



Moving Glioblastoma from terminal to treatable.
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PRESS RELEASE
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PEOPLE WITH GLIOBLASTOMA DEPRIVED OF BEST CHANCE TO SURVIVE

Survey finds gap between trial availability and patient need

People with Glioblastoma (GBM), a highly aggressive, complex, rare cancer with a median survival of 14 months, are being deprived of the best chance of survival: easy access to clinical trials and off-label treatments, according to a survey of 162 patients and caregivers conducted by OurBrainBank.

OurBrainBank is a patient-centered nonprofit designed to move GBM from terminal to treatable, powered by patients. OurBrainBank conducted the survey on social media, and received 162 responses within 36 hours—a high response rate for this rare disease.

The survey was designed by Daniel A. Orringer MD, Assistant Professor of Neurosurgery at the University of Michigan, and member of OurBrainBank's medical advisory committee, together with the OurBrainBank team.

Most recent published estimates suggest under 10% of GBM patients enroll in clinical trials.* Clinical trials are essential to transforming this deadly, aggressive, complex cancer.

The survey found:

- Patients want to be offered clinical trials.
- 78% asked their doctors about enrolling in clinical trials.
- 70.8% of those in the survey searched on the internet to find a trial they could enroll in.
- Only 28.3% were able to find a trial for which they were eligible.

More than half believe they are being treated at a hospital where clinical trials are not available.

95.5% felt trial enrolment might improve a GBM patient's sense of well being.

Patients faced with GBM are aware that it's incurable and want to be a part of the solution. Whether or not trial enrollment can prolong their lives, they want to help.

Only a minority are offered trials



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- 57% of patients have not been offered a clinical trial. Neuro-oncologists are the most common caregivers to offer trials.
- Just 20% have been offered off-label therapeutic approaches (experimental drugs).

When patients asked their physicians about clinical trials, 80% of them were told to pursue standard treatment or directly discouraged from pursuing a clinical trial.

Most were not directed towards a center where trials were offered, if outside of the hospital where they are being treated, even if they expressed interest.

Dan Orringer MD stated: "As a surgeon, I'm frustrated at how hard it can be for patients and caregivers to navigate the complex world of clinical trials. This survey reaffirms my concern that there is a broad gap between what people affected by GBM want and what is available to them."

Meredith Moore, board member of OurBrainBank and long term (14 years) GBM survivor, said: "If I hadn't gone on a clinical trial early on, I doubt whether I'd be here today. There are thousands like me who deserve the same chance. OurBrainBank is determined to use this survey to bridge the gap between trials and patients."

Fabio Iwamoto MD, Deputy Director, Division of Neuro-Oncology, Columbia University and chair of OurBrainBank's medical advisors, commented: "A patient-centered approach, combined with the opportunities technology provides, has the potential to bring trials to people, rather than the other way round. That's the challenge we have set ourselves at OurBrainBank, and it's one we know has the potential to save lives."

[OurBrainBank Clinical Trials Survey Results](#)

OurBrainBank is an innovative, patient-led movement designed to move glioblastoma (GBM) from terminal to treatable, powered by patients. Our key tool is a free app. It enables people affected by GBM to manage their disease by tracking their symptoms—an essential path to coping and surviving.

OurBrainBank, Inc. is a charitable organization tax-exempt under Internal Revenue Code Section 501(c)(3). The OurBrainBank App is certified by the New England Independent Review Board.

For further information, please contact Martha Wilkie info@ourbrainbank.org

[OurBrainBank](#), Inc. is a charitable organization tax-exempt under Internal Revenue Code Section 501(c)(3) and not a private foundation under Code Section 509(a).



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NOTE TO EDITORS

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The OurBrainBank App is made by [uMotif](#), and has been proven to work through large-scale patient studies and Randomized Controlled Trials in 21 clinical conditions. The content of the App reflects the findings from OurBrainBank's research amongst 160 people with glioblastoma. The App is beautifully designed and easy to use. Patients track symptoms and other data to help researchers gain new insights. The uMotif technology ensures patients' privacy and has been robustly tested by over 20,000 patients with conditions ranging from Arthritis to Parkinson's.

All data collected will be de-identified and made available to any qualified GBM researcher worldwide, subject to the approval of OurBrainBank's Data Access Committee, ensuring that participants' privacy is maintained. OurBrainBank's study has been accredited by the New England Institutional Research Board (IRB).

To take part, participants download the OurBrainBank App from the App Store or Google Play, and register using the code OBB100 (non-patients/caregivers may explore the App, please use the code OBBdemo). They can also register via links on www.OurBrainBank.org. The App is currently available in the US. OurBrainBank plans to extend it to other markets in the future.

[A paper published in the Journal of the American Medical Association](#) and presented at the 2017 ASCO conference shows that patients who self-track their health and use this data with their healthcare professionals have better outcomes and longer survival rates than the usual standard of care.

*Source: "The clinical trials landscape for glioblastoma: is it adequate to develop new treatments?" Vanderbeek AM, Rahman R, Fell G, Ventz S, Chen T, Redd R, Parmigiani G, Cloughesy TF, Wen PY, Trippa L, Alexander BM. Neuro Oncol. 2018 July 5;20(8):1034-1043.



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