



The Beacon

Breast Cancer
Network Australia
newsletter



Things have changed in 27 years. Eleanor McDonald highlights this in her story on page 7.

On the hunt for long-term breast cancer survivors

Lately, some of us have felt surrounded by stories of women's cancers recurring.

While this does happen, many women will never be revisited by breast cancer after their initial diagnosis. They then go on to lead long lives uninterrupted by any return of the condition.

In this issue of *The Beacon*, we are including the story of Eleanor, who was diagnosed 27 years ago.

We know there are many other

women who are long-term survivors and we'd like to hear from you.

Let's see if there are any women alive 30 or even 40 years after diagnosis.

This does not in any way ignore those women with recurrences and advanced disease, but we also need the inspiration of women many years down the track.

We welcome all your stories!

—Lyn Swinburne, Editor

Breast
Cancer
Network
Australia



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Policy Unit to promote consumer interests

To ensure BCNA is at the forefront of policy development within government and the health sector, we have established a Policy Unit to provide advice and co-ordination across a range of areas of interest to women.

The Unit is headed by Sue Timbs, a breast cancer survivor with a strong legal background. Two discussion papers have been developed.

Gene patenting: Breast cancer is something of a test case on the patenting of genes. BCNA is arguing that women at high risk of familial cancer should have access to quality gene testing and counselling support, and that patent laws should be revised to prevent gene patenting.

Prostheses: We have long recognised the need for improved breast prosthesis services, particularly to address the variations in



BCNA Policy Unit head, Sue Timbs

entitlements between states. The discussion paper will help us lobby for better services and support for women who have had mastectomies.

The Policy Unit is also examining whether women with early breast cancer are able to access appropriate travel, life, trauma and income insurance at a reasonable cost.

If you have had a problem with insurance, we need to hear from you.

For a copy of either paper or to tell us about your insurance problem, phone 1800 500 258 or e-mail stimbs@bcna.org.au

State Reports



TASMANIA

Plans are under way for the major *Field of Women* in Hobart on October 26 and we would love to hear from support groups, service clubs or individuals interested in holding a *Mini-Field* in the lead up to the major field. Contact Joan or Karen with inquiries and/or application forms.

St Luke's Private Hospital in Launceston has appointed a breast cancer nurse and a community-based breast care nurse position has been advertised for the southern region. These appointments are a direct result of the Strengthening Support Project.

Tasmanian Breast Cancer Networkers welcome these appointments and look forward to working with the nurses.

The Devonport Breast Cancer and Lymphoedema Support Group meets on the last Thursday of each month at the Devonport Community Health Centre from 2pm. Phone Jenny Littler on (03) 6429 3207.

Contact: Joan Williams (03) 6424 5886 or jwilliams9@vtown.com.au, or Karen Forster (03) 6273 4422 or dforster@vtown.com.au



SOUTH AUSTRALIA

In April, Shirley Paull became interim chairperson of Action on Breast Cancer SA, following the retirement of Liz Libregts.

The Young Women's Group, for women up to 45 years of age or thereabouts, who have had breast cancer or who are currently living with the disease, meets regularly on the first Tuesday evening of each month.

As the venue changes each meeting, phone Lyndal Outram after 7pm on (08) 8294 3057 for details or e-mail cloutram@senet.com.au

Many country groups, as well as one in Adelaide, have begun planning *Mini-Fields* and other events/displays to highlight the impact of breast cancer in their communities during October.

Contact: Sally Russell (08) 8223 7106 or salrus@senet.com.au, or Deb Martin (08) 8241 1804 or d.martin@senet.com.au



Welcome

BCNA would like to welcome Megan James as NSW's new State Representative. She will work closely with Pam Bell.



NEW SOUTH WALES

The NSW Government has allocated \$205 million to making improvements for people with cancer. The newly formed NSW Cancer Institute will allocate the funds to new initiatives over the next four years.

The money will fund projects in a range of areas including:

- expanding radiotherapy services;
- better co-ordination of patient care;
- making sure doctors are familiar with best practice cancer treatments;
- improving services for rural patients;
- public awareness programs and screening programs for early detection; and
- services to provide support to cancer patients and their families.

These reports are extracts of comprehensive quarterly reports written by our state representatives.

The complete reports can be found on our website, www.bcna.org.au

Our state representatives are always happy to hear from readers, or to promote activities within the state. Just give them a call!

The NSW Directory of Breast Cancer Treatment and Services is on-line! You can access it at www.bci.org.au/breastcancerdirectory/home.htm.

Contact: Pam Bell, (02) 9955 9313 or bellpc@bigpond.net.au, or Megan James 0418 454 953 or megan@ironladies.com



WESTERN AUSTRALIA

Recently a small but dedicated group met for an Action on Breast Cancer Think Tank (something we may look at holding on a regular basis). Some great ideas were bandied around and the result was a plan to follow.

Many of our members volunteered at the Relay for Life, doing anything from sizzling sausages to directing traffic and many jobs in between. The weekend was a huge success (despite atrocious weather) and much fun was had by all. Those involved should be congratulated on their outstanding efforts.

Our members are looking forward to the coming public speaking course being offered by BCNA and its morning tea at the Alexandra Library in Northbridge.

Contact: Carol Bishop (08) 9489 7312 or carol@cancerwa.asn.au, or Maria Waters (08) 9344 7362 or alma.waters@bigpond.com



QUEENSLAND

Ronwynne Moffitt has started 'Sisters after Stretch' at the Brisbane Wesley hospital/More Choices program. A chance for coffee, craft and chat, it is held on the fourth Tuesday of the month. For information phone (07) 3378 9919.

Lyn Moore recently spoke at the Riverbend Book & Coffee Shop, Bulimba, and to the Coorparoo and Caboolture support groups about BCNA and holding a *Mini-Field*.

Consumer representatives, Veronica Macaulay-Cross, Bev Cross and Lou Beresford, attended the Queensland Central Zone Committee of the Strengthening Support for Women with Breast Cancer Project.

Project officer, Deb Hill, is mapping existing services and a survey will be distributed to hospitals. Once the survey is completed, there will be consumer focus groups in Rockhampton, Nambour and Brisbane. You can phone Deb on (07) 3636 2284.

Veronica also attended a health forum held by Federal MP, Wayne Swan.

Contact: Veronica Macaulay-Cross (07) 3269 8083 or vonphil@bigpond.net.au, or Lyn Moore (07) 3822 5468 home or lyn.moore@bigpond.com



VICTORIA

Wonderful news! Victorian women with breast cancer, their family, friends and carers have a new service.

BreaCan provides information, support and referral and its drop-in centre is at Women's Health Victoria, 1st Floor, 123 Lonsdale Street, Melbourne.

It is staffed by trained volunteers, most of whom have experienced breast cancer, and is open between 10am and 2pm on Mondays, Wednesdays and Thursdays.

The centre will have information sessions, guest speakers, exercise classes and a resource library.

For more information, phone (03) 9664 9333, e-mail breacan@whv.org.au or visit www.whv.org.au/breacan.htm

Congratulations to Sue Smith and Jacqui Ward, the co-ordinators of the Warrior Women multi-media art project, on the launch of their CD and booklet at Parliament House, Melbourne, on May 20.

Contact: Gerda Evans (03) 9805 2500 or gerda@bigpond.net.au



NORTHERN TERRITORY

Penny LaSette continues as a consumer representative on the NBCC's Psychosocial Committee. Susan Tulley has again been involved with the Ralph Lauren Nursing Scholarship for Rural & Remote Nurses. Michelle Hanton has travelled to New Zealand, Sydney, Melbourne and Adelaide on Dragons Abreast business.

NT Breast Cancer Voice, with corporate and local business support, hosted the Surviving Survival workshop presented by NSW's Prof. Miles Little and his team. Thanks to Carol Carlton for bringing this workshop to Darwin.



Picturesque views of the Derwent River and Mount Wellington will be the dramatic backdrop for the 2003 Field of Women in Hobart.

2003 Field of Women and Mini-Fields

The 2003 *Field of Women* will be held at the Hobart Cenotaph in Tasmania on October 26.

The day will include a breast cancer forum at Hobart's Old Woolstore Hotel and the Silent Walk to the site for the launch of the *Field of Women*.

To complement the *Field of Women*, *Mini-fields* of 100 silhouettes will appear in capital cities and many communities around Australia in October. So far, confirmed *Mini-fields* for 2003 include:

Victoria – Brighton, Castlemaine, Emerald, Hamilton, Newborough,

Rosanna, San Remo, Torquay, Warrnambool.

Queensland – Alexandra Hills, Ayr, Caloundra, Laidley, Prosperine, Toowoomba East, Toowong, Yandina.

NSW – Goulburn, Keiraville, Wagga Wagga, Quaama, Merimbula.

SA – Grange, Kingston, Minlaton, Mt Gambier, Port Lincoln, Robe, Berri.

WA – Nedlands.

For more information about holding your own *Mini-Field*, phone Michelle Rule at the National Office on 1800 500 258 (toll free).

We held a session for health professionals at the Top End Division of GPs on the Friday evening and on the Saturday and were thrilled to have more than 60 participants.

Although this was a costly exercise and required a lot of time and effort from several of our members, we feel it was well worthwhile.

Planning is under way for our October activities and if any Territory readers would like to make suggestions, we would be delighted to hear from them.

Contact: Susan Tulley (08) 8927 3327 or tullynt@msn.com.au, or Michelle Hanton (08) 8941 8923 or hanton@ozemail.com.au



THE ACT

In February, 11 women from the ACT attended the Network's Science and Advocacy training in Melbourne which enthused and encouraged them to action.

One of the main issues in the ACT is the long wait for radiotherapy treatment, often outside the recommended time periods. There are

plans to pursue this issue as well as the need for another breast care nurse.

Eight women attended the public speaking training delivered by Sue Watson and Gil Paulsen and have been active ever since.

Anna Wellings Booth and Jan Skorich addressed the Zonta Club of Canberra. Anna also presented at the Office for the Status Of Women's conference 'Australian Women Speak' on behalf of BCNA.

Megan Dennis and Robyne Kellett spoke at the Launch of Weekender Clothes, while Elspeth Humphries spoke at the Bakers Delight meeting in Canberra.

There was a flash of pink during the Relay for Life survivors' lap and at the ACT Women and Girls' Fun Run.

We are planning a program for the ACT Masters' Competition in Canberra in November. Along with the dragon boat races, there will be a workshop, dinner and Parliamentary reception.

Contact: Anna Wellings Booth (02) 6247 8470 or wbfamily@ozemail.com.au, or Elspeth Humphries (02) 6239 6344 or humphries44@ozemail.com.au

What research has to say ...

Suggesting a link between memory loss and chemotherapy

Psychologists are beginning to verify what many breast cancer survivors have long suspected: chemotherapy can, in some cases, cause problems with memory and concentration.

Studies have found that 20-30% of women who undergo chemotherapy for breast cancer record lower than average scores in tests of mental function up to 10 years after completing chemotherapy.

Australian oncologist, Dr Kelly Phillips, who works in the Department of Haematology and Medical Oncology at the Peter MacCallum Cancer Centre in Melbourne, reviewed five published studies that looked into this subject in the February issue of the *American Journal of the National Cancer Institute*.

She paid particular attention to the methodological limitations of the studies.

The Peter MacCallum Centre is about to start a pilot study involving 30 women to ascertain whether the mental impairment is a real effect.

“My feeling is that it is a real effect. But the challenge will be determining what the risk factors are. It probably doesn't happen to all women, but we need to establish who's at more risk, how to prevent it and/or how to use interventions to improve memory,” Kelly said.

Is an alternative to Tamoxifen on the way?

A major trial has indicated that a real alternative to Tamoxifen may have been produced for the treatment of women with early breast cancer.

Arimidex (also known as Anastrozole) was tested against Tamoxifen in the ATAC Trial, which compared the results of 9300 post-menopausal early breast cancer women with oestrogen positive tumours.

The women were divided into three group:

- Arimidex;
- Tamoxifen; and
- a combination of the two.

On most accounts, Arimidex performed better than Tamoxifen, while the combination of the two drugs performed poorly in comparison.

The results show a 14% reduction in the risk of breast cancer recurrence for women on Arimidex compared to Tamoxifen.

It also showed a reduced risk of endometrial cancer, thrombosis, vaginal bleeding and discharge, and hotflashes.

However, Tamoxifen performed better with fractures and joint pain.

This new information may be useful for women being diagnosed over the coming years, but there is no evidence

Hormone therapy on option to chemotherapy?

Hormonal therapy may be an option to chemotherapy for early breast cancer in some pre-menopausal women, according to two studies published in the *Journal of Clinical Oncology*.

The hormone therapy Zoladex alone, or combined with Tamoxifen, was found to be effective for younger women with hormone-positive tumours.

WA surgical oncologist, Professor Christobel Saunders, estimates that about 1500 Australian women fall into this category each year.

that women already taking Tamoxifen will gain from switching to Arimidex.

The other consideration is that, while Arimidex is available in Australia, it is not yet on the Pharmaceutical Benefits List, so it is more expensive than Tamoxifen (approx. \$200 a month versus \$40).

BCNA believes it is important that alternatives are available, but also women need their doctors to present them with clear information that will help guide them to the correct choice for each individual.

Exercise, it's not what you do, but that you do it that's important

The media has recently reported on a German study which found that regular cycling appears to reduce the risk of developing breast cancer.

According to the study, three hours moderate intensity cycling each week cut the breast cancer risk by 34%.

But why single out cycling? Any

form of moderate, safe exercise is going to produce significant health benefits: physical activity elevates mood, reduces stress, assists weight loss and, when done socially, has mental health benefits, too.

Whether or not one form of exercise has a greater impact on reducing the

risk of breast cancer seems less important than the evidence that moderate, regular exercise reduces the risk of a range of health problems.

Don't feel you need to spend a fortune on a bike – a brisk walk will benefit your body, your heart, and your mind.

Second national conference for women with breast cancer

In October, it will be five years since the first national breast cancer conference for Australian women. As one of the 350 women at that first conference in 1998, I will never forget the energy and empowerment we felt as we came together in Canberra.

In fact, Breast Cancer Network Australia was formally launched immediately afterwards.

In the intervening years, much has been achieved, but more work needs to be done. With this in mind, BCNA is planning the second National Conference for Women with Breast Cancer for 2004.

It is time to consider the progress made during the past five years, to learn about the latest findings and identify the issues faced at present and in the future.

In March, the BCNA Board discussed the potential conference and agreed that it would have to be held in Canberra, Brisbane, Sydney



Canberra was the site of the first national conference for women with breast cancer and the *Field of Women*.

or Melbourne in order to attract significant national media exposure and minimise travel costs for those attending.

We have written to the Premiers of the relevant states asking for financial support, and this will help determine the conference venue.

Hopefully, we will have full details in the next issue of *The Beacon* (September), including an Expression of Interest form for you to complete.

—Lyn Swinburne

Training program for November

BCNA will hold its Advocacy and Science Training Program in Melbourne during November.

It has been designed to give women who want to be breast cancer advocates the knowledge, skills and confidence they require.

The three-day program includes lectures, interactive learning, group activities and practical sessions covering four major areas:

- consumer representation and advocacy;
- the science of breast cancer;
- the structure of the health system; and
- strategies for getting your message across, including working with the media and politicians.

The program is usually of interest to

women who have had a diagnosis of breast cancer and are committed to 'doing something' beyond the usual activities of a support group.

The program is free, but participants will have to cover the cost of travelling to Melbourne to attend. A small number of bursaries are available to women who live interstate and can demonstrate a financial need for assistance, so as to be able to attend.

BCNA members in Melbourne have offered to billet interstate and country participants.

Application forms are available on our website www.bcna.org.au under A Seat at the Table in the Projects section or phone our National Office on 1800 500 258.

Genetics workshop

BCNA is sponsoring an information morning and public workshop about genetics research and clinical trials at the Surfers Paradise Marriott Resort on September 20, as part of the Australasian Society for Breast Disease's conference.

The speakers will include bioethicist, Father Bill Uren, and medical oncologist, Dr Nicole McCarthy.

The cost will be \$7 (including light refreshments). For information and to register, phone 1800 500 258.



Mary Buchanan, Lyn Swinburne, Eileen Joffe, Gloria Freilich.

Our pink silhouettes travel the world

In March, I travelled to Zurich for a meeting of international breast cancer advocates.

On my way home, I got together in London with Mary Buchanan, Eileen Joffe and Gloria Freilich from Europa Donna, a 'sister' organisation that links women and provides breast cancer advocacy in 29 countries across Europe.

Mary is the current President of Europa Donna, Eileen is the UK President and Gloria is the founding President.

The great news is that a *Field of Women* will be held in London in 2004. Planning has begun and we will work with Mary, Eileen, Gloria and other Brits to ensure that their *Field of Women* is as powerful and successful as ours.

How wonderful to think that our pink silhouettes will be seen across the world!

—Lyn Swinburne

Anyone for therapy?

Who would have thought cancer

could be so *therapeutic!*

Multiple *therapies*

swung into action as

soon as the lump was

diagnosed.

Even before surgery, I had

begun the *vegie juice therapy*: broccoli (anti-oxidant) beetroot (blood cleanser) celery, carrot, apple.

Dietary therapy was clean, non-toxic food, home-made, fresh, organic; lots of fruit, vegies, soy, etc.

Then there was the medically prescribed *vitamin therapy*. Not just extra vitamins, but omega fatty acids, liver tonics, acidophilus.

After surgery, the big-time, wackadoo, hit-you-over-the-head therapy – *chemotherapy!*

After chemo comes *radiotherapy* – 30 daily zaps of radiation.

Then *hormone therapy* – five years of Tamoxifen every day.

Not to mention *aromatherapy*, *massage therapy* and *relaxation therapy*.

There's also *group therapy* for emotional support and information, and *family therapy* to deal with the disruptions, fears and conflicts that cancer stirs up.

I go in for yoga, meditation and homeopathy, as well – very *therapeutic* indeed.

Chats with friends are hugely *therapeutic*, as is the occasional movie or video, a wander through my garden, a walk with my dogs.

Loveliest of all is *feline therapy* – a tiny silky kitten who is alternately playful and sleepy, chases, jumps, purrs and plays my anxieties away.



– Judy Margolis, Victoria
(Diagnosed with breast cancer in 2000 and lymphoma in 2002)

Twenty-seven years on and still going strong

My name is Eleanor Margaret McDonald. I have been married for 45 years to a great bloke, Brian, and have four children aged from 31 to 41 years.

A long time ago, like a lot of you, I found a lump, a weeny, hard lump in my left breast. It frightened me, so I didn't check it again for a few days, hoping it would be gone when I did. It wasn't.

I told Brian who insisted I go to a doctor (he always did, even if I had just a sniffle).

A friend of ours was the matron at a small private hospital and she made arrangements for me to be admitted the next day to have a frozen section taken to determine whether the lump was benign. It wasn't.

My poor husband had to make the most devastating decision of his life. Should the surgeon perform a radical mastectomy while I was under sedation or wait for me to revive and discuss it?

Thinking I was going to die, he decided for me – I lost my left breast.

That was 27 years ago. I was 42 years old and he was right. I lived to rear our children, for which I thank God, and started to view life with renewed energy.



Eleanor McDonald, a 27-year breast cancer survivor with her husband, Brian.

I took up tennis and played twice a week (badly I might add) for more than 20 years, went white water rafting with our youngest daughter, rode a camel and an elephant, and learnt to snorkel in the Coral Sea.

All when I was an old girl!

I play golf now, badly of course.

Life has its compensations – we just have to learn to recognise them.

I wish all readers good health and happiness – courage to you all!

– Eleanor McDonald, Victoria

Wise words to ponder ...

I have sometimes been wildly, despairingly, acutely miserable and racked with sorrow, but through it all I still know quite certainly that just to be alive is a great thing.

– Agatha Christie

We must be willing to get rid of the life we've planned, so as to

have the life that is waiting for us. The old skin has to be shed before the new one can come.

– Joseph Campbell

Experience is not what happens to you, it is what you do with what happens to you.

– Aldous Huxley

New BCNA reference group

BCNA has established a Medical and Scientific Reference Group of breast cancer experts to provide us with another perspective in our work.

Its purpose is to:

- advise BCNA on medical and scientific issues, as requested;
- bring BCNA's attention to any issues affecting Australians with breast cancer; and
- act as a conduit between BCNA and relevant medical and scientific organisations, colleges and disciplines.

The group will not meet in person; instead members will offer expertise and advice via telephone and e-mail.

As well as playing a reactive role, this is an opportunity for the experts to bring issues of importance affecting consumers to our attention.

Some members have been invited due to their expertise and others because of the positions they hold.

We are fortunate to be able to call on the expertise, experience and networks of our reference group members, and thank them for their commitment to helping BCNA.



Raelene puts her journey in print

Raelene Boyle is a special member of BCNA. As well as being a Board member, she is totally committed to us and what we are trying to achieve.

She has attended and launched *Field Of Women* events in Canberra (1998), Brisbane (2001) and Sydney (2002) and will be there again in Hobart in October.

Raelene launched her book, *Raelene: Sometimes Beaten, Never Conquered*, in March. It covers her life as an athlete and, importantly, her journey with cancer. She talks extensively about the issues of women with breast cancer and the work of BCNA.

Her co-author, Garry Linnell, a master with words and story telling, is the editor of *The Bulletin*. His mother, Joyce Linnell, is a breast cancer survivor and Network member.

It's a great read!

THE BEACON

The Beacon is the newsletter of Breast Cancer Network Australia.

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

Layout: Substitution

Your comments and items for the next newsletter are welcome.

Send them to PO Box 4082, Auburn South, Victoria 3122.

MEMBER	EXPERTISE
A/Prof. Richard Bell (Vic.)	Medical oncology and clinical trials
A/Prof. Michael Bilous (NSW)	Pathology
Dr Fran Boyle (NSW)	Medical oncology
A/Prof. Phyllis Butow (NSW)	Psycho-social research
Prof. Stewart Dunn (NSW)	Communication in oncology
Prof. John Hopper (Vic.)	Epidemiology and familial cancer research
Dr Liz Kenny (Qld)	Radiation oncology
A/Prof. Judy Kirk (NSW)	Genetics
Prof. Neil Piller (SA)	Lymphoedema
Dr David Roder (SA)	Data collection and cancer registries
Prof. Christobel Saunders (WA)	Surgery and breast cancer research
Onella Stagoll (Vic.)	Breast cancer screening and health service delivery
Dr Jane Turner (Qld)	Psycho-social issues for women with breast cancer and their families
A/Prof. Kate White (WA)	Nursing
Organisations	
Prof. Alan Coates (NSW)	CEO, The Cancer Council Australia
John Collins (Vic.)	Chairman, Breast Section, Royal Australian College of Surgeons
Sue Murray (NSW)	General manager, National Breast Cancer Foundation

Letters to the Editor

I was diagnosed with breast cancer in 1997, and had a mastectomy, chemotherapy and radiotherapy.

I have read in *The Beacon* about the difficulties some ladies are having with special bras, swimwear and prostheses. I may be able to help some ladies with the bra problem.

I have found that a sports bra holds my prosthesis in place well; keeping in mind that I am a 12B fitting, so I am not sure that a larger bust size will benefit.

I have only had one mastectomy bra and have found that a sports bra holds firmer. My prosthesis has never fallen out and my life is quite active.

You can sometimes purchase a sports bra from as little as \$9.95 on special. They usually range from \$19.95 to \$45, and Target and Kmart are the best places to purchase them. I stock up when they are on special.

I hope this information is of some benefit to readers of *The Beacon*.

– June Villadsen, SA

Introducing our member groups

Japonica Women bloom in Bendigo

Continuing our series on our member groups from around Australia

The Japonica Women's Group is a support group in Bendigo, Victoria, for young women living with breast cancer.

The facilitators are breast care nurse co-ordinator, **Melissa Billing**, and myself, **Tanya Meigui Lea**, a breast cancer survivor of seven years.

We are a social group that meets about every six weeks, either at a member's home or we go out for dinner. Our focus is on friendship, happiness, joy and laughter.

A strong bond has developed between members, and we participate in Relay for Life and Australia's Breast Cancer Day activities, as well as other social activities.

The name Japonica Woman came about after I taught English in China.

My translator, **Yao Jian**, explained that the japonica flower symbolised strength, beauty and perseverance in Chinese art.

The japonica is the first blossom of spring. It heralds the beginning of new life after the suffering and hardship of the long winter.



The women from the Japonica Women's Group share a deep friendship.

Japonica proudly announces, "I can overcome winter. I can defeat winter and I can make the hopeful dream come true".



Japonica's fearless demeanour proves she is a real winner.

Her promise implies the truth that nobody can be defeated if they are determined to win.

Like the japonica, the Japonica Women have endured and beaten the hardship and pain of their 'winter' and they are symbols of a brighter future.

The pink japonica is the symbol of the group.

– Tanya Meigui Lea, Bendigo

All of life is a lesson

These wise words reached us via a group e-mail.

I've learned ...

That life is like a roll of toilet paper – the closer it gets to the end, the faster it goes.

I've learned ...

That it's those small, daily happenings that make life so spectacular.

I've learned ...

That to ignore the facts does not change the facts.

I've learned ...

That when you plan to get even with someone, you are only letting that person continue to hurt you.

I've learned ...

That love, not time, heals all wounds.

I've learned ...

That the easiest way for me to grow as a person is to surround myself with people smarter than I am.

I've learned ...

That life is tough, but I'm tougher.

I've learned ...

That opportunities are never lost; someone will take the ones you miss.

I've learned ...

That a smile is an inexpensive way to improve your looks.

I've learned ...

That I can't choose how I feel, but I can choose what I do about it.

I've learned ...

That the less time I have to work with, the more things I get done.

Meet our consumer representative – Jenny Morrison

Continuing our series on BCNA Consumer Representatives from around Australia

Attending the Science and Advocacy Training Program in February 2002 was an exciting experience for me.

The course deepened my understanding of the Network's work, particularly its *A Seat at the Table* program. Of equal importance was meeting other women with advanced breast cancer.

I was thrilled when the Network asked if I would be interested in sitting on a committee developing summary cards to help clinicians and nurses communicate and build relationships with women with breast cancer.

The A4-sized card contains a summary of the key principles and aspects of communication for doctors and nurses.

The work of our committee was based on a book published by the National Breast Cancer Centre, *Psychosocial Clinical Practice Guidelines: Providing Information, Support and Counselling for Women with Breast Cancer*.

Work on this committee gave me the opportunity to use my previous work experience in a constructive way. My early working life had been counselling families and children and people with disabilities. In later years, I managed programs that affected the quality of people's lives. This experience was of potential use to the committee.

The second reason I was pleased to be involved was because it was a concise piece of work that I could



– Jenny Morrison,
Queensland

manage around my fluctuating energy levels. Like other women with advanced breast cancer, my energy levels can be low at times, partly because of Xeloda, the drug I take.

Tips for consumer representatives:

1. Prepare as well as you can by reading the material provided and anything else you can get your hands on. Talk to other people about their experiences.
2. Contact the project officer responsible for the day-to-day work, to ensure your understanding of the

I don't want to get to the end of my life and find that I have just lived the length of it. I want to have lived the width of it as well.

– Diane Ackerman

work on the project meets with theirs. It is good to establish a working relationship with this person early on.

3. Recognise that project and policy officers can often (but not always) be your greatest allies. They are often people who have chosen to work in a particular field because a family member or friend may have experienced a similar condition.
4. The expertise of a consumer is unique. No matter how understanding and co-operative other committee members can be, they do not have the experience of the consumer.
5. Review the minutes from the meeting carefully, ensure that they are accurate and that the views of consumers are represented. Remember, there are always women with breast cancer who are disadvantaged in their treatment, e.g. women in rural communities. You are representing the views of a broad range of women and these must be reflected in your comments.
6. Stay as close to women with breast cancer as you can. This will vary from woman to woman, depending on your health, family, work responsibilities and other factors. Staying close to women and their families will enable you to 'keep your eye on the ball' and remain true to the issues and dilemmas we all face.

Breast Cancer Network Australia would like to thank ...

- Arthur Yates and Co. for producing a bulb pack of pink and white tulips called *Field of Women* – 40¢ from the sale of each pack will be donated to us.
- Pacific Brands for buying 50 merchandise kits to sell in its stores.
- The family and friends of Jill Supree, who died in February, for donating almost \$10,000 in memory of this extraordinary young woman.
- Sarina Lions Club in Queensland for raising funds for BCNA.
- Pam Goldstone, Denise Isaacs and Sue Auster from Melbourne for raising more than \$11,000 for us from their combined 50th birthday party in February.
- Readers of *The Beacon* who asked for extra copies of the *Helping a Friend or Colleague with Breast Cancer* brochures to distribute in their communities.

Resources

RESIDENTIAL PROGRAM

The Petrea King Quest for Life Foundation is now offering two residential programs a month for people who have/had cancer and other life-threatening illnesses.

Partners, family members and friends are also encouraged to attend.

The NSW Health Department has agreed to provide financial support for three years to ensure that those on a low income can attend the programs.

For more information phone (02) 4883 6599 or info@questforlife.com.au

WEBSITES

A new breast services website – www.breastservices.humehealth.com.au – has general information on breast-related topics and a directory of services for Victoria's Hume Region.

Window on Women – www.windowonwomen.gov.au – contains statistical information about Australian women.

Most of the data is drawn from the Australian Bureau of Statistics, with special reports from the Office of the Status of Women.

When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one that has opened for us.

– Helen Keller

RESPITE UNITS

The Otis Foundation respite units are now being enjoyed as a wonderful place for rest and retreat. They are in peaceful bushland setting near Bendigo, Victoria, and available, free of charge, to anyone affected by breast cancer.

Bookings and inquiries to Liz Martin, units manager phone (03) 5439 3220 or otisbookings@bigpond.com

INFORMATION PACKS

New state-based Information Packages are now available for women diagnosed with breast cancer in Tasmania.

Part of the Strengthening Support for Women project, these packs

contain information about state-wide and local resources for women, including practical services such as schemes for wigs, prostheses, travel and accommodation. There are also useful contacts for support groups and counsellors.

Contact: Melinda Minstrell (03) 6233 2030 or mminstrell@cancer.org.au

ART

The Creative Journey is a series of group art therapy workshops designed to help post-treatment cancer patients re-establish their self-identity and self-confidence by developing their creativity.

It is helpful for those experiencing stress, anxiety and depression or who feel empty and uncreative.

The Creative Journey is open to people of any age, with any type of cancer and treatment experience. The next Life Force Foundation program starts on July 8, in Annandale, NSW, and runs for four weeks.

For more information or a brochure, phone Fiona Fitzpatrick at Art with Heart on (02) 9552 6360 or fionaf@iinet.net.au

Heart songs in the key of C

An exciting project has been launched in Gippsland, Victoria. A series of creative writing workshops for women living with breast cancer, 'Heart songs in the key of C', was held in venues at Traralgon, Sale, Bairnsdale and Lakes Entrance.

Christine Gillespie is the writing facilitator.

The project will expand to other regional centres. Proposed dates are:

- June – Warrnambool, Philip Island; and
- August – Echuca/Moama, Shepparton, Mildura.

These workshops have acted as tasters, recruiting a variety of women

who may have little or no experience in writing and giving them the skill and belief to write their heart songs.

Under the auspice of BCNA, co-project managers, Marlene Parsons and Sharyn Dickeson, believe the project is an instrument for many women living with breast cancer to continue their healing journeys.

The inspiration for the project came from the Warrior Women tour and writing workshops which began in 2000. Both Sharyn and Marlene attended the writing workshop in Sale during March 2002 and have continued writing since then.

The finished product, a book for

Australia-wide distribution, will highlight the experiences of women living with breast cancer from a broad cross-section of society. It is envisaged that others will gain an awareness and understanding of the challenges faced by us all.

The writing workshops and book will also be an avenue to show the impact of the disease on the family and communities affected, and promoting awareness of the personal support networks available.

For more information, phone the project managers, Marlene Parsons on (03) 5146 0470 or Sharyn Dickeson on (03) 5152 6406.

Dragons Abreast report

It was a remarkable sight – multi-million dollar yachts moored at the Auckland Viaduct, people of all ages rushing about from one dragon boat race to another, groups of young Maori men and women chanting their team songs, and intermingled within the commotion were the Pink Ladies! Spirits high, out there racing with all the other teams. It made us proud to be there, supporting our Aussie girls.

Passing by a group of Pink Ladies we overheard one say to some young paddlers, “See, I am 76 years old and still paddling!”

It made us reflect on the reasons all these women had come together many miles from their own homes. Not to take home the gold, but to create awareness and to make a difference. The Pink Ladies certainly did that!

Conversations could be heard throughout the weekend from young men and women about how much they admired the ladies, how important breast cancer awareness is and what great role-models the women are.

The following weekend in Wellington was no exception.

This time the women faced a harder task, as the water on Wellington Harbour was open to the wind, and a cold harsh one it was. The water was



rough and even the most experienced teams of Dragon boaters were tipped into the cold choppy harbour. Cold, wet and a little shaken up, all were rescued relatively unharmed. Yes, Dragon boating can be challenging!

Our Pink Ladies paddled all their races with strong spirits and stayed upright for everyone. They made it into the grand finals and we were proud to be supporters.

Dragon boating is not about winning, it is about teams supporting and caring for each other. When you hear our women say to each other, “If you are not well enough to paddle, just come and sit in the boat”, you know that their care for each other is much more important than winning a race, and the examples they set for others will be remembered long after the winner of the race is forgotten. If just one woman has an early detection after seeing a race, then all the Pink ladies in the world have made a difference.

We feel proud and privileged to have witnessed such an amazing event and say thank-you Pink Ladies.

– Kay-Marie Taafe and Madeleine Luck, Rosevale, Queensland



Dragons Abreast show their style in Melbourne during March.

Dragons Abreast news from around Australia

South Australia

A new Dragons Abreast team is being formed in Adelaide for women who want to paddle for fitness and fun, rather than be competitive.

Contact: Sally Russell (08) 8223 7106 or salrus@senet.com.au or Deb Martin (08) 8241 1804 or d.martin@senet.com.au

Tasmania

Louise Woodruff and Chris Van Buuren got their hair off in March to raise funds for Dragons Abreast Tasmania (see photo on right).

Victoria

The Victorian Dragons Abreast team would like to thank the Judy Costello Memorial Fund for its new boat.

Western Australia

WA will host the Australian Dragon Boat Championships in 2004, so the WA Amazons Dragon Boat Racing Team wants new members.

Contact: Yvette Libregts on (08) 9246 0739, 0404 966 706 or amazons@iprimus.com.au

For more news about Dragons Abreast, visit www.dragonsabreast.com.au



Louise Woodruff, Tasmania.

UPCOMING EVENTS

June 7: Tasmanian Breast Cancer Network meeting, Campbell Town Fire Station, 10am-3pm.

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

June 12: Queensland BCNA fundraising theatre evening (*Beside Manners*) at Gail Wiltshire's Twelfth Night Theatre, Bowen Hills, Brisbane, 7.30pm.

Contact: Lewis, (07) 3252 5122

June 22: Breast Cancer Action Group NSW meeting, YWCA Sydney, 3pm. Prof. Stewart Dunn, Pam McLean Communications Centre – teaching doctors to communicate.

Contact: Sally Crossing on (02) 9436 1755

June 26: Breast Cancer Action Group general meeting, Level 7, Storey Hall, RMIT Melbourne, 7-9pm. Jacqui Chirgwin – Young women's issues.

Contact: Sue Lockwood, (03) 9878 0736

July 17: Lymphoedema Association of Victoria lunch, Box Hill Golf Club, 12.30pm (\$25 a head).

Contact: (03) 9890 3778

July 19-20: Basic Lymphoedema Course 2003 for health professionals, Austin and Repatriation Medical Centre, Heidelberg, Victoria (also August 2-3 and August 30-31).

Contact: Gillian Buckley, (03) 9270 2422 or gmbuckley@optusnet.com.au

August 2: Tasmanian Breast Cancer Network meeting, Campbell Town Fire Station, 10am-3pm.

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

August 24-29: Pink Ladies Golf Classic on Sunshine Coast, Queensland, proceeds to BCNA.

Contact: Jacinta Moore, (03) 9500 8954 or 0412 857 240

August 28-31: World Dragon Boat Championships, Shanghai, China.

Contact: Michelle Hanton, (08) 8941 8923 or hanton@ozemail.com.au

September 20: Breast Cancer Action Group general meeting, Level 7, Storey Hall, RMIT Melbourne, 7-9pm. Judy Shepherdson & Marlene Parsons – Rural women's issues.

Contact: Sue Lockwood, (03) 9878 0736

September 20: Consumer workshop at the Fourth Scientific Meeting of the Australasian Society for Breast Disease, Surfers' Paradise Marriott Resort, 9.30am-1.15pm.

Contact: BCNA, 1800 500 258 (free call)

September 21: Breast Cancer Action Group NSW meeting, YWCA Sydney.

Contact: Sally Crossing, (02) 9436 1755

October 4: Glitter Ball, Plaza Ballroom, Regent Theatre, Collins Street, Melbourne, 7pm. All proceeds to our *My Journey* project.

Contact: Leanne Bradford, (03) 9844 5446 or lee.bradford@bigpond.com

October 4: Tasmanian Breast Cancer Network meeting, Campbell Town Fire Station, 10am-3pm.

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

October 26: *The Field of Women – Hobart, Tasmania.*

Contact: Michelle Rule, 1800 500 258

October 27: *Australia's Breast Cancer Day.*

November 8-9: Dragon Boat races, Australian Masters Games, Canberra, ACT.

Contact: Michelle Hanton, (08) 8941 8923 or hanton@ozemail.com.au

November 19: Breast Cancer Action Group general meeting, Level 7, Storey Hall, RMIT Melbourne, 7-9pm. Dr Craig Hassed – Holistic care for women with breast cancer.

Contact: Sue Lockwood, (03) 9878 0736

December 6: Tasmanian Breast Cancer Network meeting, Campbell Town Fire Station, 10am-3pm.

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

December 7: Breast Cancer Action Group NSW AGM, YWCA Sydney.

Contact: Sally Crossing on (02) 9436 1755



Seeking Shelter

The Network welcomes these new groups under its national umbrella:

- Lower Mountains Bosom Buddies, Blue Mountains, NSW
- Albury Wodonga Breast Cancer Support Group, Albury, NSW
- Tomaree Support Group of Hunter Breast Cancer Foundation, Port Stephens, NSW
- Caboolture Breast Cancer Support Group, Qld

This brings our total to 101 member groups and five associate member groups.

Get your priorities right

Here is a little snippet from an e-mail we received from one of our ACT members:

"Things were hectic for me during January with family visiting, part-time work and the devastating fires of January 18.

"We had personal friends that lost everything; it is so hard to know, when you look around your own belongings, what you would save.

"The funniest thing was that it was boiling hot and I did not have my boobs on. So what was the first thing I did when we were thinking of evacuating as the fires raced down the hill towards our home? I grabbed them from the cupboard and put them safely in my bra.

"I didn't gather photos or important papers, rings – just my boobs!"

– Pam Robertson, Canberra

YOU'RE NOT YET ON OUR MAILING LIST?

Phone (03) 9805 2500 or 1800 500 258 (free call), or fax (03) 9805 2599,

e-mail beacon@bcna.org.au or fill in this coupon and send it to:

Breast Cancer Network Australia, PO Box 4082, Auburn South, Vic 3122

Name:

Address:

..... State: Postcode:

Phone: () E-mail:

Have you had a diagnosis of breast cancer? Yes No



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