

My Mom Was Told She Had One Year To Live: This Is What She Did

Forbes



OurBrainBankBrand Contributor

Feb 1, 2024

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What do you do when you're told you have one year to live? For my mom, she had to start by telling her three young kids after school one day that she had a "Glioblastoma" (GBM) brain tumor, and that everything was going to be okay.

She didn't know how to tell us that GBM is deadly - only 5% of individuals diagnosed with GBM survive five years post-diagnosis. It is also notoriously difficult to treat, and



resources for developing new approaches are woefully inadequate – a mere 5% of research funding applications are approved. Those terrifying statistics signified an impossibility for hope. They quickly, however, became standards she was going to defy.

In June 2017 OurBrainBank's founder Jessica Morris attended the New York launch of the Biden Cancer Initiative, the philanthropic scheme set up by Joe and Jill Biden in honor of Joe's son Beau who had died of GBM. She talked about OBB's mission to move GBM from terminal to treatable, powered by patients. "We need a sense of urgency!" she told him. MICHAEL APPLETON

She knew she had to change in herself to meet the challenge of this devastating diagnosis. But she also knew that patients like her had enormous power, if they worked together.

A year after diagnosis, she founded OurBrainBank, a patient-led movement dedicated to shifting GBM from terminal to treatable. Within two years OurBrainBank expanded to the UK, creating an international community of support and encouragement by and for people diagnosed with this terrible disease.

Our mom was one of the “lucky” ones — a strange expression to apply to someone diagnosed with such a brutal disease. She was one of the few to survive five years. Her fifth anniversary of her diagnosis fell just as Joe Biden was sworn into the White House in 2020. We found solace in the hope that his Cancer Moonshot program would integrate efforts against GBM into the national framework. This endeavor was inspired by his personal tragedy of losing his son Beau to GBM in 2015, when Beau was just 46. Beau joined the growing line of prominent American political figures, alongside Ted Kennedy and John McCain, fallen to GBM.

In 2021, we would say goodbye to our beloved mom, desperate to figure out how we were going to cope. We also had to figure out where to put all our anger. GBM still received so little attention, so little concern. The standard regime of care, including surgery, chemotherapy, and radiotherapy, was no match for the deadly disease. Still, we didn’t know the causes of GBM, nor how to prevent it.

There was room for hope, however. As her middle child, the great comfort that I do have is that my mom’s legacy is only growing. From speaking with Biden at the White House, to meeting and bonding with patients and their families from all corners of the US and the UK, she opened up a conversation on what we as a nation needed to do better. Her legacy lives on in OurBrainBank.

OurBrainBank is on a mission to support, inform and empower every person who has GBM. We’re the only GBM-focused non-profit conducting patient/carer-led data collection and research. Through our patient-centered advocacy, we hope to inspire institutional, financial, medical and regulatory reform. We will not stop until patients have access to and funding for second opinions, so that when they’re told “nothing can be done” by one doctor, they can seek out a more aggressive approach if they choose.

We want it to be easier for GBM patients to enroll in clinical trials of new drugs and therapies. Our GBM Bill of Rights, developed by those affected by GBM, is designed to

empower and inspire people living with the illness to call for improved treatment. It is a roadmap to patient power and a brighter future, a patient-centered call to action.

We also believe that tackling GBM - one of the most complex and aggressive brain cancers - may be the key to cracking them all.

In 2024, we're working to collect and share patient data and use artificial intelligence and computer learning to find new and better treatments. That's why we need your support.

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

Tess Pilkington is on the Board of OurBrainBank, an international nonprofit with active branches in the US and UK founded by her mother, Jessica Morris. 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.