

2012

BCAC Annual Report





Making a difference together

Tangata tu pakari tonu

The Breast Cancer Aotearoa Coalition:

Providing a voice for New Zealanders who have experienced breast cancer.

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

Providing information, support and representation to empower those with breast cancer to make informed choices about their treatment and care.



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Chairperson's Report



This year BCAC has continued to make strong progress in improving the lives of New Zealanders with breast cancer. Our focus has stayed with our key initiatives of:

- supplying information and resources
- providing a voice for those diagnosed
- informing and advocating for access to world class detection, treatment and care
- working to improve outcomes for Māori and Pasifika women diagnosed.

BCAC's *Step by Step* support pack has gone from strength to strength, with BreastScreen Aotearoa adopting it as a key resource for everyone diagnosed in the national breast screening programme. We surveyed women who have received *Step by Step*. The fantastic feedback we received showed us that the information booklet, treatment diary and journal are hugely valued as supportive tools to help women navigate the challenges of breast cancer diagnosis and treatment. It is great to know that this resource, built by the women of BCAC from their own experience of breast cancer with the input of cancer medical experts, is providing tangible help when and where it is needed.

Our web videos, *Kiwi Stories of Breast Cancer*, have now had nearly 5,500 views through our website and on YouTube, and our website receives around 2,000 hits every month. We have kept the website updated with news and information from within New Zealand and internationally, aiming



to keep our readers well-informed about what's up in breast cancer. Our Facebook page is active, with a growing number of 'likes' and many people commenting on our posts and letting us know of their experiences of breast cancer treatment and recovery. We also keep in touch with people with an interest in breast cancer through our Twitter account and through our e-newsletter. Our member groups are also able to use our communication media to let others know of their events and achievements.

BCAC has engaged at many levels in the New Zealand health system to ensure the voice of Kiwi women with breast cancer is clearly heard. In October we delivered a briefing on issues raised by our members and others around the country to the Minister of Health, Tony Ryall, as well as politicians from across the political spectrum and leaders of government cancer programmes. We spoke of the need for:

- greater psychosocial support
- better provision of lymphoedema treatment
- funded access to fertility treatments for young women needing chemotherapy.

BCAC expressed disappointment that women needing delayed breast reconstruction are again being dropped from surgery waiting lists in some areas, and the Minister was surprised to hear that this was happening. We asked the Minister to take advantage of a PHARMAC consultation to establish improvements to the timeliness, transparency and quality of medicines funding decisions. We reminded him of the importance of the valuable data that is collected in our breast cancer registers and asked him to ensure funding is allocated to ensure their continuation. We expressed concern that there is





insufficient quality assurance for pathology and receptor testing in New Zealand, potentially leading to incorrect diagnosis and inappropriate treatment. We also told the Minister of the latest clinical trial results with Herceptin, which show that 12 months of treatment is just as good as two years for early HER2 positive breast cancer, but that women who received only six months have worse outcomes than those treated for 12 months.

BCAC members have provided a strong voice in a wide range of meetings, working groups and conferences to ensure New Zealand women receive the best quality care, see page 21 of this report for details. A highlight is the establishment of the National Breast Cancer Working Group (NBCWG), formed to set best-practice standards for the treatment of breast cancer in New Zealand. Cambridge-based Raewyn Calvert and I are providing the consumer/patient perspective as members of the NBCWG. Standards set by the NBCWG will be based on the 2009 evidence-based best practice *Guidelines for the Management of Early Breast Cancer* that BCAC has advocated for since our formation in 2004 and subsequently helped to develop. The standards set by NBCWG will be a vital element in the implementation of the *Guidelines* and the establishment of world class care for every New Zealand-er diagnosed with breast cancer.

A National Cancer Consumer Representative Advisory Group was also formed with the support of the Ministry of Health this year, chaired by BCAC Deputy Chair Chris Walsh, with our Secretary Rowena Mortimer as a member representing consumers in the northern region. This group is a further highlight, marking progress in establishing “a seat at the table” for consumers in policy-making bodies. Those who have the experience of cancer diagnosis and treatment will now have more opportunity to contribute the



wisdom they have gained from their cancer journey to the policies that will affect others newly diagnosed, through membership of this group and others that seek consumer advice and membership. BCAC member Moana Papa has continued to engage with PHARMAC as a member of their Consumer Advisory Committee.

BCAC met regularly throughout the year with Dr Marli Gregory, Clinical Leader of BreastScreen Aotearoa (BSA) and the BSA team; and with Dr Andrew Simpson, Clinical Director of Cancer and others in the Ministry of Health leading cancer programmes. We have contributed to Regional Cancer Networks as consumers via the Māori Leadership Group, as well as the Consumer and NGO Reference Groups. BCAC has commented frequently to PHARMAC via consultations on their policies and operations and in response to their medicines funding proposals and decisions.

Moana Papa has continued to lead us in our engagement with Māori and Pasifika women affected by breast cancer. She convenes a Māori breast cancer group and a similar Pasifika group to share experiences, provide mutual support and to advise BCAC on issues of importance to those diagnosed in these communities. Moana attended the IMPACT advocate training held at the Hobart Annual Scientific Meeting of ANZBCTG, the foremost Australasian breast cancer research group.

This year BCAC launched a new fundraising campaign, *Show your Heart for Women Living with Breast Cancer*, with our major sponsor Arnott's Tim Tam. With the assistance of Progressive Enterprises Ltd, more than \$60,000 was raised for BCAC. Arnott's Tim Tam has been a dedicated and committed supporter of BCAC and without them, BCAC would not be able to offer the tangible support it does for New Zealand women with breast cancer. We are enormously grateful for Arnott's Tim Tam's on-going support.



Our committee has seen some changes during the year. Sadly, we lost our much loved committee member Jenny Williams. Jenny's commitment to develop a support network for women with inflammatory breast cancer led to the formation of IBC Australasia. Jenny was a vibrant and inspirational woman who contributed a great deal to BCAC as our expert on the social media. It was a privilege for us to have Jenny share her insights and perspective as a woman with advanced breast cancer. Her memory will live on and her appearance in our web videos leaves a lasting legacy.

It has been wonderful to welcome our newest committee member, Julie Graham, who leads a Waikato-based support group for women diagnosed with HER2 positive breast cancer. Julie attended the recent Sydney conference organised by the Breast Cancer Network Australia.

During the year Kirsty Jones returned as our Communications Executive, Celia Motion left us to return to an office environment, Bonnie Reid came on board as BCAC's Administrator and Jane Powell continued as our *Step by Step* distributor. Thanks to all of our wonderful committee members who have worked so hard during the year to achieve so much for New Zealanders diagnosed with breast cancer.

And finally, I need to acknowledge all the wonderful work done by the more than 30 breast cancer-related groups that belong to BCAC. The hard work, passion and commitment of our member groups ensures that women diagnosed with breast cancer in New Zealand will be offered a mountain of information, support, advice and assistance when they most need it.

Thank you all for the wonderful work you do.



Key Achievements for 2012

Goal 1: Supplying information and resources

- Delivered *Step by Step* support packs free-of-charge to more than 1400 women newly diagnosed with breast cancer in New Zealand.
- A survey of users of *Step by Step* returned overwhelmingly positive results, with women saying it was practical, helpful and informative.
- Established *Step by Step* as a key resource distributed to everyone diagnosed by BreastScreen Aotearoa.
- Provided up-to-date information on breast cancer diagnosis, treatment and recovery , along with the latest research results on the BCAC website.
- The BCAC web videos, *Kiwi Stories of Breast Cancer*, were viewed by nearly 5,500 people on our website and YouTube.
- Produced information brochures on BCAC and *Step by Step* to distribute to breast clinics, conferences and breast cancer support groups.



Key Achievements for 2012

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

- Responded to queries and questions lodged via the BCAC website offering support to women and assisting them with issues in the health system.
- Briefed the Minister of Health and other key politicians on the need to improve services for New Zealanders with breast cancer, in particular psychosocial care, lymphoedema management, fertility treatment and delayed breast reconstruction.
- BCAC chairperson Libby Burgess appointed as a consumer/patient representative on the National Breast Cancer Tumour Stream Working Group to develop high-quality standards of care for breast cancer in New Zealand.
- BCAC members Dr Chris Walsh and Rowena Mortimer served as members on the National Cancer Consumer Representative Advisory Group.



Key Achievements for 2012

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

- Briefed the Minister of Health and other key politicians on the need to improve quality assurance for breast pathology; to improve the quality of medicines funding decisions; and to ensure that breast cancer registers are funded and maintained.
- Informed the Minister of Health of recent research results showing 12 months of Herceptin treatment is more effective than 6 months and asked him to ensure all eligible women with early HER2 positive breast cancer receive this.
- Advocated for changes to PHARMAC's operating policies and procedures in order to see more transparent decision making around medicines funding.
- Made submissions to PHARMAC on the need to introduce the breast cancer drug lapatinib (Tykerb) as a second-line treatment for women with advanced HER2 Positive breast cancer.
- Promoted the "Tykerb Access Programme for Patients" to ensure a wider number of New Zealanders with breast cancer have access to this drug.
- Highlighted a range of breast cancer clinical trials available in New Zealand through the BCAC website and newsletter.



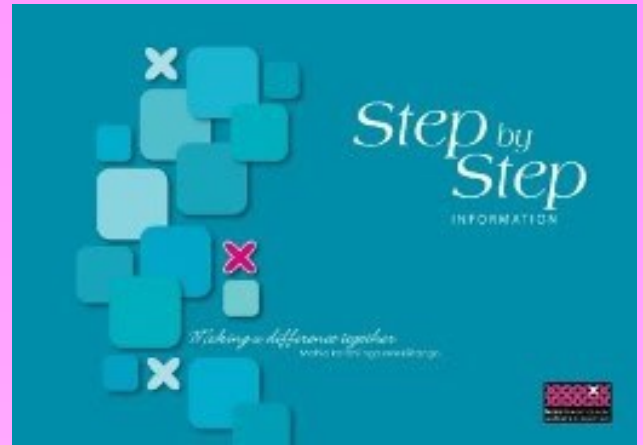
Key Achievements for 2012

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

- Liaison with Māori and Pasifika breast cancer advisory groups.
- Involvement with Wahine Toa, a Māori breast cancer support group.
- 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 2012 we delivered the *Step by Step* support pack to more than 1400 women with breast cancer—here's what some of them had to say about it:

"Inspiring, practical - a godsend."

"Thank you for this excellent resource. It is beautifully done and a real gift."

"Excellent, has helped me feel in control and is an excellent way to record the journey to look back and see where I have come from."

"I was very grateful to receive Step by Step. The information was useful and assisted myself and my family to make the adjustments necessary to cope with the condition positively."

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

"A very helpful book and diary - I love the comments from other survivors."

"Thanks for your Step by Step Diary - Wow wow wow :) !!!"



Sadly, BCAC committee member, Jenny Williams, lost her battle with breast cancer in 2012.

Jenny's passion, commitment and determination to make a difference for New Zealand women with breast cancer was inspirational. Her desire to inform New Zealand women about inflammatory breast cancer (IBC) resulted in the formation of IBC Australasia which will serve to educate women about this form of the disease for years to come.

Jenny was also a star of BCAC's web videos, Kiwi Stories of Breast Cancer. Her humour and unique take on life shine through in the videos and will undoubtedly help and inspire other women on their breast cancer journey.

Jenny, you are missed.

Committee Organisation

The BCAC committee

Those serving on the committee during 2012 were:

Chair: Libby Burgess
Deputy Chair: Chris Walsh
Secretary: Rowena Mortimer
Treasurer: Louise Malone
Members: Sue Ellis
Moana Papa
Van Henderson
Gillian Wintrup
Jenny Williams
Julie Graham



Other Involvements

In 2012, 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 National Panel to Review Breast Biopsy Errors
- Presented at the Psycho-Social Oncology New Zealand conference
- Reach to Recovery, Taiwan 2011, poster presentation



Rowena Mortimer

- Chair the Northern Cancer Network Consumer Group
- Member of the National Cancer Consumer Representative Advisory group
- Member of the Waitemata District Health Board Cancer Control group
- Attended the Northern Cancer Collaborative for cancer consumers
- Presented at the Psycho-Social Oncology New Zealand conference



Sue Ellis

- Reach to Recovery, Taiwan 2011, poster presentation
- Psychosocial Oncology Workshop
- Medicines New Zealand - Access to medicines mini conference
- International Psycho-Oncology World Congress, Brisbane 2012, poster presentation.



Moana Papa

- Consumer representative on the Maori Leadership Group for the Northern Cancer Network
- Member of PHARMAC's Consumer Advisory Committee
- Member of PHARMAC's Te Roopu Āwhina Māori
- Attended the Australia New Zealand Breast Cancer Clinical Trials Group Annual Scientific Meeting, as the Kiwi advocate on the IMPACT Advocate Programme



Evangelia Henderson

- Chief executive New Zealand Breast Cancer Foundation
- Member of CANGO (Cancer Non-Government Organisations)



Julie Graham

- Founding member of HER2 Heroes Waikato
- Attended the Breast Cancer Network Australia 2012 conference— 'Strength to Strength'.



Gillian Wintrup

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





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.

Our member groups are:

1. Age Concern
2. Alleviate
3. Boobops Dragon Boat Team
4. Breast Cancer Action Trust
5. Breast Cancer Network
6. Breast Cancer Research Trust
7. Breast Cancer Support
8. Breast Cancer Support Northland Trust
9. Breast Cancer Support Tauranga
10. Breast Health NZ
11. Busting with Life
12. Her2 Heroes
13. IBC Australasia

BCAC member groups cont'

14. Kenzies Gift
15. Look Good Feel Better
16. Lymphoedema Network
17. Mamazon Club
18. New Zealand Breast Cancer Foundation
19. Pink Dragons
20. Pink Pilates
21. Reconstructables
22. Rotorua Breast Cancer Trust
23. Skip for Life
24. Shocking Pink
25. Sweet Louise
26. Taranaki Dragons
27. Te Ha o te Oranga o Ngati Whatua
28. Terrier Race Against Time
29. Waikato Breast Cancer Trust
30. Waikato Treasure Chests
31. WONS
32. YWCA Encore



Supporters

We applaud the commitment and generosity of our principal donor Arnott's Tim Tam. Their support enables BCAC to help thousands of New Zealanders diagnosed with breast cancer each year through our *Step by Step* support pack and the information and advice provided on our website.

We were thrilled with the success of the first "Show Your Heart" fundraising campaign, carried out in conjunction with Arnott's Tim Tam and Progressive Enterprises Ltd. We look forward to building this campaign in the coming year and to an ongoing and fruitful partnership with these two organisations committed to helping women with breast cancer.

We'd also like to acknowledge the support of the Lotteries Commission and Morgan and Morgan Hair & Makeup for their generous contributions over the past year. As well, we must say a huge thank you to all of the individual donors who contributed financially to enable BCAC to continue with its work—your support is truly valued.





Plans for 2013

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, 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:
 - involvement in a wide range of local, regional and national breast cancer related working groups, committees and organisations



Plans for 2013 cont'

- 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 2013 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



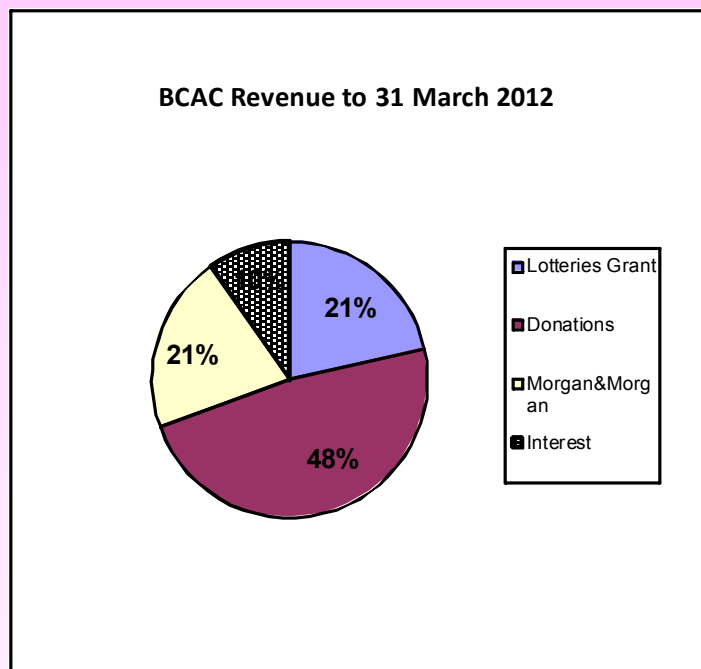
Financials



Revenue for the year to 31 March 2012

BCAC Revenue 2012	
Funding Source	Amount (\$)
Lotteries Grant	5,000
Donations	11,230
Morgan&Morgan	4,867
Interest	2,258
Total	23,355

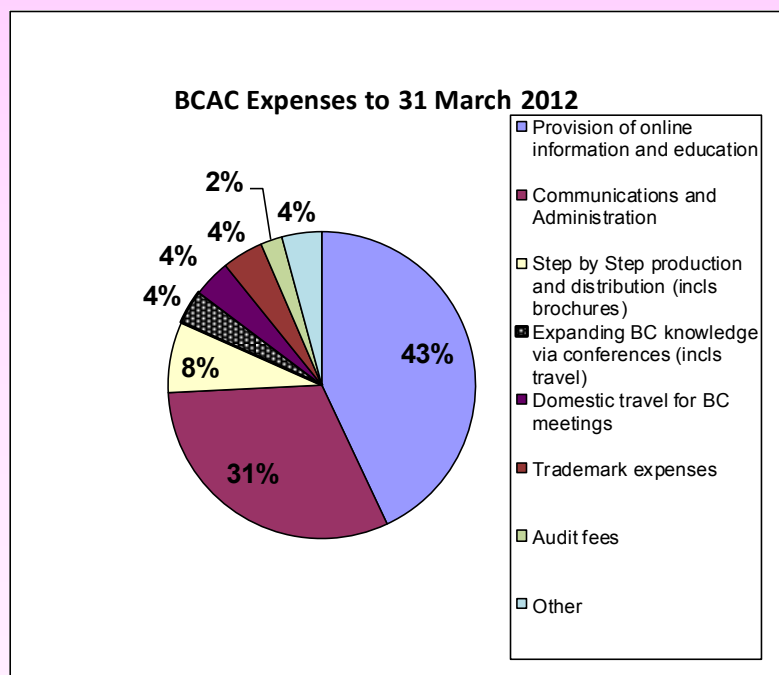
* A donation of \$60,053 from Arnott's Tim Tam was made after 31 March, 2012



Financials cont'

Expenditure for the year to 31 March, 2012

BCAC Expenses 2012	
Expenses	Amount (\$)
Provision of online information and educa-	24,576
Communications and	17,828
<i>Step by Step</i> produc- tion and distribution (incls brochures)	4,261
Expanding BC knowledge via confer- ences (incls travel)	2,065
Domestic travel for BC	2,247
Trademark expenses	2,467
Audit fees	1,300
Other	2,395
Total	57,139



A full copy of BCAC's audited financial report for the year ending March 31, 2012 is available on request.



