

# **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**

- X Age Concern
- X Alleviate
- X Aotearoa NZ Breast Cancer Community
- X Ascot Radiology Pink Dragons
- X Boobops Dragon Boat Team
- Breast Cancer Action Trust
- Breast Cancer Foundation NZ
- X Breast Cancer Cure
- Breast Cancer Support Inc
- X Breast Cancer Support Northland Trust
- Breast Cancer Support Tauranga Trust
- Busting With Life
- CanTeen Aotearoa
- X Hope Emerges
- X Horowhenua Pink Ladies BCS Group
- X Kenzie's Gift
- × Life 2.0

- X Look Good Feel Better
- X Lymphoedema Support Network
- Mamazon Club
- Metavivors NZ
- X Pinc Cancer Rehabilitation Program
- X Rotorua Breast Cancer Trust
- X Shocking Pink
- Support Crew
- X Sweet Louise
- X Taranaki Dragons
- Te Ha o te Oranga o Ngāti Whatua
- X Terrier Race Against Time
- X 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



# 2021 a Covid year!



- X Lockdowns, stresses on health system and people
  - Medical staff redeployed Medical staff redeployed
  - Mark Difficulties and delays for patients and whanau
- Delayed detection, scans, specialist appointments, pathology, surgery
- × BCF's screening petition
  - X Find 133 undetected women within 6 months
  - Maintain screening at all lockdown levels

  - $\bowtie$  Extend to 70 74
  - X Add screening as health system indicator





# Covid Vax Chat (Zoom)

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







# New Normal, Same Cancer campaign

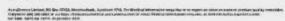
- International movement
- BCAC collaborating with other NZ patient organisations
- Remind everyone that cancer doesn't pause in a pandemic
- To strongly encourage all to push through any resistance caused by health system stress, to take the initiative, get screened, re-book and attend treatment and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





Contact your doctor Get checked

#NewNormalSameCancer









# 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





# 2021 highlights

#### Ministerial briefing

- Andrew Little & Diana Sarfati, CEO, Cancer Control Agency, Te Aho o te Kahu; other politicians

#### 

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

#### X 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

- X Step by Step packs
  - ⋈ delivered more than 1250
- × Website
- X Newsletters
- × Facebook
- **X** Twitter
- × Metavivors NZ
  - ⊠ Peer support & info
- Metavivors NZ Action
  - Advocacy for improvement
- X One to one contact





# Providing a voice for those with breast cancer

- X BCAC's lived experience of breast cancer
  - 🔀 Early, advanced, whānau
- X BCAC participates in policy-making & advisory bodies
- X 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

- - » Consumer reps
- **⋈** Breast Cancer Trials (ANZ)
  - » IMPACT consumer members; Communications and Fundraising Committee member; Associate member



- - » 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



#### 

- » 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



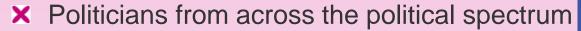


# Representing those with breast cancer

## **Meetings and communication with:**

- Pharmaceutical companies
  - AstraZeneca, Celltrion, Eisai, Novartis, Pfizer, Roche, Specialised Therapeutics









#### **Discussions on:**

- Patient empowerment
- Clinical trial access
- Medicines access
  - funding, access conditions, product registration, pricing, biosimilars & 'grandparenting', supply chain





# Advocacy and collaboration

#### X Patient Voice Aotearoa

- Review of PHARMAC processes
- Presentation of petition
  - >> >100,000 signatures

#### X Metavivors NZ

- - » Facebook, videos, Vax Chat
- ⋈ Petitions, marches, events

#### X Sweet Louise

- X Vax chat
- ⋈ Advocacy for ABC

#### X ABC Global Alliance

- ⋈ BCAC membership
- Annual Advanced Breast Cancer International Consensus Conference (ABC6)











# Advocacy and collaboration

#### X Breast Cancer Cure

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



#### X Breast Cancer Foundation

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



#### X Aotearoa NZ Breast Cancer Community

- Active and engaging
- - » 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
- X Raise awareness
- Legacy for whānau
- X 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
- X PHARMAC Review

#### **X** 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 1<sup>st</sup> line metastatic treatment and pertuzumab as neo-adjuvant treatment



## Better access to world class care

- X Met clinical directors of BSA and National Screening Unit
  - Make Discussed risk management and targeted screening
- Enhancing NZ Clinical Trials Project (UoA)
- X National Clinical Trials Alliance (MoH)
  - ⋈ Participate via a working group
- X MoH, Best practice guidelines for breast reconstruction
  - ⋈ MoH hadn't included patient reps, BCF discovered, shared!
  - Greater patient empowerment



# 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
- X In-person workshops planned for 2022





# Equity: closing gaps for Māori and Pasifika

- X Action needed to overcome serious inequities
  - access to detection, treatment and care
  - ⋈ worse outcomes
- X 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
- X Māori Health Authority to be established







# Ongoing education: conferences etc

- X San Antonio Breast Cancer Symposium
- Breast Cancer Insights (Breast SIG, BCF)
- Breast Cancer Trials (ANZ)
  - Annual Scientific Meeting
- X St Gallen Consensus Conference on EBC Treatment Standards
- X ABC Global Alliance conference
- X NZ Familial Breast and Ovarian Cancer conference
- X NZ Assoc. BC Research's NZ Breast Cancer Symposium
- VIX National Institute for Health & Care Excellence (NICE)
- BCF Nurses' Day



# NZFBOC meeting





# Providing a voice for change

- X Message to BCAC's members and friends







# Special thanks

- **X** BCAC Committee
  - Catrin, Emma, Fay, Gillian, Greer, Irene, Louise, Lynda, Maria, Philippa, Rowena, Tanya, Terre
- X BCAC staff
  - X Celia
- X Alison Davies
  - X PHARMAC submissions and responses
- X Metavivors
  - Support, engagement, advocacy, achievements. Terre Nicholson coordinates
- **X** 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
- X The women of NZ who have shared their issues and experiences
- X Patient Voice Aotearoa
  - ⋈ Malcolm Mulholland, Fiona Tolich



Jane Reeves

# Special tributes



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)
- X E- newsletter
- Brochures BCAC and Metavivors NZ
- Responded to more than 60 requests for support and information
- X Assisted women to navigate the health system





## Information and support

- X 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





## Timely access to world class detection, treatment and care

- **X** Engage with decision makers
  - Ministers, MPs, Cancer Control Agency Te Aho o Te Kahu, Ministry of Health
- X 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
- X Respond to consultations
- Promote and provide effective consumer representation for NZ women with breast cancer





#### Timely access to world class detection, treatment and care

- X 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
- X Highlight the needs of those with metastatic & early breast cancer
- × Promote the collection of high quality breast cancer data
- X Advocate for genetic testing/biomarkers for better diagnosis
- Promote an aspirational, future-focused approach to <u>all</u> aspects of breast cancer care in NZ
  - promptly embracing and adopting new technologies





#### Māori & Pasifika women

- X Support & promote consultation, engagement & empowerment
- **X** Convey key messages to policy & decision makers
- Work to overcome inequities in incidence, access to services & outcomes
- ➤ Provide Māori cultural perspective

#### Early detection

- X Promote breast awareness and participation in the BSA breast screening programme
- X Advocate for risk-based personalised screening
- X Meet with BSA & NSU to encourage and monitor progress
- X Support BCF petition requests

#### **Fundraising**

**X Fundraise** to support BCAC's work





# 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

Together we're stronger Tangata tū pakari tonu



# Tangata tū pakari tonu Together we're stronger

'Love can be an army'

Pink song

