The Field of Women continues to grow ...

The latest national statistics on cancer were released in a new document by Dr Michael Wooldridge, the Federal Minister for Health in July.

The document, ‘Cancer in Australia 1991-1994’ (with projections to 1999) shows that while the number of deaths from breast cancer appears to be stable, the incidence of breast cancer is on the rise – an average rise of 3.3% a year.

When we began our ‘Field of Women’ campaign some months ago, we planned to plant 10,500 silhouettes in the lawn outside Parliament House; 2500 white silhouettes representing the number of deaths each year and 8000 pink silhouettes – one for each woman diagnosed. Following these latest figures, we now need to plant 12,500 silhouettes instead. There are now 10,000 women being diagnosed each year.

Many of you saw Australia Post’s breast cancer stamp last year. The stamp recorded one in 14 as the lifetime risk of a breast cancer diagnosis for Australians.

The figure is now one in 11! We should be outraged.

Remember, every single one of those 10,000 statistics is a living, breathing woman with her own life, plans, dreams ... with her own family, friends, colleagues and loved ones.

This is the message we must convey through the ‘Field of Women’.

How can these statistics be overlooked when our silhouettes are planted, row after row, in the Canberra lawns?

It is vital that each silhouette carries a personal message about a real person.

We need your help to find sponsors for each silhouette. This is something you can do to give these numbers real meaning.

The Australian Breast Cancer Network is still in its infancy, but women from all around Australia have told us this Network and its activities are important to them.

Women in Tennant Creek, Flinders Island, Kalgoorlie, tell us they look forward to receiving their copy of The Beacon.

You are aware that our seeding funding runs out in October. If we are to continue, we need financial support from our silhouette sponsors – please pass on our brochure to others. They are available from Beaurepaires stores throughout Australia.

National Breast Cancer Conference for Women: Making a Difference Canberra, October 16-18

Information, conference programs and registration packs are available by phoning (02) 9334 1850
State round-up: On the road to Canberra

**Victoria**

The Anti-Cancer Council of Victoria has given a generous grant of $5000, which will pay for a coach to Canberra and overnight accommodation for 45 women. This will mean that Victorians, particularly rural women, will not be held back through lack of finances. Places on the coach are filling up fast.

Contact: Jenny James (03) 9457 5977.

**South Australia**

The advocacy group, Action for Breast Cancer SA was launched in Adelaide by the Shadow Minister for health, Lea Stevens. It is continuing to raise funds to ensure the voices of SA women are heard in Canberra.

Contact: Denise Weinert (08) 8294 6435.

**Western Australia**

A very successful Women’s Forum was held in Perth on August 3, with 320 in attendance. Getting to Canberra from WA is a huge task, but some are determined to join us and are seeking sponsors through local community service groups.

Contact: Carol Bishop (08) 9381 2070.

**Northern Territory**

A full page of the Darwin Suburban newspaper announced the NT Women’s Forum. More than 50 women from as far afield as Alice Springs and Katherine came together in Darwin on August 1.

A part from the group issues workshops, the highlight was the open question session with the NT Minister for Health, Dennis Burke. An issue for those present was the lack of any radiotherapy unit in the Territory. The Minister explained the situation from his perspective, and promised to take on board the women’s concerns.

The group is busily working to send 10 NT women to Canberra.

Contact: Susan Tully on (08) 8927 3327.

**New South Wales**

In case NSW women are having difficulty getting to Canberra, The NSW Cancer Council has agreed to sponsor a bus between Sydney and Canberra (and back!).

Women in rural NSW could consider connecting with the bus, or they might car pool direct to Canberra. Local fundraising to sponsor representatives is underway in some regions.

Contact: Sally Crossing (02) 9436 1755.

**The ACT**

Many local women have kindly offered to billet interstate women in their homes.

Volunteers from the ACT Cancer Society’s Breast Cancer Support Service will show their support in a marvellous way by helping plant the Field of Women silhouettes.

This is a huge task and will mean that most of the 12,500 silhouettes will be in place on the Sunday morning before the rest of us arrive for the ceremony and to plant the final 1000 silhouettes. Others are busy preparing for the Bosom Buddies Fashion Event and Dinner to be held on Saturday evening.

Contact: Anna Wellings-Booth (02) 6247 8470.

**Queensland**

The newly formed state advocacy group has decided that its immediate focus is to ensure the voices of Queensland women are heard in October. They have formed two committees – one to fundraise, the other to publicise their mission.

They are encouraging community groups to sponsor Queensland women to Canberra.

Contact: Janelle Gamble (07) 3353 4151 (bh), or Leonie Young (07) 3341 7570 (ah).

**Tasmania**

Following the Women’s Forum in Launceston, a state-based network has been formed under the leadership of Pat Mathew. It hopes to have Tasmanian delegates in Canberra.

Contact: Pat Mathew on (03) 6492 3257.
I t appears to me that it is still not recognised that emotional counselling and support needs to be part of the whole treatment of cancer.

At least, that was my experience after my diagnosis of and treatment for breast cancer in Canberra, and this has been echoed by many cancer patients I have met since moving to Sydney.

Why is it not accepted that the diagnosis of a life-threatening illness is a realistic trauma in anyone’s life?

My life will NEVER be the same. I may not have been given a death sentence, but I have received a life sentence. I do not live my life in fear and most of the time I am fine, but inevitably become anxious if I start feeling unusually tired or it is time for my regular review with my oncologist.

I felt there must be something wrong with me, because I didn’t want to hear how “marvellous” her life was when mine felt like hell and I had an ex-husband who couldn’t/wouldn’t take our disabled 16-year-old daughter more often while I was fighting this battle.

My self-esteem was shattered. If a man left me when I was whole, who would want me now I was mutilated?

The messages I got were that I needed to be brave and positive, people really didn’t want to hear my true feelings. I was also put in touch with a volunteer, who spoke to me on the phone twice. However, the support group was more an information source, which was valuable in its own way, but it did not address my emotional needs.

The volunteer allotted to me talked about what a loving, supportive husband she had and how her family kept her on her toes by insisting she go bushwalking with them. No, she didn’t feel devastated by the loss of her breast and several years down the track everything in her life was marvellous.

During my treatment, I tried to keep my life as normal as possible. I don’t think I had ‘room’ to deal with my emotions, but it would have been a great help to know my night-terrors were part of a grieving process.

I attended the local breast cancer support group a couple of times and was also put in touch with a volunteer, who spoke to me on the phone twice. However, the support group was more an information source, which was valuable in its own way, but it did not address my emotional needs.

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The messages I got were that I needed to be brave and positive, people really didn’t want to hear my true feelings. I was also frightened to be open with my mother and adult children, because I didn’t want to upset them.

Emotions pushed down do not go away. They bide their time and will be noticed eventually.

In my case, I had a complete emotional break-down six weeks after my treatment ended. I made some momentous decisions about my life and moved to Sydney, sending my daughter to live with her father (giving him no choice), but my problems came with me.

Fortunately, the oncologist I was referred to is patron of an experiential support group. For the first time, I had a forum to talk about what it really felt like to have cancer.

I have been going regularly to this group for the past three years and honestly feel this saved my life.

Despite a good prognosis, at the end of each treatment I was convinced I was going to die within a year. What became my true healing was finding out that other people had the same tumultuous emotions. Having a safe place to express my fears, anger and grief, and not to be told that I was irrational, not to be told that I must be positive, not to be told to put it all behind me, not to be told to forget that I had ever had cancer and get on with my life, was the best medicine for me at that time.

Sharing my experience of cancer with other group members freed me from the desperate need to try and share it with other people who were uncomfortable or afraid of these big feelings. I was then able to relate to people outside the group on other matters.

Being able to express all these ‘negative’ sentiments in a group of people who really knew what I was talking about, without being judged, enabled me to move through them and arrive at that much-touted positive place.

My conviction that this type of support is invaluable in treating cancer patients is so strong that I studied counselling for two years and will be starting a group of my own in Sydney’s North Shore, under the auspices of the group which has given me so many benefits – the Life Force Foundation.

If you recognise yourself in this story or feel an experiential support group would help you, contact Life Force for further information.

There are groups in Sydney at Edgecliff and A nnandale, and a new group will be starting at Chatswood in October. There is also an affiliated group in A lbury.

Life Force Foundation Limited, PO Box 1663 Bondi Junction, N SW 2022, ph (02) 9363 0034, e-mail: lforce@netspace.net.au or www.netspace.net.au/~lforce

ISSUES OF CONCERN ...
Caloundra Support Circle

There are lots of ways we can help ourselves but, first and foremost, attending a support group is a vital step towards self help.

According to a landmark study by Dr David Spiegel published in ‘The Lancet’ in 1989, patients attending a support group on average lived twice as long as those in the control group and with far better quality of life.

Other studies by Jean Richardson at the University of Southern California and Fawzy et al have provided evidence that psychological intervention has measurable physical consequences.

“In the past year, three meta-analyses of psychosocial interventions in cancer care have been published. Devine and Westlake reviewed 116 studies and found significant benefits. Meyer and Mark examined 45 studies and found small but significant benefits. Sheard and Maguire found that for anxiety, group therapies were at least as effective as individual, if not more so, and greater effects were found for longer therapies. These meta-analyses offer incontrovertible evidence for the benefits of psychosocial support for people with cancer” (Professor David Kissane, Peter McCallum Cancer Institute, Melbourne. Published in ‘BreastNews’, Autumn 1997 Vol 3, No 1).

Judy Irvine

Meeting the challenge of cancer

There are lots of ways we can help ourselves but, first and foremost, attending a support group is a vital step towards self help.

The message is loud and clear, if you want to improve your quality of life and give yourself the chance to extend your life, belonging to a cancer support group is the best thing you can do.

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Judy Irvine

Australian breast cancer advocates visit Washington

In May, four Australian Network members attended the US National Breast Cancer Coalition’s Conference for Breast Cancer Advocates in Washington – Sally Crossing (NSW), Linda Reaby (A CT), Sue Lockwood and Lyn Swinburne (Victoria).

For a copy of the US report, write to Lyn Swinburne, PO Box 4082, Auburn South, Victoria 3122.

Right: A damp but determined Sally Crossing makes a statement in the shadow of the Capitol Building in Washington D.C.
A support group – Why?

After completing my treatment for breast cancer in February 1996, most of my ‘support people’ went back to their daily routines, telling me that “Now everything is okay, get on with your life”. I found that slightly difficult!

Later that year, I learned there were breast cancer support groups all over Australia. While at a meeting in Sydney, Joan from Port Macquarie spoke about how she had started one in her home, meeting every so often, having a cuppa and a chat. I felt, “This is for me!”

After six months, armed with a great deal of advice and knowledge, I set the ‘opening’ date in my home for the first Tuesday of every second month.

My family and friends said, “A support group – Why?” My explanation came as a surprise, as they felt I was, “Really good; back to my old self”.

I agreed I was, to a certain point. However, underneath I still felt the need for understanding and emotional support.

Our group started with just three. Now the numbers wax and wane. The important part is not the numbers of people there, but the spirit of understanding, sharing and caring that exists between us all.

While family and friends give support in their own special way, the support we receive from each other as breast cancer survivors is unique.

The meaning of support (according to the Chambers Family Dictionary): “To hold up, bear part of the weight of, to give power of resistance, enable to endure, to supply with means of living”. Ain’t that the truth!!

Dr Noni Holmes

I protest. I didn’t want Noni to die. She was too clever, too loved, too young.

Dr Noni Holmes died May 14, 1998. She was 43 and about to move to Newcastle to take up a four-year post-doctoral National Health and Medical Research Council fellowship.

She had spent her Easter break paddling down the Murray and speaking with rural women about breast cancer as part of Following the Fenceline’s 1998 journey ‘Mainstreaming the Message’.

The day before she left for the Murray River, she had spoken clearly and passionately about research at the concluding session of the Victorian Forum for Women with Breast Cancer, in Melbourne.

She had also visited her doctor to discuss the implications of the abdominal pain she had been feeling.

A diagnosis of advanced liver metastases and bone secondaries was made on her return from the Murray.

Three weeks later she was dead.

In those three weeks, after thoroughly discussing her options, she decided against further treatment and went about systematically organising her life in preparation for a early closure.

She packed up her office at RMIT University, distributed her professional resources to colleagues and made a living will. She visited the MUA picket down at the wharves in support of the waterfront workers.

With great compassion, clarity and calm, she set about informing friends and spending time with us. She also spend reflective and quiet time alone.

Her energy and her health waned.

Noni managed her dying the way she did her living. With forthrightness, independence, and relating to lots of people individually and meaningfully.

In consultation, she assigned roles and chose tasks. From a friend with metastases, she asked for advice. With another she shared a cigarette. Others were asked to do errands or provide transport. Noni had the ability to make those who loved her feel special.

Noni was someone who got on with things. She didn’t hold back. Earlier than anyone thought, she died, released from the dreaded prospect of slow debilitation and physical deterioration and with an efficiency that shocked.

In lieu of flowers, Noni’s family requested that donations be made to the Network. Noni will be one of our silhouettes in Canberra in October.

Her obituary was published in ‘The Australian’ and ‘The Age’ and there is talk of establishing a environmental science scholarship in her name. It recognises her and is an acknowledgment of vast grief. However, none of this makes up for our loss.

– Tess Moloney
Tamoxifen: The US facts

The last issue of The Beacon reported on the US clinical trial looking at the drug Tamoxifen and the possibility it will stop the development of breast cancer. After the hype, some facts are becoming clear. About 13,388 healthy women at high risk of developing breast cancer participated in the trial, which compared Tamoxifen with a placebo over a four-year period.

The results showed a 45% reduction in the risk of breast cancer for women who took Tamoxifen, compared with a placebo. However, this ‘benefit’ was tempered with a series of side effects.

In all trials, a data-monitoring committee meets regularly to determine whether or not the results of the trial meet the previously defined criteria for success or failure.

In this case, the trial met the defined criteria for success and was closed. All the women in this trial will be followed up for two years or perhaps longer.

It will be some time before the final results are available. While it appears Tamoxifen may be help prevent breast cancer, there are other significant risks. These risks appear to be more significant in women over 50.

There are many questions still to be answered. Is this true prevention or is Tamoxifen just delaying the development of breast cancer? Will women who develop breast cancer after using Tamoxifen have tumours more resistant to treatment? Which women might benefit most from Tamoxifen taken as a preventative agent?

Similar trials, such as the IBIS trial in Australia, are continuing, in the hope of answering some of these questions.

Until the results of these trials are available, a woman should only take Tamoxifen to prevent breast cancer as part of a clinical trial. It is vital women entering these trials have all the facts, to weight up the benefits and risks.

- Sue Lockwood

The interim results of the US clinical trial of Tamoxifen.

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<th></th>
<th>Tamoxifen group (no. of events)</th>
<th>Placebo group (no. of events)</th>
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<td>Breast cancer</td>
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<tr>
<td>Ductal carcinoma in situ</td>
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<tr>
<td>Fractures</td>
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<tr>
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<tr>
<td>Pulmonary embolism</td>
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<td>6</td>
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<tr>
<td>Deep vein thrombosis</td>
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<tr>
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<td>329</td>
</tr>
</tbody>
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Lymphoedema alert!

Victorian Network member, Merran Hall, has an idea to help women at risk of lymphoedema. She has had 500 adjustable wrist bands printed featuring the warning: LYM PH OED EMA A L E R T

No blood tests, blood pressure No I.V. or injections into this arm!

Merran says women are pleased to wear these pink wrist bands, especially if they are undergoing chemotherapy, as it is easier than “going through the rigamarole of explaining why they request needles and blood pressure sleeves in the other arm”.

If you are interested in a wrist band for yourself or members of your group, Merran asks for a contribution of $1 a band and a self-addressed envelope. She is happy to cover the bracelet cost herself, if this is a problem.

You can write to Merran at 804 Burke Road, Camberwell, Victoria 3124 or telephone her on (03) 9882 7576.

Catalogue of Resources on Breast Health and Breast Cancer

‘The Catalogue of Resources on Breast Health and Breast Cancer’ is a new resource available free of charge from the National Breast Cancer Centre, 153 Dowling Street, Woolloomooloo, NSW.

The catalogue lists more than 300 booklets, brochures, books, videos and other resources for:

• the general community;
• women with breast cancer and their families;
• women from non-English speaking backgrounds;
• Aboriginal and Torres Strait Islander women; and
• health professionals.

Updated versions will be regularly listed on the centre’s Internet home page at http://www.nbcc.org.au

The materials in the catalogue can be obtained directly from the suppliers listed in the back of the booklet.

If you would like to borrow any of the books or videos listed, contact the centre’s librarian, Claire Pillar, on (02) 9334 1716 or e-mail claire.pillar@nbcc.org.au
The birth of Phoenix Breast Feather

The malignant lump, sinister and invasive, had finally been removed.

Along with it went my small and vulnerable left breast, which had harboured the insidious intruder.

I looked appraisingly at myself in the mirror and acknowledged that I would need a swag of good coping skills to help me through the next few months of radiation and recovery.

Most of the material I had read on visualisation sounded helpful, but I felt it had been written with someone else in mind – not me! I needed some magic which was strong, powerful and uniquely mine. Where would I look?

On my walk each day, I gladly embraced my surroundings, reveling in the beauty of the area I was staying in for the period of my treatment.

One morning I found a feather. It was black and shiny, rounded at the tip, and I felt it was a gift from a crow.

A keen bird watcher for many years, I had developed quite a passion for feathers, and their shape, colour and endless variety gave me great pleasure. In fact, I enjoyed them so much, I displayed my collection in a beautiful basket at the entrance to my lounge, where it created a talking point and was much admired by my friends. At the clinic, I fell into the habit of using the black feather as a bookmark in whatever I was reading. It became my talisman.

Then, as I lay under the large, computerised machinery which delivered the carefully calculated zaps of radiation to my wounded left side, it came to me clearly – I would use feathers in my healing visualisation.

I chose the phoenix because this mythical beauty was the only one of its kind, fabled to live 500 or 600 years. It would sing its death song to the sun, burn itself on a funeral pile and rise to be reborn from its own ashes, restored to live through another cycle.

I liked that word picture. I could relate to that. Hadn’t I been burnt, risen again, restored and given a new smack at life? Yes! Phoenix Breast Feather and I became one. With such a powerful name and image to live up to, I needed it to be officially bestowed on me. I felt all I had experienced deserved acclaim. I wanted to clang cymbals, ring bells, bang drums and blow horns. Medals could be struck, ribbons, perhaps a knighthood? “... A rise Phoenix Breast Feather, you have fought well and W O N, and because of this we want to give you a very high honour ... a new name.” It all sounded pretty good to me.

My friends decided to take matters into their own hands and they planned a naming ritual.

They asked two things of me – to look up the meaning of my given name, and any other names I’d been known during my life, and to write down on cardboard arrows, which they had prepared beforehand, any thoughts or feelings I wanted to be rid of.

We dressed ceremoniously, lit candles, burned incense and carefully selected drumming music. We honoured the four directions, called in any power animals, and prayed and meditated. We danced and sang, and I burnt the arrows over the charcoal pot in the centre of the circle.

I was, in truth, burning my old self, and being reborn from the ashes, just as the Phoenix of Arabia did in ancient mythology. We had a wonderful celebration. I accepted my new name with the solemnity the occasion deserved.

I still use my given name, but for sheer magic, power and strength, I can call on Phoenix Breast Feather at any time and remember well her birth, at a very traumatic period in my life.

– Judy Irvine
aka Phoenix Breast Feather

My Journey

If you would like to share your story with others, send it to Lyn Swinburne, who will have it included with our other women’s stories on the Internet. (If you like, there is no need to include your surname). The Internet address is www.nbcc.org.au
LAUNCH OF BREAST CANCER NETWORK AUSTRALIA

Breast Cancer Network Australia’s (BCNA) inaugural National Meeting will be held at 10.30am on Sunday, October 18, after the summary session of the Canberra Conference.

The agenda will include:

- organisational structure;
- identification of state and territory Network representatives;
- the Network’s strategic plan; and
- long and short-term targets.

Members’ feedback is being sought on the draft strategic plan. If you would like to comment, write to PO Box 4082, Auburn South, Victoria 3122, for a copy of the plan.

At 1pm, women attending the conference, supporters and friends will gather in front of the old Parliament House, to walk silently carrying two or three silhouettes each to the lawn area in front of the new Parliament House. Most of the silhouettes will already be in place and we will then ‘plant’ the final 1000 silhouettes in our ‘Field of Women’.

BCNA’s formal launch will follow, with some brief speeches. We will then observe a moment’s silence in memory of the women who have died from breast cancer.

Delegates will then be invited to move among the silhouettes to read the messages recorded on each figure. This will mark the end of our time together in Canberra.

UPCOMING EVENTS

September 12-13: Talking about Cancer – A workshop for professionals conducted by the Life Force Foundation.

Contact: (02) 9363 0034.

September 13: Edwardian tea at Mooloolaba House, Brisbane, 3-5.30pm, to raise funds to send two women to Canberra.

Contact: Sally Rickson (07) 3345 5263.


Contact: Leah Salo (02) 9334 1850.

October 17: Bosom Buddies Fashion Event and Dinner: A Celebration of Life. $55.

Tickets available through Ticketek, phone charge (02) 6248 7666.

Contact: A nna Wellings-Booth (02) 6247 8470.

October 24: Fourth Annual Breast Cancer Information Day for women with breast cancer, their families and friends at Royal North Shore Hospital, Sydney. $25, bookings essential.

Contact: (02) 9363 0034.


Contact: (02) 9363 0034.

October 26: Australia’s Breast Cancer Day. For information on local activities, contact your state or territory Cancer Council.

- To include events in The Beacon’s summer issue (December, January, February), please submit notices by the end of October.

THE BEACON

The Beacon is the newsletter of the Breast Cancer Network Australia. We wish to acknowledge the contribution made by the NBCC in providing funding for the production and distribution of the newsletter.

Editor: Lyn Swinburne
Design: Liz Grant, (03) 9898 8834
Layout: Substitution, (03) 9576 1510

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

YOU’RE NOT YET ON OUR MAILING LIST?

Contact: Lyn Swinburne, phone (03) 9660 6865, fax (03) 9662 3881
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

Send us your thoughts!

In the next issue ...

- Field of Women and Conference wrap up

Seeking Shelter

We welcome the following groups, which are linking up under the Breast Cancer Network Australia’s umbrella:

- M oree Breast Cancer Support Group
- Royal Adelaide Hospital Breast Cancer Support Group
- Bendigo Breast Cancer Support Group
- Breast Cancer Survivors Coffs Harbour
- Breast Cancer Support Geelong
- Inner Balance Women’s Cancer Support Group, Albury
- Friends of the Wesley Clinic, Brisbane.

Please discuss the Network with your group and let us know if we can create another link. Remember – there is strength in numbers!

Contact: Lyn Swinburne, PO Box 4082 Auburn South Vic 3122 or phone (03) 9660 6865.