

From Patient To Million Dollar Woman: The Terrible Inequity Of Brain Cancer

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About a year into her diagnosis with the most deadly form of brain cancer, glioblastoma (GBM), Jessica Morris did a calculation on the back of an envelope and found to her astonishment that she was a Million Dollar Woman.

As she describes in her memoir of her GBM journey, *All In My Head*, she added up the cost of her first-year treatment and found it easily passed the million mark. That included initial surgery to remove as much of the malignant tumor as possible; a year's worth of experimental immunotherapy infusions; electrotherapy treatment through the Optune device that beams electric current into the tumor to disrupt its cell replication; and all the other basics of radiotherapy, chemotherapy, and bi-monthly brain scans.



That jaw-dropping figure was the product of Jessica being in the right place with the right health insurance. She lived in New York City, within easy reach of world-class specialist physicians at Columbia and New York Universities, who in turn could help her secure expensive medicines through compassionate-use programs.

Jessica Morris wearing the Optune device, produced by Novocure, which beams electric current into the tumor to disrupt it. PHOTO COURTESY OF JESSICA MORRIS

She went on to get state-of-the-art care, including several cutting-edge experimental approaches, at Columbia and Harvard University's Dana-Farber Cancer Institute. While the brutal median life expectancy for GBM is just 15 months, she lived for more than five years until June 2021.

It sounds bizarre to describe a person diagnosed with one of the most punishing of cancers as lucky, but it's the sad truth. Jessica was lucky. Many other people stricken with this relentless disease do not have anything like the same experience.

That's one of the most important reasons why Jessica, in the early months of her illness, felt driven to set up a non-profit organization, OurBrainBank, that today has grown in the US and UK into a powerful transatlantic voice for change. Following Jessica's vision, we see our role at OurBrainBank as putting a spotlight on the devastating inequities that exist for those with GBM, in the hope that it will spark a debate and force more to be done for those who desperately need it.

Last year we asked our GBM community to tell us about how they got on when interacting with the medical profession. The findings were shocking.

Two-thirds of respondents said they were not informed about the possibility of genetically testing their tumor before the initial surgery. In an age in which treatment of



cancer, especially complex cancers like GBM, is increasingly focused on personal medicine and the make-up of each patient's own tumor, genetic testing is fundamental.

Yet people aren't even being told about it, let alone given the means to have their tumor sampled and analyzed. Even that minority of patients who had their tissue stored fared little better – just 43% of them had the tumor genetically tested beyond the basic diagnostic test.

Jessica Morris became the million dollar woman a year into her treatment for glioblastoma brain cancer, including bi-monthly MRI brain scans.

Overall, more than half of those who filled out our survey did not feel that their medical team had given them the information and education they needed to make informed decisions.

The findings were so alarming that OurBrainBank is now conducting a comprehensive nationwide survey across the United States that is designed to find out how GBM families are faring. The disease is a frightening and isolating beast – it makes people feel lost and alone.

By discovering what is happening to people who are not lucky enough, like Jessica, to live near medical centers of excellence with good health insurance, we hope to redouble efforts to bring families much needed relief.

Over the Atlantic in OurBrainBank's second home, the United Kingdom, things are very different – no surprise, given the very different nature of the UK's health services – but certainly no rosier. Treatment for GBM is free under the National Health Service (NHS).

But it is rigidly controlled by guidelines set by NICE (the National Institute for Health and Care Excellence), a central body which is meant to iron out disparities in the availability and quality of medical care in England and Wales. Which all sounds great, until you look beneath the surface.

The UK is ranked 22nd out of 33 comparable countries in the league table of five-year survival rates for people with all brain cancers. That's a shockingly poor ranking. So why is the UK doing relatively so badly?

Several theories have been proposed, including the UK being late to diagnose the disease, or critical treatment being slow to start. One recently retired neurosurgeon stated that his patients were waiting longer for surgery today than at the start of his career.

Or could it be that the guidelines set by NICE are themselves part of the problem? The NHS is constantly battling financial crises, and NICE places a ceiling of \$38,000 (£30,000) for any particular treatment for each quality-adjusted life year (QALY) it provides.

The result is constraints in what is available to GBM patients. For instance, the guidelines state: "Do not offer Tumor Treating Fields", which means that you cannot get Optune on the NHS, the electrotherapy device produced by Novocure to which Jessica had access under insurance in the US.

Optune has been found to extend GBM median survival by five months according to a clinical trial. That may not sound much, but it's a huge deal if you've only got nine months to live.

There is a tension between NICE's role of equalizing things from the center, and GBM's heterogeneity. No two patients are alike when it comes to this disease – their tumors are different, and their response to treatment will also differ potentially dramatically.

That is pushing GBM treatment increasingly into the realm of personalized medicine, geared to the patient's own tumor types and mutations. But in the UK, less than 5% of GBM patients are having their tumors genomically sequenced. Some clinicians don't want their patients to explore genetic analysis of their tumor because they know that under NICE best practice guidelines, it won't change their treatment plan no matter what they discover.

Given the poor ranking of the UK in the survival rate for GBM, it's not at all surprising that patients in England and Wales often vote with their feet by traveling to other countries where they can gain access to cutting-edge experimental treatments. Germany has grown increasingly attractive to patients looking for personalized vaccines geared to their individual tumor mutations.

But that too of course is a source of great inequity. With no insurance available these treatments do not come cheap.

Some of the most advanced procedures can cost as much as \$250,000 – well beyond the capabilities of all but a tiny fraction of the GBM community. The fact that some families still struggle to scrape together such large sums, making great sacrifices to do so, is testament to their desperation in the face of such a cruel cancer.

Ed Pilkington is the husband of Jessica Morris, and chair of the international non-profit she founded, OurBrainBank. Matthew Wilson is OBB's campaign and communications manager in the 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.

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