



# The Beacon

Breast Cancer  
Network Australia  
newsletter

## Learning more about a family's breast cancer risk



Sisters, Gerda and Doone, are two members of a breast cancer family. For their story, see page 6.

**T**his issue of *The Beacon* considers genetics and the role heredity plays in breast cancer.

This is a complex field, which is still evolving for the scientists. It has enormous ramifications for our society and the individual.

We have tried to address the questions most frequently asked about this subject by readers of *The Beacon*.

It is important to note that most women who get breast cancer do **not** have a family history. In fact, it seems likely that fewer than 5% of breast cancers are the result of a genetic susceptibility.

We also know that women are more likely to over-estimate their level of risk and that family members may be over-anxious as a result.

For those at high risk, due to a significant family breast cancer history, the issues can be overwhelming. We must ensure that these women are given expert advice, support and care.

The National Breast Cancer Centre has published a useful guide for

women, *Breast Cancer and Family History: What you need to know*. It includes a section explaining how you can assess your level of risk, and might be helpful for you or others in your family with concerns.

As with other issues of *The Beacon*, we've tried to offer quality information from the experts, as well as the ever-important articles by women who have been personally affected.

A matter of real concern for us is the news that US company, Myriad Genetics, has secured the patent for the testing of breast cancer genes, BrCa1 and BrCa2.

If this company were to impose a licence fee on Australian laboratories, as it has overseas, the cost of a genetic test to people outside research studies could rise to more than \$5000.

This would make genetic tests unaffordable for many Australians. It would also be an unfair extra burden for women already struggling with the complex and diverse challenges faced when considering genetic testing.

– Lyn Swinburne, Editor

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### Pedal Power

Find out about the Fenceliners' latest adventure in Tasmania on page 8.

# State round-up



## QUEENSLAND

Feedback has been extremely positive from the National Breast Cancer Centre-sponsored public forum in Brisbane on April 28.

More than 200 women (and a few men) heard presentations from **Sally Redman, Jane Turner, Neil Piller, Neil Wetzig** and **Chris Pike**.

The opening ceremony for the 2001 Field of Women will be held on Saturday, September 1, following a seminar at the Wesley Hospital Auditorium.

Everyone who attends the seminar will be transported to the gardens for a silent walk along the Grand Arbour at Southbank Parklands. Phone **Jan Bewes** on (07) 3855 1448.

On a sad note, we report the passing of **Rae Arnold** and **Maureen Kirk**, two women who worked tirelessly for Queensland women with breast cancer.

The Mater Private Breast Care Unit in Brisbane is planning a women's health forum.

A date has yet to be set, but phone (07) 3840 1166 for more information.

The Destressing Workshop hosted by the Wesley Breast Clinic featuring complementary therapies such as yoga, aromatherapy and massage was so successful that another has been planned for September.

For information, phone Barbara Quinn on (07) 3232 7594.

The Young Women's Group has hosted a successful fashion parade and has plans for many other interesting activities.

Hildegard from the Royal Brisbane Hospital Physiotherapy Department will speak to More Choices in June about Lymphoedema management.

Phone Barbara Quinn on (07) 3232 7594 for details.

If anyone missed buying one of Polly's T-shirts (proceeds go to the Network), they can be purchased from everycloud.com for \$20, plus \$5 postage and handling.

Best wishes to **Janelle Gamble** for safe and successful trips to Darwin and Toronto with the Dragons Abreast team. She will be a great ambassador for Queensland!

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

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](http://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!



## SOUTH AUSTRALIA

The National Breast Cancer Centre held a public meeting in April for SA women with breast cancer.

The meeting was organised by Action for Breast Cancer and the Anti-Cancer Foundation, and was a wonderful opportunity to hear from the Centre.

In particular, it was a chance for some country women to tell us their concerns and talk with other women with breast cancer. There are obviously still some enormous gaps in communication and we heard of women who are feeling ill-informed and neglected.

Women also heard about the SA Department of Human Services' plans for spending money on women with breast cancer in remote areas.

The Lymphoedema Screening project is under way and moving into country SA. We look forward to hearing the results of this 'first' for Australia.

Recently, I was one of 15 SA women invited to discuss our issues and concerns with **Carmen Lawrence**. This was also an opportunity to network with a group of women passionate about providing services to women.

The Action for Breast Cancer Southern Support Group at Noarlunga is holding its second birthday celebration in July. This group meets on the first Wednesday of the month. Phone **Shirley Paull** on (08) 8556 2700 for more information.

We are working hard to ensure that the WINGS web site supporting women with breast cancer is continued. Lack of dedicated funding has put this project in danger! We'll keep you posted.

**Maxine Barker** from Port Lincoln had a wonderful time in Tasmania on the Fenceliners trip with 15 gutsy ladies!

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



## THE ACT

ACT is basking in the warmth and colours of autumn and, apart from dragon boating, women have been involved in these events:

- the ACT Cancer Society's Relay for Life, where we provided a splash of fluorescent pink in the survivors' lap;
- a day's seminar at the ACT Cancer Society called *Surviving Survival*, presented by **Prof. Miles Little** and his team from the Centre for Values, Ethics and the Law in Medicine;
- the launch of the NBCC's country program, *What do you do when you find a lump in your breast?*, at Parliament House;
- a meeting at Parliament House to establish a bipartisan parliamentary support group on breast cancer;
- **Shirley Fitzgerald's** *Caring for You* workshop, where the guest speaker, **Margaret Robinson**, a pharmacist from the University of Queensland, spoke about depression; and
- representation at the NBCC's Communication Skills Workshop.

Contact: **Anna Wellings Booth** (02) 6247 8470 or [wbfamily@interact.net.au](mailto:wfamily@interact.net.au) or **Elsbeth Humphries** (02) 6239 6344



## NORTHERN TERRITORY

At long last the NT has its first breast care nurse – quite a milestone! Her name is **Deb Amery** and she can be contacted through the NT Cancer Council.

It is great to have **Michelle Hanton** on board as the Network's second NT representative. We were all proud of Michelle when she received her recent award (see box story next page).

We would encourage all the NT readers of *The Beacon* to make contact with either Susan or Michelle.

It will be interesting for us to see how far and wide *The Beacon* goes, and it is also a way for us to make and maintain contact.

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



## WESTERN AUSTRALIA

Action on Breast Cancer WA has decided to use some of the funds it has raised to sponsor two nurses to complete the breast care nursing course.

We hope to increase the availability of specialist nursing care in both our city and country facilities.

We feel this will be money well spent and would like to see breast care nurses available to all breast cancer patients.

This would aid recovery and hopefully increase awareness of conditions such as lymphoedema.

Application forms will be forwarded to the directors of nursing in our major city and regional teaching hospitals, to be completed by interested parties.

We hope to have successful applicants confirmed in the not-too-distant future.

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



## NEW SOUTH WALES

Jane Redmond did us proud in March at the ACT conference, *Cancer in the Bush*.

Jane, a dedicated 'bushie', delivered her presentation in an upbeat style that was a hard act to follow, culminating in a grand finale in which she pulled out her prosthesis and flourished it in the air!

Well done Jane – you're a feisty woman!

Meanwhile, BCAG (NSW) is busy preparing for a Mini Field of Women at Old Government House in Parramatta Park on October 20.

This will be a co-operative event, being organised by the Network, assisted by the NSW Breast Cancer Institute for the Best Breast Bunch.

Sally Crossing [(02) 9436 1755] will provide more detail closer to the event.

*Strengthening Support for Women with Breast Cancer*, a meeting to discuss the best use of funds from the Commonwealth Health and Aged Care Grant, was held at Westmead on May 24.

Among the possible uses for the funds is a phone-in centre where rural women could seek information and support.

Good news from the National Breast Cancer Foundation. It will allocate funds to lymphoedema research in this year's grants. The research committee, chaired by **Christine Clarke**, is working closely with **Pam Bell** to ensure that consumers' research priorities are included in advice to grant applicants.

Also of interest is the National Multidisciplinary Care Demonstration Project being conducted at the Randwick Campus by The Royal Women's and Prince of Wales hospitals.

It is being funded by a grant from the National Breast Cancer Centre.

A highlight of the project is the co-ordination of services and support offered by the breast care nurse.

Contact: Pam Bell (02) 9955 9313 or [bellpc@bigpond.com](mailto:bellpc@bigpond.com)



## VICTORIA

There's never a dull moment in Victoria, folks!

Between racing around the 'tan' on Mother's Day and preparing our frocks for **Raelene Boyle's** 50th birthday bash on June 15, there's barely a minute to prune the roses!

The Mother's Day Classic is an annual event in Melbourne and a great alternative to breakfast in bed on that Sunday in May.

All funds raised go to the National

Breast Cancer Foundation for research.

Raelene's birthday party is a major fundraising event for the Network this year. Joining us will be the Prime Minister, **John Howard**, the Governor, **John Landy**, and the Lord Mayor of Melbourne, **Peter Costigan**.

Interested Cinderellas should phone **Jo Cox** on (03) 9585 6880 or 0409 821 947.

All the best, Raelene! Have a fun night, together with your friends and admirers. Thank you from us all for your drive, inspiration and generosity.

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



## TASMANIA

**Jenny Littler** represented women with breast cancer at the 4th Australian Women's Health Conference in Adelaide from February 19 to 21.

She received financial assistance from the Tasmanian Women's Health Centre.

A successful Tasmanian state meeting was held in Hobart on March 4, and was attended by almost 50 women from around the state.

Women attending this meeting were delighted to have an unexpected visit from the Fenceliners at the end of their Tasmanian adventure.

Tasmanian members in various parts of the state hosted the Fenceliners as they cycled around the island.

Mainland members of the Fenceliners were joined by Devonport's **Corrine Day**.

Jenny Littler from the Devonport area was featured in an almost full-page photograph on the front of the north's *Sunday Examiner*, with a lengthy article relating her breast cancer experience.

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

## Congratulations Michelle Hanton

Northern Territory state representative, **Michelle Hanton**, has been recognised for her work for women with breast cancer with the Chief Minister's Women's Achievement Award.

After attending the first National Breast Cancer Conference for Women in Canberra during 1998, Michelle was motivated to get involved in dragon boat racing as therapy and sport for women with breast cancer.

She has represented the NT in interstate and overseas competitions, and is captain of Dragons Abreast, the Network's National Dragon Boat Team.

Congratulations Michelle!



Michelle Hanton (centre) celebrated her Women's Achievement Award with Susan Tulley and Penny La Sette.

## Congratulations

### Patricia Edgar

Congratulations to the chairperson of the BCNA's Board, **Dr Patricia Edgar**.

Patricia, a breast cancer survivor, was recognised for her contribution to Australian culture at the Centenary of Federation celebrations in Melbourne during May.

Patricia, who established the Australian Children's Television Foundation in 1981, was one of 250 Australian women listed in the Firsts and Founders section of the Inaugural Victorian Honour Roll of Women.

We were delighted to see Patricia recognised as an Australian pioneer and are proud of her involvement with our Network.

### Dianne Chellew

Network member, **Dianne Chellew**, from Wollongong, NSW, won a bronze medal in the individual class of the National Kayak Championships in Melbourne during April.

On top of that, she won gold at the State Championships a week earlier and has been selected as Australian team manager for the World Championships in England later this year.

This is fantastic news for Dianne – who is also a member of Dragon's Abreast and achieves fantastically, despite her breast cancer diagnosis.

# New Idea to sponsor of the 2001 Field of Women

**N**ew Idea will be the major sponsor for this year's *Field of Women* events.

New Idea has long been committed to supporting breast cancer initiatives, so the Network is excited by the prospect of joining forces in 2001.

As announced last issue, the Network will host two major fields this year.

The field 'planted' to coincide with Australia's Breast Cancer Day in October will be in Adelaide's Victoria Square.

To become involved, phone **Cathie Tonkin** on (08) 8333 3964 or 0408 050 594.

Network members are also planning mini-Fields in their communities.

They will be sent kits and guidelines to help make this happen.

Queensland members have seized the chance to improve the Network's profile by hosting a *Field of Women* to coincide with the Goodwill Games in Brisbane during September.

The 10,000 pink silhouettes and 2,500 white silhouettes will be planted at Southbank and remain for a week.

Thousands of pedestrians will see the silhouettes and read the messages attached for the women who have been diagnosed with, or lost their lives to, breast cancer.

Brisbane's *Field of Women* will be launched on September 1.

Project manager, **Jan Bewes**, wants to hear from Queensland women who want to attend, and are willing to help on the day or during the following week.

Phone Jan on (07) 3855 1448 or 0418 795 423

New Idea will help promote *Field of Women* events in the magazine.

Bakers Delight, Puma and Spotlight Stores will also be active with their own *Field of Women* initiatives.

Don't leave all the activity up to others. This is YOUR Network!

If you would like to hold a mini-Field in your community, contact us with your plans and we will send you guidelines and 100 silhouettes.

For ideas about becoming involved, phone **Wendy** on (03) 9805 2500 or write to us at PO Box 4082, Auburn South, Victoria 3122.



Photograph courtesy of Sunshine Coast Newspaper

## The latest on Polly ... she's still walking!

**Polly Letofsky's** Australian adventure continues! At the time of writing, she was somewhere near Mackay.

She's had fantastic support along the way from the Lions Clubs, Bakers Delight and Network members. We want to thank everyone who has helped Polly as she walks the length of the country.

The Lions Club has not only raised lots of money for the Network, but it has made sure that Polly is cared for by Lions and Lionesses along the way.

From time to time Polly sends us entertaining and humorous e-mails

recounting her adventures – the highlights (Byron Bay chocolate mud ice-cream), the downsides (flies and mosquitoes) and the amazing people she has met.

She tells us: "In one day I met four women all named Margaret who had had breast cancer. With the next person I met, I pleaded, 'Please don't tell me your name is Margaret!'"

So far, Polly has raised \$17,000 for us, and she continues to spread the word about our Network. What a woman!

To read Polly's journals, visit her web site – [www.globalwalk.org](http://www.globalwalk.org)

# Issues of concern ...



## Explaining the familial aspects of breast cancer

### *How does a family history affect my risk?*

While the main risk factors for developing breast cancer are being female and getting older, family history is a well-recognised risk factor.

As breast cancer is common, familial clusters of two or more cases may occur by chance. However, it has been estimated that a woman with an affected first-degree relative (mother, sister or daughter) has about a two-fold increased risk of breast cancer during her lifetime.

The National Breast Cancer Centre (NBCC) has developed guidelines to help health professionals estimate the risk for women concerned about their family history.

For example, a woman whose mother was diagnosed with breast cancer after the age of 50 would be considered to be at, or only slightly above, the population risk for breast cancer. More than 95% of the female population falls into that category.

At the other extreme, some women are at a higher risk because they have three or more affected female relatives on the same side of the family.

There may also be other high-risk features, such as a breast cancer diagnosis before the age of 40.

Sometimes those potentially high-risk families include women who develop ovarian cancer. It is a rare family that may carry a genetic (inherited) susceptibility to breast/ovarian cancer.



*Judy Kirk,  
Senior Staff Specialist  
in Cancer Genetics,  
Department of  
Medicine, the  
University of Sydney.*

### *What sort of a family history indicates a possible high risk?*

Women at potentially high risk of breast cancer tend to have multiple affected family members in different generations who have been diagnosed with breast or ovarian cancer, often at an early age. Strong genetic susceptibility to breast cancer is rare, accounting for less than 5% of breast cancers.

### *Is genetic susceptibility more common in some ethnic groups?*

Research suggests a genetic susceptibility to breast and ovarian cancer is more common in women of Ashkenazi Jewish descent. About one in 50 or one in 100 Ashkenazi men and women carry a gene fault that puts them at a higher risk of cancer.

### *Now I have had breast cancer, what should I tell my daughter/s?*

Although your relatives will be most concerned about you at the time of diagnosis, some may also be worried about how this may affect their risk.

You may also be worried about the

risk for your sister(s) or daughter(s).

It would be best for them visit their general practitioner, who can consult the family history guide provided by the NBCC to determine whether the family history is of concern.

If the history indicates some family members may be at a potentially high risk, referral to a specialist Familial Cancer Service can be discussed.

### *My family has a strong family history (four close relatives with breast cancer). We would like to think about genetic testing. How does it work?*

When the family history is strong enough to indicate a genetic susceptibility, genetic testing may be helpful.

The potential benefits, harms and limitations of genetic testing need to be discussed in detail at this time.

Thought needs to be given to the possible medical, psychological and social consequences of testing for those already affected by cancer and those who may be at risk.

The first step is to take blood from one of the living, affected family members. This is usually someone who has been diagnosed with either breast or ovarian cancer. The blood sample is sent to a laboratory and extensive testing is done to search for a fault in one of the two main genes are known to be involved in breast cancer susceptibility. These genes are called BRCA1 (short for breast cancer 1) and BRCA2 (short for breast cancer 2).

Testing will take six to 12 months to complete, perhaps even longer.

As yet, we cannot find all the mutations that cause genetic susceptibility to breast cancer in families attending familial cancer services.

### *My family has a history, so we had testing for BRCA1 and BRCA2. Tests on my mother (who had breast cancer at 40) found no gene mutation. What does this mean?*

Unfortunately, at this stage, it is not possible to find a breast cancer associated gene fault in some families.

This is either because the family history has occurred by chance or may be because the current methods of

testing don't find all of the mutations (faults) in BRCA1 or BRCA2.

It is possible that other breast cancer susceptibility genes will be found in future and testing may be possible as knowledge and testing improves.

### **What will it mean if I test positive for the breast cancer mutation?**

If the family mutation is known and you are found to carry the same mutation, you are at much higher risk of breast and ovarian than other women in the community.

Women with an inherited mutation in BRCA1 or BRCA2 are at a 10-20 fold-increased risk of breast cancer.

It is difficult to be precise about the

risk of breast cancer, as this may vary according to the gene. It may also depend on the specific gene fault that has been found in the family.

There will almost certainly be other genetic or environmental factors that increase or decrease that risk.

A woman who tests positive for such a mutation must consider a number of options, along with her doctors.

These include careful breast cancer screening and possible participation in a breast cancer prevention trial.

The best management has not yet to be determined.

Some women consider prophylactic (preventative) mastectomy as their best option. Prophylactic mastectomy

has been shown to reduce the risk of breast cancer in women at a potentially high risk. Surgery to remove the ovaries (prophylactic oophorectomy) may also be considered.

Counselling is important at this stage, as surgery is not the best option for every woman. The benefits and risks involved for each option need to be fully discussed. That is why genetic testing is best done through a specialist familial cancer service with links to other relevant specialists.

### **What happens at a Familial Cancer Service?**

If you are referred to a familial cancer service, a genetic counsellor or nurse

## The need for risk management

**W**ithin a few years, four members of my family were diagnosed with breast cancer. Several years later, and with the four of us all well, it is easy to make light of those experiences.

If any one of us had gone through the experience of breast cancer alone, we might be dismissive and blasé about our stories, but ours is a family *at risk*.

Many 'high risk' families tell horrific stories of how breast cancer has stolen years from the lives of several close relatives.

Some women feel like 'walking time bombs' wondering 'when' not 'if' they will get cancer.

They are scared, isolated and misunderstood, and feel as if they belong to neither of the two acknowledged groups: those with breast cancer and those without it.

What can members of such families do to alleviate their fears and deal with the realities of their situation? What can be done to reduce the risk?

At present, family members can see and be monitored by individual doctors or attend a Family Cancer Clinic (FCC) for an assessment of their risk and for management advice.

But what 'risk management' choices are they making and why? We do not know what is happening to people



*Gerda Evans, Doone Lamb and Philippa McLean are sisters who have all been affected by breast cancer.*

following an attendance at a FCC or a doctor. Are they being appropriately monitored? Are they being referred to specialists – and then perceiving themselves as 'ill' rather than 'at risk'?

There is a need for risk management and follow-up, but how should this be done, where and by whom, and how should it be funded?

One solution would be risk management clinics, perhaps attached and run by family cancer clinics.

Ideally such clinics would be multi-disciplinary and peer-reviewed, offering best practice medical and psychological support based on the latest evidence.

They would be one-stop shops providing advice, tests, participation in clinical trials and follow-up.

They could also provide periodic reviews relevant to changing family history and personal circumstances.

Issues such as monitoring younger members, contraceptive and HRT advice, mammograms, and genetic testing are concerns for all women with a history of breast cancer, but also cause confusion for 'unaffected' people in high-risk families.

A risk management clinic model would benefit family members, clinicians, researchers and the 'public purse'. It would also reduce the anxiety and confusion for families where individual members might be receiving conflicting opinions.

'Affected' women in my family would certainly agitate for best practice risk management to protect our beautiful daughters and nieces.

The Network would like to hear your views and opinions about risk management.

*– Gerda Evans, Victoria  
(with thanks to Dr Kelly-Ann Phillips)*

## Brief encounters in a familial cancer clinic

will start by taking an extended family history, noting all the affected and unaffected relatives, as well as the age of onset and type of cancers that have occurred on both sides of the family.

Sometimes the counsellor will need permission from the family to verify the history through doctors' or medical records.

It is on this basis that an assessment is made as to whether a genetic susceptibility is likely.

At the clinic visit, you can expect a review of the family history and a risk assessment based on this history.

Genetic testing will be fully discussed if it may be of benefit to the family.

It is important for the family to understand the limitations of genetic testing, as well as the possible benefits. They need to consider the possible medical and psychological implications of a positive or negative (or uninformative) genetic test.

Generally, the family is given time to discuss this before a decision is made to proceed to genetic testing.

When blood is taken to search for a mutation in one of these genes, there may be a long wait before any results are issued.

If a mutation is identified, other at-risk family members can be tested. This is a relatively quick and simple test. However, each family member will face different decisions regarding the choice to have a test and the options available for screening and prevention if they are found to be at high risk. That is why counselling is so important before and after a test.

### **Who can I speak to for more information?**

If you are concerned about your family history, first consult your general practitioner and discuss referral to a familial cancer service.

For more information about the familial aspects of breast and ovarian cancer, contact the Cancer Information Service (CIS), phone 131 120 (all states and territories except Queensland). Queensland residents can phone the CIS on 1300 361 366.

Information is also available from the NBCC web site at [www.nbcc.org.au](http://www.nbcc.org.au)

Some readers of *The Beacon* know what it's like to have breast cancer diagnosed in multiple relatives – a grandmother, mother, aunt, cousins, sisters.

It's easy to see how a girl in a family like that could grow up convinced she'll have breast cancer once she reaches adulthood.

I often wonder what it must be like to spend adolescence fearing this diagnosis.

I trained as a genetic counsellor in 1996, and did a brief placement in a familial cancer clinic.

It left many vivid impressions, especially about the family ramifications of any consultation.

Imagine what it's like to attend a counselling session, undergo testing, and finally learn that there is indeed an abnormality in one of your 'breast cancer genes'.

You then have to work out how to pass this information onto the people closest to you, however uninterested some of them may be.

One woman who's been through this (talking to me as a friend, not a counsellor) told me how stressful it was to write a letter to her brother overseas.

They hadn't been in contact for decades, and she felt he wouldn't understand that her news might be relevant to his daughters.

For my friend, as for many others who attend genetic counselling, all this brought back painful memories of her mother's early death from cancer.

Naturally it's hard to forget those family trees full of breast or ovarian cancers.

One thing that often amazed me was to see how some of these bigger families could talk openly with each other about their situation, swap information, and support each other in making hard decisions about preventive surgery.

But it's also been memorable to meet those at the other end of the



Helen Varney

spectrum, with perhaps only two family members diagnosed.

If you've asked for a referral to a familial cancer centre, and there's only one other affected person in the family, it can be a lonely experience working out what to do with this information, whether to go ahead with testing (if that's possible), and what you should do after the result.

Maybe that is where genetic counsellors can be of most help.

There are quite a few women who decide that they don't want actual testing.

They want genetic counselling – an explanation of their family history and what it might mean to them – but they decide they don't want to know the rest.

Being the sort of person who always has to know how the plot works out, I had to work hard to get in these women's shoes and understand their willingness to live with uncertainty.

One lesson I've learnt from genetic counselling is a deep respect for the way people cope with new information and the way they decide how much is right for them.

For all you women who've been to a genetics clinic – I hope the process gave you what you were hoping for.

For those who are thinking of it – remember the service is more than just genetic testing, there's a whole lot more to suit your needs.

– Helen Varney

# To be or not to be: that is the question

**M**y answer to that question is, Yes! I want to be! I want to be around to see my children grow up, marry and have children of their own. I want to enjoy my life and grow old with my husband.

Eleven women across four generations on my maternal side have died from breast cancer.

They include my grandmother who was 57, my mother who was 54 and my sister who was 47.

I have been brought up in a breast cancer family where someone had always just passed away.

I have watched two lots of treatments with my mother and my sister. I have also seen the end of their lives.

When you continually lose people you love, not just from breast cancer, from any disease, it takes its toll.

If you had the option of greatly reducing the risk to yourself and your children from dying from breast cancer would you take it?

For me there was no choice. Removing my breasts was not easy, but at least I had a choice.

My first breast lump appeared when I was 27 years old. It was removed and proved to be benign.

The following lumps were all tested,



Jan Murphy

but after a year, I decided my breast tissue should be removed and, because of my age, implants put in.

Those have since been removed and I have two external prostheses that I am happy to have for the rest of my life.

In my breast cancer work, women say, 'it must have been a hard decision to make, I would hate having my breasts removed if I didn't have to'.

It is really difficult to respond without sounding blasé, but they haven't lived my life.

When you have had your breasts removed at 27 years and brain surgery at 34 years, and surgery for other body bits, having my tissue removed was not a momentous decision if you put it in perspective.

However, it did take me 18 months

to get used to the idea and my self-esteem did take a battering.

I think your partner plays a huge role in how you cope.

My husband is my other half and has been for 28 years. He sees my soul and loves what he sees.

It is when people see you naked that it becomes interesting. The stories I could tell!

My children didn't bat an eyelid and are bulletproof to body changes, as I think they have seen their fair share.

If you are comfortable with your body and happy with life, then everyone around you will be too.

I have two daughters, Kate is 20 and Kelly is 14, and a son, Kieron, who is 23 years. They know our genetic background and the risk for them.

My son knows it can be passed from him to his children and that being a male does not exempt him.

Kate has decided to have her breast tissue removed during the next five to 10 years and Kelly knows she has a decision to make in the future.

I am very involved with breast cancer work these days and relish each and every thing I do.

"The choices we make dictate the life that we lead." That is so true.

My sister's one regret was that she didn't have her breast tissue removed when this was suggested at age 30.

At 40 she had breast cancer and by 47 she had died.

The only person who can make the choice is you. We are now fortunate enough to have people in place to help; genetic counsellors who will go through your family tree and advise how to obtain medical records to know exactly who had breast cancer.

If you have a significant history you may choose to be tested for the breast cancer genes, then the ultimate decision is yours to make.

I make decisions and never look back with regret. I look ahead with curiosity, wondering what great surprise is around the corner.

—Jan Murphy, ACT

## Fenceliners conquer the roads of Tasmania



Twenty-one breast cancer survivors from around Australia tackled the Fenceliners' third adventure in March.

This year, under the leadership of **Lorrie Ledwell** from the Gold Coast, 15 women rode their push bikes the length and breadth of Tasmania, with support from their six ground crew.

On the way, they spoke to community groups about their experiences and

raised money for breast cancer research.

Previously, the Fenceliners have ridden motor bikes around Australia and paddled down the Murray River.

Fenceliners, we salute your bravery, energy, commitment and persistence!

To join the Fenceliners or learn about new adventures, phone Lorrie on (07) 5525 6399.

## Bipartisan support from Federal Parliament

Federal politicians lent their support to the breast cancer cause by attending a meeting at Parliament House, Canberra, during April.

The meeting was led by NT Labor Senator, **Trish Crossin**, and NSW Liberal Senator, **Marise Payne**.

The aim was to discuss ways in which the men and women of the Federal Parliament could help raise Australia's awareness of breast cancer issues.

**Prof. Sally Redman**, director of the National Breast Cancer Centre, spoke to the group, as did the Network's National Co-ordinator, **Lyn Swinburne**. ACT Network members also came along to 'wave the flag'.

The meeting resulted in the



*Political support for breast cancer issues. Network co-ordinator Lyn Swinburne, flanked by Senators Marise Payne and Trish Crossin at Parliament House.*

forming of a bipartisan parliamentary support group on breast cancer.

We welcome this new group and look forward to working closely with them.

For a list of parliamentarians at the meeting, see our web site – [www.bcna.org.au](http://www.bcna.org.au)

## Sentinel node trial launched in Canberra

**Senator Jocelyn Newman** launched the SNAC trial (Sentinel lymph Node biopsy versus Axillary Clearance) in Canberra on May 8.

As reported in previous issues of *The Beacon*, this surgical technique may reduce many of the problems caused by clearing underarm lymph nodes during breast cancer surgery.

The Network has been lobbying for research to find effective and safe ways to avoid lymphoedema, a condition causing discomfort and distress to many women after surgery.

The chair of the Breast Section of

the Royal Australasian College of Surgeons, **Dr Neil Wetzig**, has been determined to bring this trial to fruition. He has funding from MBF and the Department for Health and Aged Care.

ACT state representative, **Anna Wellings Booth**, spoke at the launch of the problems many women experience with lymphoedema. She also offered the Network's support.

**Avis Macphee**, from Melbourne, is the Network's representative on the trial's management committee. She will keep us informed of progress.

## Our dragon boat crew is making a splash

The ladies of Dragons Abreast managed to squeeze in the odd paddling session between social activities at the Dragon Boat National Titles in Darwin during May.

They had cocktails at the NT's Parliament House with the Minister for Health, **Stephen Durhan**, and an early morning breakfast harbour cruise with the Lord Mayor, **George Brown**.

**Margaret Wolf** and **Anna Wellings Booth** will join **Michelle Hanton**, **Janelle Gamble** and **Caroline Bommer** in a global team in Toronto, Canada, during June, as part of a breast cancer conference and dragon boat regatta.

Network has also asked them to present the *Field of Women* concept at the conference and participate in a media panel. Bon voyage Dragons!

## Queensland advanced breast cancer group

The support group for women with advanced breast cancer continues to meet in Brisbane under the leadership of **Dr Bronwen Beacham**. Women in this group appreciate the opportunity to share feelings, concerns, highs and lows with those in similar situations.

Phone Bronwen on (07) 3843 2706.

## New Breast Book

Many Network members call *Dr Susan Love's Breast Book* 'the bible'.

The third edition has just been released in Australia and can be bought through any large bookseller or [everycloud.com](http://everycloud.com) for \$45. It is 700 pages of information on just about everything you can possibly think of regarding breast health and cancer.

## Our list for libraries

Women keep telling us about the importance of good-quality information for anyone diagnosed with breast cancer.

Later in the year, we intend to send libraries across Australia a list of the books women have found most useful – to ensure they stock books that will inform, guide and support women.

Thank you to those readers who have sent us lists of recommended books. We will now survey member groups for their input.

The list will appear in *The Beacon*.

## Donating blood

Following a query from one of our members about donating blood, the Red Cross has confirmed that women who have experienced breast cancer can donate blood five years after completing treatment, as long as there is no sign of relapse.

No doctor's certificate is required.

## A real Outback survivor

I was living in an Outback town in 1980, when first diagnosed with breast cancer.

In the ensuing months, I did not once think of it as an illness.

I had always been in good health. I played a variety of sports, attended local dances and went to the pictures. I enjoyed life to the fullest.

For a number of years I reared four children on my own.

Working on stations was hard, but I believe hard work never killed anyone.

I found employment at a hotel, when the children were of school age. I cooked, cleaned and managed the laundry, as well as other hotel work.

One day, having scrubbed the bathroom, my arms ached and I noticed a hard, flat area under my breast.

My husband took me to the hospital, where a GP examined me and then booked me into an Adelaide hospital for surgery.

My hospital room was soon filled with flowers, baskets of goodies and many get well cards.

To keep the flowers fresh, I cared for them daily. Everyone was surprised to see me lifting my arm so soon after the operation – despite the drips and drains.

I decided against an implant. I am happy with a prosthesis, which sits comfortably inside my bra.

I've had wonderful support from my husband and family.

Eighteen months after my mastectomy, a cancerous lump was found in the lymph nodes, requiring another operation.

This time I needed radiotherapy to kill the cancer cells and was surprised to learn that I had to stay in Adelaide for six weeks for treatment.

My husband drove to town every weekend to visit me.

An abscess then formed in my armpit and took months to drain. Dressings



Nell Reid,  
South Australia

had to be changed twice a day.

At my six monthly check-up, I learnt that my arm swelling was lymphoedema. I couldn't pronounce the word, let alone know what it was.

"I don't know what to do for you, other than referring you to a physiotherapist," said my GP.

### Welcome to the Network, Jen

Jen Lawlor joined the staff at the Network six months ago. She is responsible for managing the financial

and general administrative side of our operations on a daily basis. Now we can't imagine how we coped without her!

Jen's mother, **Judy Gleeson**, who lives on a farm near Willaura, Victoria, was diagnosed with breast cancer in 1993.

This gives Jen's commitment to her work an extra edge.

We are delighted to have Jen as part of our team at the Network.



My arm was swollen from the wrist to the shoulder, so I had to shift buttons on blouses and make sure any new ones had wide sleeves.

I was also advised to be careful when gardening, or during any outdoor activities, as a scratch or insect bite could cause an infection.

I now carry antibiotics with me at all times, just as a preventative measure.

GPs suggested putting my arm in a sling, but this aggravated the arm.

I have since learnt that the lymph system acts like a garbage disposal system, so it must be kept moving. When it gets blocked, through infection or damage to the lymph nodes, you're in trouble.

As my lymphoedema worsened, a GP talked me into trialing a pump mechanism I could manage at home.

Several years later, there has been an improvement in my arm, although I still need regular physiotherapy.

An hour's treatment in a private lymphoedema clinic every day for six weeks was expensive, but worth it.

The clinic arranged for me to wear a compression sleeve, which I now wear 24 hours a day.

It also put me in contact with the Lymphoedema Association, which was most helpful.

My husband and I enrolled in a six-week patients and carers trial, which certainly improved my lymphoedema, with my husband learning the required massage technique.

People believe it to be quite sexy, so we call it our 'sex session'.

As a founding member of the lymphoedema support group in my town, I help raise money for lymphoedema research. I'm known as the 'raffle lady'.

I enjoy craft work and cooking, attending exercises classes, anti-cancer support meetings and various other organisations.

I take life as it comes, knocks and all, and don't let things get me down.

I'm a true Outback survivor!

# Facing the fears and loss

I am always excited to receive *The Beacon*. I devour it from front to back at first sitting. Everything goes on hold – dinner, stories about the day, tales of hunger.

But one thing unsettled me. Wasn't there anyone like me? No one who had struggled with this life crisis?

This has not been a rejuvenating, 'love life' experience. I do not think it has made me a better person. Rather, it has been traumatic, with a slow path to recovery of mind and spirit.

I was diagnosed when I was 34 years old. My husband and I were devastated. Our son was 11 months old.

This diagnosis radically changed our plans for the future. We had planned to go overseas with an aid and development organisation, but we were no longer eligible.

Treatment included a lumpectomy, chemotherapy and radiation.

Five months later I had a recurrence. We decided on more radiation and chemotherapy. I started on Tamoxifen and underwent stem cell collection.

I developed lymphoedema due to the collection technique and then, six months later, a complete hysterectomy sent me straight into menopause.

I developed severe depression, despite loving support from friends and family.

Counsellors gave advice such as, "It's normal to feel depressed after a life event such as yours, take time out to look after yourself." But how is that possible, with a home to run, a three-year-old to play with and work to do?

Four years after the original diagnosis, I realised I was in serious need of help. I swallowed my pride and visited a psychiatrist.

With the help of anti-depressant medication and cognitive therapy techniques, I finally feel as though I (and my family) are recovering.

This experience has been one of dealing with loss for us. The loss of:

- a life plan;
- the ability to have more children;
- the naive belief that one will live comfortably until a ripe old age;



*Kathy Kuipers, in Pakistan last year, complete with her new curly hair.*

- some friendships;
- the ability to 'go, go, go';
- memory and organisational skills;
- feelings of connectedness with other people; and
- the person I was and the life I lived.

There was also the possibility of losing the chance of seeing my son, Nicolas, grow up, marry and have a family.

After reading the Autumn issue of *The Beacon*, I realised there were other women like me: "65% (of young

**"Courage is fear holding on a minute longer."  
– Gen. George S. Patton**

women reported that they suffered) on-going side effects, such as fatigue, early menopause, localised pain, low self-esteem, memory loss and depression" (p.5).

**Jane Turner's** article was obviously drawn from experiences of working with people like me.

I am finally learning to be content with what I have (including my curly hair!), and the new person I am – a little fragile; chronically tired; more compassionate, but less tolerant; less rigid; more comfortable with expressing a personal style of dress (when it comes to music, I enjoy country music); more anxious; more appreciative of family and friends; more assertive; and more willing to be vulnerable.

I particularly enjoy being able to connect with other women in similar circumstances. It is fun to walk up to a stranger, ask if they are receiving chemotherapy and encourage them in their journey.

And I am grateful for the chance to consider my life and death, and to work on issues I would otherwise have ignored.

Yes! I do believe there is life after cancer. Making ourselves vulnerable to one another by sharing our deepest fears may be the support that those of us experiencing a profound sense of loss need, rather than hanging on to our belief in the need to 'cope' and hold ourselves together.

*– Kathy Kuipers, Qld*

## Michael helps us out

Bakers Delight staff member, **Michael**

**Brownjohn**, is a great help to us in our Network office in Melbourne. He manages our web site, making sure that the information is up-to-date for those who want to find out about the Network and our projects, or to read the stories and articles written by members.



Michael is one of the many Bakers Delight staff who help us daily. Their generosity and willingness to work, without payment, reflects Bakers Delight's commitment to us.

Bakers Delight is a major sponsor of the Network.

One way they support us is by providing us with free, fully-equipped office space in Melbourne.

When you next visit your local Bakers Delight store, mention the Network and thank them for their amazing support.

Thank you Michael! Thank you Bakers Delight!

## UPCOMING EVENTS

**June 15:** Raelene Boyle's party to celebrate her 50th birthday and five years of breast cancer survival, Crown Palladium, Melbourne, in the presence of the Prime Minister. All proceeds to the Network.

Contact: Jo Cox (03) 9585 6880.

**June 23 & June 30:** *Getting on with Life after Breast Cancer* – small group program run by Breastlink, in Sandringham, Victoria, 1.30pm. Cost \$120 (\$100 conc.).

Contact: Anne Fletcher (03) 9585 7737.

**June 21:** My Fair Lady, presented by the Wollongong High School of Performing Arts – Proceeds to the Illawarra Breast Cancer Support Group.

Contact: Gloria Swift, 0413 046 968.

**July 9-15:** Warrior Women Art Exhibition, Cube 37, Exhibition Centre, Frankston, Victoria.

**July 13-15:** *Sharing the Journey – Women with Breast Cancer*, Campion Retreat Centre, Kew, Victoria.

Contact (03) 9853 8641.

**July 20-22:** Northern Exposure 2001: Cancer and Families. The annual conference of kConFab and the Australian Breast Cancer Family Study.

Contact: Heather Thorn, Peter MacCallum Cancer Institute, (03) 9656 1111 or e-mail [h.thorne@pmci.unimelb.edu.au](mailto:h.thorne@pmci.unimelb.edu.au)

**August 3-5:** Tasmanian lymphoedema conference, St. Mary's, Tasmania.

Contact: (03) 6372 2900.

**August 14:** Education and support program for male partners of women diagnosed with breast cancer, Peter MacCallum Cancer Institute, Melbourne.

Contact: Andrea Cannon on (03) 9656 1111.

**September 1:** Breast cancer seminar for women, Wesley Hospital, Brisbane.

Contact: Barbara Quinn, (07) 3232 7596

**September 1-7:** Special *Field of Women*, Tribute Lawn, Southbank, Brisbane (Silent Walk and launch September 1).

Contact: Jan Bewes, (07) 3855 1448.

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

Contact: NT Cancer Council, (08) 8927 4888

**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 Australia.

Contact: Wendy McClusky, (03)9805 2500.

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

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

Contact: Michelle Hanton, (08) 89418923

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

Contact: Norma Bradley, (02) 6254 5286

**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.

## 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](mailto: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

In next issue:  
hormones  
Send us your thoughts!



## Seeking Shelter

The Network welcomes this group under its umbrella:

- Wagga Wagga Breast Cancer Support Group, NSW
- Ringwood Luminaires, Victoria
- Echuca Moama Breast Cancer Support Group, Victoria.

We now have 52 member groups across Australia. Discuss the Network with your group and let us know if we can create another link!

## New on the web site

- *Surviving Survival workshop*: **Barbara Joss** and **Beverly Noble** have written a comprehensive report of this Sydney workshop and its value.
- *Alexandrea's story*: "I have managed industrial disputes and complex work situations with ease, but I certainly lost my confidence when diagnosed with cancer. I guess it is because I was suddenly faced with something I couldn't control and I imagine that the stress of it all must also have affected my ability to think for a while."  
**Alexandrea Cannon's** candid account of her experience with breast cancer will ring true for many women.
- *Millie's story*: In February 1993, **Millie Laccos** noticed a red patch on one of her breasts, beginning her breast cancer journey.

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

## THE BEACON

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