



BCAC Annual General Meeting 2021

*30 November 2021
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*

BCAC Committee 2020-21



BCAC Member Groups 2021

- ✕ Age Concern
- ✕ Alleviate
- ✕ Aotearoa NZ Breast Cancer Community
- ✕ Ascot Radiology Pink Dragons
- ✕ Boobops Dragon Boat Team
- ✕ Breast Cancer Action Trust
- ✕ Breast Cancer Foundation NZ
- ✕ Breast Cancer Cure
- ✕ Breast Cancer Support Inc
- ✕ Breast Cancer Support Northland Trust
- ✕ Breast Cancer Support Tauranga Trust
- ✕ Busting With Life
- ✕ CanTeen Aotearoa
- ✕ Hope Emerges
- ✕ Horowhenua Pink Ladies BCS Group
- ✕ Kenzie's Gift
- ✕ Life 2.0
- ✕ Look Good Feel Better
- ✕ Lymphoedema Support Network
- ✕ Mamazon Club
- ✕ Metavivors NZ
- ✕ Pinc Cancer Rehabilitation Program
- ✕ Rotorua Breast Cancer Trust
- ✕ Shocking Pink
- ✕ Support Crew
- ✕ Sweet Louise
- ✕ Taranaki Dragons
- ✕ Te Ha o te Oranga o Ngāti 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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2021 a Covid year!



- ✘ Lockdowns, stresses on health system and people
 - ✘ Hospital beds occupied, medical staff redeployed
 - ✘ Difficulties and delays for patients and whānau
- ✘ Delayed detection, scans, specialist appointments, pathology, surgery
- ✘ BCF's screening petition
 - ✘ Find 133 undetected women within 6 months
 - ✘ Maintain screening at all lockdown levels
 - ✘ Achieve 70% target for all 45 – 69 year olds
 - ✘ Extend to 70 – 74
 - ✘ Add screening as health system indicator



Covid Vax Chat (Zoom)

- ✕ BCAC, Sweet Louise, Metavivors NZ
- ✕ Response to vaccine hesitancy from some with ABC
- ✕ Experts: Drs Morgan Edwards, Richard Isaacs, Sarah Barton
- ✕ Pfizer vaccine is safe and effective
- ✕ Get 3rd shot if on chemo or targeted therapy, then booster



New Normal, Same Cancer campaign

- ✘ International movement
- ✘ BCAC collaborating with other NZ patient organisations
- ✘ Remind everyone that cancer doesn't pause in a pandemic
- ✘ To strongly encourage all to push through any resistance caused by health system stress, to take the initiative, get screened, re-book and attend treatment and follow up appointments



2021 highlights

- ✕ Production of 16 *Gifts to the Future, He Koha ā Mua* legacy videos for ABC in collaboration with Metavivors NZ, Sweet Louise and Breast Cancer Foundation NZ
- ✕ Lie Down for Life events – the presentation of the PVA petition seeking to review PHARMAC and double/triple its budget
- ✕ PHARMAC Review – finally! Weight of advocacy
 - ✕ Draft report expected this week, final due February.



2021 highlights

✕ Ministerial briefing

- ✕ Andrew Little & Diana Sarfati, CEO, Cancer Control Agency, Te Aho o te Kahu; other politicians
- ✕ Focus on better outcomes, greater equity

✕ Strategic areas:

- » managing risk & better targeting screening
- » greater access to medicines
- » gene-based testing for greater precision in treatment

✕ Coalface issues:

- » continuity of care
- » postcode lottery of services
- » reconstruction, going flat
- » inadequate information on options
- » poor access to allied care incl. mental, dental, visual, physio & lymphoedema
- » limited eligibility for screening & biopsy
- » inadequate surveillance



Information and resources

- ✕ *Step by Step* packs
 - ✕ delivered more than 1250
- ✕ Website
- ✕ Newsletters
- ✕ Facebook
 - ✕ Group and Page
- ✕ Twitter
- ✕ *Metavivors NZ*
 - ✕ Peer support & info
- ✕ *Metavivors NZ – Action*
 - ✕ Advocacy for improvement
- ✕ One to one contact



Providing a voice for those with breast cancer

- ✕ BCAC's lived experience of breast cancer
 - ✕ Early, advanced, whānau
- ✕ BCAC participates in policy-making & advisory bodies
- ✕ BCAC responds to consultations, makes submissions
- ✕ BCAC meets and communicates with patients, advocates, health service providers, regulators, decision makers, industry

Representing: clinical, policy and advisory groups

✕ Breast Special Interest Group

- » Consumer reps

✕ Breast Cancer Trials (ANZ)

- » IMPACT consumer members; Communications and Fundraising Committee member; Associate member



✕ Health Quality and Safety Commission

- » Chair, Consumer Advisory Panel; Consumer reps



✕ Cancer Trials NZ

- » Chair, Consumer Advisory Panel



Representing: clinical, policy and advisory groups

✕ Health Research Council

- » Assessment Committee Member



✕ NZ Familial Breast and Ovarian Cancer

- » Consumer reps



✕ Te Aho o Te Kahu, Cancer Control Agency

- » Briefing to Minister of Health and Diana Sarfati CEO
- » Libby a member of He Ara Tangata, Consumer Reference Group
 - » Input into work programmes
 - » Lots under way, will be evident soon
- » Fay engaged re personalized screening, appointed to Breast QPI group



Representing those with breast cancer

Meetings and communication with:

- ✗ Pharmaceutical companies
 - ✗ AstraZeneca, Celltrion, Eisai, Novartis, Pfizer, Roche, Specialised Therapeutics
- ✗ PHARMAC
- ✗ Politicians from across the political spectrum



Discussions on:

- ✗ Patient empowerment
 - ✗ information, support, services, policy
- ✗ Clinical trial access
 - ✗ Increase NZ involvement
- ✗ *Medicines access*
 - ✗ funding, access conditions, product registration, pricing, biosimilars & 'grandparenting', supply chain



Advocacy and collaboration

✘ Patient Voice Aotearoa

- ✘ Review of PHARMAC processes
- ✘ Lie Down for Life events across NZ
- ✘ Presentation of petition
 - » >100,000 signatures



✘ Metavivors NZ

- ✘ Peer support for ABC
 - » Facebook, videos, Vax Chat
- ✘ Ongoing advocacy for ABC
- ✘ Petitions, marches, events



✘ Sweet Louise

- ✘ Ongoing support for Metavivors and SL members
- ✘ Vax chat
- ✘ Advocacy for ABC



✘ ABC Global Alliance

- ✘ BCAC membership
- ✘ Annual Advanced Breast Cancer International Consensus Conference (ABC6)
- ✘ International advocacy for ABC



Advocacy and collaboration

✕ Breast Cancer Cure

- ✕ Submissions, clinical trials access, targeted screening, genetic testing, research strategy



✕ Breast Cancer Foundation

- ✕ Conferences & meetings
 - » Breast InSIGhts, ANZBCR's Symposium, Nurses' Day
- ✕ Consultations & submissions
- ✕ Petition
- ✕ Videos



✕ Aotearoa NZ Breast Cancer Community

- ✕ New BCAC member group based online
- ✕ Active and engaging
- ✕ Communicating, looking forward to collaborating
 - » Access to going flat



Gifts to the Future, He Koha ā Mua videos

BCAC, Metavivors, Sweet Louise, BCF

- ✖ 16 videos celebrating strength and beauty in ABC
- ✖ Raise awareness
- ✖ Legacy for whānau
- ✖ Shared experiences of ABC - empowering
- ✖ Valuable insights, wisdom, tips for others diagnosed
- ✖ Pfizer grant
- ✖ Elisa Wijohn raised funds for diversity





Better access to world class care

✕ Met Minister of Health & Te Aho o Te Kahu CEO

- ✕ Briefing from BCAC on strategic and coalface issues

✕ PHARMAC Review

- ✕ Comprehensive submission from BCAC
- ✕ Met Review Panel in person and online

✕ PHARMAC consultations

- ✕ Submission on proposed changes to consumer and clinical advisory committees
- ✕ Evidence update for application to fund nab-paclitaxel
- ✕ Submission disputing proposal to decline fulvestrant as 1st line metastatic treatment and pertuzumab as neo-adjuvant treatment
- ✕ Noted two new tyrosine kinase inhibitors should be funded – neratinib & tucatinib

Better access to world class care

- ✖ Met clinical directors of BSA and National Screening Unit
 - ✖ Discussed risk management and targeted screening
- ✖ Enhancing NZ Clinical Trials Project (UoA)
 - ✖ Steering Committee
 - ✖ Consumer representatives on focus group
- ✖ National Clinical Trials Alliance (MoH)
 - ✖ Participate via a working group
 - ✖ Contribute to consensus process to develop infrastructure
- ✖ MoH, Best practice guidelines for breast reconstruction
 - ✖ MoH hadn't included patient reps, BCF discovered, shared!
 - ✖ Greater patient empowerment
 - ✖ Going flat option

Clinical Trials meeting



Better access to world class care

- ✗ The Economist's Economic Intelligence Unit – MSD
- ✗ Patient-centred pathway for early breast cancer
- ✗ Consulted across Asia-Pacific to develop country-specific drafts
- ✗ In-person workshops planned for 2022



Equity: closing gaps for Māori and Pasifika

www.breastcancer.org.nz

- ✘ Action needed to overcome serious inequities
 - ✘ access to detection, treatment and care
 - ✘ worse outcomes
- ✘ A strong theme in all BCAC submissions
- ✘ Farewelled Irene (ongoing collaboration)
- ✘ Welcomed new committee member Maria Marama
 - ✘ provides a Māori perspective
 - ✘ advises on cultural responsiveness
- ✘ Project to scope Māori needs for *Step by Step*
 - ✘ Maria consulting
 - ✘ insert for next year's reprint?
 - ✘ addition of Māori content for next edition?
- ✘ Separate Pasifika process needed
- ✘ Māori Health Authority to be established



Ongoing education: conferences etc

- ✕ San Antonio Breast Cancer Symposium
- ✕ Breast Cancer Insights (Breast SIG, BCF)
- ✕ Breast Cancer Trials (ANZ)
 - ✕ Annual Scientific Meeting
 - ✕ Webinars, Q & A session
- ✕ St Gallen Consensus Conference on EBC Treatment Standards
- ✕ ABC Global Alliance conference
- ✕ NZ Familial Breast and Ovarian Cancer conference
- ✕ NZ Assoc. BC Research's NZ Breast Cancer Symposium
- ✕ UK National Institute for Health & Care Excellence (NICE)
 - ✕ 5-Year strategy launch – aspirational model
- ✕ BCF Nurses' Day

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NZFBOC meeting



Providing a voice for change

✕ *Message to BCAC's members and friends*

✕ *Please let us know of any issues you or your members or patients are facing so we can network, collaborate and work to resolve these*



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Special thanks

www.breastcancer.org.nz

✕ BCAC Committee

✕ Catrin, Emma, Fay, Gillian, Greer, Irene, Louise, Lynda, Maria, Philippa, Rowena, Tanya, Terre

✕ BCAC staff

✕ Celia

✕ Alison Davies

✕ PHARMAC submissions and responses

✕ Metavivors

✕ Support, engagement, advocacy, achievements. Terre Nicholson coordinates

✕ BCAC member groups & individuals

✕ Sweet Louise, BCF, BCC, Aotearoa NZ BCC

✕ Collaborators across the health sector

✕ Richard Isaacs, Sarah Barton, Marion Kuper, David Porter, Reuben Broom, Ian Campbell, Erica Whineray-Kelly, Maria Pearse, Clare Hardie, Jenni Scarlet, Cheryl MacDonald, Morgan Edwards

✕ The women of NZ who have shared their issues and experiences

✕ Patient Voice Aotearoa

✕ Malcolm Mulholland, Fiona Tolich

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Special tributes



Jane Reeves



Wiki Mulholland

BCAC Performance 2020-21

- ✕ 1,258 Step by Step packs delivered (1,352 last year)
- ✕ 50,756 website views (49,918 last year)
- ✕ 34 member groups (33 last year)
- ✕ 32 meetings & conferences attended (35 last year)

BCAC Performance 2020-21

- ✖ Facebook >2,500 followers; Twitter ([@bcac_nz](https://twitter.com/bcac_nz))
- ✖ E- newsletter
- ✖ Brochures – BCAC and Metavivors NZ
- ✖ Responded to more than 60 requests for support and information
- ✖ Assisted women to navigate the health system



Plans for 2022

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**
- ✕ Respond to requests for **information, advice and support**

Plans for 2022

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

✘ Advocate for and support development & implementation of **QPIs, Standards and Guidelines** for EBC and ABC

✘ **Champion access to proven medicines** and other treatments and techniques with clinicians, PHARMAC & pharmaceutical companies

✘ Respond to **consultations**

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

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Plans for 2022

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 **metastatic & 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

Plans for 2022

Māori & Pasifika women

- ✘ 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 **risk-based personalised screening**
- ✘ Meet with BSA & NSU to encourage and **monitor progress**
- ✘ Support **BCF petition** requests

Fundraising

- ✘ **Fundraise** to support BCAC's work

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Karakia whakamutunga

Kua mutu a mātou
mahi mō tēnei wā
Manaakitia mai mātou
katoa

O mātou hoa
O mātou whānau
Āio ki te aorangi

Our work has finished
for now
May we all be protected

Our friends
Our families
Peace to the universe



www.breastcancer.org.nz

email: bcac@breastcancer.org.nz

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Together we're stronger

‘Love can be an army’

[Pink song](#)