



Minutes of the Annual General Meeting of the
Breast Cancer Aotearoa Coalition Incorporated
held on Tuesday 10 September 2024 at 6.30 pm via Zoom

Meeting opened: 6:30 pm

Welcome

Karakia timatanga

Present:

Libby Burgess, Louise Malone, Rowena Mortimer, Emma Crowley, Fay Sowerby (BCC), Catrin Devonald (Sweet Louise), Ah-Leen Rayner (BCFNZ), Denise Lemmen (Metavivors NZ), Tanya Newman, Maria Marama, Philippa Reed (CanTeen Aotearoa), Alvina Sciascia-Bizaoui, Rachel Greenwood

Proxies received:

Carlene Wolfgram, Jane Bissell, Anne Hayden

Apologies:

Carlene Wolfgram, Jane Bissell, Anne Hayden, Julie Bunnell

The minutes of the 2023 AGM were tabled

Motion: That the minutes of BCAC's 2023 AGM be accepted as a true and correct record of that meeting.

Moved: Libby Burgess

Seconded: Ah-Leen Rayner

Passed unanimously.

Report from the Chair

Libby Burgess presented her Chair report, outlining BCAC's work and the year's activities. Presentation points included:

- Acknowledging the Committee of 2023-24 and BCAC's member groups

- Affirming BCAC's goals of providing information and support to empower those with breast cancer to make informed choices about their treatment and care; providing a voice for New Zealanders who experience breast cancer; and making world-class detection, diagnosis, treatment and care accessible to all those affected by breast cancer in Aotearoa NZ
- Describing how BCAC provides a voice for those with lived experience of breast cancer – early, advanced, whānau and organisational – by participating in policy making and advisory bodies, responding to consultations, making submissions, working with patients, advocates, specialists, nurses, pharma companies, regulators and decision makers
- Noting information and resources produced by BCAC, including delivering more than 1,400 *Step by Step* support packs; maintaining an informative and up-to-date website, producing newsletters, maintaining a presence on Facebook, including peer support groups Metavivors NZ, Metavivors Action and BCAC group
- Describing how BCAC provides support, information, collaboration and advocacy:
 - personally to people with all stages and subtypes of breast cancer who reach out and need help navigating their treatment paths
 - to groups and populations of women via advocacy for health system improvements and networking and collaborating with member groups, clinicians, researchers and pharma companies
 - by working closely with Metavivors fostering peer support and advocacy
- Acknowledging the contributions of BCAC Committee Members who have ensured that the Metavivors group keeps providing support, love, courage, hope and strength to NZers with advanced breast cancer: Denise Lemmen for administering the group, Marion Barnett for providing hugely valuable website content for BCAC (sadly Marion passed away in April), and Rachel Greenwood for representing BCAC and GPs on BreastScreen Aotearoa's Action and Equity Group and contributing to the development of the ABC NZ3 Guideline.
- Explaining how BCAC members represent NZers with breast cancer on clinical, policy and advisory groups, including:
 - Breast Special Interest Group and their InSIGhts conference
 - Breast Cancer Trials
 - NZ Familial Breast and Ovarian Cancer Group
 - ABC Global Alliance
 - Te Aho o Te Kahu's Breast QPI Working Group
 - AGenDA
 - Māori Breast and Cervical Advisory Group for Te Whatu Ora
 - Decentralised Clinical Trials Advisory Group, for University of Auckland
 - BreastScreen Aotearoa's Action and Equity Group
- Acknowledging the huge contribution of BCAC member and pharmaco-economist Alison Davies to BCAC's submissions to Pharmac to publicly fund new breast cancer medicines
- Describing the current state of play in New Zealand regarding access to breast cancer medicines, especially those for triple negative breast cancer, and giving updates on specific medicines including pembrolizumab, sacituzumab govitecan, olaparib, trastuzumab deruxtecan, ribociclib, abemaciclib, everolimus, and alpelisib
- Describing BCAC's meeting with Pharmac's Chair

- Describing BCAC and Patient Voice Aotearoa’s meetings with politicians to discuss medicines access
- Acknowledging Maria Marama’s contribution to BCAC’s efforts to address inequities in breast cancer care and outcomes for Māori women
- Noting the conferences and research meetings attended by BCAC members
- Thanking BCAC’s Committee Members, collaborators and member groups for their work
- Paying tribute to BCAC members who have passed away recently and noting their valuable contributions.

Treasurer’s Report

Louise Malone presented BCAC’s audited Performance Report for the year ending 31 March 2024 and spoke to it. Highlights of the 2023/2024 year included:

- Revenue including a bequest, a grant from the Lottery Grants Board, interest from savings, public donations, fundraising events run by supporters, and donations via The Good Registry.
- Expenses including the value of *Step by Step* packs delivered, storage and distribution of *Step by Step*, providing online information and support and answering queries, support for volunteers attending meetings and hearings to engage with health providers and decisionmakers, support for volunteers to attend breast cancer research conferences, including overseas meetings, support for providing a public voice for those with breast cancer, production and distribution of the e newsletter, bank charges, audit fees, office and other expenses.
- Subsequent to 1 April 2024, highlights were receiving donations, directly from the public and via the Good Registry, and interest on investments, and expenses for ongoing activities, including delivery, storage and distribution of *Step by Step* and maintenance of the website.
- Louise also described BCAC’s plans for using accumulated funds.

Motion: That the Treasurer’s report for 2023/24 be accepted

Moved: Philippa Reed

Seconded: Denise Lemmen

Passed unanimously.

Election of Officers

Nominations received

Chair: Libby Burgess

Deputy Chair: Emma Crowley

Secretary: Fay Sowerby

Treasurer: Louise Malone

Committee: Ah-Leen Rayner, Alvina Sciascia-Bizaoui, Catrin Devonald, Denise Lemmen, Maria Marama, Philippa Reed, Rachel Greenwood, Rowena Mortimer, Tanya Newman.

Motion: That Libby Burgess, nominated as Chairperson of BCAC, be appointed.

Moved: Fay Sowerby

Seconded: Philippa Reed

Passed unanimously.

Motion: That all those others nominated as officers and committee members of BCAC be appointed.

Moved: Libby Burgess

Seconded: Rowena Mortimer

Passed unanimously.

Appointment of Auditor

Motion: That BCAC appoint Michelle O'Meara of O'Meara & Co as the auditor for the 2024/2025 financial year

Moved: Louise Malone

Seconded: Rowena Mortimer

Passed unanimously.

General Business

Fay Sowerby thanked Libby and Louise for their contributions, and they acknowledged hers as well. All present expressed their agreement.

BCAC Plans for the coming year

Libby presented BCAC's proposed plans for 2025:

Information & resources

- Offer *Step by Step* to every NZ woman diagnosed with breast cancer
- Provide up-to-date information via our website at www.breastcancer.org.nz, our Facebook pages, and our e newsletters
- Continue to support Metavivors NZ and Metavivors NZ-Action Facebook groups
- Respond to requests for information, advice and support.

Timely access to world class detection, diagnosis, treatment and care

- Engage with policy and decision makers including Ministers, MPs, Cancer Control Agency Te Aho o Te Kahu, Manatū Hauora Ministry of Health, BreastScreen Aotearoa
- Advocate for and support development of QPIs, Standards and Guidelines for early and advanced breast cancer

- Champion access to proven medicines and other treatments and techniques with clinicians, Pharmac and pharmaceutical companies
- Respond to consultations
- Promote and provide effective consumer representation for NZ women with breast cancer
- Seek improved clinical trial access for NZ breast cancer patients
- Support calls for increased funding for NZ breast cancer research
- Support education of breast cancer advocates
- Highlight the needs of those with advanced and early breast cancer
- Promote the collection and use of high-quality breast cancer data
- Advocate for genetic testing/biomarkers for better diagnosis
- Promote an aspirational, future-focused approach to all aspects of breast cancer care in NZ, promptly embracing and adopting new technologies.

Māori and Pasifika

- Support and promote consultation, engagement and empowerment
- Convey key messages to policy and decision makers
- Work to overcome inequities in incidence, access to services and outcomes
- Provide Māori cultural perspective.

Early detection

- Promote breast awareness and participation in the BSA breast screening programme
- Advocate for screening age extension, breast density measurement and reporting, risk-based personalised screening
- Engage with BSA to encourage and monitor progress.

Fundraising

- Fundraise to support BCAC's work.

Motion: That BCAC approves the future plans just presented for 2024-2025.

Moved: Libby Burgess

Seconded: Rowena Mortimer

Passed unanimously.

[Karakia whakamutunga](#)

Meeting closed 7:37 pm.

[Abbreviations:](#)

AGenDA_ Against Genetic Discrimination Aotearoa

ABC – advanced breast cancer

ANZBCC – Aotearoa New Zealand Breast Cancer Community

BCAC – Breast Cancer Aotearoa Coalition

BCC – Breast Cancer Cure

BCFNZ – Breast Cancer Foundation New Zealand

GP – general practitioner

QPI – quality performance indicator