

Breast
Cancer
Network
Australia



Executive Summary

Introduction

BCNA has a proud 19 year history and is recognised as Australia's premier charity supporting Australians directly affected by breast cancer.

We enter 2018, our 20th anniversary year, standing on our stellar record of achievement over two decades and with a clear sense of direction based on our four strategic goals of "A Powerful Voice; Expanding Our Reach; Building Community Capacity and Strengthening Our Programs".

BCNA has led the way in advocating for Australians affected by breast cancer and has achieved significant improvements in care and support over the past two decades. However much remains to be done and, as the number of Australians affected by breast cancer is projected to increase significantly in coming years, BCNA must continue to increase its own activity levels, as well as continuing to be an effective advocate for all Australians affected by breast cancer.

One of the exciting but also challenging aspects of the current cancer landscape is that so much is changing so quickly, as new discoveries seem to be gaining pace and new treatments emerge. These rapid developments in our understanding of cancer and resulting new clinical applications increase BCNA's workload as we seek to provide the most up to date and accurate information to Australians diagnosed with breast cancer.

We plan to celebrate BCNA's 20th anniversary in a variety of ways across the course of 2018 including with a large-scale Field of Women event at the MCG on 12 August 2018. Our landmark anniversary project is the "State of the Nation" project. In addition, 2018 is the year BCNA will fully embrace the opportunities created through digital technology. BCNA's digital vision is to build a seamless, connected, multi-channel network of information, people, products and services that support the best possible journey for all Australians affected by breast cancer.

A powerful voice

One of the great strengths of BCNA has been to successfully advocate for better care for Australians affected by breast cancer. We are excited to enter 2018, our 20th anniversary year, with the launch of our new advocacy agenda, built on the stories and experiences of breast cancer consumers across the country.

During 2017, in our biggest consultation ever, we consulted face to face with more than 3,500 breast cancer patients and survivors across the nation and our member survey was completed by 10,318 breast cancer patients and survivors, making it the largest ever Australian survey of breast cancer consumers.

The resulting *Breast Cancer: the State of the Nation 2018* report will be launched in June 2018 at Parliament House in Canberra. The report highlights how the breast cancer experience has improved over time but still varies across the country. It delivers an evidence-based advocacy agenda for each state and territory in addition to one targeting the Commonwealth Government and national bodies. We will be pursuing the national and state recommendations from the report over the next few years.

In addition to the State of the Nation report, at any one time we have over 20 matters on which we are actively advocating. Examples include timelier access to breast reconstruction in the public system, access to Medicare rebates for breast MRIs, access to genomic testing to inform treatment decisions and access to new treatments.

Our major advocacy campaigns in 2017 focused on affordable access for Australian women and men with metastatic breast cancer to a new class of oral therapies called the CDK4/6 Inhibitors and on the financial costs of a breast cancer diagnosis.

During 2018 we will continue to campaign on these issues. We want to see at least one of the CDK inhibitors listed on the Pharmaceutical Benefits Scheme as soon as possible so that ordinary Australians diagnosed with metastatic breast cancer can access these drugs and enjoy the benefits they bring in terms of delaying progression of metastatic disease and enabling women to carry on with precious “ordinary life” for a period of time.

Our report, *The Financial Impact of Breast Cancer*, was released in September 2017 and attracted significant interest. It contains fourteen recommendations directed to private health insurers, government, health service providers and other bodies. During 2018, we will continue to contribute to the growing public debate on financial toxicities associated with cancer and “bill shock” attaching to medical treatment more generally, as well as pursuing the report’s recommendations with the relevant organisations.

Expanding our reach

Reaching all Australians affected by breast cancer is a key objective for BCNA. While BCNA has historically connected with over 80 percent of Australian women newly diagnosed with breast cancer, recent years have seen BCNA actively reaching out to men with breast cancer, Aboriginal and Torres Strait Islander women, people from culturally and linguistically diverse backgrounds, and Australians with a disability and a breast cancer diagnosis.

Male Breast Cancer Awareness Day was marked for the first time by BCNA during 2017 and will become an annual event. It was held on 20 October and attracted significant interest and exposure in mainstream and social media. For the first time also, two male survivors of breast cancer attended BCNA’s National Summit held in March 2017. Around 220 men who have been diagnosed with breast cancer are members of BCNA and around 50 diagnosed men have joined our membership over the past 12 months. This is double the number of new memberships of diagnosed men compared to 2015-16.

In March 2017, BCNA held a very successful Aboriginal and Torres Strait Islander Think Tank with 48 Aboriginal and Torres Strait Islander breast cancer survivors and health workers from across the nation. Out of that forum, a practical action plan to support Indigenous Australians affected by breast cancer was developed and a national reference group of Aboriginal and Torres Strait Islander breast cancer survivors established. Two very successful *Culture is Healing* projects were delivered – a possum skin cloak project in Melbourne and a weaving project in Brisbane, designed to connect Aboriginal and Torres Strait Islander breast cancer patients and survivors with one another, BCNA and treating hospitals. An MOU was also signed with the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) to support joint work on breast cancer.

More *Culture is Healing* projects are planned for 2018 along with further engagement with Aboriginal and Torres Strait Islander Community Health Services. A Reconciliation Action Plan will also be developed for BCNA.

New print and video resources for Greek and Chinese speaking women with metastatic breast cancer were released during 2017 along with a booklet on healthy eating for Chinese breast cancer survivors, developed in conjunction with CanRevive in NSW. Training of Community Liaison volunteers from culturally and linguistically diverse communities also occurred in October 2017 with participants drawn from across the nation. During 2018,

BCNA will release new resources on early breast cancer in Macedonian and Serbian and will support our CALD Community Liaison volunteers to promote the resources to their communities and relevant health providers.

2017 saw the launch of new resources to support people with a disability. During 2018, BCNA will continue to promote these resources and will also finalise a clinical trial of a card based communication toolkit originally developed by the US Metastatic Breast Cancer Alliance for use with people with metastatic disease who have poor English or low literacy and comprehension skills.

Strengthening our engagement with Australians diagnosed with metastatic breast cancer has been a key objective for BCNA in recent years. We were successful in 2017 in increasing take-up of our *Hope and Hurdles* kit for people with metastatic breast cancer by 25 per cent. During 2018 we will continue to promote our resources for Australians with metastatic breast cancer as well as holding a number of information forums for this audience.

BCNA is recognised internationally for the quality of our work on behalf of Australians with metastatic breast cancer. BCNA is an active participant in the Advanced Breast Cancer Global Alliance and for 2018-2020 has been elected onto the executive of the Alliance, where it will be represented by our Director of Policy and Advocacy and one of our Community Liaisons.

BCNA will have a special focus on the needs of young women with breast cancer during 2018. A Young Women's Think Tank will be held in the first half of the year to consider how BCNA can best support women under the age of 40 diagnosed with breast cancer. A conference for young women with breast cancer is planned for October.

BCNA's quarterly *The Beacon* magazine has been a mainstay of communication with members for many years. In 2018 we will refresh this publication by shifting to a new magazine-style format. It will be published twice a year on paper and digitally and complemented by monthly email newsletters.

Our state development managers in New South Wales and Queensland will continue to serve as the CEO's delegates on the ground in these states to strengthen the advocacy and visibility of BCNA. In addition, BCNA hopes that in honour of our 20th anniversary, many of our supporters will hold community awareness or fundraising events around the nation. Our Pink Lady luncheon events program for 2018 includes lunches in Sydney and Brisbane and, for the first time, a gala ball in Melbourne.

Building community capacity

Community awareness and understanding of the experience of breast cancer and strong support networks are an important part of the support system for Australians affected by breast cancer.

During 2018, BCNA will be refreshing our volunteer programs including training more office based volunteers at our Melbourne head office. We will also focus on activating and equipping members who are interested in undertaking advocacy, fundraising and outreach to health professionals.

We will be mounting a Field of Women at the MCG on 12 August 2018 to mark our 20th anniversary. This is a major undertaking which will require around 18,000 participants to form the Pink Lady on ground of the MCG to denote the number of Australians expected to be diagnosed with breast cancer in 2018. Field of Women 2018 will serve to raise awareness of breast cancer, commemorate those lost to breast cancer and express community support for Australians affected by the disease. We will be promoting this event through ambassadors and community champions.

Strengthening our programs

At BCNA we continue to review and revise our programs to ensure they are of the highest quality and relevant to the needs of our members.

During 2017, BCNA refreshed its helpline service, employing a number of helpline staff with nursing backgrounds and extending the hours of the service to 9.00 PM on Tuesday and Thursday evenings to better cater to members with daytime commitments. While BCNA does not provide clinical services to members we believe the knowledge and experience of the health system that our health-qualified staff will bring to their roles will enhance our helpline service. Our helpline also commenced actively following up new members who have received a *My Journey Kit* to ensure that they receive any additional assistance they require. Promoting the enhanced service provided by our helpline will be a major focus for 2018.

During 2018, we will be transitioning most of our print resources to digital, including the *My Journey Kit* and *Hope and Hurdles*. We aim to deliver better targeted, personalised information to Australians diagnosed by breast cancer with a strong focus on providing “the right information at the right time”. In addition, both the content and the technological platform for our online services directory will be updated and enhancements made to the BCNA website. This digital project is a major undertaking for the organisation. It commenced in 2017 and will continue through 2018 and into 2019 with the digitised key resources to be delivered by October 2018 through a web application named My Journey.

During 2017, our forums program was expanded and diversified to include specialist forums for more groups including young women with breast cancer, women interested in breast reconstruction and women with metastatic breast cancer. In 2018 we expect to double the number of information forums we provide around the nation and commence webcasting some forums.

We will use the results of research conducted in 2016 on the workplace experiences of people following a breast cancer diagnosis to develop resources and programs to support both employers and employees with work transitions arising from a breast cancer experience. The new service aims to assist Australians with breast cancer to maintain employment through breast cancer treatment or to return to work after treatment and will also provide information and advice on access to superannuation and insurances.

We will continue to expand our information offering with the development of new resources for women with LCIS and with DCIS and a range of resources for people in the survivorship phase of their breast cancer experience.

More than 200,000 Australians are estimated to be living post a breast cancer diagnosis with many experiencing long term physical or psychological side effects. For many women, reaching the end of treatment does not bring the relief they hoped for but, rather, underlines that life will never entirely return to the way it was pre-diagnosis. We will hold a national one-day conference on survivorship during 2018 timed to align with the Field of Women and also commence work on an online resource for breast cancer survivors. Both initiatives are designed to assist survivors to find a “new normal” that they can live with. In collaboration with Cancer Australia and other partners, we will contribute to the development of effective and acceptable models of follow up and survivorship care.

Organisational Foundations

Our focus at BCNA is on delivering the highest quality programs and advocacy to support Australians affected by breast cancer. Underpinning these activities we must have a strong and sustainable organisation.

In 2018 we will continue to develop our people and our business capability and grow our fundraising which enables us to provide our programs and services free to all Australians that need them. Over the coming 12 months we will also be pursuing operational efficiencies through the deployment of a cross-organisation Lean

Team and actively embracing the opportunities provided by new digital technologies to serve our members in new and more cost-effective ways.

Our digital roadmap commits us to:

- Simplifying and personalising the user experience of the website and making it easy to find the most up to date, individually relevant information.
- Using data and analytics to understand our audiences better so that we can personalise our information, offers, communications and grow our revenue.
- Building high levels of engagement and brand awareness in Australia for the work we do and the services we provide.
- Designing seamless, multi-channel experiences that transition our audiences to engage through digital channels where possible.
- Building an agile culture of continuous improvement that puts our members' and other users' needs first, while maintaining the highest levels of operational efficiency.

Our ongoing focus

As BCNA goes forward into 2018, we are committed to creating a better journey for all Australians affected by breast cancer by:

- Celebrating and building upon the work of all who have gone before us in creating and contributing to the BCNA of today
- Acting on what Australians affected by breast cancer have told us about their unmet needs through the State of the Nation project
- Harnessing the power of our network to ensure that every Australian facing breast cancer has the best possible patient experience
- Providing high quality, evidence-based and accessible information and services
- Reaching more Australians than ever before
- Continuously improving and strengthening our organisation, and
- Living out our values of *Energy, Openness, Caring, Connection* and *Resilience*.

Vision

A better journey for all Australians affected by breast cancer

Mission

BCNA works to ensure that Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs through supporting, informing, representing and connecting Australians affected by breast cancer.

Strategic Directions

A powerful voice	Expanding our reach	Building community capacity	Strengthening our programs
Growing our influence as a powerful, well-informed and credible advocacy voice for Australians affected by breast cancer	Reaching all Australians affected by breast cancer, wherever they live and whatever their circumstances	Building the engagement and capacity of our network and the wider Australian community to support Australians affected by breast cancer	Expanding and continually improving the range of services and programs we offer to meet the needs of Australians affected by breast cancer

Organisational Foundations

Strengthening our organisation through supporting and developing our people, improving our digital capabilities and business systems, enhancing our fundraising capacity and embracing a lean enterprise culture. We will also seek to capitalise on the skills and networks of our Board members.

Values

Energy, Openness, Caring, Connection, Resilience

Key Initiatives

A powerful voice	Expanding our reach	Building community capacity	Strengthening our programs
<ul style="list-style-type: none">• Finalise and release our State of the Nation report and work with governments and other stakeholders to address unmet needs identified within the report• Continue to promote the findings and recommendations of our 2017 report on <i>The Financial Impact of Breast Cancer</i>• Advocate for affordable access to the CDK Inhibitors for women with metastatic breast cancer• Activate members to be powerful advocates for improved treatment and care• Continue to promote Cancer Australia's Appropriate Practices• Contribute to design of effective models of follow up and survivorship care	<ul style="list-style-type: none">• Increase uptake of our resources for Australians with metastatic breast cancer, for people with a disability and breast cancer, for men with breast cancer and for Australians from CALD communities• Hold a survivorship conference targeting breast cancer survivors from rural and regional areas• Refresh <i>The Beacon</i> magazine and develop targeted monthly email newsletters for members and other stakeholders• Engage key health professionals to assist in the promotion of all BCNA services• Hold a think tank for young women with breast cancer and a young women's conference	<ul style="list-style-type: none">• Hold a Field of Women at the MCG to raise awareness of breast cancer• Engage and activate stakeholders and community champions to assist with key projects for BCNA's 20th Anniversary• Support CALD Community Liaisons to promote awareness of breast cancer and BCNA's resources in languages other than English to their own communities and local health services• Facilitate further Culture is Healing projects which link Aboriginal and Torres Strait Islander women with breast cancer with their cancer treatment centre and BCNA to create culturally safe treatment experiences	<ul style="list-style-type: none">• Deliver digitised versions of <i>My Journey Kit</i> and <i>Hope and Hurdles</i> through development of My Journey, a web based application providing a powerful, curated, right information at the right time user experience• Expand and diversify our forums program• Further develop the Breast Cancer Helpline into a contemporary information and referral service• Assist Australians affected by breast cancer to return to or maintain employment• Develop new resources for women with LCIS, DCIS and for people in the survivorship phase post breast cancer