



The Beacon

Breast Cancer
Network Australia
newsletter

What is the real chance of a cure for breast cancer?



Sharon Murphy helped carry the Network's message along with the Olympic torch. For her experience, and those of others, see pages 3 and 11.

Anyone reading the newspapers could be forgiven for thinking a cure for cancer was around the corner.

Every week there seems to be a media report of a major breakthrough.

Women living with the disease, especially those of us with daughters, are keen to know how advanced we are in our knowledge of the disease. It can be frustrating to see an 'exciting breakthrough' fizzle out.

Lately, much attention has been given to the human genome project. While it sounds promising, it is difficult for many of us to comprehend just how useful it really will be to us.

Some months ago, I participated in a panel presentation in Canberra during the Australian Science Festival.

The forum's topic was the adventurous: 'Cures for Cancer'.

I was fascinated by the presentations from researchers active in a range of work involving basic cancer research.

Speakers predicted how women with breast cancer might be managed in 20 and 35 years' time.

Many readers of 'The Beacon' have written to us asking for information about the latest research findings.

As a result, we asked the speakers at that forum to allow excerpts of their presentations to be included in this issue of the newsletter. We also invited input from other significant figures in the breast cancer world.

How will breast cancer be managed in the future? In which areas do we expect major advances? How long might it take? Will there ever really be a cure for breast cancer? Read on, to hear what the scientists have to say.

– Lyn Swinburne

Plant a message in the Field of Women

The *Field of Women* is our moving and powerful display of the breast cancer statistics in Australia.

The 10,000 pink silhouettes represent the number of women diagnosed with breast cancer each year. The 2500 white silhouettes remind us of those we lose to the disease each year.

In 1998, we launched the Network among the *Field of Women* in front of Parliament House in Canberra. Last year, the silhouettes were displayed on the Melbourne Cricket Ground.

This year, AMP will again be our major sponsor, with the *Field of Women* travelling to Perth. It will be planted along the Esplanade from Saturday, October 21, until Australia's Breast Cancer Day on Monday, October 23.

For details of the Silent Walk and launch on Saturday, phone WA state representative, **Carol Bishop**, on (08) 9489 7312.

Mini-fields will be planted in Coffs Harbour, Canberra, Melbourne and Adelaide. Phone your state representative for details or visit our website – www.bcna.org.au

There is a *Field of Women* brochure with this issue of **The Beacon**.

You are invited to sponsor a silhouette and send a message by completing the details on the brochure. Alternatively, give the brochure to someone, so they can record their message.

More brochures are available from your state representative or by phoning the Network on (03) 9805 2500.

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State round-up



WESTERN AUSTRALIA

The Western Australian Clinical Oncology Group, in a joint initiative with the Cancer Foundation of WA and the Health Department of WA, has produced a helpful booklet about the value of clinical trials in the treatment process.

Members attended a seminar held by **Professor Konrad Jamrozik** called 'Clinical trials: much more than deciding cancer treatment by the toss of a coin'.

There were many interesting points raised, including the extreme difficulty that Cancer Foundation Helpline operators have in obtaining any information about available clinical trials to pass on to consumers who ring for details.

Prof. Jamrozik said he would look into this problem and members of our subcommittee will follow up.

A member of Action on Breast Cancer recently participated in an ethics committee meeting at Royal Perth Hospital and found it of great interest.

It was encouraging that immediate note was taken of her objection to a point of protocol that she felt was not in the best interests of consumers. It was returned to the researchers for more details.

Our main effort at the moment is making a great success of the *Field of Women* in Perth on October 21-23.

The silhouettes will be planted on the Esplanade beside Riverside Drive.

We hope all readers of *The Beacon* within reach of Perth will visit the site during the weekend.

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



QUEENSLAND

A Young Women's Network is being established on the Sunshine Coast.

Phone **Cathy Apelt** for further details, (07) 5443 6300.

The Wesley Breast Clinic in Brisbane celebrated its 18th birthday in August with an exhibition of artwork by Indigenous Queensland women.

We are all looking forward to **Raelene Boyle's** dinner and fashion parade on the Sunshine Coast in October.

This event promises to be bigger and better than ever, with a chance to kick up the heels on the dance floor.

Contact: **Janelle Gamble (07) 3353 4151** or janelle@kedrononthebrook.com.au and **Leonie Young (07) 3341 7570** or leonie@everycloud.com



NEW SOUTH WALES

We are looking forward to seeing many Network members at the Second NSW Breast Cancer Consumer Forum on October 14.

If you haven't received an invitation, phone the NSW Cancer Council on (02) 9334 1993 and ask for a registration form.

The forum will be held where we met two years ago – the Women's College, University of Sydney.

It promises to be a good day for updating information, issues and progress, and catching up.

Breast Cancer Action Group (BCAG) has received a \$40,000 grant from the Department of Health to produce a directory of breast cancer treatments and services in NSW.

Production has been contracted to the NSW Breast Cancer Institute.

BCAG members and friends have donated another \$7000 to ensure that the directory is widely distributed to GPs and women in mid-2001.

We hope the concept will become a model for other states.

We support Victoria's idea for a breast cancer drop-in centre and are exploring possibilities.

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



NORTHERN TERRITORY

In May, Northern Territory Breast Cancer Voice and the NT Cancer Council hosted The National Breast Cancer Centre's public meeting in Darwin, which was attended by 40 women.

The Centre's director, **Professor Sally Redman**, generously agreed to visit Alice Springs and Darwin.

She addressed medicos, visited the Alukura Women's Clinic and NT Breast Screen, and met a wonderful cross-section of people.

October in the NT is buildup time and the high humidity is not conducive to outdoor activity, so our plan for Australia's Breast Cancer Day is to hold an invitation luncheon on the cool verandahs of the Administrator's residence, hosted by his wife, **Lesley Conn**.

Contact: **Susan Tully (08) 8927 3327** or tullynt@msn.com.au



TASMANIA

Norma, Gerry and Joan met **Lorrie Leadwell** from the Fenceliners during her recent visit to Tasmania. Following this 'reconnaissance mission', plans for the state bike ride are well under way.

Tasmanian Network members look forward to hosting the Fenceliners in March 2001.

To encourage Network members to become consumer representatives, we have included a consumer representative form with the mailout of minutes. Would all members return their completed forms to the BCNA's Victorian address listed. Please help

These are summaries of the state representatives' reports. To read the complete reports, visit our website – www.bcna.org.au



us continue to make our voices heard by the decision-makers.

On August 1 and 5, five network members experienced their 'proudest day' – representing the Network as Olympic torch bearers.

I encourage all readers of *The Beacon* to join us at regional or state meetings in Campbell Town.

We are doing our best to address the needs of Tasmanian women, but need input from *all* breast cancer survivors.

Dates for regional and state meetings are available by contacting Gerry and Joan during business.

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



VICTORIA

A successful forum, 'Feminist approaches to breast cancer', was held recently in Melbourne.

The speakers challenged us to think about how we might change the fact that medicine is practised in a masculine model.

For instance, we can add some further feminist thinking into the design of our advocacy and science training courses.

The forum was a tribute to **Marcia O'Keefe**, founder of the Breast Cancer Action Group.

A number of people, including **Jane Turner**, a Queensland psychiatrist, friend of Marcia and supporter of consumers, spoke thoughtfully and affectionately about Marcia and her role representing the views of women.

Jane also spoke about the importance of the newly released Psycho-social Guidelines from the National Breast Cancer Centre (NBCC).

Thank you to the NBCC for making Jane's visit possible.

Victorian women have recently received support from BreastCare Victoria to enable us to offer more advocacy and science training courses, to run rural workshops similar to the recent Living with Breast Cancer Forum and for consumer representatives to attend professional conferences.

This will help us represent women

Network women carry the torch for us all

As reported in the last issue of *The Beacon*, many Network women were honoured to be selected as Olympic torch bearers.

Some carried the torch through crowded city streets, others on quiet country roads.

At times, our pink silhouettes, held high by survivors and supporters, lined the torch's route.

BCNA Board member, **Raelene Boyle**, lit the cauldron at the end of the leg on the Sunshine Coast.

Tasmanian Network representative, **Pat Mathew**, was determined to make her leg of the relay, despite being unwell, carrying the torch from her wheelchair. Nothing stops Pat!

We have heard stories of excitement, inspiration and celebration. To read more about these journeys, and see the photos, visit our website – www.bcna.org.au

on many different committees and ensure that Victorian women hear about the latest developments in breast cancer.

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



THE ACT

Good news on the dragon boat front. **Joe Murray** from Aventis Pharma is sponsoring the ACT team with lighter paddles. Hopefully, they will help us glide through the water.

More great news – Dragons Abreast ACT has secured a grant from Women's Sport and Recreation ACT to support its future activities.

Some members have already put their hands up for the Nationals in Darwin in 2001 and international competition in Canada.

Shirley Fitzgerald, a Network member and consultant with Sara Lee Apparel, is training staff in small lingerie boutiques in ACT and country NSW on how to fit women with bras after breast cancer surgery.

To show fitters the importance and sensitivity needed to help women

cope with body image, the wearing of a prosthesis and self-esteem, she is joined by ACT women who have experienced different types of surgery.

When training is complete, each boutique will display a logo showing that they are accredited fitters.

This year, Canberra's *Field of Women* is being organised by **Tania Pirota**, who was instrumental in organising the students who planted the field in 1998. After a year overseas involved in a tutorship, she is using this exercise as a part of a marketing assignment.

She also wants to set up a network for young people in the community. Any other states interested?

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



SOUTH AUSTRALIA

Fundraising has been ACTION's main focus over recent months, including a successful fashion parade which helped us raise awareness of breast cancer and ACTION's role in the community.

We are re-visiting the initial goals we set for the organisation in the lead up to our second AGM on October 11.

'A Brief History of Breast Cancer 5000BC to 2000AD' was the title of visiting South African **Professor David Dent's** interesting talk for SA women with breast cancer, organised by ACTION, in association with the Anti-Cancer Foundation.

It was an entertaining presentation, accompanied by fascinating slides of some of the horrific early tools used to remove breasts and breast cancer, contrasting with beautiful hand painted illustrations of breast cancer survivors and the improved surgical techniques for treatment today.

He put SA in the top three places in the world for excellent mammography screening programs and facilities.

The next *Field of Women* committee meeting will be held in Adelaide and new members, **Helen Wiltshire** and **Sheila Evans** will join us.

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



Survey results help guide the Network

Many thanks to all those members who returned their surveys about the future of *The Beacon*.

We were absolutely delighted with the response – more than 1000 readers took the trouble to offer us written feedback. Many also sent donations.

It was satisfying to read that so many of you value our newsletter and love to read the articles.

Sometimes we put the articles together and post the newsletters off hoping, but never really knowing, the content is right.

Some responses brought tears to our eyes and reminded us that the breast cancer journey can be an isolating experience.

How wonderful to know that we are really connecting with so many of you!

Some responses were:

- 'Donations instead of subscriptions.'
- 'Photos give me more support and courage than just words.'
- '*The Beacon* helps me to bear the almost unbearable'.
- 'Invaluable for isolated country people like me'.
- 'Common thread uniting sufferers and survivors – A safe place for our views – not only heard but listened to'.

As a result of your feedback, and following further deliberations, we have decided the following:

- We will not set an annual subscription for *The Beacon*.
- We will, however, give members the opportunity to make an annual donation and allow individuals to pay an amount appropriate to them.
- We will continue to seek a sponsor for *The Beacon*.
- We will continue to provide a quality quarterly publication with photographs and an attractive and informative content which responds to the needs and directions of our readers.

Puma – Breast Cancer Network Australia partner

With great excitement, we can announce that Puma is supporting us with a three-year sponsorship.

This demonstrates the company's determination to genuinely help us be the voice of Australians affected by breast cancer.

Puma is keen to help spread the word about the Network's work to women around the country.

In future, all swing tags on Puma's women apparel will carry a message about the Network and offer women a chance to receive *The Beacon*.

Puma has prepared 500,000 swing tags and we hope to attract many more Australians affected by breast cancer to our Network.

As **Warwick Mitchell**, the managing director of Puma Australia, told us, "Breast cancer is a real issue of concern for women, and one which affects all Australians. We want to help the Network lift its profile and assist it to achieve its goals."

Puma will help us in other ways too.

New Puma posters will include our pink silhouette logo and athletes sponsored by Puma will help promote the Network in the media by wearing the new Puma/Network T-shirts.

It is wonderful to have sponsors such as Puma, Baker's

Delight and AMP helping us in practical ways to get our message to Australians, to reach those women and families who need information and support, and to have a national voice on breast cancer issues.

Watch for Puma's new swing tags.



Sound of Music cast offers its support

Before they left Melbourne, the cast of *The Sound of Music* held a cabaret night where they performed their own songs for a small group of friends.

They wanted to support the work of the Breast Cancer Network Australia and decided to donate to us the profits raised on the night.

It was wonderful to meet the cast and receive their cheque for \$3180.40. It was presented by **Sophie Viskitch**, who lost her mother to breast cancer.

I thanked them on behalf of all our Network women and let them know how much we valued their support.

– Lyn Swinburne



Network members, Gerda Evans and Lyn Swinburne, thank the Melbourne cast of *The Sound of Music*.

Issues of concern ...



Scientists' views on future advances in research

Making research user-friendly faster

Associate Professor Christine Clarke, Chair, National Breast Cancer Foundation's Research Advisory Committee

I believe the major advances in breast cancer research during the next 20 years will be in the areas of prevention strategies and targeted therapy.

The mortality caused by breast cancer is declining world-wide due to early screening and better treatments. This is the result of research during previous decades in laboratories and clinics around the world.

The delay in putting research findings into practice is decreasing sharply.

Research findings are emerging faster than ever before and the sophistication of research knowledge is increasing exponentially as new technologies create research methods able to look more deeply into the biology of normal and cancer cells.

The National Breast Cancer Foundation, in particular, encourages research which translates research findings into benefits for women with breast cancer.

This is important if we are to put into practical use the new knowledge about breast cancer that is being produced all over the world.

Research into the causes of breast cancer is actively being pursued and

Better services and better treatments



Professor Alan Coates, Chief Executive Officer, Australian Cancer Society

To make a difference to breast cancer, we need to improve screening, especially for groups of women who currently don't use mammography.

We need to improve the integration of the treatment team.

We need to give adjuvant therapy to (slightly) more women at (slightly) lower risk than we do now.

Newer drugs will help, mainly because they will have fewer side effects.

Women with breast cancer should be able to expect a breast care nurse and access to a psychologist if needed.

we can already point to the BRCA genes in familial cases.

New information about causative agents is emerging and will continue to be produced during the next decade. The development of rational and targeted prevention strategies will

be a reality within 20 years.

Research is revealing a great deal about the biology of breast cancer in individual women – the era of targeting therapy to individual women is on the way and will be routine in 20 years' time.

The clinical use of Herceptin in women with a high expression of HER2/neu is one example of recent research now being used in treatment.

Looking for answers in the genetic dictionary

Professor Chris Goodnow, Medical Genome Centre, John Curtin School of Medical Research, Australian National University

Just as each of us communicates and co-ordinates with one another by stringing words together in the appropriate sequence and syntax, our cells co-ordinate our body's organs by reading a code from our genes – about 80,000-100,000 genes, in fact.

In cancer cells, that code has been corrupted. A few key gene 'words' have been changed, fused together or misspelt in ways that cause that code to loop back on itself, playing the same sequence of events over and over to cause the excessive proliferation that are cancer cells.

If scientists knew the normal code, we'd know where in the sequence to intervene and stop this looping program, and therefore stop the excessive growth of cancer cells or their migration and metastasis.

Science has made a momentous leap with the Human Genome Project.

We have essentially worked out the sequence of the 'letters' of all of the 80,000-100,000 gene 'words' that make up our genetic dictionary.

Unfortunately, what we have in the short term, after all this sequencing, is essentially a dictionary that has all the words, but no definitions for those words.

We don't know what each word is useful for, what it means, or how it should be combined with other words to make meaningful sentences and syntax.

(Continued next page)

Locking in on a moving target

As a cancer researcher, I've often been asked, 'Why is it so difficult to develop a cure for cancer?'

I think there's really one major reason for this – the tremendous genetic variation and instability in cancer cells.

The result is that any one cancer cell is a moving target for treatment, even in a particular patient.

How can we use techniques to overcome the genetic diversity and instability of cancer cells which allow them to escape the treatments we're giving a patient at any one time?

An approach, which is a fairly obvious, is to block all options, and identify key genes and proteins that are needed for the cancer to survive and spread.

Unfortunately, those are quite rare.

In my laboratory, we've identified an enzyme called Heparanase which it appears all cancer cells need to spread.



Professor Chris Parish, head, Division of Immunology and Cell Biology, John Curtin School of Medical Research, Australian National University

That's a good example of one of the targets that the genome project will allow us to identify.

There's also the possibility that we can go for components that are required from the host for the cancer to grow and those are not genetically unstable. If we can tackle those, we don't have this problem of the cancer cells stepping around our treatment.

In my laboratory, we're working on the blood vessels that are required for cancers to grow.

For example, we are using a drug called phosphomannopentaose sulphate, which has the ability to interfere with new blood vessel growth in cancers.

It is entering clinical trials in cancer patients in Melbourne.

I'd like to make a few predictions about how cancers will be treated in 20 years time.

First, there are going to be better methods of detecting cancer early, before it becomes highly invasive.

Second, there will also be a cocktail of subtle drugs. The cytotoxic drugs we have today are going to be phased out. The new drugs will have minimal side effects, while inhibiting tumour growth and stopping cancers spreading to other organs.

Third, there will be sensitive methods for monitoring cancer recurrence. A patient who has been given a cocktail of drugs to control their cancer will know when they need to go back on this treatment if their cancer recurs.

Finally, I must emphasise that curing a patient by totally eliminating the cancer is unlikely.

In future, we're going to be able to control the disease by using subtle treatments and improved detection methods. It'll be controlling cancer in a similar way to using insulin to treat diabetes.

(Continued from page 5)

In the case of cancer, the question is: 'What are the key gene words, sequences and sentences we really need to know about to try and intervene in particular types of cancers?'

In essence, what we and many others are focusing on is putting in place the 'definitions' of gene functions for cancer.

We are working as fast as we can to highlight and fill in the key pages of the genetic dictionary where research on cures for cancer should focus.

Earlier, individualised treatments

Professor Sally Redman, Director, National Breast Cancer Centre

Over the next 20 years, as our understanding of the biology of breast cancer grows, we will be better able to select the best treatment for individual women based on the characteristics of their tumours.

This will require better ways to provide women with information that helps them understand different treatment approaches.

Research priorities

We have begun a process within the Network to identify priorities for breast cancer research as identified by those personally affected by the disease.

The National Breast Cancer Foundation recently asked for this priority list.

The foundation has given \$9 million in funding to 55 breast cancer research projects since it was established in 1994.

The initial list of research priorities is available for viewing on our website – www.bcna.org.au

If you have areas to suggest, topics to recommend or research questions to pose, please for them to the Network.

This is one way to make your views known.

Improved screening and diagnostic techniques will mean most breast cancer is found while it is still small.

Hopefully, we will also have found better strategies to help women who carry the genetic mutations which place them at high risk of developing breast cancer.

We will also have become better at rapidly translating research into clinical practice, so that all women are treated using the best available knowledge.

Co-operation needed to further treatments

Emeritus Professor Tom Reeve, ACCBE, Executive Officer, Australian Cancer Network

Breast cancer is at the centre of a changing clinical scene.

The mobilisation of multiple clinical disciplines as a front line approach to the disease allows the patient to be fully involved in decisions about their management.

It is hoped that the multi-disciplinary care will be the harbinger of better times for women with breast cancer, allowing them to choose treatments at the cutting edge.

One could comment on changes in many directions, but the raising of eyebrows when 'lumpectomy' was first introduced may be a minor affair in comparison to what can be

speculated on for the future.

With advances in localising small tumours, perhaps focused radiation or other therapies targeted to the site will become a reality.

With gene manipulation on the threshold of significant progress, women may wish to co-operate with the introduction of therapeutic

changes that will relieve them of the anxiety of surgery and hopefully allow them a greater quality of life.

Well-researched and innovative approaches may introduce more user-friendly treatments over time.

Women themselves will, however, need to participate to ensure that trials can be done to assess proposed therapeutic activity.

A positive future across generations

A question that I'm asked all the time is when will there be a cure for cancer?

The answer is, I think, unfortunately, fairly simple – never.

This is simply because cancer is really millions of different diseases.

Cancer is different in every individual patient. That means we have to personalise treatments for cancer.

To do that we need to understand genes. Cancer is a disease of genes.

Changes in DNA in normal cells leads to the formation of cancer cells, so if we're going to understand and have a rational basis for treating cancer, we need to understand what the genes are doing.

The problem is that changes to genes in cancer cells are complex and numerous.

Fortunately, the sense of optimism I can give is that I think we've turned the corner with some new technologies.

What I'd like to do is to give you some hypothetical case studies, centred around how we treat cancer today and what these new technologies might mean in 35 years' time.

The hypothetical patient is a 43-year-old woman who develops a cancerous 2cm lump in her breast.

At the moment, we would do tests on the tumour for hormone receptors and she would undergo removal of lymph glands from under the arm, to see if the cancer has spread.



Dr Grant McArthur, Medical Oncologist and Researcher, Peter MacCallum Cancer Institute, Melbourne

In this hypothetical case, two of the woman's 12 lymph glands show evidence of the spread of cancer.

How is she treated?

First she'll have surgery to remove the tumour, followed by radiation therapy to reduce the chances of the tumour coming back in the same breast.

When lymph nodes are involved, we would usually recommend chemotherapy.

This woman may well have to stop work because of the side effects associated with this treatment.

After finishing chemotherapy, she would probably take the anti-hormone treatment, Tamoxifen, for five years.

After this, she has a 65% chance of being free of breast cancer at 10 years after diagnosis.

In reality, she's living with a lot of uncertainty.

Furthermore, it wouldn't be possible to get life insurance once she had a diagnosis of breast cancer.

This woman has two daughters. In 35 years from now, the first of this woman's daughters undergoes a genetic analysis.

It is shown that she carries abnormalities in three genes and these predispose her to developing breast cancer.

She is able to take medications aimed at these genetic abnormalities to change the function of the genes. As such, she may be able to prevent the breast cancer from occurring.

Unfortunately, the second daughter develops a 1cm tumour in her breast.

In 35 years from now, the tumour could be removed and the molecules in the genes looked at using a profiling technique that would investigate chromosomes, genes and proteins.

That data could then be fed into a sophisticated computer program to come up with the best treatment strategy for this patient.

She may first receive some professional psychological support.

She may still have some radiotherapy like today and be offered chemotherapy.

I anticipate that she will also be offered anti-angiogenesis treatments which interfere with new blood vessel growth in cancers.

Furthermore, based on the gene profile in her tumour, she'll receive some drugs that target several molecules known to be abnormal in her tumour.

Finally, she may receive a vaccine, again based on knowledge about the genes that have been changed in her particular tumour.

After all of this, she will have a 98.5% chance of staying free of the spread of breast cancer at 10 years after diagnosis.

With such probabilities, I think an insurance company would feel fairly comfortable giving life insurance to someone in this situation.

Researching the psychological and social needs of people with breast cancer

Over the past couple of years, a special research collaboration has developed between the Illawarra Breast Cancer Support Group and members of the Psychology Department at the University of Wollongong.

The impetus came from the support group, via its indefatigable co-ordinator, Sr Gloria Swift, BCN.

No passive or reluctant research participants these; they wanted research done and decided the psychology department should be able to help.

As a member of both the support group and the psychology department, I am able to liaise between the two (and also know I will be promptly brought back to earth if our research wanders too far into esoteric academic realms).

Our approach is actively collaborative, shown already by the inclusion of qualitative methods (focus groups, interviews, etc), since participants have said they find this generally more satisfying and meaningful than filling out questionnaires.

Our primary aim has been to research experiences and needs in the Illawarra region (the coastal strip just south of Sydney). Treatment and care facilities in the area are excellent and the Illawarra Breast Cancer Support Group is an active and successful organisation.

What does and doesn't work in support groups needs to be investigated, as do the reasons why many women choose not to be involved.

This year though we have added a more rural perspective, with participation from the Wagga Wagga Breast Cancer Support Group.

Given the inevitable limitations of time and resources, we have broken up what is an ambitious project into a series of smaller ones – a sort of jigsaw of information that will take shape over several years.



*Beth Marlow,
Department of
Psychology,
University of
Wollongong and
member of the
Illawarra Breast
Cancer Support
Group*

This means smaller projects can be undertaken by senior psychology students, under staff supervision, as part of their course requirements.

So, the support group gets its research done, a few lucky students get invaluable experience, while my colleagues and I can be involved in some worthwhile research.

What have we been doing since we began?

Three smaller studies have been completed, two new ones are under way and a major, doctoral project is progressing well.

Last year, Tania, Holly and Sarah conducted discussion groups with women living with breast cancer, looking at the needs of women of different ages.

As might be expected, for younger

women body image and especially worries about their children were priorities.

However, most women shared a range of concerns which were summarised into four major groupings:

- reassurance (knowing what to expect);
- a sense of control (being able to make choices and decisions);
- organisation of care (an integrated support network); and
- validation of experience (being taken seriously).

Heather asked a group of younger women about their relationships with their health care providers.

The participants felt better understood and more cared for by their complementary health practitioners. It became evident that many cancer patients are not clear about the precise roles and responsibilities of their medical practitioners.

Lauren investigated the ways women related to those around them. She showed that, on average, her group living with cancer were strikingly 'normal' – able to relate to others without being either too withdrawn or demanding.

This year, Ruth C. is expanding on Lauren's study. Meanwhile, Heidi, Louise, Ruth W., Sarah and Veronica are running discussion groups to establish just what the support group means to the members.

Lis, a doctoral student, continues to test the effectiveness of different kinds of support, using a personal constructs perspective.

She has presented preliminary findings overseas and, like Nadia, Heather and myself, is presenting a paper at the Fifth World Congress of Psycho-Oncology in Melbourne, this September. Exciting stuff indeed!

Contact: Beth Marlow, University of Wollongong, (02) 4221 4073 or e-mail beth@uow.edu.au

Queensland dragons needed!

Brisbane women are needed to form a Queensland team to contest the Australian Dragon Boat Championships in Darwin on May 15-16, 2001.

We train with the Brisbane River Dragons at the 18' Sailing Club, Bulimba St, Bulimba, every Sunday at the quite civilised time of 9am.

Any one interested can come along to have a go – no experience necessary – just wear comfortable shorts, t-shirt, hat, sun screen – bring a bottle of water and lots of enthusiasm!

It is great fun!

Contact: Janelle Gamble on (07) 3353 4151 or 3353 4100.

Meet the Network's consumer representative ... Pam Bell

A member of Breast Cancer Action Group (NSW), **Dr Pam Bell**, has been appointed to the National Breast Cancer Foundation's (NBCF) Research Committee.

She was nominated by the Network.

Pam's personal and professional profile demonstrates that she has what it takes to represent us on this committee.

A former professor of nursing, she was recently appointed to the position of honorary senior research fellow at the University of Technology, Sydney.

Pam has an extensive background in health research, obtaining many grants and teaching other health professionals how to conduct research.

On a more personal level, she was diagnosed with breast cancer two years ago, requiring her to undergo chemotherapy and radiotherapy.

Now semi-retired, she is happy to contribute her knowledge and experience to advocacy work and is keen to ensure that members' views are taken into account.



She reports that the chair of the NBCF Research Committee, Christine Clarke, is working to ensure that consumers have a voice in research decision-making.

For a scholarship recently funded by 'Women in Super,' the decision was made to give a competitive advantage to a research project in an area identified by women with breast cancer.

To this end, BCNA was consulted about the Network's research priorities.

Pam maintains close links with the Network. She can be contacted on (02) 9955 9313 or e-mail bellpc@bigpond.com

The Network's 'legal eagle'

Damien Lockie is a partner with the law firm, Freehills Hollingdale & Page, and one of Australia's leading taxation lawyers.



He has been involved with the establishment and regulatory aspects of the Network almost since its inception.

"To see the vision of **Lyn Swinburne** and others who have created and are shaping the charter of the Network reach fulfillment, and make a difference for people's lives, is a fantastic reward for my involvement," said Damien, who is actively involved in community and *pro bono* activities, through Freehills and the taxation profession.

Damien is a Fellow of Leadership Victoria (the Williamson Community Leadership Program). It was through that group's SkillsBank program that Damien was introduced to the Network.

Freehills is recognised for its *pro bono* legal program. In fact, it has been awarded the 'large firm' *pro bono* award by the Attorney-General every year for the past few years.

Damien was instrumental in helping the Network appoint Freehills as its *pro bono* law firm.

"The work of the Network is so important, I'm proud to be able to be of some assistance," Damien said.

"My brother is a BreastScreen radiologist, so I really admire all the people involved with breast cancer treatment.

"I feel that the work that Freehills and I do indirectly makes a contribution too."

Thank you to Damien and Freehills for their support of the Network.

Meet our bookkeeper!

Breast Cancer Network Australia relies on the good will of many people to help us with our work.

The Network's voluntary bookkeeper is **Madge Kenna**.

Madge, who lives in Melbourne with her husband, Tony, and two children, Jo and Robert, generously gives us her time and expertise to manage the 'books'.

She has not personally experienced breast cancer, but still appreciates our work and wants to help out too.

Thanks Madge!



My Journey

A message of hope

I hope that my experience as a young woman who discovered she had breast cancer when she was just 30 years old, some 24 years ago, will give someone hope.

The bottom fell out of my world in 1976 when a lump in my left breast turned out to be malignant.

I was a 30-year-old wife and mother, with two daughters aged 11 and 6, living in country South Australia.

While preparing for a game of golf, I felt pain in my left breast. Under the shower that night I examined my breasts and found something strange. This was confirmed by my husband.

My doctor didn't seem overly concerned when I saw him, but suggested its removal.

The day after the biopsy, he entered my hospital room, closing the door behind him. Call it women's intuition, but I knew it was not good news.

The dissection showed that the walnut-sized lump he had removed was cancerous and I would need an immediate mastectomy.

My heart sank. All kinds of thoughts raced through my mind. How would my daughters cope without their mother? How would my husband manage? At this stage I wasn't worried about myself ... whatever will be, will be, I thought.



Rene Pezy,
South Australia

When I was admitted to hospital I remember demanding a single room. I needed to be alone.

It also gave me time alone with my husband, because I was worried about what was going through his head and how shattered he must have feel.

The operation was a success and found that one of the 12 lymph nodes removed contained signs of cancer.

Chest and other x-rays were taken over the next few days and I wondered why no-one enlightened me on why these were being done.

Since then, I have always asked about everything: medication, x-rays, treatment and so on. I want to know all about what and why something is being done to me.

A lady from the breast cancer support group showed me several breast prothesis which, she said, would help me feel 'normal' again!

I then underwent six weeks of daily radiation therapy.

This 'burning of cancerous cells' was as bad as the operation – blisters developed on the wound and my skin looked like a bad case of sunburn.

Cream applied regularly to the skin helped the healing.

My mother was great through it all, and I still needed her help when I returned home.

She was nearly 70 years old, but fit for her age, and I suspect she liked being needed.

I decided to try swimming, despite never having learnt how. However, contact with several non-swimming friends soon found plenty of learners to accompany me. Many others came to give us encouragement.

Once I passed the five-year expectancy, it was time to consider a breast implant, one inserted under the skin.

Two operations were necessary – one for the implant, the other to reduce the second breast to a similar size and shape.

The surgery was brilliant. I was thrilled with the result and couldn't wait to buy a V-neck top.

Twenty-four years later, I can look back on my experiences.

Not only was there physical pain, but mental hurt as well, especially the fear of the unknown: Would I survive? How long would I live?

Now I'm happy to say I am well and truly a survivor.

– Rene Pezy

Raising awareness of young women with breast cancer

A team of enthusiastic young Victorian women are organising what will hopefully become an annual, national event.

Sunday, November 12, is going to be about raising awareness of the prevalence of breast cancer in young women.

We want to help prevent misdiagnosis and encourage doctors to take the concerns of young women with symptoms more seriously.

It should also be a great way to

connect women with similar needs, to create reassurance and encouragement.

Victoria's only dedicated group for younger women is the Young Ones Social Group in Melbourne, which is difficult for country people to access.

Through this day, we also want to create networking opportunities for rural women.

At this stage, we don't have a venue, so put your name on our mailing list for more details as they become available.

We have attracted some interesting and

informative speakers who will have you on the edge of your seats.

There are already a lot of names on our list and I think the public will be surprised by the number of young women affected by breast cancer in Victoria alone – we were!

Volunteer help will be gratefully accepted.

– Michelle O'Dea

To put your name on the mailing list for this event, phone Breast Cancer Network Australia, (03) 9805 2500.

Breast cancer touches so many

A handsome, middle-aged man walked quietly into the cafe and sat down.

Before he ordered, he couldn't help but notice a group of younger men at the table next to him.

It was obvious they were making fun of something about him.

It wasn't until he remembered that he was wearing a small pink ribbon on the lapel of his suit that he became aware of what the joke was about.

At first, the man brushed off the reaction as ignorance, but the smirks began to get to him.

He looked one of the men in the eye, placed his hand beneath the ribbon and asked, quizzically, "This?"

With that, all the men began to laugh out loud.

Fighting back laughter, the man he had addressed said, "Hey, sorry man, but we were just commenting on how pretty your little ribbon looks against your blue jacket!"

The middle-aged man calmly motioned for the joker to come over to his table and sit down.

As uncomfortable as he was, the man obliged, not really sure why.

In a soft voice, he said, "I wear this ribbon to bring

awareness about breast cancer. I wear it in my mother's honour".

"Oh, sorry dude. She died of breast cancer?"

"No, she's alive and well. But her breasts nourished me as an infant, and were a soft resting place for my head when I was scared or lonely as a little boy," he said.

"I'm very grateful for my mother's breasts, and her health."

"Umm, yeah", the stranger replied.

"And I wear this ribbon to honour my wife," the middle-aged man went on.

"And she's okay, too?" the other man asked.

"Oh, yes. She's fine. Her breasts have been a great source of loving pleasure for both of us, and with them she nurtured and nourished our beautiful daughter 23 years ago," he said.

"I am grateful for my wife's breasts, and her health."

"Uhuh. And I guess you wear it to honour your daughter, also?"

"No. It's too late to honour my daughter by wearing it now," he said.

"My daughter died of breast cancer one month ago.

"She thought she was too young to have breast cancer, so when she accidentally noticed a small lump, she ignored it.

She thought that since it wasn't painful, it must not be anything to worry about."

Shaken and ashamed, the now sober stranger said, "Oh, man, I'm so sorry".

"In my daughter's memory, too, I proudly wear this little ribbon,

which allows me the opportunity to enlighten others.

"Now, go home and talk to your wife and your daughters, your mother and your friends.

"And here ..."

The middle-aged man reached into his pocket and handed the other man a pink ribbon.

The man looked at it, raised his head and asked, "Can ya help me put it on?"

– E-mailed to us by a Network member

Letter to the Editor

Hi Lyn

After seeing that you ran with the Olympic torch, I had to write to congratulate you.

What a buzz. I know it was a buzz because I also had that honour.

I was nominated by my absolutely adorable 13-year-old daughter.

I was totally pumped and psyched for it, but I wanted to stay calm and remember and cherish every moment.

On the relay bus in the moments before I was dropped off into the pelting rain and howling wind, I drew on all my strength to slowly relax and tune in to what I was about to do.

As I stepped up to receive the flame, my mind was both racing and relaxed, and I was able to clearly see and think of my Mum, who lost her battle with breast cancer, of friends who have lost or are struggling with their journey, of those who have fought and won.

As it turned out, the rain was a bonus – only mum and I know that not all the water on my face was from the rain!

I feel honoured to have been able to represent breast cancer patients in this way.

I am also incredibly proud of my daughter, Kimberley, who felt her Mum was worthy of a place in this history-making event.

I have been able to share my experience and the torch with literally hundreds of primary school children.

As a teacher, I visited all the schools in my area. It was thrilling to watch so many little faces light up as they took hold of the Olympic torch.

It is refreshing to know that these children are the future and that something seemingly simple like the Olympic spirit can put aside differences and bring joy to so many.

I hope you also cherish the special moments that we have been lucky enough to share.

Life doesn't get any better than this. It's great to be alive!!

Stay well, stay happy.

– Sharon Murphy

Insurance difficulties

The Network has received some expressions of concern from women experiencing discrimination or difficulty when seeking or attempting to maintain insurance cover.

This may apply for health, travel and life insurance.

It would help us to understand the types and extent of problems faced by you if you would write or e-mail us with your concerns and experiences.

Names and identifying details would be kept confidential.

Write to BCNA or contact Sally Crossing (02) 9436 1755 or Gil Paulsen (03) 9805 2500.

UPCOMING EVENTS

October 7: Think Pink Party, Anti-Cancer Council Victoria, Grand Hyatt, Melbourne.
Reservations: 1300 656 585

October 14: Second NSW Consumer Forum, Women's College, University of Sydney.
Contact: Sally Crossing (02) 9436 1755

October 18: Bosom Buddies Celebration of Life Fashion Event, 7.30pm,
Exhibition Hall, Canberra Convention Centre.
Contact: Norma Bradley (02) 6254 5286

October 19: Raelene Boyle's Australia's Breast Cancer Day Evening of Dinner, Dancing
and Fashion, Novotel Twin Waters Resort, Sunshine Coast (\$80.00).
For information and tickets: (07) 5476 6462

October 21-23: *Field of Women, The Esplanade, beside Riverside Drive, Perth.*
Launch at 11am, October 21.
Contact: Carol Bishop (08) 9489 7312

October 21: Breast Cancer Information Day, Royal North Shore Hospital, Sydney.
Contact: Sally Crossing (02) 9436 1755

October 22: Canberra Mini Field of Women and Silent Walk, 1.30pm.
Contact: Tania Pirotta (02) 6227 5836 or Anna Wellings Booth (02) 6247 8470

October 23: Adelaide Mini Field of Women.
Contact: Carlene Butavicius (08) 8272 2895

October 23: Coffs Harbour Mini Field of Women.
Contact: Chris Stanford (02) 6659 1483 or e-mail cstanford@doh.health.nsw.gov.au

October 23: Melbourne Mini Field of Women.
Contact: Gil Paulsen (03) 9805 2500

October 23: Information sessions for women with breast cancer, South Australia.
Contact: Margaret Tobin (08) 8291 4111

October 23: Australia's Breast Cancer Day Breakfast, Sydney.
Contact: NBCC (02) 9334 1700

October 23: Community Brunches for Breast Cancer, Victoria.
Contact: Alison Peipers on (03) 9635 5403

October 23: ABCD Women's Luncheon, Peter MacCallum Cancer Institute, Park
Hyatt, Melbourne.
Contact: (03) 9656 1124

October 25: Calvary Hospital Breast Awareness Evening, 7.30pm,
Calvary Hospital, ACT.
Contact: Janine Rogers (02) 6201 6111

October 28: Pink Ribbon Ball, NSW Cancer Council, Sydney.
Contact: NSW Cancer Council, 13 11 20

For more information about ABCD events in regional areas on October 23, visit the
National Breast Cancer Centre's website – www.nbcc.org.au

November 12: Victorian Young Women's Breast Cancer Awareness Day, Melbourne.
Contact: BCNA (03) 9805 2500

November 15-19: Fourth Leura International Breast Cancer Conference.
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 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

Mastectomy advice

A new resource is available to women considering preventive mastectomy because of a strong family history of breast cancer.

The Hereditary Cancer Clinic and the NSW Genetics Education Program have written a terrific booklet about the subject that is available for no charge from the National Breast Cancer Centre, 153 Dowling Street, Woolloomooloo, NSW 2011, phone (02) 9334 1700.

New on our website

- Robin Honeychurch's story of amazing friendship.
 - Bendigo Breast Cancer Consumer Forum report.
 - Judith Ardagh from WA shares her experiences on a recent trip to the US which, included participating in 'Race for the Cure'.
 - Clinical Trials – A personal experience: Following *The Beacon* 11, Jean Emery wrote to us of her personal experience with a trial for advanced breast cancer
- Visit our website at www.bcna.org.au.



Seeking Shelter

The Network welcomes this group under its umbrella:

- North Western Breast Cancer Support Group, Epping, Vic.
- 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

THE BEACON

The Beacon is the newsletter of the Breast Cancer Network Australia.
Editor: Lyn Swinburne (03) 9805 2500
Layout: Substitution
Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria 3122.