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Glioblastology: 2019 in Review

I’m out to leave a legacy for them and to hopefully improve the world for my brain tumor community.

December 27, 2019 By Adam Hayden

“How do you live, when you know your time is limited?”

This is the question that I faced, beginning in the summer of 2016, after being diagnosed with brain cancer. It is the question we have faced, Whitney and I, in our marriage, and it challenges how I spend my time as a parent. It is the question just beneath the surface of every interaction with family, friends, and work colleagues. This is the question I have in mind during each required call, email, form, and document submitted to fulfill the clerical and administrative responsibilities of a person receiving disability benefits. It is the question that leads me to second-guess the decisions that I have made this year. But it is also the question that prompted a successful year of new accomplishments.

In 2019, I answered this question with one word: purpose.

How do you live, when you know your time is limited?” You live with purpose. And this answer presupposes that you’ve done a little personal heavy-lifting to discern just what that purpose is in your life. In this way, my life is just like yours, purpose-driven living is an integral part of a meaningful life. But I also remain committed to the idea that while relatable, serious illness is not “I could get hit by a bus” rhetoric. Folks do not wake up each day with a bus on their mind. Folks are not reminded every few weeks of the bus by another friend facing cancer recurrence or an acquaintance entering hospice.

So that is the salient difference: we all make sacrifices to pursue our goals, and we all live with uncertainty; we are all grateful for a spouse, partner, or companion whom supports us. Our lives are fulfilled when we face challenges and achieve new milestones, but we shouldn’t lose sight of the opportunity costs, and for me, I feel the pressure of high stakes. So I pause to take stock this holiday season to share proud moments from this year, and I thank my wife, our family, and our supportive community for enabling my busy year of travel, writing, and speaking.

In community, a.

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The year began with several collaborative projects. In January, I partnered with *Cancer Health* to contribute to their “Cancer Diary” series, with this “Brain Cancer Diary.” I was interviewed by Kimberly Paul for her *Death by Design* podcast, an interview that would air during season three of the podcast, in August of 2019. February brought continued involvement with the Brain Cancer Quality of Life Collaborative, a multidisciplinary research network investigating palliative care intervention in brain cancer. And I joined the project advisory council for the Count Me In Brain Cancer Project. I also guest spoke in a Bioethics course, where I am a regular fixture, with IU School of Medicine. I was proud to see my book review of *Neuroexistentialism* published with *Polyphony: Conversations Across the Medical Humanities*.

In Spring of this year, with Whitney, our best friend Lindsay, and Revery chef/owner Mark Henrichs, we raised over $21,000 to benefit National Brain Tumor Society in our second annual #TumorTakedownTailgate, bringing our total after two years of the event to $37,000 (Stay tuned for details for this year’s 2020 event!) In May we celebrated with our NBTS family when Whitney and I attended our third Washington D.C. advocacy day, Head to the Hill. At this year’s Head to the Hill event I joined my friend Liz Salmi to give remarks in support of the Palliative Care and Hospice Education and Training Act (PCHETA), a piece of legislation that now sits in the Senate for passage. My co-facilitator Lisa O’Leary and I also announced the start of the first ever National Brain Tumor Society Virtual Support Conversations, a monthly, virtual, peer-to-peer support network for the brain tumor community.

Also in the spring of this year, I was honored to give remarks with our camper “Cheese Pizza” at the 2019 Camp Kesem Ball State Make the Magic gala. You can read my remarks here. In this same spirit, my friend and scholarship founding donor, Jack Hope, awarded the second Adam Hayden Philosophy Scholarship to a deserving student in the School of LIberal Arts at IUPUI.

My summer began with a trip to Chicago where I served on a panel moderated by my friend and End Well Foundation founder, Shoshana Ungerleider, MD, hosted by MATTER Health, discussing aging in the digital age. MATTER wrote up a great post about the event. The summer continued with the first ever Glioblastoma Awareness Day. In August I facilitated a “lunch and learn” session for my employer Briljent, enabling patient-centered care in Health Information Technology sectors.

This Fall has been the busiest one yet, and I couldn’t have made it through without my parents and in-laws providing tons of overnight childcare, and Whitney guiding me through travel as I struggled with fatigue and seizures. In September I guest spoke in another IU School of Medicine elective course where I visit annually called, “Issues and Advocacy in Medicine.” I gave an Ignite! Talk at Stanford University’s Medicine X conference, and I was on the road again in October where I gave a grand rounds talk to the neurology service at Saint Louis University hospital, and I facilitated a breakfast roundtable discussion with the SLU bioethics PhD candidates, faculty, and staff.

I was proud to see my second invited review published with the prestigious magazine, Science. I reviewed a great book on the ethics of gene editing called Altered Inheritance.

In November I organized a film screening and panel discussion of the Oscar-nominated documentary End Game, and I served my third year as a patient-reviewer for the Peer Reviewed Cancer Research Program, a grant funding organization within the Department of Defense. I also traveled to D.C where I gave remarks to researchers, clinicians, industry, and the FDA at a “research roundtable” organized by NBTS.

This year capped off with my highest profile talk, and one that I’ve dreamed of giving since shortly after my diagnosis: the End Well Symposium, in San Francisco. With 650 attendees in the theater and 2,000 viewers of the livestream, I was honored to share my message about “Living while Dying” with a broad and diverse audience. (Stay tuned for a video!)

And that concludes the round-up of my biggest accomplishments in 2019. Between trips and talks I tried to take care of my body. Each week on the road, takes two or three to recover, and headaches, seizures, fatigue, and bouts of nausea are mainstays, but drawing from Whitney’s strength and seeing the joy and energy in our kids’ eyes, I’m out to leave a legacy for them and to hopefully improve the world for my brain tumor community.

Cheers to 2020! I have some big things planned, and I cannot wait to share them with you!

This post originally appeared on Glioblastology on December 27, 2019. It is republished with permission.
