

BCAC Annual Report 2015



Together we are stronger

Tangata tū pakari tonu





Our Mission



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



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.

Contents

1. Chairperson's Report	p.5
2. Key Achievements in 2015	p.10
3. Feedback on <i>Step by Step</i>	p.18
4. BCAC Committee	p.20
5. BCAC Member Groups	p.25
6. Supporters	p.28
7. Plans for 2016	p.31
8. Financials	p.36

Chairperson's Report

Looking back at BCAC's 2014-15 year, I am delighted to report that BCAC has continued to engage widely to provide a vital voice and make a positive difference for everyone diagnosed with breast cancer in New Zealand. It is gratifying to see the huge commitment and effort of the BCAC Committee and member groups to support and empower the



3,000 New Zealanders diagnosed with breast cancer every year while working hard to make world-class detection, treatment and care a reality. This year we can report significant progress in some of the areas we have repeatedly raised as needing action and improvement.

Our *Step by Step* support pack has continued to receive fantastic feedback from patients who tell us it is a comfort, a lifeline and an empowering source of information and strength when they need it most. Our renewed website has provided up-to-the-minute news and information about every aspect of breast cancer while our Facebook page has provided a forum to discuss issues. The Metavivors NZ Facebook-based group for those with secondary breast cancer has gone from strength to strength and offers a safe and supportive place to share experiences, tips and strategies, while allowing common issues to be identified and worked on.

BCAC continued to provide a patient/consumer perspective in the development of the *Standards of Service Provision for Breast Cancer Patients in New Zealand*. The *Standards* set out the services that DHBs must provide to everyone diagnosed, and will transform many aspects of future care, including timely provision of breast reconstruction surgery, early fertility treatment for young women and lymphoedema treatment and care. Effective implementation of the *Standards* is now the priority and BCAC will monitor this and speak out where we discover DHBs are falling short. Remember we need your



help to let us know when treatment is slow or sub-standard.

We heard from women around the country who had been denied breast reconstruction surgery and approached the Minister and Ministry to encourage them to ensure implementation of the Standard to provide timely access for everyone who needs this surgery. In our most recent quarterly meeting with the Ministry we were delighted to learn that an initiative is now under way to ensure this will happen throughout the country.

We were also very pleased to learn of action in the provision of fertility services, another area we have repeatedly raised with Ministers of Health. DHBs are now required to provide assisted reproductive technologies to patients whose cancer treatment may permanently impair their fertility. It will be vital that these services are offered as soon as diagnosis is confirmed so they can be undertaken prior to chemotherapy.

The need for lymphoedema treatment is an area raised every year by our members when we consult with them prior to our ministerial briefing meeting to identify issues needing action. This remains an area needing Ministry attention to ensure lymphoedema services are available throughout New Zealand and we will continue to highlight the current regional inequity in service provision.

We focused on developing knowledgeable advocates and engaging with breast cancer clinical experts through BCAC members attending a range of specialist conferences and meetings. This is a vital element in ensuring we understand



and accurately represent the best interests of those needing treatment and care for the various forms of breast cancer and their associated treatment side-effects.

BCAC challenged PHARMAC and Roche to work collaboratively to achieve timely funding for Perjeta and Kadcyla, two breakthrough medicines that can transform care and deliver longer better quality lives for those with secondary HER2 positive breast cancer. We highlighted to the Minister, Ministry and PHARMAC how far behind other developed countries New Zealand is in providing access to effective, innovative medicines, including Perjeta, Kadcyla, Abraxane, Afinitor and Halaven, all of which are funded in Australia and would provide important treatment options here.

We also asked that the injectable form of Herceptin be funded, allowing patients to be treated with a rapid injection under the skin instead of a much longer infusion into a vein, especially given that many patients have had their veins damaged by chemotherapy. Other advantages for our oncology clinics would be reduced clinic and health care professional time and less resource cost, all offering a contribution to achieving Ministry targets for faster cancer treatment.

In a national review of the ethical environment for clinical trials in New Zealand BCAC stated strong support for increased access to well-designed clinical trials given the many benefits for patients.



However, we also identified a dangerous gap in New Zealand's ability to re-examine the status of historically approved trials where emerging data suggests patient safety is compromised.

BCAC has continued to highlight unacceptable inequities in breast cancer mortality for Māori women. Recent evidence shows Māori women are more likely to be treated in the public health system where treatment is delivered more slowly than in private healthcare and connects this with poorer outcomes. This highlights how crucial it is for our DHBs to urgently focus their resources on meeting the Ministry's Faster Cancer Treatment targets.

In summary, we're making progress in some significant areas of breast cancer treatment and care, but there are vital areas that need government investment. Perhaps most importantly, New Zealand is well behind the rest of the developed world in providing access to medicines that would give breast cancer patients longer lives of better quality. The pharmaceuticals budget should be increased and PHARMAC must be more aspirational in seeking resources to fund more medicines to bring us up to the standard of care offered in other countries. On the other side of the coin, pharmaceutical companies need to be realistic and reasonable in setting the prices of medicines. BCAC will continue to engage with all stakeholders on this crucial issue.



BCAC relies on engagement, input and information from all our member groups and individuals as well as breast cancer medical professionals to ensure we're aware of issues as they arise. Please stay in touch and let us know what the key challenges are for you or the patients you support or treat.

Together, with our combined knowledge, contacts and resources we truly are stronger and can make a positive difference in the breast cancer journeys and outcomes for those who will be diagnosed over the coming years.

Libby Burgess MNZM

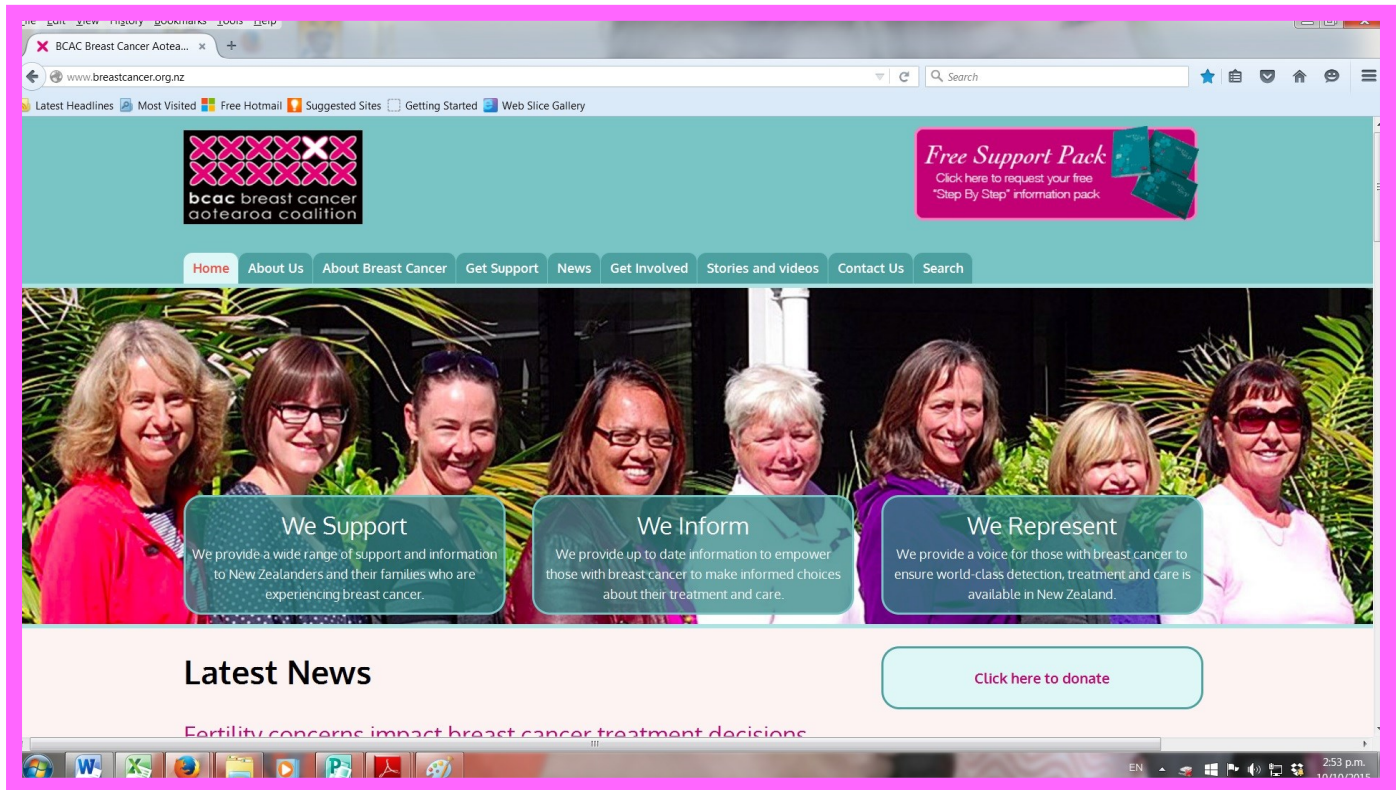
BCAC Chairperson

Together we're stronger
Tangata tū pakari tonu



Key Achievements 2015:

Supplying information and resources

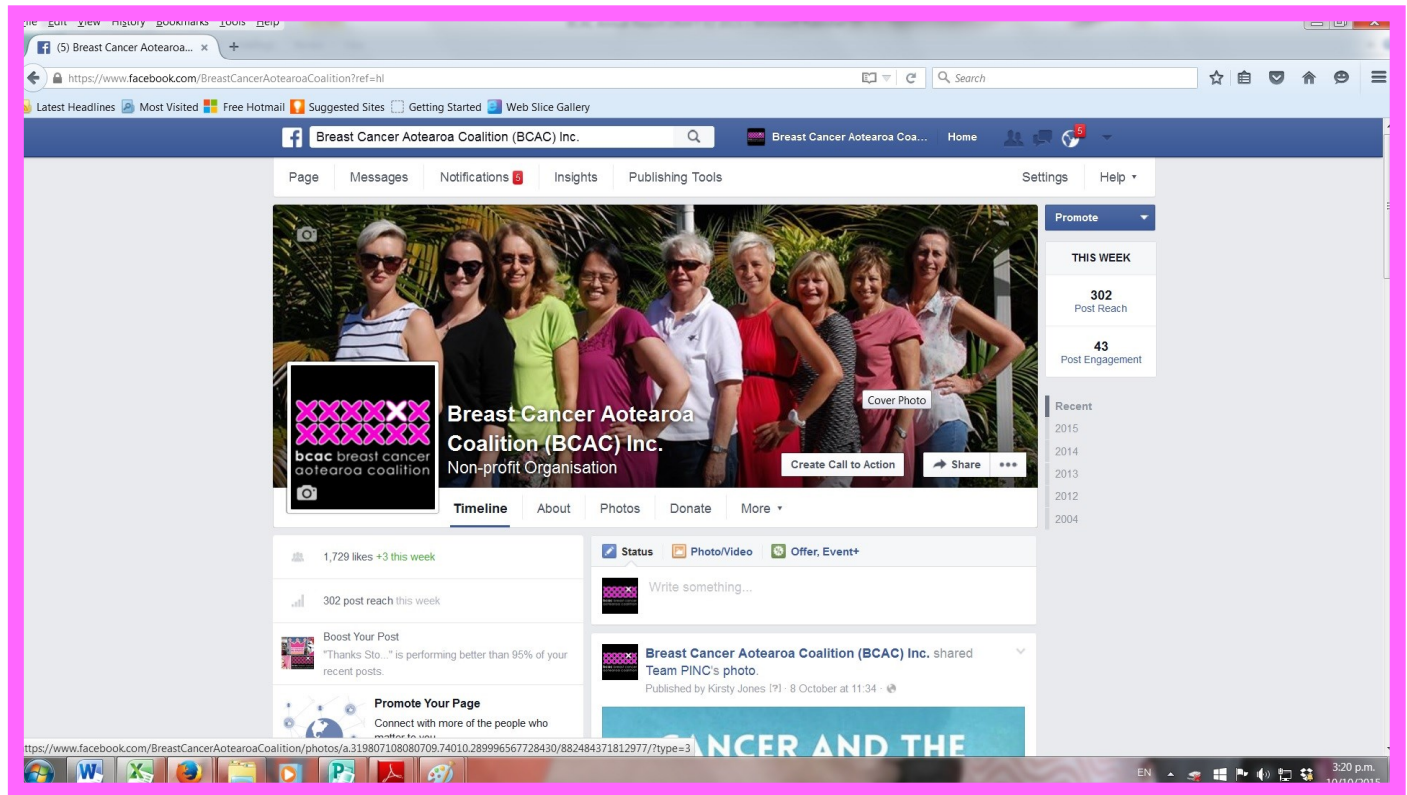


- Delivered *Step by Step* support packs free-of-charge to more than 1,500 New Zealanders newly diagnosed with breast cancer.
- Launched a new-look website, which features the *Step by Step* teal colour, has more images and is more user-friendly.
- Provided up-to-date web-based information on breast cancer diagnosis, treatment and recovery, as well as the latest research results and news.



Key Achievements 2015:

Supplying information and resources



- Enhanced an online breast cancer community through the BCAC Facebook page which disseminates breast cancer news and information to more than 1,700 people.
- Promoted the development of Metavivors NZ, an online community to support and advocate for those with metastatic breast cancer.
- Distributed an e-newsletter with relevant breast cancer news and information to hundreds of registered members and others.
- Responded to queries from women with breast cancer through the BCAC website and Facebook page.

Key Achievements 2015:

Providing a voice for those with breast cancer



- Supported women with breast cancer to negotiate the health system to ensure their needs were met and they received timely, appropriate treatment and care.
- Continued to work with the Ministry of Health to ensure that patients across all DHB's receive access to publicly-funded medicines in addition to accessing additional medicines in the private sector.
- Achieved publicity about the lack of medicines access in New Zealand.
- Provided a patient perspective through participation in the the working group developing the *Standards of Care for Breast Cancer Patients in New Zealand*.

Key Achievements 2015:

Providing a voice for those with breast cancer



- Submitted to the National Ethics Advisory Committee (NEAC) review of cross-sectoral ethics arrangements for health and disability research, noting that the current ethics review system is deeply flawed and does not allow review of the safety or ethical status of an existing clinical trial.
- Briefed the Minister of Health on the need to:
 - improve medicines access for those with breast cancer
 - enhance access to clinical trials
 - set up an independent body to review the safety and efficacy of clinical trials
 - ensure the *Breast Cancer Standards* are being implemented and monitored (in particular, access to delayed breast reconstruction, lymphoedema treatment and fertility preservation).

Key Achievements 2015:

Informing and advocating for access to world-class detection, treatment and care



- Met with PHARMAC about the need for increased access to several breakthrough breast cancer medicines as well as the need for an increased medicines budget. Also advocated for genuine consumer representation in PHARMAC's decision processes.
- Submitted emerging data to PHARMAC showing the benefits of using Perjeta as a treatment for newly advanced HER2-positive breast cancer. PHARMAC acknowledges the outstanding benefits but has not yet funded this medicine.
- Submitted in support of PHARMAC's proposal to add neo-adjuvant (before surgery) use of Herceptin to the list of funded medicines (this was subsequently approved).
- Highlighted breast cancer clinical trials available in New Zealand and advocated for greater Government efforts to increase access.

Key Achievements 2015:

Informing and advocating for access to world-class detection, treatment and care



- Met with pharmaceutical company Roche to encourage it to offer Perjeta, Kadcyra and sub-cutaneous Herceptin to PHARMAC at an affordable price.
- Secured quarterly meetings with the Ministry of Health's Cancer Team to monitor the implementation of the *Standards of Service Provision for Breast Care Patients in New Zealand* and to seek improvements and action for breast cancer patients
- Appealed to the Ministry of Health to work with DHBs to prioritise breast reconstruction surgery for women. The Ministry now has an initiative to achieve timely reconstruction for all needing it.

Key Achievements 2015:

Informing and advocating for access to world-class detection, treatment and care



- Developed knowledgeable New Zealand advocates and fostered relationships with breast cancer clinical experts through participation on the New Zealand Breast Cancer Special Interest Group meetings; the Australian New Zealand Breast Cancer Trials Group Conference in Perth; the San Antonio Breast Cancer Symposium and the C4YW International Conference for Young Women with Breast Cancer.
- Supported the National Health Committee's proposal to look further at the introduction of Intrabeam radiotherapy into the public health system to allow certain women to combine their radiation treatment with surgery.

Key Achievements 2015:

Working to improve outcomes for Māori and Pasifika women with breast cancer



- Highlighted inequities in access to timely treatments and poorer health outcomes for Māori women with breast cancer.
- Liaised with Māori and Pasifika women affected by breast cancer and related advisory groups.
- Supported and promoted BreastScreen Aotearoa's commitment to increase screening rates for Māori and Pasifika women.

BCAC's *Step by Step*



In 2014/2015 we delivered our *Step by Step* pack to more than 1500 New Zealanders with breast cancer. Here's what they said about it:

"I'm working my way through my Step by Step resources and just wanted to say how absolutely brilliant this pack is. I recommend it to all and sundry. It is such a generous gift at a tough time. Thank you to all the people and funders who made it happen!"

"Yesterday I received the Step by Step package and I just wish to record how absolutely delighted I am with it. Gone are all my little notes in a folder. Gone is my concern about the suspect Google information. Gone is the need to fire up my tablet to record additional information."

"There is sooo much useful info in it!! Everything in the pack has been well thought out and I really appreciate it."

BCAC's *Step by Step*



And here's what other breast cancer organisations and health professionals had to say about BCAC's *Step by Step*:

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

BreastScreen Aotearoa

"We have had ladies report that although they are generally not journal writers they have found your Step by Step pack a wonderful support. Anything we can do to support women going through this challenging time is great. Well done for all your fantastic work."

Cancer Society Otago Southland

"A very practical and informative resource."

NZ Breast Cancer Foundation

"A huge well done to you all at BCAC for the tremendous amount of work that's gone into compiling and producing this pack. We are sure it will be well-received by patients, clinics and the like."

Breast Cancer Cure

BCAC Committee



Those serving on the BCAC committee during 2015 were:

Chair: Libby Burgess

Deputy Chair: Chris Walsh

Secretary: Rowena Mortimer

Treasurer: Louise Malone

Committee Members:	Emma Crowley	Gillian Wintrup
	Melissa Bell	Nic Russell
	Lynda Ames	Greer Davis
	Moana Papa	

Other Involvements

In 2015 BCAC committee members have been involved in the following committees and conferences with the aim of improving breast cancer care.

Libby Burgess, Chairperson

- Consumer representative: National Breast Cancer Tumour Stream Working Group
- Consumer representative: Breast Cancer Special Interest Group (linked to NZ Association of Cancer Specialists)
- IMPACT (consumer) member and associate member: Australia and New Zealand Breast Cancer Trials Group.



Chris Walsh, Deputy Chairperson

- Chair: National Cancer Consumer Representative Advisory Group
- Consumer Representative: Breast Cancer Special Interest Group
- Consumer Representative: Ministry of Health (MoH) Cancer Treatment Advisory Group
- Member: Ministry of Health Cancer Steering Group
- Consumer Representative: Psychosocial Oncology NZ (PONZ) Executive



Other Involvements

Rowena Mortimer, Secretary

- Organised the Merthyr Ruxton exhibition
- Attended meetings with the Minister of Health and Breast Care Working Group



Louise Malone, Treasurer

- Represented BCAC at fundraisers and events



Moana Papa

- Networked and engaged within the Maori & Pasifika communities
- Formed Wahine Toa, a group for Maori & Pasifika women with breast cancer
- Attended the meetings with the Minister of Health and Breast Care Working Group



Other Involvements

Emma Crowley

- Attended the Australian New Zealand Breast Cancer Trials Group meeting in Australia in July 2015
- Represented BCAC at the Annual Cartwright event in August 2015



Nic Russell

- Founder of Kenzie's Gift, a charity caring for the well-being of children, young people and families affected by serious illness or bereavement
- Set up Hope Emerges, an initiative that aims to change the conversation around mastectomies and breast reconstruction
- Attended the San Antonio Breast Cancer Symposium in the US in December 2014



Gillian Wintrup

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



Other Involvements

Melissa Bell

- Will attend the San Antonio Breast Cancer Symposium in the US in December 2015
- Provides a voice for those diagnosed in the South Island



Greer Davis

- Member: BCS Young Women's Support Group
- Provides a voice for young women with cancer
- Will attend the Inaugural International Adolescent and Young Adult Oncology Congress in Sydney in December 2015



Lynda Ames

- Metavivors NZ co-ordinator



BCAC Member Groups



BCAC is unique in being a coalition of more than 30 different breast cancer-related groups.

This wide range of member groups enables us to stay tuned-in to the experiences and challenges of those being diagnosed and treated with breast cancer. It enables us to identify problems and work across the health system to find solutions efficiently and effectively.

We value the passion and commitment of our member groups and look forward to working with you in 2016.

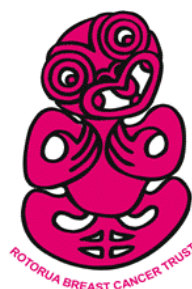


BCAC Member Groups

- 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 North-land 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
- Pink Pilates (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)



BREAST
CANCER
CURE™





Our Supporters

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

It's been a tough year for BCAC losing its long-term sponsor Arnott's Tim Tam. We were sad to see this lucrative partnership come to a close, but we extend a warm thanks to Arnott's Tim Tam for their many years of support and commitment to BCAC and New Zealand women with breast cancer.

Once again, we'd like to thank the New Zealand Breast Cancer Foundation for being the principal funder of BCAC's *Step by Step*. Without this support, we wouldn't be able to continue to update and distribute this valuable support pack free-of-charge to any New Zealander diagnosed with breast cancer.

BCAC is excited to have signed a two-year contract with Storage King NZ to assist us in fundraising during October's breast cancer action month. The enthusiasm this company has for supporting New Zealanders with breast cancer is inspiring. We're thrilled to be working with them.

This year, BCAC was also pleased to receive donations from Australian health and beauty company, Le Reve and a contribution from the Lottery Grants Board.



Our Supporters

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 Taranaki Zumba. They donated a significant amount to BCAC from a series of colourful and fun Zumba parties.

We're also grateful for the support of New Zealand artist Merthyr Ruxton, a breast cancer survivor, who held an exhibition of her work in honour of BCAC this year. Merthyr kindly donated a portion of the sales of her work to BCAC.

Finally, we'd like to recognise those individuals who gave their time and their money to help us continue our work. In particular, we'd also like to acknowledge Betty Robb, Mrs J. Ryan and Te Kura Oruamata. We thank you.

BCAC is now focused on developing new commercial sponsorships to enable us to continue to support those with breast cancer and to speak out for better access to world-class detection, treatment and care.



Our Supporters



Plans for 2016

In 2016, we plan to continue to work on BCAC's key initiatives:

- 1) To support and empower New Zealanders diagnosed with breast cancer and their family, whanau and friends, by providing information and resources to enable women to make well-informed choices about their treatment and care by:
 - offering *Step by Step* to every New Zealander diagnosed with breast cancer
 - regularly updating the BCAC website at www.breastcancer.org.nz, our Facebook page and Twitter account
 - promoting our *Kiwi Stories of Breast Cancer* patient videos, and
 - responding to requests for information and advice.
- 2) To provide a unified, evidence-based voice for New Zealanders diagnosed with breast cancer; as well as to inform and advocate for timely access to world class breast cancer care, including treatments (surgery, medicines, radiotherapy, management of side-effects, self-care) and psychosocial care throughout New Zealand by:
 - promoting the implementation and monitoring of the Ministry of Health's *Standards of Service Provision for Breast Cancer Patients in New Zealand* throughout the country
 - participating in a wide range of local, regional and national breast cancer related working groups, committees and organisations
 - meeting with the Minister of Health, Ministry leaders in cancer projects, BreastScreen Aotearoa, PHARMAC, Medicines NZ, pharmaceutical companies and other relevant individuals and groups
 - responding to consultation opportunities relating to breast cancer



Plans for 2016

- advocating to PHARMAC for funding of breast cancer medicines including Perjeta, Kadcyra, Abraxane, Afinitor, Halaven and sub-cutaneous Herceptin
 - encouraging pharmaceutical companies to register their innovative medicines in New Zealand and to offer them at affordable prices
 - increasing 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
 - promoting consumer input into cancer-related initiatives and policy making
 - engaging in and facilitating networking and collaboration among groups and individuals.
- 3) To consult and engage with Māori and Pasifika women to identify and promote breast cancer issues that could improve outcomes in these communities by:
- supporting and promoting opportunities for consultation and engagement
 - promoting the messages received from Māori and Pasifika women to policy and decision makers
 - raising awareness of current inequities in breast cancer incidence, access to services and outcomes.



Plans for 2016

- 4) To 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
 - providing information and comment on the most effective ways to achieve early detection.
- 5) To promote the collection of high quality breast cancer data to enable clear understanding of the characteristics of the disease and impacts of particular treatments at defined types/stages on outcomes by:
 - clarifying the value and importance of detailed Breast Cancer Registers to the Minister and Ministry of Health and others.
- 6) To support the activities of BCAC by:
 - promotion and fundraising.



Merthyr Ruxton

recent work | 2012 - 2015

19 February - 10 March 2015

Opening Night:
Thursday 19 February 5.30 - 8pm



Proudly supporting
Breast Cancer Aotearoa Coalition

Railway St. Studios

8 Railway Street
Newmarket
Auckland 1023

A creative journey
TUES-SAT 10AM - 3PM
www.railwaystreetstudios.co.nz

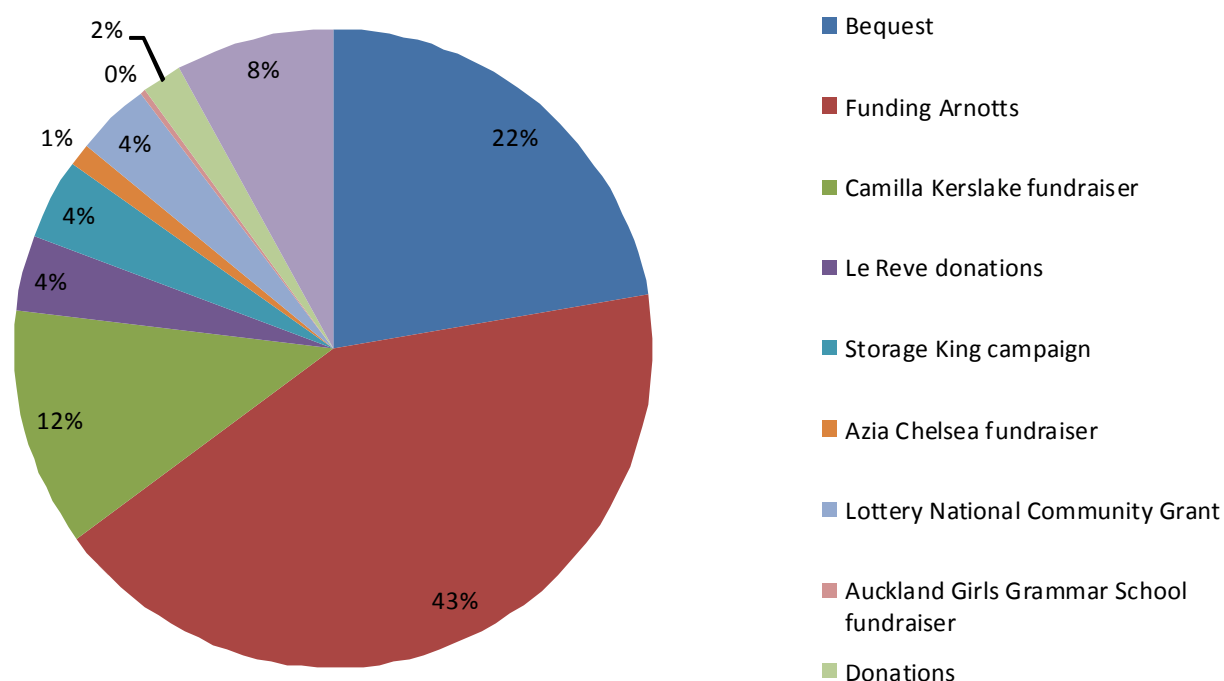


Financials

Income:

BCAC Revenue 2015	
Funding Source	Amount (\$)
Bequest	\$ 22,520
Funding Arnott's	\$ 42,821
Camilla Kerslake fundraiser	\$ 12,192
Le Reve donations	\$ 3,870
Storage King campaign	\$ 4,058
Azia Chelsea fundraiser	\$ 1,135
Lottery National Community Grant	\$ 3,800
Auckland Girls Grammar School fundraiser	\$ 265
Donations	\$ 2,066
Interest Received	\$ 8,080
Total Income	\$ 100,808

BCAC Revenue to 31 March 2015

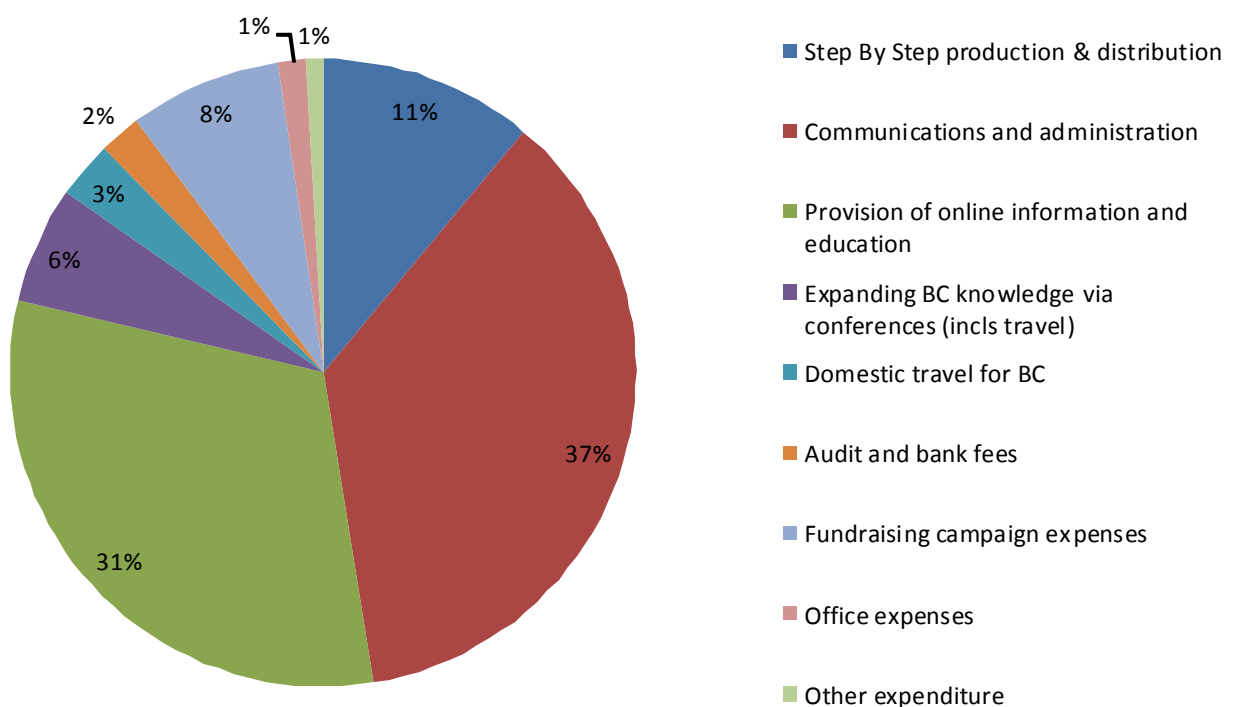


Financials

Expenses:

BCAC Expenses 2015	
Expenses	Amount (\$)
Step By Step production & distribution	\$ 9,077
Communications and administration	\$ 29,844
Provision of online information and education	\$ 25,678
Expanding BC knowledge via conferences (incls travel)	\$ 4,927
Domestic travel for BC	\$ 2,361
Audit and bank fees	\$ 1,778
Fundraising campaign expenses	\$ 6,497
Office expenses	\$ 1,116
Other expenditure	\$ 753
Total Expenses	\$ 82,031

BCAC Expenditure to 31 March 2015





Together we're stronger
Tangata tū pakari tonu