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Focus on:  
Creating change



## A change for the better

Creating change is the perfect theme for this edition of *The Beacon* as BCNA celebrates our 15 year anniversary.

Since 1998 BCNA has been the voice for people affected by breast cancer and so much has changed in breast cancer treatment and support during that time. Significant improvements in detection and treatments have resulted in much better outcomes and overall survival rates, and women have greater access to quality information and support, largely due to the work of BCNA and our members.

Individuals and groups drive change and it can occur on a small and large scale. Over the years, BCNA has campaigned for better access to treatment and improved health service delivery, provided essential online and face-to-face support, and developed a diverse range of free resources. Last year BCNA sent out 12,000 *My Journey Kits*, reaching more than 80 per cent of women newly diagnosed with breast cancer. This is an achievement in itself.

In August we held a National Summit in Sydney which brought together support group leaders and BCNA Community Liaisons from around Australia and highlighted the difference these women make to the lives

of those they support. Our Summit participants are shining examples of the power of individuals to create change.

With the federal election on 7 September, BCNA asked the two major parties what change they would bring about if successful at the election. As health consumers and as Australians who rely on the health system we wanted to know what changes they stood for. See their responses on page 3. BCNA is very fortunate to have a wonderful Board with directors who make a difference and have been actively involved in creating change through their different roles.

BCNA Chair Marg O'Donnell was recognised with an AO in the recent Australia Day honours for the positive impact she has had on many organisations over her career. Marg was recognised for

'distinguished service to public administration in Queensland, particularly in the arts sector, to the community through leadership roles in cultural, public health and social welfare organisations, and to legal education'.

BCNA also congratulates our Board Member Professor Fran Boyle on receiving the Medical Oncology Group of Australia and Novartis Oncology Cancer Achievement Award 2013. The Cancer Achievement Award is presented to an Australian oncologist who provides outstanding leadership in clinical practice, research and academic achievement.

We are incredibly fortunate to have the support of some outstanding individuals. Shane Crawford is well known to AFL fans across Australia as a former champion footballer,

premiership captain and a panellist on the AFL Footy Show. Shane completed a marathon bike ride from Melbourne to Perth in July that raised more than \$1.3 million for BCNA. An outstanding effort that not only raised substantial funds but also raised awareness of BCNA and the significant impact of breast cancer in the Australian community. He shares his experience on page 15.

Finally, next month is Breast Cancer Awareness Month. We know that some of our members, especially those of you who are newly diagnosed, can find it an unwelcome reminder. Others will be preparing to get involved in pink events around the country, such as hosting a Mini-Field of Women, celebrating with your support group or running a community-based event. It's an important time to reflect on the impact of breast cancer on communities around Australia.

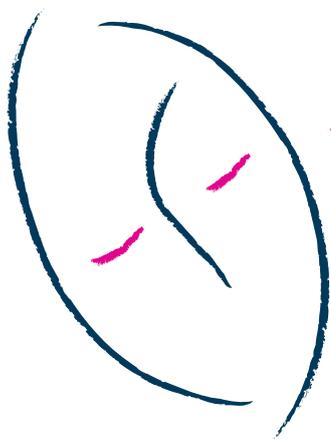
*Maxine Morand*  
Chief Executive Officer



*Women at BCNA's National Summit in August.*

Breast  
Cancer  
Network  
Australia





# Issue of concern

## BCNA's federal election submission

*In preparation for the federal election on Saturday 7 September, BCNA developed and presented to the Health and Shadow Health Ministers a submission on behalf of our members on what we believe are priority areas for breast cancer treatment and support.*

Over the past 15 years governments have made real improvements to the treatment and care of women with breast cancer – including listing some high-cost drugs such as Herceptin and Tykerb on the PBS, establishing the External Breast Prosthesis Reimbursement program, and providing BCNA

with funding (through Cancer Australia) to support our rural and regional programs. However, there is still room for improvement.

Our election submission has four major themes:

1. A range of initiatives to reduce out-of-pocket costs for Australians diagnosed and treated for breast cancer
2. Funding to train and place 50 advanced cancer care nurses in communities around Australia, including in all regional cancer centres

3. Continued funding for breast cancer research
4. Organisational funding to help BCNA meet its operational costs.

A priority is to ensure government funding for new breast cancer tests and treatments, so that all women have access to them – not just those women who can afford them. BCNA has this year called for Medicare rebates for breast MRIs and for bone mineral density tests for women treated with an aromatase inhibitor, so that women who have these

tests as part of their breast cancer treatment can claim a Medicare rebate.

We have also called on government to ensure that new breast cancer drugs recommended for listing under the Pharmaceutical Benefits Scheme are quickly approved so that they are subsidised and available to all women who can benefit from them.

People living with advanced cancer – including secondary breast cancer – need tailored support, often over a long period of time. We have called for a future Australian government to fund 50 specialist advanced cancer care nurses to support people with advanced cancer. We have proposed that 25 advanced cancer care nurses be placed in regional cancer centres around Australia to provide care to all patients living with advanced cancer, including women with secondary breast cancer. The remaining 25 positions could be allocated as specialist secondary breast cancer nurses in major metropolitan hospitals.

You can download a copy of our submission at [www.bcna.org.au](http://www.bcna.org.au) > About BCNA > Advocacy > Submissions and reviews.



*BCNA's submission to government was made on behalf of our members and all Australians affected by breast cancer.*

# Election response from Labor and Coalition

BCNA invited the major political parties to share their commitment to funding for breast cancer. Here are their responses.

## From the ALP

Labor believes all Australians, regardless of income, background or location, deserve access to high-quality health care, when they need it, where they need it.

This approach has guided the Labor Government's policy to breast cancer prevention and care, and cancer more generally, during the past six years.

Australia has made huge strides in screening, diagnosing and treating breast cancer, and a re-elected Labor Government will make sure we continue on this path.

BreastScreen Australia is a very successful government-funded program, and women diagnosed with breast cancer in Australia now have better survival prospects compared with women in most other countries and regions.

Since the inception of BreastScreen Australia in 1991, there has been a reduction in mortality in women 50–69 years of age of approximately 36.5%.

Labor is building on this by investing \$55.7 million over four years from 2013–14, to expand the target age range for BreastScreen Australia by five years – from women aged 50–69 to women aged 50–74.

Moreover, the Labor Government has brought together the National Breast and



Ovarian Cancer Centre together with Cancer Australia to form an integrated organisation to provide national leadership in cancer control through targeted research, cancer service development and education.

Improved prevention, detection, treatment and follow-up care will continue to yield much better cancer outcomes over time and Labor is working hard to achieve that.

Since 2007, the Labor Government has committed \$3.5 billion to improve the detection and treatment of cancer, including more than \$1.5 billion on cancer medicines. Labor will continue to support improved detection and treatment.

To help close the gap in outcomes for patients in regional areas, the Labor Government is spending \$672 million to construct 25 regional cancer centres and associated accommodation facilities.

Labor is committed to building a country which is a world leader in screening, diagnosing and treating breast cancer.

*The Hon. Tanya Plibersek MP  
Minister for Health,  
Minister for Medical Research*

## From the Coalition



The Coalition has a proud record in government of supporting a range of women's health initiatives. In particular, breast cancer will remain a high priority for any future government with nearly 15,000 Australian women diagnosed each year and the most common cancer affecting women.

The Coalition made cancer a national health priority and invested heavily in new screening measures, clinical treatments, research, workforce initiatives and support for patients and their families. The Coalition's Strengthening Cancer Care initiative provided a \$190 million investment in cancer care with a range of measures specifically targeted to breast cancer.

The Coalition in Opposition has continued to strongly support measures targeted at breast cancer.

The Coalition previously committed to initiatives such as breast care nurses which the government has since matched and we support.

Through the concerted efforts of clinicians, non-government organisations, the health and medical research sector and support across the political spectrum, advances have been made on a number of fronts and

the five-year survival rate has improved.

This momentum needs to be maintained.

Health and medical research will be essential to further advancing screening programs, treatments and clinical care. The Coalition in government provided a five-fold increase in funding. We have already committed in Opposition to certainty of funding going forward, simplifying grant applications and approvals, and streamlining ethics processes and clinical trials. These reforms will strengthen the sector and allow scientists and clinicians to spend more time on research and less time on paperwork, hopefully facilitating more breakthroughs in important areas such as breast cancer.

*The Hon. Peter Dutton MP  
Shadow Minister for Health  
and Ageing*

# Ask the Expert

## Sondra Davoren

*Sondra Davoren is a senior legal adviser at the McCabe Centre for Law & Cancer and Cancer Council Victoria. Her work focuses on cancer prevention, cancer treatment and supportive care.*

### **What is the McCabe Centre for Law & Cancer?**

The McCabe Centre is a joint initiative of Cancer Council Victoria and the Union for International Cancer Control. It was set up to help use the law in cancer prevention, treatment, supportive care and research. The centre conducts research, develops policy and participates in advocacy and training.

The McCabe Centre is named for Rolah McCabe, an Australian woman with smoking-related lung cancer who brought a lawsuit against British American Tobacco Australia in 2001. The McCabe family and their lawyers contributed funds towards establishing the centre as a legacy to Rolah's courage – both in dealing with her cancer and in calling the tobacco industry to account.

### **How will the McCabe Centre's work affect women with breast cancer?**

The McCabe Centre's work is based on the idea that the law can be an effective tool to make changes for improving people's health.

This can be done by using laws to help prevent cancer (such as plain packaging for

cigarettes), or by improving laws and policies that affect people with cancer, such as laws to protect people with cancer from discrimination.

In 2012, the McCabe Centre was awarded a major grant by the Legal Services Board of Victoria to support a project to identify the laws and policies that impact on Victorians diagnosed with cancer, their families and health professionals, and to examine treatment and support issues in more detail. Many of the issues faced by Victorians with cancer are faced by all Australians, including women with breast cancer.

### **What are the main legal issues affecting women with breast cancer in Australia?**

In 2012, we asked people with cancer, lawyers and health professionals about the main legal issues for people affected by cancer.

The key concerns to emerge from these consultations were:

- the financial impact on people who have to travel for treatment
- the lack of clarity in the laws around end-of-life decision making
- waiting times for cancer treatment
- protection for people with cancer and carers in anti-discrimination and workplace laws and policies.



*Sondra Davoren*

Although these issues are not unique to women with breast cancer, women are often affected as they are more likely to be the primary carers for their family.

The financial impact of a cancer diagnosis and treatment is a key concern for people affected by cancer; in particular, the costs of travelling for treatment.

One of our key pieces of work is looking at how to reduce travel costs for rural and remote patients. In Victoria, this means advocating for changes to the Victorian Patient Transport and Accommodation scheme, in collaboration with other cancer and chronic disease organisations.

### **How can women get more involved in advocating for changes to the law?**

As part of our project 'Making the law work better for people affected by cancer', we get Australian women to share their views and experiences of the law by completing an online survey. This includes questions about financial support, discrimination, and returning to work. These stories will be used to lobby for changes to the law and legal education for people affected by cancer, their carers and health professionals.

We have also released an issues paper to encourage discussions about how to make the law work better for people affected by cancer. We blog about some of these issues and regularly invite feedback from readers. You can read our issues paper, blog, and more about the work of the McCabe Centre at our website, [www.mccabecentre.org](http://www.mccabecentre.org).

If you have any concerns about practical or legal issues, contact the Cancer Council Helpline on 13 11 20. They will be able to tell you where you can find help. The Cancer Council Helpline is open Monday to Friday, 9.00 am – 5.00 pm.

# BCNA members creating change

We know that many women are keen to help improve the experiences of other women diagnosed with breast cancer, but are sometimes unsure how to do this. There are a number of ways you can help others by getting involved with BCNA. BCNA's Consumer Representatives actively participate in committees, boards and forums, representing the views of all Australians diagnosed with breast cancer to create change in a meaningful way. Sometimes this leads to improved treatments, such as the introduction of sentinel node biopsy, or the development of new resources, such as Cancer Australia's guides for women with breast cancer. Sometimes there are less obvious outcomes,

but their influence is still significant.

*I'm on a research committee focusing on familial breast cancer. I'm from a regional area so I participate by email and teleconference. Through this work I advocate on an issue I am passionate about. – Sarah*

BCNA trains Consumer Representatives to develop their knowledge of breast cancer, communication skills and ability to reflect the needs of women. Becoming a BCNA Community Liaison is another way to be involved. Community Liaisons share their own personal experience with breast cancer and represent BCNA in their local communities by speaking at

local fundraising events, staffing BCNA information tables, liaising with local health professionals and being the face of media stories. Training is provided to assist them in this role.

*It's rewarding being a Community Liaison. Raising awareness of breast cancer is important to me. I'm now connected with an amazing network of women around Australia who I met during the training. BCNA provides support when I need help preparing for an activity. – Joan*

Many women want to participate in research as a way of giving back. BCNA's Review & Survey Group allows women to do this. Members are regularly invited

to participate in surveys, focus groups, clinical trials and other types of research.

*My experiences benefit others and are not lost. Some of the studies also reaffirm just how well I'm doing – sometimes it's good to stop and realise that. – Penny*

For more information about these programs, visit [www.bcna.org.au](http://www.bcna.org.au) > About BCNA > Getting involved > Speak out. If you want to stay informed about the latest breast cancer research, without participating yourself, BCNA's *Research Bulletin* may interest you. To receive this free monthly bulletin via email, visit [www.bcna.org.au](http://www.bcna.org.au) > News > Research bulletins.

## Women talk to future doctors

Since 2005 BCNA Community Liaisons have been sharing their personal stories with medical students. This program aims to engage with students at this early stage so they will better understand the women's perspective throughout their medical career.

Each year, these women speak with University of Melbourne third-year medical students during class time. The women talk with students about how

their doctors interacted with them during their treatment and give their perspective on their breast cancer journey.

The program has recently expanded to include Sydney University and Monash University medical schools.

Earlier this year, a number of Community Liaisons spoke with students at Monash University. When asked to identify the best parts of the tutorial sessions, the students replied:

*The patient was very open and willing to share her story which allowed us a better perspective on the impact of such conditions on their social situation and their personal relationships.*

*Being able to get advice from a patient about what they look for in a doctor was very helpful.*

*It was a great opportunity to understand a good doctor-patient relationship from the patient's perspective.*

Our Community Liaisons also find these tutorials a very positive experience.

*The students were engaged, and asked extremely good and useful questions. They were obviously interested in the experience of breast cancer, and appeared very empathetic.*

BCNA thanks the Community Liaisons who kindly donate their time to speak with medical students.

# Ten years of tamoxifen may be better than five

Hormone therapies (tamoxifen and aromatase inhibitors) are used to treat hormone positive breast cancers. These are cancers that need the naturally occurring hormone oestrogen to grow and reproduce. About two-thirds of all breast cancers are hormone positive.

Decisions about how long to take hormone therapy treatment are discussed and debated by clinicians, researchers and women receiving the treatment.

Tamoxifen is taken as a daily tablet and works by stopping oestrogen from entering the cancer cells.

Two large international clinical trials have found that 10 years of treatment with tamoxifen is better for women with hormone positive breast cancer than five years. The trial results were discussed at the American Society of Clinical Oncology (ASCO) conference held in June this year and have been described as one of the top three results to come out of the conference.

The current standard treatment with tamoxifen is to take it for five years after other breast cancer treatments (surgery, chemotherapy, and/or radiotherapy) have been completed.

Previous research has shown that five years of tamoxifen substantially reduces the risk of breast cancer recurring for up to 15 years after diagnosis.

The new studies have shown that ten years of treatment is even more effective, with significantly fewer women developing a recurrence of their breast cancer, and fewer women dying from breast cancer.

Medical oncologist and BCNA Board Member Professor Fran Boyle told *The Beacon* that the study findings will change the way many women with hormone positive breast cancer are treated.

'For women who are premenopausal after five years of tamoxifen, there is now good evidence that continuing tamoxifen for another five years, or until they become menopausal, may be very beneficial,' she said.

'For women who become menopausal during their tamoxifen treatment, switching to one of the aromatase inhibitor drugs is a good alternative to tamoxifen.

'Women who were post-menopausal at the time of diagnosis may have received an

aromatase inhibitor only, with no tamoxifen, for the first five years. Whether it is beneficial to continue aromatase inhibitors beyond five years is the subject of ongoing research.'

Professor Boyle recommends that women who are taking tamoxifen or an aromatase inhibitor see their medical oncologist around the time they have been taking the treatment for five years to discuss whether continuing treatment for up to another five years may be appropriate for them. The risk of the original cancer and the side effects of treatment will need to be discussed.

BCNA's *Hormone therapy and breast cancer* booklet has more information on tamoxifen and aromatase inhibitors, including how they work and why they are so effective at preventing breast cancer from recurring. It also provides tips for managing some of the side effects of these treatments. You can order a free copy online at [www.bcna.org.au](http://www.bcna.org.au) > Shop > Information resources or by phoning BCNA on 1800 500 258.

## Financial and practical assistance fact sheet now available

BCNA's new *Financial and practical assistance* fact sheet includes information about a range of benefits, subsidies and services that may be available to you and your family to help reduce the financial impact of a breast cancer diagnosis.

We hope that the fact sheet is helpful to you as well as those who may be supporting you – whether it be a partner, adult child, friend or colleague.

You can download a copy of the fact sheet at [www.bcna.org.au](http://www.bcna.org.au) > Resources > Fact sheets and booklets, or phone us on 1800 500 258 and we'll post a copy to you.



## Making life a little easier

I was diagnosed with breast cancer in 2011 when I was 30 years old. What followed was surgery, IVF, chemotherapy, radiotherapy, genetic testing and then tamoxifen. Two years on I'm feeling healthy and strong. My hair has grown back and I can look in the mirror and recognise the woman staring back at me again.

I have been taking tamoxifen for 16 months now. When I started taking the drug I was still suffering from chemo-brain and often found it difficult to remember if I had actually taken the tablet. Eventually I resorted to using a pill box so that I could be sure. I know that in the



*Alison with her partner*

grand scheme of things this is a very small thing. It's just that I do find it annoying (and a bit depressing) that I have to fill up a

pill box each week at the ripe old age of 32! I wrote to Sandoz, the manufacturer of the tamoxifen tablet that I take, asking them to

label their blister packs with the days of the week but was told that this was not possible due to the configuration of the current packaging.

I would argue that it would be worth changing the packaging. From a commercial perspective, I would specifically request one brand over another if their packaging featured days of the week. From a medical standpoint, isn't anything that helps us take our daily dose worthwhile? If you're reading this and you agree, please send an email to the manufacturer of your tablets so that they might take this request more seriously.

*Alison, NSW*

## Sharing my experience with others

I am a young woman of 35 who has recently completed treatment for breast cancer. Diagnosis meant a lot of change for my family. We had to stop being foster carers, and had to evaluate our lifestyle. My family has been so supportive. I have a husband (my high school sweetheart) and three sons.

After my diagnosis, I said to myself, 'You know all those things you have always wanted to do? You should do them!'

The number one thing I always wanted to do, but had put on the back burner, was to be a writer.

The best support that I had through my treatment was my friend Vivienne Ramsey, who sadly passed away last year. We shared poetry, and so



*Briohne*

much about how we felt along this journey. It was after she passed away that I thought that maybe I could write a play about my experiences and all the silly things that people said that made me and Vivienne laugh. Maybe I could write

something that would bring cancer patients and support people alike together, for some entertainment, but also some understanding. I wrote a one-act play, called *Powerfully Fragile*, which is now being produced by Beenleigh Theatre Company.

At its heart, *Powerfully Fragile* is about not letting your struggle become your identity. It is the story of four women and how they journey through their respective lives, focusing on each one's recent cancer diagnosis. The women all have a burden to bear in life. The play also showcases the beautiful relationship between a man and his wife, and how strong their love is.

I am so hopeful that this play will provide cancer patients and their carers a space in time that is not only entertaining but reflective of their own experiences, creating broader awareness of the feelings of patients and their support people.

*Briohne, QLD*

# Celebrating a decade of fun and friendship

Over the past year South Australia Dragons Abreast (SADA), a BCNA affiliate, has celebrated 10 years of dragon boat paddling and supporting survivors of breast cancer, their partners, families and friends. A dinner dance attended by 330 past and present members and representatives from local clubs helped celebrate our achievement. Four of the founding survivor members who still paddle were congratulated and acknowledged for their foresight in establishing the club and its positive impact on members.

Following success at the 2011 and 2012 National Dragon Boat Championships 29 paddlers and partners travelled to Hong Kong for the Lee Kum Kee 8th International Dragon Boat Federation (IDBF) Club Crew



*SA Dragons Abreast*

World Championships on Victoria Harbour. We entered five categories in the small boat division over 200 m and 500 m. Our club was one of 300 clubs and 6,000 paddlers attending from 21 countries around the world. We won gold medals for two events.

We were able to again spread the message of breast cancer

awareness through sport and it was a great pleasure to meet the members of the Hong Kong Breast Cancer team and other survivor teams from around the world.

Following success at the State Championships, SADA competed in the 2013 Nationals. We met the Sydney DAA team and chatted to survivor members

of other interstate teams. SADA won three bronze medals which entitled us to enter events at the 2014 IDBF Club Crew World Championships in Ravenna, Italy.

As SADA enters its second decade we are excited by our club's successes, and look forward to opportunities to support breast cancer related causes. Annually we are involved in the Pink Bun campaign at a local Bakers Delight. We also support the Mother's Day Classic, Girls Night In, Mini-Fields of Women and donate to breast cancer research and related charities.

On behalf of SA Dragons Abreast members I would like to thank BCNA and *The Beacon* for their ongoing support.

*Helen Macleod*

*President, SA Dragons Abreast*

## Pursuing my dreams

As a breast cancer survivor, I recently received my Winter 2013 edition of *The Beacon*, which I read from cover to cover, and was touched by April's story 'Still bearing the impact of breast cancer'. What I related to the most was the swelling and body pain that she talks about. I, too, experience swollen painful arms, painful joints and continuing skin problems.

To deal with all of the above I decided to channel my energy in pursuing my passion which is food. Despite, at times, my extreme body pain and fatigue, I decided to open a little store

called Sweet Greek at the Prahran Market in Melbourne, where I offer beautiful Greek food to take home and delicious sweets. I cook both at the shop and at home.

Recently I took this dream even further and launched my first cookbook *Sweet Greek*, in which I talk about my breast cancer journey.

I was thrilled when *Gourmet Traveller* decided to feature the book and my recipes.

I'm sharing my story because despite all the pain and the scars and the daily reminders of breast

cancer I am so grateful that I am one of the lucky ones who is still standing here today and has had the opportunity to pursue her dreams. Throughout my journey, I have lost three dear friends to breast cancer. I continue to support BCNA in whatever way I can. Last year Sweet Greek held a Grecian morning tea and all the proceeds went to BCNA. I will continue to support this amazing organisation and anything that relates to further research. I wish April well and want her to know that she is not alone.

*Kathy, VIC*



*Kathy*

## Never giving up

Advocacy work is sometimes very frustrating but also very rewarding. I generally tell people that I feel like a termite, constantly nibbling away in the dark until some light finally breaks through. I have participated on many advisory groups and a think tank, as well as quite a few BCNA surveys.

I worked hard on getting a breast care nurse for our health district and was eventually successful, but it took years. I learnt to never give up; it always takes a long time to change government services.

I also introduced my support group to a number of initiatives they wholeheartedly embraced. We started many craft projects which were very popular, such as making cushions, scarves and toiletries packs for oncology patients.



*Jurina and Raelene Boyle*

In 2007 I started hearing a lot of complaints about long waiting lists for breast reconstruction surgery. I attended a community cabinet meeting with the Minister for Health and asked him about the Patient Assisted Travel Scheme (PATS), reconstruction after breast

cancer surgery, the lack of local haematologists and the breast prostheses policy. I didn't get any satisfactory answers so I later started a series of letters to all the relevant politicians.

Networking is important, so I started seeking information about waiting lists for reconstruction from support groups and breast care nurses. When I had the chance I spoke to the new Minister for Health and he was shocked by the information I had gathered. This led to further meetings and eventually, after a great deal of effort, extra funds were made available. Since then 63 reconstructions have been carried out.

In the meantime I had a lot of women asking for help because they could not get lymphoedema treatment in the

public system and could not afford the private services. I participated as a consumer on a NBCF Lymphoedema Research Think Tank and a community consultative committee and was able to bring attention to the lack of services. This led to prolonged efforts over many years to improve the situation but unfortunately nothing changed. It really highlighted the frustrations of dealing with bureaucracies.

The work does not stop. Reconstruction waiting lists, the lack of breast care nurses, and costs of chemotherapy drugs are just some of the issues that need addressing and reviewing. It has been difficult and has left me despondent at times, but it has also allowed me to make a difference.

*Jurina, QLD*

## Adding a touch of colour

My wife Jane was diagnosed with breast cancer in September 2006 and a full mastectomy quickly followed.

It was during her post-operative stay in hospital that she saw something that had a profound impact on her. She exercised every day as best she could by walking up and down the hospital corridors. On her walks she encountered other 'mastectomy' women who, just like her, were carrying their drainage bag in an everyday plastic shopping bag.

It struck my wife that there must be a better solution to this humiliating dilemma, and from her experience was born a specially designed drainage carry bag just for mastectomy patients.

The carry bag was made from brightly patterned light cotton with handles that were fully adjustable. It came in a variety of colours and was distributed through the breast care nurses at St George Hospital. A scarf for those undergoing chemotherapy soon followed.

Initially the quilting group, along with family and friends, was involved in making the bags and scarves, but the bag has become so successful that St Aidan's Anglican Church community help with production of both bags and scarves.

Since that very first bespoke bag, nearly 2,000 bags have been made and distributed to patients at both St George and St George Private hospitals.

*Tim, NSW*



*Jane and Tim*

## Walking for change

Three years ago, right at the start of the wet season build-up, 25 intrepid survivors met at the Alan Walker Cancer Centre, Darwin, Northern Territory to embark on a three-month challenge to walk 10,000 steps a day. The Northern Territory Breast Cancer Voice (NTBCV), a volunteer advocacy group for breast cancer survivors, coordinated the challenge. Dragons Abreast NT provided pedometers. Since then, on average, 18 to 20 survivors have successfully completed the challenge and we are now into our third year.

Every fortnight one survivor receives a prize for walking the most steps in that period and another is rewarded with a prize for improving on the previous fortnight. While the main focus of the challenge is on daily



self-motivated walks, we spice up the challenge through social events aimed at promoting exercise while having fun. These include a treasure hunt at a local hardware store, orienteering, line dancing, water aerobics and various walks including a stroll from the waterfront taking in the

old pre-cyclone structures, World War II oil tunnels and many other interesting historic localities

The challenge is enjoyed by one and all, but just to demonstrate the amount of effort and sheer determination participants go to, here's what some participants have to say:

*'I lost 2 cm off my waist ... It has been great being part of the program and I have lost a bit of weight.'*

*'My bone density reading is -4.5 for the cervical spine and -3.5 for my left hip. The right side of my body has just about been rebuilt. I have more prosthetic bits than real bone. Ironically, the best treatment for osteoporosis is weight-bearing exercise, which is the hardest thing to do when your bones are crumbling as you move. So now we are into the last week and I am feeling very proud of myself. I do hope we can do it all again in the new year. Hats off to NTBCV for getting it off the ground.'*

*Karen Dempsey, NT  
President NT Breast Cancer Voice*

## No longer feeling alone

In December 2010, after my second surgery for a borderline Phyllodes tumour and finding out that I had a second borderline tumour, I searched the internet for information and support groups for Phyllodes tumours. I was also looking for anyone else in Australia that had the same type of tumour as me – what was their treatment, what grade it was, what information they had. I wanted to know if there was anyone else who knew exactly what I was going through. I was frustrated because no one I talked to, other than my breast specialist, knew



*Katie*

what it was. In hospital, I was educating them. I felt isolated. After posting my initial blog 'Phyllodes tumour – Is there anyone else out there?' I heard from a couple of women who also had Phyllodes tumours and

were feeling the same as me with regard to lack of information and feeling isolated, so I decided to set up a support group.

I set up the group online because geographically the women that had written on my original blog were all over Australia, so meeting face to face wasn't possible. I also wanted other women diagnosed with this tumour in Australia to have somewhere to find support, information on treatments, and just a place where they could find other people who knew what they were going through.

I also set up the online support group in the hope that we increase the knowledge and awareness of Phyllodes tumours.

I get great satisfaction from the support group, which now has 45 members, knowing that we are helping to support and provide information to other women with Phyllodes tumours. I hope we have alleviated some of the frustration and feelings of isolation. It is also nice to see how supportive everyone is and how willing they are to offer information.

*Katie, QLD*

## The kindness of strangers

At 36, married to an amazing man and with a young family, life was fantastic until one warm summer night in bed chatting away with my husband Glenn, I reached up to scratch under my right arm, and I felt something very different to anything I'd felt before.

With a very scary family history of breast cancer I phoned my doctor the next morning and within a week I had been through a mammogram, an ultrasound and three biopsies. Waiting for my results seemed like an eternity. I finally received a phone call from my doctor that shattered our world. I was diagnosed with three malignant tumours.

Our children were so young and I couldn't even look at them without crying and thinking, 'Why me, what about Glenn and the kids, how will they all cope?'

I opted for a mastectomy and the operation went well, although recovery took a while.

I booked in for my second operation to complete my reconstruction, but family commitments meant I would have to travel to Perth and face the operation alone.

Under my profile name TanG, I shared my anxiety about this on BCNA's Online Network and connected with some gorgeous girls, all with different stories.

When I came out of my second operation, to my absolute delight, three of the girls I had met online were standing at my bedside. They were there for me with flowers, hugs, tears and laughs, and it's a moment I will never forget.

The kindness of complete strangers at such a tough time in my life blew me away.

Kristy, Chris (see story below) and Mich, I couldn't have done it without you! You made me smile when I thought I had forgotten how to and restored my faith in people. At times like this we work out who our real friends are. During my journey,



*Tania on her wedding day*

I lost some friends who couldn't cope with my diagnosis but the amazing friends that I have gained through BCNA will be my friends for life.

*Tania, WA*

## Meeting an old friend for the first time

In one of my support group meetings, I was listening to a woman share her story and realised that I had read it on BCNA's Online Network recently. I often read some of the entries and, about seven months after my diagnosis, I started blogging myself.

After the meeting I approached this woman and asked if she was on BCNA's Online Network. Yes, she was the same woman, and we have since become very good friends. I have met a few other women and we meet outside of the blog and share a strong bond and a friendship that continues to grow.

Having now moved from Sydney to Perth, I have reconnected with the women from BCNA and have now met many more lovely ladies like Mich and Pixie29 to name just a few. We forged an instant bond and established a new network of friends.

I had been following TanG's blog (see above), and having had the same procedure she was about to go through, it was a very easy decision to want to be there for her after her 'solo' surgery. We had already shared photos, so this was a natural next step. I was delighted to finally meet Mich who also shared the same idea, as well as Kristy who

travelled from Bunbury to be there with us when TanG woke up from surgery. The four of us met for the first time that day, and became friends through a shared history and the blog site. Being new to Perth made me realise how important it was to have someone there for you who understands.

We have now reactivated the Perth group and hope to reach out to all others in Perth who are going through this tough time. It's been wonderful to realise that these women blogging on BCNA's website are real people, just like me.



*Chris*

*Chris, WA*

# Introducing our Board members

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.

## Michael Happell

### How did you get involved with BCNA?

My wife Tatty is a breast cancer survivor. I am also a cancer survivor. We knew from our experiences in dealing with cancer how important it was to both of us to be fully informed and open with each other through the journey. We found out how it can be just as challenging for the spouse as it can be for the person diagnosed. So when Tatty was diagnosed, we both relied heavily on BCNA's *My Journey Kit* and related information.

When the BCNA Board contacted me about utilising my finance skills to support them on the Board, I jumped at the chance to 'give something back' to BCNA. I have really enjoyed making a contribution and being part of such a fantastic organisation.

### What inspires you to volunteer your time as a Board member?

I have seen firsthand the great work that BCNA does. One of the challenges BCNA faces is to ensure it has the long-term financial stability to make the current programs sustainable and available to a growing member base for years to come. To be able



Michael Happell

to use my vocational skills to help BCNA plan to achieve this gives me great satisfaction.

### What changes still need to happen for people affected by breast cancer?

There is still a lot to be done to minimise the disadvantages that many breast cancer patients face due to their geographic location or lack of financial means. There are big challenges for those in remote parts of Australia obtaining quality treatment and support. Many suffer financial hardship as a result of the cost of some treatments and the impact of treatment on their ability to earn income. These continue to be high areas of focus for BCNA.

## Fran Boyle

### How did you get involved with BCNA?

I was a very junior medical oncologist doing my PhD in 1996 when I was lured by Dr Sally Redman into doing some work for the National Breast Cancer Centre on their first treatment guidelines. Any excuse to get out of the lab was very welcome, and this work was revolutionary – for the first time surgeons, oncologists, and all members of the team were learning about breast cancer out of the one book. I subsequently volunteered to get involved in their communication skills training program when it began in 1997. It was at the NBCC that I met BCNA founder Lyn Swinburne, who was so



Fran Boyle

passionate about improving communication and teamwork to ensure better care for women and their families. At that time the first expensive breast cancer drugs were being developed and I could see that we would struggle to fund them through existing means. Lyn convinced me to arrange sessions for

women with secondary breast cancer at the first meeting of BCNA in Canberra in 2008, and then to work with BCNA on the Herceptin campaign.

### What inspires you to volunteer your time as a Board member?

I am so proud that some of the women who received Herceptin for secondary breast cancer in those early years are still alive, and that we were able to speed up access to other drugs in the years since. Through my work with BCNA I have learnt so much about the range of issues women face, and to which we as health professionals need to respond. I am inspired by the 'gutsy dames' I meet at forums, who ask those really tough 'crystal ball' questions. Medical oncologists have all been impressed by

the professionalism of BCNA in preparing our policy and research work – it has been a partnership which has changed the way we think about cancer care.

### What changes still need to happen for people affected by breast cancer?

There needs to be better tailoring of drug treatments in early breast cancer, which will require greater understanding of cancer biology and the development of better tests, including the elusive 'all clear'. I'd like to see improvements to the management of side effects such as menopausal symptoms, hair loss, neuropathy, and prevention strategies based on better understanding of the causes of breast cancer.



# Profiling our Member Groups

## Creating change in our community

*Elizabeth Anttila, Co-facilitator, Secretary and Treasurer of the Whyalla Pink Spirits Breast Cancer Support Group, shares her story and tells how the group is helping the Whyalla area.*

My experiences made me want to help others on their journeys. I knew that sometimes all that people need is a compassionate face and a listening ear with a warm, understanding touch. This sounds so simple but it is sometimes very hard to find in this busy world of ours.

Like so many support groups, ours was set up to fill the need to create a place where women could connect outside their medical appointments and after their treatment had ended. Along with help from BCNA, our local McGrath breast care nurse and my amazing co-facilitator Rae Williams, we set up the Whyalla Pink Spirits Breast Cancer Support Group.

We offer an embracing, empathetic and caring atmosphere where a hug and smile are always available. We meet weekly, with alternate meetings being coffee and chat at the Sundowner Hotel Motel which has supported us from the beginning, and craft and chat at Spotlight Whyalla who allow us to use their facilities free of charge. As you can see, chatting is always a part of our meetings!

We are a busy group that likes to get involved in activities that support the community and beyond. We make drainage bags for the hospital and also make welcome bags to be given to breast cancer patients which include information about local and national support services. Last year we collected 16 banana boxes full of bras to send to women in Central Australia. We are now involved in setting up a wig library for all cancer survivors in Whyalla which we hope will reach even more people – perhaps those that aren't interested in joining a group. In October we will be having a Mini-Field of Women at our local shopping plaza in conjunction with our totally wonderful Bakers Delight to raise awareness of BCNA.

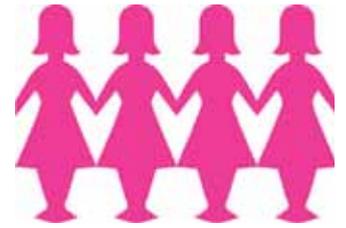
During our meetings if someone wants to talk about their breast cancer experience, we listen.

We know we don't have all the answers – that isn't our role. In response to our members' questions we occasionally organise for someone to come along to a meeting to provide answers. Sometimes people drop in for just one meeting, share their story and then don't come back. Others may come along for a few months before they feel ready to share and some never do, but there is never any pressure to do so. If we help just one person through our group members sharing their stories and the facilitators guiding members to information and local services – then it is worthwhile.

Breast cancer changes lives, and our group provides the space for women to share, express and navigate those changes and offers us the opportunity to make a difference in the lives of others.



*Whyalla Pink Spirits*



## Linking together

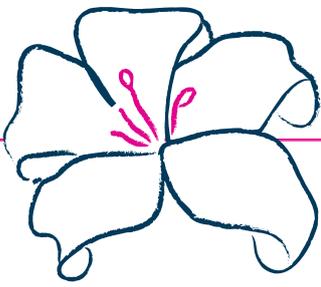
Over the past 15 years a key part of BCNA's mission has been to link together Australians personally affected by breast cancer.

We welcome new Member Groups to our network. They now total 309.

New Member Groups:

- Aldinga Breast Cancer Support Group – Aldinga Beach, SA
- Burnie Splash and Chat – Ridgley, TAS
- Busselton/Dunsborough Breast Cancer Support Group – Busselton, WA
- Elizabeth Igbinoba Breast Cancer Foundation Inc – Wentworth Point, NSW
- Gatton Breast Cancer Support Group – Gatton, QLD
- Pink Connections – Yarrowonga, VIC

To find Member Groups, including support groups, in your state or territory visit [www.bcna.org.au](http://www.bcna.org.au) > Sharing & support > Find a support group in your area.



# Thank you

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

- Anniversary Luncheon – Rose Vizzini, VIC
- Barbara Page, NSW
- Bell Charitable Fund
- Blood Service – Linda Athans, VIC
- BP Australia
- Catalent Australia Pty Ltd
- Catholic Women's League, Ayr, QLD
- Christine McComb, NSW
- Colleen Unger, QLD
- Darling Downs Cotton Growers – Stuart Armitage, QLD
- Dunlop Flooring
- Emily Chang, NSW
- Geoff Wilson, VIC
- Godfrey Hirst Carpet
- Helen Douglas, WA
- Hibiscus Bellflower Retirement Resort – Jan Rogers, QLD
- Jan McMenamin, VIC
- Janet Freeman, NSW
- Le Reve Pty Ltd
- Mad Hatters Tea Party – Sarah Colley, NSW
- Mandala Art – Jason Petruccelli & Mary Crickett, VIC
- Margaret Illman, SA
- Margaret Webb, VIC
- Megan Wheeler, VIC
- Michael Lucas, NSW
- Pamper & Purchase for Pink – Wendy Waugh, SA
- Peter McInnes Pty Ltd – KitchenAid
- Rinnai Australia, VIC
- Showcase Jewellers
- St Monica's College, Cairns, QLD

- St Paul's School, Bald Hills, QLD
- Stuart & Carolyn Rodger, NSW
- TAFE & City Council, Cairns, QLD
- Theodoros Marinis, SA
- Wagga Wagga Breast Cancer Support Group
- Yabby Lake Winery, VIC

BCNA is grateful to the participants, fundraisers and organisers of the following fun runs:

- Australian Running Festival
- Chevron City2Surf
- Gold Coast Airport Marathon
- HBF Run for a Reason
- SMH Half-Marathon
- Sun-Herald City2Surf
- The Age Run Melbourne.

A special thank you to those who contributed during our once-a-year donation request in the Winter edition of *The Beacon*.

## Memorials

We pay tribute to the lives of:

- Deanne Pointon
- Denise Pauline Martin
- Edna Elizabeth Judd
- Glenda Maureen Jemison
- Margaret (Margot) Christian
- Robyn Joy Heinnen
- Sue Livingstone

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:

- Helen Keenan
- Katrine Hitchins
- Lyn Williamson

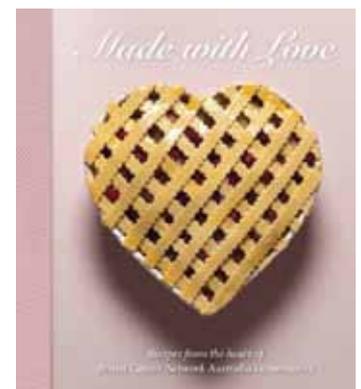
# Sussan designs a special collection for BCNA

In October, our long time sponsor Sussan is launching a beautiful BCNA sleepwear collection. This collection has been designed with you in mind – cotton and lightweight, and featuring inspirational illustrations from Meredith Gaston.

You will be able to choose from different sleepwear items including a summer dressing gown, pyjamas, nightie or camisole and boxer set. \$20 from each item will be donated to BCNA.

There will be plenty of other BCNA gift ideas instore as part of Australia's Breast Cancer Month, including the very popular *Made with Love* recipe book.

So head instore or online at [www.sussan.com.au](http://www.sussan.com.au) to spoil yourself or someone you love.



# My Tour de Crawl journey

Almost everyone knows someone affected by breast cancer, and as I discovered during my run from Adelaide to Melbourne in 2010, this disease affects not only the person diagnosed, but whole families and communities. The many women I met on the road that year changed my life and inspired me to literally saddle up again for BCNA.

When I heard the AFL Footy Show was planning a show in Perth I decided the time was right to try and make a difference to the lives of Australians diagnosed with breast cancer again. I thought, what better way than travelling across the country from Melbourne to Perth on my bike! With that, the Tour de Crawl was born. Planning for the 22 day, 3,600 km trip began, but



*BCNA members, our CEO Maxine and ambassador Raelene Boyle met Shane in Ceduna before he crossed the Nullarbor.*

all the planning in the world could not have prepared me for the journey that lay ahead. Physically, the trip was always going to be a challenge; after all, I set myself the target of cycling more kilometres in fewer days than the Tour de France. I am also not a professional cyclist.

The first time I rode my very slick Giant bike was on the first day of the tour ... and that tiny seat took some getting used to!

It was not the heavy legs, sore backside, dehydration or fatigue that impacted on me the most; I can overcome the physical barriers. It was Samantha, April, Paul, Julie and young James, who were all personally affected by breast cancer. They took the time to travel long distances, raise funds or camp for hours on the side of the road to support me. All I was doing was pedalling my bike. They were fighting for their lives, the lives of loved ones, or grieving their loss.

During my most difficult times, when the road seemed endless, exhaustion set in and I was missing my partner Olivia and our boys terribly, I would ride ahead of the convoy to be alone, shed some tears and reflect on

the harrowing stories of my army of pink supporters. Remarkable in their optimism, hope and generosity, they recharged me and pushed me across the Nullarbor.

The community spirit had to be seen to be believed. There was no need to follow the map across the country; I was guided from Melbourne to Perth by a string of pink ladies, balloons, signs, streamers and bras! I was amazed that the smaller the town, the bigger the effort. Football and netball clubs, general stores, local pubs, fire and police stations, mines, Indigenous communities and roadhouses were decorated pink and held fundraising events.

From the truly weird to the absolutely wonderful, I was overwhelmed by the outpouring of support and am truly humbled. I am also very grateful to my road crew and the team that were so critical in bringing Tour de Crawl to life. The commitment from all involved has raised valuable awareness and funds for BCNA to continue its important work supporting Australians diagnosed with breast cancer.

Thank you for supporting my journey.

*Shane Crawford*



*The town of Durham united to support Shane on his journey.*



BCNA gratefully acknowledges our partnership with Bakers Delight.





## Dates for your diary

### Free BCNA Community Forums

Registrations open six weeks before the event. Places are limited so please register early to avoid disappointment. For more information and to register phone 1800 500 258 or visit [www.bcna.org.au](http://www.bcna.org.au).

**Saturday 14 September** Living well beyond breast cancer, 10.00 am–3.00 pm, Cairns Convention Centre, Qld.

**Wednesday 9 October** Living well beyond breast cancer, 10.00 am – 3.00 pm, Australian Technology Park, Sydney, NSW.

**Wednesday 9 October** Forum for younger women, 6.00–9.00 pm Australian Technology Park, Sydney, NSW.

**Thursday 10 October** Secondary breast cancer, 10.00 am–3.00 pm, Australian Technology Park, Sydney, NSW.

**Thursday 24 October** Living well beyond breast cancer, 10.00 am–3.00 pm, The Cube, Albury/Wodonga, Vic.

**Thursday 14 November** Living well beyond breast cancer, 10.00 am–3.00 pm, TRECC, Tamworth, NSW.

**Thursday 5 December** Living well beyond breast cancer, 10.00 am–3.00 pm, Flemington Racecourse, Melbourne, Vic.

**Sunday 22 September** Blackmores Sydney Running Festival, NSW. BCNA is an Official Supporter Charity for this festival. To register for this event and fundraise for BCNA visit [www.sydneyrunningfestival.com.au](http://www.sydneyrunningfestival.com.au).

**10 October – 28 November** YWCA Encore classes Thursdays from 6.30-8.30 pm. Gold coin donation. Monash Aquatic and Recreation Centre, 626 Waverley Road, Glen Waverley. Bookings essential. Phone Cheryl Gardner 0415 958 142 or Marcelle Yoxon 0413 995 080.

**Sunday 13 October** Melbourne Marathon. For more information visit [www.melbournemarathon.com.au](http://www.melbournemarathon.com.au), email [fundraising@bcna.org.au](mailto:fundraising@bcna.org.au) or phone 1800 500 258.

**Tuesday 15 October** Pink Lady Melbourne Luncheon, Great Hall, National Gallery Victoria. For more information and to purchase tickets visit [www.bcna.org.au/events](http://www.bcna.org.au/events) or phone 1800 500 258.

**Wednesday 23 October** Pink Lady Brisbane Luncheon. For more information and to purchase tickets visit [www.bcna.org.au/events](http://www.bcna.org.au/events) or phone 1800 500 258.

**Monday 28 October** Pink Ribbon Day, Cancer Council Australia.

**Wednesday 13 November** 12.30–2.00 pm BreaCan presents a free session on 'Making a choice: What you need to know about breast reconstruction'. Queen Victoria Centre, Ground Floor, 210 Lonsdale Street, Melbourne. Bookings are essential. Phone 1800 781 500 or email [breacan@breacan.org.au](mailto:breacan@breacan.org.au).

**Saturday 23 – Sunday 24 November** Profound Healing: Sustainable Wellbeing, The Gawler Foundation's Conference, Melbourne. Register online: [www.gawler.org/other-services/conferences](http://www.gawler.org/other-services/conferences) or phone 1300 651 211.

**Sunday 8 December** Sussan Women's Fun Run VIC: 5 km, 10 km or half marathon run or walk supporting BCNA. Catani Gardens, St Kilda, Melbourne. For more information and to enter visit [www.supersprint.com.au](http://www.supersprint.com.au).

## Seeking stories – Practical matters

We are seeking stories for the Autumn 2014 issue of *The Beacon* about **practical matters**.

Did you return to work after your breast cancer? What was your experience? How did your diagnosis impact on you financially? The stories should be about half a page long (200–300 words) and can be posted to BCNA, 293 Camberwell Rd, Camberwell 3124 or emailed to [beacon@bcna.org.au](mailto:beacon@bcna.org.au) by the end of December 2013. 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](mailto:beacon@bcna.org.au) or visit [www.bcna.org.au](http://www.bcna.org.au) > Resources.



the BEACON

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