

We Are Failing Those Living With One Of The Rarest And Deadliest Cancers

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OurBrainBankBrand Contributor

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By Kelli Duprey

In 2016, my dear friend Jessica Morris received a diagnosis of Glioblastoma (GBM). That year, 13,000 people, including her, were diagnosed with this deadly brain tumor, making it very rare in a population of 330 million. The bitter truth is that most GBM patients die within 12 to 16 months. Only 5% survive beyond five years of their diagnosis. Despite the grim statistics, Jessica lived beyond the odds to see all three of her children finish high school and spread their adult wings. But we ultimately failed her and her family when she lost her battle in June 2021.

The troubling reality is that only two new treatments for this devastating cancer have been approved since 2018 – a device called Optune that beams electric fields at the tumor to disrupt its replication, and an immunotherapy drug, Keytruda. These innovations help, but there is still no sign of a breakthrough in treatment let alone a cure. People are still dying brutally quickly. Families are still being torn apart. So why are we failing our most vulnerable so badly? Where is the urgency, where is the change?



The primary obstacle hindering the development of new treatments is the exorbitant cost of developing new approaches and inadequate funding for the search. Bringing a new cancer drug to market costs between \$250 million to \$2 billion, and the total GBM

market is only valued at \$1-1.5 million, although expected to grow to \$3-3.5 million this year. Combined with the rarity of GBM and the fact that most patients die within a year, pharmaceutical and biotech companies lack incentives to invest in new treatments.

The funding disparity is evident in the comparison of allocations for GBM research. The National Cancer Institute allocates about \$180 million a year for research into all brain tumors, covering a vastly bigger field than GBM. In contrast, breast cancer receives \$580 million, with numerous approved drugs already on the market and with a much higher survival rate.

Insufficient clinical trial success, stringent FDA processes, and a lengthy development timeline further impede progress. GBM clinical trials take on average more than seven years to transition from phase 1 to phase 2, and 91% of phase 3 trials fail.

The Ivy Brain Tumor foundation states that “drug development for brain cancer lags behind in comparison to other types of cancers with larger patient populations. Only 5% of new investigational drug applications submitted to the FDA for [all] cancer therapies are successful, and for brain cancer the rate of success is closer to 1% over the past two decades.”

As the wealthiest country in the world, this is both sad and frustrating. We must do better.

Jessica had a different way of looking at it. She liked to use the analogy of a doorway. When a new building is being constructed, she would say, why not make the doorways large enough so that everybody, including people in wheelchairs, can gain easy access.

So it is with cancer research. If you focus on the toughest cancers to crack – and GBM is right up there as one of the hardest – then the scientific lessons you will learn will be to the benefit of combatting all cancers.

Hope lies in the FDA's Orphan Drug Act, offering incentives for rare disease treatment development, such as tax credits, fee waivers, and seven years of market exclusivity. Nonprofits also play a crucial role in filling the funding gap.



As government and company funding falls short, we urge your support for nonprofits. Consider donating to GBM-specific organizations like OurBrainBank (OBB), the international charity that Jessica founded a year after her diagnosis in 2017. OBB is a patient and carer-led nonprofit conducting patient-led research and data collection to advocate for GBM patients' rights.

Help us raise the alarm on behalf of GBM patients and their families. Write to your congress representative, urging increased government funding. Demand that sense of urgency that is so lacking. Help us prevent further failures like the one that struck my friend Jessica and her family.

Please contact us at info@ourbrainbank if you would like to help us, or visit our website www.ourbrainbank.org for information about this terrible disease and how to fight it.

Kelli Duprey is chief executive 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](http://www.ourbrainbank.org). 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.

Photos: Getty, OurBrainBank