

INSIDE

Clinical trials	3
My Story	9
Book reviews	10
Thank you	12
Member Group profile	13
Letters	14
Upcoming Events	16



the BEACON

Breast Cancer Network Australia's Magazine

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Register now for *Field of Women LIVE!*

Registrations are open for the *Field of Women LIVE* at Sydney's Telstra Stadium on the evening of Saturday, August 11. You can register now at www.fieldofwomen.org.au.

Don't miss out on this once-in-a-lifetime chance to stand shoulder to shoulder with 13,000 women in this powerful and moving event. As we stand together in the shape of our beloved pink lady, we will experience the strength and determination of women – survivors and supporters alike – who have made the journey from all over Australia.

We have heard from women as far away as Perth and far north Queensland, who will make the pilgrimage to Sydney; support groups in country areas that have organised buses to transport members and their families; and businesses in Sydney sponsoring their office workers to stand together in support of a recently diagnosed colleague.

All the information about the event is now on the website www.fieldofwomen.org.au and this is where you can now register. You will also be able to register multiple people at the one time. Registration is \$50 per

person and it includes a ticket to the AFL match directly following – Sydney Swans versus St Kilda, as well as free public transport to and from the venue within the greater Sydney area, and the collectable pink poncho.

We have been successful in securing corporate sponsors so that the entire \$50 registration fee goes directly to BCNA for our programs. We are grateful to our Major Sponsors in Bakers Delight, Australia Post, QBE and Sussan. Also Supporting Sponsors Multiplex, Westfield, Ticketek and Pacific Brands.

Welcome

This issue of *The Beacon* focuses on clinical trials. As with many areas involving breast cancer, the issues are complex and women's responses and considerations vary.

Clearly, clinical trials are important if we are to advance ways of best detecting and managing the disease. At BCNA, we believe that women should know what trials might be available to them; after all we all want improvements to benefit ourselves and our daughters. We acknowledge though, that women need to clearly understand what's involved and this sometimes comes at a time of great stress and multiple decision-making.

As always, we have endeavoured to provide our readers with quality information and, importantly, pieces written by women with experience of clinical trials.



Field of Women LIVE Ambassadors Naomi Milgrom, Janette Howard, Carla Zampatti and Ita Buttrose, with Raelene Boyle and Lyn Swinburne at the Ambassadors event in Sydney. To find out how they are going to help BCNA, see the article on page 2

Breast
Cancer
Network
Australia



Women gather for BCNA forums in Perth

Two BCNA forums held in March drew capacity crowds of women from Perth and surrounds.

An audience of 90 young women gathered at the first forum which highlighted the range of needs and issues for young women with breast cancer. Speakers included **Lisa Tennekoon** (a young breast cancer survivor), **Professor Christobel Saunders** (a Perth-based surgeon with a particular interest in young women and breast cancer) and **Lyn Swinburne** (BCNA's CEO). Questions from the audience demonstrated an extensive range of issues and inspired much discussion about the trials and tribulations of breast cancer for young woman.

Topics including a research project into breast cancer during pregnancy, upcoming funding for MRI screening for women at high risk of breast cancer, and treatments that might help maintain fertility after breast cancer, were well received by the audience. Questions and



Carlie Sinclair, Raelene Boyle, Lyn Swinburne and Jayne Makarein at BCNA's WA Forum.

comments from the audience inspired information sharing about local services and supports, as well as hints for coping better with treatment and supporting each other.

For many of the young women who attended it was both shocking and supportive to see so many other young breast cancer survivors in one room.

The second BCNA forum held the following morning attracted another capacity crowd of more than 250 women. It featured information about BCNA's activities, medical oncologist **Dr Arlene Chan's** terrific presentation, 'What's new in breast cancer?' and a charming presentation from BCNA Board member and Olympian, **Raelene Boyle**.

We were extremely pleased that so many women attended our forums in Perth. These gatherings not only provide a valuable opportunity for us to meet our Perth members, they also raised local issues and forged links between the women attending. Thanks to our WA State Representative, **Sue Hassett**, and her local team for helping to organise the events.

Key women come on board

We are delighted to announce that the NSW Governor, Her Excellency **Prof. Marie Bashir AC**, is to be the Patron for our **Field of Women LIVE** event. We are also supported by our event Ambassadors, who are high-profile and well-networked Sydney women. They include women in politics including **Helen Coonan, Julia Gillard, Maxine McKew** and **Bronwyn Bishop**; Australian icons such as **Mrs Janette Howard**,

Stephanie Dowrick, Maggie Tabberer, Carla Zampatti, Deborah Hutton and **Ita Buttrose**; and women seen on TV such as **Kerri-Anne Kennerley, Sandra Sully, Melissa Doyle** and **Geraldine Doogue**.

These women came together for our **Field of Women LIVE** Ambassadors' launch in May in the Sydney home of **Naomi Milgrom**, owner of the Sussan

group and outstanding champion for BCNA.

Our Ambassadors have offered us their support to spread the word about BCNA, the *My Journey Kit* and other services for women with breast cancer.

We are also proud to have our Sydney Community Champions on board – many of them having experienced breast cancer first hand. These women will make presentations in the lead up to

the event, and will help us spread the word by distributing posters and flyers in their local networks.

There are so many ways that readers of **The Beacon** can be part of this fantastic event. Head to www.fieldofwomen.org.au to find out how or to read stories from our members about them making their pilgrimage. You can also e-mail us at info@fieldofwomen.org.au.



The facts about clinical trials

Clinical trials are research studies involving patients to help find better treatments. When we think of treatments for breast cancer, we often think that only means drugs, but they can include radiotherapy, surgery, supportive care programs, complementary therapies or even exercise. In breast cancer, there are clinical trials for a range of such treatments.

We need clinical trials because they help establish whether treatment options are safe and effective. A drug, for example, can

look promising in the laboratory test tube where it was first developed. It may even have been applied to laboratory mice with positive results. However, before it can be made widely available to the patient population, it must be thoroughly evaluated for its effects on people. Common drugs that we take for granted in our lives, such as aspirin and antibiotics, have all been through clinical trials.

Clinical trials are conducted under supervision by researchers so that the effects of the

treatments being studied are properly monitored. Some trials compare new treatment options with current treatments, others look at different ways of using treatments or combining two or more existing treatments to see if they lead to improved benefits for patients.

Clinical trials play an important role in a research process that can take years before new treatment options become part of standard breast cancer care. Most of the major advances in breast cancer treatment have

occurred because the value of new treatments was first demonstrated in clinical trials. Two major advancements include breast conservation as a safe alternative to mastectomy, and the addition of chemotherapy and hormone therapy to surgery to improve survival outcomes. More recent advances due to clinical trials are the use of sentinel node biopsy as an alternative to clearing all the underarm nodes, and the introduction of Herceptin.

Some common terms in clinical trials

Randomised controlled trials (RCT)	Treatments are assigned randomly to patients in the trial. Patients do not get to choose which of the treatments they receive. This is considered the best way to compare new treatments against current standard treatments.
Control group	The group that doesn't receive the new treatment being studied but receives the current standard treatment.
Protocol	A protocol states what the study will do, how and why. It explains how many patients are involved, for how long, the treatments, tests and how the results will be interpreted. Protocols are reviewed by human research ethics committees.
Eligibility criteria	Requirements that make sure patients enrolling in clinical trials share similar factors such as age, stage of breast cancer, hormonal status, and previous treatment. When patients share the same characteristics, it gives researchers greater confidence that the results of the study are because of the treatment(s) studied rather than other factors.
Single-blind study	Where only the doctors know whether their patients are receiving the standard treatment or the new treatment under study.
Double-blind study	Neither the patients nor their doctors know which treatments they are receiving – either the new treatment or the current standard treatment.
Informed consent	The process in which a patient learns about a clinical trial – including benefits, risks and side effects – before they decide whether or not to be involved.
Phases I, II, III and IV	Trials are conducted in sequential phases. Phases I and II involve small numbers of patients, including those for whom current treatments are no longer helping. Phase III trials are large-scale international trials involving thousands of patients. New treatments become part of standard care when their value is proven in Phase III trials. Phase IV trials continue to collect information about treatments that have become part of standard care after they have passed through Phase III.
Placebo	A placebo is used only if the trial is seeking to find out whether a new treatment is better than doing nothing (the placebo). A placebo is not appropriate for Phase III trials, since these seek to compare new treatments with current standard treatments.

Adapted from the Coalition of Cancer Cooperative Groups (US) Patient Toolkit Glossary.

Participating in clinical trials

The decision to participate in clinical trials can be difficult. Patients are often asked to make their decision about trials at a time when they are only just recovering from diagnosis and surgery. There is already so much to think about.

Many women decide to join a clinical trial because:

- The treatment they will receive is at least the best available for their breast cancer.
- Current treatments are no longer working for them and clinical trials offer access to treatments under study and not widely available.

- Their health will be carefully checked by those running the trial.
- They want to be part of an effort to find better ways to treat breast cancer.
- They access free medication.

Many women decide not to join a clinical trial because:

- They want to receive the current standard treatment for their breast cancer.
- They wish to retain control of their treatment, rather than being part of a trial.
- They feel there is still too little known about the risks and side effects of treatments under study.

- Their doctor is not involved in running a trial and they don't want to change doctors.
- There is already enough to think about without having to consider a trial.

There is no right or wrong decision and a patient's treatment should **not** be neglected by doctors, no matter what she decides.

We asked our Consumer Representatives to share their experiences of clinical trials. We know their stories can be really useful for others who are in the process of deciding, so we've included their stories on the following pages.

Participating was a win-win proposition

I was in a clinical trial that compared tamoxifen and letrozole (also known as Femara®). The trial ran from 1999 to 2004. It was a double-blind study, which meant that neither I nor my oncologist knew which drug I was on until a year after I finished my treatment.

It seemed like a win-win proposition to be involved in the trial. Tamoxifen was the current 'gold standard' and the results of letrozole on patients with advanced disease were promising. I liked the idea of contributing to research and possibly gaining an advantage in my treatment. Being



Elspeth Humphries

involved in the trial also meant slightly closer monitoring over the five years of treatment.

The trial was much as I expected. I was frustrated when results from elsewhere started to come through showing the advantages of letrozole and I still did not know which drug I was on.

I did, however, push to have that information made available to me. Women should expect to have all their questions answered and to be kept up to date with what is happening with any trial they participate in. They should also understand that ethically they would never be knowingly disadvantaged by participating in a trial.

Elspeth Humphries, ACT

Informed consent

It is crucial that any patient agreeing to participate in a trial fully understands what they are agreeing to. This is called 'informed consent'.

Patients who wish to consider participating in a clinical trial must be given written information that outlines:

- the treatment under study
- all foreseeable benefits and risks (including side effects)
- full details of what is required of patients, e.g. attendances for treatments, tests, etc
- the rights of patients – the most important being the right to opt out of the trial at any time for whatever reason, without future treatment options being affected.

When patients have received the information and have been given enough time to read, discuss and absorb its contents, they are asked to give their informed consent by signing a form. In doing this, patients are saying that they have understood the information given to them and that they are consenting freely to participating in the trial.

It is important that patients take as much time as they need to understand the information given to them. They can ask as many questions of their doctors as needed, discuss things with family and friends, and even seek a second opinion from another doctor, before signing anything. They can, of course, decide not to go ahead with a trial after weighing up the pros and cons.

We can all help – ourselves and others

In September 1992, I was diagnosed with an infiltrating lobular cancer in my left breast. It had spread to my lymph nodes and I was told my prognosis was not so good. Conventional chemotherapy treatment was expected to give me perhaps two years of a quality life.

However, if I ventured onto a new trial, the doctors felt my life could be extended beyond a couple of years. With teenage children, I felt the invitation to join the trial was a must. Plus, if the trial was successful, other women could benefit.

I was told of the risks and signed papers stating that I was well aware of what I was doing and that I was happy to participate. And so I went onto my trial: An Open Label Study of High Dose Chemotherapy in Patients with Breast Cancer Using Autologous



Noel Sumner in Antarctica in 2007

Peripheral Blood Stem Cells and G-CSF Support.

I was admitted to hospital six weeks after my mastectomy and spent more time in hospital than at home over the next three months. However, my positive frame of mind, the support of my buddy (also on the trial) and the fantastic staff in the ward made me feel as if I was doing

something not only to benefit myself but many other women.

I put myself completely into the hands of the doctors and staff administering the trial. It was certainly no bed of roses, but look at the results – here I am 15 years later! So, I say to other women, please consider any trial that is offered to you, as we can all help by being a participant.

Noel Sumner, Victoria

Participating as a ‘crutch’ to wellness

I was involved with the ATLAS (Adjuvant Tamoxifen Longer Against Shorter) trial for just over 12 months and had to pull out.

My reason for pulling out was due to side effects that I had experienced even before going into the trial, which meant I was not sleeping while on the trial. An endocrinologist suggested I withdraw, so I did. Staff said they would still follow me up, but this never happened.

If problems arose, the trial staff were professional and easily contactable. I was reviewed at six monthly intervals by the doctor, although I did feel he was less than interested and my consultations were short. I always



Beverley Artiss

got the feeling I was taking up his time.

I had entered the trial for a couple of reasons. I felt I would get to see a doctor more often,

as at this time I was no longer required to see anyone other than my oncologist once a year. I was still looking for reassurance that I was doing okay. I also felt that the continued use of tamoxifen was a ‘crutch’ to wellness – mentally anyway. The idea of free medication was a bonus too.

When I entered the trial, my medical history was fed into a computer. The computer then selected me to either stay on the medication or come off it. It was a relatively easy process. I would participate in other clinical trials if appropriate and worthwhile to me in terms of the outcomes that may be gained.

Beverley Artiss, NSW

Protecting patients

Some people might believe that participants in clinical trials are ‘guinea pigs’ to be experimented upon.

While it is true that patients in breast cancer trials may try new treatments, it is equally true that the treatments they receive are at least the current standard available for their breast cancer or better. Further, those involved in trials usually receive more thorough follow-up than other patients, since their progress is closely monitored by members of the research team.

Ethical and legal safeguards exist to ensure the utmost care is given to patients in clinical trials. Trial researchers must ensure that clinical trials:

- are scientifically sound
- do not produce more harm than good
- keep all stakeholders informed of developments and results
- meet internationally and nationally agreed standards about the right way to conduct research involving people.

Researchers undergo a lengthy process to develop ‘protocols’ or guidelines about how they are going to conduct their trials. Protocols should demonstrate that trials meet the above points and must be approved by a human research ethics committee before the trials can begin. Ethics committees will refuse trials with protocols that do not meet scientific, medical and ethical standards.

Taking up a one-in-two chance

In 1993, I saw an advertisement in the local paper asking for women with a strong family history of breast cancer to participate in the double-blind five year IBIS (International Breast Cancer Intervention Study) trial. My mother, sister and two maternal cousins had all been diagnosed with breast cancer.

I made enquiries and after consideration joined the trial. This included taking a coded pill a day (tamoxifen or placebo), yearly mammograms and six-monthly check-ups. While I was on the trial, my sister's daughter was also diagnosed with breast cancer, aged 39 and still breast-feeding her fifth child.

During the trial I had no abnormalities and no side effects associated with tamoxifen. I often joked that I must be on placebo! I continued follow-up with yearly mammograms and surveillance.

Eight years after joining the trial my mammogram showed an abnormality. During the ultrasound my suspicions grew to panic when I saw a spidery shape in my left breast. The senior



Dorothy Francis

breast surgeon and local IBIS trial team leader saw me immediately and performed a needle biopsy. The preliminary result showed cancer cells.

My worst fears were confirmed. I was diagnosed with breast cancer just five hours after my routine mammogram. I chose treatment under the surgeon whom I had known since joining the trial. My trial code was broken and showed I had been

on the placebo. My breast cancer was early, aggressive, Grade 3 and oestrogen sensitive. After a lumpectomy I started tamoxifen and a course of radiation to reduce the risk of recurrence.

Evidence from the IBIS trial shows tamoxifen can reduce the risk of breast cancer, but there are some side effects. Despite being on placebo during the trial I was grateful to have participated. I doubt I would have been as conscientious with surveillance had I not been in the trial.

I knew the odds for the trial were a one in two chance of being on tamoxifen. Knowing the surgeon in charge of the trial was a big bonus when the crunch came to arrange treatment and follow-up. I have no regrets about having taken part in the IBIS trial. We really need evidence-based medicine and research is the only scientific means of getting data. I trust others may benefit from the research findings from this trial. I would certainly make the same choices again.

How to get involved in a clinical trial

As part of your treatment discussions with your doctor, he or she may suggest a clinical trial that includes a new treatment suitable to your situation.

Alternatively, you can ask your doctors whether they know of any relevant trials for you. By being knowledgeable about or directly involved in clinical trials, doctors demonstrate that they are up-to-date with the latest

developments in breast cancer treatment.

You can also find out about clinical trials yourself and then discuss their suitability with your doctor. For trials involving Australian researchers, go to www.actr.org.au, the website for the Australian Clinical Trials Registry, a comprehensive and searchable database established by the National Health and

Medical Research Council (NHMRC) in 2005. The Registry includes clinical trials for all health conditions, not only breast cancer. Unfortunately, it is a little difficult to navigate and the language can be difficult to understand.

The good news is that Cancer Australia is now working with the NHMRC to make the site more accessible to potential trial participants.

Share your story

If you have participated in a clinical trial, we would love to hear your story. We would also love to hear from you if you have decided a clinical trial is not for you. Please forward your story (with a photo) to beacon@bcna.org.au or post to BCNA, 293 Camberwell Road, Camberwell, Victoria 3124.

Your story, including those published in this issue of *The Beacon*, may be published on our website, www.bcna.org.au, under 'Stories'.

If you want to see the new clinical trials fact sheet on our website, click 'Policy and Advocacy', then 'Position Statements'.

Happiness is not a station you arrive at, but a manner of travelling.

– Margaret B. Runbeck

Travel insurance

The following BCNA fact sheets are now available:

- *Travel insurance for women with early breast cancer*
- *Travel insurance for women with secondary breast cancer*
- *Making a complaint about a travel insurer.*

For a copy, visit www.bcna.org.au or phone 1800 500 258.

Spotlight on SNAC

A trial to reduce the side effects of breast surgery

The SNAC (Sentinel Node versus Axillary Clearance) trial is run by the Royal Australasian College of Surgeons. SNAC began in 2001 and seeks to compare the outcomes of sentinel node biopsy versus axillary clearance for women with early breast cancer undergoing breast conservation treatment.

Sentinel node biopsy and axillary clearance are two different surgical procedures for detecting cancer cells in the lymph nodes. Sentinel node biopsy removes only the first few nodes most closely related to the tumour. Axillary clearance removes most of the nodes under the armpit.

Trial researchers hope that sentinel node biopsy – a less invasive kind of surgery – will demonstrate fewer of the side effects associated with the current standard treatment, axillary clearance. Side effects may include lymphoedema, shoulder stiffness and general pain.

Sentinel node biopsy had been shown to offer benefits to women in smaller studies, but still needed to be evaluated on patients in much larger trials such as SNAC. Recruitment to the trial was completed in May 2005, with the target enrolment of 1,000 women exceeded a year earlier than anticipated. The total number of women recruited for the trial was 1,088. Women were (and continue to be) followed up at one, six and 12 months



Avis Macphee

post-treatment, then annually. Follow-up is for 10 years, to determine the long-term effects of sentinel node biopsy.

SNAC is unique because it arose from concerns expressed by women about the side effects of axillary clearance. The trial is also unusual because researchers from the beginning sought input from BCNA as the organisation representing those affected by breast cancer.

Nobody can make you feel inferior without your consent.

– Eleanor Roosevelt

BCNA has been directly involved in the development of the trial's research protocol, patient information sheets and informed consent documents. BCNA has ensured outcome measures included women's experiences of their surgery and its effects, e.g. perceptions of swelling, pain and body image.

Avis Macphee, a BCNA Consumer Representative, has been involved in the trial's Management Committee since its inception and has a role in the ongoing monitoring of trial results. Avis' involvement has ensured that the SNAC trial represents the interests and needs of women.

Early results of SNAC were released at the San Antonio Breast Cancer Symposium in Texas in December 2006. Results showed that sentinel node biopsy has been performed well by surgeons, and that, at the 12-month follow-up, women undergoing the procedure had fewer problems with arm-swelling, movement and sensation compared to those undergoing axillary clearance.

Building upon the SNAC trial is SNAC2, which began taking enrolments in 2002 and will recruit a further 1,012 women. SNAC2 aims to determine whether sentinel node based management is as good as axillary clearance in preventing cancers coming back in women with larger or multiple tumours.

Who runs clinical trials?

Clinical trials are run by teams of researchers at universities, hospitals and private institutes and by drug companies. In Australia, many clinical trials for breast cancer are co-ordinated through the Australia and New Zealand Breast Cancer Trials Group (ANZBCTG). The ANZBCTG program involves more than 300 researchers in Australia and New Zealand. More than 8,500 women have participated in their clinical trials program over the past 20 years.

ANZBCTG members work with thousands of researchers all over the world through groups such as the International Breast Cancer Study Group and the Breast International Group. International collaboration on trials is important, as that means research efforts can combine. It also ensures that high numbers of patients are enrolled for large 'multi-centre' trials (those that take place in many different locations). Australian researchers belong to a world-wide movement to better understand the treatment of breast cancer.

For more on ANZBCTG and its current programs, go to www.anzbctg.org.

The sweetest partnership delivers thousands to BCNA

More than 600 Bakers Delight stores across Australia turned pink in May to spread the word and raise hundreds of thousands of dollars for BCNA. We are still counting, but so far we have raised well over \$200,000.

This year we focused on connecting BCNA representatives with their local bakers to tell local communities about how BCNA supports women with breast cancer. Women were matched with their local bakeries who held sausage sizzles (Greenacres, Palmerston, Stirling), head shave/hair colour days (Mildura, Southland), and BCNA information displays near their stores (Chatswood Chase, Kotara, Ballina Fair, Fulham Gardens, Mount Barker, Mentone, Midland Gate).

Bakers Delight Artarmon, NSW was one of the bakeries that made the promotion a great event. BCNA representatives **Karen Mills** and **Jill Buttel** attended a BCNA information stand near the bakery and were on hand to watch the auction of bakers **Mat Smallgood** and **James Thompson**, who volunteered their services as handymen for a day. Proceeds from the auction and staff wages for the day were generously donated to BCNA.

This year the public were encouraged to vote for the best 'pinked' bakery, with a trip for two to the **Field of Women LIVE** for the winning store.

After more than 6,000 votes were lodged, we congratulate



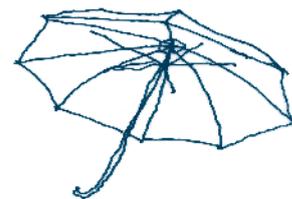
Breadhead with staff from Bakers Delight, Murwillumbah, NSW – winners of the 2007 Pink Lady Award.

Bakers Delight Murwillumbah as the winning bakery. They will send two members of their team to proudly stand on the Telstra Stadium arena in Sydney on August 11. For images of the wonderfully 'pinked' bakeries, visit www.bcna.org.au.

The top 10 bakeries will also be recognised with a 'Pink Lady' certificate for their wonderful efforts. Thank you to all the bakeries and to our women who put in such a great effort to make this another successful campaign. And thanks to everyone who bought a pink bun!



The team at Bakers Delight Whitford City, WA, looking very pink and very angelic!



Seeking shelter

BCNA welcomes:

- Strong Sisters, Lang Lang, Victoria
- Pink Phoenix, Ballarat, Victoria
- Maryborough Breast Cancer Support Group, Maryborough, Victoria
- Breast Cancer Coffee Group, Tamworth, NSW

We have more than 22,000 individual members.

Sign up for an e-list

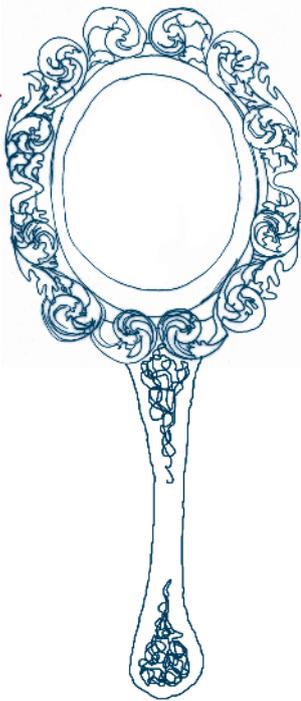
Would you like to receive e-mail updates on any of these issues?

- Young women
- Secondary breast cancer
- Rural and remote issues
- Family (inherited) breast cancer.

We call these e-bulletins. They provide regular updates on research, emerging treatments, media reports and relevant conferences. From time to time we will also ask list members for feedback on relevant issues and may even call for action on a particularly important issue.

E-bulletins will be sent to each list at least monthly.

To sign up to the e-lists email us at policy@bcna.org.au, telling us which list(s) you want to subscribe to and add your full name and postcode.



My Story

One of many important decisions

For me, the request to participate in a clinical trial came at a time when there were so many other important decisions to make.

As a 28-year-old mum with a two and four year old, making such a decision felt like the last thing I needed. And what was a clinical trial anyway?

I soon found out what it was all about as doctors explained the trial and gave me information to read. Having a sister who was a nurse and could explain things was also a godsend. I understood that the decision to take part in the trial had to be made before the first treatment commenced, but the timing of that decision was what caused the most pressure for me, particularly as I felt that my outcome would depend on it.

The trial was an international chemotherapy trial, where patients were randomly assigned to various lengths of chemotherapy treatment (CMF).

I was told that should my health be compromised in any way during the trial I could withdraw and continue with the standard treatment. I knew I would need CMF regardless – trial or no trial – so why not help research?

I signed the consent form and within a couple of weeks began treatment. I was assigned to the shortest treatment arm – three months of CMF. The chemotherapy was no picnic, but had to be done and I celebrated when it was over. At every check-up the lovely trial co-ordinator would come and chat with me. I'd be given the questionnaire that assessed my quality of life during the treatment.

The impact of the chemotherapy regime was assessed through scans, x-rays, blood collection, and countless other tests and procedures. There was one

When one door of happiness closes, another opens, but often we look so long at the closed door that we do not see the one that has been opened for us.

– Helen Keller



Melanie Adams

particular senior oncologist who refused to tell me why I was having the tests he was sending me for, except to say 'they were protocol'. As a trial participant, it was my right to have better information. However, overall, I felt lucky that my condition was being carefully monitored. Perhaps I might not have been followed-up so well had I not opted for the trial.

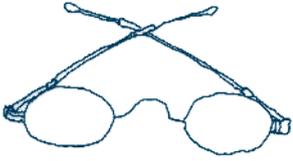
Two years post-mastectomy, I had a successful breast reconstruction. However, a lump I found proved to be a subsequent recurrence. I was not happy, but determined to conquer this one, just as I had done previously. I am now 44 years of age and my babies are 18 and 20!

My burning question is, 'If I had received six months of treatment on the trial, would I have had the recurrence?' I will never know the answer.

The findings from the trial have been written up and years later I read the outcomes with great interest. The trial established that the optimum results (best survival rates) were obtained when patients were given the (now standard) six months of CMF chemotherapy. The findings clearly indicated that the survival rates for those with node positive breast cancer who undertook three months worth of treatment had the poorest outcomes; that is, higher recurrence rates and lower survival rates. That was me!

There is no choice in which treatment is given in a trial, as participants are randomly assigned to a treatment. However, despite my minor setback and initial apprehension about my prognosis, I feel I made the right choice in taking part in the trial. I do believe that women who choose not to participate in trials should not be made to feel disadvantaged. After all, it is a big ask at a time when life can already be overwhelmingly full with a cancer diagnosis.

Melanie Adams, Victoria



Book reviews

Domini Stuart, breast cancer survivor and BCNA Consumer Representative, is the author of one of our reviewed books 'You can get through this!' Domini reviews another important book, 'Understanding Depression' by Maria Prendergast.

Both Domini and Maria are involved in various ways in the development of *Hope and Hurdles*, our important new information package for women with secondary breast cancer. For more information on *Hope and Hurdles*, which will be available soon, visit our website. If you would like to receive **The Inside Story**, our **Beacon** supplement for women with secondary breast cancer, phone us on 1800 500 258 or email beacon@bcna.org.au.

Breast Cancer: You can get through this!

By Domini Stuart
ISBN 0-9579144-0-7
2001 Domini Stuart:
www.doministuart.com

Following a diagnosis of breast cancer and subsequent treatment in 2000, **Domini Stuart** wrote this to help others to say positive while coping with surgery, treatment and the emotional pressure of having cancer.

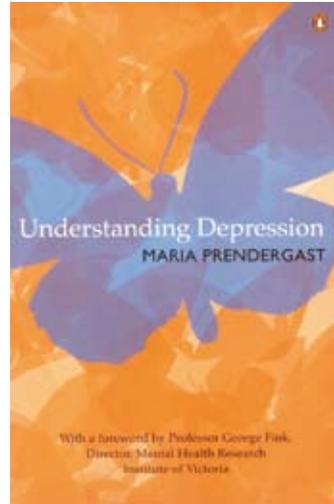
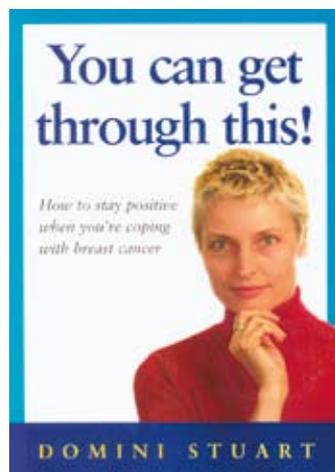
The book details Domini's own experience of breast cancer in a frank and uplifting way. She outlines how she hit rock bottom and managed to cope. She has admirably detailed the story of how she turned her life around. It is an easy to read guide about coping with surgery, chemotherapy, radiotherapy and

life beyond cancer, and staying positive through the entire process.

In a mere 128 pages, Domini manages to cover a lot of ground. The book is filled with useful and practical advice, ranging from tips about how to cope during treatment, healthy living (including some simple and terrific recipes and exercise routines), to goal setting and ways to gain control of one's life.

I first read this book not long after I was diagnosed with breast cancer in 2002 and loved it. I would highly recommend it to all women with breast cancer. The earlier after diagnosis you read it, the better, but it's still a great, quick read for all women. Reading it again recently has given me some more food for thought. I do suggest reading it – it is a guaranteed 'pick me up'. Well done Domini.

Review by Angela Verde,
BCNA Consumer Representative,
Victoria



Understanding Depression

By Maria Prendergast
ISBN 0-14-100493-2
Format: paperback book.
Pages: 145.
Publication date: 2006
Penguin books

Depression is a major health issue in Australia. According to beyondblue, a national organisation working to address issues associated with depression, the illness costs the Australian economy \$3.3 billion a year in lost productivity. This is a startling statistic, particularly in terms of the pain it represents for sufferers and those who care about them.

In her book *Understanding Depression*, **Maria Prendergast** presents a wealth of information, including the definition, incidence and diagnosis of depression and options for treatment. This is all clearly presented, authoritative

and accessible; however, it is the inclusion of personal experiences that gives the book particular power.

The quotes scattered liberally through the opening chapters clarify and humanise points as they are raised. The second half of the book is then given over to more extensive stories.

Honest, intimate and sometimes heartbreaking, these stories are extraordinary in their diversity. The author has given voice to people of all ages and backgrounds, some who feel they have won their battle with depression and others for whom the battle continues.

Their accounts paint a sobering picture of what it means to live with depression. This is not about having a bad day. It is not something to be snapped out of. It is an illness with the power to destroy relationships, as well as lives. It is also an illness that can, in most cases, be treated. Many of the stories are also inspirational; there are real prospects of recovery, or at least a significant degree of ease.

Understanding Depression is essential reading for anyone whose life has been touched by depression, or would simply like to know more about this pervasive illness.

Review by Domini Stuart,
BCNA Consumer
Representative, NSW

State Reps in action

BCNA is pleased to welcome **Jurina Demaine** as our new Queensland State Representative.

Jurina was diagnosed with breast cancer in December 1997, aged 48 years. She had just moved to Queensland from South Australia, so had no peer support network and was unable to find any support or information locally for three years.

At her local Spotlight store, she found a pamphlet advertising the Brisbane *Field of Women*, which she attended, sponsoring a silhouette for a friend who had recently died from breast cancer. Thus, Jurina discovered BCNA.

Jurina eventually found and joined the Caboolture Breast Cancer Support Group in 2000



BCNA's new Queensland State Representative, Jurina Demaine

and has been their co-ordinator since 2005. She co-ordinated the group's first *Mini-Field of Women* in 2003 and subsequent *Mini-Fields* in 2004, 2005 and 2006.

In 2004 she attended BCNA's Still Making a Difference Conference, the Science and Advocacy Training program, the *Field of Women LIVE* event at the MCG in 2005, and BCNA's National Summit in 2006.

Jurina has been married to Rob for 39 years and has two children and three grandchildren. She is looking forward to having her daughter stand alongside her on the *Field of Women LIVE* at Telstra Stadium, Sydney, in August.

As someone who is well and truly immersed in supporting women and getting involved in breast cancer issues, we are pleased that Jurina has added a BCNA State Rep 'hat' to the many hats she is already wearing.



Tribute to Veronica

Many readers will know of **Veronica Macaulay-Cross**, who had been a BCNA Queensland State Rep since 2001. Her recent death touched many BCNA members, resulting in an influx of tributes that have been posted on our website.

Veronica was an amazing woman and an inspiration to many living with breast cancer. She spoke in public about women's concerns, met with health care providers to improve services, sat on committees to influence decisions, and supported many women through their fears and times of uncertainty. She was passionate about supporting women living with secondary breast cancer, inspiring the development of our information package for these women. Aptly titled *Hope and Hurdles*, this new package will soon be available for women, and is dedicated to Veronica.

Our gratitude for Veronica's advocacy work and commitment to BCNA will be everlasting. We keep her husband Phil and daughter Bec in our hearts and thank Veronica's family for directing funds donated in her memory, by her friends and supporters, to BCNA. She has left a legacy we are proud to continue.

The State Reps in your area

BCNA's voluntary State Representatives, all breast cancer survivors, keep an ear to the ground for state and territory-based news, distribute information for BCNA, and act as contacts for local support groups.

State Representatives can be contacted through their individual email addresses listed below, or by phoning 1800 500 258. The staff at BCNA's National Office can pass messages onto them.

ACT

Kerrie Griffin

taylorclan@iinet.net.au

Elsbeth Humphries

humphries44@ozemail.com.au

NSW

Pam Bell

bellpc@bigpond.net.au

Megan James

megs3008@yahoo.com.au

Northern Territory

Pat Hancock

pathancock_is@hotmail.com

Suellen Williams

suellenwilliams@ozemail.com.au

Queensland

Jurina Demaine

jdemaine@bigpond.com

Lyn Moore

lyn.moore@bigpond.com

South Australia

Alexandrea Cannon

impian@adam.com.au

Jan Davies

jandavies@adam.com.au

Tasmania

Karen Forster

kate4star@hotmail.com

Pauline Watson

watson_cr@yahoo.com

Victoria

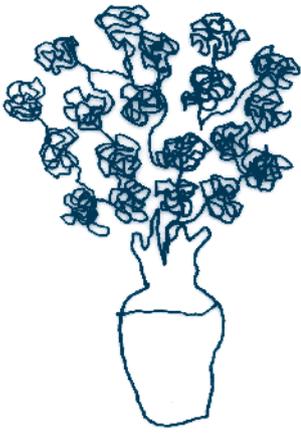
Gerda Evans

gerda@bigpond.net.au

WA

Sue Hassett

hmt1@iinet.net.au



Thank you

We appreciate the financial support given to us in so many ways by individuals, clubs, organisations and companies around Australia. We would especially like to acknowledge the help of the following recent outstanding supporters:

- AHJ Leisure Pty Ltd
- Australian Fed Cup Tennis Foundation
- Australia Post
- Belconnen Bowling Club
- Coffs Harbour Racing Club
- Crowley Family
- Dunlop Flooring
- Independent Property Group
- Jim McCarthy
- Kew Golf Club Ladies Committee

- Kirsty Hutton and Jan Curtain
- Lauriston Girls' School
- Lindsay Goodes
- Melbourne Football Club
- Southern Cross Rodeo Circuit
- Schiavello Pty Ltd
- Telugu Ladies Club
- William Ness

Celebrations

Happy birthday to **William Kajtar, Julie Frey Vears** and **Anna Mlynek-Kalman**, who asked to have money donated to BCNA, in lieu of gifts, to celebrate their special days.

In memory

We pay tribute to the lives of **Helen Chetcuti** and **Veronica Macaulay-Cross**, and are most grateful to be recipients of donations in their memory.



After his wife Elisa received our My Journey Kit, William Ness was inspired to swim across The Rip at the entrance to Port Phillip Bay, Victoria, to raise funds for BCNA. William, seen here with his team – Andrew Gilchrist, Steve Comerford, Ted Gallagher and Russell Wilson – completed the swim in 61 minutes in fine conditions. We are extremely grateful to William and his team for this generous and adventurous method of raising funds



The Coffs Harbour Racing Club hosted the Pink Silks Ladies Day, raising funds for breast cancer awareness, support and research. We gratefully received a share of the proceeds from the enormously successful day. Thanks to the organising committee, pictured here with the extra large cheque.



To mark his 60th birthday, amateur photographer Jim McCarthy held a photographic exhibition in memory of his mother, Maureen Frances McCarthy. More than \$25,000 raised from the sale of Jim's wonderful images was kindly donated to BCNA. We thank Jim for his generosity and support.



Heather Rushworth, Lyn Swinburne, Shelley Shergold and Di Robinson enjoyed a balmy March evening at the Pink Ladies cocktail party in Melbourne. The event raised more than \$25,000 for BCNA.



Profiling our Member Groups

Albury Wodonga Breast Cancer Support Group

The Albury Wodonga Breast Cancer Support Group has been meeting at the Women's Centre in Albury for more than 12 years, with about 20 women gathering at monthly meetings.

Carol Stevenson, a co-founder of the Group, says that between the guest speakers, photo days, wedding dress and craft days, the women in the group often find it hard to find time to talk about breast cancer!

About 40 members of the group, along with members of their local Young Hearts Group, took the journey to Melbourne to attend the *Field of Women LIVE* event at Melbourne in 2005. Carol says that the event brought the group together and everyone gained a lot personally from participating.

As soon as the news of another BCNA *Field of Women LIVE* event in Sydney was announced, women in the group took up the commitment to participate.

Based on its experience attending the 2005 event, the Albury Wodonga Breast Cancer Support Group has the following suggestions for other Member Groups that are considering attending the *Field of Women LIVE* in Sydney:



The Albury Wodonga Breast Cancer Support Group

- The event is a fantastic social activity for the group. It is a great opportunity for the women to connect and bond with each other, so make the most of it.
- Try to organise accommodation close to each other, so that you can stay together through the whole event.
- Make it a weekend or a long weekend trip if possible.
- Take the opportunity to fit in some other activities in Sydney if you can (dining, shopping, sightseeing, etc).
- Book your accommodation and transport early.
- Consider booking a bus or taking a train together.
- Group bookings for accommodation and travel might work for your group – ask whether discounts for group bookings apply.
- If you can, join forces with other groups in your area and take the trip together – the more the merrier.
- Take your camera.
- Take the time to share the experience and talk about it at your next group meeting.

From all accounts following the 2005 event, the *Field of Women LIVE* is a unique event that leaves a lasting impact on all who attend, forging the bonds between groups of women in a lasting way. It is not too late for your group to organise a trip of a lifetime to Sydney. For more information and to register, visit www.fieldofwomen.com.au.

Mini-Fields 2007 – we need you

Mini-Field events are an extremely important way for BCNA to communicate messages about the impact of breast cancer across the country. They promote breast cancer support groups and bring local communities together. The events also enable new breast cancer survivors to hear about how BCNA supports women.

This year, we are hoping to see pink ladies planted in at least 200 *Mini-Field* events across Australia through October. We need your help to reach this goal.

The events provide an opportunity for people to dedicate a pink lady silhouette to someone special who has been affected by breast cancer and to bring people together, which strengthens support for women. Past *Mini-Field* events have included guest speakers, entertainment, candle-lighting ceremonies, picnics, luncheons and BBQs.

If you are inspired to organise a *Mini-Field* event, Breast Cancer Network Australia will send you everything you need in an 'Event in a box' kit containing 100 pink lady silhouettes with stakes, BCNA merchandise and other helpful information.

You can find more information and great examples of past *Mini-Fields* on our website www.bcna.org.au, under the 'Events' section or you can contact Kathryn Rowarth at BCNA 1800 500 258 (free call) or minifields@bcna.org.au.



Letters

Supportive work environment

I was diagnosed in August 2005. It all came about very fast. From my first visit to the local doctor until I was in Wagga having my lumpectomy was a blur. I only spent two days in hospital, even when I went back for reconstruction. After I healed and had made the arrangements for chemo and radiotherapy, I went back to work. My bosses and staff were great and looked after me. I cannot thank them enough for treating me the same as they always did.

The customers where I work, a large supermarket chain, were also supportive and wished me well all the time. My hats and bandanas became a talking point.

My husband and my two teenage sons were terrific, doing so much for me at home, and made me laugh, as did the rest of my family. I have been cancer free now for more than 12 months. Yippee! The best thing to come out of it for me was getting the curly hair that I always wanted.

Thanks for your magazine – it is terrific and keeps us well informed and also for the *My Journey Kit* that all in my family read.

*Therese Rogers
Cootamundra, NSW*

Ed's note – it's great to hear that there are supportive workplaces out there. Many women find our

Helping a Friend or Colleague brochure extremely useful. The brochure explains what women with breast cancer are going through and suggests ways that managers and colleagues can support women going through breast cancer. Phone 1800 500 258 or email beacon@bcna.org.au for copies. We will happily send bulk copies to workplaces.



Thanks to my new-found friend

I was with my husband on the corner of Macquarie and Campbell Streets in Hobart waiting for the lights to change when a girl on a bicycle at the lights beckoned to me. To my amazement, she said that she thought we were on the same journey. We started chatting and the story of her journey unfolded.



Eleanor Clem completing her last chemotherapy treatment at Brisbane's Mater Hospital on Valentine's Day.

She told me how the chemo had not affected her enough to prevent her from bike riding.

As the lights changed, she told me the hilarious story about her bike ride down a steep and curvy mountain road with lots of cars trailing her, with the added dimension of a moth being sucked in through an air vent in her helmet. Because of the circumstances, she was unable to pull over and release her fellow traveller and so had to endure the flapping, thumping body and countless legs thrashing her chrome dome (as she described it) all the way down the mountain. I laughed more than I had laughed for the whole of the previous eight months.

We talked about the more serious side of things – why when it is 15°C do our heads feel as though it is 40°C? Why, for some strange reason, do we become better people for our experience? (I must admit that I do not think I have reached that stage).

My last chemo treatment was to be on St Valentine's Day and my new friend told me there should be some chocolates in it for me. She (I cannot believe we did not exchange names) said that I looked strong and well and should expect a good outcome.

This totally unexpected experience certainly lifted my spirits and put a new spring in my step that I hope I shall never lose.

My new friend is five years into her journey and came into mine as I reached my next crossroad (radiotherapy). My first year is not up until July. Thank you, my new found Tassie friend. I hope you will read this letter and realise how much our chance (or was it chance?) meeting meant to me. I hope others will read it too and have their confidence and spirits raised.

*Eleanor Clem
Buchan, Queensland*



Irene Moy

Swimming tip

I had a mastectomy in 2005 and now use a latex prosthetic replacement.

I wanted to take up water aerobics, but discovered that the chlorine is not friendly to latex, as it breaks down much quicker. So I made another one to use in the water. The advantage is that it was cheap: \$11 compared to \$150.

Spotlight sells foam breast pads, unfortunately only in a small size, so I sewed three pads together and placed them in a mastectomy swimming costume. It works really well and you cannot tell one from the other. It is a viable alternative for those women who cannot afford a proper prosthetic.

Irene Moy
Taree, NSW

Cost confusion

I began my journey in early 2006. Surgery and evaluation for aromatase inhibitor therapy followed. My cautious specialist ordered a bone scan due to the known risk of bone mineral loss with this therapy. Fortunately, the

results were good. The cost of the test was \$98 and I was surprised my application to Medicare for a refund was denied, marked 'criteria not met'. I can afford the cost of the test, but others may not.

It did not seem logical to me to deny a refund. The test was ordered by a specialist as part of her expert evaluation of ongoing treatment. I wrote to Medicare and my Federal member of Parliament. He passed my letter on to the Health Minister and basically I received the same answers, 'Criteria not met as set by an independent advisory body'. This begs the question, 'Had I commenced aromatase inhibitor therapy, with an undiagnosed osteoporosis, what cost to



Dora Shaw

Medicare for my future care as the condition dramatically worsened?

I have put this question and others in a further letter to the Minister and await a

reply. Perhaps I'm a lone voice in challenging such illogical reasoning, but getting mad sure beats feeling sorry for myself.

Dora Shaw
Biggera Waters, Queensland

Ed's note

We love the idea of getting mad! We heartily agree that there seems no sense in not reimbursing the scan. We also know that this is one of many costs that women might face after a breast cancer diagnosis. While we cannot avoid the personal costs of breast cancer, we can fight to reduce the considerable financial costs.

Super mum

My name is Cassi and I am 18 years old.

Two years ago my mum was diagnosed with breast cancer. Her diagnosis and treatment period was probably the hardest time of my life. It was so hard to watch her go through what she did.

She is now on the road to recovery but, as you know, it is not over yet and it never really seems to get easier.

The purpose of this email is to say thank you. When my mum was diagnosed she received a My Journey Kit and has been getting the magazine, **The Beacon**. They have been a real encouragement to her and me.

I also love buying pink ladies from Bakers Delight for her.

So once again thank you.

Cassi Herbert
Narellan, NSW

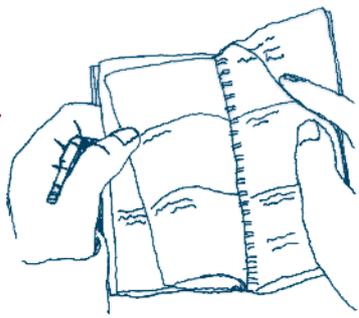


Cassi Herbert and her Mum



BCNA gratefully acknowledges our partnership with Bakers Delight.





Upcoming Events

June 14-15: Happiness and its causes, 2nd Annual Conference, Sydney Convention and Exhibition Centre, Sydney. More than 50 expert speakers from Australia and overseas, led by His Holiness the Dalai Lama. Contact: www.happinessanditscauses.com.au.

June 17: Survivorship: Living Well with Breast Cancer, Hunter Breast Cancer Public Forum 2007. The principal focus will be the psychosocial issues associated with living with a breast cancer diagnosis. Western Suburbs Leagues Club, New Lambton, NSW. Contact: Suzanne Mullen, (02) 4929 1118 or 0404 966 788.

June 30: Breast Cancer Association of Queensland's Rural Breast Cancer Seminar, Biloela (594 km north-west of Brisbane). Contact: Tracey (07) 3666 0614.

July 21: NSW Breast Cancer Action Group's Women for Women with Breast Cancer Forum 2007 and 10th birthday celebration, The Women's College, University of Sydney. Contact: (02) 9416 4487, info@bcagnsw.org.au or www.bcagnsw.org.au.

August 11: Evening – BCNA's **Field of Women LIVE**, Sydney, Telstra Stadium. To register, visit www.fieldofwomen.com.au.

August 28-31: 'Partners across the Lifespan', 9th Australian Palliative Care Conference, Melbourne Convention Centre. Contact: apcc@iceaustralia.com or (03) 9681 6288, or visit www.iceaustralia.com/apcc2007

September 27-29: Australasian Society of Breast Disease Meeting, Surfers Paradise Marriot Resort, Gold Coast, including a BCNA Consumer Forum. Phone 1800 500 258 for information.

September 28-30: Abreast in Australia – the first international survivors' regatta, Caloundra, Queensland. Contact: Dragons Abreast www.dragonsabreast.com.au.

October 13-14: Up Close and Personal – 1st National Conference for Australian Young Women Affected by Breast Cancer, Melbourne. This conference is being organised by Young Action on Breast Cancer; see www.bcna.org.au – young women's section for more details.

October 16-26: Amazon Heart Thunder Australia. Women diagnosed with breast cancer, of any age and at any stage of the disease can participate in this motorbike ride from Melbourne, along the Great Ocean Road, finishing in the Barossa Valley. To find out more or to register, visit www.amazonheartthunder.org.

October 22: Australia's Breast Cancer Day.

Would you like to be on the mailing list for *The Beacon* or *The Inside Story*?

Telephone 1800 500 258 (freecall), email beacon@bcna.org.au or fill in this coupon and send it to: **Breast Cancer Network Australia, 293 Camberwell Road, Camberwell, Victoria 3124.**

- Yes, please send me: **The Beacon**, BCNA's free quarterly magazine
- The Inside Story**, a four-page supplement on living with secondary breast cancer, mailed with **The Beacon** to those who request it.

Name:

Address:

State: Postcode: Phone: ()

Email:

Have you had a diagnosis of breast cancer? Yes No

If yes, what year were you diagnosed? What year were you born?

Have you had a diagnosis of secondary breast cancer? Yes No



PaperlinX proudly supports women with breast cancer by generously donating the paper for **The Beacon** and **The Inside Story**.

Printing kindly supported by Vega Press.



Seeking young women's stories

The final issue of **The Beacon** for 2007 (to be mailed in December) will focus on young women and breast cancer. We would love to receive contributions from our younger readers to include in **The Beacon** or on our website. Please mail or email your articles (up to 500 words) to BCNA by the end of September and please send us a photo.



the BEACON

Layout: Substitution

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