



BCAC Annual Report 2014



Together we're 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.



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CHAIRPERSON'S REPORT



This year we celebrate BCAC's tenth anniversary so let's take a moment to reflect on where BCAC stands in 2014. We have come a huge distance in the ten years since our 12 founding member groups met in 2004 to establish a clear and credible voice for New Zealanders diagnosed with breast cancer.

Since then, our membership has expanded to include more than 30 diverse groups as well as individuals throughout the country. This ensures we are closely connected to the 3,000 New Zealanders diagnosed with breast cancer each year, giving us a real-time view of the experiences of those diagnosed and treated today. Through these links we are able to identify and understand the issues that patients experience in the health system. Our close ties with oncologists, surgeons and breast care nurses provide us with the expert view of life at the breast cancer coalface.

Over time, BCAC has also developed strong relationships with the Minister of Health, the Ministry and other decision-making groups and it is gratifying to know that BCAC has come to be recognized by these bodies as providing credible and reliable patient/consumer representation. This ensures we have a direct line to those who have the power to solve problems and provide solutions for those facing difficulties. We have worked hard to ensure consumer representation in policy and decision-making groups and have made significant ground in achieving our early aim of establishing "seats at the table". We need to ensure we continue to develop knowledgeable advocates to fill these roles effectively.

We have built a strong, evidence-based platform from which to advocate for access to world-class treatment and care by ensuring our representatives are well educated in the science as well as the politics of breast cancer. We have had some notable successes, securing funding for Herceptin in 2008 and having a hand in bringing taxanes, aromatase inhibitors and other medicines to patients.

BCAC has also played a significant role in establishing best practice guidelines and more recently *Standards of Service Provision for Breast Cancer Patients in NZ*.

The Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) held its annual meeting in Wellington this year and it was marvellous to see a record number of kiwi advocates attend. If we are to be effective advocates for world-class detection, treatment and care for breast cancer in NZ, it is vital that we understand the biology of the disease as well as the clinical trials process. These are the studies that lead to breakthrough treatments that can offer improved quality of life and better survival.

We were delighted to be able to send a representative to the C4YW conference for young women in Florida and two women to the Breast Cancer Network Australia's advocacy and science training course in Melbourne.

This year we discovered that the three northern DHBs were refusing to provide funded medicines to cancer patients who chose to additionally access unfunded treatments in the private sector. As an example of the impact of this policy, those with advanced HER2 positive breast cancer wanting to access the dramatic survival benefits of Perjeta would not only have to pay the high cost for the new drug, but also pay for their Herceptin that would be funded for all other patients. We raised this in a special meeting with the Minister who determined that these DHBs were acting illegally and he promised to fix this.

We were approached by women insured with Sovereign who were told they could spend no more than \$20,000 on breast reconstruction. We met with Sovereign's CEO and Claims Manager to explain that this was a completely inadequate amount and as a result they revised and modernized their policy conditions to allow reimbursement of all reasonable costs.

The Rotorua Breast Cancer Trust put us in touch with a woman who had been told by the Waikato DHB that, given their limited capacity, her delayed breast reconstruction was of such low priority that she would not even be put onto a surgical waiting list. We facilitated media coverage and raised this with the Ministry of Health and have recently been told that the Ministry's Elective Surgery Group will deal directly with the DHB to find a solution for those affected.

We applied to the National Health Committee to introduce Intrabeam radiotherapy into our public health system and further supported this innovative technology in a submission to the Royal Australian and New Zealand College of Radiation Oncology. Intrabeam delivers a single shot of radiation into the tumour bed during initial breast cancer surgery. It offers a fantastic option for women with low-risk early breast cancer, providing effective treatment in a localized area, avoiding damage to other tissues and eliminating the need for repeated visits to the radiology clinic over several weeks. We look forward to wide adoption of Intrabeam for appropriately selected patients.

Another highlight from this year has been the revision of BCAC's much loved *Step by Step* support pack and we have produced 5,000 copies of the new 3rd edition. We have expanded *Step by Step* to include sections on dealing with the emotional fallout of a diagnosis, sexuality and intimacy, fertility, men with breast cancer and self care. We were delighted to welcome the New Zealand Breast Cancer Foundation as principal sponsor for the new edition.

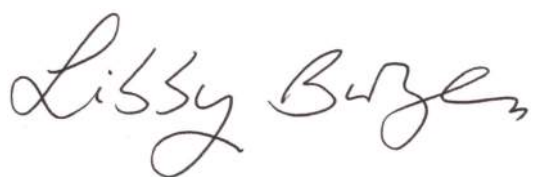
Despite our successes there's still much to achieve. Recent data shows that New Zealand's cancer mortality remains 15% higher in NZ women compared to Australian women. Outcomes are still worse for Māori and Pasifika women than for those of other ethnic groups. New highly effective medicines are emerging but they come with a high price tag and it will be challenging to get these funded to allow patients to access the benefits in improved quality and length of life.

US statistics tell us that despite recent improvements in 5 and 10-year survival rates, around a third of those diagnosed will eventually develop advanced disease. There is now a strong international push to focus more research on treatments that will make a real difference for those with metastatic breast cancer.

For kiwis with metastatic breast cancer, BCAC is thrilled to have been able to establish Metavivors NZ earlier this year and watch it grow into a thriving Facebook-based community where participants offer mutual support and empowerment through shared experiences. The group is also proving to be a great information and knowledge-sharing platform. Recently, Metavivor NZ members have been working closely with BCAC to seek access to innovative medicines.

To all BCAC's members and supporters, thanks so much for your wonderful input! Without your passion, commitment and collaboration we couldn't have achieved so much for New Zealanders with breast cancer so please continue to stand and work with us to help make the future brighter for everyone diagnosed.

Together we're stronger, *Tangata Tū pakari tonu!*







Key Achievements - 2014



GOAL 1: Supplying information and resources

- Revised, re-wrote and edited a new edition of BCAC's *Step by Step* support pack following consultation with medical professionals, BCAC member groups and others in the breast cancer sector.
- Delivered *Step by Step* support packs free of charge to more than 1300 women newly diagnosed with breast cancer in New Zealand.
- Provided up-to-date information on breast cancer diagnosis, treatment and recovery, along with the latest research results and regular weekly news items on the BCAC website, Facebook page and Twitter.
- Achieved a 58% increase in the number of visits to the BCAC website compared with 2013.
- Promoted the BCAC web videos, *Kiwi Stories of Breast Cancer* which have been viewed by more than 8,850 people on our website and Youtube.
- Responded to queries posted from women with breast cancer on our Facebook page and through the BCAC website.

Key Achievements - 2014



GOAL 2: Providing a voice for those diagnosed with breast cancer

- Appealed to the Minister of Health when a NZ cancer treatment centre was found to be refusing publicly funded medicines to patients who were accessing additional medicines in the private sector. The Minister commented that the DHBs involved were failing to meet their legal requirements and promised to resolve the issue.
- Worked on behalf of women with breast cancer who experienced trouble negotiating the health system to ensure their needs were met and that they received appropriate treatment and care.
- Established an online support group called 'MetavivorsNZ' for New Zealanders with metastatic breast cancer. The group is very active and membership is increasing weekly.
- Appealed to the National Ethics Advisory Committee (NEAC) to establish effective mechanisms to review the safety and ethical status of clinical trials operating in New Zealand. BCAC has had input into a review of cross-sectoral ethics arrangements which is currently underway by NEAC.
- Briefed the Minister of Health and other key politicians on the need to improve services for New Zealanders with breast cancer, in particular, faster cancer treatment (especially in rural areas and where patients are managed across multiple DHBs), access to delayed breast reconstruction, counselling, lymphoedema management, fertility treatment for young women diagnosed and ensuring optimal treatment and care for elderly patients.



Key Achievements - 2014



GOAL 3: Informing and advocating for access to world-class detection, treatment and care

- Continued to push for an expansion of the upper age limit for BreastScreen Aotearoa's free screening programme from 70 to 74, as has happened in Australia.
- Made submissions to PHARMAC to fund the breast cancer drugs Abraxane, Perjeta and Kadcyla.
- Worked with Sovereign Insurance to improve policy conditions for women receiving breast reconstructions.
- Lobbied the National Health Committee and the Royal Australian and NZ College of Radiologists to bring the Intrabeam radiotherapy technology into the public health system in New Zealand.
- Submitted information to be included in the Ministry of Health Cancer Information Strategy document.
- Highlighted a range of breast cancer clinical trials available in New Zealand through the BCAC website and newsletter.
- Participated in NZ Breast Cancer Special Interest Group meetings, the Australian New Zealand Breast Cancer Trials Group conference and the C4YW International Conference for Young Women with breast cancer. Attended and sponsored Shocking Pink to attend BCNA's breast cancer science and advocacy training course in Melbourne.

Key Achievements - 2014



GOAL 4: Working to improve outcomes for Māori and Pasifika women diagnosed with breast cancer

- Liaised with Māori and Pasifika women affected by breast cancer and with related advisory groups.
- Supported and promoted BreastScreen Aotearoa's commitment to increase screening rates for Māori and Pasifika women.
- Supported Wahine Toa, a group for Māori and Pasifika women with breast cancer.



BCAC's *Step by Step* Support Pack



In 2014 we delivered the *Step by Step* support pack, including our new 3rd edition, to more than 1300 women with breast cancer throughout New Zealand - here's what they had to say about it:

"I like that it has been put together by women who have had similar experience - encouraging and uplifting at a difficult time. Thank you."

Awesome! Thank you so much."

"Great information - very well done. I refer to the booklets often – it gives me peace of mind."

"Excellent. There is so much to take in so it's helpful to have everything documented in one place."

"This is a great service, and I think the pack is awesome. I really like the diary to put all specialist information into."

"Easy to read and informative without being scary."

Feedback from the public



After a Waikato woman was told her delayed breast reconstruction was too low a priority to be on a waiting list, BCAC raised the issue with the Ministry of Health and obtained media coverage for her. We received the following message:

“Huge thanks also to Libby, Nic and the BCAC team for your amazing support and work on this situation to date.”

BCAC was approached by women insured with Sovereign who were told they could spend no more than \$20,000 on breast reconstruction. Following a meeting we had with them they revised their policy conditions to allow reimbursement of all reasonable costs. Below is a response we received from one of those women:

“WAHOO - got a phone call from Sovereign last night with the good news that they will reimburse my expenses for reconstruction!!!! I’m more happy that finally there have been some policy changes that will benefit other women going through the same thing... please can you pass on my heartfelt thanks to Libby for her going into battle on this issue. I and other women all over the country are indebted to her and the rest of her team. I’m still reeling from the news. Thank you, thank you, thank you.”

Comments from our Metavivors Members:

“It’s great to be part of a positive support network.”

“I must say I find this group inspiring.”

“I’m very thankful for this group.”

BCAC Committee

Those serving on the committee during 2014 were:

Chair: Libby Burgess

Deputy Chair: Chris Walsh

Secretary: Rowena Mortimer

Treasurer: Louise Malone

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



Other Involvements

In 2014, BCAC committee members have been involved in the following committees and conferences with the aim of improving breast cancer care.

Libby Burgess

- National Breast Cancer Tumour Stream Working Group, Consumer Representative
- Breast Cancer Special Interest Group (linked to NZ Association of Cancer Specialists), Consumer Representative
- Australia and New Zealand Breast Cancer Trials Group, IMPACT (consumer) Member and Associate Member
- Attended the Australia and New Zealand Breast Cancer Trials Group Annual Scientific Meeting in July 2014.



Chris Walsh

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



Other Involvements cont'd



Louise Malone

- BCAC Treasurer
- Represented BCAC at fundraisers and events



Rowena Mortimer

- Chair of the Northern Cancer Network Consumer Group
- Consumer Representative on the Northern Cancer Network Governance Board



Moana Papa

- Networks and engages within the Māori and Pasifika communities
- Formed Wahine Toa, a group for Māori and Pasifika women with breast cancer
- Provides a voice for Maori and Pasifika people affected by breast cancer



Other Involvements cont'd



Nic Russell

- Founder of Kenzie's Gift, a charity that supports the emotional well-being and mental health of children affected by cancer
- Set up 'Hope Emerges', an initiative that aims to change the conversation around mastectomies and breast reconstruction
- Attended the Australia and New Zealand Breast Cancer Trials Group Annual Scientific Meeting in July 2014



Sue Ellis

- Represented BCAC at a *Sweet Louise* October fundraiser
- BCAC Committee Member



Emma Crowley

- Attended the G4YW Conference for Young Women with Breast Cancer in Orlando, Florida
- Organised the Camilla Kerslake fundraiser in Auckland
- Provides a voice for young women with breast cancer



Other Involvements cont'd

Gillian Wintrup

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



Melissa Bell

- Organised the Camilla Kerslake fundraiser in Dunedin
- Attended the Australia and New Zealand Breast Cancer Trials Group Annual Scientific Meeting in July 2014



Lynda Ames

- Metavivors NZ Co-ordinator
- Attended the Australia and New Zealand Breast Cancer Trials Group in July 2014



Greer Davis

- Member of the BCS Young Women's Support Group
- Provides a voice for young women with breast cancer
- Greer left NZ early this year to travel overseas and plans to return to NZ and BCAC in early 2015



BCAC Member Groups



As a coalition of more than 30 different breast-cancer related groups BCAC is unique because of our links across the breast cancer community. We have recently welcomed another member group to our community - Metavivors NZ - a support group for New Zealanders with metastatic breast cancer.

A 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 which in turn allows us to identify problems and work across the health system to address issues in an efficient and effective way.

We value the passion and commitment of our member groups and look forward to working together with you in 2015 to continue to improve breast cancer care and treatment for all New Zealanders.

Our Member Groups:

- Age Concern
- Alleviate
- Ascot Radiology Pink Dragons
- Boobops Dragon Boat Team
- Breast Cancer Action Trust
- Breast Cancer Network
- Breast Cancer Research Trust
- Breast Cancer Support Inc
- Breast Cancer Support Northland Trust
- Breast Cancer Support Tauranga Trust
- Breast Health NZ
- Busting with Life
- HER2 Heroes
- Inflammatory Breast Cancer Australasia
- Kenzie's Gift



BCAC Member Groups

- Look Good Feel Better
- Lymphodema 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)
- YWCA Encore



Our Supporters



Without the generosity and commitment of all our sponsors and donors, BCAC would not be able to reach out and provide support, information and a unified voice for New Zealanders with breast cancer.

We would like to say a special thank you to the New Zealand Breast Cancer Foundation for being the principal funder of our new edition of BCAC's *Step by Step* support pack. We're thrilled to be working with the Foundation and pleased to have them join with us to aid and empower New Zealand women with breast cancer.

We are also grateful to our long-term sponsor Arnott's Tim Tam who continue to be a supportive corporate partner to BCAC. Once again, this year BCAC and Arnott's Tim Tam worked with Progressive Enterprises Ltd on our primary fundraiser, the *Show Your Heart* campaign which ran in Countdown supermarkets in May and June and successfully raised more than \$40,000.

We would also like to thank Storage King, who for the second year running, have undertaken to donate \$1 from every tea chest sold during October's Breast Cancer Action Month to BCAC. Storage King also ran fundraising sausage sizzles for BCAC and provided storage for *Step by Step* free of charge! So far, they have raised more than \$3,500 with more to come from this year's October fundraiser.





BCAC was also grateful to receive donations from Le Reve (\$4,860), an Australasian health and beauty company which donates \$1 to BCAC from perfumes sold.

We would also like to acknowledge the support of our many individual supporters:

Talented young NZ-born opera singer Camilla Kerslake returned from the UK to watch her partner, England Rugby captain Chris Robshaw, play a Test series against the All Blacks. While in NZ, Camilla kindly performed at two pre-Test match fundraisers for BCAC - one at the Northern Club in Auckland and another at Luna Bar in Dunedin, raising more than \$12,000.

BCAC received a generous donation in memory of Mangalika Mendis, an anaesthesiologist and Herceptin hero who battled hard to get this important medicine funded. We also received a very generous bequest from Gordon Sadgrove in memory of his late wife Jean.

Our special thanks go to our key supporters in 2014:





Show Your Heart campaign



show your heart

A white plate is centered on a pink background. The plate features a large, intricate heart-shaped design in pink. The design is composed of various floral elements, including small flowers, leaves, and ferns. Three stylized birds are integrated into the heart shape: one on the left, one in the center, and one on the right. The birds are also pink and have a simple, elegant design.

for women
with breast cancer

TimTam

The bcac logo is repeated in the bottom right corner of the poster, identical to the one in the top right.

Show Your Heart campaign



Plans for 2015



In 2015 we plan to continue working 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* web videos, and
 - responding to requests for information and advice
- 2) To provide a unified, evidence-based voice for New Zealanders diagnosed with breast cancer; and 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
 - involvement 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, Cancer Control NZ, PHARMAC, Medicines NZ and other relevant individuals and groups
 - responding to consultation opportunities relating to breast cancer

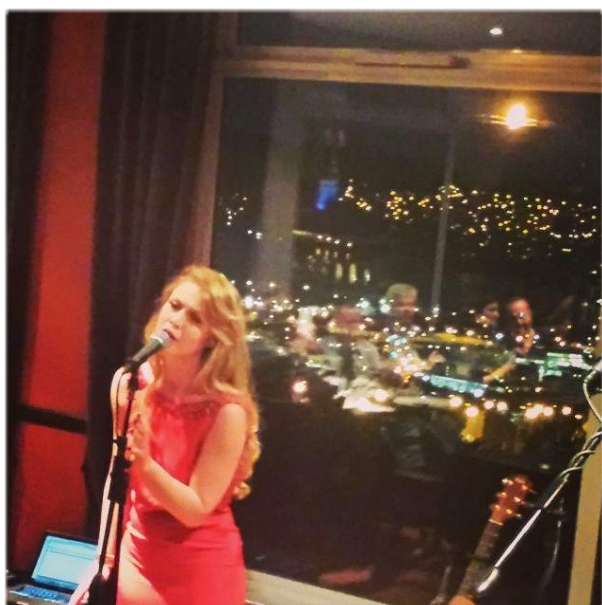
Plans for 2015 cont'd

- working with PHARMAC, pharmaceutical companies and others to secure funding for effective new breast cancer medicines (including Perjeta, Kadcyla and Abraxane)
 - 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 breast cancer groups and affected 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
- 4) To support and promote initiatives enabling the early detection of breast cancer such as mammography screening and breast awareness by:
- meeting regularly with BreastScreen Aotearoa to discuss progress with the national screening programme
 - providing information and comment on the most effective ways to achieve early detection

Plans for 2015 cont'd

- 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
 - having input to the Ministry's Cancer Information Strategy
- 6) To support the activities of BCAC by:
 - promotion and fundraising





Singing sensation Camilla Kerslake to perform at Luna Bar & Restaurant

Book your table now!



Kick off your international rugby weekend with re-nowned classical crossover singing sensation **Camilla Kerslake** and help support breast cancer charity, the **Breast Cancer Aotearoa Coalition (BCAC)**.

Performing an intimate concert at **Luna Bar and Restaurant** in Dunedin on **Friday June 13**, the Birt Award nominee (pictured here with NZ rugby legend Dan Carter) returns to NZ to support both her English rugby captain boyfriend and BCAC.

Charity auction to benefit BCAC will follow the performance. No cover charge.

When: Friday 13th June, Performance 9 pm

Where: Luna Bar & Restaurant, 314 Highgate, Roslyn

Contact: luna@roslynbridge.co.nz or 03 477 2227

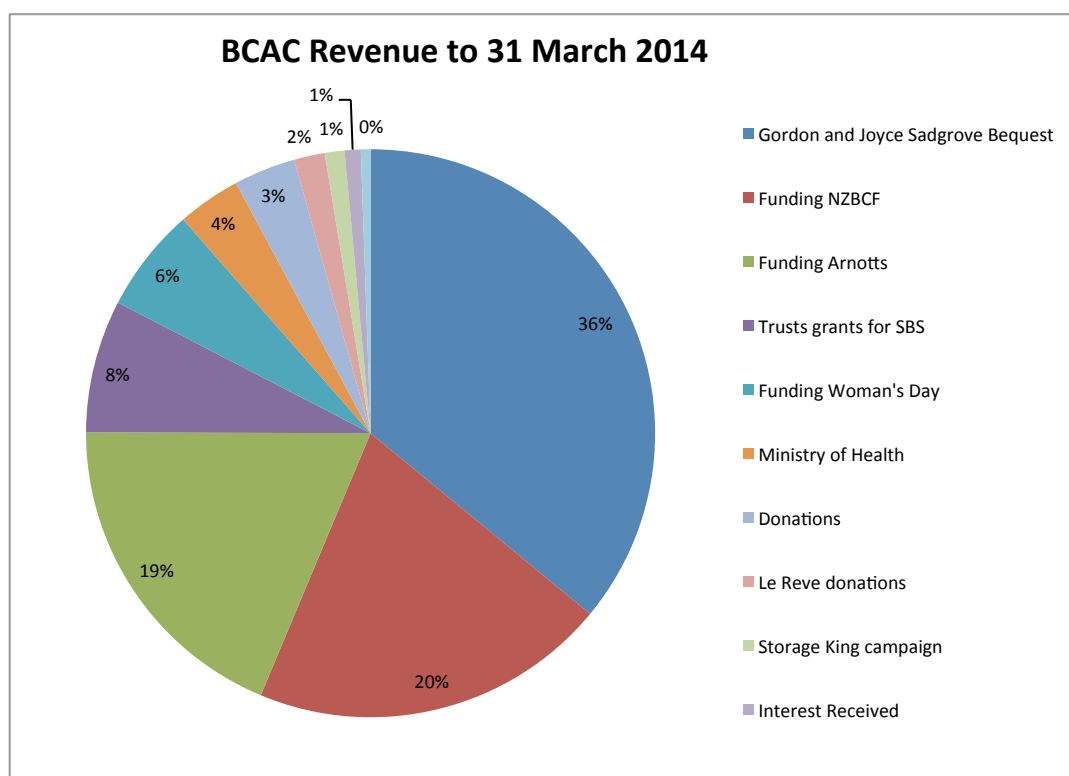
www.breastcancer.org.nz



FINANCIALS

Revenue for the year to 31 March 2014

Funding Source	Amount (\$)
Bequests	\$100,000
Funding NZBCF	\$56,522
Funding Arnotts	\$52,112
Trusts grants for SBS	\$21,000
Funding Woman's Day	\$16,542
Ministry of Health	\$10,000
Donations	\$9,762
Le Reve donations	\$4,860
Storage King campaign	\$3,115
Interest Received	\$2,538
Donations in memory of Mangalika Mendis	\$1,525
Total Income	\$277,976

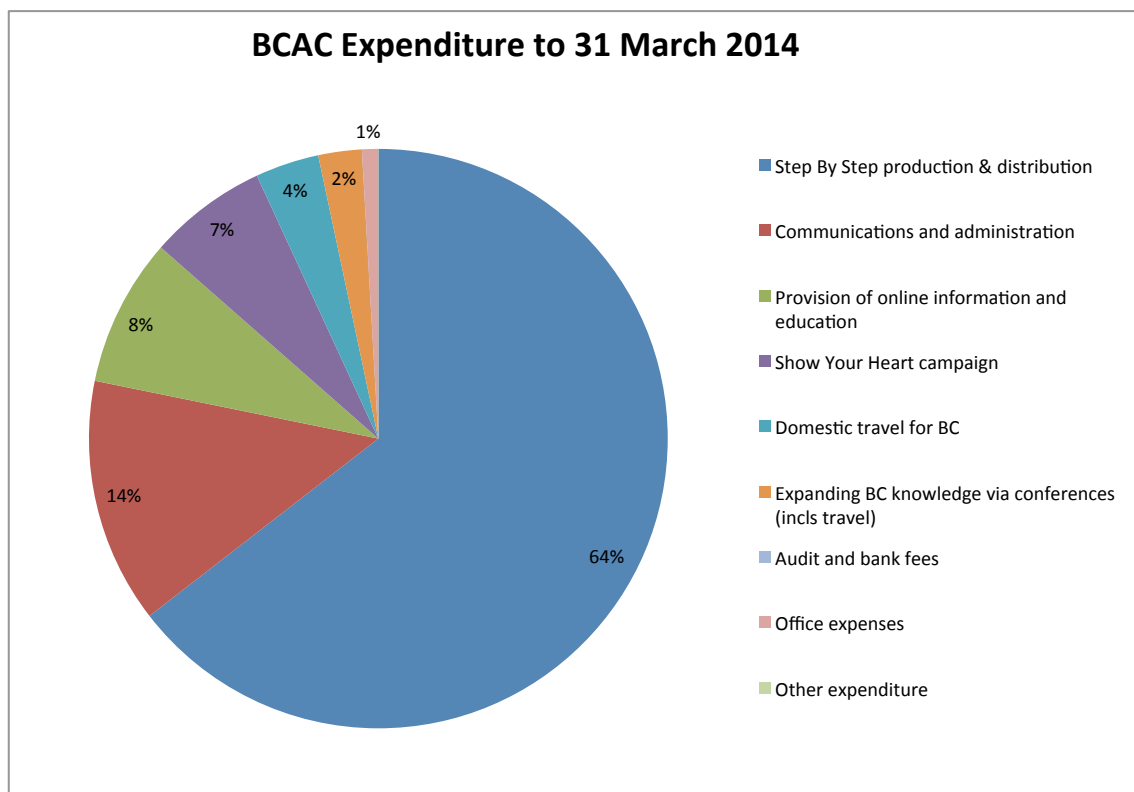


Financials cont'd



BCAC Expenses 2014

Expenses	Amount (\$)
Step By Step production & distribution	\$81,735
Communications and administration	\$17,334
Provision of online information and education	\$10,473
Show Your Heart campaign	\$8,407
Domestic travel for BC	\$4,510
Expanding BC knowledge via conferences (incls travel)	\$3,077
Audit and bank fees	\$1,996
Office expenses	\$1,149
Other expenditure	\$149
Total Expenses	\$128,832



A full copy of BCAC's financial report for the year ending March 31, 2014 is available on request.

Celebrating 10 years!





