Deviant Democracy: Cancer Advocacy on Capitol Hill

Amid bad faith politics, Adam Hayden meets with Congress members to advocate for brain cancer patients and research. Find out his asks—and the surprising results.

September 18, 2025 By Adam Hayden

Note: I write here in my own voice as a patient living with brain cancer. While I volunteer with and serve on the Board of Directors for the National Brain Tumor Society, the views expressed here are mine alone and not official positions of NBTS.

I almost didn't go.

Not because the cause isn't worth it — it is, existentially so — but because the whole process feels rotten lately. And if I'm honest, I didn't want to sit across from my elected officials and pretend their bad faith was worthy of honor. I didn't want to dignify the power they wield by playing along. Showing up felt naïve at best, complicit at worst.

And yet — I showed up anyway.

If that makes me deviant, good. Talcott Parsons, the mid-century sociologist, called sick and disabled people "deviant." Not with the charm I take in the word. For him, we were a drag on productivity — tolerable only if we hustled back into the workforce.

But disability culture has long reclaimed the language of deviation. Crip and crip time insist that living on a different clock isn't failure, it's survival. Rosemarie Garland-Thomson talks about "misfits" and "misfitting" — the way bodies and worlds grind against each other when the design of one refuses the shape of the other. These words name what Parsons missed: that deviation from norms isn't deficiency. It's a site of power, perspective, even creativity.

I'm not here to pass Parsons's test. I showed up on Capitol Hill not to play "good patient," but to remind lawmakers that patients who will never fold neatly back into "normal" still deserve more than a shrug.

This is democracy: show up, even when you don't want to, and make them hear it, but by leveraging the system's tools.

I take Audre Lorde seriously when she said, "the master's tools will never take down the master's

house.” But for the disabled life I lead, some parts of me still sit close to power. And for those of us who do, the obligation is to use that access — to show up, even when we’d rather not.

The Asks

Speaking with a neighbor some time ago, I lamented the ongoing cuts to the National Institutes of Health. They shot back: “No, they’re only cutting the DEI stuff.” As if that made it fine—cutting Diversity, Equity and Inclusion. It’s not just “the DEI stuff” we’re fighting for. Here’s what we brought to Congress in 2025:

1. The BRAIN Act (H.R. 2767 / S. 1330). Bipartisan bill to accelerate brain tumor research, open up trials, and improve survivorship.

2. FY26 Appropriations. More for NIH and NCI, plus $10M glioblastoma lines at both NCI and DoD.

3. Childhood Cancer Package. Accelerating Kids’ Access to Care Act (cut Medicaid red tape) and Give Kids a Chance Act (force pediatric trials, reauthorize rare disease incentives).

4. Awareness Resolutions. May as Brain Tumor Awareness Month, July 16 as Glioblastoma Awareness Day. (Resolutions don’t cure cancer, but they do remind Congress we exist.)

That’s the platform. In short, it calls for more access to clinical trials for brain tumor patients, restoring funds to the NIH and the National Cancer Institute for research, better trial access for kids with cancer, and low-stakes resolutions that acknowledge our rare disease.

We advance a platform of helping adults and kids with cancer. We’ve long said in the brain tumor community, “Brain tumors don’t have a political party.”

The Political Issue

Let’s be clear: the politics don’t stop at the Capitol steps.

At NIH, staff themselves are dissenting. The Bethesda Declaration bluntly accused leadership of torching more than 2,000 grants — nearly $10 billion in science — to score political points. DEI studies, climate and health, long COVID, gender and sexual health: gone. Trials halted midstream, patients left with unmonitored implants or half-finished medications. They call it efficiency. It looks a lot more like waste.

Then the Supreme Court decided to join the game. In August, by a hairline vote, the justices allowed the administration to cancel $780 million in NIH grants targeting the same “disfavored” research. Justice Jackson called it “Calvinball jurisprudence with a twist,” the twist being that the rules always bend toward power. Years of work, shredded. Graduate classes gutted. Labs shut down. All in the name of culture war theater.

Meanwhile, the new One Big Beautiful Bill Act is projected to kick 10 million Americans off insurance within a decade, 5 million thanks to Medicaid work requirements alone. The uninsured rate spikes while the share of people with access to subsidized care plummets. Apparently, “fraud, waste, and abuse” is just another name for families who need coverage.

And if you want to see how deep the cuts land in my own community: the Pediatric Brain Tumor Consortium — sixteen hospitals running early-phase trials for the most lethal childhood brain cancers — has been told its funding ends in 2026. Enrollment has already frozen. Families waiting for CAR-T therapies, neurosurgeries, or simply the hope of a Phase I trial are stuck in limbo. The doctors are clear: If this goes, we’ll simply stop doing as many impactful trials for pediatric brain tumors.

So here’s the point. None of this is neutral. Science, medicine, access — all of it is political. And yes, that tension is exhausting. Advocacy in disagreement means speaking to people you distrust, working within systems you know are broken. Parsons would call that deviant: refusing productivity, falling out of line. But here’s the trick — what if deviance is exactly the right stance? Not deficiency, but resistance. Not loss, but meaning-making.

The BRAIN Act

Brain tumors are stubborn and deadly. Survival rates haven’t moved in 45 years. Glioblastoma, the most lethal and aggressive brain cancer in adults, still carries a median survival of 15 months. For kids, brain tumors are the leading cause of cancer death. For veterans, glioblastoma is the third leading cause of cancer death on active duty.

The BRAIN Act aims to change that. It would:

- Fund the NCI Glioblastoma Therapeutics Network ($10M) for early trials.
- Expand biobank transparency so researchers can share tumor samples.
- Support immunotherapy development for brain tumors.
- Direct the FDA to reduce exclusions that shut us out of trials.
- Support survivorship models and a CDC awareness campaign.

It’s bipartisan. It’s specific. And it’s fiscally responsible. The CBO hasn’t scored it yet — which

means appropriations still determine the dollars — but the framework matters. So does the signal: Congress is paying attention.

Right now, the bill has 29 cosponsors in the House and 7 in the Senate [NB. Cosponsors tallied as of September 13, 2025; feel free to follow each link for the current count.]

The Turn

And here's the kicker.

The office I least wanted to meet with — the one I almost skipped — signed on this week as a cosponsor of the BRAIN Act following our meeting.

The lesson isn't optimism. It's responsibility — to advocate, to stay engaged, and to do it by the rules, not by violence, threat, or upheaval. I still think much of what I see from my elected officials is bad faith and performative. But our delegation showing up, stumbling through our points, mattered enough that their boss put their name on the bill.

So yes, it's a game. But the only way to win is to play.

Deviance, Revisited

Parsons thought the sick role was capitalist deviance — tolerated only if it bent back toward productivity. That's one version. But there's another: deviance as rebellion. If illness makes me deviant, I'll take it.

Because showing up as a patient advocate isn't about productivity. It's about insisting that democracy expand to include us — the people who don't fit, the ones with limited time, the ones who refuse to disappear quietly.

So call me deviant. Call me crip. Call me misfit. I'll take them all.

Who else to be brave but those with so much to lose?

Epilogue

The culture is loud with bad faith. I still believe many of my elected officials act in ways unworthy of their office. That hasn't changed. I didn't want to honor that power.

But showing up wasn't about honoring them. It was about refusing to let their bad faith be the only thing in the room.

There’s another name on the BRAIN Act. That’s not everything. But it’s not nothing. And sometimes, not nothing is enough to keep me in the fight.

Thank you to all who have advocated on behalf of the BRAIN Act and the members of Congress who have sponsored and co-sponsored it. Speaking from the reality of brain cancer, this legislation will positively impact the brain tumor community.

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