Finding the strength within

We all want our lives to go from strength to strength, but sometimes it can feel like life’s not moving forward or in the direction we want it to go. Our lives can vary from tough, unhappy days and a long, uphill battle to a soaring sense of achievement or enjoyment of a moment or experience. Our lives are impacted by so many events outside of our control. Breast cancer is just one of those.

Stories from our members in this issue of The Beacon tell us that strength is found from many different sources and sometimes it is really hard to find the necessary strength to face what lies ahead.

In the last issue of The Beacon a story from Leanne resonated strongly with many readers because Leanne had the strength and honesty to share how difficult she’s found her breast cancer diagnosis and treatment outcomes. Clearly, she is not alone. We had feedback from readers saying how important it was to share a balance of experiences from our members. We need to acknowledge that not everyone can run a marathon, or have fabulous friends and family, find new levels of fitness, or make drastic changes to their lives in general. The experience of illness and cancer is as diverse as the disease, and at BCNA we want to help in any way we can in responding to this experience. We know that hearing about the experiences of others is a great help, which is one of the main reasons we produce The Beacon.

This year BCNA celebrates our 15 years as an organisation helping Australians affected by breast cancer. This is a significant milestone that allows us to reflect on how our organisation has gone from strength to strength. Started by Lyn Swinburne at her kitchen table, in 1998 we became an organisation that now has 77,000 members and more than 300 Member Groups. We have 34 dedicated staff and 40 volunteers, 70 Consumer Representatives and 228 Community Liaisons. We strive to keep evolving and responding to change so that we can continue to do our very best to support Australians with breast cancer.

We could not have achieved our success without the support of our major sponsors. This year we also celebrate 13 years of partnership with Bakers Delight— a collaboration that has also gone from strength to strength over time, with an aim to raise over $1 million this year. Our 15 years will be celebrated in various ways throughout the year. I am really pleased to announce that celebrations will include a Field of Women in Sydney on Saturday 10 August. This will be our fourth Field of Women and we aim to have 15,000 people on the ground at the ANZ Stadium to represent the number of people who will be diagnosed with breast cancer this year. I experienced my first Field in 2010 before I was diagnosed with breast cancer a year later, and I found the event an incredible and powerful experience. I encourage you to try and find a way to get there, especially if you live in Sydney! I promise it will be an event that you will never forget.

Maxine Morand
Chief Executive Officer
Letters to the editor

Sharing stories from the heart

In the last issue of The Beacon we included a story from Leanne in WA who shared that she felt she must be the only woman not coping well when she read about the positive experiences of other breast cancer survivors. While BCNA strives to support those who do not have access to the best treatment or services, who do not have the support of family and friends, and who may not be coping well with their diagnosis, these are stories we rarely receive for The Beacon. People often share their uplifting experiences because they want to inspire and provide hope to other women. Fearing that she would bring others down, Leanne hesitated to share her story. Instead she found that many women felt the same way and now feel better knowing that they are not alone. It takes strength and courage to write as Leanne did and we are glad she shared her story.

If you feel like you are not coping, you may like to speak to your GP, phone the Cancer Council Helpline on 13 11 20, or visit BCNA’s website www.bcna.org.au to find a support group near you or connect with others on our Online Network.

Here are some of the responses from readers around the country who related to Leanne’s experience and sentiments.

“I want to agree with the letter from Leanne in the latest BCNA mag. 100%. Thanks Leanne for sharing your heart. I too struggle daily four years down the track.”

– Pamela, NSW

“A big thumbs up to Leanne to have the courage to write her story in The Beacon. In my experience, everyone appears so happy and positive after their diagnosis and I did not feel I had permission to really say how I felt after my diagnosis. Eleven years later, I still don’t. It was comforting to hear Leanne’s story.”

– Robyn, NSW

“I read Leanne’s story in The Beacon and I was glad you printed it because I feel like her too and it’s nice to see not everyone’s happy and joyful and they do go through crap. I commend her for what she’s done.”

– Chris, VIC

“I feel moved to write to The Beacon in response to Leanne’s heartfelt and honest contribution. There is certainly a place for recognising ‘the journey’, not only ‘the arrival’. We don’t want to scare people, we want to inspire and to be inspired.

As Leanne says, the positive messages from ‘survivors’ are wonderful. However, getting from wherever we are now, dealing with the loss of where we have come from, and working out how to move forward, let alone accepting that all that we were and could have been is now gone forever, presents what appears to be an impenetrable mountain.

This so-called ‘journey’ is different for everyone. It can certainly be life-changing. Maybe a positive ‘wake up’ call, maybe the loss of hopes and dreams. For Leanne, I have no ‘answer’, other than to say: ‘hang in there!’”

– Liz, QLD

“I know every woman’s experience is different, some have had a worse experience than mine and some have lost the fight. I also admire those women whose circumstances allowed them to make changes for good but, like Leanne, I cannot say my experience has been for the better.”

– Alison, WA

“Thank you for The Beacon. I do always find it helpful but particularly this issue. On page 11 there is an entry from Leanne in WA titled ‘From the heart’. I really identified with this lady and cried heaps when I read her story as it is exactly how I feel. The guilt for not feeling like celebrating my survival is enormous, but I certainly am not the strong vibrant person I was before and I resent this enormously.”

– Averil, WA

“I don’t usually respond or write to publications, but I have to say, Leanne, you are NOT alone. I consider myself a very positive person and always try to put on a brave face and positive outlook. But, this can be very tiring as I imagine you are well aware.

Still depressed, and seeking to redefine my life, meaning and future and to recover that inner spark that kept me going for so many years, through so many adventures, challenges and joyous moments.

I do, however, have hope that we will recover ourselves, I just don’t know how or when. Wishing you all the best!”

– Cathy, TAS

“Breast cancer has also been part of the tapestry of my life story. I didn’t need cancer to appreciate my loved ones or to teach me to embrace each day or follow my dreams. Thank you Leanne for your refreshing, honest letter. You aren’t alone.”

– Jen, VIC
BCNA’s Strength to Strength conference last year explored the latest in breast cancer news, treatment and research from specialist medical, surgical and health experts. A wide range of topics were presented, including:

• new and upcoming treatments for breast cancer
• sexual wellbeing and other survivorship issues
• family history and breast cancer
• lifestyle factors that may influence breast cancer risk.

Although a vast amount of information was presented at Strength to Strength, a number of key themes emerged.

The importance of hormone therapy
Women with hormone positive breast cancer are often prescribed a hormone therapy, such as tamoxifen or an aromatase inhibitor. Common types of aromatase inhibitors include letrozole (Femara), anastrozole (Arimidex), and exemestane (Aromasin). Many speakers emphasised that continuing to take these drugs for the full course, usually five years or more, is very important, as they significantly reduce the risk of breast cancer returning. Although some women experience side effects from their hormone therapy, women were encouraged to seek professional advice before deciding to stop taking their medication. Most side effects can be managed. There are also other options available, such as switching drugs to see if this eases the side effects.

New evidence also suggests that taking tamoxifen for ten years is even more beneficial than five years. Tamoxifen is very effective at reducing the risk of a recurrence, and its benefits last for many years after completing treatment with it. For more information about this research, read our 6 December 2012 news item at www.bcna.org.au > News > Latest news.

BCNA has developed a new resource that offers information and advice about how to manage side effects of hormone therapy. You may like to order or download our Hormone Therapy and Breast Cancer booklet from our website, or phone 1800 500 258 and we will send a copy to you.

Understanding risk and lifestyle factors
Many women are interested in their chances of developing a recurrence of their breast cancer. Women are also interested in what may have caused their breast cancer. There are no easy answers to these questions. In her fascinating presentation about breast cancer worldwide, Professor Dame Valerie Beral explained that the increase of breast cancer in developed countries may be in part due to differences in childbearing and breastfeeding patterns. Research has shown that in developing countries the chances of women getting breast cancer are lower.

Women in developing countries:
• have more babies than women in developed countries
• are younger when they have their first baby
• breastfeed for a much larger proportion of their life.

Our childbearing patterns are very different in the developed world. While the factors above may offer some protection against breast cancer, they do not, of course, completely prevent it. Women who breastfeed and women with multiple children can still develop breast cancer.

Strategies such as exercising, maintaining a healthy weight, taking hormone therapy (if you have hormone positive breast cancer) and minimising alcohol intake can be helpful, and are realistic for most women. These strategies have been shown to lower the risk of breast cancer developing and of a recurrence in women who have had breast cancer.

You can read a summary of all the presentations given at the Strength to Strength conference by visiting www.bcna.org.au > Events > BCNA Conferences or phone 1800 500 258 and we will send a copy to you.

She emphasised that exercise can help to manage fatigue and pain, and reduce stress, depression and anxiety.

For many women, exercise may be the last thing you feel like doing. If you have not been very active in the past, or have other things happening in your life, exercise may not be a priority or something easily done. BCNA has developed the booklet Breast Cancer and Exercise to help you set achievable goals and plan your exercise. You can order it from our website or by phoning our office.

The importance of exercise
Many speakers referred to the increasing amount of evidence in favour of exercise. Some studies show that regular exercise may reduce the risk of a breast cancer recurrence. Associate Professor Sandi Hayes gave a detailed presentation on the many benefits of exercising after a breast cancer diagnosis.
Ask the Expert

Associate Professor Judy Kirk

Associate Professor Judy Kirk is the Director of the Familial Cancer Service at Sydney’s Westmead Hospital. The service provides genetic counselling and testing for families with a strong family history of cancer.

How does a family history affect my risk?

While a family history of breast cancer is a well-recognised risk factor, it’s important to remember that breast cancer is a common disease, so a family history can occur by chance. However, women with a strong family history on either their mother’s or father’s side of the family may be at increased risk.

We classify women's risk into three categories.

Women at ‘average, or population, risk’ have no or little family history. If you have a first degree relative (mother, sister, daughter) who was diagnosed at age 50 or older, but no other family members diagnosed, you are at average risk. Most women fall into this category.

‘Moderate risk’ women have a first degree relative who was diagnosed before the age of 50, or several relatives diagnosed after 50.

‘Potentially high-risk’ women have at least two relatives on the same side of the family who were diagnosed, plus one or more additional high risk features. These features suggest that there is a gene fault (or mutation) being passed down through the family. It’s important to remember that only around one per cent of women are at potentially high risk.

How does genetic testing work?

If your family history is strong enough to indicate there may be a gene mutation being passed down through the family, genetic testing may be beneficial.

The first step is to test a family member who has been diagnosed with breast cancer to determine if they carry either of the two main genes known to increase breast cancer risk: BRCA1 and BRCA2. If they are found to be a carrier, other family members who have not been diagnosed may then be tested to see if they carry the gene mutation.

We don't test all women diagnosed with breast cancer because gene mutations are rare: around one in 800 people inherit a BRCA gene mutation. Sometimes the result of the genetic test is inconclusive, which means that mutations in the BRCA genes could not be found. This happens in around 85 per cent of families tested and, for them, genetic testing cannot progress further. While we suspect that some sort of genetic fault is being passed down in these families, the type of genetic mutation has not yet been identified. Work is being done by scientists to identify additional gene mutations involved in increasing breast cancer risk.

Can women without a strong family history be genetically tested?

There are some instances where we do test women without a strong family history because they may be at increased risk. These include women:

- of Ashkenazi Jewish ancestry
- diagnosed with triple negative breast cancer at age 40 or younger
- diagnosed with high-grade invasive ovarian cancer at age 60 or younger.

What happens if I test positive for a breast cancer mutation?

If you are found to carry a known gene mutation, you are at a much higher risk of developing breast cancer compared with the general population. In this situation, we recommend careful screening, which will usually begin at around the age of 30. Some women choose to have a bilateral risk-reducing mastectomy (prophylactic mastectomy), which dramatically reduces the risk for these women. Surgery to remove the ovaries may also be considered. We can also consider risk-reducing medication, such as tamoxifen, for women at risk of developing oestrogen positive breast cancer.

What does my diagnosis mean for my daughter?

If you don’t have a strong family history of breast cancer and you were diagnosed after 50, your daughter is at average risk of developing breast cancer, i.e. her risk is not increased. However, if you were diagnosed before 50, your daughter is at moderate risk. Annual screening will usually be recommended, and should begin when she is five to 10 years younger than the age you were when diagnosed.

Who can I speak with for more information?

If you are concerned about your family history, the first step is to speak with your GP, who can use an online assessment tool to determine your level of risk. If your family history is complicated, or the tool indicates you are at potentially high risk, your GP will refer you to a Family Cancer Service where you will be assessed further.
Healthy bones

Ensuring bones are healthy is an important part of breast cancer care. Many women are aware that their bone density can decrease as a result of ageing and natural menopause; however, some are surprised to learn that some breast cancer treatments can also reduce bone density. These include the hormone therapies tamoxifen and aromatase inhibitors such as Arimidex, Femara and Aromasin. Decreased bone density can also affect younger women who experience premature menopause as a result of chemotherapy or the removal of their ovaries. If you have reduced bone density, this can increase your risk of bone fractures (broken bones) and your risk of developing osteoporosis.

If you are on, or about to begin, a breast cancer treatment that decreases bone density, your doctor may refer you for a bone mineral density test, sometimes called a DXA test. Depending on your test score, you may then be referred for regular follow-up tests to monitor your bone density. If you are having regular tests, it’s important to have them all at the same imaging clinic to ensure the testing is consistent.

Your doctor may also recommend checking your vitamin D levels. Vitamin D helps your body absorb calcium and is an important part of maintaining bone health. If your vitamin D levels are low, your doctor may recommend you take a supplement to increase your levels.

Other ways of improving your bone health include increasing calcium levels and participating in regular exercise. Weight-bearing exercise such as brisk walking and lifting light weights has been shown to improve bone density.

You doctor may also prescribe a bisphosphonate, such as Fosamax, to help strengthen your bones.

For more information about maintaining healthy bones, speak with your GP or medical oncologist, or visit www.bcna.org.au > Living with breast cancer > Physical wellbeing > Bone health.

Neoadjuvant Herceptin listed on the PBS

Herceptin is a very effective treatment for a particular type of breast cancer known as HER2-positive breast cancer. While most women have Herceptin treatment after their breast cancer surgery, Herceptin can also be used before breast cancer surgery to shrink tumours and make it easier for the surgeon to operate. This is known as neoadjuvant Herceptin. It can be beneficial for women with locally advanced breast cancer, where the tumour may be quite large.

Until recently, women requiring neoadjuvant Herceptin were unable to access it through the Pharmaceutical Benefits Scheme (PBS), meaning they may have had to pay significant amounts for it.

In June 2012, BCNA made a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) in support of an application for neoadjuvant Herceptin to be included on the PBS for women with locally advanced breast cancer.

We were delighted that the application was approved and neoadjuvant Herceptin was listed on the PBS on 1 December last year.

BCNA thanks our members who responded to our Herceptin survey last year. The results of the survey were used in our submission.

We also acknowledge the Medical Oncology Group of Australia, who worked with us on this issue. This is a great example of organisations working together to achieve a change that will make a real difference for women.

BCNA’s submission can be found at www.bcna.org.au > About BCNA > Advocacy > Submissions and reviews.

Photo from My Journey Kit
A number of presenters at BCNA’s 2012 Strength to Strength conference spoke on ‘personalised treatment’ for breast cancer. Personalised treatment can mean many different things. Many doctors use the term to describe medication that is tailored to a specific type of breast cancer, such as Herceptin for women with HER2-positive breast cancer.

Personalised medical treatment
Clinicians and scientists around the world are working to develop treatments that are personalised, or specific to individual types of breast cancer. Some of the questions currently under investigation about hormone positive breast cancer include:

- How long should aromatase inhibitors be taken for best effect? (SOLE clinical trial)
- Do aromatase inhibitors prevent breast cancer in women at high risk? (IBIS 2 trial)
- There is also a great deal of research looking at HER2-positive breast cancer. Clinical trials are investigating if:
  - It is better to block HER2 with two drugs instead of one, for example, Perjeta (pertuzumab) and Herceptin.
  - Chemotherapy side effects can be avoided, for example, through the use of targeted chemotherapies such as Kadcyla (T-DM1). Kadcyla combines chemotherapy with Herceptin into one drug and delivers both the chemotherapy and Herceptin directly into the cancer cells. Kadcyla is currently only available through a clinical trial.

New treatments for triple negative breast cancer are also being investigated. Drugs known as PARP inhibitors, platinum based chemotherapies and oral chemotherapy are all being looked at to see whether they may be suitable treatment options for some women.

Other new and emerging practices that tailor treatment to women include considering chemotherapy before surgery (neoadjuvant chemotherapy) and genomic tests that will help predict a cancer’s response to chemotherapy, such as Oncotype DX.

The whole woman
Personalised treatment can mean more than targeted medical therapy. As Professor Fran Boyle discussed in her presentation, ‘personalised treatment’ should also mean that breast cancer decisions are made with the ‘whole woman’ in mind.

Some factors to consider:

- Where you live may also be a factor. The distance to your treatment centre may influence some of your decisions about your treatment.
- How well you are otherwise travelling is also important. You may have other health issues that will influence your breast cancer treatment, you might be pregnant, or have a family history. Perhaps your culture and language will influence your treatment decisions.

While there is still a long way to go with personalised breast cancer treatments, new research and developments in treatments mean that, in the future, more and more women will have access to treatments specifically tailored to them and their individual cancer type.

NBCF seeking help with breast cancer research
Register4 brings together researchers and willing participants interested in advancing breast cancer research. It recruits volunteers who are interested in participating in research and links them with researchers undertaking research into breast cancer related issues.

The register is an initiative of the National Breast Cancer Foundation (NBCF) and is open to all Australian women and men, whether or not they have had a diagnosis of breast cancer. If you decide to join, you will receive opportunities from NBCF to participate in research. You can also visit the Register4 website and browse current research opportunities. You will also be sent Register4’s Baseline Health and Lifestyle Questionnaire, which asks questions about your family history, reproductive history and general health. This provides Register4 with some basic information to help researchers investigate possible links between breast cancer and other factors.

It is entirely up to you whether you participate in the opportunities offered by Register4. To learn more about Register4, or to join, visit www.register4.org.au.
Shining a light for others

Anyone can give up; it’s the easiest thing in the world to do. But to hold it together when everyone else would understand if you fell apart, that’s true strength.

– Unknown

I was diagnosed with breast cancer in December 2009 at age 41. I had buried my aunty four days prior to my diagnosis; she had fought breast and ovarian cancer for 35 years. Her battle gave me strength.

I am an identical twin; we are inseparable best friends. My sister Susan had a 98 per cent chance of having the same diagnosis. Together we embarked on a journey that saw both of us have bilateral mastectomies and reconstruction. Susan suffered debilitating migraines post-surgery and with three operations in six months she never complained; she gave me strength.

I believe Susan and I have found our true inner strength and we have used this strength and positivity to make a difference to our lives and your own.

Through adversity, not only are we given an opportunity to discover our inner strength, we are also given the gift of foresight so we can shine a light for others who go through the experience after us.

– Rachael Bermingham

I had become single six weeks prior to my diagnosis, and as I watched my boys try to understand and accept their father leaving us and starting a new relationship, together with my diagnosis and surgery, their support and understanding gave me strength.

There are always times that are really difficult and trying, constantly challenging your beliefs and direction. Family, friends and counsellors help you to discover the strength that is within you. It is what you do with this strength and determination that will make a difference to their lives and your own.

Through adversity, not only are we given an opportunity to discover our inner strength, we are also given the gift of foresight so we can shine a light for others who go through the experience after us.

– Rachael Bermingham

Strong family ties

I had already lost a son to suicide when my daughter Laurel told me she’d been diagnosed with breast cancer. All I could think was: ‘Oh God, please don’t let me lose another child.’

At that time I knew nothing about the disease other than that one could die from it. Laurel lived interstate, which made it even more difficult for me to understand and cope.

Eventually we got through it, only for me to be diagnosed myself two years later. Usually the strong one, this time Laurel became my strength.

She rang me continually. She explained things to me. She told me what to expect. Then she organised a party for me in my home with the whole family coming together, some of whom had never met each other, all to celebrate before I lost my hair.

It was a wonderful party and gesture on her and her children’s part. They then flew back to their home, leaving me with wonderful memories and a million photographs. She, and my son too, continued to support me through chemotherapy and radiation, giving me the strength I couldn’t muster for myself.

I don’t think I ever adequately thanked either of those two, or expressed my gratitude for what they did in being there for me. It made me feel so guilty that I hadn’t been there for Laurel simply because I hadn’t understood what breast cancer diagnosis meant, then.

Five years on for Laurel, three for me, we have all gained strength from each other through this and continue to do so, only taking each day as it comes and enjoying it to the fullest.

– Bev, SA
Embracing change

In November 2004 I was diagnosed with breast cancer and immediately my world changed. What I thought was important then became irrelevant as a new path was awaiting me instantly.

It was only a matter of days from that initial shock that I entered hospital and had surgery – a lumpectomy and removal of lymph glands. Following that was a course of radiation and rehabilitation.

It is now almost eight years as I write this story and feel ever grateful that I am able to do so – always in remembrance of others who may not have been so fortunate to have survived.

I feel a deep sense of gratitude for life itself and find myself gazing at the sky each morning on my walk and feeling joy in simple pleasures. No longer am I in a hurry to do or have – I simply just enjoy ‘being’.

It took a serious illness to make me stop and take different steps in my own life, to think of myself a little more often and to appreciate how valuable my life is. I want to thank all the medical teams globally for their wonderful care to people like me – a big thank you to all the organisations whose mission it is to provide and nurture support for people with breast cancer.

It is in a difficult and scary time of change that we turn to these professionals.

For me, life will never be the same. Since my surgery my children have married, I have downsized my home, I volunteer at the local aged care centre, and I have become a grandmother twice. How lucky can one woman be? My arm still aches, my breast is still sore, but it is a gentle reminder that I am here and that I have a life worth living and to enjoy some ‘being me’ time.

Kathy, QLD

Looking for media talent!

Raising BCNA’s profile through print, radio, online and social media helps us reach more people affected by breast cancer and promote our programs and services more widely.

We often receive requests from journalists and media outlets looking for case studies to show the faces and stories behind breast cancer. Common media requests include younger women with breast cancer, women who have done something extraordinary or life-changing after their diagnosis, and families with a strong history of breast cancer.

If you or someone you know has a unique, interesting or powerful breast cancer experience and are happy to share it publicly, please email media@bcna.org.au and we will be in touch with you.

While there may not be any immediate opportunities, we will keep your details on file for future media requests.

Strength to strength

The road to recovery

Completely traumatised is how I was at 41, diagnosed with an aggressive breast cancer. An equally aggressive treatment plan was proposed to give me a fighting chance to be mum to my boys (four and two) including surgery, ferocious chemotherapy that sent me back into hospital making me too ill to care for myself or my family, and radiation to top it off.

Eight months later at the end of the intensive treatment, I was utterly exhausted. Emotionally, I felt like I was some distant satellite orbiting my planet family. My kids had moved on and grown without me keeping up with them, and I felt I’d lost contact with them. I was fatigued, confused and felt completely shattered.

A year after the diagnosis, under the supportive care of a compassionate psychiatrist, I landed back in hospital for forced rest.

I was in crisis. I knew that something had to change. Soon after being discharged from hospital, I was diagnosed with a sleep disorder, which explained my chronic exhaustion. Phew … I felt so relieved that I wasn’t going crazy after all!

Finally, I was on the road to recovery. I began to learn new tricks to be able to keep up with my family, such as communication techniques learnt through Parent Effectiveness Training (PET), a course for families to improve relationships. This communication tool has taught me to be a better listener; helps me identify problems, who owns them and how to prioritise them. I use these tools so much in my everyday life now, not just in the home but in my social and work-life as well.

Two years later, I’ve accepted my diagnosis. I’m so grateful that I’ve been given another chance at life. Life’s good!

Sue-Anne, ACT

Sue-Anne
The ‘bald and the beautiful’

My husband and I have four children, three daughters and a son. Recently our youngest daughter in her early 50s was diagnosed with breast cancer necessitating radical surgery and chemotherapy. Until it hit home, our family hadn’t realised how traumatic it was and how we were all involved.

After her successful surgery, our daughter needed several treatments of chemotherapy and lots of love and support. As a result of her treatment, her beautiful red hair started to fall out. She had already been warned of this so she had her hair cut short. Then it all fell out leaving her totally bald. I couldn’t imagine looking at myself in the mirror: no hair, no breasts and lots of tears.

Unbeknown to our daughter, her two older sisters both had their heads shaved to support her. They both visited her and what a surprise, what a wonderful gesture. Is this sisterly love?

Of course the tears flowed once more. So we have three bald daughters with lovely coloured scarves, looking beautiful.

Our son too contributed. When he heard of his sister’s condition, he ran in the City to Surf fun run Perth wearing his crocodile suit. He was sponsored by family and friends, raising $1200 for Breast Cancer Care WA.

What a proud mother I am.

Catherine, WA

What helped me along the way

I live in West Gippsland, just over an hour from Melbourne. On my husband’s birthday in 2004, I found a lump. Five months later, on my 50th birthday after multiple operations, I was having chemo. I had two primary cancers – breast and kidney.

My strength came from the support of a wonderful partner who remembered and translated doctors’ visits, became mother and father, chauffeur and shoulder. I had a sister, teenage children, elderly parents, a few good friends and many people whose thoughts and well wishes surprised me.

Several experiences come to mind when I ponder what pulled me through the dark times and what kept me strong.

• Diary writing and recording my feelings early in the treatment helped.
• Although not religious, I did experience a more spiritual understanding and trust in life force, which helped.
• As I got weaker and sick with chemo, just being able to let go and run with how I was feeling helped.
• Lying in bed listening to the normal sounds of family life in the lounge and knowing I could be there again thanks to the treatment I was receiving and the wonderful medical care we have here in Australia helped.
• Going to Medicare and looking up to see a daffodil with my name on it that someone had bought for fundraising for breast cancer. Even though I had to leave in tears, it helped knowing I wasn’t alone and that people cared helped.
• More practically, in order to avert becoming totally immersed in my illness we decided to jump in and renovate the kitchen, using a renovation firm. Having something to focus on, a plan for the future and a conversation topic rather than my health helped.
• Travelling on the train to radiotherapy at Peter Mac for the first three weeks helped to develop my fitness and to get me back into the world around me. Spending the last three weeks in Melbourne in the hospital unit once tiredness stopped me travelling helped.

Even eight years out, I still have dark times where the future seems uncertain and possibly limited. Recognising these feelings helps me and reminds me that, as the old saying goes, we don’t know what is around the corner, so do it now and enjoy!

Janet, VIC

Sisters Lesley, Janet and Rhonda
Unextraordinary gifts

It is now seven years since I was diagnosed with an aggressive breast cancer. I was 43 with two small children when diagnosed. It was a pretty rough ride to start with: treatments, relationship difficulties, changed friendships, changed body, changed perspectives, lymphoedema, changed work, changed finances. So much change, so quickly and not of my doing (I was so not in control).

Throughout this time I was able to experience the gift of compassion – both receiving it and giving it to others. Compassion is a value; it is now one of my values. Having cancer pushed, shoved and sent me reeling into defining what my heartfelt values were; pondering the big questions, spending time alone, just being and thinking, not doing and doing. Dealing with a life-threatening illness gave me the opportunity to consider what really matters, what I stood for, who I wanted and didn’t want in my life, what work did I want to do, how will I spend the time I have left, and what is meaningful and important to me.

I recently celebrated my 50th birthday. I’m so lucky to be alive and spending time with my beautiful family. Experiencing cancer gave me the courage to live my life according to my own values. I am a unique individual of inherent worth, I believe we have a responsibility to look within and identify our capacities, strengths and potential. Defining our values provides us with the opportunity to become self-aware and proactive about living our life with purpose. Without cancer it may have taken me decades to figure this out (if ever). Cancer was a catalyst for living true to my values and that strengthens me.

Carol, NSW

Strength of body and mind

Growing up in a very large family I quickly learnt to be tough, independent and resilient. I have always considered myself a strong person, physically, mentally, emotionally and spiritually. When I was diagnosed with breast cancer, I was not fazed. I simply thought, why not me? However, it was the treatment that caused me to unravel; the chemotherapy was killing me.

Through recognising and accepting my weaknesses I gained strength. I learnt to accept and utilise all the help, love and support that so many people offered. ‘No man is an island’ resonated with me. As the turbulent storms of the treatments battered and nearly sunk me, my strength was allowing me to reach out for a steadying hand. A guiding star became my saving grace.

Being a person of strong faith helped me tremendously because being humble, grateful and trusting of other people helped me stay strong. Through the guidance of a superb medical herbalist I have gained physical strength through knowledge and understanding of the body’s biochemical mechanisms. Once I had regained physical strength, the other aspects of my being followed.

While dealing with the devastating effects of treatment, I had to dig deep daily to find strength to help care for and nurture three young grandchildren. They helped me go from strength to strength by focusing on them, rather than on my own pain and misery, and soothing their pain and confusion.

It takes more mettle to divulge weaknesses than to conceal them, more strength to relate to and be open with people than to dominate them. Strength is in the soul and spirit rather than in any physical aspect or in a floundering mind.

Pat, WA
My source of strength

I want to tell you how a set of traffic lights and, at the time, my unknown condition changed my life. I was on my bike, riding to keep fit, when I had to stop at a red light. A girl, Deb, rode up to me and started to chat. At the end of the conversation she said, ‘I ride regularly with some girls, why don’t you join us?’

I took up her offer, but to say I was a little bit nervous on our first ride was an understatement, as these girls are strong.

Little did I know what was ahead of me. I don’t have a sister, so when I was diagnosed with breast cancer these girls became my lifeline.

A day I will never forget was the day before my mastectomy. We went for a ride, well, I cried, laughed, cried, had some hugs, and cried some more. This was all new to these girls but they didn’t falter. The emotional support these girls gave me was unbelievable. They have made me strong, and I don’t mean physically, I mean emotionally. They have taken me from strength to strength.

Ronda, VIC

Repaying the debt

The floods came through Ipswich in January 2011. The river stopped a couple of metres from my door, but I’d evacuated to a safe centre. My best friend Patricia was flooded to her roofline. A close friend died, and within weeks of her funeral I couldn’t stand for longer than a few minutes, couldn’t sit at all, and couldn’t walk properly. For two months I was confined to bed waiting for spinal surgery.

During this time I received a mammogram reminder letter, which I put aside, thinking there was enough to deal with just then, but when I was back on my feet I decided to go. Just as well. The mammogram came up with a positive result and I was in surgery for breast cancer exactly three months to the day after the spinal surgery.

I remember so vividly the day the doctor told me the diagnosis. I couldn’t take it in. I felt numb. I couldn’t focus. I kept thinking this can’t be. I still had back pain and was lost in anguish for the terrible losses around me – those of my friends, for the people of the Lockyer and Ipswich and Brisbane.

I don’t have any family close by and without Patricia I would have been helpless. It is no exaggeration to say she is the best human being I’ve ever known. This is a woman who lost virtually everything in the floods. She did everything for me for months, and supported me unstintingly through the breast cancer journey. I truly cannot imagine where she found the physical and emotional reserves. Where does that come from? I don’t know what I ever did to deserve such a friend, but my gratitude and love for her are boundless.

I could look at 2011 as my ‘annus horribilis’ but I choose to look at it differently. The strength and value of my friendships were tested and proven like tempered steel. My house survived the floods. I can walk. I survived breast cancer. I am whole. I am here. Someone up there loves me. And people down here love me. It’s a debt of honour I can repay. Hallelujah.

Audrey, QLD
Introducing our Board

BCNA’s Board is made up of 10 individuals who have been personally affected by breast cancer. They are leaders in their fields, and generously volunteer their expertise, inspiration and, importantly, compassion and understanding for those affected by breast cancer. Here we profile two of our Board members so you can get to know the people behind the Pink Lady.

Andrea Hull AO

How did you get involved with BCNA?
I was diagnosed in August 2006. Lyn Swinburne rang me and said she was sending me a My Journey Kit. Her calls and the kit were like light at the end of the dark tunnel and I didn’t feel so alone. And so the journey took its course. Two years later I became a Board member.

What inspires you to volunteer your time as a Board member?
The CEOs (Lyn and now Maxine), the staff and my fellow Board members are a wonderful, collegial group of people, all focused on doing the best possible for our 77,000 members.

Throughout your breast cancer journey, what strength did you find within yourself?
I had a lumpectomy at 29 and I remember the night before surgery thinking, ‘I don’t care if the breast goes, I want to live’. That thought resurfaced when faced with the need to have a mastectomy in 2006. I also chose not to have a reconstruction – I didn’t want any more surgery. I wanted to begin my new mono boob life! I’ve always had a yoga and meditation practice and, together with my regular exercise, kept it up during the whole journey. I heeded the advice of my insightful doctor and took four months off. For the first time, I was challenged to not put work before my needs and I loved it. And that’s when I decided I could live a different life. Not working between 60 and 80 hours a week with all the challenges of being a CEO, but a more balanced life, filled with a rich diversity of things that feed my curiosity and engage me.

Professor Christobel Saunders

How did you get involved with BCNA?
I moved to Australia from the UK in 2000 to take up a post as a cancer surgeon at Royal Perth Hospital and to work as a teacher and researcher at the University of Western Australia. Looking after patients with breast cancer meant I quickly learnt of BCNA. Inevitably I met the whirlwind that is Lyn Swinburne. I was impressed by Lyn’s passion, hard work and ‘smarts’ when it came to all things breast cancer and was always delighted to help out with any BCNA events, clinical advice, and so on. When I was asked to join the Board in 2011, I felt truly honoured and delighted. The more I get to know the organisation the more impressed I am.

What inspires you to volunteer your time as a Board member?
I am pretty passionate about improving outcomes for women with breast cancer and their families. I love research that can contribute to this. I love teaching young doctors and others about how best to treat people with breast cancer. I love helping develop national and local policy around cancer to improve patient outcomes. But mostly I love the privilege of being able to look after my patients with this disease. Being involved with BCNA gives me a better insight into what it is to be diagnosed and to live with breast cancer and helps me reach out further than just my own patients. I hope my clinical expertise and experience helps the organisation develop better programs for the women.

As a surgeon, what strength do you take from the women you care for?
I look after a few hundred women newly diagnosed with breast cancer each year. That is a lot of life stories – stories of courage, of tragedy, of hope and often just of women getting on and coping with what life throws at them. My patients really inspire me – to try to conquer this disease and do my best to treat them with every weapon I have at hand, but also personally. Being part of someone else’s journey, if only for a few months, is an awe-inspiring business. A career as a surgeon and researcher has been a pretty busy one, which has put some strains on my family and life generally, but the rewards have been infinitely greater.
Profiling our Member Groups

Dragons Abreast Townsville Inc.

Desley Ralph and Sherone Brown share how Dragons Abreast Townsville isn’t just about paddling on the water.

Commonly called ‘The Pinkies’, Dragons Abreast Townsville (DATi) is part of the national Dragons Abreast clubs which, through the team sport of dragon boat paddling, seek to help people with a diagnosis of breast cancer understand they can lead full and active lives despite the physical limitations imposed by breast surgery. Since 2010 we have encouraged individuals to achieve their dream of regaining an active, adventurous lifestyle despite a diagnosis of breast cancer.

DATi takes the responsibility of raising awareness of breast cancer in the community very seriously, and this year are proud to be organising and hosting a one-day breast cancer conference in Townsville titled ‘Keeping Qld Abreast of the Times’ on Saturday 4 May 2013 at the Riverway Arts Centre Auditorium in Queensland. All local, state and national breast cancer associated organisations and support groups will be invited to display information in the foyer of the Riverway Arts Centre.

We have both had the privilege of attending several breast cancer conferences in the capital cities over the last few years and understand the costs to attend are a big factor to consider for many survivors. This is why we wanted to bring a conference to North Queensland and to make it free. This is not a fundraising event – it is an opportunity for regional and rural breast cancer survivors to hear the same important message as their city cousins and for a similar cost.

DATi’s purpose in hosting this event is to provide the women and men in North Queensland diagnosed with breast cancer with an opportunity to hear leading authorities in Australia speak on breast cancer treatment and care; current research and other areas of interest. DATi is currently seeking financial and practical support from various sources to make it possible for participants to attend at no cost to them. We hope to have between 100 and 150 participants, with people attending from as far north as Cairns, as far south as Mackay and as far west as Mount Isa.

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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:

- Ambleside Wealth Advisors – Fiona McKenna, VIC
- Angelina Stefanelli, NSW
- Annual Women’s Breakfast – Leanne Sher & committee, VIC
- Autocare NSW – George Fajloun, NSW
- BP Oakey, QLD
- Breast Friends Great Lakes Breast Cancer Support Group, NSW
- Deloraine Craft Fair Stand – Maureen Holland, TAS
- Dragons Abreast ACT & Region – Patsy Sheales, ACT
- Elizabeth Leggo, VIC
- Gerard Dillon, VIC
- Holy Spirit College – Lisa Guillick, NSW
- Jean Thompson, NSW
- Kristy Chugg, TAS
- Loreto College, SA
- Lyn Keller, VIC
- Mackay Breast Cancer Support Service – Diane Shore, QLD
- Margaret Thompson, WA
- Meegan Taylor, WA
- Megan Ryan, NSW
- Michael Sewards & Alpine Classic Challenge Team, VIC
- Moama Bowls Club – Rhonda Goudge, NSW
- Mount Gambier Race Day – Julie Campbell & committee, SA
- Nepean Creative & Performing Arts High School – Jan Giles & committee, NSW
- Sandringham ‘Royals’ Baseball Club, VIC
- Scott Hobart
- Suburban Gallery – Lesley Hunter, VIC
- Trinity College Gawler Inc. – Nick Hately, SA
- Zumba United – Keren Green & committee, VIC

For those who were involved in our Pink Golf day campaign, thank you for your support and contribution.

Memorials

We pay tribute to the lives of:
- Jacquelene Anne Cameron
- Jill Cottee
- Kevin Walsh
- Marie Gross
- Sally Elizabeth Leavold
- Valerie Roselynn Hosking

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 Elliott
- Jan & Peter Harris
- Sharon Unger
- Susan Harrington
- Suzanne Turnbull

Mother’s Day Classic

One of the largest charity fundraising events in Australia, the Mother’s Day Classic (MDC) raises money for our sister organisation, National Breast Cancer Foundation (NBCF). This annual event is for participants and volunteers to show their commitment and support for breast cancer research. Held on Sunday 12 May in all capital cities, major metropolitan areas, and over 50 regional areas, MDC raises funds for breast cancer research, supports and remembers those touched by breast cancer and starts Mother’s Day in a fun and healthy way. Whether you walk, run, cheer or volunteer you’re helping to fund essential research – make Mother’s Day a memorable and meaningful day by registering as a participant or volunteer today. For more information, visit www.mothersdayclassic.com.au.
Buy a bun and help someone

In 2013 we celebrate 13 years of our sweet partnership with Major Partner Bakers Delight. Once again, every Bakers Delight bakery in Australia will be busy selling pink buns for the annual Pink Bun campaign from 2 to 22 May. During this time 100% of the sale of pink buns and Pink Lady silhouettes comes directly to BCNA, with every bakery generously donating the ingredients and time it takes to make each pink bun.

The Pink Bun campaign helps to raise:
- funds to help BCNA continue our work ensuring women and their families receive the very best treatment, care and support possible
- awareness of the support that is available in local communities for women and their families affected by breast cancer.

You can help make this year’s campaign the best yet by following these six simple steps:
- Develop a craving for pink buns and buy them.
- For a gold coin donation, buy a Pink Lady silhouette and write a message of support to be displayed in your local bakery.
- Regularly visit your local Bakers Delight bakery during the campaign. To find your local Bakers Delight search the Bakery Locator online at www.bakersdelight.com.au/BakeryLocator.
- Tell all your family and friends to purchase pink buns too.
- Help choose the ‘best dressed bakery’ by visiting Bakers Delight’s Facebook page.
- At the end of the campaign, visit your bakery and thank them.

I go into my Bakers Delight every year to thank them for everything they do for BCNA – it is overwhelming the time and money they put into the campaign.

– Rosie, QLD

This is a fantastic opportunity for you to be involved with your Bakers Delight bakery, local community and to help us to raise vital funds and spread the word about how BCNA supports women. Every year, local bakeries tell us how much they appreciate the visits from our members.

It makes such a difference, gives the campaign a real face and reminds you how important the Pink Bun campaign is!

– James, Bakers Delight, NSW

Thank you to everyone supporting their local bakeries and the Pink Bun campaign in 2013.

Pink Sports Day

Due to the success of Pink Footy & Netball Day last year, we are excited to be launching Pink Sports Day in 2013.

Over Mother’s Day weekend (11–12 May 2013) sporting clubs from around Australia will be turning pink to pay tribute to those in their local communities who have been affected by breast cancer. An incredible $350,000 was raised for BCNA from the 900 clubs who participated in last year’s campaign, and many are keeping the day as a permanent fixture in their sporting calendars.

It was a great day enjoyed by all for a great cause. We exceeded all expectations we had of how much we wanted to raise. It was good to see the sponsors, supporters and players all get behind it.

– Eloise, Golden Grove Football Club

Registrations for Pink Sports Day are now open online. Although it’s free for clubs to participate, registrations are essential. Once a club registers, BCNA will send a free event pack with helpful information about running your event and decorations to ‘pink up’ your sporting club.

If you have a connection with a local sports club and would like to get involved, visit our website www.bcna.org.au > Events > Key fundraising events > Pink Sports Day, or phone 1800 500 258.

BCNA gratefully acknowledges our partnership with Bakers Delight.
### Dates for your diary

**Thursday 11 April**  Free BCNA Port Lincoln community forum. For more information and to register visit www.bcna.org.au or phone 1800 500 258. Places are limited so register early to avoid disappointment.

**Monday 15 April**  BreaCan presents a free session on 'Living with uncertainty: women living with secondary cancer’. 1.00 – 3.00 pm, Queen Victoria Women’s Centre, Ground Floor, 210 Lonsdale Street Melbourne. Bookings are essential. Phone 1300 781 500 or email breacan@breacan.org.au.

**May**  Free BCNA Brisbane community forum. Keep an eye on BCNA’s website for more information.

**Saturday 4 May**  ‘Keeping QN Abreast of the Times’, hosted by Dragons Abreast Townsville Inc. A free conference providing an opportunity to hear leading authorities in Australia speak on breast cancer treatment and care; current research and other areas of interest. 8.30 am – 4.30 pm, Riverway Arts Centre, 20 Village Boulevard, Thuringowa Central Qld. Bookings are essential. Email dati.coordinator@live.com.au

**2-22 May**  Pink Bun campaign. Visit your local Bakers Delight store to show your support. For more information visit www.bcna.org.au or email pinkbun@bcna.org.au.

**11–12 May**  Pink Sports Day. Local sports clubs will turn pink on the Mother’s Day weekend to support BCNA. Clubs participating will be playing with a specially designed pink footy or netball. For more information and to find out if there is a game in your local area, visit www.pinksportsday.org.au

**Saturday 10 August**  BCNA’s Field of Women in Sydney! Join us on the field at ANZ Stadium. Visit www.bcna.org.au and register for more information.

### Challenges for you, your family and friends

BCNA is supported by fundraising participants in various fun runs. These events are a great opportunity to keep fit and healthy, achieve your personal best, challenge yourself or your friends, and raise money for BCNA.

For more information, visit the websites listed below, email BCNA at fundraising@bcna.org.au or phone us on 1800 500 258.

**Saturday 13 & Sunday 14 April**  Australian Running Festival, incorporating *The Canberra Times* Canberra Marathon, along with a half marathon and fun runs for all abilities, from serious runners to joggers, wheelchairers, pushers and walkers. Visit www.runningfestival.com.au.


### Seeking stories – creating change

We are seeking stories for the Spring 2013 issue of *The Beacon* about creating change. After your diagnosis did you help to improve things for women in your community who will be diagnosed in the future? It could be a small change – for example, a request for more comfortable chairs in the oncology clinic, or a bigger project that had some impact. Or perhaps you feel you benefited from the ideas or work of someone who came before you. Stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell VIC 3124 or emailed to beacon@bcna.org.au by the end of June 2013. Please also include a high-resolution photo.

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.

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