



**Breast Cancer Aotearoa Coalition Update:
December 2008**

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The Tim Tam Pink Parties for 2008!



Letter from the Lazyboy Chair



The members of the Breast Cancer Aotearoa Coalition (BCAC) can look back over the last year with a feeling of great achievement. I want to highlight three special milestones in our efforts to make world-class detection, treatment and care accessible to all those affected by breast cancer in New Zealand.

We have lobbied hard since 2005 for the establishment of New Zealand **Clinical Best Practice Guidelines for the Management of Early Breast Cancer**. The Ministry of Health eventually agreed to the establishment of this important resource for our doctors and we have participated as consumers on the Guideline Development Team convened by the NZ Guidelines Group. The draft guidelines were completed in late October and consultation on these is now under way. The final guidelines are due to be adopted in February 2009. Watch this space!

In 2005 one of our founding committee members, medical oncologist Nicole McCarthy, first presented us with data from the international HERA clinical trial showing the dramatic impacts of Herceptin on the prognosis of women with early HER2 positive breast cancer. For more than 3 years we have fought to achieve **funding for 12 months of Herceptin treatment** for NZ women. We have gathered and presented data and information, kept up with the emerging scientific evidence, consulted expert clinicians, met with MedSafe and PHARMAC, visited MPs, taken petitions to Parliament, made submissions to official bodies and processes, supported legal proceedings and educated the public through the media and our website on this topic. Repeated polls this year showed that 85 - 87% of New Zealanders agreed that the government should pay for this international standard of care for our women, suggesting our message was heard. This became an election issue with National pledging to fund the full course if brought to government. In November National was elected to lead the country. John Key clearly stated that funding for 12 months of Herceptin treatment was a priority for his new government and would be provided through the Ministry of Health before Christmas. On December 10 this pledge was honoured and the official announcement of funding was made, backdated to 19th November, the day the government was sworn in. Funded Herceptin is also available for those who have recently finished a 9 week course or cut a 12 month course short.

What a huge relief for our women with early HER2 positive breast cancer and for those who have fought so long and so hard to make this treatment available to all in NZ who need it! We must acknowledge the contributions of Anne Hayden, Nic Russell, Mandy Carter, Chris Walsh and the Herceptin Heroines who presented petitions to parliament and took PHARMAC to the

High Court to challenge their decisions not to fund the 12 month treatment. These courageous women stood up and represented all those affected by HER2 positive breast cancer while battling their own diagnosis. I also thank the Herceptin Riders, Skip for Life and all the wonderful Kiwis who rallied to this cause to support our women. This year we invested a huge amount of time and effort into developing a resource that will provide direct support to New Zealand women receiving a breast cancer diagnosis. This is BCAC's **Step by Step support pack** that all our member groups as well as appropriate medical professionals and support organisations around the country have recently received for review. Feedback to date is very positive and distribution to women has begun through Breast Care Nurses, Breast Physicians, and Surgeons, as well as to individual women who request packs from us.

We look forward to working closely with our member groups and individuals over the coming year to achieve even more for New Zealand women with breast cancer.

Kia pai te Tau Hou tā koutou!

Happy New Year !

Libby

Member News

In 2008 BCAC's membership expanded to 28 groups and 39 individual members. This year BCAC has been delighted to welcome on board valued member groups Breast Cancer Support Northland Trust, the Taranaki Dragons, the MARCO Trust and WONS: Nursing, Education and Health Promotion Service. BCAC is also thrilled to have founding member group The New Zealand Breast Cancer Foundation back within the membership. BCAC looks forward to long, productive collaborations with these groups and we continue to value the ongoing input and support of existing members.

Other News

Tim Tam Pink tea Parties

For the second year BCAC and key supporter Arnott's NZ encouraged New Zealanders to hold a pink tea party and raise funds for BCAC. We had another wonderful response this year and raised over \$30,000. These funds will go towards BCAC core operational costs in 2009 and will also be used to help us develop a second edition of *Step by Step*. Many party-goers from 2007 hosted parties again in 2008 and we were particularly delighted to hear again from Jane Pratley and her



daughter Sarah (pictured above at right, top in 2007 and below in 2008) who host the parties together. Jane writes: “Last year I hosted my antenatal and Plunket Coffee Groups, and this year I hosted girlfriends for a baby shower! Given she was expecting a baby girl it was very apt to dress the house in pink, pull out my grandmother’s 50 year-old pink tea set and make pink cupcakes for everyone!!! I am going to make it an annual event for Sarah (now 18mths) and I to host a pink tea party and donate to this very good cause, teaching Sarah not only the importance of donating but also of breast cancer.”

You can see from the photos how much Sarah, our youngest supporter, has grown! Read more about the 2008 parties on the BCAC website at:

<http://www.breastcancer.org.nz/PinkTeas2008.htm>

BCAC AGM

BCAC held its AGM at the Auckland Cancer Society on Friday 28 November. The Committee for 2009 were elected as follows:

Chair, Libby Burgess; Deputy Chair, Claire Ryan; Treasurer, Louise Malone; Secretary, Rowena Mortimer

Committee Members: Jane Rutledge, Chris Walsh, Sue Ellis

Suzanne McNicol from The New Zealand Breast Cancer Foundation has also joined the Committee as of 16 December.

The Committee will be holding a Strategic Planning Day in January.

From Libby: ‘I would like to express huge gratitude for the immensely valuable work that retiring committee members Sue Guthrie and Raewyn Calvert have done for BCAC. Sue has been our gallant Treasurer through thick and thin, taking us through the early years when we didn’t know where the next dollar would come from into a time where we have a more secure financial footing. Raewyn joined us from the Reconstructables, and has led us in our ongoing efforts to promote the establishment of high quality breast reconstruction throughout New Zealand. She has also been a key player in the development of Step by Step.’

Summary of Progress on BCAC Initiatives in 2008

1. To ensure consistent, high quality detection and treatment of breast cancer throughout New Zealand by promoting the development and implementation of evidence-based best practice guidelines.

We are close to achieving this original objective that was set out for BCAC when we first formed as a Coalition of 12 groups in 2004. The draft guideline sets out currently accepted standards for best practice medicine in the various specialty areas as well as general principles of care. It is aimed at ensuring a consistent and high standard of care for breast cancer patients throughout NZ and not only provides a guide for clinicians but also a means of

measuring the quality of care provided to our women. The Guideline Development Team of clinical experts was chaired by the highly respected Waikato-based surgeon Ian Campbell. BCAC members Amanda Rudd, Chris Walsh and Libby Burgess have been closely involved in developing the Guidelines, and have aimed to ensure that the consumer perspective was always represented. In future, the Guideline will need to be regularly updated to ensure new evidence-based standards of care are incorporated into New Zealand practice and monitoring will be needed to confirm that the best possible care is provided by our medical teams across the country.

2. To support the prompt and effective implementation of the extended age breast screening programme (45 to 69)

BCAC has worked closely with BreastScreen Aotearoa (BSA) this year to promote the extended age screening programme. Claire Ryan has continued to serve as a Director of Breast Screen Auckland Ltd. BCAC has collaborated with Dr Madeleine Wall and others from BSA to develop an informative screening area on our website. Since this webpage has been added, BCAC has received many enquiries from women wishing to enrol for screening and receive more information about the screening programme.

3. To inform and advocate for improved access to breast cancer treatment medicines

In addition to our advocacy for Herceptin BCAC has submitted views to PHARMAC on the need for access to high quality aromatase inhibitors. BCAC has lobbied the pharmaceutical company GSK to make lapatinib (Tykerb) available to NZ women with advanced HER2 positive breast cancer through the MA31 trial. Unfortunately GSK refused, stating that as they have pulled all of their research staff out of NZ they no longer have the capacity to collect the data from NZ participants in the trial. The Australian New Zealand Breast Cancer Trials Group (ANZBCTG) offered to collect the data but disappointingly GSK remained adamant they would not enrol NZ women. When Australian women were given government-funded access to this drug BCAC also informally requested during a meeting with PHARMAC that similar funding be provided in this country. Peter Moodie of PHARMAC stated that the PTAC advisory committee was “unimpressed by the data” and envisaged it would be unlikely that funding would be provided in a metastatic setting in NZ, but if future clinical trial data shows effectiveness (e.g. the ALTTO trial) it might one day be offered in early breast cancer.

In order to improve our access to treatment medicines, the BCAC committee believes that fundamental changes will be required to the PHARMAC funding model. BCAC presented this view in detail to a Ministry of Health consultation on the NZ Medicines Strategy. Several BCAC members attended a Stakeholder Consultation event held by PHARMAC and clearly stated the view that greater transparency and accountability were needed. BCAC also submitted considered views to Ministry of Health consultations on the Terms of Reference and the

Appointment Protocols for PHARMAC's Pharmaceuticals and Therapeutics Advisory Committee (PTAC). BCAC looks forward to a future consultation on the appointment process, membership and Terms of Reference of PHARMAC's Consumer Advisory Committee.

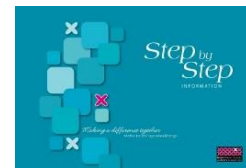
Libby and Raewyn Calvert attended the Australian New Zealand Breast Cancer Trials Group Annual



Scientific Meeting in Wellington in July, with support from ANZBCTG to engage in the Impact Advocacy Programme. Sue Guthrie continued as the sole NZ representative on ANZBCTG's Consumer Advisory Panel, providing input on proposed clinical trial research protocols.

4. To research and promote the provision of psychosocial services for breast cancer patients, their whanau, family and friends

BCAC has used the funds raised through the relationship with Arnotts NZ Ltd and the Tim Tam Pink Tea Parties held by many kiwis to produce the *Step by Step* support pack for women newly diagnosed with breast cancer. The pack is based on the *My Journey Kit* developed by the Breast Cancer Network



Australia. *Step by Step* has been

a major project for BCAC and is a huge achievement for our talented, hard-working writer and administrator Jane Bissell, as well as our committee. The funds raised produced 750 copies for a first edition and these have gone to all BCAC member groups as well as medical professionals including surgeons, breast physicians and breast care nurses for consultation on their content. Distribution has begun to women diagnosed with breast cancer. Extensive fundraising is required to enable BCAC to produce the second edition and to offer this to the 2,500 NZ women diagnosed annually.

5. To identify and promote breast cancer issues for Māori and Pacifican women

BCAC continues to build relationships with Māori Health Providers and was pleased to welcome Roslyne Bowring of Te Ha o te Oranga o Ngati Whatua to a committee meeting. Roslyne explained her role and that of Whaea Maggie in encouraging women to attend breast screening, and in supporting those diagnosed through treatment and recovery.

BCAC has provided documents and information to support the preparation of Treaty of Waitangi Claims by the Māori Women's Welfare League and by individual Māori women seeking access to Herceptin. Happily it is not necessary to progress this claim!!

BCAC is working with Rotorua-based Dell Gee and local support group Aroha Mai to distribute *Step by Step* in the Lakes District and to identify ways in which we may be able to further assist Māori women with breast cancer in the Rotorua area.

BCAC has met with Ruth Davy, CEO of WONS to discuss the services provided by WONS to women at high risk of breast cancer including those in the Māori and Pacific communities. Synergies between the two organisations have led to WONS becoming a member group of BCAC.



This will facilitate future collaborations and connect BCAC to groups representing New Zealand's ethnic communities. We hope to provide support for a WONS conference planned for October 2009.

Other Projects

Breast Physicians

The Medical Council revoked its recognition of Breast Physicians as a specialty area of medicine in June 2008. This means that breast medicine is now no longer recognised as a vocational scope in NZ. The decision was made despite strong submissions from doctors and patients alike. BCAC has supported the Breast Physicians and continues to investigate the background to this decision and whether there is a way to help re-establish this valuable profession in NZ.

Breast Reconstruction

Delayed breast reconstruction is still not offered in all centres throughout NZ. Availability varies greatly among the District Health Boards. Raewyn Calvert (pictured), Chair of the Reconstructables, is currently liaising with women in the lower North Island who awaiting long-delayed reconstructions at Hutt Hospital and she is investigating other regional inconsistencies.



Happy New Year!

We wish all our members much happiness in 2009!