

SUBMISSION FOR THE SELECT COMMITTEE INTO FUNDING FOR RESEARCH INTO CANCERS WITH LOW SURVIVAL RATES

Committee Secretary

Select Committee into Funding for Research into Cancers with Low Survival Rates

Department of the Senate

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My name is Judy Polkinghorne and I am the proud mother of one of the most noble and respectful young men that you will ever have the privilege to meet. But sadly he also has Gliosarcoma. Gliosarcoma is a rare but potentially life threatening condition requiring early diagnosis and timely treatment. I am making this submission in the hope of influencing the government to provide more funding for research into cancers which currently have a very low survival rate, in particular, brain cancer which currently lacks significant improvement in survival rates, and strategies that could be implemented to improve these survival rates.

Gliosarcoma is a type of rare brain cancer which usually presents itself in the temporal lobe. Like most cancers, it is characterized by the accumulation of mutated or diseased cells which cluster together and form a mass or tumor. Of all brain cancers, gliosarcoma is one of the most dreaded because it is more likely to spread to other parts of the body when compared to similar types of cancer.

Gliosarcoma or GS is a **very rare** form of glioma, a type of brain cancer which occurs from the glial brain cells instead of the neural brain cells. This malignant cancer is defined to be a Glioblastoma comprising of sarcomatous and gliomatous components. The main characteristic feature of this histological variant of GBM (Glioblastoma multiforme) is a typical biphasic tissue pattern, having alternate areas of mesenchymal and glial differentiation. Gliosarcoma constitutes approximately 2% of all glioblastoma, and accounts for 0.59–0.76% of all adult brain tumors. They usually affect the adult population in the fourth to the sixth decade of life. Males are more frequently affected than females but all are usually in their prime. Our son Jeff is an Electrical Engineer, Army Reservist, non-smoker, non-drug taker, who was fit and healthy, running half marathons, doing his bit in the army reserve for 8 years and raising a young family. In May 2015 at the age of 36, his life, his family's life, our lives, his brother's lives and our extended family's lives changed forever. Jeff went out running, training for his next half marathon but when he didn't come home on time his wife Kelly was worried and as history will now record, for good reason. Jeff collapsed and went into seizure on the side of the road and thanks to an angel who stopped to assist him and called an ambulance, he survived on that night. He had no previous symptoms.

Gliosarcoma Prognosis

There is a lack of proper information regarding the prognosis or outcome of the treatment. Various studies are being conducted to find out the possible outcome for patients with the disorder. Delayed treatment or leaving the tumors untreated can turn fatal in severe cases. The tumors have high risk of recurrence within 9 months to 13 months after the treatment completes. Jeff was fortunate to find Dr Sarah Olson, a Brisbane based neurosurgeon who performed surgery to remove his tumour and provided support and subsequent radiation and chemotherapy. Dr Olson is an avid supporter of brain and pituitary tumour tissue banking and she initiated the Queensland Brain Tumour Bank at the Wesley Research Hospital to accelerate brain cancer research. <http://www.wesleyresearch.org.au/tissue/braintumourbank/>

Gliosarcoma Prevention

There is no known way of preventing the occurrence of the inherited form of the cancerous tumor as the exact causes that trigger the genetic mutation leading to the cell abnormality are unknown. Scientists are carrying out various researches and tests to find out whether it can be prevented.

The overall outlook for those diagnosed with gliosarcoma is not good. Although all brain tumors are potentially fatal, gliosarcoma has a very high instance of spreading to other parts of the body. It generally moves through the blood and can infect the lymph nodes, blood, liver, and other vital organs. Once metastasis occurs, the cancer is generally very hard to treat and it is often less responsive to medications.

Jeff and his wife Kelly work tirelessly to keep him healthy with a plant based diet, alternative therapies and a positive attitude. Between him and Kelly they have raised over \$20k for Cure Brain Cancer when they took part in the "Bridge to Brisbane" not long after Jeff finished radiation and that is a testament to the type of man that he is. MRI's are performed every 3 months and the stress from one set of test results to the other take their toll to say the least but Jeff is still defying the odds having now survived past the statistical or medium survival rate for this type of cancer and for that we are truly grateful. He now lives with epilepsy caused by the tumour which is a constant cause of distress. As a parent it is heartbreaking to know that there is little that you can do to assist and that you can't 'make it better'.

I submit this personal account and trust that vital funds are channelled into 'low survival rate' cancers so that research / trials / treatments can be afforded reliable funding to give those unfortunate enough to be afflicted by Brain Cancer and other low survival rate cancers, an equitable shot at survival. These low survival rate cancers need dedicated focus and funding to ensure survival rates change for the better & families and the community are not prematurely deprived of good people like our Jeff and to give us HOPE.

Yours sincerely

Judy Polkinghorne

(Mother of one of the most amazing young men this world will ever know. Jeffrey Owen Polkinghorne.)