Our dream becomes reality: A national conference

The significant breast cancer conferences in Australia and overseas have been for doctors, scientists, researchers and health professionals to share information on research and treatment methods, and to broaden their expertise and understanding of the disease. Attendees will tell you the most valuable part of the conference is the opportunity to ‘network’ with others in their field – to informally share information and make valuable contacts. Only occasionally have those with the disease managed to attend these conferences. They have usually found out about the conference through a professional contact.

‘Consumers’ are not invited for a variety of reasons, including a belief they will not understand what is being said and that the information will not be relevant to them.

It’s time for our own conference! We will set the agenda. We will raise the issues. We will organise speakers and topics which are important to us.

The conference will be a way to:

- Share information – What information is available to us? What information do we want and need? How can we learn about new research and what is happening around Australia?
- Raise issues of importance to us – Tell those providing breast cancer services what we need, where the gaps are, what works and what doesn’t. Highlight the needs of those whose lives have been directly affected by breast cancer, including partners and families.

Provide the important personal perspective – we are the central figures in the breast cancer arena.

- Identify strategies for change – What needs to be done to make improvements for those with breast cancer? How can we make a difference for our daughters and those coming after us? How can we influence this change?

The conference will run from Friday, October 16, until Sunday, October 18, at The National Convention Centre in Canberra. It will be the major event leading up to Australia’s Breast Cancer Day on October 26.

It is important we represent the views of all those whose lives have been touched by the disease – the elderly; the young; those with early, recurrent and advanced breast cancer; and women from the cities, large regional centres, small country towns and isolated rural communities.

This is our chance to be heard and to make a difference!

Recognising the problem

This issue of The Beacon focuses on Lymphoedema.

Some women have asked us for more information about lymphoedema and ways of avoiding and managing it; others are angry and frustrated that the condition is often overlooked or trivialised by their doctors. It is not life threatening, yet women have been made miserable by a condition they will have to deal with for the rest of their lives.
State round-up: Women coming together

In the lead-up to setting our agenda for the October National Conference, women have the opportunity to share their ideas at an open forum in each state and territory. Some states have forged ahead with forum plans; others are waiting to see the outcomes of the early forums. The important thing is that everyone has the opportunity to have a say.

**Northern Territory**

Women in the Territory have not been very active of late. They tell us it’s been too hot, too wet and everyone’s been away!

However, key network members have had a teleconference to discuss possibilities and are making noises about an August forum.

They say it is relatively easy to involve Darwin women, but another matter altogether for those 1500km away in Alice Springs.

The women are hoping a Science and Advocacy Training Course might be possible later in the year, which would make the long haul to Darwin more feasible.

Women in the Territory want it to be known that they are interested. They want to be involved, not left out, which they say is often the case in rural and remote areas.

They have feelers out for funding - “maybe a chook raffle or two” - to help get several representatives to Canberra in October.

Contact: Susan Tully (08) 8927 3327.

**Victoria**

The Victorian forum will be held on Saturday, April 4, at The Queen Victoria Women’s Centre.

The keynote speaker will former Victorian Premier, Joan Kirner. She will speak on the forum’s theme, ‘Making A Difference’.

It is hoped many women from the country will come and, with this in mind, billeting is being organised by a group of women who live in Melbourne.

Contact: Jenny James (03) 9457 5977.

**South Australia**

As this newsletter goes into pre-production, Liz Libregts reports that the finishing touches are being added to the SA forum.

The forum for Saturday, February 7, is called, ‘A positive approach to breast cancer’. It is to be opened by a deliade’s mayor, Dr Jane Lomax-Smith. Well-known support group guru and author of Spirited Women, Petrea King, is to be the forum’s keynote speaker.

The main issue being investigated is the need for various types of support for women and their families. This is important as SA women report an erosion of funding for support groups.

Two women with different experiences of the support offered throughout their breast cancer diagnosis and treatment will share their stories. The final session will give women a chance to network and investigate ways to get to the national conference later in the year.

**New South Wales**

NSW is also holding its forum during pre-production for this issue of ‘The Beacon’.

The forum, at Sydney University’s Women’s College on Sunday, February 22, coincides with a visit to Australia by UK breast cancer advocate, Heather Goodare.

Heather’s keynote address is called, ‘A holistic approach to breast cancer’. There will be a report on her visit next issue.

Contact: Sally Crossing (02) 9436 1755.

**Queensland**

Following the Science and Advocacy Training Course in Brisbane last year, a band of women is keen to make sure Queensland women are heard.

The state forum is still being planned, but the group will make sure women in their state receive plenty of notice when it is time to become involved.

Contact: Janelle Gamble (07) 3353 4151.

**Western Australia**

Distance creates enormous challenges for women organising a state-wide forum in the West.

More than 60 women in WA have expressed an interest in getting together and, as the old saying goes, ‘Where there’s a will, there’s a way’.

A July date is being explored and they promise to keep us posted.

Contact: Emma Ellis (08) 9380 8834.

**Tasmania**

Network women in Tasmania began planning their state’s forum following a public lymphoedema seminar in Devonport during the first week of February.

They have so many issues to address, they need two days for their forum! A date is yet to be fixed.

Contact: Joan Williams (03) 6424 5886 or Norma Hudson (03) 6431 6472.
Our concerns

Our concerns seem to fall into five categories:

• prevention;
• diagnosis;
• treatment;
• information; and
• research.

Prevention

Far more energy needs to go into preventing the condition.

Alternative surgical treatments and radiotherapy methods also need to be considered to minimise the likelihood of lymphoedema.

Other non-surgical ways need to be developed to assess lymph node status.

Diagnosis

Clinicians need to recognise lymphoedema as a legitimate and relatively common occurrence. Then it is more likely to be diagnosed and treated earlier.

Treatment

Women with lymphoedema need ready access to clinics and therapists. They should also be able to obtain correctly fitted compression garments. There should be financial assistance for those in need.

Information

Women need clear, timely information about the risk of developing lymphoedema and ways of avoiding the condition before they begin experiencing arm problems.

Women with lymphoedema need advice on treatment options and the support available to them. This information also needs to reach doctors and other professionals dealing in breast cancer treatment.

Research

A lack of recognised research seems to be stopping us from achieving many of these points.

Quality research needs to be promoted, with an emphasis on prevention.

Unlike other types of research, a break through in lymphoedema could radically improve the quality of life for women with breast cancer.

For further information about lymphoedema and the support available, see the list of state contacts on page 5.
Not so many years ago, women told they needed a mastectomy would ask if they would get a fat arm? For many, it was an expected but dreaded sign of breast cancer treatment.

Their concerns were dismissed, as the surgeons and radiotherapists saw it as a small price to pay for successful breast cancer treatment.

Lymphoedema is still a significant factor. Having worked with women with breast cancer for more than 20 years, I am familiar with the struggle to put this condition on the breast cancer agenda.

However, we can discuss the treatment programs provided by trained therapists and, at last, the consumer’s voice is being raised and will be heard.

The national Breast Cancer Support Service (BCSS) was established in 1975. As a Queensland state coordinator, I travelled throughout the state for years, setting up services and meeting hundreds of women treated for breast cancer who volunteered to help other women just diagnosed.

It seemed that if lymphoedema was acknowledged as a problem then the hapless woman would be told “that nothing can be done” and to “learn to live with it”. This was not only in Australia but all around the world.

In 1987, the European consultant for Reach to Recovery, Francine Timothy, wrote that it was rather a hushed subject in Europe. However, some action was taken, with the formation of the British Lymphology Group in 1986. It recognised “a need to improve the treatment of lymphoedema sufferers and to overcome the neglect of this branch of medicine”.

Strangely enough, post-mastectomy lymphoedema in Australia was the subject of a 1984 Florence Nightingale Scholarship by the Radiotherapy Unit’s charge nurse at The London Hospital.

Contacting that researcher Heather Pierce so soon after doing my own research, ‘Lymphoedema – Is it a problem?’, confirmed what we both knew – information for patients and health professionals was scant.

In March 1986, New Idea published a letter by Glenys Kirk, the BCSS co-ordinator in WA, in response to an article on the use of a pressure pump for lymphoedema and some inappropriate advice.

Her letter recommended readers contact their local BCSS to find out about lymphoedema clinics, such as the one at Sir Charles Gardiner Hospital.

The rest of us were inundated with inquiries from confused, disheartened women who lacked explanations and understanding. They wanted help, care and support, or at least someone who would acknowledge the problem!

The difficulty was then whom to refer? Some physiotherapists had been using the pressure pumps with minimal success, others offered exercise, but most were unsure of what to do.

Occupational therapists (OTs) proved my best allies for assessment and management at this particular time.

In 1989, we formed the Queensland Lymphoedema Advisory committee. It consisted of physios, OTs, registered nurses and a couple of doctors who tried to be sympathetic but were somewhat bemused by the depth of our concerns.

We aimed to educate the health professionals who could or should be treating the condition and those caring for women in the post-operative phase.

However, it seemed the only place where lymphoedema was being seriously researched and treated with meaningful results was in SA, by Dr John and Judith Casley-Smith and Neil Pillar PhD.

Through their endeavours, we learned about the work of husband and wife team Michael and Ethel Foldi in Germany. They brought together a range of existing techniques to develop Complex Physical Decongestive Therapy.

This formed the basis of the treatment program developed in the second part of the 1980s by the Casley-Smiths and practised by Michael Mason in Adelaide. With some variations and modifications, it has come to be known as Complex Physical Therapy or CPT.

The first training program for therapists in English anywhere in the world, and the first in any language outside Germany, was conducted in Adelaide during 1990.

With sponsorship from Jobst, a Beiersdorf company producing lymphoedema aids and appliances, occupational therapist Sandra King and myself co-authored the first national information brochure titled – surprise surprise – ‘What is Lymphoedema?’ It is still in circulation through treatment centres and support groups.

This was an initiative of the BCSS’ national committee, which had, from its inception, been advocating hand and arm care in the information given to every woman seen by this service.

Lymphoedema seems to have come out of the wilderness. Trained therapists and treatment centres are available in many cities and towns throughout the country and support and self-help groups/associations have been formed in all states and territories, remembering that lymphoedema affects a wider group than those treated for cancer.

While we have come a long way in the past 10 years or so, there is much more to be done. I believe this network will make the difference, for it seems the answer to ‘Whose problem?’ will ultimately rest with those of you at risk or who have lymphoedema as the result of breast cancer treatment.

- Anne Fletcher, Breast Link, Brisbane, (07) 3399 5237.
Fighting for a lymphoedema clinic

In 1991, a long, hard fight began for a lymphoedema treatment facility, incorporating Complex Physical Therapy, at the community hospital in Port Macquarie, NSW.

A few years later, that persistence and determination was rewarded with the opening of a Lymphoedema Clinic on January 2, 1996.

The following November, the holders of the purse strings decided the service would not continue in the new year due to a lack of funds.

Fortunately some prompt action and hard-hitting publicity saved the day - the decision was reversed and the clinic continues!

Lymphoedema patients should not be excluded simply because of the nature of their illness and the type of treatment required. This is an essential service for those afflicted.

With community support, we will be ever watchful and alert to ensure its continuance.

- Joan Van Every

A sufferer’s story

Heather Rutherford, from the Bundaberg area in Queensland, tells an amazing story of her experiences with lymphoedema.

Her story covers a series of low times, including having to sleep with her shirt sleeve attached to a hook in the ceiling to keep her arm elevated at night. She had to rest her arm against doors, walls, on friends’ shoulders, the backs of chairs, pillows, even her own head!

She was near desperation, but through determination and help from many quarters, can now announce, “It is marvellous to understand what is happening and be able to MANAGE the arm myself.”

- Read the complete story of Heather’s remarkable journey on the Internet at www.nbcc.org.au (go to ‘What’s New’). You will also find stories of Heather’s remarkable journey on the Internet at www.nbcc.org.au (go to ‘What’s New’).

Australian lymphoedema support groups

National
The Lymphoedema Association of Australia
Dr J. Casey-Smith (Director)
98 Cambridge Terrace, Malvern, SA 5061

ACT
Lymphoedema Support Group
Ms Meryl Evans
66 Bindagai Street, A randa, ACT 2614
Ph (02) 6251 1294

NSW
NSW Lymphoedema Network
Mr John Fidlar (President)
8/2-6 Sheehy Street, Glebe, NSW 2037
Ph (02) 9552 2204

Western Australia
Lymphoedema Association of WA
Ms Carol Bishop (Secretary)
Cancer Foundation
334 Rokeby Road, Subiaco, WA 0009
Ph (08) 9381 4515; Fax (08) 9381 4523

Queensland
Lymphoedema Association
Ms Marilyn Elliot (Secretary)
PO Box 117, Petrie, QLD 4024
Ph (07) 3833 4376

South Australia
Lymphoedema Patient Support Group
Mr Keith Puckridge (Chairman)
PO Box 1006, Kent Town, SA 5071
Ph (08) 8349 5151

Tasmania
Lymphoedema Support Group
Ms Jill Wood
A2 Staley Street, Bellerive, TAS 7018
Ph (03) 6244 4634

Victoria
Lymphoedema Association of Victoria
Ms R. Wall
8 Kerro Place, Wantirna South, Vic 3152
Ph (03) 9801 7547

A real pain in the neck

Lymphoedema really is a pain in the neck or, to put it another way, a big, fat F - Frustration!

I had a partial mastectomy in August 1996, followed by six weeks of radiotherapy. I had a vague idea I might have trouble with my arm as a result, but my surgeon dismissed my questions. He said it didn’t happen nowadays.

A nurse gave me a run down of things to avoid with the at-risk arm, but there was no explanation of the reasons behind the list.

My surgeon didn’t believe in his patients having too much information about their condition – our first frustration – so I didn’t have contact with the Breast Cancer Support people until I got home from hospital.

Early last year, my arm and hand began to swell and I had cramps in my hand. A part from being painful, I was having trouble holding things and found it difficult to turn on taps, etc.

My GP said, “you’ve got a bit of lymphoedema there”, with no suggestion about treatment. The implication was I should be grateful I was still alive and stop moaning about a minor inconvenience like a swollen limb.

My surgeon said he was so good that none of his patients got lymphoedema and I should blame the radiotherapists.

W hat a great help that was!

My husband and I decided to chase up some information. This was our second frustration – easy to understand, comprehensive information is hard to come by.

The Cancer Council’s information is all right, but it wasn’t comprehensive enough for us. The library was no better. A search of the Internet yielded more information and we began to develop a better understanding of the how and why of lymphoedema.

More importantly, we realised the importance of treatment and learning to manage the condition.

- Pat Mathew, Tasmania
New Idea for breast cancer

The New Idea Breast Cancer Fund was launched in Melbourne during January by ex-Olympian and breast cancer survivor, Raylene Boyle, who spoke about the importance of finding research answers.

New Idea magazine aims to raise funds for breast cancer research by donating a percentage of the cover price of each magazine sold throughout the year. The money will be given to two organisations – Melbourne’s Austin Hospital, to continue its research into a vaccine for breast cancer, and the Kathleen Cuningham Foundation, Australia’s largest national breast cancer research fund.

New Idea’s publisher has told us she is also keen to raise awareness of the disease among Australian women and will include regular personal stories, as well as important messages for women.

Several network members have already appeared in articles and the network will be promoted through the magazine. This should be an effective way of reaching women who have never hooked into a group before.

We also look forward to a strong coverage of our Canberra conference.

Service directory for Northern Territory

A service directory for women diagnosed with breast cancer has finally made it into production in the Northern Territory.

Copies of the poster and the Top End and Central Australian brochures have been sent to health centres across the Territory. It has taken two years to achieve, but women there say it has been worth the wait.

We would like to acknowledge the fine work done by Tracey Varney, the National Breast Cancer Centre’s Territory co-ordinator, and to thank her for her efforts.

Tackling the problem

We approached Dr Sally Redman at the National Breast Cancer Centre in Sydney to find out what the centre is planning to do about women’s lymphoedema concerns.

Dr Redman is well aware that this is an important issue for women. She recognises the need for more research about all aspects of the condition.

The centre has written to the Kathleen Cuningham Foundation suggesting it consider lymphoedema research as a priority area.

Janet McDonald has also told the centre that AMP has agreed to fund a special research initiative, to be based with Professor Stuart Renwick at the Sydney Breast Cancer Institute.

As Dr Redman notes, it is evident that treatments that affect the axilla, such as axillary dissection, contribute to the development of lymphoedema. As a result, the centre has established a project to look at the role of axillary dissection and irradiation in relation to this condition.

The first step will be to develop some evidence-based recommendations for the use of axillary dissection and irradiation, looking at the reasons and indications for their use.

It is intended that these reviews be discussed at a national meeting, to include consumers, to be held in the first half of 1998.

The recommendations emerging from this meeting will be used to develop evidence-based information for women with breast cancer about the reasons for using axillary surgery and irradiation, the situations in which their use is recommended and their potential role in the development of lymphoedema.

We shall watch these developments closely.

Spotlight on a group

Encore: A new beginning

“Sometimes what appears to be an ending can really be a new beginning. Breast cancer will probably change your entire outlook on what you have always considered to be your normal lifestyle. Recovery can be a fresh love of life and many experiences await you on the path to regaining your health and vitality,” contends the brochure promoting the Encore program.

Encore has helped many women regain mobility and flexibility, as well as their self-confidence, which may have taken a battering during the diagnosis and treatment of breast cancer.

Encore is a YWCA-registered, Australia-wide program, sponsored by Avon.

It is a program of gentle floor and pool exercises and relaxation techniques designed for women who have experienced mastectomy, lumpectomy or breast reconstruction surgery.

However, it is more than an exercise program. The sessions always include time for a chat. Sharing experiences, concerns and feelings are also important parts of the recovery process. Friendship and understanding go a long way towards healing emotional scars.

Network member, Judy Sammut, believes the loss of body image was one of the greatest challenges following her mastectomy.

“Women’s self-esteem and whether they see themselves as attractive is a difficult thing for many of us,” says Judy. “To restore my fragile body and shattered emotions, I had regular massages, shiatsu and yoga exercises.”

Judy is now a qualified instructor at the Encore program in Melbourne.

For more information, contact your nearest YWCA centre or YWCA Australia, PO Box 1022, Dickson, ACT 2602 or e-mail: natoffice@ywca.org.au
The wind whistled over the gap between Mount Twynam and Mount Carruthers. The cloud was coming in fast.

Earlier it had been clear, though windy, for the first Walk for Wigs in the Snowy Mountains, on the Saturday of the Australia Day weekend. About 60 walked 13km, raising nearly $3000 for the ACT Cancer Society's wig library.

The walk is one of the most spectacular in Australia at that time of year. It starts at Charlotte's Pass and winds across the Snowy River, past Blue Lake (one of Australia's few glacial lakes) and up the ridge of the Great Divide, with splendid views into Victoria, before reaching the summit of Mount Twynam – at 2010m – Australia's third-highest mountain.

You don't have to climb the highest mountain, but why Mount Twynam for the Walk for Wigs?

It goes back to 1988, when my wife, Lynne, was diagnosed with breast cancer. She had a lumpectomy and put it behind her, continuing with her favourite sports – squash and skiing.

We had tried several times to climb Mount Twynam on cross-country skis, but had been driven back. Then we arranged another attempt for a weekend in October 1992.

The previous Thursday, Lynne went for a three-month check-up. They were almost routine by then. Alas, the doctor found a lump in her neck. It would need a biopsy to confirm, but it was certain her cancer had spread.

She refused to let it imprison her. We went skiing as planned. It was a cloudless day. In winter, the way up Twynam is longer and more difficult than the summer route.

We made the top and skied gloriously down. It was Lynne's act of defiance and liberation in the face of her terrible news. She was like that till the end.

She died on January 19, 1997 and we scattered her ashes on Mount Twynam.

On that walk with family and close friends, the idea of an annual walk to raise money for cancer research and its patients evolved.

I recalled an incident during Lynne's treatment. When the doctors recommended Lynne have chemotherapy, we paid a visit to the wig library at Canberra Hospital. A woman in a grey wig was looking in a mirror saying, “But I had blonde hair. Haven't you got any blonde”. “I'm afraid not” was the reply.

We left quietly. On reasonably good incomes, it was easy for us to buy some very good wigs. At that stage, we were too concerned with Lynne's condition to give it much further thought.

But there must be many women who have chemotherapy and cannot afford their own wig.

It might not seem important. Indeed, some doctors add hair loss almost as an afterthought when describing the side effects of chemotherapy. But for most women, and men come to that, it is a major concern.

Hair loss adds stigma and further isolation and differentiation to a difficult time. A good-quality wig can do wonders for self-confidence. Lynne's wigs were so good many people said, “Oh, I like your new hairdo”.

The money raised will help many women during a difficult time. It will help the wig library build a stock of wigs so that good matches can be made.

We had great support from the ACT Cancer Council. Everyone enjoyed the walk – the mountains, the wildflowers and supporting a good cause.

Among the walkers were oncologist Dr Richard Pembrey, several oncology nurses, including Joy Easter, a group from the ACT Cancer Society, ACT MLA Michael Moore, women with breast cancer and men whose partners had died from breast cancer.

Donations can be sent to Walk for Wigs, c/- ACT Cancer Society, 159 Maribyrnong Ave, Kaleen, ACT 2617.

If the support is there, it could become an annual event to support wig libraries nationally.

- Crispin Hull
### Upcoming Events

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<tr>
<th>Event</th>
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<tr>
<td><strong>March 20</strong>: Exploring the Horizons of Cancer Nursing</td>
<td>A day that explores the rich tapestries of cancer nursing concepts for the patient, staff and relatives.</td>
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<td><strong>March 20-22</strong>: Australian Lymphology Association's Annual Conference</td>
<td>Includes the Lymphoedema Public Seminar on March 20. A seminar for people with lymphoedema, their partners and families. Specialists from many states will discuss ways to best manage the condition.</td>
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<td><strong>March 25</strong>: Hypnotherapy and Psychotherapy Public Seminar</td>
<td>by ‘MACS’ Cancer support group for women under 40 years old.</td>
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<td><strong>March 30-May 2</strong>: Murray River Paddle for Breast Cancer Awareness</td>
<td>This is the latest adventure organised by ‘Following the Fenceline’. Fifteen women who have had breast cancer will paddle 1000kms down the Murray River from Tocumwal to Mildura.</td>
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<td><strong>April 4</strong>: Victorian Women’s Breast Cancer Forum</td>
<td>9am-5pm, Queen Victoria Women’s Centre, Melbourne.</td>
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<td><strong>April 19</strong>: General Meeting of the Breast Cancer Action Group (NSW)</td>
<td>Lymphoedema: The Current Status of Research and Treatment. 2pm, YWCA, Sydney.</td>
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<td><strong>April 21</strong>: General Meeting of the Breast Cancer Action Group (Victoria)</td>
<td>2.30-5pm, ‘O tira’, Walpole St, Kew.</td>
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<tr>
<td><strong>April 29-May 1</strong>: Canberra Advocacy and Science Training Course</td>
<td>for Breast Cancer Advocates.</td>
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<td><strong>May 2</strong>: ACT Forum for Women</td>
<td>Contact: Anna Wellings-Booth (02) 6247 8470.</td>
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<tr>
<td><strong>May 1</strong>: Port Macquarie Base Hospital Oncology Unit’s 10th Birthday</td>
<td>O pen day for the public, with promotional material and information on display. Two oncologists will be on hand to talk and answer questions, as will BCSS volunteers and Joan Van Every representing the network.</td>
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- To include events in The Beacon's winter issue (June, July, August), submit notices by the end of April.

### The Beacon

The Beacon is the newsletter of the Breast Cancer Network Australia. We wish to acknowledge the contribution made by the NBCC in providing seeding funding for the production and distribution of the newsletter.

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Layout: Substitution Pty Ltd, (03) 9329 3535  
Your comments and items for the next newsletter are welcome. Send them to PO Box 4082, Auburn South, Victoria 3122.

### You’re Not Yet on Our Mailing List?

Contact: Lyn Swinburne, phone (03) 9660 6865, fax (03) 9662 3881  
Or fill in this coupon and send it to: Breast Cancer Network Australia, PO Box 4082, Auburn South, Vic 3122

Name: .............................................................................................................  
Address: ...........................................................................................................  
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State: ........ Postcode: ........ Phone: (   ) .............................................

### In the next issue...

- Young women and breast cancer

... and much more