Glioblast-OMG: What Is GBM, Anyway? Part I

I am a smart guy, who reads, who wants to live as long as possible, and I view myself as active in my own self-care and treatment.

October 9, 2016 By Adam Hayden

In Part I, I'll share with you the journey that led to my GBM diagnosis (dx). In Part II I will share more information about what GBM actually is.

When an MRI scan revealed a 71mm primary brain tumor on May 13, 2016 (more background on the About page), my PCP called Whitney and me into her office. Together, we read the radiology report. You know the expression, it's all Greek to me? Well it was, but for those who know me, you know that I'm a head-first, dive-in, full-commit student of topics that pique my interest. A baseball-sized tumor in my brain was an interest-piqueing phenomenon. At this early stage, though—that is, on 5/13/16, armed only with the radiology report, the pathology still a mystery, my appetite for knowledge would have to wait for more substantive medical information. That next piece of the portrait was painted by my talented neurosurgeons, affiliated with IU Health and Goodman Campbell Brain and Spine. Drs. Troy Payner and Aaron Cohen-Gadol. Drs. Payner and Cohen, with the assistance of resident Dr. Bracha, and an incredible anesthesiologist and OR team performed an awake craniotomy and surgical resection on May 26, 2016 (two weeks out from MRI).

Likely there is medical nuance I neglect, but I'll use the following terms somewhat interchangeably: resection, craniotomy (cranio), or debulking surgery—surgery with the intent to resect/remove the maximum amount of tumor, while protecting the maximum amount of healthy brain tissue. A cranio is the first step in standard of care (SOC—remember that acronym, I'll use it frequently) for treating primary brain tumors. The cranio was performed while the patient was awake—oh, the patient, that's me! Dr. Payner's decision, with the support of his colleagues, to perform the procedure while I was kept awake was to functionally map eloquent cortex functions (sensory and motor), while resecting tumor. The goal of this procedure is to aggressively remove tumor and leave the patient's quality of life in-tact, to the extent it is possible.

Aside.

I went to grad school for philosophy, and I cannot tell you how excited my friends and faculty were to hear that a fellow philosopher would undergo awake brain surgery. I can finally put to bed the question whether we are living in the Matrix! On that cliffhanger, let's save the awake brain

surgery story for a future post.

Before retiring this brief aside concerning surgery, I will say, and I say it every chance I get, my neurosurgeons are absolutely gifted, and I am in their debt for balancing aggressive tumor removal, with protection of my sensory and motor function. Drs. Payner and Cohen successfully performed a gross total resection (GTR—another acronym), meaning >90% tumor resection. Patient outcomes—overall survival (OS), is greatly improved by a GTR vs. partial resection. My surgeons' skills have added time to my life, more time with my wife, more time with my kids. Thank you to my entire medical team.

Seriously. More on the cranio in future posts. I can't wait to tell you about being awake for my own brain surgery.

Back to the narrative.

OK! The resection gave my medical team tumor tissue to perform the biopsy and generate the pathology report. (We opted not to biopsy the tumor pre-op because the damned thing was so big, it was coming out, no matter what it turned out to be.)

Post-op I was inpatient at the operating hospital for some time prior to moving to an acute rehab facility, where I continued to be inpatient, working with a neuro-specific physiatrist and OT/PT team to recover lost function resulting from brain injuries caused during surgery—even successful surgery requires rehab and recovery. It is of note that my acute rehab facility included my residency in a locked brain injury unit. (More fodder for future posts.) On June 10, 2016 (four weeks out from MRI; two weeks out from surgery), Whitney and I caught a wheelchair-accessible ride to the IU Neuroscience building in downtown Indianapolis to hear the official diagnosis.

Tough diagnosis.

Glioblastoma multiforme (GBM): the most common and aggressive form of primary brain tumor. The cause of GBM is unknown. GBM develops either from a lower grade astrocytoma or as a mutation from healthy brain tissue. Tease, tease, tease, I must say that mutating cells reflects the current dogmatic view in cancer research that cancer is a genetic mutation. Research dating to at least the 1920s suggests that rather than genetic, a metabolic origin may be at work in the development of some forms of cancer. I hope you're as excited to read the posts I'll have on this topic, as I am to share them with you. My post-dx transition to a calorie restricted ketogenic diet is a lifestyle change I have embraced to take an active role in my own treatment. Nutritional supplements or diet changes are not SOC, they are not FDA approved, and if you ask the medical community, research does not support the efficacy of such metabolic or nutritional resolutions for cancer. That said, clinical trials are underway. This topic (therapeutic ketosis) will be a feature of my blog. Plenty more to come.

I must say unequivocally, loud and clear, please hear me: I am not a trained medical professional. I am a smart guy, who reads, who wants to live as long as possible, and I view myself as active in my own self-care and treatment. I trust my doctors. I have followed and will continue to follow

SOC. I am wearing the Optune device. Big pharma is not out to hide the cure to cancer. My disagreements with SOC, where they appear to be disagreements, at any rate, are avenues of research for me because I want to beat the statistics. Please know that the blog you are reading is my first step toward documenting my battle with GBM. Let those things that work and those things that fail play out here so that when my case study is written there is primary source material available.

Recall I said the radiology report was all Greek to me. So was the pathology report. But here the Greek can help us. Glioblastoma, from the Greek glial, affects the “glue” of the brain—non-neuronal cells. This is what makes GBM so hard to fight: It moves about the cabin of the brain, with no regard for the fasten seatbelt sign. Hey, GBM, you’re in my seat, causing edema, seizures, possible personality changes, unconsciousness, and other such problematic symptoms. By the numbers patients see 12-15 months of survival post-dx. Approximately 3-5% of the diagnosed population is with us 5 years out from dx. These are statistics, folks, and just because 3 out of 5 dentists recommend Crest, Colgate is still doing fine. (God, I hope Colgate didn’t just go out of business.)

This is where I will leave things for now. In Part II, I will say more about glial cells—astrocytes, oligodendrocytes, and share how my neuro-oncologist (NO) thinks my GBM developed.

I would love to hear what questions, thoughts, ideas, or topics you’d like to hear more about. Tweet me, comment here, or drop an email.

Keep learning. Keep fighting.

Cheers —AH

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