Annual Review 2021-22

Breast Cancer Network Australia

Connection and belonging

No Climbing Breast Cancer Network Australia acknowledges Aboriginal and Torres Strait Islander people as the traditional owners and custodians of the land, sea and ncer nations and we pay our respect to Elders, past and present.



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Letter from the Chair and CEO



Kathryn Fagg AO Chair



Kirsten Pilatti Chief Executive Officer

This year, our members continued to navigate the ongoing challenges of the COVID-19 pandemic while BCNA adapted the way we delivered information, support and connection to our network of more than 175,000 people across Australia.

The past year has been a particularly isolating time to be diagnosed with breast cancer. We had to find new and better ways to create connection and a sense of belonging, which are essential for people's wellbeing.

We invested funding from the Australian Government Department of Health and Aged Care into further strengthening key services and programs which support and connect our members, including regional and rural Information Forums, our free and confidential Helpline, online network community, and influential Consumer Representative program.

As COVID-19 restrictions were lifted, many people wanted to reconnect in person. We know those living in rural and regional areas have higher unmet needs, so we presented our first face-to-face Information Forums in Ballarat in Victoria and Launceston in Tasmania for people to find out about the local support available in their area and to connect with others going through a similar experience.

Our Helpline was an essential resource for those diagnosed and their families navigating the complex and everchanging healthcare system, while My Journey remained a trusted source of information about treatment and care. We launched tailored content for First Peoples, LGBTIQ+ communities and men diagnosed with breast cancer to address their needs and empower them throughout their breast cancer experience.

Our strong collaborations across the healthcare sector ensured the voices of those diagnosed were included across a range of issues that directly affect them, such as the development of Cancer Australia's National Cancer Plan and the Australian Government's Medical Cost Finder portal.



After a two-year hiatus, we also welcomed back volunteers to the BCNA office and community events. For those unable, or not comfortable, to connect in person, we continued to meet the demand for online support. More than 20,000 people attended our digital events, 22 podcast episodes were downloaded nearly 68,000 times, and our online network had more than 220,000 unique visits.

Our strong collaborations across the healthcare sector ensured the voices of those diagnosed were included across a range of issues that directly affect them, such as the development of Cancer Australia's National Cancer Plan and the Australian Government's Medical Cost Finder portal.

Our voice continued to be strong as we brought the diverse lived experiences of our network together to inform priority areas of policy and advocacy work. Our Breast Reconstruction in Australia report, based on the insights and experiences of 3,350 respondents, revealed unacceptable delays and inequalities in costs for elective breast surgery. We continued to advocate for changes to address these issues.

Our advocacy saw Trodelvy listed on the Pharmaceutical Benefits Scheme for people living with triple negative metastatic breast cancer. This offers

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hope for extending the lives of people with metastatic disease and affirms our mission to ensure everyone has equal access to the best breast cancer care.

We couldn't have achieved all that we have without the ongoing support of our incredible nework. This was acknowledged by Former Australian Minister for Health Greg Hunt who said, 'BCNA has been a leader in consumer advocacy and involvement. Hearing directly from those living with a disease like breast cancer brings many great advances to healthcare in this country.'

Thank you also to our dedicated staff who have worked tirelessly to adapt and support our members. There is a lot for us to be proud of.

Thank you to our major partners and supporters, and all the organisations, communities, individuals and governments who supported our work over the past 12 months. We want you to be proud that your generosity and personal contributions have made a positive difference to everyone affected by breast cancer.

Thank you for being part of our Network. **We are stronger together.**

Kathryn Fagg AO Chair

Kirsten Pilatti CEO

Highlights 2021–22

Our reach

175,000 members across Australia, with 25,000 new members this year



Coming together

Online network - 1,000+ peer-to-peer discussions and **220,000+** visits to our online network

Information and support



free to people

after surgery

315,000+ unique visits to bcna.org.au



Social media reached more than 3.1 million people



Tailored content for **First Peoples**, LGBTIQ+ communities and **men** with breast cancer

added to My Journey

Two Information Forums held in regional areas: **Ballarat** (Vic) and Launceston (Tas)



20,000+ people attended digital events, 27 per cent from regional, rural and remote Australia





600+ events

held to benefit BCNA in communities across Australia, from sporting clubs to groups of friends

Four health professional events held in rural and remote locations gave over 60 health professionals an opportunity to connect with BCNA and find

out more about our services and resources

Highlights 2021-22

Creating change

Advocacy wins:



Breast Reconstruction in Australia report released -**3,350 people**

surveyed, revealing disparities in costs and unacceptable

delays for breast surgery

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Supportive communities

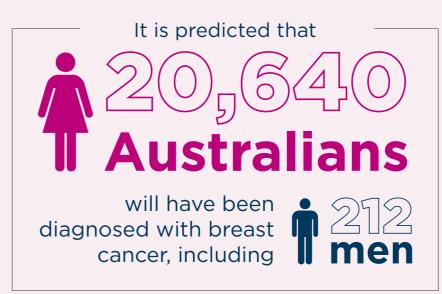


Carman³ Carman's Fun Run returned with more than **2,250 participants,** including a virtual option

Bakers Delight's Pink Bun campaign **raised \$1.6M**



2022 breast cancer statistics in Australia



Metastatic breast cancer drug, **Trodelvy**, listed on the PBS +

Telehealth access extended





BCNA's Federal Election Manifesto

called for better access to supportive care, mental health, and Telehealth, as well as measures to reduce the cost of breast cancer

BCNA's Think Tank event

in March brought together Consumer Representatives from across Australia with a lived experience of breast cancer to network, share ideas and work collaboratively with BCNA staff and Board members to provide input on critical policy, advocacy and organisational development priorities



Two Pink Lady Matches, partnered by Red Energy - one virtual (July 2021) and one faceto-face (June 2022) **raised \$600,000**



3,214 people will die from breast cancer each year.

Empowering with information and support

Information Forums

Information Forums and our

four virtual conferences, five

webcasts and four 'Ask the

Expert' interactive sessions

Since our Major Partnership

with Berlei began in 2005,

together we have provided

more than 185,000 free kits

to women diagnosed with

breast cancer after breast

surgery. The kit includes a

specially designed Berlei bra,

soft form/s and information

to assist with the experience.

attracted 7,816 live and 4,978

and digital events

We held two regional

on demand viewers.

My Care Kit

A breast cancer diagnosis impacts a person's physical, mental, emotional and financial wellbeing. As Australia's leading breast cancer consumer organisation, BCNA continued to help people seeking information and support after a breast cancer diagnosis.

We provided essential support for BCNA members through our:



Helpline

Our free and confidential telephone service answered 10,778 enquiries for support, information, resources and referrals.



My Journey

We updated our popular online information resource to reflect the unique information and support needs of First Peoples, LGBTIQ+ communities and men with breast cancer and launched a symptom tracker to help people record their symptoms and get more out of their appointments with clinicians.

I feel heard, appreciated and not judged.

- Helpline caller



The Beacon

Our quarterly digital magazine provided thousands of members with a trusted source of breast cancer news, plus updates from BCNA and personal stories.



Podcasts

We produced 22 podcasts, downloaded nearly 68,000 times, on a range of breast cancer topics. Macquarie University's evaluation of BCNA's online cancer resources indicate our podcasts 'have a positive impact on listeners', with many reporting they will continue to listen to them.



The voice of experience filled a void with 40,000+ downloads

Dr Charlotte Tottman's 10-episode podcast series, 'What you don't know until you do', was a hit with listeners. Charlotte's personal breast cancer experience, combined with her professional insights as a psycho-oncologist, offered listeners practical advice, support and comfort. More than 83 per cent of the listeners we surveyed agreed the podcast series helped them make more informed decisions about their health.

The power of personal stories

We also launched our 'In Conversation' podcast series, featuring two BCNA members talking to each other about their breast cancer experiences, the challenges they faced and advice they have for others. Topics included metastatic breast cancer, being diagnosed as a young woman, and living in regional and rural locations. More than 2,000 listeners tuned in for each episode.

This [podcast] series is probably the single most useful and accurate detail of what it's like to go through a breast cancer diagnosis, treatment, physical and mental recovery. It has covered ALL the things that I went through with a beautifully articulated explanation or guidance to understanding the what's and why's. Thank you so much for producing this.

- Online review by Mrs Macafee of 'What you don't know until you do' podcast series, 31 January 2022

Bringing people together

A breast cancer diagnosis can be very isolating and even more so during a global pandemic. A sense of connection is essential for wellbeing. Once people connected with BCNA, we provided ways for them to connect with each other.

Reconnecting in person and online

Our face-to-face and digital events encouraged people to share their own breast cancer experiences and learn from experts and the experiences of others. This helps to create a sense of belonging for people, no matter who they are or where they live.

With the easing of COVID-19 restrictions, many in our network were keen to meet in person, but we continued to offer an online option so everyone in our network could connect in the way they preferred.

BCNA's online network is an active community of individuals and interest groups who provide peer-to-peer support. This year, it connected more than 21,000 people with each other, generating more than 1,000 discussions and 8.000 comments.

Volunteers reunite for the cause

We are stronger together when members of our network get involved.

Our wonderful volunteers returned after COVID's disruption, including those who pack My Care Kits, help in our office, and contribute to the success of Pink Lady Matches and the Carman's Fun Run. Members also shared their personal stories at hundreds of community events, extending the power of BCNA's network into local communities across Australia.

Reaching rural and regional communities

People diagnosed with breast cancer in rural and regional areas face additional barriers to accessing the care and support they need. With funding from the Australian Government Department of Health and Aged Care, BCNA went back on the road and hosted Information Forums in Ballarat, Victoria, and Launceston, Tasmania, to support those communities and facilitate stronger connections. We filmed the events so people had the choice to watch them online. We also held dedicated events for health professionals to reinforce and further develop the strong links BCNA has with them. Up to 90 per cent of Information Forum attendees said the event was an important opportunity to connect with others who shared a similar breast cancer experience.



I love the networking opportunity and hearing others' views on breast cancer care.

- Adelaide health professional event attendee





Men with breast cancer can feel isolated and find it difficult to access tailored information and support. BCNA presented a menonly webinar 'Blokes and Breast Cancer' to address some of the common concerns men with breast cancer have and help them to feel less alone.

Thank you for the opportunity to discuss male breast cancer for the first time in my life with other men who are in my position. I feel very fortunate to have been able to be part of this.

- Pieter, BCNA member

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Working with decision-makers to create change

As a leader in consumer advocacy and engagement, BCNA ensures consumer voices play a central part in influencing and driving transformational change across health policy development and the healthcare system.

Advocating for affordable and equitable care

Key issues of concern for BCNA members continued to be the financial burden of a breast cancer diagnosis and timely access to treatment and care.

In this, the first year of our three year policy and advocacy strategic plan, the focus was on the financial impact of a breast cancer diagnosis. BCNA:

- Advocated for faster approvals for new and innovative drugs, devices and tests to be listed on national health care benefit schemes. Our advocacy led to the listing of the drug Trodelvy (sacituzumab govitecan) on the Pharmaceutical Benefits Scheme, for people with metastatic triple negative breast cancer called on the Australian Government to retain telehealth Medicare subsidies
- Advocated for greater subsidies for lymphoedema treatment.
- Worked with the Australian Government to refine its Medical Cost Finder Portal to ensure the cost of treatment in the private health system is clear
- Engaged with the private health sector

Valuing the lived experience

BCNA's policy and advocacy work is informed by the diverse voices of those with lived experiences of breast cancer.

Our Review & Survey Group is a way for BCNA members with a lived experience of breast cancer to contribute to research projects and improve breast cancer treatment and care. This year, Review & Survey Group members contributed to projects from across Australia, including research by the Westmead Breast Cancer Institute and University of Sydney on engaging with patients from different backgrounds and people's support preferences.

We formed two new consumer-led special interest reference groups:

- The Financial Impacts Working Group, comprising members with expertise in the financial sector, seeks to address the financial impact of a breast cancer diagnosis.
- The Rural and Remote Lived Experience Reference Group focuses on addressing the additional barriers people face when they live outside metropolitan areas. Their insights will support the planning and delivery of information to people in rural and regional areas.

These groups will continue to guide our work and reinforce BCNA's commitment to consumer engagement.



Trodelvy has enabled me to see my eldest daughter graduate, witness my youngest daughter start high school and for me to be here almost 18 months after my terminal metastatic triple negative breast cancer diagnosis. I hope this is only the first of many more targeted and subsidised treatments for triple negative breast cancer so we can have hope and a brighter future.

- Alison Day, **BCNA** member



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Breast reconstruction report revealed inequities

We asked our network about their experiences accessing breast reconstruction surgery. Our Breast Reconstruction in Australia 2021 report received 3,350 responses and revealed unacceptable delays and inequalities in costs for elective breast surgery. We called on federal and state governments, professional associations and health professionals to work together and with BCNA to identify ways to reduce the costs associated with breast surgery and address the disparities. Successes from our advocacy include the Western Australian Government's commitment to increase its Patient Assisted Travel Scheme subsidies, BCNA's continued input into the Australian Government's Medical Cost Finder portal, and our work with the Australian Access to Breast Reconstruction Collaborative Group's taskforce to determine reasonable out-ofpocket breast reconstruction costs.

Working with decision-makers to create change

Amplifying the consumer voice

BCNA has run its internationally recognised Consumer Representative program, Seat at the Table, since 2001, bringing together people who have been diagnosed and/ or affected by breast cancer to train them as Consumer Representatives. These representatives work with breast cancer researchers, advisory committees, policy makers and service providers across Australia to ensure the diverse views, needs and experiences of people living with a breast cancer diagnosis are considered in decision making.

COVID-19 impacted the program by limiting opportunities for Consumer Representative involvement. This year, we strengthened the program by:

- Completing a skills audit to better align participant skills and experience with key Seat at the Table projects and stakeholders
- Updating the online training program to prepare for 2023 recruitment
- Providing ongoing training to ensure skills and knowledge are up to date
- Hosting a Consumer Think Tank, bringing together 21 Consumer Representatives from across Australia to connect and inform BCNA's work.

This group of highly skilled, experienced and confident consumers continued to represent BCNA nationally and internationally on several working groups and committees, including Cancer Australia, Cancer Council Australia and the ABC Global Alliance. 6

Truly understanding the experiences of others. Treasuring diversity and the individual journey whilst working together as a collective.

- Consumer Think Tank participant, 2022

Strengthening collaboration

BCNA's advocacy and influence creates change for those living with breast cancer. By improving the way the health system works, our work also benefits people with other health conditions.

This year, we continued to work closely with health professionals, other cancer groups and health providers as part of various working groups and taskforces, including the Victorian COVID-19 Cancer Network taskforce, in which BCNA represented the consumer voice for all those affected by cancer.

We also ensured consumer voices were heard by decision-makers of Cancer Australia's Australian Cancer Plan, the Australian Government's Medical Cost Finder initiative, and its temporary re-instatement of longer telephone Telehealth consultations with specialists on the Medicare Benefits Scheme, providing much-needed support for people with breast cancer across Australia.

Our manifesto for change

The federal election was an opportunity to influence national decision-makers. Our Election Manifesto called on state and federal governments to commit to improving breast cancer outcomes in six key areas, and consider 17 specific recommendations. Informed by our network and the most recent findings in cancer and healthcare research across Australia and worldwide, our recommendations focused on system investment and policy change to improve equity and care for all Australians affected by breast cancer. Our advocacy ahead of the election contributed to the extension of Telehealth.



BREAST CANCER NETWORK AUSTRALIA INFORMATION FORUM

Breast

Cancer Network

Australia

Partnering for progress

The ongoing support of corporate partners and individuals is vital for BCNA to achieve its mission.

Federal Government support

The Australian Government Department of Health and Aged Care's \$6.6 million funding for 2021-24 commenced, strengthening the key services and programs of our Helpline, Online Network, Consumer Representative program, regional and rural Information Forums and digital events.

Berlei's 'In Support of You' campaign

Berlei's Pink Bra campaign in October 2021 featured the stories of members and BCNA Ambassadors Thredbo landslide survivor Stuart Diver, Olympic gold medallist Raelene Boyle AM MBE, AFLW player Sophie Conway, and social justice advocate, BCNA champion and Yorta Yorta Elder Aunty Pam Pedersen. Berlei donated \$10 for every bra sold from the Pink Bra Collection to BCNA.

Sussan's support grows

Sussan supported key BCNA projects, including the Seat at the Table program through ongoing training and development for consumer representatives, new My Journey content for diverse users and BCNA's 'In conversation with' consumer-toconsumer podcasts.

Red Energy's BCNA Saver plan

Since December 2020, Red Energy has donated up to \$10 per month to BCNA on behalf of every customer signed up to the plan, raising awareness of BCNA and almost \$150,000 by 30 June 2022. New customers of the Red BCNA Saver plan increased 300 per cent on the previous year.

Key partners and sponsors

Bakers Delight's Pink Bun campaign

Thanks to the generosity of Bakers Delight's franchisees, staff, customers, local communities and the Gillespie Family Foundation, this year's Pink Bun campaign raised nearly \$1.6 million.

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Bakers Delight has supported BCNA for over 20 years and will continue the partnership as long as there is a need for the amazing services that BCNA provides. Over time the BCNA team, the volunteers, and the women and men they support have become a part of the Bakers Delight family, and we feel proud to be associated with the work that they do.

- Elise Gillespie and David Christie, Joint CEOs

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A gift from the heart

BCNA's impact on people remains strong long after they finish treatment. Josephine Simelius was diagnosed with early breast cancer in February 2010 at the age of 82. A few days later, she became a BCNA member. When Jo died in 2021, she left an incredible gift of nearly \$600,000 to BCNA in her Will, recognising the impact BCNA has on those affected by breast cancer. Her bequest has been transformative and will play a vital part in maintaining a strong foundation for BCNA's future.



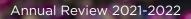
Re-united in support

Our enthusiastic teams of community fundraisers and volunteers brought together those affected by breast cancer and their supporters to raise awareness of BCNA's work. After a two-year hiatus, this year's events were bigger and better than ever, breaking our previous fundraising records.

The annual Pink Lady Match, presented in partnership with the AFL's Melbourne Football Club in July 2021 inspired online support and, in June 2022, people travelled to Melbourne from as far away as Perth, with thousands more supporting from home. Fifty people formed a guard of honour on the field before the game, while people left tributes for loved ones in the Mini-field of Women outside the stadium.

The Carman's Fun Run brought participants together in Elsternwick Park in Melbourne, while others opted for the virtual 'run anywhere, anytime' option, and Pink Sports Days kicked off and reconnected their local communities with a common goal.

Corporate cycling challenge, Alliance Airlines Hangar2Hangar, raised \$165,000 for BCNA. Our members came out to cheer on the riders as they tackled the three-day, 400km event, riding from Margaret River to Perth.





Financial summary

Despite the ongoing challenges of COVID-19, BCNA achieved a strong financial result with a net surplus (before comprehensive income) of \$1.15 million in the financial year ending 30 June 2022. No income tax is payable .

This ensured BCNA could focus on continuing to deliver information and support to Australians affected by breast cancer, while advocating for access to better breast cancer care.

There was strong growth across all income streams. In particular, significant bequests increased our donation income and another successful Bakers Delight Pink Bun campaign boosted our corporate income. We also received the first year of funding under our three-year agreement with the Australian Government Department of Health and Aged Care to provide support services to people with breast cancer through the BCNA Helpline, Information Forums and consumer representative activities, with a focus on regional and rural areas.

The organisation has continued to build strong cash reserves adding to our investment portfolio. These investments form part of specific long-term investment funds, which aims to support the long-term sustainability of the organisation, using the income generated to support spending on BCNA's programs.

After three successive years of strong surpluses, we plan to invest in the digital transformation of the organisation. We are planning to spend significantly on our digital programs, services and internal systems to deliver a significantly enhanced experience of our services to Australians affected by breast cancer.

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME

	2022*	2021**
	\$	\$
TOTAL REVENUE	8,559,941	3,558,763
EXPENSES		
Salaries and employee benefits expense	4,295,466	1,619,025
Cost of sales for merchandise sold	285,105	58,465
Program related expenses	1,033,055	284,146
Administration expense	351,619	176,484
IT expense	957,667	347,465
Distribution and travel expense	217,657	73,787
Amortisation and depreciation expense	236,758	149,815
Finance costs	30,495	18,837
GAIN FOR THE PERIOD	1,152,119	830,739

OTHER COMPREHENSIVE INCOMERevaluation on available for sale financial assets410,247321,656TOTAL COMPREHENSIVE GAIN FOR THE YEAR741,8721,152,395

* 2022 results for 1 July 2021 - 30 June 2022

** 2021 results for 1 January - 30 June 2021 when BCNA changed its financial year end.



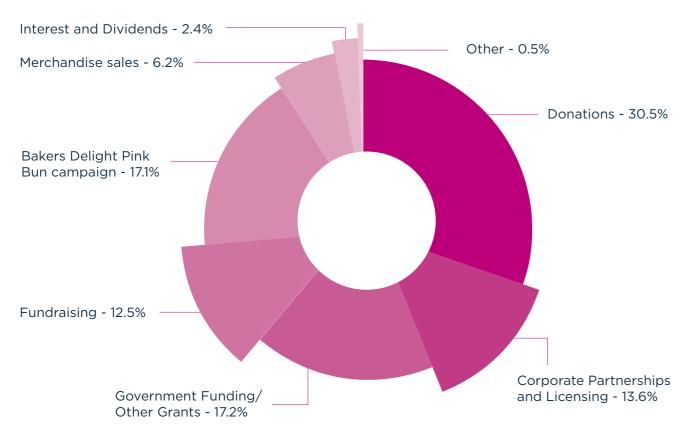
Financial summary

REVENUES FROM CONTINUING ACTIVITIES

	2022	2021
Donations	2,610,846	1,016,329
Corporate Partnerships and Licensing	1,163,584	293,842
Government Funding/Other Grants	1,475,799	163,230
Fundraising	1,069,075	343,614
Bakers Delight Pink Bun campaign	1,460,728	1,480,052
Ticket sales	-	-
Merchandise sales	533,864	122,105
TOTAL	8,313,896	3,419,172

OTHER COMPREHENSIVE INCOME			
Interest and Dividends	203,849	123,132	
Other	42,196	16,459	
TOTAL REVENUE FROM CONTINUING ACTIVITIES	8,559,941	3,558,763	

REVENUES FROM CONTINUING ACTIVITIES





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Our Board

Thanks to our Board members, all of whom have a personal or professional experience of breast cancer, for their expertise, guidance and governance. Read more about them on BCNA's website



Kathryn Fagg AO (Chair)



Professor Jacinta Elston (Deputy Chair)



Raelene Boyle AM MBE



Sarah Donnelly



Professor Bruce Mann



Clare Power





Lisa Montgomery (Deputy Chair) (retired March 2022)

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Acknowledgements

Thank you to all the organisations and individuals who supported BCNA's work throughout the year.

Supporters

Good2Give

Barefoot Projects

Melbourne Vixens

One Small Step Collective

Star Packaging Solutions

Meredith Gaston

Nine Network

Seven Network

BLK

SEN

Foundation Partner

Bakers Delight

Major Partners





Partners

Alliance Airlines Collins Foods Limited Estee Lauder Companies HWL Ebsworth John Cotton Konica Minolta Manildra Group Melbourne Football Club Middy's Nak Hair Opal Vic Mix

Major Donors

Thank you to our supporters who have donated more than \$5,000 to BCNA this year.

Sue Coppack Mandy Forteath OAM and Launceston Breast Cancer Support Group Erica Foundation Pty Ltd Freemasons Foundation Victoria Gaudry Foundation Gillespie Foundation Pty Ltd John T Reid Charitable Trusts Mem Kirby Manildra Foundation In memory of Cathy McEllister Mott MacDonald Australia Pty Ltd Julia Nancarrow Mehdi Qerim Nancy Roth Maureen Stevenson Stephanie Stewart Thomas Cook Boot & Clothing Company Pty Ltd Jeanette Tilney

Product Partnerships

Boob Armour Gilbert Netball Goodman Wine Gray-Nicolls Just Hockey Momentum Foods My Breast Friend Ref Warehouse Ritchies Supermarkets Russell Corporation Showcase Jewellers Vevoke Zena

Consumer Engagement

Thank you to all our members for their roles in helping BCNA connect decision making and lived experience.

Financial Impacts Working Group

First Nations Advisory Group

LGBTIQ+ Lived Experience Reference Group

Metastatic Breast Cancer Advisory Group

Review and Survey Group

Rural and Remote Lived Experience Reference Group

Seat at the Table, Consumer Representatives

Strategic Advisory Group

Consumer Representatives Jodie Lydeker Andrea Smith

Health Professionals

Prof. Fran Boyle AM Dr Susan Fraser Mrs Jenny Gilchrist Dr Belinda Kiely Dr Gillian Lamoury Prof. Bruce Mann Dr Vivienne Milch Ms Kerry Patford Assoc. Prof. Michael Penniment Assoc. Prof. Wendy Raymond Prof. Christobel Saunders AO Prof. Joanne Shaw Dr Magdalena Simonis Prof. Andrew Spillane Dr Charlotte Tottman Prof. Jane Turner AM Miss Melanie Walker Dr Michelle White

How to get involved



Volunteer

Help out at a BCNA event or in our office in Camberwell, Melbourne.

Share your experience

Contribute to a research project or share your personal story.

Fundraise

Challenge yourself in a Pink Sports Day or personal challenge or show your support at a Pink Lady Event or Mini-Field of Women.

Pink up

Buy quality products from our BCNA Shop.

Donate

Become a regular donor through Workplace Giving or Regular Giving, make a one-off donation or leave a gift in your Will.

Visit bcna.org.au/fundraise/get-involved

Phone BCNA's Helpline on 1800 500 258

BREAST CANCER NETWORK AUSTRALIA

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