

Michelle Patterson

To the attention of the Select Committee into Funding for Research into Cancers with Low Survival Rate,

Firstly I wish to begin by thanking you for taking the time to read my submission. I also wish to apologise if it lacks the required structure, content or depth or if the tears I'm shedding while typing it show through a little more than they should. I honestly believe this is the most important thing I've ever written in my thirty years and I hope it will be received as such.

One year ago this week my beloved husband had a seizure while we were on holidays overseas. Long story short I was a long way from home alone with a husband now in hospital when a neurosurgeon showed me an MRI on a light box, pointed at a grey area on the scan and said 'see that, that's a brain tumor'. A medivac flight home and four days later my husband was in the hands of the wonderful Dr Terese Withers having a seven hour operation to remove the tumor. Several days later on our wedding anniversary the biopsy results came back and the curtain around the bed was pulled and a doctor sat on the end of the bed and said 'mate it's a high grade GBM and you've got around a year give or take'. After the shock set in I challenged the doctor and said hang on my husband's 40 (I'm 30 and he's a cradle snatcher), and he's fit and healthy how can you just say less than a year. I quickly learned the dismal statistics.

The doctor then began to explain the abysmal survival rates for his kind of cancer a Glioblastoma Multiform or GBM for short. Please excuse me if I'm telling you information you already know but this is the stuff that makes me angry and by god I'm angry. Less than one in ten people with a GBM survive to five years. This is compared to the nine out of ten people with breast cancer who make it to the same five year mark. According to the ABS brain cancer kills more children in Australia than any other disease and it is also the highest killer of people aged under 40 in Australia \* I'll never forget what the doctor said when we were talking about survival rates. He said 'brain cancer isn't a sexy cancer, people don't want to talk about it because the survival rates are so low and they're so low because we only get 5% of the total federal government cancer funding in Australia'.

When he was diagnosed we flew back into Australia on the Thursday and he was operated on first thing Tues morning. We didn't see an oncologist for weeks afterwards and the only information I had was what Dr Google told me. I threw myself into research. I understood the odds, the numbers and the facts but by God I wasn't going to let my husband die without a fight. I found one or two clinical trials but upon talking to our Oncologist I learned that we weren't

*\*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)*

*\*\* The Cost of Cancer NSW – report by Access Economics, Australia wide, April 2007.*

eligible for any of them because he'd had radiation and chemo by that stage. Talk about a catch 22. Have the treatment that will extend his life but then you can't go on a clinical trial to access what could be the drug that saves his life. Or the trial start in a few months... he'll probably be dead by then. Or that trials on the other side of the country and he can't fly. It just feels like a road block at every turn.

I understand the nature of clinical trials. I understand the regulations needed and the protocols that need to be in place but you have to understand that when you're working with a cancer that kills people in a few months from diagnosis red tape just isn't going to cut it. How are we going to get anywhere here if we can't even get onto a trial for the frustrating reasons I mentioned above? Something drastically needs to change here. We need more funding and more access to clinical trials. I'm sure you're aware that brain cancer costs more per patient than any other cancer because it is highly debilitating, affects people in their prime and often means people like myself have to give up work to care for them full time\*\*. Wouldn't it makes sense to put in increased focus on brain cancer, increase the funding needed to improve the survival rates and lessen the financial impact this cancer has on the economy? 5% of the federal government's cancer research funding just isn't enough.

In summing up, I'm staring down the barrel of being a widow at thirty and it's taken all of my strength but I've accepted it. Sometimes bad things happen to good people but the thing that I cannot and will not accept is that my husband's cancer 'isn't sexy' and he's going to die because of it. I find myself jealous of people's breast cancer or prostate cancer because their odds are better and that is absolute madness. They say the definition of insanity is doing the same thing over and over again and expecting a different result. If we want to get a better result for all the people with brain tumours but especially all the children and young people suffering with this cruel disease, let's do things differently. Please I implore you.

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