



*Ellise, diagnosed age 4,
with her brother Archie*

Hon Shane Reti
Minister of Health
Freepost Parliament
Private Bag 18 888
Parliament Buildings
Wellington 6160

26 July 2024

Dear Minister Reti,

Re: Briefing for Minister's meeting with Child Cancer Foundation

Thank you for responding to our Briefing for Incoming Ministers (BIM) last November and agreeing to meet with Child Cancer Foundation and Nick Laing from CanTeen on the 31st July 2024. We appreciate your time is precious and the many demands placed on you as Minister with responsibility for one of your government's largest portfolios at a time of transformative structural change and acute service demand and workforce shortages.

How we support world class outcomes for children with cancer and their families

We noted in our BIM that 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 years of age, the outcomes are essentially equitable regardless of ethnicity, geography, or socio-economic status.

This success is largely due to the two small groups of paediatric oncologists and specialist support staff based at Starship and Christchurch hospitals who are supported by regional shared care centres, national protocols, access to pharmaceuticals and clinical trials and the tailored one-to-one support services Child Cancer Foundation provides from diagnosis for as long as needed. This well-coordinated and effective system of service delivery reflects the combined experience and insights of our dedicated teams that shape the treatment plans designed for each child to address the often complex and unique cancers they experience.

Our priorities for discussion at our meeting with you

Issues we would like to discuss are summarised below and followed by additional information.

1. Challenges for us and other Not-for-Profits (NFPs)
2. Areas for potential social investment funding to support outcomes for children, young people and families with a paediatric oncology diagnosis and late term affects.



Roman, diagnosed at 11 months old

3. Continued action on the National Travel Assistance Programme with the opportunity to trial new models of delivery.
4. Pharmaceutical Schedule Rule 8.1(b) and Patients' Voices
5. Using the Children's, Young People's Health Collective to improve services and improve equity of outcomes for sick children and their families
6. Tackling other issues that affect childhood cancer outcomes (Ministers Information only).

1. Not-For-Profit Sector

1.1 There is no doubt that the role of not-for profits (NFPs) in the provision of health and wellbeing services in Aotearoa/New Zealand is increasingly under pressure.

1.2 Child Cancer Foundation has never been funded by government. We need to fundraise six million dollars a year to deliver our services to families wherever they live in Aotearoa/New Zealand and whatever their circumstances. While we believe that a healthy and engaged civil society reflects a mature democracy, delivering services within the current environment is becoming increasingly affected by our challenges to raise the funds we need in a cost-of-living crisis alongside increased needs of those we serve.

1.3 We note, for example, that philanthropic organisations are increasingly declining applications from health-related 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 deploy a focus to increase equity and address the climate crisis. While we aim to be agile and adaptable alongside the impact of these pressures, in reality the effect is that increased costs make it challenging to support the same level of service delivery to the families we help.

2. Areas for potential social investment funding

2.1 Paediatric Palliative Care

Recent studies, including one published in the New England Journal of Medicine (Palliative Care for the Seriously Ill, Kelley, A.S. et al, NEJM, 2015) notes that Palliative care is interdisciplinary (medicine, nursing, social work, chaplaincy, and other specialties when appropriate) that focuses on improving quality of life for persons of any age who are living with any serious illness and for their families.¹ Evidence from these studies suggests patients with a serious illness who received palliative care lived longer than those who did not receive this care and they or their parents have more control over their care and consequently quality of life.

Paediatric palliative care for all conditions is in a variable state in New Zealand due to a lack of a nationally coordinated and funded service and strategy and training. While the Foundation is aware of expertise in some locations, the provision of care is primarily locality based. As such, the Foundation wishes to bring this to your attention and offer our expertise to support what we see as vital work being done by small, dedicated teams who are under resourced and often not able to respond out of hours or do so in their own time. Effective palliative care for children and young people, while requiring upfront investment, has the potential to save many thousands of dollars as discussed in Benini et al, International Standards for Paediatric Palliative Care: From IMPaCCT to GO-PPaCS.²

2.2 Mental Health and Wellbeing

As a children's charity, Child Cancer Foundation is committed to listening to the voice of children. As part of this process, we have undertaken Children's Voices workshops. Coming through clearly from these sessions and a thesis by Dr Olivia Jennison³ are the mental health impacts of a child

cancer diagnosis not only for the children diagnosed with a childhood cancer but also for their siblings. The long-term traumatic impacts of a child losing their hair from chemotherapy, or getting nasogastric tubes or other ports, as well as the process of flushing or the death of a sibling can live in the memories of whānau for long periods of time and certainly well past the end of treatment.

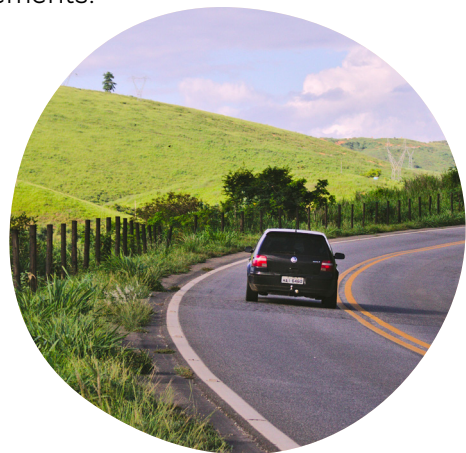
Child Cancer Foundation provides counselling for families without receiving any government funding, but improved specialist mental health system responses for both children with a cancer diagnosis and their siblings is an area for improvement. Another area where we add value is ensuring sibling connections, particularly for those outside of the two main treatment centres. We do this by supporting families to fly siblings to visit their brothers or sisters; feedback from our Children's Voices sibling groups have highlighted the importance of these for both children with a cancer diagnosis and their siblings.

3. National Travel Assistance Scheme (NTA)

3.1 Child Cancer Foundation notes the increased funding for the NTA and commends government for swift action on this. We believe strongly that travel and accommodation costs should be factored into the delivery of care model within a national service provision framework and that this is particularly important for children and their families.

3.2 While the increased funding is something to be celebrated, we believe additional work still needs to be done. Areas we outlined in our BIM that the families we support continue to report remain, including:

- Delays in approval and reimbursement of costs.
- Inconsistent application across different geographic regions (postcode inequalities).
- A failure to keep up with inflation which has seen an average 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.
- 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 tamariki or rangatahi's diagnosis and treatment on their physical wellbeing.



4. Pharmaceutical Schedule Rule 8.1(b) and Patient Voices

4.1 Child Cancer 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 childhood 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.

The key takeouts from our submission included:

- Recommending Rule 8.1(b) of the Pharmaceutical Schedule be maintained as it is currently devised now and into the future.
- Our belief that the best people to make decisions on treatments are medical professionals, and Rule 8.1(b) allows for this.

- We also recommended that Pharmac provides a clarifying statement about what access to existing drugs for existing patients means in practice.
- The Foundation recommended 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 noted that 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.

4.2 We are pleased to note that your government and Pharmac listened to the voices of families, clinicians and the sector and has agreed to retain Rule 8.1(b) in its current form albeit with additional governance oversight. We are further pleased to inform you that we have met with Pharmac at their instigation, and we were heartened by the spirit in which they engaged in this dialogue. They seemed to be genuinely interested in the voices of parents as well as those experts who work in the sector.

We can facilitate meaningful input from health service providers and families within our scope of influence that can be of benefit to the health system.

5. Children’s Health Action Plan and a voice for children

5.1 The Children, Young People’s Health 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. Collectively the group supports over 130,000 children and young people each year. Child Cancer Foundation is a member.

5.2 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.

5.3 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.

We ask for government to prioritise children and young people’s health through:

- Immediate attention to the development of a comprehensive National Health Strategy for Children and Young People.
- Representatives of the Collective to be invited to work collaboratively with other agencies.



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



6. Additional issues related to childhood cancers

While the following issues sit outside your brief, we wish to highlight our advocacy agenda and would appreciate any support the Minister can provide to progress the following as matters of urgency.

6.1 Funeral expenses

Sadly, while New Zealand childhood cancer survival rates are currently comparable to the best in the world, many children still do not survive. These children's families not only struggle with their loss, but also face the additional burden of funeral costs. For a demographic (parents) that tends to be younger with other young children, this financial burden can be severe.

Families from lower socio-economic or ethnic groups with different funeral customs can experience effects that are detrimental to the financial wellbeing of the families of palliative children and recently bereaved parents/caregivers.

Currently the average cost of a funeral for a child is between \$6,000 and \$8,000. Work and Income funds a maximum funeral grant payment of up to \$2,559.20 which is also asset tested. The ability of some families to pay for funeral expenses is significantly compromised.

The Foundation currently assists financially with funeral costs, bill payments and additional fuel and grocery support to help families alongside other financial assistance and grants.

6.2 Extended leave, carer benefits and educational needs

Currently there is little provision for earning parents to be able to take the time off in palliative situations with the onus of financial support being in the context of 'gifted' extended leave. This sits with the employer in most cases and is dependent on the employer's support and generosity. In many instances it is not uncommon for one or both parents to leave employment during a child's illness as one parent remains with the sick child while the other parent takes care of any siblings as there is often geographic dislocation. These situations add further financial and other pressures to an already stressful period in the lives of families supporting a child with cancer.

More than 50% of our families must travel more than 100 km to treatment, meaning travel costs are compounded when families live outside of Auckland (Starship) or Christchurch (Children's Haematology and Oncology Centre – CHOC).

While the Foundation is committed to the two-treatment centre model wholeheartedly, we remain concerned that some of the broader structures to support families to engage with a national service disproportionately impact those who reside outside of the main treatment centres. These impacts do not show up in statistics of survivability, such as family cohesion and social isolation, mental wellbeing, and educational delays. As with the NTA we are strongly of the view that within a national service provision framework, costs and the time required in situations such as these should be factored into the delivery of care model and fully funded. This is, in our view, particularly important for children and their families.

6.3 Carer benefits and educational needs

Child Cancer Foundation is also concerned about the Child Disability Allowance (CDA) which is a fortnightly payment made to the main carer of a child or young person with a serious disability. This payment is worth \$59.23 a week for each child. Given the current financial environment and the significant impacts on families, particularly those outside of the main treatment centres, the Foundation believes this needs urgent review and adjustment for cost of living, geographic location in relation to the treatment centre and the additional pressure of extra siblings or family situations.

This concern is also highlighted with the narrowing of criteria for carers accessing Carer Support. This previously enabled a



Nicole, diagnosed age 7

wider scope of respite for carers which is not available now for parents we are supporting. This is especially difficult for families of children with late effects and significant disability which is more evident post brain tumour diagnoses.

Higher health needs funding is required to access additional assistance for children at school. It is currently difficult to access and due to this we often approve Personal Development Grants which pay for teacher aide assistance. This is a challenge for the Foundation to then be assured that the teacher aide funding we do provide is utilized for the specific individual and knowing that we are filling a gap that should be government funded, thereby diverting our limited funds.

We have anecdotal evidence that this funding may go into each school's Resource Teachers/ Learning and Behaviour funds to be utilized for the shortfall they experience in aiding many students with learning difficulties. This is an ongoing challenge and one we have discussed at length with the Health School principals. Essentially, we have more survivors as treatment options advance. We also have more living with late effects due to these advanced treatments. We are currently engaging with our Late Effects colleagues on their views about this; it isn't in response to education gaps due to time off school but more so the students who have deficits due to treatment. Children and young people with brain cancers are the most impacted by these events.

While the above are all important issues they are ones we increasingly struggle to have funded as many philanthropic funders view these 'health and education supports' and 'grants for personal benefit' as the responsibility of Government – particularly those in the disability support and education spheres.

Conclusion

We welcome the chance you have offered us to discuss these issues and look forward to hearing from you about your priorities. We would also welcome the opportunity to explore how we can work constructively with government on these and other priorities to improve health outcomes for children and their families. Any thoughts or considerations you may have on this would be gratefully received.

Yours sincerely



Mae, diagnosed at 8 months old, with her mum Charlotte



Monica Briggs

Chief Executive of Child Cancer Foundation