Committee Secretary
Select Committee into Funding for Research into Cancers with Low Survival Rates
Department of the Senate
PO Box 6100
Canberra ACT 2600
cancer.research.sen@aph.gov.au

Dear Committee Secretary

RE: Funding for Research into Cancers with Low Survival Rates

I write this submission as a bereaved parent. My eldest child, , aged 12, died from a paediatric brain cancer called Ependymoma, 5 years ago. It is the third most common form of childhood brain cancer. It has very poor survival rates of less than 30%. She was diagnosed at age 11.

was a vibrant, outgoing and vivacious child. As school captain of her school, her leadership qualities were recognised early. She was a talented musician (flautist) and a high achiever. She was a much cherished daughter, a devoted grand-daughter, a loving and generous sister, a model student and dedicated friend with a wonderful sense of humour. She so loved her family and we so loved her. Her life was cut short by more than 70 years because there is no cure for her disease. There have been no changes in protocols for brain cancer treatment in 30 years. In the same month she died, 5 other children we knew, all died from the same disease, ranging in age from 18 months to 12 years. So tragic.

“Brain cancer survival rates are low and have hardly changed for 30 years, despite significant increases in survival for Australians diagnosed with other types of cancer, such as prostate and breast cancer. Brain cancer costs more per person than any other cancer, yet only receives a small fraction of federal government cancer research funding.
Brain cancer kills more children in Australia than any other disease.”

**Australian Bureau of Statistics (published 2012 – 2016), 3303.0 Causes of Death, Australia (2010 – 2014), 'Table 1.3: Underlying cause of death, Selected causes by age at death, numbers and rates, Australia, Ages 1 - 14 (2010 – 2014)* Source link

The diagnosis of her disease was slow, taking over 3 months. It involved multiple visits to her GP, multiple visits to her paediatrician and 2 hospital admissions before an MRI was undertaken. Her symptoms were not classic. She did not present with headaches, impaired vision, nor impaired mobility. Her ongoing nausea and rapid weight loss were dismissed as "psychological" in nature. It was only after an episode of uncontrollable vomiting and unconsciousness that her symptoms were taken seriously and a CT scan performed. It was hydrocephalus, swelling in her brain, a blockage of CSF (cerebral spinal fluid) caused by the large brain tumour. Had she been an adult, I am positive that a CT scan would have been performed as a first line investigative tool, not the last. Within hours she was rushed with the assistance of an intensive care team, by ambulance from a local public hospital to the children's hospital. Emergency surgery occurred 2 days later to remove a large cylindrical 10 cm tumour in the right lateral ventricle of her brain. A very large tumour for a child's small head. The diagnosis of anaplastic ependymoma, Grade 4, a malignant and aggressive tumour, meant her survival statistics were very low, much less than 30% and probably closer to zero.

Her neuro-oncologist was upfront from the very beginning. Surgery, with 100 % resection, was the only hope for her. No neuro-surgeon will ever guarantee 100% resection of a tumour in the brain as there are no margins to cut it all out. Cancer treatments would only buy her time and no cure was possible. There were no protocols, no drugs, nothing to specifically treat ependymoma. One treatment option offered by her oncologist was to do nothing. I only understood this statement after embarked on her cancer treatment. Current brain cancer treatment comes at a very high price of impact on quality of life. Recovery was slow for from her brain surgery. She was very aware of her new limitations and she became very depressed. It did leave her with many physical deficits, namely memory issues which deeply impacted her learning and musicianship. The physical limitations, left her with temporary paralysis and a longer term left sided weakness. She was lefthanded so her daily living, like writing, mobility and sporting endeavours were heavily impacted. Surgery did buy her 9 months of life, so called “cancer free.”

Further cancer treatment was necessary (due to the malignant diagnosis) and were very painful and with very serious side effects. For the next 10 months, most of her waking hours were spent in the children’s hospital either at day clinic appointments with her specialists, day treatments/procedures, or longer stays. The treatment made life very difficult for . Ongoing nausea, debilitating fatigue, memory loss, hair-loss, and the onslaught of heavy medications to counter-act the effect of radiation sickness, took its toll on her tiny body. The heaviness we endured as parents for making decisions, knowing that the radiation would more than likely cause her a secondary cancer later in life, sterility and impact further on parts of her brain. She lost the sensation for appetite (felt no hunger), had poor memory and irreversible damage to her pituitary gland (stopped on her growth, no cortisol production and no sexual maturation). Invasive procedures like frequent lumbar punctures, 3 months of daily radiation to her brain, blood tests almost every week for hormones & platelet counts, MRI’s, PET scans, eye tests, occupational therapy to regain motor skills, etc., became her new way of life.

cancer recurred within 11 months. Another complex brain surgery with 2 entry points drilled into in her skull, because the cancer had spread to multiple sites, left her physically and mentally broken. A once fearless and extroverted child she now suffered panic attacks, was anxiety ridden, introverted and defeated. She had to deal with daily seizures and was heavily medicated. This made her feel “out of it”. She had lost the ability to speak and she became “lost” in her own world, unable to communicate. Chemotherapy was eventually denied, even to buy her a little time. This was decided by her specialists at children’s the hospital. We sought second opinions from a specialist from Memphis, USA seeking new ependymoma treatments and clinical trials. His opinion was the same. We sought second opinions from other neurosurgeons for additional surgery. The brain tumour was inoperable. There were no medical treatment out there, no clinical trial that would take her, she had run out of all options.

Had the aggressive cancer treatment bought her more time and a better quality of life we could at least say the pain she endured and the impact on her life would have been worth some of it. When your child dies, after all of her suffering, it leaves us parents with deep regrets and heavy sadness. Should we have taken her overseas for treatment earlier? Should we have sought out clinical trials overseas? Promises of good outcomes and small side effects were left behind as it did not match the experience of what our daughter endured.

The fallout of losing your child to cancer is all encompassing. Family relationships have become strained. Extended family walk away as it is too confronting for them to watch a child die. Trying to raise a surviving children, who watched their sibling die an agonising death, is parenting in un-chartered territory and comes with its fair share of grief management. Financial pressures consumed our family. As 2 working parents, we both had to leave our jobs and have no income as we were now full time carers. There was no support from Centrelink. Palliative care services were very limited.
wish was to die at home with her family. We cared for our child 24/7 at home for the last 3 months of her life with 1 x 1 hour visit per week from a palliative care team (a doctor, a nurse, a social worker). There was no support for additional at home nursing services, even though we were saving the NSW government the cost of a hospital bed c. $800 per day and paid for medication bills of at least c. $300 per week. The only help offered was a washing bed linen service however I was told it would cost us $60 a week. And we only lived in 50 km radius of the hospital. Parents of children from regional and remote areas have it far worse. was denied a procedure in the children's public hospital due to the "unavailability of theatre beds." This was for cardiac surgery to insert a port to deliver chemotherapy drugs. She was not deemed "an emergency" in the public hospital system. We were asked to go to a private hospital to have it done. I can't understand that a child with a malignant recurrent brain cancer was not deemed an emergency?

I write because if I don't, those that are charged with making important, informed decisions on where medical tax dollars are spent, would never know the tragic story of a little girl who so desperately wanted to live. She had so much to give. I write because I want to give a voice to other children and families going through the same situation today. It's not as though there is no cure out there, the frustrating thing is that nothing is being done to find that cure.

From my experience, some things which I think may make a difference to improve brain cancer survival rates in children –

1. An early screening program, like breast and bowel cancer for adults, brain screening program for children. I was told by specialists that would have had this cancer growing from the age of 6, perhaps even earlier. It lay undetected for at least 5 years. Had it been found earlier, there is a good chance she would still be alive today. And allowing a GP to order a CT scan for child without the need to jump through 100 approval hoops.

2. Increased training of GP's and paediatricians to recognise the subtleties of symptoms in brain cancer in children.

3. More government funding into medical research for paediatric brain cancer. We send "men to the moon" however in 30 years brain cancer developments have moved nowhere. There is not one brain cancer drug specifically developed for children. Oncologists are forced to use adult drugs developed for adult cancers (Avastin for eg. is a breast cancer drug) on children with brain tumours.

4. Developing a way for parents to network with more than one specialist both here in Australia and overseas (especially when specialists are unavailable here) if they so choose. Being able to access in a timely manner overseas paediatric cancer trials unavailable in Australia or granted access to newly developed, less harmful drugs.

5. Funding projects into targeted cancer treatments which do less harm to children's bodies. Funding into molecular profiling of the genetics of the tumour to match with drugs that have better outcomes.

6. Access to gamma knife radiation and proton radiation for children. These options were unavailable in 2011, are they available now?

7. Funding to assist parents with palliative care of children dying from cancer to stay at home. And an option to have palliative chemotherapy delivered in home rather than at hospital.

Confidentiality

I would like my name to remain confidential and not be published on the internet because we still suffer from the social stigma of losing a child to cancer. Whilst specialists offered the best care they could even when they were limited by resources in no way would I wish them to feel, by writing of our experience, any anguish or personal upset. Far from it, we know they did the best they could in at times an underfunded, under staffed and under resourced NSW paediatric hospital system. We wish to not suffer from any persecution from the writing of our experience.

Yours faithfully,

Parents of