

Surviving Brain Cancer: Those Who Live Long



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OurBrainBankBrand Contributor

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Glioblastoma (GBM) is a rare and deadly disease: roughly 12,000 new patients are diagnosed every year in the US, a country of 330 million people. Most GBM patients die within 15 months and fewer than one in 10 live past five years.

Sabine Schwab has managed to defy these terrifying odds.

Sabine was diagnosed in 2014 — at the age of 32 — after a massive seizure in her bathroom. She had just completed her doctorate degree, moved from Germany to the US, and was on the cusp of starting a new life with her husband and baby daughter. She had big plans for her life and her career.

Sabine Schwab with her husband and daughter at Denali National Park, Alaska, in 2023 (SABINE SCHWAB)

So when she was diagnosed with GBM brain cancer — which directly impairs cognition on top of other cancer related indignities — she took it as a “personal attack on her most prized possession.”

She went through the standard treatment of GBM care which involves surgery followed by chemotherapy and radiotherapy, and braced for the worst.

Fast forward to today, she is not only thriving, but will soon celebrate her 10-year anniversary since her diagnosis this spring.

Sabine attributes her long-term survival to a tumor with a favorable profile, a healthy diet and lifestyle, and frequent naps.

But how can we be sure that's a universal panacea for all GBM patients?

Dr. Fabio Iwamoto, a leading neuro-oncologist at Columbia University Irving Medical Center, says that only about 10 percent of his GBM patients live past 5 years – and that percentage falls sharply as they approach the 10-year mark.

“For the long-term survivors, it most often comes down to the molecular profiles of their tumors versus any medical treatments that doctors can provide,” he tells me. For example, methylated tumors (a subtype of brain tumors) are more treatable than non-methylated ones.

“Other than that, it's all just very random,” Dr. Iwamoto states matter-of-factly.

So, is there any way out of this brutal disease?

Dr. Iwamoto is working on various treatments – including vaccines, targeted therapies, and immunotherapies – that have the potential to meaningfully improve survival. But he thinks more funding and legislation is needed to address the gaping holes in the care of GBM patients. The only available treatments right now extend survival by just a few months and are far from the breakthrough that is so desperately needed.

That's one of the reasons OurBrainBank exists. We are a non-profit committed to raising awareness about this woefully underserved community devastated by GBM. We need your help to turn this disease from terminal to treatable, so that patients can live not just longer, but healthier, fuller lives.

In the meantime, Dr. Iwamoto urges his patients to live in the present, make the most of every moment, and not fixate on the tumor. We are all on borrowed time, after all.

Sundas Hashmi is a member of the US board of OurBrainBank, an international non-profit that is sounding the alarm on behalf of GBM patients and their families in both the US and the UK. Please contact us at info@ourbrainbank.org if you would like to help, or visit our website www.ourbrainbank.org for information about this terrible disease and how to demand more resources in the search for new treatments.

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

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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.