



ANNUAL REPORT **2017**



Together we're stronger
Tangata tū pakari tonu



Chairperson's Report

BCAC has continued to provide a strong voice across many issues for all New Zealanders diagnosed with breast cancer. In our meeting with the Minister of Health we again emphasised the need to provide greatly improved access to medicines for everyone diagnosed. We were supported by 2,800 people in our online campaign to let the Minister know of the desperate need for better treatments for those with advanced breast cancer. The lack of funding for vital medicines was brought starkly home to us through the loss of our beloved committee member Moana Papa. Mo ran out of treatment options for her advanced hormone receptor positive (HR+) breast cancer. Nothing new has been funded for this very common form of breast cancer since 2006. Ibrance is a recently registered breakthrough treatment that could make a real difference to women with HR+ breast cancer and we are working to explain the benefits of funding to PHARMAC and the Minister. But this is just one of several much needed breast cancer medicines along with hundreds of other medicines that New Zealanders miss out on because of PHARMAC's paltry, capped budget. This must be changed if the government is serious about improving the survival rate of breast cancer patients and the health of all Kiwis. BCAC met with other patient groups that share this concern, and joined with them in a new grouping called Patient Voice Aotearoa. We're hoping this collaboration will increase awareness of the need to increase government investment in medicines to give us all healthier, longer lives.

We also petitioned the Minister to extend the breast screening age band up to 74 years as this has been shown to save lives. The Ministry is "assessing the evidence" on this, but we are hopeful that they will move to extend the screening age promptly. BCAC also believes that if our screening programme measured and reported breast density that women with a higher risk of developing the disease would be made aware of their need for high vigilance. We are seeking a conversation with BreastScreen Aotearoa and the Ministry to formulate a New Zealand response to this emerging evidence.

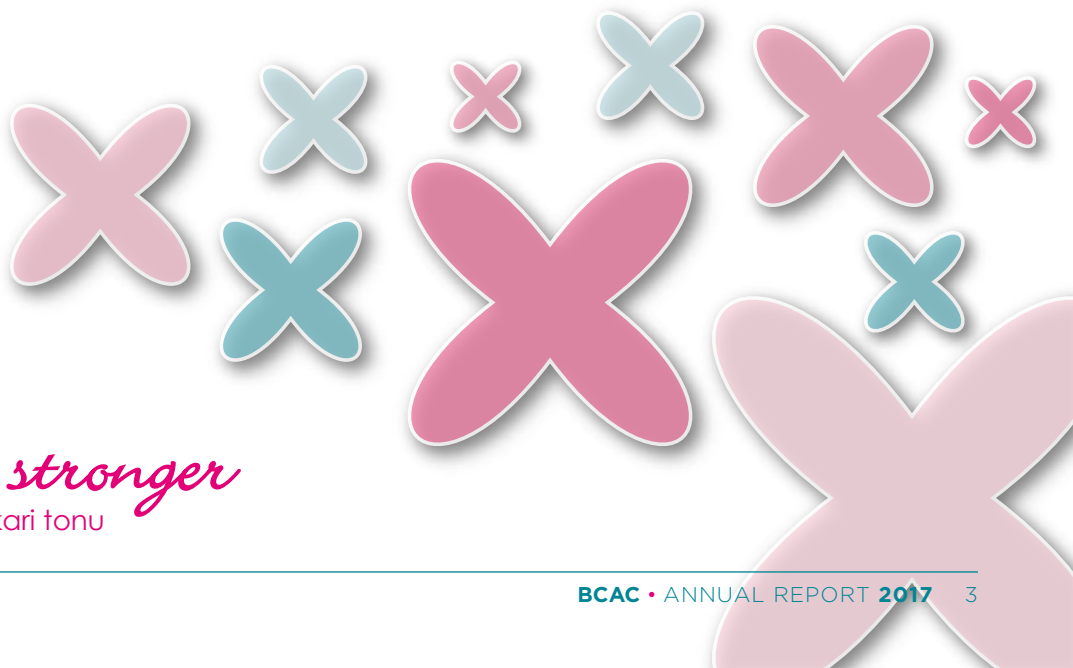
BCAC is disappointed that the Ministry has not implemented intra-operative radiotherapy (IORT), a technique allowing those with early, low-risk breast cancer to receive all their radiation treatment in a single dose during surgery to remove their breast cancer tumour. The National Health Committee (NHC) reviewed IORT and outlined many benefits to patients as well as efficiency and economic gains for the health system, but implementation of health innovations appears to have ground to a halt since the independent NHC was replaced by a Ministry committee established to evaluate innovations.

The passing of our beloved Moana Papa and of Cheryle Moreton-Robins, co-founder of Shocking Pink, represent huge losses to the breast cancer community. Both were inspirational, passionate and articulate in supporting others and in seeking better outcomes for New Zealanders with breast cancer. They both participated in BCAC's videos made to raise awareness of advanced breast cancer and the need for better medicines. Many other wonderful, accomplished and loved New Zealand women and men have also lost their lives to this disease, bringing grief to so many families. This ongoing tragedy is the reason we are fighting to establish the earliest possible detection, world-class timely treatments and best practice care for those diagnosed with breast cancer.

Our many member groups have continued to play their vital roles including offering support, providing information and advocacy and funding research. Please keep up the great work you're doing and stand with us in our efforts to minimise the impacts of breast cancer on our women, our families and our communities.



Libby Burgess, MNZM
BCAC Chairperson



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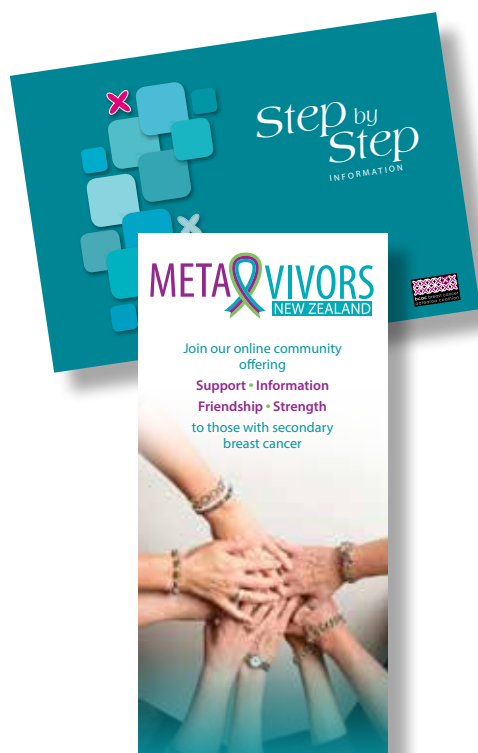
Key Achievements in 2017

Information and resources

- Delivered more than 1200 Step by Step support packs to New Zealanders newly diagnosed with 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
- Delivered a regular e-newsletter to hundreds of registered members and others
- Supported more than 2000 New Zealanders through the BCAC Facebook page
- Supported more than 200 New Zealanders with advanced breast cancer through the online community Metavivors NZ
- Distributed more than 1000 brochures to promote Metavivors NZ
- Responded to more than 50 queries through the BCAC website and Facebook page.

Providing a voice for those diagnosed with breast cancer

- In October 2016 BCAC launched a campaign highlighting the need for better access to medicines in New Zealand. More than 2800 submissions were delivered to the Minister of Health.
- BCAC produced an online video featuring New Zealanders with advanced breast cancer discussing their need for better access to medicines and this reached more than 50,000 via Facebook.
- BCAC committee member Melissa Bell joined Breast Cancer Trials (formerly the Australian New Zealand Clinical Trials Group) as a consumer representative.
- Fay Sowerby, BCAC secretary, is a member of the Breast Cancer Trials Fundraising and Communications Committee.
- BCAC Chair Libby Burgess is an Affiliate Member of Breast Cancer Trials.



Fay Sowerby

- BCAC Deputy Chair Emma Crowley and committee member Ros Day are members of the Consumer Advisory Panel of Clinical Trials New Zealand.
- A number of BCAC committee members attended the Wellington symposium “Building a Sustainable Future – The role of the patient voice”.
- BCAC supported many women as they negotiated the health system to secure timely and appropriate treatment and care.
- Presented to the New Zealanders for Health Research Clinical Trials workshop on patient participation and recruitment.
- Met with Health Literacy NZ to provide feedback on resources for the national breast screening programme provided by BreastScreen Aotearoa.
- BCAC is a participating member of the new consumer group, Patient Voice Aotearoa - He Reo Tūroto o Aotearoa.
- Provided an invited speaker and panel member to the Breast Cancer Cure Breast Cancer Summit October 2017.
- Met with the executive of the NZ Society for Oncology to develop closer collaboration between cancer consumer representatives and researchers.



Louise & Emma

Improving access to world class treatment and care

- Represented New Zealanders with breast cancer at key international conferences including the combined Clinical Oncology Society of Australia and Breast Cancer Trials Annual Scientific Meeting.
- Met with the Minister of Health Hon. Jonathan Coleman and briefed him on a number of key breast cancer issues in New Zealand including: medicines access, the need to introduce intra-operative radiotherapy into the public health system, extending the age cohort for publicly funded breast screening to 74 years, highlighting that high breast density is a significant but currently unmanaged risk factor for breast cancer, providing timely breast reconstruction and prophylactic mastectomies, highlighted worse outcomes for Māori from breast cancer, access to clinical trials, FISH testing delays and the need for improved fertility treatment following breast cancer diagnosis.
- Delivered the Ministerial Briefing to Labour’s health spokesperson Annette King and to Peter Dunne, Associate Health Minister.



Annette King



Jonathan Coleman



Peter Dunne

- Followed up with Peter Dunne to progress implementation of use of frozen ovarian tissue as a fertility treatment for young women diagnosed with breast cancer.
- Met Ministry of Health officials to follow up on issues raised in our Ministerial briefing.
- Made a detailed submission to PHARMAC in response to their consultation regarding changes to their procedures as a result of TPP requirements.
- Met with PHARMAC representatives to discuss the urgent need for better access to new and innovative medicines.
- Met with pharmaceutical companies to encourage them to apply for registration and funding for key breast cancer drugs and to offer their products at affordable prices.
- Made a submission to PHARMAC supporting their decision to fund Perjeta for HER2+ metastatic breast cancer patients.
- Made a further joint submission with the Breast Cancer Foundation New Zealand to PHARMAC to re-consider the criteria for the funding of Perjeta and strongly urged PHARMAC to extend funding for this medicine to all patients currently being treated with trastuzumab for metastatic breast cancer.



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.
- Appealed to BreastScreen Aotearoa, the Ministry of Health's Cancer Team and the Minister of Health to achieve real and significant improvements in the engagement of Māori women as well as the speed of detection and treatment for those with breast cancer.





Step by Step - Feedback in 2017

Patients

- “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.”

“Really grateful for the information. Forewarned is forearmed and the information gives peace of mind about what I need to know and expect.”

- “I believe it is God-sent really. The appalling shock of being diagnosed with breast cancer is unbelievable. But thank you so much for Step by Step. It is inspirational and encouraging. I actually wept while going through the package.”
- “A really nice surprise at a stressful time in my life.”
- “Daunting but very worthy information to take in at your own pace.”

“Very impressed with the information and the record books. Having used them during my surgery and radiation, they have proved invaluable to help my thought process over each step...”

- “Thanks, your Step by Step Diary, Wow wow wow :) !!!”
- “Awesome. I am so very grateful for the support. These booklets and journal will be a huge help. Thank you.”

Breast care nurses and cancer support teams

Great service, arrived this afternoon. Thanks for your fantastic resources.

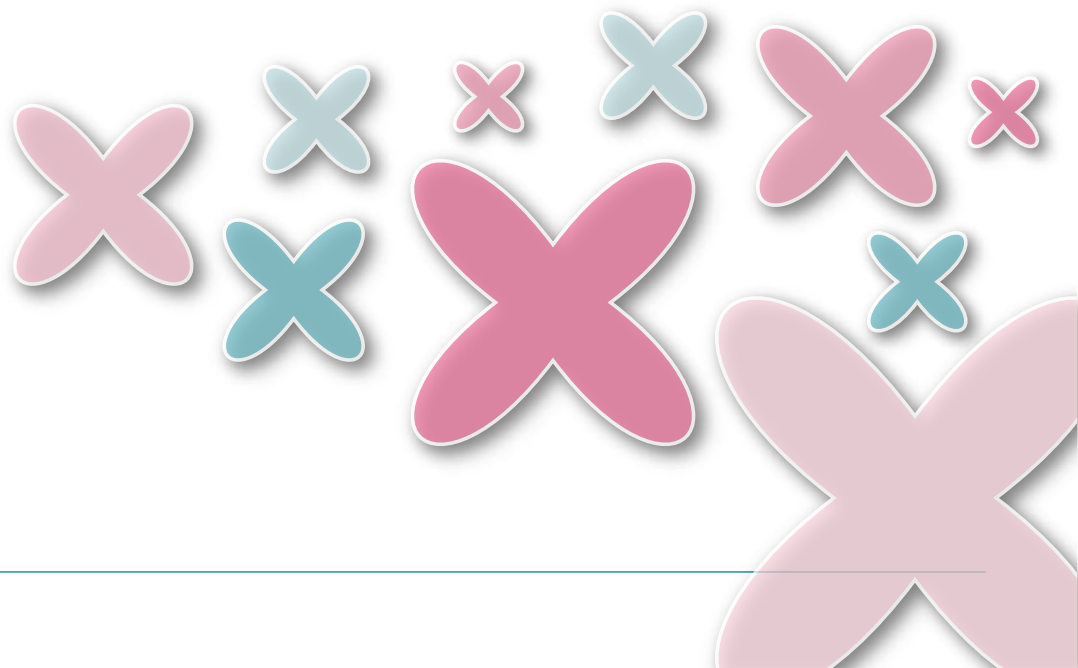
Taranaki Cancer Society

It's such a great resource and support.

BreastScreen Aotearoa

It certainly makes our job easier to have really good, really informative and really professional information to pass on.

Breast Care Nurse



BCAC Committee

Those serving on the BCAC committee during 2017 were:

Chair:	Libby Burgess	
Deputy Chair:	Emma Crowley	
Secretary:	Fay Sowerby	
Treasurer:	Louise Malone	
Committee Members:	Rowena Mortimer	Gillian Wintrup
	Melissa Bell	Nic Russell
	Lynda Ames	Greer Davis
	Moana Papa	Chris Walsh
	Irene Kereama-Royal	Ros Day

In 2017 BCAC committee members have been involved in the following committees, conferences and meetings 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 (BCSIG)
- IMPACT (consumer) Member and Associate Member: Breast Cancer Trials
- Attended combined Clinical Oncology Society of Australia and Breast Cancer Trials Annual Scientific Meeting.
- Attended the symposium “Building a Sustainable Future – The role of the patient voice” April 2017
- Attended meetings with other patient group representatives and contributed to formation of Patient Voice Aotearoa
- Enrolled to attend San Antonio Breast Cancer Symposium Dec 2017 as a consumer advocate.





Emma Crowley, Deputy Chairperson

- Consumer representative: Breast Cancer Special Interest Group (BCSIG)
- Appointed to the consumer advisory panel of Clinical Trials NZ
- Attended the symposium “Building a Sustainable Future – The role of the patient voice” April 2017
- Represented BCAC at the Medicines NZ dinner June 2017
- Represented BCAC at fundraising and awareness events.



Louise Malone, Treasurer

- Represented BCAC at fundraisers and events
- Met with IBM to better understand the use of Watson Oncology, Watson Genetics and the development of a screening project August 2017
- Researching and developing a Breast Density Discussion document February - December 2017 for consultation
- Received an Alamo Breast Cancer Foundation scholarship to attend the San Antonio Breast Cancer Symposium Dec 2017 as a consumer advocate.



Fay Sowerby, Secretary

- Appointed to the Communications and Fundraising Committee, Breast Cancer Trials
- Represented BCAC at Breast Cancer Special Interest Group (BCSIG) meetings
- Attended the symposium “Building a Sustainable Future – The role of the patient voice” April 2017
- Represented BCAC at Patient Voice Aotearoa meetings
- “Cure for Cancer – Myth or Reality”, Auckland Medical Research Foundation May 2017
- Spoke at the Commonwealth Women Parliamentarians Breakfast Meeting May 2017
- Represented BCAC at the Medicines NZ dinner June 2017
- Presented at the New Zealanders for Health Research Clinical Trials Workshop August 2017
- Attended the New Zealanders for Health Research Opinion Poll August 2017
- Met with IBM to better understand the use of Watson Oncology, Watson Genetics and the development of a screening project August 2017
- Researching and developing a Breast Density Discussion document February - December 2017 for consultation
- Enrolled to attend the San Antonio Breast Cancer Symposium Dec 2017 as a consumer advocate.

Chris Walsh

- Represented BCAC at fundraisers and events.

Rowena Mortimer

- Attended meetings with the Breast Care Working Group.



Lynda Ames

- Metavivors NZ Co-ordinator
- Attended meetings with the Minister of Health, PHARMAC and Opposition MPs.

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.

Gillian Wintrup

- Provides a voice for those with advanced breast cancer.

Melissa Bell

- Provides a voice for those diagnosed in the South Island
- Appointed as a consumer representative (CAP member) for Breast Cancer Trials
- Attended the Breast Cancer Trials Annual Scientific Meeting July 2017 as a CAP member.





Greer



Irene



Ros

Greer Davis

- Member: BCS Young Women's Support Group
- Provides a voice for young women with cancer
- Represented BCAC at a Digital Health Workshop organised by the Ministry of Health
- Attended meetings with the Minister of Health, PHARMAC and Opposition MPs.

Irene Kereama-Royal

- Advocates for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori, Pasifika and rural women.

Ros Day

- Joined the BCAC committee in March 2017
- Attended the Breast Cancer Trials Annual Scientific Meeting July 2017 as an IMPACT member
- Appointed to the consumer advisory panel of Clinical Trials NZ.



In Memory – Moana Papa

The Committee noted with deep sadness the passing of committee member Moana Papa in February 2017. Moana joined BCAC in 2008 and was our guide, mentor and active leader in our ongoing efforts to improve health outcomes for Māori and Pasifika women with breast cancer. She represented us on the Māori Leadership Group of the Northern Cancer Network, working to influence the Northern District Health Boards, and she served on PHARMAC's Consumer Advisory Committee. Moana formed Wahine Toa, an informal South Auckland group to consult Maori and Pasifika women on breast cancer issues. She was an important participant in our annual briefings for the Minister of Health, an active contributor to the Metavivors' Facebook group, and was always ready to offer herself as the face and voice of breast cancer when media attention was needed. Moana will never be forgotten for her tenacity, love and leadership in trying to make things better for those affected by breast cancer in Aotearoa and their whanau.



Supporters

BCAC is very grateful to all the organisations and individuals who support us both financially and in kind.

In particular, BCAC would like to acknowledge its partnership with the Karen Louisa Foundation which allowed us to advocate on behalf of New Zealanders with advanced breast cancer. With the Foundation's financial support we were not only able to create a successful campaign highlighting the need for better access to medicines, but also promote the Facebook support group, Metavivors NZ, set up specifically for those with advanced breast cancer.

We were also grateful to receive an educational grant from Roche New Zealand which provided BCAC with assistance towards attending national meetings and international conferences. These occasions provide essential learning opportunities for our advocates, who then bring this knowledge back to our local breast cancer communities.

BCAC was proud to continue its association with Storage King NZ in October 2016, which again enthusiastically supported us during Breast Cancer Awareness Month. Our relationship with Australian health and beauty company, Le Reve, also continues and BCAC thanks them for their ongoing support.

We were also thrilled to receive many donations from those in the community and thank all those who have contributed and supported us during the year.





BCAC Member Groups

BCAC is very proud of the fact that we are a coalition of more than 30 breast cancer-related charities and many individual members. We value the close working relationship we have with all of these groups to improve the care and treatment of New Zealanders with breast cancer.

Age Concern
Alleviate
Ascot Radiology Pink Dragons
Boobops Dragon Boat Team
Breast Cancer Action Trust
Breast Cancer Foundation New Zealand
Breast Cancer Network (disestablished in May 2017)
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
Pinc Cancer Rehabilitation Program
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 Research Trust
Waikato Treasure Chests
Well Women and Family Trust



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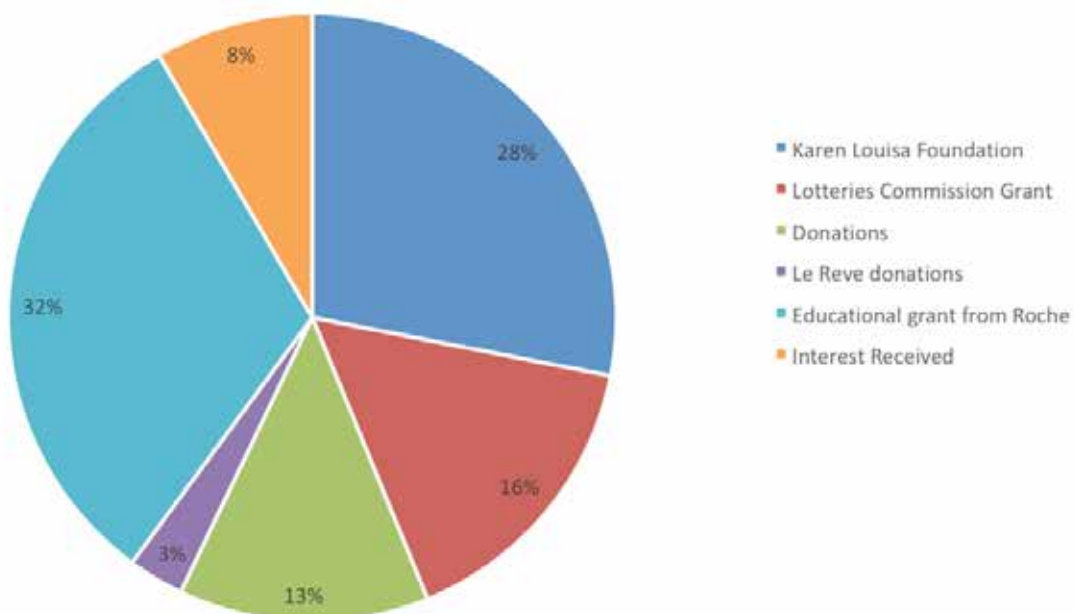


Financials

BCAC Revenue 2017

Funding Source	Amount (\$)	percent
Karen Louisa Foundation	\$17,826	28
Lotteries Commission Grant	\$10,000	16
Donations	\$8,455	13
Le Reve donations	\$1,890	3
Educational grant from Roche	\$20,000	31
Interest Received	\$5,347	8
Total Income	\$63,518	100

BCAC Revenue to 31 March 2017



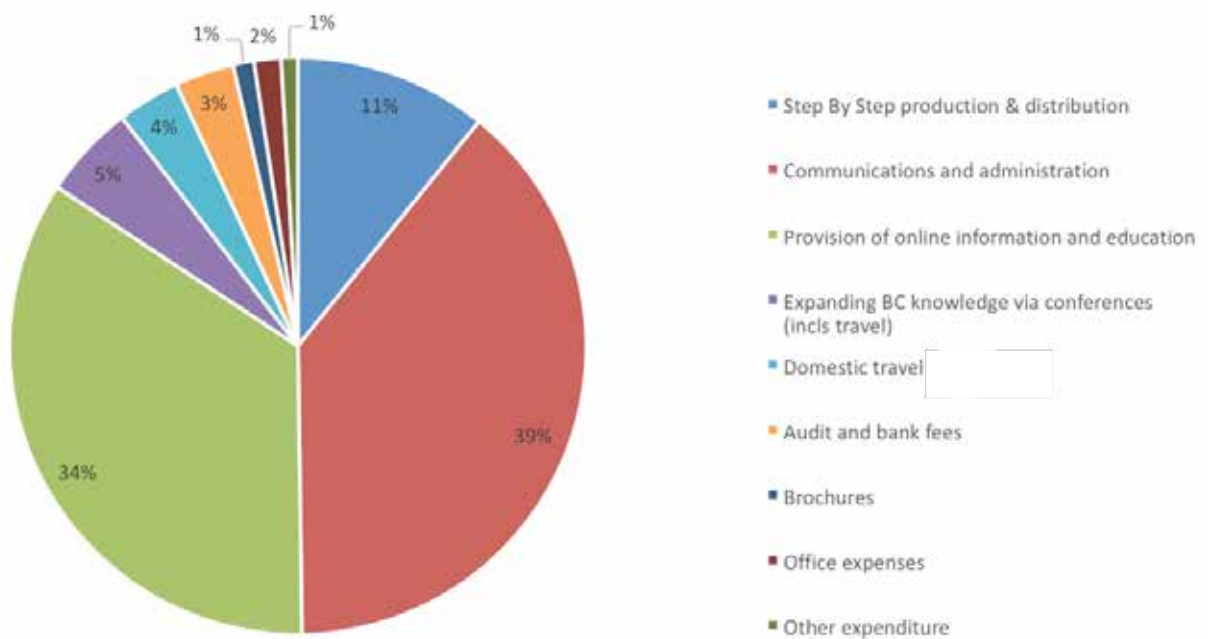


Financials

BCAC Expenses 2017

Expenses	Amount (\$)	Percent
Step By Step production & distribution	\$6,140	11
Communications and administration	\$22,143	39
Provision of online information and education	\$19,604	35
Expanding BC knowledge via conferences (incl's travel)	\$2,993	5
Domestic travel	\$1,996	4
Audit and bank fees	\$1,890	3
Brochures	\$660	1
Office expenses	\$858	2
Other expenditure	\$533	
Total Expenses	\$56,817	100
Net surplus	\$6,701	

BCAC Expenditure to 31 March 2017





Plans for 2018

Plans for 2018

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

- Regular Ministry of Health liaison
- Brief the Minister of Health on relevant issues in the breast cancer community
- Raise awareness of new and emerging medicines
- Increase education and knowledge of breast cancer, treatments, supportive care and emerging clinical trial results by attending and promoting local and international expert meetings and conferences
- Increase access to clinical trials
- Meet with pharmaceutical companies and encourage them to register their innovative medicines in New Zealand and offer them at affordable prices
- Engage and facilitate networking and collaboration among groups and individuals
- Continue to highlight inequities in timely treatments and poorer health outcomes for Māori women with breast cancer
- Consult and engage with Māori and Pasifika women to identify and promote breast cancer issues that could improve outcomes in these communities
- Meet with PHARMAC regarding access to innovative medicines.

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

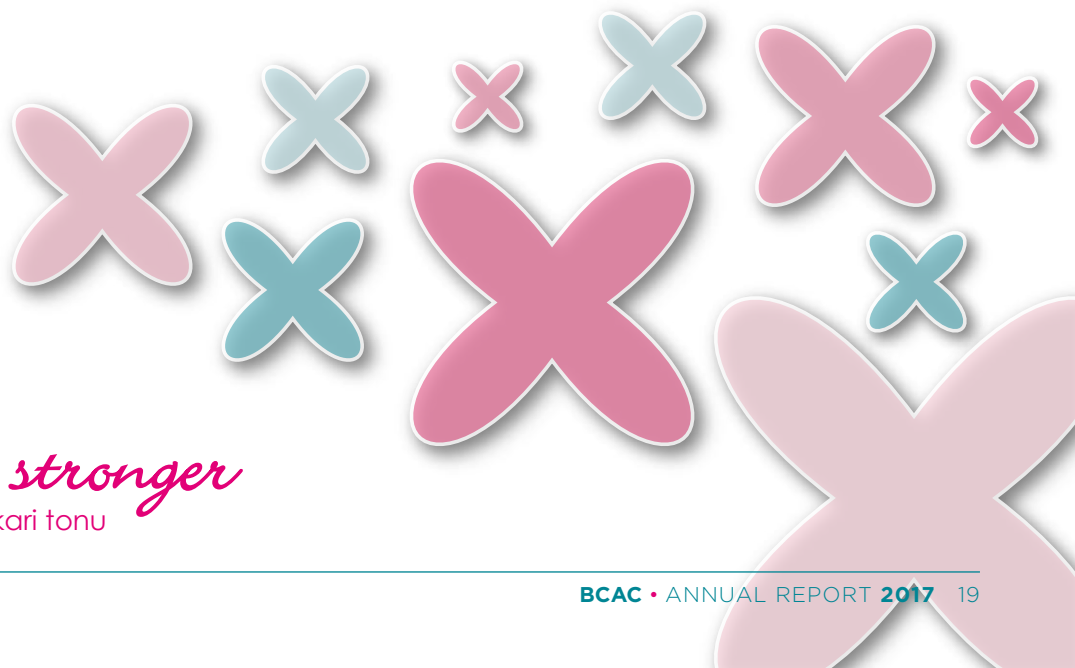
- Continue to distribute our Step by Step support packs
- Produce an updated 4th edition of Step by Step
- Develop and print a Step by Step information book for those with advanced breast cancer
- Provide up to date information via our website
- Communicate with the breast cancer community via our Facebook page and Twitter

- Distribute news and information via our e-newsletter to hundreds of subscribers
- Respond to requests for information and support.

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

- Advocate for timely access to world-class breast care, including treatments and psychological care in New Zealand
- 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, breast density reporting and breast awareness by meeting regularly with BreastScreen Aotearoa to encourage continual progress with the National Screening programme
- Provide information and comment on the most effective ways to achieve early detection.

To support the activities of BCAC through promotion and fundraising



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Breast Cancer Aotearoa Coalition
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www.breastcancer.org.nz