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Briefing on Breast Cancer Issues in New Zealand 2018

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From: Breast Cancer Aotearoa Coalition (BCAC)

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Executive Summary

On behalf of the thousands of New Zealanders diagnosed with breast cancer every year, Breast Cancer Aotearoa Coalition (BCAC) is grateful to have the opportunity to discuss some of the key breast cancer issues affecting New Zealand.

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

Recent research has brought to light the need for urgent action to address the unacceptably high mortality rates from breast cancer in New Zealand for all women. These mortality rates are disproportionately high for Māori and Pasifika women, highlighting the need for targeted steps including work led by Māori and Pasifika communities.

i. Key facts about breast cancer in New Zealand

Breast cancer is the most common form of cancer to affect women.

- Breast cancer accounts for more than 30% of all new female cancers.
- It is the second most common cause of cancer death for women.
- More than 3000 New Zealand women are diagnosed each year, and more than 600 die each year.
- Māori women are 76% more likely to die from the disease after five years than New Zealand European women.
- Pasifika women are twice as likely to die from the disease after five years than New Zealand European women.
- Young women are also affected by breast cancer, around 400 women under the age of 44 are diagnosed each year.
- About one per cent of all diagnosed cases of breast cancer in New Zealand will be in men.
- 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.

ii. Consultation

BCAC is an umbrella organisation representing more than 30 breast cancer-related groups in New Zealand. We regularly consult with:

- patients with breast cancer
- our member groups

- cancer clinicians and researchers.

iii. Key issues

This document highlights some of the key issues facing those with breast cancer 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 this disease.

The issues we wish to raise, and the actions needed to address them, are given in brief below and discussed in further detail later.

Summary – Issue 1: Medicines Access

New Zealanders have insufficient and slow access to effective innovative medicines. This is impacting on quality and length of life for New Zealanders diagnosed with breast cancer and other cancers. Between 2009 and 2014, New Zealand ranked last out of 20 OECD countries in access to new medicines.²

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 throughout the decision-making process, including as Pharmacology and Therapeutics Advisory Committee (PTAC) members.
- Ensure PHARMAC applies new criteria to fund medicines based not only on cost, but on value and on the needs of people, whānau and communities, e.g. extending women's lives so that they can care for their children for longer.
- Ensure that PHARMAC's decisions take into account their impact on the efficient functioning of other parts of the health system, e.g. an injectable version of a drug that would reduce pressure on infusion services, or drugs that improve survival and reduce palliative care costs.

Summary – Issue 2: Inequity for Māori and Pasifika

Māori and Pasifika women are disproportionately affected by breast cancer, with alarming mortality rates that need to be addressed with better screening and treatment. Māori women are 76% more likely and Pasifika women twice as likely to die from the disease after five years than New Zealand European women. Māori women are less likely to be diagnosed through mammographic screening, or receive chemotherapy, Herceptin or surgery. Pasifika women are diagnosed with breast cancer younger than other groups, and the cancer is almost twice as likely to be an aggressive form.

Actions:

- Increase health literacy including women's understanding of the need to take part in breast cancer screening and to continue with their treatment.
- Introduce breast cancer screening programmes targeted to population groups, such as Māori and Pasifika.
- Introduce screening at age 40 to increase the likelihood of Māori and Pasifika women's cancers being detected earlier.
- Enable contact with women via their NHI number to enrol them in the national breast screening programme.
- Increase breast cancer funding in the public health system and ensure the public system welcomes women of all cultures equally and appropriately.
- Support New Zealand-based clinical trials to find ways to improve outcomes for Māori and Pasifika with breast cancer.

1.0 Issue 1: Medicines access

Breast Cancer Aotearoa Coalition (BCAC) calls for better access to breast cancer medicines for New Zealanders – to ensure equity, improve quality of life, reduce suffering and prevent unnecessary deaths. New Zealanders expect to have fair and reasonable access to effective medicines to ensure best possible health outcomes for individuals and the community. The statistics show that this is not happening and sadly, the result is that New Zealanders are losing their lives earlier than they need to.

1.1 A comparative analysis

New Zealanders' access to new and innovative medicines is significantly lower than other OECD countries. Some key facts:

- Between 2009 and 2014, New Zealand ranked last out of 20 OECD countries in access to new medicines.³
- In the UK, 80% of approved new medicines are publicly funded, in Australia 39%, but in New Zealand it's only 13%.⁴
- Each year Australia spends \$435 per person on medicines, but in New Zealand we spend a mere \$180 per person, and we have far fewer funded medicines.⁵

1.2 New Zealanders affected by the lack of access to medicines

Breast cancer affects women of all ages, and about one per cent of all diagnosed cases of breast cancer in New Zealand are men. This is a real issue affecting real people. People experiencing breast cancer are mothers, fathers, daughters, sons, friends, partners, employees. They deserve to have quality of life with their families, in their community and to have the very best opportunities for recovery.

Many people experiencing breast cancer 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.

Every person in this situation is surrounded by a network, and their quality and length of life affects the people in their lives, their ability to work, to care for themselves and others, and their demands on their healthcare providers.

Perspectives of people with advanced breast cancer

Resources that give insight into the lives of people with advanced breast cancer you may find useful:

- Videos of women and men with advanced breast cancer pleading for access to new medicines (www.breastcancer.org.nz/metavivor-videos)

- Recent media coverage about Auckland detective and mother Sarah Cato, forced to fundraise for the drug Perjeta (pertuzumab) which could extend her life, because she is one of more than 100 women who fall outside the PHARMAC funding criteria:
 - ['Warrior woman' cop calls on Kiwis to help raise \\$130K for cancer treatment](#), New Zealand Herald, 24 May 2018
- Media article about women with breast cancer joining Sarah Cato's call for extended funding for Perjeta:
 - [Incurable breast cancer: Women denied access to drugs feel 'brushed aside'](#), New Zealand Herald, 9 June 2018.

For people with advanced breast cancer, 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”.

Even in advanced breast cancer, improved treatments are being developed all the time and every year longer that a person can live gives them the chance of being cured, as has happened recently with advanced melanoma and the drug Keytruda.

1.3 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.⁶

1.4 Medicines requiring funding in New Zealand

There are a number of breakthrough cancer drugs that provide longer, healthier lives to women with different types of breast cancer that are not available in New Zealand. Many are publicly funded in Australia but not New Zealand. Why should our women face poorer outcomes than their Australian counterparts?

- **Kadcyla, Abraxane, Afinitor and Halaven** are funded in Australia but not New Zealand.⁷
- **Perjeta** is funded in Australia and in New Zealand – except for those who fall outside New Zealand's funding criteria.

- **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.
- **Faslodex** is another important option for advanced breast cancer that is not provided in New Zealand.
- **Ibrance** is a new breakthrough medicine currently being considered for funding in Australia and New Zealand. A petition requesting that **Ibrance** be funded in New Zealand currently has 18,500 signatures.
- Other breakthrough medicines including **Caelyx**, **Xgeva** and checkpoint inhibitors such as **Keytruda** are on the horizon for breast cancer.

Waiting list for funding

Four of the above medicines are on the “waiting list” of medicines that PHARMAC has approved for funding but not yet funded - one has been waiting since 2006, another since 2009.

These medicines are:

- **Abraxane**: BCAC applied to PHARMAC to have this funded in May 2018. It has been on the waiting list since 2010.
- **Faslodex**: BCAC applied to PHARMAC to have this funded in May 2018. It has been on the waiting list since 2006.
- **Ibrance**: Pfizer applied for PHARMAC funding in February 2018.
- **Kadcyla**: Roche applied for PHARMAC funding in August 2017 – recommended for funding but with a low priority.

Another medicine, **sub-cutaneous Herceptin**, which could save time and money because it is easier to administer than the currently available version of this drug, has been on the waiting list for four years.

➤ **See Appendix 1 for further details.**

1.5 Changes required to New Zealand’s pharmaceuticals funding system

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 approach 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.

- 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 2017/18 year it is set at \$870M, representing an investment of \$184 per person.⁸ In contrast, in 2015 Australia spent \$435 per person on medicines.⁹ We believe the medicines budget needs to be significantly increased to bring New Zealand into line with other OECD countries.
- New medicines are being developed and brought to market at an ever-increasing speed. In order to address this issue in a sustainable way, BCAC urges 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.¹⁰
- Cancer medicines are also becoming increasingly sophisticated and more precisely targeted to sub-groups of patients who will definitely benefit from their use. This greater precision means that fewer resources are wasted by giving medicines to patients whose cancer sub-type means that they will not gain benefit. These new medicines are also less likely to produce harmful and unpleasant side effects than the more general 'blunt instrument' chemotherapy drugs, and give breast cancer patients better quality of life.
- Breast cancer is a complex disease with a variety of sub-types; patients often require a multiplicity of drugs for their treatment. Clinicians tell us that having access to the full range of options is paramount for ensuring the best outcomes and optimal quality of life for their patients. PHARMAC should ensure that those treating breast cancer in New Zealand have access to the full 'tool kit' of medicines.
- Finally, the Government should ensure PHARMAC abides by its criteria for deciding which medicines to fund by including not only impacts on the pharmaceutical budget but also on people, whānau and communities, as well as the wider health system.¹¹

1.6 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 throughout the decision-making process, including as members of its advisory committee, PTAC (Pharmacology and Therapeutics Advisory Committee).
- Ensure PHARMAC applies new criteria to fund medicines based not only on cost, but on value and on the needs of people, whānau and communities.
- Ensure that PHARMAC's decisions take into account their impact on the efficient functioning of other parts of the health system.

2.0 Issue 2: Action to address Māori and Pasifika inequities in breast cancer

Major breast cancer study highlights need for urgent work to address inequities

Important research released by the University of Waikato on 21 June 2018, *How to Improve Outcomes for Women with Breast Cancer in New Zealand*¹² shows huge disparities in breast cancer mortality rates, screening, treatment and outcomes for Māori and Pasifika women in New Zealand. This is unacceptable and immediate action is needed to improve this situation.

2.1 Mortality rates

In New Zealand we have the ninth highest breast cancer rates in the world and the seventh highest mortality rates. The outcomes for Māori and Pasifika women are particularly concerning.

- Māori women diagnosed with breast cancer are 76% more likely to die from the disease after five years than New Zealand European women. They are less likely to be diagnosed through mammographic screening, or receive chemotherapy, Herceptin or surgery.
- Pasifika women diagnosed with breast cancer are twice as likely to die after five years than New Zealand European women. They are diagnosed with breast cancer younger than other groups, and the cancer is almost twice as likely to be an aggressive form.

2.2 About the research

The research was funded by the Health Research Council through the University of Waikato with assistance from Waikato District Health Board. It was led by Professor Ross Lawrenson.

The extensive three-year study analysed data from Auckland and Waikato breast cancer registers to determine what could improve survival rates. It looked at data for more than 12,000 women in Auckland and Waikato, reflecting the wider New Zealand population.

2.3 Diagnosis and screening

The research highlights the need for more proactive screening and treatment across New Zealand, including programmes targeted to the needs of particular population groups.

The research shows that Māori women have similar outcomes to non-Māori women when their breast cancers are detected by screening, rather than waiting until symptoms appear.

- **Screening of more Māori and Pasifika women, and beginning screening at a younger age**, is recommended as a first strategy to help close the inequity gaps. Breast cancer tends to occur at a younger age in Māori and Pasifika women but diagnosis is often late.

- BCAC believes publicly-funded screening should begin for all women at 40, rather than at the current age of 45, and Māori and Pasifika women should be the highest priority for this.
- **Targeted initiatives, national and regional hui and expert focus groups with Māori and Pasifika communities** to develop strategies encouraging more women to participate in the Breast Screen Aotearoa screening programme, will help significantly to reduce inequities in breast cancer outcomes in New Zealand.
 - We need Iwi and Pasifika leaders, heads of communities, elders and youth to engage with their communities, encouraging everyone to participate in finding solutions for their women of all ages.
 - Exemplary leadership was shown by the late Talei Morrison in her #smearyourmea campaign. She encouraged Māori women to have cervical screening at all kapa haka events and the campaign spread widely through iwi connections, through social media and supported by the Māori King's whānau, the Māori Women's Welfare League and by kapa haka proponents.
 - A successful programme on the East Cape of New Zealand run by Te Whānau ā Apanui Community Health Service saw breast screening rates go from 45% to 98%.
- **Access to National Health Index (NHI):** The researchers explained that one of the biggest obstacles to getting more women to screening was the lack of access to a list of all eligible women.
 - Concerns about privacy at the time the breast screening programme was set up prevent it from having access to the **National Health Index (NHI)** which has identity information on about 95% of New Zealand citizens.
 - The more recent colorectal cancer screening programme does have access to these data. Allowing Breast Screen Aotearoa access to the NHI database would be a huge help in identifying eligible women, keeping track of women as they move and encouraging them to attend.

2.4 Hormone receptor positive cancer and endocrine therapy

For women with hormone receptor positive breast cancer it is important to continue endocrine therapy. The research found that at five years:

- Only 60% of European women were still taking their therapy
- Only 55% of Māori women were still taking their therapy

BCAC believes that we need to put supports in place to ensure women understand the benefits and continue their endocrine therapy. This treatment reduces mortality by a third after five years and even more in the years beyond that.

2.5 HER2 positive breast cancer

The research confirmed the benefit of giving Herceptin treatment for HER2 positive breast cancer. New Zealand women who received it had 42% better survival than those who did not, showing that 'real world data' confirm what clinical trials have shown.

More Pasifika women in particular are diagnosed with HER2 positive breast cancer and at a younger age, when cancers tend to be more aggressive. However, fewer Māori and Pasifika women received Herceptin treatment.

It is absolutely fundamental these groups are assisted to access, and actively encouraged to take, Herceptin. We need to put support in place to ensure women understand the benefits and take part in the treatment they require.

2.6 Advanced breast cancer

More Māori and Pasifika women have advanced breast cancer at time of diagnosis. They tend to be from lower socio-economic backgrounds with lower access to health care. Rural Māori women's outcomes were worse than urban Māori women's outcomes. Rural Māori women with breast cancer tended to be older, more likely to be diagnosed with advanced disease and less likely to be screen detected than urban Māori.

Again, this emphasises the need for programmes tailored for specific population groups, delivered locally.

2.7 ACTION POINTS

- Increase health literacy including women's understanding of the need to take part in breast cancer screening and to continue with their treatment
- Introduce breast cancer screening programmes targeted to population groups, such as Māori and Pasifika
- Introduce screening at age 40 to increase the likelihood of Māori and Pasifika women's cancers being detected earlier
- Enable contact with women via their NHI number to enrol them in the national breast screening programme
- Increase breast cancer funding in the public health system and ensure the public system welcomes women of all cultures equally and appropriately.
- Support New Zealand-based clinical trials to find ways to improve outcomes for Māori and Pasifika with breast cancer.

Appendix 1: Breast cancer medicines awaiting funding in New Zealand

In recent years, a number of innovative new medicines have become available for the treatment of early and advanced breast cancer. However, many of these medicines are not funded in New Zealand. Many are available and publicly funded in Australia. Some are available privately if a patient is able to pay for them. A number of New Zealand women travel to other countries to access and pay for medicines they need to extend or improve their lives. This can see homes being mortgaged, family lives disrupted and increased stress in an already stressful situation.

All these drugs offer potential advantages in quality and length of life for New Zealanders with breast cancer and would give oncologists additional options for optimising treatment of the different sub-types of breast cancer.

We also list some new medicines that are still being investigated in breast cancer clinical trials for effectiveness and safety.

Medicine name	NZ approval and funding status
<p>Abraxane (nab-paclitaxel) – is used to treat advanced breast cancer in people who have already received other medicines.</p> <ul style="list-style-type: none"> • It is a taxane that fights cancer by interfering with cell division. Abraxane is a less toxic formulation of the taxane Taxol (paclitaxel), with the advantage of causing reduced side effects as it is delivered in protein nanoparticles rather than the toxic solvent that Taxol and another taxane Taxotere (docetaxel) are dissolved in. • Abraxane is particularly helpful for patients who have an allergic reaction to Taxol or Taxotere. <p>Abraxane has been publicly funded in Australia since 2009 and has since become the preferred taxane, with 71% of Australian patients who use a taxane being treated with this drug by September 2011.</p>	<p>Abraxane is available in New Zealand and Medsafe registered, but not publicly funded. In February 2018 BCAC applied to PHARMAC to have this medicine funded.</p>
<p>Afinitor (everolimus) – is used in the treatment of hormone-receptor-positive, HER2-negative advanced breast cancer in post-menopausal women, in conjunction with the aromatase inhibitor Aromasin (exemestane) after failure of Femara (letrozole) or Arimidex (anastrozole).</p> <ul style="list-style-type: none"> • It is only used in patients whose tumour has tested negative to HER2. • Afinitor stops a particular protein called mTOR from working properly. mTOR controls other proteins that trigger cancer cells to grow. <p>Afinitor has been funded in Australia since 2014. BCAC has heard that the patent on Afinitor is due to expire soon, potentially leading to a</p>	<p>Afinitor is Medsafe registered but not publicly funded for breast cancer in New Zealand.</p>

drop in the price, increasing the likelihood that PHARMAC may fund this medicine for breast cancer.	
Caelyx (pegylated doxorubicin) – is the chemotherapy drug doxorubicin, contained within a liposomal coating, and is used to treat metastatic breast cancer.	Approved by Medsafe in 1997, but not publicly funded in New Zealand. It is funded in Australia.
Faslodex (fulvestrant) – is used to treat hormone-receptor-positive advanced breast cancer in post-menopausal women with disease progression following anti-oestrogen therapy.	BCAC applied to PHARMAC to fund this in May 2018.
<p>Halaven (eribulin) – is used to treat late stage metastatic breast cancer that is hormone-receptor-positive and HER2-negative that has previously been treated with anthracycline and taxane chemotherapies.</p> <ul style="list-style-type: none"> • It is a “non-taxane microtubule inhibitor” that kills cancer cells by inhibiting cell division. 	Halaven is not funded in New Zealand. It has been registered and publicly funded in Australia since 2013.
<p>Ibrance (palbociclib) – is a new medicine for treating advanced oestrogen-receptor-positive, HER2-negative breast cancer.</p> <ul style="list-style-type: none"> • The drug was reviewed and approved under the USA’s Food and Drug Administration’s (FDA) accelerated Priority Review and Breakthrough Therapy designation programs in 2015 (in combination with Femara (letrozole)). • The PALOMA-2 clinical trial showed that adding Ibrance to letrozole on average increased the time to progression of the cancer to 24.8 months compared to 14.5 months in those who took letrozole alone. • Ibrance is a CDK4/6 inhibitor, a group of medicines that prevent over-proliferation of cancer cells. These drugs offer very promising new treatments for those with advanced oestrogen-receptor-positive breast cancer. Other CDK4/6 inhibitors are abemaciclib (Verzenio, Lilly) and ribociclib (Kisqali, Novartis). • In November 2017 the UK drug funding agency NICE made both Ibrance and Kisqali available through the National Health Service. • Many clinical trials are under way with CDK4/6 inhibitors, including the Monarch-E trial which is testing the effects of adding Verzenio to hormonal therapy in early breast cancer. Some women being treated in Auckland, Waikato and Palmerston North are participating in this trial. 	<p>Pfizer gained Medsafe registration for Ibrance in 2017 and applied for PHARMAC funding in February 2018.</p> <p>In March Pfizer established a Patient Assistance Programme that offers four months of Ibrance free to patients who have purchased eight months of Ibrance in New Zealand, as long as the treating oncologist confirms that the patient may benefit.</p>
Kadcyla (ado-trastuzumab emtansine or T-DM1) – is used in patients with HER2-positive advanced (or metastatic) breast cancer who have received prior therapy with Herceptin and a taxane.	Kadcyla is available and Medsafe registered but is not yet publicly funded in New Zealand, although it

<ul style="list-style-type: none"> • As it is used after earlier treatments for advanced disease it is known as a “second-line” strategy. Kadcyla is a combination of Herceptin (trastuzumab), an antibody that shuts down growth signalling pathways in HER-2-positive breast cancer, and a cytotoxic chemotherapy agent DM-1 (emtansine). • Herceptin targets the T-DM1 to the HER-2-positive tumours, delivering the toxin directly to the tumour cells and reducing effects on other normal cells in the body. Latest results from the international clinical trial EMILIA show patients receiving Kadcyla had a median overall survival benefit of 5.8 months (30.9 months vs. 25.1 months), compared to those given the combination of Xeloda (capecitabine) and Tykerb (lapatinib). <p>The drug is not yet publicly funded in New Zealand – Roche has established a patient access programme for Kadcyla.</p> <ul style="list-style-type: none"> • Under the Kadcyla Access Programme a number of doses or ‘cycles’ of the medicine are provided free (the cost of the Roche medicine only). • The Kadcyla Access Programme also limits or caps the total amount you pay for this medicine at \$63,000 (excl. GST), so only those who can afford this can be treated. This amount is for the drug cost only and other administration fees may apply. • Once a patient reaches the cap, Roche will provide ongoing Kadcyla at no cost, for as long as you continue to respond to treatment, or until you experience disease progression. • See more information here http://cancerinfo.co.nz/accessing-treatment/funding-medicines 	<p>was funded in Australia in 2015.</p> <p>Roche applied to PHARMAC for Kadcyla funding in August 2017 and it was recommended for funding, but with low priority.</p> <p>Medicines can remain on PHARMAC’s recommended list for months or years without progress but BCAC hopes the breakthrough nature of this medicine in extending the length and improving the quality of life will see it funded in the near future.</p>
<p>Keytruda (pembrolizumab) – is an antibody used in cancer immunotherapy.</p> <ul style="list-style-type: none"> • It is one of a number of new medicines called checkpoint inhibitors that support the body’s immune system to recognise and destroy cancer cells. Some types of cancers have a protein on the cell surface that masks the cancer from the body’s immune system. • Keytruda and other similar new drugs are designed to lock onto and deactivate this protein, exposing the cancer cells to the body’s immune system, allowing the body’s T-cells to destroy the cancer. 	<p>Breast cancer clinical trials currently under way with Keytruda (Keynote trials) and other similar drugs are producing very promising results, particularly in triple negative breast cancers that test positive for the tumour masking protein, PD-L1.</p> <p>Keytruda has recently been funded in New Zealand for treating advanced melanoma.</p>

<p>Perjeta (pertuzumab) – is used for the treatment of HER2-positive metastatic breast cancer in conjunction with Herceptin and the chemotherapy medicine, Taxotere (docetaxel).</p> <ul style="list-style-type: none"> • It is used as a “first line” treatment for advanced breast cancer, i.e. as the first treatment to be given once the cancer has advanced. • It works in a complementary way with Herceptin, inhibiting different proteins that cause HER2-positive breast cancers to grow. • Results from the CLEOPATRA clinical trial reported in October 2014 showed an extraordinary survival benefit of 15.7 months longer than for patients who did not receive the drug. 	<p>Perjeta became publicly funded in New Zealand from January 2017, 18 months after it was funded in Australia.</p> <p>BCAC petitioned PHARMAC to fund the drug for women who had already begun Herceptin treatment for their advanced HER2-positive cancers, as was done in Australia, but PHARMAC declined to provide funding for this group of around 160 women.</p> <p>Some of those who missed out on Perjeta are fundraising to obtain Perjeta and there has been recent media coverage of their plight.</p>
<p>Tykerb (Lapatinib) – Since 1998, Herceptin® (trastuzumab) has been used to successfully treat HER2 positive breast cancers that have spread beyond the breast and the lymph nodes under the arm to other organs within the body (advanced or metastatic breast cancer).</p> <ul style="list-style-type: none"> • However, in the majority of patients with advanced HER2 positive breast cancer, the disease will eventually progress despite Herceptin treatment. In some cases, the cancer will spread to the brain probably because Herceptin and other chemotherapy regimens cannot adequately cross the blood-brain barrier. These problems highlight the need for new drug treatments. • Tykerb (lapatinib) is an oral therapy that targets the HER2 protein inside the tumour cell (in a different way to Herceptin®). It is a small molecule and can also enter the central nervous system (i.e. cross the blood brain barrier). Tykerb represents an effective way of treating advanced or metastatic HER2 positive breast cancer. 	<p>Tykerb is only funded in New Zealand for an extremely limited use that oncologists advise makes it inaccessible to the vast majority of patients who need it.</p>
<p>Xgeva or Prolia (denosumab) is a monoclonal antibody that reduces tumour formation and growth in people whose cancer has spread to the bones.</p> <ul style="list-style-type: none"> • Recent Australian research has shown this drug also has the potential to prevent breast cancer in people with a BRCA gene mutation who are at high risk of getting breast cancer. 	<p>This medicine is Medsafe registered but not funded in New Zealand.</p>

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| <ul style="list-style-type: none">• It was approved by the US FDA in 2010 for prevention of skeletal events (fractures) in patients with bone metastases from solid tumours.• It is funded in Australia for elderly patients with low bone density and people with osteoporosis who have had a fracture after minimal trauma. | |
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Appendix 2: Global Trends

There are a number of developments¹³ globally 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 targeted and immunotherapies, 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 through effective use of new prognostic tools to guide therapy.
- 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.¹⁴
- 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.¹⁵
- Neo-adjuvant therapy (chemotherapy, targeted therapies and hormone treatments used before surgery) provides a rapid means of identifying which treatments are likely to be effective for individual patients and those with identified sub-types, and in some cases can eliminate early tumours without the need for surgery and further treatment in some instances aside from hormone therapy.
- Clinical trials are focusing on the following key research areas:
 - A move toward precision medicine through patient and tumour genetics alongside other 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 to guide therapy at an individual level.¹⁶
 - 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+. ¹⁷
 - The level and combination of chemotherapy required, including testing new and advanced treatments including immunotherapies. ¹⁸
 - Determining whether radiation is required and when Intra-Operative Radiation Therapy is appropriate instead of External Beam Radiation Therapy. ¹⁹
 - Recognising that radiotherapy used alongside combination therapies can motivate an immune response which is superior to either in isolation
 - Exploring preventative treatment to reduce the risk of recurrence including, energetics and nutrition²⁰, green prescription programmes, prophylactic mastectomy, and monitoring for early detection through targeted screening technologies. ²¹
- 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. ²²
- New findings show that having high mammographic 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. Over 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.

Appendix 3: 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.²³



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 Associate Minister of Health

	<p>Chairperson: Libby Burgess</p> <p>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, timely access to detection, treatment and care, and action to overcome inequities for Māori and Pasifika with breast cancer. 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.</p>
	<p>Secretary: Fay Sowerby</p> <p>Fay is a Board Member of Breast Cancer CURE (BCC) (2009-Present), Secretary of BCAC (2015-Present), and a consumer member of the New Zealand Breast Cancer Special Interest Group (2017-Present). Fay joined BCAC in 2015 because she saw an ongoing need to improve: outcomes for Māori and Pasifika women, access to medicines and medical devices and access to clinical trials for breast cancer patients in New Zealand. Fay is a member of Breast Cancer Trials, ANZ, Comms and Fundraising Committee (2017-Present). She helped initiate a research partnership between the New Zealand Health Research Council (HRC), the Breast Cancer Foundation of New Zealand and BCC to make breast cancer a survivable disease with improved quality of life. Fay has been a member of the HRC Breast Cancer Research Partnership Assessment Committee (2013-Present). This Partnership funds ongoing research into prevention, earlier detection, improved prognostics, and new targeted and immune therapies with a combined investment of \$4M over 4 years and for BCC \$11M over 10 years. She was a business and change strategist with KPMG for 20 years, a Crown Owned Entity board member for 9 and managed her own consultancy for 7 years. Fay was diagnosed with breast cancer in 2013.</p>

	<p>Committee member: Irene Kereama-Royal</p> <p>Irene is of Ngāpuhi, Ngāti Raukawa, Tūwharetoa and Parehauraki descent. Diagnosed in 2015 and again in 2016 with HER2+ breast cancer and losing her son to cancer in 2011, Irene has an avid interest in advocating the removal of barriers and improving access to the latest research in breast cancer diagnosis, treatments and reconstruction options for Māori, Pasifika and rural women. Irene is also a member of the Royal Society of New Zealand’s expert panel on gene editing technologies with specific interest in the development of gene editing for breast cancer treatments. In her spare time, Irene is the matriarch of three adult children, nine mokopuna and an energetic teenager. She is currently enjoying rehabilitation provided by the Pinc & Steel Programs whilst on leave from her job as Māori Research Manager at Unitec in Auckland.</p>
	<p>Metavivors NZ member: Terre Nicholson</p> <p>Terre is originally from the US and became a New Zealand citizen in 2017. She was diagnosed with ER/PR+ early stage breast cancer in 2007 with a less than 5% chance of recurrence. However, in 2013, Terre was diagnosed with Stage 4 breast cancer. She was given less than two years to live but has beaten the odds and is still stable over five years later. Terre is passionate about obtaining funding for life-extending medications for Stage 4 breast cancer. She believes that every day Stage 4 metavivors are alive, they’re closer to a cure, so these medications are critical and they deserve the chance to extend their lives without having to fundraise to do it. Terre works full time as an environmental engineer and is committed to making New Zealand cleaner and safer. She is involved with contaminated land clean up and helping assure that high-hazard facilities are as safe as possible. Terre is involved in several committees to promote environmental awareness, sustainability, and safety. In her spare time, she rescues cats who are desexed, microchipped, and adopted out to loving homes.</p>

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