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## Briefing on Breast Cancer Issues in New Zealand

**For:** Hon. Tony Ryall, Minister of Health  
Hon. Jo Goodhew, Associate Minister of Health  
Hon. Dr Jackie Blue, Deputy Chair, Health Select Committee

**CC:** Hon. Maryan Street, Member, Labour Health Spokesperson  
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**From:** Breast Cancer Aotearoa Coalition (BCAC)

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## Contents

1. Introduction
2. Government Initiatives on cancer care
  - 2.1 Chemotherapy target
  - 2.2 Faster cancer treatment
  - 2.3 Medical Oncology Implementation Plan
  - 2.4 Funding for cancer nurses
  - 2.5 Tumour specific working groups
  - 2.6 National Cancer Consumer Representative Advisory Group
3. Priority Issues
4. Health and wellbeing for those with breast cancer
  - 4.1 Psychosocial support
  - 4.2 Fertility preservation
  - 4.3 Lymphoedema treatment
  - 4.4 Breast reconstruction
5. Delivery of Breast Cancer Services
  - 5.1 PHARMAC's Operating Policies and Procedures
  - 5.2 Breast cancer data
  - 5.3 Quality assurance for pathology and receptor testing
  - 5.4 Duration of Herceptin treatment
6. Information on BCAC
  - 6.1 What BCAC does
  - 6.2 BCAC committee members attending the briefing
  - 6.3 BCAC member groups

## 1. Introduction

BCAC is grateful for the opportunity to meet with the Minister of Health and other Members of Parliament and policy makers to discuss key issues for the breast cancer sector in New Zealand.

These issues are of national importance given the significant impact breast cancer has on the New Zealand community.

Breast cancer:

- is the most common form of cancer to affect women, with more than 2,700 women diagnosed annually
- accounts for more than 28 per cent of all new female cancers
- affects more than 150 women under the age of 40 each year
- kills 658 women every year and is the second most common cause of death from cancer for women
- disproportionately affects Maori women who are more than 40 per cent more likely to get the disease and more likely to die from it than non-Maori women.

*(All figures taken from: Cancer: New Registrations and Deaths 2009)*

These statistics show that there is clearly still work to be done to improve the health outcomes for New Zealanders with breast cancer. We hope this document will highlight the areas where a real difference can be made for those diagnosed with this disease.

In this document we outline:

- our feedback on the latest Government initiatives on cancer care
- issues that need to be addressed to improve breast cancer care.

## 2. Government initiatives on cancer care

Since BCAC met with you last year, the Government and Ministry of Health have taken some positive steps to improve the treatment pathway and outcomes for cancer patients, including those with breast cancer. These measures include:

- introducing a new four-week target for the provision of chemotherapy
- introducing the Faster Cancer Treatment wait time indicators
- formulating the Medical Oncology Implementation Plan to implement the Medical Oncology Models of Care (MOMOC)
- funding new positions for nurses to coordinate care and support for cancer patients
- initiating national working groups to develop tumour-specific quality standards and pathways
- establishing a National Cancer Consumer Representative Advisory Group

BCAC applauds all of these initiatives. Each of them will contribute to improved, more efficient and effective treatment and care for the growing number of New Zealanders diagnosed with cancer.

## 2.1 Chemotherapy Target

We frequently hear from patients concerned about the long waiting times they must endure before receiving chemotherapy treatment and from medical oncologists worried that they are unable to see and treat patients in a timely fashion to achieve best outcomes. Given the success of the four week target for radiation treatment we are confident that a similar target will work for chemotherapy. This target will ensure commitment from DHBs to provide the necessary resources to achieve timely treatment.

## 2.2 Faster Cancer Treatment

This initiative will drive further commitment by the DHBs to achieve timely cancer treatment across all tumour groups and fits well with the targets for the delivery of specific services.

## 2.3 Medical Oncology National Implementation Plan

This plan aims to implement the MOMOC with the intention of increasing treatment and clinical capacity, quality and efficiency in order to achieve equitable high quality cancer care throughout New Zealand. We see the Implementation Plan as outlining a sound and sensible approach to achieving efficient and effective use of New Zealand's scarce medical oncology resource. A key element of the plan is to free up the time and capacity of senior medical staff by delegating identified tasks to appropriately trained nursing staff. ***We believe commitment to the development of a workforce programme including sustainable workforce models and education pathways, as described in the Implementation Plan, is critical to the success of this initiative.*** Clearly it is essential that anyone delivering medical oncology treatment must be fully trained to do so in a safe and effective manner. It will also be necessary to increase the number of medical oncologists within the service and this specialty should be promoted as a career choice by Health Workforce NZ.

## 2.4 Funding for Cancer Nurses

Providing a dedicated coordinator of care for each cancer patient will help those diagnosed navigate the often multiple and complex elements of the cancer journey. Patients and their carers will have better access to information leading to increased understanding of the disease and the value of treatments. This should not only improve the patient's wellbeing during the treatment pathway, but also reduce the number of 'Did Not Attend' appointments, saving precious clinician and treatment facility time and ultimately leading to better patient outcomes.

## 2.5 Tumour Specific Working Groups

We note that the recently established lung cancer standards have already led to improvements in service delivery and clinical practice for lung cancer and believe the breast cancer working group has the potential to achieve a wide range of improvements for this disease. ***We are hopeful that many of the issues in breast cancer treatment and care that we wish to raise in this briefing will be dealt with through the setting of service standards for best practice breast cancer management by the National Breast Cancer Working Group.***

## 2.6 National Cancer Consumer Representative Advisory Group

We are delighted to see the establishment of this group which aims to ensure active involvement of consumer representatives across the spectrum of cancer control. The inclusion of well-informed consumers will add value and help to ensure that the reality of patient experience and knowledge is taken into account at all levels of policy and decision-making within Cancer Control in New Zealand. We believe a position should be established on the Cancer Programme Steering Group for a member of NCCRAG. ***We note there is still no consumer representative appointed to the Board of Cancer Control New Zealand and hope to see the establishment of such a position in the near future.***

## 3. Priority Issues

Through our dealings with the membership of BCAC and with cancer clinicians around New Zealand we have identified a number of issues that we believe need to be dealt with urgently in order to ***improve the health and wellbeing*** of those with breast cancer in New Zealand. These are:

- greater access to psychosocial support
- availability of subsidised fertility preservation treatment
- better access to lymphoedema treatment
- improved access to delayed breast reconstruction surgery.

In addition, we believe the following issues need to be addressed within the health system to ***improve the delivery of breast cancer services***. These include:

- changes to PHARMAC's policies and procedures to allow for timely, transparent and evidence-based decisions on medicines funding
- the ongoing collection and storage of breast cancer data of the quality now collected in the four regional Breast Cancer Registers
- better quality assurance for pathology and receptor testing
- implementation of 12 months Herceptin treatment as the standard of care for those with early HER2 positive breast cancer.

## 4. Health and Wellbeing for those with breast cancer

The following treatment areas all impact greatly on the health and wellbeing of those with breast cancer. Whilst not forming part of the core cancer treatment programme, all of these services need to be easily accessible for women in order to limit on-going and future health problems and to ensure the best possible quality of life.

### 4.1 Psychosocial Support

Psychological and social support during breast cancer diagnosis, treatment and recovery is crucial as many women and their families struggle to deal with the mental and emotional stress of cancer and its associated invasive treatments.

It's estimated that up to 25 per cent of all cancer patients will suffer from clinical depression<sup>1</sup>. Further research has shown that major depression is frequent among breast cancer patients, but is often unrecognised and untreated and can amplify physical symptoms and result in poor treatment adherence<sup>2</sup>.

Counselling, cognitive behavioural therapy, and/or support groups can help women to overcome stress and depression in a healthy way, ultimately leading to better physical and emotional outcomes. In recognition of this point, the *New Zealand Guidelines on the Management of Early Breast Cancer* recommend that psychosocial support should be available to all women with early breast cancer. In addition, one of the six goals of the New Zealand Cancer Control Strategy is to “improve the quality of life for those with cancer, their family and whanau through support, rehabilitation and palliative care”. This goal includes an objective to ensure that those with cancer have access to appropriate resources for support.

However, BCAC is aware that psychosocial support is not offered as a matter of course in every DHB. In some areas, such as Waikato, there is no psychosocial support offered through the DHB at all. In other areas, such as Auckland, a psychologist may be available, but has such limited resource that he or she cannot meet the demand from breast and other cancer patients. In Christchurch, access to a psychologist is free for those who have received private treatment at the Cancer Care Centre, but this service is not available to those treated in the public system. For some patients counselling may be available through the Cancer Society of New Zealand, but the number of sessions they receive is limited and variable throughout the country.

BCAC believes breast and other cancer patients should be offered psychosocial support to optimise their quality of life and potential health outcomes. Clearly patients should be able to access such support equitably wherever they live in New Zealand. Counselling should also be available for couples and families given that the stresses of cancer diagnosis and treatment can impact negatively on relationships.

We are aware that Don Bevan of Psychosocial Oncology New Zealand and Susan Sutcliffe of the Cancer Society are drafting standards for supportive care for the National Breast Cancer Tumour Stream Working Group (NBCTSWG) to consider. We would expect this group to include the availability of psychosocial support as a standard of care within the breast cancer pathway.

*Action Point:*

- Include provision of psychosocial support for cancer patients as a necessary element of service provision by DHBs

<sup>1</sup>Henriksson MM, Isometsä ET, Hietanen PS, et al.: Mental disorders in cancer suicides. *J Affect Disord* 36 (1-2): 11-20, 1995.

<sup>2</sup> [Fann JR](#), [Thomas-Rich AM](#), [Katon WJ](#), [Cowley D](#), [Pepping M](#), [McGregor BA](#), [Gralow J](#).: Major depression after breast cancer: a review of epidemiology and treatment.

## 4.2 Fertility Preservation

Around 150 New Zealand women under the age of 40 will be diagnosed with breast cancer every year. Many of these women will either have not started their families or have not completed them.

Younger women are frequently diagnosed with a more aggressive form of breast cancer and this is more likely to require chemotherapy treatment. The chemotherapy agents used to treat breast cancer can have a detrimental effect on the ovaries, with 20 to 70 per cent of women becoming menopausal as a result of treatment. Women are also usually advised to delay conception for a number of years after a breast cancer diagnosis which can further impact on fertility.

In order to preserve their fertility options, younger women who are about to undergo chemotherapy need to consider either oocyte (egg) or embryo cryopreservation, in which eggs or embryos are frozen for potential future use. For some, ovarian tissue cryopreservation may be an option. When these women are ready to become pregnant the frozen egg or ovarian tissue is thawed, fertilised and transferred to the uterus as an embryo.

However, cryopreservation of oocytes, ovarian tissue and embryos is not currently publicly funded for women who become menopausal as a result of chemotherapy treatment.

We believe women should have choices about their future fertility options and that women who have been treated for breast cancer should have access to publicly funded fertility treatment, just as other women who have been identified as infertile do.

We would like to see New Zealand women affected by breast cancer receive a funded first assessment with a fertility specialist to discuss their options. Where the woman is medically fit, has sufficient time and is informed of the potential risks of hormonal treatment, she should be offered a publicly funded cycle of oocyte or embryo cryopreservation.

We estimate that around half of the 150 women aged 40 or less diagnosed with breast cancer each year would wish to access a specialist assessment and approximately half of these women may wish to undergo either oocyte or embryo cryopreservation. The cost of subsidising this service for around 75 women a year at a cost of \$7,500 per treatment would be approximately \$550,000. We believe this spending would be well received by the general public and would make a dramatic difference for young women with breast cancer for whom the prospect of losing their fertility can be extremely distressing.

We are aware that the current providers of fertility treatments in New Zealand have the capacity and the willingness to provide a comprehensive fertility preservation service. The National Child Cancer Network has recently established a Fertility Preservation Working Group. This group is currently working on nationally agreed guidelines for fertility preservation that will include recommendations for adult cancer patients.

*Action Points:*

- Provide funding for women with breast cancer under the age of 40 to have an initial assessment with a fertility specialist to discuss treatment options.
- Publicly fund oocyte, ovarian tissue and embryo cryopreservation treatment for women under the age of 40 with breast cancer.

### 4.3 Lymphoedema Treatment

Lymphoedema is a common side effect of breast cancer surgery, particularly when women have lymph nodes removed as part of their treatment. Around 13 per cent of those who have axillary node dissection during breast cancer surgery will develop significant lymphoedema that requires treatment<sup>3</sup>. Lymphoedema often occurs in the arm or hand on the side of breast surgery, but it can also occur in the breast, underarm, torso, or back. The condition results in an excessive build-up of fluid in one or more of these areas and requires specialist and ongoing care. If women do not receive treatment, swelling can worsen and result in permanent changes to the tissue. Lymphoedema can be a debilitating condition that can severely impact on quality of life.

Currently, the Ministry of Health does not require DHBs to provide a lymphoedema service for breast cancer patients so many women are not getting the care they need. The service levels provided throughout the country are patchy. In some areas women receiving breast cancer treatment through a public hospital have no access to lymphoedema services and women in many rural areas have poor access to lymphoedema practitioners.

Lymphoedema is a common side-effect of breast cancer surgery and treatment should be provided within any comprehensive breast cancer treatment programme. We'd like to see the Ministry of Health direct DHBs to include this as part of breast cancer service coverage.

A cost-effective way to address this issue would be to offer training to breast care nurses to provide some of the lymphoedema treatment required by women. To address service inequalities in rural areas we suggest the establishment of a mobile lymphoedema service in which a trained breast care nurse or lymphoedema practitioner could travel to rural areas to provide treatment on a regular basis for women who need it.

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<sup>3</sup> Muhammad Asim, Alvin Cham, Sharmana Banerjee, Rachael Nancekivell, Gaelle Dutu, Catherine McBride, Shelley Cavanagh, Ross Lawrenson, Ian Campbell, 2012. Difficulties with defining lymphoedema after axillary dissection for breast cancer. *NZ Medical Journal* 125 No 1351, pgs. 29-39.

*Action points:*

- Ministry of Health to include lymphoedema treatment as part of breast cancer service provision by District Health Boards.
- Provide a training budget to upskill breast care nurses in lymphoedema massage and kinesio taping so that they can provide treatment for women with lymphoedema.
- Establish a mobile lymphoedema service so that women in rural areas can access this treatment if they need it.

#### 4.4 Breast Reconstruction

The Government has recognised that breast reconstruction, either at the time of breast cancer surgery or at a later time, is an important element of any breast cancer treatment programme. While not all women decide to have breast reconstruction, it's important that women have the choice to pursue this option.

Many women who have a mastectomy choose to have immediate breast reconstruction, but a large proportion of women require delayed reconstruction. This may be because they need further surgery, radiation therapy or other treatment that is incompatible with immediate reconstruction, or because they are simply not yet emotionally ready to undergo a reconstruction operation.

BCAC has learned that many women in New Zealand are once again being removed from surgery waiting lists while awaiting delayed breast reconstruction surgery. We are told that delayed breast reconstruction is not available at all within the public sector in the Bay of Plenty or Auckland regions and this may well be more widespread than we are aware.

This situation causes high levels of stress and can impact on a woman's emotional wellbeing and quality of life. It can also put pressure on women to make hasty decisions to have immediate reconstruction when this is not the best option for them either medically or psychologically.

We ask that DHBs be instructed that delayed breast reconstruction surgery is deemed by the Government to be a high priority service that must be provided as an integral part of the breast cancer treatment programme.

*Action point:*

- Instruct District Health Boards that delayed breast reconstruction surgery must be provided as an integral part of the breast cancer treatment programme.

## 5. Delivery of Breast Cancer Services

The following areas impact on the delivery of breast cancer services to all New Zealanders. These are systemic issues that need to be addressed to ensure that New Zealand provides world-class and comprehensive healthcare for those with breast cancer.

### 5.1 PHARMAC's Operating Policies and Procedures

PHARMAC is currently conducting a public consultation on its Operating Policies and Procedures (OPP). We see this as a vitally important opportunity for PHARMAC, the Government, health consumers and a range of stakeholders to improve elements of PHARMAC's operations, to the benefit of all. The assessment and decision processes around the funding of medicines and medical devices must be robust and transparent to engender public confidence in the quality of decisions.

Our view, shared by many other organisations and individuals within the New Zealand health sphere, is that there is a need to introduce greater **transparency, timeliness and stakeholder input** into PHARMAC's assessment and decision processes. This will become increasingly important as PHARMAC's functions broaden to include hospital pharmaceuticals and medical devices, resulting in PHARMAC's decisions having a greater impact on the health system and community. This will lead to increased scrutiny of the processes used to reach these decisions as well as the quality of decisions.

There is also a need for a **process by which PHARMAC's decisions can be independently reviewed**. Currently the only option available is a Judicial Review, which is a costly and complex process not available to the vast majority of stakeholders. **Budgeting and forward planning** are important elements of a responsive process for medicines funding, but PHARMAC's role in these elements is currently unclear. This function should be properly defined so adequate time is available for budget shifts to allow the early acquisition of innovative high impact medicines.

An issue of great concern that needs to be highlighted is that **PHARMAC decisions appear not to be based on the best available clinical evidence or on patient need**. The recent decision on the funding of the breast cancer drug, lapatinib, provides an example. The evidence for efficacy of lapatinib lies with its use as a second-line strategy, to be used in metastatic HER2 positive breast cancer after trastuzumab (Herceptin®). This is also where the clinical need lies, and where patients want to see it funded. This was confirmed to PHARMAC in a submission from the expert medical

oncologists of the Breast Cancer Special Interest Group (BCSIG) of the New Zealand Association of Cancer Specialists, while patient need for treatment at this stage was also explained by BCSIG and in a submission from BCAC. Sadly the advice of BCSIG, soundly based on published evidence, was not acted on, and lapatinib was instead funded as a first-line alternative to trastuzumab.

This example illustrates the need for PHARMAC's assessment and decision processes to be required to include, at an early stage, expert independent clinical input from bodies such as BCSIG. Relevant patient groups should also have the opportunity to explain the impact of a medicine funding decision on patients, to allow PHARMAC to properly take into account "the health needs of eligible people", one of PHARMAC's current decision criteria. This input should be provided to PHARMAC's relevant committees (e.g. the Pharmacology and Therapeutics Advisory Committee (PTAC) and its Cancer Treatments sub-committee (CaTSoP)). The influence of input from independent clinical and patient bodies on PHARMAC's considerations and decisions should be recorded and made evident to all stakeholders.

Currently the "consultation" element of PHARMAC's processes involves PHARMAC circulating proposals to stakeholders, including clinical experts and consumers, after negotiations with the relevant pharmaceutical company have concluded. By this time, PHARMAC has already decided on a course of action and seeks input prior to the announcement of its decision, when only minor changes are possible. For example, with the recent lapatinib proposal, stakeholders were given 14 days to respond and the decision was announced 21 days after the deadline for stakeholder input. None of the stakeholder input altered the funding decision in any way.

BCAC has made an independent submission to PHARMAC on the OPP consultation (Appendix 1) and has also contributed to a joint submission from a number of patient groups and pharmaceutical companies, chaired by Medicines New Zealand (Appendix 2).

*Action point:*

- Ministry of Health to establish an independent group to assess PHARMAC's OPP consultation and ensure the implementation of reforms that will strengthen PHARMAC's policies and procedures.

## 5.2 Breast Cancer Data

Accurate, meaningful and timely cancer data are crucial and underpin all research and much decision-making around cancer care. BCAC applauds the initiative by the Government and the National Information Technology Board to progress the development of a national Cancer Data Register. We look forward to seeing this tool completed and operational.

We also welcome the Government's decision to provide partial funding for the existing regional Breast Cancer Registers for the next two years. Detailed breast cancer data have been collected in

Auckland since 2000, Waikato since 2005, Christchurch since 2009 and Wellington since 2010. These Registers detail clinical, pathological, treatment and outcome data along with patient information on age, gender and ethnicity. The consent rate is around 90 per cent across the various treatment centres, making this an extremely powerful tool for understanding the nature of the breast cancer in our country, its treatment and resulting outcomes in different sections of the population.

In the past, the Breast Cancer Register has been largely funded by the New Zealand Breast Cancer Foundation (NZBCF) but the Foundation can no longer continue to provide the \$400,000 annually to collect and maintain these data. The Breast Cancer Register embodies a valuable national asset recognised in the Implementation Plan for the Evidence-based Best Practice Guideline for the Management of Early Breast Cancer, which notes:

*The Implementation Advisory Group has rated the strengthening of infrastructure for national data collection on breast cancer care as the most important step towards achieving sustained improvements in quality of care, and patient survival and quality of life. High quality data is essential for a wide range of functions, including:*

- *service planning*
- *documenting, and reducing, inequities of access*
- *caseload management and workforce development decisions*
- *describing patterns of patient care (for example, prescribing and other decisions, entry to clinical trials) and resulting patient outcomes*
- *documenting recurrence and survival data*
- *monitoring of timeliness of treatment*
- *comparison with international best practice.*

BCAC strongly recommends that the Government takes responsibility for the long-term funding of an integrated, detailed national Breast Cancer Register overseen by the Ministry of Health as a key element of national cancer data collection.

**Action point:**

- Provide long-term funding to ensure the continued collection of detailed data and maintenance of a National Breast Cancer Register; roll out the collection of data nationwide.

### 5.3 Quality Assurance for Pathology and Receptor Testing

The recent discovery of several serious errors in breast biopsy analysis underlines the importance of stringent and robust quality assurance for pathology laboratory testing. BCAC endorses the recommendations of the National Panel to Review Breast Biopsy Errors. We ask that the Minister monitors the implementation of these recommendations to ensure we do not see a repeat of these kinds of errors which can lead to a lack of confidence in pathology reporting and the breast screening programme. We're particularly interested to see the advancement of technology to standardise laboratory processes.

As noted in the Implementation Plan for the Evidence-based Best Practice Guideline for the Management of Early Breast Cancer:

*Pathology assessment of a tumour specimen following surgery provides prognostic and predictive information which forms the basis for all subsequent diagnostic and treatment decisions.*

Receptor testing for hormone receptor and HER2 positive status is a key element of diagnosis in breast cancer. However, a Canadian audit found wide variation in the results produced by different laboratories leading to misdiagnosis<sup>4</sup>. External Quality Assurance (EQA) schemes in Australasia (RCPA QAP) and the UK (UKNEQAS) have found laboratories consistently missing low oestrogen expressing tumours. Current New Zealand standards for quality and competence in New Zealand medical laboratories (NZS/ISO 15189: 2007) require only participation in external quality assessment with internal processes for undertaking corrective actions. This is inadequate to ensure avoidance of errors with negative outcomes for patients, potentially leading to loss of public confidence in the health system as occurred in Canada.

*Action points:*

- Enforce acceptable levels of EQA for all laboratories undertaking breast receptor testing
- Introduce greater scrutiny of EQA results in the breast receptor testing module
- Provide assistance to improve receptor testing where poor performance is detected
- Remove accreditation for laboratories failing to rapidly remedy poor performance

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<sup>4</sup> Furlow B. Special report: National Cancer inquiry unveils Canada's troubled health system. *Lancet Oncol* 2008;9:823-824.

## 5.4 Duration of Herceptin Treatment

Earlier this month at the European Society for Medical Oncology (ESMO) congress, two studies reported results from clinical trials designed to determine the optimum duration of Herceptin treatment in early HER2 positive breast cancer. Results from these trials have been anticipated with great interest by the breast cancer community worldwide.

The HERA trial, involving 5102 women, reported that the benefits in disease free survival and overall survival after 12 months of Herceptin treatment vs no Herceptin remained stable after 8 years follow-up. It also reported that extending Herceptin treatment to 24 months did not improve patient outcomes. Both these results were reassuring to patients worldwide who have received 12 months treatment as the internationally established standard of care. This enduring result is particularly remarkable given that the early strong benefits of 12 months of Herceptin treatment meant that those randomised to the “no Herceptin” arm were, for ethical reasons, offered cross-over to receive Herceptin treatment. Over 50 per cent of those trial participants chose to receive Herceptin, potentially diluting the apparent benefits of treatment vs no treatment.

Four year follow-up data was also presented from the PHARE clinical trial, involving 3880 women, designed to determine whether 6 months Herceptin treatment is non-inferior to 12 months treatment for early HER2 positive breast cancer. Although further follow-up is needed in this trial, there was a clear trend favouring the 12 month arm over the 6 month arm, with a hazard ratio of 1.28, meaning that those given the shorter duration treatment were 28 per cent more likely to die or have their cancer return than those who received 12 months. Further analysis of results for sub-groups of patients with different disease characteristics will be presented in December at the San Antonio Breast Cancer Symposium.

Researchers at ESMO concluded that the results of these two trials confirm that 12 months of Herceptin treatment remains the standard of care for those with early HER2 positive breast cancer. This is the treatment duration stated as the New Zealand standard of care in the Guideline for the Management of Early Breast Cancer.

The results of the PHARE trial, showing worse outcomes for women treated with a shorter duration than 12 months, are of concern to BCAC in relation to New Zealand women who have received only nine weeks of treatment, either in the PHARMAC-funded SOLD trial or outside a clinical trial. The SOLD trial aims to compare outcomes for women given nine weeks of Herceptin treatment to those given 12 months.

In our 2010 Ministerial briefing we presented Ministry of Health data that revealed regional differences in the duration of Herceptin treatment provided to patients. It appeared that cancer treatment centres that were recruiting patients to the SOLD trial, notably Auckland and Christchurch, were also treating a significant number of patients with only nine weeks of Herceptin outside the context of the trial. In our 2010 briefing we noted:

*Given the importance of ensuring that New Zealand women with breast cancer receive best-practice care in order to ensure optimal outcomes, we urge the Minister look into this matter in detail and to require all Cancer Treatment Centres to provide best practice Herceptin treatment to their patients.*

We further suggested in 2010:

*The Minister may wish to conduct an audit of the Herceptin treatments delivered to patients in each of the Cancer Treatment Centres since December 2008 as well as monitoring of long-term patient outcomes.*

The recent data from the HERA and PHARE trial clinical trials add further weight to these suggestions. We do not have recent data on patterns of treatment duration in New Zealand so cannot provide an update on this situation. BCAC has long maintained that results from studies of 6 months vs 12 months Herceptin treatment should be examined before patients are exposed to an even shorter treatment regimen. Our concerns are for the safety of New Zealand women. We question whether it is now ethical to continue to recruit patients to the SOLD clinical trial and reiterate the importance of providing the evidence-based 12 month treatment regimen to all eligible patients.

*Action points:*

- Ensure that all New Zealand cancer treatment centres provide 12 months of Herceptin treatment to all clinically eligible women with early HER2 positive breast cancer
- Examine the ethics of continuing to fund and recruit patients to the SOLD clinical trial

## 6. Information on BCAC

### 6.1 What BCAC does

The Breast Cancer Aotearoa Coalition (BCAC) is an incorporated charitable society established in 2004 to provide a unified, evidence-based voice for the New Zealand breast cancer sector. Our membership comprises more than 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. We work 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 [www.breastcancer.org.nz](http://www.breastcancer.org.nz) and our web videos at <http://www.breastcancer.org.nz/share-your-story/web-videos>

## 6.2 BCAC committee members attending the Ministerial briefing



**Chairperson: Elisabeth (Libby) Burgess (MNZM).** Ms Burgess is a scientist living in Auckland. She is currently on the National Breast Cancer Working Group. She 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.



**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 is on the National Cancer Consumer Regional Advisory Group and represents consumers on the Northern Cancer Network Collaborative and chairs their Consumer Reference Group. She is also a member of the Northern Cancer Network Breast Cancer Tumour Stream Steering Group, the Clinical Guidance committee of Pro Care Health Limited.

## 6.3 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
- Inflammatory Breast Cancer Australasia
- 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
- Sweet Louise
- Shocking Pink
- Taranaki Dragons
- Te Ha o te Oranga o Ngati Whatua
- Terrier Race Against Time
- Waikato Breast Cancer Trust
- Waikato Treasure Chests
- WONS
- YWCA Encore