



BCAC Annual General Meeting 2023

*21 November 2023
online via Zoom*

Together we're stronger
Tangata tū pakari tonu

Karakia timatanga

Pou hihiri
Pou rarama
Pou o te whakaaro
Pou o te tangata
Pou o te aroha
Te pou e here nei i a tātou
Haumi e, hui e, **taiki e**

*May clarity be yours
May understanding be yours
Through reflection
Through personal endeavour
Through respect
The virtues that bind us as one
May we be filled with wellbeing*

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Agenda

- ✘ Welcome
- ✘ Karakia timatanga
- ✘ Roll call, Apologies, Proxies
- ✘ Minutes of 2022 AGM
- ✘ Report from the Chair - *Libby Burgess*
- ✘ Treasurer's Report - *Louise Malone*
- ✘ Motions
 - ✘ Election of Committee
 - ✘ Appointment of Auditor
 - ✘ Ratification of revised constitution
- ✘ General business?
- ✘ Approval of future plans
- ✘ Questions & discussion
- ✘ Karakia whakamutunga

CHAIR REPORT

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BCAC Committee 2022-23



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BCAC Member Groups 2023

- ✘ Age Concern
- ✘ Alleviate
- ✘ Aotearoa NZ Breast Cancer Community
- ✘ Ascot Radiology Pink Dragons
- ✘ Boobops Dragon Boat Team
- ✘ Breast Cancer Action Trust
- ✘ Breast Cancer Cure
- ✘ Breast Cancer Foundation NZ
- ✘ Breast Cancer Support Aotearoa
- ✘ Breast Cancer Support Northland Trust
- ✘ Breast Cancer Support 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

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Purposes: Support, Inform, Represent

- ✘ To provide **information and support to empower** those with breast cancer to make informed choices about their treatment and care
- ✘ To **provide an evidence-based patient voice** and advocate for New Zealanders who experience breast cancer

✘ Our Mission:

To make **world-class detection, diagnosis, treatment and care** accessible to all those affected by breast cancer in Aotearoa, New Zealand

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Providing a voice for those with breast cancer

- ✘ Lived experience and knowledge of breast cancer
 - ✘ Early, advanced, whānau, organisational
- ✘ We participate in policy-making & advisory bodies
- ✘ We respond to consultations, make submissions
- ✘ We work with all stakeholders: patients, specialists, nurses, regulators, decision makers, advocates, other patient groups and pharma companies

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Information and resources

✘ Step by Step packs

- ✘ Sent >1,500
- ✘ Expanding distribution
 - » Māori health & rongoā clinics
 - » Breast clinics

✘ Website

- ✘ Information, news, events, videos, webinars (BCF, BCT)

✘ Quarterly newsletters

✘ Facebook

- ✘ BCAC Page
- ✘ Groups: Metavivors, Metavivors Action, BCAC
- ✘ Share to ANZBCC group



Support, inform, advocate, collaborate

- ✘ Personal support for people who reach out
 - ✘ All stages and sub-types of breast cancer
 - ✘ Help navigate treatment and care path
- ✘ Support for groups and populations of patients
- ✘ Advocate for health system improvements
- ✘ Network and collaborate with member groups, clinicians, researchers, pharma companies

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Metavivors NZ



- ✘ Active Facebook-based group for those with ABC
- ✘ Inspired by US Metavivors' influence
- ✘ Fantastic peer support and information
 - ✘ 540+ members
 - ✘ Strong connections to Sweet Louise
- ✘ Metavivors NZ Action group for advocacy
 - ✘ Includes partners, supporters
- ✘ 5 talented MV on BCAC Committee this year

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BCAC's Metavivors

www.breast

✘ Denise Lemmen

- ✘ Administers Metavivors NZ and MV Action groups
- ✘ Attended ABC7 in Portugal

✘ Marion Barnett

- ✘ Medical writer, fantastic website content
 - » Paper on ABC treatment in Aotearoa NZ
- ✘ Attended ABC7 online
- ✘ Patient Advisory Group – taking oral meds, side effects

✘ Rachel Greenwood

- ✘ Invercargill GP
- ✘ Represents RNZCGP on BSA's Action Group

✘ Lynda Ames

- ✘ Long-standing member
- ✘ Helped set up Metavivors in 2014
- ✘ Inspirational HER2+ Herceptin super-survivor
- ✘ Retiring for travel and fun

✘ Sara Cato

- ✘ UN Investigator



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ABC7 Global conference in Portugal

✘ Great NZ presence:

✘ BCAC/Metavivors, Sweet Louise, BCF, NZ oncologist



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Represent on clinical, policy and advisory groups

✘ Breast Special Interest Group (BSIG)

- ✘ NZ oncologists, surgeons, pathologists, researchers, nurses, advocates
 - » Consumer reps

✘ Breast Cancer Trials (BCT ANZ)

- ✘ Australasian research organisation focused on breast cancer
 - » Affiliate; Consumer Advisory Panel; IMPACT advocate members
 - » Attend the Annual Scientific Meeting



✘ Cancer Trials NZ (CTNZ)

- ✘ Clinical cancer research
 - » Chair, Consumer Advisory Panel

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Breast Cancer Trials Annual Scientific Meeting



Structure of Antibody-Drug Conjugates

Tumor antigen: abundant in tumours, minimal in normal tissues; internalised upon ADC binding

Antibody: high affinity, avidity for antigen; optimal PK; internalised

Linker: stable in plasma; efficient release of cytotoxic agent inside tumour cells

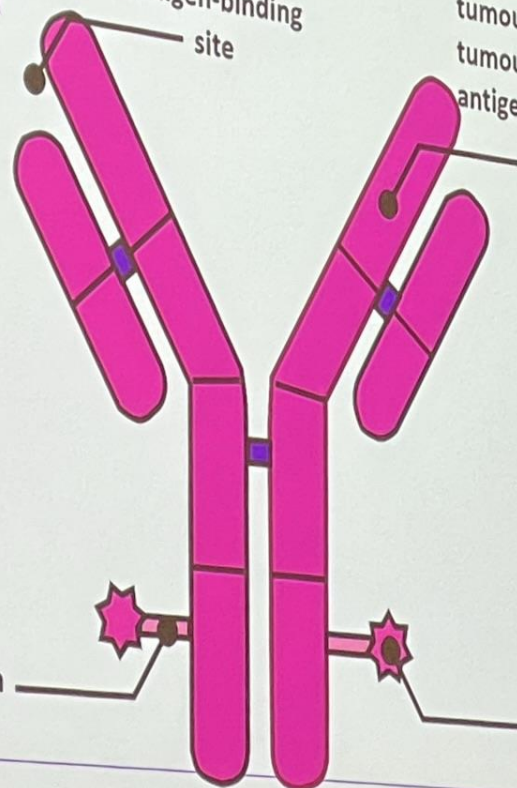
Payload: drug cytotoxic to targeted tumour cells; must be potent since limited number of molecules can be attached to antibody

Tumor antigen



Antigen-binding site

mAb: targets tumour-specific or tumour-associated antigens



Stable linker releases payload only in target cell

Potent cytotoxic payload

Represent on clinical, policy and advisory groups

✘ Health Research Council (HRC)

- ✘ Funds high quality, high impact research
 - » Assessment Committee Member

✘ NZ Familial Breast and Ovarian Cancer (NZFBOC)

- ✘ To improve outcomes for familial breast & ovarian cancer
 - » Consumer reps

✘ ABC Global Alliance

- ✘ To improve and extend lives of people with ABC in all countries
 - » BCAC, Sweet Louise, BCF membership
 - » Attended ABC 7 conference

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Represent on clinical, policy and advisory groups

✘ Te Aho o te Kahu, Cancer Control Agency

- ✘ National Breast Cancer Working Group: Breast QPIs
- ✘ Using BCF Breast Cancer Register data



✘ Enhancing NZ Clinical Trials Project

- ✘ Steering Cttee and consumer input

✘ Against Genetic Discrimination Aotearoa (AGenDA)

- ✘ Aligned, collaborating

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Breast Screening

✘ BSA Programme needs update

✘ Measure and report breast density

- » High density increases risk of BC, masks tumours on mammograms
- » We have a right to be told
 - » Know if we need more surveillance
 - » Avoid late detection
- » Submission to BSA

✘ Extend screening age band from 45-69 to 40-74

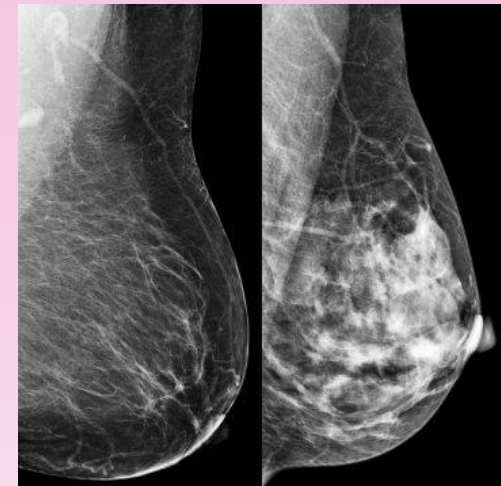
- » Cross-party support for Reti Bill to extend to 74

✘ Implement smarter risk-based screening

✘ Early adoption of innovation

✘ New BreastScreen Aotearoa Action Group

✘ Two BCAC Committee members



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Better access to medicines

BCAC's Superpower

Alison Davies, pharmaco-economist

- ✘ Rare and treasured expertise
 - ✘ Only a handful in NZ
- ✘ Understands medicines
 - ✘ How they work
 - ✘ Benefits and risks
- ✘ Understands Pharmac
 - ✘ Writes our medicine funding applications at no cost
- ✘ Founding BCAC committee member & BC survivor so totally 'gets it'



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Better access to medicines

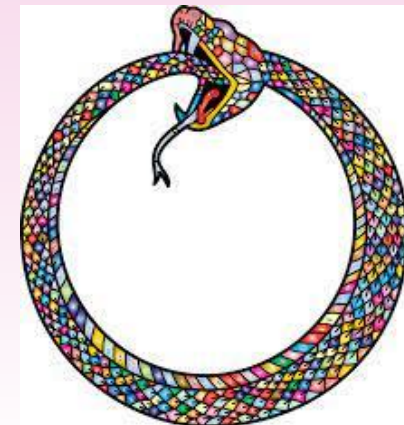
✘ Keytruda (pembrolizumab)

- ✘ 2022 Pharmac application to fund for early and advanced TNBC, MSD in June 2023
 - » Considered by CTAC Oct 2023
 - » Minutes take 4 months....
 - » Funded in Australia Sept 2023 for advanced, soon to fund for early



✘ Halaven (Eribulin)

- ✘ 2022 Pharmac application as a later line treatment in ABC
 - » PTAC declined for ridiculous reasons
 - » We appealed and successfully sought CTAC review
 - » CTAC recommended decline
 - » Funded in Australia since 2013



Better access to medicines

✘ Teva Goserelin replaced with Zoladex

- ✘ Blocks oestrogen production in pre-menopausal women
- ✘ Teva applicator caused pain, bruising, bleeding, failure
- ✘ Pharmac listened, acknowledged patient advocacy!
- ✘ A rare success



✘ Herceptin switched for Herzuma

- ✘ We encouraged Pharmac since 2020 to switch to a biosimilar
- ✘ Australia switched in 2019
 - » 5 funded, all safe and effective
- ✘ Wasting millions of precious pharmaceutical dollars for 3 or 4 yrs
- ✘ Crushing decision to exclude retreatment after progression in ABC
 - » In all international guidelines, adopted in all countries
 - » we're disputing this with BCF



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Better access to medicines

✘ Enhertu

- ✘ Game changer for mHER2+ and mHER2 low
- ✘ Medsafe priority review for registration – slow!
 - » We urged Medsafe to speed up
- ✘ AstraZeneca applied to Pharmac Nov 2022 for HER2+
- ✘ Given high priority by Pharmac's CTAC in Aug 2023
- ✘ Still not on Pharmac's Options for Investment list
- ✘ Funded in Australia for HER2+ ABC Nov 2023
- ✘ HER2 low will follow



✘ Trodelvy

- ✘ Game changer for mTNBC
- ✘ Interacted with Gilead Sciences for 21 months
- ✘ Promises broken on registration, cost share
- ✘ “NZ is a non-reimbursed market”
- ✘ Funded in Australia for mTNBC Mar 2022



Better access to medicines

✘ Afinitor (everolimus)

✘ BCAC applied to Pharmac in 2018

- » PTAC declined in 2019
- » Australia funded in 2014
- » **Approached by patient** needing access
- » We asked Novartis for compassionate access, price cap and reduced price
- » They initiated a 30% price reduction



Better access to medicines

✘ My Life Matters campaign

You are one diagnosis away from moving to Australia

There is an unfunded medicines crisis in New Zealand

Our politicians need to act now to save lives

Seeking:

- ✘ Increased investment, timely access to medicines, parity with other OECD countries
- ✘ Patient-focused wellbeing benefits included in decision-making processes

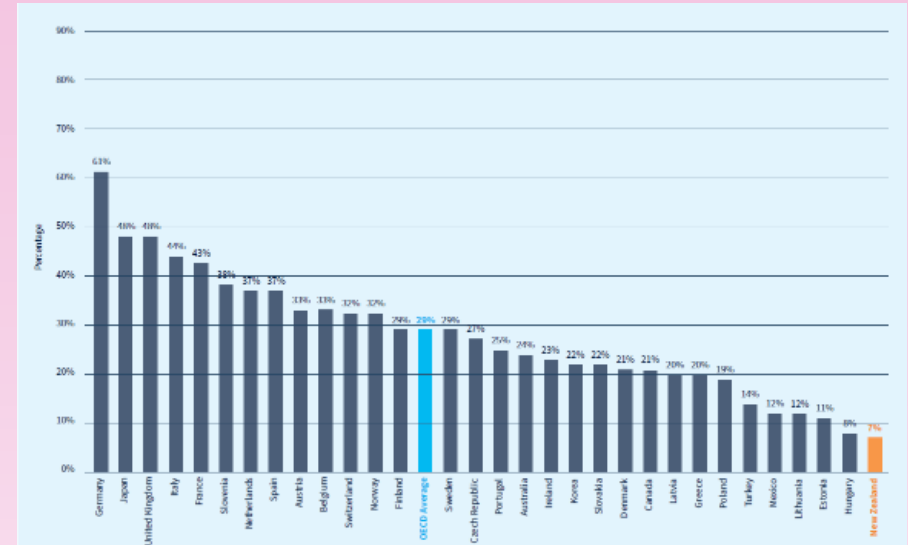


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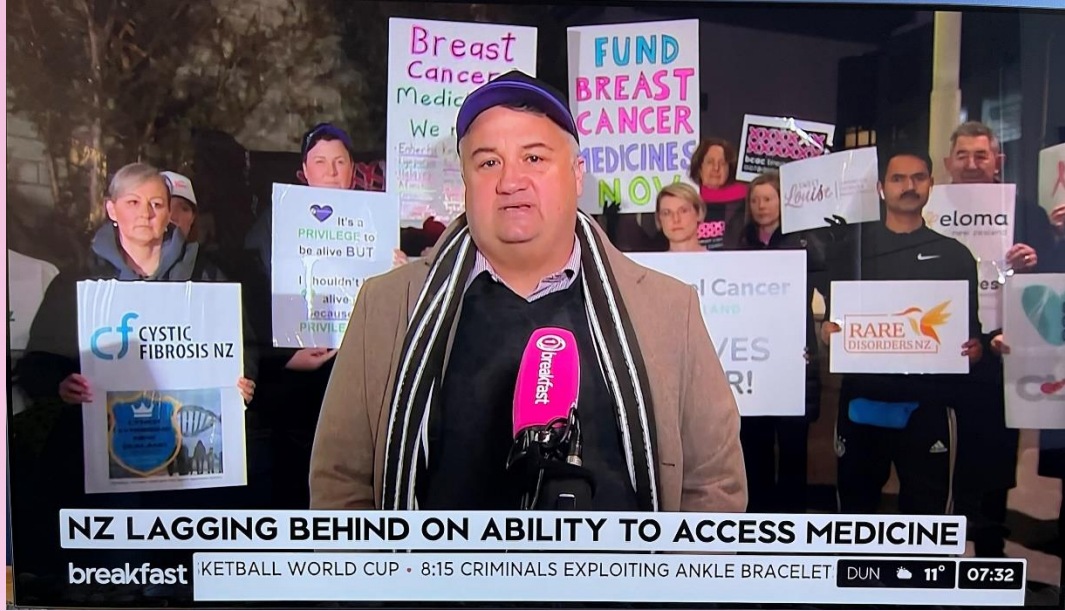


How is breast cancer doing?

- ✘ 18 ABC medicines recommended in international guidelines that Pharmac doesn't fund
- ✘ 12 of these are funded in Australia:
 - ✘ Abraxane, Afinitor, Avastin, Enhertu, Halaven, retreatment with Herceptin/Herzuma, Keytruda, Kisqali, Tecentriq, Trodelvy, Tykerb, Verzenio
- ✘ All subtypes miss out
- ✘ Marion's paper:
 - ✘ Treating advanced breast cancer in New Zealand – do we match other countries?



% of new medicines funded by OECD country
NZ is dead last



You are one diagnosis away from moving to Australia.

There is an unfunded medicine crisis in New Zealand.

Our politicians need to act now to save lives.

MY LIFE MATTERS

DEBATE
Medicines Access in Aotearoa

Moderated by **Guyon Espiner**

Wednesday 4 October 2023
6:30 PM - 8.45 PM
University of Auckland Library
Room B28
Princes Street
Auckland CBD

RSVP now on Facebook:

[MYLIFEMATTERS.ORG.NZ](https://www.mylifematters.org.nz)

	Dr Ayesha Verrall Labour Party
	Dr Shane Reti National Party
	Jenny Marcroft NZ First Party
	Ricardo Menéndez March Green Party
	Todd Stephenson ACT Party

Other submissions

✘ Precision Health (MoH)

- ✘ Opportunities to improve healthcare in Aotearoa through the uptake of innovative technologies

✘ Proposal to stop funding child cancer medicines (Pharmac)

- ✘ We objected, this should be a model for all cancers and other diseases

✘ Women's Health Strategy (MoH)

- ✘ Asked that breast cancer be specifically covered

✘ Action points:

- » Modernise screening
- » Improve medicines access
- » Increase precision

✘ Therapeutic Products Bill

✘ Disputed clauses that threatened:

- » Importation of unregistered medicines
- » Advocacy and communication on unregistered medicines
- » Timely access to clinical trials

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Equity: empowering Māori and Pasifika

- ✘ Maria Marama - a Māori perspective and advice on cultural responsiveness
 - ✘ HRC funded research with Irene Kereama-Royal, *Ma Hinewai Kōpua e Whakahau – Te Ao Māori* and Tiriti-led hauora pathways for wāhine Māori with breast cancer
 - ✘ Expert panellist and media commentator on Breast Cancer Trials Q&A *Breast Cancer in Māori Pasifika and Indigenous People*
 - ✘ Invited to contribute to book on *Indigenous and Tribal Peoples and Cancer*
 - ✘ Cultural lens on Sex and Breast Cancer
- ✘ Equity a strong theme in all BCAC submissions
- ✘ More Māori health providers and rongoā clinics received *Step by Step*



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Ongoing education: conferences

- ✘ SABCS (San Antonio Breast Cancer Symposium)
- ✘ BCT ASM (Breast Cancer Trials Annual Scientific Meeting)
- ✘ ABC7 conference run by ABC Global Alliance
- ✘ NZSO (New Zealand Society for Oncology) conference
- ✘ ASCO (American Society of Clinical Oncology) conference
- ✘ Breast Cancer inSIGhts conference
- ✘ Linking the Vines – Te Aka Mātauranga Matepukupuku
- ✘ ESMO (European Society for Medical Oncology) conference
- ✘ St Gallen International Breast Cancer conference
- ✘ Breast Cancer Trials & BCF webinars, Q & A sessions
- ✘ Asia Pacific Oncology Alliance

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Special thanks

- ✘ BCAC Committee
 - ✘ Ah-Leen, Belinda, Catrin, Denise, Emma, Fay, Greer, Hazel, Linda, Louise, Lynda, Maria, Marion, Philippa, Rachel, Rowena, Sarah, Tanya
- ✘ Louise
 - ✘ Assembling, packing & sending every Step by Step, Treasurer, Admin, website
- ✘ Fay
 - ✘ Multiple committees, conferences, meetings
- ✘ Marion
 - ✘ Medical writing
- ✘ Alison
 - ✘ PHARMAC applications, submissions, wisdom
- ✘ All the BCAC member groups
 - ✘ BCF, Sweet Louise, Metavivors, BCC, ANZBCC, Canteen
- ✘ Collaborators across the health sector
 - ✘ Richard Isaacs, Marion Kuper, Sheridan Wilson, Sarah Barton, Reuben Broom, Naera Waters, Ian Campbell, Clare Hardie, Andrew Shelling, Cris Print, Jenni Scarlet, Cheryl MacDonald
- ✘ The women of NZ who have shared their issues

Let's work together to get the best results for everyone diagnosed

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TREASURER'S REPORT

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BCAC Financial Performance: 1 April 2022 to 31 March 2023

Revenue points to note:

✘ Bequest	\$180,230
✘ BCFNZ funding: Step by Step production, distribution	\$58,054
✘ Ministry of Health grant for Step by Step	\$40,000
✘ Trusts grants for Step by Step printing	\$74,000
✘ Grants from Pfizer & Merck for website upgrade	\$30,000
✘ Lotteries grant	\$7,079
✘ Public donations	\$17,402
✘ Interest on savings	\$8,618
✘ The Good Registry donations	\$3,964
✘ Total revenue	\$420,312

BCAC Financial Performance: 1 April 2022 to 31 March 2023

Expenses points to note:

✘ Providing online information and support	\$3,949
✘ <i>Step by Step</i> storage & distribution	\$3,885
✘ Value of <i>Step by Step</i> packs delivered	\$24,535
✘ Producing He Koha ā Mua Legacy videos	\$2,425
✘ Attending meetings and conferences	\$1,515
✘ Audit and bank fees	\$1,761
✘ Office expenses/other expenditure	\$2,265

Total expenses **\$40,339**

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BCAC Financial Position: 31 March 2023

Assets:

✘ Bank accounts and cash	\$86,817
✘ Debtors and prepayments	\$369
✘ Inventory (Step by Step packs)	\$100,731
✘ Investments	\$430,504

Liabilities:

✘ Creditors and accrued expenses	\$755
✘ Unused grants with conditions	\$4,589

Net Assets

\$613,078

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Subsequent to 1 April 2023:

Revenue

✘ Donations, including via Good Registry	\$8,102
✘ Lotteries Grant	\$4,589
✘ Interest	\$10,382
✘ Bequest	\$5,000

Subsequent to 1 April 2023:

Expenses

✘ Bank and audit	\$1,745
✘ Office and other expenses	\$2,325
✘ <i>Step by Step</i> distribution & storage	\$2,030
✘ Website maintenance, including upgrade	\$24,000
✘ Travel and conference fees	\$800
✘ Value of <i>Step by Step</i> packs delivered	\$10,545
✘ Current bank balance	\$599,702

Audited Annual Performance Report 2022-23:

✘ <https://www.register.charities.govt.nz/Charity/CC22456>

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Motions

- ✘ To accept Treasurer's Report
- ✘ Election of Committee for 2023–2024
- ✘ Appointment of Auditor
- ✘ Ratification of new Constitution

Committee nominations received

- ✘ Libby Burgess – Chair
- ✘ Emma Crowley – Deputy Chair
- ✘ Fay Sowerby – Secretary
- ✘ Louise Malone – Treasurer
- ✘ Ah-Leen Rayner, representing BCFNZ
- ✘ Hazel Jennings, representing ANZBCC
- ✘ Catrin Devonald, representing Sweet Louise
- ✘ Denise Lemmen, representing Metavivors NZ
- ✘ Maria Marama
- ✘ Philippa Reed, representing CanTeen Aotearoa
- ✘ Rowena Mortimer
- ✘ Tanya Newman

Motions

- ✘ Motion: that Libby Burgess, nominated as Chairperson of BCAC, be appointed
- ✘ Motion: that BCAC elects the above-mentioned candidates to the positions noted
- ✘ Motion: that BCAC appoints Michelle O'Meara as auditor for the 2023-24 financial year
- ✘ Constitution revision...

Revision of BCAC Constitution

✘ Reasons for revision:

- ✘ Recent changes to the Incorporated Societies and Charities Acts require us to review our Rules (Constitution)
- ✘ BCAC has not reviewed its Constitution since it was first drafted in 2006
- ✘ The Constitution needs to be changed to reflect modes of communication and data storage that are commonly accepted in business in 2023 (e.g. email, online meetings, online data storage, electronic transfer of funds)

Motion and General Business

- ✘ That BCAC's Constitution be replaced with the revised version as circulated
- ✘ Is there any General Business?

FUTURE PLANS

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Plans for 2023-2024

Information and support

- ✘ Offer **Step by Step** to every NZ woman diagnosed with breast cancer
- ✘ Provide up to date information via our **website, Facebook, Twitter and newsletters**
- ✘ Continue to support **Metavivors NZ** and **Metavivors NZ-Action** Facebook groups
- ✘ Respond to requests for **information, advice and support**

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Plans for 2023-2024

Timely access to world class detection, treatment and care

✘ Engage with decision makers

✘ Ministers, MPs, Cancer Control Agency Te Aho o Te Kahu, Ministry of Health Manatū Hauora, BreastScreen Aotearoa and others

✘ 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, policy & decision makers, Pharmac & pharmaceutical companies

✘ Respond to **consultations**

✘ Promote and provide effective **consumer representation** for NZ women with breast cancer

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Plans for 2023-2024

Timely access to world class detection, treatment and care

- ✘ 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 & 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

Plans for 2023-2024

Māori & Pasifika

- ✘ Support & promote **consultation, engagement & empowerment**
- ✘ **Convey key messages** to policy & decision makers
- ✘ Work to **overcome inequities** in incidence, access to services & 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

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Motion

- ✘ Motion: that BCAC approves the future plans just presented for 2023-2024

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QUESTIONS AND DISCUSSION

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Karakia whakamutunga

Kia tau ngā manaakitanga a te
mea ngaro
Ki runga ki tēnā, ki tēnā o
tatou
Kia mahea te hua mākihikihi
Kia toi te kupu, toi te mana, toi
te aroha, toi te Reo Māori
Kia tūturu, ka whakamaua kia
tīna! Tīna!
Haumi e, Hui e, Tāiki e!

*Let the strength and life force of
our ancestors
Be with each and every one of us
Freeing our path from obstruction
So that our words, spiritual
power, love, and language are
upheld;
Permanently fixed, established
and understood!
Forward together!*



www.breastcancer.org.nz

email: bcac@breastcancer.org.nz

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