



Minutes of the Annual General Meeting of the Breast Cancer Aotearoa Coalition Incorporated held on Tuesday 21st November 2023 at 6.30 pm via Zoom

Meeting opened: 6:30 pm

Welcome

Karakia timatanga

Present via Zoom:

Libby Burgess, Louise Malone, Rowena Mortimer, Fay Sowerby (BCC), Catrin Devonald (Sweet Louise), Alison Davies, Ah-Leen Rayner (BCFNZ), Denise Lemmen (Metavivors NZ), Tanya Newman, Maria Marama, Greer Drake, Philippa Reed (CanTeen Aotearoa), Marion Barnett, Liz Pennington (BCS)

Proxies received:

Marilynn Johnson, Carlene Wolfgram, Julie Bunnell, Melissa Bell, Sue Wall-Cade, Kirsty Jones, Jenni Scarlet (BCRT), Jane Bissell, Rachel Greenwood, Hazel Jennings (ANZBCC)

Apologies:

Marilynn Johnson, Carlene Wolfgram, Julie Bunnell, Melissa Bell, Sue Wall-Cade, Kirsty Jones, Jenni Scarlet (BCRT), Jane Bissell, Rachel Greenwood, Hazel Jennings (ANZBCC)

The minutes of the 2022 AGM were tabled

Motion: That the minutes of BCAC's 2022 AGM be accepted as a true and correct record of that meeting.

Moved: Libby Burgess

Seconded: Alison Davies

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 2022-23 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 delivering more than 1,500 *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
- Acknowledging the contributions of BCAC members who have ensured that the Metavivors group keeps providing support, love, courage, hope and strength to NZers with advanced breast cancer, and acknowledging those who attended the ABC7 International Consensus Conference in Portugal this month.
- Explaining how BCAC members represent NZers with breast cancer on clinical, policy and advisory groups, including:
 - Breast Special Interest Group
 - Breast Cancer Trials (ANZ)
 - Cancer Trials NZ
 - Ministry of Health and Health Research Council
 - NZ Familial Breast and Ovarian Cancer Group
 - ABC Global Alliance
- Describing BCAC's interactions with Te Aho o Te Kahu, Cancer Control Agency, including contributing to development of QPIs.
- Describing BCAC's interactions with BreastScreen Aotearoa, advocating for measuring and reporting breast density, extending the screening age down to 40 and up to 74 and membership of BSA's new Action 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 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
- Describing BCAC's participation in the My Life Matters campaign

- Noting BCAC's submissions to Manatū Hauora Ministry of Health on Precision Health, Pharmac's position on child cancer medicines, the Women's Health Strategy and the Therapeutic Products Bill
- 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
- 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 2023 and spoke to it. Highlights of the 2022/2023 year included:

- Revenue including a bequest, grants for printing, storage and distribution of 7,000 *Step by Step* packs from BCFNZ, various trusts and the Ministry of Health, a grant from the Lottery Grants Board, grants from Pfizer and Merck Sharp & Dohme for a website upgrade, interest from savings, public donations 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 providing a public voice for those with breast cancer, production of He Koha ā Mua Legacy videos, production and distribution of the e newsletter, bank charges, audit fees, office and other expenses.
- Subsequent to 1 April 2023, highlights were receiving another bequest, a Lottery Grants Board grant, 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 and upgrading of the website.

Motion: That the Treasurer's report for 2022/23 be accepted

Moved: Fay Sowerby

Seconded: Maria Marama

Passed unanimously.

Election of Officers

Nominations received

Chair: Libby Burgess

Deputy Chair: Emma Crowley

Secretary: Fay Sowerby

Treasurer: Louise Malone

Committee: Ah-Leen Rayner, Catrin Devonald, Denise Lemmen, Hazel Jennings, Maria Marama, Marion Barnett, Philippa Reed, Rachel Greenwood, Rowena Mortimer, Tanya Newman.

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

Moved: Fay Sowerby

Seconded: Rowena Mortimer

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.

Appointment of Auditor

Motion: That BCAC appoint Michelle O'Meara of O'Meara & Co as the auditor for the 2023/2024 financial year

Moved: Libby Burgess

Seconded: Alison Davies

Passed unanimously.

Other Motions to be considered

Motion: That BCAC replace its Constitution with the new version proposed by 16 members and circulated to all members before this meeting.

Moved: Fay Sowerby

Seconded: Denise Lemmen

Passed unanimously.

General Business

None.

BCAC Plans for the coming year

Libby presented BCAC's proposed plans for 2024:

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, X (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, 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 2023-2024.

Moved: Libby Burgess

Seconded: Rowena Mortimer

Passed unanimously.

Questions and discussion

The Committee discussed the possibility of having a strategic planning meeting in early 2024, with a view to identifying specific areas of need where BCAC could expand its activities in future.

Denise, Catrin and Marion shared their insights from the recent ABC7 conference.

Fay thanked Libby and Louise on behalf of the Committee.

Karakia whakamutunga

Meeting closed 7:40 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

QPI – quality performance indicator