



# The Beacon

Breast Cancer  
Network Australia  
newsletter

## Regular news from the Centre

It is vital that women with breast cancer stay up-to-date with the latest research findings and resources developed for them.

From now on, each reader of *The Beacon* will also receive an insert from the National Breast Cancer Centre providing such an update.

We hope you find this informative and useful. Let us know!

## The need for clinical trials

**T**his issue of *The Beacon* is about clinical trials – research studies which use patients.

Hundreds and thousands of women form the backbone of the clinical trials which have transformed the treatment of breast cancer in the past 20 years. These women have provided information that has helped improve treatment.

For individual women, the decision to participate in a trial can be difficult. They may be approached at a time when they are recovering from the shock of diagnosis and are expected to make a whole series of vital decisions.

Also, most clinical trials require that women be randomly given different treatments, so an individual cannot choose the treatment she will receive.

Nor, because the point of the trial is to find out which treatments are better, can it be assumed that the new treatment is necessarily better.

The general side effects of the new treatment may be known, but the details of how they affect women and how many are affected are not always known, so there is always an element of risk. Sometimes the side-effects of the new treatments may lead to more time

in hospital or time away from work. This may lead to increased costs for the individual woman.

As well, it is not always clear whether or not the new treatments may interfere with future treatment options.

Why do many thousands of women participate in clinical trials?

For many it is the chance of getting a new and presumably better treatment. Women with advanced disease, for example, are often actively searching out clinical trials for which they might be included. For others it is the knowledge that their actions are assisting women in the future, possibly their daughters. For some it is a great pleasure to know that they are helping others.

Clinical trials are an important way of improving treatment practices, but the implications for individual women and the consumer movement are profound.

As advocates, we need to make sure that there are mechanisms to influence the ways in which trials are conducted, to ensure that the interests of individual women are protected and that the views of women, as a whole, are represented.

– Sue Lockwood

BCNA Victorian state representative

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Di Parlane, Karen Finch, Leonie Young, Linda Reaby and Jo Cockwill are working hand-in-hand with clinical trial researchers. Find out more on page 7.

# State round-up

**T**his time our reports include photographs of our state and territory representatives.

These women are all breast cancer survivors and **your** representatives.

Your can find out more about them on our web site – [www.bcna.org.au](http://www.bcna.org.au) (Thanks to our photographer, David Lorem).

## THE ACT

Canberra is glowing in its autumn colours and Lake Burley Griffin is a quieter place without our Dragons Abreast training sessions!

We had about 20 names by the end of the season and 12 stalwarts who arrived every Thursday for training at 7.00am.

Thanks to the Canberra crew for their support in rallying to my many messages.

Dragon boats have been our focus for some months. However, we also participated in the ACT Cancer Society's Relay for Life by walking the survivor's lap of honour under a pink umbrella of the Network. We couldn't be missed in our pink polo tops!

Planning for the Bosom Buddies' Celebration of Life Fashion Event is underway for the end of September.

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



## NORTHERN TERRITORY

The AGM of the Northern Territory Breast Cancer Voice was held in April. We are now a fully incorporated group. We are also pleased to welcome **Senator Trish Crossin** as a committee member.

A successful fundraising Quiz Night was held in April and Bakers Delight, Palmerston, generously provided supper for the 150 participants.

We are still looking for any old prostheses – they are going to be put to good use in September.

Three of our members are off to Vancouver, Canada, in June to participate in the largest dragon boat festival in North America.

The wife of the NT Administrator, **Lesley Conn**, has kindly offered to host a luncheon for us at Government House in October.

We are hoping for some positive news about breast care nurses positions in the NT soon.

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



## QUEENSLAND

Breast cancer action is alive and well in north Queensland!

In Mackay recently, the Federal Minister for Health, **Dr Michael Wooldridge**, launched a multi-disciplinary project for this area.

We have many people to thank for this project becoming a reality. They include:

- **Prof. Peter Donnelly** of Townsville for his submission;
- the National Breast Cancer Centre; and
- locally, our GPs, surgeons, pathologists, radiologists, oncologists, BreastScreen Queensland and our Breast Cancer Support Service.

This has been a great accomplishment, which proves what can be achieved when health providers from the private and public sectors work together to improve services for rural breast cancer patients.

Two of our Mackay breast cancer support women have been working hard on a district services/patient pathway.

This booklet will be available to all local women at the time of diagnosis.

The impetus for this project came from **Dr Cathryn Heathwood**, a Mackay surgeon, following the 'Making a Difference' report from our national conference in Canberra. Thank you Fiona and Gwen.

The next Breast Cancer Queensland meeting will be on July 18 in Brisbane. Contact: Janelle Gamble (07) 3353 4151 or [janelle@kedrononthebrook.com.au](mailto:janelle@kedrononthebrook.com.au) (pictured left) and Leonie Young (07) 3341 7570 or [leonie@everycloud.com](mailto:leonie@everycloud.com) (pictured right)



## SOUTH AUSTRALIA

**Denise Wehnert**, whom many of you will have met at the Canberra conference, has resigned as President of Action For Breast Cancer SA, to return to her homeland, Canada.

We will miss Denise, but she has promised to keep in touch with information about breast cancer issues in Canada.

Action For Breast Cancer SA has been busy planning its May fundraiser fashion parade and selling bulbs through Bulb Express.

The speaker for the next Action presentation will be **Assoc. Prof. Helen Wynfield**, who will discuss the results of the 'On-line support for Breast Cancer Patients' survey.

We have approached all members to become BCNA consumer representa-

tives by sending them registration forms. We hope for a good response.

The Action committee has voted to donate a percentage of the funds raised to the Network and ACF.

It has also begun working on a survey to gather information with which to address the anomalies in prostheses funding.

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



*Apology: We accidentally omitted the SA report from our last issue of The Beacon. The women of SA are active and committed, and we hope we haven't upset too many by our oversight!*

## TASMANIA

Tasmania has set the date for its public meeting. It will be held on Saturday, October 7. The venue is to be confirmed.

We have been having discussions with Fenceliners about its proposed bicycle ride around Tasmania in March next year. While arrangements are still in the preliminary stages, we look forward to helping make this a success.

Tasmanian women interested in joining in the ride should contact either Fenceliners or our state reps.

**Pat Mathew** will be on holidays for a while, so **Joan Williams** and **Gerry Rockliff** will be acting as joint co-ordinators until mid-July.

Both Joan and Gerry can be contacted during business hours on (03) 6421 7700, otherwise Joan can be e-mailed on [joan.williams@dchs.tas.gov.au](mailto:joan.williams@dchs.tas.gov.au) (Pat Mathew pictured)



## NEW SOUTH WALES



A busy few months in NSW, particularly for the Breast Cancer Action Group NSW.

We entered the NSW Cancer Council's Cancer – Smart Community Awards; finalised our audit of research organisations – who's doing what and where in breast cancer research; revised and reprinted our leaflet, 'Breast Cancer: Life After Diagnosis'; and participated in (and captained – onya **Deb Read!**) the Network's Dragons Abreast team.

We have also begun distributing funds to country women to help with expenses incurred by travelling to Sydney for treatment.

On behalf of the Network, I addressed the National Breast Nurses Conference in Sydney during March. It was a good opportunity for nurses in the field to hear about and talk to us.

Put October 14 in your diary! That is the day of Breast Cancer Update 2000, sponsored by the NBCC.

**Contact:**  
**Sally Crossing**  
(02) 9436 1755 or  
[crossings@bigpond.com](mailto:crossings@bigpond.com)



## VICTORIA



The brochure, 'How to reduce my risk of getting lymphoedema' has been launched.

Now we need women-power to distribute it. We encourage as many women as possible to get a copy and to make more copies to give to nurses, surgeons, oncologists, support groups, etc. It is available from the Network office or your state representative.

It is often hard to get good-quality information about breast cancer when you need it most, so we are giving some thought to how best to provide timely information.

For example, would a women-focused breast cancer information centre be a good idea? What services would such a

centre offer? What would be best for women who live outside capital cities? Are there existing information centres which already provide good services?

These are some of the questions that need to be answered – we would be really interested in your thoughts.

**Contact:**  
**Sue Lockwood**  
(03) 9878 0736  
or [lockwood@bigpond.com](mailto:lockwood@bigpond.com)



## WESTERN AUSTRALIA



Members of Action on Breast Cancer WA (AOBC) are excited that *The Field of Women* will be planted in Perth this year on October 21, 22 and 23.

We have the beginnings of an enthusiastic committee who are busy putting things into place.

AOBC has finally found a 'home'. We have negotiated office space in the Cancer Foundation's Crawford Lodge.

As a major objective is to have more accredited breast care nurses, we are working closely with the newly formed Breast Care Nurse Network, which is made up of nurses working in breast care in private and public hospitals.

Our group has formed committees to research or deal

with particular subjects, such as lymphoedema, complementary therapies, clinical trials and so on.

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



If your group would like to highlight an activity or a project, contact your state representative on this page to have it included in the next 'State Round-Up'.

## Field of Women 2000 goes West

The people of Perth will have a chance to experience *The Field of Women* first hand on the Esplanade in Perth on Saturday, October 21, Sunday, October 22, and Monday, October 23 (Australia's Breast Cancer Day).

The thousands of Australians who have already seen the field know what a moving vision the bright pink and white silhouettes create. Each silhouette is also a powerful statement about breast cancer's impact.

An organising committee is being formed under the leadership of our WA representative, **Carol Bishop**.

If you hail from the West, this is your chance to be involved! We will need all sorts of volunteers and helpers, so if you can help out in any way, contact Carol on (08) 9489 7312 (BH) or e-mail [carol@cancerwa.asn.au](mailto:carol@cancerwa.asn.au)

Smaller fields will be springing up across the country.

**Ruth Cooper** and her fellow Network members plan to mark Australia's Breast Cancer Day by planting their own field in Coffs Harbour, NSW.

You may be interested in organising a similar ceremony in your own part of the country. If so, please let us know.

## Vivianne's contribution

Vivianne's Collection representatives, **Vanessa Michaelsen** and **Lorraine Baum**, recently presented a \$5000 cheque to BCNA's National Co-ordinator, **Lyn Swinburne**.

The Network is grateful to Vivianne's Collection, a direct sale designer clothing chain, which raised these funds for the Network by holding a clothing sale in Melbourne's Exhibition Building.

If you would like to share your story with others, send it to Gil Paulsen, who will have it included with our other women's stories on the Internet (If you like, there is no need to include your surname).

The Internet address is

[www.bcna.org.au](http://www.bcna.org.au)

# The Network is part of a 'Delightful' new partnership

**W**e had no idea what adventures lay before us when we found ourselves looking for an office at the end of December 1999!

Until then, we had been kindly 'taken in' by BreastScreen Victoria, but it needed the room for its own expansion.

It wasn't just a matter of finding some space, we had no equipment ... not even a chair!

The originators of the Bakers Delight bakery chain, **Roger** and **Lesley Gillespie**, heard me speak about the Network at a dinner in the Melbourne Town Hall early in December. Afterwards they offered help if ever it was needed.

Was help ever needed!

We arranged a meeting a few days later. They were excited about having the chance to help women with breast cancer and for Bakers Delight to be involved with a cause which has affected so many of its customers.

They have helped us in so many ways.

Our Executive Officer, **Gil Paulsen**, and I now have an office in Bakers Delight's central office at Camberwell Junction in Melbourne.

Not only have we been supplied with furniture, we have all the equipment needed to run the Network – computers, phones, a fax/scanner.

The Bakers Delight people have lots of ideas to help us achieve our objectives. It's wonderful for Gil and I to know that people genuinely want to make a difference for our cause.

Later in the year, Bakers Delight paper bags will carry a message about our Network to the millions of Australians who buy its products.

It will be another way for us to spread the message and reach women and families affected by breast cancer.

In this issue of *The Beacon* you will find a coupon that entitles you to a complimentary loaf of bread valued at \$2.10 (see back page).

*When you collect your loaf, we would love you to make the connection at a local level between Bakers Delight and Breast Cancer Network Australia.*

*Each store is owned by a franchisee, so take the time to say hello and let them know how much you appreciate their support of our Network.*

– Lyn Swinburne



The Network's new sponsor, Bakers Delight, is offering readers of *The Beacon* a complimentary loaf of bread (see back page for details).

# Issues of concern ...



## Clinical trials – One woman's experience

Shortly after moving from Melbourne to Sydney late in 1994, I became concerned about a lump in one of my breasts.

Not having a family doctor, I attended a local clinic and asked to see a female doctor.

Within 48 hours, I was discussing a mastectomy with a surgeon.

Shortly after the operation, the surgeon referred me to the Royal Prince Alfred Hospital Oncology Unit, in particular, **Professor Alan Coates**, who is now Chief Executive Officer of the Australian Cancer Society.

Prof. Coates discussed treatment options with me. I fell into the category of 'adjuvant therapy for pre-menopausal patients with node negative breast cancer'.

### Choices

I was given a choice, given my medical results, of whether or not to further undertake treatment.

If I chose treatment, I would be invited to participate in an international clinical trial of three treatments designed for women with the same breast cancer characteristics as me.

I decided to undertake treatment. I became and remain part of the 'International Breast Cancer Study Group Trial 8'.

I had been warned by well-wishing women, whom I'd met in hospital, against committing to a trial.

However, I felt my participation might help women in the future and it

was inexcusable not to participate.

Each person must evaluate their reasons for agreeing to be a part of a trial. The choice was absolutely voluntary, no pressure was placed on me and it was made clear I could terminate the trial at any stage.

I was given written information explaining the objects of the trial and the nature of the treatments being trialed, including possible side effects.

### Treatment

The next task was for Prof. Coates to ascertain the nature of the treatment.

The three treatments being trialed (following breast surgery, if required) are:

1. Zoladex for two years (hormonal therapy).

2. Six cycles of chemotherapy
3. Six cycles of chemotherapy followed by Zoladex for 1.5 years.

A computer revealed which of the three types of treatment I would be given: conventional chemotherapy for a six-month period.

The object of the trial was to evaluate the relative effectiveness of the three types of treatment over time.

### Follow-ups

The treatment was accompanied by check ups and visits to the Royal Prince Alfred Hospital, which included blood tests, chest X-rays and mammograms on a routine basis throughout the period.

The effects of the treatment were evaluated on a regular, three monthly, six monthly and now yearly basis.

As part of the trial is to measure 'quality of life', a questionnaire needs to be filled out yearly.

The questions require an evaluation of a range of physical and other side effects arising out of the diagnosis of breast cancer.

It is straightforward, but I have often thought that the best time to objectively answer questions about quality of life is not during an examination to assess whether or not the cancer has returned.

Anxiety, which accompanies those visits, may well influence the way in which the questionnaire is answered.

### Benefits for all

I have been queried as to whether I should remain on the trial, constantly revisiting the past, and my cancer has not recurred after five years.

However, the value of a longitudinal study – the first of its kind – lies in the length of time over which the data is collected.

I can discern no sound reason not to remain an active participant in the trial. Any inconvenience to me is well and truly outweighed by the potential benefit the findings of the trial may provide to other women.

I also believe the 'quality of life' questionnaire represents the broadening of the medical profession's approach to treatment – a development for which I am a strong advocate.

## Is this trial sound and well run?

If you are considering a trial, here are some questions you should ask to find out whether the study is well run.

- What is the trial's purpose?
- Who has reviewed and approved the study?
- Who is sponsoring the study?
- How are the study data and patient safety being checked?
- Where will information from the study go?

From a US National Cancer Institute booklet, 'What Are Clinical Trials All About?'

# Researching better research

For more than a century, doctors have been grappling with the question “Have we the right to perform experiments ... on man... and within what limits?”

On the one hand, most doctors feel that it is unethical to give patients a treatment which has not been proven to be effective.

In previous centuries, on the whole, more people were harmed than cured by doctors. At best, the treatments did no harm. Widely used treatments, such as blood letting using leeches, were shown to be of no benefit.

In recent decades, there have been examples of great harm when treatments were introduced without being compared with old treatments first. The use of Thalidomide in pregnancy or deep sleep therapy for psychiatric disorders highlights the dangers of using promising new treatments without proper evidence.

## The need for studies

In order not to repeat the mistakes of the past, doctors know that the best way to test new treatments is to conduct proper studies.

It is clear that the community, *as a whole*, benefits from people being treated within clinical trials (and most people, including those with breast cancer, agree clinical trials should be conducted, and that they should be informed if there is a suitable clinical trial for them).

On the other hand, many doctors have argued that patients do not understand why clinical trials are necessary, or how they work. Furthermore, they should not be required to, when grappling with a life-threatening disease.

There is enough new information and uncertainty to cope with at this time, without adding the extra complication of a clinical trial.

Doctors worry that their patients will lose faith in them, if they introduce the idea that the medical community is still trying to work out the best treatment for their condition. Many people find their doctor's clear advice and direction extremely comforting, and the idea of



by Prof. Phyllis Butow, director of the Medical Psychology Unit, the University of Sydney

treatment being decided by chance (randomly) is disturbing. Many doctors find it very difficult to discuss clinical trials with their patients.

## Patient protection

Today, there are a rules in place to ensure that patients are not harmed by participating in clinical trials.

New drugs are first tested in the laboratory. Those that appear promising are tested on small numbers of people who have not been helped by existing treatments.

Only once it is established that a new drug can be safely given and appears to work as well as current treatments, is it directly compared to the current treatment/s to find out if the new drug is better. This process is monitored by ethics committees within hospitals to protect the rights of patients.

The other important way in which patient rights are protected is the process of informed consent. Informed consent requires that the doctor not only communicates the risks and benefits of all treatment options to the patient, but also makes sure that the patient understands the information and voluntarily consents to participate in the study.

However, a number of studies have demonstrated that informed consent does not always work well. For example, when patients agree to participate in a clinical trial, they often do not understand why a trial is needed and may not even remember they are receiving treatment in a clinical trial.

In another study, consultations in which patients were invited to participate in a trial were audiotaped

and analysed. The researchers found that doctors gave enough information and were caring, but often did not encourage and help the patients to think through their own feelings and ideas about the options in front of them. Thus, it was questionable whether these patients had really given ‘informed’ consent.

## Training package

The Medical Psychology Unit at the University of Sydney has developed a training package to help doctors effectively and ethically gain informed consent for clinical trials. This study was funded by the National Health and Medical Research Council.

We started by analysing 20 consultations in which clinical trials were discussed.

Linguists from the Centre for Discourse and Interaction, Department of Linguistics at Macquarie University, and medical ethicists from the Centre for Values, Ethics and the Law at the University of Sydney aided the analysis.

We identified five areas needing attention:

- the facts presented or left out;
- the order in which ideas are presented;
- how clearly the information is presented;
- ways in which patients are encouraged or discouraged to express themselves in the consultation, and participate in the decision; and
- ways in which certain options are emphasised or encouraged versus presented in a balanced way.

We developed a booklet recommending strategies in each of these areas, and asked a panel of people, including consumers, doctors, nurses, medical researchers, medical ethicists and psychologists, to review them. We then revised the booklet and developed a workshop to train doctors in these strategies.

We are seeing whether the training actually helps doctors and patients discuss clinical trials, and whether this results in better outcomes for patients.

*Ed: Because of limited space, Prof. Butow's references have been removed. If you would like to see the complete article, copies may be obtained from the BCNA office.*

# Giving consumers a voice in breast cancer research trials

Until the latter part of the 20th Century, health professionals controlled health care research decision making. Involving consumers in this process would have been seen as foreign and inappropriate.

That mind set has changed over the past two decades. There is respect for patient autonomy and the inclusion of consumer representatives and research participants in advisory roles.

The Australia New Zealand Breast Cancer Trials Group (ANZ BCTG) has led the inclusion of consumer representation into research decision making. It has had consumer represen-

tation on its scientific committee since 1994. In April 1999 it launched a Consumer Advisory Panel (CAP).

Introducing the CAP members:

- **Linda Reaby**, associate professor in nursing at University of Canberra and CAP co-ordinator. Diagnosed with breast cancer in 1990, she has been a member of the ANZ BCTG scientific committee since 1994.
- **Karen Finch**, chairperson of Northern Territory Breast Cancer Voice. She was diagnosed with breast cancer in 1995.
- **Diane Parlane**, an arts administrator in Newcastle. She was diag-

nosed with breast cancer in 1998.

- **Carol Whiteside**, a teacher from Newcastle. Diagnosed in 1994, she has been a breast cancer clinical trial participant.
- **Leonie Young**, Queensland's state BCNA representative and a founding member of the young Women's Network.
- **Lexie Brans**, a nurse, bioethicist and senior lecturer at the University of Canberra.
- **Beverley Rees**, a registered nurse and member of the ANZ BCTG scientific advisory committee. She has nine years' experience supporting women with breast cancer as a nurse counsellor.
- **Jo Cockwill**, Hunter Breast Cancer education officer and CAP facilitator.

Each panel member believes clinical trials are necessary and without them we will never learn how to prevent breast cancer, how to best treat it, how to cure it and eventually how to eradicate it.

The panel is committed to finding strategies to increase women's participation in research because it is the only means to test newer and better treatments, and thus save lives.

ANZ BCTG has realised the important role that consumers play in research decision making for clinical trials.

The group recognises the benefits of the CAP in its ability to bridge the gap between the research community and the public, in its experience of the realities of breast cancer treatment and psycho-social issues, and in its ability to communicate the importance of clinical trials because of first-hand experience with the disease.

ANZ BCTG and the CAP are creating a research environment of understanding, respect, and shared commitment. These scientists and consumers are building a powerful fellowship that will hasten the achievement of a mutual goal: ending the breast cancer epidemic.

– Linda Reaby, CAP co-ordinator

To learn more about the CAP, visit the Network's web site at [www.bcna.org.au](http://www.bcna.org.au)

## Letter to the Editor

In November 1988, I went to my GP with a small lump in my breast. He sent me for a needle aspiration and the results came back inconclusive. I was told to keep tabs on the lump.

Six weeks later, I made another appointment and saw a different GP. He was concerned and sent me off to have a mammogram. This was when the nightmare began.

In January 1989, I was diagnosed with breast cancer. I was 34 years old, had been married for nine years, and had two sons aged 5½ years and 4 years.

I had a radical mastectomy. Then cancer was found in my lymph nodes, so chemotherapy was next. I felt trapped on a merry-go-round I could not get off.

I made it through six months of chemo and was doing well until September 1992, when I was told the cancer had spread to my liver.

Since this diagnosis, I have been on many treatments and clinical trials, trying to outsmart the cancer.

Clinical trials are an important part of treatment. Run under strict protocol and caring medical staff, clinical trials have given me the time I needed.



When the cancer has outsmarted the treatment, I have been fortunate to find another trial on offer.

For me it is a sobering thought, that scientists and doctors are working towards if not a cure, at least treatments with less toxic side effects, which means better quality of life.

As a cancer patient for 11 years, I am happy to be part of progress. It has given me a longer life to share with my supportive family, friends and medical staff.

– Maria Waters, WA

# Fraud and high-dose chemo

Virtually all major advances in breast cancer management have been the result of women's participation in large, randomised, clinical studies.

Such studies require informed, consenting women being randomly selected to receive 'gold standard' therapy versus a novel change in treatment that has a sound scientific basis.

If the novel approach proves advantageous, it is likely to become the new gold standard in treatment. If not, it is appropriately abandoned.

Increasing public and media scrutiny of clinical trials has heightened awareness of valuable new findings in breast cancer management. It has equally heightened awareness of something going wrong. This is appropriate, given patient's contribution to the process and the cost to the community of large clinical trials.

In Australia, randomised studies are usually multi-institutional, often involve international collaborations and absolutely require clearance by (and reports to) an institutional ethics committee.

This process necessitates transparency and an active peer-review process. In addition, studies are often subject to on-site auditing.

High-dose chemotherapy for breast cancer is a novel form of treatment that has undergone recent scrutiny. The concept evolved from the observation that higher doses of chemotherapy are associated with higher responses.

Several randomised studies have explored the use of high-dose therapy in 'high-risk' patients with breast cancer, to test whether 'more is better' to prevent relapses and improve survival.

Australian women have participated in one such international, multi-centre study, known as IBCSG-15. Outcomes from this study are not yet known.

To date, only one study (the Bezwoda study) has shown a survival benefit for high-risk patients receiving high-dose chemotherapy. Recently this study, carried out in a single institution in South Africa, was shown to be grossly fraudulent.

Scrutiny of patient records by a revealed major discrepancies in reporting, patient records and treatment protocols. In fact, the protocol had never even been submitted to the appropriate institutional ethics committee. The investigator has been fired and the institution's reputation tarnished.

The Bezwoda study has emphasised the continuing need for proper audits and transparency in the clinic trial process. It has also reinforced the role of institutional ethics committees.

We are fortunate in Australia to have a well-organised collective of clinicians, nurses, data managers and patient advocates to facilitate the peer review process. Effective organisations such as the Australian New Zealand Breast Cancer Trials Group and the NH&MRC review process should ensure large, randomised studies pass the test of open peer review.

This is the best way to secure the public's trust and continuing participation in clinical trials, something that will continue to underpin advances in breast cancer treatment and prevention.

The results of IBCSG-15, which evolved from pioneering laboratory and clinical research in Australia, will be closely scrutinised by the international community. The transgressions that occurred in the Bezwoda study will not have occurred in Australia.

What does all this mean for high-dose chemotherapy in breast cancer? Certain unique elements in the dosing schedules for the IBCSG-15 will make an important contribution to the international community's evaluation of this approach.

It is fair to say, however, that there has been a lack of evidence of advantage from other studies to date.

Even a negative result will be important. It will ensure that, in the longer term, women are treated with the most appropriate therapy.

— Geoffrey Lindeman  
Medical Oncology, Royal Melbourne  
Hospital and Breast Cancer Lab, Walter  
& Eliza Hall Institute, Melbourne

## Well done Maureen

The ZONTA Club of Nepean, NSW, has presented Brisbane Network member, **Maureen Kirk**, with an award for her dedication and commitment to breast cancer control in Australian Aboriginal women.



## More Olympic torchbearers

Last issue we named five breast cancer survivors who have been chosen to help carry the torch to the opening ceremony of the Sydney Olympics.

Now we can give you a more complete list of BCNA member torchbearers, who will also be spreading a positive message about breast cancer.

### ACT

Linda Reaby

### NSW

Jane Redmond      Felicity Lehmann

Rosanna Martinello      Marea Wright

Dot Beaupeunt      Jane Redmond

### Queensland

Raelene Boyle      Louise Kynoch

### South Australia

Carlene Butavicius

### Tasmania

Pat Mathew      Norma Hudson

Margaret Batchelor      Eileen Langridge

Joan Williams

### Victoria

Lyn Swinburne      Tanya Wilson

Sue Lockwood      Avis Macphee

Marlene Parsons      Gil Paulsen

Peggy Cresp      Margaret Brewer

Wendy Crofts      Gerda Evans

Karen Russell      Pam O'Brien

## Southern Fencelines

**Raimonda Te Maiharoa**, founder of Following the Fenceline, has a new business, Southern Fencelines.

For a price, she is offering guided adventures in New Zealand by boat, car, aeroplane or walking for women with breast cancer.

Contact: Raimonda, (03) 5169 1657.

## A man with breast cancer

“Well then, Geoff,” said the surgeon, as he sat rather precariously on the end of my hospital bed, “I’ve got some bad news ... The lump we removed yesterday was cancerous, and we’ll need you back here next week for a mastectomy and further node removal.”

Mastectomy? I am a *healthy* 32-year-old *male*! Surely this is not happening?

The journey had begun.

Certainly it was not something I ever considered would happen – Not to *me*! I’m male and invincible, right?

I was thrust almost immediately into a world I never knew existed. A world of hospitals, doctors, oncology, drugs, pain, hormones, mood swings, anxiety and depression.

The treatment of male breast cancer follows the well-worn path afforded to female breast cancer patients, as there is little research into the peculiarities of the male disease.

The worst stuff came first – chemotherapy – six months of denigrating, debilitating, dastardly chemicals otherwise known as AC/CMF.

It left me physically and mentally bewildered, even though my health was in the best possible shape it could have been before the chemotherapy started.

Then, Tamoxifen, a hormone drug, for two years. The side effects can be severe for the female body, but are reasonably well tolerated by my male body, which contains comparatively small amounts of estrogen.

Return to your life young man, the life you had before this interruption six months ago.

Unfortunately (as one doctor put it, “Geoff is a very unlucky man”), the disease began to spread to my bones.

What at first seemed to be a torn muscle in the hip was a significantly more heinous problem affecting both hips and a vertebrae (T11) in my back.

Forever onwards. This time it was on to another medical world – another hospital, more doctors, radiology, radiographers and large off-white machines for tasks such as radiotherapy, CT, X-rays, MRI, Pet scans and ultrasounds. Then there was more hormone therapy.

In the midst of all this radiotherapy treatment, I procured a brain tumor.

It announced itself violently in April 1999 with migraine-like symptoms – intense pain, reduced vision and hearing problems.

Fortunately, this tumor could be operated on and was removed with few apparent side effects.

“Am I insane yet ?” I asked my long-suffering and supportive girlfriend. “No, no ... not quite yet,” she said.

My family, friends and especially my partner, have all been extremely helpful during this difficult time. I wish to thank them for their incredible support.

Although the side effects of some cancer treatments can be horrific

(especially for someone who is conscious of their appearance), being male meant that the loss of my breast was mostly inconsequential. As my hair was always quite short, losing it totally was not a problem. However, I can sympathise with women for whom these two events can be much more of a problem.

Mood swings and depression are another interesting problem. The hormone treatment – a monthly subcutaneous pellet of Zoladex (something akin to chemical castration) – brought on violent changes in mood and sporadic fits of crying which I still don’t understand. Maybe I never will?

The reaction from my female friends was mostly ecstatic rather than sympathetic. “Now you know what it’s like !” they said.

It is more than 2½ years since the original diagnosis and my friend the breast cancer seems to be mostly under control.

I am often stiff and sore from the cancer in my bones, extremely tired, sometimes emotional and regularly in pain, but managing to lead a mostly normal life. I think.

– Geoff Roberts



This is Geoff in the Field of Women in Melbourne, October 1999, with his contribution – a little blue man.

“When I saw this magnificent spectacle, with cutout figurines representing the 10,000 women who contract breast cancer each year, I felt it necessary to make a stand. Not *only* women get this disease,” he said.

“Although the number of males with breast cancer is a small minority of the total breast cancer sufferers (less than 1% of breast cancer patients are male), all the literature, help groups, newspaper articles and, more importantly, treatment trials ignore the male perspective!”

Geoff recommends visiting the male breast cancer web site at <http://interact.withus.com/interact/mbc>

# Upon reflection

**Fred Clausen** sent us these thought-provoking reflections after losing his wife to breast cancer.

**Upon reflection**, I wonder what I could have done better or differently to help ease the pain I have felt for 18 months after the passing of my wife of 34 years from metastatic breast cancer.

**Upon reflection**, should I have read her daily diary entries, after diagnosis and not after death, or not at all, to better understand what was happening to her, and be of greater support?

**Upon reflection**, should we have talked more openly about the event that awaits us all, to be better prepared and accepting, and not relied on hope and faith and the fear of the loss? The pain of the loss lingers longer for living loved ones.

**Upon reflection**, should we have not put all our faith and hope in the medical professions, that they would do their best to understand and advise of the options on our pending tragedy?

**Upon reflection**, should we have sought second and third honest, forthright opinions, and tried alternative treatments? Statistics show that the outcome is almost the same – ‘demise’ sooner rather than later.

**Upon reflection**, should the available support services have been more visible and pro-active after diagnosis, not at or after death, as they had received our support for many years?

**Upon reflection**, should we have sought ‘pain management’ in these circumstances to help cope with life at the time?

**Upon reflection**, should we have reviewed our life experiences to better understand what brought this disease tragedy to us?

**Upon reflection**, should I bite my lip, in the hope that these emotions will be overcome, and get on with what is left of my life and regard what has happened as a necessary experience of life with some past treasures that are now clouded by sadness?

– Now uncertain bloke

# Feminism and breast cancer

*Breast Cancer Action Group's Marcia O'Keefe Memorial Forum, Sunday, July 16, 2000, Anti-Cancer Council of Victoria Conference Room, 100 Drummond Street, Carlton.*

**Marcia O'Keefe** founded Breast Cancer Action Group (BCAG) in Melbourne in 1994.

A committed feminist, she knew it was imperative for the experiences of women to be heard and pioneered the role of consumer representation in the breast cancer field. Marcia died on October 14, 1997, after an eight-year battle with metastatic breast cancer.

As a memorial to Marcia, the BCAG will conduct a forum, ‘Feminist Approaches to Breast Cancer’. Some of us came to the experience of breast

cancer with a feminist perspective. For others, experiencing the disease has been politicising – a powerful example of the personal being the political.

While there is knowledge and research about how western medicine and science deal with women's bodies, feminist knowledge and analysis is lacking within breast cancer networks.

The forum will seek to redress that imbalance by bringing together women engaged in key academic feminist research (some of whom are breast cancer survivors!) and those of us living with breast cancer. This will be an opportunity to learn from each other!

**Contact: Dorothy McManus, (03) 9269 1391 (work) or e-mail dorotheym-rd@nmit.vic.edu.au**



*As a result of long-term lobbying by women, the Lymphoedema Summit was held in Adelaide. Senator Jocelyn Newman, Robyn Wicks and Janet McDonald were speakers at the summit.*

## Farewell Judy

With sadness we report the death of Network member, **Judy Burley**, on March 10 in Bendigo, Victoria.

Judy's story was featured in the Spring 1999 issue of *The Beacon*.

Judy was a passionate advocate for women with breast cancer and, among other roles, represented the Network on the editorial group of the National Breast Cancer Centre's newsletter, ‘BreastNews’.

Judy's circle of friends and family paid tribute to her life with moving ceremonies in Bendigo, Melbourne, Adelaide and Cheltenham, England.

Judy's husband, Andrew, and parents, Joan and Noel, requested that, in lieu of flowers, donations be given to Breast Cancer Network Australia. We thank them for their support.

Andrew and the Bendigo community are now working to establish the Otis Foundation, to be named after a much-loved dog of Judy's. It is important that they fulfill Judy's long-time dream of building studio apartments on their beautiful land just outside Bendigo. These will be used as a retreat for women with breast cancer.

– Lyn Swinburne



## Dragons Abreast – we did our best

The Breast Cancer Network Dragon Boat Team, *Dragons Abreast*, have enjoyed a wonderful first season.

The team competed in the Chinese New Year Dragon Boat Carnival at Darling Harbour in Sydney and the Canberra Multicultural Festival.

The team, which was made up of women from ACT, NSW, NT and Qld,

worked hard together to finish its season by competing at the National Dragon Boat Championships at Penrith in Sydney during March.

Dubbed the 'Pink Ladies' team by the crowd, they were a big hit and received tremendous support from the crowds and sponsors – AMP, Bakers Delight and Puma.

## Did you receive your Beacon 10?

We had problems getting the last issue of *The Beacon* to some of our readers.

Some readers received newsletters addressed with an incorrect name, others missed out altogether.

The problem occurred at the mailing house, where electronic mistakes were made that affected the database.

We apologise for this problem.

Several readers contacted our office to

notify us of the mix-up or to let us know that *The Beacon* 10 had not arrived.

Many of you also took the opportunity to tell us how important *The Beacon* is to you, and we thank you for your positive comments.

Please notify us if you have still not received issue 10.

We have since changed mailing houses and expect that everything will be smooth in the future.



Canberra women came together under the Network's umbrella for the Relay for Life event, raising funds for breast cancer research.

## GST, lymphoedema garments and prostheses

Women have been wondering how the GST might affect prostheses and lymphoedema garments.

Pressure management garments and associated lymphoedema pumps will be GST-free under Item 71 in Schedule 3, which covers medical aides and appliances.

External breast prostheses are also GST-free and listed as Item 84 of Schedule 3.

Internal prostheses will also be GST-free when used for women undergoing breast reconstruction following breast cancer surgery.

For any other GST inquiries, phone the Tax Reform Hotline on 13 61 40 or e-mail the Australian Taxation Office on GSTmail@ato.gov.au

## Discreet alterations

BCNA member, **Annette Arends** is running a new business called Discreet Alterations, which provides advice and service on bra alterations. Contact: Annette, (02) 9457 8027.

## Laser scanner for Eyre Peninsula

Congratulations to Network member, **Maxine Barker**, and the Southern Eyre Laser Fundraiser Group.

In just six months, it has raised \$26,000 to buy a laser scanner for use in the treatment of lymphoedema. It was also able to buy \$5000 worth of compression garments.

Community support, achieved through an education program, helped the group achieve its target in record time.

The scanner was launched in October. It is only the sixth in Australia and the first to be installed in a public hospital.

It has many other medical applications besides lymphoedema, so will be well used.

## Comfort wrap

**Tracey Goodrich** designed The Comfort Wrap, a sheepskin cover for seat belts, following the discomfort she experienced while pregnant. She has been contacted by women with breast cancer wanting to use it after surgery.

Contact: Tracey, (03) 9841 7554.



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**Offer expires 31 July, 2000**

Bakers Delight is a major sponsor of Breast Cancer Network Australia

## UPCOMING EVENTS

**June to September:** Petrea King Quest for Life Centre Workshops

Contact: (02) 4883 6599

**July 16:** Feminism and Breast Cancer Forum, Melbourne.

Contact: Dorothy McManus, (03) 9269 1391 or e-mail [dorothy-rd@nmit.vic.edu.au](mailto:dorothy-rd@nmit.vic.edu.au)

**July 18:** Breast Cancer Queensland meeting.

Contact: Janelle Gamble, (07) 3353 4100, or Leonie Young, (07) 3341 7570 or e-mail [leonie@everycloud.com](mailto:leonie@everycloud.com)

**August 19:** Greenfield Yoga Centre Relaxation & Meditation for Women Living with Breast Cancer.

Contact: Fay Abromwich, (03) 9853 8552.

**August 24:** ACT state meeting.

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

**September 3-7:** Fifth World Congress of Psycho-Oncology, Melbourne Convention Centre.

Contact: The Conference Organisers, (03) 9521 8881 or e-mail [conforg@ozemail.com.au](mailto:conforg@ozemail.com.au)

**September:** Bosom Buddies Celebration of Life Fashion Event.

Contact: Norma Bradley (02) 6254 5286

**October 7:** Tasmanian state meeting. Venue to be confirmed.

Contact: Joan Williams, (03) 6421 7700.

**October 14:** NSW Breast Cancer Update Day 2000.

Contact: Sally Crossing, (02) 9436 1755 or e-mail [crossings@bigpond.com](mailto:crossings@bigpond.com)

**October 21:** BreastScreen NSW 6th Annual Breast Cancer Information Day, Royal North Shore Hospital, \$25 (bookings required).

Contact: (02) 9926 7246

**October 21-23:** *The Field of Women*, Perth.

**October 23:** *Australia's Breast Cancer Day*.

**November 15-19:** Fourth Leura International Breast Cancer Conference, Leura, Blue Mountains, NSW. Contact: NSW Breast Cancer Institute, (02) 9845 8450.

## 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: ( ) .....

Have you had a diagnosis of breast cancer?  Yes  No

## Field of Women video

Breast cancer survivor, **Sue Smith**, from Generations Productions, has completed a video of our 1999 *Field of Women* at the Melbourne Cricket Ground and the Treasury Gardens.

We are grateful to AMP for the funds to make this video possible.

If you were there, the video will recapture the experience. For others, it will be like being there!

Videos are \$15 each (including postage) for BCNA members and \$20 for others.

Send a cheque, with return address details, to BCNA, PO Box 4082, Auburn South, Victoria 3122.



## Seeking Shelter

The Network welcomes this group under its umbrella:

- Consumer panel, ANZ Breast Cancer Trials Group.

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

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

## THE BEACON

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

Editor: Lyn Swinburne

Layout: Substitution

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

