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BCAC Annual General Meeting 2019

3 December, 2019
Auckland Cancer Society,
Grafton, Auckland

Agenda

- Welcome
- Apologies, Proxies
- Minutes of 2018 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
- Speaker – *Malcolm Mulholland, Patient Voice Aotearoa Chair*

BCAC Committee 2018-19

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BCAC Member Groups 2019

- 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
- HER2 Heroes
- Hope Emerges
- Horowhenua Pink Ladies BCS Group
- Inflammatory Breast Cancer Australasia
- Kenzie's Gift
- Life 2.0
- Look Good Feel Better
- Lymphoedema Support Network
- Metavivors NZ
- PINC & STEEL
- 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
- The Mamazon Club
- Waikato Breast Cancer Trust
- Waikato Treasure Chests
- Well Women and Family Trust

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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

Medicines for advanced breast cancer funded

- Wonderful news! Funding for:
  - Kadcyla (T-DM1)
    - Roche (August)
    - PHARMAC (December)
  - Faslodex (fulvestrant)
    - AstraZeneca (November)
    - PHARMAC (early-mid 2020)

  - A CDK 4/6 inhibitor to be provided *first* and *second line*: palbociclib (Ibrance, Pfizer), ribociclib (Kisqali, Novartis) or abemaciclib (Verzenio, Lilly)
    - Pfizer or Novartis (?)
    - PHARMAC (RFP; April 2020)

Getting medicines funded – what it takes

- Petitions:
  - Terre Nicholson & Sue Wall-Cade petition for Ibrance (palbociclib) and Kadcyla (T-DM1) - Oct 2018
  - BCAC Emma Crowley petition to increase funding so all ABC meds recommended by ESMO can be funded - May 2019
- Submissions to Health Select Committee:
  - supporting petitions in March and August 2019
- BCAC applications to PHARMAC:
  - fulvestrant (Faslodex)
  - 2nd-line palbociclib (Ibrance)
  - nab-paclitaxel (Abraxane)
  - everolimus (Afinitor)

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Metavivors taking action

- **New *Metavivors – Action* facebook group**
- A forum for Metavivors, their families and supporters who wanted reform – more funded medicines
- Put themselves out there in front of the public, politicians and media
- Metavivors took part in a range of powerful media interviews throughout NZ

Terre,
Ibrance petitioner

Tracy,
Tauranga activist

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Sue, Kadcyla petitioner, Tauranga *Local Hero*

Photo credit: New Zealand Herald / NZME

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Wiki, Manawatu Standard's *Woman of the Year*

Photo credit: Stuff / Manawatu Standard

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17 MPs accepted Ibrance and Kadcyla petitions

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Louise, getting the message across

Politicians have the power to reform

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Getting medicines funded – what it takes

- Publicity and pressure
  - Good advice from those in the know (Malcolm)
  - Brave people with breast cancer willing to tell their stories
  - Collaborating with others – a louder voice
  - Patient Voice Aotearoa - united voice with others needing medicines, many diseases
  - Media coverage – marches, speeches, TV, newspaper, radio, social media
  - Sustained campaign, ongoing

Emma presenting BCAC petition

Photo credit: James Griffin, Edgeline Photography
- courtesy of Lung Foundation NZ

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Growing collective voice

Photo credit: James Griffin, Edgeline Photography - courtesy of Lung Foundation NZ

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Patient Voice Aotearoa

Photo credit: James Griffin, Edgeline Photography
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More petitions, more political parties

Photo credit: James Griffin, Edgeline Photography
- courtesy of Lung Foundation NZ

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Health Select Committee hearings

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Getting medicines funded – what it takes

- Ongoing battle
  - We can't be doing this every time a new medicine is developed!
  - The medicines budget must increase
    - Of 36 OECD countries only Mexico spends less per capita than NZ
  - PHARMAC must be reformed
  - 2020 is election year….

Photo credit: James Griffin, Edgeline Photography - courtesy of Lung Foundation NZ

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Step by Step: new 4th edition

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Step by Step

- Loved by women with breast cancer and breast nurses
- Delivered free to 1,400 newly diagnosed women

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Thanks to:

- Funders:
  - Breast Cancer Foundation NZ – principal funder
  - Ministry of Health – Breast Screen Aotearoa
  - Ralph & Eve Seeleye Trust
  - Southern Trust, Oxford Sports Trust
  - Pub Charity Ltd, Trust House Foundation
  - Crest Hospital and other donors
- Louise and Celia for researching, writing and revising
- Our team of helpful breast cancer specialists
- Carolina at Dot Design Ltd for design services

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Closing gaps for Māori and Pasifika

- We know, and research shows, that there are **serious inequities** for Māori and Pasifika women with breast cancer

- BCAC is committed to world-class detection, diagnosis, treatment and care for Māori and Pasifika women

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Engaging with DHBs to eliminate inequity

- July 2018 - Irene wrote on behalf of BCAC to the Chairs of Counties-Manukau and Auckland DHBs about the lack of provision of chemo at Middlemore Hospital
- Oct 2018 – BCAC met with Pat Snedden Chair ADHB, Richard Sullivan – of Auckland Blood and Cancer Services and others. Snedden asked for our input
- Nov 2018 – Fay and others wrote a discussion paper: *How can ADHB achieve greater equity and improved outcomes for Māori and Pasifika breast cancer patients and how could BCAC assist?*
- Feb 2019 – met again with ADHB oncologists Richard Sullivan, Fritha Hanning, Sheridan Wilson
- April 2019 - Irene wrote to Margie Apa, CEO CMDHB
- May 2019 - Apa replied – describing **significant improvement in services…and ongoing commitment**
- Progress! And continuing engagement

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Viewpoint article for NZ Medical Journal

- BCAC collaborated with AUT researchers to produce:

"Resisting ethnic inequities in advanced breast cancer: a call to action"

Irene Kereama-Royal, Sara Jones, Elisa Lavelle Wijohn, Claire Doole, Elisabeth Burgess, Heather Came

NZMJ 13 December 2019, Vol 132, no. 1507

DRAFT

Resisting ethnic inequities in advanced breast cancer: a call to action

Irene Kereama-Royal, Sara Jones, Elisa Lavelle Wijohn, Claire Doole, Elisabeth Burgess, Heather Came

ABSTRACT

Māori women with advanced breast cancer are less than half as likely as their Pākehā counterparts to reach the five-year survival mark. We argue that this inequity is unacceptable. We trace the inequity back to i) inadequate screening and risk assessment, ii) lack of support for patient navigation, iii) failure to offer accessible state-of-the-art treatments, and iv) delays in receiving life-prolonging care. We posit that each of these factors is a site of institutional racism and privilege as they cause Māori women to experience significantly worse outcomes than non-Māori. In the active pursuit of justice, cancer survivors, women living with cancer and their supporters across the country have been engaging in passionate advocacy to address inequities. As the Ministry of Health develops a new cancer control plan, in this viewpoint opinion piece, we seek to amplify these distressing inequities and offer evidence-based recommendations to improve the quality of care and ultimately survival rates. Breast cancer inequities are modifiable. We recommend prioritising breast cancer screening and risk assessments for Māori women, reducing treatment delays, providing Māori-centered patient navigation, increasing funding for treatments and drugs to align with the OECD standard of care, and holding health providers accountable for ethnic inequities. We call on policy makers drafting the new cancer control strategy, and those working across the cancer continuum, to take action to improve breast cancer outcomes so Māori women will gain valuable life-years.

Cancer is the leading cause of death in Aotearoa New Zealand.[1] There are systemic ethnic inequities across the cancer continuum, from diagnosis and receiving treatment, through to mortality rates.[2] This pattern is repeated within advanced breast cancer (ABC), which is the focus of this paper.[3] Research commissioned by the Breast Cancer Foundation New Zealand found Māori women in Aotearoa with a diagnosis of ABC (stage IV) have a 5% five year survival rate while New Zealand European women have a 15% survival rate.[4] The evidence suggests these rates persist even when all factors except ethnicity are controlled for.[5] As Wiki Mulholland, while advocating on behalf of women with ABC, highlighted in her 13 March 2019 Health Select Committee submission, we need to recognise that Māori women are the heart of the whānau and wider community and we need to keep them well.

Through *te Tiriti o Waitangi*, international human rights agreements and core health policy and legislation, the New Zealand Government has an obligation to protect and promote Māori health and pursue health equity.[6,7] Systemic ethnic inequities in cancer outcomes suggest a failure of the Ministry of Health in its role of stewardship.[8] If, as the data suggest, all other factors are controlled for and ethnic inequities persist, we argue it is likely to be institutional racism—a pattern of behaviour that benefits one ethnic group and disadvantages another. Institutional racism can manifest through policy, investment decisions, mono-cultural structures and inaction. Critically, racism does not need to be intentional.

In this viewpoint paper, written by Māori and non-Māori breast cancer survivors (and allies), we overview some of the modifiable contributing factors to ethnic inequities experienced by Māori in ABC. Our focus

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Submission on the Cancer Action Plan 2019-2029

- BCAC and Breast Cancer Cure joint submission
  - Uptake of world class technologies and treatments
    - Risk assessment, diagnosis, treatment
    - Greater investment needed; expanded workforce
  - Consumer engagement & empowerment
    - *Not* insular health system handing processes & decisions down
  - Co-design with Māori & Pasifika
    - systems, implementation, monitoring
  - Benchmark with other countries
  - Establish independence for Cancer Agency
- *Asked for an aspirational approach leading to system-wide transformation*
  - *focus on the value of opportunities, not costs and burdens*

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Representing women with breast cancer at the system level

- BCAC participates in policy-making & advisory bodies:
  - **Breast Special Interest Group** - consumer reps
  - **Breast Cancer Trials (ANZ)** – Communications & Fundraising Committee member; Associate member; IMPACT advocate members
  - **Health Quality and Safety Commission** - Chair, Consumer Advisory Panel; Cross Sector Alliance Group - consumer rep
  - **Clinical Trials NZ** – Chair, Consumer Advisory Panel
  - **Health Research Council Assessment Committee** – member
  - **NZ Familial Breast and Ovarian Cancer Group** – consumer rep

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Representing women with breast cancer at the system level

Consultation responses, submissions on:

- Proposed Cancer Action Plan 2019-2029
- NZ Health Research Strategy
- Health and Disability System Review
- Finance and Expenditure Select Committee on the Budget
- PHARMAC consultation on medical devices
- Charities Act Review 2019

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Education and representation

- San Antonio Breast Cancer Symposium
- Asia Pacific Oncology Stakeholders Forum
- Cancer Trials NZ Scientific Meeting
- NZ Breast Cancer Research Workshop
- Cancer at a Crossroads Conference
- NZ Society for Oncology Meeting

Cancer at a Crossroads Conference

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Special thanks

- BCAC Committee
  - Emma, Fay, Louise, Irene, Gillian, Greer, Lynda, Philippa, Rowena, Terre
- BCAC staff
  - Celia, Ali
- Alison Davies
  - PHARMAC applications
- Metavivors
  - Support, friendship, Metavivors – Action (advocacy)
- BCAC member groups & individuals
- Collaborators across the health sector
  - Richard Isaacs, Marion Kuper, David Porter, Reuben Broom, Ian Campbell, Jenni Scarlet, Erica Whineray-Kelly, Maria Pearse, Claire Hardie, Alison McEwan, Alice Christian, Janice Wood
- The women of NZ who have shared their issues and experiences
- Funders & fundraisers

Together we're stronger
Tangata tū pakari tonu

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Fabulous fundraiser: High Tea in memory of Moana Papa

Thanks to Charlene Barnett

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Going the extra mile for BCAC: Lachlan McKenzie and mum Julie Bunnell

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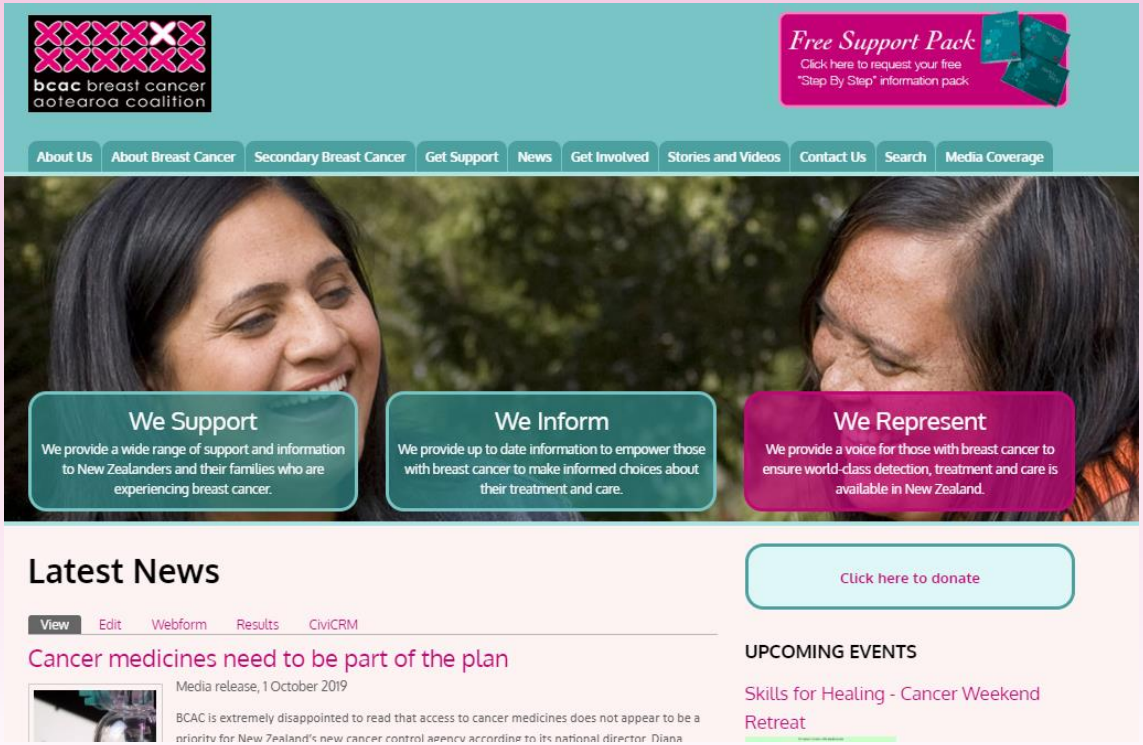
Treasurer's report

- Louise Malone

BCAC Performance 2018-19

- 1,384 Step by Step packs delivered (1,196 last year)
- 42,032 website visits (31,682 last year)
- 33 member groups (31 last year)
- 22 meetings & conferences attended (20 last year)



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BCAC Performance 2018-19

- Facebook >2,414 followers; Twitter (@bcac_nz)
- E- newsletter
- Brochures – BCAC and Metavivors NZ
- Responded to requests for support and information
- Assisted women to navigate the health system

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Breast Cancer Aotearoa Coalition (BCAC) Inc.

@BreastCancerAotearoaCoalition

Home

Like Follow Share ...

Sign Up

BCAC Financial Performance: 1 April 2018 to 31 March 2019

Revenue points to note:

Breast Cancer Foundation NZ Grant	$62,009
Breast Screen Aotearoa	$10,000
Lotteries Grant	$10,000
Public donations	$37,671
Trust Grants	$21,000
Le Reve	$1,080
Karen Louisa Foundation	$1,079
Interest on savings	$4,605
Total revenue	**$146,701**

BCAC Financial Performance: 1 April 2018 to 31 March 2019

Expenses points to note:

Step by Step printing	$79,960
Provision of online information & education	$9,985
Comms & admin	$20,801
Step by Step storage & distribution	$9,095
Expanding knowledge via conferences	$8,666
Attending meetings and hearings	$5,693
Audit and bank fees	$1,899
Office expenses	$1,698
Total expenses	**$91,051**
Net surplus	**$55,651**

Subsequent to 1 April 2019:

Revenue

Trusts grants	$5,000
Donations	$8,627
Lotteries Grant	$10,000
Le Reve	$8,627
Interest	$4,259
Current bank balance	**$180,355**

Audited Annual Performance Report 2018-19:

- https://www.register.charities.govt.nz/Charity/CC22456

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Further business

- Election of Committee for 2019–2020
- Appointment of Auditor
- Motions
- General business
- Approval of future plans
- Speaker: ***Malcolm Mulholland***

Plans for 2020

Information and resources

- Offer the updated 4th edition ***Step by Step*** to every NZ woman diagnosed with breast cancer
- Help Sweet Louise promote their information book:
  - ***A Guide to Life with Secondary Breast Cancer***
- Provide up to date information via our **website, Facebook page and newsletter**
- Respond to requests for **information, advice and support**

Plans for 2020

Evidence-based voice for timely access to world class risk assessment, detection, diagnosis, treatment and care

- **Meet & brief** Minister of Health, politicians, Cancer Control Agency, MoH, BSA, PHARMAC etc
- Advocate and support development of **QPIs and standards** for early and advanced breast cancer
- Work with PHARMAC & pharmaceutical companies to secure funding for **new medicines**
- Respond to **consultations**
- Promote and provide effective **consumer representation** for NZ women with breast cancer

Plans for 2020

Evidence-based voice for timely access to world class risk assessment, 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 **metastatic breast cancer**
- Promote the collection and analysis of high quality **breast cancer data**
- Advocate for **better diagnosis** through genetic testing/biomarkers
- Promote an aspirational, **future-focused approach** to all aspects of breast cancer care in NZ – promptly embracing and adopting new technologies for all

Plans for 2020

Māori & Pasifika women

- Support & promote **consultation & engagement**
- **Convey key messages** to policy & decision makers
- **Raise awareness** of current inequities in incidence, access to services & outcomes
- Advocate for Māori and Pasifika **involvement in trials** to ensure new initiatives are validated for NZ populations

Early detection

- Promote **breast awareness** and participation in the BSA **breast screening** programme
- Seek timely extension of breast **screening age**
- Highlight **breast density** as a risk factor
- Meet regularly with BSA to **monitor progress**

Fundraising

- **Fundraise** to support BCAC's activities

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Tangata tū pakari tonu

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Thanks!

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www.breastcancer.org.nz

email: bcac@breastcancer.org.nz

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Tangata tū pakari tonu

Malcolm Mulholland

- Chair, Patient Voice Aotearoa
- PVA petitioner: increased medicines funding and reform of PHARMAC
- Passionate advocate for new medicines for women with advanced breast cancer
- Māori scholar, historian and author
- Wiki's husband!

Photo credit: Stuff / Manawatu Standard

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