I’m Telling You for the Last Time

You can’t live with brain cancer and stay safe, so let’s take risks.

March 1, 2022 By Adam Hayden

Sometime in the early 2000’s I was in a Ford Aerostar with four other dudes, touring the midwest and East Coast. The band on tour with us tipped us off to the solution for long drives: Stand-up comedy albums (pre-podcast days). In the handful of CDs (cassettes?) they loaned us: Seinfeld’s 1998, I’m Telling You for the Last Time.

I’m sure as shit no Seinfeld, but that idea tucked itself into my pocket and rode along for the past couple decades. Burn out before you fade away type shit. Now it’s my turn.

I’m telling you for the last time.

Five years of material, and it’s time to let go. You may know some of it; I hope you do. Anyway:

I’m telling you for the last time.

The healthcare system strips patients of their personhood and observes the body with a clinical gaze that pays no mind to our identities and certainly not our distress. In fleeting moments of restorative justice amidst toning alarms and proning patients, a healer catches your eyes in theirs and you are seen.

But mostly it’s wristbands and gowns, murmurs outside your inpatient door, and rounding physicians so busy they carry their sealed tupperware lunches into the room to take a look at your incision.

It’s not the doctors, it’s the system, and when we see each other, doctors and patients, the admins are in trouble. May it be soon.

I’m telling you for the last time.

We can learn so much about patients without even meeting them (us). But to know a disease is not to know the person who has it. And we’re rich on data but short on humanity.

I’m telling you for the last time.

I don’t care about your language: I learned only the jargon so that you would hear me. Maybe it’s time to use ours: we speak in experience and emotion.

I’m telling you for the last time.

I’ll dismiss your suggestion that I wait for our visit to hear the results: I’ll read the test report when it’s posted, because it’s my data; my body. I don’t need your paternalism, I need your partnership.

I’m telling you for the last time.

I don’t care what you think about Dr. Google: I read everything I can because it’s my life, and I won’t allow your distrust or skepticism of my capacity to absorb medical information stand in the way of pursuing my care as an equal member of the team.

I’m telling you for the last time.

You don’t know who I am in a gown, and I don’t know who I am in a tie and button down, but you make me wear both, when I’m inpatient and when I’m advocating, us patients have to wear a uniform because our power is a threat. I’m too damned tired to keep up the act. You’ll see and hear me for my wisdom, not my formality.

I’m telling you for the last time.

You sequenced my disease thirty years ago, the one I share with thousands of others, to revolutionize medicine, but genomic sequencing is a luxury, not a standard of care, and all my friends are dying. There is death in the hype; death in disparities.

I’m telling you for the last time.

Your tailored scrubs and contrast Nike trainers, a few quick keystrokes and a joke with your peers, while you fluidly navigate the halls of the ill. My hairy legs and awkward gait, uncertain and unsure. Information is currency, and patients are impoverished.

I’m telling you for the last time.

I’ve honed my material for five years, and I’ve had a good run with it. All of that material you’ve heard: here and there, this talk and that, roundtables and panels, guest talks and presentations, op-eds and articles, filmed interviews and vignettes, five years of my life drafting, crafting, revising, delivering: it’s exhausted, and so am I.

I’m telling you for the last time.

Whatever I wasn’t brave enough to do before got buried in the traction that kicked up mud while the machine lurched forward. Advocacy is the product we sell. And my best work is a compilation you’ll find sooner or later. I’m proud of the work, but for my health, my ability to transform–or to reclaim, the middle finger of my skater punk youth–my liberation from the smiles and inspiration, it’s time to smash a guitar.

Thank you to everyone who gave me the stage to work that material. It was born on this blog in

October 2016, when a naive 34 year old with a terrible diagnosis took to Facebook live in an Optune cap in my parents' bedroom, after we sold our condo and turned our lives upside down. It's time to let those memories be glossed by the nostalgia of time marching on and work the new material of long-term survivorship.

Five years of brain cancer, from diagnosis to major milestones: I've told that for the last time.

You can't keep creation down, and something new, something fresh, something from a man who will turn 40, when his death was supposed to be at 35 is agitating.

Hang around for the thing I'll say for the first time. You can't live with brain cancer and stay safe, so let's take risks.

More soon. -a.

This post originally appeared on Glioblastology on February 22nd, 2022. It is republished with permission.

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