



BCAC Annual General Meeting 2022

8 November 2022
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

Agenda

- ✘ Welcome
- ✘ Karakia timatanga
- ✘ Apologies, Proxies
- ✘ Minutes of 2021 AGM
- ✘ Report from the Chair - *Libby Burgess*
- ✘ Treasurer's Report - *Louise Malone*
- ✘ Election of Committee
- ✘ Appointment of Auditor
- ✘ Motions
- ✘ General business
- ✘ Approval of future plans
- ✘ Guest speaker – Dr Emma Nolan
- ✘ Questions & discussion
- ✘ Karakia whakamutunga



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CHAIR REPORT

BCAC Committee 2021-22



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BCAC Member Groups 2022

- ✘ 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

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 a voice** for New Zealanders who experience breast cancer
- ✘ 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 of breast cancer
 - ✘ Early, advanced, whānau, organisational
- ✘ BCAC participates in policy-making & advisory bodies
- ✘ BCAC responds to consultations, makes submissions
- ✘ BCAC works with patients, advocates, specialists, nurses, regulators, and decision makers

Information and resources

- ✘ *Step by Step* packs
 - ✘ Sent >1,500
 - ✘ Fundraised, printed 7,000
 - ✘ Expanding distribution
 - » >Māori health & breast clinics

- ✘ Website
 - ✘ Information, news, events

- ✘ Newsletters

- ✘ Facebook
 - ✘ BCAC Page
 - ✘ Metavivors, Metavivors Action, BCAC Groups



Support, information, collaboration and advocacy



- ✘ Personally to people who reach out
 - ✘ All stages and sub-types of breast cancer
 - ✘ Help navigate treatment path

- ✘ To groups and populations of women
 - ✘ Advocacy for health system improvements

- ✘ Network and collaborate with member groups, clinicians, researchers, pharma companies

- ✘ Work closely with Metavivors
 - ✘ Strong Metavivor presence on BCAC Committee
 - ✘ *Metavivors NZ*, peer support, great info & connections
 - ✘ *Metavivors NZ Action*, advocacy for change



International MBC Awareness Day 2022 www.breastcancer.org.nz

Metavivors Living Life to the Max



Gifts to the Future, He Koha ā Mua

- ✘ Videos of women with ABC
- ✘ Fantastic resource for others diagnosed
- ✘ Insights on living life with ABC
- ✘ Elisa Wijohn fundraised for 3 more videos of wāhine Māori



Representing: clinical, policy and advisory groups

✘ Breast Special Interest Group (BSIG)

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

✘ Breast Cancer Trials (BCT ANZ)

- ✘ Australasian research organisation focused on breast cancer
 - » Affiliate, fundraising, IMPACT advocate members

✘ Health Quality and Safety Commission (HQSC)

- ✘ Works with health system and people to improve health services
 - » Chair, Consumer Advisory Panel

✘ Cancer Trials NZ (CTNZ)

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

Representing: 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 membership

✘ Enhancing NZ Clinical Trials Project

- ✘ Address infrastructure, access and capability needs
 - » Steering Cttee and consumer input
 - » Report due soon
 - » Hoping this will drive earlier access to innovation

BreastScreen Aotearoa Review



- ✘ Consumer input into Review
- ✘ Reviewed draft epidemiology and BSA reports
- ✘ Key advocacy points
 - ✘ Supported strong equity drive
 - ✘ Measure and report breast density
 - ✘ Extend screening age band from 45-69 to 40-74
 - ✘ Implement smarter risk-based screening
 - ✘ Aspire to innovate
 - ✘ Incorporate consumers at all levels
- ✘ Invited to nominate a member of new BSA Action and Advisory Group

NZ Consensus Guidelines for Advanced BC

- ✘ Evidence-based summary of best practice management
 - ✘ Adapted from ESMO Guidelines (Fatima Cardoso *et al.*)
 - ✘ Led by oncologist Dr Marion Kuper
 - ✘ Support from BCF, especially Adèle Gautier
 - ✘ Input from Metavivors, Sweet Louise, BCAC

- ✘ A guide for clinicians, patients, advocates, government health organisations

- ✘ Useful tool to lift standard of care to deliver longer, better quality lives with ABC



Metavivors Living Life to the Max



Te Aho o Te Kahu, Cancer Control Agency

✘ On Consumer Reference Group, He Ara Tangata

- ✘ Lived experience perspective

✘ Objected to inadequate report on medicines

- ✘ Triple filtering removed all but one bc medicine
- ✘ ESMO Guidelines but not funded 4 EBC, 22 ABC
- ✘

✘ Input into Quality Performance Indicators

- ✘ Frustrated BCF Register data not used
- ✘ QPIs should eventually allow measurement of health system performance
- ✘ NZ needs updated EBC Clinical Guidelines – Te Aho not supportive
 - » Perhaps BSIG could use the ABC model and adapt ESMO for Aotearoa

✘ Cancer Services Planning Report

- ✘ Good analysis of current system and how it could be improved
- ✘ Will we see action or advocacy from TAoTK to implement change?



Against Genetic Discrimination Aotearoa (AGenDA)

- ✘ Knowing our genetic risk e.g. BRCA can be life-saving
 - ✘ Early screening, detection, prophylactic surgery
- ✘ In NZ, insurance companies can discriminate
 - ✘ Can refuse cover, load premiums, void policy cover if not disclosed
 - ✘ Disincentive to test
- ✘ AGenDA seeking moratorium and protective legislation
 - ✘ For insurance and employment as in Canada, UK, Australia
- ✘ BCAC joined AGenDA
 - ✘ Along with doctors, researchers, lawyers, Māori, Pasifika, medical charities, patient groups



Analysis of NZ's early breast cancer pathway

What can we do better?

- ✘ The Economist's Economic Intelligence Unit analysis
 - ✘ Population awareness, screening & diagnosis, treatment, survivorship
 - ✘ Input from BCAC, BCF, Hei Āhuru Mōwai, clinicians
- ✘ Report: *Enhancing patient-centred approaches to optimise early-breast cancer care: A review of current practice and opportunities for improvement in New Zealand*
- ✘ Recommendations:
 - ✘ Outcome measures should include quality of life, not just mortality
 - ✘ Establish an alliance of advocates, clinicians, industry, academia to influence decision-makers
 - ✘ Aspire for world-class care and access to innovative treatments
 - ✘ Ensure equitable access to screening uptake by Māori and Pasifika
 - ✘ Update EBC Guidelines

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'



Better access to medicines

Pharmac interactions

- ✘ Responded to consultations:
 - ✘ Zometa – supported greater access, argued for widening further
 - ✘ Kadcylla – supported post-neoadjuvant approval, opposed ABC restriction
 - ✘ Trastuzumab biosimilars – supported, sought later line ABC use and sub-cutaneous
 - ✘ Evidence update for Abraxane → Pharmac's '*options for investment*'
- ✘ Submitted new applications:
 - ✘ Halaven – later line ABC treatment (funded in Aus 2013)
 - ✘ Keytruda – early and late TNBC (in prep.)
- ✘ Sought replacement of Teva goserelin
 - ✘ Zoladex (ovarian suppression), generic has blunt/faulty applicator
 - ✘ Metavivor Karen Nimmo led advocacy
 - ✘ BCAC and BSIG letters - new consultation in December

Better access to medicines

Pharmaceutical company engagement

- ✘ BCAC encourages & supports key steps to access:
 - ✘ Importation, Medsafe registration, Cost-share/access programmes, Pharmac funding applications
- ✘ Halaven – Eisai
 - ✘ Later line ABC chemo option
- ✘ Keytruda – MSD
 - ✘ Early and late TNBC
- ✘ Enhertu – AstraZeneca
 - ✘ Later line HER2+ (and HER2 low) ABC
- ✘ Trodelvy – Gilead Sciences
 - ✘ Later line TNBC for ABC
- ✘ Phesgo – Roche
 - ✘ Neoadjuvant pertuzumab with trastuzumab HER2+
- ✘ Tukysa – MSD
 - ✘ Later line HER2+ ABC

Equity: empowering Māori and Pasifika

- ✘ Maria Marama provides a Māori perspective, advises on cultural responsiveness
 - ✘ BSA Review
 - ✘ Research design & engagement by NZABCR
 - ✘ HRC funding proposal to build high quality Māori engagement into breast cancer research
- ✘ Serious inequities
 - ✘ access to detection, treatment and care
 - ✘ worse outcomes
- ✘ A strong theme in all BCAC submissions
- ✘ Identified and provided *Step by Step* support packs to Māori health providers supporting Māori with breast cancer throughout Aotearoa



Metavivors Living Life to the Max



Ongoing education: conferences

- ✘ SABCS (San Antonio Breast Cancer Symposium)
- ✘ BCT ASM (Breast Cancer Trials Annual Scientific Meeting)
- ✘ Breast Cancer Trials webinars, Q & A sessions
- ✘ ABC6 conference run by ABC Global Alliance
- ✘ COSA (Clinical Oncology Society of Australia) conference
 - ✘
- ✘ NZSO (New Zealand Society for Oncology) conference
 - ✘
- ✘ ASCO (American Society of Clinical Oncology) conference
- ✘ Breast cancer inSIGhts conference
- ✘ NZ Breast Cancer Symposium

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Help us improve outcomes for NZ patients

✘ *Message to BCAC's members and friends*

✘ *Please let us know of any issues you or your members are facing so we can work together to find solutions*



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Special thanks

- ✘ BCAC Committee
 - ✘ Belinda, Catrin, Elisa, Emma, Fay, Gillian, Greer, Linda, Louise, Lynda, Maria, Philippa, Rowena, Sarah, Tanya, Terre
- ✘ BCAC staff
 - ✘ Celia
- ✘ Alison Davies
 - ✘ PHARMAC applications, submissions, wisdom
- ✘ Metavivors
 - ✘ Support, engagement, advocacy, achievements
- ✘ BCAC member groups & individuals
- ✘ Collaborators across the health sector
 - ✘ Richard Isaacs, Marion Kuper, Sheridan Wilson, Sarah Barton, Reuben Broom, Naera Waters, Ian Campbell, Clare Hardie, Jenni Scarlet, Cheryl MacDonald
- ✘ The women of NZ who have shared their issues and experiences
- ✘ Patient Voice Aotearoa
 - ✘ ongoing advocacy

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Gillian Wintrup



Elisa Wijohn



Terre Nicholson

TREASURER'S REPORT

BCAC Financial Performance: 1 April 2021 to 31 March 2022

Revenue points to note:

✘ Bequest	\$30,000
✘ Lotteries grants	\$15,068
✘ Public donations	\$3,037
✘ Le Reve donation	\$4,263
✘ Interest on savings	\$4,940
✘ The Good Registry donations	\$6,953
✘ Grant from Pfizer: making <i>Step by Step</i> more accessible	\$6,360
✘ Total revenue	\$70,621

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BCAC Financial Performance: 1 April 2021 to 31 March 2022

Expenses points to note:

✘ Providing online information and support	\$4,615
✘ Admin support: volunteers engaging with health providers & decision-makers	\$3,553
✘ Admin support for providing public voice for those with BC	\$3,553
✘ Distributing e-newsletter; answering queries	\$3,553
✘ <i>Step by Step</i> storage & distribution	\$4,664
✘ Value of <i>Step by Step</i> packs delivered	\$19,396
✘ Attending meetings and hearings	\$575
✘ Audit and bank fees	\$1,756
✘ Office expenses/other expenditure	\$2,600

Total expenses

\$44,265

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Subsequent to 1 April 2022:

Revenue

✘ Funding for printing, storage & distribution of 7,000 <i>Step by Step</i> support packs:	
✘ Trusts grants	\$74,000
✘ BCFNZ grant	\$58,054
✘ Ministry of Health grant	\$40,000
✘ Donations, including via Good Registry	\$14,815
✘ Lotteries Grant	\$1,668
✘ Interest	\$2,261
✘ Other revenue	\$964

Subsequent to 1 April 2022:

Expenses

✘ Bank and audit	\$1,735
✘ Office and other expenses	\$734
✘ <i>Step by Step</i> distribution & storage	\$2,653
✘ Website maintenance, IT support	\$1,201
✘ Travel and conference fees	\$875
✘ He Koha a Mua video production	\$2,425
✘ Value of <i>Step by Step</i> packs delivered	\$13,442
✘ Printing 7,000 <i>Step by Step</i> packs	\$113,041
✘ Current bank balance	\$116,502

Audited Annual Performance Report 2021-22:

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



Further business

- ✘ Motion to accept Treasurer's Report
- ✘ Election of Committee for 2022–2023
- ✘ Appointment of Auditor
- ✘ Motions
- ✘ General business
- ✘ Approval of future plans
- ✘ Guest speaker: Dr Emma Nolan
- ✘ Questions and discussion
- ✘ Karakia whakamutunga

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Committee nominations received

- ✘ Libby Burgess – Chair
- ✘ Emma Crowley – Deputy Chair
- ✘ Fay Sowerby – Secretary
- ✘ Louise Malone – Treasurer
- ✘ Ah-Leen Rayner, representing BCFNZ
- ✘ Belinda Tran-Lawrence, representing ANZBCC
- ✘ Catrin Devonald, representing Sweet Louise
- ✘ Denise Lemmen, representing Metavivors NZ
- ✘ Greer Drake
- ✘ Linda Fatialofa
- ✘ Lynda Ames
- ✘ Maria Marama
- ✘ Philippa Reed, representing CanTeen Aotearoa
- ✘ Rowena Mortimer
- ✘ Sarah Cato
- ✘ Tanya Newman

Motions

- ✘ Motion: that BCAC elects the above-mentioned candidates to the positions noted
- ✘ Motion: that BCAC appoints Michelle O'Meara as auditor for the 2022-23 financial year
- ✘ Is there any general business?

FUTURE PLANS

Plans for 2022-2023

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 2022-2023

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, 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 & pharmaceutical companies
- ✘ Respond to **consultations**, apply for **funding**
- ✘ Promote and provide effective **consumer representation** for NZ women with breast cancer

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Plans for 2022-2023

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 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

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Plans for 2022-2023

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 2022-2023

GUEST SPEAKER

Dr Emma Nolan



QUESTIONS AND DISCUSSION

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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