



ANNUAL REPORT **2024**



Together we're stronger
Tangata tū pakari tonu



Chairperson's Report

Kia ora koutou,

Firstly, I want to acknowledge all our awesome member groups and the great work you do to support the people of Aotearoa with breast cancer. There's a real community of great people and organisations with big hearts and open arms ready to welcome and support everyone diagnosed who reaches out for friendship, information, advocacy and services. Heartfelt thanks for the fantastic work you do! Thanks also for your collaboration with BCAC across our diverse member groups - we're so much more powerful when we link up and work together.

We've had another busy year, attending many local and international meetings and conferences to ensure ongoing learning and networking with expert researchers, clinicians and advocates. We've engaged with policy makers in the health system through our roles as consumer/patient representatives on various bodies and we've worked closely with Patient Voice Aotearoa to educate politicians on issues shared across a wide range of patient groups. We've collaborated closely with our awesome member groups to ensure the best possible experiences and results for those with the disease. Most importantly, we've connected with and listened to those diagnosed and living with breast cancer through everyone who reaches out for support and information, via our website and social media as well as our own experiences of breast cancer. Metavivors NZ has remained a constant source of wisdom for us, as have the other groups and individuals on our BCAC Committee.

Throughout the year we continued our efforts to increase the availability of medicines to effectively treat the various subtypes and stages of breast cancer. Oncologists need the full toolkit of treatment options to provide the best outcomes for everyone diagnosed with breast cancer. Patients shouldn't have to fundraise to be treated with modern medicines in private clinics - these should be offered in our public health system to all who would benefit. We listened to patients struggling to afford the treatments that are offered in Australia, the UK, Canada and European and Asian countries. We represented these women in our engagements with clinicians, researchers, health system officials, Pharmac, pharmaceutical companies, patient groups and politicians. We aimed to raise awareness, find solutions and seek reform of NZ's medicines system and its

funding model. We worked closely with the wider coalition that is Patient Voice Aotearoa (PVA) to take a unified collective voice to our politicians and policy makers. We're optimistic that finally we are being heard and that positive change is happening.

PVA and Medicines NZ convened Valuing Life, a well-attended parliamentary summit hosted by the Associate Health Minister (Pharmac) David Seymour and MP Todd Stephenson. This offered a great opportunity for BCAC, along with a wide range of other patient groups, to discuss critical medicines issues with all stakeholders, including many health system officials. We were heartened at the level of agreement across the diverse parties at the summit. <https://www.breastcancer.org.nz/content/strong-breast-cancer-presence-valuing-life-summit>



The subsequent Letter of Expectations (LoE) to Pharmac from the Minister contains many elements that we have sought for years. The LoE asks Pharmac to demonstrate a professional and respectful culture, greater collaboration and positive relationships with stakeholders in the health sector, to build trust and better outcomes. It states the Government's intention to reform Pharmac's funding model to account for the positive fiscal impacts of funding more medical technologies, noting that greater investment could not only reduce expenditure elsewhere but provide societal benefits. This could free Pharmac from the legislative "spend within budget" constraint established in 1993 that has driven a culture constantly focused on minimal investment resulting in the harsh rationing of medicines. The LoE notes the need for greater transparency and timeliness in assessment and decision processes and seeks greater involvement of patients, whānau and patient groups. This is great as Pharmac's processes are notoriously slow and opaque. Pharmac is unique internationally in being both the evaluator of clinical benefit and the purchaser of medicines, creating tension between the two distinct roles. The LoE asks Pharmac to consider separating out the purchasing function. We think this could lead to more positive recommendations on medicines, more in line with other countries and international guidelines. In summary, the expectations outlined in the LoE could bring long overdue reform to a system that has stood in the way of longer, healthier lives. We were pleased to have a positive meeting with Pharmac's new Board Chair, Paula Bennett, who will be responsible for implementing the Minister's directives.

The Government's Policy Statement on Health backs up this drive for change, identifying cancer as an area of focus for accelerated action. Priority areas for health services are access, timeliness and quality, with critical enablers being workforce and infrastructure, while targets will be a means of ensuring accountability. Faster access to medicines and pharmaceuticals is stated as a priority area, with an expectation of improved availability and access to cancer medicines. Let's hope these aspirations can be achieved!

We joined more than twenty other PVA disease groups to visit Dr Ayesha Verrall, former Health Minister and Labour's health spokesperson, asking for multi-party agreement

to ensure long-term solutions to NZ's poor medicines access that will not be abandoned with future changes in Government. We noted that NZ's medicines budget must increase from the lowest in the OECD to at least the average, to bring our treatments up to the standard of similar countries. We pointed out that the recent Government uplift in medicines funding immediately enabled Pharmac to move forward in funding several cancer and other medicines, but this merely scratched the surface of the deficit. Ongoing substantial increases are needed. <https://www.breastcancer.org.nz/content/advocates-get-political-drive-reform>

The great news for breast cancer was that the uplift allowed Pharmac to fund Keytruda® (pembrolizumab) for advanced triple negative breast cancer (TNBC). BCAC had applied to Pharmac in 2022 to fund this important medicine for both early and advanced TNBC and we had written during the year asking



Pharmac happy meeting Keytruda announcement

that funding be urgently provided. We responded to Pharmac's consultation on this funding decision by asking that the criteria for access be widened for those with locally advanced TNBC and that it be extended to include those with early stage TNBC. We're hopeful that this will happen soon and that other vital medicines such as Enhertu (T-DXd) might make it over the line with the increased funding. It's worth noting that we had a very pleasant and collegial meeting with Pharmac when they told us that Keytruda would be funded. We're hoping such meetings involving positive news will become more frequent!

We've worked hard to raise awareness of NZ's medicines crisis this year and we've done our best to progress funding for a range of medicines. Marion Barnett, medical writer, BCAC Committee Member and Metavivor, wrote an excellent paper on medicines for advanced breast cancer, comparing access in NZ to what is recommended in international expert guidelines and funded in Australia. Her conclusion regarding the massive treatment gaps was that reform is urgently needed. <https://www.breastcancer.org.nz/sites/default/files/Breast%20cancer%20treatment%20in%20NZ%2014th%20Nov%202023.pdf>

We urged Medsafe to undertake priority reviews to speedily register Enhertu for both HER2+ and HER2-low advanced breast cancer. Medsafe agreed for HER2+ but is using the normal slow process with HER2-low because of limited capacity. We hope the Government soon implements their Coalition Agreement requirement to "register in 30 days if two or more similar jurisdictions have already registered".

We supported Pharmac's proposal to fund Kisqali® (ribociclib) for advanced hormone receptor positive breast cancer and asked that patients have access to

both palbociclib and ribociclib, and at least be able to switch between the two if there are significant side-effects. Pharmac restricted access to one funded product per person but agreed to a side-effect switch. We asked Novartis to provide Kisqali for free until Pharmac funding began and they agreed. We're hopeful Novartis will respond positively to our request for a cost-share programme for those whose oncologists recommend Kisqali but find they don't fit Pharmac's funding criteria.

We disputed Pharmac's proposal to decline funding for Afinitor® (everolimus) which we had applied for in 2018. Pharmac agreed to halt the decline process to allow us to update the evidence on this medicine, which is used to treat advanced hormone receptor positive breast cancer.

Thanks to our fabulous pharmacoeconomist, Alison Davies, we have now formally applied to Pharmac to fund Lynparza® (olaparib) for early and advanced BRCA-mutated HER2-negative breast cancer.

For over two years we have regularly met with Gilead Sciences to encourage them to bring Trodelvy® (sacituzumab govitecan) to NZ, register it with Medsafe and apply to Pharmac for funding. This is vital medicine doubles survival time in advanced TNBC after other medicines have been used. It has been funded in Australia since early 2022. The company has been reluctant to bring Trodelvy to NZ given the difficulty of getting medicines funded here, but we believe our conversations have been worthwhile as the registration process has finally begun and access for NZ patients will become easier and less expensive.

Another important focus area for us this year was seeking to have BreastScreen Aotearoa (BSA) measure and report breast density. Dense breasts are biologically at greater risk of developing a cancer while the dense tissue can mask tumours in mammograms. We believe women have a right to be told if their breasts are at elevated risk so they can understand their need for high vigilance and choose to use additional screening tools. Ultimately, we hope BSA will offer extra screening for high-risk women. Committee Member Fay Sowerby sits on BSA's Action and Equity Team and has long advocated for this to happen. We were pleased to see the Royal Australian and NZ College of Radiologists recommend mandating of breast density reporting and we responded to a BSA consultation with a detailed submission providing evidence of the benefits of reporting. <https://www.breastcancer.org.nz/content/milestone-celebrate-college-radiologists-recommends-breast-density-reporting>



Our Committee Member Maria Marama (Te Arawa, Ngāti Whakāue, Cook Islands) has stood tall as a Kaupapa Māori researcher and advisor on issues and challenges

for wāhine Māori with breast cancer, gaining insights from attending an international conference on cancer in indigenous communities in Norway.

BCAC is a member of AGenDA, a group dedicated to ensuring New Zealanders will be able to receive the health benefits of their genomic information, without risks to their insurance status. Fay has worked closely with AGenDA this year, aiming to ensure the revised Contracts of Insurance Bill will contain anti-discrimination clauses. This has involved participating in working groups with the Financial Services Council and Financial Markets Authority and assisting with a presentation to the Select Committee considering the Bill.

In April our hearts were broken to lose Marion, our much loved and appreciated Metavivor, Committee Member and medical writer, to her breast cancer. We're never far from the cruel reality of this disease and we're absolutely committed to ending the tragedies by continuing our fight for better detection, diagnosis, treatment and care. The new motto of Breast Cancer Trials (Australia and NZ) is a goal we've always had: No more lives cut short.

BCAC's own motto holds true: Tangata tū pakari tonu, Together we're stronger.

Ngā mihi aroha kia koutou katoa,

A handwritten signature in blue ink that reads "Libby Burgess". The signature is written in a cursive, flowing style.

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 2024

Information and resources

- Delivered more than 1400 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**
- Delivered up-to-date breast cancer news, research results and events via our website (47,000 page views) and Facebook page (23,200 reached).
- Delivered a regular e-newsletter to nearly 1400 subscribers.
- Supported nearly 3000 New Zealanders through BCAC's main Facebook page and more than 500 members in our public Facebook group.
- Supported more than 570 New Zealanders with advanced breast cancer through the online communities Metavivors NZ and Metavivors NZ - Action.
- Sent out brochures and posters promoting the Metavivors NZ online peer support group.
- Contributed to the design of and promoted a webinar on pain management for those with advanced breast cancer.
- Provided new information on sexuality after breast cancer via our website.
- Wrote a comprehensive overview of triple negative breast cancer treatment strategies, and New Zealand's current situation in relation to the rest of the world, and published this on our website.
- Produced a series of popular articles based on presentations at the Advanced Breast Cancer Seventh International Consensus Conference, covering many issues of concern for those with advanced breast cancer and published these on our website.
- Responded to more than 100 queries through the BCAC website and Facebook page.

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 Manatū Hauora's (the Ministry of Health's) second consultation 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 responded to a request from BreastScreen Aotearoa for views on breast density by providing a comprehensive summary of the benefits of incorporating the measurement and reporting of breast density within breast screening programmes. We made the case for BSA to measure and inform women of their breast density as high density is both a risk factor for breast cancer and masks tumours in mammograms. BCAC contends that it is our right to be informed of this significant risk factor so we can understand whether we need additional screening and surveillance, to avoid late detection of breast cancer.
- BCAC Chair Libby Burgess represented New Zealand breast cancer patients at a meeting on 'Common Sense Oncology', and responded to and distributed their survey on clinical trial endpoints.
- In June 2024 BCAC Committee Members met with Pharmac's new Chair, Paula Bennett, and also with Labour health spokesperson, Ayesha Verrall, to discuss improving access to breast cancer medicines.
- BCAC Secretary Fay Sowerby continued to act 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.
- Committee Members Fay Sowerby and Dr Rachel Greenwood continued to represent New Zealanders with breast cancer on the BreastScreen Aotearoa Action and Equity Group.
- 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 is fully supportive of and continues to collaborate with Patient Voice Aotearoa on actions to improve access to medicines for patients with a wide range of treatable diseases in our country.
- 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.

- BCAC supported many women as they negotiated the health system to secure timely and appropriate detection, diagnosis, treatment and care.

Improving access to world class treatment and care

- BCAC met with the Breast Cancer Foundation's Clinical Advisory Group seeking access to data from the breast cancer register on triple negative breast cancer to be used in applications to Pharmac for medicines for this subtype.
- Medical writer Marion Barnett, BCAC Committee Member and Metavivor, summarised access to medicines for advanced breast cancer in Aotearoa New Zealand. Marion's paper lists medicines available by breast cancer sub-type and compares our access to that recommended in international guidelines and medicines funded in Australia.
- In December 2023 BCAC wrote to Medsafe asking that they prioritise evaluation and approval of Enhertu® (trastuzumab deruxtecan, T-DXd) for use in advanced HER2-low breast cancer. The DESTINY-Breast04 clinical trial showed that this treatment doubled the time before progression of the cancer and increased overall survival time by 39%. In January 2024 we learned that our request for priority review had been declined.
- In January 2024 BCAC responded to a Pharmac consultation on a proposal to introduce Kisqali® (ribociclib) as an option for treatment with a CDK4/6 inhibitor for advanced hormone receptor positive, HER2 negative breast cancer. We supported the proposal to fund ribociclib but asked that access criteria be expanded so that patients would not be restricted to using only a single CDK4/6 inhibitor. We argued that side effects differ between these two medicines and that patients should be able to be treated with both palbociclib and ribociclib. Pharmac agreed to allow switching if side effects are severe.
- In July 2024 we learned that Pharmac will fund Kisqali® (ribociclib) for those who haven't previously had funded access to Ibrance® (palbociclib). BCAC asked Novartis to provide Kisqali® free to patients until Pharmac funding kicks in and they agreed.
- In January 2024 BCAC wrote to Pharmac strenuously opposing their proposal to decline funding for Afinitor® (everolimus) to treat advanced oestrogen receptor positive, HER2 negative breast cancer. We noted that the use of everolimus was supported by 100% of the expert panel who wrote the NZ Guidelines for advanced breast cancer and is recommended in several international guidelines for breast cancer. As of July 2024, this medicine remains on Pharmac's 'decline' list, but we maintain that there is still a need for some patients to have funded access it.
- In April 2024 several BCAC Committee Members attended a parliamentary summit on medicines access, entitled Valuing Life, organised by Patient Voice Aotearoa with the support of Medicines New Zealand. The summit was attended by 150 people including patients and patient groups, clinicians, researchers, politicians, innovators, industry and health system leaders from

Health NZ and Ministry of Health and Pharmac. BCAC Chair Libby Burgess was a panellist in a workshop on a new Medicines Strategy for New Zealand where she shared ideas on what a good medicines strategy should include, how it should be built and by whom.

- In May 2024 BCAC wrote to Pharmac expressing frustration at the slow pace of funding for Keytruda® (pembrolizumab) for early and advanced triple negative breast cancer (TNBC). We requested that funding be urgently provided for this high risk early and late stage disease that threatens the lives of many New Zealand women. We noted that three classes of medicines recommended for TNBC (immunotherapies, antibody-drug conjugates and PARP inhibitors) remain unfunded in NZ.
- In July 2024 BCAC learned that its formal application to Pharmac to fund Keytruda® (pembrolizumab) both for high-risk early-stage and advanced triple negative breast cancer had been partially successful, with Pharmac approving its use for advanced breast cancer. We continue to encourage Pharmac to fund this vital medicine for early stage disease as well.
- In May 2024 BCAC Secretary Fay Sowerby participated in a panel discussion ‘Why doesn’t NZ fund modern medicines? Separating the Myths and Facts’ organized by Te Aka Mātauranga Matepukupuku – Centre for Cancer Research at the University of Auckland. Several BCAC Committee Members and Metavivors attended this event.
- In June 2024 BCAC signed an open letter to the Prime Minister, Minister of Finance and Associate Minister of Health imploring them to make good their election promise to fund 13 cancer medicines. Although breast cancer medicines were not on this list, BCAC hoped that this letter would raise awareness of New Zealanders’ growing discomfort at our poor access to all kinds of cancer medicines. We asked that the list of ‘essential cancer medicines’ be updated as many breast cancer medicines and uses would now qualify.
- 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 continues to meet regularly with representatives of pharmaceutical companies to encourage them to supply New Zealanders with modern breast cancer medicines at affordable prices.
- 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. As part of this work, Fay has met with the Financial Services Council, attended their conference on the topic of ‘The Great Genomic Debate’, participated in a working group with representatives from the Financial Services Council and the Financial Markets Authority, contributed to a submission on the Contracts of Insurance Bill and helped to present it to the Finance and Expenditure Select Committee.
- 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 has continued to participate in discussions with various stakeholders interested in bringing precision healthcare to New Zealanders with breast cancer.
- BCAC Committee 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 Committee Members attended conferences and meetings (in person and online) throughout the year to remain up-to-date with breast cancer science and clinical practice. These included:
 - the Breast inSIGhts conference, March 2024
 - the European Society for Medical Oncology (ESMO) Breast Cancer Annual Congress, May 2024
 - Te Aka Mātauranga Matepukupuku Centre for Cancer Research Symposium in November 2023 and Cancer Precision meeting, December 2023
 - the Breast Cancer Trials Annual Scientific Meetings, July 2023 and July 2024
 - the New Zealand Society for Oncology (NZSO) conference, September 2023.
- BCAC Committee Members attended the Advanced Breast Cancer Seventh International Consensus Conference (ABC7) Lisbon, Portugal November 2023.
- BCAC Committee Members also attended the foremost international breast cancer research conference, the San Antonio Breast Cancer Symposium, in December 2023 in person and online.

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 was awarded a Masters Scholarship from the Māori Cancer Researcher Awards scheme run by the Cancer Society (Te Kāhui Matepukupuku o Aotearoa) and Hei Āhuru Mōwai (Māori Cancer Leadership Aotearoa). Maria (Ngāti Whakaue, Tūhourangi) will explore the integration of traditional and complementary approaches to cancer care within conventional breast cancer treatment for wāhine Māori. She will use a Kaupapa Māori research approach to identify potential benefits and challenges for wāhine Māori.
- Maria attended the NAISA (Native American and Indigenous Studies Association) Indigenous Conference in Norway in June 2024.



Step by Step - Feedback in 2024



PATIENTS

“My breast nurse gave me one at diagnosis. They are fantastic, I used it heaps and still have it. And think of how much work by so many went into creating such a fabulous resource – very grateful to them and to BCAC for making it happen. Definitely recommend them.”

“It’s great. Have been using the journal every day. Also been keeping records in the Step by Step diary book.”

“Wonderful, easy, user friendly.”

“These were fantastic, I don’t know where I would have been without mine. Definitely great for all those appointments, writing important questions or notes... and I did keep a personal diary of my journey. Thank you for these.”

“It is an excellent resource, clear and well laid out.”

“Very informative. Many thanks to all that put it all together.”

“It’s such a great pack. Everything organised for you just so that you can fill in pages as you go and the info book telling you everything you need to know. Thanks again.”

BREAST CARE NURSES AND ONCOLOGY SUPPORT TEAMS

“The Step by Step pack is actually one of my favourite things to give to women, they love it. I tell them to keep the blank journal by their bed as a ‘worry book’, so that when they can’t sleep in the middle of the night they can pass their thought to the book to look after it for them. Then they can have a good sleep and phone us with their worry in the morning! Some women really like this.”

“Thank you so much, we really appreciate you sending us your Step by Step support pack for wāhine who are diagnosed with breast cancer.”

“We think it’s an awesome resource and would love to get some more to keep on hand at our GP and nursing clinics to further support our wāhine battling breast cancer.”



Those serving on the BCAC committee during 2024 were:

Chair:	Libby Burgess	
Deputy Chair:	Emma Crowley	
Secretary:	Fay Sowerby	
Treasurer:	Louise Malone	
Committee Members:	Ah-Leen Rayner	Alvina Sciascia-Bizaoui
	Catrin Devonald	Denise Lemmen
	Hazel Jennings	Maria Marama
	Marion Barnett	Philippa Reed
	Rachel Greenwood	Rowena Mortimer
	Tanya Newman	

This year we welcomed Alvina Sciascia-Bizaoui who joined the Committee in May 2024, taking the place of Hazel Jennings who had resigned as representative for the Aotearoa NZ Breast Cancer Community Trust. Several long-serving members did not stand for re-election at the in 2023 AGM; at this time we farewelled Lynda Ames, Greer Drake, Sarah Cato and Linda Fatialofa.

With great sadness we note that Committee Member Marion Barnett passed away in April 2024.

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 2024, all with the aim of improving breast cancer care in New Zealand.



Libby Burgess, Chairperson

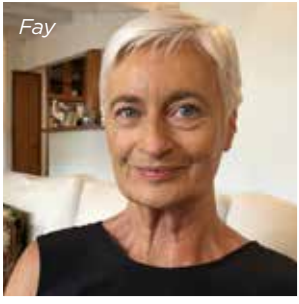
- Consumer representative: Breast Special Interest Group (BSIG)
- IMPACT (consumer) member and associate member: Breast Cancer Trials. Libby attended the Annual Scientific Meetings in July 2023 and July 2024
- Met regularly with BreastScreen Aotearoa
- Met regularly with Patient Voice Aotearoa representatives to advocate for better access to cancer medicines

- Regularly corresponded and met with Pharmac and Medsafe and responded to consultations on Pharmac advisory committees, operations and medicines funding proposals
- Met with the Breast Cancer Foundation's Clinical Advisory Group seeking access to data from the Breast Cancer Register on triple negative breast cancer to be used in applications to Pharmac for medicines for this subtype
- Panellist in a workshop on a new Medicines Strategy for New Zealand at the Valuing Life parliamentary summit run by Patient Voice Aotearoa
- Represented New Zealand breast cancer patients at a meeting on 'Common Sense Oncology'
- Responded to and distributed the Common Sense Oncology survey on clinical trial endpoints
- Met with Pharmac Board Chair Paula Bennett
- Met with Labour health spokesperson Ayesha Verrall
- Met with a representative of Medicines Australia to discuss consumer attendance at breast cancer research conferences
- Interviewed for television about Pharmac's decision to fund Keytruda® (pembrolizumab)
- Attended a number of meetings with pharmaceutical companies seeking timely, affordable access to breast cancer medicines for New Zealand patients
- Attended presentation by Australian oncologist Belinda Yeo giving information on the use of Kisqali® (ribociclib)
- Attended meetings of the New Zealand Familial Breast and Ovarian Cancer Group
- Attended the San Antonio Breast Cancer Symposium in December 2023 as a consumer advocate
- Wrote a comprehensive overview of triple negative breast cancer treatment strategies and New Zealand's current situation in relation to the rest of the world
- Attended a parliamentary summit on medicines access, entitled Valuing Life, organised by Patient Voice Aotearoa with the support of Medicines New Zealand
- Supported many women negotiating the health system and seeking timely access to breast cancer medicines and other treatments.



Emma Crowley, Deputy Chairperson

- Chair of the consumer advisory panel of Cancer Trials NZ
- Member of the Consumer Advisory Panel of Breast Cancer Trials
- 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)
- Attended Breast Cancer Trials Annual Scientific Meetings in July 2023 and July 2024
- Helped to revise BCAC's Constitution.



Fay Sowerby, Secretary

- Chair of Breast Cancer Cure
- Member of the National Breast Cancer QPI Working Group attending meetings as required.
- Member of the BreastScreen Aotearoa Action and Equity Group. Attending meetings, networking and sharing information as required
- Wrote a submission to BreastScreen Aotearoa on the topic of mammographic breast density
- Wrote a follow-up letter to BreastScreen Aotearoa stressing the importance of measuring and reporting breast density
- Attended meetings of the Breast Special Interest Group (BSIG) presenting on Unfunded Medicines 2024
- Affiliate member of Breast Cancer Trials and participated in the Annual Scientific Meetings in July 2023 and July 2024
- Member of the University of Auckland research Rōpū as consumer, facilitating introductions and agreeing to be a consumer representative on projects
- Ministry of Health, Precision Health: Genomics Expert Advisory Group Inaugural meeting.
- Attended several meetings with pharmaceutical companies and with Pharmac
- Met regularly with BreastScreen Aotearoa
- Attended a presentation of Te Whatu Ora's Health Workforce Plan 2023-24
- Attended a parliamentary dinner on Genomic Medicine hosted by Medicines NZ
- Served on an International BRCA Cancer Patients Insight Advisory Board
- Attended Breast Cancer InSIGhts conference and BSIG meeting
- Attended (on line) the San Antonio Breast Cancer Symposium in December 2023
- Attended a parliamentary summit on medicines access, entitled Valuing Life, organised by Patient Voice Aotearoa with the support of Medicines New Zealand
- Attended a presentation about advocacy for better access to medicines by Ben Thomas and Neale Jones partners of Capital (consultancy)
- Met with Pharmac Board Chair Paula Bennett
- Interviewed for television about the roll-out of the age extension for breast screening
- Met with several local breast cancer researchers seeking consumer input into their projects
- Presenter and panelist at the Financial

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- Services Council conference - The Great Genomic Debate, August 2023
- Worked alongside Prof. Andrew Shelling and other AGenDA members, Against Genomic Discrimination Aotearoa
- AGenDA member of the Financial Services Council Working Group with Geneticists and representatives from the Financial Services Council
- Initiated and co-wrote a submission on the Contracts of Insurance Bill, alongside others and appearing before the Finance and Expenditure Select Committee on 26 June 2024
- Spoke on Nine to Noon and interviewed alongside Andrew Shelling regarding Preventing Genomic Discrimination
- Attended Te Aka Mātauranga Matepukupuku Centre for Cancer Research Symposium in November 2023 and Cancer Precision meeting in December 2023
- Panelist for the presentation and discussion event 'Why doesn't NZ fund modern medicines? Separating the Myths and Facts' organized by Te Aka Mātauranga Matepukupuku - Centre for Cancer Research at the University of Auckland
- Telephone Conversation with David Hughes regarding issues raised during Panel Discussion
- Attended presentation by Australian oncologist Belinda Yeo giving information on the use of Kisqali® (ribociclib)
- Facilitated the development of a pain management webinar for those with advanced breast cancer
- Attended and presented at New Zealand Familial Breast and Ovarian Cancer Group meetings
- Attended NZSO conference
- Attended the 2024 ESMO Breast Cancer Annual Congress
- Attended monthly Research to Practice and ESMO webinars on topics of interest
- Provide support to breast cancer patients on an ongoing basis.



Louise

Louise Malone, Treasurer

- 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 promoting Metavivors NZ
- Attended a number of meetings with pharmaceutical companies
- Attended presentation by Australian oncologist Belinda Yeo giving information on the use of Kisqali® (ribociclib)
- Wrote news articles for BCAC's website
- Wrote BCAC's quarterly e newsletter
- IMPACT (consumer) member, Breast Cancer Trials
- Attended the San Antonio Breast Cancer Symposium in December 2023 as a consumer advocate.

Ah-Leen



Ah-Leen Rayner, Committee Member

- Chief Executive of the Breast Cancer Foundation NZ, a BCAC member.

Alvina



Alvina Sciascia-Bizaoui, Committee Member

- Joined the Committee in May 2024
- Represents BCAC member group, Aotearoa New Zealand Breast Cancer Community Trust.



Catrin

Catrin Devonald, Committee Member

- Chief Executive of BCAC member group, Sweet Louise
- Involved in various initiatives to support women with advanced breast cancer (ABC)
- Organised the development and production of a pain management webinar for women with ABC
- Sweet Louise's Head of Member Services Lorraine Bailey is engaging with BCF on the ABC-NZ treatment guidelines update
- Attended meetings with Patient Voice Aotearoa
- Attended meetings with the Breast Cancer Foundation New Zealand
- Met with pharmaceutical companies wanting to organise campaigns to highlight ABC
- Attended the Advanced Breast Cancer Seventh International Consensus Conference (ABC7) Lisbon, Portugal November 2023.



Denise

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
- Contributed to the development of a pain management webinar
- Attended a Q and A event organized by Breast Cancer Trials on Breast Cancer in Māori, Pasifika and Indigenous Peoples



Denise, Catrin and Lorraine at ABC7 Portugal



- Attended the Advanced Breast Cancer Seventh International Consensus Conference (ABC7) Lisbon, Portugal November 2023.

Hazel Jennings, Committee Member

- Represented BCAC member group, Aotearoa New Zealand Breast Cancer Community Trust.
- Helped to revise BCAC's Constitution.



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
- Member, Māori Breast and Cervical Cancer Advisory Group, Te Whatu Ora
- Member, Decentralised Clinical Trials Advisory Group, University of Auckland
- 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
- Contributor to Book: Indigenous and Tribal Peoples and Cancer. Chapter Title: Expression of My Mana Motuhake (Self-Agency) to Guide Breast Cancer Recovery
- Māori Researcher, Completing Research "He Oranga U" (formerly Ma Hinewaikōpua e whakahou), Health Research Council
- Awarded a Masters Scholarship from the Māori Cancer Researcher Awards scheme run by the Cancer Society (Te Kāhui Matepukupuku o Aotearoa) and Hei Āhuru Mōwai (Māori Cancer Leadership Aotearoa) to explore the integration of traditional and complementary approaches to cancer care within conventional breast cancer treatment for wāhine Māori
- Recipient of Kapenga M and Raniera Te Tawhiti Kingi Scholarships for Masters degree research
- Attended the World Indigenous Cancer Conference, Melbourne, May 2024
- Attended the NAISA Indigenous Conference in Norway in June 2024.



Maria Masters scholarship award



Marion

Marion Barnett, Committee Member

- Medical writer, contributed in-depth articles for publication on BCAC’s website
- Metavivors NZ member
- Wrote a comprehensive summary of access to medicines for advanced breast cancer in Aotearoa NZ. Marion’s paper lists medicines available by breast cancer sub-type and compares our access to that recommended in international guidelines and medicines funded in Australia
- Provided a voice for women with advanced breast cancer
- Attended the Advanced Breast Cancer Seventh International Consensus Conference (ABC7) Lisbon, Portugal November 2023 online
- Wrote a series of popular articles based on presentations at ABC7, covering many issues of concern for those with advanced breast cancer.



Philippa

Philippa Reed, Committee Member

- Partnerships Manager of BCAC member group Canteen Aotearoa
- Canteen Aotearoa supports rangatahi (13-24) impacted by cancer, whether it’s a diagnosis of their own or cancer in their whānau.



Rachel

Rachel Greenwood, Committee Member

- RNZCGP endorsed General Practice representative member of the BreastScreen Aotearoa Action and Equity 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

- Provided legal advice for BCAC to comply with new requirements of the Charities Act and Incorporated Societies Act
- Helped to revise BCAC’s Constitution
- Ensured BCAC re-registered with the Companies Office.



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

BCAC has once again received generous and kind support from a number of organisations and individuals during our 2023/2024 financial year.

We are especially grateful to our regular donors and those who have donated in memory of others with breast cancer.

Jess Coate's fundraiser in support of young women with breast cancer contributed significantly to BCAC, as did as did sponsorship of a runner in the Auckland marathon this year.

BCAC was very grateful to receive a bequest this year from the estate of B Gilray.

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.

The balance of a Lotteries grant received in 2023 continued to support the maintenance of BCAC's website, distribution of the **Step by Step** resource pack, and liaison with member groups and healthcare providers.

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.



*Packing **Step by Step** June 2024*



*Picking up **Step by Step***



BCAC Member Groups

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.

Age Concern
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



Together we're stronger
Tangata tū pakari tonu

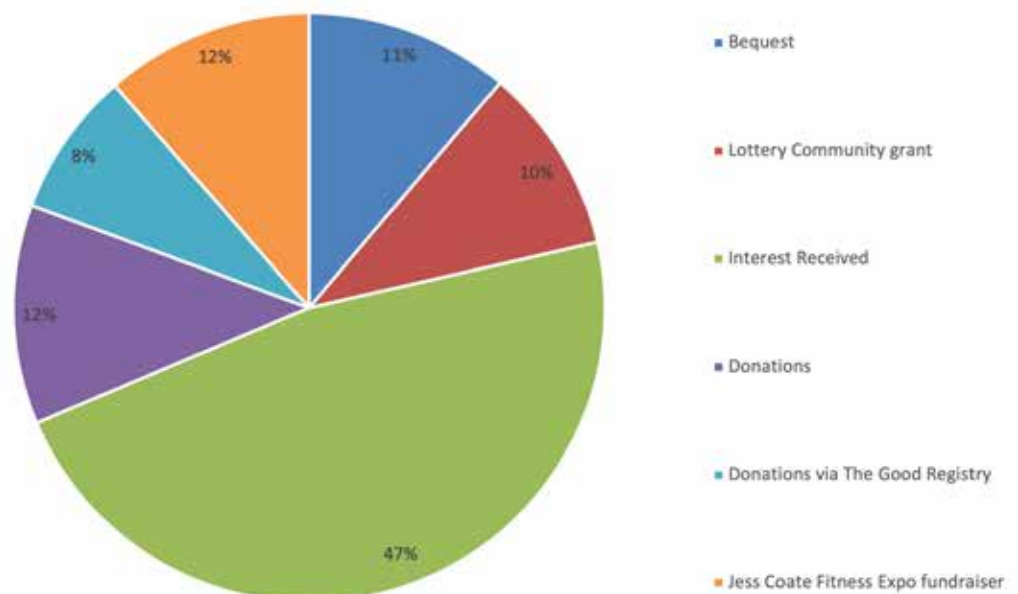


Financials

BCAC Revenue 2022/23

Funding Source	Amount (\$)
Bequest	\$5,000
Lottery Community grant	\$4,589
Interest Received	\$21,110
Donations	\$5,386
Donations via The Good Registry	\$3,565
Jess Coate Fitness Expo fundraiser	\$5,100
Total Income	\$44,750

BCAC Revenue to 31 March 2024



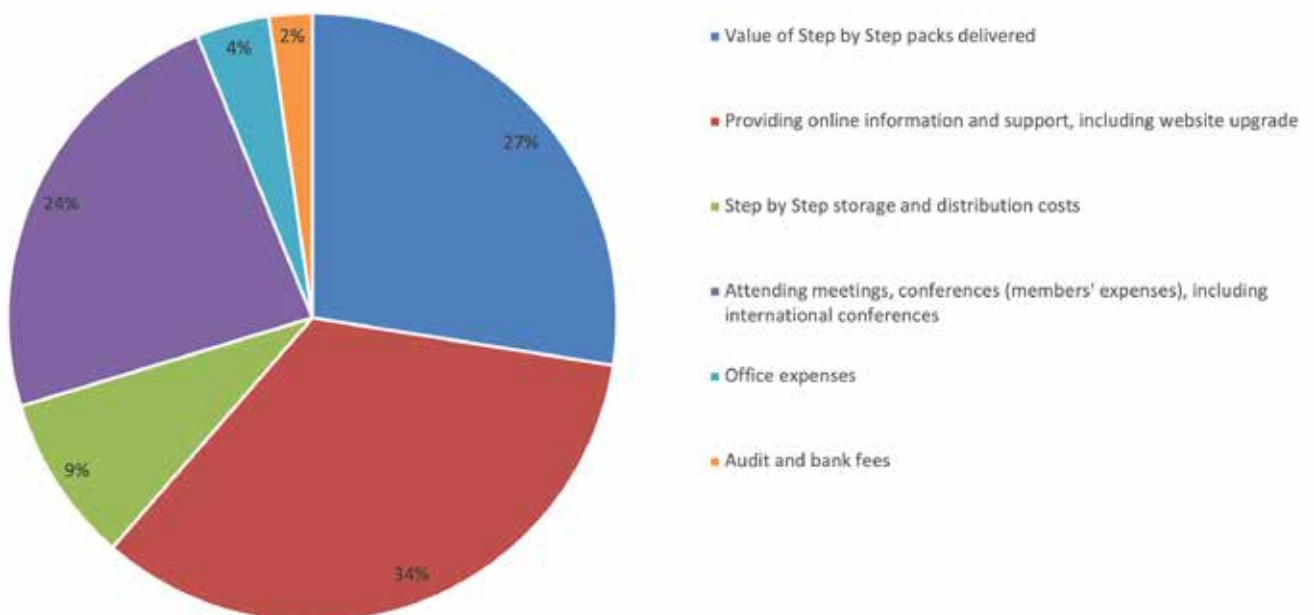


Financials

BCAC Expenses 2023/24

Expenses	Amount (\$)
Value of Step by Step packs delivered	\$21,108
Providing online information and support, including website upgrade	\$26,022
Step by Step storage and distribution costs	\$6,849
Attending meetings, conferences (members' expenses), including international conferences	\$18,040
Office expenses	\$2,985
Audit and bank fees	\$1,761
Total Expenses	\$76,765

BCAC Expenditure to 31 March 2024





Plans for 2025

FOR 2025, 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 Medsafe registration and 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 New Zealand
- 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 group
- 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
- 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