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Striving for gold standard care for everyone

Welcome to our newest readers of **The Beacon**, some of whom will have been diagnosed over the Christmas holiday period. It has always struck me how challenging it must be to receive dark news at a time when everyone else is celebrating.

Annie Young shares such a story on page 11.

When long-term advocates, such as myself, hear distressing stories from women whose care is nowhere near optimal, we wonder whether improvements have been made or if our efforts might be for nothing.

I learnt, first-hand, over the holiday break that excellent care CAN be given. One of my closest friends, Prue, was told on Christmas Eve that she had breast cancer. Prue was the one, way back in 1993, who was totally 'there for me'. She was the one who urged me to ring the doctor in the first place, a surrogate mother for my young children when I was having treatment, a shoulder to cry on in my darkest moments, the host of my five-year celebration and then my tenth. Now she was facing her own breast cancer journey.

Through all the shock, the questioning and the surgery, the thing that struck us both



Survivors and friends, Lyn Swinburne and Prue Holyman

was how differently we were managed and how much things had changed in the intervening 13 years. We each underwent a lumpectomy, but I was in hospital for two weeks waiting for my drainage bottles to start clearing. Prue was in overnight. Prue was offered a sentinel node biopsy, whereas I struggled to recover from the removal of all the lymph nodes in my armpit. The excellent news for both of us was that our nodes were clear. For me, recovery from this surgery took a long time and I am still, all these years later, attending monthly sessions with a lymphoedema therapist.

The other enormous difference was Prue's access to quality information and support. She received the *My Journey Kit* (ironically after fundraising for this over many years) and was directed to helpful websites. She really appreciated the contact from Jo, her breast care nurse, who spoke to her on a number of occasions. She also appreciated the way her husband, Richard, was encouraged to attend consultations.

Prue was never rushed. Her surgeon not only explained the situation thoroughly to her, but wrote it all down, so that she could recall afterwards what was said.

Prue's experience was not a 'piece of cake' by any means – a breast cancer diagnosis and treatment is always a trauma – but at least there was recognition that this was so.

I now can see, in the most powerful and satisfying way, that gold standard care IS possible. That said, I also recognise that Prue lives in the city, has private health insurance, is a well-educated and articulate woman, and has an extremely supportive network of family and friends. Not all women are so fortunate.

Our challenge now is to ensure that ALL women diagnosed with breast cancer and their families, right across the country, have access to the type of management, care and support that Prue was offered. If the gold standard exists, let's make sure it exists for all women.

*Lyn Swinburne,
Chief Executive Officer*

Breast
Cancer
Network
Australia



Helping our breast cancer advocates speak out

Twenty-four special women from around Australia completed our Advocacy and Science Training Program in Melbourne during November.

The women brought a variety of experiences and backgrounds to the three-day residential program. Some live in capital cities, while others live on the land, hours

from a major town. What they have in common is a personal experience of breast cancer and a passion to improve things for women who will be diagnosed in future. They will do this by becoming BCNA Consumer Representatives.

Training is an essential part of our 'Seat at the Table' program and

a vital way of enabling women to do the best job they can as consumer representatives. They heard from 18 skilled presenters, leaders in their respective fields. The positive feedback from the women attending has been overwhelming. It has made a significant mark on them and will certainly help BCNA in future.

'The program has been excellent and exceeded my expectations. I now feel better informed and empowered. I have learnt so much from the presentations. I have also learnt a great deal from many of the other women and really feel part of a wonderful network,' said **Suzanne Mullen** from NSW.



Participants in the 2005 Advocacy and Science Training Program hard at work

Host a Mini-Field of Women 2006

Would you like to:

- highlight the impact of breast cancer in your community
- promote your local breast cancer group and its services
- promote the availability of the *My Journey Kit*

while raising the profile of Breast Cancer Network Australia, our programs and services?

If so, why not host a *Mini-Field of Women* in your community in October?

Mini-Fields are held annually on or around Australia's Breast Cancer Day – this year it is Monday 23 October. The event revolves around displaying 100 pink lady silhouettes and giving the community the opportunity to honour those affected by breast cancer. The rest of the activities are up to you. We provide simple, yet detailed, guidelines containing invaluable tips and suggestions, together with an 'Event in a Box', which contains all you'll need to successfully run a *Mini-Field of Women*, including the silhouettes.

Last year, a record 81 *Mini-Fields* were held. This year we'd love to see our pink ladies planted in even more communities across Australia!

If you or your breast cancer support group are interested in holding one of these memorable events, or want to find out more, visit our website at www.bcna.org.au, (find *Field of Women*, under the 'Programs' tab) or phone us on 1800 500 258.



Julie Tonkin and Min Wilson at the Mini-Field in Yorketown, SA



Our big pink lady, Veronica, was a big hit at the Grand Prix media launch

The Pink Lady goes high octane

BCNA received exciting news late last year when we were named the official charity for the 2006 Formula 1 Australian Grand Prix.

The event runs from Thursday 30 March to Sunday 2 April in Melbourne.

Once again, BCNA steps into an internationally publicised sporting event to raise awareness of breast cancer and funds for our programs for Australians affected by breast cancer.

The Australian Grand Prix Corporation has enthusiastically embraced our Pink Lady, offering to brand parts of the event with her image.

She will appear on the lanyards worn with all track passes and pink gravel pits around the course will be a constant reminder

of our cause. A BMW car decorated with Pink Lady livery will compete in the celebrity challenge race and 'Veronica', our five-metre high inflatable Pink Lady will be visible from many vantage points around the track.

We will also have a tent where we will be selling a special pink lady FM radio designed to keep those on the track up-to-date with race progress.

BCNA will receive the proceeds of the auction to be conducted at the Official Grand Prix Ball on Friday 31 March. The Ball, to be held at The Palladium at Crown Casino, promises to be '... a glamorous, star-studded evening in Melbourne's calendar', according to the Grand Prix.

In support of BCNA, Rio Tinto has generously donated

a stunning 3.35 carat pink champagne Argyle diamond, which will be a special auction item. This unique diamond has been described by Argyle's chief diamond cutter and polisher as 'very special' – it is only the second time in 20 years that he has worked a diamond of this colour complexity, a mix of reds, brown, orange and pink. To highlight the beauty of this rare gem, the diamond will be crafted into a beautiful setting designed and made by Hardy Brothers Jewellers.

Before the auction, **Lyn Swinburne**, BCNA CEO, and **Terry Bracks**, BCNA Board Member, will speak to the audience in a special presentation designed to bring to life the importance of BCNA.

Organ and blood donations after breast cancer

In the last issue of *The Beacon*, we attempted to clarify the situation regarding the donating of blood and organs after breast cancer.

Following advice from LIFEGift, the Victorian Organ Donation Service, we reported that people were ineligible to donate blood for the rest of their life following breast cancer. Several readers of *The Beacon* queried this, as their experience was different, and those who were active blood donors were particularly concerned.

We sought clarification and the Australian Red Cross Blood Service reported that it defers blood donors who have had breast cancer for five years after the completion of their treatment.

We apologise to readers for any anxiety or confusion the publication of this incorrect information caused. It is an example of one of the many issues facing breast cancer survivors – the need to work out the implications of having had breast cancer on other activities and commitments, and to make decisions in the face of sometimes contradictory or misleading advice from health professionals.



BCNA gratefully acknowledges our partnership with Bakers Delight.



Information and support for women with advanced breast cancer

Last year, as we travelled around the country presenting State-based forums, we looked forward to the time on the program for audience questions. Inevitably, the question would be asked, 'What about a My Journey Kit for women with advanced breast cancer?'

We are excited to announce that we are developing such a kit.

The kit will target women at the point when they are first diagnosed with secondaries. Like the *My Journey Kit*, this kit will bring together the voices and experiences of women who have been there.

While we will draw on our experience of developing the *My Journey Kit*, this is a new and, in

some ways, quite different project. Project Manager, **Anne-Maree Polimeni**, has started work and over the first half of this year is seeking ideas and information from women who have advanced breast cancer.

Like the *My Journey Kit*, this kit will aim to provide a package of useful resources, stories and experiences from women to help others diagnosed with advanced breast cancer in the future.

We know there will be many challenges in developing this resource. In particular, we are aware that women's experiences of advanced breast cancer are each different. We know, too, that about 12% of women when first

Messages of hope

A new 32-page edition of our booklet, *Messages of Hope and Inspiration from Women Living with Advanced Breast Cancer*, is now available. If you would like a free copy, email beacon@bcna.org.au, phone 1800 500 258 or write to BCNA, 293 Camberwell Road, Camberwell, Victoria 3124.

diagnosed with breast cancer are diagnosed with advanced disease.

This kit is by no means the end of our planned work for women

with secondary breast cancer. The Advanced Breast Cancer Working Party continues to be a mighty force – raising issues and assisting BCNA in advocacy work. We also have plans to develop a project to help women with advanced breast cancer gain the most from their medical consultations. This project will build on some of the training being undertaken with doctors to improve their communication skills, but will focus on women rather than their doctors. It is in its infancy at this stage, but we are really excited about this project.

We'll keep you informed about this important work.

Dianne continues to inspire

Dianne Chellew was diagnosed with breast cancer in 1997 and had a bilateral mastectomy in 1999. Earlier she had lost two sons in a car accident and then her best friend, Julie, died from breast cancer. Her story was featured in the Summer 2000 issue of *The Beacon* and she continues to inspire others with her tenacity and endurance.

In December, with paddling partner, **Bernie Craggs**, Dianne won the Mixed Veterans 50 category in the 2005 Murray Marathon and finished 14th on handicap in the world's longest annual canoe race.

Dianne writes that the Murray Marathon is a combination of endurance, commitment and

camaraderie, and the most challenging event of its kind in the world.

Paddling from Yarrowonga to Swan Hill, a distance of 404 km, Dianne and Bernie battled strong winds, low river levels, thunderstorms and hail, blisters, skinned butts and the hottest December day on Victorian records, which nudged 50°C.

On the first two days, they broke three rudders and were forced to repair their rudder shaft by jamming it into a knot hole in a mighty Murray gum and using their weight to straighten it!

On the final day it was so hot that Dianne and Bernie dived into the water to keep cool. That was



A hot, but victorious, Dianne

a mistake, as other crews gained ground, but with only 1½ km to go they managed to edge in front to beat their nearest rivals by four seconds! Although three hours outside the record, their result was amazing.

Dianne was inspired by cyclist **Lance Armstrong's** book, *Every Second Counts*, and was motivated through the race by his advice, 'Pain is temporary, quitting lasts forever'.

My Journey Kit – a challenge to our readers

BCNA is delighted to report that we have distributed more than 13,000 My Journey Kits since it was launched in May 2004. Around 60% of women diagnosed with breast cancer across Australia now receive a My Journey Kit.

Ideally, women are introduced to the My Journey Kit at the time that they are diagnosed with breast cancer – perhaps by their surgeon or a breast care nurse. However, we know that there are many women who still don't know about the kit.

We need your help to make sure that every woman in Australia diagnosed with breast cancer knows about the My Journey Kit.

The My Journey Kit is a vital resource for women and families. It brings together helpful information directly from women who have had breast cancer. It provides links to other resources, services and websites, along with a friendly and hopeful voice.

We receive daily feedback from women who have received the kit, often telling us that it has provided a lifeline for them.

Individual women diagnosed within the past 12 months can phone the My Journey Kit request line on 1300 78 55 62 to ask for their free copy. This automated service is available 24 hours a day, seven days a week.



The network in action – Consumer Rep, Marie Polla-Mounter, makes sure every health provider in Gippsland knows about the My Journey Kit

Honours for BCNA supporters and members

In the Order of Australia Awards announced on Australia Day, we were thrilled to see our long-time friends and the founders of Bakers Delight, **Lesley and Roger Gillespie**, receive recognition for their fantastic work and support of others.

Lesley and Roger were each awarded a Medal of the Order of Australia (OAM) for their service to the community through the support of charitable and sporting organisations, and to business and commerce.

BCNA's CEO, **Lyn Swinburne**, was awarded a Member of the Order of Australia (AM) for her service to women with breast cancer and their families through the establishment and development of BCNA.



Recognised for their contribution supporting women with breast cancer, Lesley and Roger Gillespie, with Lyn Swinburne

Also honoured were BCNA members, **Linda Reaby**, ACT, and **Barbara Walker**, Victoria.

In December 2005, Lyn received a Tattersall's Monthly Award for Enterprise and Achievement, and a \$20,000 cheque for BCNA.

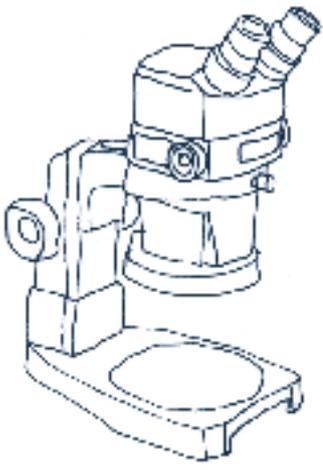
My Journey Kit 2006 calendars

If you received a My Journey Kit in 2004 or 2005, your Personal Record may not include a 2006 calendar. Visit our website, www.bcna.org.au, select 'My Journey Kit' and then the 'Introduction' page to download and print calendars for 2006, 2007 and 2008, or phone BCNA on 1800 500 258. The calendars are a useful way of keeping track of appointments and treatment dates.

We need your help

- Plug the My Journey Kit to your medical team. Ask them to tell women about it. Tell them how important it was for you. Remind them that the kit has been endorsed by the key medical colleges.
- Keep the My Journey Kit promotional card included in this issue of **The Beacon** handy, so that you can pass it on or have the number available as a handy reference.
- Ask your doctor to display our A4 poster.

We can send you some promotional material to deliver to a breast cancer service near you! We can also send health professionals a sample copy of the kit, along with promotional posters and postcards. Phone **Louisa Shepherd**, the My Journey Kit Project Co-ordinator on 1800 500 258 with any queries.



Research Update

Herceptin progress

Over summer, BCNA saw considerable media reporting about the huge financial impact on women who have decided to pay for the drug Herceptin.

As we write this article, at the beginning of February, Roche Australia is planning to make a submission to the Therapeutic Goods Administration (TGA) later this month. It will include data from the three large international studies on the use of Herceptin in early breast cancer (results from these trials were reported in **Beacon 32**).

The submission will also include data about the drug's safety. We know that the trial results have shown clear links between taking Herceptin and cardiac problems for some women. In some cases, women had to withdraw from the trials because of this reaction.

It is hoped that Herceptin will receive TGA approval for use in early breast cancer and we have been advised that the TGA will view this submission as a priority, although it is unclear how long this process will take.

If Herceptin receives TGA approval, Roche will then make an application to the Pharmaceutical Benefits Advisory Committee (PBAC), which will decide whether Herceptin will be reimbursed (through the Pharmaceutical Benefits Scheme [PBS]) for use in early stage HER2 positive breast cancer. We are not sure how long this process will take, although the Federal Health Minister, **Tony Abbott**, has indicated that the process will be fast-tracked.

The Federal Government is well aware of the considerable community interest in a quick resolution of this issue.

In the interim, Roche Australia has made a commitment to offer women who undertake a 12-month course of Herceptin, one free dose in every six treatments, in an attempt to reduce the overall cost to women.

It is not possible for Roche to implement this program until after the TGA has approved the drug for use in early breast cancer, but the company has undertaken to backdate this subsidy until June 2005, so that women who have paid for the drug since that time will be eligible for the subsidy program. The details of the program are yet to be finalised. While the cost of Herceptin remains prohibitive, this initiative will reduce an individual's cost by approximately 16%.

This will not, in itself, impact on the timeframe for Herceptin to be considered for listing on the PBS and many women are faced at this time with an extremely difficult decision about whether they can afford to take this treatment option. BCNA continues to work to encourage the fast-tracking of approval for Herceptin to be made available to women under the PBS.

In November 2005, **Lyn Swinburne** attended a meeting

Key points

- Herceptin trials have shown significant benefits for women with HER2 positive breast cancer. That is approximately 2500 Australian women a year.
- Herceptin may cause cardiac problems in some women. Cardiac monitoring is essential for women taking Herceptin.
- Herceptin is not yet listed on the Pharmaceutical Benefits Scheme (PBS) for use in early breast cancer. At \$50-70,000 a year, Herceptin is an expensive drug.
- The process for subsidy approval for all drugs in Australia is an important way of ensuring the safety and efficacy of drugs. However, this process must be quick and effective to ensure rapid access to effective treatments.
- BCNA will continue to push for a rapid subsidy for Herceptin for use in HER2 positive early breast cancer.
- A Roche subsidy program will provide some assistance to women who pay for Herceptin while it is not subsidised.
- Women who pay now for Herceptin will not be retrospectively reimbursed by the Federal Government.
- Some far-sighted private health funds have contributed to the cost of Herceptin.
- Recent research suggests that some oncologists are not telling patients about Herceptin if they think the patient cannot afford the treatment. Oncologists should tell women with HER2 positive early breast cancer about Herceptin. Women have the right to make their own informed (although difficult) decisions about treatment.
- Communities across Australia have shown amazing resourcefulness, energy and compassion in raising funds to help individual women receive Herceptin.
- Herceptin is subsidised for treatment for HER2 positive women with advanced breast cancer.

in Sydney about improving access to oncology drugs in Australia. It was hosted by the Medical Oncology Group of Australia. Medical oncologists met with representatives of Medicines Australia, private health insurers, the PBAC, the TGA and the National Breast Cancer Centre to explore options to address issues to do with people's access to oncology drugs in Australia, particularly expensive drugs. Also in attendance was **Sally Crossing**, representing consumers via NSW Cancer Voices.

The discussion was not about specific drugs, but about the whole range of targeted cancer drugs that will become available over the next few years.

The meeting was an opportunity for engagement in considered debate about access to new cancer drugs. BCNA's view is that women should have timely access to drugs that potentially reduce their risks of recurrence, extend their life or improve its quality.

Presentations at the meeting indicated that the processes involved in achieving timely and affordable access to these new drugs are thorough, probably not unreasonably lengthy (as long as the guidelines are adhered to) and in line with world standards. BCNA acknowledges and respects the process, but wants it to be as speedy and flexible as possible, without compromising patient safety.

The group will continue to meet and BCNA represent its members in this forum.

Another interesting development in the ongoing debate about access to expensive, unsubsidised drugs was the publication of results from a survey of oncologists' views on this subject conducted by medical oncologist, **Michael Jefford**, and colleagues from the Peter MacCallum Cancer Centre in Melbourne. The results were published in *Annals of Oncology* recently. An associated ethical analysis/commentary was published in

the *British Medical Journal* last November.

The authors found that 28-41% of oncologists surveyed were not likely to discuss an expensive drug option with their patients if that drug was unsubsidised.

'It is difficult for patients, their families, and doctors to accurately predict what a competent patient would want in the face of serious or lethal illness. In such complex cases, the default position of medical consultation should be to inform patients of reasonable options, without directing them or attempting to persuade them to take unsubsidised drugs.'

The authors further proposed a guide as to when a drug should be mentioned. They propose: 'Would a reasonable doctor offer or would this patient (given their individual values) reasonably desire this drug or treatment if it were free?'

BCNA's view is that women should be given as much information as they require to

make an informed choice about their own treatment. It is crucial that it is individual women, rather than doctors, who make decisions about what a woman can afford.

Over the past few months at BCNA, we have heard many stories of communities banding together to raise funds so that an individual woman might take Herceptin. Sponsored bike rides or walks, community parties and the establishment of tax-deductible trusts have helped women pay for their Herceptin treatment. Others have had some success with their private health funds (although it is important to note that many women have reported no success with their health fund). We have also heard sad stories of hardship and, in the extreme, families selling their home to pay for treatment. A successful application to the PBAC would thankfully mark an end to this.

We will continue to report on this important issue in future issues of **The Beacon**.

New choices for women finishing tamoxifen

While it is known that the risk of breast cancer recurrence is highest in the first few years after initial diagnosis, the risk of recurrence does not drop down to nil, even after five years.

Some women taking tamoxifen are pleased to reach the five-year milestone and finish treatment altogether. However, some women's doctors will recommend – and some women will consider – taking more medication after finishing five years of tamoxifen, to further reduce their risk of recurrence. It depends on a lot of factors, including a woman's original diagnosis and prognosis.

This individual decision is one best made in consultation with the doctor.

In past issues of **The Beacon**, we have written about a group of drugs that block oestrogen production in post-menopausal women. These drugs are called aromatase inhibitors and one of them is called letrozole (brand name, Femara). A large study has shown that post-menopausal, hormone receptor positive women who took letrozole after they had completed five years of tamoxifen had a 3.5% risk of developing a breast cancer recurrence, compared with a

6% risk in the group that took a placebo after five years of tamoxifen. As a result, letrozole was registered by the Therapeutic Goods Administration in January 2005 for 'extended adjuvant treatment of early breast cancer in post-menopausal women who have received prior standard adjuvant tamoxifen therapy'.

This drug is not available on the Pharmaceutical Benefits Scheme. However, Novartis, the company that manufactures this drug, has decided to provide it at no cost to women who are eligible.

If you have completed between 4½ and six years of adjuvant

tamoxifen treatment within the past six months, you may be eligible to receive Femara under the program. You will need to speak to your doctor about whether or not the treatment is appropriate for you. If the treatment is suitable, your doctor can apply to enrol you in the program.

This can be a difficult area of decision-making. BCNA's general position is that women should be given all of the information about their options, so that they are able to make an informed decision.

Bakers Delight and BCNA – working to make a difference

One in 11 Australian women will be diagnosed with breast cancer; many of them have no family history or anything to indicate that they are at risk. We know that it affects so many, yet we are always shocked and saddened to hear news of someone close to us being diagnosed. We were stunned to receive news late last year that one of our great supporters, Bakers Delight franchisee, **Jo Harrington**, had been diagnosed with breast cancer.

It is ironic to think that those who have worked the hardest to ensure we can continue our work may one day need that support.

With Jo's permission, we are reproducing her letter, which eloquently expresses how the enthusiasm and hard work of the Bakers Delight team has contributed to making a real difference for women diagnosed with breast cancer.

Dear BCNA Team

For five years we have raised money for BCNA through our two Bakers Delight bakeries. We have always approached this fundraising as our 'special project' and have successfully conducted on-air radio auctions and in-store promotions. We did it because BCNA's work was a cause we believed in and we felt proud to be part of the Bakers Delight partnership with BCNA.

During our fundraising drives, I have worked across the sales counter and heard so many



Jo Harrington with her husband, Geoff, and their children, Daniel and Georgina

women say 'Thank you – I am a survivor'. I have been moved to tears when our pink silhouettes were purchased by relatives who wanted to honour someone special. I wept with them as they struggled to hold their pens upright when they recorded the names of those that had lost the battle.

Four weeks ago, I joined the ranks of survivors. With no family history of cancer, aged 41 and with two small children, I had never considered that I would be a candidate. In my wildest dreams, I could not have imagined that my relationship with BCNA would become anything more than donor/fundraiser.

Last month we were raising funds for the *My Journey Kit*. This month I have my own copy. Life has its own way of throwing up ironies.

As I sit here recovering from surgery and nervously awaiting the next round of pathology results, I would like to say thank you to BCNA and my Bakers Delight colleagues, for making the *My Journey Kit* a reality. Each time I use it, I think of the wonderful partnership that created it. I think of my staff and the staff in other Bakers Delight bakeries that have worked tirelessly to raise the money for it, and I think of all those women that have come up to our sales counters who may one day benefit from it.

Thank you BCNA, this kit has meant so much, at a time when little else made any sense.

*Jo Harrington,
Bowral, NSW*

Bakers Delight bakeries go pink again in May

Once again, our fabulous supporters at Bakers Delight bakeries nationally will run fundraising activities to raise money for, and awareness of, BCNA in the lead-up to Mothers' Day.

Following the runaway success of last year's Pink Bun promotion, you will again be able to buy pink buns for \$1.20 from 18 April to 14 May 2006, and that money will go directly into the BCNA tin.

Action you can take to help

- Tell friends and colleagues about the Pink Bun promotion in the lead-up to Mother's Day
- Visit your local Bakers Delight bakery and buy a pink bun
- Thank your local Bakers Delight bakery for its support for BCNA.





Issues of Concern ...

Complementary therapies: To do or not to do? To tell or not to tell?

The use of complementary therapies among cancer patients is commonplace and controversial.

One thing's for sure, within days of telling people you have breast cancer, suggestions, recommendations and other people's stories – good and bad – will start to flood in. Inevitably, these recommendations will include doctors to visit, miracle cures to pursue, therapies that are worth a go, and books that will tell you why you got cancer and what you have to do to cure yourself. There's an industry out there built up around cancer and an eager, desperate market.

Which way to head?

It's hard to know. There's such pressure to choose the right thing, make the biggest effort and go the extra distance to maximise recovery. The more you read and are told, the worse it can get. What's shark cartilage and what possible good could it do? How? Why? How much? It's not just a matter of 'Should I juice?', but should I buy a \$700 juicer because of its reputed enzyme-friendly extracting technique? Do I meditate? Do I meditate with the aim of curing my cancer or to help me stay calm? Who can I discuss my list of options with?

It's overkill, but that's the point, isn't it? Doing everything possible. Weighing the odds in your favour. Green tea may not help, but will it hurt or harm? Don't Japanese women have lower rates of breast cancer? What lifestyle factor is responsible – diet, environment, stress?

Some things we know.

Most women try some complementary therapy alongside their conventional western medicine combination of surgery, radiotherapy, chemotherapy and hormones. A few women – in the face of much disapproval and shaking of heads – will choose to

eschew standard treatment and devote their energy to a holistic alternative approach only.

Most health professionals will be scathing about alternative approaches. This dismissal makes it hard for their patients to reveal, let alone discuss, what they are considering or want to do.

Some health professionals are trying harder these days to appear open-minded; not necessarily because they are convinced about complementary approaches, but because they want to know what else their patients are doing. It appears

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Information and advice isn't always welcome

Our readers commonly report that they receive unsolicited information or advice following their cancer diagnosis.

Some advice and information may come from well-meaning family or friends, while other sources include companies selling particular products or services. Some information may conflict with what people have been told by their medical practitioners and some of it may be inaccurate.

In February 2004, **Jim Bacon**, the then Premier of Tasmania, publicly revealed he had lung cancer. In an article published in

the *Medical Journal of Australia* last December, **Professor Ray Lowenthal**, Director of Medical Oncology at the Royal Hobart Hospital, analysed 157 items of correspondence about complementary and alternative medicines that were sent to Mr Bacon following this announcement. The items sent to him included books, postcards, CDs, letters, emails and audiotapes. They came from all parts of Australia and some were even from overseas.

Mr Bacon forwarded these items to Prof. Lowenthal, who

found that the treatments recommended 'ranged from those for which some evidence of benefit exists to others with no evidence of benefit or evidence of harm, due to adverse interactions or their own specific dangers'.

Some correspondents said they would only reveal their 'secret methods' if Mr Bacon contacted them directly and in some cases, requested a fee for this information.

Mr Bacon's experience, as reported in this article, highlights the need for people with cancer to have access to good

information, including about complementary and alternative medicines, and to maintain open communication with their medical practitioners about their use of, or intention to use, complementary medicines.

For BCNA's position statement on complementary medicines, visit our website, www.bcna.org.au.

The full text of Prof. Lowenthal's article, as well as his recommendations, can be found at www.mja.com.au/public/issues/183_11_051205/low10491_fm.html.

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that the despised unorthodox approaches can go from being regarded as ineffective to having some power to negatively affect the success of standard treatments.

It is also known that some women experience an increased depression and anxiety when treatment finishes, because while undergoing treatment at least someone feels they are doing something to combat cancer. Unlike other illnesses and diseases, cancer is so often talked about in terms of a personal fight or war. People who die have lost their 'battle'.

Even the language – conventional, traditional, orthodox, alternative, western, eastern – is a minefield that reveals prejudices and positions.

Then there is the whole question about the right to choose and informed choice. What is informed choice when it comes to complementary treatment? Complementary approaches or treatments have not usually been subjected to western medicine's scientifically controlled clinical testing. Where's the evidence, the doubters ask? The case for alternative therapies is built on anecdotal accounts and a different philosophical approach to disease.

Money is the next troubling issue. A public patient may be able to get chemotherapy for nothing, but will shell out lots of money for organic vegetables, biodynamic rice, wheatgrass, foul-tasting tonics, lessons, courses and therapies. Cost would be less of an issue if the 'treatment' came with a guarantee.

Cancer prompts people to make lots of choices about their life,

Complementary therapies study

During 2005, the National Breast Cancer Centre began a project to develop information for women about complementary therapies and breast cancer.

BCNA provided consumer representation for the project advisory committee and subsequently circulated the

research survey to some of our members.

The results from this preliminary work will be released later in the year, but you can find an early report of the outcomes in the *From the Source* insert included with this copy of *The Beacon*.

generally and in reference to treatment and managing side effects. Many people, when first diagnosed, seek a personal explanation for why they have cancer. Subsequently, they modify their stance to accept the scientific explanation of cancer as an arbitrary, degenerative disease of the genes. Similarly, many people seek to make decisions about allied treatments that take into account individual preferences or beliefs, ones that allow a customised or personalised solution.

In the end, it is hard to assess the value of complementary therapies. BCNA supports high-quality research into complementary therapy. More knowledge will emerge in the next few decades. It is important to respect someone's choices, but understandably difficult to see someone choose a path of treatment that you regard as futile, expensive and creating hardship. Given the popularity of such treatments and women's interest in them, it is important to subject them to rigorous scrutiny, rather than dismiss them out-of-hand. It is important to be kind,

listen and realise that someone recently diagnosed with cancer or a recurrence needs support.

Pathology, not personality

Throughout history, whenever the exact causes of a disease have not been understood, the cause has often been attributed to personality factors.

In the early 19th century, it was believed that consumption was a constitutional trait associated with gifted and talented people. However, after germs were discovered, we learnt that tuberculosis or TB is an infectious disease that can be treated by antibiotics.

More recently, it was thought that people with stomach ulcers worried too much. A flare-up of ulcers was attributed to acidity treatable with diet. These beliefs have since been overturned with the discovery of the *Helicobacter pylori* bacteria.

The troubling inclination to either blame the patient for their initial illness or to hold them responsible if they don't get better is still with us.

Some useful definitions

Complementary treatments: Used **with** conventional medicine.

Cannot cure cancer, but may help relieve side effects and improve well-being. Examples include yoga, acupuncture and visualisation.

Alternative therapies:

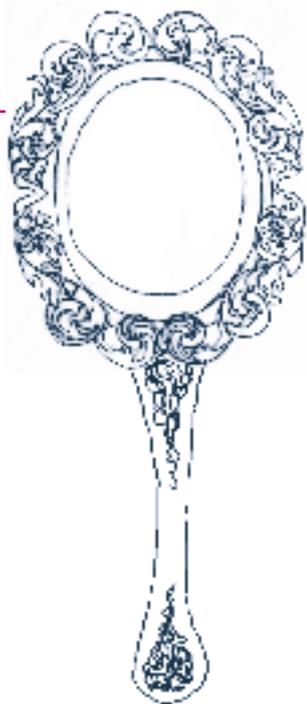
Used **instead of** conventional medicine. Examples include the Laetrile and Gersen diets, and some herbs, such as mistletoe. A treatment can be used alongside or instead of conventional medicine, so the difference is sometimes not intrinsically in its use, but in how it is used and with what aim.

More information

Most Cancer Councils have some printed information about alternative remedies.

An online web search easily turns up claims about loads of treatments. Websites that evaluate, comment or assess alternative treatments include:

- National Center for Complementary and Alternative Medicine (US) – nccam.nih.gov
- Quackwatch – www.quackwatch.com
- Therapeutic Goods Administration – www.tga.gov.au
- Alternative Dietary Supplements – dietary-supplements.info.nih.gov



My Story

Christmas 2005 and the yin and the yang of our lives

Annie sent us her story early in the new year. It is a poignant account that many readers will identify with. No matter where we were, who we were with or what we were doing, the memory of being told you have cancer is etched in your mind.

I am in the workroom and the phone rings. A colleague answers it and hands the phone to me. Sensing a private call, I retreat to another room. A quiet, calm voice is suggesting that I need another appointment at the breast care clinic. My whole world begins to close in.

'What seems to be the problem?' I ask weakly.

'Two radiologists have looked at your x-rays and they have seen something they want to look at more closely,' I'm told.

I stay in the room for minutes. I want to stay there forever. I come out to the workroom and hear my voice announce that I have to return to the breast care clinic. Everyone is immediately reassuring, supportive, positive.

I ring Rob. As usual he is quiet, concerned and calmly reassuring. 'Let's wait until Thursday. It could be nothing. They're just being super careful. That's their job.'

The night is so dark when you're terrified. Thursday finally dawns and I am up with the birds. My appointment is first. Rob is with me.

Alison introduces herself. She is my carer for the morning. She becomes the relayer of good news and bad. I learn to place my faith in her as the morning evolves.

I will be the one woman who sits there as the morning progresses, smiling brightly, falsely as other women come and go, cheerfully wishing me good luck as they go back to their safe lives for Christmas.

Mammogram, ultrasound, gentle, gentle radiologist. Needle biopsy, apologising if he hurts. Pathologist taking biopsy away and returning an hour later with a good result. No cancer. I am ready to run. Gentle radiologist and caring nurse come back to apologise again, but they want a bigger sample. Core biopsy.

Bigger needle, a bigger piece of me is taken out. Breast is numbed and gentle radiologist is so kind. He is being so cautious and I am ultimately grateful for that.



Annie Young

I wait a week. Sleep is a little easier. I am in good hands. Rob comes with me again, this dear, quiet man. Alison introduces me to the surgeon who has seen my results.

It is breast cancer. Again my whole world closes in.

However, the surgeon assures me that this cancer is a good one, if you have to have cancer. I can't believe this is me sitting here quietly, politely listening, while he explains the cancer I have and the procedures which will follow.

It is two days to Christmas.

Appointments are made. There are no hospital theatres open until after new year.

'Go home. Try not to think about it. Try to relax. Try to enjoy your Christmas.'

We ring the children. They're shocked and so strong.

How can I do this to my beautiful son, who is expecting his first child in the new year?

I tell my dearest friends and my lovely brothers. They gather around me with warm hugs and strong embraces.

I try to sleep. I imagine the lump nestled cosily in my left breast. I try to shrink it in my mind. I'm not good at that. Just feel more terror and fear in the darkest of the night. It is Christmas Eve.

I am woken at 3am. It's my son. Amanda is in labour. Another call at 7am. 'Mum, we have a beautiful healthy son.'

My son is crying. I am crying. This is the yin and the yang of our lives. This is what family is all about. We had a wonderful, joyous Christmas.

Whatever follows will be fine. We have a new grandchild, born in my tears, but he has brought us such new hope and joy.

Welcome baby Nicholas John. I will be here to help you through your childhood. I am ready for the next stage of this journey. All is well.

Annie Young,
Bendigo, Victoria



Book Review

Level One of the Healing Journey Workbook: An active response to the crisis of cancer

By Alastair Cunningham, Ontario Cancer Institute, Canada

(70 pages, can be ordered or downloaded from the website www.healingjourney.ca. The workbook alone costs \$7 Canadian, packaged with two CDs [or audio tapes]; the cost is \$22.50 Canadian.)

I loved this workbook, but it may not be for everyone. I enjoyed reading it. I did not find that anything in it was particularly new or innovative, rather it was a sort of central repository where several different schools of thought were pulled together in one easy-to-understand package.

The psychological and spiritual techniques are designed to support medical treatment by making the body and mind as healthy and strong as possible, hand in hand with conventional medicine, and to give people a meaningful, useful place in their own medical team.

I felt that the writer had got it right. There were elements of **Louise Hay** and **Petrea King**, and he also mentioned *Feeling Good* by **David Burns**. He gave ideas of who else and what to read. It gave the workbook a warm feeling – he was agreeing with others, not saying, 'Here's my way of doing things, which is different to everyone else'.

The workbook dealt with a specific issue, followed by

a question(s) in italics that appeared wherever I would have asked a question or made a comment on the preceding section. This was followed by useful answers that were not judgemental or dismissive.

The language was everyday. There was the right balance between setting out quite complex thought patterns and explanations in a reasoned and articulate way, intermingled with a chatty, down-to-earth, inclusive language.

It set down many of the healing techniques that I used when first diagnosed and still use now: meditation, relaxation, yoga, being active in my journey. That meant I felt I had some control over my health, making a chart of where

I wanted to be in the short, medium and long term, stress management, morbid thought management, etc.

The workbook outlines practical approaches in a simple way. The various colour figures were helpful. The steps in the workbook were logical and the book flowed well from one subject to the next.

Not everyone would be able to use the workbook for self help. Some people would benefit more from working through it in a group (as the writer says himself).

The workbook covers so much that it only scratches the surface in some areas.

Ann Revell, WA



A number of breast cancer survivors have carried the Queen's Baton in the relay leading up to the Commonwealth Games. Pictured here is Susan Tulley, a former BCNA Northern Territory State Rep, with local politician, Fay Miller, in Katherine during February

Who helped you through?

Did someone special help you through the difficult times?

We are inviting readers to send in articles and will publish a selection of them in the next issue of *The Beacon* and on our website. We are particularly interested in hearing about the practical ways people helped, as this might inspire others who are searching for ways to help those close to them.

Articles should be no more than 400 words and will need to be submitted by the end of April. Please email beacon@bcna.org.au or mail to BCNA, 293 Camberwell Road, Camberwell, Victoria 3124.



Operation Pink Band – update

With funds raised from the sale of BCNA's bright pink wristbands now more than \$80,000, many of our members, their friends and families are wearing their support on their wrists!

You can buy pink bands from a variety of retailers nationally. To find out more, visit www.pinkband.com.au or telephone (02) 9869 0229.



Profiling our Member Groups

Launceston Breast Cancer Support Group

Pauline Watson attended BCNA's Consumer Advocacy and Science Training in 2002 and decided she wanted to set up a support group in her home town of Launceston, Tasmania.

Pauline is a long-time breast cancer survivor, having been diagnosed with early breast cancer in 1990, then advanced breast cancer in 1993. As well as running a support group, Pauline is a Cancer Connect volunteer.

Initially, Pauline's group met informally at her home, but early in 2005, and with the help of some other local women, the Launceston Breast Cancer Support Group was formed.

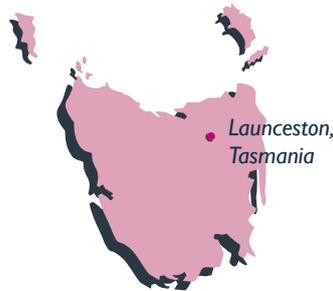
'I organised a free room for us to meet in at the Kingsmeadow Community Health Service. Mary did a fabulous flyer for the group and Jude organised with a local Member of Parliament to have the flyer copied free-of-charge.

For the first meeting, I was a little bit terrified but it has worked out well,' Pauline said.

The group meets monthly, alternating between morning and evening meetings. The morning meetings tend to have the best attendance, attracting an average of 12–15 women. The group has drawn women with both early and advanced breast cancer.

The group's program is informal and they make sure there is no pressure for anyone to speak. Sometimes women just want hear other women's stories.

Pauline puts out a pink silhouette



Group members Margaret Tassell, Shelley Sexton and Pauline Watson (Photo courtesy of The Examiner)

to make sure women know about the group's connection with BCNA and displays our *My Journey Kit* and copies of **The Beacon**.

The conversation might focus on a particular issue or discuss a local service. As well as talking in the larger group, there is time for individual discussion over a cup of tea for those women who are

more comfortable talking one-on-one or in a small group.

The group has established a good relationship with the local media, and meetings and activities are advertised in *The Examiner* newspaper.

Shelley Sexton, one of BCNA's two Tasmanian State Representatives, is also an active member of this group.

Two new members for BCNA Board

BCNA is delighted to announce that publicist and breast cancer survivor, **Suzie Howie**, and medical oncologist, **Dr Fran Boyle**, have joined our Board.

Suzie has publicised more than 700 productions, comedies, musicals, dramas, films, opera and cultural events, over 25 years. She began as a publicist with Michael Edgley International, and established her own public

relations company, Howie & Taylor, with her husband, Paul Taylor, in 1985. Since then, the productions she has presented include *Cats*, *The Phantom of the Opera* and *Les Miserables* in Australia and Asia. Suzie, who lives in Melbourne, was diagnosed with breast cancer in 2004.

Fran is a medical oncologist in Sydney, where she is involved in breast cancer treatment and

research and is the Medical Director of the Pam McLean Cancer Communications Centre at the University of Sydney. Fran is a member of the Board of the ANZ Breast Cancer Trials Group. She is known for her contributions to breast cancer research, policy and education, and for advocacy on behalf of women with breast cancer, and is passionate about improving

doctor–patient communications. Fran was a popular speaker at our 2004 *Still Making a Difference National Conference*.

BCNA would also like to acknowledge the contribution and hard work of those Board members who resigned or retired in 2005: **Debbie Goodin, Cherrell Hirst, Libby Maynard, Anna Wellings Booth** and **Mary Wooldridge**.



Dragons Abreast

We were delighted to see **Abby King** crowned as *Tunarama Ambassador at the 2006 Tunarama Festival in Port Lincoln.*

Abby nominated Dragons Abreast as the recipient of her fundraising and Dragons Abreast Port Lincoln received a cheque for \$8200.

In January, Dragons Abreast NT hosted the 're-birth' of the dragon boat Sunshine, complete with sparkling new paintwork.

We are making our presence felt across the country, with members participating in many local events over Australia Day and Chinese New Year. The highlight was on Sunday, 12 February 2006, when 12 boat loads of Dragons Abreast members – all breast cancer survivors – participated in the Chinese New Year Regatta at Darling Harbour, NSW.

For many members, this was their first experience of a major



Dragon Boaters celebrating Chinese New Year in Sydney

regatta. It was an incredible sight, with the Flowers on the Water ceremony acting as a powerful statement to remind and bring home to the public the fact that breast cancer is a disease that is all too common, one that kills women and that we, the women who have survived, are determined to keep breast cancer in the public eye and encourage the search for a cure.

The other highlight of the day was the Hospital Challenge,

organised by Dragons Abreast Sydney. Once again, we were thrilled to have 11 teams made up of multi-disciplinary breast cancer services staff from various hospitals join in the races. It gave the medical professionals a chance to flex their muscles and test their paddling prowess against each other, while also providing them with a first-hand experience of the magic that is part of being involved with Dragons Abreast. Those breast

care professionals are awesome, not just in how they care for us, but in the water too!

For details of our groups, visit our website www.dragonsabreast.com.au or telephone 1300 889 566 to talk to a representative in your State or Territory.

*Michelle Hanton,
National Co-ordinator,
Dragons Abreast Australia,
T: 0418 898 082 or
[nationalcoordinator@
dragonsabreast.com.au](mailto:nationalcoordinator@dragonsabreast.com.au)*

Thank you for supporting BCNA

We appreciate the financial support given to us in so many ways by individuals, clubs, organisations and companies around Australia. We would especially like to acknowledge the help of the following outstanding supporters between October 2005 and January 2006.

- Women's International Motorcycle Association
- Reece Australia
- Manildra Flour Mills
- Harriet Moore, Prue Troedel and the Pink Ladies Golf Day
- East Malvern Tennis Club
- Queenwood School for Girls, Mosman, NSW
- Melbourne Business Women's Luncheon
- Dunlop Flooring
- Cabaret fundraising committee of SA BCNA
- Yates
- Ladies Committee Kingston Heath Golf Club
- Kingswood Golf Club
- Blue Illusion Australia
- Treble AAA group of companies
- Paul Clarke Creative
- Paul Gleeson & Associates
- Salmat Document Management Golf Day
- Lyndsay Takacs, Sandra Girardin and Frances Cook's Pink Lunch at Sorrento Community Centre
- Aviva staff
- Lions Clubs International District 201Q2
- Port Macquarie-Hastings Council Golf Day
- Shell Refining Geelong Area North Maintenance Team
- Shell Refining Geelong

Christmas donations

Clifton Coney Group, Australian Olympic Committee and WHK Services

Birthday celebrations

Happy birthday to Sylvia Joachim, Sharon Jones and Bruce Humphries who celebrated their respective 90th, 40th and 60th birthdays and nominated that we receive money in lieu of gifts.



Letter to the Editor

We often receive letters about issues surrounding different treatments, and about side effects and consequences of treatments further down the track. Glenys raises an issue related to Zoladex, a hormonal treatment sometimes given to hormone receptor positive pre-menopausal women that involves implants given by injection.

Having been diagnosed with breast cancer on Christmas Eve 2003, surgery (mastectomy) followed on 2 January 2004. My chemotherapy treatment continued until June 2004, when I was prescribed Tamoxifen for five years and Zoladex for two years.

I need to make others aware of something about the Zoladex implants. Had I not met a nurse who is involved with the Royal Adelaide Hospital's Oncology

Unit, I would never know – and others may never know unless advised.

At hospitals in the public system, a local anaesthetic is automatically given before a Zoladex implant. I have been receiving implants for the past 12 months at least, oblivious to this practice.

I have now been to my GP who was happy to treat me with a local anaesthetic. Previously he had not offered this and had been giving me my Zoladex implants (Painful? Yes!) without any local anaesthetic.

It is important that people know that they don't have to endure implants without a local anaesthetic. Please make this known!

Thank you for being there!

*Glenys Videon,
South Australia*

Editor: We followed up this query with members of BCNA's Medical and Scientific Reference Committee. It seems that some practitioners offer the local anaesthetic as a matter of course, but others do not. There are differing views about the discomfort associated with the Zoladex needle. It is quite a large needle and apparently very sharp. The local anaesthetic is also provided by needle, but patches may also be an option. Women should feel free to ask for a local anaesthetic before receiving Zoladex if that is their preference.



Upcoming Events

10–11 March: Eighth National Breast Care Nurses Conference, Sydney (March 9 Pre-conference Communication and Sexuality Issues workshop). Contact: info@bcnc2006.com; www.bcnc2006.com or Breast Cancer Interest Group, PO Box A2, Arncliffe, NSW 2205

1–8 April: Amazon Heart in New Zealand – 12 breast cancer survivors will walk and cycle through the South Island's spectacular high country. Contact: www.amazonheartexpedition.org

18 April – 14 May: Bakers Delight Pink Bun promotion. All bakeries nationally.



Seeking shelter

BCNA welcomes the following new Member Groups:

- Mallee Support Group Network, SA
- Berwick Bosom Buddies, Victoria
- Booby Bunch, Mt Gambier, SA

This takes our Member Groups to 151.

You're not yet on our mailing list?

Telephone (03) 9805 2500 or 1800 500 258 (freecall), or fax (03) 9805 2599, email 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: () Email:

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

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

Welcoming two new State Representatives for 2006

We have two State Representatives in each State and Territory. Our State Reps have a two-year term, with the option to renominate at the end of their term. In 2006, we are delighted to welcome two new State Reps to our ranks.

Luisa Giuffre – Western Australia

Luisa is our youngest State Rep. She was a 30-year-old mother of two boys when she discovered a lump in her right breast in 1999. Luisa undertook BCNA's Advocacy and Science Training Program in 2004 and has been a member of our Young Women's Working Party. Drawing on her experiences, Luisa has maintained a strong interest in issues for young women with breast cancer and ran a support group for young women with the Breast Cancer Foundation of WA. Although she has finished in this role, she remains an active member of the Foundation.

Pat Hancock – Northern Territory

Pat lives in Darwin and shares State Rep responsibility for the NT with **Suellen Williams** in Alice Springs. In her professional capacity, Pat works for the NT Parliament, supporting parliamentary committees. She was diagnosed with breast cancer in 2001, has been active in NT breast cancer advocacy for some years and is a keen Dragon Boater. Pat was a member of the 2003 Advocacy and Science Training Group.



Luisa and Pat join the State Reps team

Our State Representatives, who are all breast cancer survivors, keep an ear to the ground for news, distribute information and are a local contact for women with specific enquiries or issues.

ACT

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Thanks for your feedback

We've had lots of responses to our survey of randomly selected readers in the last mailout of *The Beacon*. We are working through the comments and will report back next issue.



the BEACON

The Beacon is the magazine of Breast Cancer Network Australia.

Editor: Lyn Swinburne
Layout: Substitution

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