

# NZCCR REPORT 2013

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 (CRAs) at each specialist paediatric oncology unit and submitted electronically to the NZCCR National database. The NZCCR Working Group is responsible for monitoring the collection and the reporting of anonymised registry data. The group includes CRAs, oncologists and haematologists, and the NZCCR research analyst.

Welcome to the 2013 update from the NZCCR Working Group. This is the first time that we have released a report of our activities and a snapshot of the children who were diagnosed with cancer in the previous year. It is our intention to complete a similar update each year and make it widely available to families, health practitioners and agencies who have an interest in children's cancer research.

2013 has seen the completion of the first outcome analysis of the NZCCR for the period 2000-2009. Two separate reports describing New Zealand cancer incidence and survival will be released in 2014. These reports represent the most comprehensive analysis of child cancer in New Zealand ever completed. They allow us to provide our patients and their families with current data which reflects New Zealand's unique ethnic make-up and to compare New Zealand's child cancer survival with international benchmarks. The first wave of analysis has provided us with many ideas about how we can conduct regular analyses of the registry, small enhancements that can be made to our database and additional research projects to pursue.

The NZCCR incidence and survival analysis has also been replicated for New Zealand's Adolescent and Young Adult (AYA) population using data from the New Zealand Cancer Registry. The analysis was used by the AYA Advisory Group to inform their recommendations to the Ministry of Health regarding the future

delivery of AYA cancer services. The AYA cancer incidence and survival 2000-2009 report was released in December 2013 and is available to download from the NCCN website

[www.childcancernetwork.org.nz](http://www.childcancernetwork.org.nz)

The NZCCR Working Group considers requests for registry data to be used in research of benefit to New Zealand children with cancer. Dr Andrew Dodgshun recently led a project utilising NZCCR data to determine New Zealand's current participation in international clinical trials and to identify potential barriers to enrolment. The study has been accepted for publication in 2014. Andrew completed this project as part of his paediatric oncology fellowship at Christchurch Hospital.

In February 2013 Dr Michael Sullivan resigned from his position at Christchurch Hospital and role as NZCCR Working Group Chair in order to take up a new position as Head of Neuro-Oncology and Solid Tumours at the Royal Children's Hospital in Melbourne. Michael was instrumental in the establishment of the NZCCR and we thank him for his commitment to ensuring that we have detailed, accurate and timely data about childhood cancer in New Zealand. Michael has maintained an involvement with the registry while the 2000-2009 analysis is submitted for publication in international journals. Dr Peter Bradbeer is our new Working Group Chair. In addition, the National Child Cancer Network continues to provide funding for a part-time NZCCR research analyst.

We hope that you find this 2013 snapshot informative, ahead of the comprehensive registry reports which will be released in the upcoming months. We wish to especially thank all children and their families whose data has been submitted to the registry.

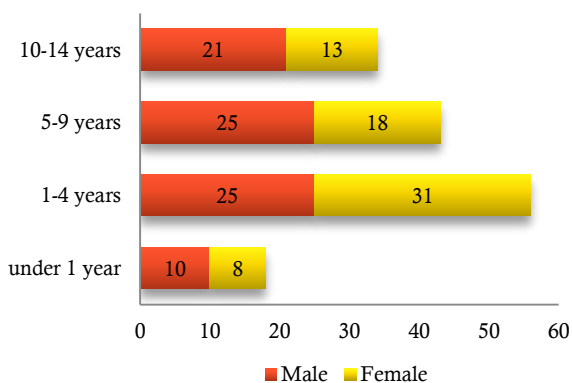
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# NZCCR SNAPSHOT 2013

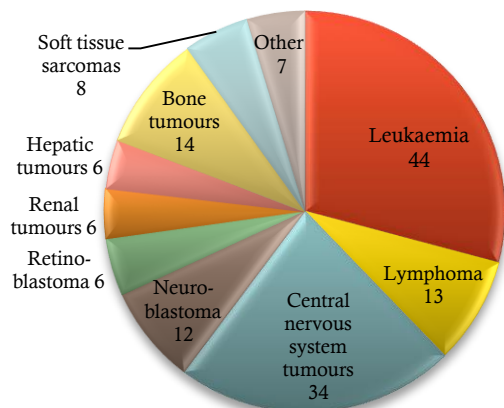
## NEW CASES DIAGNOSED

151 children under the age of 15 were diagnosed with cancer in 2013; 70 females and 81 males. In addition, 14 young people over the age of 15, 5 children from overseas, and 9 children with a diagnosis other than a malignant primary tumour (such as Langerhans Cell Histiocytosis) were also registered on the NZCCR due to having some involvement with paediatric oncology services. The data for these individuals are not included in the charts below.



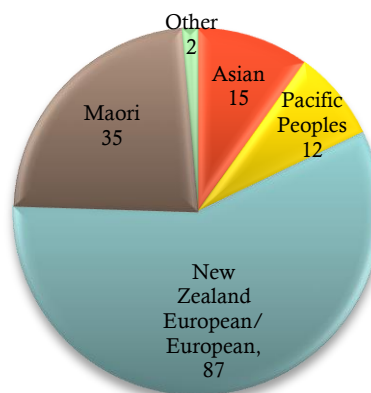
## TYPES OF CANCERS DIAGNOSED

The most frequently diagnosed childhood cancer in 2013 was leukaemia, followed by central nervous system tumours. Those children diagnosed with retinoblastoma and neuroblastoma were predominantly aged under 5. In contrast, of the 14 children diagnosed with a bone tumours in 2013, 11 were aged 10-14 years. More males (36) than females (21) were diagnosed with a haematological malignancy.



## NEW CASES BY ETHNICITY

By prioritised ethnicity, 23% children diagnosed in 2013 were Maori, 8% Pacific Peoples, 10% Asian, 1% 'Other' and 58% NZ European/European.



## SHARED-CARE CENTRES

97 of the children diagnosed with cancer in 2013 are under the care of Starship Blood and Cancer Centre in Auckland and 54 are under the care of the Central & Southern Child Cancer Service (based in the Children's Haematology and Oncology Centre in Christchurch). 67 children (44%) diagnosed in 2013 do not primarily reside in either Auckland or Christchurch.

