

To The Senate Select Committee into Fundraising for Research into Low survival Cancers.

My name is Margaret Shonk,

I am making this submission in the hope that the government will allocate more funding towards brain cancer research.

Brain cancer is a rare disease but is responsible for the death of many children and adults under the age of forty years. About 1600 new cases are diagnosed in Australia every year. It currently has a very low recovery rate. Only one in five people diagnosed with a grade three tumour survive. If you are unlucky to have a grade four tumour then you are facing a life span of only a few months as virtually none of these people survive.

Unfortunately these statistics are my reality. In 2004 my husband Evan was diagnosed with a grade three tumour. Within eighteen months my brother Joe and my brother in law Peter, were diagnosed with grade four tumours. Fortunately Evan is alive today but my other relatives both died from this disease.

All of these men were fathers of young children at the time of their diagnosis. Between them they had nine children. Seven of these children were left fatherless. This disease effects the patient, the family, friends , co-workers and health workers. It hits you emotionally and financially. It steals childhoods, careers, one's future and hope. I cannot describe the stress inflicted on us all. I remember attending a seminar given by the Sydney Neuro Oncology Group (S.N.O.G.) after Evan's operation in 2004. They displayed a graph showing the survival rates of people with various cancers and how this had improved since the 1950s. The survival rates of women with breast cancer and Hodgkins Lymphoma patients had improved remarkably over the decades. The one cancer that showed virtually no improvement was brain cancer it certainly meets the criteria of this inquiry as a low survival cancer.

Brain cancer has received very little funding over the years. Until recently, there seemed to be very little publicity given to this disease. Other cancer groups such as breast cancer seemed to get the lion's share of publicity and funding. One reason given for this is the fact that so few people survive brain cancer. This means they are not around to push for funding it is left to their relatives. My partner Evan is an ambassador for S.N.O.G. He attends fundraising functions and is often a speaker on behalf of S.N.O.G.. Groups that research Brain cancer are largely self-funded and work tirelessly to raise sufficient funds to maintain research programs.

A second reason that brain cancer does not get the funding it should could be because of fear. There seems to be a stigma surrounding anything to do with mental health. It certainly isn't a glamour disease.

The cost of treating tumours is enormous, finding a way to prevent them or an early screening system would save the country millions of dollars.

The brain is still one of the last frontiers of science. There is still so much to learn about its functioning and health. Rather than ignoring the brain and labeling this area of research as being too hard, think of any money invested in brain tumour research as an investment in the future. This investment will open the doors to greater knowledge and ultimately will save lives.

Please underline brain cancer research as a priority when allocating research funding.

Thank you for considering this submission

Margaret Shonk