Aide-Mémoire

Meeting with Child Cancer Foundation and CanTeen on Wednesday 31 July 2024

Date due to MO:	24 July 2024		
To:	Hon Dr Shane Reti, Minister of Health		
Security level:	IN CONFIDENCE	**Health Report number:**	H2024043435

Contact for telephone discussion

Name	Position	Telephone
Rami Rahal	Chief Executive, Te Aho o Te Kahu | Cancer Control Agency	s 9(2)(a) [redacted]
Bridget Kerkin	Manager, Knowledge Translation and Implementation, Te Aho o Te Kahu | Cancer Control Agency	

Minister's office to complete:

☐ Approved
☐ Needs change
☐ See Minister's Notes

☐ Decline
☐ Seen
☐ Withdrawn

☐ Noted
☐ Overtaken by events

Comment:

TE AHO
O TE KAHU
CANCER
CONTROL
AGENCY

Aide-Mémoire

Meeting with Child Cancer Foundation and CanTeen on Wednesday 31 July 2024

Details of Meeting	Wednesday 31 July 2024 12:00-12:30pm Room: 6.6 EW
Purpose of Meeting	This meeting was requested by the Child Cancer Foundation (CCF) in their letter dated 28 November 2023.
Summary	The key topics covered in this aide-memoire include: • attendee profiles • overview of NGOs • background on child and adolescent/young adult (AYA) cancer • Child and AYA national cancer networks • discussion topics; Pharmac rule 8.1b, national travel assistance (NTA) scheme, Child and Youth Wellbeing Strategy, non-for-profit sector role, other possible topics of discussion.
Talking points	s 9(2)(g)(i) [redacted]

	s 9(2)(g)(i) [redacted]

Attendees

Monica Briggs MNZM *Chief Executive Officer, Child Cancer Foundation*	Monica Briggs has been Chief Executive Officer (CEO) of the Child Cancer Foundation since 2021 with a background in governance and management. In addition to her role at CCF, Monica also serves on the Auckland University of Technology's Business School Industry Advisory Group and is a Board Member of the Grief Centre.
Kerry Price *Project, Research and Advocacy Manager, Child Cancer Foundation*	Kerry Price is the Project, Research and Advocacy Manager for CCF. Kerry has experience in Health Management and Business Development having worked with DHBs in Otago/Southland and Auckland and at The University of Auckland's commercialisation company, Auckland UniServices Ltd, as Manager Medicine and Health then as Executive Director Government and Industry.
Nick Laing *Chief Executive Officer, CanTeen and Chair of the Children and Young People's Health and Disability Collective*	Nick Laing has been the CEO of CanTeen since 2019. Nick has a background in social work and has held leadership roles within the health sector for more than 20 years. Nick is the current chair of the Children and Young People's Health and Disability Collective.

Child Cancer Foundation

1. The Child Cancer Foundation (CCF) has been a charitable organisation for over 40 years with the vision "to walk alongside and support all children and their families on their cancer journey and advance improvements to child cancer care."

2. CCF work includes advocacy, supporting child cancer research, and Family Support Coordinators who give one-to-one support for families. The majority of CCF revenue is from donations, bequests, fundraising, sponsorship, grants and investments.

CanTeen

3. CanTeen supports rangatahi aged 13-24 impacted by cancer across Aotearoa. CanTeen's unique governance model means that half of the board is made up of rangatahi who provide a strong voice for those who utilise the services that CanTeen offers.

4. CanTeen work includes Psychosocial Support Workers and Youth Workers providing a range of free services tailored to the specific needs of each rangatahi. This includes individual support and therapy, peer-to-peer events and programmes, 24/7 online support, and rangatahi development. The majority of CanTeen revenue is from fundraising, bequests, donations, sponsorship and grants received.

Children and Young People's Health and Disability Collective

5. Nick Laing (CEO of CanTeen) is also the Chair of the Children and Young People's Health and Disability Collective, which is a group of seven charities that work at the coalface providing daily support to tamariki and rangatahi experiencing health issues and to their whānau and families.

6. This collective is made up of CanTeen, Child Cancer Foundation, HeartKids, Kidney Kids NZ, Make a Wish Foundation, Ronald McDonald House and the Starship Foundation.

Child cancer background

7. Around 150 children (0-14 years) are diagnosed with cancer each year. The most common cancers diagnosed are leukaemia, brain tumours and lymphomas; and most cancers are diagnosed in children under the age of 5 years[1].

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[1] https://childcancernetwork.org.nz/wp-content/uploads/2022/08/Final-July-2022-Childhood-Cancer-Incidence-2015-2019.pdf

8. There are two specialist child cancer centres in Aotearoa; the Starship Blood and Cancer Centre in Auckland and the Children's Haematology/Oncology Centre (CHOC) based in Christchurch Hospital. These specialist treatment centres work closely with other hospitals (shared care centres), to ensure that the diagnosis, management, and follow-up of children with cancer is safe, effective and delivered as close to the patient's home as possible.

9. The CCF note in their letter that they are of the view that Aotearoa is at the "forefront of treatment and survivability of childhood cancers". There is a range of evidence supporting this assertion. A recent study showed that childhood cancer incidence and survival in Aotearoa are comparable to other high income countries[2]. In many ways the outcomes achieved for child cancer in Aotearoa New Zealand, through a collaborative networked approach, have been one of the most impressive success stories for out health system in recent times.

Adolescent and young adult (AYA) cancer background

10. Around 190 adolescents and young adults (12-24 years) are diagnosed with cancer each year. The most common cancers diagnosed are carcinomas, lymphomas, germ cell tumours, leukaemia, melanomas, and bone tumours[3]. Māori have a higher incidence of Ewing tumour and carcinoma of the gastro-intestinal tract.

11. AYA patients have varied needs due to their stage of social, emotional, and cognitive development. AYA cancer services are specialised treatment and support services, developed to most effectively respond to these varied AYA patient needs.

Child and AYA cancer networks

12. Te Aho o Te Kahu funds two independently operating networks; the National Child Cancer Network (NCCN) and the AYA Cancer Network Aotearoa.

13. Both NCCN and AYA connect a diverse range of health professionals, voluntary organisations and carers. The networks provide national leadership and oversight, strategic direction and clinical guidance for child and AYA cancer services respectively. CCF and CanTeen are engaged with these networks.

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[2] Pugh G, Bradbeer P, Wood A, Hunter S, Cross S, Denton K, Copeland K, Laughton S; New Zealand Children's Cancer Registry Working Group. Childhood cancer incidence & survival in Aotearoa, New Zealand 2010-2019. Cancer Epidemiol. 2023 Oct;86:102433. doi: 10.1016/j.canep.2023.102433. Epub 2023 Jul 31. PMID: 37531729.

[3] https://ayacancernetwork.org.nz/research-and-evaluation/

Likely items for discussion

14. In their letter dated 28 November, the Child Cancer Foundation highlighted four topics of interest;

    i. the Pharmac proposed change to rule 8.1(b),

    ii. the National travel assistance scheme,

    iii. a need for wider action on child health

    iv. concerns around increasing pressures on the not-for-profit sector.

Pharmac proposed change to rule 8.1b

15. Rule 8.1b of the Pharmaceutical Schedule allows clinicians to prescribe medicines that are not publicly funded, without cost for children diagnosed with cancer who are treated in a paediatric setting.

16. Of the approximately 150 children diagnosed with cancer each year, up to 15 access medicines using Rule 8.1b.

17. Following a comprehensive review (initiated by due to concerns around fairness compared to other populations), Pharmac announced in March 2024 that the rule will remain in place[4]. CCF wrote their letter before this announcement. They are strong advocates for maintaining the rule and have expressed support for this decision.

National travel assistance (NTA) scheme

18. The attendees, and their organisations, have strongly advocated for changes to the NTA scheme, alongside the Cancer Society, CanTeen and other non-governmental organisations (NGOs).

19. You announced an $18 million funding boost to the NTA scheme on 26 March 2024 to be delivered in tranches from 1 April 2024.

20. CCF's letter predated the recent announcements on updates to the NTA scheme and they have since expressed support for these changes.

21. NGOs have highlighted the importance of careful implementation of the changes to the NTA scheme. This includes a need for refined eligibility criteria that considers adolescents/young adults over 17 years who are currently unable to access NTA support for their families because they are considered as adults.

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[4] https://pharmac.govt.nz/assets/Uploads/Update-on-Rule-8.1b-Summary-of-submissions-to-the-review.pdf

Wider action on child health

22. In their letter, CCF called for the development and funding of a Child and Youth Wellbeing Strategy and Action Plan, developed in collaboration with the Children, Young People's Health, and Disability Collective.

23. The Children's Act 2014 sets a legislative requirement for successive governments to adopt a Children's Strategy to improve the wellbeing of all children, including those with greater needs. The current Child and Youth Wellbeing Strategy was published by the previous government in 2019[5].

24. The Minister for Child Poverty Reduction, Hon. Louise Upston, has indicated her interest in refreshing the Strategy to better reflect and align with the current Government's priorities and targets. This aligns with the requirement in the Children's Act 2014 for regular reviews of the Strategy, and for it to set out the policies the Government will implement to achieve its intended outcomes. The Strategy was last reviewed in 2022. This work is being led by the Child Wellbeing and Poverty Reduction Group, within the Ministry of Social Development (MSD).

25. The refresh will change legislated components of the Strategy (the measurement framework and the policies). The Children's Act 2014 establishes a requirement for consultation on those changes. The Child Wellbeing and Poverty Reduction Group have completed their consultation and engagement on the Strategy refresh and will be providing their summary finding to Minister Upston in August. They will be submitting a Cabinet paper in October to confirm the direction. The publication of the refreshed strategy is due in November.

26. Workstreams under the Strategy include the key priorities (reducing child material hardship, supporting children and families in the first 2000 days, and preventing harm against children), targeted stakeholder consultation and engagement on the refresh of the Strategy, child poverty reduction targets, and the measurement framework used for monitoring and reporting.

27. The Ministry of Health and Te Whatu Ora have provided input into the First 2000 days priority area; and have been involved in providing feedback on advice to the Minister for Child Poverty Reduction, Cabinet papers, and collateral to support meetings of the Child and Youth Wellbeing Ministers Group.

28. A key governance structure of the Strategy is the Child and Youth Wellbeing Ministers Group which meets on an ad hoc basis to discuss various elements of the

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[5] https://www.msd.govt.nz/documents/about-msd-and-our-work/child-youth-wellbeing/strategy-and-plan/child-youth-wellbeing-strategy-2019.pdf

Strategy. Ministers on this group, in addition to yourself, are Ministers Upston, Bishop, Goldsmith, Mitchell, Chhour, Willis, Stanford, Doocey and Potaka.

Not-for-profit (NFP) sector

29. CCF raised concerns in their letter regarding the increasing role of not-for-profit organisations (NFPs) in the provision of health and wellbeing services in Aotearoa. They also note in their letter that NFPs are increasingly regarding some requests for support from health service providers as “the responsibility of the State to fund”, and therefore choosing to decline applications.

30. Their request is for the Government to consider NFPs in any changes to the health and wellbeing sector. Te Aho o Te Kahu recognises the value that NFPs provide to many cancer patients and their families in Aotearoa and agrees that system and service changes should adequately consider consequential impacts to the NFP and NGO sectors. In addition, services provided by NFPs are significantly impacted by downturns in the New Zealand economy and therefore their funding streams, such as that experienced during the response to the COVID-19 pandemic.

Additional relevant information

31. An additional key issue of relevance to child and AYA cancer patients, and their families, is reported difficulty in accessing timely and specialised psychosocial services, particularly outside of main centres. Since 2023, CCF have administered and provided funding for the Child Cancer Counselling Network, which was set up as a collaboration between NCCN, CCF and Massey University in 2021. CCF report that the Child Counselling Network has seen a reduced referral time down to 5-7 days, a better geographical spread of counsellors and better accessibility for families.

Rami Rahal
Chief Executive
Te Aho o Te Kahu