



# BCAC Annual General Meeting 2020

*24 November 2020  
online via Zoom*

*Together we're stronger*  
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# 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

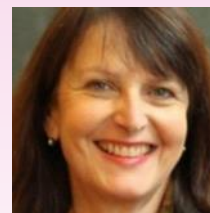
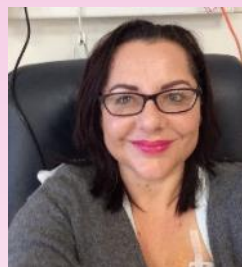
- ✘ Welcome
- ✘ Apologies, Proxies
- ✘ Minutes of 2019 AGM
- ✘ Report from the Chair - *Libby Burgess*
- ✘ Treasurer's Report - *Louise Malone*
- ✘ Election of Committee
- ✘ Appointment of Auditor
- ✘ Motions
- ✘ General business
- ✘ Approval of future plans
- ✘ Draw for bouquet
- ✘ Discussion

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# CHAIR REPORT

# BCAC Committee 2019-20



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# BCAC Member Groups 2020

- ✘ Age Concern
- ✘ Alleviate
- ✘ 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 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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# 2020 highlights

- ✘ Funding of key medicines for advanced breast cancer
- ✘ Louder NZ patient voices - PVA petition; election promises
- ✘ Representing women with breast cancer in submissions to health system reviews, strategies and plans
- ✘ Cancer Control Agency, Te Aho o te Kahu formation and our interactions

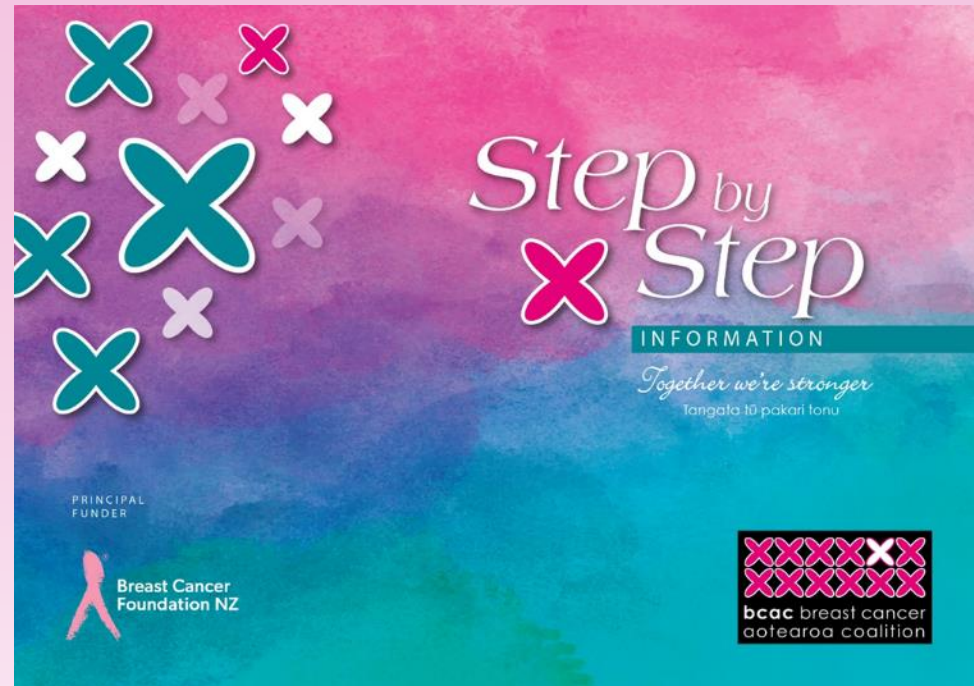
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# Information and resources

- ✘ *Step by Step* packs
  - ✘ delivered 120 per month
- ✘ Website
  - ✘ 50,000 visits
- ✘ Newsletters
- ✘ Facebook
  - ✘ Group and Page
- ✘ Twitter
- ✘ *Metavivors NZ*
  - ✘ Peer support & info
- ✘ *Metavivors NZ – Action*
  - ✘ Advocacy for change
- ✘ One to one contact



# Providing a voice for those with breast cancer

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

# Representing: clinical, policy and advisory groups

## ✘ Breast Special Interest Group

- » Consumer reps

## ✘ Breast Cancer Trials (ANZ)

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

## ✘ Health Quality and Safety Commission

- » Chair, Consumer Advisory Panel; Consumer rep, Cross Sector Alliance Group

## ✘ Cancer Trials NZ

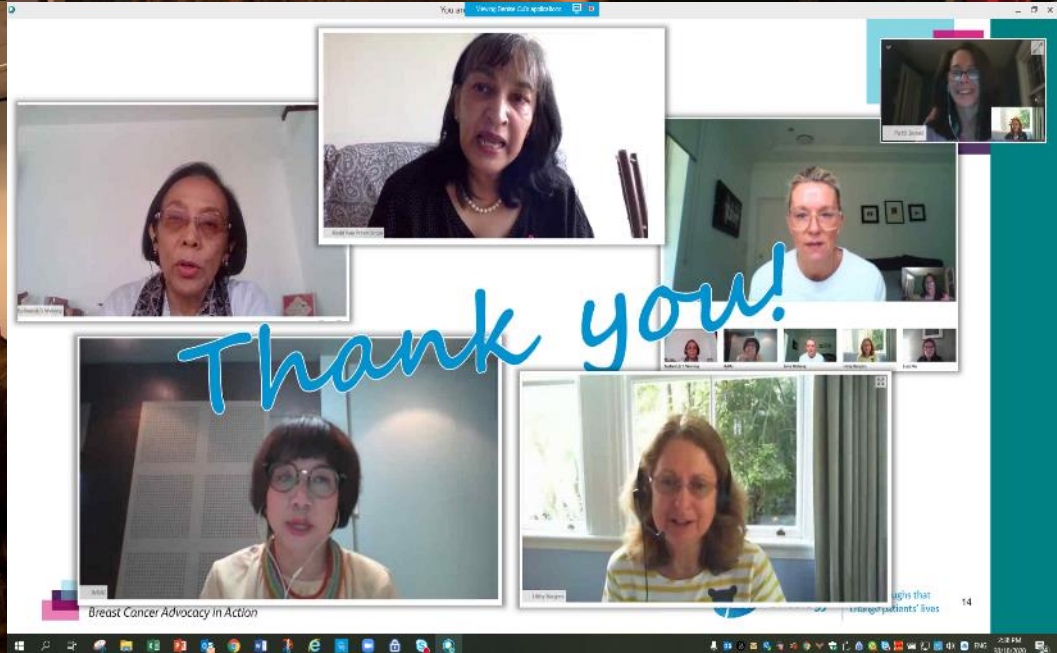
- » Chair, Consumer Advisory Panel

## ✘ Health Research Council Assessment Committee

- » Member

## ✘ NZ Familial Breast and Ovarian Cancer Group

- » Consumer reps





2020 IMPACT Virtual Workshop Program Breast Cancer Trials

# The Future – Challenges and Emerging Topics

## De-escalation, Targeted Therapies, Biomarkers (TILs), AI, Quality of life

Dr Nick Zdenkowski, Medical Oncologist and BCT Medical Advisor  
IMPACT Forum, 5<sup>th</sup> September 2020

Trials Save Lives  
breastcancertrials.org.au

Chat: Event, Stage, People

- John Fitzgerald: a few seconds ago Thanks Paul!
- Kyle Bachemba: a few seconds ago Thanks Paul!
- Liz Kline: a few seconds ago Thanks Paul!
- Paloma Burnett: a few seconds ago See you at 4pm in 1hr! I need to pack out. Doing Paul and Nick's talks every now!
- Leslie Gilman: a few seconds ago See you then Paul!
- Jane Symon: a few seconds ago It's all good!
- John Fitzgerald: a few seconds ago Welcome Jane, this is an amazing talk but we'll start again shortly.
- Jane Symon: a few seconds ago Thank you! I thought I missed on some of the key points on Zoom with my son and Terry.
- John Fitzgerald: a few seconds ago See a couple of videos playing before we get underway. Hope everyone is getting OK so far. Thanks for attending!

# Quality of Life - The general wellbeing of an individual or group

Understanding the impact of cancer and cancer treatments

- Can be integrated into clinical trials
  - Questionnaires
  - Interviews



Findings ways to improve quality of life

- Clinical trials to test strategies
  - New treatments for side effects
  - De-escalation (less treatment, therefore fewer side effects)

## TOP IDEAS

- Support specific policy advocacy initiatives related to structural changes in governments, such as advocating that drug review and reimbursement agencies are well funded, able to consider new treatments for their citizens, and includes meaningful patient input into their processes; and/or that governments fund cancer research in countries.
- Support nurse/navigator to provide patients, family/caregiver and HCPs with personalized information, how to navigate system, etc.
- Support discussion and creation of materials for family members, such as educating older children and family members on the disease and providing support during treatment.
- Create/support creation of a central platform for organizations to share to experiences in policy advocacy, such as raising awareness, choosing policy priorities, collaborating with multi-disciplinary stakeholders, advocating for access to care, and/or communications strategies to advance change.
- Host training with PAGs and HCPs on how to communicate effectively about clinical trials.

Global BC Impact Summit 2020  
Breast Cancer Advocacy in Action

# EXPERT Schema

**A randomised phase III trial of RT vs observation after breast conserving surgery for patients with molecularly characterised luminal A early breast cancer**

**N = 1170**

≥ 50 years, any menopausal status  
pT1 pN0 grade 1 or 2 invasive breast carcinoma  
ER and PR positive ≥ 10% , HER2 negative  
Treated with BCS with negative margins and SNB or AD  
Planned for adjuvant endocrine therapy

**Stratification**

- Centre
- Age (50-59, 60-69, ≥ 70 years)
- ROR score (≤ 40, 41-60)
- Minimum radial surgical margins for invasive carcinoma and associated DCIS (< 1, ≥ 1 to < 2, ≥ 2 mm)

**REGISTRATION**

**Tissue Submission – Prosigna (PAM50) Assay**

Luminal A intrinsic subtype  
Risk of Recurrence score ≤ 60  
Sites notified of eligibility to confirm randomisation

**RANDOMISATION**

- Arm A RT and endocrine therapy
- Arm B No RT (endocrine therapy only)

**Follow-up:**

- End of RT (A) or 3 mths after RDM (B)
- 6 and 12 mths after RDM (A & B)
- Annually to 10 yrs (A & B)

Current BCT recruitment: 315/350  
Total recruitment: 315/1170 (intra activation pending)  
BCT Activation: 33/36 (7 additional AU sites)

# Pandemic Pros and Cons

## POSSIBLE PROS

- Enforced time for contemplation
- Selective fast-tracking of ethics
- Increased profile and regard for research
- Enthusiasm for remote access research

## CONCLUDABLE CONS

- Delay of research funding applications
- Slowing of some ethics processes
- Suspension of recruitment to many trials
- Increased risk of face-to-face assessments
- Difficulty of trial oversight
- Information release speed up at cost of accuracy

# Immune cells and tumour cells

Tumor cells bind to T-cells to deactivate them

Immunotherapy drugs can block tumor cells from deactivating T-cells

T-cell OFF Tumor T-cell ON Drug

# Representing: clinical, policy and advisory groups

## Te Aho o Te Kahu, Cancer Control Agency:

- ✘ Fay and Irene attended a hui to design the agency's consumer engagement model
- ✘ BCAC responded to consultation on Cancer Action Plan 2019-2029
- ✘ BCAC met with Diana Sarfati CEO
- ✘ Fay met with Te Aho re personalized screening
- ✘ Libby appointed to Consumer Reference Group



# Te Aho o te Kahu, Cancer Control Agency

- ✘ Fewer cancers
- ✘ Better survival
- ✘ Equity for all



- ✘ *To provide national leadership for, and oversight of cancer control*
- ✘ *To provide sound policy advice to the Government on cancer control*
- ✘ *To be accountable for ensuring transparency in progress towards the goals and outcomes in the Cancer Action Plan*
- ✘ CEO, Diana Sarfati reports directly to the Minister
- ✘ Independence?
- ✘ Sufficient budget and drive for innovation?

# Representing those with breast cancer

## BCAC meetings with representatives of:

- ✘ Pharmaceutical companies
  - ✘ Astra Zeneca, Roche, Pfizer, Specialised Therapeutics, Celltrion
- ✘ Medicines NZ
  - ✘ Parliamentary Dinner;
  - ✘ Policy Solutions Working Group – Medicines Strategy refresh
- ✘ Southern Cross Health
- ✘ PHARMAC

## Discussions on:

- ✘ Patient empowerment: *information, support, policy*
- ✘ Clinical trial access: *facilitate NZ involvement*
- ✘ Medicines access: *funding, access conditions, product registration, pricing, biosimilars & ‘grandparenting’, supply chain*
- ✘ COVID-19: *how to mitigate impacts*
- ✘ Breast reconstruction: *reimbursement conditions*



# Advocacy and collaboration

- ✘ Patient Voice Aotearoa - [sign4life](#) petition
  - ✘ Review of PHARMAC processes
  - ✘ Double/triple medicines budget
  - ✘ 85,000 signatures so far...
  
- ✘ ABC Global Alliance
  - ✘ BCAC membership
  - ✘ *Improve and extend the lives of people living with ABC worldwide; fight for a cure; raise awareness of ABC; Lobby*
  
- ✘ *Gifts to the Future, He Koha ā Mua* video project
  - ✘ Metavivors NZ, Sweet Louise and Breast Cancer Foundation NZ
  
- ✘ CanTeen
  - ✘ New member group





Medicines  
Inequity - the problems  
& potential solutions

Woman 1: Black dress with a bright pink shawl draped over her shoulders.

Woman 2: Red long-sleeved top and black trousers.

Woman 3: Olive green off-the-shoulder top and matching trousers.

Woman 4: Grey dress with a dark red shawl draped over her shoulders.

Woman 5: Black top and trousers with a colorful floral patterned jacket.

Woman 6: Red top and black trousers with a black shawl draped over her shoulders.

# Better access to world class care

- ✘ **Kadcyla** (T-DM1) funded Dec 2019
  - ✘ for advanced HER2 positive bc
- ✘ **Ibrance** (palbociclib) funded April 2020
  - ✘ for advanced HR positive bc, 1<sup>st</sup> and later line (BCAC application)
  - ✘ BCAC submissions on PHARMAC funding proposal:
    - » Removed '12 month post-menopausal'; second and subsequent line
- ✘ **Faslodex** (fulvestrant) funded April 2020
  - ✘ Single agent and as a partner for Ibrance (BCAC application), HR +
- ✘ **Petitions**
  - ✘ Terre Maize; Sue Wall-Cade; BCAC
- ✘ **Health Select Committee submissions**
  - ✘ Metavivors; BCAC; Sweet Louise, BCFNZ
- ✘ **Media**





# META VIVORS

ACTIVISTS' PAGE

NEW ZEALAND

Massive effort!!



# Better access to world class care

## ✘ Established medicines we don't have

- ✘ Nab paclitaxel, a gentler taxane (BCAC applied and resisted deletion)
- ✘ Everolimus, advanced HR positive (BCAC applied)
- ✘ Trastuzumab beyond progression in advanced HER2 +
- ✘ T-DM1, post-neoadjuvant, early HER2 + (Roche applied)
- ✘ Eribulin, advanced, later line
- ✘ PARP inhibitor (olaparib?), triple negative (TNBC, BRCA)
- ✘ Denosumab, bone metastases, BRCA
- ✘ Zoladex replacement, triptorelin – smaller needle!

## ✘ Innovation is continuous, *e.g.*:

- ✘ TNBC: atezolizumab; sacituzumab govectin, ipatasertib
- ✘ HER2 +: trastuzumab deruxtecan
- ✘ HR +: alepsilib, tucatinib, neratinib





# Tailoring screening to risk

- ✘ NZ needs more effective, risk-personalised screening
  - ✘ Ethnicity – Māori and Pasifika
    - » earlier breast cancer, more aggressive disease, worse outcomes
  - ✘ BRCA and familial cancers
  - ✘ Breast density
- ✘ Screening modality
  - ✘ Mammogram
  - ✘ Ultrasound
  - ✘ MRI, abbreviated MRI
  - ✘ Contrast-enhanced mammogram
- ✘ Screening frequency
- ✘ Age at first screen and last screen
- ✘ Genetic testing
  - ✘ Cancer at young age; high risk; aggressive cancers



# Equity: closing gaps for Māori and Pasifika

- ✘ Serious inequities
  - ✘ access to detection, treatment and care
  - ✘ worse outcomes
- ✘ A strong theme in all BCAC submissions
- ✘ Irene attended Indigenous Genomics conference
- ✘ Spoke at Australian Cancer Genomics webinar
- ✘ Presented at Precision Health Summit
- ✘ Engaged with DHBs on Māori perspectives on data and tissue storage and research





# Education and representation

- ✘ San Antonio Breast Cancer Symposium
- ✘ Global Breast Cancer Advocacy Summit (Virtual, v)
- ✘ Breast Cancer Trials IMPACT Workshop (v)
- ✘ Breast Cancer Trials Q & A session (v)
- ✘ Cancer Trials NZ Workshop (v)
- ✘ NZ Society for Oncology Meeting (v)
- ✘ INFORMD Breast Density webinar (v)
- ✘ Breast Cancer InSIGhts Conference
- ✘ Medicines NZ Parliamentary Dinner
  - ✘ Medicines Inequity – the problems and potential solutions
- ✘ Te Aho o te Kahu Consumer Reference Group



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# Special thanks

- ✘ BCAC Committee
  - ✘ Catrin, Emma, Fay, Gillian, Greer, Irene, Libby, Louise, Lynda, Philippa, Rowena, Terre
- ✘ BCAC staff
  - ✘ Celia, Ali
- ✘ Alison Davies
  - ✘ PHARMAC applications
- ✘ Metavivors
  - ✘ Support, engagement, advocacy, achievements
- ✘ BCAC member groups & individuals
- ✘ Collaborators across the health sector
  - ✘ Richard Isaacs, Marion Kuper, David Porter, Reuben Broom, Ian Campbell, Erica Whineray-Kelly, Maria Pearse, 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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# 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 raise and work to resolve these*



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# FUTURE PLANS

# Plans for 2021

## 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 2021

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 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**

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

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# Plans for 2021

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

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# Plans for 2021

## Māori & Pasifika women

- ✘ Support & promote **consultation & engagement**
- ✘ **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 regularly with BSA to encourage and **monitor progress**

## Fundraising

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

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# Kia ora!



# 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](http://www.breastcancer.org.nz)

email: [bcac@breastcancer.org.nz](mailto:bcac@breastcancer.org.nz)

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