

New Zealand Children's Cancer Registry News



National Child
Cancer Network ^{NZ}

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The New Zealand Children's Cancer Registry is now 21!

The New Zealand Children's Cancer Registry (NZCCR) officially started registering all new childhood cancers in the year 2000. That means that the 1st of January 2021 was technically the NZCCRs 21st birthday.



Publications from 2020

NZCCR working group publications and other publications utilising NZCCR data can be found online at childcancernetowkr.org.nz. Below is a snapshot of articles released in 2020;

- *Global Retinoblastoma Study Group, Global Retinoblastoma Study Group; Global Retinoblastoma Presentation and Analysis by National Income Level, JAMA Oncol. 2020 May 1;6(5):685-695. doi: 10.1001/jamaoncol.2019.6716.*
- *Shum M, Mahoney E, Naysmith K, Macfarlane S, Corbett R, Narsinh M, Natarajan A, Ramadas Y, Hitchings E, Anderson H. Associations between childhood cancer treatment and tooth agenesis. N Z Med J. 2020 Oct 9;133(1523):41-54. PMID: 33032302.*
- *Drysdale H, Fawcner-Corbett D, Solomon Z, Cundy O, Loveland J, Perrin J, Lane R, Price N, Anyanwu LC, Wilson S, Lakhoo K. Bilateral Wilms' tumour: An international comparison of treatments and outcomes. J Pediatr Surg. 2021 Jan 29;S0022-3468(21)00090-7. doi: 10.1016/j.jpedsurg.2021.01.040. Epub ahead of print. PMID: 33573802.*
- *Slykerman, R.F., Jenner, E., Tsui, K. and Laughton, S. (2021), Neuropsychological assessment of paediatric brain tumour survivors: Factors associated with assessment. J Paediatr Child Health. <https://doi.org/10.1111/jpc.15568>*

2021 Projects in the Pipeline

Updated Incidence & Survival Analysis

- The incidence of childhood cancer 2015-2020
- Childhood cancer survival 2015-2019

Margaret Lewis Analysis

- New Zealand child cancer incidence and survival between 1978 – 1999
- Incidence of second malignancies following childhood cancer treatment
- Excess mortality following childhood cancer treatment

The Margaret Lewis Dataset

Although the NZCCR technically commenced at the start of the new millennium, the registry was pre-dated by what we now refer to as the Margaret Lewis Dataset. This was a dataset of demographic and diagnostic information collected by Dr Margaret Lewis between 1978 and 1999. Dr Lewis painstakingly recorded each child cancer registration on index cards by hand, these records have recently been transferred to electronic format.

We are using the Margaret Lewis dataset to learn more about the long term effects of cancer for children treated in the 80s and 90s, including the risk of developing new cancers in later life and of a person dying of causes that might be linked back to their childhood cancer and treatment. Few – if any – countries have the data to undertake such a study and it is largely thanks to Margaret's tenacity that we have the opportunity to do so.

Registry Management

Kirsten Ballantine, the long-serving NZCCR manager and analyst, has taken a new role as Data Project Lead with the AYA Cancer Network Aotearoa. Kirsten has established the NZCCR as an internationally recognised childhood cancer registry. Thank you Kirsten for all your hard work over the last ten years!

Gemma Pugh commenced as the new full time Research Lead for the NCCN in April. Her role will include continuing NZCCR analysis but also support the National Child Cancer Networks broader research agenda.

With such an extremely well-verified dataset, and the on going input of all new child cancer diagnoses, NZCCR is increasingly utilised as a valuable research tool. Appropriately qualified New Zealand researchers who have a specific interest in childhood cancer are invited to request a dataset from the NZCCR.



For more information contact

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