

# The Beacon

Breast Cancer  
Network Australia  
newsletter

## Breast cancer and young women – extra challenges



The organisers of Young Women's Breast Cancer Day: Michelle O'Dea, Jill Johanson, Jenny Childs, Amelia James and Anne Agresta. Read about the day on page 5.

**W**e all know that breast cancer affects the whole community, and that no woman is immune to its reach.

Most women will say they were shocked by the diagnosis – that it was the sort of thing that happened to 'other people'.

There is no clear understanding of the significant risk factors for an individual, except perhaps if you are from one of those rare families where breast cancer is common, generation after generation.

Diagnosis is a shock because you can be fit and healthy, have done all the 'right things' and still get breast cancer.

For some women the shock is more profound, because they are far younger than the average age for a breast cancer diagnosis in Australia – 64 years. They may have to deal with a whole range of added issues simply because of their age.

In this issue of *The Beacon* we take a closer look at breast cancer and young women.

We have asked Brisbane psychiatrist, **Jane Turner**, to share a presentation she made at the Young Women's Awareness Day in Melbourne at the end of last year.

This successful day, an initiative of a group of five young Victorian breast cancer survivors, was attended by 250 people.

A survey of the young women there who had been diagnosed with breast cancer, revealed some interesting results which have been included on page 5.

The day also highlighted the value of

bringing women together to learn and share information, meet other women in a similar boat and swap phone numbers.

Support networks for young women are springing up around the country. We have groups in Brisbane, Canberra and Melbourne, while **Rosanna Martinello**, in Sydney, is keen to link these groups together to form a powerful, combined voice.

Rosanna's article, on pages 6 and 7, raises the need for clear messages for women under 40 years.

We have also included some personal stories from young women. Readers continue to tell us how important these personal testimonials are to them, during their journeys.

Finally, what do we mean by young? The definition is a subjective one – we all know 'elderly' women who are perennially young!

For the purposes of this discussion we are usually referring to pre-menopausal women.

When I was diagnosed at 40, with two small children, I thought I was very young. Everyone else undergoing treatment seemed much older ... but at the Young Women's Day, I felt positively ancient, among the 20 and 30-year-olds.

It makes me sad to know that so many young women are dealing with breast cancer at a time when their lives should be filled with happier pursuits.

All the more reason for the Network to stay involved, to keep raising these issues and to make a difference!

– Lyn Swinburne, Editor

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# State round-up



## NORTHERN TERRITORY

Life in the top-end of Australia over the Christmas break was fairly quiet, not too hot, with some rain, so everything is looking green.

To update our progress on the breast care nurse position, the Cancer Council of the NT is undertaking a 'needs analysis' before the position can be filled.

In May, the NT will be hosting the national dragon boat titles. The National Breast Cancer team, 'Dragons Abreast', will be competing, and we are working hard to make their visit a memorable and enjoyable time.

Contact: Susan Tulley (08) 8927 3327 or [tullynt@msn.com.au](mailto:tullynt@msn.com.au)



## WESTERN AUSTRALIA

Western Australia now has a Dragon Boat Team, in conjunction with The Cockburn Dragon Boat Club, which will train us.

We have contacted many women through the Cancer Helpline and Breast Cancer Support Service, as well as through the media.

We were launched on January 25 in Fremantle and so far have 16 members.

To join, phone Carol Bishop on (08) 9489 7312. All you need is enthusiasm and a sense of fun. No experience in paddling or a high level of fitness needed!

Two major areas of concern and action for us this year will be the provision of breast prostheses for women, and the cost and availability of reconstruction following a mastectomy. We would like to hear from any one in WA who has concerns about either of these issues.

Action on Breast Cancer has been asked to speak at a BreastScreen conference for practitioners in March and to attend a Lymphoedema Strategy meeting being conducted by the WA Cancer Foundation.

We have established an international link with the Susan G. Komen Race for the Cure in the US, after one of our members participated in 1999.

This group has more than 35,000 volunteers internationally and has raised nearly US\$200 million in the 15 years it has been in place.

Contact: Carol Bishop (08) 9489 7312 or [carol@cancerwa.asn.au](mailto:carol@cancerwa.asn.au)



## NEW SOUTH WALES

Thanks to all those who have responded with case histories of insurance discrimination. These are valuable, as they are real evidence for our concerns.

I was invited to write a piece for 'Health Issues', the journal of the Health Issues Centre (No. 65, December 2000), publicising the issues and suggesting a project to canvass them more fully.

Keep sending us your experiences, so we can make the case even stronger.

I am delighted to announce that Pam Bell has agreed to share the NSW Network representative position with me.

Breast Cancer Action Group NSW has a new committee for 2001 of 19 members. This is the result of the increased interest created by the various events around October 2000.

All these committee members are Network members and eager to contribute to national issues, when called on!

Contact: Sally Crossing (02) 9436 1755 or [crossing@bigpond.com](mailto:crossing@bigpond.com) or Pam Bell (02) 9955 9313 or [bellpc@bigpond.com](mailto:bellpc@bigpond.com)



## QUEENSLAND

Queensland's state public forum sponsored by the National Breast Cancer Centre will be held at the Queensland Cancer Fund in Brisbane on Saturday April, 28. We hope lots of readers of *The Beacon* will attend.

Remember the Field of Women in Brisbane during the Goodwill Games.

The field will be planted on Sunday, September 2, and will be displayed until Friday, September 7. Let us know if you want to be involved.

Connect Programs are scheduled for Maryborough on March 8 [phone (07)

4132 8733] and Gympie on March 30 [phone (07) 5483 6588]. These are free educational and support programs for women who have had a diagnosis of breast cancer.

Lyn Swinburne and Leona Furstenburg were guest speakers at the More Choices meeting at the Wesley Hospital in February.

For information about future meetings and programs, phone Barbara Quinn on (07) 3232 7596.

A special request to all women and support groups in Queensland: We would like to report on activities all over the state, not just in Brisbane. If you would like something reported, phone Leonie or Janelle or e-mail [leonie@everycloud.com](mailto:leonie@everycloud.com)  
Contact: Leonie Young (07) 3255 2355 or Janelle Gamble (07) 3353 4151.



## SOUTH AUSTRALIA

Carlene Butavicius and Vanessa Lambert represented the BCNA at the Clinical Oncological Scientific Society of Australia's (COSA), 'Communication and Cancer' meeting in Adelaide on November 29 and December 1.

ACTION FOR BREAST CANCER SA has had a break during the festive season, but resumed meetings on February 5.

Vanessa Lambert is offering women with breast cancer reduced price accommodation at Pumpkin Hall, her seaside B&B in Port Elliot. If you are interested, phone Vanessa on (08) 8554 3389.

Planning is under way for the major 2001 Field of Women, which is to be planted in Adelaide.

The first lymphoedema screening project is being conducted in SA. It is being funded by the Eastwood Lions Club, in collaboration with Flinders University School (FUS) of Nursing and Midwifery, the School of Medicine, and staff at Flinders Medical Centre Lymphoedema Assessment Clinic.

Neil O'Brien (Eastwood Lions), Professor Neil Pillar (FUS School of

## Putting on our 'thinking caps'

The second BCNA Think Tank was held in Melbourne from February 9 to 11.

Now an annual event, two representatives from each state came together to exchange ideas and set priorities for the year ahead.

One thing we will work for is an 1800 freecall phone number, to make it easier for women all over Australia to make contact.

We'll keep you posted on this!



Medicine and principal researcher for the NBCC project 'Encouraging research into lymphoedema') and **Jenny Donovan** (lecturer in Nursing at FUS and ACTION member) are collaborating with volunteer members from the Eastwood Lions Club. This is a world first! Screening began on February 10.

Contact: **Carlene Butavicius** (08) 8272 2895 or [butavic@chariot.net.au](mailto:butavic@chariot.net.au)



### THE ACT

**Elsbeth Humphries** has joined **Anna Wellings Booth** as joint ACT co-ordinator.

Towards the end of last year, Elspeth and Anna spoke to two groups of medical students at The Canberra Hospital. They hope the Network will be included in the Clinical Education Program each year.

Canberra 'shuts down' over the holiday period, but members of the Network's indomitable 'Dragons Abreast' team only took a few weeks off.

They are training three mornings a week in preparation for the Chinese New Year at Darling Harbour, Canberra's Multicultural Festival, the Nationals in Darwin during May, and three or four will be travelling to Canada in June.

On March 30, the crew will be joined by members of Bosom Buddies and the ACT Cancer Society Breast Cancer Support Group, under the Network umbrella, in the second Relay for Life event to support the ACT Cancer Society's research program.

The annual Walk for Wigs, instituted

by **Crispin Hull** in memory of his wife **Lyn**, was held on February 3 from Charlotte's Pass to Mt Twynam in the Snowy Mountains.

Contact: **Anna Wellings Booth** (02) 6247 8470 or [wbfamily@interact.net.au](mailto:wbfamily@interact.net.au)



### TASMANIA

Our state group, along with individual members, have written to the Cancer Council of Tasmania supporting a submission to provide lymphoedema treatment training for occupational therapists at the NW Regional Hospital, Burnie.

Thanks to sponsorship the Hobart Women's Health Centre, **Jenny Littler** attended the 4th Australian Women's Health Conference in Adelaide on February 19 to 21.

ABC Radio interviewed **Pat Mathew** about improving communication between doctors and patients. She highlighted the importance of clear communications, and the need for women to understand their options and have all their questions answered properly.

**Beth Batchelor** attended the 5th World Psycho-oncology Conference in Melbourne last year. She has since completed a report, which is available on the BCNA website.

These are summaries of the state representatives' reports. To read the complete reports, visit our website – [www.bcna.org.au](http://www.bcna.org.au)

Arrangements for the state public meeting in Hobart on March 24 are being finalised. Phone **Maureen Ramsden** on (03) 6336 2249 for more information.

Contact: **Joan Williams** (03) 6421 7700 or [joan.williams@dchs.tas.gov.au](mailto:joan.williams@dchs.tas.gov.au)



### VICTORIA

Hello, my name is **Gerda Evans** and I am the new Victorian state representative.

Unfortunately, **Sue Lockwood's** breast cancer has recurred and she is undergoing chemotherapy. We send Sue our love and hope her treatment flies past as quickly as possible.

The most marvellous thing to happen in Victoria of late was the Warrior Women Exhibition at Melbourne's Span Galleries (see page 11). This multi-media exhibition included contributions from about 50 breast cancer survivors, each exploring their various experiences.

It was a powerful demonstration that breast cancer wasn't just about chopping off breasts and zapping women with chemicals. It was a glimpse into the innermost thoughts of these women and showed that everyone's journey and way of dealing with it was unique.

We hope the exhibition will tour regional Victoria and recommend it to anyone with the chance to see it.

Congratulations to **Sue Smith, Jacqui** and the entire team!

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



## Congratulations and thank you

**Debbie Goodin** has been awarded the Victorian State Chairman's Young Professional Community Service Award by the Institute of Chartered Accountants, in recognition of her pro-bono work, particularly for the Breast Cancer Network Australia.

Congratulations Debbie!

Debbie is a member of the Network's Board and provides us with invaluable financial advice.

She has been touched by breast cancer, as her mother has been diagnosed with the disease.

NSW Network member, **Dianne Chellew**, whose story was featured in the last issue of *The Beacon*, has won Kiama's Sportsperson of the Year award.

Congratulations Dianne!

One of the Network's greatest supporters received the highest honour in the Australia Day's Honour List.

**Sir Peter Derham** was awarded the Companion of the Order of Australia (AC) for service as an innovator in tourism development, commerce and science, to the community and to the preservation of heritage sites in Antarctica.

Sir Peter was instrumental in helping create our first Field of Women. He continues to support us with wise counsel, advice and encouragement.

Congratulations Sir Peter!

And a big Network thank you to these generous supporters:

- Bakers Delight for raising the amazing sum of \$50,000 at its Christmas Ball in Melbourne.
- East Malvern Ladies Tennis Club in Melbourne, for its fantastic \$8000 donation to help cover the cost of this issue of *The Beacon*.
- Mailing Solutions in Melbourne for supplying the envelopes for *The Beacon* mailout.
- Compuware Asia Pacific in Sydney for donating the Dreamweaver and Fireworks software packages for the BCNA website.

## Letter to the Editor

I have just received my second copy of *The Beacon*. Thank you and keep up the good work. I look forward to the next issue of *The Beacon* dealing with young women and breast cancer.

Without going into details, I'm nearing the end of my treatment and looking forward and positively to a long life. As most women in the family make a healthy 80, I've got 50-odd years to achieve in.

The issues I would like to see addressed also concern employment and insurance (disclosure, etc). I have another 30 years I would like to spend in the workplace and feel these issues aren't significantly addressed.

Also, as most of my female friends are single, how do you cope without a partner or strong family support? We have to keep on working because there is no-one we can rely on.

Enclosed is a copy of the Christmas card we sent out this year. It has had an interesting response – not all of it favourable.

I am amazed at how many wish me to put my 'hairless' episode behind me and be pleased with my new crop of curly hair.

Personally, I'm having a 'Number 1' cut as soon as possible. I found something extremely liberating (and feminising) in the loss of my hair.

My male friend in the picture is still waiting for his hair to grow!

Being involved with the arts, most people thought I'd made a fashion statement.

– Sharyn Meade,  
Dandenong East, Victoria.

P.S. If I get any more parking tickets while waiting for treatment I will scream!



## Winging in breast cancer support and information

The WINGS website run out of the University of Adelaide was set up in 1998 to provide information and support for women with breast cancer, especially those from rural and remote areas.

WINGS can be reached at <http://wings.adelaide.edu.au>

It includes a moderated e-mail discussion group, 'Bush Telegraph', where members have raised topics such as dealing with the side-effects of medication and the diagnosis of breast cancer in young women.

'Your Say' is a chance for visitors to

the site to air opinions, tell of their experiences and share tips.

Despite this positive work, the future of WINGS is unclear. Without further funding, it will be difficult to continue with the website and a valuable resource for Australian women and families will be lost.

The WINGS team would like to ask readers of *The Beacon* to complete their online survey which considers the role of the internet for people with chronic illnesses. To add information to the WINGS website, click on to 'Your feedback'.

# Promoting the cause of young women

About 250 people attended the Young Women's Breast Cancer Awareness Day in Melbourne during November – more than double the 70-100 people that were anticipated.

Around 80% of those who attended were young women who have had breast cancer. Others were supporters, family members and interested individuals.

Some travelled from interstate to attend the day, including women interested in starting breast cancer support groups in their own areas.

The day was an initiative of five young women who have had breast cancer during the past four years (see page 1). Their experiences identified a lack of support services, networks and information for women under the age of 45 years who were diagnosed with breast cancer.

In response, they organised this event to help correct this imbalance.

Hosted by **Jackie Woodburne**, from the television program, *Neighbours*, the free event featured six guest speakers discussing a range of informative, inspiring and challenging ideas.

Comedienne, **Linda Gibson**, closed the day with a hilarious summary of her experience with chemotherapy. It brought roars of healing laughter from every person in the room.

Young women who attended the day were invited to complete a questionnaire. The results highlighted some interesting issues:

- 9% of women who attended were aged 25-30 years old when diagnosed, 26% were 31-35 years, 40% were 36-40 years and 25% were 41-45 years;
- 24% were initially misdiagnosed;
- in 60% of cases the cancer had spread beyond the breast when diagnosed;
- 30% sought a second opinion;
- most were generally happy with their treatment and surgeons;
- 11% were unhappy with how their diagnosis was explained;
- 16% were unhappy with how their



*What energy! The room was full of young women who had all experienced breast cancer.*

- treatment was explained;
- reported treatments were – mastectomy 45%, lumpectomy 68%, reconstruction 15%, radiotherapy 73%, chemotherapy 76% and hormone therapy 32%;
- 26% reported a family history of breast cancer;
- 66% were not offered fertility options during treatment;
- 34% did not get help from a breast cancer nurse during treatment;
- 20% suffered lymphoedema; and
- 65% suffered on-going side effects (such as fatigue, early menopause, localised pain, low self-esteem, memory loss and depression).

The event gave women opportunities

to connect with others. There was inspiration and encouragement to set up support groups around Victoria and interstate. It also raised issues about how women in this age group can be supported and have their needs met.

The number of women attending the day indicated that a huge number of young women in our community are affected by this condition.

Raising the profile of breast cancer in young women not only brought benefits to those who attended, but to all young women who have had or will have breast cancer in the future.

Planning for the next conference has started, more details in due course.

– Michelle O'Dea, Melbourne

## Polly's still spreading word of the Network

Many readers will recall the story in our last issue about **Polly Letofsky**, the young US woman who is walking the world for breast cancer.

In Australia, all money raised is going to the Network to help cover costs, including the production and distribution of *The Beacon*.

By the end of January, Polly had raised more than \$6000 for us! She was then on the central coast of NSW, heading steadily north!

You can track Polly's progress via her website – [www.globalwalk.org](http://www.globalwalk.org)

Polly's latest update has fascinating stories about people she has met on the way, including Len, a truck driver who stopped to offer Polly a ride at the bottom of a hill outside Cootamundra.

When Polly explained why she

couldn't accept his offer (she is *literally* walking across Australia), Len jumped out of his truck and gave her a donation. His wife, Diane, had had a mastectomy four days earlier!

As well as raising funds, Polly is spreading the word about the Network and letting women know how to get their own copies of *The Beacon*.

Thank you to all of you who have taken Polly into their homes and hearts.

If you live on the coast north of Brisbane, Polly should not be too far away when you receive this issue. She will be on her way to Cairns, so if you can offer her a bed, a meal and some hospitality, she will appreciate it ... and so will we!

Call Polly on 0415 537 783 or send an e-mail to [polly@globalwalk.org](mailto:polly@globalwalk.org)

# Issues of concern ...



## Hope of a better tomorrow for young women

**H**ere we are in a new millennium and what do we know about young women with breast cancer under 40 years?

According to **Prof. Sally Redman** of the National Breast Cancer Centre (NBCC), we know that 51% of young women under 40 are diagnosed with breast cancer that has spread to the lymph nodes, compared to 38% of women over 40.

We know that women under 40 have more aggressive cancers, poorer prognosis and are much more difficult to diagnose.

We know we have unique needs and greater psychological distress. We know we are more likely to die from breast cancer than older women.

Despite all of this, we know many of our needs and concerns remain unmet



*Rosanna Martinello,  
Co-ordinator, Young  
Breast Cancer  
Action Group NSW*

– we are told our issues are too difficult and we are too few.

But we are not that few. According to 'Cancer in Australia – 1997' from the Australian Institute of Health & Welfare, we account for 7% of all breast cancers, with around 700 of us diagnosed each year. Our pain is real.

*I have hope* of a better tomorrow for all young women with breast cancer.

### The facts of the matter

About 10% of all female breast cancer cases diagnosed in Australia are in women under the age of 40.

However, of all the lives lost to breast cancer (up to age 75), about 40% are women diagnosed with the disease before the age of 40 years. A major component of the mortality due to breast cancer is from early onset cases.

Apart from the usual costs to women and society due to breast cancer, these early onset cases often cause major disruption and hardship to young families and the loss of valuable years of working life for adult women.

Furthermore, about 5-10% of early onset cases are now known to be caused

by inherited faults in the genes BRCA1 and BRCA2. These faults can be passed on to future generations.

Women with an inherited fault in these genes have at least a 10-fold increase in the risk of both breast cancer and ovarian cancer.

To date, most breast cancer research has – not necessarily inappropriately – been associated with women who develop the disease in their post-menopausal years. Therefore, there is an urgent need for research into how to prevent breast cancer in young women, including those who have an inherited risk, and how to optimise the effectiveness of treatment.

*I have hope* that one day all young women with breast cancer in Australia, whether in cities or small country towns, whether dinky di or from non-English speaking backgrounds, regardless of education, social or economic status, or stage of disease, have access to support programs specifically designed for young women.

These support programs will address the issues confronting young women, such as fertility, early menopause, young families, body image, relationships, confronting mortality at a young age, peer support and isolation.

This hope should become a reality in NSW in 2001. The NSW Cancer Council has agreed (following approaches by Young Breast Cancer Action Group, a committee under Breast Cancer Action Group NSW) to design a support program specifically for young women across NSW.

A Working Party, with young women represented, has been formed and held its first meeting at the end of January. This creates opportunities for a public awareness campaign later in the year.

Last year saw progress in NSW thanks to the oncology team at Prince of Wales Hospital, which set up NSW's inaugural, much-needed support group for young women.

*I have hope* that one day all young women in Australia will know exactly what they must do to assist in early detection of breast cancer.

We need a program similar to ones where women know they 'should' have a pap smear every two years to ensure earlier detection of cervical cancer, and women over 50 know they 'should' have a mammogram every two years to assist in the earlier detection of breast cancer.

These clear, specific guidelines do save lives – young women should be informed of what they 'should' do to detect breast cancer earlier.

We are a long way off, as reflected in Prof. Redman's alarming statistic.

The figure is not surprising to me, given that the current guidelines and practices for detecting breast cancer early in young women are mixed, confusing and outdated.

The NBCC and the Australian Cancer Society (ACS) both agree there is a problem.

In response to my letter raising the issue, **Prof. Alan Coates** from the ACS agreed that “we should review the current state of the evidence and come up with revised guidelines for young women”.

Prof. Redman from the NBCC acknowledged that “the real problem is that we do not have effective techniques to find breast cancer early in young women”.

This is a good start in acknowledging there is a problem, but we cannot stop here. It is particularly important that we address the issue now as various ‘solutions’ enter the public arena with a ‘vocal’ demand for earlier detection.

This follows the high profile this issue received during National Breast Cancer Awareness Month last October. Media personalities called for free mammography screening and the Prime Minister stated a willingness to investigate what could be done.

The debate is healthy, but we need to find the right answer for ensuring earlier detection. The right answer is communicated to all young women and health professionals.

We are making progress. During our January meeting, Prof. Redman agreed to recommend establishing an NBCC working party to address young women’s issues.

Revised guidelines for earlier detection in young women have also been earmarked as a priority issue.

*I have hope* that one day young women will receive the best care, with recognition of our special needs.

Young women must not only continue to push for such initiatives as greater integration in the treatment team and access to a breast care nurse/psychologist.

Our special issues also need recognition. The NBCC has established a project to improve care for young women. It is designed to ensure that those managing young women with breast cancer have access to information about the best approaches to clinical care and support. A working party will be set up shortly with representation from younger women.

## Young women’s groups around Australia

The Young Women’s Network (YWN) meets at the Queensland Cancer Fund in Brisbane at 6.30pm on the last Wednesday of each month.

Bi-monthly meetings are held on the Sunshine Coast on the first Monday of each month.

Other groups can be found on the Gold Coast and in Toowoomba, Townsville and Cairns.

The YWN is looking at establishing a teleconferencing facility so that young women in rural and remote areas can

interact with other women being treated for breast cancer.

The YWN website can be accessed through the Queensland Cancer Fund’s site – [www.qldcancer.com.au](http://www.qldcancer.com.au)

‘The Young Ones’ is the young women’s support group in Melbourne. Contact **Tanya Wilson** on (03) 9330 2785 or e-mail [tanya\\_wilson@optusnet.com.au](mailto:tanya_wilson@optusnet.com.au)

To learn more about the ACT Young Women’s Group, phone **Leona Furstenburg** on (02) 6262 4545 or e-mail [leona\\_furstenburg@bigpond.com](mailto:leona_furstenburg@bigpond.com)

*I have hope* that one day young women with breast cancer across Australia will be given a ‘voice’ to raise issues affecting young women and to have a seat at the table whenever decisions are being made affecting our breast cancer journey.

Far too often our ‘young’ voices are not heard because we are in the minority, and our special issues overlooked.

Here in NSW I am pleased to say that our ‘young’ voices are beginning to be heard, with representation already assured on NSW Cancer Council’s committees.

During 2000, Young BCAG seized opportunities to increase public awareness of our special needs through the media. We were involved in newspaper and radio interviews, and initiated a segment dedicated to young women on the current affairs program ‘Today Tonight’.

The second NSW Breast Cancer Consumer Forum in October 2000 also recognised our special needs and included a workshop specifically for young women.

As a result, Young BCAG has evolved (we are rethinking our name!)

Young BCAG had its inaugural meeting in December and started 2001 on a roll – it has agreed on a definition of ‘young’ and identified key issues to be addressed this year, most with national ramifications.

We could make even greater inroads if we follow the Network’s footsteps and combine our ‘young’ voices at the national as well as at the state level.

As a united, national voice, we are more likely to foster a partnership with all the major stakeholders in the breast cancer business, including government bodies, the NBCC and the ACS, and ensure a seat at all the decision-making tables.

This way, we may more effectively influence the direction of the research which will, inevitably, be needed to find the best solution to a number of our special issues.

I invite young women in other states to join forces and set up a National Young Women’s Network under the auspices of Breast Cancer Network Australia. Many of the issues we young women confront know no geographic boundaries.

Interested? Please contact Breast Cancer Network Australia on (03) 9805 2500. I hope you do!

Together, let’s make our young women’s hopes and dreams a reality!

## In the next issue ...

- Now that I’ve experienced breast cancer, what is the likelihood of my daughter being affected?
  - Is my family in a high-risk group?
  - Where is genetic research heading and what is it telling us?
- These questions and others will be covered in the June issue of *The Beacon*.

If you have any questions you would like us to address or stories to submit, please make sure they reach us before April 27.

# Key issues facing young women with breast cancer

A diagnosis of breast cancer is a tremendous shock for any woman, but for younger women it raises fears about the future and being different, and concerns about the effect on relationships and family.

Many young women also feel highly traumatised by the circumstances surrounding diagnosis, perhaps having been told, “You are too young for this to be breast cancer”.

Making decisions about treatment is a time of considerable anxiety, but for young women this can be complicated by a need to maintain the fabric of daily life for young children or infirm parents.

The distress is compounded by the inevitable drain on finances due to an unexpected absence from work, medical costs and increased childcare.

Moving forward requires negotiating changes in relationships and self-concept, including re-appraising old values.

For many women, an important step is acknowledging that too much has happened for life to resume previous patterns. They must accept that the future will be different.

A key area of difference for young women is the impact a cancer diagnosis and treatment on body image and sexuality.

Although a woman's response to her breasts may be influenced by the portrayal of women in society, most women believe sexuality involves far more than just physicality, and that the woman *as a whole person* is paramount to the experience.

Treatment also plays a major role. Although, in general, mastectomy has been associated with more body image problems, breast-conserving surgery does not leave a breast ‘good as new’.

Many women are concerned about changes in shape, texture and sensation following conservative surgery and radiotherapy. Many of these



Jane Turner,  
senior lecturer,  
Psychiatry  
Department,  
Royal Brisbane  
Hospital,  
Queensland

women felt unprepared for the final result of this treatment, and sometimes feel they have received less support – perhaps because the community believe this treatment is ‘less serious’ than a mastectomy.

Research shows that a major factor affecting sexual adjustment is whether or not a woman experiences menopause following chemotherapy.

The chances of a woman becoming menopausal after chemotherapy depend on the type and duration of chemotherapy treatment, and her age.

Common symptoms of menopause include hot flushes, night sweats, vaginal dryness, changes in skin texture and mood swings.

Hot flushes seem to occur when oestrogen is decreasing, but there is no clear association between the precise level of oestrogen and the number of flushes a woman experiences.

During a hot flush, the blood vessels near the surface of the skin expand, causing an increase in skin temperature. There is also an increase in heart rate, but no change in blood pressure.

Interestingly, some trials of antidepressants such as Prozac, Efexor, and Aropax have shown that they may provide some relief from hot flushes.

The impact of menopause is not just in relation to sexual adjustment and hot flushes.

For many women, losing the possibility of having further children is deeply painful and often poorly acknowledged by others who assume that having children after breast cancer would be foolish or selfish.

In fact, there is evidence that women who have children after treatment for breast cancer do not experience higher parenting stress. They claim that family issues “provide the greatest degree of satisfaction and importance to quality of life”.

Breast cancer affects the whole family and many partners feel isolated by the woman's experience. They feel like a helpless bystander.

Although many partners have high levels of distress, it seems too hard for partners to seek help. They tend to remain silent about their worst fears, especially that the woman may die.

For children, too, there are huge changes to domestic life, and anxiety is common.

Despite the popular idea that children should be ‘protected’ from upset, the evidence clearly suggests they need information appropriate to their age. An opportunity to talk about their fears and concerns will help children cope.

Because of the multiple issues they face, it is not surprising that research has found that younger women are more at risk of depression following breast cancer.

The notions that depression is normal, a sign of weakness or that nothing can be done to help are completely false.

Treatment of depression, if it occurs, is usually highly effective, improving a woman's ability to cope with the disease and promoting family coping.

There is increasing awareness of the special issues young women with breast cancer face. This is reflected in the recent establishment of a project group at the National Breast Cancer Centre that specifically considers the needs of young women.

The courage, support and humour of others, as demonstrated at the Young Women's Breast Cancer Awareness Day, will provide a powerful impetus for young women to continue raising issues of importance and seeking the help they need.

– Dr Turner presented these views  
as part of Young Women's Breast  
Cancer Awareness Day in Melbourne.

# My Journey

## Live life as if everything is a miracle

I was born in the Ukraine, in the former USSR, and migrated to Australia in 1979, just before the 1980 Olympic Games in Moscow.

After arriving in Australia, I trained as a nurse at the Queen Victoria Hospital in Melbourne, before getting married and starting a family. I have two children, Nicole, 15, and Daniel, 12.

Three years ago, at the age of 37, I was diagnosed with breast cancer.

I found a lump after a routine check and my GP immediately referred me to a surgeon.

Initially, the surgeon thought it was a false alarm, as the mammogram was clear, but took a fine needle biopsy as a precaution.

Feeling quite sure that this was all a false alarm, I attended my follow-up appointment alone. Imagine my shock



Irene Krause,  
North Caulfield,  
Victoria

when I was told that the cells they had tested were positive for breast cancer.

The following couple of weeks were like watching someone else's life unfolding in front of me – hospital, operations, dozens of visitors, trying to keep a brave face. At the same time, I was busily reassuring my husband and parents, and comforting my children.

It was only after returning home that

I slowly started coming to terms with what had been happening and what lay ahead.

My treatment involved lumpectomy, chemotherapy, radiotherapy and then more chemotherapy – I called it a sandwich!

It was difficult, physically and emotionally, but my wonderful family and outstanding friends gave me the courage, support, amazing strength and inspiration to go on.

I fought one day at a time and ultimately emerged a winner. I now feel stronger, more confident and full of hope for the future.

I would like to end my story with a quote from **Albert Einstein**: “There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle!”

## Living because of breast cancer

“I'm young, fit and healthy, it's probably nothing to worry about. It's surely just cyclical and will go away next month.”

My name is Natalie and I was 26 years young when I discovered 'it'.

'It' was a lump; a rather large, painful lump in my right breast that I chose not to ignore, but to investigate.

My local GP said it was probably nothing to worry about, but suggested I should have an ultrasound, just to be sure. It was to be a simple procedure and all over in about 15 minutes.

My results were forwarded to my GP and, to everyone's relief, it was fibrous tissue and not a concern.

The next month the lump had not disappeared. In fact, it had grown a little larger and was still painful.

My GP suggested I visit the Wesley

Breast Clinic. The day started with a visit to the doctor, then a surgeon. I had an ultrasound and mammogram.

By this time I was getting worried; apparently with good reason.

My worst fear was confirmed that afternoon. I had breast cancer – a ductal carcinoma with spread to the lymph nodes.

Four days later I went in to hospital to have a modified mastectomy.

This operation was the scariest and hardest thing I thought I would ever have to face. I soon realised it was the simple part; chemotherapy and radiotherapy were to follow.

I had my chemotherapy in hospital – high dose with bone marrow stem cell transplantation. Physically and mentally, it was the toughest experience I hope I will ever have to endure.

Shortly after, radiotherapy continued for 25 sessions, but I made it through

and am a much stronger person for it.

It's been just on two years since I was diagnosed, and I am happy and healthy.

The support I received from family and friends was magnificent, and I cannot thank them enough. However, I found I needed to share my journey with other women who had had a similar experience. Their support and friendship has been marvellous.

I guess I feel as though I'm not living with cancer, but living because of it.

It has been a life-altering experience, and I believe having lived through it has made me a better person. I have a new sense of worth and feel everything in my life is now in the right perspective.

– Natalie Dower, Queensland

# New resources

## Volunteers grants

The Commonwealth Government is offering groups grants of up to \$5000 as part of the International Year of Volunteers. The next funding round closes on April 10.

A 'Volunteer Story Book' is also been created. It will feature real-life stories about volunteers in the community. You may know just the person to be included in this book!

For information and application kits phone 1300 653 227.

## Secondary cancer group

There is a support group in Melbourne specifically for women with secondary breast cancer. It meets fortnightly on Tuesday mornings at the Anti-Cancer Council of Victoria in Carlton.

Contact: Jan Pignalosa (03) 9635 5393.

## Mum's got cancer

'My Mum's got cancer' is a brochure for kids who know someone close to them is being treated for cancer.

It includes basic information, and is produced and distributed by the Anti-Cancer Council of Victoria.

For copies, phone 13 11 20 (Victoria only) or visit [www.rch.unimelb.edu.au/gcrc/patinfo/kids.htm](http://www.rch.unimelb.edu.au/gcrc/patinfo/kids.htm)

## everycloud.com

As well as supplying books about breast cancer, everycloud.com (originally Breast Cancer Book Service) sells books, music, videos and audio tapes about health and lifestyle topics by mail order and online. See [www.everycloud.com](http://www.everycloud.com) for product reviews and other services.

Contact: Leonie Young, (07) 3341 7570, or [leonie@everycloud.com](mailto:leonie@everycloud.com)

## Help for hair

US researchers have developed a gel that may help prevent the hair loss and baldness often associated with chemotherapy. The treatment works on rats and mice, but its safety must be tested before it can be made available to humans. Ironically, the compound works by stopping hair growth.

## Meet our representatives

One of the Network's most important projects is *A Seat at the Table*. It aims to find women who can represent other women with breast cancer on boards and committees around Australia.

Here are a couple of our women hard at work as 'consumer representatives'.

In the last issue of *The Beacon* we ran an article about the Sentinel node biopsy clinical trial (SNAC trial) being conducted by the College of Surgeons.



Avis Macphee

The College has now appointed Avis Macphee of Victoria to ensure that the interests and issues of women are considered during the trial.

Avis is a long-time advocate and supporter for women with breast cancer.

Following her diagnosis in 1992, Avis was the fifth patient treated with high-dose chemotherapy and stem cell transplantation in Australia.

Since then, Avis has set up a support group for women at the Bone Marrow Donor Institute and continues to be its co-ordinator. She considers this one of her most important jobs, but is

also interested in research, information for women, early detection and issues for younger women, lesbians and rural women.

Avis represents women on a number of boards and committees, including BreastScreen Victoria, the Victorian



Diane Shore

Breast Cancer Research Consortium, and the trials committee for the Victorian Cooperative Oncology Group.

Diane Shore of Mackay, Queensland, has been

appointed to the Mackay District Health Council for a four-year term.

Diane was first diagnosed with breast cancer in 1985 and then again in 1996.

She has been involved in the Breast Cancer Support Service for a number of years and co-ordinates a local social cancer support group.

An initial member of the National Breast Cancer Centre's Consumer Advisory Group, Diane became interested in becoming a representative after completing advocacy and science training for women with breast cancer in 1997. She is particularly interested in issues for rural women.

## Stretch your way to better health

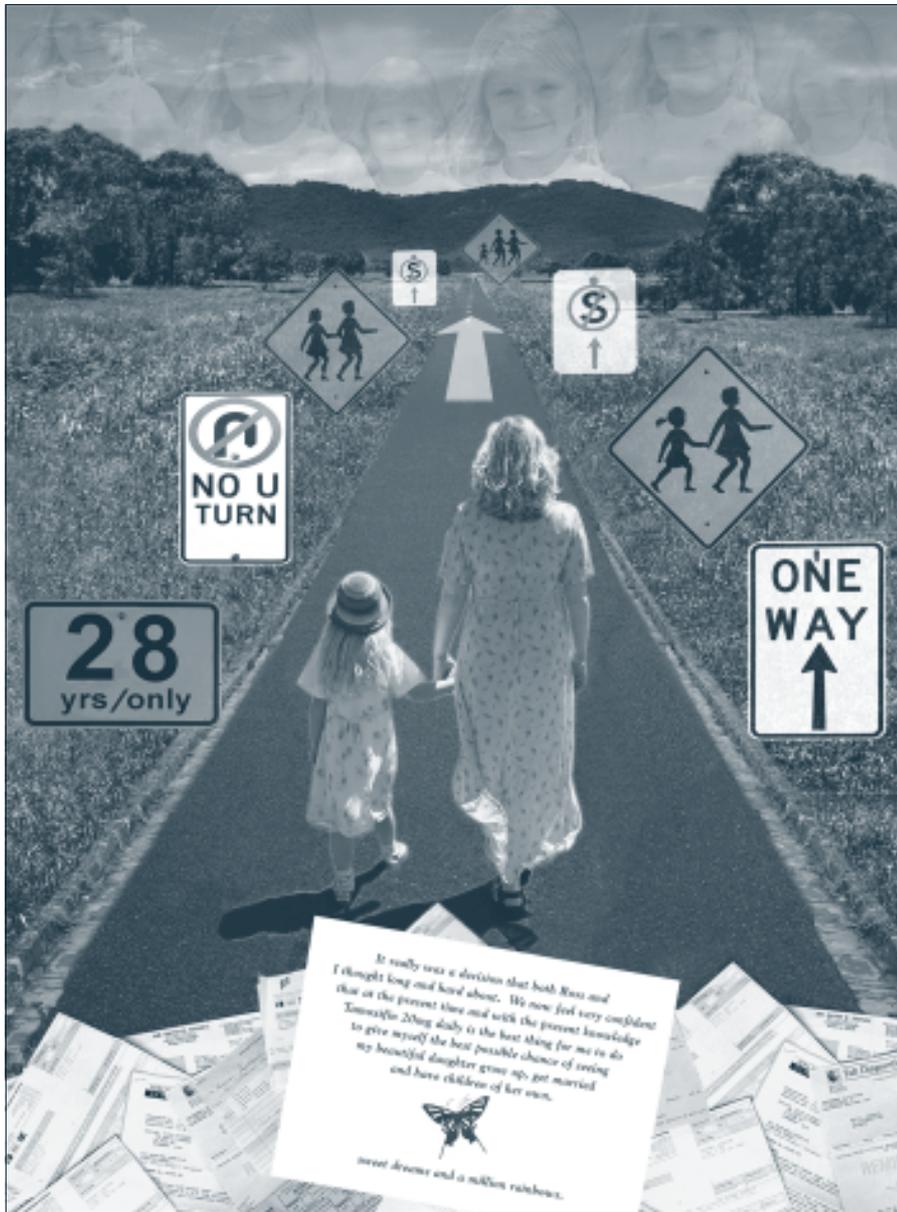
Brisbane's Wesley Breast Clinic has released a new version of its Stretch exercise program on video.

The program is designed to help women work through issues associated with breast cancer by maintaining a positive and confident attitude. This is combined with exercises to aid shoulder mobility and re-adjustment after breast surgery.

This 35-minute video is helpful for all women, particularly those living in rural and remote areas, and anyone unable to access services due to transport restrictions, domestic commitments or physical symptoms.

The video costs \$10.00 and is available through the Wesley Breast Clinic or everycloud.com.

# Warrior women illustrate their battles against breast cancer



This piece was one of the moving exhibits in the recent Warrior Women exhibition held in Melbourne (See Victorian state report on page 3).

## YOU'RE NOT YET ON OUR MAILING LIST?

Contact: Gil Paulsen, phone (03) 9805 2500, 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: ( ) .....

Have you had a diagnosis of breast cancer?  Yes  No

## Field of Women 2001 to come to local communities

The Field of Women sends home the Network's most powerful and visible message.

The 10,000 pink silhouettes remind us of the 10,000 Australian women diagnosed with breast cancer each year. The 2500 white silhouettes say that we lose far too many women to this disease.

The statistics are immense, but each pink silhouette makes its own statement. It says that breast cancer is not just about tests, treatments, doctors, scientists, etc. It is about the WOMEN who face this disease, and the need to focus on them and their families, and provide the best care on offer.

This year's major Field of Women will be planted in Adelaide during October.

To take the silhouettes and their message to as many people as possible, we will also plant a Field in Brisbane during September to coincide with the Goodwill Games.

Last year, women across Australia planted their own fields in places such as Coffs Harbour, Whyalla and Kalgoorlie. This year, we'd like to see even more mini-fields planted around the time of Australia's Breast Cancer Day on October 22.

If you are interested, the Network could send you 100 pink silhouettes for a Field of Women ceremony in your community.

A set of guidelines has been developed, to ensure the Field of Women remains a Network event.

Why not see if you can get others involved? If you are interested, ring your state representative (contact details are in the state reports), phone our national office on (03) 9805 2500 or write to BCNA, PO Box 4082, Auburn South, Victoria 3122.

This is your chance to get involved!

## UPCOMING EVENTS

**March 2-28:** Cycle for Abreast. The latest adventure for the Fenceliners group. This time they are cycling around Tasmania.  
Contact: *Lorrie Ledwell 0417 433 389.*

**March 7:** Communication course for health professionals – weekly sessions (Wednesdays 5.30-8.30pm) at 10 St Andrews Place, East Melbourne.  
Contact: *Dr Michelle Bishop (03) 9656 1111.*

**March 17-April 7:** Life after breast cancer – supportive and informative small group sessions conducted by Breast Link (4x2 hour, Saturdays 2-4pm), Sandringham, Victoria. Cost \$120 (\$100 conc.).  
Contact: *Anne Fletcher (03) 9585 7737.*

**March 24:** Free public meeting sponsored by National Breast Cancer Centre, Hobart. Speakers include Sally Redman and Lyn Swinburne.  
Contact: *Maureen Ramsden (03) 6336 2249.*

**March 27:** Annual General Meeting of Fenceliners Inc., 1pm Devonport, Tasmania  
Contact: *Lorrie Ledwell 0417 433 389.*

**March 28:** 'Time Bomb', a play from the UK about breast cancer, YWCA Sydney.  
Contact: *Sue Jennings (02) 6649 3202.*

**April 7:** Free state public meeting sponsored by the National Breast Cancer Centre. Speakers include Sally Redman and Lyn Swinburne.  
Contact: *Anti-Cancer Foundation of SA on 13 11 20 or Carlene Butavicius, BCNA State representative on (08) 8272 2895.*

**April 9 and 11:** 'Time Bomb', a play from the UK about breast cancer, Grafton, NSW. Followed by a natural therapies demonstration. Cost is \$20 (\$10 conc.)  
Contact: *Sue Jennings (02) 6649 3202*

**April 17:** 'Time Bomb', Lismore, NSW.  
Contact: *Kirsty Pavlovic (02) 6622 3547.*

**April 18:** 'Time Bomb', John Flynn Private Hospital, Inland Drive, Tugun, Queensland. Cost is \$20 (\$10 conc.).  
Contact: *Jackie Morgan (07) 5591 1500.*

**April 20-23:** Spirited Women Workshop for under 45s.  
Contact: *Quest for Life Centre (02) 4883 6599 or e-mail [info@questforlife.com.au](mailto:info@questforlife.com.au)*

**April 28:** Free public forum sponsored by National Breast Cancer Centre, Queensland Cancer Fund, Brisbane. Speakers include Sally Redman, Jane Turner, Neil Piller, Chris Pyke and Neil Wetzig.  
Contact: *Megan Collier (07) 3258 2264.*

**April 28:** Advances in the prevention and management of lymphoedema, a free public seminar, 2pm, St Vincent's Breast Centre, Toowoomba, Queensland.  
Contact: *Margaret Dittman (07) 4688 5300.*

**May 15:** Male partners of women diagnosed with breast cancer – education and support program, Peter MacCallum Cancer Institute, Melbourne.  
Contact: *Andrea Cannon (03) 9656 1111 (page 1203).*

**May 27:** Breast Cancer Action Group NSW general meeting, 3pm, YWCA, Sydney.  
Contact: *Sally Crossing (02) 9436 1755.*

**July 13-15:** 'Sharing the journey', Champion Retreat Centre Kew, Victoria.  
Contact: *(03) 9853 8641.*

**August 3-5:** Tasmanian Lymphoedema Conference, St. Mary's, Tasmania.  
Contact: *(03) 6372 2900.*

**October 22:** Australia's Breast Cancer Day

**October 25:** Bosom Buddies 1901-2001 Celebration of Life Fashion Parade, 7.15pm, National Convention Centre, Canberra.  
Contact: *Norma Bradley (02) 6254 4286.*

## New on the Website

- Four Women and a Funeral: A moving and personal story, with accompanying photos, by four-year survivor, **Bronwyn Taylor**.
- Jill's story: Thirteen years ago, when she was 26, **Jill Meissner** found a breast lump and was diagnosed with breast cancer.

Her cancer returned in 1997 starting a battle with bone metastases and secondaries in her lungs, then a brain tumour in January 1999. Jill has survived all this to become a Network consumer representative, using her experiences to help others.

Visit our website at [www.bcna.org.au](http://www.bcna.org.au)

## Recommended reading

We are often asked to recommend books for women with breast cancer.

We are happy to suggest good books, such as 'My Left Breast' by Sydney woman, **Barbara Joss**, but think it is time to make up a list based on feedback from our readers.

Which books or tapes have you found useful, inspiring, informative? Were there any you recommended to partners, friends, children, etc?

Write or e-mail us your recommendations and we'll publish the list in the next issue of *The Beacon*.



## Seeking Shelter

The Network welcomes this group under its umbrella:

- The Noosa & District Breast Cancer Support Group.

Discuss the Network with your group and let us know if we can create another link!

Contact: *Gil Paulsen, PO Box 4082, Auburn South, Victoria 3122, phone (03) 9805 2500 or e-mail [beacon@bcna.org.au](mailto:beacon@bcna.org.au)*

## THE BEACON

*The Beacon* is the newsletter of the Breast Cancer Network Australia.

Editor: *Lyn Swinburne (03) 9805 2500*

Layout: *Substitution*

Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria 3122.

