bcac breast cancer aotearoa coalition

Making a difference together
Tangata tū pakari tonu

BCAC Annual Report from the Chair 2011

Introduction

Compiling the Annual Report provides an opportunity for us to reflect on BCAC's activities in the past year and review our achievements. As you will read it is evident that we have achieved much in the last 12 months and made excellent progress towards the goals we agreed at the Annual General Meeting in 2010.

This year we have completed two major projects that have created valuable resources for New Zealanders diagnosed with breast cancer. We have participated in many discussions, conferences and meetings allowing us to have valuable input into a number of health policy and decision-making bodies and processes.

Our key areas of focus continue to be to support and empower those diagnosed with breast cancer, as well as their family, whanau and friends, by providing information and resources; to provide a unified, evidence-based voice for New Zealanders with breast cancer; to inform and advocate for timely access to world class breast cancer care, including treatments and psychosocial care; and to consult and engage with Māori and Pasifika women to identify and promote initiatives that could improve breast cancer outcomes in these communities.

Before I report our progress on each of these key initiatives I will highlight a few achievements of note this year:

- In early May BCAC re-launched our website following several months of research, writing and development. The new website provides a comprehensive resource supplying detailed information about all aspects of breast cancer and the supports that are available.

- We launched *Kiwi Stories of Breast Cancer*, a series of web-videos exploring Kiwi experiences of breast cancer, at a special screening in early July. These can be viewed through our website or YouTube and have generated a great deal of very positive feedback.

- A delegation of BCAC committee members delivered a briefing to the Minister of Health when we met with him in July. We focused on significant breast cancer issues needing attention and proposed practical solutions for each of these.

- We continue to distribute copies of our *Step by Step* support pack and have now given out more than 3500 copies to New Zealanders newly diagnosed with breast cancer. We continue to receive many messages of appreciation on *Step by Step* from the women who use it.

- We were delighted to welcome two new member groups, *Shocking Pink* and the *Australasian IBC Network* (AIBCN) to BCAC over the last month. Christchurch-based Shocking Pink will focus on providing online information and resources for young women with breast cancer and their families. AIBCN will link women diagnosed with inflammatory breast cancer in NZ and Australia to provide much needed information and support.

- BCAC Secretary Rowena Mortimer was appointed Deputy Chair of the recently formed Breast Cancer Steering Group within the Northern Cancer Network.

- BCAC was delighted to accept a generous offer of support from *Morgan and Morgan Hair & Makeup* based in Takapuna, Auckland. Jennifer Morgan has established a system of regular donations to BCAC based on the number of customers visiting her business.

- We continued to receive the wonderful support of our principal donor, Arnott's Tim Tam, without whose generosity we could not have achieved our project objectives throughout the year.

- In my position as BCAC Chair I was appointed a Member of the New Zealand Order of Merit (MNZM) in the New Year's Honours list, for services to women's health. This honour provides tangible recognition for all of us who contribute to BCAC's work. Along with that bestowed on Dr Chris Walsh last year, it demonstrates that other New Zealanders appreciate *Team BCAC* and all that we have achieved together for the women of New Zealand.

Progress on key initiatives

Psychosocial support

Our first major project of the year was the re-launch of our website following several months of research, writing and development. The new website, largely written by Kirsty Jones, is a comprehensive resource supplying detailed information about breast cancer.

As well as explaining BCAC and our work, the website provides information about the early detection of breast cancer, the diagnosis and treatment of the disease and the supports available if you have been diagnosed. As well as information about all aspects of breast cancer, we provide regularly updated news about the latest research and treatments, as well as news from all our member groups. I must acknowledge and thank Kirsty Jones for managing this project and for the considerable skill and hard work she put into the research and writing needed to bring the website upgrade to successful fruition.

BCAC also succeeded in developing and producing a series of web videos, *Kiwi Stories of Breast Cancer* this year. These feature New Zealand women and men talking about their experiences of breast cancer diagnosis, treatment, care and life afterwards. This was a major project for BCAC and Dr Chris Walsh, our Deputy Chair, committed a huge amount of time and energy to it, along with producer Emma Robinson, to ensure the finished product was professional, accessible, informative and compelling.

Those featured in the videos have different types of breast cancer and are from a wide range of backgrounds, age groups and ethnicities. They talk candidly about their experiences and feelings during the 'breast cancer journey'. Partners, a sister and a son also share their reactions and describe the support they provided, while health professionals discuss treatment options.

BCAC's aim in producing these web videos was to demystify breast cancer and offer those diagnosed hope and reassurance that they are not alone. With the courageous help of all the participants we believe we have created an accessible resource via our website and You Tube that offers support, information and encouragement to those newly diagnosed with breast cancer and those who walk alongside them.

We continue to offer *Step by Step* resource packs to all those newly diagnosed with breast cancer, distributing it largely through the national network of breast care nurses. We are also delighted that BreastScreen Aotearoa recently evaluated the resource and have agreed to offer it to all patients at diagnosis appointments. *Step by Step* has now been given to more than 3500 women since it was first published in 2008 and we regularly receive many positive comments from women who have used the resource.

As part of BCAC's ongoing commitment to extending the effective psychosocial support available for New Zealanders diagnosed with breast cancer, a number of committee members will again attend the *Psychosocial Oncology New Zealand (PONZ)* conference in Hamilton later this month. A team from the BCAC committee including Dr Chris Walsh, Rowena Mortimer and Jenny Williams will take part in a presentation about the production and development of the web videos, *Kiwi Stories of Breast Cancer*.

BCAC committee members Dr Chris Walsh and Sue Ellis will attend the *16th International Reach to Recovery Breast Cancer Support Conference* in Taiwan in November. This will provide another opportunity for Chris to highlight the web videos and their value in a verbal presentation while Sue will present a poster describing the project.

Standards of care

BCAC believes the implementation of the *Guideline for the Management of Early Breast Cancer* is a key step towards ensuring that all New Zealand women receive world-class care and treatment, regardless of ethnicity or where they live.

At the end of last year we reported that our longer term focus had shifted from input into the development of the Guideline and the associated implementation plan to monitoring to ensure DHBs and clinicians are providing the standard of care outlined in it.

BCAC recently requested information from both the Auckland and Waikato Breast Cancer Registers on the time between diagnosis and surgery. This revealed that waiting times for breast cancer surgery are several weeks longer for those treated in the public health system than for those who receive surgery in the private sector. We raised this discrepancy with the Minister of Health, provided him with the data and suggested he establish a target for timely provision of surgery and chemotherapy along with the recently established four week radiotherapy target that has been successfully implemented. We suggested that resources would need to be allocated to DHBs to enable such targets to be met.

Our ability to acquire accurate data from the Breast Cancer Registers that could not be obtained from any other source demonstrated the great value of the Registers. They contain a wealth of information on the diagnosis, pathology and nature of the disease, treatments and resulting outcomes for patients of different ages, ethnicities and genders. This allows a detailed understanding of the disease and its impacts on our communities and provides an invaluable resource in enabling its effective management and in planning for future needs.

During the year we were contacted by women in Tauranga who had been removed from surgery waiting lists while awaiting delayed breast reconstruction. We took a team approach to solving this problem. The DHB was reminded that the government deems breast reconstruction to be a high priority and the Ministry of Health offered the women surgery at the Hutt DHB. Credit goes to the women who raised this issue with us, their breast care nurses and clinical specialists who were passionate about the importance of this surgery to the well-being of the women and all those involved in finding a solution.

We successfully joined forces with Claire Doole of the Lymphoedema Network as well as member groups Breast Cancer Support, the New Zealand Breast Cancer Foundation and the Breast Cancer Network to encourage the Waitemata DHB to support patients in re-establishing lymphoedema services following breast cancer surgery.

We continue to follow up on the issue of regional differences in the duration of Herceptin treatment given to women with early HER2 positive breast cancer.

Māori and Pasifika

Committee member Moana Papa has worked hard during the year to establish a network of women within the Māori and Pasifika communities that BCAC can consult and engage with when identifying and addressing the issues facing those diagnosed with breast cancer in these communities. Wahine Toa, the breast cancer support group Moana initiated for Māori women continues to meet regularly in Manukau.

Moana was one of three women selected to talk about her breast cancer journey in a DVD developed by the New Zealand Breast Cancer Foundation as a health promotion tool to encourage Māori women to have mammograms.

In addition to her role on the PHARMAC Consumer Advisory Committee (CAC), Moana is the sole consumer representative on the Māori Leadership Group of the Northern Cancer Collaborative, a member of the Consumer Advisory Committee to Otara Health Trust and a volunteer with BreastScreen Aotearoa in Counties Manukau DHB and the Raukura o Hauora o Tainui ki Tamaki Makaurau Screening Unit.

As a representative of Non-Government Organisations (NGOs) on the Northern Cancer Network (NCN), I organized a meeting between the NGOs and the NCN's Māori Leadership Group. In addition to BCAC the NGOs involved were the NZ Breast Cancer Foundation, the Cancer Society (Auckland) and the Leukaemia and Blood Foundation. The aim was to determine how the NGOs could best engage with Māori and whether a collaborative approach across the NGOs could be beneficial. We will meet again following discussions within the governance bodies of each of the NGOs.

Access to effective treatments

In July BCAC again visited the Minister of Health, Tony Ryall to brief him on issues relevant to the breast cancer community in New Zealand. This year BCAC focused on three key issues in its meeting with Mr Ryall. These were:

- the shortage of medical oncologists to provide effective treatment including chemotherapy and follow up for New Zealand cancer patients;
- the need for more timely cancer treatment, particularly chemotherapy and surgery;

- the need to regionally extend and fund New Zealand’s Breast Cancer Registers to capture detailed data about breast cancer.

We noted that the serious shortage of trained medical oncologists in some areas means patients are currently being forced to wait longer than the recommended times to receive chemotherapy and in some cases treatment is not being provided. Oncologists in the country’s cancer treatment centres have been under enormous pressure, especially in the Midlands, MidCentral and Capital and Coast areas.

BCAC recommended a number of measures to the Minister to address this issue, including:
- incentives for trainees to remain in NZ
- incentives for overseas-based oncologists to return to NZ
- increasing remuneration for oncologists in this country.

BCAC acknowledged the recent improvements in access to radiation therapy for cancer patients (nearly all cancer patients who require radiotherapy are now receiving treatment within four weeks), but stressed the need for timely access to treatment in other areas too. We suggested that targets also be introduced for chemotherapy and surgery.

We raised the importance of the existing Breast Cancer Registers in quantifying and understanding the nature of breast cancer in New Zealand, its treatment and outcomes as well as its impacts on different sections of our population. We requested that Ministerial funds be made available to allow the continuation and regional roll-out of the Registers.

BCAC raised a number of other issues with the Minister, including a suggestion that the subsidies provided for wigs and prostheses be increased.

During the year, we met with senior Ministry of Health officials Dr John Childs, National Clinical Director, Cancer, and Deborah Woodley, National Programme Manager, Cancer, to ensure ongoing communication and good working relationships with those involved in making and implementing the policy and funding decisions that affect women with breast cancer.

Moana Papa continues to participate in PHARMAC’s Consumer Advisory Committee (CAC), providing us with an opportunity to seek to establish effective consumer representation for New Zealand women with breast cancer within New Zealand’s medicines purchaser.

Dr Chris Walsh and I attended the November 2010 and April 2011 meetings of the Breast Cancer Special Interest Group (BCSIG) of the NZ Association of Cancer Specialists as consumer members of this specialist group. These meetings not only provide us with an opportunity to network and build relationships with our cancer doctors, but also give us insight into the important issues under discussion by breast surgeons, medical and radiation oncologists and pathologists and to have input. These insights help to demonstrate where our advocacy is needed to advance access to effective, evidence-based treatments. BCAC member Raewyn Calvert and I will attend the next BCSIG meeting later in November. Raewyn is a consumer representative for the Midland Cancer Network and the NZ representative on the Consumer Advisory Panel of Australian New Zealand Breast Cancer Trials Group (ANZ BCTG)

BCAC provided positive feedback to PHARMAC's proposal of May 2011 to remove the Special Authority criteria for the taxane chemotherapy drug docetaxel and thus widen funded patient access to this medicine. This proposal was subsequently accepted and funded patient access to docetaxel is now available to those who need it.

In response to consultation we also made a formal submission in March 2011 to PHARMAC on its Exceptional Circumstances funding, pointing out that the changes proposed would not make access to medicines any easier for those in desperate need.

Screening

BCAC met regularly during the year with BreastScreen Aotearoa (BSA) representatives Jacqui Akuhata-Brown (Group Leader, National Screening Unit (NSU)), Marli Gregory (Clinical Leader), Barbara Irwin (Programme Leader) and Deborah Harris (Corporate Services Manager). This follows our commitment last year to work more closely with BSA to promote breast awareness, mammographic breast screening and participation in the National Breast Screening programme for women aged 45 to 69,

These meetings have further strengthened the relationship between BCAC and BSA and established good, frequent communication to ensure BCAC is kept up to date with developments and issues. We were pleased to learn that significant gains over the past two years have seen the Māori screening coverage increase from 47 to 57% and Pasifika screening grow from 49 to 62%, although further effort is needed to reach the 70% target. There was further good news in that all mammography funded by the Ministry of Health must be digital by 2013 and that four of the eight BSA screening providers already use digital technology. Another positive move from BSA is the roll out of centralised digital screening image storage as this will greatly improve data capture and retrieval.

We are especially pleased to report that BSA has agreed to distribute the BCAC *Step by Step* support pack at their breast cancer diagnosis appointments. This ensures many more women will receive empowering information as soon as they receive their diagnosis.

Consumer representation and education

BCAC committee members attended many meetings, workshops, training courses and conferences in ongoing efforts to up-skill, learn and provide input where it is needed and requested. This continuous learning and involvement is vitally important in ensuring effective consumer representation for New Zealanders with breast cancer. In addition to the organizations I have already mentioned to which BCAC committee members contribute, there are several conferences, workshops, meetings and events we have been involved in or will be over the coming months.

Three BCAC committee members, Moana Papa, Sue Ellis and Rowena Mortimer, travelled to the USA in early December 2010 to attend the 33rd Annual San Antonio Breast Cancer Symposium (SABCS) in San Antonio, Texas. SABCS is a key international breast cancer research conference, attended each year by around 9,000 researchers and advocates from all over the world. The Alamo Breast Cancer Foundation offers scholarships to advocates to attend the Symposium and the associated Advocate Programme. Sue Ellis and Moana Papa from the BCAC committee both won scholarships to attend the entire event. Attending this event emphasised for all three of our representatives the value of the advocacy programme and highlighted just how much research is currently underway to investigate many aspects of breast cancer with the aim of developing improved treatments.

Early this year BCAC committee member Gillian Wintrup attended the 11th Annual Conference for Young Women Affected by Breast Cancer held in Florida. Young women with breast cancer often face different challenges with their care, treatment and survivorship from those confronting older women. It is important to educate and update ourselves about these issues as we work towards ensuring New Zealand women have access to world-class evidence-based treatment and care. Gillian is a member of the Rotorua Breast Cancer Trust and has provided a valuable link to the women of Rotorua who are fighting breast cancer.

This year the Australian New Zealand Breast Cancer Trials Group (ANZ BCTG) held its Annual Scientific meeting in Queensland, Australia in July. I attended this conference as a member of IMPACT, the programme for Improving Participation and Advocacy for Clinical Trials associated with ANZ BCTG's Consumer Advisory Panel (CAP). Conference highlights included sessions on clinical implications of emerging basic science, neo-adjuvant therapy, new trial designs and improving patient-focused care.

BCAC Secretary Rowena Mortimer has continued to chair the Consumer Reference Group of the Northern Cancer Network (NCN). She was recently appointed as Deputy Chair of the NCN's newly formed Breast Cancer Tumour Stream Steering Group. Rowena is also the consumer representative on ProCare's Clinical Guidance Committee where she provides a non-academic viewpoint. I attend NCN meetings on behalf of BCAC as a representative of the NGO Forum of the NCN and I also participate in the Breast Cancer Steering Group.

Dr Chris Walsh represents BCAC as a member of the governing committee of the Consumer Collaboration of Aotearoa (CCA), a coalition of consumer-driven health-related organizations. Chris participated in the Patient Diary Group facilitated by the Cancer Society and is a consumer representative on the MidCentral Research Group, which is conducting a study to investigate communication at first consultations.

Until her departure for the UK in May this year, Pat Fairbrother was a member of the Consumer Representative Forum for the Central Cancer Network (CCN) and a Board member and recently appointed Trustee of Cancer Voices New Zealand. She was the consumer representative on the National Volunteer Information and Support Advisory Committee for the Cancer Society and also the patient representative of the Plastics Network Group CCN.

Supporters

Without the support of our principal donor Arnott's Tim Tam, many of our achievements of the past year would simply not have been possible. We acknowledge the ongoing and crucial contribution of this generous company to our projects, particularly to the *Step by Step* and *Kiwi Stories of Breast Cancer* resources. In the coming year we are planning a major fundraising campaign with Arnott's Tim Tam to take place around Mother's Day in May 2012.

As previously mentioned *Morgan and Morgan Hair & Makeup* based in Takapuna, Auckland has become an important financial supporter of BCAC's work thanks to Jennifer Morgan.

BCAC Organisation

Administration

In December 2010 Jane Powell came on board to assist with distributing *Step by Step* and to undertake some administrative duties. Kirsty Jones and Celia Motion continued to share BCAC's communications work. In August 2011 Kirsty went on maternity leave and Celia will continue in the communications role until early 2012.

Committee

I have chaired the BCAC committee with Dr Chris Walsh as Deputy Chair, Rowena Mortimer as Secretary, Dr Louise Malone as Treasurer and Sue Ellis, Pat Fairbrother, Moana Papa, Evangelia Henderson, Gillian Wintrup and Janet Neale as committee members. During the year Pat stood down from the committee as she returned to the United Kingdom and more recently Janet Neale also stood down. We have been very fortunate to recently recruit Jenny Williams who brings energy and commitment to the committee as well as her valuable perspective as a woman diagnosed with inflammatory breast cancer that has recently become metastatic. Jenny's social media skills are a great asset to BCAC.

Membership

Two new groups were recently added to BCAC membership: *Shocking Pink* is a Christchurch based group for young women with breast cancer that will provide online resources and information; the *Australasian IBC Network* (AIBCN) is the vision of our own BCAC committee member Jenny Williams, along with Sandra Wilson of Australia. AIBCN will establish a website providing support and information and linking women with IBC and their carers throughout Australasia.

BCAC now has 32 breast cancer related member organisations around New Zealand and around 50 individual members. It's wonderful to see the breadth and strength of our coalition growing to provide the resources needed by our diverse population of women diagnosed with breast cancer.

Our member groups have been involved in a wide range of great projects that benefit kiwi women with breast cancer, but I'd like to highlight a particular achievement of the Waikato Breast Cancer Trust (WBCT). This year WBCT has been the top recruiting site in Australia and New Zealand for both the SNAC2 and LATER clinical trials and the third highest recruiter to the IBISII trial. SNAC2 compares sentinel node biopsy based removal of lymph nodes with full axillary node clearance for those with larger, multifocal or more aggressive breast cancer. LATER investigates whether letrozole can prevent recurrence of hormone receptor positive breast cancer five to fifteen years after initial diagnosis. IBISII is testing whether anastrozole can prevent breast cancer occurrence in women at high risk. It's fantastic to see a New Zealand breast cancer team at the forefront of clinical trial recruitment. Clinical trials are the means by which evidence is gathered to test new and improved treatments, leading to better outcomes for future patients. Well done WBCT and the women of Waikato participating in these important trials!

Providing a unified and effective voice for New Zealanders with breast cancer is one of BCAC's main priorities and to do this we need to maintain good communication with our members. We aim to do this through our much improved website, our new e-newsletter, through personal contact with our members and provision of support and information, and via involvement in our member groups' activities. I encourage all our members to send us your stories so we can share them on the website and in the newsletter, to stay in touch and let us know if we can help you or your members in any way.

BCAC's current member groups:

- Age Concern
- Alleviate
- Australasian IBC Network
- Boobops Dragon Boat Team
- Breast Cancer Action Trust
- Breast Cancer Network
- Breast Cancer Research Trust
- Breast Cancer Support
- Breast Cancer Support Northland Trust
- Breast Cancer Support Tauranga
- Breast Health NZ
- Busting with Life
- Her2 Heroes
- Kenzies Gift
- Look Good Feel Better
- Lymphoedema Network
- Mamazon Club
- New Zealand Breast Cancer Foundation
- Pink Dragons
- Pink Pilates
- Reconstructables
- Rotorua Breast Cancer Trust
- Skip for Life
- Shocking Pink
- Sweet Louise
- Taranaki Dragons
- Te Ha o te Oranga o Ngati Whatua
- Terrier Race Against Time
- Waikato Breast Cancer Trust
- Waikato Treasure Chests
- WONS
- YWCA Encore

Plans for the coming year

- Offer ***Step by Step*** to every New Zealand woman diagnosed with breast cancer.
- Support and promote the provision of other beneficial **psychosocial care and resources**.
- Regularly update the **BCAC website** at www.breastcancer.org.nz
- Continue to promote implementation of the **Guideline for the Management of Early Breast Cancer** and monitoring of adherence to this standard of care for all New Zealand breast cancer patients, e.g. monitor access to medicines, waiting times for treatments etc and highlight significant issues.

- Continue to work towards making a positive difference for **Māori and Pasifika** women diagnosed with breast cancer.
- Promote **timely access to effective treatments** (surgery, medicines, radiotherapy).
- Continue to promote breast awareness, **mammographic breast screening** and participation in the BreastScreen Aotearoa breast screening programme.
- Promote the collection and timely analysis of comprehensive **cancer data**, especially through the **Breast Cancer Registers**.
- Continue to promote and provide **consumer representation** within the health sector for NZ women with breast cancer.
- Increase the New Zealand platform of **evidence-based advocacy** and further develop our **educated consumer population** through supporting BCAC members to attend relevant conferences.
- Engage in **other projects** that will make a positive difference for NZ women with breast cancer, e.g. continue to promote improved access to high quality breast reconstruction.
- **Fundraise** to support BCAC's activities by conducting a major campaign with our principal sponsor Arnott's in May 2012 and applying to charitable trusts and foundations. New funding initiatives will include:
  - creating information leaflets and flyers to support the distribution of *Step by Step* and to inform stakeholders about BCAC;
  - providing ongoing support for BCAC's website;
  - supporting our administration and communications contractor positions.

Conclusion

Once again I acknowledge the commitment and hard work of our wonderful committee members and staff who have dedicated their efforts throughout the year to improving the experience and outcomes of New Zealand women diagnosed with breast cancer. We can look with particular satisfaction at our new website and web videos and acknowledge the skill and professionalism that have made these both such valuable resources for kiwi women.

The expansion of BCAC's membership to include groups providing information and support for young women with breast cancer and those with inflammatory breast cancer reflects the diverse nature and the maturity of our broad coalition.

Every group within BCAC's membership is driven by fine New Zealanders, all giving of their time and energy to help others diagnosed with breast cancer. I salute and warmly congratulate each and every one of you!

Tangata tū pakari tonu – Together we are stronger.

Libby Burgess
BCAC Chair