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## Briefing on Breast Cancer Issues in New Zealand

**For: Hon. Tony Ryall, Minister of Health  
Dr Jackie Blue, Member of Parliament**

**CC: Hon. Tariana Turia, Associate Minister of Health; Grant Robertson, Member of Parliament; Hon. Heather Roy, Member of Parliament; Kevin Hague, Member of Parliament**

**From: Breast Cancer Aotearoa Coalition (BCAC)**

**Date: 13th July 2011**

BCAC is grateful for the opportunity to meet with the Minister of Health and other Members of Parliament to discuss key issues for the breast cancer sector in New Zealand. These issues are of national importance given that breast cancer was the most commonly registered cancer for women in 2008 (2713 women, 19 men), and accounts for 28% of all new female registrations (*Cancer – New Registrations and Deaths 2008*). Breast cancer was the second most common cause of death from cancer for women in 2008, accounting for 15% of female cancer deaths (618 women, 6 men).

As agreed at the meeting between BCAC and the Hon. Tony Ryall in July 2010, we have met and communicated throughout the year with Jacqui Akuhata-Brown and other senior staff from the National Screening Unit (NSU) and BreastScreen Aotearoa (BSA) as well as Deborah Woodley and Dr John Childs representing the Ministry of Health and Cancer Control. This has been extremely valuable in keeping us up to date with progress in Cancer Control initiatives and has allowed us to keep these key people and the organisations they represent in touch with issues arising for patients around New Zealand.

In this document we highlight the following:

- three priority issues that need to be addressed urgently: two of these impact directly on the health outcomes for women with breast cancer, the third relates to the capture of important data
- an update on issues raised with the Minister of Health in 2010
- an outline of the latest initiatives introduced by BCAC to support breast cancer patients
- further information on BCAC and the committee representatives who will meet with Minister and other MPs.

## 1. Priority Issues

### 1.1 Critical shortage of medical oncologists

#### *Urgent action and long-term solutions needed*

There is a serious shortage of trained medical oncologists in New Zealand, creating pressure on medical staff and their provision of services in many of our Cancer Treatment Centres. We are specifically aware of shortages in the Midlands, MidCentral and Capital and Coast areas, although the problem may be more widespread. Timely and appropriate provision of treatment depends on having a skilled, relatively stable specialist workforce in place.

Patients are currently being forced to wait longer than the recommended times to receive treatment and in some cases treatment is not being provided. We submit that this is a priority issue for cancer patients and their families that may impact on disease outcomes and will add significant stress to all concerned during the treatment process.

We support the workforce review currently being undertaken by Cranleigh and Health Workforce New Zealand to develop *Models of Care* as this will analyse the roles of different staff in cancer treatment teams and develop an overview of how these might be optimised. This review may identify elements of care currently undertaken by specialists that could be undertaken by breast nurses or breast physicians in expanded roles, thereby increasing the efficiency and effectiveness of teams. However, any such changes are likely to involve further training so impacts will not be immediate.

This means urgent action is required now to provide relief to stressed medical oncologists and their teams so that patients can receive optimal care. We understand this issue arises in the context of a global shortage of oncologists and suggest Ministry of Health resources be focused on developing both short and long-term solutions for New Zealand patients.

Our suggestions for addressing this complex problem follow.

- *BCAC applauds the recently announced increases in numbers of medical students to be trained and suggest this strategy be actively continued in future years.*
- *We encourage the establishment of incentives for trainees to remain in this country at the completion of their training, and of further incentives for NZ-trained graduates who are resident overseas to return home.*
- *We suggest that medical and other specialist oncology disciplines be promoted to medical students as a positive career option, much as general practice currently is. We note that the only area of oncology included in Health Workforce NZ's Advanced Trainee Fellowships is paediatric oncology and we suggest that Fellowships be offered in medical oncology.*
- *We note that New Zealand rates of remuneration for medical oncology are significantly less than those offered in Australia, the UK and other similar countries and suggest that these be adjusted to make a specialist career in oncology more attractive to our graduates, particularly given the high level of student debt carried by medical trainees. This would impact both on recruitment and retention of these vital professionals.*
- *We encourage the Ministry to tackle this serious problem with multiple strategies to secure the future of our oncology services.*

## 1.2 Timely provision of treatment

### *Establishment of targets, focusing of resources*

As noted above, timely provision of cancer treatment impacts on disease outcomes as well as the levels of stress experienced by patients and their families and supporters during the treatment processes. Timely treatment was one of the top priorities identified in the Implementation Plan for the *Guideline for the Management of Early Breast Cancer* (2009).

We commend the Minister on the establishment of a four week target for provision of radiation therapy following a first specialist appointment. We are delighted to hear that nearly 100% of recent patients ready for treatment have been treated within this timeframe, demonstrating the success of this approach and we encourage the continued focus on this target.

BCAC has been informed that a similar four week target is to be established for medical oncology following consultation with the Ministry's Medical Oncology Working Group. We understand that monitoring has been established from 1<sup>st</sup> July.

- *BCAC fully supports the establishment of a target for timely provision of medical oncology.*

We do recognise that a treatment target may put additional pressure on our already stressed medical oncology teams but we hope it will provide the motivation needed for DHBs to prioritise the allocation of resources in this area.

- *We suggest a similar target be established for the provision of breast cancer surgery.*

We are aware of some women having waited three months and more for breast cancer surgery and this is clearly unacceptable. We are also aware that the Ministry does not formally collect data on time to breast cancer surgery so we have made a request of the Auckland and Waikato Breast Cancer Registers for data on times from first specialist appointment (FSA) to provision of surgery and will provide the information to the Minister as it comes to hand.

## 1.3 Cancer data

### *Resource needed to support the Breast Cancer Registers*

BCAC is aware that the Government and the National Information Technology Board deem collection of effective national data on cancer to be a priority, and that the National Data View is to be trialled later this year, evaluated and then rolled out nationally. A comprehensive Cancer Data Register is an important tool in enabling us to analyse and understand the nature and impact of cancer in our country, as well as the ways we manage the disease and the impact of interventions on outcomes in our diverse population. It will be essential in allowing effective planning for the provision of future cancer treatment services, and BCAC is fully supportive of this initiative.

We wish to again draw the Minister's attention to the Breast Cancer Register – a detailed dataset that has been collected in Auckland since 2000, Waikato since 2005, Christchurch since 2009 and Wellington since 2010. The Register collects detailed clinical, pathological, treatment and outcome data along with patient information on age, gender and ethnicity. The consent rate is around 90% across the various treatment centres, making this an extremely powerful tool for understanding the nature of the disease in our country, its treatment and resulting outcomes in different sections of

the population. The greater level of detail in this data compared to that collected in general registers makes the Breast Cancer Register a hugely valuable asset in understanding and effectively managing the disease. The national roll-out of the Register was identified as a priority in the Implementation Plan for the Early Breast Cancer Guideline.

BCAC is aware that the Minister has received a communication signed by a representative of each of the regional Registers to request establishment of ongoing funding to support the continuation of the Register and its expansion to the remaining two Cancer Treatment Centres.

- *BCAC strongly endorses and supports the request to the Minister to invest the level of funding needed to enable the regional expansion of the Breast Cancer Register and ensure the continued viability of this valuable national database.*

## **2. Update on issues raised with the Minister of Health in 2010**

### **2.1 Consumer representation**

BCAC is disappointed to see that there has been little progress in establishing positions for consumer representatives on cancer-related organisations and other key health bodies such as Cancer Control New Zealand, the National Health Committee and Health Workforce New Zealand. As we have previously submitted there is strong evidence that the informed, representative consumer perspective brings immense value to such groups.

- *We note that new appointments will be made to both the Cancer Control Council and the National Health Committee in the coming year and we strongly encourage the Minister to take advantage of these opportunities, and others as they arise, to appoint genuine consumers.*

### **2.2 Māori breast cancer**

BCAC has previously briefed the Minister on the high breast cancer incidence for Māori women (29% higher than non-Māori), late detection and poor outcomes (78% higher mortality than non-Māori) (*Cancer – New Registrations and Deaths 2008*). We note the age-standardised mortality rate has remained unchanged for Māori women between 1998 and 2008 while the rate for non-Māori has reduced by 27%.

We are pleased to learn that Māori nurse, Dr Nina Scott, working with the Māori Health Business Unit of the Ministry, has been commissioned to prepare a report identifying specific actions that are achievable and able to be implemented that will have a positive impacts on Māori cancer outcomes. BCAC sees this as a positive and worthwhile initiative to overcome these unfortunate inequities.

We are pleased to see that the efforts of BreastScreen Aotearoa (BSA) to enrol more Māori women in the national screening programme are having an impact on screening rates, although further work is needed to reach the 70% target.

BCAC continues to support the community-based Whanau Ora approach to engaging Māori women in health-enhancing activities including breast screening, breast cancer treatment and follow-up.

### **2.3 Extension of MoH grant for breast prostheses and bras**

We suggested to the Minister in July 2010 that the \$600 grant provided every four years to women to purchase prostheses and bras after breast surgery be extended to cover lymphoedema sleeves, pocketed swimsuits and other related items. We still await action on this and are hopeful that we may hear news from Deborah Woodley prior to the July 13<sup>th</sup> meeting.

Breast care nurses and patients have requested that BCAC seek an increase in the grants for wigs and for prostheses and bras. The wig grant of \$400 is around \$200 short of the current cost and the prosthesis grant is sufficient only for a prosthesis and one or two bras every four years.

- *We again request extension of the prosthesis and bra subsidy to cover lymphoedema supports.*
- *We ask the Ministry to look into the level of subsidies provided for wigs as well as prostheses and bras with a view to increasing these to 2011 levels.*

## 2.4 Breast screening

BSA has recently achieved great gains in screening coverage with the numbers screened in the 50 – 69 year group approaching the target of 70%. Significant gains over the past two years have seen the Māori coverage increase from 47 to 57% and Pasifika screening grow from 49 to 62%, although further effort is needed. We support BSA's gathering of evidence from Australia and the UK to determine whether women over 70 years of age should be screened. BCAC is supportive of this extension given that in 2008, 445 women aged 65-74 were diagnosed with breast cancer and 116 of these women died of the disease, while 479 women over 75 were diagnosed and 205 died of it. These extremely high rates of mortality suggest a significant number of lives could be saved by early detection. This is in the context of extended working lives, improving health and increasing longevity in older New Zealanders.

BCAC is pleased to learn 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. We suggest the Ministry investigate whether some DHBs will need financial assistance to acquire compliant machines.

BCAC supports BSA's roll out of centralised digital screening image storage as this will improve data capture and retrieval.

## 2.5 Quality assurance in pathology and receptor testing

The Implementation Plan for the Early Breast Cancer Guideline identified the need to establish quality assurance programmes in breast receptor testing as a priority and this was raised with the Minister by BCAC and pathologist Gavin Harris on behalf of the Breast Cancer Specialist Group. We are delighted to learn that a professional advisory group has been established to work with the Ministry to establish much needed standards. We trust this will lead to accreditation of laboratories and certainty regarding the appropriateness and accuracy of testing methodologies.

## 2.6 Access to medicines

We commend the government on increasing the investment in medicines by \$180 million over the past three years. While this has made a real difference to the quality and length of life of many patients, New Zealanders continue to have limited access to innovative medicines compared to other OECD countries, e.g. 96 fewer than Australia. Of thirty countries, only Poland has access to a lower proportion of all available medicines and first-in class medicines (*Medicines New Zealand Annual Review 2010*).

BCAC is pleased that breast cancer patients will benefit from gaining funded access to the improved taxane, docetaxel, from 1<sup>st</sup> July, as it causes less nerve damage so patients are less likely to experience painful and debilitating neuropathy. This medicine also has greater proven effectiveness in chemotherapy combinations and is three times faster to infuse than its predecessor, saving cancer clinical team resources. However, access was provided several years after Australia funded this medicine; approximately two years after it came off patent; and nearly two years after a formal application to PHARMAC by the Breast Cancer Special Interest Group.

- *We strongly encourage the Government to continue increasing its investment in medicines.*

## **2.7 Tumour stream analysis**

Tumour stream analysis (TSA) leads to more effective and economic cancer service provision and while the national focus in tumour stream analysis remains lung and bowel, BCAC is pleased to see other TSAs initiated in regional Cancer Networks, including breast cancer TSA in the Northern region.

### **3. Update on BCAC activities**

#### **3.1 Step by Step**

We have now distributed more than 3000 copies of the BCAC *Step by Step* support pack, including 1032 over the past year. Our distribution networks centre mostly on Breast Care Nurses, Breast Clinics and breast cancer support groups. BreastScreen Aotearoa is currently considering distributing *Step by Step* at its diagnosis appointments and we believe this would be an extremely effective distribution tool for *Step by Step*. We continue to receive very positive feedback from patients who find *Step by Step* immensely helpful during their cancer journeys.

#### **3.2 Website**

We have recently completely revised and rebuilt the BCAC website, with the aim of providing a comprehensive resource of support and information for New Zealand breast cancer patients. The website has information about the disease, the various treatments offered and the support available for patients and their families, as well as current news items. We hope the site will complement *Step by Step* in empowering New Zealanders facing breast cancer to make well informed choices about their treatment and care and to access the support they need. We welcome feedback on the site, [www.breastcancer.org.nz](http://www.breastcancer.org.nz)

#### **3.3 Web videos**

In a further initiative to provide support and information to New Zealanders experiencing breast cancer, BCAC has created a series of fourteen web videos, available on our website and on YouTube. *Kiwi Stories of Breast Cancer* features New Zealanders of different ethnicities, genders, ages, backgrounds and with different types of breast cancer talking candidly about diagnosis, treatment and recovery. The short videos each focus on a different aspect of the breast cancer experience from diagnosis, to surgery, chemotherapy, radiation therapy, hormone therapy, and breast reconstruction. The participants talk about their experiences of these treatments and provide tips on coping and how to adjust to life after breast cancer. As well as those diagnosed with the disease, *Kiwi Stories of Breast Cancer* also features the partners, siblings and children of those diagnosed; and medical professionals talking about the intricacies of treatment. The videos can be accessed from the BCAC website at [www.breastcancer.org.nz/share-your-story/web-videos](http://www.breastcancer.org.nz/share-your-story/web-videos)



## 4. Information on BCAC

### 4.1 What BCAC does

The Breast Cancer Aotearoa Coalition (BCAC) is an incorporated charitable society established in 2004 to provide a unified, evidence-based voice from the New Zealand breast cancer sector. Our membership comprises 30 breast cancer-related groups from around New Zealand, as well as many individual members.

BCAC is run by a committee of women, most of whom have experienced breast cancer, working as volunteers to make world class detection, treatment and care accessible to all those affected by breast cancer in New Zealand. By virtue of our experience and knowledge of this disease, we are able to provide unique insights into improvements that can be made in the provision of breast cancer services. BCAC provides direct support to those diagnosed with breast cancer through provision of our *Step by Step* resource pack, our informative website at [www.breastcancer.org.nz](http://www.breastcancer.org.nz) and our newly released web videos at <http://www.breastcancer.org.nz/share-your-story/web-videos>

### 4.2 BCAC committee members attending the Ministerial briefing



**Chairperson: Elisabeth (Libby) Burgess (MNZM).** Ms Burgess is a scientist living in Auckland who is also a member of Breast Cancer Support and the Breast Cancer Network. Libby has participated as a consumer representative in the development of the best practice *Guideline for the Management of Early Breast Cancer* and contributes to the Northern Region Cancer Network. She had breast cancer in 1998. Libby became a Member of the New Zealand Order of Merit in the 2011 New Year's Honour list for her breast cancer work.

**Deputy Chair: Dr Chris Walsh (MNZM).** Dr Walsh is Director of HER Solutions (Health, Education and Research). Her breast cancer diagnosis in 2006 prompted her involvement in the campaign to get Herceptin fully funded for 12-months and she led the Judicial Review of Pharmac's decision-making on Herceptin funding. She represented consumers in the development of the *Guideline for the Management of Early Breast Cancer* and attends meetings of the Breast Cancer Special Interest Group as a consumer. Dr Walsh was awarded Membership of the New Zealand Order of Merit in the 2010 New Year Honours for her work in women's health.





**Secretary: Rowena Mortimer.** Ms Mortimer is a lawyer who was diagnosed with breast cancer in 2005. She lives in Auckland, is married and has two children, one a lawyer and the other a medical student. She believes that consumers can play an important role in the planning and delivery of health services. She represents consumers on the Northern Cancer Network Collaborative and chairs their Consumer Reference Group, is a member of the Northern Cancer Network Breast Cancer Tumour Stream Steering Group, the Clinical Guidance committee of Pro Care Health Limited, and a NZ Guidelines Group committee on suspected cancer.

### 4.3 BCAC member groups

- Age Concern
- Alleviate
- Ascot Radiology Pink Dragons
- Boobops Dragon Boat Team
- Breast Cancer Action Trust
- Breast Cancer Network
- Breast Cancer Research Trust
- Breast Cancer Support Inc
- Breast Cancer Support Northland Trust
- Breast Cancer Support Tauranga Trust
- Breast Health NZ
- Busting With Life
- HER2 Heroes
- Kenzie's Gift
- Look Good Feel Better
- Lymphoedema Support Network
- The Mamazon Club
- The New Zealand Breast Cancer Foundation
- Pink Pilates
- Reconstructables
- Rotorua Breast Cancer Trust
- Skip for Life
- 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