

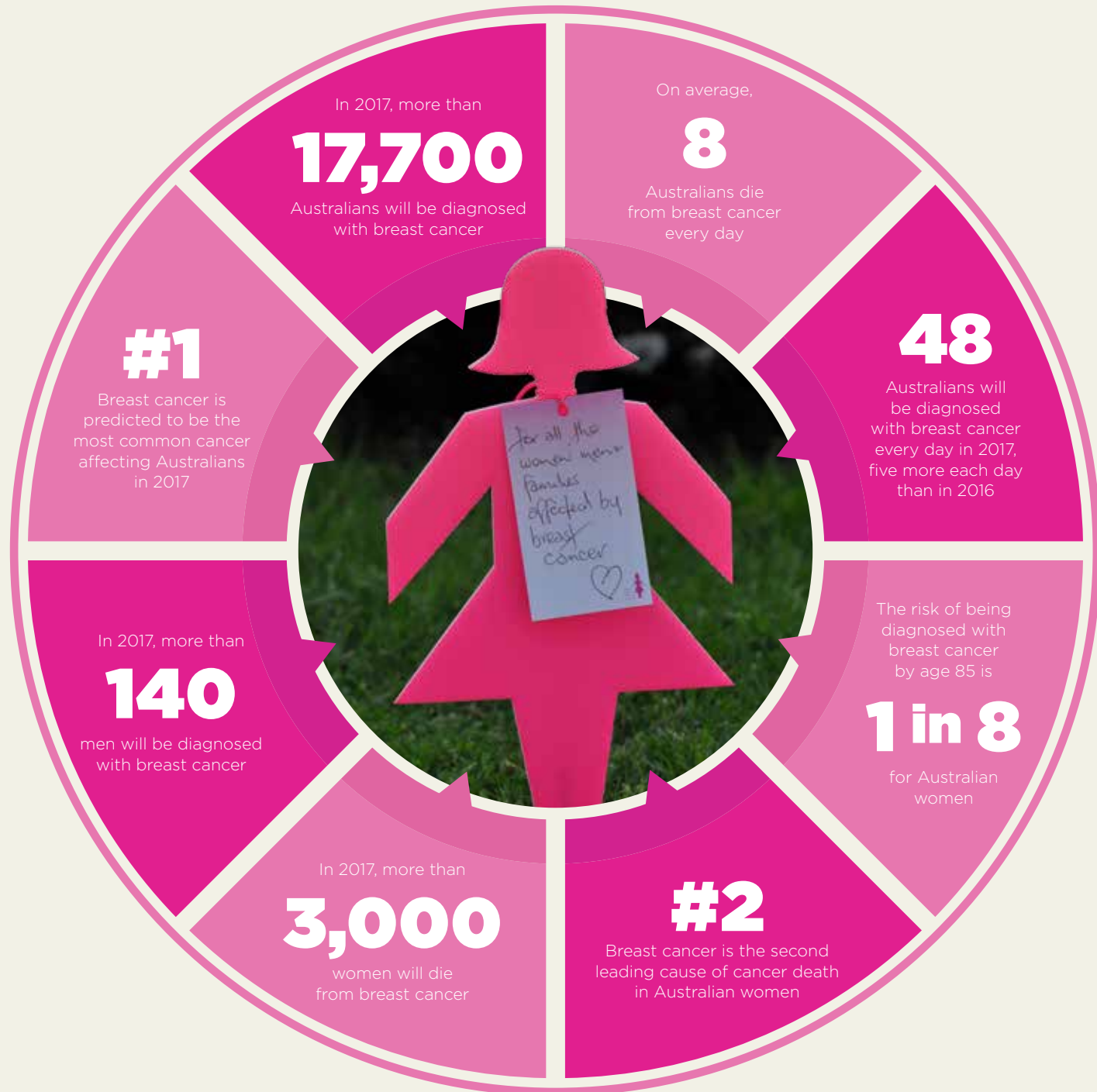
Breast
Cancer
Network
Australia



BREAST CANCER NETWORK AUSTRALIA

ANNUAL REVIEW 2016

A better journey for all Australians affected by breast cancer



Source: Australian Institute of Health and Welfare, *Cancer in Australia 2017*, Cancer series no. 101. Cat. no. CAN 100, AIHW, Canberra, 2017.



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Cover: Renee, breast cancer survivor, with her sons Asher and Eden.
Photo credit: Matt Harvey.

Highlights for 2016



Berlei launched The Chrissy Bra range



New online network



12,839

people received a My Journey Kit



MCG



Hosted our first information forums in Vietnamese

Highton



Bakers Delight's Pink Bun campaign raised **\$1.5 million**

Burwood



Mountain Gate

New fact sheets produced



Lobbying led to two key drugs added to the PBS

Studfield



Third edition of **hope & hurdles** launched



13,790

women received a My Care Kit

Our vision

Breast Cancer Network Australia (BCNA) strives for a better journey for all Australians affected by breast cancer. BCNA works to ensure Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.

Our mission

BCNA supports, informs, represents and connects Australians affected by breast cancer.

Support

We support and empower all Australians with a breast cancer diagnosis through our services, resources and programs.

Inform

We develop and provide high-quality information in a range of formats including information that can empower participation in decisions about treatment and care.

Represent

We advocate on behalf of Australians affected by or at risk of breast cancer and work to set the best possible treatment and care standards.

Connect

We strive to help Australians affected by breast cancer to feel less alone throughout their treatment and beyond. We connect people through their shared breast cancer experience to build support for individuals, groups and communities.

Our values

Our values set the standard for who we are and what we do, as individuals and as an organisation.

Energy

Openness

Caring

Connection

Resilience



From the Chair

I first became aware of BCNA through my good friend, Andrea Hull. She was diagnosed with breast cancer in 2006, and then served as a member of the BCNA Board from 2008 to 2015. At Andrea's invitation, I attended Raelene Boyle's 60th birthday party in 2011, which raised funds for BCNA. It was a great evening, and I was really inspired by BCNA's work.

Just over a year later, I was diagnosed with inflammatory breast cancer, a rare and aggressive form of invasive breast cancer where cancer cells block lymph vessels in the skin of the breast. The initial diagnosis was that it was inoperable. I turned down the interim CEO role I was about to take up so I was able to focus on my treatment.

I was worried about telling my husband and my son, who was 15 at the time. Luckily, he was away on year nine camp, so I could process what had happened before telling him.

This wasn't my family's first experience with breast cancer. My mum was diagnosed 20 years earlier, and then in 2010 my younger sister Jenny was diagnosed at 46. Supporting my sister through her journey gave me the courage to face my own diagnosis.

Both Andrea and Lyn Swinburne, BCNA's founder and then CEO, were great supports during my treatment.

Lyn founded BCNA after her experience following her own breast cancer diagnosis in 1993 left her frustrated and angry that a system that was meant to be working for women really wasn't working for them. The work of BCNA has seen tremendous improvements since then, but there is still much to be done.

My treatment started with chemo. I'm one of the fortunate people where the drug Herceptin made a very big difference to my prognosis, so I'm deeply grateful for BCNA's advocacy efforts in making Herceptin available in Australia through government subsidies.

I'm originally an engineer and so a natural problem solver. As I went through my treatment, like Lyn, I kept thinking 'This could be done better'. Given my professional life has been about fixing problems, I realised that I needed to put my hand up and see if I could make a difference. When I was approached about joining the BCNA Board as I was coming towards the end of my treatment, I didn't hesitate.

When Lyn founded BCNA, she wanted to ensure that all Australians - no matter who they were or where they lived - would receive the very best treatment and care possible. I was the beneficiary of fantastic medical treatment, and I too want all Australians to be able to



access that same level of treatment, regardless of their location and their financial resources.

After two years serving on the BCNA Board, I became Chair in May 2016. I'm very proud of all that BCNA has achieved in my first year as Chair. I look forward to building on these achievements and continuing our focus on a better journey for all Australians affected by breast cancer.

Kathryn Fagg
Chair

From the CEO

The increasing number of Australians diagnosed with breast cancer has meant another busy year of activity for BCNA in supporting them and all those around them.

Every day in 2016, 43 women were told they had breast cancer. What they want to know is: 'Why? What can I do? What are my treatment options? What can I do to improve my chance of survival and my quality of life? What about my family? What does it mean for my sisters and daughters? What about my job? What are the costs going to be? How will I get through this? Will I die?'

BCNA aims to help answer these and many more questions through the information we provide in a range of formats, including information that can empower participation in decisions about treatment and care.

Nearly 13,000 Australians newly diagnosed received our *My Journey Kit* in 2016, which goes some way towards providing that vital information and support. We have released our third edition of the *Hope & Hurdles* kit for Australians with metastatic breast cancer. It has been substantially revised and reformatted.

We know that it is not only the person diagnosed, but families, friends and whole communities that are affected by a breast cancer

diagnosis. They too will have many questions. This is often a time when people turn to the internet.

While there is plenty of helpful information to be found online, there is also information that may be unhelpful, inaccurate and scary. Our website provides a significant and credible resource for anyone looking for answers about breast cancer. In 2016, our website had more than 1.5 million page views with an average of more than 22,000 visitors per month.

The support of family, friends and colleagues is vital after a breast cancer diagnosis. However, even with a support network to draw on, our members often tell us their diagnosis made them feel isolated and alone.

Communicating with someone who has experienced breast cancer can be of enormous benefit. After its launch in September, our new online network had almost 10,000 visitors in less than four months.

At all hours of the day and night, the online network saw great geographic distances breached as visitors connected through their shared breast cancer experience.

Whether 10 days or 10 years post-diagnosis, all Australians affected by breast cancer deserve



to have their needs represented and their voices heard whenever important decisions about breast cancer are made.

We draw on the strength of our network to advocate on behalf of Australians affected by breast cancer, and work to ensure best practice in treatment for all Australians.

In 2016, BCNA supported, informed, represented and connected many thousands of Australians affected by breast cancer. This would not have been possible without our wonderful partners, supporters, volunteers, members, board and staff. Thank you to all who contributed to the ongoing achievements of BCNA in ensuring a better journey for all Australians affected by breast cancer.

Christine Nolan
Chief Executive Officer

Our Board



Chair

Kathryn Fagg

Kathryn is a member of the board of the Reserve Bank of Australia and Note Printing Australia as well as three ASX-listed company boards – Boral, Incitec Pivot and Djerriwarrh Investments. In addition, she is president of Chief Executive Women, chairman of the Melbourne Recital Centre and is on the board of the Australian Centre for Innovation. She is a former chairman of Parks Victoria. As a Fellow of the Academy of Technology and Engineering, she chairs the Industry and Innovation Forum. Prior to becoming a non-executive director, Kathryn enjoyed an extensive senior executive career in banking, manufacturing and logistics across Australia, New Zealand and Asia, after commencing her career as a petroleum engineer with Esso Australia and working as a management consultant with McKinsey & Co. Kathryn was diagnosed with inflammatory breast cancer in 2012.



Deputy Chair

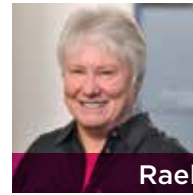
Michael Happell

Michael is an independent non-executive director. His current directorships include the Melbourne Cricket Club (Vice President), Supra Capital Pty Ltd (Chairman) and MyProsperity Pty Ltd. Previously Michael was a partner at PwC for 24 years. He was Chairman of PwC Australia and a member of the PwC Global Board. Other former directorships include Scotch College and Lauriston Girls School. Michael has three daughters and is married to Tatty, who is a breast cancer survivor.



Lisa Montgomery

With more than 30 years experience in the consumer lending and finance sectors, Lisa Montgomery is a respected leader, commentator and consumer advocate within the Australian financial services industry. Lisa has held chief executive roles in both public and privately held companies and is a regular on Sky News Australia and Sky News Business Channel, where she appears as a consumer finance and property specialist. In 2012, Lisa was diagnosed with breast cancer and subsequently retired from her role as Chief Executive Officer of Resi Mortgage Corporation. She continues to enjoy her 'encore' career as a strategic business adviser and finance specialist. She is a foundation committee member of the Sydney chapter of the Hunter Medical Research Institute (HMRI).



Raelene Boyle, AM MBE

Raelene represented Australia in track and field at three Olympic Games. She won three Olympic silver medals, seven Commonwealth gold medals and two Commonwealth silver medals. In 2007, she was made a Member of the Order of Australia in recognition of her work with cancer organisations, particularly BCNA. Raelene is one of the National Trust's 100 Living Treasures, a member of the Sport Australia Hall of Fame and of the Australian Track and Field Hall of Fame, and was named in Australia's Top 100 Sportswomen of All Time. Raelene was diagnosed with breast cancer in 1996.



Bruce Mann

Bruce trained as a surgeon in Melbourne and then as a breast specialist at Memorial Hospital in New York. He came back to Melbourne in 1998 as a consultant surgeon, and was appointed Director of the Breast Service at Royal Melbourne and Royal Women's Hospital in 2007, and Director of the Breast Tumour Stream of the Victorian Comprehensive Cancer Centre in 2015. He has been active in many organisations, including Cancer Australia, the Royal Australasian College of Surgeons, the Clinical Oncological Society of Australia, and the Australia and New Zealand Breast Cancer Trials Group. His interests relate to systems for optimal breast cancer care and research to tailor the extent of breast cancer treatment to the individual patient.



Jacinta Elston

Jacinta is an Aboriginal woman from Townsville who has worked in Aboriginal and Torres Strait Islander health in higher education for more than two decades. In her current role, she is Associate Dean, Australian Aboriginal and Torres Strait Islander Education and Strategy in the Division of Tropical Health and Medicine, and Co-Director of the Anton Breinl Research Centre for Health Systems Strengthening at James Cook University. Jacinta was diagnosed with breast cancer in 2003.



Megan James

Megan is the General Manager at Australian Data Centres. She has an Advanced Diploma of Marketing in business and marketing. She has worked in IT since 1998 with her experience covering software, hardware, storage and the data centre market. Megan has a passion for starting new businesses, seeing them evolve and setting future strategic directions. Her current role involves providing solutions to the Australian Government and commercial enterprises. She moved to Canberra in 2014 to give the business a greater focus. Megan has a passion for health and wellbeing and is involved with her children in AFL, swimming and athletics. Megan was diagnosed with breast cancer in 1996 and again in 2012.



Dorothy Keefe

Dorothy graduated in medicine from the University of London in 1986, migrated to Australia and became a Fellow of the Royal Australasian College of Physicians (FRACP) in 1996. She received her Doctorate of Medicine from the University of Adelaide in 1999. Dorothy is the Clinical Ambassador for the Transforming Health initiative in SA, Professor of Cancer Medicine at the University of Adelaide, and a Senior Medical Oncologist at Royal Adelaide Hospital Cancer Centre. In the 2013 Queen's Birthday Honours, Dorothy received the Public Service Medal for 'outstanding service in the areas of public health, medical research and oncology'.



Debbie Smith

Debbie has been a partner with PwC for more than 10 years. She is the Managing Partner for Queensland, leading a team of 700 people. She has an extensive background in audit and governance and works with organisations in the public and private sectors. Debbie also sits on the Board of St Margaret's Anglican Girls School. She has two children and is a breast cancer survivor.

In 2016 we farewellled Marg O'Donnell AO and Christobel Saunders from the Board after many years of service. We thank them for their significant contribution to BCNA.

Our Patron



I have valued enormously the opportunity to support the work of Breast Cancer Network Australia since it was established. I have been deeply impressed by the organisation's commitment and creativity, and the hard work that Breast Cancer Network Australia does day after day.

The Honourable Dame Quentin Bryce AD, CVO



Community Liaison

Lan

When I was diagnosed with high-grade breast cancer about two-and-a-half years ago, I was largely clueless about cancer. There was no doubt in my mind that there would be life after cancer for me. I had three young children who were five, eight and nine at the time, and a partner with whom I'd made lifelong plans.

In my search for information, I was able to find answers to my questions from BCNA's website, along with other valuable information that I hadn't thought about, such as how to assist family and friends affected by my diagnosis. BCNA's online network also connected me with other women like myself.

There were lots of decisions I had to make in a very short time frame. The information and support services provided by BCNA online were exactly what I needed. The *My Journey Kit* and *My Care Kit* I received from BCNA free of charge were also a godsend.

A friend suggested I become a Community Liaison representative for BCNA. I'd been privately supporting others going through breast cancer, so the opportunity to do this through BCNA was perfect.

BCNA has connected me with many like-minded people and organisations so that I can better support others affected by breast cancer. I'm very honoured to be one of BCNA's Community Liaisons.

Lan
BCNA Community Liaison
and breast cancer survivor

Our members

Our members are people from around Australia who have been affected by breast cancer. These include women and men who are newly diagnosed, undergoing or who have finished treatment, and people living with metastatic breast cancer. More than 90 per cent of our members have had a breast cancer diagnosis. The remaining members have been affected by breast cancer through the personal experience of a family member, friend or colleague. In 2016, our membership grew to more than 120,000.

Member Groups

From Bunbury to Bundaberg, from Darwin to Devonport and everywhere in between, BCNA Member Groups support people in their local communities around Australia. Each group is unique, providing its own form of peer support. Member Groups help to spread the word about our resources and services, participate in our programs and events, and raise awareness about breast cancer and BCNA.

By the end of 2016, there were 288 BCNA Member Groups.

57 per cent of Member Groups are in regional areas.

4 per cent of Member Groups are in remote areas.

Community Liaisons

Many people who have experienced breast cancer want to know how they can give back to their local community. Our Community Liaison program, established in 2007, helps to give people diagnosed with breast cancer the skills and training they need to connect with others in their communities.

We recruit, train and support volunteer Community Liaisons to raise awareness of the impact of breast cancer, support others at a community level, promote BCNA and expand the network.

This program also broadens BCNA's understanding of and reach into communities where support may be limited. We received funding from the *Supporting Women in Rural Areas Diagnosed with Breast Cancer* program, funded by the Australian Government through Cancer Australia.

Community Liaisons



In 2016, 14 women completed Community Liaison training, including three from culturally diverse backgrounds.

By the end of 2016, 242 trained Community Liaisons volunteered in their communities. This included 15 women with metastatic breast cancer and 17 women from culturally diverse backgrounds.

As a national organisation with community volunteers Australia-wide, opportunities for ongoing training are limited. In 2016 we piloted two online learning programs that could be accessed by participants in all locations across Australia. The programs increased the knowledge, skills and confidence of BCNA volunteers in supporting people in their communities affected by breast cancer.

Our services

A diagnosis of breast cancer marks the beginning of a journey for each person and the people around them. It's a journey that BCNA shares with our members, and we work to provide the information and support that our members need at different stages.

My Journey Kit

Most of our members start their journey with BCNA with our *My Journey Kit*. This free, comprehensive resource aims to help them navigate a very challenging time in their lives. The *My Journey Kit* provides information in a way that is easy to understand. It helps women make decisions about treatment, understand their emotions and consider life after treatment. It provides a place for women to keep track of appointments and links to other resources that may help them.

In 2016, 12,839 people received a *My Journey Kit*. More than 80 per cent of women newly diagnosed with breast cancer received a kit in 2016.



My Care Kit

For most women diagnosed with breast cancer, surgery will form part of their treatment. The free *My Care Kit* aims to help in their recovery from surgery. It contains a specially designed Berlei bra and soft forms, as well as a Pilates DVD to help women regain strength following their surgery.

In 2016, 13,790 women received a *My Care Kit*.



Helpline

When your world is turned upside-down by a breast cancer diagnosis, the reassurance of a voice on the end of a telephone can go a long way. Our Helpline provides information about breast cancer and issues that may be concerning callers, and refers them to available supports.



The Beacon

The Beacon is our free quarterly magazine that has resonated with BCNA's membership since the first issue was sent out in 1998. Each edition includes stories from women sharing their experiences, as well as information on the latest research and treatment, events, programs and issues relevant to women and their families.

More than 114,000 subscribers received a copy of *The Beacon* each quarter.

In 2016, more than 12,000 people read *The Beacon* online.



The Beacon

Booklets and fact sheets

We provide free information to people to allow them to keep up to date and informed on key aspects of breast cancer research, treatment and care.

Our range of booklets and fact sheets, available to order and download, covers important information for people affected by breast cancer. This year we produced and distributed the following new resources:

- BRECONDA online breast reconstruction decision aid
- *Sleepless nights: breast cancer and sleep* fact sheet
- *Superannuation and insurance payments for people with a terminal illness* fact sheet.

We distributed more than 10,000 booklets and fact sheets in 2016.

The Beacon online



Sleepless nights fact sheet

In November 2014, only a few short months after starting a new job, I was told that the lump on my left breast was breast cancer. I was 29, fit and strong (I could do 11 chin-ups), with no family history and no known risk factors.

Cancer changes everything. The treatment strips you bare. It snatches away your control, your identity, and makes you address hard and difficult things, like death and dying. Cancer can make you feel like a non-human – alive, but not fully functioning.

Despite all the wonderful support I received from friends and family, most times, nobody wanted to talk about the 'bad' stuff – as long as I remained positive then everything would be okay.

According to the Tasmanian Cancer Registry, on average one woman in her 20s is diagnosed with breast cancer each year. Local support groups for young women do not exist.

Thanks to BCNA's online network, I was able to connect with other young women just like me from all parts of Australia. Connecting with other women helped me to feel less isolated – I now had an opportunity to talk about my pimply bald scalp, the joy of chemically induced menopause, my very real fears of recurrence and how to reclaim my sense of self after treatment.

Thank you BCNA and the wonderful women on the online network for holding my hand during such a difficult period in my life.

Tiffany
Breast cancer survivor



Online network member

Tiffany

Online support

After receiving a diagnosis of breast cancer, many people look to the internet for answers. While there is plenty of helpful information to be found, there is also information that may be unhelpful, inaccurate and scary.

BCNA's website is a comprehensive resource for those wanting information or to learn about the activities, initiatives, support groups, programs and services we offer.

In September, we launched our new online network. The online network provides a secure, positive and supportive environment for people diagnosed with breast cancer and their supporters, 24 hours a day.

The new platform provides an easy-to-use, mobile and tablet friendly community, designed for the unique needs of people diagnosed with breast cancer.



Online network

BRECONDA

Women who undergo mastectomy face the difficult decision of whether to restore breast shape after surgery. Studies show that 20-30 per cent of Australian women feel regret following their decision about breast reconstruction. This can be because women are stressed at the time of making a decision and don't have enough information on the sorts of things they need to think about in making their decision.

In 2016, we made a free decision-making tool available on our website for women considering whether to have a breast reconstruction. BRECONDA guides women through a series of questions to help decide if a breast reconstruction is right for them. The tool was developed by researchers at Macquarie University.

Promoting healthy eating and exercise

Research shows that healthy eating and exercise can not only help to manage the physical and emotional side effects of breast cancer treatment, but can also reduce the risk of breast cancer recurrence. However, there are very few health and lifestyle programs targeted specifically at women diagnosed with breast cancer.

In 2016, 104 of our Community Liaisons and Member Groups leaders participated in our first online wellbeing workshop. The training included three comprehensive modules, which aimed to increase healthy lifestyle knowledge, skills and confidence by improving accessibility of information.

In September, we also held our first four-week walking challenge. The 170 registered participants formed teams and collectively walked 46,396 km.



Walking challenge

Forums

Our members often tell us their breast cancer diagnosis made them feel isolated and alone. We provide them with information, support and connection, in person and online.

Information forums are free for people diagnosed with breast cancer, their partners, family and supporters. They provide information about the latest treatment and care, medical and holistic wellbeing and breast cancer services and support available in local communities. Our forums are developed from identified needs in the community and help establish connections with local cancer-related service providers and people who have had similar experiences.

In 2016, more than 2,100 people attended forums. The forums were held in Traralgon, Orange, Perth, Busselton, Kalgoorlie, Mackay, Brisbane, Roma, Newcastle, Sydney, Healesville and Hahndorf.

Our rural and regional forums were presented as part of the *Supporting Women in Rural Areas Diagnosed with Breast Cancer* program, funded by the Australian Government through Cancer Australia.



We also presented our first information forums in Vietnamese. Forums were held in Sunshine North and Springvale in Victoria. The events were a success due to our strong partnerships with Springvale Indo-Chinese Mutual Assistance Association (SICMAA), the Vietnamese Community in Australia (VCA) and the VCA Women's Association.



I was first diagnosed with breast cancer more than 20 years ago. I wish that BCNA was around then – there was very little information and I found it hard to find a support group.

After my treatment, for 15 years I had annual mammograms and ultrasounds, which always came up clear. However, at 66 years old, I began experiencing terrible back pain. After an X-ray and bone scan, I was diagnosed with metastatic breast cancer in the bones.

I was back on the roller-coaster ride that is breast cancer. It was during this time that I found BCNA. After ringing the BCNA office, I spoke to a lovely lady who was very helpful. She sent me a copy of *Hope & Hurdles*, plus information on bone metastases. I also discovered there were forums that I could attend to connect with others in a similar situation.

I have attended two BCNA forums – at Port Macquarie and Newcastle. I have found them very informative, giving me more knowledge about metastatic disease, new treatments and support with coping. It was good to meet and talk with other women and realise that I am not alone. My husband attended as well and said it was good to talk to other men and carers.

It has been five years now since my metastatic breast cancer diagnosis. I am so pleased I found BCNA for all the help and support they have given me.

Wendy

Living with metastatic breast cancer

Forum attendee

Wendy

In September 2009, at the age of 49, I was shocked to discover a lump in my breast. After tests, it was confirmed I had breast cancer. A few weeks later, I was devastated when told the cancer had already metastasised to my liver.

I found out about BCNA through a poster at my oncology unit. I rang up for the *My Journey Kit*, which had lots of information about the tests and my diagnosis. However, it wasn't specifically aimed for my situation.

Luckily, a few months later I was told of *Hope & Hurdles*, BCNA's resource for metastatic breast cancer. I gained hope by reading of other women's experiences, which made me feel less alone. I am glad that there is a section within *Hope & Hurdles* specifically for those with metastatic breast cancer as their first diagnosis.

Since that time, I have had two recurrences - in 2011 in my brain and in 2014 in lymph nodes in my neck. Thankfully, treatment has worked in both cases and I continue with three-weekly infusions of Herceptin.

I am grateful to BCNA for giving me hope, through talks by oncologists and medical specialists at BCNA information forums and by being able to connect with other women in a similar situation.

Gillian
BCNA Community Liaison
living with metastatic breast cancer



Hope & Hurdles recipient

Gillian

Metastatic breast cancer is breast cancer that has spread from the breast to other organs in the body, most often the bones, lungs or liver.

Hearing that your breast cancer has spread can be devastating. For some people, their diagnosis of metastatic breast cancer is their first diagnosis of breast cancer. BCNA works to support the thousands of Australians living with metastatic breast cancer, recognising that they face complex emotional, practical and physical challenges associated with lifelong treatment pathways. We also aim to raise awareness of metastatic breast cancer throughout the community and advocate for improved access to specialised support services and new and innovative treatments.

Hope & Hurdles

BCNA's *Hope & Hurdles* information pack provides information to help people diagnosed with metastatic breast cancer to cope with their diagnosis and to make decisions about treatment, care and wellbeing.

After a comprehensive review, the third edition of *Hope & Hurdles* was launched on 13 October to coincide with Metastatic Breast Cancer Awareness Day.

The review took into account extensive feedback from people living with metastatic breast cancer, as well as the health professionals involved in their treatment and care.

829 people received a *Hope & Hurdles* kit in 2016.



The Inside Story

The Inside Story is a supplement to *The Beacon* and provides tailored information and support written for people diagnosed with metastatic breast cancer.

More than 7,500 subscribers received a copy of *The Inside Story* each quarter.



Someone to talk to

Due to the overwhelming evidence around the need for improved access to emotional support, including support for families, BCNA continued to offer a free expert telephone counselling service throughout 2016 for people affected by metastatic breast cancer. Women, men and their family members can access confidential professional counselling over the phone with experienced oncology counsellors, at a time and place that is convenient for them.

Our voice

Advocacy

A key part of our mission is to advocate on behalf of Australians affected by breast cancer. We work to ensure their voices are heard whenever decisions about breast cancer are made and to ensure they receive the best possible treatment and care. We listen to the diverse experiences of people diagnosed with breast cancer, as well to their family, friends and colleagues.

In 2016, we made submissions to both major political parties in the lead-up to the federal election, outlining our priorities for new funding to better support Australians with breast cancer.

We also advocated throughout the year on a number of issues of relevance to Australians affected by breast cancer, including:

- proposed changes to Medicare bulk billing incentives
- in-home child care for families with very young children with a parent with cancer
- Medicare rebates for breast MRI
- retention of pathology specimens beyond 10 years
- improved access to specialised breast care nurses for people with metastatic breast cancer
- improved access to superannuation and insurance for people with terminal illness.

We continued to advocate for drugs to be made available through the Pharmaceutical Benefits Scheme (PBS), including Nolvadex (tamoxifen) for women at increased risk of developing breast cancer and Herceptin SC (the subcutaneous form of Herceptin). Both of these were subsequently listed on the PBS.

Submissions were made to the Medical Services Advisory Committee in support of fertility items for young people diagnosed with cancer and access to the Oncotype DX gene assay test.

State of the Nation

BCNA was founded on the voices and experiences of Australians diagnosed with breast cancer. In 2016, we began our landmark State of the Nation project. As well as documenting how far we've come in the past 20 years, this project is helping to identify the gaps in treatment and care for our members of today, and will set our agenda into the future.

In 2016, we identified international and national best practice, developed our member survey and began consultations with people affected by breast cancer. The State of the Nation report will be released in 2018 to coincide with our 20th anniversary.

Strategic Advisory Group

BCNA's Strategic Advisory Group comprises health professionals who work in a wide range of cancer-related fields. The group informs and supports our work on behalf of women, men and their families.

We thank the members for their ongoing support: Prof Fran Boyle, Assoc Prof Meagan Brennan, Prof Phyllis Butow, Dr Susan Fraser, Prof Dorothy Keefe, Dr Mustafa Khasraw, Dr Gillian Lamoury, Prof Bruce Mann, Dr Vivienne Milch, Ms Kerry Patford, Assoc Prof Wendy Raymond, Prof Christobel Saunders, Dr Magdalena Simonis, Prof Andrew Spillane and Prof Jane Turner.

I was only 48 years old when I was diagnosed with breast cancer. My husband and I were truly shocked when we heard those four chilling words, 'You have breast cancer'. However, those four words provoked a determined desire in me to survive – I had a lot more living to do.

I was first introduced to BCNA within days of my diagnosis, through the *My Journey Kit*. This kit quickly became my daily companion during treatment. That was in 2009, and while the edges have softened, the memories of that time never truly abate.

The year after my diagnosis, a friend and BCNA volunteer introduced me to the welcoming team at BCNA. That was the start of various volunteering roles – the most enjoyable and challenging being that of a BCNA Consumer Representative.

Through this role, I have been involved in various research committees alongside scientists and medical practitioners. I always strive to represent the views of those affected by breast cancer. It has been rewarding to see increased recognition in the value and experience a Consumer Representative can bring to the table.

I am proud to be a part of the BCNA Consumer Representative cohort. I look forward to continued involvement in raising the profile of this vital role and advocating on behalf of Australians affected by breast cancer.

Kym

BCNA Consumer Representative, Community Liaison and breast cancer survivor



Consumer Representative

Kym

Review & Survey Group Seat at the Table

BCNA members have the opportunity to be involved in a range of research projects through our Review & Survey Group. The group is comprised of approximately 2,400 people diagnosed with breast cancer. We connect researchers to members of this group who have experiences relevant to the research. Our ability to connect with our membership and to link them to researchers and decision makers will continue to help improve outcomes. In 2016, Review & Survey Group members were invited to participate in 23 research projects, including:

- the Sexual Wellbeing After Breast Cancer (SWAB) Study, which examines the effectiveness of a low-dose testosterone cream to reduce vaginal side effects of aromatase inhibitor therapy
- a study exploring whether an online program can help increase the physical activity levels of people diagnosed with breast cancer
- research exploring the experiences of women living with metastatic breast cancer and their expectations of the health system.

Since 2000, BCNA has run the internationally recognised Consumer Representative program Seat at the Table. This program ensures decision makers in the national and state health systems are connected to the experiences of women and men diagnosed with breast cancer, and those who support them.

We invite, train, appoint and support our members to become BCNA Consumer Representatives. They participate on committees and research panels across the country and internationally, and provide the consumer perspective on a wide range of research and program development. Consumer Representatives also contribute to the development of BCNA submissions and resources.

In 2016, 14 women completed Consumer Representative training and five current Consumer Representatives completed refresher training. By the end of 2016, there were 92 BCNA Consumer Representatives on 76 ongoing committees and research projects, including:

- a Cancer Australia working group to update a guide on the investigation of a new breast symptom
- BreastScreen South Australia State Quality Committee
- research exploring the experiences of women aged over 70 who have been diagnosed with low-risk DCIS via a screening mammogram
- the Register4 Access Committee.

Consumer Representatives



Research

Leading and collaborating on a diverse range of research projects is a key advocacy strategy for BCNA.

Our research agenda is driven by our knowledge of the experiences and issues facing women with a breast cancer diagnosis. We have established strong connections with academics who need women to assist their breast cancer research. Our members provide powerful insights into the physical and emotional effects of a breast cancer diagnosis and treatment.

In 2016, BCNA led the following research projects:

- evaluation of BCNA's regional forums (funded by Cancer Australia)
- financial impact of breast cancer (contracting Deloitte Access Economics to conduct the quantitative component)
- generic medicines survey (testing awareness of For Benefit Medicines)
- return to work scoping (funded by Sussan Group)
- review of *Hope & Hurdles* (in preparation for the third edition)
- research to support the development of metastatic breast cancer resources for Chinese and Greek women
- treatment decisions of rural women diagnosed with breast cancer (funded by Cancer Australia).

BCNA participated in 14 collaborative projects with external researchers, including:

- Breast cancer and chronic illness (Flinders University)
- Breast cancer in pregnancy: surveillance, management, outcomes and experiences (University of New South Wales)
- Demystifying palliative care for Australians affected by breast cancer (Palliative Care Australia)
- development of a DCIS information resource and decision aid (University of Sydney)
- development of a tailored supportive care intervention for women living with advanced breast cancer (Peter MacCallum Cancer Institute, BreaCan, Cancer Council Victoria)
- effect of aromatase inhibitors on the muscular-skeletal health of women being treated with an aromatase inhibitor (ANZ Breast Cancer Trials Group)
- exploring the socioeconomic impact of living with lymphoedema (Macquarie University)
- exploring women's concerns about neoadjuvant chemotherapy for breast cancer (ANZ Breast Cancer Trials Group)
- lymphoedema services in Victoria (Cancer Council Victoria, Australasian Lymphoedema Association, Lymphoedema Association of Victoria)

- Maximising benefits and minimising harms in the BreastScreen program: a population health economics modelling approach (University of Melbourne)
- routine screening of Ashkenazi Jewish women (Ovarian Cancer Australia)
- testing and evaluation of a patient decision aid for women with early stage unilateral breast cancer considering contralateral prophylactic mastectomy (University of Sydney)
- the Women's Wellness after Cancer Program (Griffith University)
- women's experiences of recall and assessment through BreastScreen Australia following mammogram (BreastScreen, Monash University, Deakin University).

Men with breast cancer

In 2016 we undertook a consultation project to look at the gaps in information and support for men diagnosed with breast cancer and what BCNA and others can do to better support them. The project has helped us to tailor information for men, reach more men who are newly diagnosed and promote awareness of male breast cancer in the community.

I had been a Bakers Delight franchisee for five years when I was diagnosed with breast cancer in 2006.

Our Bakers Delight-BCNA partnership saved my life by raising my awareness to seek early medical help. It sustained me during my darkest treatment days and now gives me hope that we are reaching and helping so many more people affected by this insidious disease.

Customers sharing their breast cancer stories across the counter, staff dressing up in crazy pink clothing, bakers working through the night and then lovingly icing our pink finger buns to help others is a humbling experience. It is a privilege that I am lucky enough to share.

I like to think that our two stores are a couple of sprinkles on a giant Bakers Delight-BCNA finger bun that stretches across Australia. We all come together once a year to build this bun, reach out to our communities and then leave a wonderful lingering taste until the next year. I hope this finger bun reaches those that need it and gives them the strength and support BCNA gave me.

Knowing that I am part of this finger bun mosaic fills me with a purpose and sense of pride. It also reminds me of how much work we still need to do and how our Bakers Delight-BCNA partnership is something we should all treasure.

Joanna
Bakers Delight franchisee and breast cancer survivor



Bakers Delight franchisee

Joanna

Our supporters

We know that working with others helps us achieve better results. Our strong connections with organisations and individuals to help strengthen our network, raise awareness of our cause and reach more women, men and supporters. We are very proud of our long-term and enduring partnerships with organisations that are committed to supporting Australians affected by breast cancer.

Major partners



Foundation Partner Bakers Delight has supported BCNA since 2000, with more than \$16 million in funds and pro-bono services donated to date. Every year since 2004, Bakers Delight bakeries across Australia have 'pinked up' for the annual Pink Bun campaign. To date, Bakers Delight has sold almost five million buns through the Pink Bun campaign. In May, almost 600 Bakers Delight bakeries turned pink for three weeks, and raised an incredible \$1.5 million.



Focus on Furniture's relationship with BCNA began through Shane Crawford's Tour de Crawf in 2013. Focus on Furniture has continued to support BCNA through the sales of a specially designed cushion range, from which 100 per cent of profits are donated to BCNA.



Berlei has worked with BCNA to support women affected by breast cancer for the past 11 years. Over this time, Berlei has donated more than 120,000 mastectomy bras for our *My Care Kits*, for women who have recently had breast surgery. In October, The Chrissy Bra range was launched in tribute to rock icon Chrissy Amphlett. The range includes a post-surgery bra and a t-shirt bra, with 100 per cent of the profits donated to BCNA.



Red Energy began supporting BCNA with the inaugural Pink Lady Match in 2015. Since then, the organisation has become one of our Major Partners. Red Energy was the Major Event Partner for the Pink Lady Match, as well as the Pink Lady luncheons in Melbourne and Sydney, and has supplied volunteers at events.



Our relationship with Sussan began in 2005 with the in-store sale of a limited edition bag. Since then, Sussan has donated more than \$1.7 million to BCNA. In 2016, Sussan continued to support our work with women from culturally diverse backgrounds and also supported new research around the challenges in returning to work after a breast cancer diagnosis. From October, Sussan stores featured a beautiful gift bag range, with \$1 from every sale donated to BCNA.



The Australian Government supports BCNA through Cancer Australia's *Supporting Women in Rural Areas Diagnosed with Breast Cancer* program and also contributes towards producing the *My Journey Kit* and *Hope & Hurdles*.

Partners

- Alliance Airlines
- Collins Foods Limited
- Department of Health and Human Services (Victoria)
- Estée Lauder Companies
- Fernwood Fitness
- Konica Minolta
- Manildra Group
- New Idea Charitable Fund
- SkyBus
- Star Packaging Solutions
- The Finishing Touch
- Vic Mix

SkyBus



Product partnerships

- Ardor Home Australia
- Australian Charity Christmas Cards
- Callaway
- Carman's Fine Foods
- Cold Rock
- Dunlop Flooring - Carpet One and Harvey Norman
- Earth Bottles Australia
- First Class Hampers
- Florsheim
- Godfrey Hirst - Commercial
- Jaggad
- JOCO Cups
- KitchenAid
- LIV Giant
- Lluís&Co.
- Ritchies Supermarkets
- Russell Corporation
- Showcase Jewellers
- Spa Wellness Travel
- Vevoke
- VS Sassoon
- Yabby Lake
- Yates

Supporters

- Australian Football League
- *The Australian* newspaper
- Australian Multiwall Bag
- Australian Radio Network Company
- Chandler Macleod
- DesignGrant
- For Benefit Medicines
- Good2Give
- Herbert Smith Freehills
- HWL Ebsworth Lawyers
- Melbourne Cricket Club
- Melbourne Football Club
- Nine Network
- SEEK
- Seven Network SME360
- South Bank precinct, Brisbane
- Sports Technology Group
- TLA Worldwide



VIC CONCERT MIX

Carman's
Real food made with real passion.



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sussan



Without the generosity of everyday Australians we would not be able to continue to support those affected by breast cancer. Through national and local events, we reach out to communities around Australia to build our profile and raise essential funds to maintain and expand our programs and services. Our events also help to ensure our members feel supported in their own communities.

Pink Lady Match

Following the success of the inaugural event in 2015, the 2016 Pink Lady Match celebrated our 10-year partnership with the Melbourne Football Club, the Australian Football League, and the Melbourne Cricket Club.

On Sunday 15 May, the Melbourne Cricket Ground was sea of pink, thanks to Major Event Partner Red Energy, which provided 7,000 pink caps for fans attending the match.

Before the game, breast cancer survivors and supporters participated in a walk of honour on the ground, and a minute's silence was held in honour of all Australians affected by breast cancer.

The day also included the inaugural Pink Lady Match Exquisite High Tea.



Pink Lady luncheon series

After successful events in Melbourne, Brisbane, Perth and Canberra, we were thrilled to expand our Pink Lady luncheon series in 2016 to include Sydney.

Guests heard from inspiring special guest speakers Ita Buttrose OA, OBE; The Hon. Dame Quentin Bryce AD, CVO; Rosemary Vilgan; The Hon. Nick Greiner AC and Christine Holgate.

Dine Pink

In October, retailers and landmarks in Brisbane's South Bank precinct were lit in pink. The week-long event saw more than 20 restaurants participate in our Dine Pink campaign, which featured pink tables and specially themed menus, with proceeds donated to BCNA.

Pink Butcher

Inspired by an Adelaide breast cancer survivor, butcher and BCNA supporter, the Pink Butcher campaign saw independent South Australian butchers turn pink for the month of October, and sell a range of special products to support BCNA.

100K for BCNA

The 100K for BCNA campaign saw 69 Fernwood Fitness clubs nationwide join together to raise an incredible \$128,000 for BCNA during November. Throughout November, clubs hosted a range of fundraising activities.

Many clubs held additional events to get their local communities involved, including silent auctions, raffles, fitness challenges and morning teas. A number of BCNA Community Liaisons delivered presentations in their local Fernwood clubs, sharing their personal stories and inspiring the local community to get involved.





Brave for BCNA

The Brave for BCNA challenge dared BCNA supporters to raise funds and awareness for BCNA by skydiving. In February, 39 daring participants skydived from up to 14,000 feet and together raised more than \$127,000.

Mini-Fields of Women

Mini-Fields of Women give communities the opportunity to come together to pay tribute to those affected by breast cancer, to provide messages of hope, and to mourn. One hundred Pink Lady silhouettes, on which people can leave messages, are planted in formation.

118 communities held Mini-Fields of Women.

Pink Lady events

Pink Lady events are fundraising events that also raise awareness of support within communities and the information and assistance BCNA provides.

449 supporters held Pink Lady events.

Pink Sports Day

From netball courts to football fields and soccer pitches, sporting grounds around Australia turned pink for Pink Sports Day in 2016. Held throughout the year, Pink Sports Days raise funds and awareness, while showing support for families affected by breast cancer in the community.

284 Pink Sports Days were held with 890 clubs participating.



Fun runs

From 3 km walks to marathon runs, in 2016 fun run events were held all across the country. In December, we were thrilled to be the official charity partner for the Carman's Women's Fun Run, which raised more than \$180,000.



Inspired Adventures

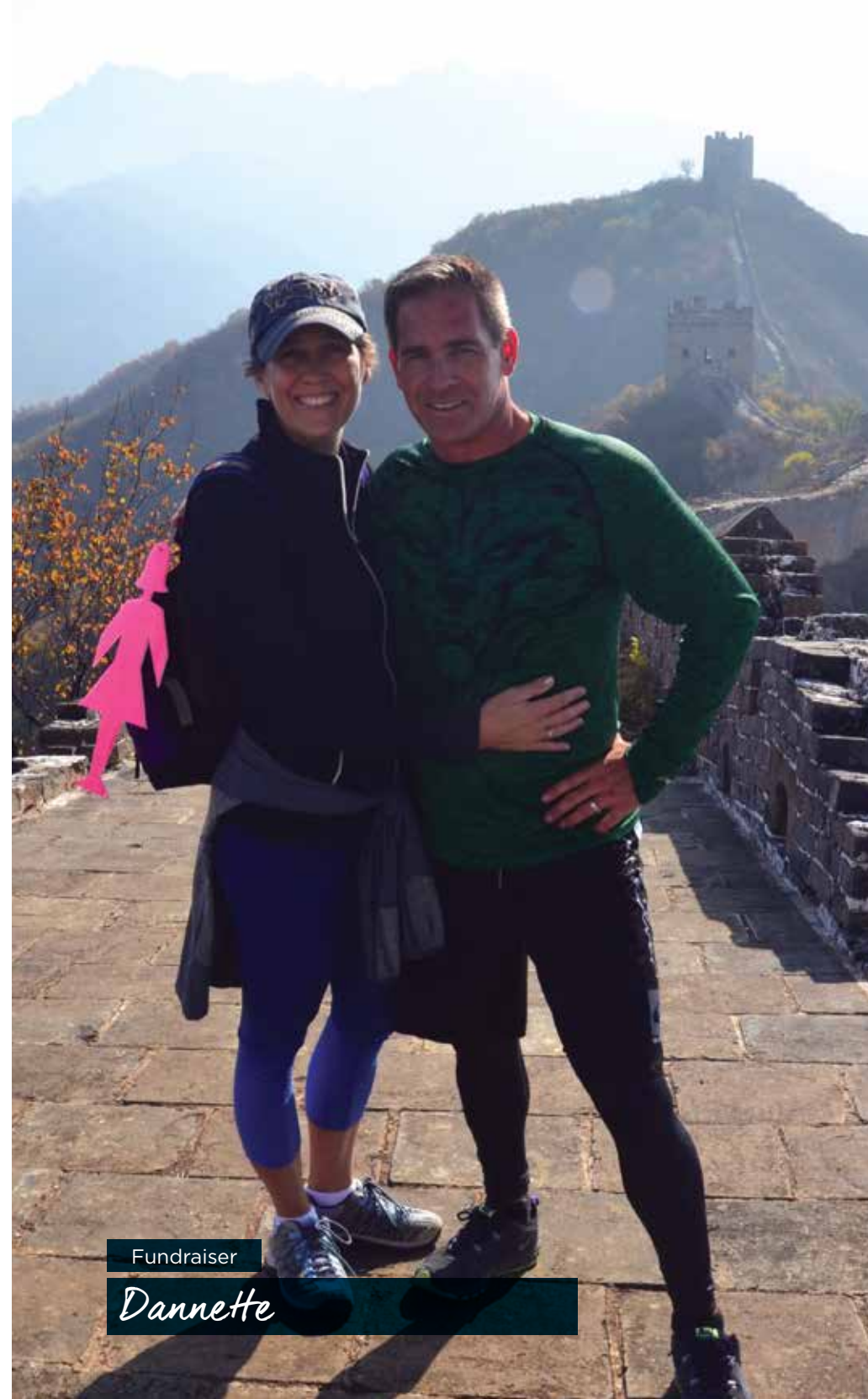
For some, an Inspired Adventures challenge is a celebration – at completion of treatment, or to mark another year of survival. For others, a personal challenge is taken in tribute to a loved one diagnosed.

In May, 27 supporters trekked the El Camino in Spain. Then in October, 22 participants scaled the Great Wall of China as part of the Steps for Support challenge. Together the groups raised more than \$280,000.

Dannette and her husband completed the Inspired Adventures trip to the Great Wall of China.



El Camino group



Fundraiser

Dannette

At 41, I was very busy, with two beautiful daughters and working full-time, but I still tried to maintain a fit and healthy lifestyle. I was the fittest I had ever been, which is why my breast cancer diagnosis came as a complete shock.

BCNA gave me the most amazing support and information throughout my diagnosis and beyond. After finishing treatment, I wanted to give back to BCNA for the support that was given to me, and when the opportunity to complete a bucket list item popped up on my Facebook feed, I jumped at it.

I had always wanted to walk the Great Wall of China, and BCNA's Inspired Adventure was the perfect chance to celebrate the end of my treatment with my husband and give back to BCNA.

It also gave me a goal to aim for and a time frame to complete it in, which helped me to get my fitness and strength back.

The Inspired Adventure gave me an opportunity to meet and connect with other women who have also travelled the breast cancer journey. We bonded during a much more enjoyable journey, trekking along one of the most amazing landmarks in the world.

Together, my husband and I raised almost \$10,000 for BCNA. In return, we received valuable memories to last a lifetime.

Dannette

BCNA fundraiser and breast cancer survivor

Our finances

Where our money comes from

Thanks to our generous supporters, BCNA's income in 2016 was \$7,855,863, \$821,665 more than 2015. Our fundraising income is generated through corporate partnerships, community fundraising, appeals, donations, bequests, challenges and BCNA events, campaigns and activations.

We wish to acknowledge the support received from Cancer Australia and the Department of Health and Human Services, Victoria.

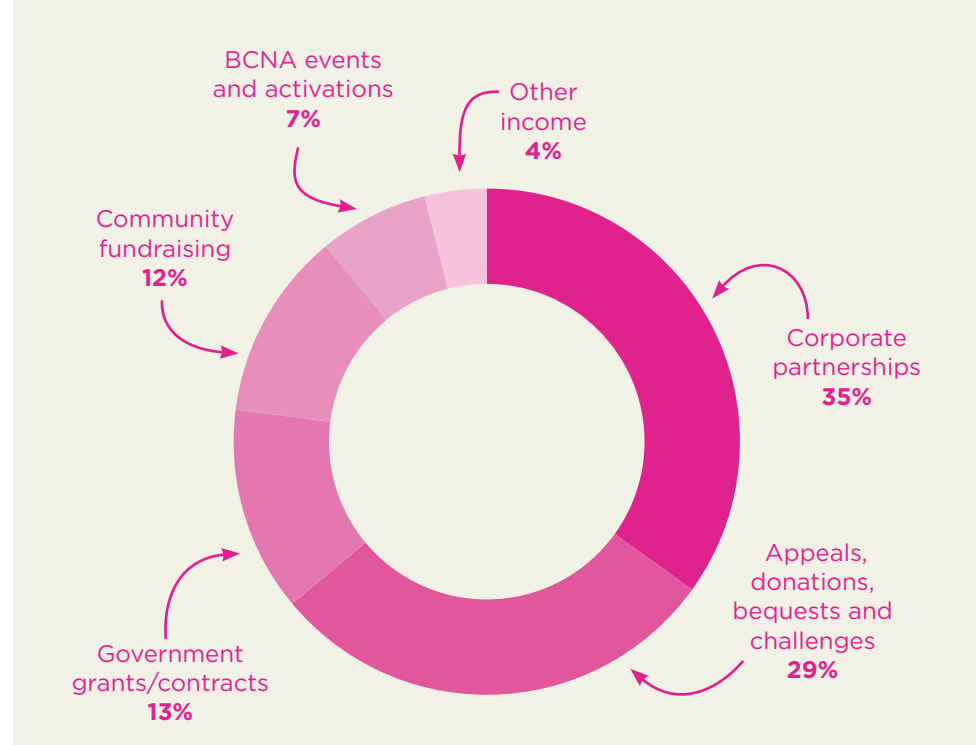
BCNA also maintains a modest investment portfolio, including term deposits, managed funds, listed investment companies and hybrid securities. These investments generate an income that is used to support spending on BCNA's programs.

Corporate partnerships \$2,735,000

Our biggest source of income comes from corporate sponsorship, licensing and workplace giving, including the Pink Bun campaign.

Appeals, donations, bequests and challenges \$2,290,000

This is money donated to us by members and other generous supporters in the community,



either as a one-off donation, or as a regular contribution. Donations raised through participation in fun runs, Inspired Adventures and other challenge events are also included here.

Government grants/contracts \$1,025,000

We received grants from the *Supporting Women in Rural Areas Diagnosed with Breast Cancer* program, funded by the Australian Government through Cancer Australia and from the Victorian Government through the Department of Health and Human Services *Victorian Cancer Survivorship Program*.

Community fundraising \$964,000

This is income from events held in communities across Australia, including Pink Lady events, Mini-Fields of Women, Pink Sports Days, Pink Butcher and Dine Pink.

BCNA events and activations \$521,000

We also raised money through our own events, including the Pink Lady luncheon series and the Pink Lady Match.

Other income \$321,000

This includes interest and investment income generated from our bank accounts and investments.

Where our money goes

As the number of Australians diagnosed with breast cancer continues to increase, so too does the demand for BCNA's support and services. In 2016, BCNA's Board supported the Senior Leadership Team's request for an investment from reserves in order to build the organisation's capacity.

Through this investment we sought to better meet the complex and diverse needs of the growing number of Australians affected by breast cancer.

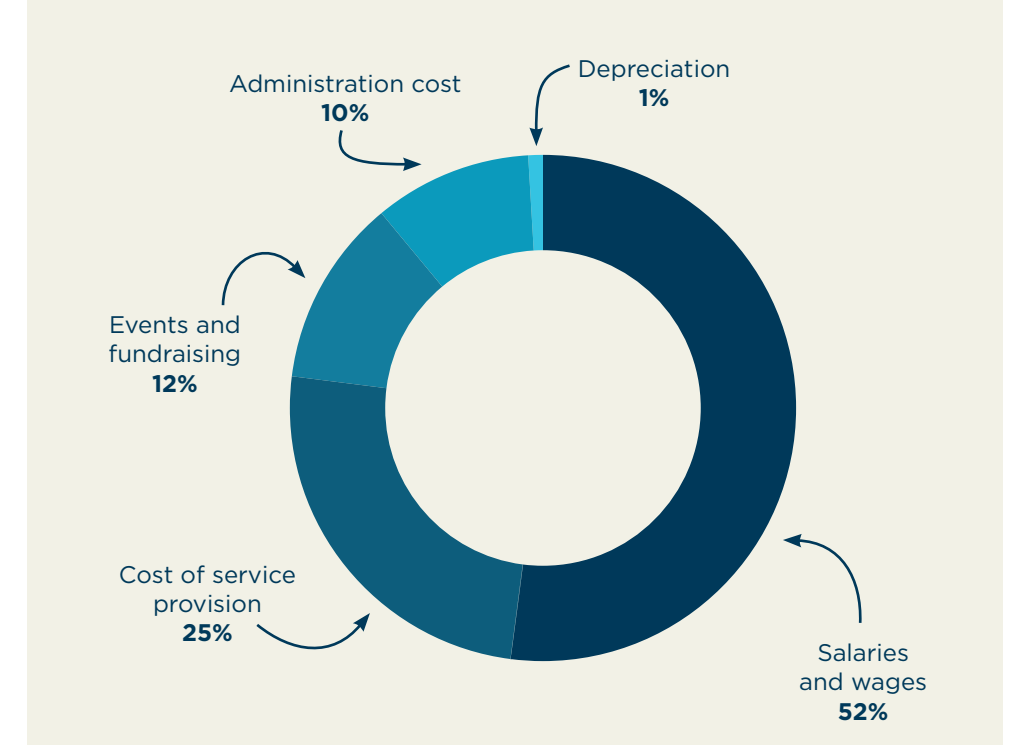
It allowed us to expand our reach by enhancing our national footprint, diversifying our fundraising base and strengthening our organisation, in particular, our people and our digital strategy.

Salaries and wages \$4,527,000

The work of BCNA staff includes developing resources, coordinating and delivering programs and services, lobbying government, undertaking research, holding forums and other events, and much more.

Cost of service provision \$2,137,000

This includes the non-salary costs of providing programs, services and information, such as printing and posting our resources, hosting our forums and providing our online network.



Events and fundraising \$1,056,000

This is the money we spent on supporting our community events, fundraising events, campaigns and activations.

Administration cost \$826,000

Administration costs include all office costs and support functions, including information and communication technology (ICT), finance and business systems.

Depreciation \$124,000

This is a standard business expense relating to the decrease in value of assets over time.

This information is based on the audited financial statements of BCNA and should be read in conjunction with those financial statements.

In accordance with our reporting obligations to the Australian Charities and Not-for-profits Commission (ACNC), a full copy of our audited financial statements can be found at acnc.gov.au.

Our organisation

Staff and volunteers

At the end of 2016, BCNA had a dedicated team of 59 staff in full-time, part-time and casual roles.

In 2016, we appointed two State Development Managers to help expand our reach in New South Wales and Queensland. We hope to appoint State Development Managers in other states and territories in the future.

BCNA is supported by an enthusiastic and committed team of volunteers. This includes office volunteers who help us on a daily basis, and trained breast cancer survivors who represent us in a range of ways in the community.

We could not have achieved what we did in 2016 without our volunteers. We thank them for their ongoing support.



BCNA staff →

Senior Leadership Team as at 31 December 2016



Christine Nolan
Chief Executive Officer



Allison Southwell
Head of Corporate Services



Rozalee Erceg
Head of Development, Fundraising and Events



Kathy Wells
Head of Policy, Research and Advocacy



Danielle Spence
Head of Quality Practice



Louise Rudzki
Head of Brand and Communications



Felicity Munt
Head of Programs and Services

State Development Managers



Jill Rowbotham
New South Wales
March 2016 – present



Margaret Jolly
Queensland
February 2016 – March 2017



Michelle Farquhar
Queensland
March 2017 – present

Get involved with BCNA

Attend a BCNA event

From our annual luncheon series to major events such as the Field of Women, our events bring people together to help make a difference.

Connect with others

Join our online network to connect with others affected by breast cancer.

Donate

Make a one-off donation, set up a regular monthly donation or leave a gift in your will.

Give back while you work

Workplace giving brings employers and staff together to support BCNA. It is an easy and convenient way to donate via pre-tax payroll deductions.

Help with research

If you have been diagnosed with breast cancer, join our Review & Survey Group so you can be involved in research.

Hold a fundraising event

A Pink Lady event can be anything from a simple afternoon tea to a fancy cocktail party. A Pink Sports Day is the perfect way for local sporting clubs to show their support.

Partner with us

We nurture relationships with selected organisations and individuals to help strengthen our network. Contact BCNA to find out how we can work together.

Pink up!

Add a touch of pink to your life and show your support for BCNA by shopping online at bcnashop.org.au.

Set a personal goal

From fun runs to overseas adventures, we have some great ways you can take on a challenge while supporting BCNA.

Speak out


BCNA Consumer Representatives represent the views of Australians affected by breast cancer in a wide range of forums, while Community Liaisons speak about their personal experiences with breast cancer in their local communities.

To find out more, visit
bcna.org.au



 @BreastCancerNetworkAustralia

 @BCNAPinkLady

 @bcnapinklady

1800 500 258
beacon@bcna.org.au



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Network
Australia