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Briefing on Breast Cancer Issues in New Zealand

For: Hon. Dr Jonathan Coleman, Minister of Health

CC: Hon. Peseta Sam Lotu-Iiga, Associate Minister of Health
Hon. Peter Dunne, Associate Minister of Health
Hon. Annette King, Labour Health Spokesperson
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From: Breast Cancer Aotearoa Coalition (BCAC)

Date: 01 December 2016

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Executive Summary

On behalf of the thousands of New Zealanders diagnosed with breast cancer, BCAC is grateful to meet with the Minister of Health, Dr Jonathan Coleman and other Members of Parliament to discuss key issues affecting the breast cancer community.

These issues are of national importance given the widespread reach breast cancer has in our society and its impact on women, their families, their workplaces and the health system.

With this in mind, it's important to note some key facts about breast cancer in New Zealand:

- Breast cancer is the most common form of cancer to affect women, with more than 3000 women diagnosed each year.
- It accounts for more than 30% of all new female cancers.
- More than 600 women die every year from breast cancer and it is the second most common cause of cancer death for women.
- Māori women are disproportionately affected by breast cancer. They are more likely to get the disease and 60% more likely to die from it than non-Māori women.
- Young women are also affected by breast cancer, around 400 women under the age of 44 are diagnosed each year.
- New Zealanders are more likely to die from breast cancer than Australians.[1]

These statistics indicate significant work is needed to improve health outcomes for New Zealanders with breast cancer.

This document highlights some of the key issues facing New Zealanders with breast cancer, explores the global trends in breast cancer prevention and treatment and suggests areas in which a real difference can and should be made in the lives of the thousands of New Zealanders who either have breast cancer or are at risk of developing breast cancer.

In order to identify priority issues, BCAC consulted with:

- patients with breast cancer
- the more than 30 breast cancer-related groups that make-up our membership
- cancer clinicians and researchers.

The issues we wish to raise and the actions needed to address and solve these are given in brief below. They are discussed in further detail in later sections of this paper.

Issue 1: Medicines Access

New Zealanders have low and slow access to effective innovative medicines. This is impacting on quality and length of life for New Zealanders diagnosed with breast and other cancers.

Actions:

- Increase funding for the pharmaceuticals budget to the OECD average.
- Explore options to facilitate access to new and innovative medicines, including Early Access Schemes and Cancer Drug Funds.
- Reform PHARMAC's processes to increase transparency, establish defined timelines for funding decisions and involve consumers, e.g. as PTAC members.
- Ensure PHARMAC applies new criteria to fund medicines based not only on cost, but on value and on the needs of people, whanau and communities.

Issue 2: Intra Operative Radiation Therapy

This new effective technology provides radiation therapy in a single shot during surgery to remove a low risk breast cancer tumour, reducing tissue damage and saving patient distress, time and costs. Its introduction into New Zealand's public health system has taken far too long.

Action

- Facilitate the rapid introduction of intra-operative radiotherapy (IORT) as a radiation therapy option for selected breast cancer patients within the public health system.

Issue 3: Screening Age Band and Breast Density

New Zealand's upper age limit of 69 years in the BreastScreen Aotearoa programme leaves women at increased risk of breast cancer outside our world-class screening programme, resulting in late detection and loss of life. High breast density is a significant but unmanaged risk factor for breast cancer.

Actions:

- Extend the upper age limit for publicly funded breast screening via BreastScreen Aotearoa to 74 years of age.
- Create a high-level working group to investigate how breast density as a risk and masking factor in screening can be addressed to ensure women and specialists effectively manage this risk.

Issue 4: Breast Reconstruction and Prophylactic Mastectomy

Despite a Ministry initiative to encourage DHBs to provide timely breast reconstruction when patients are ready to receive it, little progress has been made.

Surgeons are concerned that insufficient resources are available to provide prophylactic mastectomies to women who have tested positive for BRCA gene mutations.

Actions:

- Ensure adequate surgical resources are in place to:
    - provide timely post-mastectomy breast reconstruction for all women who need it, including those who do not make a decision to reconstruct at the outset of their treatment
    - offer timely prophylactic mastectomies for those who test positive for BRCA gene mutations.

Issue 5: Inequity for Māori

Māori women suffer higher incidence and worse outcomes from breast cancer for a number of reasons including later diagnosis, more advanced cancers when detected and slower access to treatments.

Actions:

- Increase funding for BreastScreen Aotearoa to further engage and support Māori women to participate and remain in the screening programme.
- Provide resources allowing establishment of community and iwi-based programmes for detection of breast cancer.
- Direct DHBs to ensure that Māori women with breast cancer are treated in a timely and effective manner.

Issue 6: Access to Clinical Trials

Access to clinical trials for New Zealand patients is still extremely limited. Clinical trials offer breast cancer patients the opportunity to gain early access to innovative life-saving or life-extending treatments.

The lack of a robust clinical trial environment in New Zealand is outlined in the 2011 Report of the Health Committee chaired by Paul Hutchinson, entitled *Inquiry into improving New Zealand's environment to support innovation through clinical trials*. Five years later, patient access to clinical trials has not improved, suggesting little progress has been made in implementing the recommendations of the report.

Actions:

- Implement the recommendations of the Hutchinson Report, including:
    - achieving optimal clinical trial frameworks, infrastructure, and coordination in New Zealand and making funding available for this purpose

  - working to improve industry collaboration and promoting New Zealand as a destination for clinical trials.

Issue 7: FISH Testing Delays

Cancer specialists from around the country are concerned at the slow provision of FISH test results. This is slowing the diagnostic pathway and compromising the ability to meet Faster Cancer Treatment targets.

Action:

- Ministry to require accredited FISH testing laboratories to provide test results within three working days.

Issue 8: Revision of Standards of Service Provision for Breast Cancer Patients to include neo-adjuvant treatment and pathology protocols

Cancer specialists across all disciplines are concerned that the *Standards of Care for Breast Cancer Patients* do not contain recommendations for neo-adjuvant therapy. Practice is uneven within and across DHBs and standardisation to best practice is needed.

Action:

Re-convene the Working Group that developed the *Standards* to develop an update for this and any other areas needing revision.

Issue 9: Fertility treatment following breast cancer diagnosis

Ethical approval has recently been granted for the freezing of ovarian tissue as a means of preserving future fertility in young women who are soon to undergo treatment for breast cancer. This now needs only the Minister's approval to proceed.

Action:

Minister please provide your timely approval for this process so that fertility can be preserved in women urgently requiring this procedure before their breast cancer treatment commences.

Global Trends

Before exploring these priority issues in greater detail, it's important to be cognisant of the global trends in breast cancer detection, treatment and care. There are a number of recent developments[2] that offer New Zealand new opportunities to manage risk; improve policy, detection, treatment, care and prevention of recurrence, including providing better access to new and innovative medicines. These include the following:

- ➢ Research continually reveals more details of the pathways involved in the different sub-types of breast cancer and identifies novel treatments that can effectively interfere with these. Treatments are becoming more targeted and effective, and will be used in smaller populations of patients whose cancers are susceptible to specific inhibition.

- With the advent of more refined and targeted treatments, researchers are investigating which patients can avoid certain treatments such as cytotoxic chemotherapy, External Beam Radiation Therapy and axillary dissection (removal of lymph nodes in the armpit). Patients, clinicians and funders share enthusiasm to identify when aggressive treatments can safely be avoided.

- Many developed countries are providing timely access to a range of advanced and innovative cancer treatments through investment in medicines and technologies and through the establishment of early access programmes. New Zealand lags behind the rest of the developed world in this area.[3]

- At policy level consumers are being included in greater numbers in cancer review panels (e.g. PTAC's equivalent in Canada) as important contributors working alongside clinicians and advisors. [4]

- Neo-adjuvant therapy provides a rapid means of identifying which treatments are likely to be effective for individual patients and those with identified sub-types.

- Clinical trials are focusing on the following key research areas:

    - The use of advanced diagnostics to further define the nature of subtypes of breast cancer, including pathway differences and hormonal differences. This can involve liquid and/or tumour biopsies, genomics, multiplex panels and other predictive and prognostic tests.[5]
    - Whether surgery is required and whether breast conserving surgery is appropriate for specific subtypes, grades and stages of breast cancer.
    - Predicting the success and efficacy of targeted treatments including antibodies, pathway inhibitors and hormone treatments.
    - Identifying the extent and nature of treatment needed for lower grade and stage specific subtypes of breast cancer such as DCIS, ER+ and Her2+. [6]
    - The level and combination of chemotherapy required, including testing new and advanced treatments including immunotherapies.[7]
    - Determining whether radiation is required and when Intra-Operative Radiation Therapy is appropriate instead of External Beam Radiation Therapy.[8]
    - Exploring preventative treatment to reduce the risk of recurrence including, energetics and nutrition[9], green prescription programmes, prophylactic mastectomy, and monitoring for early detection through targeted screening technologies.[10]

- There is increasing recognition that survivorship needs to be discussed with patients in the context of a cancer care pathway, particularly for those diagnosed with advanced breast cancer. This serves to educate and inform patients and can determine a person's psychosocial tolerance for certain treatments. For some patients this may reduce the level of treatment and intervention required.[11]

- There are new findings in the mammographic density have shown that high breast density can increase the risk of developing breast cancer by 20-25%. Dense breast tissue may mask the ability to detect cancer, and is also now known to be a 'breeding ground' for tumours. This has raised concerns about the need for targeted and supplementary screening for this new at-risk group. Half of all US states have legislated to recognise breast density and Western Australia now advises all women of the risk associated with dense breasts. This is also occurring in the UK.

Issue 1: Medicines access

This year BCAC launched a campaign calling for better access to medicines for New Zealanders. This campaign saw more than 2,500 emails sent to the Minister of Health asking for the Government to take action to improve access to medicines for New Zealanders with breast cancer, New Zealanders with other cancers, and New Zealanders with chronic diseases.

We acknowledge this year's budget increase in funding for PHARMAC as a step in the right direction, but stress that this is not enough to address the urgent need for new and innovative medicines in New Zealand.

New Zealanders' access to new and innovative medicines is woeful compared with other OECD countries. Some key facts:

- New Zealand's death rate from breast cancer is 40% higher than that of Australians, with 10 New Zealanders losing their lives in the time that seven Australians die.[12]
- Each year Australia spends $435 per person on medicines, but in New Zealand we spend a mere $180 per person.[13]
- In the UK, 80% of approved new medicines are publicly funded, in Australia 39%, but in New Zealand it's only 13%.[14]
- Between 2009 and 2014, New Zealand ranked last out of 20 OECD countries in access to new medicines.[15]
- Breast cancer drugs including Perjeta, Kadcyla, Abraxane, Afinitor and Halaven are publicly-funded in Australia but not in New Zealand.[16]
- Out of 13 OECD countries, New Zealand has the lowest ranking for access to cancer medicines.[17]

The Minister of Health has overall responsibility for ensuring New Zealanders have fair and reasonable access to effective medicines to ensure best possible health outcomes for individuals and the community. However, the statistics above show that this is not happening and sadly, the result is that New Zealanders are losing their lives earlier than they need to.

New Zealanders affected by the lack of access to medicines

This is a real issue affecting real people. Please watch our recently-produced videos of women and men with advanced breast cancer (www.breastcancer.org.nz/metavivor-videos) and hear their heart-breaking pleas for access to new medicines. These New Zealanders, and many others like them, are desperate for the Government to take action on their behalf.

The five breakthrough breast cancer medicines listed above as publicly funded in Australia but not New Zealand give longer, healthier lives to women with different types of breast cancer. In addition, Tykerb is only funded here for an extremely limited use that oncologists advise makes it inaccessible to the vast majority of patients who need it. Fulvestrant is another important option for metastatic breast cancer that is not available in our country. Other breakthrough medicines including Ibrance and checkpoint inhibitors such as Keytruda are on the horizon for breast cancer.

Why should our women face poorer outcomes than their Australian counterparts?

Many of these women are young, they have small children, they work, and they have much to contribute to society, but they are being denied the best chance at life. Improving their quality of life and extending their lives should not be seen as a charitable act towards an individual who is "going to die anyway". Every person in this situation is surrounded by a network and their quality and length of life affects this community: their parents, spouses and children, their friends and workmates, their ability to work, to care for themselves and others, and their demands on their healthcare providers.

The societal benefits of better access to medicines

The costs associated with a lack of access to new and innovative medicines are not merely individual: there are significant social and economic costs associated with providing less-than-optimal medicines for those living with advanced breast cancer, in particular the health care costs associated with caring for someone who is unwell for a long period of time.

The benefits of providing better access to medicines deliver on nearly every measure, including:

- providing longer, better lives for patients
- saving our health system resources
- reducing hospital stays
- keeping people working and reducing sickness benefit costs
- reducing palliative care costs
- keeping families together.[18]

Changes required to New Zealand's pharmaceutical budget

One of the reasons for New Zealand's low and slow access to medicines is that, unlike other OECD countries, New Zealand's medicines funding agency, PHARMAC, has a capped pharmaceutical budget. This means there is a fixed amount of money available to invest in medicines, so for a new medicine to be funded, cost savings must be made elsewhere and this often involves removing funding for another medicine. This "robbing Peter to pay Paul" approach to medicines funding is antiquated, unfair and unreasonable and leads to the system being rigid and unresponsive when a breakthrough new treatment becomes available.

We believe this approach needs to be reviewed so that PHARMAC can approach the funding of new medicines in a more flexible and timely fashion. New medicines are being developed and brought to market at an ever-increasing speed. In order to address this issue in a sustainable way, we'd urge the Government to explore additional strategies adopted by other countries, such as Early Access to Medicines Schemes, and Cancer Drugs Funds. The Canadian New Drug Funding Programme provides access to a range of innovative medicines, using an assessment process that reaches a decision within 100 days and involves consumer participants.[19]

Furthermore, the medicines budget needs to be enhanced with more funding. Not only is New Zealand's medicines budget capped, it is also very small. For the 2016/17 year it is set at $850M, representing an investment of $180 per person.[20] In contrast, in 2015 Australia spent $435 per person on medicines.[21] We believe the medicines budget needs to be significantly increased to bring New Zealand into line with other OECD countries.

Finally, we'd urge you as the Minister of Health to ensure that PHARMAC abides by its criteria for deciding which medicines to fund by including not only impacts on the pharmaceutical budget but also on people, whanau and communities, as well as the wider health system.[22]

ACTION POINTS

- Increase funding for the pharmaceuticals budget to the OECD average.
- Explore options to facilitate access to new and innovative medicines, including Early Access Schemes and Cancer Drug Funds.
- Reform PHARMAC's processes to increase transparency, establish defined timelines for funding decisions and involve consumers, e.g. as PTAC members.
- Ensure PHARMAC applies new criteria to fund medicines based not only on cost, but on value and on the needs of people, whanau and communities.

Issue 2: Intra-operative radiation therapy and the public health system

Intra-operative radiotherapy (IORT) is a new technology which that delivers a single treatment of radiation therapy during surgery to remove the breast cancer tumour in low-risk patients. It provides an extremely convenient, efficient and effective option for patients as well as for radiation treatment clinics, in contrast to current standard courses of treatment with whole breast external beam radiation therapy (EBRT) which is given each weekday for three to five weeks.

The extended treatment period required for EBRT is often stressful and disruptive to the lives of patients, and can cause financial hardship, especially for those living at significant distance from radiation oncology treatment facilities. This drives women to make treatment choices that are less than optimal, e.g. women living in Northland are more likely to choose mastectomy ahead of wide local excision or to refuse radiation therapy altogether because of the disruption involved in attending treatment sessions in Auckland.

IORT by contrast can be delivered in around 20 to 30 minutes during surgery for low-risk early stage breast cancer and provides many advantages for patients, including:

- a reduction in radiation treatment time
- minimised radiation exposure to healthy tissue and organs, such as the ribs, lungs, heart and opposite breast
- no treatment delay for those who must also undergo chemotherapy as part of their breast cancer treatment
- same-day treatment
- no travel required to a radiotherapy centre for up to six weeks of daily treatment
- less stress because patients spend less time away from family and support networks
- a reduction in expense for those live remotely and need to pay for travel and accommodation.

Furthermore, IORT offers benefits to the health system by:

- Reducing the time and resource needed to treat qualifying patients
- Freeing-up conventional linear accelerator machines for use in other patient groups
- Potentially reducing waiting times for radiation therapy treatment because fewer women with breast cancer need to be treated
- Achieving cost-savings through a decreased demand for conventional EBRT.

International research highlights the effectiveness of IORT treatment and shows, with five years follow-up that rates of breast cancer recurrence and mortality did not differ between IORT delivered during surgery vs EBRT. However, IORT was associated with fewer non-breast cancer-related (cardiovascular and other cancer) deaths and reduced skin and cosmetic damage.[23]

The recently disestablished National Health Committee (NHC) had evaluated IORT and recommended its implementation within the public health system. The NHC has been replaced by the Strategic Technology Prioritisation and Innovation team (STeP-In) which BCAC understands is again assessing the value of IORT.

We would stress that the value of IORT has already been established by the NHC and we'd urge the STeP-In to move forward and ensure this effective and cost-saving procedure is made available in our public health system for the benefit of patients, clinicians and the health budget.

ACTION POINT

- Facilitate the rapid introduction of intra-operative radiotherapy (IORT) as a radiation therapy option for selected breast cancer patients within the public health system.

Issue 3: Extending the age cohort for publicly-funded breast screening to 74 and breast density

Screening age band

The current upper age limit of the BreastScreen Aotearoa screening programme is 69 years of age. However, a woman's risk of developing breast cancer does not suddenly reduce or disappear as she turns 70, and in fact the risk increases with age. There is good evidence that extending the upper age limit to 74 years would detect cancers earlier and reduce breast cancer mortality.

- More than 730 women aged 70 and over are diagnosed with breast cancer each year. That's around a quarter of all breast cancer cases.[24]

- Women over 70 diagnosed with breast cancer are more likely to die from the disease. Although around a quarter of all diagnoses of breast cancer are in women 70 and over, more than 40 per cent of all deaths from breast cancer are in women in this age group. [25]

- Women over 70 are more likely to end up with advanced breast cancer. Around 16% of women diagnosed with breast cancer in their 70s end up with metastatic disease, compared with 11% of those diagnosed in their fifties and 10% of those diagnosed in their sixties.[26]

- New Zealand women mistakenly believe that their breast cancer risk is lower once they turn 70 and are no longer eligible for our national screening programme. This belief may reduce the level of vigilance for possible symptoms.[27]

- A review of the Australian breast screening service cited evidence of benefit in relation to a reduction in mortality from breast cancer associated with screening in women aged 70 to 74. [28]

- A 2007 Australian study found that screened women aged 70 – 74 had a 57% reduction in breast cancer mortality compared with unscreened women. [29]

- A more recent study concluded that increased screening participation by women aged 70 – 74 years is associated with reduced tumour size … without a concomitant increase in cancer incidence”.[30]

- The World Health Organisation’s International Agency for Research on Cancer noted that the evidence for benefit of screening in women aged 70 – 74 years is equivalent to that for women aged 50 – 69 years and noted that “A substantial reduction in the risk of death from breast cancer was also consistently observed in women of 70 – 74 years of age who were invited to or attended mammographic screening…”.[31]

These findings provide compelling evidence of the need to extend the age range for BreastScreen Aotearoa to 74, as is the case in Australia and the UK.

Providing free screening to women until they are 74, will only result in two more screenings per woman. This will not represent a very significant increase of the workload of BreastScreen Aotearoa, but will achieve early detection and lead to better outcomes for this age group.

We refer the Minister and Ministry of Health to the *Written submission to the Health Select Committee concerning the Petition of Evangelia Henderson on behalf of the New Zealand Breast Cancer Foundation* (Petition 2014/0061): *“That the House of Representatives recommend to the Government that New Zealand’s free national breast screening programme for women, currently offered to women aged between 45 and 69, be extended to women aged 70 to 74.”*

Breast density

The density of a breast is now understood to contribute to the lifetime risk of developing breast cancer by 20-25%. Although it was previously understood that density may mask the ability to detect cancer it is now known that dense tissue may also be a ‘breeding ground for tumours’. This has raised concerns about the need for targeted and supplementary screening for this ‘new’ at-risk group.

Half of all US states have legislated for this change and we are aware that Western Australia now advises all women of the risk associated with dense breasts, as does the UK.[32] However, we in New Zealand remain silent on the issue. Understandably there are sensitivities around potentially weakening recruitment of Māori and Pasifika women to the BreastScreen Aotearoa screening programme and of unnecessarily frightening women.

We acknowledge these sensitivities but believe it is critical that we gain clarity on this issue in New Zealand. By ignoring it we are putting New Zealand women at risk. Boyd (1995) identifies 40-50% of women have medium to high density breasts and it is now known that changes in the stromal microenvironment and immune changes may be responsible for the increased breast cancer risk. In addition, dense breasts are associated with more advanced stages of diseases.[33] This risk is identified as a heritable risk and may for example explain some of the issues Māori women face.

ACTION POINTS

- Extend the upper age limit for publicly funded breast screening via BreastScreen Aotearoa to 74 years of age.
- Create a high-level working group to investigate how breast density as a risk and masking factor in screening can be addressed in New Zealand to ensure women and specialists effectively manage this risk.

Issue 4: Access to delayed breast reconstruction and prophylactic mastectomy

BCAC is aware that many women across the country are still having difficulty accessing timely breast reconstruction surgery after mastectomy. This issue has been ongoing for several years and has remained unresolved by many DHBs despite a Ministry of Health initiative to encourage timely provision of this surgery.

Many women choose not to have an immediate breast reconstruction and instead wait to have this surgery sometime after their treatment has finished. This delay is clinically desirable for most women, as radiation therapy can cause severe damage to reconstructed breast tissue leading to ongoing recovery issues and potential disfigurement and the need for further surgery. Unfortunately, many of the women choosing delayed reconstruction are treated by their DHBs as needing lower priority "elective" surgery. This is inappropriate as breast reconstruction after mastectomy, no matter when it is performed, is an integral component part of the breast cancer treatment programme.

BCAC would like to see a consistent policy applied to delayed breast reconstruction across all DHBs so that every woman needing reconstructive surgery receives this within four months of stating she is ready for it. This aligns with the *Standards of Service Provision for Breast Cancer Care* Standard on Breast Reconstruction:

Standard 8.6 Breast Reconstruction

Clinicians discuss delayed or immediate breast reconstruction with all women who are due to undergo mastectomy, and offer it except where significant comorbidity precludes it. All appropriate reconstruction options are offered and discussed with women, irrespective of whether they are all available locally.

BCAC is aware that the Ministry of Health is actively encouraging DHBs to provide delayed reconstruction in a timely way once a woman is physically and psychologically ready for it. However, we are told by clinicians that surgical resources are inadequate so this is simply not happening in many parts of the country. In order to assist DHBs implement this action, we'd like to see additional resources allocated for reconstructive surgery to ensure the necessary facilities and staff are available to manage this workload.

An additional worrying concern expressed to us by surgeons is that resources are not available to perform prophylactic mastectomy in women who have tested positive for BRCA gene mutations. Given the extremely high risk of these women developing aggressive forms of breast cancer such as triple negative disease, we ask the Ministry to investigate this and ensure resources are allocated for this as a priority.

ACTION POINT

- To ensure adequate surgical resources are in place to:
    - provide timely post-mastectomy breast reconstruction for all women who need it, including those who do not make a decision to reconstruct at the outset of their treatment
    - offer timely prophylactic mastectomies for those who test positive for BRCA gene mutations.

Issue 5: Action to address Māori inequities in breast cancer

New Zealand needs to take action to address the inequities for Māori with breast cancer. As we stated above:

- ➢ Māori women are disproportionately affected by breast cancer. They are more likely to get the disease and 60% likely to die from it than non-Māori women.

However, recent research has highlighted further inequities for Māori women with breast cancer, including the following:

- ➢ Māori women have significantly higher rates of advanced and higher grade breast cancers.[34]
- ➢ Māori women experience longer delays in getting surgical treatment for breast cancer.[35]
- ➢ Māori women have lower rates of breast screening (65% compared with 72% for European women).[36]
- ➢ Breast cancers in Māori women are less likely to be picked up via mammographic screening (49%) compared with European women (62%). [37]

Research on whether Māori women are genetically more susceptible to breast cancer is inconclusive, but even if this is the case it is an indictment on the New Zealand health system that Māori women are screened at lower rates, are diagnosed later and wait longer for treatment.

Much more needs to be done to engage Māori women in the breast screening programme and in the health system overall so that they are able to access timely and effective treatment. BCAC urges the Minister in the strongest terms to provide BreastScreen Aotearoa with further resources to connect and engage with Māori women. We believe there is a need for more iwi-based screening programmes that can more effectively recruit and support Māori women in this area.

Furthermore, DHBs need to be instructed and supported to do more to ensure Māori women are treated in a timely and effective manner.

ACTION POINTS

- Increase funding for BreastScreen Aotearoa to further engage and support Māori women to participate in the screening programme.
- Provide resources allowing establishment of community and iwi-based programmes for detection of breast cancer.
- Direct DHBs to ensure that Māori women with breast cancer are treated in a timely and effective manner.

Issue 6: Access to clinical trials

Access to clinical trials for New Zealand patients is still extremely limited. Clinical trials offer breast cancer patients the opportunity to gain early access to innovative life-saving or life-extending treatments, particularly through neo-adjuvant clinical trials. Many patients are frustrated to learn of innovative medicines available in overseas trials that they cannot participate in.

BCAC is aware of New Zealand women, particularly those with advanced disease, who have chosen to move to Australia to participate in trials that offer access to promising new medicines. Relocating is difficult and disruptive for these patients and their families, and can mean separation from loved ones at a time when every day together is precious.

The lack of a robust clinical trial environment in New Zealand is outlined in the 2011 Report of the Health Committee chaired by Paul Hutchinson, entitled *Inquiry into improving New Zealand's environment to support innovation through clinical trials* (the Hutchinson Report). Five years later, patient access to clinical trials has not improved, suggesting little progress has been made in implementing the recommendations of the report.

The Hutchinson Report outlines the many benefits of clinical trials to patients, clinicians, the health system and the wider economy.

For patients, some benefits of clinical trial participation include:

- Receiving new medicines and treatments
- Better or more intensive medical care than they would otherwise receive
- Education about their conditions to enable them to manage their health better.

NZ's public health system and its clinicians would also benefit from having a stronger clinical trial environment. Some of these benefits include:

- Specialist clinicians involved in clinical trials benefit by learning and the opportunity to develop a global presence in their fields
- Top clinicians seek to engage in clinical research and are likely to stay in New Zealand if offered the opportunity to conduct clinical research as an integral part of their employment
- DHB staff involved in clinical trials gain additional knowledge which can be applied to benefit other patients.

Significant financial benefits to the economy were also documented in the Hutchinson Report including:

- A USA study projects that for every dollar spent on clinical trials at least a four-fold projected net economic benefit to society
- Positive clinical trial data adds significant value to intellectual property generated in the biotechnology, pharmaceutical, medical device, bioactive and functional health food sectors.

The Hutchinson Report notes that New Zealand already has many of the key requirements for a successful clinical trial environment to operate in. These include patients who have not been exposed to medicines previously, diverse patient groups, ethnic sub-population groups, and an English-speaking health sector with high ethics and well-respected physicians. (*Hutchinson, P12*) The Report indicates that alongside the many benefits of clinical trials that low investment in clinical trials can have an adverse effect on health service outcomes and patients' outcomes. Breast Cancer Cure, a member of BCAC is in the early stages of establishing a fundraising programme in partnership with Australia & New Zealand Breast Cancer Trials Group to try and bridge this gap.

ACTION POINTS

- Implement the recommendations of the Hutchinson Report, including:

  - achieving optimal clinical trial frameworks, infrastructure, and coordination in New Zealand and making funding available for this purpose *(Hutchinson Report, p52)*
  - working to improve industry collaboration and promoting New Zealand as a destination for clinical trials *(Hutchinson Report, p53)*.

Issue 7: FISH testing delays

Fluorescence in situ hybridisation (FISH) is the methodology used to determine whether breast cancers are HER2 positive or negative. Cancer specialists from around New Zealand have expressed concern to BCAC at the slow and uneven turn-around times for FISH test results among different hospitals and DHBs. This was raised at the November 25th 2016 meeting of the Breast Special Interest Group of New Zealand cancer specialists and the meeting requested that we raise this matter with the Minister and Ministry to seek improvement. While some test results are being provided within 48 hours, other hospital clinicians are regularly having to wait seven to ten days. This creates a delay in diagnosis and slows the treatment pathway for patients, compromising the ability to meet Faster Cancer Treatment target timeframes.

ACTION POINT

- Ministry to require accredited FISH testing laboratories to provide test results within three working days.

Issue 8: Revision of *Standards of Service Provision for Breast Cancer Patients* to include neo-adjuvant treatment and pathology protocols

An issue raised by surgeons, pathologists, medical oncologists and radiation oncologists at the November 2016 Breast Special Interest Group is that there is no guidance relating to neo-adjuvant treatment of breast cancer in the 2013 standards. The neo-adjuvant treatment setting is evolving quickly and being adopted increasingly widely. There is an urgent need for standardisation of protocols to achieve accurate diagnosis allowing selection of the most effective treatments to achieve the best possible outcomes for patients.

For example, when patients experience a pathological complete response (complete disappearance of tumour) following neo-adjuvant therapy, unless clips have been inserted at the initial tumour location surgeons have difficulty finding the right area to sample for pathology and pathologists are uncertain where sections should be taken from. Clips are being used by some specialists at some DHBs but this is by no means standardised within or across DHBs.

ACTION POINT

Re-convene the Working Group that developed the Standards to develop an update for this and any other areas needing revision.

Issue 9: Fertility treatment following breast cancer diagnosis

Ethical approval has recently been granted for the freezing of ovarian tissue as a means of preserving future fertility in young women who are soon to undergo treatment for breast cancer. This now needs only the Minister's approval to proceed.

ACTION POINT

Minister please provide your timely approval for this process so that fertility can be preserved in women urgently requiring this procedure before their breast cancer treatment commences.

Government Initiatives on Breast Cancer Care

BCAC applauds the steps this Government has taken to improve cancer care through the Faster, Cancer Treatment programme and other initiatives. Of note is:

- Faster Cancer Treatment wait time indicators, including the 62-day cancer target introduced in October 2014.
- $124 million extra for PHARMAC over four years as part of Budget 2016.

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

About BCAC

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.[38]

BCAC is run by a committee of women who 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, as well as our networks across breast cancer patients, groups and clinicians around the country 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:

- The delivery of a *Step by Step* resource pack free to anyone diagnosed with breast cancer in New Zealand
- Our website www.breastcancer.org.nz
- Our Facebook and Twitter pages (www.facebook.com/breastcanceraotearoacoalition and www.twitter.com/BCACNZ)
- A Facebook support group for New Zealanders with advanced breast cancer (www.facebook.com/groups/metavivorsnz)
- A series of web videos for those with primary breast cancer and advanced breast cancer (www.youtube.com/nzbreastcancer)

BCAC representatives visiting the Minister of Health

	**Chairperson: Libby Burgess** Libby is an Auckland-based scientist and was a member of the Guideline Advisory Team that developed Evidence-based Best Practice Guidelines for the Management of Early Breast Cancer in New Zealand. She is a consumer representative of the Breast Cancer Special Interest Group and the National Breast Cancer Tumour Stream Working Group that developed the Standards of Service Provision for Breast Cancer Patients in New Zealand. Libby has actively campaigned on a range of breast cancer issues including the need for fully funded access to Herceptin and other breast cancer medicines, provision of breast reconstruction and timely access to treatment and care. Libby had breast cancer in 1998. She became a Member of the New Zealand Order of Merit in the 2011 New Year's Honours List for her breast cancer work.
	**Secretary: Fay Sowerby** Fay joined BCAC in 2015 and is also a board member of Breast Cancer Cure and a member of the Health Research Council Breast Cancer Research Partnership Assessment Committee (2013-Present). Fay sought appointment to the Breast Cancer Cure (formerly Breast Cancer Research Trust) Board to ensure funding for ongoing research to improve early detection, predictive and prognostic diagnosis with the discovery and development of new targeted treatments and prevention. In 2013 Fay was diagnosed with breast cancer and her focus sharpened and become more personal. Earlier in her career, Fay was a business and change strategist with KPMG and KPMG Consulting. She managed her own consultancy from 2005-12 and for seven years was a Crown Owned Entity board member.
	**Committee member: Moana Papa** Moana is of Māori (Te Arawa, Ngati Kahungunu, Te Whanau-a-Apanui) and Samoan heritage and lives with her husband and two children in Otara, South Auckland. For the last 15 years Moana has worked in community development and education in Manukau and Auckland City. Moana was first diagnosed with breast cancer in 2005 aged 32, but has more recently been diagnosed with metastatic breast cancer.

	**Committee member: Lynda Ames** Lynda lives in Auckland and was 38 years old when she was first diagnosed with breast cancer in 1990. After radiotherapy, mastectomy and chemotherapy Lynda enjoyed good health and continued to work and travel with her husband, Richard. Unfortunately in 2008 her cancer returned. Although Lynda accepted everything conventional medicine had to offer she also looked into how complementary medicine could help her. Lynda and Richard then attended the Life and Living retreat at The Gawler Foundation where Lynda learned how to help herself and play an active role in her own healing. Lynda is currently a volunteer at The Ambury Park Centre – Riding Therapy for disabled children.
	**Committee member: Greer Davis** Greer was 25 when she was diagnosed with breast cancer in 2012. Through her unexpected experiences as a young woman dealing with treatment decisions, surgery, chemotherapy and reconstructive surgery, she became very interested in how young women's experiences of breast cancer can be improved in New Zealand, and was determined to make something positive out of her experience. In 2013, with assistance from BCAC, Greer attended a conference in the USA specifically for young women with breast cancer (C4YW 2013). She was impressed with the resources and support that young women with breast cancer receive in the US and is keen to see what can be done in New Zealand.

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[4] Dr Bill Evans Presenter: Clinician Involvement in Cancer Medicines Access Decisions, COSA, ANZBCTG, Gold Coast, November 2016.

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[5] Dr Bill Evans Presenter: Clinician Involvement in Cancer Medicines Access Decisions, COSA, ANZBCTG, Gold Coast, November 2016.

[6] Controversies in the Management of non-invasive breast disease. Panel: Boon Chua, Laura Esserman – Surgeon, Sunil Lakhani Translational Researcher, Kelly Phillipa Medical Oncologist, Janine Porter Steel Nurse, Michelle Reintals – Radiologist, Claudia Rutherford Research Fellow Quality of Life, Leonie Young, Consumer, COSA, ANZBCTG, Gold Coast, November 2016.

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