



Breast Cancer Aotearoa Coalition

Annual Report 2016



bcac breast cancer
aotearoa coalition



Our Mission

**To make world-class
detection, treatment and
care accessible to all those
affected by breast cancer in
Aotearoa.**



**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 have
experienced breast
cancer.**





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Chair Report



This year, while continuing to represent all New Zealanders with breast cancer on a range of issues, BCAC has focused on making a difference for Kiwis with advanced breast cancer (ABC).

This vital area has received too little attention over the years and it's time for that to change. We have continued to support Metavivors NZ, a Facebook-based group for Kiwis with ABC that is going from strength to strength. Our partnership with the Karen Louisa Foundation (KLF) has enabled BCAC to progress a number of initiatives including: the development of Metavivors videos (now live), a poster and a brochure (soon to be released). The Sweet Louise/NZ Breast Cancer Foundation ABC forum, with its themes of knowledge, support and empowerment, was inspirational. I presented ideas on the Power of Advocacy in Improving Cancer Care, noting that silent issues receive no attention.

BCAC was delighted that ten conference attendees were happy to share their stories on video to help us raise awareness of ABC. We have also made a compilation video of our brave Metavivors commenting on the dire lack of access to modern medicines faced by Kiwis with ABC. We're using this awesome video as the key driver in our current campaign for better access to breast cancer medicines. The campaign aims to inform the public and persuade the Minister of Health to fund more medicines by bringing New Zealand's investment closer to the OECD average. As it stands NZ invests the least of all OECD countries, has the worst access to medicines and shockingly, we have a breast cancer death rate 40% higher than Australia's.

Chair Report

Watch the videos at www.breastcancer.org.nz/metavivor-videos and please support the campaign by signing our letter to the Minister at www.breastcancer.org.nz/meds.

Over the year, we have had regular meetings with the Ministry of Health's Cancer Team, BreastScreen Aotearoa and other Ministry officials. Discussions included access to breast reconstruction, screening coverage, faster cancer treatment, Intrabeam Intra-Operative Radiotherapy, Mepitel film for reducing radiation burns, medicines needed and clinical trial access. This year BCAC will brief the Minister on a range of breast cancer issues in early December.

It was great to see BCAC members continuing to learn about the biology of breast cancer as well as the latest medicines, surgical techniques, radiation technologies and biomarker development at national and international conferences and meetings. This education is essential in ensuring BCAC's advocacy remains solidly evidence-based.

BCAC provided a credible consumer voice across the health system on a wide range of issues. We educated clinicians and officials about the value of engaged consumers in delivering high quality healthcare and informed GPs of the qualities and behaviours required in an effective GP. We continued our involvement with expert clinical groups and committee members were recruited into new consumer representative roles relating to clinical trials.

Our efforts continue to ensure New Zealanders with breast cancer have access to world-class medicines, technologies, techniques and care. We are also working hard to establish better access to clinical trials.



Chair Report

We were pleased to collaborate directly with BCAC member groups on specific projects and to see other groups working together as well.

Many women approached BCAC for guidance and support during the year and we were delighted to assist.

Thanks so much to all our members and supporters and to the experts we have worked with and learned from during the year. Special thanks to all the women who have come to BCAC for support and information, and to raise issues they have faced during their diagnosis, treatment and recovery. This contact has enabled us to identify the key issues facing New Zealanders diagnosed with breast cancer so we can engage with officials and policy-makers to address problems and find solutions.

Tangata tū pakari tonu, Together we're stronger.

Libby Burgess, MNZM
BCAC Chairperson





Key achievements

• Information and resources

- Delivered more than 1,200 *Step by Step* support packs to New Zealanders newly diagnosed with breast cancer.
- Produced a series of videos highlighting the experience of New Zealanders with advanced breast cancer.
- Created an online video advocating for better access to medicines for Kiwis with advanced breast cancer.
- Provided information on breast cancer diagnosis, treatment and recovery via our website www.breastcancer.org.nz.
- Delivered up-to-date breast cancer news, research results and events via our website, Facebook page, and Twitter account.
- Supported more than 1,900 New Zealanders through the BCAC Facebook page.
- Supported more than 160 New Zealanders with advanced breast cancer through the online community, Metavivors NZ.
- Designed a brochure and poster to promote Metavivors NZ.
- Distributed an e-newsletter with relevant breast cancer news and information to hundreds of registered members and others.
- Responded to 50+ queries through the BCAC website and Facebook page.



Key achievements

- Providing a voice for those diagnosed with breast cancer
- Launched a campaign highlighting the desperate need for better access to medicines in New Zealand, including:
 - o an online video stressing the need for better access to medicines
 - o a series of videos featuring Kiwis with secondary breast cancer
 - o a direct email campaign to the Minister of Health on the issue
 - o widespread media coverage of the issue.
- Delivered more than 1,700 submissions to the Minister of Health highlighting the need for better access to medicines.
- Supported women with breast cancer to negotiate the health system and secure timely and appropriate treatment and care.
- Presented at the Advanced Breast Cancer Symposium: *BCAC and Metavivors: The Power of Advocacy in Improving Cancer Care*.
- Presented to the Health Safety and Quality Commission Forum on Clinical Leadership: *Valuing Empowered Consumers*.
- BCAC member Melissa Bell appointed as a consumer representative on the Australian New Zealand Breast Cancer Clinical Trials Group.
- BCAC member Emma Crowley appointed to the Consumer Advisory Panel of Clinical Trials New Zealand.



Key achievements

• Improving access to world-class treatment and care

- Made a joint submission with the Breast Cancer Network Australia supporting the introduction of intra-operative radiotherapy into the public health system.
- Wrote to the Minister of Health advocating for the introduction of intra-operative radiotherapy in the public health system.
- Engaged with Southern Cross Healthcare to follow other health insurance companies and reimburse policy holders for intra-operative radiotherapy treatment.
- Made a submission on the New Zealand Health Research Strategy.
- Presented to the Royal New Zealand College of General Practitioners: *Your Partnership Promise – A Patient Perspective*.
- Lobbied pharmaceutical company Roche, to offer Perjeta, Kadcyla and sub-cutaneous Herceptin to Pharmac at affordable prices.
- Had quarterly meetings with the Ministry of Health's Cancer Team to seek improvements and action on issues for breast cancer patients.
- Highlighted breast cancer clinical trials available in New Zealand.
- Represented New Zealanders with breast cancer at key international conferences.

Key achievements

- Improving outcomes for Māori and Pasifika women
 - Liaised with Māori and Pasifika women affected by breast cancer and related advisory groups.
 - Highlighted the poorer outcomes of Māori women with breast cancer with a series of website articles.
 - Appealed to BreastScreen Aotearoa, the Ministry of Health's Cancer Team, and the Minister of Health to achieve real and significant improvements in the speed of detection and treatment for Māori women with breast cancer.





Step by Step

Step by Step feedback 2016:

"Tonight I plucked up the courage to read the chemo pages in my Step by Step book. It is such a wonderful resource and so informative. Thank you for compiling such a useful, user-friendly and informative resource."

"Absolutely marvellous. Clear and easy to read. Very informative."

"Awesome! I am so very grateful for the support. These booklets and journals will be a huge help. Thank you."

"Very informative. Thank you and very handy & useful. Love the diary and journal to fill in."

"Good for schedule and what to expect for procedures."

"Thanks for your fantastic resources. I have had great responses about your packs and that they are so useful and helpful."

Taranaki Cancer Society

"It's such a great resource and support."

BreastScreen Aotearoa





Chairperson:

Deputy Chairperson:

Secretary:

Treasurer:

Committee Members:

Libby Burgess

Chris Walsh

Rowena Mortimer

Louise Malone

Mona Papa

Greer Davis

Nic Russell

Gillian Wintrup

Lynda Ames

Fay Sowerby

Melissa Bell

Emma Crowley

Irene Kereama-Royal



Libby Burgess, Chairperson

- National Breast Cancer Tumour Stream Working Group: consumer representative.
- Breast Cancer Special Interest Group: consumer representative
- Australia and New Zealand Breast Cancer Trials Group (ANZBCTG): Affiliate Member
- Enrolled for joint 2016 COSA and ANZBCTG Annual Scientific Meeting Nov 2016
- Invited speaker at a number of forums



Chris Walsh, Deputy Chairperson

- Represented BCAC at fundraising events



Rowena Mortimer, Secretary

- Breast Care Working Group

BCAC Committee



Louise Malone, Treasurer

- Represented BCAC at events and fundraisers.



Moana Papa

- Convenor of Pasifika and Māori breast cancer advisory groups
- Assisted to front BCAC's access to medicines campaign
- Represented BCAC at Breast Cancer Cure charity dinner
- Member of Metavivors NZ
- Member of Sweet Louise



Greer Davis

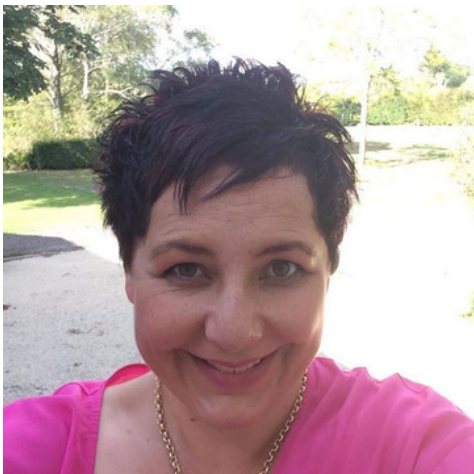
- Member of Breast Cancer Support's Young Women's Support Group
- Attended International Adolescent and Young Adult Oncology Congress
- Enrolled for joint 2016 COSA and ANZBCTG Annual Scientific Meeting as IMPACT member

BCAC Committee



Nic Russell

- Founder of Kenzie's Gift
- Created Hope Emerges, to change the conversation around mastectomies and breast reconstruction
- ANZBCTG Advocate Training Workshop



Gillian Wintrup

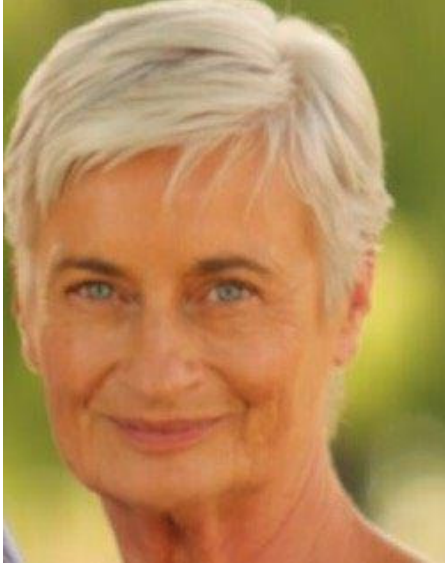
- Member Rotorua Breast Cancer Trust
- Provides a voice for young women with breast cancer



Lynda Ames

- Metavivors NZ Coordinator
- ANZBCTG Advocate Training Workshop
- Enrolled for joint 2016 COSA and ANZBCTG Annual Scientific Meeting

Fay Sowerby



- Attended the Maurice Wilkins Centre - Immune Therapy Symposium
- Attended the Auckland Cancer Society Research Centre (ACSRC) 60th Anniversary Symposium
- Participated in PHARMAC consultation on medicines and medical devices
- Enrolled for joint 2016 COSA and ANZBCTG Annual Scientific Meeting

Emma Crowley



- ANZBCTG Advocate training workshop
- Represented BCAC at fundraising events
- Attended BCSIG meetings
- Attended the second Australasian Breast Congress
- Attended NZBCF Patient Day

Melissa Bell



- Provides a voice for those diagnosed in the South Island
- Enrolled for joint 2016 COSA and ANZBCTG Annual Scientific Meeting
- Attended San Antonio Breast Cancer Symposium



Irene Kereama-Royal

- Joined the BCAC committee mid-2016





BCAC Member Groups

BCAC is enormously proud of the fact we're a coalition of more than 30 breast cancer-related charities and groups.

We value the close working relationship we have with all of these groups to better the care and treatment for New Zealanders with breast cancer.

- 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
- Busting With Life
- HER2 Heroes
- Hope Emerges
- Horowhenua Pink Ladies BCS Group
- IBC Australasia
- Kenzie's Gift
- Look Good Feel Better
- Lymphoedema Support Network
- Metavivors NZ
- The Mamazon Club
- The New Zealand Breast Cancer Foundation
- Pinc and 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
- Waikato Breast Cancer Trust
- Waikato Treasure Chests
- Well Women and Family Trust



BCAC Supporters

BCAC is hugely grateful for the generosity of all those who support us financially and in kind.

BCAC is still working to find a long-term commercial sponsor for our work to support for New Zealanders with breast cancer and to speak out for better access to world-class detection, treatment and care.

We'd like to acknowledge our recent partnership with the Karen Louisa Foundation to advocate on behalf of New Zealanders with secondary breast cancer. We're thrilled to be working with an organisation that has goals so closely aligned with our own and with the Foundation's financial support we've launched a successful campaign highlighting the need for better access to medicines to improve the lives of women with advanced breast cancer.

BCAC is pleased to continue its association with Storage King NZ. The enthusiasm this company has demonstrated in its support for New Zealanders with breast cancer is inspiring. We're proud to be associated with them and delighted to work with them for another successful Breast Cancer Awareness Month in October.

BCAC was also proud to continue its relationship with Australian health and beauty company, Le Reve and thank them for their ongoing donations and support.

We're always thrilled when members of our community gather together to fundraise to support our initiatives. This year we'd like to acknowledge the support of the Move Dance Company for their efforts in fundraising for BCAC.

Finally, we'd like to recognise those individuals who gave their time and their money to help us continue our work. We thank you.



BCAC Supporters





Plans for 2017

1. Make world class detection, treatment and care accessible to all affected by breast cancer in New Zealand

- Quarterly Ministry of Health liaison
- Raise awareness of new and emerging medicines
- Increase education and knowledge of breast cancer, treatments and supportive care and emerging clinical trial results by attending and promoting local and international expert meetings and conferences
- Increase access to clinical trials
- Meet pharmaceutical companies and encourage them to register their innovative medicines in New Zealand and to offer them at affordable prices
- Engage and facilitate networking and collaboration among groups and individuals
- Brief the Minister of Health
 - Promote consumer related initiatives and policy making
 - Medicines access, clinical trials, safety of ethical trials
 - Breast Cancer Standards to be implemented
- Highlight inequities in timely treatments and poorer health outcomes for Māori women with breast cancer
- Promote the collection of high quality breast cancer data
- Consult and engage with Māori and Pasifika women to identify and promote breast cancer issues that could improve outcomes in these communities by:
 - Supporting opportunities for consultation and engagement
 - Promoting the messages received from Māori and Pasifika women
 - Raising awareness of current inequities in breast cancer incidence, access to services and outcomes.
- Meet with Pharmac – regarding access to innovative medicines.

Plans for 2017

2. To provide information and support to empower those with breast cancer to make informed choices about their treatment and care

- *Step by Step* support packs
- Website – up-to-date information
- Facebook page – online breast cancer community for 1,900 and Twitter
- E- newsletter to hundreds of registered members
- Responding to requests for information and support.

3. To provide a unified evidence-based voice for New Zealanders who have experienced breast cancer

- Promote implementation and monitoring of *Standards of Care for Breast Cancer Patients in New Zealand*
- Advocate for timely access to world class breast care, including treatments and psychological care in NZ
- Participate in a wide range of local, regional and national breast cancer-related working groups, committees and organisations
- Respond to consultation opportunities relating to breast cancer
- Support and promote initiatives enabling the early detection of breast cancer such as mammographic screening and breast awareness by meeting regularly with BreastScreen Aotearoa to discuss and encourage progress with the National Screening programme
- Provide information and comment on the most effective ways to achieve early detection.

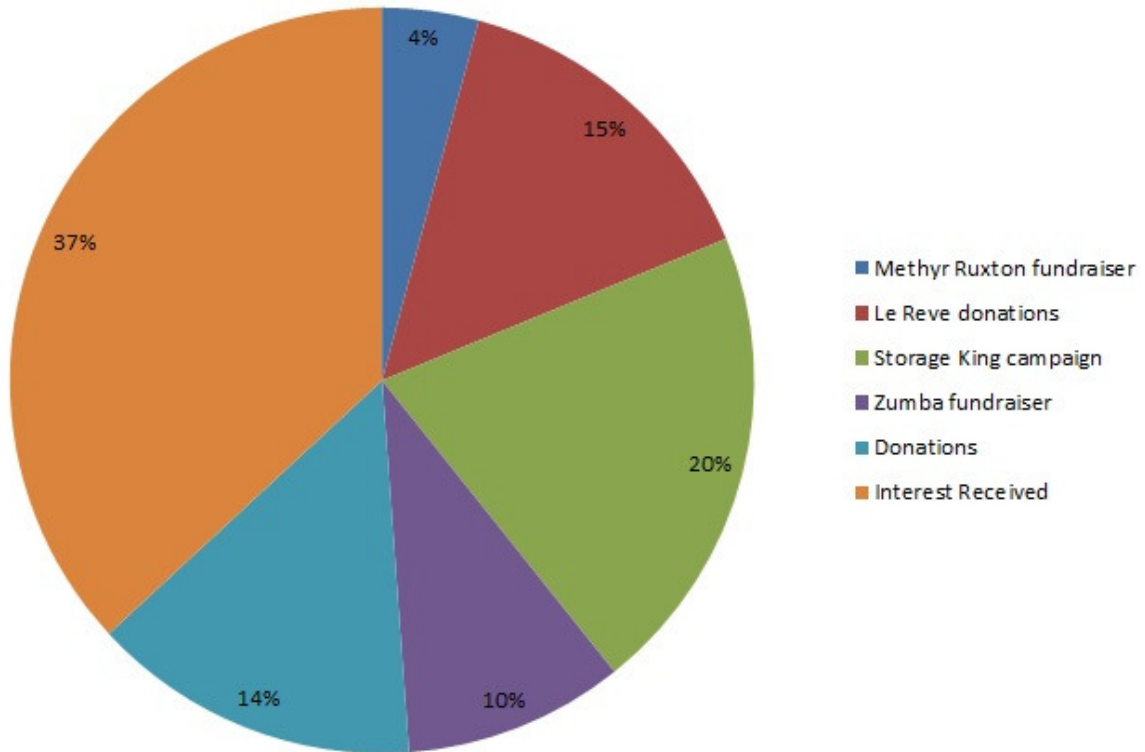
Plans for 2017

4. To support the activities of BCAC through promotion and fundraising.



BCAC Financials

BCAC Revenue to 31 March 2016



BCAC Expenditure to 31 March 2016

