



# 2013

## BCAC Annual Report





## *The Breast Cancer Aotearoa Coalition's 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.*



*To provide a voice for New Zealanders who have experienced breast cancer.*





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## Chairperson's Report



Taking a moment to look back over BCAC's work over the past year makes me realise how far we've come in our nine years as a Coalition. BCAC formed in 2004 when 12 kiwi breast cancer groups gathered and made the commitment to work together to gain access to world-class treatment and care for everyone diagnosed in New Zealand. Now in 2013 we have *Standards of Service Provision for Breast Cancer* almost ready for Ministerial sign-off that will require our health system to provide the high standards we have strived for. I was delighted to be included as a consumer/patient representative in the team of expert health professionals gathered to write these Standards. The working group was skilfully chaired by breast cancer hero and Waikato surgeon Ian Campbell who was this year deservedly honoured with an ONZM for his services to breast cancer.

BCAC recently celebrated and supported another positive advance in the form of the Intrabeam radiotherapy machine that will allow women with low-risk early breast cancer to receive all their radiation treatment in a single dose during their breast cancer surgery. Breast surgeon Erica Whineray-Kelly has tirelessly driven this project and we applaud her for bringing this effective, convenient new treatment to New Zealand women. Intrabeam is currently available in one Auckland clinic but we hope to see it widely adopted in our public health system in the near future.





A further highlight for women with breast cancer in New Zealand has been the recent registration by MedSafe of two medicines identified as among the top breakthroughs in cancer treatment in 2012. Kadcyla® and Perjeta® are now available here to treat women with advanced HER2 Positive breast cancer. Sadly, these drugs are not yet subsidised in New Zealand, so patients will have to pay for them. BCAC is, however, committed to ensuring widespread and timely access to new medicines and we'll be striving to see that these drugs are fully-funded in future.

A lowlight of 2013 was BCAC's experience with the Health and Disability Ethics Committees (HDECs). Late in 2012 results were released from a large French clinical trial, named PHARE, which showed that six months of Herceptin treatment was not as effective as 12 months in preventing cancer return and death in women with early stage HER2 positive breast cancer. This was of deep concern to BCAC as New Zealand women, mostly in Auckland, are being recruited into the SOLD clinical trial that compares 12 months of Herceptin with a dramatically shortened 9 week treatment. BCAC made several detailed submissions to the HDEC expressing our grave concern for the health and safety of women involved in this trial and requesting that ethics approval be withdrawn. Sadly, the HDEC made it clear that it was unable to review the scientific merits of clinical trials. We have asked the Minister of Health to urgently review this situation and establish an expert body that is capable of ensuring that clinical trials are worthy and safe for participants.

In contrast, a highlight of my year was attending the renowned San Antonio Breast Cancer Symposium (SABCS) last December.



Breast cancer researchers and advocates from all over the world gather at SABCS each year to hear the latest clinical trial results that shape continual improvements in the effectiveness and tolerability of treatments. I was pleased to represent New Zealand by participating as a consumer/patient representative on an expert panel discussing challenging breast cancer cases from around the world. One of the revelations for me at SABCS was the strength and eloquence of the contingent of women with advanced breast cancer at the conference. These women are having a very positive effect as their advocacy has increased the focus of researchers to bring new treatments forward faster and to further explore ways to beat aggressive disease. BCAC has worked with Sweet Louise to form a virtual group of New Zealand women with advanced breast cancer who may wish to provide a voice in this area. Please let us know if you'd like to join.

In the same vein, BCAC has learnt that it's possible to secure significant and lasting change in New Zealand too, but we need your help. During our recent briefing to the Minister of Health, Tony Ryall, and Associate Minister of Health, Jo Goodhew, we were able to raise issues of slow and sub-standard care that had been flagged to us by BCAC member groups and individual patients around the country. Many of these were in rural areas and smaller cities. Both Ministers were committed to solving these problems and strongly encouraged us to get in touch as soon as we become aware of any issues so that they can be dealt with right away. This means **we need to hear from you throughout the year if you or patients in your area are having problems accessing timely treatment and care.** We will take the Ministers at their word and expect them to act rapidly and do their best to solve these problems.



I also want to acknowledge the fruitful collaborations among this country's many breast cancer-related groups. This year, the New Zealand Breast Cancer Foundation has joined forces with BCAC to become the principal funder of our *Step by Step* support and information pack. Their backing will help us to review, print and distribute thousands more copies of this vital resource which helps so many women through a breast cancer diagnosis and treatment.

BCAC is made up of so many wonderful breast cancer groups, all determined to support the 2,800 Kiwis diagnosed with breast cancer each year. Thank you for the positive difference you make to the lives of all those women and their families.

A handwritten signature in blue ink, reading 'Lissy Burgen', is centered on a light pink rectangular background. The signature is written in a cursive, flowing style.







## Key Achievements for 2013

### Goal 1: Supplying information and resources

- Delivered *Step by Step* support packs free-of-charge to more than 1,000 women newly diagnosed with breast cancer in New Zealand.
- Reviewed and edited *Step by Step* content following consultation with medical professionals, BCAC member groups and others in the breast cancer sector with a view to printing a further 5,000 copies of this valuable resource.
- Provided up-to-date information on breast cancer diagnosis, treatment and recovery, along with the latest research results and news on the BCAC website and Facebook page
- Achieved an 80 per cent increase in the number of visits to the BCAC website compared with 2012.
- Promoted the BCAC web videos, *Kiwi Stories of Breast Cancer*, which have been viewed by nearly 7000 people on our website and YouTube.
- Responded to queries and questions posted from women with breast cancer on our Facebook page and through the BCAC website.
- Participated in web videos produced by Medicines New Zealand to further the understanding of medicines funding and patient support.
- Continued to distribute information brochures on BCAC and *Step by Step* to breast clinics, conferences and breast cancer support groups.



## Key Achievements for 2013

### Goal 2: Providing a voice for those diagnosed with breast cancer

- Appealed to the Health and Disability Ethic's Committee (Northern B) for a review of the SOLD clinical trial on the grounds that it puts New Zealand women with breast cancer involved at unnecessary risk.
- 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.
- Supported and facilitated the establishment of an advocacy group for New Zealand women with metastatic breast cancer.
- Briefed the Minister of Health and other key politicians on the need to improve services for New Zealanders with breast cancer, in particular access to delayed breast reconstruction, counselling, lymphoedema management, and fertility treatment for young women diagnosed.
- Established links with an Australian Triple Negative Breast Cancer (TNBC) support group in order to help better inform New Zealand women.
- BCAC chairperson, Libby Burgess, participated in the National Breast Cancer Tumour Stream Working Group as a consumer/patient representative to develop high-quality standards of care for breast cancer in New Zealand.







## Key Achievements for 2013

### **Goal 3: Informing and advocating for access to world-class detection, treatment and care**

- Requested that the Minister of Health establish an independent body with the medical knowledge necessary to properly review the ongoing safety and ethical status of clinical trials involving New Zealanders.
- Pushed for an expansion of the upper age limit for BreastScreen Aotearoa's free screening programme from 69 to 75, as has occurred in Australia.
- Promoted the registration of two new breast cancer drugs, Perjeta® (Pertuzumab) and Kadcyla® (ado-trastuzumab emtansine) and provided information on access programmes for both medicines.
- Advocated for changes to PHARMAC's operating policies and procedures in order to see more timely and transparent decision-making on medicines.
- Made submissions to PHARMAC on funding for lapatinib (Tykerb®) as a second-line treatment for metastatic HER2- positive breast cancer and supporting the proposal to list pegfilgrastim (Neulastim®) for the treatment of neutropenia in cancer patients.
- Supported the introduction of the Intrabeam technology to New Zealand, a one-dose radiation treatment for women with breast cancer.
- Highlighted a range of breast cancer clinical trials available in New Zealand through the BCAC website and newsletter.
- Participated in the San Antonio Breast Cancer Symposium; the 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.



## Key Achievements for 2013

### **Goal 4: Working to improve outcomes for Māori and Pasifika women diagnosed with breast cancer**

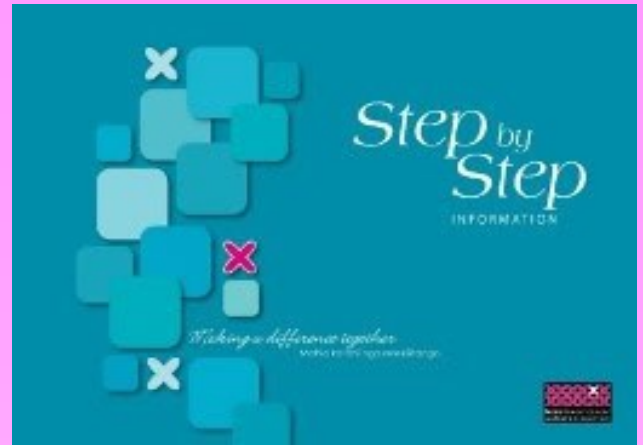
- Liaison with Māori and Pasifika breast cancer advisory groups.
- Promotion of BreastScreen Aotearoa's commitment to increase screening rates for Māori and Pasifika women.
- BCAC committee member, Moana Papa, was the consumer representative on the Māori Leadership Group contributing to the work of the Northern Cancer Network .
- BCAC committee member, Moana Papa, contributed as a member of PHARMAC's Te Roopu Āwhina Māori to provide advice on the impact of the drug-buying agency's decisions on Māori.







## **BCAC's Step by Step**



**In 2013 we delivered the *Step by Step* support pack to more than 1,000 women with breast cancer—here's what some of them had to say about it:**

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

*"Excellent. My doctor explained a lot but reading it in my own time was great."*

*"Things happen so quickly, it is good to be able to note everything down so easily. Thank you."*

*"A really wonderful idea having all information and records together."*

*"Absolutely marvellous. Thank you."*

*"A helpful, encouraging and empowering resource. Thank you."*

*"Great to have, makes the situation much easier to follow, thank you so much."*

*"Absolutely fantastic - easy to understand information booklet, thank you"*

*"Thanks for your Step by Step Diary - Wow, wow, wow!!!"*









## Committee Organisation

### The BCAC committee

Those serving on the committee during 2013 were:

Chair: Libby Burgess

Deputy Chair: Chris Walsh

Secretary: Rowena Mortimer

Treasurer: Louise Malone

Members:	Sue Ellis	Moana Papa
	Gillian Wintrup	Julie Graham
	Greer Davis	Melissa Bell



## Other Involvements

In 2013, 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
- Northern Cancer Collaborative, NGO Representative
- Northern Cancer Collaborative Breast Cancer Tumour Stream Working Group, Consumer Representative
- Breast Cancer Special Interest Group (linked to the NZ Association of Cancer Specialists), Consumer Representative
- Australian New Zealand Breast Cancer Trials Group, IMPACT (consumer) Member and Associate Member

### Chris Walsh



- Chair of the National Cancer Consumer Representative Advisory Group
- Consumer Representative on the Breast Cancer Special Interest Group
- Consumer Representative on the Ministry of Health, Cancer Treatment Advisory Group

### Louise Malone



- Treasurer for BCAC
- Involved in numerous breast cancer fundraisers



### **Rowena Mortimer**

- Chair of the Northern Cancer Network Consumer Group
- Member of the Waitemata District Health Board Cancer Control group
- Consumer Representative on the Northern Cancer Network Collaborative
- Consumer Representative on the newly-formed Northern Cancer Network Governance Board
- Member of the Northern Cancer Network Breast Cancer Tumour Stream Steering Group



### **Sue Ellis**

- BCAC Representative at the Access to Medicines Coalition Working Group
- BCAC Representative at the New Zealand Organisation for Rare Diseases Review Forum on PHARMAC's Operating Policies and Procedures



### **Moana Papa**

- Consumer Representative on the Maori Leadership Group for the Northern Cancer Network
- Member of PHARMAC's Consumer Advisory Committee and Te Roopu Āwhina Māori





### **Greer Davis**

- Attended the C4YW Conference for Young Women with Breast Cancer in Seattle, Washington, USA
- Member of the BCS Young Women's Support Group
- Provided a voice for young women with breast cancer



### **Julie Graham**

- Founding member of HER2 Heroes Waikato
- Provided a voice for women with HER2 Positive breast cancer



### **Gillian Wintrup**

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



### **Melissa Bell**

- Joined the BCAC Committee in late 2013
- Organised a "Positively Pink" fundraiser at St Hilda's Collegiate in Dunedin.







## 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 are totally tuned in to the experiences and challenges of those being diagnosed and treated. This enables us to identify problems and work across the health system to address issues in an efficient and effective way.

We love the passion and commitment of our member groups and look forward to working with you all in the coming year to improve breast cancer care for all New Zealanders.

- |                                 |  |
|---------------------------------|--|
| 1. Age Concern                  | 9. Breast Cancer Support Northland Trust   |
| 2. Alleviate                    |  |
| 3. Ascot Radiology Pink Dragons | 10. Breast Cancer Support Tauranga Trust   |
| 4. Boobops Dragon Boat Team     | 11. Breast Health NZ                       |
| 5. Breast Cancer Action Trust   | 12. Busting With Life                      |
| 6. Breast Cancer Network        | 13. HER2 Heroes                            |
| 7. Breast Cancer Research Trust | 14. Inflammatory Breast Cancer Australasia |
| 8. Breast Cancer Support Inc    | 15. Kenzie's Gift                          |



## BCAC member groups

- |                                      |   |
|--------------------------------------|---|
| 16. Look Good Feel Better            | 25. Terrier Race Against Time                   |
| 17. Lymphoedema Support Network      | 26. The Gift of Knowledge                       |
| 18. Pink Pilates                     | 27. The Mamazon Club                            |
| 19. Rotorua Breast Cancer Trust      | 21. The New Zealand Breast Cancer Foundation    |
| 21. Shocking Pink                    | 22. Waikato Breast Cancer Trust                 |
| 22. Sweet Louise                     | 23. Waikato Treasure Chests                     |
| 23. Taranaki Dragons                 | 30. Well Women and Family Trust (formerly WONS) |
| 24. Te Ha o te Oranga o Ngati Whatua | 31. YWCA Encore                                 |



## Supporters



We applaud the commitment and generosity of all our sponsors and donors, without them BCAC would not be able to reach out to provide support and information to New Zealanders with breast cancer.

This year, the New Zealand Breast Cancer Foundation (NZBCF) has come on board as the principal funder 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, as ever, grateful to our long-term sponsor Arnott's Tim Tam. They are truly committed to making a difference in the lives of women with breast cancer and we're lucky to have such a supportive corporate partner.

This year, BCAC and Arnott's Tim Tam worked together with Woman's Day and Progressive Enterprises Ltd on our primary fundraiser, the *Show Your Heart for Women Living with Breast Cancer* campaign. We were thrilled to have Woman's Day join our stable of sponsors and this year's campaign was enormously successful, raising more than \$70,000 and achieving excellent publicity about issues of concern to women with breast cancer.

We're also pleased to welcome Storage King as a supporter of BCAC. In October's Breast Cancer Action Month, Storage King undertook to donate \$1 from every tea chest sold to BCAC. We were excited to see how enthusiastically the Storage King team got in behind the campaign.

## Supporters



We'd also like to acknowledge the support of our many individual donors. In particular, we'd like to pay tribute to Clearspan Property, who generously donated \$5,000 after seeing an article about 26-year-old BCAC committee member, Greer Davis' battle with breast cancer. Thanks also to Olivia MacLean who scaled some mighty hills on the Motutapu Miners Trail and raised more than \$500 for BCAC and finally a special thanks to the family and friends of one-time BCAC member, Mangalika Mendis. Mangalika sadly died this year, but her friends and family paid tribute to this impressive fighter for improved breast cancer services by donating more than \$1,500 to BCAC. We truly appreciate your generosity.

*Our thanks go to our key supporters in 2013:*



Show Your Heart for Women

Living with Breast Cancer 2013



**ARNOTT'S**  
**TimTam Woman's Day**



**TIM TAM AND WOMAN'S DAY WILL DONATE FROM EVERY PURCHASE THIS WILL HELP WOMEN WITH BREAST CANCER**

For purchases of 165-200g Tim Tam range and Woman's Day between 22 April until 19 May 2013

\*50c donation only valid when you purchase Arnott's Tim Tam and Woman's Day in one transaction when you swipe your OneCard. Conditions apply.

JDBC190513A



# Show Your Heart for Women Living with Breast Cancer 2013





## Plans for 2014

In the coming year we plan to continue working on BCAC's Key Initiatives:

1. To support and empower those diagnosed with breast cancer, and their family, whanau and friends, by providing information and resources allowing 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](http://www.breastcancer.org.nz), our Facebook page and Twitter account
  - promoting our *Kiwi Stories of Breast Cancer* web videos
  - responding to requests for information and advice
2. To provide a unified, evidence-based voice for New Zealand women 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

## Plans for 2014 cont'

- 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 New Zealand and other relevant individuals and groups
  - responding to consultation opportunities relating to breast cancer
  - 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 2014 cont'

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 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

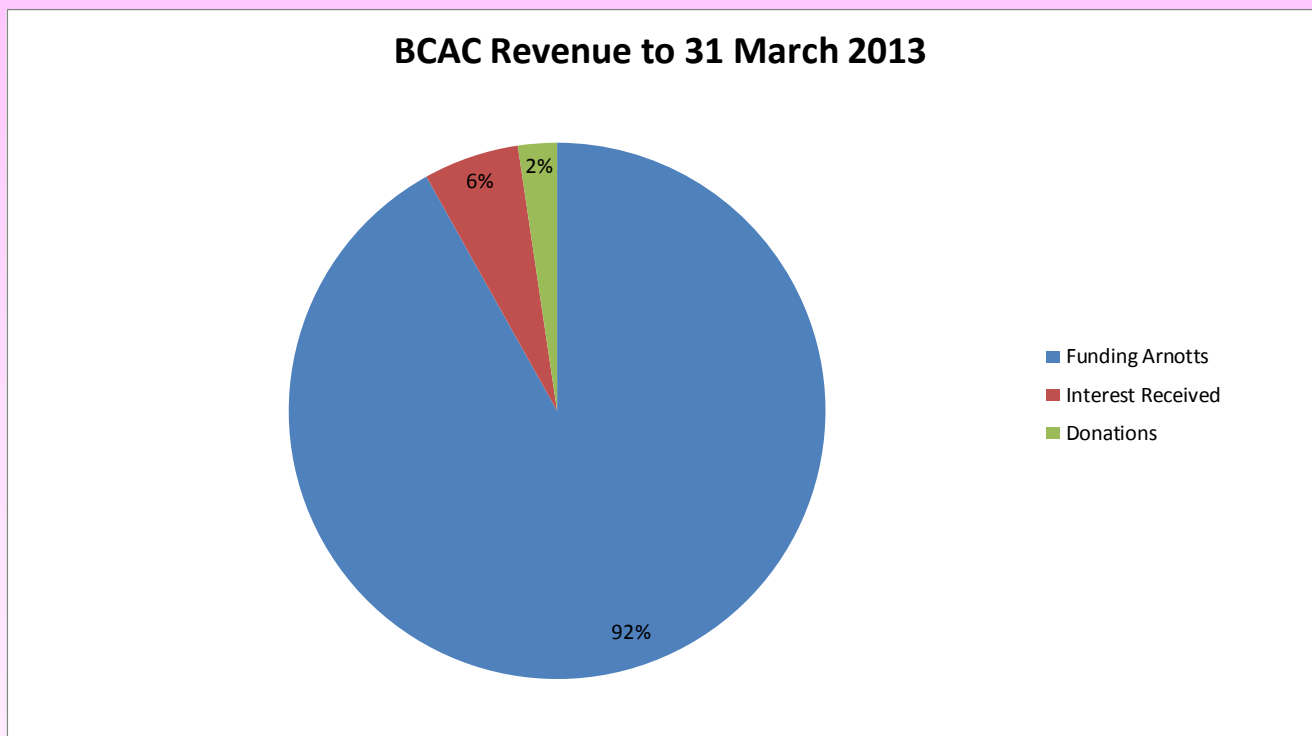


## Financials



### Revenue for the year to 31 March 2013

BCAC Revenue 2013	
Funding Source	Amount (\$)
Funding Arnotts TimTam	\$ 60,053
Interest Received	\$ 3,758
Donations	\$ 1,533
Total Income	\$ 65,344



A full copy of BCAC's audited financial report for the year ending March 31, 2013 is available on request.



BCAC Expenses 2013	
Expenses	Amount (\$)
Communications and administration	\$ 22,708
Step By Step production & distribution	\$ 10,375
Expanding BC knowledge via conferences (incls travel)	\$ 7,159
Provision of online information and education	\$ 7,075
Show Your Heart campaign	\$ 3,000
Domestic travel for BC	\$ 2,557
Audit and bank fees	\$ 2,248
Office expenses	\$ 1,292
Trademark expenses	\$ 544
Other expenditure	\$ 485
<b>Total Expenses</b>	<b>\$ 57,442</b>

### BCAC Expenditure to 31 March 2013

