lyn and Raelene along for a paddle in the boat that the women had constructed themselves!

Our next forum for the year coincided with the Australasian Society for Breast Disease's

biannual scientific meeting at the **Gold Coast** on Saturday September 29. Thanks to members from the Redlands Cancer Support Group who readily helped us welcome our audience on the day.

Raelene Boyle, Julie Hassard, **Amanda Berra**, our *Seat at the Table* Coordinator, and Brisbane medical oncologist Dr **Nicole McCarthy** presented to another audience of about 120 women and men.

Question and discussion sessions at the end of our forums around the country always raise a mix of general and local issues of importance to women. Being aware of available clinical trials and 'getting on with life after cancer' were two of the issues raised at the Gold Coast.



Raelene Boyle beats the drum for the Brave Hearts (Courtesy of The Border Mail).

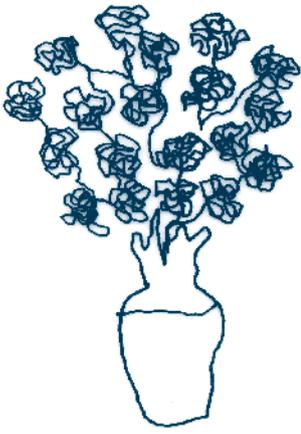
Highway to Health

Highway to Health: better access for rural, regional and remote patients is a report from the Senate Community Affairs Committee. The committee investigated the operation and effectiveness of schemes that reimburse those who have to travel to receive specialist treatment. The report highlights how some patients face financial hardship and sometimes choose not to have treatment rather than leave their home town. The committee recommended 16 changes to the Patient Assisted Travel Schemes (PATS) run by the states and territories.

One of the committee's key recommendations was that health ministers set up a taskforce to develop national standards for PATS, to ensure equal access to medical services for people living in rural, regional and remote areas. It also recommended that transport and accommodation subsidies through PATS better reflect a reasonable proportion of actual travel costs.

BCNA's submission to the committee, developed in consultation with members of our Rural & Remote Working Party, included 10 recommendations for a unified system with streamlined processes. All submissions (including BCNA's) have been published on the Senate website. You can access the Senate website via our website at www.bcna.org.au > Policy and advocacy > Submissions and reviews.

BCNA will continue to advocate for implementation of the Senate committee's recommendations, and will provide updates on progress in this important area.



Thank you

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

- AFL NSW/ACT
- Arlene Clarke
- Barb's Girls
- Barb Moore
- Bob and Bev Boyson
- Carpet One Australasia Ltd
- City of Kingston
- Coleraine Primary School
- Dunlop Flooring
- GBI Holdings Pty Ltd
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- Icon Construction Australia Pty Ltd
- Inverell Saints Football Club
- Jellis Craig
- Knight Frank Valuations
- Leanne Carroll
- Lisa Swards – Pink Lady Art Exhibition
- Lois Mifsud
- Lord Mayor's Charitable Fund - Melbourne Football Club
- Le Reve
- Lyn Dimmock
- Lynn Brewster
- Mantech Systems Pty Ltd
- Margaret Dix
- Mark Clatworthy
- Mark Griese
- Moree Breast Cancer Support Group – Marie Onus
- Newstead Hair
- Nufarm Australia Ltd
- Open Financial Services Pty Ltd
- Panasonic
- Pink Ladies Golf Classic 2007 – Jacinta Moore, Kirsty Hutton, Jan Curtain
- Premium Floors Pty Ltd
- Quakers Hill Bombers AFL Club
- Rachel West
- Redlands
- Ritchies Stores Pty Ltd
- Roadmaster Pty Ltd
- Rural Ambulance Victoria – Olga Bartasek
- Sterling Capital Pty Ltd
- Sunchip Transport Pty Ltd
- Sunshine Coast Turf Club Inc
- Tabeel Trading Nominees Pty Ltd
- TASAR Association of New South Wales
- Tesselar Tulip Farm
- Yarra Yarra Golf Club

In memory

We pay tribute to the lives of **Phyllis Azarnikow, Joan Birkett, Annabella Di Gioacchino, Eva Maria Gavalas, Christina Gray, Jeanette Higgins, Rose Hannah Hill, Madilyn Pawley, Jennifer Redford, Lyal Smith, Elaine Tiley, Edna Gladys Watson, Merle Williams and Karen Worthington.**

We are most grateful to their families who requested donations to BCNA in their memory, in lieu of flowers at their funerals.

Celebrations

Happy birthday to **Amanda Berntsen, Adrian Mordech, Adrian Roberts, Cynthia Rosen, David Sonenberg, Monika van Raay and Bryan Winthrope** who asked to have money donated to BCNA in lieu of gifts to celebrate their special day.

Workplace giving

BCNA is delighted to be part of the workplace giving programs of a number of organisations. Our thanks go to **Aviva, Coles and Sussan** who generously support BCNA through their workplace giving programs each year.



Michael Swards and his team of 15 riders cycled more than 200 km in Melbourne's Around the Bay in a Day bike ride in the sweltering heat, raising more than \$31,000 with the help of 160 individual sponsors for BCNA. Congratulations on this amazing effort and thanks to Michael, his team and their many supporters.



Breast cancer survivor and BCNA member, Arlene Clarke, harnessed the support of the local Busselton community in WA when she shaved her partner's hair to raise funds. The Crop for cancer raised in excess of \$5500 to help BCNA continue its important work.



Profiling our member groups

BCAG NSW – a decade of achievements

With 187 BCNA member groups across the country, we introduce one of the largest – Breast Cancer Action Group (BCAG) NSW.

This year Breast Cancer Action Group NSW, the oldest and largest BCNA member group in NSW, celebrated its first decade of providing a voice for people affected by breast cancer in NSW.

BCAG NSW began by attracting women interested in making a difference through an article in *The Sydney Morning Herald* in October 1997. Soon after, 120 women met at Sydney's YWCA and the decision was made – BCAG NSW was in business! Colleagues from BCAG Victoria helped get the group on its feet and the rest, as they say, is history – well, 10 good years so far!

Chaired by **Sally Crossing** since 1997, with 730 members across NSW, the group has worked in partnership with others on issues related to diagnosis, treatment, care, support and research. The group has provided a forum for women and men to share experiences and information.

To mark its decade of achievement and its 10th birthday, BCAG NSW held *Women for Women with Breast Cancer 2007*, a free forum for 200 women, in July. The pink party at the end of the day was attended by BCAG NSW's patron, Her Excellency **Professor Marie Bashir AC CVO**, Governor of NSW, with entertainment by the Young Divas from Melbourne and Wollongong's Tip Top Tappers. The forum offered information about current topics of interest to those affected by breast cancer

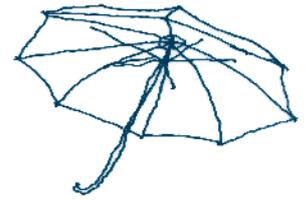
and the opportunity to hear from women about their needs, to help shape the group's future advocacy efforts.

One of BCAG's major achievements is its *Directory of Breast Cancer Treatment and Services* – in both printed and electronic versions. Produced in collaboration with the NSW Breast Cancer Institute, the Directory went national in 2006. They also organised the first *Mini-Field of Women* in Sydney in 2000 – with 100 silhouettes planted at Circular Quay with a view of the Opera House.

BCAG NSW produces a quarterly newsletter and membership is free. For more information, visit its website www.bcagnsw.org.au, phone 02 9436 1755, or email info@bcagnsw.org.au



BCAG NSW members with Her Excellency Professor Marie Bashir AC CVO, Governor of NSW.



Seeking shelter

BCNA welcomes:

- Titivators Inc. – Coffs Harbour, NSW
- canSA sisters – North Adelaide, SA
- Sussex Inlet Cancer Support Group, NSW
- Blue Mountains Cancer Help – Katoomba, NSW

We now have 187 member groups and more than 24,000 individual members!

You can visit our website to find member groups in your state.

MRI screening for high-risk women

Federal Health Minister **Tony Abbott** announced in February that funding would be made available for screening young women at high familial risk of breast cancer. However, the wheels have moved slowly and the funding process is not yet in place.

We are aware that the Department of Health and Ageing continues to work on this issue and we hope that the Medicare item will be introduced as soon as possible.

This has been a long-term advocacy project for BCNA and we will be delighted to see the Medicare item finally available to these women.

Have your say – sign up for BCNA’s Review and Survey Group

‘When I was first diagnosed I just wanted to know what had caused my breast cancer. I thought everyone else would too – that there should be studies going on left, right and centre to understand more about breast cancer. This thought didn’t go away after treatment as I battled with lymphoedema, side effects from Tamoxifen and living with one breast that was scarred from surgery, damaged by radiation treatment and significantly smaller than the other.’

BCNA has created the Review and Survey Group so that we can help make sure women’s voices are heard in research. Increasingly we are approached by researchers interested in surveying our members. We know that lots of our members are interested in participating in surveys and research that will help other women in their breast cancer journey. We are hoping as many as 1,000 women will sign up to help out with surveys

Seeking your stories

The winter issue of **The Beacon** 2008 (to be mailed in June) will highlight how breast cancer impacts on work for women, including paid employment, unpaid work such as caring for children and household duties, and voluntary work.

We welcome contributions from our readers to include

in **The Beacon** or on our website. Articles about your experiences, both good and bad, will be helpful to others.

Please email your contribution of a half to one page, with a photo, to beacon@bcna.org.au or send a copy to us through the post, by the end of March.

and research to improve breast cancer care.

We also hear about new resources such as books, videos, DVDs and websites produced for women and their families. We often ask women to review them and share the reviews in **The Beacon** or on our website.

You can register online or we can send you information about joining the group. You will need

an email address, and we will send email notices of surveys, studies and requests to write book reviews. Women who sign up for this group are under no obligation to participate in the studies.

To find out more about the Review and Survey Group, you can visit www.bcna.org.au > Policy and Advocacy > Seat at the Table > Get involved or you can email ras@bcna.org.au

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

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

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

Name:

Address:

State: Postcode: Phone: ()

Email:

Have you had a diagnosis of breast cancer? Yes No

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

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



PaperlinX proudly supports women with breast cancer by generously donating the paper for **The Beacon** and **The Inside Story**.

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Interested in our e-bulletins?

‘The bulletins are really useful – a good read and something I share with the rest of my family.’

We email regular bulletins to keep women up to date on issues of particular interest, including:

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

If you want to receive our e-lists email policy@bcna.org.au and include the name(s) of the list(s) you wish to sign on to, your first and last names and your postcode.



the BEACON

Layout: Substitution

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