# Camp Kesem BSU Make the Magic 2019

For this year’s annual gala, Make the Magic 2019, I was invited to share our family’s story. Thank you, CK at BSU, for your love and care.

April 13, 2019 By Adam Hayden

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Our family has been uplifted in so many ways by our experience with our Camp Kesem local chapter at Ball State University. Camp Kesem is a week-long summer camp for children whose parents or guardians have been affected by cancer. CK supports kids “through and beyond a parent’s cancer.” The camp is provided at no cost to eligible children, supported by the generous donations of their national network. For this year’s annual gala, Make the Magic 2019, I was invited to share our family’s story. I delivered the following remarks on Saturday, April 13, 2019. Please consider a donation by following the link. Thank you, CK at BSU, for your love and care. xoxo

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Glioblastoma. An aggressive brain cancer with a five-year survival rate of 5-8%. Abbreviated usually to its medical moniker, GBM, this cancer is so-far incurable, and sadly, treatment options are strikingly limited: only three new chemotherapeutic agents have been approved for the treatment of GBM in the past 30 years. The disease presents with a host of neurological disorders: seizures, called “tumor-associated epilepsy,” severe headaches, memory loss, confusion, often personality changes, and depending on the location of the tumor in the patient’s brain, the size of the tumor, and the side effects from surgery and radiation, other impairments can develop, for example, my left-sided sensory and motor impairment, which affects my balance, and my sense of where my body is in space, a sense called “proprioception.” This proprioceptive impairment is like a blind spot on your car’s rearview mirror. This explains why I constantly run into door frames or furniture and the one awkward time I unwittingly stood too close to a woman old enough to my grandmother in the deli line. “I thought you were my husband!” she exclaimed when I brushed against her. I was surprised as she was.

GBM is thankfully rare, affecting only three people in 100,000. When I was diagnosed in June 2016, I was 34 years old. The average age of diagnosis for GBM is 56. Our family faced a rare, life-limiting disease, and in this rare population, I fell into a smaller sub-group, 20 years younger than the average patient. For other parents or guardians diagnosed with GBM, if they fall into the average patient profile, that could mean another two decades for their children to age. Our youngest, Gideon, was only eight months old, when we received my diagnosis. Noah, two, who gave himself his camper name at the Friends and Family reunion this Spring, “Green Bean,” and our “Cheese Pizza,” who is our first camper to join the CK family was four. For our family, common to many families affected by brain cancers, educational resources are few. For a family with very young children like ours, there are practically no resources for educational tools or books. I recall our family therapist being so excited to give me a book about talking to kids about a parent’s cancer she picked up at a local meeting of this or that society. Thumbing the pages, my enthusiasm dimmed when I read, “Doctors are the good guys and can wipe out the bad guy cancer!” Not only am I not a fan of this oppositional good guy-bad guy trope, the doctors told us that I had a cancer that they couldn’t “wipe out.” Of course, the grimness of this reality is not limited to brain cancer. Breast, lung, melanoma, pancreatic, our lives are threatened by the primary cancer, and if manageable in the near term, for our entire lives the threat of “mets,” or metastasis, looms large.

This is not the end of the story, but the start of something new. Us parents and guardians diagnosed with cancer and our loved ones understand in the fear and uncertainty, we may also find tremendous joy. A source of that joy for me and Whitney are our children, the “Hayden Hooligans,” as our favorite preschool teacher dubbed them. Whitney and I shared the difficult news of my diagnosis with Isaac by treating him like a partner in my care. We empower our kids through our vulnerability. Cheese Pizza, “Cheesey,” is a smart guy. We practice seizure drills with him to know what to do if I lose consciousness while Whitney is at work. We ask our kids to help dad get a blanket and glass of water on bad days. Isaac’s school recently had a “Senior Citizens Day” for spirit week, and he used one of my adjustable canes to complement his outfit. He shuffled around the house saying, “I’m an old man.” (This is sort of a dig on me, because hey, it’s my cane, and I’m not an old man!) I joked with Isaac, “How cool, I bet the other dads don’t have canes for their kids to borrow!”

The first step in my treatment was surgery. A brain surgery called a craniotomy. My operation was an awake procedure allowing me to interact with my surgeon and follow commands. My 7cm tumor—about the diameter of a baseball—pressed and invaded my sensory motor cortex, in the right parietal lobe of my brain. I was kept awake to allow the surgeon to carefully “map” the functional areas of my brain, while removing cancerous tumor. During the operation we reached a decision point when the surgeon said to me, “it is difficult to see the ‘margins’ between tumor and healthy tissue. I can continue to remove tumor, at the risk of permanent left-sided paralysis, or we can end the procedure now, leaving tumor remaining.” After brief discussion, I replied, “I have three young kids. Permanent paralysis is not compatible with rolling around on the floor and playing with my kids. Let’s stop the operation now.” Making difficult decisions with our kids in mind is a responsibility parents and guardians with cancer know too well.

Adults are fortunate to have access to support groups, therapists, books, and often faith-based communities to process our complicated emotions. These resources are not so readily available for kids. Camp Kesem, as their mission and purpose states, “is there for children through and beyond a parent’s cancer.” Nervously approaching the campgrounds last summer on the last day of camp, Whitney and I prepared to pick up a sobbing mess of a Cheese Pizza. It was his first sleep-away camp and one of the few times Whitney and I left one of our kids for more than a long weekend.

Instead, Cheesey ran over, offered a half-hug, and sprinted back to GaGa Ball. On the hour car trip home Whitney and I could barely get a word in between Isaac yelling, “Heeeeeey Burrito!” He told us all about camp and how he plans to be a counselor when he’s too old to be a camper. Tonight, we make the magic, and we do it for our kids, our source of joy in the darkness of cancer. Let’s give generously to spread this light.

This post originally appeared on Glioblastology on April 13, 2019. It is republished with permission.

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