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Briefing to Minister of Health, Hon. Dr Shane Reti, from Breast Cancer Aotearoa Coalition

24th September 2024

We appreciate the leadership shown to date by the Minister and Government in addressing critical areas in breast cancer.

Medicines funding

Ongoing uplifts in the medicines budget are needed to provide the standard of cancer care New Zealanders expect. We support other changes outlined in the 2024 Letter of Expectations to Pharmac.

The uplift in funding provided by the Government has already led to Pharmac proposing to fund two vital medicines for breast cancer, pembrolizumab (Keytruda) for newly diagnosed inoperable triple negative breast cancer and trastuzumab deruxtecan (Enhertu) for advanced HER2 positive breast cancer. This is fantastic news for the patients who will benefit and their families, friends and colleagues. We are very grateful as both these medicines will provide longer, healthier lives for New Zealanders. However, there are many more vital breast cancer medicines and uses that would benefit more people, cure early breast cancer and extend lives in advanced disease. When Pharmac funds Keytruda and Enhertu there will still be 23 medicines and 27 uses of these recommended in international guidelines and/or standard of care overseas. Sixteen of these are funded in Australia. We understand this is now more of a focus for Hon. David Seymour, the Associate Minister of Health (Pharmac), but we're also aware that your commitment to better cancer care was the initial motivator for the extra funding and you followed through to get it done. We'd like to encourage you to continue this commitment and action by providing additional funding that moves us to the OECD average for investment in medicines, as New Zealand remains well below the level of investment and access of similar countries.

We note the need for significant changes to Pharmac including its assessment processes, timeliness and transparency, its culture and relationships with stakeholders as well as its statutory role and were pleased to see these matters raised in Assoc. Minister Seymour's Letter of Expectations to Pharmac. This fresh approach could drive beneficial changes long sought by advocates.

Cancer treatment targets

We support the cancer targets and note the need from a shorter time to FSA for cancer patients.

We are extremely pleased to see the reintroduction of cancer treatment targets as we agree this will support urgency in the treatment pathway, reduce unnecessary delays and lead to better patient outcomes. The target of 90% of patients receiving cancer management within 31 days of decision to treat will clearly support this, as will shorter wait times for first specialist assessment (FSA). However, a four-month wait for FSA is at the outer limit of what is safe for cancer patients and we believe an earlier FSA is needed for this disease.

Workforce and capacity issues

We note the urgent need to expand the oncology workforce and infrastructure. We see opportunities for greater efficiency through use of a shared public/private oncology model. We encourage the adoption of practices that allow cancer treatment at medical clinics closer to home and reduce pressure on hospital oncology services.

It is widely acknowledged that there are workforce and capacity issues across cancer detection, diagnosis and treatment pathways. This may be an impediment to achieving faster cancer treatment targets and to the timely delivery of newly funded medicines. We are supportive of all Government efforts to expand our radiology, pathology and oncology workforce and to provide the necessary infrastructure to deliver treatment faster and cost effectively.

We suggest development of a shared public/private model in which publicly funded medicines can be delivered in private clinics. This would free up capacity in hospital infusion clinics and ease the pressure on public oncology teams. A shared delivery model alongside additional training and recruitment of oncology specialists and nurses would create a more efficient oncology service. Rapid implementation of such a model would allow patients earlier access to such game-changing medicines as Enhertu (trastuzumab deruxtecan).

We encourage adoption of practices that could increase efficiencies in delivering cancer care. For example, utilising AI in pathology, radiology and oncology. Providing medicines in subcutaneous injectable form could take pressure off infusion chair capacity, as in the case of Phesgo, a sub-cut version of pertuzumab and trastuzumab. Phesgo would allow patients with HER2 positive breast cancer (around 15 – 20% of those diagnosed) to be treated much faster in medical clinics closer to home, which we note is another laudable Government aim.

Breast screening and detection

Screening age band extension

We support the breast screening age extension to 74yo and welcome early introduction between October 24-25. Ultimately, we also seek extension to 40yo.

We are very pleased to see work beginning on extension of the screening age band up to 74 years as this will allow earlier detection and intervention and save lives.

We also see the benefits of lowering the screening age to 40, allowing those at higher risk to access screening and earlier detection. This would benefit wāhine Māori, Pasifika and Asian women given their higher rates of incidence at a younger age. In Australia, free screening is

available every 2 years from 40 to 50, while women aged 50 to 74 are actively invited to be screened. The US Preventative Task Force also recommends 40 – 74 while the European EUSOBI seeks risk-based screening that starts even younger for those at high risk.

We are also very supportive of initiatives to improve access to and better participation in the programme within the current screening age and it is pleasing to see the participation statistics finally reaching 70%.

Risk-based screening – breast density

We seek the measurement and reporting of breast density by BreastScreen Aotearoa along with support for additional surveillance in dense breasts.

High breast density both obscures tumours in mammographic images and increases the risk of developing breast cancer. This results in underdiagnosis and late detection in those with dense breasts, with interval cancers occurring in dense breasts at four times the rate in fatty breasts. Mammographic density can be seen in mammograms and measured with additional software. We believe those with dense breasts should be told of their higher risk. This information is now shared in private clinics. Ultimately, we would like to see the national screening programme or another pathway offer additional surveillance for those with high breast density. GPs need to be educated on this and empowered to order additional imaging such as ultrasound /or MRI for those with high density and/or at greater risk.

In 2023, the RANZ College of Radiologists recommended that breast density should be measured and reported to patients as an element of breast screening. NSU/BSA recently consulted stakeholders on breast density and policy development is currently being undertaken by a technical working group. Options will go out for consultation to key stakeholders.

Use of AI to identify those at high risk

We are supportive of the integration of AI into mammographic reading to better identify those at high risk and create system improvements and efficiencies.

Integration of artificial intelligence into breast screening pathways can create cost efficiencies, productivity benefits, provide risk stratification, more efficient allocation of resources and health benefits. For example, Karolinska Institute researchers showed that using AI to triage those needing supplemental MRI following mammogram was four times more efficient than using traditional breast density measures. In the UK the use of AI to guide risk stratified mammography screening intervals demonstrated a significant monetary benefit with additional health benefits and fewer resources. Integration of AI into the BSA screening programme would alleviate system pressure resulting from the current shortage of radiologists. We understand BreastScreen South has a project under way to determine resource benefits available through AI integration.

Additional measures in BSA screening programme

We recommend the expansion of data collected within the BSA screening programme to include interval cancers and stage at diagnosis.

Currently participation in the programme and mortality are measured. Reporting interval cancers and stage at diagnosis would provide information that would allow a better understanding of the performance of the programme and improvements to be made.

Precision health

We are fully supportive of technology-driven precision health initiatives. We were pleased to see the Ministry of Health's Long-Term Insights Briefing: *Precision health: exploring opportunities and challenges to predict, prevent, diagnose, and treat health needs more precisely in Aotearoa New Zealand* (2023). The Genomics Expert Advisory Group now collaborating with Te Whatu Ora is examining opportunities through comprehensive genome sequencing, AI and other technologies to improve health outcomes and mitigate risks. Breast cancer is well positioned to benefit from this approach, e.g. more than 60% of those with advanced hormone receptor positive breast cancer were shown to harbour at least one mutation. Additional treatment options will be needed to take full advantage of this knowledge.

Germline testing, gene expression profiling and genomics

We seek mainstreaming of germline testing, funded access to gene expression profiling for select patients and access to genomic testing for all advanced cancer patients, to provide equity and best outcomes in our public health system.

Germline and genomic testing enable precise diagnosis and tailored treatment in breast cancer. Adoption of universal germline testing of those at high risk or diagnosed with breast cancer would identify people with pathogenic germline genetic variants that can inform prognosis, risk management and treatment paradigms.

A small pilot study is under way, led by a Wellington surgeon and oncologist collaborating with Genetic Health Services NZ (GHSNZ), to undertake germline testing for those referred to GHSNZ for high-risk germline testing for breast cancer, to identify inherited genetic variants and to establish counselling and cascade testing processes. There would be significant benefits to mainstreaming germline testing for those at high risk and to universally test those diagnosed.

There is also a nurse-led initiative under way to establish a pathway and guidelines for nationally available testing for the DPYD gene. Those with germline genetic variation in the DPYD gene can experience life-threatening toxicity when treated with the commonly used cancer medicines fluorouracil or capecitabine.

There are several whole genome sequencing and briefer gene panels now available that patients are accessing in private cancer clinics to more precisely define their cancer and its germline, gene expression and genomic drivers. This enables primary care, surgeons and oncologists to tailor treatments for greater efficacy, as well as providing advice on prognosis and the need for increased surveillance, preventative surgery, chemotherapy and the most effective treatment options.

We encourage adoption of an Omico-type approach to facilitate the implementation of precision health in Aotearoa New Zealand.

This could be effectively delivered through an 'Omico-type' (www.omico.com.au) collaboration model involving cancer institutes, researchers, clinicians, industry partners, Health New Zealand Te Whatu Ora and consumers. Adoption of such a model would accelerate access to next generation diagnostics and treatments through fast-tracked genomic screening and biomarker-led trials. It is notable that Omico expect, by the end of 2024, to have provided genomic profiling at no cost to 23,000 Australians and to be six times more effective in bringing targeted treatments to patients. In the UK, Genomics England with the NHS undertook the

10,000 Genomes Project to evaluate opportunities for genomics in people with cancers and rare disorders and to make genomics part of routine healthcare.

Genomic discrimination

We look forward to contributing to policy development to enable legislation protecting New Zealanders from genetic discrimination, providing benefits for individuals, whānau and our health system.

Under current New Zealand law insurers are able to use the results of genetic testing to refuse cover or increase premiums for individuals and their immediate relatives. This is a deterrent to undertaking potentially life-saving genetic testing, creating a burden on the health system.

We welcome the Finance and Expenditure Select Committee's recent recommendations regarding the Contracts of Insurance Bill. Against Genomic Discrimination Aotearoa (AGenDA) will work with yourself, Minister Bayly and other Ministers and officials to develop policy that will inform appropriate legislation to prohibit or regulate the conduct of insurers to protect those undergoing genomic testing. This will remove a barrier to early detection and better enable preventative interventions to reduce risk, encourage more precise disease management as well as access to appropriate clinical trials.

Such legislation will align Aotearoa NZ with a range of countries including Canada, where insurers are prohibited from asking for and using genomic test results to refuse access to services or charge more for them. Australia will move from a moratorium on the use of genetic test results in life insurance to a total ban, announced by the Federal Government this month.

Further information and references to all the above and can be provided on request.

Breast Cancer Aotearoa Coalition

The Breast Cancer Aotearoa Coalition (BCAC) is a patient-based incorporated society and registered charity that aims to make world class detection, treatment and care accessible to everyone affected by breast cancer in Aotearoa. We provide support and information to empower those with breast cancer to make informed choices about their treatment and care and provide a voice for those who have experienced breast cancer. BCAC has over 30 member groups from across New Zealand with a number of these represented on our committee. We as advocates, continuously seek improvements in breast cancer healthcare delivery to achieve greater equity and better health outcomes for all New Zealanders diagnosed.

BCAC Chair, Libby Burgess

Libby was diagnosed with breast cancer aged 41 and has chaired BCAC since 2005. She has advocated on a range of issues including access to screening, timely diagnosis and treatment, innovative medicines, provision of breast reconstructive surgery and equitable access to high quality cancer services for all New Zealanders. She is a consumer member of the Breast Special Interest Group of NZ breast cancer specialists and attends their meetings and InSIGhts conferences. She is a consumer member of the NZ Familial Breast and Ovarian Cancer Group. Libby is an affiliate member of Breast Cancer Trials (Australia and NZ) and regularly attends their Annual Scientific Meeting. Libby attends the San Antonio Breast Cancer Symposium and has received three Alamo Advocate Programme Scholarships. She was a panellist in a Medicines Strategy workshop at the recent *Valuing Life* parliamentary summit. Libby has served as a member of the Consumer Reference Group of New Zealand's Cancer

Control Agency, *Te Aho o te Kahu*. She contributed to *Guidelines for the Treatment of Early Breast Cancer* as well as the *Standards of Service Provision for Breast Cancer Patients in New Zealand*. In 2011 Libby was made a member of the New Zealand Order of Merit (MNZM) for services to women's health.

BCAC Secretary, Fay Sowerby

Fay, diagnosed symptomatically in 2013, had been a member of Breast Cancer Cure's (BCC) board for 4 years and became Chair in 2017. BCC is a funder of innovative breast cancer research. Fay has immersed herself in working across the health system to address issues relating to poorer outcomes. She attends meetings and conferences to remain up to date. Today she is *Co-leader of Against Genomic Discrimination Aotearoa (AGenDA)* (2.5 years) and a Consumer representative on: *Te Aho o te Kahu's National Breast Cancer Quality Performance Indicator Working Group* (4 years); *BreastScreen Aotearoa's Partnership, Action and Equity Group* (1 year); *Breast Special Interest Group* (8 years); *Ministry of Health's Precision Health Genomic Expert Advisory Working Group* (4 months); *NZ Familial Breast and Ovarian Cancer Group* (5 years), *Chair DPYD Governance Group* (2024-25), *BSA National Policy and Quality Standards (NPQS) Expert Advisory Panel* (2024- 25). Fay is a member of the *NZ Society for Oncology*, *European Society for Medical Oncology* and *Institute of Directors NZ*. Fay attends the *San Antonio Breast Cancer Symposium* annually.

CC

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