



*Mae, diagnosed at 8 months old, with her parents Charlotte and Jayden*

**Hon Dr Shane Reti**  
Minister Of Health  
Minister for Pacific Peoples  
Freepost Parliament  
Private Bag 18 888  
Parliament Buildings  
Wellington 6160

28 November 2023

Dear Minister,

**Re: Child cancer in New Zealand – an overview of key issues**

Congratulations on your appointment to Minister of Health and Minister for Pacific Peoples.

We are committed as an organisation to a free, frank, and transparent relationship with the Crown, and as such we have prepared the following briefing on key issues currently affecting children with cancer and their families.

Child Cancer Foundation has recently attended the annual congress of the International Society of Paediatric Oncology. We came away from the congress with the view that New Zealand is at the forefront of treatment and survivability of childhood cancers.

**New Zealand childhood cancer survival rates are currently comparable to the world-class outcomes of Australia, the UK and the USA. For children up to ten, the outcomes are equitable regardless of ethnicity, geography, or socio-economic status.**

This success is achieved by New Zealand's two small groups of paediatric oncologists and specialist support staff, based at Starship and Christchurch hospitals. Their combined experience and insights shape the treatment plans designed for each child to address the often complex and unique cancers they experience.

But we cannot be complacent. There are several issues currently impacting the sector that we wish to raise with you.

**Pharmac Proposed Change to Rule 8.1(b)**

The Foundation facilitated a response from our parent community to Pharmac on the proposed changes to Rule 8.1(b) of the pharmaceutical schedule. This rule was put in place when Pharmac was established, recognising the unique challenges of treating child cancer. It allows clinicians to access whatever medicines they judge would be effective for their patients. The cost impact of prescribing drugs that are not on Pharmac's schedule is minimal but the impact on patient outcomes is substantial.



*Roman, diagnosed at 11 months old*

The key takeouts from our submission included:

- We recommend Rule 8.1(b) of the Pharmaceutical Schedule is maintained as it is currently devised now and into the future.
- We believe 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.
- We also recommend that Pharmac provides a clarifying statement about what access to existing drugs for existing patients 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?
- The Foundation 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.

Finally in this section, we note that in the documentation provided by Pharmac outlining feedback indicates that repeal of the rule is universally unpopular. The rule is a core component of the system, and any changes increase the likelihood of a breakdown in the system which is already under strain from workforce issues.

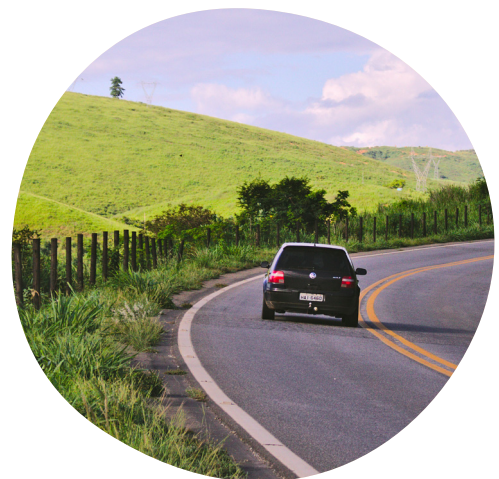
***In your first 100 days in office, we would ask that you instruct Pharmac to drop the review and instead request them to look at how it can be adapted to other childhood conditions.***

## National Travel Assistance Scheme

Child Cancer Foundation support our fellow not-for-profit organisations, CanTeen, Cancer Society and Ronald McDonald House in their calls for an urgent review of the National Travel Assistance Scheme (NTA).

While we do not provide accommodation services like our sister organisations, we are increasingly receiving requests from the families we support to provide aid to get tamariki and rangatahi to treatment. This essentially revolves around several key issues:

- Delays in approval and reimbursement of costs.
- Inconsistent application across different geographic regions.
- A failure to keep up with inflation which has seen an averaged increase of 3% between 2017 and 2022 and a projected average increase to 3.73% by 2024 (from 2017).
- The impact of health system cancellations on reimbursements.
- Long duration stays and the impact on families.
- A failure to recognise the composition of families and what this means for family cohesion, employment, or ability to pay for extraordinary travel and accommodation.
- A realistic understanding of a tamaiti or rangatahi’s diagnosis and treatment on their physical wellbeing.



We strongly and unequivocally support the view that a child's or adolescent's best interests can only be met if they are not separated from their family during treatment. We are of the opinion that within a national service provision framework, travel and accommodation costs should be factored into the delivery of care model.

***In your first 100 days in office, we ask for your commitment to develop a fit-for-purpose NTA Scheme that is fully funded and in place by December 2024 that recognizes the shifted cost burden onto NFPs.***

## Wider Child Health Action

The Children, Young People's Health, and Disability Collective is a seven-strong group of Aotearoa New Zealand charities that provide support to children and young people experiencing chronic health issues and their whānau and families<sup>1</sup>. Collectively the group supports over 130,000 children and young people each year. Child Cancer Foundation is a member.

In December 2021, the collective released the He oranga ake, he oranga ānamata Better Health - Brighter Futures report. The aim of the report was to drive system change so that children, young people, and their families and whānau in Aotearoa New Zealand receive the best healthcare and outcomes possible and can thrive.

The report identified four pillars to improving health outcomes for children and young people:

- The unacceptable inequities in health outcomes for children and young people urgently need to be eliminated.
- Family and whānau wellbeing must be central to the delivery of children's and young people's health services.
- All services provided must be appropriate for the developmental and cultural needs of children and young people.
- Service design must include input from children and young people and their family and whānau.

It called for the voices of children, young people, and their families and whānau to be central to the development and delivery of their healthcare.

***In your first 100 days in office, we ask for you to prioritise children and young people's health by:***

- ***Immediate attention to the development of a comprehensive Child and Youth Wellbeing Strategy and Action Plan.***
- ***A seat at the table for representatives of the Collective to work collaboratively with other agencies to design the strategy.***
- ***Commitment to a fully funded model including government funding support to deliver the Child and Youth Wellbeing Strategy and Action Plan.***

## Not-For-Profit Sector

Finally, we wanted to note the increasing role of not-for-profits (NFPs) in the provision of health and wellbeing services in Aotearoa/New Zealand. While we believe that a healthy and engaged civil society reflects a mature democracy, the



*Manaia (right), diagnosed age 7, with his siblings Tui and Taika*



*Maggie, diagnosed age 6, with her parents Emma and Lewis*

challenges of delivering services within the current environment is becoming increasingly pressured due to the challenges of raising funding in a cost-of-living crisis and the increased regulatory requirements imposed on charities and incorporated societies.

We note for example that philanthropic organisations are increasingly declining applications from health service providers on the grounds that they see this as the responsibility of the State to fund.

Many philanthropic funders continue to report their experience of increased contestability for grant funding and calls to increase philanthropic funding for organisations working to increase equity and address the climate crisis.

And while we aim to be agile and adaptable the impact on the NFP sector is one of increased administrative costs to deliver services to the families we serve.

***In your first 100 days in office, we ask for you to consider NFPs in any changes to the health and wellbeing sector and the communities we serve.***

Once again congratulations on your appointment to Minister of Health and thank you in advance for considering these important issues.

I would welcome the opportunity to meet with you in person to explore these and other matters.

Yours Sincerely,



A handwritten signature in blue ink, appearing to read 'Monica Briggs'.

**Monica Briggs**

*Chief Executive of Child Cancer Foundation*