



# BCAC and Metavivors NZ:

## The power of advocacy in improving cancer care

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*Kings School, Auckland*

*Together we're stronger*  
Tangata tū pakari tonu

# BCAC, Metavivors, the power of advocacy



# BCAC formation and motivation

## ✕ 2004 Forum

- ✕ 12 of NZ's key breast cancer groups
- ✕ NZ cancer specialists and Australian advocates

## ✕ Key 2004 messages:

- ✕ Compared to Australia and other developed countries:
  - » NZ provides worse cancer services
  - » We NZ patients have worse outcomes
- ✕ Patient advocates in Australia and the USA are transforming care
- ✕ *Evidence-based patient advocacy is vital, and is lacking in NZ*

# BCAC formation and motivation

What was wrong with breast cancer care in NZ?

- ✗ Late detection
- ✗ No national guidelines for cancer specialists
- ✗ Poor access to effective treatments, especially medicines
- ✗ Slow delivery of cancer treatment
- ✗ Scant supportive care available
  - ✗ Cancer nurses, counselling, fertility treatment, lymphoedema care
- ✗ Breast reconstruction not offered to all
- ✗ Worse outcomes – higher mortality

# BCAC formation and motivation

- ✕ Challenging for the women gathered!
- ✕ Motivated to make a positive difference

*“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has”* Margaret Mead

- ✕ Formed Breast Cancer Advocacy Coalition
  - ✕ **Breast Cancer Aotearoa Coalition** when incorporated (2006)



# BCAC formation, 2004

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



# BCAC Strategic Focus

## ✕ Key initiatives

- ✕ Timely access to world-class treatment & care
- ✕ Information and resources to empower
- ✕ Unified, evidence-based voice

## ✕ Additional projects

- ✕ Māori and Pasifika – close the gaps
- ✕ Early detection
- ✕ High quality data
- ✕ Improve clinical trial access

# BCAC Member Groups 2015

- ✕ Age Concern
- ✕ Alleviate
- ✕ Ascot Radiology Pink Dragons
- ✕ Boobops Dragon Boat Team
- ✕ Breast Cancer Action Trust
- ✕ Breast Cancer Network
- ✕ Breast Cancer Cure
- ✕ Breast Cancer Support Inc
- ✕ Breast Cancer Support Northland Trust
- ✕ Breast Cancer Support Tauranga Trust
- ✕ Breast Health NZ
- ✕ Busting With Life
- ✕ HER2 Heroes
- ✕ Hope Emerges
- ✕ Inflammatory Breast Cancer Australasia
- ✕ Kenzie's Gift
- ✕ Look Good Feel Better
- ✕ Lymphoedema Support Network
- ✕ Metavivors NZ
- ✕ PINC & STEEL
- ✕ Rotorua Breast Cancer Trust
- ✕ Shocking Pink
- ✕ Sweet Louise
- ✕ Taranaki Dragons
- ✕ Te Ha o te Oranga o Ngati Whatua
- ✕ Terrier Race Against Time
- ✕ The Gift of Knowledge
- ✕ The Mamazon Club
- ✕ The New Zealand Breast Cancer Foundation
- ✕ Waikato Breast Cancer Trust
- ✕ Waikato Treasure Chests
- ✕ Well Women and Family Trust (formerly WONS)
- ✕ (YWCA Encore)



# BCAC Committee & staff, 2015



*Together we're stronger*  
Tangata tū pakari tonu



# BCAC Strategies

- ✘ Educate advocates ➡ evidence-based advocacy
  - ✘ Attend conferences, meetings, training courses
  - ✘ Engage with breast cancer specialists (develop strong allies)
- ✘ Establish a “seat at the table”
  - ✘ Representation on policy groups
- ✘ Influence the decision-makers
  - ✘ Regular meetings with Minister & Ministry of Health, BSA, PHARMAC, pharma companies
- ✘ Keep it real and fresh
  - ✘ Continually engage with those diagnosed
  - ✘ Empower the patient voice
    - » real people affected by issues



# BCAC visit to Minister of Health 2015



# Progress and achievements

- ✕ Breast screening age widened (45-69)
- ✕ Some medicines now funded
  - ✕ E.g. Herceptin, taxanes, aromatase inhibitors
- ✕ Breast Cancer Clinical Guidelines 2010
- ✕ ***Standards of Care 2013 (provisional)***
  - Define the services that DHBs should provide to BC patients
    - ✕ Faster cancer treatment
    - ✕ Multi-disciplinary care
    - ✕ Medical treatments
    - ✕ Supportive care
      - » Counselling, fertility treatment, cancer nurses, lymphedema care
- ✕ Breast reconstruction becoming an integral part of care

**Advocacy has driven much of this change**

***Silent issues receive no attention***



# *Breast Cancer Standards Working Group*



# What about secondary breast cancer?

- ✘ BCAC is dedicated to improvement for MBC
- ✘ 3 of our 9 Committee now have MBC, we have lost others
- ✘ Some BC issues are shared whatever the stage
- ✘ **MBC has its own unique issues needing focus**
- ✘ San Antonio Breast Cancer Symposium 2012 I met Dian Corneliussen-James (CJ) – inspirational founder of US Metavivor movement



# US-based Metavivor movement

- ✕ Run by passionately committed patients with MBC
- ✕ Exists to sustain hope for those living with metastatic breast cancer (MBC)
- ✕ Mutual support and common purpose
- ✕ Powerful voice for those with MBC
  - ✕ Rallies public attention to the urgent needs of the MBC community
- ✕ Gaining influence on decision-making bodies
  - ✕ Successfully advocated to speed up FDA approval process for medicines for MBC
- ✕ Works to re-focus research agenda towards longevity with quality of life
  - ✕ *“30% will become metastatic so 30% should be invested on MBC”*

# Metavivors NZ

- ✕ BCAC recognised the gap in NZ
- ✕ Established Metavivors NZ
- ✕ MV Facebook provides a forum to connect, offer mutual support & identify issues
  - ✕ Dynamic group, 115 members
  - ✕ Safe space for sharing personal experiences with others who completely understand
- ✕ Website [www.metavivors.org.nz](http://www.metavivors.org.nz)
  - ✕ Information, stories and links



# Metavivors NZ – opportunities

- ✕ Provide a profile and raise awareness of MBC and its specific needs
  - ✕ Public, decision-makers in health system, doctors etc
- ✕ A voice for people with MBC in NZ
- ✕ Advocate for positive change
  - ✕ e.g. medicines, treatment options, clinical trial access, better support
- ✕ Metavivors can decide on targets



# Are we missing out on important medicines for MBC?

- ✘ Last BCAC submission to Minister Coleman listed 5 meds: Perjeta, Kadcyca, Abraxane, Afinitor, Halaven
- ✘ All potentially increase length and/or quality of life in MBC
- ✘ All now funded in Australia, none in NZ!!
- ✘ NZ has the worst access to innovative meds of all OECD countries
- ✘ Clinical trials reveal new advances, e.g. Ibrance, maybe Keytruda (immunotherapy) in future

# Can Metavivors NZ improve access to medicines?

Work with BCAC to:

## ✕ Understand the evidence

✕ Talk to your oncologist

- » Is there an unfunded medicine they'd like to give you?
- » What difference could it make?

## ✕ Develop clear, consistent messages

## ✕ Engage with key people to improve access

✕ Minister, Ministry, PHARMAC, pharmaceutical companies and the public (via media)

## ✕ Metavivors NZ could provide strong impetus

## ✕ **The voice of someone affected is powerful**

✕ Really helped the campaign to have Herceptin funded









# Where to from here?

- ✘ BCAC is passionately committed to achieving world class detection, treatment and care
- ✘ We realise there's a need for a strong voice for those with MBC
- ✘ We'd love to help empower Metavivors NZ and work with you to make a real difference

**Together we're stronger!** *Tangata tū pakari tonu*

# Metavivors videos

- ✕ Idea came from the MV Facebook group
- ✕ Opportunity to be a face and a voice
  - ✕ to show people with MBC are ordinary/great kiwis who deserve every chance at a long, high quality life
- ✕ Looking for volunteers today!
- ✕ Brief interview about:
  - ✕ Yourself (e.g. career, hobbies, family)
  - ✕ Something you're passionate about
  - ✕ How MBC has affected you and your family
  - ✕ Any unfunded treatment that could help you





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

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

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