

The White House War On Glioblastoma



Forbes

OurBrainBankBrand Contributor

Mar 1, 2024

By Ed Pilkington

It's a strange sensation sitting at the keyboard and writing this sentence: I have a deep and personal connection to the President of the United States. But I do. And no, I'm not talking politics.

Joe Biden and I have both lost our loved one to the cruel, relentless and currently incurable brain cancer glioblastoma (GBM). In his case, his beloved son Beau was taken from him by the illness on May 20, 2015.

Eight months later, my wife Jessica Morris was diagnosed with the same brain cancer. In her own words, she threw everything and the kitchen sink at it, signing up for experimental new treatments including a personalized vaccine created in Germany geared to the genetic mutations of her own tumor.



It was a formidable struggle that astounded and inspired all who were touched by her. Yet she too succumbed to the brutal force of GBM on June 8, 2021.

Jessica Morris

In June 2017, a year into her diagnosis, Jessica spotted that Biden, fresh out of the White House as the former vice president, was launching with his wife Jill a new philanthropic push to fight cancer in New York City where we live. Jessica was an unstoppable force. Within months of her GBM diagnosis she had set up a non-profit, OurBrainBank, with the mission of turning GBM from its present terminal status to treatable, powered by patients and caregivers like us.

With that force driving her, she wrangled herself onto the invite list of the launch event in New York, then hustled her way to the front of the meet-and-greet line until there she was, face-to-face with Joe. “Mr. Vice President, I’m Jessica and I have what Beau had,” she told a rather startled Biden. Then she went on to tell him, in no uncertain terms, that more needed to be done to address this terrible illness.



Jessica Morris and Former Vice President Joe Biden at the launch of the Biden Cancer Initiative at the Alexandria Center in New York on Monday, June 26, 2017. MICHAEL APPLETON/BIDEN CANCER INITIATIVE

Seven years on from that encounter, Jessica is no longer here. But the fight against GBM that she joined very much is, and in strange ways it continues to bring Jessica’s legacy and the US President together.

In May 2023 the Biden Cancer Moonshot, the initiative that he and Jill reignited from the White House with the goal of reducing the death rate from cancer in the US by at

least half by 2047, held its first [brain cancer forum](#). For the 13,000 people who are diagnosed with GBM in the US every year, as well as their families, the summit came none too soon for us.

For too long we have had to put up with GBM being treated as an after-thought. This form of cancer is too rare to attract big pharma money as the costs of developing new therapies are high and the promise of a pay-back slim.

Governmental funding bodies and philanthropic donors similarly tend to veer towards the most common forms of cancer. And yet, as both Joe Biden and I can attest, the devastation wrought by GBM across extended families and friendship networks is massive.

So it came as a large boost of morale to find myself inside the cavernous room next to the West Wing set aside for the White House brain cancer summit. I attended on behalf of OurBrainBank, along with other groups of GBM patients and caregivers as well as those wrestling with Diffuse Intrinsic Pontine Glioma (DIPG), a highly aggressive brain tumor which strikes about 300 children in the US each year.

World-class neuro-oncologists and -surgeons were present too, drawn from leading centers such as Duke University, Dana-Farber Cancer Institute and UC San Francisco. What was so heartening was that everybody there expressed a common sense of urgency, a burning desire to do more, to speed things up, to work harder and quicker towards finding the desperately needed breakthrough that eludes us all.

One of the neuro-oncologists put it succinctly. “Why don’t we declare a national emergency for GBM,” he said, “because that’s what the most aggressive brain cancers are.” We couldn’t agree more.

Since the White House brain cancer forum was held, it has catalyzed a stream of [new initiatives](#). They include the launch of an online hub to support children with brain cancer throughout their journeys with the disease, new clinical trials on the use of focused ultrasound to treat brain cancer, and quality of life research for brain tumor patients spearheaded by the [National Brain Tumor Society \(NBTS\)](#).

The Advanced Research Projects Agency for Health (ARPA-H), a groundbreaking new way of funding research and innovation, is pumping \$240 million into accelerating new ways to prevent and treat cancer. Work is also being done to increase access for patients and their families to navigation services to help them make sense of the extremely complex and often confusing system of GBM clinical trials.

These actions and collaborations are not, on their own, going to move GBM from terminal to treatable. The tumor remains a formidable foe, taking on multiple forms and even changing its genetic make-up over time.

But they are signs of a new determination on the part of everybody in this space – patients, their loved ones, scientists, pharma companies, philanthropists, and the White House – to work together, to work harder to find the way forward. We are doing it for Beau, we are doing it for Jessica, and most importantly, we are doing it for those who are diagnosed after them with this terminal, and we hope one day soon treatable, disease.

Ed Pilkington is chair of OurBrainBank, an international nonprofit with active branches in the US and UK. OBB is dedicated to turning GBM from terminal to treatable, powered by patients.

To find out more about OurBrainBank, or to support OBB's work, visit its [website](#). Follow OBB on [Twitter](#) or [LinkedIn](#).



OurBrainBank

OurBrainBank is an innovative, patient-led movement designed to move glioblastoma from terminal to treatable, powered by patients. It's the first non-profit created by, with, and for people living with glioblastoma, an aggressive and rare brain cancer. Founder Jessica Morris (1963-2021) survived for five years after her diagnosis. The five-year survival rate is 5%. We believe in patient power and the importance of donating data to medical research. Patient-driven data is the new currency in medical research. OurBrainBank is a registered nonprofit 501(c)3 based in the US and registered charity in the UK.