



ANNUAL REPORT **2022**



Together we're stronger
Tangata tū pakari tonu



Chairperson's Report

It was another full-on year for BCAC as it has been for all our wonderful member groups doing great work to support New Zealanders with breast cancer across Aotearoa.

We were running short of BCAC's much-loved **Step by Step** support packs, so our Treasurer Louise Malone embarked on a major fundraising effort, successfully writing proposals to multiple Trusts to enable us to print a further 7,000 copies. Fantastic work Louise! Thanks also to the Breast Cancer Foundation (BCF) for remaining the principal funder of this resource. To ensure we offer **Step by Step** free of charge to everyone diagnosed we've been strengthening our connections with breast clinics and Māori health providers around Aotearoa, and we've had a great response. We've also continued sending packs to member groups and people who order them through our website. Thank heavens for the NZ Post Delivering for Good award that gives us free door to door courier services for a year!

Thanks to fundraising by our late committee member Elisa Wijohn, we were able to film Gifts to the Future, He Koha ā Mua videos of three awesome wāhine Māori with advanced breast cancer (ABC). Elisa was motivated to ensure the videos were accessible to Māori, and as ever, she put her energy where her passion lay to achieve this. We know the Gifts, He Koha video series offers fantastic support for anyone diagnosed, as it's a huge comfort to see how others live with ABC. The videos show that life in no way ends with a diagnosis of ABC, in fact it's a reminder to live your best life now! To celebrate women living with ABC we asked Metavivors NZ to send us images to illustrate this annual report. The pics we received were so stunning we made a gallery of them on our website and released it on International Metastatic Breast Cancer Awareness Day. Check this out on our website, where I promise you'll enjoy, crack a few smiles and perhaps shed some tears seeing these gorgeous women rocking their favourite pastimes, living life to the max! <https://www.breastcancer.org.nz/content/metavivors-living-life-max>

On the early breast cancer front, BCAC was pleased to be involved in a project run by The Economist's Economic Intelligence Unit to review the early breast cancer pathway in NZ and identify opportunities for improvement. BCF and experts spanning surgery, medicines, radiation, nursing and Māori Cancer Leadership, Hei Āhuru Mōwai, also contributed. The EIU's report recommends some great patient-centred approaches to improve the experiences and outcomes for those diagnosed.

BCF released a progress report, 30,000 voices: Informing a better future for breast

cancer in Aotearoa New Zealand from data gathered over 20 years in the National Breast Cancer Register Te Rēhita Mate Ūtaetae (BC Register). Key findings were that although 5-year survival has generally improved, younger women, those who struggle to access screening (particularly Māori), Pacific women, and those with aggressive, higher risk and later stage cancers face the biggest threats. Too many of these women have their breast cancer come back after more than five years, and too many women are diagnosed at a young age. The BC Register continues to be an invaluable source of insights on breast cancer in the women of Aotearoa, informing priorities for action.

BCF is now producing a new version of their 2018 *I'm Still Here* on living with ABC in Aotearoa. They recently undertook a survey of affected women and their clinicians, and will combine the results with BC Register data on ABC. The 2018 report led to international ABC expert Fatima Cardoso's visit Aotearoa and proved to be a powerful catalyst for awareness and advocacy for improvement for those with later stage disease. We hope for at least as big an impact from the 2022 version.

Updated Guidelines for advanced breast cancer in NZ (ABC-NZ2) were released in October and are now available from the BCAC website www.breastcancer.org.nz/sites/default/files/ABC-NZ2-guidelines-oct2022-digital.pdf

These were based on guidelines developed by Fatima Cardoso and ESMO in Europe. The New Zealand version was carefully reviewed and amended by local expert clinicians led by oncologist Marion Kuper, with the help of BCF and the input of advocates, our late committee member Terre Nicholson from Metavivors, Lorraine Bailey from Sweet Louise and myself from BCAC. The guidelines will be a fantastic resource ensuring that all NZ clinicians understand the latest recommended treatments for ABC and that patients can also access this knowledge and discuss it with their doctors. The guidelines list medicines recommended for the different sub-types of ABC and helpfully note whether they are Medsafe registered or Pharmac funded.

The Cancer Control Agency, Te Aho o Te Kahu (TAoTK) has been working to establish Quality Performance Indicators (QPIs) to monitor services provided for a number of cancers and committee member Fay Sowerby was on the working group to help select QPIs for breast cancer. It was frustrating that the detailed, informative data in the BC Register collected for up to 20 years from Auckland, Waikato, Wellington and Christchurch could not be used, as the QPI data gathering was limited to information collected across the entire health system. The QPIs should help determine whether key elements of care are equitably provided across the country. We're hopeful for timely implementation of many of the recommendations in TAoTK's report He Mahere Ratonga Mate Pukupuku, Cancer Services Planning: A vision for cancer treatment in the reformed health system. Too often, well-researched reports and recommendations simply gather dust in our under-resourced health system.

TAoTK produced a deeply disappointing report on cancer medicines in which they recommended only one medicine for early breast cancer that was already planned

for Pharmac funding and none for metastatic breast cancer. This left out a multitude of important treatments funded in other countries that NZ patients are missing out on. If there is ever a repeat of this exercise we would urge that T AoTK completely revise their methodology, as it appears designed to filter out almost everything. They should also include local experts and knowledgeable consumers in their analysis and reporting.

Advocacy from a broad range of patient/disease groups under the Patient Voice Aotearoa banner prompted the Government to commission an independent review of Pharmac. BCAC met with the Review Panel and made a substantial submission on much needed reforms. The Panel's report revealed the organisation needs to be more equitable for Māori, Pasifika and disabled people; engage more with Māori and include Māori in decision making, honour Te Tiriti; act in a more timely, open and transparent way; include consumer advice and lived experience in its work and decision making; and connect and collaborate more with the rest of health system. These recommendations, if acted on, could all lead to better processes. But the Review Panel was critically limited in its Terms of Reference, as the medicines budget was excluded from consideration. The deliberate omission by the Government of the impact of Pharmac's small, capped budget meant that the most important driver of our poor medicines access was ignored. This was a wasted opportunity!

BCAC saw the introduction of the Pae Ora Healthy Futures legislation as a great way for the Government to review Pharmac's objectives, functions and operations. Sadly, they chose to enshrine the 29 year old version. Constraining the cost of medicines remains the underlying purpose, with the opportunity lost to shift Pharmac's focus to seeking healthy lives.

BCAC engaged with Pharmac in other ways this year. Our wonderful volunteer pharmacoeconomist Alison Davies compiled a formal funding application for eribulin (Halaven), an important chemotherapy option for ABC. We responded to consultations on zoledronic acid and T-DM1 (Kadcyla) and we're engaging now over the introduction of biosimilar versions of trastuzumab (Herceptin). We continue to urge Pharmac to replace goserelin Teva as the delivery device causes unnecessary pain to patients and has even caused some to cease treatment.

Committee member Belinda Tran-Lawrence, who leads the online Aotearoa NZ Breast Cancer Community, advocated on behalf of women choosing to 'go flat' (double mastectomy). Elisa Wijohn complained to Auckland DHB when she was assigned 'Do Not Resuscitate' without her knowledge and then worked with the DHB to produce a staff training video to prevent this happening to

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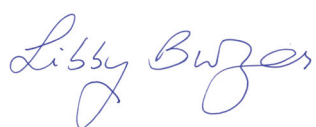
others. Many committee members served as consumer representatives on health system advisory panels and policy groups and attended local and international breast cancer conferences, mostly online. Maria Marama provided valuable Māori insights and knowledge in many of BCAC's engagements with researchers and the health system. We contributed to initiatives to improve clinical trial access for New Zealanders and joined Against Genomic Discrimination Aotearoa to fight discrimination by insurance companies based on the genes we carry. We engaged with pharmaceutical companies, urging them to bring their medicines to Aotearoa, register them with Medsafe, establish affordable patient access 'cost share' programmes and apply for Pharmac funding. We contributed to a review of BreastScreen Aotearoa in which we urged that our screening programme measure and report breast density and extend screening from 69 out to age 74.

You might wonder what motivates the women of BCAC to volunteer their time over the months and years advocating, engaging, learning, submitting and fighting for earlier detection, faster more accurate diagnosis, more effective and accessible treatment, support and care for everyone diagnosed with breast cancer in Aotearoa. It's not just our own personal experiences of the disease. It's our knowledge of the brutal effects on the lives of women diagnosed and their loved ones. This year BCAC lost three much loved and respected committee members to breast cancer. Terre Nicholson, Elisa Wijohn and Gillian Wintrup were all wonderful, inspirational, passionate, talented, wise and generous women that we've worked with, respected, formed friendships with and cared deeply for. Women we know as sisters, colleagues, fellow warriors. This is very personal for us. We've lost many other treasured Metavivor friends this year. And Aotearoa has lost so many more loved women that we've never met. Precious lives lost too soon. When will it end? We're absolutely committed to our work to reduce the impact of this cruel disease, to enhance the lives of everyone dealing with breast cancer now, whether it's early or advanced and to create a better future for our daughters and mokopuna, the generations that will follow.

BCAC's motto remains a guiding principle for us - tangata tū pakari tonu, together we're stronger. So let's collaborate and make a difference!

Ngā mihi mahana kia koutou katoa, warm greetings to everyone. Kia kaha, kia koa, kia haumarū, stay strong, be happy and safe.

Arohanui,



Libby Burgess, MNZM
BCAC Chairperson



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 2022

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**
- 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 1000 subscribers.
- Supported more than 2600 New Zealanders through BCAC's main Facebook page and more than 375 members in our public Facebook group.
- Supported more than 500 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.
- Raised funds for and printed 7,000 new copies of the **Step by Step** support pack.

Providing a voice for those diagnosed with breast cancer

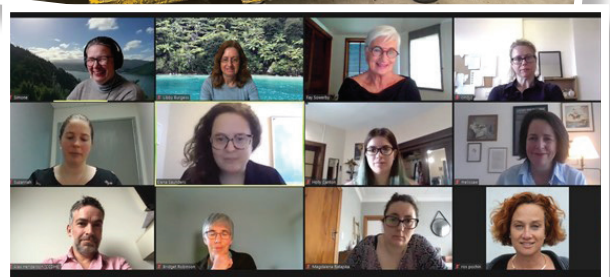
BCAC committee members participate in a number of consumer and specialist breast cancer groups throughout New Zealand to ensure breast cancer patients are represented in the health system. We also engage in other activities and projects designed to raise the voices of those diagnosed with breast cancer.

- BCAC and Sweet Louise filmed stories from Māori women living with advanced breast cancer to add to the collection of He Koha ā Mua, Gifts to the Future legacy videos. This collection is the result of a collaboration between BCAC, Sweet Louise, Breast Cancer Foundation NZ and Metavivors NZ that aims to record the experiences of these women, as well as wisdom and insights that they would like to share. BCAC is extremely grateful to the women who agreed to tell their

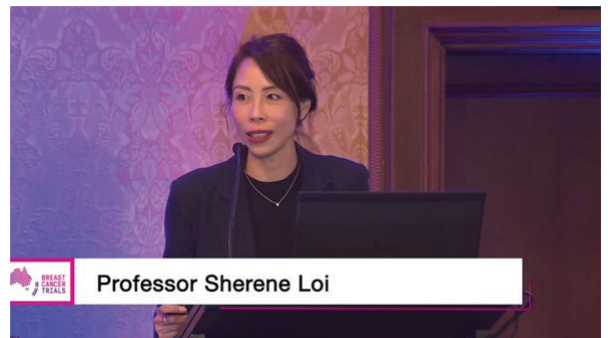


stories and to former Committee Member and Metavivor Elisa Wijohn, who raised funds specifically to ensure that Māori women were included in the series.

- BCAC contributed extensively to a project run by The Economist's Economic Intelligence Unit to develop A Patient-Centred Framework for Early Breast Cancer Care in New Zealand.
- BCAC represented New Zealanders with breast cancer in responding to Pharmac's consultations on zoledronic acid and trastuzumab emtansine (Kadcyla). Although we were pleased to see new access to Kadcyla for those with early breast cancer, we were disappointed that Pharmac chose to exclude these patients from further access to this medicine should they relapse and require it in the metastatic setting.
- BCAC met with the Government-appointed independent panel which reviewed Pharmac this year, and shared insights from our members on their experiences and interactions with Pharmac in relation to access to medicines.
- BCAC commented on the Pae Ora Health System Reform Bill, requesting that the new legislation incorporate any findings of the Pharmac Review Panel as well as revision of Pharmac's objectives, functions and operations.
- 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 professional standards for breast cancer treatment in New Zealand.
- BCAC contributed to a review of BreastScreen Aotearoa.
- BCAC commented on Te Aho o Te Kahu's Medicines Report, released in May 2022.
- BCAC contributed to a number of initiatives from the Breast Cancer Foundation NZ: their Breast Cancer Register Report, the next 'I'm Still Here' report, Advanced Breast Cancer Guidelines (ABC NZ2), and their Nurses' Day.
- BCAC and Metavivors NZ attended the Asia Pacific Metastatic Breast Cancer Forum, contributed to the Living with Stage 4 Project and the ABC Awareness Campaign.



- BCAC Committee member Belinda Tran-Lawrence advocated for women with breast cancer who wish to 'go flat' (double mastectomy by choice).
- BCAC Committee member Elisa Wijohn challenged her local District Health Board over a Do Not Resuscitate order issued without proper patient consultation, and contributed to a staff training video to remedy this problem.
- 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 was appointed to the Consumer Advisory Panel of Breast Cancer Trials (Australia and New Zealand), and continued as Chair of the Consumer Advisory Panel of Cancer Trials New Zealand.
- Libby was a member of the NZ Cancer Control Agency's Te Aho o Te Kahu Consumer Reference Group, He Ara Tangata (HAT).
- Fay was a member of the Breast Cancer Trials (BCT) Fundraising and Communications Committee.
- BCAC Committee member Rowena Mortimer was Chair of the Consumer Advisory Panel of the Health Quality and Safety Commission.
- 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 members attended the virtual Advanced Breast Cancer 6th International Consensus Conference (ABC6) in November 2021.
- 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.
- 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. Terre Nicholson and Libby Burgess participated in a consumer focus group and 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 supported in The Medicine Gap, a campaign run by journalist Rachel Smalley, highlighting New Zealanders' lack of access to modern medicines compared to other countries.
- BCAC is a member of the Advanced Breast Cancer Guidelines NZ Working Group.
- 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.
- Fay has also met with stakeholders (Te Aho o Te Kahu, CanShare) to discuss the formation of a registry for families at risk of hereditary cancer.
- BCAC joined a new group, AGenDA - Against Genomic Discrimination Aotearoa - aimed at ensuring that New Zealanders will be able to receive the health benefits of genomic information, without risks to their insurance status.
- BCAC continued to meet with pharmaceutical companies to learn about new products coming to the market, and to encourage them to apply for registration and funding as well as providing cost share programmes for key breast cancer drugs in NZ.
- 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 ABC6 conference run by the ABC (Advanced Breast Cancer) Global Alliance
 - the COSA (Clinical Oncology Society of Australia) conference
 - the NZSO (New Zealand Society for Oncology) conference
 - the ASCO (American Society of Clinical Oncology) conference
 - the Breast Cancer Trials Annual Scientific Meeting
 - the NZ Breast Cancer Symposium
 - the Breast cancer inSIGhts conference.



- BCAC also attended the foremost international breast cancer research conference, the San Antonio Breast Cancer Symposium in December 2021, via their online programme as consumer advocates and will do so again in 2022.
- BCAC members attended webinars on medicines development and breast cancer recurrence, and attended a panel discussion on Challenges and Opportunities with Genomic Medicine.



Improving outcomes for Māori and Pasifika women

- BCAC continued to advocate for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori, Pasifika, rural and disadvantaged women.
- Identified and provided **Step by Step** support packs to Māori health providers supporting Māori with breast cancer throughout Aotearoa New Zealand.
- Liaised with Māori and Pasifika women affected by breast cancer and related advisory groups.
- Highlighted the poorer outcomes of Māori and Pasifika women with breast cancer and identified opportunities for improvement.
- BCAC committee member Maria Marama provided a Māori perspective and advised on matters relating to ethnic equity in NZ breast cancer care.
- 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 2022



PATIENTS

“Excellent, well presented, plenty of information. Sets one’s mind at ease about survival rates. Gives a sense of confidence in medical team.”

“I found it a really helpful good starting point at my initial diagnosis. The diary in particular with all the appointment schedules and notes for questions etc was a great navigating point for me with my initial appointments and questions. The website recommendations were also helpful when I was a bit lost to start with. Good guidance so as not to overload myself with confusing information.”

“Fantastic resource! The information booklet is the perfect size for going back and referring to, & I’ve used it a lot since my diagnosis. I like the way the notebook is separated into sections for easy access.”

“This was an awesome resource for me and am sure it would benefit everyone who has a bc diagnosis.”

“I received my journal pack yesterday and it is amazing – thank you so much. Will definitely use them. The info booklet is good.”

“I think **Step by Step** is wonderful and very informative.”

“It’s a wonderful resource – I am very grateful.”

“Great and generous resource.”



BREAST CARE NURSES AND ONCOLOGY SUPPORT TEAMS

“Thank you so much, we have received the packs. They are fantastic and what a great tool.”

Cancer Pathway Kaiawhina

“I have just received your invaluable **Step by step** pack and would love to have this to add to the information I provide ladies with in the BCFNZ canvas bag they send me.”

Breast Care Nurse Specialist

“I showed our new clinical manager the free sample pack you sent me and she absolutely loved it - she thought it was such a beautiful resource.”

Community Health Worker

“What a wonderful mahi that you are doing.”

Breast nurse, Māori Health Provider

“Thank you for the support pack, what an amazing resource! Beautifully presented and love the addition of the organizer.”

Māori Health Provider



BCAC Committee



Those serving on the BCAC committee during 2022 were:

Chair:	Libby Burgess	
Deputy Chair:	Emma Crowley	
Secretary:	Fay Sowerby	
Treasurer:	Louise Malone	
Committee Members:	Rowena Mortimer	Gillian Wintrup
	Lynda Ames	Greer Davis
	Philippa Reed	Terre Nicholson
	Catrin Devonald	Tanya Newman
	Maria Marama	Elisa Wijohn
	Belinda Tran-Lawrence	Sarah Cato
	Linda Fatialofa	

BCAC would like to thank and acknowledge the contributions of Gillian Wintrup, Elisa Wijohn and Terre Nicholson who sadly passed away in June July and October this year. We welcome Belinda Tran-Lawrence, Sarah Cato and Linda Fatialofa who joined the committee in February and March. 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 2022, all with the aim of improving breast cancer care in New Zealand.



Libby Burgess, Chairperson

- Consumer representative: Cancer Control Agency Te Aho o Te Kahu Consumer Reference Group He Ara Tangata (HAT)
- Consumer representative: Breast Special Interest Group (BSIG)
- IMPACT (consumer) member and associate member: Breast Cancer Trials (Australia and New Zealand). Libby participated in the virtual Annual Scientific meeting in July 2022
- Regularly corresponded with Pharmac and responded to consultations on Pharmac advisory committees, operations and medicines funding proposals
- Submitted a formal application to Pharmac for funding of chemotherapy medicine eribulin

- Attended online meeting with Pharmac Review Panel; wrote BCAC submission to the Panel
- Attended a number of meetings with pharmaceutical companies
- Attended online meetings of the New Zealand Familial Breast and Ovarian Cancer Group (NZFBOCG)
- Asia-Pacific regional panelist and invited participant in The Economist's Economic Intelligence Unit project developing a 'A patient-centred framework for early breast cancer care in New Zealand'
- Attended the Asia Pacific Metastatic Breast Cancer Forum
- Participated in Enhancing Clinical Trials Consumer Focus Group meeting
- Responded to consultation on Pae Ora Healthy Futures Health System Reform Bill
- Supported The Medicine Gap initiative by Rachel Smalley
- Participated in an ABC Awareness Campaign
- Attended meetings with researchers from the NZ Association for Breast Cancer Research to discuss Treaty-based partnership with Māori in breast cancer research
- Attended meeting with Auckland DHB to discuss Do Not Resuscitate orders issued without patient consultation
- Met with developer of a NZ breast cancer risk assessment tool
- Met with BCFNZ to discuss Covid-related breast screening delays and NZ's health budget
- Consulted by BCFNZ on the follow-up to their 'I'm Still Here' report on advanced breast cancer in NZ; distributed the new survey via Metavivors NZ and other member groups
- Contributed as a Working Group member to development of ABC Guidelines NZ2
- Contributed to review of BreastScreen Aotearoa and provided consumer review of the draft report
- Responded to a Te Aho o Te Kahu consultation on Breast Quality Performance Indicators
- Attended a Parliamentary Dinner and panel discussion on Challenges and Opportunities with Genomic Medicine, August 2022
- Attended Breast cancer inSIGhts conference and BSIG meeting, September 2022
- Attended an Asia Pacific webinar on medicines development
- Attended BCFNZ's 'How well are we doing' webinar reporting updated data from the Breast Cancer Register, Te Rēhita Mate Ūtaetae
- Helped to organise more He Koha ā Mua, Gifts to the Future legacy videos
- Attended the virtual NZ Breast Cancer Symposium in November 2021
- Attended the ABC6 Conference, ABC Global Alliance, November 2021
- Attended the virtual San Antonio Breast Cancer Symposium in December 2021 as a consumer advocate
- Contributed to a post-operative bra design project.



Emma Crowley, Deputy Chairperson

- Chair of the consumer advisory panel of Cancer Trials NZ
- Consumer representative on two breast cancer trials.
- Appointed to the Consumer Advisory Panel of Breast Cancer Trials (BCT) (Australia and New Zealand)
- Attended a Parliamentary Dinner and panel discussion on Challenges and Opportunities with Genomic Medicine, August 2022
- Attended Breast cancer inSIGhts conference and BSIG meeting, September 2022.



Louise Malone, Treasurer

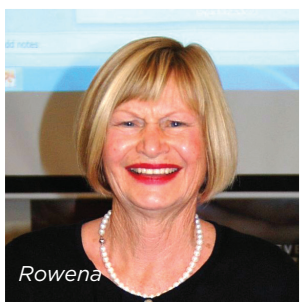
- Completed BCAC's funding applications and wrote reports to BCAC's funders
- Responsible for distribution of **Step by Step** support packs
- IMPACT (consumer) member, Breast Cancer Trials
- Attended the ABC6 Conference, ABC Global Alliance, November 2021
- Attended the virtual San Antonio Breast Cancer Symposium in December 2021 as a consumer advocate
- Attended a number of meetings with pharmaceutical companies
- Organised funding for and printing of 7,000 **Step by Step** support packs, April to July 2022
- Wrote successful application for free courier services from NZ Post's Delivering for Good programme, April 2022
- Identified and distributed **Step by Step** support packs to Māori Health Providers
- Attended a Parliamentary Dinner and panel discussion on Challenges and Opportunities with Genomic Medicine, August 2022.



Fay Sowerby, Secretary

- Chair of Breast Cancer Cure (BCC), which agreed to fund research in association with the Cancer Research Trust New Zealand
- Member of Breast Cancer Trials (BCT) (Australia and New Zealand) Communication and Fundraising Committee (concluded 5 years in May 2022)
- Selected Member of the National Breast Cancer QPI Working Group
- Steering Committee Member of the Enhancing NZ's Clinical Trials Infrastructure Project
- Affiliate member: BCT and participated in the virtual Annual Scientific meeting in July 2022
- 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
- Participated in several virtual BCT Question and Answer sessions in 2021
- Attended New Zealand Familial Breast and Ovarian Cancer Group (NZFBOC) meetings

- Attended the ABC Global Alliance – Bridging the Gap meeting in October 2021
- Attended the virtual NZ Breast Cancer Symposium in November 2021
- Attended COSA conference in November 2021
- Attended the San Antonio Breast Cancer Symposium in December 2021 as a consumer advocate
- Attended ASCO online conference in May 2022
- Attended online meetings with Pharmac Review Panel and wrote an individual submission
- Met with developer of a NZ breast cancer risk assessment tool utilizing BODICEA
- Met with Te Aho o Te Kahu to discuss an integrated registry for families identified at risk of hereditary cancer
- Met with New Zealanders for Health Research
- Consulted by BCFNZ on the follow-up to their ‘I’m Still Here’ report on advanced breast cancer in NZ
- Participated in a Precision Driven Health Survey by Orion Health
- Contributed to review of BreastScreen Aotearoa
- Met with Mercy Breast Clinic and Southern Cross to discuss a study identifying high risk NZ women for more customised screening
- Attended Breast Cancer InSIGhts conference and BSIG meeting, September 2022
- Attended online sessions of NZSO conference, September 2022
- Attended Clinical Trials NZ meeting, September 2022
- Attended Why Study Mammographic Density meeting, September 2022
- Attending the San Antonio Breast Cancer Symposium in December 2022 as a consumer advocate
- Quoted in two media articles:
 - New Health Boss “extremely disappointed” at breast cancer screening delays. Rachel Thomas, Dominion Post, 25 May 2022.
 - Lumping it: Is NZ’s breast cancer system failing high risk women? Sarah Catherall, Listener, 12 September 2022.



Rowena Mortimer, Committee Member

- Chair, Consumer Advisory Panel to Health Quality and Safety Commission (HQSC)
- IMPACT (consumer) member, Breast Cancer Trials
- Attended the virtual San Antonio Breast Cancer Symposium in December 2021 as a consumer advocate
- Commented on Pae Ora Health System Reform Bill.



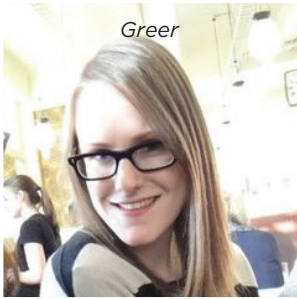
Lynda Ames, Committee Member

- IMPACT (consumer) member, Breast Cancer Trials
- Attended online meeting with Pharmac Review Panel
- Attended meetings with pharmaceutical companies.



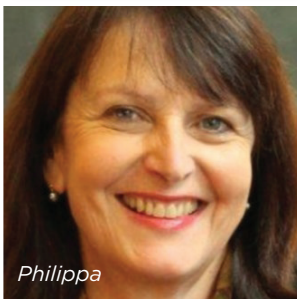
Gillian Wintrup, Committee Member

- Provided a voice for those with advanced breast cancer.



Greer Davis, Committee Member

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



Philippa Reed, Committee Member

- Partnership Manager of BCAC member group, CanTeen Aotearoa
- Contributed to BCAC submissions to Pharmac and various consultations
- Attended online meeting with Pharmac Review Panel.



Terre Nicholson, Committee Member

- Co-ordinated both Metavivors NZ and the Metavivors NZ - Action Facebook groups
- Participated in the patient group meeting for the Pharmac Review Panel
- Attended meetings with pharmaceutical companies
- Participated as a consumer representative in the Enhancing NZ Clinical Trials Consumer Focus Group
- Co-ordinated Metavivors NZ actions in relation to medicines access and liaised with Patient Voice Aotearoa
- With BCAC's support, assisted Metavivors to obtain better medical outcomes
- Participated in Enhancing Clinical Trials Consumer Focus Group meeting
- Attended the Asia Pacific Metastatic Breast Cancer Forum
- Participated in The Medicine Gap initiative by Rachel Smalley
- Participated in an ABC Awareness Campaign
- Participated in the Living with Stage 4 Project
- Contributed to development of ABC Guidelines NZ2.



Catrin Devonald, Committee Member

- Chief Executive of Sweet Louise
- Sweet Louise is a member of Advanced Breast Cancer Alliance and was showcased as best practice for services to ABC patients
- Attended online meeting with Pharmac Review Panel

- Helped to organise more He Koha ā Mua, Gifts to the Future legacy videos
- Contributed to development of ABC Guidelines NZ2.



Tanya Newman, Committee Member

- Invited to present at the virtual Breast Cancer Foundation's Nurses Day, November 2021
- Attended webinar on breast cancer recurrence
- Accepted for Radical Remission training to become a certified Radical Remission health coach and teacher.



Maria Marama, Committee Member

- Joined the BCAC committee in October 2021
- Provides a Māori perspective and advocates for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori
- Coordinated online meeting with Board of New Zealand Association for Breast Cancer Research to improve relationships with Māori and Māori researchers
- Attended online meeting with Pharmac Review Panel
- Attended the virtual NZ Breast Cancer Symposium in November 2021
- Met with developer of a NZ breast cancer risk assessment tool
- Interviewed for Te Karere TV in connection with the Te Aho o Te Kahu's Medicines Report
- Helped to organise more He Koha ā Mua, Gifts to the Future legacy videos
- Identified and distributed **Step by Step** support packs to Māori Health Providers
- Contributed to review of BreastScreen Aotearoa
- Joint HRC application to Establish a Māori Breast Cancer Community Trust
- Attended a Parliamentary Dinner and panel discussion on Challenges and Opportunities with Genomic Medicine, August 2022.





Elisa Wijohn, Committee Member

- Joined the BCAC committee in November 2021
- Raised funds specifically so that Māori women's voices could be added to the He Koha ā Mua, Gifts to the Future legacy videos
- Challenged her local District Health Board over a Do Not Resuscitate order issued without proper patient consultation, and contributed to a staff training video to remedy this problem.



Belinda Tran-Lawrence, Committee Member

- Joined the BCAC committee in February 2022
- Runs the online support community, Aotearoa New Zealand Breast Cancer Community
- Advocated for women with breast cancer who wish to 'go flat' (double mastectomy by choice).



Sarah Cato, Committee Member

- Joined the BCAC committee in February 2022
- Advocates for better access to modern medicines
- Provides a voice for those with advanced breast cancer.



Linda Fatialofa, Committee Member

- Joined the BCAC committee in March 2022
- Provides a voice for Pasifika women with breast cancer.





Supporters

BCAC has once again received generous and kind support from a number of organisations and individuals during our 2021/2022 financial year.

BCAC's relationship with The Good Registry, an organisation which helps people to give charitable donations as gifts, has continued to grow this year. We have been very grateful for the regular donations we have received from them and their 'givers' and especially for being awarded a large share of the value of unredeemed corporate vouchers 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.

Two organisations that have supported us for a number of years continued to do so this year. Health and beauty company, Le Rêve (NZ) Ltd, once again made a generous donation and Storage King NZ provided discounted storage for our **Step by Step** support packs.

BCAC was very grateful to receive an educational grant from Pfizer which allowed us to investigate ways to make **Step by Step** more accessible to Māori and Pasifika women with breast cancer.

We were also very grateful to receive bequests from the estates of GN Cashmore and D M Sawyer this year.

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.





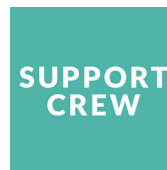
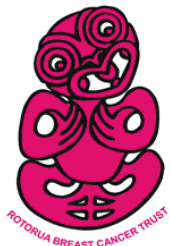
BCAC Member Groups

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
Ascot Radiology Pink Dragons
Boobops Dragon Boat Team
Breast Cancer Action Trust
Breast Cancer Foundation New Zealand
Breast Cancer Cure
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 Breast Cancer Research Trust
Waikato Treasure Chests
Well Women and Family Trust



BREAST CANCER ACTION TRUST



Together we're stronger
Tangata tū pakari tonu

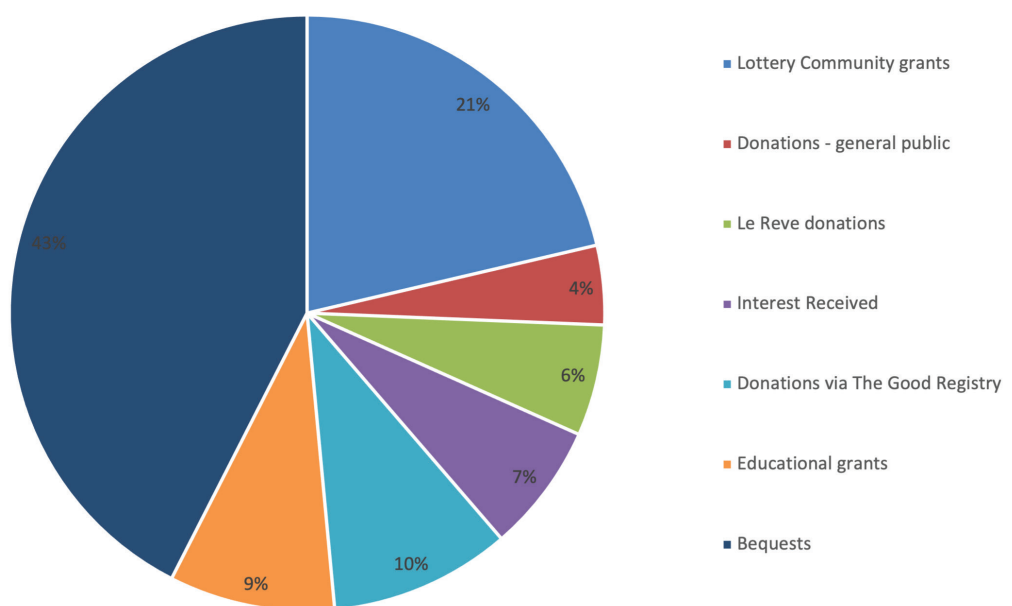


Financials

BCAC Revenue 2021/22

Funding Source	Amount (\$)
Lottery Community grants	\$15,068
Donations - general public	\$3,037
Le Reve donations	\$4,263
Interest Received	\$4,940
Donations via The Good Registry	\$6,953
Educational grants	\$6,360
Bequests	\$30,000
Total Income	\$70,621

BCAC Revenue to 31 March 2022



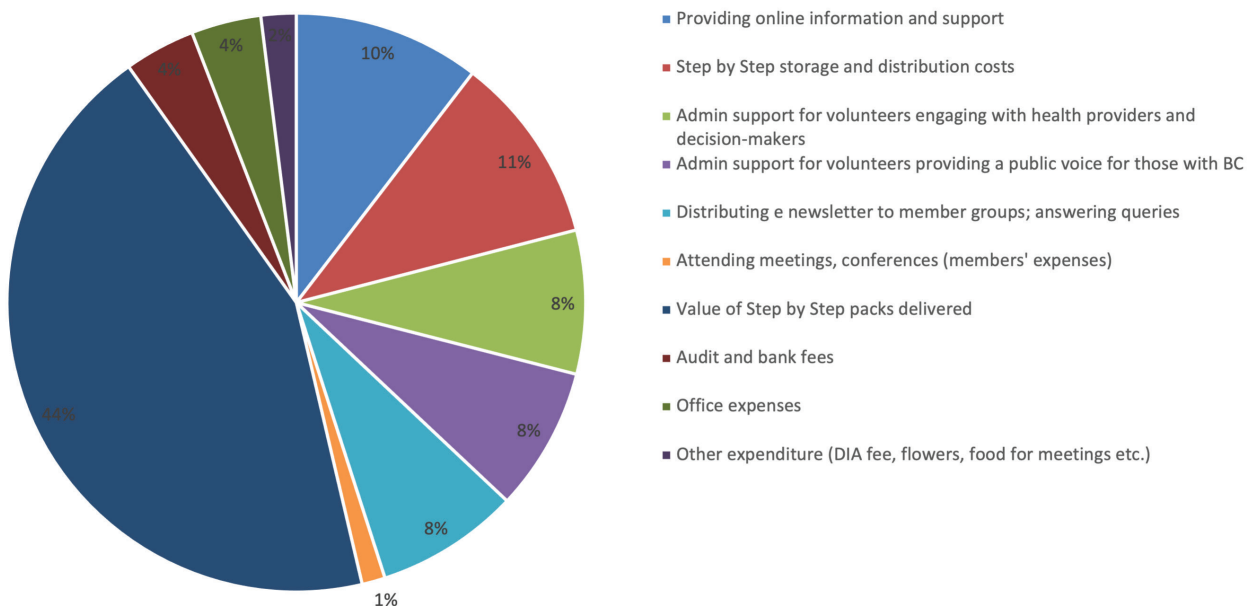


Financials

BCAC Expenses 2021/22

Expenses	Amount (\$)
Providing online information and support	\$4,615
Step by Step storage and distribution costs	\$4,664
Admin support for volunteers engaging with health providers and decision-makers	\$3,553
Admin support for volunteers providing a public voice for those with BC	\$3,553
Distributing e newsletter to member groups; answering queries	\$3,553
Attending meetings, conferences (members' expenses)	\$575
Value of Step by Step packs delivered	\$19,396
Audit and bank fees	\$1,756
Office expenses	\$1,729
Other expenditure (DIA fee, flowers, food for meetings etc.)	\$871
Total Expenses	\$44,265

BCAC Expenditure to 31 March 2022





Plans for 2023

FOR 2023, 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 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
- Consult to determine the best fit-for-purpose formats for additional resources, specifically targeted to Māori and to Pasifika women, to complement the **Step by Step** pack in these communities
- 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
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Auckland 1142, New Zealand

www.breastcancer.org.nz