Yes to Herceptin, but …

Beacon readers will know that getting access to the drug Herceptin for early breast cancer has been a major battle for BCNA. Since May 2005, when favourable clinical trial findings were announced in the US, we have worked hard on many fronts to make sure that this is funded as a treatment option for Australian women.

It was with great excitement that we were informed on 14 July that the Pharmaceutical Benefits Advisory Committee (PBAC) had made its decision, with a positive recommendation to the government to fund Herceptin for women with HER2 positive early breast cancer.

We hoped that women would have almost immediate access, but it seems there are still some sticking points which need ironing out. You can read about the issues on page 7.

In the meantime, BCNA is committed to speeding up the process. We hosted a round-table meeting in August with all the key stakeholders involved, including the PBAC, the Department of Health and Ageing, relevant medical groups and researchers, the National Breast Cancer Centre, the Cancer Council Australia, and the pharmaceutical company involved, Roche. The purpose of the meeting was to sort out the glitches and move forward.

We were delighted that all these groups accepted our invitation to attend the meeting in Melbourne. It was an important opportunity to receive a progress update and to engage in discussion about the best way forward. The meeting provided an opportunity for BCNA to raise the stories and experiences that women have shared with us over the last year as they have wrestled with the difficulties of accessing this expensive drug. It was a productive meeting and we commend all the attendees for committing their time to this important issue. We also thank the women for sharing their stories with us and hope we will soon see a resolution to this issue.

Our final step will be to make sure Federal Cabinet also moves swiftly. Our members and all those Australian women with early breast cancer who are looking to incorporate Herceptin in their treatment cannot wait indefinitely!

Lyn Swinburne
Chief Executive Officer

STOP PRESS: Herceptin funded from 1 October

On top of the world: 11 breast cancer survivors on the summit of Mt Hope during a one-week Amazon Heart hike through the Southern Alps of New Zealand.

This Beacon’s Inside Story supplement about secondary breast cancer has more on one walker’s journey. If you would like to receive The Inside Story please fill in and return the form on page 13.

Do you have a strong family history of breast cancer?

Four Corners recently screened ‘The Price of Life’, a program about a young woman who opted for surgery because of her high risk of breast cancer. After the program screened Gerda Evans, one of BCNA’s Victorian State Representatives and our Australian representative on the Steering Committee for the Cancer Family Registries meetings, was a guest panellist on an online discussion forum.

Are you a member of a high-risk family? Do you carry the mutation? Have you considered genetic testing? Have you not been diagnosed with breast cancer but are concerned about your risk?

We plan to focus on family breast cancer in the Autumn issue of The Beacon (March 2007). We would love to hear your stories of family breast cancer for inclusion in The Beacon or on our website. Stories (up to 500 words) may be mailed or emailed until 7 December. Please send a photo with your story.
In response to this often asked question we have outlined the three key national breast cancer organisations.

Breast Cancer Network Australia

BCNA is the peak national body representing Australians personally affected by breast cancer. As you know, BCNA is represented by our Pink Lady logo. For us the logo says it all. Our work focuses on the women who have been diagnosed with breast cancer. Women are at the centre of our work—we produce information for women with breast cancer, we are driven by women who have themselves experienced breast cancer. We draw on real people and their experiences to influence key decision-makers about treatment, care and services for women affected by breast cancer. Our mission is to inform, empower, link together, and represent women affected by breast cancer. BCNA represents more than 18,000 members and more than 160 member groups across Australia. We run a number of programs for women and hold events to highlight issues. BCNA is based in Melbourne. Our Chief Executive Officer is Lyn Swinburne and our Chairperson is Patricia Edgar. Both are breast cancer survivors. www.bcna.org.au

National Breast Cancer Centre

NBCC is funded by the Federal Government. NBCC is responsible for promoting the early detection of breast cancer. It also has an important role in making sure that progress made through research is passed on to doctors in a way that ensures that women across Australia get the best possible care. NBCC produces clinical guidelines and other resources for doctors. It also produces consumer guidelines so that women with breast cancer have good treatment information available. Its Guide for Women with Early Breast Cancer is included with every copy of BCNA’s My Journey Kit. The From the Source newsletter included in each issue of The Beacon is produced by NBCC to keep you informed about its work. NBCC is based in Sydney. Dr Helen Zorbas is the Director and Dr Megan Kearney is the Acting Chairperson. www.nbcc.org.au

National Breast Cancer Foundation

NBCF raises money nationally for breast cancer research. Funds raised are used to support a range of research. While some research looks for hints to cure or prevent breast cancer, other research funded by NBCF considers better detection of breast cancer or further treatment options for breast cancer. NBCF draws on the well-known Pink Ribbon for its logo. The Pink Ribbon is an international symbol for breast cancer and is also used by other organisations—such as the Cancer Councils—when they promote breast cancer issues. Each year NBCF presents a national research update to better inform the community of progress made. BCNA representatives from around the country attend this session. NBCF is based in Sydney. Sue Murray is its General Manager and Ros Kelly its Chairperson. www.nbcf.org.au

BCNA is proud to work closely with both the National Breast Cancer Foundation and the National Breast Cancer Centre.

Queen’s Birthday honour

We were thrilled to see Veronica Macaulay-Cross recognised in the Queen’s Birthday honour roll. Veronica was awarded the Medal of the Order of Australia (OAM) for ‘service to the community as an advocate for women with advanced breast cancer and for services to education’. Veronica has been one of our Queensland State Representatives since 2001 and is a long-standing member of our Advanced Breast Cancer Working Party. She is also an outstanding Consumer Representative for BCNA and an absolute inspiration! Well done Veronica. Your honour is well-deserved.

‘As I grow to understand life less and less, I learn to love it more and more.’

Jules Renard
BCNA has been working with the National Breast Cancer Foundation (NBCF) and National Breast Cancer Centre (NBCC) for many years. By working in partnership we have been successful in contributing to improvements in the health care system and therefore outcomes for women.

Maryanne Maher and Rosetta Manaszewicz share their experiences as BCNA’s Seat at the Table Consumer Representatives working with the NBCF and NBCC.

Maryanne Maher

As a breast cancer survivor and trained lawyer with many years of business management experience, Maryanne wanted to contribute all of her skills to ensure that other young women’s experiences led to a better breast cancer journey than she had experienced during the mid-1990s.

NBCF is the national fundraising body for breast cancer research. Its Research Advisory Committee (RAC) consists of members of the medical and scientific community, clinicians and policy advisors—and now three BCNA Consumer Reps who, in accordance with established guidelines, review, assess and make recommendations to the NBCF for awarding research grants.

Maryanne explains: ‘I didn’t realise what I was getting myself into at the time. I received several packages in the mail, each containing about 20 Postdoctoral Training Fellowship applications and 20 Postgraduate Research Scholarship applications—each one approximately 25 pages. It took me two solid weekends to read through them and then assess them according to the specific scaled criteria. We then all met in person and spent half a day discussing the applications, contributing our comments and ultimately deciding on the few successful applications.’

Given the potentially daunting task, Maryanne realised the value of her involvement. ‘At first I was concerned that I would not be able to assess the applications as well as the others because I was the only non-scientific member of the RAC. But I soon realised that my contribution was not medical—it was practical. I could use knowledge gained over the years of listening to other women’s experiences and discussing their needs with them. In fact I had a lot to contribute’.

Maryanne is satisfied with her role: ‘It brings me a great deal of extra work, but I feel I am making a significant contribution’.

Rosetta Manaszewicz

We recently received a request from the NBCC for a Consumer Representative to participate in the review of reports and research it had compiled on the way that women seek information about breast cancer. Jane Salisbury, NBCC’s Manager of Public Affairs, explained that the Consumer Representative’s principal role was to review its report to assist NBCC to reach women newly diagnosed with breast cancer more effectively and guide NBCC’s future strategies in this area.

BCNA’s appointed Consumer Representative Rosetta Manaszewicz remarked: ‘A document reviewing reports and research on the topic was posted to participants before the meeting with the terms of reference for the project. NBCC was extremely helpful and organised the flights and made other arrangements from its end.’

When Rosetta attended the first meeting, she found: ‘Since I was the only consumer, it was important this perspective play a role in the discussions. I made several recommendations. I thought NBCC could analyse its online survey and potentially integrate the findings into the existing research which could lead to a possible re-design of part of the website. I also stressed the importance of tailoring information to the individual and was also able to suggest other published research relevant to the project.’

Rosetta said that she felt she was able to contribute as a representative of women with breast cancer and also find out more about how the NBCC works. She learnt more about ‘the rigorous processes involved in establishing guidelines and potential policies’.
Radiotherapy – ask about costs upfront

Women are paying out for radiotherapy, often unexpectedly. The high cost of radiotherapy for some women around Australia is ringing alarm bells in many quarters. There are a number of issues and concerns.

Public patients often find that when it is time for their radiotherapy treatment there is no public facility available nearby. They may be referred to a private radiotherapy clinic and face large costs. In some cases women were or had not been aware that it was a private service until they received their bill. We have heard stories of women receiving bills of several thousand dollars which they have to pay up-front—before they could claim back the Medicare rebate. Even after the Medicare rebate, women can be out-of-pocket by hundreds of dollars. This can cause great difficulties for many women—and is particularly difficult when they have not been anticipating the extra costs.

Some radiation oncology centres around Australia bulk-bill some or all of their clients. We encourage women to ask upfront about the costs involved in their radiotherapy and then, if possible, see if there is an equivalent quality service at a lower price. Alternatively women may be able to negotiate either a repayment plan or to be bulk-billed before treatment starts. The key is to discuss treatment costs BEFORE treatment begins so that there are no surprises when the bill arrives.

Women with private health insurance can also face considerable costs when they start radiotherapy. Radiotherapy services are generally delivered as ‘outpatient services’ and attract different private health cover rebates to ‘inpatient services’. It is important for private patients to be aware that under current arrangements most women will not get any money back through private health insurance, although they will receive the Medicare rebate.

The Federal Government has raised this issue recently with the Private Health Insurance Ombudsman but this situation is unlikely to change in the near future. It is important to ask direct questions about how much your radiotherapy services will cost and how much will be rebated. You might consider asking your doctors and your health fund about ways to reduce these costs.

State by State

Our BCNA State Representatives investigated costs for radiation oncology services around the country and this is what they found:

- At the Canberra Hospital, all patients are bulk-billed but it has a limited facility and women sometimes have to travel elsewhere to receive treatment within the recommended period. If they have to go elsewhere, they may not be bulk-billed.
- The only radiation oncology service in Wagga, NSW, is private and therefore people are not automatically bulk-billed. However, if a person is experiencing financial difficulties they may be able to negotiate with the hospital to be bulk-billed. Generally out-of-pocket costs are around $400 but could be as high as $1,400.
- At Sir Charles Gairdner Hospital in Perth, radiotherapy services are bulk-billed and public patients don’t have to meet any costs. At the Royal Perth Hospital, radiotherapy services are provided through the privately run Perth Radiation Oncology Clinic. Medicare covers most of the costs of the treatment, but patients can incur out-of-pocket expenses, varying from $750 to $1,500 depending on treatment.
- In Tasmania, there are radiation oncology services at Launceston and Hobart. All radiation oncology patients at the Royal Hobart Hospital are bulk-billed. Some patients at the Launceston General Hospital are bulk-billed.
- In Victoria, there is a wide range of cost arrangements. Some public hospitals with no access to public radiotherapy services refer all patients to a private clinic where they face out-of-pocket costs of up to $1,200 unless they are pensioners. Most of the larger metropolitan hospitals bulk-bill for radiotherapy services.
- One woman told us that while she had received most of her treatment in her local rural community she decided she couldn’t afford the private radiotherapy service that was recommended there. She chose instead to head to a large city-based public hospital for radiotherapy treatment that was bulk-billed.
- Throughout the Northern Territory, women are unable to access either private or public radiotherapy services and generally travel to Adelaide or another major city for treatment.

We have included these few examples to highlight how important it is to ask about costs and to show that it can be worthwhile negotiating about cost of treatment.

BCNA gratefully acknowledges our partnership with Bakers Delight.
Rosalie Brittliff was shocked to hear that waiting lists in her home town of Canberra meant that she would need to travel to receive radiotherapy after her initial breast cancer treatment.

Rosalie travelled to Wagga—three hours by car—to attend her daily radiotherapy sessions. Her husband travelled with her and they were pleased to stay at Lilier Lodge, a relatively new patient facility with 20 motel-style rooms. The cost of their accommodation was paid directly by the government-funded patient travel scheme, but Rosalie found the rest of her radiotherapy experience expensive. ‘This is one of the worst times in your life and having to travel for treatment makes it even harder. It’s also expensive being away from home.’

Rosalie had thought she would come home each weekend but found treatment and travel exhausting. ‘After two weeks I said that’s it. I’ll just stay till I’m finished. It took too much out of me.’

Rosalie found it hard being away from home—away from her own bed! Buying food and bits and pieces proved expensive and keeping contact with friends and family by mobile phone led to a sizeable phone bill. There was some travel assistance available, but $40 for a six-hour return trip didn’t even begin to compensate Rosalie for her travel costs. Rosalie’s radiotherapy treatment cost more than $5,000. After Medicare rebates she and her husband were more than $1,500 out-of-pocket.

The Inside Story strikes a chord

The response to the first issue of The Inside Story supplement to The Beacon has been positive, with women with secondary cancer and women with early breast cancer wanting to subscribe.

Fran wrote: ‘Congratulations on the idea of an extra “Beacon” for those of us who are battling secondary breast cancer. Congratulations and thank you to those who shared their stories in the fantastic first issue. Please keep up the good work’.

Lisa emailed: ‘I am 43 years old, having been first diagnosed in 1996, and then again in 2002 with advanced cancer in the liver. I found the article on central ports particularly useful as I am at the spot of making that decision. The Inside Story is a great inspiration in a dark time.’

Judy wrote: ‘I was especially moved by Di’s Story and particularly interested in the articles about BreaCan and “Life with a port”. I had a primary breast cancer in 2000. Since then a close friend has died of secondary breast cancer and I have other friends living with this disease. I asked for The Inside Story so I could keep up-to-date with developments and better understand and support my friends’.

It’s clearly time for the needs and concerns of women with secondary breast cancer to be heard. BCNA is committed to advocacy and change on a range of issues—on a personal level in the lives of individual women and on a systemic level in our hospitals, treatment centres and in our community.

We love receiving news and stories for The Beacon and The Inside Story and we welcome your feedback and ideas.
Townsville women turn out for forum

In August women with breast cancer from North Queensland travelled to Townsville to join locals for an afternoon forum with BCNA. Board member Raelene Boyle described her own breast cancer journey and entertained the group of approximately 50 women with stories, including that of her first meeting with BCNA CEO Lyn Swinburne. Raelene told how impressed she was with Lyn’s enthusiasm and the concept of speaking up for the women affected, which immediately convinced her to be part of our organisation.

The Townsville visit also gave BCNA staff, Lyn Swinburne, Julie Hassard and Kirsten Pilatti, and BCNA Queensland State Representative Veronica Macaulay-Cross the chance to talk with and listen to local women. Lyn says, ‘We were able to hear about the issues that are important to these women, as well as to let them know what we are doing for women across Australia.’

We heard about the enduring challenges of distance—women spoke of their experiences of travelling hundreds of kilometres a day for treatment over many weeks. They spoke of other difficulties such as lymphoedema, and their frustrations in dealing with authorities such as Centrelink and patient transport schemes.

Women wove the network over afternoon tea, sharing stories and making connections with one another—which is what BCNA is all about. We welcomed a new Member Group and gathered a few women interested in becoming BCNA Consumer Representatives.

We also benefited from a very productive meeting with some health care professionals at Townsville Hospital. We gained a greater insight into the unique issues and challenges facing these dedicated clinicians in treating and supporting women with breast cancer.

All in all it was a fabulous occasion for BCNA to connect with our women. At the time of writing, we are about to hold a forum in Canberra. Our final forum will be held in Perth in mid-November, with forums being planned for a number of other locations during 2007.

Encore: a journey forward

YWCA’s Encore program, which provides gentle exercise and support for women after breast cancer, is well known. Now Encore: a journey forward, a short film charting a woman’s emotional journey through breast cancer by Bec Lorrimer and Kate Gwynne, two Sydney filmmakers in association with YWCA NSW, is about to be released.

The film will be launched in Sydney in October and screened on the Encore website, www.encore.net.au.

Carolyn Altman, on whose story the film focuses, says ‘When you are first diagnosed with breast cancer everyone says, “I wish I could understand what you are going through, but I can’t”’. I did this short film in the hope that family and friends of newly diagnosed women will be able to understand. Encore helped me so much both in providing a support group of local women and giving me back my physical mobility and strength, that I wanted other women to understand the benefits of this program’.

The film combines realistic and abstract elements. The use of film, digital video, still photographs and mammogram scans evoke the difficult experiences that many women go through.
In our Winter 2005 Beacon we first reported on promising new trial results using Herceptin to help reduce the risk of recurrence for women with early breast cancer. Herceptin targets women with HER2 positive tumours—approximately 20% of all women diagnosed with breast cancer.

At a hefty $50,000–$80,000 for a year-long course of treatment, Herceptin is very expensive. Some women have decided that this is the best treatment option for them and have found the money to pay for treatment through various means. Still others have started paying for their treatments each three weeks, hoping that funding is near.

Securing the Pharmaceutical Benefits Scheme (PBS) subsidy for Herceptin remains a key goal for BCNA. We want to see as many viable treatment options as possible available and funded so that women, together with their medical team, can make the best possible decisions about their individual care. We are keen to see these decisions based on good evidence rather than on the cost of a particular treatment.

On 14 July the Pharmaceutical Benefits Advisory Committee (PBAC) issued its recommendation to list Herceptin on the Pharmaceutical Benefits Scheme.

Approval was recommended for ‘… treatment of patients with HER2 positive early stage breast cancer following surgery, for a maximum period of twelve months to be commenced concurrently with adjuvant chemotherapy’.

This was another great step forward but the fine print left a number of questions unanswered. In particular, we are still not clear about the implications of taking Herceptin concurrently with adjuvant chemotherapy. Data from the large international HERA trial showed a benefit for women taking Herceptin once their chemotherapy was finished.

In its recommendation the committee noted that Herceptin’s manufacturer Roche would need to make particular commitments for the PBS listing to go ahead.

These commitments included:
- immediately reporting any developments from trials which add to understanding the optimal dose and duration for treatment with Herceptin
- funding appropriate testing for HER2 status
- considering minimisation of wastage caused by the size of the Herceptin vial.

We are encouraging both Roche and the government to work quickly to finalise this longstanding issue.

We are encouraging both Roche and the government to work quickly to finalise this longstanding issue.

Good news in the PBAC recommendation is that tumour size will not influence whether or not a woman can have subsidised Herceptin. This became a concern when the earlier Therapeutic Goods Administration (TGA) approval included a tumour size limitation for women with no lymph node involvement.

There are many outstanding questions about Herceptin that will hopefully be resolved over time. Perhaps the most significant question is the ideal treatment period. While a very small study in Finland suggested that nine weeks of Herceptin produced positive results, the large international trials have been considering one and two years of treatment.

We understand there is a new French trial being established to consider the value of a six-month treatment time. The PBAC recommendations place requirements on Roche to provide future data about optimal treatment periods. We support this, agreeing that this is also key information for women making informed decisions about their treatment.

Through regular email updates we are able to keep interested BCNA members informed of developments with Herceptin as soon as they come through. We have also been posting regular updates on our website. If you would like to receive regular Herceptin email updates please call 1800 500 258 or email us with your email address.
We appreciate the financial support given to us by individuals, clubs, organisations and companies around Australia. Thanks to all who responded with donations following the last Beacon. We would especially like to acknowledge the recent help of these outstanding supporters and fundraising events:

- Heritage Finance Golf Day
- Melbourne Football Club
- Kitchen Aid mixers
- Aviva’s Guiding Star Committee
- Condamine community
- Point Gellibrand Rotary Club
- Halina and Garry Hatcher
- Medicare Greensborough
- Merovic Schrank
- Whipstick Quilters
- Sunshine Coast Turf Club
- St Catherine’s School, Toorak, Vic
- Girls Boarding House, Ballarat and Clarendon College

Celebrations

Congratulations to Tamar Simai, who celebrated her Bat Mitzvah, and happy birthday to Lyn Heffernan, Rosa Screpis and Pauline McCausland. Tamar, Lyn, Rosa and Pauline asked that money be donated to BCNA in lieu of gifts.

In memory

We remember James Addison, Martina Bailey, Helen Cunningham, Deborah Johnston, Glenda May Lowry, Cindy Kunde, Anna Mazzurco, Ann Pragnell, Kerrin Rennie and Mary Kathleen Terry and are grateful to be recipients of donations in their memory.

Sussan joins forces

We are delighted to announce a new partnership with the Sussan Group. With more than 220 stores nationally, the partnership will focus on promoting the My Journey Kit and raising money for BCNA.

The partnership has been kick started with $23,000 from the sale of an exclusive leather bag. In August, Lyn Swinburne spoke to Sussan store managers, who are all excited about the opportunities for our partnership and are keen to involve women in their local area. Keep an eye out in your local Sussan stores and on our website for the great in-store promotions.
My Story

Supported by faith, prayer and promises

We went home. What could I say? It was Thursday. I had a large family, was involved in community and church, and what did it mean? It was almost Christmas!

I was in hospital a month after a complete radical mastectomy. No-one even spoke of cancer! As I began to heal the surgeon did say, ‘You must get that arm working as soon as possible. It will be painful, but if you don’t it will adhere to the chest wall and you’ll never get it free.’ As I left the hospital he said, ‘you won’t need any deodorant under that arm. That will be a save!’ Then, ‘I don’t know much about what happens next but the staff at the Peter MacCallum hospital will tell you. I will make an appointment for you in the New Year.’

Only my husband’s love, my family, and my faith sustained me during those days of questions. How do I look at myself? How will my husband look at me? How can I relax to regain my strength? There was no one to share this strange experience with.

But it was summer, I was alive, and it was a sweet time to rejoice. We had always had a hammock in our backyard strung between two trees and during those early days of nothingness it became my resting place. To lie in a hammock is to completely relax. I called the hammock Faith. The two strong trees suspending me I called Prayer and Promises.

As the weeks passed my daughters decided it was time to experiment with prostheses so that I could go out and look balanced. Into a soft pocket we tried cotton wool, too soft. Next it was beans, too hard, rice, no, then we tried bird seed. The family laughed about me being caught in the rain and bursting into song or whistling!

Then it was Melbourne, for a month of ray treatment at Peter Mac. That was a new adventure. I still have the after-effects of the treatment. I was moved to see little children, weary mothers, youths and elderly people there. We shared compassion, patience and laughter, and the staff and doctors were wonderful.

At last, home. Prostheses were expensive and had to be replaced at times, but life was good and the months gave way to healing. Exactly 20 years later, almost to the day, I was in hospital for a second mastectomy. What a change to discover, even through the trauma, the help and care that was available through staff and surgeon in 1992.

Life is a beautiful gift. I have been blessed seeing my crab-apple tree in blossom again. Life has purpose and meaning. I pray with empathy, love and faith that I can encourage others on the way.

Nell Hodgson, Morwell, Victoria
Dragons Abreast

Dragons Abreast is made up of a variety of wonderful people from all across the nation. We hear so many incredible stories of what a life-changing experience being part of Dragons Abreast is for women post-breast cancer. However the story of the team in Albury/Wodonga—Brave Hearts—is really remarkable!

The group hails from north-east Victoria and went to extraordinary lengths to become part of Dragons Abreast Australia—they built their own dragon boat. The fact that they had limited carpentry skills did not stop this group. With the experts and teachers of the TAFE NSW, Riverina Institute, Albury Campus and volunteers alongside—they created a wonderful boat!

Breast cancer survivor Jodie Hart summed up the experience: ‘Building this boat has given the power back to participants, many of whom have felt powerless due to their breast cancer journey. It has pushed their close friendships through to lasting, more robust relationships. It has also allowed us to regain some of the innocent, carefree happiness that is often lost with a cancer diagnosis. It has marked the beginning of a wonderful, positive group for the whole community to embrace and be inspired by.’

One member, Robyn Daly, said that when she was first diagnosed with breast cancer, she couldn’t think ahead six months and now she is planning for the International Dragons Abreast regatta at Caloundra in 2007.

There is a lot more to Dragon Boating than racing other teams along a carefully measured course for the honour and glory of winning, accompanied by the huge adrenalin rush that comes with competition. It is also about teamwork, forming bonds with other paddlers and forging friendships along the way.

For those who have survived breast cancer treatment, and for those who have watched loved ones undergo the varying medical indignities that cancer involves, it is this side of the sport that is so important.

Thirteen members of Illawarra Dragons Abreast Club and 16 members of ACT Dragons Abreast visited Eden-Merimbula recently for the sole purpose of strengthening the bonds of friendship that have been growing since the Sapphire Water Dragons Abreast team began competing 18 months ago.

In another exciting development that reflects a growing awareness of the organisation, Dragons Abreast has been included as part of the ‘Watermarks—Adventure Sport & Play’ exhibition at the Australian National Maritime Museum in Darling Harbour.

The dragon spirit continues to move across the land and pave the way for those living with breast cancer to reach out to one another in a wonderfully fun, physical and positive way.

If you would like to find your nearest group, telephone 1300 889 566 to connect to a representative in your state.

Michelle Hanton
National Co-ordinator
Tel: (08) 8941 8923
0418 898 082
www.dragonsabreast.com.au

My Journey Kit reaches more than 16,000 women

Since we launched the My Journey Kit in May 2004 we have distributed more than 16,000 kits to women diagnosed with breast cancer. The positive feedback we receive confirms that the Kit is a unique and truly valuable resource for women, offering current, relevant and comprehensive information when they most need it.

One recipient recently wrote: ‘The My Journey Kit has become my best friend, at each stage of my journey I have found a personal story or a paragraph of information pertinent to my situation’.

We need your help to spread the word. If you know of a woman who has been diagnosed with breast cancer in the last 12 months who has not received a My Journey Kit she can order it any time through our automated ordering service on 1300 78 55 62.

Easy on the environment

You might have noticed that The Beacon is now mailed to you in a BioWrap envelope. The Beacon has grown too large to fit into a regular envelope. The clear BioWrap envelope is 100 per cent degradable plastic. This plastic wrap will break down totally into water, carbon dioxide and a small amount of biomass.
Bald in the Land of Big Hair

By Joni Rodgers

272 pages, paperback,

Joni Rodgers has a wicked sense of humour as she explains her true-life story of how she dealt with daily life after having a cancer diagnosis. Her unusual style of writing can be hard to follow at first but once you get started the book is hard to put down. Joni has a theatrical flair to her writing and she is a very flamboyant character.

One of the many insights in the book is when Joni gives examples of how people feel compelled to give free health advice and some of the wacky ideas they suggest, such as coffee enemas and Bolivian healing knee socks. I also enjoyed the way she wrote a satirical play about a doctor’s appointment, making the people come to life with her witty banter.

Joni shares her feelings on being bald in the land of big hair and how it had an overwhelming impact on her life and her self esteem. The true account of Joni’s sex life gives an honest if somewhat confronting overview of this time of her life. She talks about her faith, which was challenged during her treatment and how she becomes much more accepting by the end of her treatment. The chapter where she talks about platitudes that people offer is very funny. She gives some excellent examples of what people say and how insensitive and cold they can be without even knowing it.

I love the simplistic definition of cancer given by Joni’s, son who says, ‘Cancer is what happens when your cells decide to go funky.’ Joni describes cancer as being ‘Not what I am.’ She also writes, ‘It is not a gift or a curse — it is a profound learning experience.’ I couldn’t agree more with this statement.

I enjoyed reading an honest account of how Joni dealt with her life during and after cancer treatment, and the challenges she faced with everyday life and her immediate family and friends. She gave a vivid insight into the often roller coaster ride of having cancer and how life is never the same again. Two things became very important to her. They were surviving and healing. Joni chose to be enlightened by her experience, not embittered.

Reviewed by Ann Town, NSW

Book review

Seeking shelter

BCNA welcomes:

Member Groups

- ABC Girls—Advanced Breast Cancer Group, Newcastle, NSW
- Macarthur Cancer support Group, NSW
- Geelong Regional Activity Caring and Education (GRACE), Vic
- Policewomen’s Breast Cancer support Group, Vic
- Wollondilly Cancer support Group, NSW
- Metastatic Breast Cancer Group, Sydney, NSW
- The Hills Cancer support Group, SA
- Ex-RNSH [Royal North Shore Hospital] BC Lunch Group, NSW
- BC Mosman Support Group, NSW
- Positive Energy Breast Cancer Support Group, Daylesford, Vic
- Hervey Bay Breast Cancer Support Group, Qld
- Dragons Abreast Gold Coast, Qld

This takes our tally to 168, with 156 Members Groups and 12 Associate Member Groups. We now have more than 18,000 individual members.

Breast Cancer Network Australia

Profiling our Member Groups

Murray Bridge Breast Cancer Survivors’ Group

Murray Bridge is a large rural town of 17,000 people located about 80 kilometres east of Adelaide. It is situated on the River Murray in a region that attracts many visitors. Before European settlement the area was inhabited by the Ngarrindjeri people.

The Murray Bridge group formed in 1994 in response to a request from a local GP who saw a need for a breast cancer support group. Carla Vicary, the community development worker for women’s health, who was working at the Murray Mallee Community Health Service, contacted four breast cancer survivors. They were keen to be members of the new group.

A meeting was called and Sylvia Ballantyne, co-ordinator of a long-standing support group in Strathalbyn, was invited to talk about her experiences.

The group meets monthly in a coffee shop in Murray Bridge. The format of the meetings has changed over the years, ranging from health information sessions, guest speakers and informal discussion.

“We are a flexible group and generally review the progress of the group as we go. It is crucial that the needs of the women attending are met and they decide how that is to happen,” Carla says.

There are 14 women on the mailing list, but numbers fluctuate at meetings, which have a core group of about seven. It can be a challenge to keep a small group active, but the women who come describe the group as being ‘genuine, enthusiastic, with something in common, it’s like a family—that is what makes it different from other groups and clubs’.

There are four breast cancer support groups in the area: Murray Bridge, Pinnaroo, Strathalbyn and Mannum. Because of distance, isolation and a decreasing membership, the groups come together twice a year in June and November. These ‘regional lunches’ or ‘moveable feasts’ are an opportunity for survivors to share stories, give each other courage and sustenance, and generally provide support. Members look forward to these times together.

Living in a rural area has its challenges for breast cancer survivors. Members feel it is important to stay connected to a wider group, and local and state services. Pinnaroo held a Mini-Field of Women and all the area groups attended. Rosalie and Glenys from the Pinnaroo group attended the Field of Women—Live in 2005 at the MCG, and gave a personal and emotional account of their experience at our regional lunch gathering. We wept and laughed together, and felt we had been there.

The group participated in the national project ‘Strengthening Support for Women with Breast Cancer in Rural and Remote Regions’ through consultation and membership on the state steering committee. This action led to the training and implementation of breast care nurses in rural South Australia and an increased awareness in rural hospitals about the needs of women with breast cancer. This may have led to fewer women joining support groups but the groups are there if they would like to attend.

Australia’s Breast Cancer Day is celebrated—with guest speakers and a lunch at the local golf club or a barbeque and display in the local shopping centre, supported by Bakers Delight. Promotion for these events is in itself a community awareness process, drawing public attention to the fact that breast cancer is in everyone’s local community and affects many, many lives.

The Murray Valley Standard, our local newspaper, is supportive and always responsive to our requests for promotional articles on breast cancer awareness and education.
State Reps in action

BCNA’s voluntary State Representatives, 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
Anna Wellings Booth
T: (02) 6247 8470
wbfamily@homemail.com.au
Elspeth Humphries
T: (02) 6239 6344
humphries44@ozemail.com.au

NSW
Pam Bell
T: (02) 9955 9313
bellpc@bigpond.net.au
Megan James
T: (02) 9440 0373
megs3008@yahoo.com.au

New South Wales
Pam Bell
T: (02) 9955 9313
bellpc@bigpond.net.au
Megan James
T: (02) 9440 0373
megs3008@yahoo.com.au

Northern Territory
Pat Hancock
T: (08) 8948 1333
pathancock_is@hotmail.com
Suellen Williams
T: (08) 8952 9018
suellenwilliams@ozemail.com.au

Queensland
Veronica Macaulay-Cross
T: (07) 3269 8083
vonphil@bigpond.net.au
Lyn Moore
T: (07) 3822 5468
lyn.moore@bigpond.com

South Australia
Alexandrea Cannon
T: (08) 8416 9428
impian@acenet.net.au
Jan Davies
T: (08) 8388 4825
jandavies@adam.com.au

Western Australia
Ann Revell
T: 0403 020 531
bmanya@iinet.net.au
Luisa Giuffre
T: 0419 046 733
luisaa@bigpond.net.au

Tasmania
Shelley Sexton
T: (03) 6331 5841
shelley.sexton@bigpond.com
Karen Forster
T: (03) 6273 4422
dforster@vtown.com.au

Victoria
Pamela Williams
T: (03) 9592 6352
pwil1957@yahoo.com.au
Gerda Evans
T: (03) 9805 2500
gerda@bigpond.net.au

Would you like to be on the mailing list for The Beacon or The Inside Story?
Telephone 1800 500 258 (freecall), email beacon@bcna.org.au or fill in this coupon and send it to: Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.

Yes, please send me:
☒ The Beacon, BCNA’s free quarterly magazine
☒ The Inside Story, a four-page supplement about secondary breast cancer. It includes stories and information about resources, services and issues for women living with secondary breast cancer. It is mailed with The Beacon to those who nominate to receive it.

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

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

State: .................................. Postcode: ................ Phone: (     ) ........................................................

Email: .........................................................................................................................................................................................................................................................................

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

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

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

‘I get up, I fall down, meanwhile I keep dancing.’
– Hillel
Letters to the Editor

Reconstruction dilemma
Robyn wrote about the implications for reconstruction with a pacemaker:

I am writing in the hope that my experience will help other women in a similar situation. I am a breast cancer survivor of three years who has a pacemaker that was on the same side as my mastectomy (left). On being told I would need radiation after chemotherapy and surgery, and that the pacemaker would have to be relocated, I had no time to research my reconstruction options and no idea the choice I made would impact on this. Time was of the essence, so I was told. My cardiologist found a surgeon, at the same hospital where I was having radiation, who would relocate the pacemaker. The morning of surgery the doctor and I discussed the new location. I decided to have the leads extended and tunnelled down to a site on the same side just below the ribs.

If I chose the righthand side I was told I would have to have another set of leads into the heart, which made four altogether in the aorta, and I would need to be on Warfarin for the rest of my life. I was also worried if cancer showed up on the right side, then life. I was also worried if cancer might be on Warfarin for the rest of my life. I was also worried if cancer showed up on the right side, then life. I was also worried if cancer showed up on the right side then life.

Since then I have been told of a surgeon in Sydney who removes old leads to reduce congestion in the aorta and eliminate the need for Warfarin.

I know doctors specialise in their own areas and I am not blaming anyone for my predicament, so it is up to us to share what knowledge we can and experiences we have. If you want a reconstruction there are things to consider when you have a pacemaker.

I am 54 and stuck with a prosthesis until the leads need replacing and then, hopefully, if I still want reconstruction, I will have a choice.

I am just so relieved to be alive with the chance to grow old with my family and friends.

Robyn Hodder, Coutts Crossing, NSW

We asked two surgeon members of our Medical and Scientific Reference Group for their opinions to assist in responding. Here’s a summary of what they said:

This story highlights an uncommon problem with women with pacemakers who require radiotherapy. It is correct that if the pacemaker is on the side to receive radiotherapy it needs to be placed elsewhere. This is most simply achieved by tunnelling the wires further away from the front of the chest. Even in this situation the pacemaker function has to be monitored during therapy, as the radiation can affect the workings of the electronics.

The example also shows the complexities that can be encountered when planning mastectomy with immediate breast reconstruction. It requires a multidisciplinary team approach where members of the surgical and oncology team discuss planned treatments and their impact on reconstruction before surgery is undertaken. It is also a good reminder that it is generally not necessary to rush into treatment. Taking a little time to get the right advice, perhaps a second opinion, can lead to greater piece of mind and more informed treatment choices.

An iPod, pedicure and other treats
Jenny wrote, in response to our ‘Who helped you through’ stories in the last Beacon:

When the Autumn issue of The Beacon came out, I was in hospital having a mastectomy and breast reconstruction. I had wonderful support from family and friends and intended to write to you of my experiences, but in those first few weeks just didn’t have the energy. So I was interested to see what other people wrote about people helping them through, and would now like to add a few ideas.

Before I went into hospital, my niece came shopping with me to buy an iPod on which she then recorded my favourite music. A great alternative to a radio or television when recovering.

A friend came to the hospital on the day I left to help my husband pack up and carry home all the flowers. She brought over lunch, arranged flowers, went home and returned later with dinner, which was a simple meal suitable for the microwave.

An interstate friend posted a large box of specialty biscuits, nuts and brownies, which was great to offer visitors in those first few weeks.

My first outing, other than the doctors, was another thoughtful gift from a friend—a pedicure. It was so good to be out in the world again, especially doing something like a beauty treatment.

While I was in hospital, my husband sent a daily email to friends and family in my email address book, updating them on my progress, and then in the evening brought in their responses, which was wonderful for my morale.

I hope some of these suggestions might be helpful to others.

Jenny Wantoch-Smith, NSW
We don’t usually publish poetry in The Beacon, but we do add poems to our website. We have included this one because it gave us a laugh and covers a topic lots of women write to us about and struggle with. Read on …

They could hire me out for hauntings,
I give people quite a scare,
I’m missing bits I used to have,
And now I have no hair.

I have no brows or lashes,
I got a Brazilian for free,
I throw up almost daily,
It’s not from booze but tea.

Let’s not forget the trauma and pain that cancer patients are facing, and while we offer support and encouragement that the future will most likely hold good things, let’s recognise that they have the right at times to be angry, to be fearful and to be depressed. The expectation that sufferers should be brave and positive at all times is a heavy burden to place on individual shoulders. Let’s return to expectations that are more realistic and much kinder.

Breast cancer is not good for you. There are positives that can come from the experience but if I was asked the question, ‘Are you glad you’ve had breast cancer?’ the answer would be a resounding ‘No!’ Let’s offer encouragement and support but allow room for sufferers to voice their deeper fears and pain without feeling they have failed to reach the super-human standards that have emerged lately as the ideal.

Nedra Orme, NSW

Ode to Chemo

Mary Brunton

It hardly seems very fair,
That I’m in this awful mess,
I used to go out on the town,
And I always looked my best.

I often used to curse my bra,
And let my breasts hang free,
Now I take them off at night,
But that’s something no one sees.

We went to town to buy a wig,
Now hubby calls me Cindy,
God only knows how I’ll keep it on
If it blows and gets quite windy.

They said I’d get hot flushes,
It’s Tamoxifen for me,
I said ‘You must be kidding,
I’m only 43!’

I know I should be grateful,
Believe me I truly am,
But I wish that I could have one more night,
To dress up and look glam.

I’m very lucky to be loved a lot,
By Ray and family,
If I didn’t know they cared so much,
I’m afraid I’d cease to be.

So keep a sense of humour,
When life deals you a blow,
It’s mostly through life’s challenges,
We have the chance to grow.

Mary Brunton, Vic

Acknowledging drama

Nedra wrote after seeing the Australian movie Look Both Ways. The movie has been described by several reviewers as a wry comedy. Look Both Ways centres on a character, played by William McInnes, who is suffering from testicular cancer. ‘What’s amusing about cancer?’ she asks.

It is 18 years since I lay in a hospital bed recovering from the pain of a mastectomy, trying to come to terms with the fact that I was suffering from a life-threatening disease, trying to cope with the loss of my breast, and trying to be stoic for my husband, family and friends. Into the room came the partner of one of my sons who took one look at my ashen face and my dressings, burst into tears and said, ‘Oh Nedra, I’m so sorry’. We wept together. For me it was such a relief to be given permission to give way to my fears, my anger and my pain.

Gill Walker and her team are raising BCNA’s profile in NT! Gill races a Pink HQ Holden on the Hidden Valley Circuit.
Upcoming Events

23 September: ‘Surviving Cancer in Rural and Regional Australia’ Satellite Symposium, 9am to 12.30pm. A community forum for people with cancer, their families and their carers. To be held in the John Lowenthal Auditorium, Westmead Hospital, Sydney, and broadcast by Sky Channel to 59 sites across Australia from Broome to Hobart.

Contact Cancer Council 13 11 20 for information about the venue nearest you.

27–28 September in Broome, 2–3 October in Derby: Two-day Indigenous Breast Cancer Forums from 10am to 3pm (lunch provided) by Breast Cancer Foundation of WA. Day 1 is for breast cancer survivors to share experiences and develop support networks. Day 2 is open to all community members and Aboriginal health workers to learn about breast cancer and how to better support those living with the disease.

Contact: Nikki Thompson, (08) 9324 3703, nikki@breastcancer.org.au, RSVP 25 September.

29 September – 1 October: The Port Douglas Primer: Practical Updates in Breast Cancer Diagnosis and Management, an Australasian Society for Breast Disease Meeting, Port Douglas, Queensland.

Contact: (07) 3847 1946 or info@asbd.org.au; www.asbd.org.au.

4 October: Ladies Day during the 52nd annual Tisselaar Tulip Festival, 10am to 5pm, 357 Monbulk Road, Silvan Vic (Melways Map 123 B5). Cost: $14.50 Adults, $12 concession, $9.50 groups of 10 or more (bookings essential). Part proceeds to BCNA. The Festival runs from 14 September – 11 October.

Contact: (03) 9737 7777 or 1300 428 527.

4 October: NT Government House lunch for breast cancer survivors. Preference given to women who have not previously participated. Register your interest to receive an invitation.

Contact: Penny Lasette, (08) 8981 9625 or sadgrove@d130.aone.net.au

13 October: Business and Professional Women’s Association (NT) Sunset Cocktail Party for breast cancer, 6-8pm, La Beach, Cullen Bay, Darwin.

Contact: Sharyn Innes, 0400 626 065.

13–23 October: Mini-Fields of Women

Mini-Fields held around Australia. See the insert in this issue of The Beacon for your nearest location or visit BCNA’s website www.bcna.org.au.


Contact: (03) 5967 1730; info@gawler.org; www.gawler.org.

22 October: Annual ecumenical service of reflection and hope for all who are affected by breast cancer, noon, St George’s Cathedral, Perth. Everyone is welcome.

Contact: Josephine@perthcathedral.org.

Throughout October: ‘encore—A Journey Forward’ a short film, showing at The ArtHouse Hotel, 275 Pitt St, Sydney (Monday – Friday 11am to midnight, Saturday 5pm to 6am) No entry charge. Regional NSW screenings to follow.


23 October: Bosom Buddies Alice Springs are entered in the 5km walk, 2006 Masters Games.

Contact Liz on (08) 8952 6966 or Lesley by email reilly5@octa4.net.au.

1 November: BCNA Members’ Forum, Perth.

Contact: 1800 500 258.

3 December: Sussan Women’s Fun Run 2006, Melbourne.

Contact: (03) 9596 2340; info@supersprint.com.au

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Field of Women 2006

Sunday 22 October, 1–4pm. The Field of Women will be planted on the WIN Stadium, Wollongong, NSW —12,000 silhouettes presented by the Illawarra Breast Cancer Support Group.

Contact: Gloria Swift: (02) 4295 8219 (work), 0414 422 463 or at domino@etherwave.com.au.