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the BEACON

Breast Cancer Network Australia's Magazine Issue 26 Summer 2004

Don't miss the news about Australia's 2nd National Breast Cancer Conference for Women and the registration form on pages 15 and 16.

Welcome to our new-look Beacon!

After 25 issues of *The Beacon*, we have decided to freshen up its look with a new format, which we hope you will like.

For those readers who have grown to look forward to the arrival of your magazine, please be assured that the changes are not too substantial and that the 'old favourite' sections have been retained.

You may have guessed by the photo below that this issue

looks at pregnancy following breast cancer.

For some of us, this was never a consideration. However, especially for younger women, the ability to have any children, or to have more children, is a major concern when they are advised to have chemotherapy. We are delighted to announce that two of our BCNA State Reps, **Megan James** (NSW) and **Deb Martin** (SA), have

both given birth to healthy sons in recent months.

Inside this issue, Megan will share her thoughts with us on pregnancy and the miracle of her new life with baby **Griffin**. We know Megan's experiences will inspire others.

In years gone by, the expectation was that women should never get pregnant after experiencing breast cancer, but recent research has demonstrated that this is no longer the position, as you will read inside.

National Conference

Finally, you will find lots of information this time about our National Conference, to be held in Melbourne in August.

A tear-off registration form is included on the back page for your convenience.

I urge you to join us for what will be an action-packed, stimulating and empowering three days.

We'd love to see you there!

Lyn Swinburne,
Chief Executive Officer

My Journey Kit launch

We are delighted to announce that our *My Journey Kit* will be launched at the beginning of May.

The *My Journey Kit* is a comprehensive information guide for women newly diagnosed with breast cancer.

The Kit has been developed over several years and brings together the important messages that hundreds of women have shared with us about their journeys with breast cancer.

We aim to get the Kit to women within two weeks of their diagnosis.

The Kit will be available through a dedicated 1800 number that will be announced at the launch. Women will also be able to order it via a direct link on our website.

We are currently developing a distribution strategy and will bring you more information on how you can spread the word about the *My Journey Kit* in the next issue of *The Beacon*.



Megan James with her new son, **Griffin**, and husband, **David**.

Breast
Cancer
Network
Australia



A reason to celebrate Christmas

At numerous times in the past 10 weeks, while sitting on the couch at night with my husband, David, it suddenly dawns on me that we have a baby and that we are parents.

I'm sure most new parents go through this feeling, although I feel it might be a little more special for us.

After being diagnosed with breast cancer in December 1996, we were not sure if we would ever be lucky enough to have a baby.

I was 31 years of age, there was no family history of breast cancer, and I was healthy and fit as a fiddle – I'm sure you all know the deal.

After a lumpectomy, followed by the removal of my lymph nodes, I was told that I was going to have to have a range of treatments including chemotherapy.

My oncologist said I could freeze some eggs as the chemo might affect my fertility, but we decided not to do that for a few reasons:

- I'd had two operations within a short period and we didn't think it would be good to 'go under' again.
- We wanted to focus on the now and the priority was to get me better.
- We'd throw the decision into the lap of the gods and if it was meant to happen it would.

We are happy to say that, seven years on, we have a healthy baby boy, Griffin Thomas Hutchins.

My pregnancy was textbook. I didn't have a day of sickness. I was well the whole way through and in the last few



Megan James' little miracle, Griffin, was born in October 2003, almost seven years after her breast cancer diagnosis.

weeks, when most women get fed up with it all, I seemed to enjoy it the most – the thought of meeting our little baby, the way he was moving in utero, the anticipation of what we would have, what he/she would look like and be like.

Seven years on and the last thing on my mind was breast cancer. I had a pregnancy to work through. David and I were going to bring a life in to this world – what an amazing thing.

My experience with breast cancer has never left my mind completely, however, for many years now it had been in the back section and something that I had not thought of daily. Now it was even less apparent.

I even stopped worrying as much about taking care of my arm where I had the lymph nodes removed. I had to stop the vitamins that I had taken religiously since breast cancer as they were potentially

harmful to our baby – and they had always been a bit of a security blanket. I stopped seeing my naturopath.

I kept on with my relaxation exercises, yoga and general health regime. It was great to give myself a break – I could clear my mind of all things breast cancer related. I could turn off that tape at the very back of my mind that liked to play every now and then.

During my pregnancy, I enjoyed going to see my doctors. I enjoyed the ultrasounds. I enjoyed all the positive and encouraging news every time I saw a medical professional. I didn't need to get nervous that they were going to find something; I knew they were not looking for nasties. What a change for us.

On October 21, Griffin came into our world. I wasn't sure how well I would be able to breast feed or for how long,

but there was no reason why I couldn't feed from one breast.

Latching him on the first time was just amazing – this was what my breast was for – to feed our child.

We had much success. My milk came in right on time and there was plenty for him.

I was quite worried about nipple damage, as I didn't have back up, so it was important to spend the time trying to get the feeding right from the start.

I had wonderful support from the lactation consultant and the midwives at the Mater Hospital in Sydney. Some of them went way beyond the call of duty in helping me.

I used a nipple shield for two weeks which worked well, then transitioned off and continued to feed *au naturel*, which was much nicer for both of us.

My breast cancer happened in December of 1996, right before Christmas. Since then I have been diligent in having my tests and doctors' visits before Christmas, so I could celebrate another year clear.

Christmas since breast cancer has been a different experience for me, one where I reflected on the unwell and lonely people I came across during my journey – a yearly reminder of many things not all worth celebrating.

This year was our son's first Christmas. We bought a tree, wrapped presents, sang songs and I felt Christmasy for the first time in a long time.

I'm pleased to say I haven't even rung my oncologist for a referral for my tests yet, but I will in good time – funny how life changes.

Megan James, NSW

Questions and answers about falling pregnant after breast cancer



Dr Fran Boyle

We posed these most frequently asked questions about pregnancy after breast cancer to Sydney oncologist, Dr Fran Boyle.

1. What is the current clinical advice given to women about falling pregnant after they have had breast cancer?

There has never been (and never will be) a randomised trial, where half the women are made pregnant and half are not after breast cancer, so all the data we have is imperfect.

The existing information comes from matching women who became pregnant with those with similar tumours who did not. This does not point to a higher risk of recurrence for those who did and is reassuring overall.

It's a good idea to give yourself some time to recover

from any treatment effects (such as fatigue) and some emotional space as well.

Tamoxifen is not contraceptive and it is recommended that you do not take it if you could become pregnant, as it may effect the foetus.

2. Does one have to wait five years?

There is evidence that five years of tamoxifen is better than two at preventing a recurrence and some women will want to wait, but your age will clearly be a factor here.

The risk of breast cancer recurrence is highest at 2-3 years, so we generally recommend waiting until you are through that period, but it does not magically become safe on the dot of five years.

3. Is the advice very specific to the individual? For example, is the advice based on whether the woman's tumour was ER+ or any other features of her cancer?

It is specific to the individual – to do with the risk of recurrence, more than the hormone receptor status.

If you have ER (oestrogen-receptor) negative cancer and hormone treatment is not needed, tamoxifen is not a complication, but ER is only one of the factors that identifies the risk of relapse, so can't be taken out of context.

4. What percentage of pre-menopausal women regain fertility after chemotherapy? What factors are relevant in this?

Age is most important – 30% menopause at 30 years, 50% at 40 and almost all at 50.

Chemotherapy that includes anthracyclines (Adriamycin) is less likely to induce menopause than CMF and shorter chemotherapy is better than longer.

Your previous history of fertility is important. If you have had several children without difficulty and are 40 years old, another one is more likely than if you have had problems with irregular cycles, never been pregnant and are 40.

5. Is it possible to breast-feed a baby from a breast that has been irradiated?

This varies – the breast and nipple may be scarred and expand less on that side, but there is no danger in trying.

6. Any other comments?

One of the confronting issues for anyone deciding to have a baby includes thinking through those 'What if's'. What if the cancer came back and you were to leave a small child – who would be around to support and care for the child in your absence or during protracted illness? What practical, financial and

emotional platforms need to be built for the child's safety?

It's my view (as a working mother of twins, now nearly 10 years old), that it takes a network to raise a child, whether you have cancer or not. Making those links to other adults who provide support is vital for your sanity and the child's future. Going it alone is a hard road. Neighbourhoods and peers can influence children's achievement as much, or more, than parents.

So, if you are reading *The Beacon*, you may be off to a flying start as a skilled networker already!

Plant a Mini-Field of Women

Mini-Fields of Women are conducted all over Australia in the week of Australia's Breast Cancer Day (October 25).

Last year, we had 54 *Mini-Fields* across Australia and we are aiming for more in 2004.

We provide *Mini-Field* co-ordinators with a comprehensive 'how to' kit, as well as 100 silhouettes to plant in your chosen field.

Phone us on 1800 500 258 if you would like more information about running a *Mini-Field*.

Pregnancy after breast cancer

Only a small number of breast cancer survivors become pregnant.

In WA, we have been studying all breast cancer survivors who became pregnant and found that only 4% of these women conceived after a diagnosis of breast cancer.

This is similar to overseas findings and we estimate that about 100 breast cancer survivors become pregnant in Australia each year.

The overall pregnancy rate in WA is 7-8% and the low pregnancy rate in young breast cancer survivors may be due to their treatment causing infertility or perhaps because they choose not to, or are told not to, become pregnant.

Breast cancer survivors who become pregnant are thought to have a better prognosis than those who do not.

We have found that breast cancer survivors in WA who conceive have a better five-year survival rate (92%) than those who do not (75-85%).

The women in our study who conceived had larger tumours at diagnosis than other breast cancer survivors, but were less likely to have cancer spread to their lymph nodes; that is, they had a better prognosis or what is called the "healthy mother" effect.

Most of these women were

managed by the combination of breast-conserving surgery and radiotherapy; some of them also had chemotherapy, but very few had hormone therapy.

Most doctors recommend that young breast cancer survivors wait at least two years after treatment before they attempt conception.

This is to avoid women becoming pregnant and developing an early recurrence at the same time, and to allow women to get over the initial treatment.

There is no evidence to suggest that postponing pregnancy will alter the outcome of the breast cancer or pregnancy.

In our WA study, the timing of the pregnancy did not affect survival for these breast cancer survivors. In fact, 60% of the women who did become pregnant did so within two years of their diagnosis.

The reason for this isn't clear, but we think contraception issues may be a factor – many women are told to stop taking the oral contraceptive pill when diagnosed with breast cancer.

More of our women had healthy babies than terminated their pregnancies.

Most of the women who chose to terminate their pregnancy conceived when they were still

undergoing treatment.

Whatever the pregnancy outcome, it had no effect on the women's survival.

The decision to attempt pregnancy is ultimately the woman's (and her partner's).

An informed decision can only be made if fertility issues are fully discussed at an early stage in the management of the breast cancer – and this is not an easy thing to do.

With continual improvements in breast cancer management and, therefore, women surviving longer, more women may want to keep their options open, so that they can consider pregnancy in the future.

Favourable prognostic features obviously do play a part in survival, but chemotherapy treatments can be adapted to give women a better chance of remaining fertile.

We, therefore, recommend that young breast cancer survivors be able to make an informed decision about whether they become pregnant and should be supported in their decision.

Christobel Saunders, Professor of Surgical Oncology, School of Surgery and Angela Ives, Research Associate, School of Population Health University of WA



Loretta and Jayne Lilford

Belief

Jayne Lilford is a talented young woman from country Victoria.

Inspired by her aunt, a breast cancer survivor, and her mother, a breast care nurse, Jayne wrote a beautiful song, *Belief*, to perform at a breast cancer forum in Shepparton in 2003.

Her performance proved such a success that she produced a CD single. All profits from its sale go to BCNA, and already more than \$2500 has been raised.

Our thanks go to Jayne and everyone involved, particularly Dillmac Entertainment, Jayne's mum, **Loretta, Judy Shepherdson** from BCNA and **Anthony Tenance** of AT Studios.

If you would like to purchase a copy, send a cheque or money order payable to 'Breast Cancer Network Australia' to:

'Belief' CD
Dillmac Entertainment
PO Box 791
Kyabram, Vic. 3620.

Or, phone
(03) 5852 1358 or e-mail
dillmac@theoffice.net.au

The cost is \$10, plus \$3.50 postage and handling.

Include your name, address and contact phone number.

Please allow up to four weeks for delivery.

Calling all members in the ACT

If you have participated in a Science & Advocacy Training Course, or have represented BCNA on any committees, please note in your diaries that

March 30 is the tentative date for a meeting about any issues to be taken to the State Representatives' Think Tank in April.

Contact: Anna, e-mail wbfamily@homemail.com.au, or Elspeth, e-mail humphries44@ozemail.com.au, who will confirm the date, time and place.



Issues of concern ...

Travel insurance troubles

At BCNA, we continue to get calls from women who have had difficulties getting travel insurance following a diagnosis of breast cancer.

Last June's insurance survey showed us the size of the problem. Of the 750 women who responded, 181 said they had difficulty obtaining insurance. We then rang 80 of those women to ask more detailed questions and found:

- most calls concerned travel insurance;
- 15 women had been refused travel insurance totally;
- some women could get travel insurance, but only if breast cancer-related events were excluded;
- others could get travel insurance that covered their pre-existing breast cancer, but had to pay a higher premium; and
- others who applied were refused cover for their pre-existing breast cancer, but were still charged a higher premium.

Issues identified by the calls included:

- women were unsure whether to apply for cover for their pre-existing breast cancer;
- some travel insurers used inconsistent and inadequate risk assessment methods – some insurers use a medical assessment group (doctors or nurses), while others assess all cancers together regardless of type, prognosis, time since diagnosis and

- current health status;
- insurers were not consistent in how they granted cover, e.g. some women were both granted and refused cover by the same insurer;
- some travel agents put women off applying for cover if the agent was aware of the breast cancer diagnosis; and
- many women experienced anxiety and felt they were reliving the diagnosis because of the approach of some of the insurers.

Having identified these issues, we are:

- reviewing the insurance policies and application forms of a range of travel insurers;
- asking insurers what type of assessment they carry out and the factors they take into account in deciding whether to grant cover; and
- looking at developing a list of travel insurers whose policies and risk assessment processes are the most appropriate for breast cancer survivors.

BCNA has also appeared before the Productivity Commission's inquiry into the Disability Discrimination Act, where we presented our survey results. A further submission is being prepared.

In future issues of *The Beacon*, we will update you on the results of our review and enquiries. In the meantime, we would like to share these practical hints for readers applying for travel insurance:

- Before submitting any application forms, speak to an insurance broker and have them phone insurers on a no-names basis. This avoids you receiving a letter of refusal or limited cover. This is important, as most insurance applications ask whether you have been refused cover and consider this when deciding whether to grant cover.
- If you do not want to use an insurance broker, make inquiries without revealing your identity and before submitting the application form. Ask if the insurer uses a medical risk assessment group to review applications for pre-existing condition cover. If so, phone the medical assessment group and ask about the likelihood of cover being granted, given your medical status.
- Check the wording of the insurance policy carefully, particularly for exclusions, as sometimes the insurer will not pay claims even if the cover has been granted. For example, some policies state "that the insurer will not pay any claim for travel booked or undertaken after a terminal illness has been diagnosed (where terminal illness is defined in the policy as any medical condition which is likely to result in death)".

Sue Timbs,
BCNA National
Policy Manager



Sue Timbs

Genetic Discrimination Project

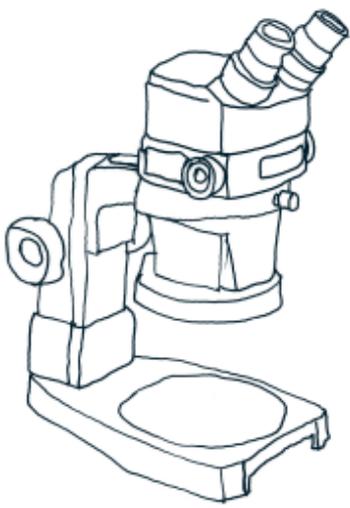
A research project is now under way in Australia about discrimination based upon real or perceived genetic status.

The Genetic Discrimination Project is being funded by a grant from the Australian Research Council (2002-04).

The research team is seeking to explore the nature and extent of any genetic discrimination in Australia, particularly through the perspective of three key stakeholder groups:

- consumers (particularly those who are assumed or known to have a genetic predisposition to a specific condition, whether on the basis of family medical history or a genetic test);
- third parties (especially insurers and employers); and
- legal authorities (such as anti-discrimination boards and other bodies dealing with genetic discrimination complaints).

For more information, or to register an interest in participating, phone 1800 554 000 (FreeCall) or visit www.gdproject.org



Research

KConFab Psychosocial Study



Prof. Phyllis Butow

The KConFab Psychosocial Study is examining the role of life event stress, social support and other common psychological states, such as anxiety and depression, in the development of breast cancer.

The study is being led by **Professor Phyllis Butow**, at the University of Sydney. **Dr Melanie Price** co-ordinates the project from the Department of Psychological Medicine at Sydney's Royal North Shore Hospital.

The National Health and Medical Research Council of Australia has provided funding for 2001-06. On-going funding will be sought for 2007-10.

This research has grown from a common belief that stress and other psychosocial factors may affect the risk of developing cancer, particularly breast cancer.

It is unclear from existing research whether psychosocial factors, such as stress, can and

do change cancer risk; and, if so, over what sort of timeframe.

The Psychosocial Study is an important opportunity for us to understand more about how these factors may influence risk and provides the potential for identifying specific risk factors that may be modified to reduce individual cancer risk.

Women currently without cancer, but who are members of high-risk breast cancer families and are already participating in the **Kathleen Cunningham Consortium for Research into Familial Breast Cancer (KConFab)**, are participating in the study.

KConFab was established in 1996 to co-ordinate the collection of genetic, demographic, and clinical data in Australian and New Zealand families with multiple cases of breast and/or ovarian cancer.

More than 1050 women have been recruited for the study. It is hoped to involve a further 2000.

Participation involves completing a questionnaire about emotional responses, thoughts and feelings, and social support. A telephone interview is also requested, during which we ask about recent situations of stress or change.

KConFab is planning to interview participants every three years, to make sure it is up to date with what is going on in people's lives.

While the outcomes of the main study questions are years away (we plan to follow everyone for at least 10 years), we do have some results of a small survey about the impact

of receiving genetic testing results.

As part of the study, we interviewed 47 women without breast cancer about their experiences of receiving results for hereditary breast/ovarian predisposition genes between one month and five years ago.

We asked about:

- the impact the results had on them, and their immediate and extended family relationships;
- any advantages and/or disadvantages of receiving results; and
- any changes in lifestyle made as a consequence of the test result.

Initial response

Women described varying responses when they first received the results, including intense feelings of shock, guilt and distress, while for others it was relief and acceptance.

The initial emotional impact was surprisingly similar for both a positive and a negative result, although the thinking behind the reaction was different. For example, relief for women with a mutation-negative result was for themselves and their children; whereas relief for women with a mutation-positive result related to the removal of uncertainty, having their own self-image of being at risk validated and feeling a greater sense of control.

A proportion of women within both groups expressed, even initially, a strong sense of acceptance, based on having

seen other family members cope with cancer.

Thus, any test result (positive or negative) resulted in a short period of emotional turmoil for most, but not all, women.

Longer-term response

Most women confirmed long-term advantages and cited no disadvantages to knowing their mutation status.

Those with a mutation-positive result were reassured that they could take decisive steps to reduce their risk (i.e. screening/surgical options). Knowing their mutation status was described as empowering, and as providing an opportunity to prepare emotionally and mentally for a potential cancer diagnosis.

Indeed, some women, particularly those who were younger, reported the mutation testing experience had generated important and positive life changes. Moreover, they felt future generations could benefit from this knowledge.

Most women who received a mutation-negative result felt a new peace of mind and a sense of normality. As one woman said, "I now feel part of the normal population." However, some women who were mutation-negative, said that the results had not changed their sense of being at risk and reported that they had gone ahead with prophylactic mastectomy regardless. Other women reported that they felt a need for continuing careful screening.

Varied reactions were reported from the family, and this added another layer of complexity.

Breast reconstruction access

Two recent Australian studies have shown that women are missing out on breast reconstruction following mastectomy.

A study by the National Breast Cancer Centre found that only 8% of mastectomy patients had reconstruction surgery in Australia.

High GAP fees for privately insured women and logistical difficulties in organising the procedure were cited as the main reasons.

In addition, the availability of the procedure was limited by negative attitudes to breast reconstruction in some public hospitals.

A second study by the University of Western Australia found that only 9.1% of women had reconstruction surgery following mastectomy, half the rate of the US.

This study found that those most likely to have surgery were younger women living in the metropolitan area, privately insured and treated at a private hospital.

BCNA's response

BCNA's Chief Executive Officer, **Lyn Swinburne**, responded to these reports with a letter that

was published in *The Age* newspaper (20/10/03), stating. "You report that research shows Australian women are missing out on reconstruction surgery after losing a breast to cancer because of costs and difficulties in organising the procedure. While reconstruction is not for everyone, women certainly should be informed that it is a legitimate option and theatre times made available for this purpose.

In a world where cleavages are constantly thrust at us from billboards and in the media, it is no wonder that some women retreat from society until they can be made to appear 'womanly' again.

Breast reconstruction is not a frivolous cosmetic exercise, but must be offered as an integral part of a woman's treatment and recovery process."

Member feedback

BCNA member, **Lea Chapuis**, responded to Lyn's letter with the following:

"I couldn't agree more with the sentiments expressed. I was one of the lucky ones who had a breast surgeon and plastic surgeon who work closely

together at the Strathfield Breast Centre in Sydney. Although I live in Canberra, my medical family contacts said this was the best way to go in terms of treatment.

"Two years down the track, the more I read and hear, the more I realise how lucky I was to get constructed, not only on the mastectomy side, but in matching the other one as well.

"My breast surgeon encouraged me to have tissue expanders inserted into both breasts at the same time as the mastectomy operation, which only necessitated one more operation, four months later, with the plastic surgeon, to have these expanders removed and replaced with silicon implants.

"Each implant had to be a different size and shape for each breast, but the overall effect was a matching pair and it feels great to look and feel a new woman.

"I've yet to make up my mind about going for the last stage of nipple reconstruction, but I do appreciate how fortunate I have been and feel for other women who haven't been able to access such good-quality medical advice and care."

HRT after breast cancer

Few studies have been done to tell us whether or not hormone replacement therapy (HRT) is safe after a breast cancer diagnosis.

A recent Scandinavian study (HABITS) on the effect of HRT on breast cancer survivors produced an "unacceptably high risk" of the cancer recurring.

The study was stopped early after the results showed that women who took HRT had more new breast cancer events (such as a recurrence) than women who did not.

There were 365 women in the study and after two years the investigators found that 26 women who took HRT had a new breast cancer event, compared with only seven women who did not take HRT.

However, a similar Scandinavian study, conducted at the same time did not find an increased risk of recurrence.

The research material that BCNA has reviewed states that there is not enough data to explain the difference in the findings.

However, combining the results of both studies shows a *significantly increased overall risk for breast cancer with HRT*. Both studies have now been stopped.

The results of the HABITS study have implications for the management of menopausal symptoms after breast cancer. BCNA believes survivors need full, clear information about the risks of HRT, so they can make informed decisions.

Smoking and breast cancer

According to research published in the *Journal of the National Cancer Institute*, women who smoke may have a higher risk of breast cancer than those who do not, or those who have quit smoking.

Peggy Reynolds and her team at the California Department of Health Services studied 16,544

women between 1996 and 2000.

During that time, 2005 of these women were diagnosed with invasive breast cancer.

Women who described themselves as current smokers had a 30% higher risk of being among the cancer patients.

There was a higher incidence among those who started

smoking before age 20, who began smoking at least five years before their first full-term pregnancy, and who smoked the most or the longest.

Women who had once smoked but quit did not have a higher risk of breast cancer, Dr Reynolds' team found.

Passive smoking did not seem to increase breast cancer risk.



My Story

Kerry Parker



It is a little daunting putting pen to paper (and, subsequently, fingers to the keyboard) to recall my breast cancer journey. The journey has been interesting because it has taught me so much about myself!

It was almost three years ago when I noticed my left breast was a little sore. A week later, after a range of tests, it was decided the lump was to be removed for further exploration.

A slight complication was that I was due to go overseas for three weeks, but my specialist agreed to the travelling.

I spent time in Turkey, Italy and France, touring with good friends and feeling that the outcome of the upcoming surgery would rate at the less serious end of the scale.

On my return, the lump was removed and I was later told more surgery would be needed – the cancer was more serious than I had imagined.

By this time, my positive outlook was crumbling a little, but I was fortunate to have a specialist who realised I was a potential candidate for a *latissimus dorsi* flap reconstruction. An appointment was organised with a plastic surgeon, who agreed.

Quite quickly I was back in hospital for the removal of the nipple area of my left breast, tissue excision, and the lymph nodes under my left arm.

The surgeon and plastic surgeon worked together in the same operation and the reconstruction was successfully completed.

Some time later, when I looked down on my chest, it did not look any different. I felt I would be able to cope with whatever the future held.

After my recovery from surgery, I undertook six months of chemotherapy and six weeks of radiotherapy.

From the initial discovery of the lump, throughout the surgery, tests, chemotherapy and radiotherapy, I met dedicated, skilled, considerate and empathetic people within the medical profession. I had the support of a wonderful breast-care nurse. Each one gave me the time I needed to discuss treatment, answer my questions openly and be available when I needed to talk.

I agreed to participate in a clinical trial in chemotherapy. It was important to me to do something that might improve treatment for breast cancer patients in the future.

Losing my hair was a shock; it seemed so much a part of my 'femaleness.' Before I began losing my hair, I sought the skills of a wig-maker. She saw how I wore my hair and the basic colour, and the wig she made amazed all I met – if I told them!

What of my job? Over many years, I had accumulated hundreds of 'sick days', so during chemotherapy and radiotherapy I was on sick leave, but worked in a school library on a voluntary basis four days a week.

This arrangement provided the stimulation I needed and maintained the connection with children and education that had been my entire working life. It also gave me flexible working hours that accommodated chemotherapy and radiotherapy sessions, and meant I could sleep-in or leave early if I needed.

A year after surgery, I made an appointment with the plastic surgeon to discuss nipple reconstruction. This was completed in a day-surgery procedure.

Recovery was quick and the result amazing.

I then had a permanent make-up artist colour the nipple to closely match the other. Now I was confident that I could remove my clothes in the

change-room at the gym without anyone noticing my breasts were different.

It may seem odd that I describe my journey as a positive experience. Once, at an appointment with my surgeon, I described my nature as stoic – a characteristic inherited from my father. He smiled and explained I was very positive and saw the glass as half full, rather than half empty.

The people in my life have helped me greatly during this experience.

My family has been a great source of encouragement and care. The younger members have coped well with me having had cancer because 'you were never miserable.'

I know I am loved and admired, and have amazed family, friends and colleagues.

Previously, I may not have been aware of my particular strengths. It has taken a diagnosis of cancer, the treatments and my approach to my new life, to get a better perception of myself.

Since completing my treatment, I have spoken by phone to a number of women. They have been open, asked many questions and have wanted a description of my experiences. I am now an advocate/consumer representative for women with breast cancer.

After years of difficulty with body image (real or imagined) I now look at myself in the mirror and see nothing but the miracle.

Kerry Parker, Victoria

Congratulations Carol



Carol Bishop

*We are delighted to announce that BCNA's WA State Rep, **Carol Bishop**, was awarded an Order of Australia in the general division of this year's Australia Day Honours. The citation read: "For service to the community, particularly through a range of breast cancer support organisations and initiatives".*

It is pleasing that Carol's contribution over a long timespan has been acknowledged in this way.

Carol is a registered nurse who trained at the Princess Margaret Children's Hospital (PMH) in Perth.

After marrying and raising three daughters, she returned to nursing and worked in the oncology ward at PMH for five years.

She was diagnosed with breast cancer around 15 years ago, and had a mastectomy and six months of chemotherapy.

In 1990, she joined the Cancer Foundation of WA as its Breast Cancer Support Service Co-ordinator, providing support for women and their families.

She has served on several

boards and committees, including the National Breast Cancer Centre's Management Committee, WA's BreastScreen Advisory Committee and the Lymphoedema Association of WA. She was also a founding board member of Breast Cancer Network Australia and has been BCNA's State Representative in WA since 1997.

Some years ago, Carol lost her husband to cancer and, although devastated by his sudden and untimely death, she continued with her work, particularly focusing on helping people with cancer in palliative care.

She is a worthy recipient of such a fine honour and we are all proud of her and her achievements.



A BCNA wedding ...

Two of BCNA's Board members, **Mary Wooldridge** and **Andrew Barling** (above), were married at the National Gallery of Victoria on December 29, 2003.

Mary and Andrew asked their guests to donate money to BCNA in lieu of wedding gifts – a generous gesture that exemplifies their commitment to us. These funds will be used for initiatives on behalf of women in rural and remote areas who have breast cancer.

Tory rediscovers the art of life

It has been a very busy year! I was diagnosed with breast cancer just over a year ago, so the last year has been filled with three operations, six sessions of chemotherapy, six weeks of radiotherapy, a dull sickness, tears of sadness and joy, vomiting, love, soul-searching and discovery. In July, I went on a 'final treatment holiday' to the Kimberley, WA, with my cousins (one of them lives in Broome).

It was a fantastic experience, physically and mentally. I saw a beautiful place with new eyes and my painting skills have changed radically.

Meeting the Indigenous people and their painters has helped



me with my simplification and abstraction.

I had my first solo exhibition a week before Christmas and it was a huge success – I sold all 23 paintings. This would never have eventuated if I had not experienced the last year.

My cancer experience has helped me with my confidence, simplification and hunger to get on with the job.

Tory Burke

Editor's note: We are very grateful to Tory, whose exhibition raised \$3495 for BCNA.



... and a BCNA baby

Many of our readers will be interested to learn that **Gill Paulsen**, BCNA's Program Manager for three years, delivered a son, **Mikka**, on January 9.



Meet our Consumer Representatives



Pam Robertson, ACT

A breast cancer diagnosis is difficult for the patient and the health professionals involved. While I am sure there are many good stories about how an initial diagnosis was communicated by a health professional, let me relate an unprofessional one.

Mary was sitting on the other side of the GP's table waiting for the results of her first routine mammogram.

He had sent her for it as part of a general check up she had requested when she turned 50. The GP opened the report,

Pam Robertson

read through it and matter of factly said, "The report says you have breast cancer".

Unable to take in what he had said, Mary began to cry uncontrollably.

"I don't know why you're crying, I have other patients with worse things wrong with them than this," he said.

So started Mary's long journey with breast cancer, one that should have started with empathy and understanding, but left her shattered, unsure, confused and untrusting.

Can you relate to that story?

When I was first diagnosed I was treated with gentleness and understanding by my GP, a start on my breast cancer journey that helped me cope with what lay ahead.

My journey has continued over 11 years, beginning with my first tumour in 1992. A mastectomy and axillary clearance resulted in lymphoedema.

In 1998, I was diagnosed with two tumours in the other breast, which meant another mastectomy, chemotherapy and tamoxifen.

I have been an active member of the ACT Bosom Buddies breast cancer support group since its inception.

It provides much-needed support for those newly diagnosed with breast cancer.

Another role I value is that of an advocate, both locally and nationally.

In May 2000, I was appointed BCNA's consumer representative on the National Breast Cancer Centre's (NBCC) Communication Skills Training, National Advisory Committee.

NBCC set up this committee to "ensure that health professionals providing care to those diagnosed with breast cancer have high-quality communication skills".

Among other things, this committee has provided advice and leadership for communication training for health professionals working in cancer care.

My feelings before the first meeting were nervousness and a lack of knowledge, but this was soon overcome when the other committee members made me feel welcome and valued.

Representation is important for us as consumers. *We can make a big difference!*

Oops

Last issue we reported that **Deb Martin** was stepping down from her role as South Australia's State Representative.

While our other rep, **Sally Russell**, has stepped down, due to the pressures of a new job, Deb will be continuing as BCNA's SA State Rep.

Sorry for any confusion!

Bosom buddies meet in Alice Springs

Our BCNA member groups are spread far and wide.

During Bakers Delight's National Conference in Alice Springs last September, BCNA CEO, **Lyn Swinburne**, and Board member, **Raelene Boyle**, met with some of the women from the local Bosom Buddies group.



Left to right: Liz Locke, Lesley Reilly (both from Bosom Buddies Alice Springs), Raelene Boyle, Nina Odgers (Radiographer, Alice Springs Hospital), Lyn Swinburne, Jill Burgoyne (BCNA Representative) and Liz Mowatt (Director – Emergency Department, Alice Springs Hospital).



Dragons Abreast

The 2004 **John West Tunarama Festival** in Port Lincoln, South Australia, over the Australia Day long weekend featured dragon boat racing for the first time, thanks to the efforts of **Chris Jettner, Maxine Barker** and **Sandra Sinclair**, founding members of **Dragons Abreast Port Lincoln** and **Christine Sherry**, the newly crowned Tunarama Ambassador.

We were joined by our new Adelaide team, **Warriors Abreast**.

We also took part in the street parade on a beautiful float built in **Sandra Sinclair's** backyard.

Warriors Abreast trains at West Lakes on Saturdays from 1pm. New paddlers are most welcome and can phone **Jan Davies** on (08) 8388 4825.

ACT Dragons Abreast supplied marshals for the Australia Day triathlon and participated in the three dragon boat crews that showed their skills on Lake Burley Griffin while Canberrans gathered for the Australia Day Fireworks.

For ACT inquiries, phone **Jan Skorich** on (02) 6241 8061.

Dragons Abreast Victoria has 50 paddlers/supporters registered. Of these, 20 are new to the sport, the other 30 belong to the **Bendigo** team.

They expect to enter three or



Carolyn New, Kay Gailey, Margot Case (NSW), Pat Pye and Margaret Tudor (ACT) in Sydney.

four boats in the Melbourne International Dragon Boat Festival on March 7.

Twenty-five members in Geelong have completed the VDBA-accredited safety drill, so the group now has enough BCS paddlers and supporters to train on the Barwon River.

For information about the Victorian groups, phone **Pru Menzies** on (03) 9570 4896.

Dragons Abreast Sydney hosted members from Victoria, the ACT, Queensland, the Northern Territory and NSW at the Chinese New Year races on **Darling Harbour**.

Margot Case and her committee did a wonderful job of making everyone feel welcome.

Thanks to **Unique Water, Bakers Delight, So Natural**

and **Harris Farm** for their support over the weekend.

A big thank you to **DBNSW** for its support with the first 'Mum in a Boat' race – all funds raised were donated to Dragons Abreast Australia.

Sydney Tsunami got behind our cause with a full team of mums, but they were pipped at the post by **Breast Friends**, a composite crew featuring BCNA State Reps **Lyn Moore** (Queensland) and **Pam Bell** (NSW), as well as paddlers from **Sydney Dragon Blades** and **Sloths**, and their mums.

The **Dragons Abreast Challenge** was contested by five teams, with a photo finish required to separate **ACT** from **Sydney**.

Line honours went to **ACT**, but it was only by a dragon's whisker!

The Flowers on the Water Ceremony followed, with a sixth boat – carrying the women who were unable to race and our paddlers' offspring – joining the racing boats.

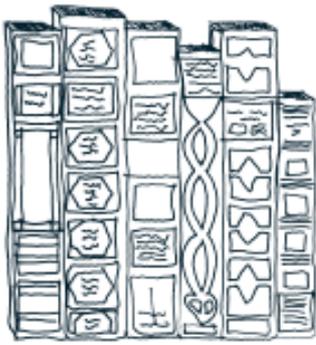
For NSW inquiries, phone **Margot Case** on (02) 9542 1704.

The **Australian National Titles** are in Perth over the Easter weekend.

We have about 50 women signed up for the event from around Australia and lots of socialising will take place!

Any readers interested in joining our social functions in the West should phone either **Yvette Libregts** on (08) 9246 0739 or myself.

*Michelle Hanton,
National Co-ordinator,
e-mail: nationalcoordinator@dragonsabreast.com.au
www.dragonsabreast.com.au*



Resources

We need your help

A bookmark listing 'must have' books, compiled by women who have experienced breast cancer, has been included with this issue of *The Beacon*.

Every community library in Australia has been sent a copy of the list with a request to stock these books on their shelves.

We would like BCNA members to visit their local library during the next month and find out whether these books are available. If not, please ask your librarian if they will get these books in for you.

A simple enquiry at your local library could result in a woman who has been diagnosed having

ready access to resources that might help with her breast cancer journey.

We would appreciate you letting us know the outcome of your research, either by e-mailing us at beacon@bcna.org.au or writing to us at BCNA, 293 Camberwell Road, Camberwell, Victoria 3124.

Please include your name and that of the library you contacted. We will be doing a follow-up survey with libraries later in the year.

We are interested to see if personal contact helps get these books on the shelves!



Seeking shelter

BCNA welcomes the:

- Scone Breast Cancer Association Inc. (NSW)

under its national umbrella:

This brings our total to 109 member groups and 6 associate member groups.

Address change

All BCNA's mail is now delivered to our office at 293 Camberwell Rd, Camberwell, Victoria 3124. Please make this change to your records.

Audio tapes can be useful

Research by the University of Sydney has found that people diagnosed with cancer remembered only a quarter of the information told to them by their specialist.

A trial, involving 1000 patients, showed that people had a greater understanding of their disease and treatment when they replayed the consultation on an audio tape.

It also found that taping the conversations benefited doctors and improved a patient's psychological state.

As a result, the Sydney Cancer Centre at the Royal Prince Alfred Hospital will be giving its specialists recording devices.

A Fenceliners adventure

Looking for a challenging adventure? Join other breast cancer survivors for the Fenceliners' next exciting activity – hiking South Australia's Heysen Trail – from September 27 to October 23.

It promises to be an active, rewarding and fulfilling experience that will give participants a chance to raise breast cancer awareness and make new friends.

Contact: Pam Cowan, 31 Phillipson Crescent, Calwell, ACT 2905. Phone (02) 6291 7632 or e-mail johnpamlizzie@hotmail.com

The Gawler Foundation

The Gawler Foundation, based in Melbourne, supports an integrated medical approach to self-help, recovery and well-being, including running meditation retreats and a number of programs – non-residential and residential – for people with cancer.

Contact: phone (03) 5967 1730 or e-mail info@gawler.org

Opportunities in Brisbane

The Wesley Hospital Kim Walters Choices Program is offering a range of activities throughout 2004 to women with breast cancer. These include:

- water STRETCH and gym;
- tai chi;
- Caring For You workshops;
- meditation and relaxation sessions;
- information seminars; and
- young women's groups.

Bookings are essential.

Contact: Janine Porter-Steele on 0417 622 652 or Leonie Young on (07) 3232 7596.

Breast Cancer: Beyond Convention

BREAST CANCER: Beyond Convention. The world's foremost authorities on complementary and alternative medicine offer advice on healing. Edited by Mary Tagliaferri, M.D., L.Ac.; Isaac Cohen, O.M.D., L.Ac.; and Debu Tripathy, M.D. Atria Books, New York, 2002. ISBN 0-7434-1011-4.

This book relates reader-friendly information about studies and statistical data regarding complementary and alternative medicines relevant to breast cancer.

The best description of it is given in the preface by one of the editors, **Mary Tagliaferri**: "It has become clear to us, through our research endeavours, that there is no good resource or guidebook to help women make decisions about the use of alternative therapies for breast cancer. Moreover, most of the available literature justifies the use of complementary and alternative therapies based on the author's recommendations or experiences, not on scientific data. Our intention, with this collaborative project, is to provide women with the most up-to-date scientific findings

that support the use of alternative therapies for breast cancer ... We hope the chapters in our book will clarify many of the questions that may arise about the risks and benefits of treatments you encounter after being diagnosed with breast cancer. This is the book I dreamed of when I was diagnosed with breast cancer six years ago".

A US team, including PhDs, medical doctors and other experts in their fields, have contributed chapters. There is also a section on resources (most with websites), notes and an index.

The best way to illustrate the breadth of the content is to list the chapter headings:

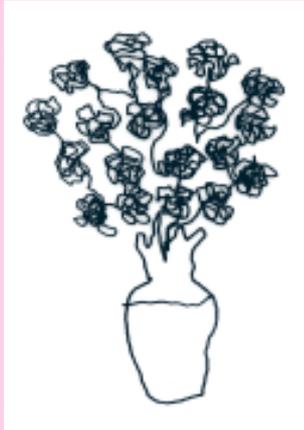
1. A diagnosis of breast cancer: taking your first steps
2. Building bridges from conventional to alternative medicine
3. Choices in healing
4. Chinese medicine and breast cancer
5. Diet and breast cancer
6. Food as medicine: the role of soy and phytoestrogens
7. The will to live and other mysteries

8. Natural products in the management of breast cancer
9. Micronutrients: vitamin and mineral supplementation
10. Naturopathic medicine
11. Meditation
12. Directed prayer and conscious intention: demonstrating the power of distant healing
13. A mind-body-spirit model for cancer support groups
14. The Charlotte Maxwell Complementary Clinic: a healing place for low-income women
15. Evaluating health information

This book contains a wealth of information for anyone interested in analysing alternative approaches, and the apparent expertise of the contributing authors gives it credibility.

I was fortunate to find this, and other worthwhile reads, at my local library. If it is not available at your library, you should try for an inter-library loan.

*Reviewed by Sandra Shively,
San Remo Breast Cancer
Support Group, Victoria*



BCNA would like to thank ...

- Reece Pty Ltd
- Harry Secomb
- Grosvenor Settlement Trust
- The Lions Club of District 201Q2 (Old)
- East Malvern Tennis Club's Mid-Week Ladies
- Ninety Milers
- The Lady Members of Kingswood Golf Club
- Le Reve
- The following schools for their fundraising –
Methodist Ladies' College Kew, Pascoe Vale Girls' Secondary College, School of the Good Shepherd Gladstone Park, Killester College, Camberwell Girls Grammar, Ruyton Girls' School, Sacred Heart College Oakleigh, Somers Primary School and Cootamundra High School

Otis Foundation Retreat

The Otis Foundation invites applications from women at any stage of their breast cancer journey who wish to experience the peace and refuge of the bushland near Bendigo, Victoria.

Continual fundraising means the accommodation is free.

The units are available for a week or weekend. Return visits



are available, if space permits. To book, phone **Liz Martin**, on (03) 5439 3220, e-mail

otisbookings@bigpond.com or visit www.otisfoundation.org.au



Upcoming Events

March 20: Lymphoedema Association of Victoria's 2004 Public Seminar, Royal Women's Hospital, Melbourne.

Contact: 1300 852 850.

March 27: Lymphoedema in the Cycle of Life – a public awareness day, Hilton Hotel, Brisbane, hosted by the Lymphoedema Association of Queensland.

Contact: (07) 3269 1498.

March 27: Information Forum for Young Women with Breast Cancer, 9am – 2pm, Royal Women's Hospital, 132 Grattan Street, Carlton. Registration is essential.

Contact: 13 11 20 (Victoria only).

April 18-25: Meditation in the desert - eight-day fully residential retreat at Hamilton Downs (150km from Alice Springs), led by Ian and Ruth Gawler. Cost ex-Alice Springs is \$1870.

Contact: (03) 5967 1730 or email info@gawler.org.

April 21: Sharing It Together – a session for women and their partners, BreaCan, 123 Lonsdale Street, Melbourne.

Contact: BreaCan, (03) 9664 9333 or visit www.whv.org.au.

April 24: Tasmanian Breast Cancer Network Meeting, Campbell Town Fire Station, 10am to 3pm.

Contact: Joan Williams (03) 6424 5886 or Karen Forster (03) 6273 4422.

June 26: Tasmanian Breast Cancer Network Meeting, Campbell Town Fire Station, 10am to 3pm.

Contact: Joan Williams (03) 6424 5886 or Karen Forster (03) 6273 4422.

July 17: Sydney Breast Cancer Trials Symposium (SBCTS) Consumer Forum, Sydney Convention and Exhibition Centre. Learn about the latest developments in breast cancer clinical trials from an international panel of experts.

Contact: www.sbcts.org.

August 22-27: Pink Ladies Golf Classic 2004, Hyatt Regency Sanctuary Cove Resort, Gold Coast, Queensland.

Contact: Jacinta Moore (03) 9500 8954.

August 27-29: 2nd National Breast Cancer Conference for Women, Melbourne Convention Centre.

Contact: BCNA, 1800 500 258 or www.bcna.org.au.

October 25: Australia's Breast Cancer Day (ABCD).

November 10-14: Leura V International Breast Cancer Conference, Sydney Convention & Exhibition Centre.

Contact: www.bci.org.au.

There are other locally based events happening around Australia, but too many to list here.

Readers can learn about these by logging onto Upcoming Events on our website – www.bcna.org.au.

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



K.W.DOGGETT Fine Paper



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A journey of a thousand miles starts with a single step.

– Chinese proverb



the BEACON

The Beacon is the magazine of Breast Cancer Network Australia.

Editor: Lyn Swinburne, free call 1800 500 258, (03) 9805 2500 or beacon@bcna.org.au

Layout: Substitution

Your comments and items for the next issue are welcome.

Send them to
293 Camberwell Road,
Camberwell, Victoria 3124



Conference

Still making a difference

Our 'Still Making a Difference' Conference will be held over three days at the Melbourne Convention Centre (cnr Flinders and Spencer Streets, Melbourne) from August 27 to 29.

We hope to bring together up to 1000 women from across Australia to learn more about breast cancer, raise issues, develop networks, inspire one another and have fun.

We have planned a substantial program of outstanding presenters designed to appeal to the wide range of women who read *The Beacon*.

We promise a friendly and fun atmosphere, and hope to meet lots of women who have never attended a BCNA event or perhaps even a conference.

Those attending the Conference will receive a wealth of information and can help set the agenda for BCNA's future advocacy work to improve the care, treatment and services for those affected by breast cancer. The Conference will revisit the *Making a Difference Report*, which resulted from our first national conference in Canberra in 1998. It will also be an opportunity to document current breast cancer issues.

We are grateful to the Australian Government Department of Health and Ageing, and BreastCare Victoria – the Conference's major sponsors – for their financial support.

Program

The Conference program aims for a balance between large group forums with high-profile

speakers, small workshops and some light relief.

We have secured two international guest speakers:

- **Dr Susan Love**, the world-renowned author of *Dr Susan Love's Breast Book*; and
- **Stella Kyriakides** from Cyprus, the president of Europa Donna, a breast cancer advocacy coalition representing women with breast cancer across 29 European countries.

The Conference will also include top-notch Australian speakers presenting a series of issue and information-based plenary sessions.

We will report on BCNA's achievements and activities, and key national organisations will report on the progress made in the treatment and care of breast cancer over the past five years.

There will also be a spirited and controversial session involving women with breast cancer and health professionals.

The workshops will feature presentations by women from all over Australia, showcasing projects and ideas, big and small, from individuals and local groups (thanks to all those who responded to our call in the last issue of *The Beacon* to present their group or activity). Conference attendees will need to make some tough decisions about which workshops to attend. Workshop details will be distributed to Conference delegates closer to the event and you will be asked to nominate your preferences.

To break up this heady program, there will also be some light relief on offer (current ideas include belly dancing, chair aerobics, tai chi, river walks and massages).

Accommodation

A range of accommodation is available in and around the Melbourne central business district. If you need help finding accommodation in Melbourne, try the Victorian Tourism Information Service on 132 842 or www.visitvictoria.com

Evening celebration

The evening celebration will be on Friday, August 27. This will be a great opportunity to relax outside the more structured environment of the Conference and to meet other women. We are hoping that everyone will choose to attend.

Please ensure you record your intention to attend and include your payment when you fill out your registration form. More information will be available later.

Conference cost

We have kept the Conference registration fee to a minimum (\$100) to encourage as many women as possible to attend. We understand that this cost may seem considerable once flights and accommodation are added, so if you need financial assistance to attend, we encourage you to seek support from your local service clubs (e.g. Zonta, Lions Club, Rotary), the local council or other organisations. Not only will this

Billet program

A group of Melbourne women have agreed to organise a billeting program, to provide a more personal and affordable accommodation option.

If you would like to be billeted in Melbourne during the conference, contact either:

- Heather Beanland
rbeanland@rmit.com.au or phone (03) 9415 6279; or
- Alison Greenland
alisonmae28@yahoo.com.au or phone (03) 9439 6025.

Alison and Heather would also love to hear from Melbourne-based readers with room to spare for an interstate or country guest.

help you get to the Conference, it will promote a greater awareness of breast cancer and the event.

We also encourage anyone reading this who would like to sponsor another woman to attend the Conference to specify their intention on the Registration Form in the space provided under 'Packages and Prices'.

Scholarship fund

BCNA has a limited scholarship fund to help women who would not otherwise be able to attend. However, applications will not be considered until other funding opportunities have been pursued.

We are particularly keen to support women from remote areas of Australia, to ensure national representation at the Conference.

As we are unlikely to be able to help all applicants, the length of the trip will be considered.

For a Conference scholarship application form, visit www.bcna.org.au or phone 1800 500 258.

