



Minutes of the Annual General Meeting of the  
Breast Cancer Aotearoa Coalition Incorporated  
held on Tuesday 8th November 2022 at 6.30 pm via Zoom

Meeting opened: 6:30 pm

Welcome

Karakia timatanga

Present via Zoom:

Libby Burgess, Louise Malone, Philippa Reed (CanTeen Aotearoa), Rowena Mortimer, Fay Sowerby (BCC), Catrin Devonald (Sweet Louise), Irene Kereama-Royal, Alison Davies, Ah-Leen Rayner (BCFNZ), Sharon Taylor (Taranaki Dragons), Helen Alice (BCSSTT Tauranga), Denise Lemmen (Metavivors NZ), Ria Kaire (BCSNT), Karen Nimmo (Metavivors NZ), Emma Crowley, Tanya Newman, Linda Fatialofa, Greer Drake, Belinda Tran-Lawrence (ANZBCC).

Proxies received:

Maria Marama, Lynda Ames, Carlene Wolfgram, Jane Bissell, Julie Bunnell, Carol Scott-Dye (BCS), Jenni Scarlet (BCRT), Anne Hayden and Marilyn Johnson.

Apologies:

Maria Marama, Lynda Ames, Carlene Wolfgram, Jane Bissell, Julie Bunnell, Carol Scott-Dye, Jenni Scarlet, Anne Hayden and Marilyn Johnson,

The minutes of the 2021 AGM were tabled

**Motion: That the minutes of BCAC's 2021 AGM be accepted as a true and correct record of that meeting.**

Moved: Libby Burgess

Seconded: Fay Sowerby

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 2021-22 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, regulators and decision makers
- Noting information and resources produced by BCAC, including printing 7,000 more *Step by Step* support packs and widening their distribution to include more Māori and other health providers; 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
- Highlighting Metavivors' 'Living Life to the Max' initiative for international MBC Awareness Day
- Highlighting the Gifts to the Future, He Koha ā Mua legacy videos of women with advanced breast cancer
- Explaining how BCAC members represent NZers with breast cancer on clinical, policy and advisory groups, including:
  - Breast Special Interest Group
  - Breast Cancer Trials (ANZ)
  - Health Quality and Safety Commission
  - Cancer Trials NZ
  - Ministry of Health and Health Research Council
  - NZ Familial Breast and Ovarian Cancer Group
  - ABC Global Alliance
  - Enhancing NZ Clinical Trials Project
- Describing BCAC's contribution to a review of BreastScreen Aotearoa
- Describing BCAC's interactions with Te Aho o Te Kahu, Cancer Control Agency, including membership of its consumer reference group, pointing out shortcomings in its report on medicines, contributing to development of QPIs, and reviewing its Cancer Services Planning Report.
- Describing BCAC's input into the development of NZ Consensus Guidelines for Advanced Breast Cancer (ABC-NZ)
- Explaining why BCAC has joined Against Genetic Discrimination Aotearoa, a group aiming for better protection of NZers' genetic information, noting the potential for personal genetic information to help breast cancer patients and the need for their rights to insurance and employment to also be protected

- Describing BCAC's participation in an analysis of NZ's early breast cancer pathway, including ideas for improvement
- 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 BCAC's interactions with Pharmac, making submissions for new medicines, responding to consultations and seeking replacements for inadequate versions of medicines
- Describing BCAC's interactions with pharmaceutical companies to encourage and support key steps in the processes to allow NZ breast cancer patients to obtain access to the medicines they need
- Acknowledging Maria Marama's contribution to BCAC's efforts to address inequities in breast cancer care and outcomes for Māori women
- Listing conferences and research meetings attended by BCAC members
- Calling for all BCAC members and friends to raise any breast cancer issues of concern with the Committee.

### Treasurer's Report

Louise Malone presented BCAC's audited Performance Report for the year ending 31 March 2022 and spoke to it. Highlights of the 2021/2022 year included:

- Revenue included a bequest, grants from the Lottery Grants Board, a Le Reve donation, a grant from Pfizer, interest from savings, public donations and donations via The Good Registry.
- Expenses included 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 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 2022 BCAC received grants for printing, storage and distribution of 7,000 *Step by Step* packs from BCFNZ, various trusts and the Ministry of Health. Donations, directly from the public and via the Good Registry, have continued to be received, along with another Lottery grant.

### **Motion: That the Treasurer's report for 2021/22 be accepted**

Moved: Emma Crowley

Seconded: Philippa Reed

Passed unanimously.

## Election of Officers

### Nominations received

Chair: Libby Burgess

Deputy Chair: Emma Crowley

Secretary: Fay Sowerby

Treasurer: Louise Malone

Committee: Ah-Leen Rayner, Belinda Tran-Lawrence, Catrin Devonald, Denise Lemmen, Greer Drake, Linda Fatialofa, Lynda Ames, Maria Marama, Philippa Reed, Rowena Mortimer, Sarah Cato, Tanya Newman.

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

Moved: Fay Sowerby

Seconded: Denise Lemmen

Passed unanimously.

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

Moved: Libby Burgess

Seconded: Alison Davies

Passed unanimously.

Libby asked for further nominations from the floor – there were none.

## Appointment of Auditor

**Motion: That BCAC appoint Michelle O’Meara of O’Meara & Co as the auditor for the 2022/2023 financial year**

Moved: Louise Malone

Seconded: Fay Sowerby

Passed unanimously.

## Other Motions to be considered

None.

## General Business

Alison Davies thanked Libby and Louise and the rest of the Committee for their work over the past year and Fay Sowerby endorsed this.

Irene Kereama-Royal reported that her application for a research grant had just been approved by the Health Research Council 2022 Ngā Kanohi Kitea Community Advancement Fund Grants Committee and she thanked BCAC and BCFNZ for their letters of support.

## BCAC Plans for the coming year

Libby presented BCAC's proposed plans for 2023:

### 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](http://www.breastcancer.org.nz), our Facebook pages, Twitter 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, treatment and care

- Engage with policy and decision makers including Ministers, MPs, Cancer Control Agency Te Aho o Te Kahu, 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, apply for medicines funding
- 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 of high-quality breast cancer data
- Advocate for genomic testing/biomarkers for better diagnosis
- Advocate against genomic discrimination and provide support for legislation/moratorium
- 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.

- Advocate for improvements to the symptomatic pathway, including consistency of care for those deemed high/moderate risk including appropriate surveillance and screening

### **Fundraising**

- Fundraise to support BCAC's work.

### **Motion: That BCAC's plans for 2023 presented in the chairperson's report be adopted.**

Moved: Libby Burgess

Seconded: Karen Nimmo

Passed unanimously.

### Guest speaker

Dr Emma Nolan from the University of Auckland gave a presentation on her research on breast cancer.

### Questions and discussion

### Karakia whakamutunga

Meeting closed 8:30 pm.

### Abbreviations:

ANZBCC – Aotearoa New Zealand Breast Cancer Community

BCAC – Breast Cancer Aotearoa Coalition

BCC – Breast Cancer Cure

BCFNZ – Breast Cancer Foundation New Zealand

BCRT – Breast Cancer Research Trust (formerly Waikato Breast Cancer Research Trust)

BCS – Breast Cancer Support Aotearoa

BCSNT – Breast Cancer Support Northland Trust

BCSSTT - Breast Cancer Support Service Tauranga Trust

QPI – quality performance indicator