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Focus on:
Giving back



The joy of giving back

Our network was and continues to be founded on clear insights about women with breast cancer. One of our key acknowledgements is that generally women want to give back.

Perhaps this is the basic nature of women; perhaps it is our gratitude for getting through this disease. Maybe it's simply that we want to turn a negative experience into one which has some benefit for others and, ultimately then, for ourselves. I have always been keen on the old Chinese proverb, 'Better to light one small candle than to curse the darkness'.

'Giving back' is the theme of this edition of *The Beacon* – our 57th issue. We wanted to explore this concept because we are constantly impressed with the range of ways women find to give back. It warms our hearts and we wanted to share some of these examples with you, our readers.

In the Spring issue of *The Beacon*, we focused on the financial burden of breast cancer diagnosis and treatment. We included a story from Tracey who shared with us that she was \$15,000 out of pocket. Tracey and her family were clearly not in a financial position to easily afford anything like this.

A short time after *The Beacon* arrived in letterboxes across Australia, I was contacted by one of our members, let's call her 'Margaret', who was incredibly touched by Tracey's plight. She was a woman who'd been more recently diagnosed and who felt she'd been 'let off lightly' with her own experience. She wanted to give Tracey back the \$15,000 to lighten the load on her family. Margaret was adamant that she remain anonymous; this was simply to be a gesture from one woman to another.

I had the wonderful task of ringing Tracey to share this news. She was, of course, over the moon with relief but especially happy to know that people like Margaret still exist in the world. Tracey was keen to write to Margaret and I passed on her letter. In turn, Margaret was so touched by Tracey's letter that they have since spoken together on the phone and are planning a get-together.

Margaret has since told me that she now really appreciates the saying 'There is more joy in giving than receiving'.

Of course, giving back does not always involve money; in fact from my experience this is rarely the case, as you will see from our stories inside.

BCNA is chockers with women



giving back to others every single day of the week. They run support and activity groups, they represent us on committees, they work to improve the system, they visit women in hospital, they deliver meals on wheels, they promote BCNA's services to others in the community, they reach out to one another. Being diagnosed with a disease like breast cancer reminds us of the precariousness of life, and we may feel more compelled to contribute to the community in which we live – to make a mark while we can and *because we can*.

This is the final time I will be writing this piece before my retirement as CEO of BCNA.

I am one of those women who feels privileged to have been able to give back after my own diagnosis almost 19 years ago. I have had the good fortune to

see such wonderful work being done across the country. For me, one of the greatest joys has been speaking to newly diagnosed women and being able to offer them hope and reassurance.

Like Margaret, I can honestly say I have experienced that great joy in giving back.

There have been some massive improvements for women and men with breast cancer, but believe me there is still so much more to be done. I urge you to keep being active to ensure that our vision is realised: *That Australians diagnosed with breast cancer and their families receive the best information, treatment, care and support, no matter who they are or where they live.*

Thank you all for your warm interest and loyal support over the years. I wish you well.

*Lyn Swinburne
Founder & CEO, BCNA*

Fond farewell to our founder and CEO

There could be no more fitting issue of *The Beacon* to farewell our founding CEO in than this, our 'Giving back' issue. Lyn Swinburne truly personifies this theme.

Diagnosed with breast cancer in 1993, Lyn underwent surgery, radiotherapy, chemotherapy and hormone therapy. Her experience left her feeling 'like a faceless person on a conveyor belt, and angry that the system seemed so cold and uncaring'. Four years later, she took her experience as a breast cancer survivor and founded BCNA, determined to make sure women diagnosed with breast cancer got a better deal.

In the first issue of *The Beacon* in 1997/98, she stated her aims for the organisation:

'We need to communicate with each other across the country.

We need to share information and experiences. We need to investigate the research being done, both in Australia and overseas.

We need to support one another and ensure that there is support available for each woman and for those close to her. We need to raise issues important to us, to educate ourselves and the community about breast cancer and its impact. We need to speak up when decisions are being made, so that services will best meet the needs of those affected by breast cancer.'

BCNA's success is a result of the efforts and hard work of many wonderful individuals. One of Lyn's greatest strengths has been to bring together great partners, Board members, staff and volunteers. This has made BCNA strong and effective. We

are proud to say that we have achieved those aims that Lyn articulated all those years ago. And she leaves the organisation with a 62,000-strong network of members as part of her legacy.

Over the years Lyn has met so many people, spoken at countless events, and received numerous awards, but her greatest satisfaction is in meeting women with breast cancer who are being supported and who are well-informed. She is able to establish instant rapport with them. In turn, their high regard for Lyn is obvious.

I have had the privilege of working with Lyn for the past five years. During that time I have admired her unique ability to inspire and attract key people to help with the cause.

I have marvelled at her outspokenness, her bravery, her unwavering focus and constant bloody hard work – she's been available 24/7 and given her all to the organisation and, most importantly, to the cause at large.

Her genuine warmth and often irreverent sense of humour is evident to everyone she meets and she has a gift for putting people at ease.

On behalf of the Board and the team at BCNA I want to thank Lyn for everything she's done and to wish her every success and happiness for the next exciting phase of her life.

*Marg O'Donnell
Chair, BCNA Board*

Welcome to our incoming CEO – Maxine Morand

Maxine Morand starts as Breast Cancer Network Australia's new Chief Executive Officer from 28 November 2011.

I am delighted that Maxine has accepted this vital role and have no doubt that she will do the job with great passion and ability.

Maxine is a well-respected advocate for women, with extensive experience in the community and health sectors and in government, and is renowned for her collaborative approach and focus on building strong relationships.

Maxine was diagnosed with breast cancer earlier this year, so she understands what many women have been through.

She joins us determined to build on BCNA's achievements and to continue our focus on providing quality information and support for those personally affected by breast cancer.

Maxine is keen to use her strong advocacy skills to work now on behalf of women diagnosed with breast cancer and ensure their voices continue to be heard whenever decisions are made

that affect their treatment and care.

Lyn herself is delighted with Maxine's appointment and is confident that she is leaving the organisation with a solid foundation and a dynamic and passionate new leader who will unite and support communities, and activate businesses and government for the benefit of all Australians affected by breast cancer.

It's a new chapter for BCNA and we trust you'll embrace our new CEO with your usual warmth



Maxine

and generous spirit. You'll hear directly from her in the next issue of *The Beacon*.

*Marg O'Donnell
Chair, BCNA Board*

We can't do it without you

You may not realise it, but just by being a BCNA member and receiving *The Beacon*, you are making a major contribution to BCNA and our important advocacy work!

Our strong membership – currently more than 62,000 Australians who have been personally affected by breast cancer – gives us huge credibility and has helped to make us one of Australia's leading consumer advocacy organisations. Our membership gives us a national voice and allows us to advocate on behalf of women to ensure they are able to access the best treatment and care possible.

Some of our major successes include campaigns to have important breast cancer drugs such as Herceptin, Tykerb and Zoladex made available to women at subsidised costs through the Pharmaceutical Benefits Scheme (PBS). We work with other key stakeholders, such as the Medical Oncology Group of Australia, to achieve these outcomes.

We also work closely with health professionals on a wide variety of issues. For example, we supported a group of doctors develop the submission for a Medicare rebate for MRI screening for young women at high risk of breast cancer.

BCNA also influences decision-makers through submissions to inquiries. Our submissions to Parliamentary inquiries into gene patent laws, Patient Assisted Travel Schemes, and the PBS have ensured that politicians hear the views of women with breast cancer. We were pleased



our submission this year to the PBS inquiry and our involvement in a public campaign on this issue helped to pressure the Australian Government to change the way it lists new drugs on the PBS. A win for consumers!

BCNA's internationally acclaimed *Seat at the Table* program trains and supports women with breast cancer as Consumer Representatives. These women actively participate in committees, boards and forums. Sometimes this work leads directly to improved treatments for women, such as the introduction of Sentinel Node Biopsy for many women undergoing breast cancer surgery.

Consumer Representatives help to develop new resources, such as Cancer Australia's *Guide for Women with Early Breast Cancer*. Sometimes there are less obvious outcomes, but our influence is still great.

For a number of years, BCNA has appointed Consumer Representatives to the National Breast Cancer Foundation committees that select major projects to be funded for research.

Our extensive membership gives us an ideal base to conduct research into issues that affect women. We have already surveyed members on topics such as Herceptin and heart health, breast reconstruction, and sexual wellbeing. This is a growing part of our work as we look to inform ourselves on issues that matter to women so we can use our influence to advocate for further improvements.

We know other consumer organisations look to BCNA as a role model when developing their own systems and resources. Our *My Journey Kit* has been used as a model for resources developed by other organisations, including Ovarian

Cancer Australia and several international breast cancer groups.

We are also proud of our *Hope & Hurdles Pack* for women with secondary breast cancer. It was developed in consultation with women with secondary disease. It provides women with information about secondary breast cancer and helps them realise they are not alone. Before the days of our Online Network, many women told us they had never met another woman with secondaries. The quotes and stories included in *Hope & Hurdles* helped them make a connection with others whose experiences were similar.

BCNA pays tribute to you, our members, for your commitment to our work and for your continuing support. We could not do it without you.

If you would like to learn more about our advocacy work, visit www.bcna.org.au > About BCNA > Advocacy.

Ask the Expert

Professor Michael Bilous



Michael Bilous

Professor Michael Bilous is Clinical Associate Professor at the University of Sydney and a Consultant Pathologist with Healthscope, a private health care provider. He has worked for many years in the area of breast pathology, has written extensively on the topic, and has presented at BCNA forums.

Why are pathology reports important?

The pathology report contains information which determines the prognosis of the breast cancer, i.e. how it is likely to behave if left untreated. Your medical team will use this information, together with the clinical and imaging findings, to make recommendations about your treatment.

How does the pathologist examine the tissue?

After breast cancer surgery, the portion of breast containing the cancer is taken to the pathology laboratory. The pathologist removes samples of the cancer and surrounding breast tissue for processing, as well as samples from the margins to make sure they are free of cancer cells. The samples are preserved in paraffin blocks, from which thin slices are cut and mounted on glass slides for examination under the microscope.

What sort of information is included in the report?

The information includes a detailed description of the specimen of breast tissue and of any lymph nodes that have been removed by the surgeon

(Macroscopic Examination) and what the pathologist finds on examination of the specimens on the glass slides (Microscopic Examination).

The most important information is the type, size and grade of the cancer. Some types of breast cancer carry a better prognosis and are known as Special Types. The most common of these is called Tubular Carcinoma. The size of the cancer is a component of the stage of the breast cancer and this is important in determining prognosis. Breast cancers are divided into three grades, 1–3, with 1 being the slowest growing.

It is very important to know whether the cancer has spread to any lymph nodes, so the pathologist examines sections of all the nodes removed to look for cancer cells.

Tests are performed to determine whether there are receptors for oestrogen (ER), progesterone (PR) and HER2 on the cancer cells. This will help the medical team decide whether hormone treatment and HER2-targeted treatment may be beneficial.

The pathologist also assesses the margins of the cancer to ensure that all the cancer has been removed. If the margins are not free of cancer, the surgeon may recommend further surgery to remove any remaining cancer cells.

What happens to my tissue samples?

The paraffin blocks are kept for a minimum of 20 years and

can be used over and over again to generate new sections for examination. Sometimes pathologists are asked to re-examine a cancer sample, or may be asked to send paraffin blocks or glass slides to another pathology laboratory. This may happen, for instance, if a patient changes her medical team and the new oncologist wants his/her regular pathologist to review the findings and discuss them at a Multidisciplinary Team Meeting.

There are a number of other tests that can be performed using paraffin blocks, including some of the newer Gene Expression Profile tests such as Oncotype DX. Genetic testing for BRCA1 and 2 mutations is not done using paraffin blocks, however. They are done via a separate blood test.

Any leftover tissue that has not been used for the paraffin blocks is discarded, usually around four weeks after the pathology report has been completed.

Are there any emerging issues in pathology that may be of interest to women?

Basic pathology information about your cancer will always be required to determine what further treatment may be recommended for you.

There are, however, some exciting new developments that may give additional information relevant to treatment decisions. These involve examining the genes that are (over)active in the cancer. The combination of new computer technology, together with the identification of all of our genes through the Human Genome Project, has meant that we can now examine all the genes in a given cell to see which ones are switched on or off and which ones are overactive.

In cancer cells a number of genes that control growth and cell division are overactive. Other genes control how our bodies metabolise certain types of drugs. Identifying these genes in a cancer cell may help doctors decide what drugs to use in a particular patient. There is new technology being developed that can do this, although it is not yet widely available. This technology is called Gene Expression Profiling, and it can help your medical team to personalise your treatment by determining which particular drugs will be likely to have the most effect on your particular cancer cells. This is definitely an area we need to watch in the future.

BCNA's Breast Cancer Pathology fact sheet provides more detailed information on pathology reports, including what the terminology means, how the information is used, and how you can obtain a copy of your pathology report. To obtain a copy visit www.bcna.org.au > News > Resources > Fact sheets, or call us on 1800 500 258 (Freecall) and we will send a copy to you.

Breast reconstruction: the nurses' view

In the 2010 Summer issue of *The Beacon* we reported on a survey we had undertaken with women about their breast reconstruction experiences. With support from Cancer Australia, we recently surveyed more than 100 breast care nurses (BCNs) to understand their experiences.

Public hospital waiting times

Eighty-three per cent of the BCNs told us that women in their local area can access breast reconstruction surgery in a public hospital within two years of being placed on a waiting list. Fourteen per cent said women had to wait two to four years, while one regional Queensland BCN said women in her area wait up to five to six years for reconstruction surgery in a Brisbane public hospital.

Almost half of BCNs (49%) said they believe waiting times are an issue for women.

A lot of patients feel 12–24 months for a delayed reconstruction is too long to wait.

Cost of private surgery

Many BCNs who completed our survey work only in the public system and were unable to answer questions about out-of-pocket costs for private surgery. Of the 52 who did answer this question, the largest number said women in their area have an out-of-pocket cost of between \$5,000 and \$8,000.

The gap fee if using private health insurance can be enormous.

Issues for women in the country

In open-ended comments, many BCNs raised issues for rural women, including having to leave home for more treatment, the frequency of visits for appointments and reconstruction procedures, and travel and accommodation costs.

There are multiple trips ... the cost of travel and being away from home and unable to work during this surgery and recovery period can result in a huge financial burden even in the public system.

The shortage of plastic surgeons who work in regional areas was also raised.

Information for women

BCNs also commented on the need for more and better

information to be available to women about options for reconstruction.

I would like to see information about breast reconstruction surgery made available to women in public hospitals, and women given the opportunity to find out about reconstruction surgery before their original breast surgery.

We thank all the BCNs who participated in our study. The results will help us inform decision-makers on issues surrounding access to breast reconstruction surgery.

To read a report about the survey's findings and a summary of BCNA's breast reconstruction project, visit www.bcna.org.au > About BCNA > Advocacy > Research reports.

Intravenous chemo drugs to be cheaper

In some good news for women, the Australian Government has announced changes to the way intravenous chemotherapy drugs listed on the Pharmaceutical Benefits Scheme (PBS) will be dispensed, making them cheaper for women. These changes came into effect on 1 December.

We know that many women have to pay the PBS co-payment, or prescription (script) fee, for their chemo-therapy drugs. The script fee is currently \$34.20 per script, or \$5.60 if you qualify for a concession. These fees can add up, especially if you have several different drugs at each treatment

session. If you are being treated with FEC chemotherapy, for example, you may currently pay three script fees for each treatment session (one for each of the three drugs that makes up this combination). You may also pay a script fee for other chemo-related medications, such as anti-nausea and neutropenia drugs. This can bring the total out-of-pocket cost to more than \$150 per treatment session.

The Government has advised that as of 1 December you only pay the script fee the first time a chemotherapy script is filled. You will not pay a script fee for any repeats – so if your doctor writes

a script with three repeats, you only pay the script fee the first time you have the script filled, but not for any of the following treatments.

It's important to note that this change applies only to chemotherapy drugs administered by injection or infusion – it doesn't apply to chemotherapy drugs supplied as pills.

If your doctor changes your chemotherapy dose or type, you will receive a new script and so will have to pay the script fee the first time that script is filled. Any repeats will then be free of charge.

Changes have also been made for women treated with Herceptin for early breast cancer. If you are currently on Herceptin and use one of each vial size, you may previously have paid two script fees. Under the new arrangements, women using more than one vial size pay only one script fee.

BCNA congratulates and thanks the Government on implementing these changes, which will help to reduce the cost of breast cancer treatment for many women.

For more information, talk to your pharmacist or call BCNA on 1800 500 258 (Freecall).

Supporting those who give back

Every two years BCNA hosts a National Summit, bringing together key members of our network who all contribute in various ways and who, importantly, provide enormous support to others in their own communities.

In August, almost 300 BCNA members attended our 4th National Summit in Melbourne, with the theme 'the heart of our network'. The three-day program was designed to inform and inspire these women who contribute so much. It was also an opportunity to make sure these women connected with each other, left feeling well-equipped and supported in their work, and arrived home feeling reinvigorated.

On the first evening, we held a special *Mini-Field of Women* in the shape of



a heart. During the days, attendees saw presentations by guest presenters, including breast cancer clinicians and motivational speakers. Small workshops then covered a range of topics such as responding to loss and grief, as well as information sessions on subjects such as hormonal therapies and menopause.

The Summit gave those attending a chance to share their experiences and to connect with people from across Australia who have taken up similar roles. In turn, BCNA had the opportunity to find out more about what women need.

A highlight of the Summit was an inspirational speech from Moira Kelly, who has been recognised internationally for her humanitarian service to both the Australian and international communities. She is the adoptive mother of previously conjoined

twins Trishna and Krishna, and of Emmanuel, who performed 'What a Wonderful World' during the Summit.

The National Summit was BCNA's way of thanking hundreds of women for reaching out to others, for sharing their experiences and for spreading the word about what BCNA does. BCNA appreciates the Australian Government's support in contributing to funding for the Summit through the *Supporting Women in Rural Areas Diagnosed with Breast Cancer* program.

Review & Survey Group – a way to give back

Becoming a member of BCNA's *Review & Survey Group* is a great way for women to 'give back'. As a member you can participate in surveys and other forms of research to help solve some of the puzzles of breast cancer.

Review & Survey Group members receive emails outlining opportunities to participate.

There is no obligation to take part – you can decide which you want to be involved in.

Recent opportunities include a survey about waiting times and out-of-pocket costs for breast reconstruction surgery, and an

invitation to trial a new exercise bra for women who have had a mastectomy.

If you are interested in joining the group, or would like to find out more, visit www.bcna.org.au > Help with research. Please note that you need access to the internet and an active email address to participate.

After my breast cancer journey I wanted to do something more, and Review & Survey Group has given me this chance. It's easy; I decide what I want to do and I can do it in my own time.

A seat at the table

As part of BCNA's Seat at the Table program, 20 Consumer Representatives have completed training in Advocacy and Science and will represent us on various committees. These women have recently been appointed and represented us at:

- 8th Scientific Meeting of the Australasian Society for Breast Disease Conference & BreastScreen Australia Conference – Susan Timbs (VIC)
- BreastScreen Australia Conference – Jillian Lawrow (VIC)
- BreastScreen Australia Conference – Kerri Guy (VIC)
- Research Advisory Committee (National Breast Cancer Foundation) – Pat Hancock (QLD)
- Review and update clinical practice guidelines for breast cancer (Cancer Australia) – Lorraine Woods (QLD)

On reflection

A few days ago a close friend telephoned to tell me that a recent photo of me was just amazing. She said 'Dressed in pink transforms you into a totally different person; more confident, wise and determined. I am so proud of you!'

Her comment made me think about what was different about me. I didn't think I had changed that much; I tried very hard not to change post-diagnosis. All I wanted was for my world to return to normal – whatever that may have been.

But the more I thought about it, the more I realised I have changed. Today I have a bit more experience and so many more friends – including those I met in hospital while having my chemotherapy treatment seven years ago. I especially remember a woman sitting adjacent to me, watching those around her with sad eyes and a worried face. She asked me how I felt and it

seemed quite natural for me to relay my journey. This is when I started to 'give back'. I have shared information, tips, worries, concerns, fears, tears and laughs. I know that the world hasn't stopped for us, it has just begun. It is just a new world with a new beginning and a new journey.

The impact of giving back had an amazing and prolonged effect. I am able to talk openly about my journey, offer help to those women who are newly diagnosed, and relay information to those seeking it. I have attended BCNA Summits, Community Liaison training and the 2010 *Field of Women LIVE* – all of which have enabled me to raise awareness of the needs of others and spread the word about BCNA. And all of which strengthened my resolve to give back.

I also decided to pursue the idea of establishing a Breast Cancer Rose Bed garden in Launceston.



Mandy

With the support of the Mayor, the garden was opened in City Park in September. It features 52 roses, most of which are a hot pink variety called Best Friends plus a few Blue Moon roses to remind us of men affected by breast cancer. It's not a memorial garden but somewhere I hope people will go to contemplate and be thankful.

I think you learn from your experiences and come to understand the lessons taught. I realised that I could help someone else who's now faced with the same phases we all go through.

It feels natural to give back by supporting others experiencing the breast cancer journey.

Mandy, TAS

Mandy Forteach with the Mayor of Launceston, Albert van Zetten, in the Breast Cancer Rose Garden. Photo: Launceston Examiner

*From what we get,
we can make
a living;*

*What we give,
however, makes
a life.*

– Arthur Ashe



A mother's labour of love

I have just completed an online donation to BCNA of \$1000 on behalf of myself and my mother. I would like to tell you how this donation came about.

I was diagnosed with breast cancer in October 2009 and my journey through treatment has just concluded.

It probably took my mother more time to come to terms with my diagnosis than it did me, and she keenly felt the physical distance that separated us and circumstances that prevented her from rushing to my side to be with me. I live in Brisbane, while Mum lives in Urunga, NSW. We were both so impressed with the many support services that were available to women in my

situation, particularly with the *My Journey Kit* that was sent to me soon after my diagnosis and surgery.

We felt we would like to do something to contribute to the continuation of these services.

Mum is a well-respected bobbin lace maker and she hit on the idea of making lace key rings to sell.



Pat's lace work

She worked a selection and sent them up to me to see if I could sell some to my colleagues at school. Well, those key rings went like hot cakes and in no time I had orders for many more.

Mum was also trying to keep up with orders from her own community and, to date, we have raised \$1000.

Each key ring takes two to three hours to work and each pattern is an original design of Mum's.

The lace is worked on a horsehair pillow and may involve up to 20 pairs of bobbins.

It is truly a labour of love on Mum's part.

I am an only daughter and in working these beautifully unique



Patti's mother, Pat

creations, Mum feels that she can contribute to my continuing recovery and aid in the recovery of many other women who are yet to be diagnosed.

Patti, QLD

Getting through the dark times

I was diagnosed with breast cancer in 2000, just before my 38th birthday. At the time, my daughter Emma was 16 months and my baby Amy was 12 weeks old. It was a dark and scary time. I had a partial mastectomy – I did not have to have any treatment because it was confined to the milk duct. I had the nodes removed. Then in 2002 I decided to have both breasts removed because I'd had many problems with the breast that was partially removed.

With no regrets my life went on. I had a fifth 'PINK' party, then had a 10th 'PINK' party. Ten years after my diagnosis, I decided to have reconstruction.



Grace and her daughters

My family and friends and my mother Mary got me through the dark 'why me?' times. Now I'm a stronger person and lucky to have my beautiful girls growing up and my husband, Tony, by my side.

When I hear of someone who has been diagnosed with breast

cancer I'm happy to go talk to them, and if they want, to show them my new breasts! It's so rewarding to talk and share my experience with many women – even women I don't know who are recommended by friends. Life's great!

Grace, SA

You give but little when you give of your possessions. It is when you give of yourself that you truly give.

– Kahlil Gibran

Finding something worthwhile

Those first months after being diagnosed with breast cancer, undergoing surgery, chemotherapy and radiotherapy were challenging but through it all I knew a lot of people were giving to me.

Afterwards I decided I didn't want to go back to work or study, but I did want to find something constructive I could do to help others – something I could put my energies into that would be worthwhile. I wanted to help others as I had been helped, and it had to be fun.

I decided on raising a guide dog puppy. I thought it would be a blessing to my young family and a nice distraction for my children after the wild ride we'd all been through. Raising Earl gave me an outlet, a puppy I could shower with my love and affection.

I also figured it would get me out walking every day. It was more work than I realised, but it was a joy and it got me walking the kids to school.

Looking back, this experience has made me more aware of others and their needs and how we all need each other in society. For all my health challenges there were others with different needs I could help. As you give, you receive and my whole family has received something precious with the memories of raising Earl.

While I was out at the shops one day with Earl, a stranger talked with me. This man was pushing his wife in a wheelchair. She had undergone surgery for a brain tumour. Together they asked me lots of questions about raising a guide dog and I have just heard



Fiona and her daughters with Earl

from Guide Dogs Queensland that they've applied to be puppy raisers too. I hope they get as much joy and satisfaction out of this unique experience as I did.

There's a time for all things and now I am going back to work,

but I will never forget or regret my year with our adorable mate Earl. We are all looking forward to his graduation in two years' time.

Fiona, QLD

Filling the silence with radio waves

I am a volunteer reader with Radio 1RPH – a community radio reading service for the print-handicapped. I became aware of this wonderful radio station in late 2008 when I was undergoing chemotherapy, after breast cancer surgery.

Normal everyday activities and pleasures were put on hold during my six sessions of chemotherapy over five months as I experienced pain, nausea, fatigue and anxiety.

Usually an avid reader, I found during this time that even the most appealing novels lay

unread, or would be abandoned after a few chapters. It was the same with newspapers and magazines. Either the 'chemo-brain' syndrome I was warned about, or just a general lethargy, had set in. One side effect, watering eyes, made reading particularly difficult.

I found I couldn't concentrate on television either. A friend had dropped off some audio books on CD, but even the effort of switching discs seemed all too much.

Radio was my lifeline – music, news, talkback – by just pressing

a button on the remote. I listened, eyes closed, as I lay on the sofa during the day, and in those sleepless lonely early morning hours when the rest of the family slept.

Then a friend mentioned Radio 1RPH. I was hooked. How nice to hear newspaper and magazine articles and books read out so clearly by people who sounded like kind friends.

In 2010 when I was feeling stronger, and already having made the decision to retire, I was accepted as a volunteer reader on Radio 1RPH.

When I am reading on air, I try to imagine not just our vision-impaired listeners but also those having chemotherapy or recovering from an illness, who may be listening in. I hope it helps them to relax and forget their fears and discomfort for a while, as it did for me.

Judith, ACT

Out of my comfort zone

The champagne cork popped and I silently raised a toast, a salute to my survival, exactly two years to the day since my diagnosis of breast cancer.

I thought about the last two years and asked myself, 'What did I do with what might have been my last two years with family and friends?'

The simple answer was that I had received endless support and encouragement from everywhere – from both expected and unexpected quarters. Then and there I decided it was time to give something back in thanks for this incredible support. I knew I could add little to the rich and extensive breast cancer

networks, so I thought about my skills and where else I could make a difference.

I searched 'Volunteering' on the web. I checked with my breast surgeon who gave me total support and encouragement. Three months later I was on my way to the Maldives for six months helping to further teacher education on a remote atoll through the VIDA (Volunteering for International Development from Australia) program funded by AusAID. I organised all my regular medical appointments just before and after my placement.

Volunteering in the Maldives was hot, isolated and remote.

It was confronting, confusing, frustrating and exhausting. Although it was stunningly beautiful, it was marred by garbage.

For me, all this was outweighed by wonderful friendships, constant humour and the vibrant island community who wholeheartedly embraced my

husband and me. It gave me a renewed perspective about giving back and that, for me, being a survivor isn't about just surviving, it's about living life to the full and knowing that you can keep to your medical schedule while doing something you might not have considered prior to your diagnosis.

Karen, ACT



Karen

Spreading hope, help and support

When I was diagnosed with breast cancer I was shattered. My fear was astronomical because of my strong family history. I wanted answers to so many questions, but didn't know where to get them and the doctors only told me so much.

Through BCNA I received the *My Journey Kit*. Wow! This information was just what I needed. It explained all the treatments, the drugs, and what to expect.

After I was well enough I wanted to return the favours, so I joined a support group and began talking to newly diagnosed women and their partners.

I became a BCNA Community Liaison and recommended BCNA and what it had to offer.

I held *Mini-Fields of Women* and information talks to get the

breast awareness message out there.

When I speak, many people are surprised to learn that there are

many different types and stages of breast cancer, and to hear what is available to them either through BCNA or the Cancer Council. I have given out copies of *The Beacon* and they are amazed at the openness of those whose stories are published.

I feel privileged to be able to give back some of the hope, help and support that I searched for and eventually found. It does all help make a really awful journey just a tad more bearable, and gives us back just a semblance of the control that has been taken from us.

Fran, VIC



Fran

A message of hope

Seven years ago I was diagnosed with breast cancer. I had a husband and two pre-school-aged children. It was a tough time.

I didn't know how to reach out for support, or even if I wanted to. I felt I had to tough it out and felt very isolated, even though I had fantastic family support around me. I now realise that I wanted to protect my loved ones and not expose them to my fears.

It was not until I had gone through surgery and chemo that I really started to struggle with my own feelings. I was hard on myself, telling myself to just get on with it. It was at this point



Frederika

that I decided to find out about BreaCan, an information and support service in Melbourne for people affected by breast and gynaecological cancers.

I walked into BreaCan with no real expectations and walked out feeling as if a huge load had been lifted from me. To be able to go into a space that was welcoming, to meet women who had had a similar experience, and to be able to express openly my own feelings and fears was an incredible experience.

Yes, I cried a lot, but it was a release without fear of upsetting the ones I love.

I began to understand that what I was feeling was quite normal. It gave me the strength to get information on particular issues. I felt I got back

some control over what was happening to me.

A couple of years later, I saw that BreaCan was seeking volunteers and, as I felt I was in a good place emotionally to support others, I applied. To be able to offer women support at their most vulnerable times is so important.

I feel that, as a volunteer, I complement the care provided by health care professionals. But most of all, for me, being a volunteer is sending a message of hope to those beginning their breast cancer experience.

Frederika, VIC

Prostheses to PNG

Thinking about a project that my local Burdekin breast cancer group could take on, I came up with the idea of sending second-hand prostheses and bras to PNG, where I had lived some years ago. I knew that there was not a lot of help for women who needed them.

Word got out about what we were doing, and the prostheses and bras started rolling in. In the course of the year we filled up two shopping trolleys with goodies.

I started making enquiries via the internet to find someone to coordinate the project from PNG. I eventually tracked down the breast cancer coordinator at the hospital, Joyce, a wonderful woman who was a breast cancer

survivor herself. She was thrilled at what I proposed.

I then had to find a way to get the prostheses to PNG free of charge.

Our local travel agent approached Air Niugini, which agreed to transport the boxes for free, and the Cancer Council in Cairns arranged to get the boxes to the airport.

Three of us spent a morning going through all the prostheses and bras we had collected, and putting a prosthesis into each bra with a note to the women who would be receiving them.

Two weeks later Joyce received the boxes and had a wonderful time opening them with some of the breast cancer women.



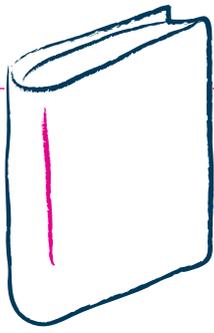
Breast cancer survivors in Port Moresby with donated prostheses and bras

We have started collecting again and hope to send more in the near future.

I feel we are lucky to have

the support that we have in Australia, and if we can make some other woman's life better, then how wonderful is that?

Carolyn, QLD



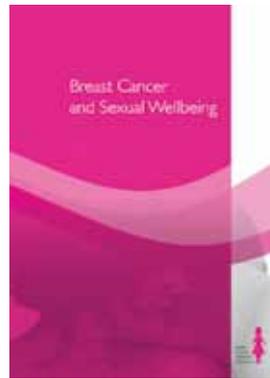
Reviews

Breast Cancer and Sexual Wellbeing

*Breast Cancer Network
Australia, 2011
24pp free information booklet*

Brilliant! I wish this had been available for me three years ago. After chemotherapy I went into treatment-induced menopause and found my otherwise helpful doctors at a loss to assist me.

I was offered nothing to deal with the hot flushes that occurred about every 20 minutes day and night, and was met with



glazed looks when I mentioned loss of libido and vaginal dryness.

In general, I felt that friends and family took the view, and

in some cases actually said, 'but you've finished treatment and you're all right now'.

It would have been wonderful to have this booklet, which acknowledges and validates the physical difficulties and emotional grief that I was experiencing.

In addition, the booklet offers very detailed and practical suggestions and information

about where to go for help. The booklet caters well to all age groups – I especially like that the quotes are taken from younger and older women. While the booklet may be helpful to partners, especially as a conversation starter or background information, I feel that it is mainly suited for women themselves.

*Sian Fereday
BCNA Community Liaison*

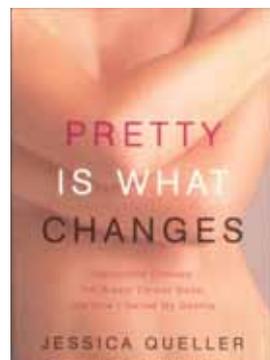
To order or download a copy visit www.bcna.org.au > Living with breast cancer > Sexual wellbeing, or phone BCNA on 1800 500 258 (Freecall).

Pretty is What Changes: Impossible Choices, the Breast Cancer Gene, and How I Defied My Destiny

*by Jessica Queller
Random House, 2008
(paperback) 247pp, RRP \$29.95*

What do you do when you are told that you have up to an 87% lifetime risk of getting breast cancer and a 44% chance of ovarian cancer?

Jessica Queller and her sister, Danielle, lost their mother, a breast cancer survivor, to ovarian cancer at the age of 52. Their mother's history put both sisters into the high-risk category for developing cancer themselves, possibly at an early age. Jessica decided to have the test for BRCA1 mutation that would predispose her to breast and ovarian cancer.



She tested positive.

For this 35-year-old American writer, the decisions to be made were momentous. Should she have a mastectomy or just remain vigilant with regular checkups? To whom should she turn for personal and medical advice? How would her future life choices be affected?

After researching options with experts, looking to her friends

for support and meeting with people who had been through similar experiences, Jessica made her decision.

It is interesting that her sister initially took the opposite approach and refused to have the test.

The focus then turns to Jessica's very moving personal experiences following the devastating news and also provides a wealth of important medical information (although it is from an American perspective).

After receiving her test results, she states that 'positive is bad', but then moves on to do something about it.

Pretty is What Changes is important for those who are facing cancer. It is a reminder that we must always be prepared to make well-informed decisions

about our own health by investigating options, asking questions and persisting until satisfied with the answers.

I would highly recommend this book as an inspiring story about life's uncertainties and challenges told by a remarkable young woman.

It is thought-provoking, absorbing and entertaining, and involves the reader every step of the way.

*Margaret Ward
Review & Survey Group
member*

If you have a history of breast cancer in your family, you may like to read the information on the BCNA website, www.bcna.org.au > About breast cancer > Breast cancer in the family.



Profiling our Member Groups

Strathpine Coffee Club, Qld

Lynne Dorreen from Brisbane had her mastectomy in June 2010. She was back at work not long after and thought everything should be fine – but it wasn't. She didn't want to sweep her experience under the carpet. She wished she could talk to someone who understood what she was going through. Lynne tells the story of how the Strathpine Coffee Club began.

I was searching on the internet, trying to find a group I could join or someone I could talk to. I had wonderful support at home but what was missing was that connection with someone who had been there themselves. On the outside I looked fine, I looked like I always had, but something was different and I needed to talk to someone who understood that.

In my search I came upon the BCNA Online Network. Through reading some of the stories I felt that this would be a great place to start.

I decided to put a call out through the network. So I wrote a blog about who I was, my breast cancer experience and asked if there was someone in the Online Network with a similar story who lived near me who wanted to meet for a coffee.

This is where Lynda found me. She responded to my blog and soon we were meeting up at the local coffee shop. Our first meeting was amazing – for both

Connect with others on BCNA's Online Network by registering at:
www.bcna.org.au/network

of us. To be able to connect with someone who understands this journey was exactly what we needed. We met up a couple more times and knew that we wanted other women to experience the benefits of such a connection.

We set up an online group through the BCNA Online Network and the group gradually grew. From week to week women found out about us and joined our coffee catch-ups. Soon our gatherings were getting so big we were just too noisy for the cafe! We needed to find a new place to meet.

The local bowls club was able to meet all our needs, and, besides, they had a 'pancakes and cream' special every Wednesday morning!

There are 12 in the group now and it is very important to all of us. We have found ways to ensure we can support women who can't make a morning meeting due to work or other commitments.

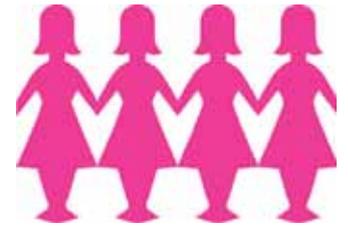
We now meet fortnightly (every second Wednesday), alternating between morning and evening. We also have an online group where members can share their stories and connect in between meetings.

There is something very special about support groups; that automatic bond that is created. We know what each of us is thinking without us even having to say it.

I don't know where I would be without this group ... probably still trying to find someone to talk to. I don't think we would have found each other if it weren't for BCNA's Online Network.



Strathpine Coffee Club



Linking together

Over the past 13 years a key part of BCNA's mission has been to **link** Australians personally affected by breast cancer.

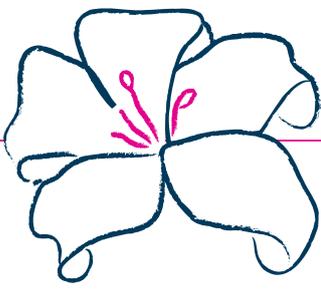
We welcome new Member Groups to our network. They now make a total of 315.

BCNA also has more than 62,000 individual members across Australia.

New Member Groups:

- Blackwood Valley Breast Cancer Support Group – Blackwood, WA
- Can Laugh Cancer Support Group – Noosa, QLD
- Daylesford Breast Cancer Support Group – Daylesford, VIC
- Gold Coast Sunshine Sisters – Coolangatta, QLD
- Naracoorte Pink Ladies – Naracoorte, SA
- St Vincent's Hospital Early Breast Cancer Information and Support – Darlinghurst, NSW
- Warrior Mummies – Margate, QLD
- WIGS Cancer Support Group – Warragul, VIC

To find Member Groups, including support groups, in your state or territory visit www.bcna.org.au > About BCNA > Sharing & support > Find a support group in your area.



Thank you

Thousands of generous supporters across Australia donate their time and money to support BCNA. We would especially like to acknowledge significant financial contributions recently received from:

- Blush Ball Veneto Club – Nadia Bearzatto and Committee, VIC
- Collins Foods Group, QLD
- Deb and Pearl's Pink Party – Deb Murray and Sandra Parker, VIC
- Donna Rosa Pink Carpet Event – Jayne Britton, VIC
- Gala Girls Night Out – Bianca Dorevski, Margaret Doucas and Committee, VIC
- Goulburn Ovens Institute of TAFE, VIC
- Hunter Business Women's Network, NSW
- Jog for Jugs, Peta Burton, QLD
- Malcolm Stewart, NSW
- Margaret Malouf, NSW
- Melbourne Breast Cancer Bra Walk – The Pink Sisters, VIC
- Morisset Country Club Golf Club Ladies Day – Gail Gear, NSW
- Movie Night – Alison Carbery, VIC

- National Council of Jewish Women of Australia, NSW
- Panton Hill Football Club – Kerrie Tyler, VIC
- Pink Afternoon Tea – Edith Shaw, QLD
- Pink Lady Breakfast Kiama – Cathy Delhaas, NSW
- Pinking Up Drysdale – Annette Campbell, VIC
- Players for Pink, Ballarat Clarendon College – Jenny Poppe, VIC
- Queen's College Breast Cancer Awareness Dinner – Ella Price, VIC
- Quill, NSW
- Rainbow Beach Surf Lifesaving Club – Maree Van Oirschot, QLD
- Redcliffe Golf Day – Elly Squire, QLD
- Royal Motor Yacht Club, NSW
- Shane Crawford – Nine Network Celebrity Apprentice and The Footy Show
- Shirley O'Brien, NSW
- Simon Costello, VIC
- Simone Vanden-Driesen, VIC
- Springvale RSL – Barbara Richards, VIC

We would like to acknowledge the Honan family and the Manildra Foundation for their generous contribution and outstanding ongoing support.

- St Catherine's School, Toorak, VIC
 - St Mary's Senior Football Club – Peter Minuz, VIC
 - Sue Beinke, SA
 - Sunday Herald Sun staff sale, VIC
 - Supré, SA
 - The Learning Ladder, Penguin Group, VIC
 - The University of Western Australia Rugby Supporters' Day – Rob Young, WA
 - Thirteenth Beach Ladies Christmas Golf Day – Barbara Epstein, VIC
 - Victorian Pink Ribbon Ride – Marcel Gomperts, VIC
 - Wantima Country Club Golf Day – Elly Squire, QLD
 - Yvonne and Kylie Hargreaves, VIC
- Special thanks to the participants, fundraisers, volunteers and organisers of the Blackmores Sydney Running Festival.

Memorials

We pay tribute to the lives of:

- Angelina Plink
- Anne Maree Dwight
- Beverley Holgate
- Elisa Brooke Sharp
- Enid Sherwell
- Helen Patricia Brown
- Josie Salvatore
- Simone Louise Miles
- Wayne Critchley
- Wilma Bott

We are grateful for the donations we received in their memory.

Celebrations

Thank you to those who celebrated a special occasion and asked for donations to BCNA in lieu of gifts:

- Denise Burgess
- Kylie Bourke



The Blush Ball at the Veneto Club, Melbourne



Gala Girls Night Out, Thomastown, VIC



BCNA gratefully acknowledges our partnership with Bakers Delight.



Community spirit on show

Once again, there was a flurry of Pink Lady silhouettes around the country this October (Australia's Breast Cancer Month) with more than 200 *Mini-Fields of Women* held in local communities. These displays pay special tribute to those diagnosed with breast cancer and are a powerful reminder of how breast cancer affects so many.

From Darwin in the Top End, to Blackmans Bay in the south of Tasmania, the Pink Lady silhouettes brought to life the spirit of each community. People interpreted the event to suit their area – from high teas and picnics in botanic gardens, to a stroll along the river – and helped to spread the word about the support available for women in their local area.

It was so lovely to see the 40 local businesses pinking up their windows in the week leading up to the event. It showed real community spirit!

Dahlia, Pink Sunday Woollahra

BCNA Member Groups seized the opportunity to share with women their knowledge of the services and support available, and many of the *Mini-Fields* featured BCNA Community

Liaisons sharing their personal breast cancer stories and making inspirational addresses.

More than 20,000 personal messages were written for women affected by breast cancer and their families and placed on the silhouettes.

Thank you to all the 2011 coordinators and their supporters – your enthusiasm and commitment made this year's *Mini-Fields* a success!

We acknowledge the generous support of our major partner Bakers Delight. Bakeries around Australia joined in the community events, providing delicious pastries, bread for sausage sizzles, and treats for schoolchildren. We also thank Australia Post, the sponsor of *Mini-Field of Women* events.

Last year I decided to hold a Mini-Field in my community – it had been on my bucket list for a couple of years. It was such a success that we did it all again this year – only bigger and better. After this year it is set to be a fixture in the region.

Helene, Blackwood Mini-Fields



Our gift to you

The Pink Lady sticker enclosed in this issue of *The Beacon* is our gift to you.

We hope you will display it with pride on your car or in your office window, as a symbol of your connection to our organisation and to help raise awareness of BCNA throughout your community.

The sticker works just like a car registration sticker: simply peel it off and stick it to the inside of the window. If you have tinted windows it can also be placed on the outside but may not last long in the weather.

Thank you for all your support – from the team at BCNA, we wish you all the best for 2012 and beyond.



We wish all our readers a happy, safe and healthy festive season and new year.



Pinking up the Lodge

In October, the Prime Minister's partner, Tim Mathieson, hosted a reception at the Lodge to promote the launch of BCNA's new online support group for male partners of women diagnosed with breast cancer. BCNA Deputy Chair Terry Bracks and CEO Lyn Swinburne are pictured here with the Prime Minister and Tim Mathieson. Keep an eye out in the next issue of The Beacon for more about the online support group or visit www.bcna.org.au/network. (Photo: Andrew Sikorski)

Seeking stories – Communication counts

We are seeking stories for the Winter 2012 issue of *The Beacon* about **communication**. This includes communicating with doctors, friends, family or even strangers. What sorts of things have people said to you that

have helped you? Has anyone said anything outrageous that's made you laugh or cry? Perhaps your doctor had a great bedside manner, or perhaps you changed doctors because you didn't feel understood.

Please email articles of 200–300 words (about half a page) to beacon@bcna.org.au by the end of March 2012. We ask you to include a high-resolution photo, or post your photo to us and we will scan and return it to you.

Join our mailing list

Would you like to be on the mailing list for *The Beacon* or *The Inside Story* (a supplement for women with secondary breast cancer)? To subscribe, telephone 1800 500 258 (Freecall), email beacon@bcna.org.au or visit www.bcna.org.au > Resources.



the BEACON

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If you wish to unsubscribe to *The Beacon* or *The Inside Story* please contact BCNA.

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