



**Breast Cancer Aotearoa Coalition Update:
June/July 2008**

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What have our members been up to?

**Busting With Life
Celebrate 10th anniversary!**



Letter from the Intrepid Chair at the Hluhluwe-Imfolozi Game Reserve in South Africa



Well what a month or two it has been! BCAC has made some wonderful positive gains among our member groups and in our projects, I have had some time out watching the wildlife in South Africa and we have had to tolerate PHARMAC's harsh decision to continue refusing to fund the 12 month Herceptin course.

But first let's focus on the good news! BCAC has gained another exceptional member group in the Breast Cancer Support Northland Trust (BCSNT). These fine women have been supporting newly diagnosed women for many years. Forming an independent Trust will enable BCSNT to work even more effectively in providing the information and support so important to those facing a breast cancer diagnosis in Northland. Welcome to BCAC, ladies! We know we can all achieve so much more by working together, and the other members of BCAC look forward to

collaborating with you and hearing of your achievements.

The second piece of great news for BCAC is the wonderful progress being made in the development of our 'Step by Step' Support Pack. BCAC has had a sub-committee working tirelessly on this project since its initiation following last October's Tim Tam Pink Tea Party fundraisers with Arnotts. The project is modelled on the acclaimed 'My Journey Kit' developed by the Breast Cancer Network Australia (BCNA) and now distributed to the over 13,000 women diagnosed with breast cancer every year in Australia. Following a fact-finding visit to BCNA, our sub-committee has prioritised the development of the diary, journal and the information booklet as first elements of the pack that will be distributed to member groups, other support organisations and most importantly to newly diagnosed women. Information about local breast cancer groups and support services will be an important part of the kit that member groups will be able to contribute to as the project moves to Phase 2 in 2009. We will also be seeking inspirational and practical tips from our members that will make the breast cancer journey a little easier for those who follow us. Look out for the 2008 Tim Tam Pink Tea Parties that will help us support this project as well as BCAC's work in other areas.

Sadly I must mention PHARMAC's decision not to fund the 12 month Herceptin course for New Zealand women with HER-2 positive breast cancer. This is an unfathomable decision made despite the strong and unequivocal support for 12 months treatment and rejection of 9 weeks by 33 of New Zealand's breast cancer specialists (the Breast Cancer Special Interest Group of the NZ Association of Cancer Specialists). The vast majority of submissions took this view, including those from NGOs such as BCAC, BCN, NZBCF and St Marks Breast Clinic, as well as those from individuals. The decision leaves around 400 NZ women and their families each year

in the unenviable position of having to decide whether to fundraise to cover the extra costs of accessing the year's course of 18 treatments of Herceptin once they have had the 3 government-funded infusions. Depending on where women are living when diagnosed with HER2 positive breast cancer they may have the option of entering either the ALTTO or the SOLD clinical trial. ALTTO will offer 12 months of HER2-targeted therapy to all participants, either Herceptin, lapatinib (Tykerb) or a combination of the two. SOLD will give half the patients 12 months of Herceptin and the other half 9 weeks. BCAC will be providing information about these trials on our website as it comes to light, but if you are in this situation, you may wish to ask your oncologist whether you can participate in a trial that could improve your treatment options.

BCAC has been fighting since 2005 to gain access to Herceptin for NZ women. This decision is a setback but it is certainly not the end of the road. Although PHARMAC is not prepared to listen to the strong urging of expert oncologists in New Zealand and overseas, or to act to alleviate the hardship and suffering of patients and their families, it seems some in parliament are. We all have the opportunity to listen to what the political parties say and to cast our votes later in the year.

Mahia kotahi nga rerekētanga

Together we *can* make a difference!

Libby

Member News

(a) Welcome to the Breast Cancer Support Northland Trust (BCSNT)!



BCAC began in November 2004 with just 12 member groups and in July we welcomed our 24th member to the Coalition, the Breast Cancer Support Northland Trust (BCSNT). Some of us had the pleasure of attending the special afternoon tea in Whangarei earlier this year when the BCSNT became an official Trust but the group itself has been supporting women in the Northland area for many years.

Representative Kathleen Paterson says, "We are a group of Breast Cancer survivors who offer practical and emotional support to women diagnosed with Breast Cancer. We hold monthly meetings where people can get information and support. Also we organise public meetings and panel discussions to help educate the public about Breast Cancer." The Trust can be contacted by calling 021 046 8718 or 021 048 7863.

(b) Te Ha o Te Oranga o Ngati Whatua Health Promoter Roslyne Bowring

Roslyne Bowring is the new health promoter for Te Ha o Te Oranga o Ngati Whatua. Roslyne is of Ngati Whatua descent.



Roslyne (pictured with Whaea Maggie) will be working alongside Whaea Maggie and together they will promote breast screen awareness and provide

relevant information to encourage the recruitment of eligible wahine. They will also offer support for screening appointments, assessments, and treatments within the Ngati Whatua rohe. Contact with Roslyne can be made by telephoning any of the following Te Ha o Te Oranga o Ngati Whatua offices:

Glenfield	09 442 5417
Helensville	09 420 6514
Wellsford	09 423 8538
Dargaville	09 439 1690

More information about Te Ha o Te Oranga o Ngati Whatua can be found under our Māori and Pacific section later in this Update.

(c) Busting With Life Celebrates 10th Anniversary

(This report from Trea Kenny)

After 10 months of planning (worse than having a baby), the weekend of 12/13 July finally arrived. All the hard work that went on behind the



scenes came to fruition on the Saturday night when approx 70 ex paddlers, supporters and

current team members came together to celebrate Busting With Life's 10th anniversary. What followed was a night of reconnecting, reminiscing, laughter and great food.

A slideshow of some of the many photos taken of the team over the years played throughout the evening. These created a lot of laughter at old hairstyles etc and brought back many memories.

A lovely meal was interspersed with speeches from founder Trici Nelson and former president, Marcia Fraser. It was great to hear the colourful and eventful journey that the team has had.

All in all it was a wonderful evening, thoroughly enjoyed by everyone.

Sunday dawned fine and still. On the shores of Lake Pupuke we gathered to remember those paddlers no longer with us. 9 in all. As their names were read out we stood in silence, arm in arm, tears flowing as we threw our pink flowers into the lake in their memory. Afterwards we had a time of fellowship over coffee.



It was a fitting and lovely end to a weekend that had had it all.

(d) The Breast Cancer Research Trust (BCRT) Fire and Ice Ball

BCRT will be holding their famous Fire & Ice Gala Dinner/Ball event on 4th Sept and the special WOW 24th Sept dress rehearsal show in Wellington (now sold out). For more information about the Ball visit the website at <http://www.bcrt.co.nz/events/future-events?id=77a53650-12d7-4368-9604-6e620d2cd409> or call the administration office on 0800 227 828.

(e) Skip For Life Pink Yourself!

(This information from Jacqueline Harrison)

Pink Yourself! And Join The Challenge on Friday 26 September!



Pink Yourself! is a student Event Production initiative from the Event Management Programme at Auckland University of Technology. **Pink Yourself!** aims to raise awareness for the charitable trust Skip for Life. **Pink Yourself!** challenges businesses in the Auckland CBD to encourage their staff members to wear pink on one day a year, Friday 26 September. This appeal is to visibly highlight the needs of those suffering with breast cancer unable to afford a full course of Herceptin.

Skip for Life is a charitable organisation formed to assist those in this group who choose to undergo a 12-month course of the drug Herceptin but who, because of a lack of government funding, must raise between \$70,000 to \$100,000 themselves. All money collected for Skip for Life goes directly to these women.

Our Challenge: To get firms on board with this important initiative. All firms, if they desire, will be mentioned on our website and media material. We also encourage all firms who participate, to donate \$20 to the Skip for Life on the \$20 donation phone number 0900 4 HER 2.

For more information: <http://www.skipforlife.org.nz>

(f) Kenzie's Gift Fundraiser Heaven Bent Gospel Choir 30 August

(This information from Nic Russell)

Fancy a heavenly night out?

Come and listen to the beautiful harmonies of the truly amazing Heaven Bent Gospel Choir.

They will be performing a beneficiary concert in aid of local cancer charity Kenzie's Gift.

Evening also features "A Taste of Africa" and Rangitoto College's National Champion Quartet "BYOB". Tickets selling fast - don't miss out!

Saturday 30th August 2008, 7:30pm - 10:00pm. Light Refreshments provided.

Holy Trinity Church, Church St, Devonport.

Tickets Adults \$15 Children \$5. For tickets call 09 446 1100 or 027 345 2514 or email

kenziesgift@kenziesgift.com



Other News

The Tim Tam Pink Teas are coming!

BCAC is teaming up with key sponsor Arnott's again this year to encourage New Zealanders to host Tim Tam

Pink Tea Parties to raise funds for BCAC. The campaign kicks off in the first week of October with launch party/media events and then it's all on!

The BCAC website will have details on how to register for a party and extensive coverage of all the events and happenings.

Once again, Arnott's will donate to BCAC from every pack of Tim Tam Pink biscuits sold during the campaign. Funds raised this year will go towards

further development and production of the Step By Step support pack and also help support BCAC's operational activities and initiatives.



(a) BreastScreen Aotearoa Launches New Ad Campaign

(This information taken from the National Screening Unit website at <http://www.nsu.govt.nz/Current-NSU-Programmes/2715.asp>)



On 2 July BCAC Claire Ryan and Jane Bissell met with representatives from the Communications and Marketing Department of the National Screening Unit (NSU) to hear about the new BreastScreen Aotearoa (BSA) Communications Campaign 2008 set to launch on 17 August.

The current BSA campaign has been running since 2002 so the NSU felt it was time to develop a new campaign with fresh, relevant images and strengthened messages around the importance of screening in reducing deaths from breast cancer. The campaign specifically aims to increase participation and coverage for Māori and Pacific women within the target range of the programme (45 - 69 years) who are at a higher risk of dying from breast cancer. Messages encourage women to enrol if they haven't been screened and emphasise the need for regular screening every two years.

The campaign seeks to:

- ◆ increase participation and coverage for Maori and Pacific women. Current screening rates are Maori women 46 percent and Pacific women 48 percent
- ◆ increase understanding of the benefits of early detection
- ◆ increase understanding of the benefits of two-yearly breast screening
- ◆ develop and raise the campaign profile with providers and key stakeholders, ensuring buy-in and readiness for action from these groups.

Key messages include:

- ◆ breast cancer is the most common cancer in New Zealand women and the risk of developing breast cancer increases with age
- ◆ Maori and Pacific women are at higher risk of dying from breast cancer
- ◆ the goals of the new campaign are to raise awareness of breast screening, increase calls to the 0800 number and support the programme and providers in their efforts to reduce the number of women who die of breast cancer
- ◆ two-yearly breast screening reduces the chances of dying from breast cancer for women under 50 by about 20 percent, by about 30 percent for women between 50 and 65, and by about 45 percent for women aged 65-69
- ◆ early detection is the best protection

- ◆ breast screening can find very small cancers before a lump can be found on the breast
- ◆ if you are aged 45 to 69 years of age you can have a free screening mammogram every two years through BreastScreen Aotearoa (BSA), even if you don't have symptoms of breast cancer or if you have not had a mammogram in the last 12 months
- ◆ if you are not pregnant and are eligible for public health services in New Zealand you are welcome to join the free screening programme. To see if you qualify you can visit www.moh.govt.nz/eligibility, or ring Freephone 0800 270 200

(b) ANZBCTG Conference, Te Papa, Wellington 2-5 July

Libby and Cambridge-based BCAC committee member Raewyn Calvert attended the recent Annual Scientific



Meeting of the Australia New Zealand Breast Cancer Trials Group Conference (visit www.anzbctg.org) and both found it to be an outstanding conference, very relevant to BCAC's work. Their attendance was supported by ANZBCTG's IMPACT Advocacy Programme. Information was provided in a very accessible way and the event offered wonderful opportunities for advocates to meet with experts and hear the latest news in breast cancer research and care. The IMPACT programme was most worthwhile and afforded good opportunities to speak at length with the researchers. BCAC's Treasurer, Sue Guthrie, is a member of ANZBCTG's Consumer Advisory Panel, a group that reviews and has input into all of ANZBCTG's proposed clinical trials from a consumer perspective. In association with the conference, ANZBCTG held public forums in Hamilton and Wellington to provide more information about breast cancer research and to explain the benefits of participation in well-designed clinical trials. Libby hopes to see more IMPACT consumer advocate scholarships made available to allow more New Zealand women to attend this excellent conference in future.

A conference participant bringing expertise from Canada, Dr Kathy Pritchard, spoke about the current Herceptin funding issues. After reviewing all of the data from the published studies, Dr Pritchard concluded that the weight of evidence supported 12 months as a cost effective approach leading to improved survival for those women diagnosed with early stage HER2 positive breast cancer. She noted NZ's drug approval agency Medsafe was first in the world to recognise this and expedited an approval for 12 months of therapy.

Other key issues at the Conference:

(This taken from ANZBCTG Press Release 5 July 2008)

1. Associate Professor Fran Boyle said that a better understanding of breast cancer biology and clinical trial research have been vital in improving breast cancer survival.

2. Associate Professor Martin Stockler of the NHMRC Clinical Trials Centre in Sydney demonstrated the effectiveness of seed funding from the NSW Cancer Council to support centres and individual clinicians to recruit for clinical breast cancer trials. The funding for research staff resulted in higher recruitment into the trials and a similar approach in NZ would increase access for women here to participate in trials.
3. Professor Richard Gelber from the USA outlined how the period between diagnosis after biopsy and before surgery offers an opportunity to evaluate new drugs and their effects on growth pathways in cancer cells. Such research could lead to more individualised treatment in the future.
4. Associate Professor Papaarangi Reid of Auckland University discussed how effective consultation with the Māori community will be essential to encourage participation in clinical trials to overcome disparities in access and outcomes for Māori women.
5. Margo Michaels from ENACCT USA (www.enacct.org) discussed innovative approaches to community education which could be adapted to facilitate clinical trial participation in NZ.

(c) ING fulfils first insurance claim for Herceptin treatment

(This information taken from an ING Press Release 30 July 2008)

ING today announced that it has accepted and is fulfilling its first claim for Herceptin a targeted therapy for HER2 positive breast cancer.

The claimant, a self-employed woman in her 50s based in Auckland, had no history of breast cancer in her family but specifically took out medical cover with ING because of the company's policy of covering non-PHARMAC funded treatments, including the full year course of Herceptin.

Naomi Ballantyne, Managing Director, ING Life (NZ) Limited, said, "Although much of the treatment regime for breast cancer will be covered under the public system, health insurance is there to fund the gap between what the public system can provide and what is available privately. For ING, this means providing funding and access to a full year's course of Herceptin and access to instant, private medical care.

"If you are diagnosed with the specific form of breast cancer that Herceptin treats, you want to know that you are doing everything possible to fight it and this means being able to access the best drugs and treatments available without having to wait."

ING is the only insurance company in New Zealand that includes cover of non-PHARMAC funded, but Medsafe approved, treatments as a standard part of its major medical cover.

Updates on the Five BCAC Initiatives

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 clinical guidelines.

Chris Walsh attended the Guideline Advisory Team meeting in Wellington 22/23 July. The meeting went well, with NZ Guidelines Group researchers reporting the results of their literature searches on pharmaceutical treatments for consideration by the expert advisory team and formulation of recommendations. Work has also begun on the psychosocial area. The Guidelines for Early Breast Cancer are due to be launched on Feb. 17 2009, with a draft planned for consultation in October.

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

BCAC is pleased to note BreastScreen Aotearoa (BSA) has placed information about the pathway for symptomatic women on their website <http://www.nsu.govt.nz/Current-NSU-Programmes/1556.asp>. BCAC is looking forward to the launch of the new promotional campaign mentioned earlier in this Update and supports the important messages emphasised in this campaign: women aged from 45 to 69 are eligible for the programme and screening is free, early detection and regular screening with BSA can save lives.

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

(a) Herceptin

PHARMAC announced on 7 August that, once again, it would not fund 12 months of Herceptin for women with early stage HER2 positive breast cancer.

PHARMAC's reason for declining funding is "not about the money" (Mathew Brougham stated on TV3 news 7 August) but all about what they see as insufficient data to convince them that 12 months offers greater "health benefits" than the currently funded 9 weeks. BCAC is very concerned by this announcement as there will be no data available from the only trial testing the effectiveness of 9 weeks against 52 weeks for at least 7 years (revealed in PHARMAC documents). In the interim, around 2,000 women could be exposed to the 9 week treatment that is supported only by the weak evidence of a single small trial. NZ's regulatory agency Medsafe refused to register the 9 week regimen because of "insufficient data of a regulatory quantity and quality". 33 other countries have funded 12 months for their women and NZ oncologists recommend 12 months to their patients as the accepted standard of care for their early stage HER2+ breast cancers. 12 months treatment is based on multiple large studies involving over 12,000 women and has shown real benefits in overall survival whereas 9 weeks is based on a single small study involving only 232 women that has not shown survival benefits.

Whilst not entirely unexpected, the decision was nonetheless a huge disappointment for all of those who have worked on this campaign for so long - and of course a devastating blow for our women who still cannot have funded access to the course of 12 months recommended by their oncologists.

Media coverage was extensive and Talk Back lines ran hot on the day after the announcement. Libby, Chris Walsh, Anne Hayden and Nic Russell were interviewed and we were fortunate to have well known Australian oncologist Fran Boyle appear on the Sunrise show (8 August) with PHARMAC's Mathew Brougham. Associate Professor Boyle (pictured - see below for further information about Prof. Boyle) was in NZ attending a meeting with our oncologists. NZ oncologist Dr Richard Isaacs, chair of the Breast Cancer Special Interest Group of the NZ Association of Cancer Specialists also expressed his concern about the decision on radio. Dr Isaacs and Prof. Boyle also wrote a media release entitled '*Herceptin: keeping faith with clinical trial participants*' and summarised this in a letter to the newspapers. This article is available from a link on the BCAC homepage at www.breastcancer.org.nz. Our medical specialists are becoming more outspoken on the issue of 12 months treatment because it is supported by strong data from large clinical trials and they believe our women should have funded access to this internationally accepted standard of care.



Where to from here? BCAC will not give up on Herceptin and will continue to support those women and their families who need 12 months of it. As Libby stated in her press release (7 August): "Increased funding for medicines - including 12 months of Herceptin - may well become an election issue. Voters will decide. It's unbelievable that we are still denied the standard of Herceptin care offered in 33 other countries."

(b) Associate Professor Fran Boyle AM, MBBS (QLD) FRACP PhD AM

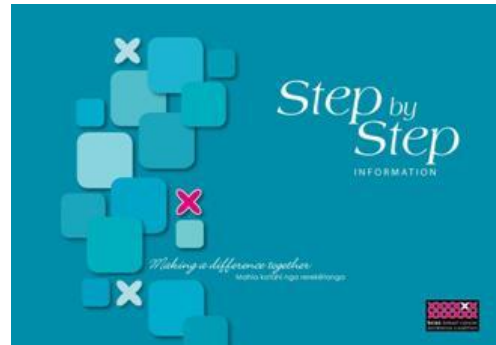
Associate Professor Fran Boyle is a Medical Oncologist at Sydney's Mater Hospital, where she is Director of the Patricia Ritchie Centre and Assoc Prof of Medical oncology at the University of Sydney. She has served as Chairman of the Medical Oncology Group of Australia, and as a Senior Clinical Advisor to the National Breast Cancer Centre (NBCC). In 2002, Fran was awarded the AMA Women's Health Award for her contributions to breast cancer treatment. She was honoured with Membership of the Order of Australia in 2008 for services to breast cancer treatment and research (this information taken from the National Breast and Ovarian Cancer website <http://www.nbcc.org.au>).

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

(a) Update on 'Step By Step'

Our support pack, 'Step By Step', is on its way! The ultimate goal is for every woman diagnosed with breast cancer to receive a pack and we are now taking firm 'steps' towards that goal.

Thank you all for responding so quickly to our urgent requests - both for a name and for information about your organisations. We are



working to a very tight deadline to ensure the packs are available for promotion during October to tie in with our Pink Tim Tam Tea Parties and other fundraising activities.

We will be producing a limited number of packs in the 'first edition'. Packs will initially be made available for women diagnosed within a defined geographic trial area. Each of our BCAC member groups will receive a number to circulate for feedback, ideas for improvement and further development. Packs will also be sent to oncologists, breast care nurses and other cancer related organisations and individuals for their comment and suggestions.

In 2009, our Step By Step sub-committee will work extensively with the women who receive a pack, all BCAC members and the groups and individuals mentioned above to develop a larger and more comprehensive support resource.

The first edition will contain a personal diary for recording appointments and medical information, a journal for writing down thoughts and experiences and an information booklet containing contact details for all BCAC member groups and other support organisations, information about available subsidies (e.g. breast prosthesis payment) and lists of useful websites and books.

The BCAC committee are very excited about the developing project and feel confident Step By Step will be a valuable and useful resource for our women.

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

(Information for this item has been taken from the Te Ha website at www.teha.co.nz)

(a) About Te Ha o Te Oranga o Ngati Whatua

KAUA E MAHUE TE TAHI ATU KI WAHO

Don't Leave Anybody Out



OUR VISION

“A *committed* partner with a *united vision* to optimise health gains for the population we serve.”

KAUPAPA - VALUES

The kaupapa of the organisation is based on the Maori elements of *Tika*, *Pono* and *Aroha* which are enshrined in Nga Tikanga O Ngati-Whatua. **Te Ha o Te Oranga o Ngati Whatua** is a Māori Health Provider for the Ngati Whatua region, an area covering from Auckland as far north as the Hokianga.

Te Ha has been a member group of BCAC since the first Forum in November 2001 when representatives from 12 groups gathered together to discuss the formation of a united consumer group to work on behalf of all women affected by breast cancer in New Zealand. Gaylene Campbell was BCAC's first contact within Te Ha. We thank Gaylene for her contributions to BCAC and now welcome both Rosylne Bowring and Whaea Maggie as our new contacts.