Submission to Pharmac on the consultation around **Rule 8.1(b)** of the Pharmaceutical Schedule

From Child Cancer Foundation

March 2023

> *We currently have a system that achieves world-class outcomes for very little resource; why would we want to change this?* - Monica Briggs, CEO Child Cancer Foundation

Introduction

Child Cancer Foundation (CCF or the Foundation) would like to thank Pharmac for the opportunity to provide feedback on consultation around Rule 8.1(b) of the Pharmaceutical Schedule. We have undertaken extensive consultation with our parent community including a parents' forum, submission writing support, parent video interviews (see below for link), and sharing our draft submission for feedback with our membership. As such, this submission represents the views of the many parents who participated in the forums and the other activities the Foundation supported.

The Foundation is a charitable membership organisation which provides support to families who have or have had a child diagnosed with cancer. Our vision is to walk alongside and support all children and their families on their cancer journey and to advocate for improvements to childhood cancer care. In the 2021/2022 year, CCF supported 367 families with a child undergoing cancer treatment, from Te Kao in the north to Invercargill in the south, with provision of peer support services to 1,300 families across the motu.

Paediatric cancer is a leading cause of death for children and adolescents globally. While innovation in cancer treatments is making huge strides, children generally wait longer than their adult counterparts to experience the same benefit of newer therapies. The time period between first trials of new therapeutics in adults versus the same trials in children is typically 6.5 years[2]. Inequality in care and access based on socioeconomic and geographic factors means survival rates for children and adolescents with cancer doesn't exceed 29% in some low and middle-income countries[1].

In contrast, paediatric oncology services in Aotearoa/New Zealand are a shining example of what the provision of health services that deliver equity of access looks like. This is attributable to the excellent care provided by our specialist services, which includes timely access to internationally best-practice and standard therapeutics through 8.1(b). Through this system, New Zealand paediatric oncology services have almost achieved equality of outcome irrespective of ethnicity, locality or other factors such as socio-economic status. CCF believes it is important that we ensure equity of access of cancer therapeutics for all children of New Zealand, including Māori and Pacifica children.

While we remain committed to our vision, the Foundation supports a solution that lifts outcomes for paediatric disease types in New Zealand. We do not want to see a solution that impacts negatively on the success of paediatric oncology or other disorder outcomes (which is to say, levelling up not levelling down).

[1] *World Health Organization. Childhood Cancer. December 13, 2021. https://www.who.int/fr/news-room/fact-sheets/detail/cancer-in-children*
[2] *Neel DV, Shulman DS, DuBois SG. Timing of first-in-child trials of FDA-approved oncology drugs. European Journal of Cancer. 2019 May 1; 112:49-56.*

For clarity, we use the following definitions in this submission:

Equity: the unequal distribution of resources to ensure an equal outcome.
Equality: the same or similar distribution of resources which may or may not ensure an equal outcome.
Inequality: disparity between groups which may be the result of resource distribution or other factors impacting on individual groups.
Inequity: unless directly quoting the literature, we prefer to use the term inequality.

CCF Feedback on the Discussion Document

Question One: Is our understanding of the overall health outcomes being achieved for people with paediatric cancers, correct? If not, please provide any further information or context.

CCF agrees with Pharmac's understanding of the overall 5-year survival rate of 86% across all childhood cancers in Aotearoa/NZ, which is comparable to rates reported in Australia and other high-income countries in Europe and North America[3]. What this disguises is that inequalities still exist for Māori, who between 2010 and 2019 had a 5-year survival rate of 81%, seven percent below non-Māori[4].

Question Two: In what other clinical contexts is participation in clinical trials the 'standard of care'?

CCF does not work within other clinical contexts and as such we would encourage Pharmac to undertake research into this question.

Question Three: To what extent is access to paediatric cancer clinical trials dependent on access to medicines through Rule 8.1b?

Participation in clinical trials is integral to the attainment of world-leading survival rates for children with cancer in Aotearoa/New Zealand. In general, participation in clinical trials is premised on maintaining access to drug treatments, many under Rule 8.1(b). Without access to first-line cancer treatment, children are ineligible for enrolment in clinical trials. Based on anecdotal feedback from paediatric oncology clinicians, we estimate that through participation in global clinical trials the New Zealand system receives an additional $3m (38%) investment in paediatric oncology drug treatments. For a very modest investment by the New Zealand health system, we achieve phenomenal results.

CCF believes that it is the responsibility of the whole system to support and enrich that clinical working environment so that we can recruit and retain the best personnel; this includes Pharmac, if somewhat indirectly. We therefore offer the view that some of our clinical workforces are also engaged in the system because of the opportunity to participate in global clinical trials. Clinician fulfilment and satisfaction is important for retention and recruitment. We propose that being a clinician working in a system which does not offer access to the best medications, or at least a therapeutic that has demonstrated promise, would be incredibly challenging. This could ultimately lead to or exacerbate clinician compassion fatigue, which must already be an issue for many clinicians and would only be exacerbated if 8.1(b) therapeutics were not available into the future.

Given there is little evidence (other than outcomes) to concisely address questions three and four of the consultation document in any manner other than speculative, CCF recommends that Pharmac uses its powers under 69(1)(c) of the Pae Ora (Health Futures) Act 2022 to engage "in *(independent peer reviewed)* research to meet the objectives set out in section 68(1)(a) (of the Act), specifically to secure for eligible people in need of pharmaceuticals the best health outcomes that are reasonably achievable.

Question Four: How sensitive is this system of care to changes to Rule 8.1b?

System sensitivity to changes in Rule 8.1(b) is substantial (subject to what it may be replaced by) given it is an integral part of a system that has achieved equity of access for children diagnosed with cancer. The entire system and component parts (e.g., shared care, national protocols, Specialist Hubs, Rule 8.1(b) and no private provision) work in harmony to enable world-class outcomes to be achieved. Disaggregating any component will have an impact and potentially negative downstream consequences too (see below).

[3] *National Child Cancer Network. 2022. Childhood cancer incidence in Aotearoa, New Zealand 2015-2019*
[4] *Childhood Cancer Survival in Aotearoa, New Zealand 2010 – 2019 National Child Cancer Network. 2022*

We support the NCCN view that "The consequence of not having Rule 8.1b, without a fit for purpose revised equivalent pathway, would mean countless hours of burdensome applications, with delays in approvals beyond what may be clinically safe, the risk of inconsistent approvals and the potential reliance on decision makers without sufficient paediatric oncology expertise."[5]

Question Five: To what extent are good health outcomes for children with cancer in New Zealand dependent on making paediatric cancer treatments available through Rule 8.1b?

Rule 8.1(b) is part of a 'model of care or treatment pathway' which supports paediatric cancer patients in Aotearoa/New Zealand. Without rule 8.1(b) it is reasonable to question whether we would see health outcomes for many in this patient population being the same or similar as those in similar high-income jurisdictions. The current system of care (which includes but isn't limited to 8.1(b)) has worked to get survival outcomes for NZ children with cancer up from 66% in the 1990s to 86% in the 2010-19 period.

Unlike most other diseases, childhood cancer is not a single disorder with a limited number of therapeutic options. It is a group of related diseases which can impact almost every body system, and therefore there are not always best practice, evidence-based therapeutics for many childhood cancers, in particular the less common ones. This is due mainly to the more limited research of paediatric cancer therapy and smaller sample sizes, especially for rare cancers. Paediatric oncology is also burdened by very few therapeutics being designed with children in mind, necessitating the adaptation of drugs designed for adults.

If access to new therapeutics was available in the future this could save some children's lives that cannot be saved now, but without assurance that these novel therapeutics will be available, these children will still be at risk of dying. Gentler therapeutics may come available in the future. They may have the same ultimate 5-year survival, but the treatment side effects may be far less than what occurs with current treatments.

The current system is not an "open chequebook". Every time a child gets access to medications through 8.1b, this is carefully evaluated by the team of specialist paediatric oncologists, who are undoubtably the best people in NZ to make these recommendations and decisions. Any other system which does not include a team of informed, current clinicians will undoubtably have less current knowledge of the optimal therapeutics than the current system via 8.1b offers.

Removing this option or reducing access in any way will very likely see children in Aotearoa/New Zealand having lesser outcomes for childhood cancers than those in other high-earning countries. This is because many New Zealand children would not receive the standard of care therapeutics needed to ensure eligibility for clinical trial participation and consequently access to new and evolving therapeutics. This is not to suggest that there are no other factors in play; clearly the nationally integrated service model with two regional hubs, shared care and national protocols also plays its part in achieving these outcomes. It really is a case of "the whole being greater than the sum of its parts". We have a range of inputs and capabilities from which has emerged a simple and efficient eco-system which in real terms has seen near health outcome equality in paediatric oncology.

Even though these various individual inputs cannot be singularly denoted as the key determinant to achieving this result, the combined properties and capabilities of the larger system achieve this positive outcome. For one part of the system to be withdrawn in whole or in part may very well create detrimental impacts or unintended consequences, such as the loss of highly sought-after clinical staff who may prefer to work in a system which allows for a degree of academic engagement or a two-tier system (see below) based on family income, ethnicity or location.

While CCF is concerned with whānau experiencing a cancer diagnosis in one of their tamariki, we support the view that health outcomes for children overall would be improved if the Rule was extended to other paediatric diseases or conditions and more effort across the (health and welfare) systems occurred to support whānau living with a disability, in poverty or deprivation.

[5] *NCCN Submission to Pharmac 2023*

Question Six: Is timely access to paediatric cancer treatments more important than timely access to other medicines or for other populations? If so, why?

Rule 8.1(b) provides timely access to medications for children who are likely already in a medically fragile state. Unlike many other childhood conditions, cancer frequently presents acutely and there is little time for extensive consultation on access to medications. The current system through 8.1(b) provides rapid access to the most appropriate therapeutics available. In general, the longer the time between diagnosis and initiation of therapy, the sicker the child may become and more complications they are likely to experience.

Many other diseases are slower to progress and not likely to cause imminent mortality, therefore many other disease presentations allow more time to thoroughly evaluate the risks/benefits, financial cost and likely outcomes of various treatment options.

More broadly, when viewed through a systems lens, timely access to paediatric cancer treatments is an important piece of the overall model of care. Given that the primary health goal of treating cancers in children is curative and based on effectiveness of the paediatric oncology treatment pathway [for many patients, irrespective of demographics], the investment in timely access to pharmaceuticals as discussed above is imperative to their future prognosis and survival. We are of the view that the original rationale for Rule 8.1(b) has not changed since it was introduced; these factors are:

- the specialised nature of some treatments.
- usage differences between children and adults.
- the small number of patients each year for most indications.
- the enrolment of some patients in international clinical trials.
- some of the medicines and indications being unregistered.

Given five-year survival rates for paediatric cancer patients average 86% and the fact the vast majority go on to live healthy and productive lives, the average cost of medication for a child with cancer of around $8,000 per patient (under the age of 25) per annum[6] would appear to be a 'value for money' investment for the New Zealand taxpayer. It is also important in our view to consider length of treatment. Most children with cancer are treated for around two years, therefore the cost of treatment is finite. Coupled with the fact that 86% of children diagnosed with cancer are still alive at five years post treatment and, in general, survivors go on to live normal duration lifespans, the societal return on investment is huge. This is in contrast to many other chronic diseases where therapy is continual and lifelong.

The second part of this question is more difficult to address. It, alongside questions eleven, twelve and fifteen *[How might we address equity and fairness concerns related to paediatric cancer medicines through Rule 8.1b and access to medicines for other groups? Do you consider Rule 8.1b to be inequitable from the perspective of other children or those with rare disorders? Why? How might we address equity and fairness concerns related to paediatric cancer medicines through Rule 8.1b and access to medicines for other groups?]* are unfortunate and rather provocative questions in our view and set up a race to the bottom. Pharmac's remit is to lift treatment accessibility for all children rather than potentially creating conflict between different groups of people within different disease cohorts. Further we are of the view that these types of questions privilege non-Māori as they reinforce institutional biases that are supported by health literacy of western concepts of healthcare provision. Given finite resources, there is always going to be a need to draw a line somewhere. Removal of 8.1(b) is likely to reintroduce inequalities into a system which has been working hard to and has *almost* reached a position of equality between Māori and non-Māori.

CCF does not dispute the fact that Rule 8.1(b) creates inequality of access to certain therapeutics between some children with a cancer diagnosis and those with other rare conditions. Nor do we dispute that there are possible inequalities between those accessing paediatric oncology services and those accessing adult cancer services. At the same time, we would make an argument that healthcare spend generally creates inequalities between children and young people who are underserved (in comparison to adults), and Māori and non-Māori.

For example, Mills et al. conclude that *"Persistent child health inequities result in significant societal economic costs. Eliminating child health inequities, particularly in primary care access, could result in significant economic benefits for New Zealand."*[7] They go on to say *"child health inequities between Māori and non-Māori in New Zealand are cost saving to the health sector. However, the societal costs are*

[6] *Funding of paediatric cancer treatments in New Zealand. Discussion paper on Rule 8.1b of the Pharmaceutical Schedule. Pharmac 2022 Figure 4 page 21.*

significant. A conservative "base case" scenario estimate is over $NZ62 million per year, while alternative costing methods yield larger costs of nearly $NZ200 million per annum." Thus we would argue, in part due to Rule 8.1(b), this situation has been mitigated or minimised and in terms of te Tiriti o Waitangi, the sector is meeting its obligations to Māori. The question then becomes, do we, as a society, wish to remove something that will potentially disproportionately impact young Māori and Pacifica citizens?

Question Seven: Is our understanding of how Rule 8.1(b) operates in practice correct? What else should we know?

In the consultation document, Pharmac states that *"Expenditure on paediatric cancer treatments through Rule 8.1b has not been a major concern in the past as the vast majority of medicines are accessed through the Pharmaceutical Schedule, as well as the relatively small overall budgetary impact on the CPB".* Given this, we do not believe Pharmac has made a case for change.

It is difficult to make an accurate assessment of Pharmac's understanding of the way 8.1(b) operates due to the way data is used and presented in the consultation document. For example, in section 3.6 of the document it is noted that *"According to our annual expenditure data, the total cost of all paediatric cancer treatments used to treat people aged 25 and under in the 2020/21 financial year was approximately $5.5 million."* Using this information, approximately one third of patients (assuming even distribution) were above 18 years of age and would have been seen as adults in adult services and therefore ineligible for treatments under Rule 8.1(b). What this would suggest is that the figure of seven percent as the proportion of paediatric patients using the Rule to access treatments is much higher and therefore the cost to paediatric patients of removing the Rule is quantifiably greater.

CCF believes that the best people to make decisions on treatments are medical professionals, and Rule 8.1(b) allows for this. Anecdotally it has been our experience that both clinicians and whānau are incredibly prudent and cautious when making medical decisions such as what drugs they use, how frequently and perhaps, sadly, when to stop. Should there be any changes to the Rule, ongoing engagement with clinicians is imperative.

Question Eight: How much increase in the use of Rule 8.1b do you think will happen as a result of the growing range of new paediatric cancer treatments?

Question Nine: Do you see the costs of paediatric cancer treatments accessed through Rule 8.1b increasing significantly in the foreseeable future?

Question Ten: How could we assess what value paediatric cancer treatments provide against other medicines that could be funded with the same money?

CCF supports the aims and objectives of the Pae Ora (Healthy Futures) Act 2022, which at its core behoves Pharmac, alongside other health service providers to work in an integrated manner to support the health outcomes of New Zealanders. As such, we believe that when assessing the value of medicines, Pharmac must not only focus on the cost of the medicine but also use a values and wellbeing-based approach. This approach supports patients but also reduces the overall cost of services health-system wide. This may mean higher costs in some areas but at the same time may see reduced costs in other areas.

For example, as noted above, childhood cancer treatment interventions are generally designed to be 'curative' as opposed to 'palliative' and are relatively short term in comparison to chronic conditions. Given the relatively young age of most patients, intervention with new medicines as soon as possible avoids premature death. In very real terms, this ensures a long and fulfilling life for the 86% of children who survive a cancer diagnosis. This therefore means pharmaceutical intervention leads to a high, quality adjusted life years (QALY) calculation for those who experience a paediatric cancer illness.

Aside from that which has already been discussed in this section, there is little evidence (other than outcomes) to concisely address questions eight through ten of the consultation document, in any manner other than speculative. We would therefore again suggest that Pharmac provides data they have available including QALY data to inform a transparent debate.

[7] *Mills, C., Reid, P. & Vaithianathan, R. The cost of child health inequalities in Aotearoa New Zealand: a preliminary scoping study. BMC Public Health 12, 384 (2012). https://doi.org/10.1186/1471-2458-12-384*

Question Eleven: What should Pharmac take into account when considering equity issues with respect to Rule 8.1b of the Pharmaceutical Schedule?

We have raised several issues in the above response and would outline again here the following points:

- The system achieves near equality of outcome, regardless of socioeconomic status, ethnicity or other factors, something the wider health system does not achieve.
- The existing system is well managed by clinicians and is efficient and simple.
- Removal or changes to 8.1(b) now or into the future, should this occur, needs to result in a system which allows equitable access to all NZ children, no matter their socioeconomic status, ethnicity or postcode.
- An alternative system which does not ensure access to therapeutics for all children will likely result in children from well-resourced families receiving better drugs (more effective, gentler etc). This potential two-tiered system is very likely to result in inequitable outcomes (survivability, quality of life), dependent upon the ability of the family to self-fund therapeutics.
- Many of the families that we work with are struggling to make ends meet already, and there is little funding to support families with a child with cancer. In many situations, one caregiver needs to end employment to focus on the care of the child. For example, we are supporting one family in Northland with three other young children, requiring both parents to take time off work to support their child undergoing treatment at Starship while simultaneously taking care of the child's siblings. CCF provides this family with support to purchase groceries and, more importantly, travel costs to support them traveling between Auckland and Northland. For this family and many others, self-funding medication is totally out of the question.

> *"I would hate for other families to have to go through more trauma than necessary because of a change in the Rule that doesn't make sense. Why do anything to make that lifelong journey more fraught or more difficult or complicated?*
> - Leigh Honnor, parent of child cancer survivor, Taranaki "

Question Twelve: Do you consider Rule 8.1b to be inequitable from the perspective of other children or those with rare disorders? Why?

Most dictionaries define equity as the unequal distribution of resources to achieve an equal outcome. Given a range of factors such as the aggressive nature of childhood cancers, the time-sensitive nature of treatments and likely prognosis if treatment does not occur quickly, versus the generally curative nature of paediatric oncology interventions, a case can be made that Rule 8.1(b) is not unequal. The model of care in New Zealand which includes access to treatments via Rule 8.1(b) has developed in such a way that inequalities between tamariki Māori and Pacific children have been massively reduced in comparison to non-Māori (81, 83 and 88 percent respectively[8]). This therefore suggests that to achieve further gains we need to continue research on additional health system interventions and must also look outside the health system to other socio-economic determinants of health. This will require additional research to answer this question in an evidence-based manner.

In adult services, looking at one cancer, we can see that Māori men had significantly poorer survival rates than non-Māori when diagnosed with prostate cancer. Despite improvements in survival for all men diagnosed after 2000, the survival gap between Māori and non-Māori men has not been reduced with time.[9] While it is impossible to determine any one factor as the key to such divergent outcomes between childhood cancers and a fairly common adult cancer, the systems approach which Rule 8.1(b) is a significant part of and clearly plays a fundamental role in survivability and equality of outcome between the different population cohorts.

As noted above, we believe it is unhelpful to engage in a discussion where children of differing age groups or children with other rare conditions are compared. While there are some significant differences between paediatric cancers and some other rare conditions, CCF strongly believes that the overall model within

[8] *Childhood Cancer Survival in Aotearoa, New Zealand 2010 – 2019. NCCN 2022*
[9] *Survival disparities between Māori and non-Māori men with prostate cancer in New Zealand, Obertová Z, Scott N, Brown C, Stewart A, Lawrenson R.BJU Int. 2015 Apr;115 Suppl 5:24-30. doi: 10.1111/bju.12900.*

paediatric oncology demonstrates what success looks like in treating other diseases/conditions in children. As such, we would urge Pharmac to be looking at replicating its contribution to this model of care and not withdrawing it or altering it now or into the future.

Question Thirteen: To what extent do the current policy settings, including Rule 8.1b, contribute to the health outcomes achieved for tamariki Māori and Pacific children with cancer?

Currently, families do not have to think about funding cancer medications that the team of oncologists at their specialist centre recommends for their treatment. If there is a change to this Rule where newer therapeutics become available but are not funded, the oncologist still has a legal/ethical obligation to put these to the family. These drugs may be more effective, have less short- and long-term side effects and be required to be administered for a shorter duration. Some families will be able to afford these, some may need to find money through selling their home or 'Givealittle' pages, and sadly for many families accessing funding is impossible. This is where the inequality will become clear. Poorer families (and the statistics show Māori and Pacific families are more likely to be in this category) will therefore have less access to medications which will lead to poorer health outcomes for this population cohort.

It is fair to say that the publicly funded paediatric oncology system without barriers to funding for drug treatments minimises poor health outcomes for tamariki Māori and Pacific children with cancer. Rule 8.1(b) can be viewed as an important tool to reducing structural or institutional racism and the negative outcomes that evolve from these systemic issues. CCF believes the Human Rights Commission (HRC) opinion could challenge Aotearoa/New Zealand to lift access to other groups, not by reducing access and funding benefits to one cohort (children with cancer) at the expense of a portion of that cohort (specifically Māori and Pacifica children with cancer). And while the HRC presented an opinion in relation to pharmaceutical access by children with chronic conditions, CCF has already been asked if removal of Rule 8.1(b) could be the subject of a Waitangi Tribunal determination should a family be motivated to pursue a claim.

Question Fourteen: Do you consider Rule 8.1b to be inequitable from the perspective of adolescent and young adults with cancer? Why?

CCF does not dispute the fact that Rule 8.1(b) creates inequalities of access to certain therapeutics between some children with a cancer diagnosis and those who are older, nor do we dispute that there are possible inequalities between those accessing paediatric oncology services and those accessing adult cancer services. At the same time, we would make an argument that healthcare spend generally creates inequalities between children and young people who are underserved (in comparison to adults), and between Māori and non-Māori.

Ideally, we would support AYA access to therapeutics under Rule 8.1(b) if particular treatment options funded under this Rule are the most appropriate. We do however reiterate a point made in our answer to Question 12. We believe it is unhelpful to engage in a discussion where children of differing age groups or children with other rare conditions are compared. While there are some significant differences between paediatric cancers and some other rare conditions, CCF strongly believes that the overall model within paediatric oncology demonstrates what success looks like in treating other diseases/conditions in children and AYA. As such we would urge Pharmac to be looking at replicating its contribution to this model of care and not withdrawing it or altering it now or into the future.

Question Fifteen: How might we address equity and fairness concerns related to paediatric cancer medicines through Rule 8.1b and access to medicines for other groups?

There is an assumption in this question that Rule 8.1(b) does not address equity and fairness when in fact it allows for equal access to a high-quality standard of care and access to drug treatments irrespective of ethnicity, gender, cancer diagnosis or postcode. The real question that needs to be asked is, within a system of finite resources, do we wish those inequalities to exist? And if the answer is yes, where do we wish those inequalities to exist? Given our failure as a society to invest in children and young adults' health at the same rate as adults' health, years of accumulated under-investment have created a situation where this failure is magnified. Rather than further disadvantaging children with cancer, we urge Pharmac to look to expand the criteria of 8.1(b) to include rare disorders, chronic illnesses and AYA. Children and adolescents are one of the most underserved populations in Aotearoa/New Zealand. All children deserve to receive the medicines to support their health and wellbeing in the same way we invest in adults, and we have a duty of care to the most vulnerable in society.

Recommendations

The following section provides an overview of our recommendations:

- We recommend Rule 8.1(b) of the Pharmaceutical Schedule is maintained as it is currently devised now and into the future.
- CCF believes that the best people to make decisions on treatments are medical professionals, and Rule 8.1(b) allows for this.
- If 8.1b is revoked or changed in any way, ongoing engagement with senior clinicians is paramount in a co-design process and any replacement or modification needs to be robust to ensure timely access to medications. In addition, prior to any changeover in process, any alternative system/s should be tested against the current model of access (i.e., 8.1b) for evaluation and refinement prior to any change in system or parameters to accessing the current rule.
- CCF also recommends that Pharmac provides a clarifying statement about what access to existing drugs for existing patients actually means in practice. For example, will clinically sound innovations be available to clinicians or does Pharmac intend to impose new rules or requirements around therapeutic usage?
- CCF recommends that Pharmac uses its powers under 69(1)(c) of the Pae Ora (Healthy Futures) Act 2022 to engage "in (independent peer reviewed) research", specifically to address the unknowns around removal of a tool that appears to support equality of outcome with regards to childhood cancers in Aotearoa and specifically for Māori and Pacifica tamariki.
- We further recommend that Rule 8.1(b) is expanded to other conditions impacting children and AYA so that health outcomes for these groups are improved overall.

Concluding Comments

The outcome of any review of Rule 8.1(b) which does not result in the continued access to current and/or new therapeutics will be the largest single impactor on the paediatric oncology treatment eco-system in a decade. As noted above, the real question that needs to be asked is, within a system of finite resources, do we wish those inequalities to exist? And if the answer is yes, where do we wish those inequalities to exist? It would seem that from a paediatric oncology perspective, those within the sector would generally make the argument that if it isn't broken there is no need to mess with it.

At the same time, we acknowledge that from an organisational perspective, it is difficult for Pharmac to manage a budget when it doesn't have control of the outputs. Notwithstanding this, we believe the motivations of clinicians who, in our view, are the best decision-makers and perhaps Pharmac's best gatekeepers when it comes to pharmaceutical use are vital to continue in this role to ensure the continued success in the paediatric oncology sphere. We make this observation based on our experience with clinicians, who are placed in the unenviable position of determining almost daily when to treat, what to treat with, and, most difficult of all, when to stop treatment.

A cancer diagnosis is an incredibly traumatic time for anyone, adult or child. What is perhaps more challenging for children and their whānau is the possible lost potential a cancer diagnosis can create. The challenge for those of us who work in the sector more broadly is to provide as much engagement as we possibly can so the cancer journey is as supported, equitable and world-leading as it can be.

Dennis Turton
Chair CCF

Monica Briggs
CEO CCF

> *"I really feel for families moving forward who find out that their child has cancer and the potential hardship that they may face on their journey with treatment potentially not being subsidised or accessible. I feel really pōuri – really sad – for all those whānau. I don't know how people will be able to cope with additional layers put on top of them."*
> - Ori Nolan-Edwards, parent of a child cancer survivor, Palmerston North

This submission is supported by the following organisations:

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