

Online submission to the PBAC regarding Avastin® (bevacizumab)

Submissions to be lodged by 13 February 2019 at:

http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form

Medicine: Avastin® (bevacizumab)

Date of PBAC register: March 2019

Submitted by:

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Declaration of interest:

My name is Annabelle Wilson, I am a widow and a single mother. My husband, FLTLT Joshua Mark Chalmers, served in the RAAF for 10 years. On ANZAC day in 2008, he returned from an eight-month deployment to Afghanistan. Two months later, he was diagnosed with brain cancer. Josh and I had 10 wonderful years together, and he passed away on the 25th of November 2017. Our daughter Primrose was born two-and-a-half months later, on the 13th of February 2018. She shares a birthday with her dad.

In my professional capacity I work for Cure Brain Cancer Foundation and in the past, I have worked as a radiotherapist at Peter MacCallum Cancer Centre. My primary role at Cure Brain Cancer Foundation is to advocate with, and on behalf of, the members of our incredible community. I am passionate about improving the health, well-being and quality of life of Australians living with brain cancer, so that no other family must go through what my family has.

Consumer input:

I wholeheartedly support the inclusion of the medication bevacizumab (marketing name Avastin®) to the Pharmaceutical Benefits Scheme (PBS) as I firmly believe that this will improve the lives of many people living with this insidious disease, as it did for Josh. Bevacizumab is a tumour-starving drug, which can halt tumour growth. Josh had several months of bevacizumab treatments and I believe that this prolonged both his length and quality of life. I strongly believe the provision of more affordable and accessible treatments will give other families this same benefit.

My family represents an example of the benefit of taking financial struggles out of the equation. Due to Josh's military service, his medical expenses were wholly covered by the Department of Veterans Affairs. As a result of this Josh was able to try a range of medications, including bevacizumab, without financial hardship. One of the most important elements in our brain cancer experience was a sense of control and focus. Bevacizumab gave us another option to try, and gave us more time together doing what we loved. For these reasons alone, this must be made a viable treatment option that every Australian with recurrent GBM has access to. Allowing families to trial drugs and try different options with no fear of the cost involved will greatly increase not only survival, but the peace of mind associated with the cancer journey. Ours is a situation that I strongly believe all Australian families deserve.

For families without financial support, bevacizumab can cost up to \$20,000. Considering that this treatment is usually provided as an option for patients once their tumour has recurred, or in the final stages of disease, this figure is a huge ask for families who have already experienced so much incapacitation, both physically and financially.

Although there are documented instances of significant side effects, Josh tolerated bevacizumab markedly well, as have many others who I've spoken with in the brain cancer community. I firmly believe that even though bevacizumab hasn't been shown to improve overall survival, it has been shown to increase progression-free survival. Every family deserves the right to try so that they can hopefully experience the increase in progression-free survival, as well as the improvement of quality of life that my family experienced.

Brain cancer kills more young people under 40 than any other cancer. These are young adults who are just getting started in life. They have just secured their dream job, or have bought their dream home. They have defended their country. They are studying a PHD full-time, or travelling the world following their passion. They have just got their licence and a brand new car. They have a young family, or are starting a family. I have seen so many of my friends achieve great things in the face of their own mortality and with fluctuating health. I think that we can all agree that, while this community is inspiring and courageous, they shouldn't have to face brain cancer on top of the challenges that all young people face.

Josh and I lived for 10 years with the knowledge that our forever wasn't guaranteed. Nobody should have to live with the knowledge that only 20% of people with brain cancer will survive past five years. There were 7,173 Australians living with brain cancer by the end of 2013. Most of these people had a glioblastoma (GBM), which is the most deadly form of the disease. Only 4.6% of Australians diagnosed with GBM will survive past five years. It is also extremely likely to recur, in which instance it is almost always fatal. Survival rates haven't improved in over 30 years.

Current treatments are largely ineffective and cause people living with this disease to live with debilitating side effects, significantly reducing quality of life for them, as well as their families. The reality of this is that a brain cancer diagnosis leaves many families without income, as most of our community are unable to retain employment due to these side effects. More often than not, one or more members of the family will also be unable to work as they take the role of caregiver. Add to that the cost of expensive treatments like Avastin, and it is clear how a brain cancer diagnosis can have a disastrous financial effect on Australian families.

I feel very strongly that families like mine should be able to access treatments without having to reach deep into their pockets. We have an incredibly generous community who donate their time and money to philanthropy and research. It is unfair to continue to expect young families like mine, alongside paying taxes and also funding research into possible treatment options and trials, to have to also pay to actually access these drugs that they financed the research for.

The per person loss productivity cost of brain cancer is higher than any other form of cancer, especially for young families. This also places higher burden on the Australian economy than any other form of cancer. A 2008-2009 study estimated the annual cost of brain cancer to the Australian health system alone was \$127 million, but the lifetime annual economic cost of brain cancer in Australia is estimated to be \$1 billion. Each incidence of brain cancer in Australia costs the economy roughly \$3 million per year, and this incidence is on the rise.

Bevacizumab has already been assessed for efficacy and safety and approved for use in recurrent GBM by the US Food and Drug Administration (FDA). I strongly feel that Australian families deserve the same affordable access as those living with brain cancer overseas. The Australian Government has an obligation to ease the overwhelming financial pressure, both for families, and the Australian economy as a whole, by providing our young families with more affordable treatments. Access to treatments such as Avastin, is an essential advancement to ease the health and economic pressure of a diagnosis improve lives of people living with brain cancer.

One of the reasons I decided to give up my work as a radiotherapist and focus solely on brain cancer (besides the obvious personal connection) is that I found that the inequities of the people that I treated were so vast. The level of government assistance, community support, treatment options and survival outcomes were completely different depending on where the tumour was located in the body. I found that very hard to comprehend.

People living with brain cancer have to learn very quickly, and as a result, we have an incredibly intelligent community. This, I'm sure, will be reflected in the calibre of the submissions and in the sophistication of the recommendations and suggestions from those living with this disease every day.

I appreciate you considering this treatment for inclusion on the PBS and I am grateful for the opportunity for myself and my community to let our voice be heard, and for the encouragement and respect given as we share our experiences.