

The Luminous Fund Sponsors the 2020 #TumorTakedownTailgate to Benefit National Brain Tumor Society

By Adam Hayden



Employees, contractors, clients, and c-suite leaders gathered around the elevator bay in the lobby of the tall building where our team was deployed across two floors to support the “legacy” operators prepare for a transition to a new health information system. It was Monday morning, and building tenants scrolled their phones, gripped their coffee for dear life, and squeezed into the several elevators servicing the twenty floors in the office tower.

The jargon for this work is “design, delivery, and implementation,” but the real work includes subject matter expertise, business process enthusiasm, and, if we’re being honest, moral support.

I joined Brilljent in 2015, fresh out of grad school, earning a master’s in philosophy, but already under my belt was nearly ten years of progressive responsibilities at Starbucks Coffee Company, where my journey into learning and development began as a trainer for newly hired retail store managers. My next step was an organizational change management certification when I joined the team to implement a new dashboard reporting structure for retail stores. I then worked for several years in the role of training consultant reporting to regional business leaders for their professional development and training within their regions to decrease turnover while

increasing operational excellence. I left the organization as a “workforce analyst.” This was a new position, on a new team, in a newly organized enterprise after several reductions in force through the recession years beginning in 2008.

In my final role I became distanced from the daily consulting I enjoyed that connected my skillset to driving tangible results, and I stepped away to pursue graduate school—really, to find a rewarding use for my passion: teaching, learning, asking big questions, and working one-to-one with learners.

I embraced my role at Brilljent with enthusiasm. The team assigned to our contract would work side-by-side with operators to understand their work and processes, to learn the new system for ourselves, and in so doing, to learn how best to support operations training and implementation for this seismic shift in technology and standard operating procedures.

Loading into the elevator that Monday morning, one of my colleagues entered a few steps behind me. We began chatting about the upcoming client meeting.

That’s when it happened.

A frightening episode that was becoming all too familiar: a tingling began at the base of my skull and wrapped around my head. The strange pins and needles then traveled down the left side of my body, and I began to feel dizzy. I casually stepped toward the back wall of the elevator car, and I gripped the decorative rail. Dizzy, lightheaded, with the left-side of my body becoming weak, I did my best to stay engaged with my coworker, but I was gripped by fear and partial loss of motor control.

This episode was one of countless others that increased in frequency, duration, and intensity throughout 2015, into the Spring of 2016. In May of that year, I suffered the worse episode yet, while driving home from this same office tower. Aware of the risk to myself and others, I knew it was time to do something other than chase down these mysterious symptoms with specialists and really get to the bottom of things with my GP. After pressing the outpatient family medicine clinic for an urgent appointment, my doc administered an extensive neurological exam. Ultimately, she would order me to an MRI.

“STAT!”

I would leave my morning appointment and stop by home before showing up for my noon MRI.

An MRI is a special imaging scan, or procedure, to peer into our bodies, and in my case, into my brain.

I sent an email to our team that morning noting that I had one more appointment, and naively, I concluded the note by saying, “I’ll be back online by 3:30 at the latest, I’m sure.” I then put my healthcare knowledge to work, and I telephoned our insurance provider to ask whether a prior

authorization is required for the procedure! In a strange cosmic coincidence, the work I did professionally came to my aid personally.

That MRI revealed a seven-centimeter primary brain tumor. Seven centimeters is roughly the diameter of a baseball! The episodes were undiagnosed seizures, and I would be scheduled for an *awake* brain surgery the Thursday of the following week. After surgery, my wife, Whitney, and I received the diagnosis: the aggressive and incurable brain cancer, glioblastoma, or “GBM.” This is the cancer that Senator John McCain would be diagnosed with a year later in 2017 and the same cancer that would take his life a year after that.

After discharge from the hospital where my surgery was performed, I was admitted to an inpatient rehabilitation hospital where I would relearn to walk, to bathe myself, to feed myself, and develop the strength to safely lift our youngest, eight months old at the time.

My knack for writing, speaking, and sharing information with others showed up several months after diagnosis, when I addressed a gathering of 250 friends, family, and community partners in March 2017. There was clear interest in hearing the story of incurable brain cancer from an unlikely source: a 34-year-old dad and husband.

Whitney and I brainstormed how we could use our platform for good, and one year later, in 2018, we launched the #TumorTakedownTailgate, an annual fundraiser to benefit National Brain Tumor Society (NBTS). Our name comes from the hashtag my wife and I, Adam and Whitney, or “A&W,” use across social media to share our story: #AandWTumorTakedown.

National Brain Tumor Society is the largest non-governmental, non-profit funding organization for brain cancer research in the United States. NBTS has a special program called the Defeat GBM Research Collaborative began in 2014 that pledged an initial five-year, ten-million-dollar commitment to glioblastoma research. This collaborative is unique in the world of scientific research funding. Rather than award funds to individual researchers or labs, Defeat GBM awards grants to “collaboratives”: joint researchers working together across labs and institutions to build on each researcher’s specialty. Our annual fundraiser directs our efforts toward this ongoing initiative. You can read last year’s Defeat GBM annual report [here](#).

Met with early success, our small, but mighty fundraiser racked up \$16,000 in our first year, but we knew we could do more! We grew to \$22,000 in our second year, and we gladly welcomed The Luminous Fund as a Silver sponsor. Preparing for our third year, the #TumorTakedownTailgate has set its goal for \$25,000, and giving us a huge boost toward meeting this ambitious goal, The Luminous Fund increased their sponsorship level to Gold sponsor for the 2020 Tailgate.

Brain tumors are considered a “rare disease,” and by the stats, that’s true compared to the incidence rate of other cancer types, but while rare in incidence, the size and scope of the devastation for brain tumors are substantial. Unlike cancers in other parts of the body, brain tumors come with a host of neurological symptoms: seizures, cognitive deficits, physical

impairment, language deficits, personality changes, and trouble with memory are a few of the common symptoms.

There are close to 700,000 people living with a brain tumor in the United States, and 80,000 more people are newly diagnosed with a brain tumor each year (Figure 1). That's enough newly diagnosed folks to fill Lucas Oil Stadium every year, the home of the Indianapolis Colts, near Adam and Whitney's house. Imagine the scale of loss for this disease that has a five-year survival rate for all malignant brain tumors of only 35%. Looking specifically at glioblastoma, my brain cancer, the five-year survival rate drops to a staggering 6%. At my eighteen-month follow-up with my radiation oncologist, he congratulated me for becoming a "long term survivor."

At 35 years old.

Thank you to The Luminous Fund for helping us extend and enhance the lives of people like me and our families, including Whitney, and our three boys, Isaac, Noah, and Gideon. Whitney and I have dedicated ourselves to raising awareness and research dollars to improve treatments for brain tumors and to ultimately discover a cure. If you'd like to support, your tax-deductible donation can be made at our dedicated event [donation page](#). Thank you to Briljent for standing by our family through our three-and-a-half year journey with brain cancer, and thank you to The Luminous Fund for your generous support.

Living our Briljent organizational values, or "non-negotiables," I pledge to [Never, Never, Never Give up](#).

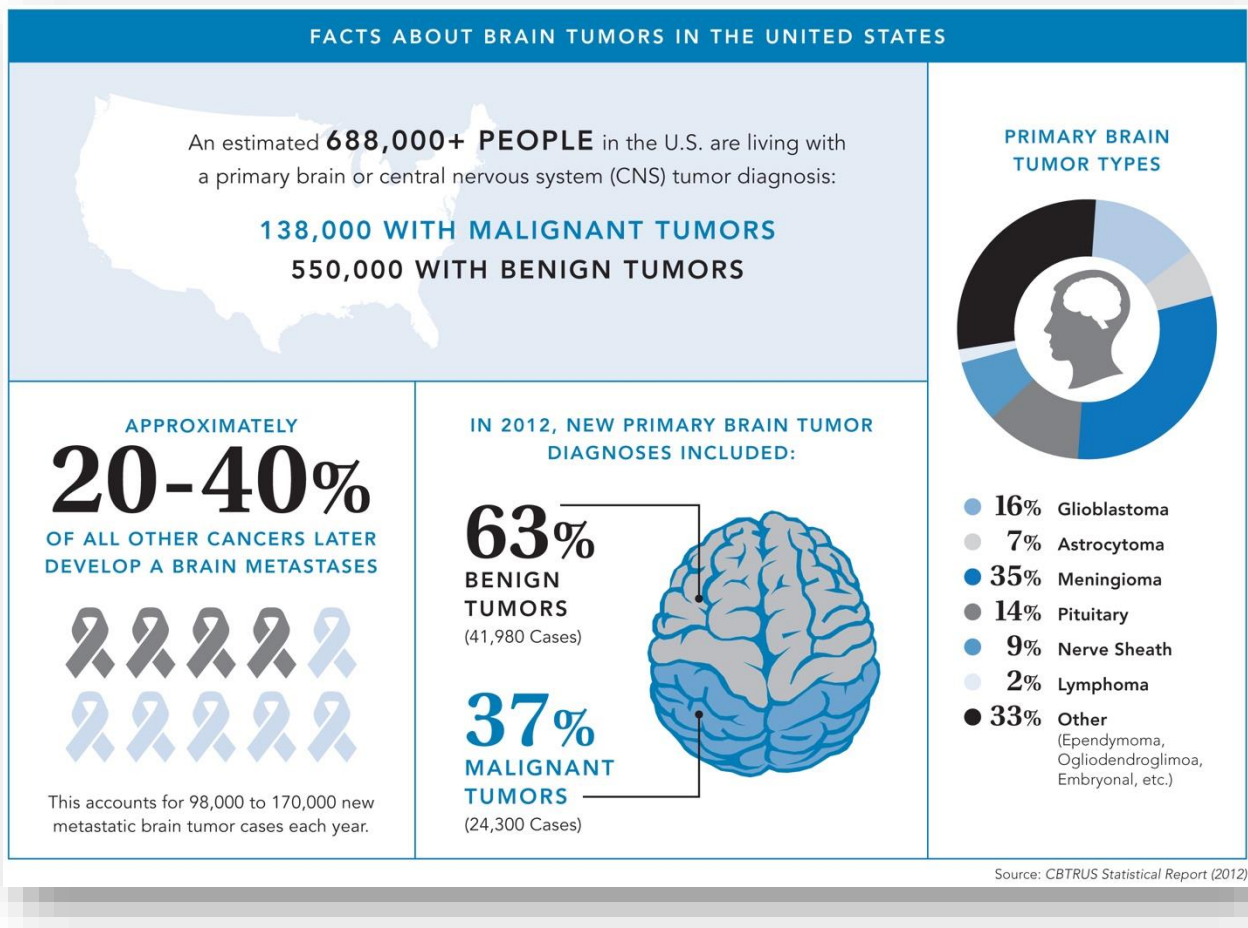


Figure 1: Brain Tumor Facts in the United States