



**House Bill 230  
Proponent Testimony  
Jenna Heilman  
Head for the Cure, Executive Director  
November 5<sup>th</sup>, 2019**

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.

As Executive Director of the Head for the Cure Foundation, I've had the absolute honor of leading the fight to build awareness, raise funds and ignite hope for all who have been faced with brain cancer. I had the privilege of presenting Representative Crossman's mom, Rose, with the Keeping the Faith recognition at our Cleveland 5k two years ago. During her battle, Rose inspired so many around her because her generosity, empathy, passion for life and tenacity. The fact that she is still inspiring loved ones to act on her behalf, which in turn inspired the community in Ohio to join in this movement, is a true testament to what one person's journey can mean to so many.

Cancer, in general, is a word that finds its ways into too many conversations because we all know someone who has been diagnosed. There have been many advances across the board to help raise awareness and ultimately funding to find real treatments for most types of cancer over the past several decades. Most notably, breast cancer has had an immense presence nationally since the late 1980's and has had tremendous support and calls to action to help in honor of the thousands of people who are diagnosed each year. Because of these efforts, the mortality rate of breast cancer patients dramatically decreased by 39% from 1989 to 2015, according to the American Cancer Society. The need for a similar movement is ever-present in order to defeat brain cancer.

Unlike other types of cancer, brain cancer is an incredibly elusive disease, and the statistics have remained constant, if not worsened each year. According to the American Brain Tumor Society and Children's Brain Tumor Project, there will be an estimated 80,000 new patients diagnosed in 2019 alone, the median survival rate for glioblastoma is still 14-16 months; and 28,000 children are currently fighting brain cancer. Brain Cancer can also affect anyone, at any time, at any place. It does not discriminate, and there is no behavior known to cause or prevent the disease.

What makes brain cancer challenging to battle is that each person's brain is mapped completely differently from the next. Brain tumors are also unique with their own make up. Because of the rarity, the success rates of new treatments to combat these tumors is extremely challenging and expensive for all parties involved. Currently, there are only 4 FDA approved drugs and 1 device approved to treat ALL 120 different types of brain tumors. That is simply not sufficient to improve the survival rate of those diagnosed.

All of those statistical reasons are scary enough until you see the faces and hear the stories of those who are affected by this diagnosis. These parents, grandparents, children, friends and loved ones will never be the same, even after treatment is complete. Going through multiple brain surgeries, radiation, chemotherapy and other treatments commonly cause life-altering cognitive challenges. Those range from loss of speech, site, memory and mobility to name a few. But, their fight for survival still goes on.

Designating May Brain Cancer Awareness Month in Ohio is one step in the right direction to raise awareness why the need to defeat this disease is so crucial. May is already acknowledged widely by the brain tumor community including Head for the Cure Foundation, American Brian Tumor Association, National Brain Tumor Association, End Brain Cancer, International Brain Tumor Association, The Musella Foundation and many more. What's more, other states have also moved forward this designation, like Michigan this past year. There was also the adoption this past summer of a national day of awareness for glioblastoma patients championed by Senators Graham and Warren. Supporting this month officially in the state of Ohio would support the other efforts already established nationally.

It's not acceptable to simply say that a brain cancer diagnosis is a death sentence as it has been in the past. Ignoring this cause and call to action is succumbing to that sentiment. At Head for the Cure, we continue to ignite the hope to fight this disease... the hope for a cure, hope to see tomorrow and hope that those affected are not fighting alone. This is the next step in providing that hope not only for patients in Ohio, but nationally as well.

I wanted to leave you with these parting thoughts. When we asked neuro-oncologist Dr. Sarah Taylor about why people are so terrified with a brain tumor diagnosis and the thought of having surgery, she said, "Because the brain is where the sole lives." The brain is what makes us who we are as a human being, our sense of humor, attitude, mechanics and personality, and this disease can quickly alter everything about who we are while facing the ultimate reality of mortality.

Members of the committee thanks for your times and consideration.

Sincerely,

A handwritten signature in cursive script that reads "Jenna Heilman".

Jenna Heilman  
Executive Director  
Head for the Cure