

Natalie Bunworth

Committee Secretary  
Select Committee into Funding for Research into Cancers with Low Survival Rates  
Department of the Senate  
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Dear Committee Secretary,

Funding for Research into Cancers with Low Survival Rates

I have prepared a submission for this inquiry as I believe it is critical that changes are made to the funding for research into children's cancers with low survival rates such as relapsed neuroblastoma.

Jai introduced me to the world of childhood cancer. Jai went to school with my boys. At 4 1/2 years, old Jai was diagnosed with Neuroblastoma. He went through chemotherapy, radiotherapy, surgery and a stem cell transplant, spending many months in hospital and regular hospital visits. As an outsider, I was oblivious to most of the details and naively believed that once he got through the treatment that would be the end it. Jai's cancer did go into remission. As an enthusiastic sportsman, Jai embraced the chance to play basketball, cricket and football as well as start school and make many close friends. He was a happy 6-year-old who loved spending time with his family and friends.

However, I clearly remember the first day of school in 2013 when Jai was not in the first assembly and one of the parents told me "Jai's cancer was back and he had been put into palliative care" .... now palliative care meant preparing to die and Jai was 7 years old, this could not be happening, but his parents had been told there were now limited treatment options. I was to learn there is no cure for relapsed Neuroblastoma

Our local community came together firstly, to try to support Jai's family and to help give them quality time together. Jai's Mum then pointed out that the only thing that would, really, help Jai was to find a cure. That meant funding for research and clinical trials. So, our community formed Jai's Falcons and did what we could to fundraise for The Kids Cancer Project and to date we have raised \$70,000. Although, I personally believed our fundraising would find a cure for Jai. I overheard Jai on one of our cake stalls explaining to his mate

that “the money we were raising wasn’t his, but was to help other children” That is the sort of selfless kid Jai was.

Jai opened a window for me into childhood cancer and I was shocked and horrified by what I learnt.

- Most of the drugs used to treat children are 30-40 years old and extremely toxic. So much so that one third of children that survive cancer will suffer long term health problems for the rest of their lives.
- Childhood cancers are different from adult cancers which means that research and funding for adult cancers will not necessarily benefit children with cancer.
- 3 children die in Australia each week from childhood cancer and childhood cancer is the major cause of death from disease in children. Somehow, Childhood cancer is considered rare ?????? as it accounts for 1% of total cancer incidence in Australia.
- Being considered rare means research is not financially attractive to pharmaceutical companies or government funding. With less than 3.7% NHMRC funding going to childhood cancer research.

When you lose a child to cancer and all that they could have been over their lifetime it doesn’t make sense for their life to be lost due to lack of funding. There is no dollar value on their life.

After relapsing, Jai did get access to numerous MIBG treatments, where he was isolated in a lead lined room and given radioactive medicine which meant no one could go near him for 4 days and then further isolation from his siblings and other children for 10 days. This did slow down the cancer for a while. So, that he could go on 3 rounds of an Immunotherapy trial...one of the most painful treatments he endured, which was not successful. He missed out on a place in a DFMO clinical trial. There were only 6 vacancies and he was number 7. He had to wait 6 months for another place to open, 6 months he did not have. Would he still be here if the trial had funding for 7 places??? The child that got the 6<sup>th</sup> place is. During this time Jai’s major concern was not being able to go to school and struggling to play his beloved football.

When we first started fundraising in 2014 full of hope for a cure, we were excited by the work Professor Gunning was doing with The Kids Cancer Project and a drug company Novagen to bring a new drug Ansina for neuroblastoma to clinical trials in children. We were hoping for trials to start mid-2014, but we are still waiting.... Cancer does not give Kids time to wait.

Funding for research into childhood cancers should not rely on community cake stalls and movie nights. There needs to be incentives for pharmaceutical companies to develop new treatments for children. Government funding needs to reflect the value of our children. Children should not suffer and finding nontoxic treatments with no side effects needs to be a priority. Access to quality, world class, local clinical trials is critical to finding cures for childhood cancer. Families need to be able to access treatment close to their support networks and not have to be isolated far from home.

Jai was taken from his family and friends just before his 10<sup>th</sup> birthday on the 5<sup>th</sup> of March 2015. We promised Jai we would keep fighting to find a cure and “Never Give Up”. For us to keep this promise funding for children’s cancer research and clinical trials needs to change.

Sincerely

Natalie Bunworth