# Brain Tumor Awareness Month: Recap of #BTAM 2023

I recount the Race for Hope DC, advocacy on the Hill with my son and more—including my official "Crani-versary."

May 29, 2023 By Adam Hayden

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## Going Gray in May

May is Brain Tumor Awareness month, and it's been a busy one for us! With so much going on, I wanted to recap a few major events to share what advocacy looks like for our family.

I'll share more about…

- The Tumor Takedown Tailgate
- National Institutes of Health: Neuro Oncology Branch
- Race for Hope: Washington D.C.
- National Brain Tumor Society: Head to the Hill
- Quality of Life Research Roundtable
- Roon: The most helpful place online for people navigating complex health conditions

I also pause to recognize that May 26, 2023 is my official "Crani-versary," or the anniversary of my brain surgery (awake craniotomy) and resection of my primary brain tumor. I don't want to share too much about this milestone in this post because I haven't quite sorted through the complicated emotions, and I don't want to take away from the community tone of this post to center myself

and a personal milestone. My diagnosis anniversary is next month, June 10 (several days between surgery and official pathology/diagnosis), and you can expect that between May 26 and June 10, I'll publish a post reflecting on seven years living with brain cancer, but for today, for this post, let's keep it topical for Brain Tumor Awareness Month.

## The Tumor Takedown Tailgate: TTT4

Our annual local fundraiser to benefit National Brain Tumor Society was a huge success, despite rain and even sleet–because Indiana in April, but the sun broke, and the huge tent and hard-working volunteers at Folktale Greenwood had no problem with accommodating the bad weather. We raised more than $20,000 to benefit National Brain Tumor Society, bringing our four-year total donations to $85,000!!

When we started the #TumorTakedownTailgate we had no idea that we'd create an anticipated annual event that connects our community and puts up these huge dollars for brain cancer research. I don't want to get ahead of myself, but I can't wait to bring us all together next year for TTT5 when I know we'll push over $100,000 raised in five years to benefit NBTS.

Thanks again to Folktale (book your next wedding or event here), Dashboard Food Truck and Catering (eat your next meal here), Jack's Donuts (snag your next breakfast here), Mashcraft Brewing (buy your next beer here, and invite me to join you), and Ramona (find this delicious organic wine spritz on your next beer run (B double E double R U N, beer run).

To Lauren Casey from RTV Indianapolis, thank you for your incredible emcee duties, Jay Elliot (book him for your next party or event), and Ben Tatum (catch him around town and ask him for a Green Day cover in my honor), you all brought energy, talent, and set the tone for the day.

Special thanks to my wife, Whitney, and our best friend, Lindsay, along with Chef Mark Henrichs, and literal superwoman Katie Henrichs for your partnership in pulling this event together each year!

Follow the TTT Facebook and Instagram to be first to learn about our next event.

## NIH: Neuro Oncology Branch Visit

I was humbled to be invited with my dear friend, Kim Wallgren, Executive Director of the Collaborative Ependymoma Research Network (CERN) for us each to deliver guest lectures at the National Institutes of Health Neuro Oncology Branch. Drs. Mark Gilbert and Terri Armstrong are dear friends of the brain tumor community and world-leading clinician-researchers at the NIH. This was a truly humbling experience to get a tour of an NIH lab and meet with researchers, then deliver our perspectives on survivorship and patient advocacy.

We even grabbed a sandwich at Call Your Mother. My middle name is Jewish Deli, if you didn't know.

## Race for Hope DC

The Race for Hope DC is one of the largest brain tumor fundraising events all year! This 5k around the Capitol raised over $1.3M for brain tumor research this year alone!! It was awesome to be on hand for this powerful event, and it's one of the few times all year when all of our social media brain tumor pals are together in one place! In the photo at the top of this blog, I am with two of my closest friends, Liz Salmi (middle; my fellow punk rocker) and Lisa O'Leary (right; my co-facilitator for our monthly support group, Brain Tumor Support Conversations).

## Head to the Hill

Head to the Hill is the signature event for National Brain Tumor Society and our brain tumor community. We mobilize nearly 400 advocates from across the country to bring our legislative priorities to Congress through meetings with members of Congress from advocates' districts and states. This year we asked Congress to…

- Fund the National Institutes of Health at $51B

- Fund the Department of Defense Peer Reviewed Cancer Research Program at $150M and maintain pediatric brain tumors and adult brain cancers are eligible research areas

- Co-Sponsor the Stop the Wait Act that will eliminate deadly waiting periods for Social Security Disability benefits and Medicare coverage for people facing serious and terminal diagnoses

What was most special for our family this year was having our oldest, Isaac (11yo), join us. Isaac joined Whitney and me to meet with our elected officials to tell our stories and make our asks to Congress. Isaac was amazing! By the end of the day he even led one of our advocacy meetings in the lead speaking role! One of the staffer's asked Isaac on the way out if he was going to be a lobbyist. Without missing a beat Isaac replied, "Nope, a lawyer."

It was such a proud moment to share my life of advocacy with our oldest son. I travel a lot for speaking and advocacy events, and it was so meaningful to share some of this with Isaac. He's incredible.

Head to the Hill is the signature event for National Brain Tumor SocietyCourtesy of Adam Hayden

## Quality of Life Research Roundtable

A few years ago my pal Liz, you already met her above, invited me to join as a co-investigator in a project that she won grant funding to convene through the Patient Centered Outcomes Research Institute (PCORI). We called ourselves the Brain Cancer Quality of Life Collaborative, or BCQoLC, and our goal was to create a research network to define and innovate on interventions to enhance the quality of life for people living with brain tumors.

After years of research and a few published papers, the group took a further step this May by convening a multi-disciplinary research meeting hosted by NBTS. I can't say too much about this event yet, but each person in the picture below is a patient or caregiver in the community with deep relationships, engagement, and influence in the field. I am humbled to call them friends. This picture is my Twitter timeline come to life!

Left to right: Adam, Lisa, Liz, Sabine, Emily, Jeremy, and GuyCourtesy of Adam Hayden

## Roon: Launch of the iOS App

Speaking of brain cancer quality of life, I met Rohan Ramakrishna, MD and Vikram Bhaskaran in 2021 when they approached me about a new platform they were building to transform the way medical information is delivered to patients and caregivers.

It’s our goal to be the best place online for people navigating hard health conditions, starting with the aggressive brain cancer, glioblastoma. The app has recently launched on iOS and the web at www.roon.com. On the app, you’ll find  educational videos delivered by experts as well as answers to many questions that come up during the journey of glioblastoma. These short form videos from researchers, physicians, nurses, mental health professionals, patients, and caregivers deliver medically vetted information in a human way. We launched with glioblastoma, and dementia, Long Covid, and ALS are the conditions already underway to be released on the app soon.

Scan the QR code to check out the app–you can access many of the resources without even creating an account!

## Conclusion to #BTAM

As Brain Tumor Awareness Month draws to a close I have a super secret special announcement to share that you'll just have to wait to hear more about! It's coming up next week, so stay tuned to my social feeds and right here on the blog to get the update!

Follow my Link Tree to see all my social channels! Until next time, peace, love, brain. Adam out.

Adam Hayden and son Isaac in DCCourtesy of Adam Hayden

This post originally appeared May 20, 2023, on Glioblastology. It is republished with permission.

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