



ANNUAL REPORT **2023**



*Together we're stronger*  
Tangata tū pakari tonu



## Chairperson's Report

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Kia ora koutou,

As ever, BCAC has been fully engaged in working across the spectrum of breast cancer issues to support those diagnosed and seeking the very best in timely detection, diagnosis, treatment and care. We valued all our connections with those experiencing breast cancer and represented their needs and concerns at many levels in the health system. We appreciated, supported and promoted the work of all our marvellous member groups that provide the support and services needed every day by New Zealanders with breast cancer and we've collaborated whenever possible.

An area of focus for us this year has been screening and early detection. We have long advocated for extension of the screening age to 74 for all women and down to 40, especially for those at greater risk. There's unequivocal evidence that extension to 74 will save lives and the 2017 incoming Government promised to do this, so it has been hugely frustrating to see no progress six years on. We're delighted to see that Shane Reti's Private Member's Bill seeking extension to 74 has now received cross-party support and we wish it speedy and successful progress through the post-election Parliament. We've been having regular catch-ups with BreastScreen Aotearoa (BSA) and while there is a will to move forward, resources for the screening programme are limited and much has slowed with the restructuring of the health system. BSA is implementing a new IT system that will soon allow greater data capture and remove barriers to including more women for screening. BCAC contributed to a review of BSA and advocated for our screening services to aspire to early innovation, rather than being a late follower of global trends. We asked for introduction of measurement and reporting of breast density, given that high density both masks the presence of tumours and increases the risk of getting breast cancer. High density can be seen on mammograms, but this information is not shared with women by BSA, although those using private screening providers are often told. Women clearly have a right to know if they are at higher risk of breast cancer and should be given advice on additional screening that they may choose to have. BSA recently asked for submissions on breast density and BCAC has made a strong case for reporting. We're pleased that BCAC Committee Members Fay Sowerby and Dr Rachel Greenwood have been appointed to BSA's Action Group and hope this will lead to positive change.

An ongoing battleground for BCAC is the fight to get more breast cancer medicines funded. The lack of treatment options has harsh impacts on many New Zealanders with breast cancer and their whānau every day. Pharmac was established 30 years ago to constrain spending on medicines and it has developed an entrenched culture and set of operating protocols that effectively ration the medicines New Zealanders can access. This leaves us well behind the rest of the world including Australia, the UK, Canada and Europe. Many diagnosed with breast cancer and other diseases are faced with the dilemma of how to access the modern medicines recommended in guidelines and funded in other countries that will deliver longer, healthier lives but remain unfunded in New Zealand. We shouldn't have to mortgage the family home, spend all our savings or move to Australia to be treated. BCAC is collaborating with other patient groups, led by Malcolm Mulholland under the Patient Voice Aotearoa banner, on the My Life Matters campaign, see [www.mylifematters.org.nz](http://www.mylifematters.org.nz). Representatives of a broad range of NGOs representing over a million New Zealander patients support this campaign to raise awareness, promote policy changes and engage politicians. The shared vision is that everyone in New Zealand should have access to essential medicines. Check out the website to learn how you can help.



As it stands, companies with innovative medicines are often hesitant to bring them to the New Zealand market because the road to getting medicines funded here is long and arduous. Even the medicines that make it all the way through Pharmac's slow and difficult processes to reach their 'Options for Investment' list take an average of 7.7 years to receive funding. Other good modern medicines are never applied for, are put on Pharmac's 'Only if Cost-neutral' list (they must be offered at the same price as an older funded medicine) or their 'Decline' list.



BCAC takes an active role in many of the steps needed to make effective modern medicines available in NZ. We encourage companies to import their medicines - if they hold stock here the exorbitant costs of importation for individual patients are removed. We ask companies to seek Medsafe registration - that allows some reimbursement for those with private health insurance. And we ask them to apply for Pharmac funding - when this is achieved everyone needing the medicine (if they conform with Pharmac's sometimes restrictive criteria) can access it free of charge in the public health system. That of course is the ultimate goal! Before funding is achieved, we ask companies to set up cost-share programmes that reduce the price, offer free treatment cycles and are capped at a reasonable level. This is

an important way for companies to make their medicines affordable to more patients while we all await a positive funding decision from Pharmac.

BCAC also applies directly to Pharmac to fund vital medicines. We have a wonderful volunteer pharmaco-economist who does a fantastic job of applying when companies decline to apply, or have given up after waiting years for Pharmac to fund, or are taking too long to apply. We engage frequently with Pharmac staff, seeking to explain the need and speed the progress of medicines through the consideration and funding processes and to improve the policies and processes they use. The staff are good people doing a horrendously difficult job. They're trying harder to be more communicative since the recent Pharmac Review, but while existing policies and legislative objectives remain unchanged and the medicines budget remains less than half the OECD average they must continue the harsh processes of rationing.

This year BCAC made two formal funding applications to Pharmac, one for eribulin (Halaven®), a chemotherapy medicine that has been funded in Australia since 2013 and provides another option for later line treatment of advanced breast cancer. We also applied for the funding of pembrolizumab (Keytruda®) for the treatment of early and late-stage triple negative breast cancer (TNBC). Patients with the TNBC sub-type are in desperate need of targeted medicines such as Keytruda®, Tecentriq®, Lynparza® and Trodelvy®, because the only publicly funded medicines are old fashioned chemotherapy drugs. The other two main breast cancer sub-types, HR+/HER2- and HER2+ are also missing out on targeted modern medicines. For details check our website at [www.breastcancer.org.nz](http://www.breastcancer.org.nz).

We supported a Pharmac proposal to switch from Herceptin® to the biosimilar Herzuma® as this has been used safely and successfully in Australia and NZ's private clinics since 2019/2020. We asked that Pharmac extend access to those needing retreatment after progression in advanced breast cancer. They declined, leaving us without a treatment that is the standard of care available across the world that is defined in all international guidelines. We still await funding of the rapidly injectable combination anti-HER2 treatment Perjeta® that would allow fast treatment in doctors' rooms and take pressure off hospital infusion services.

One good piece of news is that Pharmac will revert to the original Zoladex® brand of goserelin, replacing the cheaper type that caused pain and difficulty for many. Pharmac has told us the switch is the result of strong patient advocacy. For us, this was initiated by Metavivor Karen Nimmo, who was directly affected and was determined to see change. We followed up with several letters from BCAC and encouraged BSIG, the breast specialist group, to also write seeking a brand switch.

We've just heard that Enhertu®, a vital medicine for advanced HER2+ breast cancer, is very close to registration and has been recommended as high priority by Pharmac's Cancer Treatments Advisory Committee (CTAC). This will put it on the Options for Investment list. May it progress rapidly to funding! Enhertu is also proven for HER2 low breast cancer and we hope to see it registered and funded for this very soon as well. Abraxane®, a less toxic option to paclitaxel, has also received the CTAC 'high priority' tag for those who have a serious hypersensitivity reaction to paclitaxel. It has taken Pharmac 13 years from the first application to reach this conclusion and we still await funding. BCAC applied for Abraxane in 2018 and we hoped to see it available for a wider patient group to avoid unnecessary toxicity for all, but at least those most seriously affected will eventually have access.

BCAC made multiple submissions on important health policy topics this year. These included, in addition to our submissions on BreastScreen Aotearoa and breast density, support for a timely move to Precision Health for more innovative precise and individualised healthcare; opposition to elements of the Therapeutic Products Bill that threatened to prevent patients from accessing unregistered medicines and to ban advocacy for these; we argued that the Women's Health Strategy must include breast cancer (the draft didn't!); we engaged with Manatū Hauora seeking to increase availability of clinical trials; and we opposed a Pharmac proposal to stop treating child cancer with the best available medicines. We argued that the world-class treatment given to paediatric cancer patients under an 'exception' rule should be a model for treating breast cancer and other diseases.

Our Māori Committee Member Maria Marama (Te Arawa/Ngati Whakaue/Cook Islands) guided us and provided her expertise on a range of breast cancer related issues. Along with former BCAC Committee



Member Irene Kereama-Royal, Maria was awarded an HRC Grant for 'Ma Hinewai Kopu e Whakahou', a project to design advocacy approaches for Āo Māori and Tiriti led hauora pathways, to enhance wāhine Māori experiences with breast cancer and to inform action research, community-led responses and equity driven outcomes.

We attended conferences and expert meetings to ensure we stayed up to date with the latest research results, supported cutting edge researchers and their projects. We networked with specialists and nurses, lobbied politicians, distributed our **Step by Step** support pack and most importantly we listened to patients and their concerns to inform us of priorities in our work.

We were delighted to welcome new Committee Members Ah-Leen Rayner (CEO, Breast Cancer Foundation), Hazel Jennings (ANZBCC) and three Metavivors, Denise Lemmen, Marion Barnett (medical writer) and Dr Rachel Greenwood (GP). Along with individual members from Invercargill to Whangarei, our BCAC Committee includes representatives of Aotearoa NZ Breast Cancer Community, Breast Cancer Cure, Breast Cancer Foundation, Canteen, Metavivors and Sweet Louise. This ensures we are truly representative, collaborative and can share our strengths and coordinate and synergise our activities.

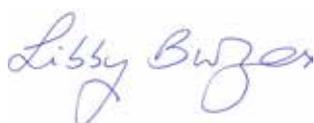
We've done a lot this year but there's so much more to do. I'm incredibly grateful to everyone who has communicated or worked with us to get the best we possibly can for New Zealanders with breast cancer.

Kia kaha, kia māia, manawanui – be strong, brave and steadfast.

Tangata tū pakari tonu – together we're stronger!

Wishing all our friends, collaborators and supporters joyful times ahead.

Arohanui,



Libby Burgess, MNZM  
BCAC Chairperson

*Together we're stronger*  
Tangata tū pakari tonu

BCAC is an umbrella organisation representing more than 30 breast cancer-related groups in New Zealand. Our role is to support, inform and represent people with breast cancer. We are committed to transforming the lives of those diagnosed with breast cancer by seeking world-class detection, treatment and care.

## Key Achievements in 2023

### Information and resources

- Delivered more than 1500 **Step by Step** support packs to New Zealanders newly diagnosed with breast cancer.
- Provided information on breast cancer diagnosis, treatment and recovery via our website [www.breastcancer.org.nz](http://www.breastcancer.org.nz)
- Delivered up-to-date breast cancer news, research results and events via our website, Facebook page and Twitter account.
- Delivered a regular e-newsletter to over 1300 subscribers.
- Supported more than 2800 New Zealanders through BCAC's main Facebook page and more than 440 members in our public Facebook group.
- Supported more than 540 New Zealanders with advanced breast cancer through the online communities Metavivors NZ and Metavivors NZ - Action.
- Responded to more than 100 queries through the BCAC website and Facebook page.
- BCAC Deputy Chair Emma Crowley appeared in a video raising awareness of breast cancer in young women produced as part of an event run by fitness instructor and bodybuilding pro Jess Coate (Ngapuhi).

### Providing a voice for those diagnosed with breast cancer

BCAC committee members participate in a number of consumer and specialist breast cancer groups throughout New Zealand to ensure breast cancer patients are represented in the health system. We also engage in other activities and projects designed to raise the voices of those diagnosed with breast cancer.

- BCAC responded to a Pharmac consultation on whether to replace Herceptin (trastuzumab) with a biosimilar equivalent medicine, Herzuma. We noted the switch should be safe and that funding should be extended to provide for the internationally recommended retreatment after the cancer progresses.



- BCAC responded to a Pharmac consultation on the funding of oral vinorelbine for treatment of advanced breast cancer. We supported this, noting that the first application to Pharmac for the oral form was in 2007 so it had taken 16 years to implement.
- BCAC responded to Pharmac’s consultation on potential changes to Rule 8.1b of the Pharmaceutical Schedule that governs the way in which treatments for paediatric cancers are funded. We asked that the excellent standard of child cancer treatment should be retained and that Pharmac should aspire to extend this to other cancers.
- BCAC wrote a submission to the Ministry of Health on the new Women’s Health Strategy, stressing the importance of ensuring that breast cancer was explicitly covered in the strategy and suggested three key areas needing change and better resourcing.
- BCAC wrote a submission on the Therapeutic Products Bill, noting grave concerns, particularly the loss of any ability to import medicines not registered in New Zealand, the broad definition of ‘advertising’ that could effectively prevent any information on new medicines being made available to patients, and the potential to discourage clinical trials of new medicines in New Zealand.
- BCAC responded to Manatū Hauora’s (the Ministry of Health’s) first and second consultations on its draft Long-Term Insights Briefing on Precision Health: Exploring opportunities and challenges to predict, prevent, diagnose, and treat disease more precisely in Aotearoa New Zealand. We outlined the wonderful opportunities to improve healthcare for the people of Aotearoa through commitment to the development and timely uptake of innovative technologies.
- BCAC members met with New Zealand breast cancer researchers to provide consumer input into their projects as well as letters of support to funders for worthy projects.
- BCAC Secretary Fay Sowerby represented New Zealanders with breast cancer at ‘Linking the Vines’, the inaugural symposium of Te Aka Mātauranga Matepukupuku – Centre for Cancer Research at the University of Auckland.
- BCAC Chair Libby Burgess was interviewed for a project run by The Economist’s Economic Intelligence Unit to develop A Patient-Centred Framework for Early Breast Cancer Care in New Zealand. Libby and Fay attended a consultative workshop on this topic.
- BCAC Secretary Fay Sowerby participated as a consumer representative on the National Breast Cancer QPI (Quality Performance Indicators) Working Group, run by Te Aho o Te Kahu, to develop abbreviated professional standards for breast cancer treatment in New Zealand.
- BCAC had regular meetings with BreastScreen Aotearoa to receive updates and provide consumer input and perspectives.
- Libby and Fay provided input into a formal review of



BreastScreen Aotearoa and then reviewed the draft report as well as a related epidemiological report, noting opportunities to provide a more tailored, innovative service to those participating in the screening programme.

- Committee Members Fay Sowerby and Dr Rachel Greenwood were appointed to the newly formed BreastScreen Aotearoa Action Group (BSAAG).
- BCAC provided consumer representation on the Breast Special Interest Group (BSIG) of breast cancer specialists, with BCAC Chair Libby Burgess, Deputy Chair Emma Crowley and Secretary Fay Sowerby attending BSIG meetings this year.
- BCAC also represented consumers on the New Zealand Familial Breast and Ovarian Cancer Group of specialists, with Fay and Libby regularly attending their meetings.
- BCAC Deputy Chair Emma Crowley continued to represent New Zealanders with breast cancer as a member of the Consumer Advisory Panel of Breast Cancer Trials (Australia and New Zealand). Emma also continued as Chair of the Consumer Advisory Panel of Cancer Trials New Zealand.
- BCAC Chair Libby Burgess was a member of the NZ Cancer Control Agency's Te Aho o Te Kahu Consumer Reference Group, He Ara Tangata (HAT).
- BCAC is a member of the ABC Global Alliance, a European-based organization dedicated to improving and extending the lives of women and men living with advanced breast cancer worldwide. Committee Member Marion Barnett has been awarded a travel grant to attend Advanced Breast Cancer 7th International Consensus Conference in Lisbon in November 2023.
- BCAC supported many women as they negotiated the health system to secure timely and appropriate diagnosis, treatment and care.

## Improving access to world class treatment and care

- BCAC submitted a formal application to Pharmac to fund chemotherapy agent eribulin (Halaven®) as a treatment for advanced breast cancer. We successfully encouraged the company that owns this medicine to import it into New Zealand, apply for registration and set up a generous cost share programme.
- BCAC submitted a formal application to Pharmac to fund pembrolizumab (Keytruda®) both for high-risk early-stage and advanced triple negative breast cancer.
- BCAC wrote to Pharmac requesting that the current funded form of goserelin be replaced with a different brand with a better applicator as both patients and physicians had reported difficulties with the current brand.

- BCAC wrote to Medsafe urging them to progress with urgency the registration of Enhertu® (trastuzumab deruxtecan, T-DXd), a new effective medicine for treating advanced HER2 positive breast cancer.
- BCAC continues to meet with the Australian-based representatives of the company that owns Trodelvy® (sacituzumab govitecan) encouraging them to import their product into New Zealand, set up a cost share programme and apply for Medsafe registration and Pharmac funding.
- BCAC communicated with the company that owns everolimus (Afinitor®) asking that they establish a cost share programme for this medicine. The company responded with a significant price reduction.
- During Pharmac's consultation on whether to introduce a biosimilar version of trastuzumab (Herceptin®), BCAC urged Pharmac to fund retreatment after progression of advanced disease. This is the standard of care in all international guidelines that is provided in other countries. To date Pharmac's committees have declined this, but our advocacy continues.
- BCAC is fully supportive of and collaborating with the Patient Voice Aotearoa led My Life Matters campaign to improve the poor access to medicines experienced by patients with a wide range of treatable diseases in our country. For details and to participate visit [www.mylifematters.org.nz](http://www.mylifematters.org.nz)
- BCAC is contributing to the Enhancing Clinical Trials Infrastructure Project run by the University of Auckland and funded by the Health Research Council and the Ministry of Health. Fay Sowerby is a member of the project's Steering Group. Better access to clinical trials can provide access to innovative new treatments for New Zealanders with early and advanced breast cancer.
- BCAC's Libby Burgess and Terre Nicholson met with breast cancer specialists and provided consumer input into the 2nd New Zealand Consensus Guidelines for Advanced Breast Cancer (ABC-NZ2).
- BCAC has continued to actively promote the concept of risk-based breast screening. With this approach, women are given different schedules and types of routine screening based on an assessment of their personal risk of breast cancer, instead of the one-size-fits-all approach used currently by BreastScreen Aotearoa. Secretary Fay Sowerby has taken the lead in this, meeting with relevant stakeholders throughout the year.
- BCAC's Fay Sowerby wrote a submission to BreastScreen Aotearoa in response to a consultation on whether BSA should measure breast density and report it to those receiving mammograms in the screening programme. As high breast density both masks the presence of breast tumours and increases the risk of getting breast cancer, BCAC's view is that it is a woman's right to know this important health information.
- BCAC has continued to participate in discussions with various stakeholders interested in bringing precision healthcare to New Zealanders with breast cancer.
- BCAC Secretary Fay Sowerby has continued to work closely with AGenDA - Against Genomic Discrimination Aotearoa - a group aimed at ensuring



that New Zealanders will be able to receive the health benefits of genomic information, without risks to their insurance status.

- BCAC committee members attended conferences and meetings (many online) throughout the year to remain up-to-date with breast cancer science and clinical practice. These included:
  - the Breast inSIGhts conference 2022
  - the 18th St. Gallen International Breast Cancer Conference 2023
  - the 2023 ESMO Breast Cancer Annual Congress
  - the Asia Pacific Oncology Alliance webinar
  - the Breast Cancer Trials Annual Scientific Meeting 2023
  - the NZSO (New Zealand Society for Oncology) conference 2023.
- BCAC also attended the foremost international breast cancer research conference, the San Antonio Breast Cancer Symposium in December 2022, via their online programme as consumer advocates, and will do so in person and online again in 2023.

## Improving outcomes for Māori and Pasifika women

- BCAC continued to advocate for removing barriers and improving access to breast cancer screening, diagnosis, treatments and reconstruction options for Māori, Pasifika, rural and disadvantaged women. We encouraged healthcare providers and Pharmac to facilitate delivery of services and treatments close to home.
- BCAC identified and provided **Step by Step** support packs to Māori health providers supporting Māori with breast cancer throughout Aotearoa New Zealand.
- BCAC committee member Maria Marama provided a Māori perspective and advised on a wide range of issues relating to ethnic equity in NZ breast cancer care.
- Maria represented Māori women with breast cancer as a panelist at a Q and A event organized by Breast Cancer Trials on Breast Cancer in Māori, Pasifika and Indigenous Peoples.
- Maria and former BCAC Committee Member Irene Kereama-Royal were awarded a Health Research Council Development Grant for their proposal 'Ma Hinewai Kopu e Whakahou' to design advocacy approaches for Āo Māori and Tiriti led hauora pathways to enhance wāhine Māori experiences with breast cancer and provide a conduit for the narratives of Māori women with breast cancer that can inform action research, community led responses and equity driven outcomes.
- Maria was invited to contribute to a book on Indigenous and Tribal Peoples and Cancer.
- BCAC had a series of meetings with New Zealand researchers to discuss the importance of building Treaty-based partnerships with Māori for breast cancer research in Aotearoa.

## Step by Step - Feedback in 2023

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### PATIENTS

*"The pack was so helpful. I have used the diary for all my appointments, and the journal has been so helpful in allowing me to express my thoughts and feelings. The information booklet was very helpful, breaking down processes and possibilities into easy to understand language."*

*"Excellent, informative reading in an easy to understand format."*

*"I found it so useful and it explained all the things I didn't know in an easy to understand manner. I realised on reading the book, how little I actually knew about breast cancer and all the variables."*

*"Tino pai, absolutely fabulous!!"*

*"Very informative, well presented. Great to have as a resource to read at your own pace."*

*"It's great. Have been using the journal every day. Also been keeping records in the **Step by Step** diary book."*

*"Very helpful. Everything all covered that I wanted to know."*

*"It's brilliant - thank you for this wonderful resource."*

*"I think it is amazing and got a lot of information. It helped me a lot."*

### BREAST CARE NURSES AND ONCOLOGY SUPPORT TEAMS

*"The packs are always very well received and it's lovely seeing the diaries come back in results appointments full of questions, and other details, our ladies have!"*

*"The packs have been well received by wahine on their breast cancer journey."*

*"Thank you, they are a wonderful resource for our patients."*

*"Thanks so much, they are a fantastic resource."*

*"Our surgeon uses them all the time, they are a great tool for our newly diagnosed patients."*

## Those serving on the BCAC committee during 2023 were:

<b>Chair:</b>	Libby Burgess	
<b>Deputy Chair:</b>	Emma Crowley	
<b>Secretary:</b>	Fay Sowerby	
<b>Treasurer:</b>	Louise Malone	
<b>Committee Members:</b>	Ah-Leen Rayner	Belinda Tran-Lawrence
	Catrin Devonald	Denise Lemmen
	Greer Drake	Hazel Jennings
	Linda Fatialofa	Lynda Ames
	Maria Marama	Marion Barnett
	Philippa Reed	Rachel Greenwood
	Rowena Mortimer	Sarah Cato
	Tanya Newman	

This year we welcomed Ah-Leen Rayner and Denise Lemmen who joined the Committee in November 2022 and Dr Rachel Greenwood and Marion Barnett who joined in May 2023. Belinda Tran-Lawrence resigned from the Committee in August 2023 and Hazel Jennings took her place, representing the Aotearoa NZ Breast Cancer Community Trust. In addition to the wide-ranging representation outlined earlier in this report, BCAC committee members have been involved in many other committees, conferences and meetings in 2023, all with the aim of improving breast cancer care in New Zealand.



### Libby Burgess, Chairperson

- Consumer representative: Breast Special Interest Group (BSIG)
- IMPACT (consumer) member and associate member: Breast Cancer Trials. Libby attended the Annual Scientific Meeting in July 2023
- Consumer representative: Cancer Control Agency Te Aho o Te Kahu Consumer Reference Group He Ara Tangata
- Met regularly with BreastScreen Aotearoa
- Met regularly with Patient Voice Aotearoa representatives to advocate for better access to cancer medicines

- Regularly corresponded with Pharmac and Medsafe and responded to consultations on Pharmac advisory committees, operations and medicines funding proposals
- Submitted formal applications to Pharmac for funding of chemotherapy medicine eribulin and targeted therapy medicine pembrolizumab
- Attended a number of meetings with pharmaceutical companies seeking timely, affordable access for New Zealand patients
- Attended meetings of the New Zealand Familial Breast and Ovarian Cancer Group
- Was interviewed for The Economist's Economic Intelligence Unit project developing a 'A patient-centred framework for early breast cancer care in New Zealand' and attended a consultative workshop
- Attended Asia Pacific Oncology Alliance online workshop
- Attended the virtual San Antonio Breast Cancer Symposium in December 2022 as a consumer advocate
- Attended Breast Cancer InSIGhts conference and BSIG meeting, September 2022
- Attended an online Q and A event organized by Breast Cancer Trials on Breast Cancer in Māori, Pasifika and Indigenous Peoples
- Wrote BCAC's submission on the Therapeutic Products Bill
- Contributed to BCAC's response to Manatū Hauora's consultations on its draft Long-Term Insights Briefing on Precision Health: Exploring opportunities and challenges to predict, prevent, diagnose, and treat disease more precisely in Aotearoa New Zealand
- Contributed to BCAC's submission on the draft Manatū Hauora Women's Health Strategy
- Supported many women negotiating the health system and seeking timely access to breast cancer medicines and other treatments
- Contributed as a Working Group member providing consumer input into the 2nd New Zealand Consensus Guidelines for Advanced Breast Cancer, ABC NZ2
- Spoke at awareness raising events
- Met with sex therapist Edit Horvath to discuss updating BCAC's website on the topic of sex after breast cancer
- Met with researchers seeking consumer input into projects on patient treatment preferences and nipple reconstruction
- Met with the Clinical Advisory Group managing the Breast Cancer Register, Te Rēhita Mate Ūtaetae, seeking data on triple negative breast cancer to assist in the preparation of a BCAC submission to Pharmac to fund Trodelvy® (sacituzumab govitecan).



### **Emma Crowley, Deputy Chairperson**

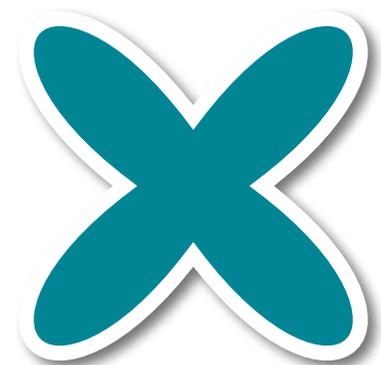
- Chair of the consumer advisory panel of Cancer Trials NZ
- Consumer representative on two breast cancer trials
- Member of the Consumer Advisory Panel of Breast Cancer Trials (BCT)

- Attended Breast cancer InSIGhts conference and BSIG meeting, September 2022
- Attended Breast Cancer Trials Annual Scientific Meeting in July 2023
- Appeared in a video raising awareness of breast cancer in young women produced as part of an event run by fitness instructor and bodybuilding pro Jess Coate (Ngapuhi).



### Fay Sowerby, Secretary

- Chair of Breast Cancer Cure (BCC)
- Member of the National Breast Cancer QPI Working Group
- Member of the BreastScreen Aotearoa Action Group
- Steering Committee Member of the Enhancing NZ's Clinical Trials Infrastructure Project
- Affiliate member: Breast Cancer Trials and participated in the Annual Scientific Meeting in July 2023
- Member of the University of Auckland research Rōpū as consumer, attending several meetings, introducing other members and facilitating introductions
- Attended several meetings with pharmaceutical companies
- Attended meetings of the Breast Special Interest Group (BSIG)
- Met regularly with BreastScreen Aotearoa
- Met with a breast prosthesis designer
- Met with several local breast cancer researchers seeking consumer input into their projects
- Met with Mercy Breast Clinic and Southern Cross to discuss a study identifying high risk NZ women for more customised screening
- Continued to work closely with AGenDA - Against Genomic Discrimination Aotearoa
- Updated Te Aho o Te Kahu on the AGenDA initiative
- Attended New Zealand Familial Breast and Ovarian Cancer Group (NZFBOC) meetings
- Attended NZ Clinical Trials meeting
- Represented New Zealanders with breast cancer at 'Linking the Vines', the inaugural symposium of Te Aka Mātauranga Matepukupuku - Centre for Cancer Research at the University of Auckland.
- Attended a presentation on Te Whatua Ora - Health Workforce Plan 2023-24
- Wrote BCAC's responses to Manatū Hauora's consultations on its draft Long-Term Insights Briefing on Precision Health: Exploring opportunities and



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challenges to predict, prevent, diagnose, and treat disease more precisely in Aotearoa New Zealand and attended related meetings

- Wrote a letter to Genetic Health Services about reporting moderate breast cancer risk
- Wrote a submission to BreastScreen Aotearoa on the topic of mammographic breast density
- Contributed to BCAC's submission on the draft Manatū Hauora Women's Health Strategy and attended a related hui
- Attended a Parliamentary Dinner and panel discussion on Revisiting Genomic Medicine - where are we now?
- Attended online conference 'Why Study Mammographic Density', hosted by MyBRISK
- Attended Breast Cancer InSiGhts conference and BSIG meeting
- Attended online sessions of NZSO conference
- Attended Clinical Trials NZ meeting
- Attended the San Antonio Breast Cancer Symposium in December 2022 as a consumer advocate
- Attended the 2023 ESMO Breast Cancer Annual Congress
- Attended the 18th St. Gallen International Breast Cancer Conference 2023
- Attended Financial Services Council conference - The Great Genomic debate, August 2023
- Attended meeting of the National Breast Cancer Working Group, August 2023.



### Louise Malone, Treasurer

- IMPACT (consumer) member, Breast Cancer Trials
- Completed BCAC's funding applications and wrote reports to BCAC's funders
- Responsible for keeping accounts and reporting on BCAC's financial performance
- Responsible for distribution of **Step by Step** support packs
- Identified a number of new health providers including Māori health clinics for distribution of **Step by Step**
- Distributed material publicising Metavivors NZ
- Attended a number of meetings with pharmaceutical companies
- Wrote news articles for BCAC's website
- Wrote BCAC's quarterly e newsletter.



### Ah-Leen Rayner, Committee Member

- Joined the BCAC committee in November 2022
- Chief Executive of BCAC member group, the Breast Cancer Foundation New Zealand
- Attended a Parliamentary Dinner and panel discussion on Revisiting Genomic Medicine - where are we now? July 2023.



### **Belinda Tran-Lawrence, Committee Member**

- Represented BCAC member group, Aotearoa New Zealand Breast Cancer Community
- Advocated for women with breast cancer who wish to 'go flat' (double mastectomy by choice).



### **Catrin Devonald, Committee Member**

- Chief Executive of BCAC member group, Sweet Louise
- Sweet Louise's Head of Member Services Lorraine Bailey contributed to development of ABC Guidelines NZ2
- Involved in various initiatives to support women with advanced breast cancer (ABC)
- Attended meetings with Patient Voice Aotearoa
- Attended meetings with the Breast Cancer Foundation New Zealand, including input into follow-up to the 'I'm Still Here' research report
- Met with Pharmac to discuss the switch to a trastuzumab biosimilar medicine
- Met with pharmaceutical companies wanting to organise campaigns to highlight ABC
- Input into Breast Cancer QPIs and submissions on the Therapeutic Medicines Bill and Women's Health Strategy.



### **Denise Lemmen, Committee Member**

- Co-ordinates both Metavivors NZ and the Metavivors NZ - Action Facebook groups
- Identified health providers for distributing promotional material for Metavivors NZ
- Co-ordinated Metavivors NZ actions in relation to medicines access
- Attended a Q and A event organized by Breast Cancer Trials on Breast Cancer in Māori, Pasifika and Indigenous Peoples.



### **Greer Davis, Committee Member**

- Member: BCS Young Women's Support Group
- Provides a voice for young women with cancer.



### **Hazel Jennings, Committee Member**

- Joined the Committee in September 2023
- Represents BCAC member group, Aotearoa New Zealand Breast Cancer Community Trust
- Founding Trustee and Secretary/Treasurer Aotearoa New Zealand Breast Cancer Community Trust

- Attended Pharmac meeting on possible implementation of a trastuzumab biosimilar
- Advocates for women wanting to stay flat (no reconstruction)
- Advocates for alternative access routes to screening, diagnosis and medical care in South Auckland.



Linda

### Linda Fatialofa, Committee Member

- Provided a Pasifika lens for activities involving Pasifika women with breast cancer.



Lynda

### Lynda Ames, Committee Member

- IMPACT (consumer) member, Breast Cancer Trials
- Metavivors NZ member
- Identified health providers for distributing promotional material for Metavivors NZ.



Maria

### Maria Marama, Committee Member

- Provides a Māori perspective and advocates for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori
- Represented Māori women with breast cancer as a panelist at a Q and A event organized by Breast Cancer Trials on Breast Cancer in Māori, Pasifika and Indigenous People. Commented in media on this topic
- Along with former BCAC Committee Member Irene Kereama-Royal, was awarded a Health Research Council Development Grant for their proposal 'Ma Hinewai Kopu e Whakahou' to design advocacy approaches for Āo Māori and Tiriti led hauora pathways to enhance wahine Māori experiences with breast cancer and provide a conduit for the narratives of Māori women with breast cancer that can inform action research, community led responses and equity driven outcomes
- Participated in discussions with Mercy Breast Clinic and Southern Cross about a study identifying high risk NZ women for more customised screening
- Was invited to contribute to a book on Indigenous and Tribal Peoples and Cancer.



Marion

### Marion Barnett, Committee Member

- Joined the Committee in May 2023
- Medical writer, contributing in-depth articles for publication on BCAC's website
- Metavivors NZ member
- Provides a voice for women with advanced breast cancer.



Philippa

### Philippa Reed, Committee Member

- Partnerships Manager of BCAC member group Canteen Aotearoa
- Canteen Aotearoa supports rangatahi (13-24) with cancer (including breast cancer) and impacted by cancer in their whānau.



Rachel

### Rachel Greenwood, Committee Member

- Joined the Committee in May 2023
- RNZCGP endorsed General Practice representative member of the BreastScreen Aotearoa Action Group
- Provides a physician's and patient's perspective on breast cancer
- Provides a voice for women with advanced breast cancer.



Rowena

### Rowena Mortimer, Committee Member

- IMPACT (consumer) member, Breast Cancer Trials
- Wrote BCAC's response to Pharmac's consultation on potential changes to Rule 8.1b of the Pharmaceutical Schedule that governs the way in which treatments for paediatric cancers are funded
- Contributed to BCAC's submission on the draft Manatū Hauora Women's Health Strategy.



Sarah

### Sarah Cato, Committee Member

- Advocates for better access to modern medicines
- Metavivors NZ member
- Provides a voice for those with advanced breast cancer.



Tanya

### Tanya Newman, Committee Member

- Certified Radical Remission health coach and teacher
- Provides links to counselling services.



*Together we're stronger*  
Tangata tū pakari tonu



## Supporters

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BCAC has once again received generous and kind support from a number of organisations and individuals during our 2022/2023 financial year.

Funds to print 7,000 more **Step by Step** support packs in July 2022 were obtained from the Breast Cancer Foundation NZ, BreastScreen Aotearoa (Ministry of Health), The Trusts Community Foundation, The Lion Foundation, Pub Charity Ltd, Oxford Sports Trust, Mainland Foundation, Pelorus Trust, North & South Trust, Milestone Foundation, Grassroots Trust Central, Dragon Community Trust, Trust House Foundation, Bendigo Valley Sports & Charity Foundation, Nelson Surgical Associates and Penny Breast Care. Storage King St Lukes provided us with a discounted rate to store the packs and NZ Post's Delivering for Good programme provided free courier services to allow us to deliver them.

BCAC's relationship with The Good Registry, an organisation that helps people to give charitable donations as gifts, has continued to thrive this year. We have been very grateful for the regular donations we have received from them and their 'givers' this year.

As in previous years, a Lottery Community grant provided vital funding so that BCAC could continue to distribute **Step by Step** support packs to those newly diagnosed with breast cancer and maintain our online presence via our website, e-newsletters, and our Facebook peer support networks.

A project to upgrade BCAC's website platform was funded via educational grants from pharmaceutical companies, Pfizer and Merck, Sharp and Dohme.

BCAC was extremely grateful to receive a very generous bequest this year from the estate of Shona B Campbell.

Generous donations in memory of our beloved Committee Member and friend Terre Nicholson were received this year and we continue to be honoured with regular donations from her friends. We are also grateful to those who donated to BCAC in memory of Metavivor Sue Cooper.

As always, we have been touched and extremely grateful for donations received throughout the year from members of the public.

Finally, we would like to acknowledge the generosity of Carolina at Dot Design who supports BCAC with her wonderful design work for our Annual Report, **Step by Step** and our e newsletter.

BCAC thanks all these organisations and individuals who have supported us this year and made our work and achievements for New Zealanders possible.



## BCAC Member Groups

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BCAC is proud to work closely with all our members from the community to improve detection, care and treatment for all New Zealanders with breast cancer. Along with many individual members, BCAC is made up of more than 30 breast cancer related groups.

Alleviate  
Aotearoa NZ Breast Cancer Community Trust  
Ascot Radiology Pink Dragons  
Boobops Dragon Boat Team  
Breast Cancer Action Trust  
Breast Cancer Cure  
Breast Cancer Foundation New Zealand  
Breast Cancer Research Trust  
Breast Cancer Support Aotearoa  
Breast Cancer Support Northland Trust  
Breast Cancer Support Service Tauranga Trust  
Busting with Life  
CanTeen Aotearoa  
Horowhenua Pink Ladies BCS Group  
Kenzie's Gift  
Look Good Feel Better  
Lymphoedema Support Network  
Mamazon Club  
Metavivors NZ  
Mindfulness Aotearoa  
Pinc Cancer Rehabilitation Program  
Rotorua Breast Cancer Trust  
Shocking Pink  
Support Crew  
Sweet Louise  
Taranaki Dragons  
Te Ha o Te Oranga o Ngati Whatua  
Terrier Race Against Time  
The Gift of Knowledge  
Waikato Treasure Chests  
Well Women and Family Trust



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Tangata tū pakari tonu

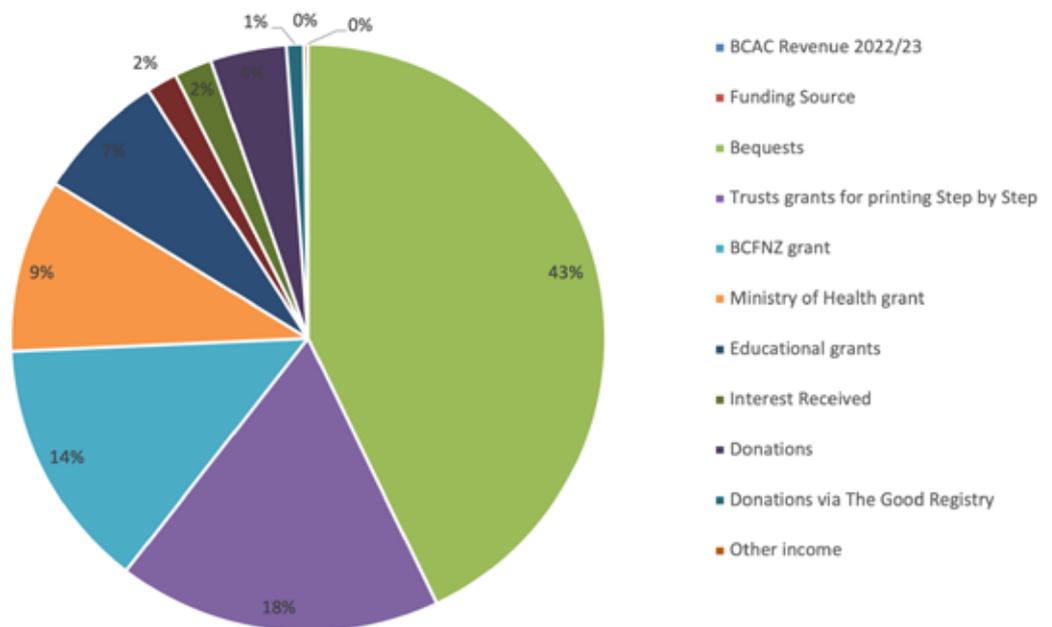


## Financials

### BCAC Revenue 2022/23

Funding Source	Amount (\$)
Bequests	\$180,230
Trusts grants for printing <i>Step by Step</i>	\$74,000
BCFNZ grant	\$58,054
Ministry of Health grant	\$40,000
Educational grants	\$30,000
Lottery Community grant	\$7,079
Interest Received	\$8,618
Donations	\$17,403
Donations via The Good Registry	\$3,964
Other income	\$964
<b>Total Income</b>	<b>\$420,312</b>

BCAC Revenue to 31 March 2023





## Financials

### BCAC Expenses 2022/23

Expenses	Amount (\$)
Value of <b>Step by Step</b> packs delivered	\$24,536
Providing online information and support	\$3,949
<b>Step by Step</b> storage and distribution costs	\$3,885
Producing Metavivor videos	\$2,425
Attending meetings, conferences (members' expenses)	\$1,516
Office expenses	\$1,473
Other expenditure (DIA fee, flowers, food for meetings etc.)	\$793
Audit and bank fees	\$1,762
<b>Total Expenses</b>	<b>\$40,339</b>

### BCAC Expenditure to 31 March 2023





## Plans for 2024

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### FOR 2024, OUR ACTIVITIES WILL INCLUDE:

#### **To make world class detection, treatment and care accessible to all affected by breast cancer in New Zealand**

- Continue engagement with decision makers at all levels
- Continue to update our knowledge of effective treatments through interaction with medical experts and attendance at research meetings
- Support the establishment and implementation of Quality Performance Indicators for breast cancer
- Support the development and implementation of NZ Guidelines for Advanced Breast Cancer
- Raise awareness of new and emerging medicines and the need for increased medicines funding
- Meet with Pharmac to champion access to new and innovative medicines proven to deliver results
- Meet with pharmaceutical companies and encourage them to import and register their innovative medicines in New Zealand, apply for Pharmac funding and offer them at affordable prices in cost-share patient access programmes and free of charge to patients when funding is imminent
- Continually review the performance of the Cancer Control Agency Te Aho o Te Kahu and provide patient-focused input
- Advocate for new ways that breast cancer care can be provided to improve outcomes
- Consult, engage with, empower and, when appropriate, represent Māori and Pasifika women on breast issues and advocate for actions needed to increase access to services, and improve breast cancer experiences and outcomes
- Increase education and knowledge of breast cancer, treatments, supportive care and emerging clinical trial results by attending and promoting local and international expert meetings and conferences
- Advocate for the establishment of schemes enabling early and broader medicines access

- Engage and network with the key stakeholders across the health system to encourage and support consumer, Māori, and Pacific involvement and participation in breast cancer clinical research and its translation by partnering at a governance, local/regional level
- Continue networking and collaboration among groups and individuals.



**To provide information and support to empower those with breast cancer to make informed choices about their treatment and care**

- Widely distribute **Step by Step** to women newly diagnosed with breast cancer throughout NZ
- Provide information and support for those with early and advanced breast cancer
- Provide up to date information via our website about breast cancer and our advocacy work
- Communicate with the breast cancer community via our Facebook page and Twitter
- Continue to support the Metavivors NZ and Metavivors NZ - Action Facebook groups
- Distribute news and information via our e-newsletter to hundreds of subscribers
- Share findings of breast cancer research through our website and social media
- Respond to requests for information and support.



**To provide a unified evidence-based voice for New Zealanders who have experienced breast cancer**

- Advocate for timely access to world-class breast care, including treatments and supportive care in New Zealand
- Raise awareness of advanced breast cancer and related needs for support and services
- Actively participate in a wide range of local, regional and national and international breast cancer-related working groups, panels, committees, organisations and conferences
- Respond to consultation opportunities relating to breast cancer
- Provide a public voice through ongoing liaison with media, interviews and media releases
- Support and promote initiatives enabling the early detection of breast cancer such as mammographic screening, breast density reporting and breast awareness by meeting regularly with BreastScreen Aotearoa to encourage continual progress with the national breast screening programme, including broadening the eligible age band and ensuring the backlog of screening caused by Covid-19 related issues is adequately addressed
- Provide information and comment on the most effective ways to achieve early detection.

**To support the activities of BCAC through promotion and fundraising**

- Apply for grants from charitable trusts
- Approach businesses for funding to support specific projects and activities
- Welcome public donations via our website and newsletters.



*Together we're stronger*  
Tangata tū pakari tonu



**Breast Cancer Aotearoa Coalition**  
PO Box 90224, Victoria St West  
Auckland 1142, New Zealand

[www.breastcancer.org.nz](http://www.breastcancer.org.nz)