

Chairman Burke, Vice-Chairman Huffman, Ranking Member Antonio, and all members of the Senate Health, Human Services, and Medicaid Committee: Thank you for giving me this opportunity to provide testimony in support of HB 230 which seeks to designate May as Brain Cancer Awareness Month for the State of Ohio

My name is Julie Wilson. I live in North Olmsted, OH. I am 36 years old and I am a widow. Three years ago I had a husband, a house, a career and a savings account. I lost all of those things to brain cancer. My husband, Travis, died on February 6th, 2019, 28 months after being diagnosed with glioblastoma. Travis lived his life in service of others dedicating his career to preserving and protecting our natural resources. He was a civil servant with the United States Forest Service, a volunteer EMT, a wildland firefighter, and the kind of guy who would pull over to pick up a discarded bottle or can from the side of the road. As a brain cancer patient he became an advocate for people like himself. Knowing his time would be limited by this disease he focused his efforts on helping others. He completed two marathons post-diagnosis (one under his own power and one being pushed in a wheelchair by his friends and family), and raised over \$50,000 for brain tumor research in the process.

The fact that Travis lived for 28 months post-diagnosis means that statistically he's a brain cancer success story, given that the median survival among glioblastoma patients is around 14 months. He was lucky to experience a significant period of good health as the majority of GBM patients often become disabled soon after diagnosis, and generally require significant personal care at a level that can be emotionally and financially devastating for the person's family. Approximately 13 months after

diagnosis Travis became permanently disabled and not long after I left my job to care for him full time. We lost 75% of our income seemingly over night, and had to rely on Social Security Disability and the generosity of family and friends to cover his mounting medical bills and our other daily expenses. Even though we were better prepared for a disaster than many people are, and although we had a lot of advantages that others don't have, our lives were completely turned upside down.

Since brain cancer is relatively rare in comparison to other cancers, we were in many ways left to our own devices to find resources that could help us understand the gravity of our situation, and to help keep us afloat as the disease progressed. I learned to navigate clinical trial databases and made cold calls to major cancer institutes. I researched grant programs and financial resources specifically for brain tumor patients. I became an expert at writing and submitting insurance appeals, and I found an online community of wives and widows who helped me to realistically manage my expectations and prepare for what was ahead. Having these resources at our finger tips would have dramatically improved our quality of life, but we were truly unaware of what was out there. For today's patients, awareness is vital to ensure access to everything needed to make adequate decisions about treatment and care, and to make sure that families don't feel alone in those earliest days. Awareness events and activities give individual advocates and advocacy organizations a platform to spread and disseminate this information, getting it into the right hands quickly and efficiently.

For tomorrow's patients awareness is about hope. The Ice Bucket Challenge was about raising awareness. From that awareness grew a movement that netted millions of dollars for ALS research which in turn has led to a broader knowledge base about the disease, and is accelerating the march towards viable treatment options for patients worldwide. Since 1985, when October was first declared breast cancer awareness month, the pink wave has swept the nation with the backing of retailers, every major sports team, and government officials like yourselves. And in that time rates of progression free and overall survival among breast cancer patients have improved dramatically. They are living longer and living better because awareness turned to action, and action has brought about real change in prevention, early detection and treatment for those who are diagnosed with breast cancer.

It's exactly this kind of change the brain tumor community needs after decades without any significant improvement in the survivability of the deadliest and most common forms of the disease.

Because of Travis there are hundreds, perhaps even thousands of people who are more aware of the devastating impact that brain cancer can have on an individual and their family. He put himself out there, told his story, and with his relatively limited platform and the brief window of good health that he enjoyed during treatment, raised awareness in a way that inspired his community to give their time and resources to support research and patient programs.

Travis never asked to be a champion for this cause, but that's how these movements generally begin. They begin with Brad, a 27 year old Army veteran and father of three from Loveland, OH whose wife spent last summer planning a funeral instead of a family vacation. They begin with Deany, a forever 7 year old from Pickerington, OH, whose mother had to suffer through the experience of picking out a small green casket for her son. And they begin with Liliana, a forever 7 year old from Elyria, OH whose family was still holding out hope for more good days with their little girl when I testified before the house subcommittee last year, but who died this past February only 9 months after her initial brain cancer diagnosis.

And, unfortunately, without the help of those who have the means to advance awareness beyond our small communities, these movements also tend to end with Travis, Brad, Deany & Liliana. Awareness before brain cancer strikes can make a world of difference: it can mean more understanding, more resources, more research, and in time real change.