



BCAC Annual General Meeting 2024

*10 September 2024
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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CHAIR REPORT

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BCAC Committee 2023-24



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BCAC Member Groups 2024

- ✘ 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 network and collaborate with all stakeholders: patients, specialists, nurses, regulators, decision makers, politicians, advocates, other patient groups and pharma companies

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Information and resources

✘ Step by Step packs

- ✘ Sent >1,400
 - » Breast clinics
 - » Māori health & rongoā clinics
 - » Individuals via website orders

✘ Website

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

✘ Quarterly newsletters

✘ Facebook

- ✘ BCAC Page
- ✘ Groups: Metavivors, Metavivors Action, BCAC
- ✘ Share to ANZBCC & PVA groups



Support, advocacy

- ✘ 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

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Metavivors NZ



- ✘ Active Facebook-based group for those with ABC
 - ✘ 580 members
- ✘ Fantastic peer support and information
 - ✘ Strong connections to Sweet Louise
- ✘ Metavivors NZ Action group for advocacy
 - ✘ Includes partners, supporters
- ✘ 3 talented MV on BCAC Committee this year

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BCAC's Metavivors

✘ Denise Lemmen

- ✘ Administers Metavivors NZ and MV Action groups



✘ Marion Barnett

- ✘ Medical writer, fantastic website content
 - » Paper on ABC treatment in Aotearoa NZ vs Guidelines and Australia
 - » Articles from online attendance of ABC7
- ✘ Passed away in April



✘ Rachel Greenwood

- ✘ Invercargill GP
- ✘ Represents RNZCGP on BSA's Action & Equity Group
- ✘ Representing Metavivors in ABC NZ3 Guideline development
- ✘ Raises GP issues re BC so we can seek solutions



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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
 - » Attend InSIGhts conference



✘ Cancer Trials NZ (CTNZ)

- ✘ Clinical cancer research
 - » Emma chairs Consumer Advisory Panel



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Represent on clinical, policy and advisory groups

✘ Breast Cancer Trials (BCT ANZ)

✘ Australasian research organisation focused on breast cancer

- » Consumer Advisory Panel; Affiliates; IMPACT advocates
- » Expert panellist and media commentator on Breast Cancer Trials Q&A *Breast Cancer in Māori Pasifika and Indigenous People*
- » Attend the Annual Scientific Meeting
- » Seek to get more trials to NZ patients



Breast Cancer Trials Annual Scientific Meeting



BCT ASM in Cairns



Novel endocrine therapies may address endocrine resistance in MBC

SERD : Mechanism of action

The diagram illustrates the mechanism of action of SERD. It shows Estrogen (orange dots) binding to Estrogen receptor α (EreA). SERD (green hexagons) competes for binding to EreA. This leads to EreA degradation and ERE antagonism, which inhibits transcription of the Estrogen responsive gene. The diagram also shows the Estrogen response element (ERE) on the DNA and the resulting transcription of the Estrogen responsive gene.

Key advantages

- Oral formulation
- Higher potency
- Activity in ESR1 mutant MBC
- Activity in post-ET and CDK4/gi treated pts

Other therapies: SERM, PROTAC, CERAN, SERCA

Hernando et al, Int J Mol Sci 2021; slide adapted from Erika Hamilton

Challenges^{1,2}

- Fear and uncertainty about the future
- Facing mortality
- A loss of control
- Impacted sense of identity
- Reprioritisation of values or goals
- Dealing with constant or changing treatment schedules
- Tolerance of lifelong side effects
- Acceptance of stable disease as a desirable treatment outcome
- Acceptance of a progressive loss of functional ability
- Fear of loss of independence or dependency on others
- Social isolation
- Communicating with others about illness and mortality

While medical treatments are improving, diagnosis brings significant challenges and impact

Clinically elevated distress

Impaired QOL

Unmet needs in up to 68% of women surveyed

QOL: Quality of life.
References: 1. Gains PA et al. Adv Exp Med Biol 2015; 862: 243-54. 2. Visovsky C et al. J Cancer Surviv 2023.

Antibody drug conjugates in breast cancer^{1,2}

Molecule	Sacituzumab Govitecan	Datopotamab Deruxtecan	Trastuzumab Deruxtecan	Trastuzumab Emtansine
Antibody	Humanised anti-TROP2	Humanised anti-TROP2	Humanised anti-HER2 IgG1	Humanised anti-HER2 IgG1
Payload	Topoisomerase I inhibitor SN-38 payload	Topoisomerase I inhibitor Derivative of exatecan	Topoisomerase I inhibitor	Microtubule inhibitor Maytansine DM1
Linker	Hydrolysable pH sensitive linker	Tetrapeptide based cleavable linker	Tumour-selective cleavable linker	Non-cleavable MCC thioether linker

adapted from Dumortier C et al. 2023¹
Dumortier C et al. Mol Ther Oncol 2023;2019:611-81. 2. Barak et al. Breast Cancer Research 2014; 20(16): 1-12.

GILEAD | Oncology



Represent on clinical, policy and advisory groups

✘ 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
 - » Input, conference attendance



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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



✘ Against Genetic Discrimination Aotearoa (AGenDA)

- ✘ Aligned, collaborating
- ✘ Fay wrote submission seeking anti-discrimination clauses in Contracts of Insurance Bill
- ✘ Select Committee has recommended:
 - » Consultation & policy development on regulation of genetic discrimination



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Represent on clinical, policy and advisory groups

✘ **Māori Breast and Cervical Advisory Group**, Te Whatu Ora



Health New Zealand
Te Whatu Ora

✘ **Decentralised Clinical Trials Advisory Group**, UoA

✘ Enabling more cancer patients to access trials remotely, rurally

✘ HRC funding to pilot this



Breast Screening

✘ BSA Action and Equity Group

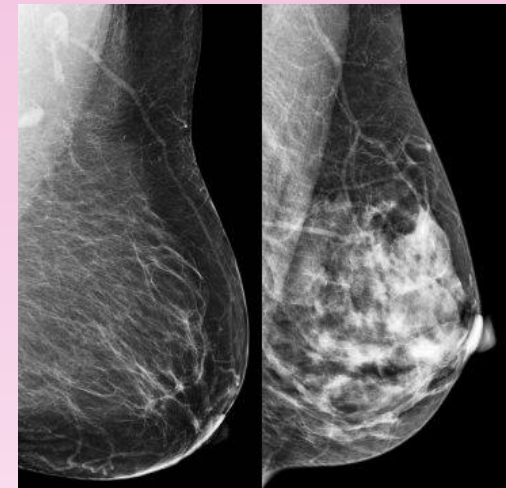
- ✘ Rachel represents RNZCGP
- ✘ Fay active on many fronts



✘ BreastScreen Aotearoa

✘ Should measure and report **breast density**

- » RANZCR recommends mandating
- » 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



✘ Broaden **screening age band**, 45-69 to 40-74

- » Extending up to 74 (slowly)

✘ Implement risk-based screening

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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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Medicines: the state of play

STAGE, SUB-TYPE	UNFUNDED MEDICINES
Early HR+	Verzenio , Kisqali
Advanced HR+	Trodelvy , Verzenio , Truqap , Piqray , Orserdu , Afinitor
Early HER2+	Herceptin sub-cutaneous (SC) , Perjeta , Phesgo
Advanced HER2+	Herceptin sub-cutaneous (SC) , Phesgo , Herzuma (retreatment) , Enhertu , Tykerb , Nerlynx , Tukysa , Margenza
Advanced HER2-low	Enhertu
Early TNBC	Keytruda , Lynparza (BRCAm)
Advanced TNBC	Tecentrig , Trodelvy , Lynparza (BRCAm) , Talzenna , Infinzi
Various sub-types	Abraxane , Halaven , Xgeva/Prolia , Avastin

- ✘ NZ is bottom of OECD in investment and access
- ✘ 31 BC medicines & uses recommended in international Guidelines or standard of care overseas
- ✘ 16 of these funded in Australia

State of play: TNBC

Recent advances in triple-negative breast cancer

Melinda Telli, MD

Associate Professor of Medicine
Stanford University School of Medicine
Director, Breast Cancer Program
Stanford Cancer Institute

✘ SABCS Dec 2023

✘ Essay for Alamo scholarship on TNBC

✘ NZ treats TNBC same as US in 2007

✘ Neo-adjuvant therapy often not implemented in early TNBC

» Chemo/immunotherapy before surgery

✘ No immunotherapy for early or advanced

» Keytruda (pembrolizumab)

✘ No antibody drug conjugates

» Trodelvy (sacituzumab govitecan)

✘ No PARP inhibitors for BRCAm

» Lynparza (olaparib)

Keytruda (pembrolizumab) for e & mTNBC

- ✘ BCAC applied to Pharmac in 2022 to fund for early and advanced TNBC (MSD, BSIG later)
- ✘ Australia funded both in 2023
- ✘ We've written multiple letters urging action
- ✘ 2024 Government funding uplift – **Pharmac will fund for newly diagnosed advanced**
- ✘ We've asked to include de novo as well as recurrent
 - ✘ They agreed
- ✘ We've asked (repeatedly) to fund for early TNBC
- ✘ We asked MSD to provide it for free until Pharmac funds
 - ✘ They agreed



Keytruda for mTNBC!

A happy meeting with Pharmac



Trodelvy (sacituzumab govitecan) for mTNBC & mHR+



- ✘ Funded in Australia for mTNBC Mar 2022
- ✘ We've lobbied Gilead >2 years
- ✘ Promises made and broken on registration, cost share
 - ✘ *"NZ is a non-reimbursed market"*
- ✘ Gilead Medsafe registration application and price drop in July 2024 *"because of BCAC's advocacy"*
- ✘ BSiG Pharmac application for mTNBC

Lynparza (olaparib) for e & mBRCAm HER2- (incl TNBC)

- ✘ Medsafe-registered for early & advanced
- ✘ Funded in Australia for eHER2- 2024
- ✘ We applied to Pharmac for funding for both in July 2024
 - ✘ BSIG support



Enhertu (trastuzumab deruxtecan) for mHER2+, mHER2-low, mHER2-ultralow



- ✘ Game changer in ABC
- ✘ We've encouraged:
 - ✘ AstraZeneca (AZ) to register, seek funding, affordable cost-share, educate oncologists on side-effect management
 - ✘ Medsafe to review as high priority
 - ✘ Pharmac to review and fund
- ✘ Now Medsafe registered for HER2+ and HER2-low
- ✘ Australia funded HER2+ in 2023, HER2-low in 2024
- ✘ AZ applied to Pharmac for HER2+ (2022), HER2-low (2024)
- ✘ On Pharmac's Options for Investment list for HER2+
 - ✘ CTAC high priority
- ✘ Outrageously expensive cost share (\$176K/2yrs) but AZ "will drop the cost" now fully registered



Kisqali (ribociclib) for mHR+

- ✘ Pharmac proposed to fund, but limited to *either Ibrance or Kisqali*
- ✘ We asked that patients be able to access both, especially if severe side effects
 - ✘ Pharmac agreed to side effect switch
- ✘ We provided evidence of benefits of switch and sequential use
- ✘ We asked Novartis to provide free until Pharmac funding
 - ✘ They agreed

Verzenio (abemaciclib) for e & mHR+

- ✘ Funded in Australia for e (2024) & mHR+(2020)
- ✘ Clinics have imported the Eli Lilly product from Europe
- ✘ Eli Lilly ANZ registered it in NZ 2023, applied for Pharmac funding 2024
- ✘ \$500 jump in cost of Verzenio from Europe
 - ✘ Eli Lilly “didn’t look at previous price”
 - ✘ Think “the new price is value for Pharmac to reimburse”
- ✘ We’ve met and asked them to urgently set up cost share
 - ✘ Capped price and/or free cycles

Afinitor (everolimus) for mHR+



- ✘ Australia funded in 2014
- ✘ BCAC applied to Pharmac in 2018
 - ✘ Declined
- ✘ 2024 Pharmac proposed final decline
- ✘ We objected, they've relented
- ✘ We're gathering new evidence

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Piqray (alpelisib) for PIK3CAm HR+

- ✘ Registered 2021
- ✘ Currently patients import from Europe – very costly
- ✘ We've asked Novartis to import its product directly & implement affordable cost-share
- ✘ They say they're on it
 - ✘ "6 months"



Getting political for better access

✘ *Valuing Life* Parliamentary Summit

✘ Organisers:

- » Patient Voice Aotearoa, Medicines NZ

✘ Host:

- » David Seymour (Assoc Minister of Health, Pharmac)

✘ Attended by:

- » Ministry of Health & Pharmac staff
- » Wide range of patient groups
 - » **BCAC, BCF, BCC, Sweet Louise**
- » Clinicians, researchers, innovators
- » Pharmaceutical companies

✘ Presented on updating Medicines Strategy

✘ *Stakeholders must collaborate to build a modern medicines system* *Together*



Getting political for better access

- ✘ Briefed Paula Bennett, new Pharmac Board Chair
 - ✘ Outlined needed changes
- ✘ Attended release of David Seymour's Letter of Expectation to Pharmac
 - ✘ Professional, respectful culture
 - ✘ Greater collaboration and better relationships to build trust, improve outcomes
 - ✘ More transparency, faster processes
 - ✘ Budgeting to reflect true need
 - ✘ More input from patients, carers, whānau, patient groups
 - ✘ Reform of statutory role
 - ✘ Separation of evaluation & purchasing?



Getting political for better access

- ✘ Patient Voice Aotearoa visit to Ayesha Verrall
- ✘ Discussed current problems and solutions
 - ✘ Medicines budget
 - ✘ Pharmac processes
 - ✘ Need for cross-party support for positive changes



Empowering Māori

- ✘ Maria Marama - a Māori perspective and advice on cultural responsiveness
- ✘ Advocates to remove barriers & improve access to breast cancer diagnosis, treatments and breast reconstruction for Māori
- ✘ Kaupapa Māori research
 - ✘ Masters scholarship from Cancer Society Te Kāhui Matepukupuku and Māori Cancer Leadership He Āhuru Mōwai, researching culturally responsive ways to improve breast cancer treatment and outcomes for wāhine Māori
 - ✘ Masters scholarship from Kapenga M and Raniera Te Tawhiti Kingi



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Empowering Māori



- ✘ Kaupapa Maori research:
 - ✘ HRC funded research *He Oranga U* – defining Te Ao Māori and Tiriti-led hauora pathways for wāhine Māori with breast cancer

- ✘ Contributor to book: *Indigenous and Tribal Peoples and Cancer*. Chapter: *Expression of My Mana Motuhake (Self-Agency) to Guide Breast Cancer Recovery*

- ✘ World Indigenous Cancer Conference, Melbourne

- ✘ Native American and Indigenous Studies Conference, Norway

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, led BCF across the landscape
- ✘ Alvina & Hazel, connected us to ANZBCC
- ✘ Catrin, led Sweet Louise to support those with ABC
- ✘ Denise, led & nurtured Metavivors & Metavivors Action
- ✘ Emma, represented consumers re clinical trials, legal
- ✘ Fay, breast screening, precision health, genomics, genetic discrim.
- ✘ Louise, countless hours as Treasurer, *Step by Step*, website, admin
- ✘ Maria, engagement and research for wāhine Māori
- ✘ Marion, medical writing, conference reports
- ✘ Philippa, connection to Canteen, prev. Sweet Louise CEO
- ✘ Rowena, legal work on constitution, re-registration
- ✘ Tanya, *Staying Positive* article, info on counsellors, *Step by Step* packing

✘ Alison

- ✘ Applications, letters, consultation responses, advice on medicines



Terry (Teresa Ann) Nicholson
Born 1955 - October 2022



Wiki Michelle Mulholland
1978 - 2021



Elisa Lavelle Wijahn
JUNE 1966 - JUNE 2022



Marion Barnett



Tracy Ann Barr-Smith
SEPTEMBER 1970 - APRIL 2023

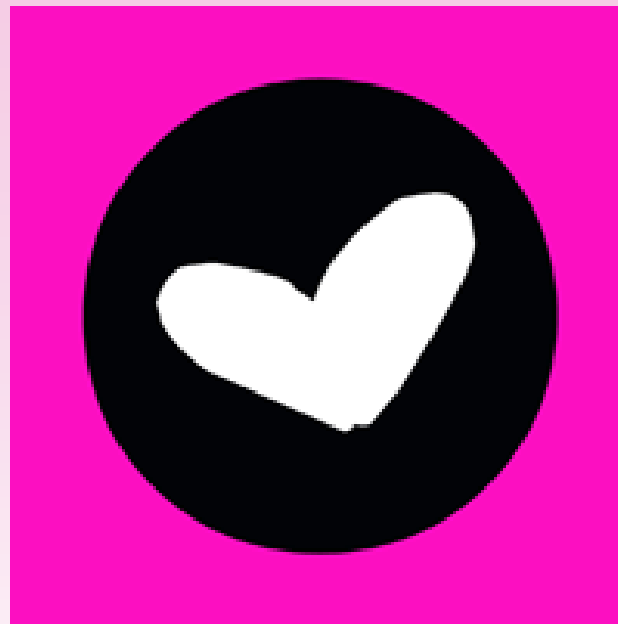


Gillian Wintrup
1973 - 2022



*Let's keep working together to get the best results
for everyone diagnosed*

Tangata tū pakari tonu, together we're stronger



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FUTURE PLANS

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Plans for 2024-2025

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 2024-2025

Timely access to world class detection, diagnosis, 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 2024-2025

Timely access to world class detection, diagnosis, 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 2024-2025

Empower 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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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

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