# **NZCCR REPORT 2015**

The New Zealand Children's Cancer Registry (NZCCR) was established in 2002 and holds verified diagnostic, demographic and treatment information for children diagnosed with cancer in New Zealand since the year 2000. All data is entered by clinical research associates at each specialist paediatric oncology unit. The NZCCR Working Group, under the governance of the National Child Cancer Network, is responsible for monitoring the on-going collection and the regular reporting of anonymised registry data.

Welcome to the 2015 annual update from the NZCCR Working Group. This brief report provides a summary of our recent activities and a snapshot of the children who were diagnosed with cancer in 2015.

The NZCCR recently finalised our submission to the 3<sup>rd</sup> volume of the International Incidence of Childhood Cancer (IICC), a collaborative project between the International Association of Cancer Registries and the International Agency for Research on Cancer. Over 400 cancer registries are contributing data to this 3rd volume in the IICC series and it is the first time that the NZCCR has participated. The monograph is due to be published in both print and electronic form later in 2016.

We also recently collaborated with the New Zealand Cancer Registry to verify our 2010-2014 child cancer registrations and ensure that we had complete case ascertainment. This was a valuable undertaking and has led to improvements for both registries. The NZCR and NZCCR serve different yet complementary purposes and we look forward to working on more projects with the NZCR in the future.

The NZCCR continues to be utilised for a wide range of research projects. In 2015 we approved applications for an international case-control study on the risk factors for brain cancer in young people (MOBI-KIDS), a national Dental Late Effects study (Dr Erin Mahoney and colleagues), gene mutations in children with Acute Lymphoblastic Leukaemia (lead by Dr Tristan Pettit) and a comprehensive analysis of medulloblastoma (Dr Karen Tsui).

The World Health Organisation have recently made a number of additions and changes to cancer histology codes which are impacting cancer registries. We are fortunate that the registry was designed so that it is extremely easy to make modifications when required. In addition, in 2015 we completed one page tumour group summaries for our most common childhood cancers to make it simpler for entering new cases. Annual reviews by designated consultants ensure that the information being collected by the NZCCR meets their requirements for patient health passports and future research.

In December Kirsten Ballantine presented the adolescent and young adult (AYA) cancer incidence and survival analysis at the Inaugural International AYA Congress in Sydney. This study, undertaken at the request of the AYA Advisory Group, was a replication of the 2000-2009 NZCCR analysis and her attendance was funded by the National Child Cancer Network.

Following the AYA Congress, the NZCCR received an invitation to attend the Asia-Pacific Cancer Leaders Summit to be held in Brisbane in April 2016. As the NZCCR only recently joined the International Association of Cancer Registries, this will be an excellent opportunity to network and learn from experts in cancer registration from across the region. We will also be presenting a paper on the unique integration of the NZCCR with the Late Effects online clinical tool. The NZCCR has been generously awarded a travel grant by the William Rudder Memorial Fund to attend the three day summit.

Please feel free to share this report with your colleagues who have an interest in childhood cancer. If you have any questions about the registry or wish to find out more about how to request registry data, please contact us using the email addresses below.

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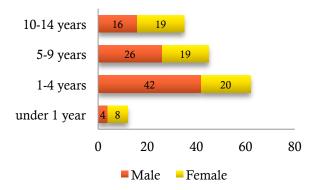


## **NZCCR SNAPSHOT 2015**

Note: this snapshot relates to NZ children aged 0-14 years *diagnosed with cancer* in 2015. It does not include patients receiving on-going treatment for tumours diagnosed in previous years, non-NZ residents who receive treatment here, those aged over 14 years, or those diagnosed with other non-malignant/haematological conditions. The number of patients *receiving treatment* in our paediatric oncology specialist centres each year is significantly higher.

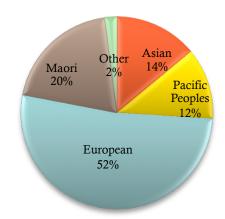
#### AGE AND GENDER

154 New Zealand children under the age of 15 were diagnosed with cancer in 2015, 88 males (57%) and 66 females (43%). Nearly half were under the age of five at the time of diagnosis. 48 patients (31%) participated in an international collaborative clinical trial.



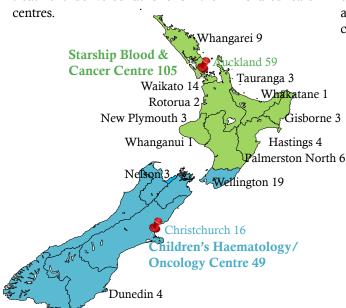
#### **ETHNICITY**

By prioritised ethnicity, 20% of children diagnosed in 2015 were Maori, 12% Pacific Peoples, 14% Asian, 2% African/Middle Eastern, and 52% NZ European/Other European.



#### **SHARED CARE CENTRE**

105 of the children diagnosed with cancer in 2015 were referred to Starship Blood and Cancer Centre and 49 to the Children's Haematology and Oncology Centre (CHOC). Around half of the children diagnosed do not primarily reside in either Auckland or Christchurch and may have some of their treatment delivered at one of the 14 shared care centres.



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### **DIAGNOSTIC GROUP**

Leukaemia was the most commonly diagnosed childhood cancer for 2015 followed by central nervous system (CNS) tumours. However, this varied considerably by age and gender. A higher number of males were diagnosed with lymphoma (18 vs. 3 cases) and renal tumours (7 vs. 2 cases). Older children were more likely to be diagnosed with bone and soft tissue sarcomas, germ cell tumours and carcinomas.

