



The Beacon

Breast Cancer
Network Australia
newsletter

New Network logo

Since the Network was established in October 1998, many people have associated the pink silhouette from our *Field of Women* with the Network.

Breast
Cancer
Network
Australia



Following much discussion and many suggestions from our supporters, we have decided to adopt the pink silhouette as our permanent logo.

The silhouette will help highlight the Network's primary focus – the *woman* with breast cancer, her needs and issues, rather than on the disease itself.

The Beacon is printed
with the generous
support of PMP Print.

INSIDE...

STATE ROUND-UP	2
ABREAST INTERNATIONAL	4
HAPPY BIRTHDAY RAELENE	5
ISSUES OF CONCERN	6
MY JOURNEY	8
NEW RESOURCES	10
UPCOMING EVENTS	11

The Field spreads its reach

The *Field of Women* is the Network's powerful annual display of the impact of breast cancer in Australia.

It was the venue for the Network's launch in Canberra in 1998, where the silhouettes were displayed on the lawns in front of Parliament House.

Since then, the *Field* has been seen in Melbourne (1999) and Perth (2000). It will be seen in Brisbane as this newsletter reaches readers.

The *Field* says so much of what we need to tell people. That breast cancer:

- affects so many women and their families – 10,000 newly diagnosed each year;
- takes an enormous toll – more than 2500 women die each year; and
- hits real people, who are far more than mere statistics.

The messages attached to the silhouettes offer hope, encouragement and inspiration to those living with breast cancer; while others pay tribute to the women we have lost.

In October, the *Field* will appear again – in Victoria Square, Adelaide.

The *Field* will be in place from October 20 to 22, with the official launch on Sunday, October 21. Join the *Field* at 10.30am for the launch at 11am. As part of the ceremony, a silent walk will take place through Victoria Square.

We hope that thousands of South Australians will pay their own tributes by visiting the *Field* in Adelaide and reading the messages attached.

Many members have contacted the Network's office keen to hold a mini *Field of Women* in their local community on October 21 or 22, to coincide with Australia's Breast Cancer Day.

We have produced guidelines for this and will offer Network members a resources kit, including 100 pink silhouettes, to help make this happen. A listing of all the mini *Field* sites is on page 3.

We are including a *Field of Women* sponsorship brochure with each copy of **The Beacon**. You, or someone in your family, might want to record a message on a silhouette, or you might pass it on to a friend.

The cost of a silhouette sponsorship is \$20. Once a message is recorded, it becomes a permanent part of the exhibition. Next year's *Field of Women* will be seen in Sydney.

We are grateful to **New Idea** for sponsoring this year's *Field of Women* events.

New Idea
Major Sponsor
The Field of Women 2001

Bakers Delight give even more help!

Bakers Delight helps the Network in so many ways. It gives us free, fully equipped office space in Melbourne, and has raised money to help us implement projects for Australians affected by breast cancer.

Now Bakers Delight has found a new way to lend a hand. On October 20, Bakers Delight will give the Network 50¢ from every \$2.30 block loaf sold in its stores around Australia.

Field of Women sponsorship brochures will also be available in their stores in

the weeks before, as will posters to tell the public about the event and the opportunity to dedicate a message.

Tell your friends and colleagues about the Bakers Delight block loaf offer.

We would like to encourage you to buy a block loaf and, while you're there, tell the Bakers Delight manager about your Network connection.

It'd be great if you'd thank your local Bakers Delight people for supporting the Network so much. Their generosity should be acknowledged!

State round-up

SOUTH AUSTRALIA



Preparations for the *Field of Women* on October 22-24 are well underway, with the program in the competent hands of project manager, **Cath Tonkin**.

For information about the Field or to offer your help, phone Cath on (08) 8333 3964.

Action for Breast Cancer SA held a one-day workshop in Adelaide for the co-ordinators of their breast cancer support groups on July 14.

Ten groups, including one for Greek women, and others in Port Lincoln and Whyalla are well established, but we have identified a need for several more, particularly for Italian women in the north-eastern suburbs.

SA has been introduced to the dragons boat concept. We are working under the auspices of the Department of Recreation and Sport, and with the assistance of **Tim Monson**, president of the Dragonboat Club SA. Phone me on the number below for information.

The public Lymphoedema Screening Project moved to Port Augusta in June. This will further the work of **Professor Neil Piller** and **Jenny Donovan** from Flinders Medical Centre in detecting lymphoedema in 'at risk' people before the problems can progress.

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

NEW SOUTH WALES



Among the recent activities attended was the opening of the Pam McLean Cancer Communications Centre, performed by **Professor Marie Bashir**, Governor of NSW.

The day's convenor, TV personality, **Julie McCrossin**, gave DragonsAbreast a huge mention, insisting that even the Governor join in the round of applause.

On May 29, the importance of consumer participation in health care was highlighted when I spoke at the University of Technology, Sydney's Faculty of Nursing, Midwifery and Health Graduation and Prize Giving Ceremony. The address focused on the topic of consumerism in health care.

Dr Philip Clifton-Bligh gave an informative talk about osteoporosis as a side effect of chemotherapy at the May meeting of Breast Cancer Action Group (BCAG).

For the record, BCAG (NSW) now has the honour of Vice-Regal Patronage, recognition of its support for breast cancer services.

Another active band is the Illawarra Breast Cancer Support Group. Following the advice of oncology nurse consultant, **Gloria Swift**, I got myself on the mailing list for the group's newsletter. Their activities are not only inspirational but sound like fun. Phone **Robin Gregory** on (02) 4296 4200 for information.

The NSW state representative contact from August 21 to October 16 will be **Robyn Wicks** on (02) 9843 3172.

Contact: **Pam Bell** (02) 9955 9313 or bellpc@bigpond.com

VICTORIA



Recent activities in Victoria highlighted the variety of interests and concerns of those affected by breast cancer.

The Breast Cancer Action Group held a meeting to update and inform us about the drug Herceptin and, with the Network, to formulate a policy for treatments such as this – caught in the politics of pharmaceutical companies and the public purse.

A Consumer Science and Advocacy Training Program has prepared 20 women to join committees and review panels.

The Warrior Women exhibition is touring country Victoria, so many more people will have the opportunity to see the members' artistic and creative talents.

We will celebrate Australia's Breast Cancer Day with mini *Fields of Women* in Melbourne and around the State.

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

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

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

Raelene Boyle's 50th birthday and five-year breast cancer survival party was a most successful evening for Raelene and the Network, something reflected in the media coverage of the event.

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

THE ACT



Having been absent from Australia for seven weeks, all I can talk about is dragon boating (see article on page 4).

However, I must emphasise that even though dragon boating takes up a lot of my time, I am involved in many other activities on behalf of the Network, as indeed are fellow members.

Many of us are on local committees, including Breast Screen, Health Care Consumers ACT, Breast Cancer Treatment Group – ACT and South Eastern NSW Region, as well as representing consumers on national committees.

We are serious about representing you in State and Commonwealth arenas.

Contact: **Anna Wellings Booth** (02) 6247 8470 or wfamily@interact.net.au or **Elspeth Humphries** (02) 6239 6344

WESTERN AUSTRALIA



There was some minor changing of the guard at the recent annual general meeting of Action on Breast Cancer, which well attended.

One of our members, **Kris Spackman**, attended the Consumer Participation in Cancer Care Meeting held by a COSA Steering Committee in Melbourne in July.

The Health Consumer Council of WA recently hosted a consumers' advocacy course. Several of our members attended and found it interesting and informative.

The Western Australia Clinical Oncology Group has asked Action on Breast Cancer (AoBC) members their views regarding Herceptin. We want to join with them in lobbying the PBAC to make this drug more affordable.

AoBC has been offered sponsorship from Vianet, which has agreed to develop our web page. We thank it for its support and hope our association will be a long and happy one. The site should be up and running shortly.

A small committee has been formed to promote breast cancer awareness by holding mini fields of FOW silhouettes in several shopping centres throughout the state (To be involved call me at the number below). We are being supported in this by Breastscreen WA.

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



NORTHERN TERRITORY

Weather-wise, the NT is the best place in Australia at this time of year. In the Top End we think it's cold if it gets below 20°C at night!

More news on the breast cancer nurse front – **Stephanie Gaynor** has been appointed as Central Australia's first breast care nurse. Phone her at the Cancer Council on (08) 8927 4888.

On September 29, **Senator Trish Crossin** will host a public meeting for women who live in the Palmerston area – please phone Senator Crossin's office on (08) 8931 0830 for details.

Our new Administrator and his wife have agreed to host a lunch at Government House in October, following last year's successful luncheon.

Many activities have been planned across the NT for Australia's Breast Cancer Day – contact us for details.

If you are in Darwin, don't forget that the Darwin Runners Club will be holding a gold coin donation running event on October 24 – all proceeds will go to the NT Breast Cancer Voice (we're sure you can also walk this event).

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



QUEENSLAND

The Wesley Breast Clinic is planning a gala fashion event at the Greek Club and Convention Centre in the West End on October 25. All the models will be breast cancer survivors, modelling fashions by **Bianca Steffini**, as well as underwear and swimwear by Coloplast. If you would like to join this evening of fashion and fun, phone **Barbara Quinn** on (07) 3232 7594.

Workshops for the Strengthening Support for Women with Breast Cancer Project took place in Brisbane on August 3. They addressed issues for women in south-east and central Queensland.

A luncheon at Lennons on October 24,

as part of Breast Cancer Awareness week, will be a joint project for the Queensland Cancer Fund, BreastScreen and Queensland Women in Public Service.

The guest speakers will include the Premier's wife, **Heather Beattie**, **Jenn Scott** and **Janelle Gamble**. For bookings, phone **Megan Collier** at the Queensland Cancer Fund on (07) 3258 2200.

Cairns – far-north Queensland

A workshops for the Strengthening Support for Women with Breast Cancer Project were held on August 25 to address issues for women in far-north Queensland.

During Breast Cancer Awareness Week, the following activities have been organised for Cairns:

- October 22 – breakfast meeting with a special guest speaker.
- October 24 – Looking Good after Breast Cancer Surgery workshop.
- October 27 – Connect Program.

For more information, phone **Mal Fraser** at the Queensland Cancer Fund Cairns, (07) 4031 1555.

Contact: Leonie Young (07) 3255 2355 or Janelle Gamble (07) 3353 4151.



TASMANIA

Several of our members attended the Tasmanian Cancer Summit in May. Its purpose was to bring people together from across the State to discuss the issues relating to the impact of cancer in Tasmania.

Siobhan Harpur has started work on the three-year project, Strengthening Support for BC, based on Making A Difference, and has been talking with groups and individuals from urban and remote areas.

Pat Mathew spoke about the Network, lymphoedema and the role of consumer advocates to Smithton, Burnie and Devonport Palliative Care volunteers in July and August. She also spoke to the Devonport Caprice Club, which has decided to buy a variable height massage table for use in lymphoedema treatment at the Devonport Community and Health Centre.

Some of our members will be involved in the Palliative Care Conference in Hobart on September 11-14. It is to be attended by 500-700 delegates.

The next meeting of the Tasmanian Network will be at the fire station in Campbell Town on November 17.

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

Join one of our mini Fields of Women

Not everyone will be able to join us at this year's main *Field of Women* in Adelaide.

However, many women are planning mini Fields in their own communities around Australia (see list below).

For more information, contact your state representative or phone Wendy at the Network's head office on (03) 9805 2500.

ACT

Canberra

NSW

Campbelltown	Illawarra region
Griffith	Goulburn
Sydney	Taree
Penrith	

Queensland

Toowoomba	Cairns
Victoria Point	North Brisbane
Southport	Bundaberg
Laidley	Ipswich

South Australia

Mount Gambier	Murray Bridge
---------------	---------------

Tasmania

Hobart

Victoria

San Remo	Bendigo
Ringwood	Traralgon
Meadow Heights	Melbourne
Ferntree Gully	Heidelberg
Ararat	

Western Australia

Perth	Midland
Rockingham	Albany
Geraldton	Karratha
Kalgoorlie	Booragoon
Cannington	Mirrabooka
Warwick	Joondalup
Floreat Park	Innaloo
Whitfords	

New Idea

Major Sponsor

The Field of Women 2001



Twenty two hearts beat as one in Canada

I was extremely privileged and humbled to be part of the Internationally Abreast team that competed in Toronto, Canada, during the dragon boat festival in June.

The organisers had also asked me to make a presentation about the *Field of Women* at a breast cancer conference in conjunction with the festival and it was extremely well received.

There were 13 crews of breast cancer survivors competing in the festival; that is 13 x 22 women in each boat.

We competed in the open division, as well as the breast cancer survivor races and won our division admirably.

There were five Australians on the international team: **Janelle Gamble** from Queensland, **Caroline Bommer** from Sydney, **Margaret Wolf** and me from Canberra, and our indomitable captain, **Michelle Hanton**, of Darwin.

Michelle's captaincy was inspirational and we were indeed 22 hearts beating as one as the call was made and the starter's gun sounded.

Emotions were high and the feeling of camaraderie and oneness with



The victorious Australians of the Internationally Abreast dragon boat team. Clockwise from the back: Anna Wellings Booth, Caroline Bommer, Janelle Gamble, Margaret Wolf and Michelle Hanton.

women we had never met before was something we shall never forget.

There were women in wheelchairs, women with metastatic disease, women from all walks of life united in demonstrating that we can and will beat breast cancer.

The following quote is from a letter written by Charles, the husband of Eleanor, one of the conference organisers and the woman I paddled

behind. He wrote: "This weekend has been a special kind of success. You have earned the right to wear your cancer experience as a special badge of honour. Your joie de vivre, excitement and caring for one another help to slay the dragons of fear and anger. The search for the elusive 'grail' is not easy for anyone, but together you light the way."

Dragon boating is not for everyone, but if you give it a go, I hope you all experience an international festival.

You don't have to paddle to be part of it. And if you do paddle, you don't have to be super-fit (I'm a prime example). Supporters are of equal importance and extremely welcome. We represent the Network wherever we go and the pink silhouettes also enjoyed their Canadian experience.

I would like to take this opportunity to thank Michelle Hanton for setting the Australian dragon boat movement in motion after hearing **Sharon Batt** at our Canberra conference in 1998.

Go the Pink Ladies!

– Anna Wellings Booth, Canberra.

National dragon boat championships

As an unlikely person to go paddling, the National Dragon Boat Championships in Darwin was some of the most fun I've had post-breast cancer.

Part of the bribe to get me to participate was a promise that I would be the team's drummer. Having never seen a dragon boat up close, I wrongly assumed this was a cushy job.

I will never forget our sweep Steve's advice, when I asked – white-faced and white-knuckled – how I was to keep my balance on that tiny seat high above the crew. His response – "Spread those buttocks and hang on in" – will be imprinted in my memory forever.

It was amazing how quickly I learnt to paddle – just to get out of the hot seat; even though I did fancy myself in the daisy-adorned pink wig I had bought for the role of drummer.

A poignant moment came at the conclusion of the day, when the three



Almost the little drummer girl! Pam Bell at the National Dragon Boating Championships in Darwin.

dragon boat teams cast orchids on the water during a minute's silence in honour of the more than 2500 Australian women who die of breast cancer each year. On-lookers joined in the tribute, adding to its significance.

As we came ashore, the crews of the other dragon boats formed a guard of honour. There wasn't a dry eye in the place – even spectators were choked up as we ran under their outstretched arms.

Another memory was the Dragons Abreast team escorting the torch for the commencement of the Arafura Games being held the following week.

I even worked a Darwin anecdote into my presentation as occasional speaker at the University of Technology, Sydney's graduation ceremony a few weeks ago. Official photos were taken for its web site, but now there has been a request for a dragon boat one!

Bakers Delight staff from two local outlets (Crows Nest and Neutral Bay) were thrilled to see evidence of their sponsorship. I suggest others with similar photos take them in for a 'show and tell' session, so that the franchisees can see the good they help generate.

We came home with more than just our gold, silver and bronze medals – we also won a sense of achievement and happy memories.

– Pam Bell, NSW

Happy birthday Raelene, a real survivor

On June 15, 1100 friends, family and supporters helped celebrate **Raelene Boyle's** 50th birthday and five-year survival of breast cancer.

It was a spectacular evening in Melbourne, generously sponsored by **Australia Post, Crown** and **FCL Transport**. TV personality, **Eddie McGuire**, did a sensational job as MC.

Moving speeches from Raelene, the Prime Minister, **John Howard**, and the Network's National Co-ordinator, **Lyn Swinburne**, highlighted the achievements and challenges of Raelene's life.

Film tributes and poignant images of those personally affected by breast cancer were also shown.

We raised the amazing amount of almost \$350,000 for the Network. This will help cover our core costs, and fund important projects such as 'A Seat at



The Prime Minister, John Howard, was among the guests who helped Raelene Boyle celebrate her 50th birthday.

the Table', the My Journey resource folder for newly diagnosed women, seminars for women with breast cancer and the production of **The Beacon**.

Australia Post and Raelene also provided financial support so that Network members, many of them from country Victoria, could come and help her celebrate.

Their appreciation was obvious in the many letters of thanks Raelene received. For example: "What a great night on Friday. Thank you Raelene

Left: Breast cancer survivors, Carole Heap, Jenny Childs, the Network's National Co-ordinator, Lyn Swinburne, and Donna Rullo, with the Prime Minister, John Howard.



Right: Another athletics champion, Marjorie Jackson, was on hand to help Raelene celebrate.

for opening your heart and giving us the chance to celebrate your birthday and life. As a survivor, it was my celebration also!"

New Idea set up a birthday message hotline and e-mail so that Raelene's friends and supporters who could not join the party could send messages.

These messages were compiled into a book and presented to Raelene at a special function at Government House in Melbourne the following week.

We are grateful to Raelene for her outstanding contributions to the Network, and to those who supported the event through their participation, sponsorship and donations.

The event did so much more than raise funds. The media attention highlighted many issues for women with breast cancer and certainly raised the Network's profile.



Warrior Women win

BreastCare Victoria has agreed to fund a tour by the Warrior Women exhibition through regional Victoria.

First displayed in Melbourne in February, and more recently in Frankston, this exhibition received such positive responses that it was essential to make it available to as many people as possible.

The exhibition is the result of more than 100 women from diverse backgrounds, ages and regions who have had breast cancer. They collaborated

with women photographers, digital designers, video producers, and writers to create images and words reflecting the effect of breast cancer on their lives.

The tour will be launched in Melbourne on October 22 at the Goya Gallery, Southbank. It will then travel to seven locations throughout Victoria.

The Warrior Women wish to thank BreastCare Victoria for its generosity in funding this tour.

Victorians, we urge you to show your support by visiting this impressive and

unforgettable exhibition when it comes to your region. For more information, phone (03) 8430 8419.

Tour dates

Melbourne – October 17-28, 2001

Daylesford – December 1-13

2002

Bairnsdale – March 7-20

Benalla – April 6-20

Warrnambool – May 5-19

Geelong – May 21 – June 2

Bendigo – June 15 – July 1

Mildura – July 5 – August 11

Issues of concern ...



The role of hormones

The role of hormones both before and after a breast cancer diagnosis is an issue of concern to many of our members. The issues are complex and often need to be considered on an individual basis.

We approached **Dr Fran Boyle** with a list of the questions we are frequently asked by members in letters and during phone calls.

Fran is a Sydney medical oncologist and clinical adviser to the National Breast Cancer Centre.

One of her outstanding skills is her ability to explain complex issues in simple ways that we can all understand.

What role do hormones play in the development of breast cancer?

Imagine that breast cancer rises like a weed from a seed under the lawn.

The seed may lie dormant for many years; then, with the right growth conditions, sprout and become visible.

Hormones are like the fertiliser you put on the lawn – they make the grass grow, and, if they are there, the weeds sprout faster.

The hormones, primarily oestrogen, that make the normal breast grow, come from the ovaries in young women in cycles. Throughout life, a smaller, steady trickle of oestrogen is also made in fat cells.

Oestrogen may also support the growth of breast cancer, but hormones are not what puts the 'seed' there in the first place – that is unknown in most cases.

HRT is like continuing to have cycles



Fran Boyle, medical oncologist, Sydney.

– it increases the total time the breast is at risk, but if there are no seeds there, it is perfectly safe.

When I had breast cancer, pathology reports showed my hormone receptor status. What does it mean to be hormone receptor positive or negative?

Receptors are like the doorways that hormones use to get into the breast cell to deliver messages that its time to grow. They are still present on most breast cancer cells and can be seen when a special stain is applied to the tissue (receptor positive). This allows oestrogen to support the growth of the cancer cell.

Blocking the receptors (e.g. with Tamoxifen) or reducing the amount of

oestrogen being made by fat cells (e.g. with aromatase inhibitors) may therefore starve the cancer cell and help in treatment.

Some cancer cells lose the doorways as they grow (receptor negative) – probably because they are able to switch on growth in other ways, so don't bother to keep making doorways. That means that receptor blocking drugs will not help in treatment.

How many pre-menopausal women who have chemotherapy never have a period again?

After CMF chemotherapy for six months, women under 40 years have a 40% chance of menopause, over 40 it is 70%. With Adriamycin-containing chemotherapy for three months, menopause is less likely. With longer treatments, the risk is higher.

When I had chemotherapy, I went into instant menopause. I now have hot flushes. What can I do about them? How long will I have them?

Hot flushes happen because the pituitary gland (at the base of the brain) senses that there is not enough oestrogen around. It puts out hormones to 'kick start' the ovaries and it is these that cause the flushing. The pituitary is most active at night, so flushes may be worst at night. This same process happens during natural menopause.

In some women, the pituitary gets the message quickly that its activity is not getting anywhere and flushes settle within a few months or never happen.

On average, they are bad for six months, then gradually improve. However, even after natural menopause, one sometimes meets women who flush forever. Why the difference? Maybe it is due to different background levels of oestrogen.

Flushes can be helped by:

- avoiding things that precipitate them – some triggers may be coffee, alcohol and stress;
- relaxation and meditation – their effectiveness is currently being studied;
- a blood pressure tablet called clonidine

New book

A new book has been released called, *Surviving Survival: Life after Cancer*, by **Miles Little, Christopher Jordens, Kim Paul and Emma-Jane Sayers.**

It is available from the Australian Consumers Association for \$25, plus postage. Phone (02) 9577 3399.

- anti-depressants – venlafaxine is the one that has been trialled, but others probably also help;
- a herbal preparation called remifemen may help; and
- hormone replacement therapy (see below).

Soy diets and other ‘natural’ supplements have proved disappointing in trials.

Should I be concerned about osteoporosis in the longer term? What can I do about this?

Osteoporosis is less common in women with breast cancer and Tamoxifen appears to protect against it. For women with menopause before the age of 50 who are not on Tamoxifen there is a risk of bone loss. It is worth checking bone density to ensure it’s okay at baseline, especially if there are other risk factors, including thyroid disease and a family history.

Calcium, vitamin D and regular weight-bearing exercise are important.

Studies are on-going for drugs such as clodronate and these should be considered if bone density is falling despite other measures.

Is hormone replacement therapy safe for a woman who has had breast cancer? Is anyone doing research in this area?

Traditional wisdom is that the fertiliser should be put away if there might be weeds in the lawn, so HRT has been avoided in the past.

Several recent studies have compared women who continued HRT with those who stopped and found no additional risk of breast cancer relapse. However, these studies are likely to be biased in a number of ways, so a randomised trial is being performed to test the issue properly.

The study is called HABIT and is available for Australian women. Information can be obtained by phoning the ANZ Breast Cancer Trials Group on (02) 4968 9803.

Are there any ‘natural’ therapies that can help with menopausal symptoms?

See above

I suffer from a dry vagina and intercourse is uncomfortable. I do not want to take hormone replace-

ment therapy. What else can I do?

Some things that help vaginal dryness are:

- not washing with soap – use a substitute, as you would on your face;
- regularly using a moisturiser, e.g. Replens or Silk;
- using a lubricant during intercourse;
- treating infections such as thrush; and
- using oestrogen in the vagina – Vagifem is recommended, as it is not absorbed into the rest of the body

I feel I need specialist advice – what sort of doctor should I see?

Most medical oncologists will be able to assist, but consider a gynaecologist with an interest in menopause or gynaecological oncology, or an endocrinologist who specialises in osteoporosis as an alternative.

For women in NSW, the Natural Therapies Unit at the Royal Hospital for Women in Randwick runs a number of trials and can provide information.

Dr Susan Love’s Hormone Book

Many readers of *The Beacon* know and love *Dr Susan Love’s Breast Book*; considered by many as ‘the bible’ on anything ‘breasty’.

Dr Susan Love has also written a book about hormones, *Dr Susan Love’s Hormone Book*. It is published by Random House.

In an empowering and demystifying book about menopause, Susan, a noted breast surgeon and women’s health advocate, tells it straight about hormones.

“Hormone therapy is neither a fountain of youth nor an ‘evil empire’,” writes Susan and her co-author, **Karen Lindsey**.

“I can’t tell you in this book whether or not you should take hormones, but I can spell out the pros and cons, examining the various promises that have been made for

menopausal hormone therapy, and letting you know what the side effects and dangers can be.”

Before she gets into the promises and the pros and cons, Susan explains what menopause is biologically and how its symptoms can vary widely. Particularly fascinating is the second chapter, *The Medicalization of Menopause*.

Susan’s examination of how women in other cultures look forward to menopause, and why the medical establishment and the pharmaceutical industry have a vested interest in making menopause a disease, is a convincing one. It puts menopause and hormone therapy into a new light.

Chapter by chapter, Susan reviews the scientific evidence for the promised benefits of hormone therapy – protection from osteoporosis and heart disease – and for the potential

risks – an increased chance of breast and endometrial cancer.

She also answers almost every imaginable question about alternatives to hormones – dietary changes, to exercise, acupuncture and herbs.

While Susan and Karen, who worked together previously on *Dr Susan Love’s Breast Book*, are up-front about their perspective on hormone therapy, they give women the information they need about the various hormones available and a questionnaire to help them assess their values. That means readers can make an informed choice about hormones during menopause.

This book is not specifically aimed at women who have experienced breast cancer. It has been written for the general population, making it an excellent reference book.

No longer an imposter

My daughter, my sister and I were diagnosed with breast cancer within five years.

You could say that we have a sort of nod-nod, wink-wink camaraderie between us now – our own private speak that tells others they simply wouldn't know what we know, because they haven't faced what we've faced – the experience of cancer.

We are members of an exclusive subgroup of the wider group of breast cancer survivors!

I can only speak for myself in describing the experience of a breast cancer family – tell my own story – although I can make some observations.

Breast cancer has given us all a heightened appreciation of the pleasures of life – large and small.

It has ensured that we are more self-centred and devoted to our health and wellbeing – often a difficult exercise for mothers.

We are also enthusiastically involved in physical activities that keep us fit and strong, eat lots of fruit and vegetables, and drink lots of water and a glass or two of red wine in the evening for its demonstrated health effects, miss no opportunity to walk in the bush and on the beach, travel overseas or interstate, dine with friends, go to the theatre, read good books and see good films. In short, we have adventures.

My sister, a grandmother, has a passion for spending time with her grandson.

My daughter's diagnosis at the age of 31 – she was the first – stands in my memory as the most awful event of my life. Beside it, my diagnosis and treatment seem almost insignificant.

My sister's diagnosis a couple of years later was sad and unwanted, but I did not feel the level of devastation I had when it was my daughter.

By then I had learned a great deal by joining breast cancer advocacy groups, participating in National Breast



Judith Maher (above), her daughter and her sister were all diagnosed with breast cancer within five years.

Cancer Centre workshops and attending cancer conferences.

"You are an imposter," my daughter chided me when I joined breast cancer survivors in lobbying activities. "You haven't had cancer – you don't know what the real experience is!"

When my diagnosis was made a couple of years further on, I knew a lot more about breast cancer and its treatment. I had joined the International Breast Cancer Study (the IBIS) trial of Tamoxifen four years

Welcome to Wendy

Wendy McClusky recently joined the Network team as our community relations officer.

Wendy is busy co-ordinating the *Field of Women* for

Brisbane and Adelaide, as well as all the mini *Fields* around the country.

She is married to Michael and has three young boys to keep her busy.

Wendy has been touched by breast cancer through the diagnosis of her mother-in-law, her cousin and a close friend, and is finding her work at the Network office in Melbourne rewarding, stimulating and challenging.

Welcome Wendy!



earlier to make my contribution to cancer research. I was alert to the signs and was being carefully monitored as a trial participant.

Certainly my diagnosis was a surprise, but only a mild one. The sharpest aspect of that surprise was in knowing I was taking Tamoxifen (I knew this because of the side effects it initially caused me) and having believed that its preventative effects would protect me from cancer.

It didn't and the reason seems to be that this family tends towards the oestrogen-negative cancers that Tamoxifen has no positive effect on.

I got over that surprise and undertook a core biopsy that took nine samples and yet returned a negative result – a result that indicated there was no malignancy.

Before I could get my mind round this pleasing result, I had the offending lump surgically removed and subsequent pathology indicated two small cancers. This was an emotional roller-coaster I hadn't expected!

The best part of the year that followed was when the younger of my wonderful sons put his life on hold and travelled from Brisbane to care for me.

He shopped, cooked, cleaned, and took me to appointments and on outings to enjoy myself. He determined that I needed high-protein meals to speed my recovery – and they needed to be attractive and tasty. He became innovative. It was like having Jamie Oliver in the kitchen!

There is no conclusion to this tale – like all cancer stories it is a work in progress. As my daughter and sister do, I am carrying on my life as before – but with extra verve and greater focus – the gym, swimming, walking with friends, fine dining and entertainment.

I also carry on my advocacy work on behalf of breast cancer survivors – but I am no longer an imposter!

– Judith Maher, Canberra

* *Judith's complete story, including the difficulties she experienced with drainage tube problems, can be found on our web site – www.bcna.org.au*

Bon voyage Polly

Polly Letofsky wandered into our office in October 2000, not knowing anyone at the Network, or really anyone else in Australia.

She said she wanted to raise \$10,000 on the Australian leg of her global walk.

Having collected \$30,000 in donations (ranging from 50¢ to \$2000), she is leaving us.

Life at the Network just won't be the same without Polly's cheery "Hellooo there" every few weeks and her bubbly spirit (even when she has been drenched, cold, hot, driven mad by the flies, dust, humidity or anything else that's gone her way).

In addition to her fundraising, Polly has spread the word about the Network through public speaking engagements, newspaper articles and one-to-one conversations with Australians personally affected by breast cancer.

Thank you to all of those people and groups who have supported Polly and



Victorian state representative, Gerda Evans, with Polly Letofsky.

the Network on the Australian leg of her global walk for breast cancer, especially all the **Lions Clubs**, which were sensational.

Polly is continuing her walk through Asia and would love to hear from those she has met in Australia.

To keep track of her, visit her web site – www.globalwalk.org – or send an e-mail to askpolly@globalwalk.org

Thanks Polly!

More seats at the table

Since our *A Seat at the Table* project began in 2000, 145 women have registered as potential 'consumer representatives'. More than 65 women have been appointed to committees, contributed to decision-making forums and presented at conferences.

Since the last issue of **The Beacon**, these women have been appointed to working groups and committees: *National Breast Cancer Centre's (NBCC) team working with family cancer clinics to improve the quality of the services that they offer to women* – **Sally Lynch** (NSW).

NBCC Improving supportive care for younger women with breast cancer team – **Karen Wright** (Qld) and **Rosanna Martinello** (NSW).

NBCC Young Women's Advisory Group – **Mary Macheras-Magias** (Vic.), **Rosanna Martinello** and **Maryanne Maher** (NSW).

NBCC team developing a web site for use

by clinicians with women newly diagnosed with breast cancer who have a family history of the disease – **Judith Maher** (ACT).

Anti-Cancer Council of Victoria's Cancer Connect Program Planning and Advisory Committee – **Judy Sammut** (Vic.).

NHMRC-funded project 'Consumer information materials and a communication aid for diagnostic tests for breast disease' – **Alex Forster** (NSW).

Queensland Health's Strengthening support for women with breast cancer planning workshop – **Veronica Macaulay Cross, Margaret McKenzie, Julie McGilvray, Sylvia Gustaffson, Kaye McAlister, Leonie Young, Diane Shore, Margaret Petrie, Joan Giachin, Mena Crew, Teresa Sese, Janet Buckett, Beverley Cross and Gladwys Pound** (Qld).

To learning more about *A Seat at the Table*, phone Gil Paulsen on (03) 9805 2500 or e-mail gpaulsen@bcna.org.au

Thanks

In the winter issue of **The Beacon**, we asked readers to help us with the running of the Network by making a donation.

Thank you to all those who sent in donations, which totalled almost \$14,000.

We were also touched by the letters of appreciation we received, especially from those who told us how useful, informative and supportive they found **The Beacon**.

Congratulations Judy

Network member, **Judy Shepherdson**, recently had her volunteer work recognised by the Murray Shire Mayor.

A tribute in *The Riverina Herald* highlighted Judy's endeavours to establish the Echuca Moama Breast Cancer Support Group:

"Judy, having recovered from breast cancer herself, saw a great need for a support group to help women and families dealing with breast cancer in our area. She founded a much-needed group that has assisted many in the region with support and loving care."

We know Judy has worked hard to build up the group and are delighted to see that her efforts have been recognised and appreciated.



Designer help

Liz and Fran at Elisabeth Grant Design in Canterbury, Victoria, are great supporters of the Network.

They have been with us since our Network's earliest days, working on with pro-bono designs and layouts for many of our publications and brochures.

Thanks Liz and Fran!



Helping a friend with the 'Big C'

It's really difficult at times to find the words to say when someone close is undergoing treatment for cancer. We want to help – but we're not sure we know the best way.

Network member, **Kathy Kuipers**, has put together a list of do's and don'ts, as well as some great examples of ways she was helped by friends when it was her turn.

We think this is a fabulous list. Wouldn't it be a really useful resource to hand to a friend who says, 'How can I help?'

We intend to prepare a brochure of Kathy's many strategies for helping for just that purpose. If you have some other ideas, please send them to us for consideration.

Do

- Provide regular meals (if your friend is receiving chemotherapy, ask what she likes to eat).
- Leave cakes and other delights on the doorstep.
- Send cards and flowers for no reason.
- Take your favourite bucket, gloves and cleaning materials when you visit and insist on cleaning the bathroom/tidying the kitchen/hanging out the washing/cleaning the windows/making the beds (make sure your friend isn't in it).
- Help out in the garden, mowing/taking stuff to the dump/weeding.
- Keep your visits short and always ring first.
- Be persistent with following your friend up – she needs you.
- Give her a hug.
- Let her cry and be sad.
- Listen.
- Let her talk about dying.
- Tell her specifically when you can be called on and what you can do (lifts to and from treatment/visiting at the hospital/coffee afterwards/emergency childcare/help with the shopping/going to the library, etc).



Kathy Kuipers,
Queensland

- Help her to make a list of people who can help out in an emergency (phone numbers, times and days of availability).
- Lend her trashy novels or mindless magazines.
- Organise outings with groups of friends (without the kids).
- Care for her partner too (ask your partner to meet him for lunch, take him out for a drink, go to the movies).
- Ask after him as well, not just your friend.
- Ask him about his fears and his feelings (scary, I know).
- Hang in there for the long haul, treatment goes on for months.

Don't

- Tell her about the latest cure you have heard about (she's probably already been told about it by five other people).
- Say things like 'There must be some reason for this', 'Everything will

turn out well in the end' or 'You look good' (Yeah, yeah, sure!).

- Tell her all your other cancer horror stories.
- Tell her all the ways she ought to be modifying her diet/changing her lifestyle/doing more relaxation (it's hard enough getting out of bed in the morning without thinking about changing *anything*).
- Give up on her or stop ringing.
- Be offended if she doesn't get back to you (life may be overwhelming and energy lacking).
- Be afraid of taking the first step and offering to help out, have a cuppa, a chat or whatever.
- Be afraid that you 'Won't know what to say' – be yourself, that is your gift to someone whose life is changing.
- Accept 'I'm fine' when you ask after her or her partner.
- Say 'Call me anytime' or 'If there's anything you need ...' Be specific – 'I will bring a meal on Tuesdays', 'I will pick your child up from pre-school', 'I will baby-sit your child while you have a nap', etc (it can be incredibly difficult to ask for help).

Good things my friends gave me

- A celebration morning tea on the day I finished chemo.
- Wonderful meals (and desserts).
- One group of friends all wore hats on an outing when I had no hair!
- Encouragement to keep going when I wanted to give up.
- Cleaning the bathroom, cleaning windows, hanging up the washing (a problem after surgery that reduces the strength and endurance of arm movement) and pushing the shopping trolley.
- A week's holiday at a resort!
- Many treasured gifts, such as a special teacup, books, beautifully fragrant soap and a massage each week.

ABCD web site

The iSource National Breast Cancer Centre has launched the Australia's Breast Cancer Day (ABCD) web site, containing a nation-wide calendar of events.

The site is a chance to facilitate a co-ordinated approach to breast cancer activities during October in the lead-up to ABCD on October 22.

If you would like your event listed on the site, forward your details to **Jenny Davis** at jennyd@nbcc.org.au or phone (02) 9334 1711.

UPCOMING EVENTS

September 1-7: Special *Field of Women*, Suncorp Metway Park (opposite Treasury Casino), Brisbane (Silent Walk and launch September 1).

Contact: Lyn Pelgrove, *Twelfth Night Theatre*, (07) 3252 5122.

September 7: New Idea Breast Cancer Forum, Wollongong (\$5).

Contact: (02) 4272 4482.

September 15: Gawler Foundation's 18th annual conference, 'Holistic Approach to Surviving Cancer', Camberwell Centre, Victoria (\$80, bookings essential).

Contact: (03) 5967 1730.

September 15: Metastatic Breast Cancer Information Day, Royal North Shore Hospital, Sydney (\$20, bookings essential).

Contact: Mandy O'Reilly, (02) 9926 7810, or Louise Kippist, (02) 9926 6584.

September 20-22: Australasian Society for Breast Disease Meeting, Marriott Resort, Surfers Paradise, Queensland.

Contact: (07) 3846 1585 or e-mail info@asbd.org.au

October (date to be advised): NT Breast Cancer Photographic Exhibition.

Contact: NT Cancer Council, (08) 8927 4888.

October 3: Action for Breast Cancer SA's AGM, Anti-Cancer Foundation, Adelaide.

Contact: Bridget Mills, (08) 8336 8140.

October 13-14 and November 4: Cancer Consumer Advocacy Training, Sydney (free).

Contact: Ron Gale, (02) 9334 1748.

October 17-28: Warrior Women Exhibition, Goya Gallery, Southbank, Melbourne.

Contact: (03) 8430 8419.

October 20: Best Breast Breakfast, BCAG(NSW) and NSW Breast Cancer Institute, at Old Government House, Parramatta (\$10).

Contact: (02) 9845 8450 or 8468.

October 20-22: Major Field of Women, Victoria Square, Adelaide.

Contact: Cath Tonkin, (08) 8333 3964 or 0408 050 594.

October 21-22: mini Fields of Women across the country.

Contact: Wendy McClusky, (03) 9805 2500.

October 21: Moving Forward – young women and breast cancer forum, Novotel, Darling Harbour, Sydney.

Contact: NSW Cancer Council, (02) 9334 1846.

October 21: ACT mini *Field of Women*, Lake Burley Griffin (meet at Regatta Point).

Contact: Anna Wellings Booth, (02) 6247 8470, or Tania Pirotta, (02) 6230 9154.

October 22: Australia's Breast Cancer Day.

October 22: 'Pink Ribbon Breakfast on Australia's Breast Cancer Day', Sydney.

Contact: Belinda Gibson, (02) 9300 6735 or e-mail belinda.gibson@bigpond.com

October 24: Darwin Runners Club's special gold coin donation running event (All proceeds to NT Breast Cancer Voice).

Contact: Michelle Hanton, (08) 8941 8923.

October 24: Australia's Breast Cancer Day Lunch, Lennons Hotel, Brisbane, hosted by Queensland Women in the Public Service (QWIPS), supported by Queensland Cancer Fund and BreastScreen Queensland. Guest speaker: Heather Beattie.

Contact: Marianne Zangari, (07) 3350 7426.

October 25: Bosom Buddies 1901-2001 Celebration of Life Fashion Parade, National Convention Centre, Canberra, 6.15pm for 7.15pm.

Contact: Norma Bradley, (02) 6254 5286.

October 27: Early breast cancer information day, Royal North Shore Hospital, Sydney (\$30).

Contact: Mandy O'Reilly, (02) 9926 7810, or Louise Kippist, (02) 9926 6584.

October 28: Thanks to women for participating in clinical trials, Goya Gallery, Southbank, Melbourne, 2pm. All welcome.

Contact: Susan Fitzpatrick, (03) 9635 5175.

November 13: Education and support program for male partners of women diagnosed with breast cancer, Peter MacCallum Cancer Institute, Melbourne.

Contact: Andrea Cannon, (03) 9656 1111.

November 17: Tasmanian Network meeting, Campbell Town fire station.

Contact: Joan Williams, (03) 6421 7700.

December 9: BCAG (NSW) final general meeting for the year.

Letters to the Editor

I wish to thank **Kathy Kuipers** for the article, *Facing the Fears and Loss* in issue 15 of **The Beacon** (see my letter below).

Thanks also to the Network for putting together such an informative newsletter. I haven't known about **The Beacon** for long, which is a shame, but I am making sure that everyone I come into contact with in my situation is fully aware of it and able to benefit as I do. Please keep up the good work.

– Wendy Hall,
Palm Beach, Queensland

Dear Kathy

After reading the article you wrote in the latest issue of *The Beacon* I felt I had to come here to my computer and write to you immediately.

Thank you for putting into words so many of the emotions I have felt over the past 11 months. Thank you for admitting that it's not such a wonderful experience and thank you for showing me that there is light at the end of the tunnel.

Your words have given me such a boost, just by letting me know that I'm not alone – a feeling I'm sure you're no stranger to. I agree that a lot of good can come from the horrible experiences we must go through and I try hard to make my life better because of them (sometimes I think I succeed, but other times I probably don't do such a good job). We all need words of encouragement and it makes all the difference when they come from someone in the same boat.

Kathy, if your aim in writing this article was to reach out and touch others, let me say that you have most definitely succeeded. I wish you happiness, health, strength and courage in your journey.

– Wendy Hall

I am writing to highlight the marvelous efforts of the Illawarra Breast Cancer Support Group.

Gloria Swift and a group of ladies travelled to Albury, Wagga Wagga and Griffith to hold meetings for the breast cancer support groups.

They gave us an insight into how and why their support group was successful.

And this was done at no cost to us. They paid for all their accommodation, travel costs, etc.

The Albury group would certainly would like to say a big thank you to them. That's what networking is about!

– Carol Stevenson, Albury



BreastCare supports Victorian women

BreastCare Victoria is an initiative of the Victorian Department of Human Services. It is working to improve outcomes for Victorian women and their families affected by breast cancer.

Many Network women are on BreastCare committees across the State and, together with doctors and administrators, are trying to make things better for women in their area.

Many organisations pay lip service to the need for consumer input, but BreastCare Victoria has 'put its money where its mouth is'. It has recognised the need for women involved in this work to be supported and trained, and

to increase their knowledge of the latest areas of interest in breast cancer.

Health professionals attend conferences to update their knowledge; and now our representatives can too. BreastCare Victoria has set up a grant scheme, to be administered by the Network, that will allow women to attend these conferences.

Guidelines and application forms are available from the Network's head office if you want to apply for a grant.

This is a wonderful initiative, which the Network is delighted to support. We hope other state Health Departments will follow Victoria's lead.

THE BEACON

The Beacon is the newsletter of 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.

Young women's day

Moving Forward will be a forum for young women with breast cancer.

It will be a chance for young women touched by breast cancer, their families and health professionals to hear from Australia's top experts; express their concerns; address the specific issues that apply to young women; and propose solutions.

In addition to the up-to-date medical information, the day will offer advice about fertility, health and lifestyle factors such as relationships, nutrition and coping strategies.

Young women will also be able to meet other young women and get practical help to act on now.

This is an initiative of Young BCAG (Breast Cancer Action Group) NSW and is endorsed by the Cancer Council NSW. Breast Cancer Network Australia also supports this initiative.

Moving Forward will be held at the Novotel, Darling Harbour, Sydney on October 21, from 9am until 4pm.

Contact The Cancer Council NSW on (02) 9334 1846 to register.

New risk management clinic in Melbourne

A risk management clinic will open at the Familial Cancer Centre of Melbourne's Peter MacCallum Cancer Institute during September.

The clinic will be for women with an especially high risk of developing breast or ovarian cancer. For example, women with a strong family history or a mutation in BRCA1 or BRCA2.

These women, who will have had their risks assessed by a family cancer clinic, will attend the new clinic every six months for mammograms, transvaginal ultrasounds, blood tests (e.g. Ca125) and breast examinations.

A breast surgeon, a gynaecologic oncologist and a cancer genetic specialist will be on hand for breast examinations and to discuss the results of the day's tests or any other issues that come up about each woman's personal risk management plan.

Each woman will see the same team

of specialists during their visits, and a specialist nurse will be a first point of contact for problems between visits.

Although this will be Australia's first risk management clinic, similar bodies have been running for several years in the UK and Canada.

Contact: *Mary-Anne Young*, (03) 9656 1064.

New on the web site

- Judith's story – **Judith Maher**.
- Details about the *Field of Women* and mini-Fields across Australia.
- Guidelines for conducting a mini-Field in your community.
- A full report about **Raelene Boyle's** birthday celebrations and acknowledgements.
- The Network's policy on Herceptin.
- The Network's member groups.
- Complete state reports.

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: () E-mail:

Have you had a diagnosis of breast cancer? Yes No



Seeking Shelter

The Network welcomes these groups under its umbrella:

- Albury Wodonga Breast Cancer Support Group, NSW
- Port Adelaide Breast Cancer Support Group, SA

During the next few months we will be contacting all our member groups. We hope that each of them will be able to identify a woman from their group willing to be their Network contact person. This should make contact between us all much easier, and allow us to involve you all much more in our projects and activities.

