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Focus on:

When treatment is not the only obstacle



Different perspectives

On 10 May, I stood on the MCG as part of the Field of Women. The last time I stood on the Field of Women was in 2010 as an ambassador with my good friend Pat who had been diagnosed five years before. This year I stood there as BCNA's CEO and as a survivor, supported by my family.

As thousands of people in pink ponchos streamed into the pink lady shape, it reinforced the enormity of the event and the impact on so many lives. Young and old, friends and family, men, women and children all connected in that space and time on the G. There was a powerful feeling of mutual understanding and support. Our speakers Sherone, Sharon and Megan gave honest and brave reflections that connected with the participants and represented those who could not be there. The AFL and the Melbourne Football Club have been outstanding partners in this event and are very keen to continue their support into the future – stay tuned! Enjoy some photos from the night overleaf. Thanks to everyone who supported our annual Pink Sports Day and Pink Bun campaigns. Once again Bakers Delight rallied their Australian

photo: AFL



Field of Women 2014

bakeries to raise more than \$1 million for BCNA in an impressive display of community support. Netball, footy, hockey and pony clubs are among the 335 clubs who supported BCNA during May and, in particular, over the Mother's Day weekend. The fact that more than 100 men are diagnosed with breast cancer each year was highlighted when former NSW Premier Nick Greiner shared the story of his recent

diagnosis. BCNA member Lionel has shared his own experience in this edition of *The Beacon*, which explores a variety of challenges people face as well as their breast cancer diagnosis and treatment. Each contribution gives perspective to our own experience.

I have had the great pleasure of meeting Thuong, who shares in this issue her achievement of establishing Breast Cancer

Network Vietnam. Thuong and other women from diverse cultural and language backgrounds have been trained as BCNA Consumer Liaisons. They will support our new program that aims to help women from language groups that have the highest number of women affected by breast cancer, and those with the lowest English proficiency. The language groups are Italian, Greek, Chinese, Vietnamese and Arabic. Find out more about this program in the next edition of *The Beacon*.

Finally, you will find enclosed an invitation to donate. Please support us if you are able to so BCNA can continue to provide free programs and resources to the growing number of people affected by breast cancer.

Maxine Morand
Chief Executive Officer

Breast
Cancer
Network
Australia



A sparkling success!

On Saturday 10 May, the Pink Lady sparkled on the MCG, representing the 15,000 people who are expected to be diagnosed with breast cancer in 2014.

Thank you to everyone who stood on the ground and supported the event. We also received messages of support from many of our members who were not able to be there but stood with us in spirit.

The event was a wonderful celebration of life, and a powerful tribute to loved ones people have lost.

Special thanks to the Victorian Government and our Event Partners, and Christie Whelan Browne and the Australian Youth Choir who performed on the night. We also acknowledge the following organisations that contributed to the event's success:

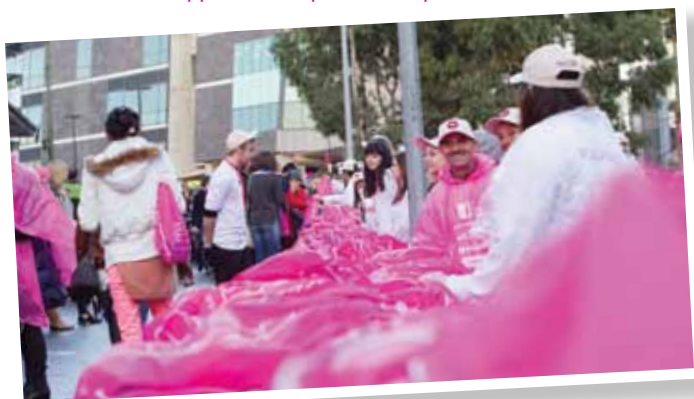
- Medibank
- BHP Billiton
- Focus on Furniture
- Jellis Craig
- Konica Minolta Australia



Such an emotional experience but standing side by side to make a difference is so empowering. – Emma



I felt the excitement, the strength, the sadness, the joy, the fear, the love, the support, the hope AND the pride! – Lee



It was a very emotional evening as I myself am receiving treatment for the disease as we speak. To stand with my two amazingly supportive and beautiful friends for such a great cause was a privilege. – Tammy



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It was my first and it was amazing. Walking onto the field with our support group as well as everyone else, was such an exhilarating experience. – Trisha



It was a fabulous event. My friend who finished her treatment about six weeks ago was moved to tears knowing so many cared about her personally and the impact of this event on herself and so many other women. – Rosemary

Thank you so much, and congratulations on a fantastic evening. I feel so certain that there must be hundreds of men 'out there' who do have breast cancer and who do nothing about it until it is possibly too late. – Mark





Issue of Concern

Breast cancer creates new challenges

While most people affected by breast cancer will face challenging times, for some people there can be very specific challenges that make their journey more difficult.

Women from diverse backgrounds

Today, one in four Australians was born overseas and approximately four million people speak a language other than English. There is a need for information and resources about cancer to be available in many languages. Women from culturally and linguistically diverse (CALD) backgrounds who speak little or no English can find it difficult to make decisions about treatment and care if resources in their preferred language are not available. It can also be challenging for women if discussions with their medical team are in English, or are not culturally appropriate.

I got information from the doctor, but it was all in English. At the Chinese Cancer Society, I got a lot of information in Chinese – so I learnt a lot about cancer.

Some women may also find it hard to talk about their breast cancer with family and friends

if cancer tends not to be spoken about openly in their community. This can make receiving information, as well as practical and social support, particularly challenging.

[People in our community] are scared to name the disease. But I can't tell myself I had the 'bad disease'. That doesn't help me. I have to say, 'I have been diagnosed with breast cancer'.

BCNA's Cultural Diversity Program is developing information resources in five languages (Italian, Greek, Chinese, Vietnamese and Arabic) to help address challenges women from CALD backgrounds may experience.

Men diagnosed with breast cancer

Each year in Australia around 125 men are diagnosed with breast cancer. They may face a number of challenges, due in large part to the lack of community awareness that men can get breast cancer.

My main concern is the general lack of knowledge that men can get breast cancer. There is a perception that it is a disease that only affects women.

Some men feel uncomfortable or self-conscious talking about their diagnosis.

For me, one of the big things was the embarrassment of having what was considered a woman's disease ... I have always considered myself a bit of a man's man, and being struck down with this at a very fit and physical point of my life was quite crushing.

The lack of information specifically for men can also be challenging.

My surgeon gave me a pile of brochures about breast cancer but only one pamphlet was about male breast cancer.

BCNA developed the booklet *Men get breast cancer too* to help support men with breast cancer. To download or order a copy, visit www.bcna.org.au > News > Resources > Fact sheets and booklets.

Women in same sex relationships

Women in same sex relationships have told us about difficulties they face because of their sexuality.

When I went to see my new oncologist, my partner was shunned completely. It was as if she wasn't even in the room. Every time she asked a question, the oncologist looked at me, but did not acknowledge her.

Some women are concerned about discussing their sexuality with their medical team if they are unsure about the team's attitudes. It is important to see health professionals with whom you feel comfortable, and who respect your privacy, relationship and your partner's involvement. If you are not happy with your medical team, you can ask your specialist or GP for a referral to someone else.

For information about support for lesbian women, visit www.bcna.org.au > News > Resources > Reviews – books and other resources > Resources for lesbians.

Ask the Expert

Associate Professor Jane Turner

Jane Turner is Associate Professor in Psychiatry at the University of Queensland and has been caring for people with cancer for 25 years. Her research interests include the impact of cancer on patients, their families and, in particular, young children.

What are the main issues for young women with breast cancer?

Firstly, the injustice of it all. Breast cancer is a disease of the ageing, so a diagnosis causes shock and even rage in younger women.

Fertility is another key issue. Women respond in different ways when they become infertile; some are okay, while others are devastated. Even women who do not plan on having more children may grieve. This can contribute to their loss of 'self'.

Women with young children face the challenge of talking to them about breast cancer. Children may express their emotions in different ways, from behaving badly to putting on a brave face. It's best to talk openly with them, in an age-appropriate way. Make it clear that the cancer is not their fault, and reassure them that someone will be there to take care of them. The Cancer Council NSW has a great booklet that explains ways to talk with children about cancer.

Young single women can face challenges with new

relationships. It's difficult enough to meet new people, but they must decide when to share their breast cancer diagnosis with a potential partner. The timing of this is a complex issue and there are no right answers.

Body image concerns can also be a major issue. Some worry about the appearance of their chest or find hair loss distressing because it's so public. Younger women tend to put on and keep on more weight than older women.

Younger women diagnosed with breast cancer are also at higher risk of experiencing depression than older women. This is especially so if they have dependent children, are experiencing financial strain, have a past history of depression, or are experiencing relationship problems.

Chemo brain can be particularly disabling for younger women who are juggling multiple roles, such as employment, looking after children, managing finances and running the household.

What are some ways young women can manage their concerns?

Seek information – this can be very empowering – and seek support from others, including health professionals, family members, friends, or a support group. It is important to be clear about the support you need.



Jane Turner

It is also critical to be comfortable with your medical team. If you are unhappy with an aspect of your care, speak with the relevant health professional. If it is not addressed, find another one. You may feel intimidated by this, or worry that your treatment will be compromised; however, it is your right to feel comfortable.

There's also very good evidence to show that talking about your feelings is very helpful, either with a friend or family member or with a counsellor.

What can family and friends do to support young women?

Ask what matters to them. What can you do to help, either practically or by just being there to listen? Some women worry about being a burden. However, accepting help from others will make them feel good.

Don't underestimate the value of just being there to listen. It's often difficult for women to find someone who will give them the space to talk about the 'what ifs'. Women are often reassured by others when sharing their concerns, but it is important for them to be heard and acknowledged. Simply listening without trying to reassure them can be very helpful.

Which health professionals can help?

When it comes to emotional wellbeing, it can be difficult to access counsellors, psychologists and social workers in the private health system. Your GP can refer you to someone suitable who can provide different types of therapy, practical strategies to help you cope, and antidepressants if required. Women treated in the public health system may have better access to counselling services.

If you could give a young woman one piece of advice, what would it be?

Be selfish! Women have a low sense of personal entitlement in general and can be reluctant to put themselves first. Think about what *you* need and be prepared to talk to people about your feelings. And remember that people can't read your mind. Tell them what you need.

When breast cancer isn't the only illness

The two greatest risk factors for breast cancer are being a woman and getting older. Breast cancer is mostly a disease of older women, with 60 being the average age of diagnosis.

Some women diagnosed with breast cancer will already be living with other chronic health conditions, such as diabetes, a heart condition, arthritis, osteoporosis or depression.

In some cases, breast cancer and its treatments can result in new health problems – for example, lymphoedema, depression, or peripheral neuropathy (pain and numbness in the hands and feet).

Living with a chronic health problem in addition to breast cancer can be physically, emotionally and financially challenging.

I had an underlying medical condition (rheumatoid arthritis) that I hadn't had any issues with before breast cancer. However, it has flared like an angry animal now and my medical team is finding it hard to control.

– Sherry

If you have been newly diagnosed with breast cancer and are living with other health problems, this will be taken into account by your treating doctors.

They will consider your current health and any medications you are taking when planning your breast cancer treatment.

If you have an ongoing medical issue that began before or as a result of your breast cancer treatment, your GP can tell you if you qualify for a chronic disease management plan. These aim to support your overall health care needs, by putting in place a plan to provide you with access to a range of health professionals to support you.

In consultation with you, your GP can develop a written plan that will identify all your health

care needs. If you need to see an allied health professional such as a physiotherapist, psychologist, dietitian, osteopath or exercise physiologist, the plan will provide Medicare rebates for up to five consultations each year.

If you are experiencing anxiety or depression, your doctor can also create a mental health treatment plan for you, which allows you to up to 10 Medicare-subsidised appointments with a clinical psychologist, specialist GP, social worker or clinical occupational therapist.

Your GP can tell you more about these two plans.

BCNA: working on behalf of our members

Policy and advocacy is an important part of BCNA's focus. We work to help improve outcomes for Australians affected by breast cancer.

This year, we have provided five submissions in support of new breast cancer treatments and tests.

Three submissions were made to the Medical Services Advisory Committee (MSAC), which makes recommendations on treatments and tests to be listed on the Medicare Benefits Schedule. This means that people having those procedures can receive a Medicare rebate for them.

The new items MSAC is considering are:

- Breast MRIs for a range of purposes

- Intraoperative radiotherapy for low-risk early breast cancers
- PET scans to assist in staging of locally advanced and secondary breast cancer.

MSAC is also currently considering an application to extend the Medicare rebate for breast MRI to women under the age of 50 who have been diagnosed with breast cancer.

We have also provided submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) in support of two new drugs used to treat HER2-positive secondary breast cancer, Kadcyla and Perjeta.

We often hear from our members about the high financial cost

of breast cancer, particularly for women having treatment in the private health system. In May, we made a submission to a federal parliamentary inquiry investigating the out-of-pocket costs of health care in Australia.

BCNA's submissions are available on our website, www.bcna.org.au > About BCNA > Advocacy > Submissions and reviews. We will update the website with the outcomes when they are known.

In March, BCNA participated in a two-day meeting hosted by the Cancer Drugs Alliance to discuss how new cancer drugs can be made available more affordably and quickly. The meeting included key cancer clinicians and representatives from cancer consumer organisations, the

Department of Health, the PBAC and pharmaceutical companies. Speakers from the UK and Canada spoke about how their countries make new drugs available, and a series of workshops discussed ways Australia could move forward in this area. The consumer representatives called for greater input from consumers into the PBAC process.

Breast cancer opens another beautiful page of my life

My journey with breast cancer has been more than a year with two lumpectomies and an upcoming double mastectomy, but the first week after receiving my secondary breast cancer diagnosis I wanted to commit suicide many times.

Cancer was actually like a vandal to me. I just turned 30 and I was excitedly waiting for a dream wedding with a man I loved after four years together. I had a job I loved as a lecturer at the Faculty of Journalism and Communication of Vietnam National University.

The cancer came and brought a mountain of fear and distress over my soul and my thoughts. I could not sleep at nights, kept crying and imagining awful things coming to myself and my loved ones. I did not fear cancer by itself. I was terrified of how cancer could affect my present and my future.

My wedding could be cancelled and never happen. It was impossible for me to carry out my work plan. I worked so hard for almost 10 years but I earned just enough to live in Hanoi and support my family a bit. My very little savings were intended to use for the wedding and a family's start up was now straight to cover some initial treatment cost. My family could not afford my treatments and I was sure I would become a burden for everyone who loved me.



Thuong

Ten years before my diagnosis, I spent all my spare time organising charity events that provided support, both physical and financial, for women and children living with cancer and HIV-AIDS. However, I did not know anything about breast cancer. Now I believed that I was going to die very soon, every beautiful thing I dreamed about and I was doing would terminate. Life was not fair to me at all, I was depressed and blamed myself for being diagnosed with cancer.

Fortunately, there was no suicide. When the cancer squeezed me almost to the end, all my friends and co-workers, students, my former co-workers and many strangers gathered and raised more than \$10,000 to indicate how they wanted to save my life. All my family,

my fiancé and his family gave me endless love and support. I got brilliant breast cancer care from Brisbane Mater hospital, Queensland Cancer Council and Breast Cancer Network Australia. I was thrilled and empowered by stunning love from people around and what I had received. My thoughts were unlocked and I realised that thousands of Vietnamese women were much less fortunate than me; they were fighting cancer without support, without knowing anything about the disease and were very lonely. They got ready to die when being diagnosed with cancer and gave up in first steps of their journeys.

Throughout my examination about how Breast Cancer Network Australia (BCNA) started and what they had

done, a fierce desire appeared in my heart that all Vietnamese women diagnosed with breast cancer would have an improved quality of life and would be strengthened to fight cancer to the best.

I established Breast Cancer Network Vietnam (BCNV) on 3 March 2013 in spite of a wide range of challenges about my own health, financial condition and barriers of Vietnamese culture and policy. BCNV is more than one year old now and has brought certain changes in terms of breast cancer support and awareness. You can see what BCNV has done at www.bcnv.org.vn/en.

Breast cancer has made me realise how much I am loved and supported. The disease has turned my life into a new life-direction and I intimately know that it is a full and rewarding life.

Thuong

QLD and Hanoi, Vietnam

To read Thuong's story in Vietnamese, visit www.bcna.org.au.

Finding my own way

I was diagnosed with breast cancer in December 2012 at age 47. My treatment experience has been similar to that of other women, but it also has been different because of additional challenges that arose because of my blindness.

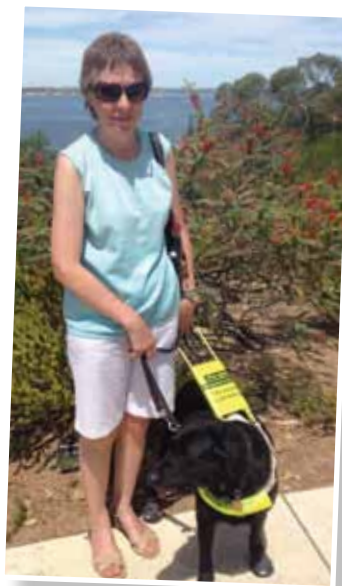
I required relatives to read to me the considerable amount of printed resource material which, if it had all been available online, I could have browsed independently. Furthermore, although I was initially pleased to receive BCNA's Pilates DVD, thinking it would be easy for me to follow, I was disappointed as it provided insufficient verbal description so I had to pay a physiotherapist to show me the post-surgery exercises.

I also gave up in frustration trying to participate in the

Breast Cancer Care WA online support group because the website's technical design wasn't compatible with my computer's screen reading software.

I needed help from relatives to simply find clinics and doctors' rooms. Usually, as part of being independent, I learn routes beforehand and then go by myself to appointments, but treatment and working left me with little energy and time to do this.

The treatment team showed me great consideration. However, there were instances when I had to correct assumptions made about my capabilities and assertively encourage some flexibility with the way things were usually done. For example, my surgeon had to describe and physically show me the



Rachel

procedure instead of drawing diagrams for a relative, and hospital staff needed to call me up by name as I couldn't use the queuing system.

At a general level, I felt connected with other diagnosed women and I knew I wasn't on my own, but at the same time I also have felt quite alone because I haven't met or read about anyone else facing these disability-related challenges.

My experience was certainly made easier by all the practical help I received from my support network, but other blind women may not be so fortunate. Having accessible information and services as well as staff familiar with the needs and abilities of women with disabilities will go a long way towards providing us with better care.

Rachel, WA

Not just breast cancer

In 2007 I was diagnosed with diffuse scleroderma, which is a disease of the body's connective tissue. The most common symptom is a thickening and hardening of the skin, particularly of the hands and face but also of the internal organs. There is no cure but the symptoms can be managed.

Things progressed quite rapidly with the skin thickening and then scleroderma renal failure.

Then two years later my left breast started to swell and became tender. A mammogram showed inflammatory breast cancer. This is a rare form of invasive breast cancer that

affects the lymphatic vessels in the skin of the breast.

So how did my scleroderma affect treatment choices?

The breast surgeon and the oncologist came up with a treatment plan that started with chemo to decrease the breast swelling. This was followed by a mastectomy, but with no chance of a reconstruction because of the scleroderma. Also they had a lot of trouble accessing my veins due to my tight skin, so I had a port inserted at the same time. My medications were adjusted to stop the scleroderma flaring up. A second round of chemo and then radiation followed,

though only after a great deal of research, as my doctors were concerned about the radiation causing more skin thickening. Extra vitamins and creams are required. I had my mastectomy scar and chest wall massaged twice a month for 12 months to try and stop any tightening of the skin occurring.

So how am I today?

So far my chest skin has not thickened anymore, my cancer is still in remission and my scleroderma is stable. It's still early days, with side effects from the radiation, and the doctors will not take my port out for



Cheryl

five years. I make sure I stretch and exercise to keep my chest wall moveable, and my general health has improved over the years.

Cheryl, NSW

Breast cancer from an autistic perspective

I went through breast cancer treatment in 2011 at the age of 47. As a person with autism the process was a bit different for me. I was diagnosed with autism when I was 2 and am one of the luckier ones in that I am now quite 'high functioning'. I've come a very long way but I'm still quite severely 'face blind', have language processing and visual perceptual disorder and I struggle to process on several sensory channels at once so I keep losing track. I'm also immune deficient and have a genetic collagen disorder, so when it came to chemo my body was behaving like a three-ring circus.

My autism affects everything. In spite of this, I made friends, lived independently, became a teacher, a published author, an



Donna

international public speaker and a respected autism consultant and married a wonderful person – Chris – who I've been with now for 14 years. Cancer put a sharp bend in our road. I still have some involvement with the autism world, but cancer changed so much in my life, most of it positively.

Experiences I had to make autistic sense of included: the mammogram experience, getting the news from my GP, a biopsy in a dark room with machines and body invasion, visually navigating the hospital, MRI machines, meeting new specialists, being expected to stay in hospital, two mastectomies, the chemo suite, severe autonomic dysfunctions and chemo brain ... all on top of my autism challenges. What a party!

I feel my autism did me great favours in coming to terms with cancer and cancer treatment with a degree of logic and decision making that perhaps I'd not have had if I were not autistic.

My GP and specialists are used to me arriving with lists (otherwise

I struggle to track my speech or know what I've asked) and they are all great with it.

And this may all sound pretty normal to most folks, but when I was a kid I couldn't be physically handled. It's only been since my 40s that I easily handle strangers initiating communication with me. So although I know my specialists are lovely people, I know I'm still 'odd' when I see them, I do feel the social awkwardness of that, but I can't do anything about it. I hope they know how grateful I am for all they do, their commitment to their profession, to people with cancer, and the accommodations they make for each patient, including me.

Donna, VIC

A different type of diagnosis

I was diagnosed with a rare triple negative breast cancer back in 2010. I found during my journey that there was not much information about this sort of breast cancer. This made it even scarier for me. Only about 15 per cent of breast cancer diagnoses in Australia are triple negative. Talking to my oncologist about my cancer was very upsetting, but to come away and not be able to find out much about it made me feel very isolated. I joined a support group but found out that didn't work because most women spoke about hormonal breast cancer.

I was different.

I went on a medical trial for eight months during my journey to help with more research.

I have now just had a right hip replacement, which was a throw-back from my treatment.

I am now in my third year clear of my cancer with six months of oncology check-ups ahead.

Janet, NSW



Janet

Finding a sense of belonging

My husband and I came to Australia six years ago, so when I was diagnosed with breast cancer last year one of the first things I thought was, 'All our family and long-term friends are in the Netherlands'. We don't have the same level of support here, so when the surgeon asked whether I would like to meet a breast care nurse I said, 'Yes please!'

She gave me a lot of information but also encouraged me to check out local support groups, which I did. A week and a half after my lumpectomy I sat in a dragon boat and paddled along with a heap of unfamiliar men and women, but they were very



Jacqueline with her husband

kind. I also started going to the local support group meetings but still, I felt very lonely.

In the meantime there seemed no end to the bad news for

several weeks, and I had to gear up for a much tougher fight than first anticipated. What made it worse was the loneliness I felt. Apart from my husband there was no family to hug and cry with. There were no meals being cooked, not many offers for practical help. Some friends really let me down, but some acquaintances stepped up unbelievably. Still, on days when I was alone, I cried so much.

It took a while before I got to know people better. When I started radiation therapy someone offered to take me once a week. That gave me the courage to ask others to take me every now and then so it

wouldn't be such a lonely trip.

I recently finished all my treatment, and am now recovering from the side effects. I'm starting to make new friends; amazing women who have gone through the same ordeal. Some have made inspiring changes in their lives, others are just trying to enjoy every new day. They're taking me by the hand and keep ringing, texting, staying in touch, meeting for coffee.

I hope that this hard, scary and lonely journey will result in me beating breast cancer, but I wonder ... could it also be a journey towards belonging?

Jacqueline, NSW

Healthy body, healthy mind

I thought it would be a lot easier being a young breast cancer patient. I was fit and healthy when diagnosed at 32, and in the best possible shape to take on the battle. I didn't feel sick; I didn't look sick. The problem I had – and I use the word 'problem' very loosely – was I couldn't relate to the majority of resources available.

Continuing to remain active was going to be how I remained positive and charged through treatment.

Before my diagnosis I was training and racing triathlons. I knew I'd have to be patient with recovery and getting back to my normal life, but five weeks after

my lumpectomy, I had itchy feet. The BCNA DVD 'Strengthen Your Recovery' was perfect in the initial weeks, but I felt that I breezed through the movements and was ready for something else.

I spent hours on the Internet trying to see what other peoples' experiences had been with recovery times and training through treatment. I stumbled across two inspiring stories, including a woman who continued to train for Ironman! For someone whose dream it is to compete in an Ironman event, there was finally a glimmer of hope.

After this I was eager to meet with my physiotherapist. I stuck



photo: Man Cheung

Rochelle

to their recommendations and followed the six-week recovery program for the upper body. I did, however, like to prove to

anyone willing to listen, that I had my full range of movement back. I was often seen randomly swinging my arms in the air!

Through chemotherapy, I continued to run and train when I felt I had the energy. I listened to my body and adjusted the distances or intensity. The biggest advice I can give anyone who is young and fit and faced with this challenge is: everyone is different. Seek advice from the medical professionals then find what works for you; you know your limits.

Rochelle, QLD

Opening up about a closed subject

I am BCNA's first Aboriginal Community Liaison. My people are very shy and won't talk about breast or ovarian cancer or anything like that. We call the parts of our body different names even from other dialects and it's just a closed subject. But after I was diagnosed with breast cancer I had to make it more open and talk about it in our yarning circle. In our culture all women sit in a circle and we have a talking stick and that's how it started me talking about breast cancer with other women. When I was diagnosed I said, 'It's only cancer – I'm not going to die from it' but I was very shocked. I talked to Mother Earth and asked 'why me?' I was really angry but decided that I had

the strength and will to fight it. The treatment was really intense and it was hard. There was nobody who was Aboriginal in the hospital who knew anything about breast cancer or about my culture or my heritage so I was lonely not having any friends or family around to support me or explain things.

Now I'm doing well and I advise all the women in my community and in rural areas of the benefits of early detection and I encourage them to have mammograms and to keep a check on their boobs – we call them yamman. Anything to do with my yamman I now will go to my doctor straightaway. I tell the women that early detection can save lives. They



Aunty Marg with Raelene Boyle

have to learn not to be ashamed or embarrassed. That's the best message I can get out to the women in our community. Don't use that word 'shame'; knock it off your shoulder.

I now travel a lot around Queensland. Aboriginal women are now coming forward and asking me to tell them about breast cancer and what sort of journey I had and what might happen to them. I hope there will be more Aboriginal liaisons with BCNA. Aboriginal women need to see another black face in hospital – just having Aboriginal support services can make you feel 100 per cent better.

I now use the phrase 'black, bold and beautiful'. I now have a voice in my journey, and sharing and caring are the best things we can share with other women.

Aunty Marg, QLD

Not a vasectomy, a mastectomy!

I was having a routine check-up in 2003 with a surgeon who had recently operated on my appendix. I mentioned to him about the lump behind my right nipple and he sent me off for a mammogram which I found out was a bit difficult/ impossible for a male when I went to get it done. I got some funny looks from the staff at the radiology department. Ultimately, they settled on an ultrasound and core biopsy. Two days later I received the results. A huge weight was put on me as a father of two very young children. It could have been worse

I suppose; it could have been their mum. I saw the breast surgeon and had a mastectomy. Goodbye right man boob!

I spent the next week in hospital, which surprised friends as they assumed that Linda, my partner, was mistaken in telling them I had had a mastectomy and that I had actually had a vasectomy!

I never felt sorry for myself; someone is always worse off somewhere, but I have tried to raise awareness that men get breast cancer too. Eighteen weeks of chemo and five weeks of radiotherapy is a life

experience that allows you to understand what others are going through. I have been approached by those about to undergo treatment and I can share the positive experience I had and hopefully ease their fears or dispel certain myths.

One of the nice things that happens every year at our local Bakers Delight is they modify a pink lady into a pink man and they have a spot for it in the centre of the others.

Lionel, VIC



Lionel with his daughter

Realising my most fragile dream

As I look down at my large belly I can see and feel our baby kicking, reminding me constantly that he is in there. I am 28 weeks pregnant. Not long to go now. Getting to this point has been a long and intense experience.

In 2006, at the age of 23, I was diagnosed with breast cancer. At the time, my ongoing fertility was certainly not at the forefront of my or my doctors' minds. I didn't even know that chemotherapy affected fertility. I learnt that egg freezing before chemotherapy was not an option for me; my cancer was aggressive and had spread.

A year or so after chemotherapy, I agitated to undergo treatment to freeze my eggs. After two years on Tamoxifen, I was allowed to go ahead with two rounds of egg freezing and boy did they go badly. It became apparent that my ovarian function was extremely poor. I was devastated,

but also so happy that I had done it. This experience was just as hard, if not harder, than treatment. I was young and scared, in my first year as a lawyer, trying to plan my future, and most of all, trying to control something I really could not.

In August 2012 I finally came off Tamoxifen. The pressure was then on. I needed to start trying to have a child as soon as possible. I was single and 29 years old. Blood tests showed my fertility was extremely poor. I was confused and anxious about what to do.

As it turned out, I met a wonderful man and fell in love late that year. Within six weeks of our new relationship I cried and told him everything about having cancer and the possibility that I could not have children but that I desperately wanted to try, and soon. His reaction was

nothing short of amazing. He was 100 per cent supportive and understanding. In September the following year, after trying to conceive naturally for some time, we bit the bullet and started IVF. I found it harder to undergo this treatment in 2013 with a partner than in 2009 on my own – I felt guilty we had to go through it. I felt a weight on my shoulders that I had never carried before.

I then had some medical luck – not something I was accustomed to. Our first round of IVF worked.

I fear that IVF treatment or pregnancy may encourage a recurrence of my cancer. I can do nothing much but hope this does not happen.

As we eagerly await the arrival of our son I cannot help but think of the whole thing as a miracle. Getting pregnant and having a baby was the greatest and most distressing challenge



Nikki

I experienced following my cancer treatment. I am incredibly grateful to my doctors and happy that IVF worked for us. I thank my lucky stars every day.

Nikki, WA

Our Strategic Advisory Group

BCNA's Strategic Advisory Group was established in 2012 to help inform and support our work, particularly the important advocacy work we undertake on behalf of women and men and their families.

The group includes 14 health professionals who work in a wide range of cancer-related fields. Many of them also represent key medical or cancer organisations.

The group helps BCNA by:

- informing our policy, research and advocacy focus
- assisting in the development and updating of our resources

- linking us with relevant medical and scientific organisations
- bringing to our attention any issues affecting women and men with breast cancer
- working with us to determine issues affecting women and men and develop appropriate responses or strategies
- assisting with the implementation and promotion of our programs and resources
- presenting at international forums.

Membership of the Strategic Advisory Group is honorary

and members give their time and expertise to help us work together to continue to improve treatment and care for people with breast cancer.

- Ms Elisabeth Black, Breast Care Nurse
- Professor Fran Boyle, Medical Oncologist
- Professor Phyllis Butow, Psychologist
- Dr Mustafa Khasraw, Medical Oncologist
- Professor Bogda Koczwara, Medical Oncologist
- Dr Gillian Lamoury, Radiation Oncologist

- Dr Helen Frazer, Radiologist
- Dr Vivienne Milch, General Practitioner
- Dr Chris Pyke, Breast, Endocrine and General Surgeon
- Associate Professor Wendy Raymond, Pathologist
- Associate Professor Andrew Spillane, Surgical Oncologist
- Professor Christobel Saunders, Surgical Oncologist
- Dr Julie Thompson, General Practitioner
- Associate Professor Jane Turner, Psychiatrist



Profiling our Member Groups

Great Lakes Breast Cancer Support Group

Great Lakes Breast Cancer Support Group was established in 2007. Heather Kelly, group facilitator, shares some of the ways the group supports women in the local community.

When we formed Breast Friends in 2007, we quickly established a group agreement, put together a committee, chose our name and adopted our logo.

We meet once a month of an evening at our local bowling club with an average attendance of 20 women. We often invite guest speakers on topics relating to cancer issues and wellness. Our members range from 50 to 80 years of age and are at all stages of treatment, some more than 12 years on from their breast cancer diagnosis. We also meet informally once a month for a social coffee morning chat at local venues.

We produce a newsletter that we send to our mailing list of more than 110 members of our group and local medical professionals. We have a close working relationship with our local breast care nurse and oncologist.

Our main objective is to be a support group. We hold an annual fundraising raffle, which is drawn at our Mini-Field of Women in October. The amount raised covers our very basic yearly running costs. However, we have been fortunate to receive regular cash donations from local community groups and

businesses that have allowed us to meet other expenses.

Each year we set up a stall for the Pink Bun promotion at our local Bakers Delight and assist in selling pink buns and raising funds for BCNA, while at the same time raising awareness for our group. We have developed a friendly relationship with the owners of Bakers Delight and they attend the luncheon we hold following our Mini-Field of Women planting ceremony as our invited guests.

A few years ago we were fortunate to have a local TAFE teacher donate his services to design and build our website www.breastfriends.org.au.

We have put together a library of breast cancer resources including books, DVDs, booklets, and so on, in a special bookshelf at our local private hospital, available for borrowing free of charge.

Last year we produced a printed colour brochure to advertise our

group and we have distributed this to all local hospitals, doctor's surgeries, pharmacies, pathology rooms, etc.

One of our major projects is to produce satin cushions with matching drainage bags for the hospitals to distribute to women undergoing mastectomies. We also make drawstring gift bags (containing a coffee mug, handmade soap and knitted washer) which we pass on to women who we hear are newly diagnosed and undergoing treatment. We attach a small card featuring our logo with the message: 'To show we care'.

We have a solid core of women within our group who have taken ownership of Breast Friends and are keen to assist in any way they can. We have lots of laughs together and feel strongly the bond that we share having all been through the breast cancer journey.



Great Lakes Breast Cancer Support Group at their annual Mini-Field of Women



Connecting people

A key part of BCNA's mission is to connect Australians personally affected by breast cancer. We welcome new Member Groups to our network. They now total 310.

New Member Groups:

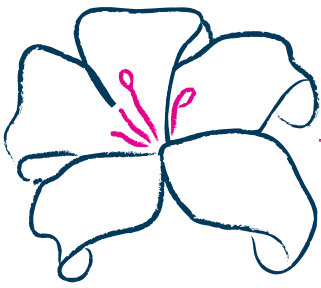
- Pink Connections – Mona Vale, NSW
- Living Well – Whatever your circumstances, Burwood East, VIC
- Sutherland Shire Breast Cancer Support Group, NSW

To find a group in your state or territory visit www.bcna.org.au > Sharing & support > Find a support group in your area.

If you can't find a face-to-face support group in your area, consider joining our online network and connecting with one of our online support groups. We have more than 130 topic-based groups, including:

- Breast reconstruction
- Inflammatory breast cancer
- Living with secondary breast cancer
- Men diagnosed with breast cancer
- Partner support
- Recipes you can taste
- Supporting a parent
- Triple negative breast cancer
- Young women.

For more information, visit www.bcna.org.au > Network, or phone 1800 500 258.



Thank you

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

- Ballarat and District Trotting Club – Steve Salter, VIC
- Bei's Booby Bazaar – Rebecca Jones, Terri Tholstrup and Deb Shearer, WA
- Bevan Brunckhorst, NSW
- Caroline Brown, QLD
- Cathy Norton, ACT
- Emily Stothers, VIC
- Faith Holbourn, SA
- Georgia Buist, NSW
- Headworx Hair Design – Kyra Harding, SA
- Home in the Hamptons – Julie Nikolovski, VIC
- Horsham Golf Club – Julie Obst, VIC
- Jeffrey Fung, NSW
- Kingswood Golf Club
- Lai Peng Endeavour Hills, VIC
- Landmark Operations Ltd, VIC
- Leigh Park, QLD
- Leopold Primary School – Tammy McDonald, VIC
- Liz Edmonds, NSW
- Louise Gellatly, WA
- Melba Hyne, QLD
- Melbourne North Police Station – Ashlie Patterson, VIC
- Mel Wainwright, VIC
- Natalie Jalkanen, VIC
- Ocean Grove/ Barwon Heads Breast Cancer Support Group – Julie Rodger, VIC
- OPC IT – Cathy Norton, ACT
- Oakes Family, NSW
- Plenty Parklands Primary School, VIC
- Royal Motor Yacht Club, NSW
- Shannon Cross, VIC
- Vicki Watts, WA
- Yarra Valley Country Club – Denis Littleford, VIC

Celebrations

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

- Dorothy & Sam Fletcher
- Carol Hutchison
- Debbie Lee
- Maria Rebarbas
- Rebecca Siri
- George Stavrianos

Memorials

We pay tribute to the lives of:

- Veronica Hamilton
- Iris Estelle Hughes
- Lovonne Hunter
- Jeanette Judd
- Rosalie Milne
- Deanne Walker

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

Skechers help you get walking

We are thrilled to announce a new partnership with Skechers Australia, with the launch of a great range of very hot pink BCNA Go Walk shoes.

If ever we needed a perfect excuse to get moving these are it! \$2 from every pair of Hot Pink Go Walk 2 Skechers purchased at Myer or through Skecher stores will be donated to BCNA.

Our team at BCNA are decked out in the shoes for all our events and we have even been inspired to start a walking group twice

a week. We can guarantee they are comfortable, light and look great!

For more information about the Skechers partnership or where to purchase visit <http://www.skechers.com.au/stockists.html>.

We are looking forward to a long partnership with the Skechers team.



The power of pink buns

Thank you once again for allowing us to 'pink up' our bakery. We have had our best support ever which makes us smile! – Bakers Delight, Noosa, QLD

Each year the Pink Bun campaign gains momentum, and 2014 has been no exception. Bakeries around Australia turned pink again to raise money for BCNA.

The campaign is not just about selling sweet pink buns. Over the last 10 years, pink buns have become a powerful symbol of support that unites each bakery with their customers and the broader community. Every dollar raised from the sale of pink buns and paper Pink Ladies comes directly to BCNA. Without this generous support we could not have achieved as much as we have.

Some stores help local support groups throughout the year.

We often hear about stores generously donating bakery goods to a family in need or to a support group holding a Mini-Field of Women.

It is our pleasure to help such a great cause and we make the pink buns every day with love. – Bakers Delight, Carnegie, VIC

Thanks so much for your association with BD – it's a wonderful and touching time of year in our bakery for both our staff and our customers. – Bakers Delight, Karratha, WA

We would like to thank all of the BCNA members and Member Groups who supported Pink Bun – your commitment and enthusiasm is a great way to strengthen our connection with local communities and help promote a very special partnership.



BCNA member and Community Liaison, Sue, with her family

We hope that you feel proud of this special partnership when you walk past a Bakers Delight store in your community.

It provides a wonderful opportunity for me to connect one on one with these women, men and children to share their experiences and feelings. Every time someone buys a pink

bun I feel like they have given me a warm hug! Vicki – BCNA Member, WA

As this issue of *The Beacon* goes to print, we are still counting the funds raised. Keep your eye on the website for our final fundraising total, and check out the photos at www.bcna.org.au.

Sussan and BCNA – a partnership to be proud of

The very first Field of Women in 2005 sparked a partnership between two organisations – BCNA and Sussan – where women are at the very heart of every decision we make.

We are proud that our Sussan BCNA partnership continues to grow, eight years later. We hope you enjoyed the beautiful BCNA merchandise instore this May.

From cards to bracelets and other gifts, there are so many ways Sussan customers are supporting BCNA.

We were delighted to once again have the Sussan team join us on the Field of Women this year. So what is the secret to our partnership success – everyone from Sussan head office to store managers, staff and customers

believe in helping us to support all Australians affected by breast cancer.

So next time you walk past a Sussan store – step in and thank them for their contribution. It makes such a difference to hear directly from the women they are helping to support.



Bakers Delight
We're for real.

BCNA gratefully acknowledges our partnership with Bakers Delight.

Bakers Delight
We're for real.

The power of paddling

Dragons Abreast Australia (DAA) encourages wellness, fitness, fun and camaraderie for breast cancer survivors through the sport of dragon boating. It is a leader in the movement for people affected by breast cancer; spreading awareness, empowering individuals and educating on the benefits of an active lifestyle after diagnosis.

There are Dragons Abreast groups around the country, so if you have finished your treatment and are looking to get a little fitter, have fun and make new friends, then Dragons Abreast might just be right for you!

DAA's philosophy is *Awareness, Participation and Inclusiveness*, and it welcomes breast cancer survivors of all ages, backgrounds, athletic abilities and interests. Members tend to be fun-loving positive women who really enjoy life and the experience of dragon boating with a Dragons Abreast group, whether it be a gentle paddle on the local waterway, or a chance to race in a regatta.

DAA has some exciting events coming up this year – such as the international breast cancer survivors' regatta in Florida where a number of its members are participating with more than



photo: Steve Taylor

Dragons Abreast ACT on Lake Burley Griffin

2000 breast cancer survivors from around the world. Also the Dragons Abreast Festival, its major fundraiser for corporate teams, will be held on 11 October 2014 at Penrith.

If you would like to know more about Dragons Abreast,

whether to come and try with your local group or how to start a group in your own area, please contact DAA via email office@dragonabreast.org.au or phone 1800 899 566. To find a group near you visit www.dragonsabreast.com.au.



BCNA CEO Maxine Morand (front) enjoying dragon boating recently with the Melbourne DAMBusters.

Seeking stories – Getting off the couch

We are seeking stories for the Summer 2014 issue of *The Beacon* about what motivates you to move. What stops you doing the things you want to do? What sort of advice would

you give to others who may be struggling to return to a sense of normality?

The stories should be about half a page long (200–300 words) and can be posted to BCNA,

293 Camberwell Road, Camberwell 3124 or emailed to beacon@bcna.org.au by the end of September 2014. Please also include a high-resolution photo.

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, email beacon@bcna.org.au or visit www.bcna.org.au > Resources.



the BEACON

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