

The Beacon

Breast Cancer
Network Australia
newsletter



Reconstructive surgery has given Fay Abromwich a chance to begin again. Read her story on page 6.

Field of Women at the MCG

Breast cancer statistics are just that – statistics – until you see a Field of Women. The messages on the silhouettes remind us that the statistics are about real women.

The 10,000 pink silhouettes represent Australian women who were diagnosed last year. Most of these women had no known risk factors, no family history.

While the pink silhouettes tell us most women will survive, it is also important to promote the 2500 white ones that pay tribute to women who will lose their lives to breast cancer.

Feedback from last year's Field of Women in Canberra was so impressive that it is to become an annual event. This year it is Melbourne's turn.

The 1999 Field of Women will be launched at the Melbourne Cricket Ground (MCG) on Sunday, October 17, at 1.00pm.

This location should attract lots of media attention, which will help get our agenda across, encourage the public to come and read our silhouettes, raise the profile of the Network and tell women we are here and they can join us.

The 100,000 empty seats at the MCG will symbolise the number of Australian women estimated to have received a breast cancer diagnosis.

Again, we will begin with a silent walk. We will gather at 12.30pm on the corner of Yarra Park, opposite the Hilton Hotel, and then carry the white silhouettes along the path to the MCG.

At the end of our silent walk, there will be a ceremony inside the MCG and the white silhouettes will be planted alongside the pink ones already planted by school children, AMP staff members and volunteers.

AMP and the Field of Women

Last issue, *The Beacon* announced AMP's support for our project.

AMP recognises the value of our work and is helping in many ways. Its financial support has allowed us to appoint a project team and promote the project around Australia.

AMP staff members are also helping us find silhouette sponsors and will supervise the school students who will plant the silhouettes.

We wish to thank AMP for its on-going assistance and support.

Between October 18 and 23, the field will be displayed in the Treasury Gardens, on the corner of Spring Street and Wellington Parade.

We hope thousands of Victorians will come and read the messages attached to the silhouettes. There will also be an opportunity to get information about breast cancer and the Network from survivors and breast care nurses.

As our Network is national, mini fields of 100 silhouettes will also be planted in other states and territories on October 17. If you can't make it to Melbourne on October 17, join with other Network members for the ceremony in your state.

State ceremonies

Fields of Women will be planted across Australia on October 17. For the location in your state, phone these state representatives:

Adelaide: Carlene Butavicius (08) 8272 2895
Brisbane: Leonie Young (07) 3341 7570
Canberra: Anna Wellings Booth (02) 6247 8470
Darwin: Susan Tully (08) 8927 3327
Hobart: Rosemary Kerrison (03) 6273 4192
Melbourne: Lyn Swinburne (03) 9660 6865
Perth: Carol Bishop (08) 9381 2070
Sydney: Sally Crossing (02) 9436 1755

INSIDE...

STATE ROUND-UP	2
ISSUES – RECONSTRUCTION	4
WHAT THE SURGEON SAYS	5
NEWS FROM THE NBCC	10
LETTERS TO THE EDITOR	11
COMING EVENTS	12

State Round-up

NEW SOUTH WALES



The NSW Consumer Advocacy and Science Training course will run over three weekend days – September 18 and 19, and October 9.

If you are interested in being involved in the Breast Cancer Dragon Boat Team in Sydney during April 2000, contact **Melba Mensch** on (02) 4926 2861.

BCAG NSW has a new web site at <http://www.users.bigpond.com/crossings/>

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

VICTORIA



Victoria's Department of Human Services recently introduced a program to enhance the provision of services for women with breast disease, particularly breast cancer.

To meet the increased demand for women to participate on these committees, we have developed an advocacy course based on the one previously run by the National Breast Cancer Centre, but tailored to our needs. It will be run over two weekends in August and 30 dedicated women have said they will participate. However, I am sure we will need to repeat the course regularly to keep up with future requests.

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

TASMANIA



The location has not been finalised for Tasmania's Field of Women, but if you can help out, phone **Rosemary Kerrison** on (03) 6273 4192.

We have been corresponding with Tasmania's College of Surgeons since before the Action Plan created at the national conference. Its secretary has now asked us for information about the Network for its next newsletter.

A committee of four people in the Devonport area organise a Wedding Extravaganza each year, with proceeds going to charity. This year, breast cancer was the chosen recipient, with the funds shared by the Tasmanian Network and the Cancer Council's Support Service.

Contact: **Rosemary Kerrison** (03) 6423 3637

THE ACT



It's winter, so we're hibernating and storing energy for our Field of Women. Contact me if you can help! What else is happening?

- Some members participated in a fashion parade in Sydney on July 30 for breast cancer research.
- The Vice-Chancellor's Cocktail Party at Canberra University on August 21 began activities for Australia's Breast Cancer Day, with proceeds going to the Breast Cancer Institute Australia.
- **Jan Murphy's** education program has been extended to women's groups.
- 'The House that Bev built' is almost finished and raffle tickets are on sale for \$5 each (house and land valued at \$155,900) if you phone (02) 6231 2658.

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

QUEENSLAND



Here in Queensland, we are planning to plant our Field of Women in the Queen Street Mall on October 17.

Breast Cancer Queensland will next meet at the Kedron on the Brook conference room, 700 Lutwyche Road, Kedron, on Tuesday, September 14, from 6.30 to 8.30pm. See you there.

Contact: **Leonie Young** (07) 3341 7570 (ah), **Janelle Gamble** (07) 3353 4151 (bh) or medusa_998@yahoo.com

NORTHERN TERRITORY



Our submission for a breast care nurse has been completed and handed to our Minister for Health.

Local libraries have agreed to stock our suggested list of books. This will be launched on Australia's Breast Cancer Day (ABCD), along with our 'Australian Face Of Breast Cancer' calendar.

Two members attended the Sydney conference and our poster presentation for 'My Journey' was well received. It is pleasing to know there is now funding to help promote this concept nationally.

Our constitution is nearly finished.
Contact: **Susan Tully** (08) 8927 3327 or tullynt@msn.com.au

SOUTH AUSTRALIA



Action For Breast Cancer SA has been making its presence felt, circulating its brochure to hospitals, doctors' rooms and clinics.

There are five Action breast cancer support groups, with two more to be established in the near future.

Action has formed a sub-committee to help with the SA Field of Women. We are also helping **Helen Winefield** with her research about support groups.

Guest speakers at our meetings have included **Sarah Tyson** (Breast Surgery Audit) and **Shelley Scholes** (BCEP and 'What women want from diagnosis onwards').

These meetings also keep us up to date with local studies and activities associated with breast cancer. We are looking forward to our AGM in September, when our guest will talk about predicting recurrence after breast cancer – of interest to most of us!

WESTERN AUSTRALIA



Advocacy training is our next focus. We are also meeting with two guest speakers for the months ahead.

There has been some interest in starting a young women's group and members have plans for a gathering to support the Field of Women.

Members have been asked to comment on the making of an up-to-date reconstruction video and communication training for medical students.

An article in the 'West Australian' recently included comments from two of our members. The narrative was written from personal and informative views.

This year's gala event will be a fashion parade, organised by La Femme Boutique, at the Burswood Hotel on Friday, September 3. Tickets are \$35 and are available at all BOCS outlets.

AOBC WA hopes to broaden its network, so that families in remote WA can also be involved.

Contact: **Carol Bishop** (08)9381 2070

To highlight an activity or a project, contact your state representative and have it included in the next 'State Round-up'.

What can I do to help?

The Network exists for us all. We do not ask for membership fees or that women pay to receive *The Beacon*.

However, it costs a great deal to produce and mail our newsletter, to recruit and co-ordinate women to represent us on committees, and to participate in discussions and debates about breast cancer. It costs us money to run our office.

We try to keep our costs down, but we need your help.

Some Network members and supporters have sent us donations and we thank them for their generosity.

We have so many things we'd like to do, but they will only be possible if we collect many silhouette sponsorships.

We are including three Field of Women sponsorship brochures with *The Beacon*. If each Network member could collect three sponsors, we would have enough money to assure our future.

There are also other ways to be part of this year's event

Beforehand:

- Ask stores to carry our brochures.

- Leave brochures at your gym, golf/bowling club, local library, etc.
- Give a presentation to a local group (We can give you a kit, including a video).
- Tell others about the Field of Women – invite them to come.
- Promote the event through your local paper (We can help with a press release).
- Hand out brochures at shopping centres.
- Join an organising committee.
- Let us know of other groups that might include our brochure in their mailouts.

On the day:

- Come along to the Melbourne Cricket Ground! Bring your family and friends.
- If you're in Melbourne, help out at the information booth during the week in the Treasury Gardens.

The Field of Women project managers are **Jan Bottcher** on (03) 9801 8636 and **Lyne Geier** on (03) 9853 0557.

If you value the Network, your help is needed to make sure it survives.

BCNA becomes a company

Breast Cancer Network Australia (BCNA) has been incorporated. We are now a Company Limited by Guarantee (we have received permission to drop the Co Ltd from our title).

We would like to thank the steering committee created to develop our constitution and establish BCNA as a legal entity.

It is especially important to recognise the contribution of the legal firm Freehill, Hollingdale & Page, which offered us pro bono legal assistance.

The staff at Freehills, especially Damien Lockie and Kaman Tsoi, have been unflinching in their support. It would not have been possible to create such a foundation for BCNA without their assistance.

Lymphoedema summit

In response to calls from affected and concerned women, the National Breast Cancer Centre (NBCC) will hold a lymphoedema summit at the end of the year.

It will bring together researchers, funding agencies, experts in the field and women, in an attempt to establish a high-quality research program about lymphoedema within Australia.

Funding will come from the NBCC and the Office for the Status of Women. We will keep you posted.

Network meeting in Sydney

The recent Australian Cancer Society Conference in Sydney gave Network members the chance to get together for the first time since our conference in Canberra last October.

Lyn and Jenny brought everyone up to date with what has been happening over the past year and what is planned for this year's Field of Women.

For a copy of our report, 'Achievements to Date' and financial report, send us a large, stamped, self-addressed envelope and your request.



New project for the Network

The Federal Government wants to know more about the Network's consumer representatives, who are increasingly being invited to join committees and working parties.

It wants to know how we find representatives, their training and support, and how they report to the Network and the women they represent.

We have been given project funding

to do this work by the beginning of December – to establish procedures and document what we do, so that other groups can follow our example.

We are working on this project and have appointed a project officer, **Anne Fletcher**. If you want to become a consumer representative or know more about the project, phone Anne on (03) 9585 7737 or your state representative.

Issues of concern ...



Reconstruction

The loss of a breast is traumatic for any woman. Our breasts have been fundamental to our sense of self and femininity since our early teens. They brought us joy and nurtured our babies.

The loss of one, or both, of them forces us to confront the loss of a part of our bodies that has been crucial to how we see ourselves. We need to grieve for the loss and reassess ourselves in terms of what we essentially are.

For women who have lost a breast to this disease, the issues surrounding reconstruction are many. Every time we look at ourselves in the mirror we remember what we have been through and the continuing risk to our lives.

Scars recede, hair grows back and burns heal, yet our flat chest can become a reminder of what we have been through. For some, this is not an issue, but many of us long to be whole again.

We have probably all considered

reconstruction. For some, the thought of more surgery is enough to put them off the idea. For others, the cost involved will mean that it is out of the question.

Whatever we do, we must make sure that in this, as in everything we do that affects our health and well-being, we are fully informed about the procedure.

We must be clear about why we are undertaking such lengthy and complex surgery. Does it really matter if we lack one or even both breasts? Isn't our flat chest a kind of badge of honour, a mark of courage, a reminder that we have survived what a short time before would have been unimaginable? Isn't our health – regained so slowly after breast cancer – the paramount concern?

Ultimately though, it is your choice. Make sure you are thoroughly informed of all aspects of the operation you are considering. Only you can decide if the benefits, with all the costs, attendant risks, pain and debility are worth it.

Do it, if you decide to, for yourself alone.

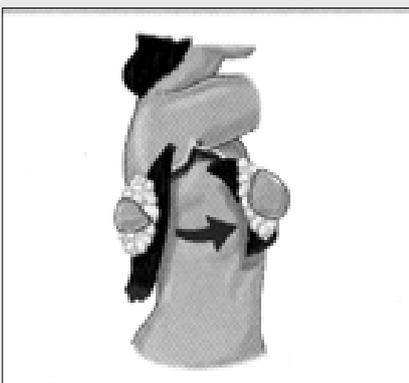
– Jenny James

Different types of reconstruction

Saline implant

A silicone shell implant, filled with saline (salty water), is inserted under the pectoralis major, the muscle behind the breast.

If the reconstruction begins at the time of the mastectomy, an expander is inserted and filled with saline over the next few months until the required size is reached and a permanent implant can be inserted. If the implant ruptures, the saline is reabsorbed into the body.



The latissimus dorsi added fat flap technique uses tissue from the back to help recreate a breast.

Back muscle transfer (latissimus dorsi added fat flap muscle transfer)

A flap of muscle, fat and skin is transferred from a patient's back to her chest, where it is shaped and sewn in place. This tissue fills the hollow left by the mastectomy and provides a layer of tissue to hold a saline implant.

A small implant is usually placed behind it, to be replaced later by a larger implant. Sometimes there is enough fat to build a new breast without an implant.

Free T.R.A.M. flap (transverse rectus abdominus myocutaneous flap)

This uses part of the abdominal rectus muscle and tissue from the stomach area.

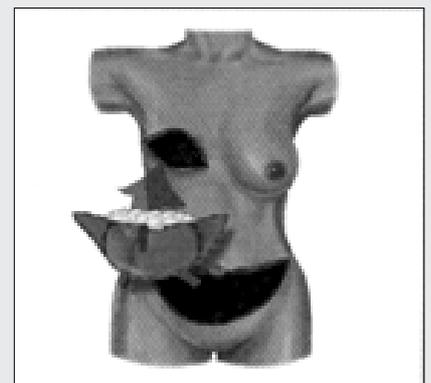
All the redundant skin and fat below the umbilicus is cut from the lower abdominal area, together with the blood vessels. A breast shape is constructed on the chest wall, and the blood vessels are connected to the blood circulation system with microsurgery. A nipple can be grafted or tattooed on later.

This procedure carries the risk of

complications and requires a longer recovery period. There is a risk the tissue transfer will not take and that a further procedure will be required.

There is also the risk of a bulge in the area from which the flap was removed, but this can be minimised by the use of a mesh graft in the repair.

As it removes part of the muscle in the lower abdomen, this procedure may reduce abdominal strength. There will be a scar across the lower abdomen.



The free TRAM flap technique uses tissue from the tummy tuck area to recreate the breast.

What the surgeon says

The Beacon asked plastic surgeon, **Dr Geoff Barnett**, some important questions about breast reconstruction.

Is every woman a candidate for reconstruction following a mastectomy?

Up to 90% of women have the option of reconstruction following a mastectomy. The most important decision they must make, however, is that the initial treatment will be best for their cancer.

If the best option is a mastectomy, then discussions should begin early on about an immediate reconstruction.

Sometimes reconstruction will be inadvisable, if a woman has poor health, for instance, or is a heavy smoker.

Each woman is different, so the operations must be judged for each individual patient.

Which type of reconstruction do you prefer?

I prefer to use a woman's own tissue for a breast reconstruction. It can be tissue from the abdomen or the back.

I find this gives a much better result, a more natural appearance and softer feel to the breast than an implant.

Do you think it is better for a reconstruction to be done at the time of the mastectomy or later?

I prefer to do the reconstruction immediately following the mastectomy, although it can be done later.

Performing both operations together avoids the need for two separate operations and I think it has major psychological advantages for the woman. She wakes after the mastectomy and still has a breast. It changes the focus and removes the hurt following mastectomy.

When she wakes, a woman can focus on the new breast and not on the mastectomy – the flat chest, the loss.

It also means a better result, as the breast skin is saved during the mastectomy.

A simultaneous mastectomy and reconstruction allows chemotherapy and, occasionally, post-operative radiotherapy.

How long does it take to recover from a reconstruction?

It depends, but usually a woman can resume some work three or four weeks

after a TRAM flap or latissimus dorsi-added fat flap operation. Some women will need longer to recover completely and some take a holiday before returning to work.

A tissue transfer is a bigger operation than an implant operation and a woman must spend 3-5 more days in hospital. This is acceptable, because it does produce a better outcome for women.

Do you try and make sure that women are fully informed before deciding on reconstructive surgery?

Of course we try to make sure they are fully informed. We give each prospective patient an information sheet and a pamphlet which fully explains each operation and outlines the possible complications.

We also discuss, at the first consultation, the possibility of the reconstruction not being successful.

There is a 5% failure rate with a TRAM flap operation, but we have had no failures with the latissimus dorsi reconstruction.

A woman considering this operation should have the opportunity to talk to other women who have had the same operation, and who have actually been through the whole thing. It reduces anxiety when a woman can see for

herself how delighted another woman is with the outcome.

Do women find that certain movements are restricted after a reconstruction? Do they lose arm movement or abdominal strength?

There may be a slight loss of arm strength with the latissimus muscle and fat operation. Certain extreme overhead reaching movements, such as serving at tennis and competition swimming, may be weakened. Similarly, minimal loss of abdominal strength occurs when tissue is taken from the abdomen. This is more obvious with a bilateral reconstruction. Some women find it difficult to sit up from a lying position even before the operation. Women generally report that there is little loss of function.

We usually use mesh to strengthen the abdomen after a TRAM flap operation. One woman had a successful pregnancy afterwards.

What are the risks of recurrent breast cancer being masked by an implant?

It is possible. Implant reconstructions make follow-up mammograms difficult, whereas natural tissue reconstruction do not. A recurrence is usually palpable in both forms of reconstruction.

What about a nipple reconstruction?

This is most important and can be made from local tissue or the flap. The other nipple and genitals are not used, as integrity of these organs is important. A tissue mound is made for the nipple and the surrounding areolar shape is scored and later tattooed.

How can women find a good plastic surgeon?

They should phone the Australian Society of Plastic Surgeons on 1800 633 475 for a list of surgeons in their state who specialise in breast reconstruction.

The time needed for the operation will be greatly reduced if the plastic surgeon specialises in breast reconstruction. We find that the latissimus dorsi operation using tissue from the back takes 2-4 hours, while a TRAM flap operation takes 4-5 hours. A bilateral TRAM flap reconstruction with an experienced team will take about six hours.

Reconstruction Costs

Reconstruction procedures cost thousands of dollars. Make sure you thoroughly investigate the costs of the operation you choose.

If you are privately insured, you may have between \$500 and \$1500 in out-of-pocket expenses, but find out from your health insurance company exactly what you are covered for.

If you do not have private insurance, you may be able to have a reconstruction operation as a public patient following a mastectomy. However, you may have to wait. How long will depend on where you live, as waiting lists vary from hospital to hospital.

A chance to begin again

These days, I have resumed a career where I am often bending over for other people.

In fact, I spend time each day bending backward, forward, sideways and stretching upwards as I demonstrate yoga postures to students in class and work with my own regular practice.

Eight years have passed since undergoing the 'super-charged' TRAM flap reconstructive surgery that resulted in a tummy tuck and renewed cleavage.

The description of TRAM flap surgery sounded like a cut-and-paste task at the computer. You select the bit to be moved, cut it from its original spot, move it to the new position and click it in place. Just like that.

The words TRAM flap have a certain comforting, Melbourne feel about them. However, they have nothing to do with my hometown's public transport system.

In the early 1990s, this operation was still experimental and a woman would be on the operating table for 10 hours of work, before spending seven days and nights immobile while the body adjusted through the pain to begin its healing.

This is not cosmetic surgery, but an intricate micro-plastic surgery linking veins, arteries and tissue. The nerve endings twitch around for a while before settling down.

At the end of this century, with the incidence of breast cancer not diminishing, the experts continue to refine the procedure.

The first 12 months after surgery were spent like an injured cat – licking its wounds. I stayed close to home.

Walking was prescribed as the best therapy, so I began by walking out of the front door, past two houses and then back home.

I found it difficult to drive a car with a clutch, as the constant movement of the leg up and down to change gears proved troublesome.

I spent time building vegetable and



Fay Abromwich

herb gardens, regarding this activity as a therapeutic tool in the healing process.

The kids helped with carrying the shopping from the boot of the car into the house. They lifted the washing out of the washing machine and passed each item to me as I hung it on the line. On Sunday mornings we would lie in bed for our cuddles and chats, and they would make me laugh till it hurt.

On the first anniversary of my reconstruction surgery, I embarked on a journey of return to the Sinai Desert. Before being diagnosed with breast cancer, I had led a group of women on this spiritual journey.

This was a challenge not only to my mental state but to the handiwork of those who had sewn me together.

The doctors had said walking was the best exercise. As I had already done quite a bit, I planned for lots more. There was also crawling, climbing and dancing!

With my guide, a man who had accompanied me four years earlier, I stayed with Bedouin tribes and climbed with them into the tall mountains behind the Santa Katarina Monastery. Here we slept out in mountain crevasses, bathed in pools of clear fresh water and witnessed miracles of nature.

I believe the experiences of breast cancer AD (after discovery), through the stages of diagnosis, treatment and survival (and, perhaps, life after BC) are major initiatory experiences.

Reconstruction is much more than a physical rearrangement of body parts.

During my experiences with this intricate subject, I have observed and felt its effects ripple through the mental, emotional and spiritual nature of my being.

I continue to share this excursion with some wonderful, inspirational, brave women and I sorely miss those who have passed away over the years.

Reconstruction offers a chance to begin again and/or to continue.

It is important to be informed about the risks involved in surgery (all surgery has its risks).

Also, you need to have total trust and belief in the professionalism of the surgeon and his/her team.

Ask as many questions you can think of – then think of more! Speak to other women who have undergone the technique. Read documentation about reconstruction and look at the photos. But, above all, follow your heart.

If I had known how much pain was involved or how challenging it would be to relearn things once performed automatically, I might not have undergone the operation. Now, I'm glad I did.

Perhaps the surgeon who advised me, and who led the team, sensed strengths and abilities I did not know I had.

Above all, no matter what happens on the operating table, it is up to us to keep the body stretched, toned, supple and healthy; and the mind untroubled and at ease.

Not a day goes past when I don't give thanks for this (new) body that allows me to achieve much of what I dream of.

An encounter with breast cancer demonstrates to many women, their loved ones and work colleagues, the importance of becoming passionate about life – however brief or long it may be.

– Fay Abromwich, Victoria

Discomfort, difficulties – then – delight

As a lumpectomy visitor for the Breast Cancer Support Service (BCSS), my training had taught me something about breast reconstruction.

It was, however, only of academic interest, as neither I, nor the ladies I visited, had had such extensive surgery as to need the services of a plastic surgeon. We were the lucky ones!

That changed in February 1997. Exactly 10 years after my original operation, a mammogram showed that problems had again arisen. This time mastectomy was the only option.

Once I had recovered from the initial shock, my background with BCSS turned my thoughts to reconstruction.

My surgeon's advice was to deal with the immediate problem first and take my time to examine reconstruction options.

However, seven months after my mastectomy I was still keen on reconstruction. The latissimus dorsi operation with tissue expander, followed by the insertion of a permanent implant at a later date, was deemed most suitable.

I knew to expect a fair bit of pain (the word 'ordeal' seemed to crop up during conversations with BCSS girls who had some form of reconstruction!), but I



Judy Burn

don't think I was quite prepared for the degree of discomfort I experienced – particularly for the first 24 hours or so.

Pain notwithstanding, I was absolutely thrilled with my new 'breast' and had to stop myself from flashing the little bit of exposed flap skin at each and every visitor to my bedside.

Six months later, the tissue expander was removed, the permanent saline implant inserted and a nipple created.

Weeks later, my new breast seemed to be becoming quite hard. Then, over the following months, it tended to distort and push towards the centre.

This was capsular contraction – scar

tissue had formed around the implant, making it hard and misshapen. Not only did it not look right, it was getting quite uncomfortable.

As a further operation was necessary – a capsulotomy to clear away the scar tissue – it was also decided to replace the implant with a silicone gel implant.

That surgery, performed this year, was a little more complicated than anticipated, but everything turned out well – until I developed a low-grade staph infection. This needed extended treatment with antibiotics and left me feeling somewhat the worse for wear.

I am pleased with my reconstructed breast. It is by no means a perfect match with the other one, but then I'm not into skinny-dipping at the local nudist beach, and in a bra it looks great.

However, reconstruction is not to be taken lightly – do your homework and have realistic expectations about the degree of discomfort, recovery time and cosmetic result.

Also, as in my case, even with the best possible care, problems can still arise.

Even with the setbacks, I do not regret choosing the reconstruction. For me, the result has all been worth it – finally!

– Judy Burn, WA

Love yourself as you are

Two years ago, I needed a second mastectomy.

I was still only in my 40s, so I decided to investigate different forms of reconstruction.

I settled on a bilateral TRAM flap reconstruction, to be done at the same time as the mastectomy.

My medical husband advised against an operation as large as a mastectomy and two reconstructions, but by this time, I could see myself with two beautiful new breasts and nothing would deter me.

I spent a lot of time choosing a top plastic surgeon and seeing photos of his past successes.

There were unavoidable complications. During the operation it was found that the blood vessels supplying one side of my chest were too small to carry sufficient blood to keep the reconstructed tissue alive.

The operation was extended over 20 hours and I returned to theatre five times in the first week.

Despite the surgeon's best care, part of my left breast became gangrenous.

All the surgery, anaesthetics and blood loss was a huge blow to my health. It has taken almost two years to feel truly fit and well again.

In fact, I still have no reserve against tiredness. If I become fatigued, it is

immediate, debilitating exhaustion. No gentle decline. And I'm a fence-sitter and don't give in easily!

My vanity has caused more problems than my cancer. After the first mastectomy I needed chemotherapy, but even that was preferable to the side effects of the reconstruction.

More surgery is needed to correct the scarring from the gangrene, but I have decided to accept myself as I am.

Consider carefully before choosing the right method for you. TRAM flap is a serious operation and may have side effects for some patients.

Love yourself as you are.

– Name supplied

Needing to make the right decisions

Being told you should have your breast removed at the age of 33 years is a daunting experience.

In October 1996, I was diagnosed with ductal carcinoma *in situ*, along with some invasive cells.

It started in July 1995, when a lump was found adjacent to my left nipple. After several ultrasounds and a fine needle aspiration, I was told it was a 'benign fibroadenoma' and asked to return in six months for a follow-up check.

Some months later, I discovered another lump and my GP referred me to a breast surgeon.

My ultrasound showed 'benign thickening' and again I sighed with relief. But eight weeks later, the surgeon recommended a biopsy, as the lump had grown and was very tender. That showed several 'suspicious' cells.

The surgeon recommended a lumpectomy. He warned that I might lose my nipple because of the position of the lump and asked if this worried me!

The lumpectomy went well, but the surgeon was not satisfied with the overall result, as the pathology stated "unclear margins". Suddenly the topic of conversation was mastectomy.

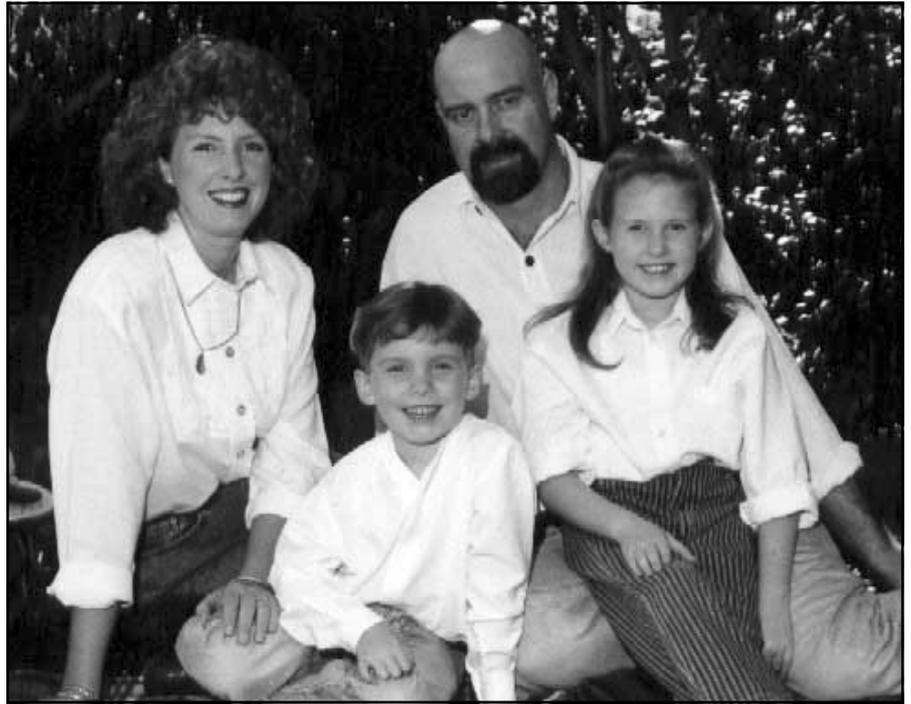
The doctor provided me with literature, a video, surgery options, and the opportunity to go away and think about my decision. I was also referred to the Head of Radiology Oncology at the Royal Brisbane Hospital for a second opinion.

My choices were either radical mastectomy or six weeks radiation therapy and hopefully no future recurrence.

It became paramount that I make the right decision. I was a widow ... after the death of my husband, Alan, in February 1995, my life was uncertain and meaningless.

Alan was diagnosed with small cell carcinoma of the liver in October 1994 and after his three-month illness and death, I was a single parent to our children. Louise was five years and my baby, Hayden, only 18 months old.

I had picked up the pieces of our shattered lives and been blessed with love again. I met a wonderful man and



Karen Wright with her husband, Kevin Loveridge, and children, Hayden and Louise.

suddenly had a reason to smile and laugh again. Life was on the up and up, and my new boyfriend, Kevin, willingly accepted me and my children (emotional baggage and all).

It was because of my age and relationship with Kevin that I opted for the mastectomy with simultaneous reconstruction and a saline implant.

My surgeon was confident that this was my best option. However, I wanted to be as informed as possible and, having spoken to my surgeon on numerous occasions over the next week, decided I really needed to speak with a woman who had 'been there, done that'.

This was harder than I thought. It was impossible to find anyone on the volunteer level through the Queensland Cancer Fund, as it simply didn't have a volunteer who had had reconstruction with an implant.

If you would like to share your story with others, send it to Lyn Swinburne, who will have it included with our other women's stories on the Internet (If you like, there is no need to include your surname). The Internet address is <http://www.users.bigpond.com/bcan>

Finally, my surgeon provided me with the name of a patient.

Caroline put all my worries to rest. Not only had she been in the care of the same surgeon, she had had the same type of breast tumour and surgical procedure.

After spending hours over coffee, she removed her blouse and bra and revealed all. She looked great, and her positive attitude and outlook raised my spirits so much that I rang my surgeon and gave him the go ahead.

I was in and out of hospital in three days, and with the help of family and friends was soon on the road to recovery.

I am thrilled with the results and have become a breast cancer support volunteer. I am also a member of The Young Women's Network.

Kevin and I married in September 1997 and the children call him Dad.

Cancer has raised its ugly head twice in my life and I must admit that it has been a huge reality check.

I have had the opportunity to reassess my life, make some major adjustments and now can live the rest of it knowing I have done the best I possibly could for myself and those around me.

– Karen Wright, Qld

Reconstruction? Not for me

Why would I want a reconstruction? I'm happy about the way I look.

Sure, when you see me side-on I'm flat-chested, but quite frankly I'm not worried. For me, enough is enough.

Is my shape radically different to the norm? I don't think so. After all, women come in all shapes and sizes, and the so-called 'norm' can be pretty radical.

My changed silhouette is just that – changed. A bilateral mastectomy has not affected my brain, nor my personality.

What's wrong with the smooth look? True, it's not fashionable, but it is wonderfully comfortable – no more bra straps digging into the shoulders. As I had a 36-inch bust, not having to carry that weight around is also amazingly liberating.

My clothes size had dropped. I used to be a size 16, now I'm a 14 – top half only, of course.

I don't drop crumbs on myself and sweat doesn't trickle down my cleavage in the summertime. Chaffing is a thing of the past, so is that constricting feeling of the base of the bra.

But breasts do keep you warm, something I only realised after they had gone.

It's just so wonderful to be able to rub my hands over this part of my body, which strangely enough feels liberated.



What about breasts and intimacy? I have never believed that the absence of breasts means an absence of femininity or sex appeal (likewise, the presence of breasts is no guarantee of femininity or sex appeal). A loving relationship will survive with or without breasts.

There is an interesting time when you first hold another in your arms and find yourself holding them at a distance, allowing for the space that was your breasts. Then your brain overcomes this and you hold the person against your chest wall. Suddenly they are very close.

Breast reconstruction for me? I don't think so.

– Ramonda Te Maiharoa

Want to be in the movies?

'Following The Fence Line' is a non-profit organisation that runs adventures for women who have had breast cancer, to demonstrate that there is life afterwards.

As part of our activities leading up to the millennium, we are exploring the feasibility of making a one-hour documentary profiling women whose lives have changed in a positive way because of breast cancer.

We are looking for women from across Australia who have changed the direction of their lives following breast cancer. We are looking for women who

are doing what they always wanted to do or had only dreamt of doing; women who are living their lives in a way they never thought possible; women who think of themselves as bigger, better and happier people. We know you are out there! We want to hear from you!

If you feel this life-threatening disease has given your life a kick-start, this is an opportunity to show and tell another woman. It could be her lifeline!

Phone or write to: **Ramonda Te Maiharoa**, Following the Fence Line, 24 Alder Street, Caulfield South, Victoria, 3162. Phone/fax (03) 9528 6321.

Need more
Field of Women
brochures?
Get them from
your local Amcal
chemist

A new breast reconstruction video

'Reconstruction – A woman's choice' is essential viewing for any woman contemplating reconstructive surgery – or anyone wanting confirmation of her decision *not* to undertake it.

Commissioned by the Wesley Clinic in Queensland and produced by the National Breast Cancer Centre (NBCC), the video is available free of charge by phoning the clinic on (07) 3232 7246 or the NBCC on (02) 9334 1700.

On the move?

Don't forget to let us know if you are moving house. We don't want you to miss a single issue of *The Beacon*. Phone us on (03) 9660 6865.

The faces of breast cancer

'The Australian Face of Breast Cancer' calendar for 2000 features women from around Australia who have all had a diagnosis of breast cancer.

The aim of the calendar is to show the diversity of these women and promote awareness of breast cancer. The calendar, produced by NT Breast Cancer Voice (NTBCV), retails for \$10.

Order from NTBCV, GPO Box 1948, Darwin, NT 0801. Phone (08) 8941 8923 or fax (08) 8941 0821.

News from the NBCC

The May Federal Budget allocated another four years' funding to the National Breast Cancer Centre – about \$2 million a year.

We were pleased the centre's value was recognised and would like to thank the many women with breast cancer who have contributed our work over the past four years.

The centre greatly appreciates your time, advice, support and wisdom, which has helped ensure our work is relevant and useful. We look forward to working with you over the next few years.

Over the next few months, the centre is planning a project to look at rates of breast reconstruction.

'NHMRC clinical practice guidelines for the management of early breast cancer' emphasises that breast reconstruction should be discussed with women following mastectomy. However, only about 10% of women who have

mastectomies have breast reconstruction. The project will explore the reasons why few women decide to, or are able to, have breast reconstruction.

The NHMRC has called for public comment on the centre's, 'Psychosocial clinical practice guidelines: providing information, support and counselling to women with breast cancer'.

These guidelines offer evidence-based recommendations about providing information and support for women with breast cancer. They emphasise the need for women to be involved in decisions about their treatment and make recommendations about how clinicians might best do this.

The guidelines cover a range of issues, from breaking bad news to providing practical and financial support. If you want to comment on the guidelines, copies are available from the NHMRC web site at <http://www.health.gov.au/>

nhmrc/advice/contents.htm

The centre has also developed a monthly publication to up date breast cancer developments.

'Breast Fax' is a one-paged document that can be sent to you by fax or e-mail. It is intended for organisations rather than individuals.

If your organisation is not receiving a copy and would like one, fax your details to (02) 9326 9329 or e-mail director@nbcc.org.au

The centre has also released a document summarising the research about risk factors for breast cancer called, 'Summary of risk factors for breast cancer'.

A brief version of this report will be published on our web site at <http://www.nbcc.org.au> in time for Australia's Breast Cancer Day.

– Prof. Sally Redman, Director,
National Breast Cancer Centre



Meet our representatives ... Judy Burley

Judy Burley is the consumer representative on the National Breast Cancer

Centre's editorial group for its quarterly newsletter, 'Breast News', so we asked her to tell us something about herself:

"Sometimes I still can't quite believe that it was me diagnosed with breast cancer in September 1992, at 29 years of age, eight months after marrying Andrew. Yet, it has been a path on which to travel and learn, re-prioritising, and to really know what is and isn't important in my life.

"After surgery to my right breast, I returned to my much-loved students and underwent chemotherapy and radiotherapy.

"Fortunately, at this time, we lived by the beach in Adelaide. I enjoyed many

long walks, dog by my side, birds to envy and the occasional dolphin swimming by at high tide.

"I yearned for my old life of fun and freedom from worry. I drank greedily of the tonic that nature provided on my walks, therapy for my wounded mind and body; inspiration on which to draw and dream of a full recovery.

"By March 1995, we found ourselves living in the beautiful Cotswold Hills town of Cheltenham, in England, a longed-for chance to live and work overseas and to travel in Europe; cherished memories now.

"During a routine mammogram in September of that year, another lump was discovered in my right breast. In January 1997, several months before our intended return to Australia, I was diagnosed with metastatic disease in my liver.

"This was a body blow and we returned home to Melbourne to be with family and friends.

"After spending six months being successfully treated with Tamoxifen, we moved to Bendigo for my husband to commence his current employment.

"When we first arrived here, we loved to drive through the surrounding countryside and imagine where we'd buy several acres and build our dream home.

"There was one spot in particular we loved – a place with a big dam, a nearby rise on which to place a house, the land falling gently away to a creek and rising up towards beautiful gum tree covered hills.

"The rise now has about a sixth of our house built on it. My wonderful husband insisted we buy it and build our dream home, *now!*

"He knew what was best for me – a home where I could be happy and bring family and friends, surrounded by the simple beauty of nature. A place to dream of a full recovery. That's a dream I'll never give up."

Letters to the Editor

Congratulations to *The Beacon* for the story of **Kerry Glover**, as it was touching to read a similar experience to my own.

I too have a 'miracle' three-year old boy, after being diagnosed with breast cancer at 25 weeks pregnant. Kerry's story was inspirational, and one of strength and courage.

At the time of my diagnosis, I searched in vain for someone who had been through a similar experience. If I had known someone it would have significantly reduced the stress at the time.

The Beacon provides a network and resource to women who have had similar experiences and no doubt provides a vital link on the journey with breast cancer.

I thank you for this wonderful resource and support.

– Lyn Voss

I listened with interest to the ABC's 'Health Report' on breast cancer and its follow up on 'Life Matters', and very interesting both programs were.

But, as usual, there was nothing at all for women like myself in whom the disease has metastasised.

It was as though we no longer exist, which is very far from the case, and I am sure I was not alone in finding this extremely isolating.

The prospects for us, we had to assume, are too fearful to mention and therefore better ignored.

Diagnosed with advanced breast cancer in 1995, I was extremely frightened, wept with my family, made a new will and prepared to die.

Yet, four years later, I live a full, busy and happy life. I ride horses every week, walk the dog every day, dig the garden and run the house.

I have travelled to Europe, holidayed in the eastern states and am planning a trip to friends in Hong Kong.

All this with a much-feared illness for which there is as yet no cure.

Today, many women, with the benefit of modern treatment, can live good-quality lives for long periods. Yet we seldom hear of them in reports or articles, nor of the advances in treatment that

can maintain a patient's quality of life for years.

A diagnosis of metastatic disease may have sent me to hell and back, but it has also brought me many amazingly wonderful things. I receive unstinting love and support from my family and friends, and great humanity from all members of the medical profession, whose skill gives me the chance to continue leading a most fulfilling life.

I share a great deal of laughter and I know more about myself, my strengths and weaknesses than ever before.

I wrote to **Geraldine Doogue**, who presents 'Life Matters', and urged her along the above lines to let the frightened women out there know that all is not necessarily bad news. I was glad to know my letter was broadcast twice on Radio National and hope it brought some cheer to those coming to terms with a new diagnosis.

– Jane Murch, WA

Thank you for my winter issue of *The Beacon*. I really enjoy it and find it very informative.

I think it is really helpful reading about people's experiences and journeys, and particularly in this issue hearing how the diagnosis of breast cancer has affected other family members.

I work for the Cancer Fund of WA, as a nurse counsellor and volunteer supervisor, and facilitate two general support groups.

I encourage the women I meet who have been touched by breast cancer to join BCNA and often discuss issues that *The Beacon* brings up at our group meetings.

You must put a lot of time and effort into *The Beacon* and it is really appreciated. Many thanks, and keep up the wonderful work.

– Julie Ryan

If you have something to say, send your letter to Lyn Swinburne, PO Box 4082, Auburn South, Victoria 3122 or e-mail bcan@bigpond.com

A Night Of Surprises

The Bosom Buddies Fashion Parade in Canberra last October made such an impression on **Raelene Boyle** that she and a group of friends will hold their version on the Sunshine Coast this year.

It will be on the evening of Australia's Breast Cancer Day – Monday, October 25. The venue will be the fabulous Queensland Sunshine Coast resort, Novotel Twin Waters.

Raelene says it will be a night of surprises, with a fashion parade, entertainment ... and much more.

All proceeds will go towards Breast Cancer Network Australia, to help develop the 'My Journey' folder for newly diagnosed women.

The Queensland Teachers' Health Union has kick-started this Network project by donating \$5000. We are grateful for its support.

This is a night not to be missed.

For details, phone Judy on (07) 5445 2181.

Swingin' Birdies help us out

A group of lady golfers from Kew Golf Club in Victoria banded together to give us a helping hand.

Under the leadership of **Slavka Abrahams**, who lost a good friend to breast cancer, the Swingin' Birdies held a fundraising evening and gave the proceeds to the Network.

They raised \$9400 in one night. Wow!

We thank the Swingin' Birdies for their support and hard work, and for understanding the importance of our Network's aim to link women, and provide information, support and advocacy.

Books on the move

The Breast Cancer Book Service has moved to Queensland. For information or a mail order catalogue, phone Leonie Young on (07) 3341 7570.

THE BEACON

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

We are currently seeking sponsorship for *The Beacon*.

Editor: Lyn Swinburne

Design: Liz Grant, (03) 9898 8834

Layout: Substitution,
(03) 9329 3535

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



Seeking Shelter

Breast Cancer Network Australia now shelters these groups, under its umbrella. Is your group here?

- ACT Cancer Council BC Support Group (ACT)
- Action for Breast Cancer SA Inc. (SA)
- Action on Breast Cancer (WA)
- 'B' Friends – Bateman's Bay, Moruya, Tuross Head, Narooma and Tilba (NSW)
- Bendigo Breast Cancer Support Group (Vic)
- Bone Marrow Institute Breast Cancer Support (Vic)

- Bosom Buddies (ACT)
 - Breast Cancer Action Group (NSW)
 - Breast Cancer Action Group (Vic)
 - Breast Cancer Support Geelong (Vic)
 - Breast Cancer Support Group Beaudesert (Qld)
 - Breast Cancer Survivors Coffs Harbour (NSW)
 - Breast Cancer Queensland (Qld)
 - Breastlink (Qld)
 - Daffodils Breast Cancer Support Group (Vic)
 - Encore
 - Following the Fenceline
 - Forget-Me-Nots Breast Cancer Support Group (Vic)
 - Friends of the Wesley Clinic, Brisbane (Qld)
 - Illawarra Breast Cancer Support Group (NSW)
 - Inner Balance Women's Cancer Support Group, Albury (NSW)
 - Kyabram Cancer Support Group (Vic)
 - Lesbian Cancer Support Group (Vic)
 - Life Force Foundation (NSW)
 - MACS-under 40 Support Group (Vic)
 - Mastectomy Association of Victoria (Vic)
 - Mastectomy Society of Victoria Inc. (Vic)
 - Moree Breast Cancer Support Group (NSW)
 - Murray Mallee Breast Cancer Support Group, Pinnaroo (SA)
 - NT Breast Cancer Voice (NT)
 - Parkes/Forbes Breast Cancer Support Group (NSW)
 - Quest for Life Foundation (NSW)
 - Riverland Breast Cancer Support Group 'Breast Friends' (SA)
 - Royal Adelaide Hospital Breast Cancer Support Group (SA)
 - 'Stepping Stones' Breast Cancer Support Group for Younger Women, Frankston (Vic)
 - Sunshine Coast Breast Cancer Support Circle (Qld)
 - Tasmanian Breast Cancer Network (Tas)
 - Tasmanian Breast Cancer Group (Tas)
 - The Young Women's Network (Qld)
 - Waratah Breast Cancer Support Group, Sale (Vic)
 - Warrnambool & District Breast Cancer Support Group (Vic)
- Please discuss the Network with your group and let us know if we can create another link. Remember – there is strength in numbers!
- Contact: Lyn Swinburne, PO Box 4082, Auburn South, Victoria 3122 or phone (03) 9660 6865.

COMING EVENTS

September 17-19: Spirited Women, a weekend program for women who have/had cancer or another life-threatening or serious illness, at Killarney, Bundanoon, NSW, with Petrea King.

Contact: *Quest for Life* (02) 4883 6599.

October 13: Bosom Buddies Fashion Event, National Convention Centre, Canberra.

Contact: *Norma Bradley* (02) 6254 5286.

October 17: Field of Women ceremonies in all capital cities. Major field in Melbourne.

October 22: Launch of 'Living Record' – a 10-day photographic breast cancer exhibition at Ballarat Fine Art Gallery organised by Ballarat Breast Cancer Services Action Group.

Contact: *Sandy* 0414 235 077.

October 24: ACT Cancer Society's Breast Cancer Support Group's Ecumenical Service at Wesley Uniting Church, National Circuit, Barton, ACT, 7pm.

Contact: *Susan Cattoi* (02) 6258 1491.

October 23: Fifth Annual Breast Cancer Information Day, Royal North Shore Hospital, St Leonards, NSW. \$25.00 all inclusive – bookings essential.

Contact: *Di Montague* (02) 9926 7246 or *Louise Kippist* (02) 9926 6584.

October 25: Australia's Breast Cancer Day.

October 30: Wesley Breast Clinic Workshop – Healing through Creativity.

Contact: *Barbara Quinn* (07) 3232 7595.

October 31: Breast Cancer Action Group NSW meeting – Advances in Adjuvant Treatment (especially chemotherapy), YWCA, Wentworth Avenue, Sydney, 3pm.

Contact: *Robyn Wicks* (02) 9622 5998 (AH).

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

YOU'RE NOT YET ON OUR MAILING LIST?

Contact: Lyn Swinburne or Jenny James, phone (03) 9660 6865, fax (03) 9662 3881, e-mail bcn@bigpond.com, web site <http://www.users.bigpond.com/bcn> or fill in this coupon and send it to: Breast Cancer Network Australia, PO Box 4082, Auburn South, Victoria 3122

Name:

Address:

.....

State: Postcode: Phone: ()

Have you had a diagnosis of breast cancer? Yes No