



**THE POTENTIAL OF
PATIENT POWER**



**Progress Report
November 2019**



OurBrainBank

**Moving glioblastoma from terminal to
treatable. Powered by patients.**

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OurBrainBank is a registered nonprofit 501(c)3 #82-2307232. UK Charity #1184699
IRB-approved app is US only, expanding soon

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THE POTENTIAL OF PATIENT POWER

Our achievements, our goals

OurBrainBank was launched nearly two years ago by, with and for people living with glioblastoma. Our mission was clear: to see if a human-centered approach to tackling GBM could help people with the disease now, and in the future. Two years is a long time for a newly diagnosed GBM patient, longer than median survival. OurBrainBank has made those two years count.

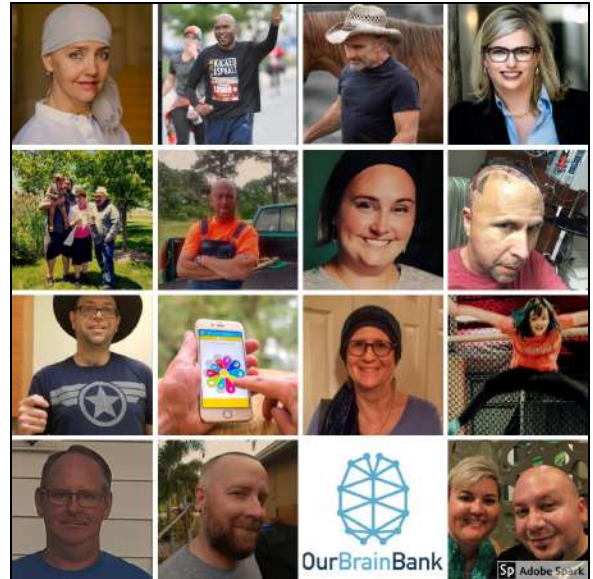
OurBrainBank is an innovative, patient-led movement designed to move glioblastoma from terminal to treatable, powered by patients.

OurBrainBank secured IRB approval and 501(c)3 status in early 2018. Our app went live in March 2018. Since then, we've recruited 530+ people to our app, collected 10,700+ data points, and added 1000+ members to our community.

Our global community is patients, care-givers, and loved ones whose lives have been affected by the deadliest of brain cancers — with the diagnosis typically coming as a life-changing shock.

The power of this shared experience is immense: it drives us forward and gives us direction as we assess what we've learned, building on our successes and branching out into new territories.

Our key initial tool is the OurBrainBank app that allows patients to track their symptoms and donate their de-identified data to research.



Post on National Glioblastoma Day, July 17, 2019

Patients love the way the app empowers them as individuals, and they want more: there's a real desire to connect with other patients, and to support each other with critical information about treatments, surgeries and strategies.

OurBrainBank conducted a survey for the first national #GBM Awareness Day to establish principles to reform the standard of care in GBM treatment. We received 400+ responses in less than a week.

Patients are overwhelmingly in favor of patient-centered changes to treatment protocols (including mandatory second opinions, genetic testing, psychological support, and fast turnaround of MRI results). The collective strength of these reactions is the springboard for our new program: OBB **Engage**. We're collaborating with patients, and other brain cancer nonprofits, to identify global principles for a GBM patient charter, to be launched in early 2020.

Recent studies reveal that symptom tracking improves quality of life and has the potential to extend survival. This powerful research supports our self-tracking methodology and helps us assess and improve our app.

In the busy world of clinical care, there's often a gap between patients and doctors — we're working to close that gap, empowering patients to be collaborators in their healthcare.

We've had great success recruiting patients, and our focus is now on retaining their active input. In symptom-tracking studies, patients are required to share their self-tracked data with their medical teams — that data has immediate value, and treatments are adjusted accordingly.

While we encourage our app-users to share their data, not everyone is doing this, and without feedback, interest wanes.



As motivation, we offer a 100 Day Certificate (signed by Fabio Iwamoto MD, Deputy Director Neuro-Oncology at Columbia University and Chair of our Medical Advisors, Bruce Hellman, CEO of uMotif, designer of our app, and OBB Technical Advisor, and Jessica Morris, Founder and Chair of OBB) plus a beautiful pin badge by designer Diana Kane.

Our new program, OBB **Explore**, works to meet the demand from scientists who want to use the data we've collected to drive progress in the field, as well as the demand from doctors and patient groups in other countries who want to bring the app to their communities.

We're pleased that doctors in the US, UK, Australia and Singapore are including our app in their studies and trials, bringing hundreds of new users to our app, and to our growing, global community.

Our app will go live in the UK on December 3rd 2019, when we launch OurBrainBank UK with a pro bono ad campaign including large-scale digital billboards in London's city center.

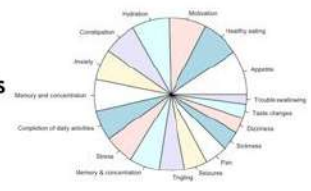
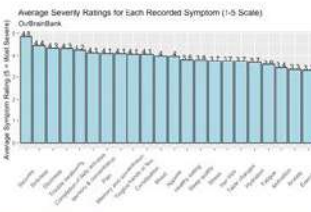
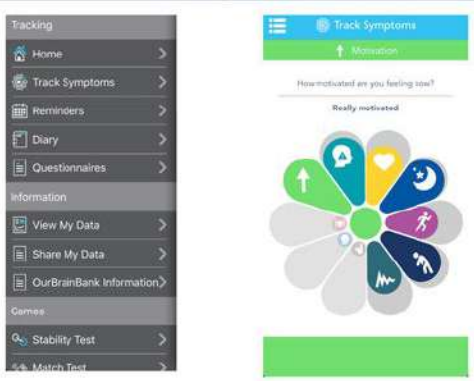


Another of our surveys revealed a gap between patients and clinical trials. The vast majority of our GBM community believes that trial enrollment has the potential to improve outcomes, but had not been offered a trial. A brand new venture, OBB **Empower**, will focus exclusively on matching GBM patients with clinical trials.

Each member of our community is a collaborator; each shares the desire for better understanding, better treatments, better outcomes. We are listening and we are learning. We are working together, growing in strength and in number, to achieve our mission: **to move GBM from terminal to treatable, powered by patients.**



OurBrainBank Founder, Jessica Morris

Our data

A smartphone-based symptom assessment (OurBrainBank) for subjects with glioblastomas Jessica Morris, Kelli Duprey, Bruce Hellman, Jacob Ellen, Lakshmi Nayak, Fabio Iwamoto		
Background	Methods	Results
<ul style="list-style-type: none"> Self-reports from patients done monthly or every few months in the doctor's office have several limitations, including poor recall, under- or over-reporting of events, among other biases. We developed a glioblastoma specific app (OurBrainBank) using a platform designed by uMotif, which was previously used in other conditions but has been customized for glioblastoma. All data is sent to a HIPPA compliant database. Subjects can view or export their own data as well. This study was initiated and led by patients with glioblastomas who are active on social media. 	<ul style="list-style-type: none"> Recruitment was mostly through social media, word-of-mouth. Parameters such as sleep quality, exercise, mood, and fatigue were captured in all. Patients were allowed to pick 6 other relevant parameters. Here we report analyses from March 2018 - Nov 2019. Symptoms tracked informed by survey of 512 GBM patients. 	<ul style="list-style-type: none"> 512 patients (255M, 257W) Median age 50 (18-83) Time from GBM diagnosis <ul style="list-style-type: none"> < 1yr: 53% 1-2 years: 25% 2-5 years: 19% > 5 years : 3% Total number of motifs submitted: 10,828 Most patients found symptom tracking useful(average rating of 7 in 0-10 scale) <p>Parameters most commonly tracked (sleep quality, exercise, mood + fatigue were mandatory for all)</p>  <p>Average Severity Ratings for Each Recorded Symptom (1-5 Scale)</p> 
<h3>Methods</h3> <ul style="list-style-type: none"> This is an IRB-approved study (New England IRB). Inclusion criteria included: <ul style="list-style-type: none"> age 18 years or older diagnosis of glioblastoma English-speaking subject availability of a smartphone or tablet with iOS or Android All patients provided electronic informed consent. 	<h3>Figures</h3>  <p>Screen shots of the app tracking capabilities and the 'petal' motifs</p> 	<h3>Conclusions</h3> <ul style="list-style-type: none"> This is the first app for symptom tracking developed for and by patients with glioblastomas. This is a grassroots organization developed and run by glioblastoma patients with the objective of capturing the patient experience with significant more granularity to improve outcomes. This study is ongoing and the next steps are: <ul style="list-style-type: none"> to accrue more patients to expand internationally to integrate into clinical trial to advocate for improved standard of care protocols <p>Contact details: info@ourbrainbank.com www.ourbrainbank.com</p> 

Updated version of the poster presented by Dr. Fabio Iwamoto of Columbia University at SNO 2018

Our approach

A patient-centered approach to medicine is increasingly considered best practice. Symptom tracking is central to this approach.

Shifting conventional thought on glioma is important because, more so than in many other types of cancer, symptoms of the disease play a key part in the disease process.¹

— Terri Amstrong, Senior Investigator at the Center for Cancer Research Neuro-Oncology Branch of the National Cancer Institute, and OBB MedicalAdvisor

The OBB app is a self-tracking tool which enables GBM patients to provide evidence-based information to their medical teams — vital when the time between visits is weeks, often months.

Research shows that cancer patients who self-track and share their health data could have better outcomes and survival rates.

The formative symptom-monitoring study led by Ethan Basch, (presented at ASCO 2017) concluded that clinical benefits are associated with symptom self-reporting in cancer patients².

Another study conducted by health sciences researcher Lisa Barbera at the University of Calgary (presented at ASCO 2019) revealed similar results.

There is a strong argument to be made for using these measures (self-reporting) in routine care... this idea, that we have to change how we do our assessments with patients, is paradigm-shifting.³

— Lisa Barbera, University of Calgary

Jeffrey Wefel PhD, Associate Professor and Neuropsychology Section Chief in the Department of Neuro-Oncology, University of Texas MD Anderson Cancer Center, conducted a study on GBM patients, the results of which “suggest that routine neuropsychological assessment of mood and cognition may help refine prognosis and facilitate initiation of psychological and cognitive interventions, which can improve patient quality of life.”⁴

Many medical centers and individuals throughout the neuro-oncology community are looking for ways to integrate patient-based symptom reporting into clinical workflows. It is critical to make patients a partner in their choices.

— Jeffrey Wefel to Jessica Morris

1

<https://www.nature.com/articles/d41586-018-06706-5>

2

<https://meetinglibrary.asco.org/record/147027/abstract>

3

https://www.washingtonpost.com/health/for-some-cancer-patients-monitoring-symptoms-can-extend-their-lives/2019/11/01/81f438a6-de31-11e9-8dc8-498eabc129a0_story.html?fbclid=IwAR1HCeuJkHqZkN-DT2GlmkedidbIYsj28R2XPlkemfZbgyhWNUqv4K4zfH0

4

https://www.researchgate.net/publication/330608268_Depressive_symptoms_and_executive_function_in_relation_to_survival_in_patients_with_glioblastoma

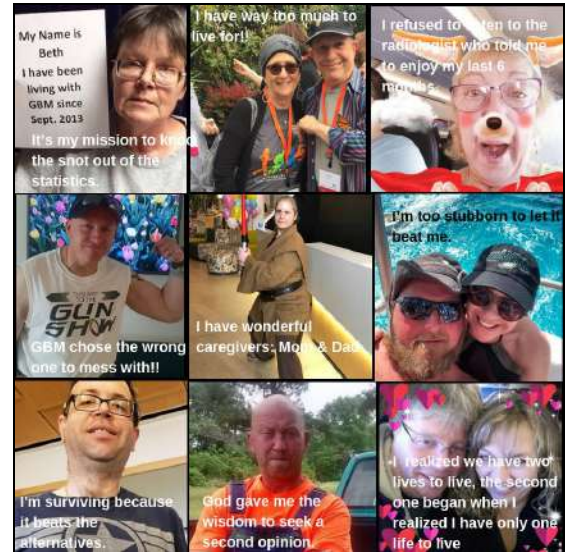
Our community

Our online community is active, engaged and growing!

Patients and caregivers engage on a daily basis, supporting each other, sharing advice, information and insights.

OurBrainBank Voices live video chats focus on relevant issues such as access to trials, keto diet, health insurance. Many chats are hosted by experts in the field — some living with GBM themselves.

Our community also represents a significant portion of the GBM community at large — a ready-made patient pool for researchers offering the potential to speed up trial recruitment.



Social media stats, analytics, and recruitment numbers

- [Twitter.com/ourbrainbank](https://twitter.com/ourbrainbank): 766 followers
- [Facebook.com/OurBrainBank](https://facebook.com/OurBrainBank) (page): 1007 followers; 100+ fundraisers
- [Facebook.com/groups/OurBrainBank](https://facebook.com/groups/OurBrainBank) (group): 729 members
- [YouTube.com/c/OurBrainBankForGlioblastoma](https://youtube.com/c/OurBrainBankForGlioblastoma): 142 followers, 27 videos
- [Instagram.com/OurBrainBankForGlioblastoma](https://instagram.com/OurBrainBankForGlioblastoma): 232 followers
- OurBrainBank Voices/Patient Advisors: 25

Twitter



Facebook



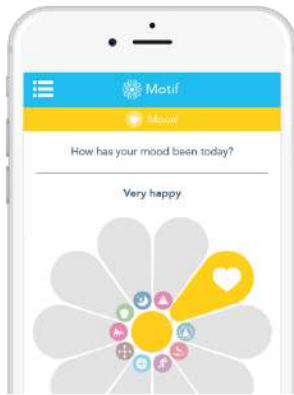
Our surveys

Online surveys are an excellent tool to gather opinions; patients want their voices heard. We've conducted two in 2019: one on clinical trials, and another on regulatory and medical reforms to the GBM standard of care. 162 people took the clinical trials survey⁵ and 400+ people took the standard of care survey.⁶ We conducted this to coincide with the first GBM Awareness Day, July 17th, 2019. The surveys' success indicates the motivated nature of the GBM community and the huge need for change in treatment and trial protocols.



Our app

OBB leverages technology designed by uMotif, which designed a modular platform for e-consent, eCOA/ePRO data capture, and patient engagement. The OBB app is aesthetically pleasing, easy to use, and the underlying technology has been through a rigorous process to protect patient confidentiality.



Through a screen that looks like a flower with 10 petals ("motifs"), people swipe on a petal to select a score on aspects of quality of life that matter to them. This method has been used in one-off studies of more than 100 conditions including Parkinson's disease, rheumatoid arthritis, and chronic pain. Patients can view, download and share their own data, and anonymized data is made available for research purposes. **It empowers patients while also advancing research.**

Clinical research to discover new and improved drugs, therapies, devices, and methods is historically designed around the needs of researchers, clinicians, and data managers. The status quo fails to fully engage the most important stakeholder: the patient.

— Bruce Hellman uMotif, OBB TechnicalAdvisor, designer of the OBB app

Patients love our app

App users complete a satisfaction questionnaire after 100 days of app use, and the results of this survey are overwhelmingly positive.

The OurBrainBank app has helped me to monitor my progress. My data is there for me to review during my ups and downs of my journey.

— Bratton Fennell



⁵ <http://www.ourbrainbank.com/media/trials-survey>

⁶ <http://www.ourbrainbank.com/media/GBMDay>

I very much enjoy it! It makes me aware of how I'm feeling, whereas before I never gave it much thought. Now I can visualize and make adjustments as needed. I think it will be a great tool for doctors visits too. I can't always remember how I've been feeling so now I can see!

— Alex O.

This approach is very important to me, it's keeping doctors and patients up to speed on symptoms and ways to control them, which will inevitably lead to the cure. I believe the more facts the better.

— Michael C.

OBB is extremely important so that we can monitor and track the data from people that are going through GBM, in order to build a bigger set of data, in order to better understand this disease, so that future patients can benefit from us.

— Meredith Moore, OBB board member, living with GBM since 2005

The OurBrainBank app was extremely helpful in keeping track of treatment side-effects. I'm two years post-diagnosis, 21 months No Evidence of Disease. I'm still recovering from treatment, and I also still use OurBrainBank frequently to track fatigue and sleep issues.

— Patrick K.

I have been using the OurBrainBank App since shortly after my diagnosis and I find it extremely useful in monitoring my daily symptoms!"

— Lynn O.



This is amazing!! I LOVE tracking the different symptoms such as memory issues, as hubby doesn't remember having any. I'm looking forward to being able to bring this to our NO to share. As a caregiver for my husband—I can tell you this is much needed!

— Anonymous.

I'm looking forward to being able to bring this to my NO to share. I'm positive she'll tell her other patients about it as well! Thank you so much. It's obvious a lot of effort went into this and you all should be very proud of the gift you've created and are sharing with the rest of us."

— Anonymous

Doctors love our app

OurBrainBank will collect data that is vital to researchers seeking to turn glioblastoma around. The key to tackling this disease lies in research, and for too long we've lacked this critical insight from patients. The OurBrainBank app closes that gap, and I'm excited at the implications. This has the potential to have a real impact on our ability to extend lives.

— Fabio Iwamoto MD, Deputy Head of Neuro-Oncology at Columbia University; Chair, OBB Medical Advisors

We've been approached by doctors and trial specialists in the US, UK, Australia, and Singapore who want to use our app in their studies. The app content is easily customizable for particular symptoms/interests of specific studies. These studies will bring hundreds of new users to our app, and to our community.

Dr. Kim Kaufman (Head of Cancer Research) and Dr. Brindha Shivalingam (Director of Neurosurgery) are at Chris O'Brien Lifehouse, one of the premier comprehensive cancer centers in Australia. Their study, GlioNET, is a multi-center observational trial for newly diagnosed glioma patients, aiming to track and observe patients over the entire course of their cancer journey.

We love the OurBrainBank app — it's a user-friendly, elegant solution to capturing this really important, but under-sampled information. We are so pleased to be able to bring it to Australia and offer it to patients enrolling on our GlioNet observational study.

— Dr. Kim Kaufman

Dr. Florian Boele, Leeds Institute of Medical Research at St James's/Leeds Institute of Health Sciences, gained ethics approval for use of the OBB app in the UK and we're planning to launch soon.

We aim to make the OurBrainBank app available to patients in the United Kingdom, and to learn about patient participation and compliance. The app is simple and intuitive and I am excited to be able to collect and analyse this important data.

— Dr. Florian Boele

Dr. Laura Donovan, Neuro-oncology attending at Columbia University, is developing a mindfulness-based intervention for people with brain cancer and their caregivers. She wants to use our app to measure patient-reported outcomes.

The OurBrainBank app is intuitive and easy to use. As a researcher, I like that the symptom wheel can be customized to track the same symptoms across all study participants. The fact that this app was designed by people with glioblastoma makes it unique among other symptom monitoring apps. As a clinician and researcher, OurBrainBank provides an invaluable opportunity to partner directly with people living with glioblastoma to help improve the experience of people living with this disease.

— Dr. Laura Donovan



OurBrainBank at conferences

- Head to the Hill, NBTS 2018
- ASCO 2018, 2019
- ABTA National Conference, 2018
- Biden Cancer Summit, 2018
- Partnerships in Clinical Trials Europe: Jessica Morris presented with Dr. Alexis Demopoulos, 2018
- SNO Dr. Fabio Iwamoto presented poster: "Pilot Study of a Smartphone-Based Symptom Assessment for Subjects with Glioblastomas" Abstract published, 2018
- IBTA 4th Biennial World Summit of Brain Tumour Patient Advocates, 2019
- GBM Drug Development Summit: Jessica Morris opening speaker, December 2019



Our Programs

OBB Explore

We're continually exploring how our self-tracking technology and data can best serve patients and the medical community, and how to expand our user-base in the US, and internationally. Global expansion is already in full swing — see “Doctors love our app” above.

OurBrainBank UK is planned to launch in London on 3 December 2019!



OBB Engage

We're joining a collaboration with the International Brain Tumour Alliance and the National Brain Tumor Society who have been updating and broadening the Brain Tumour Patients Charter of Rights in conjunction with other brain tumor nonprofits around the world. The new Charter will significantly expand on the previous Charter and contains patient-centered principles covering the various rights, challenges and aspirations along the trajectory of the brain tumor patient and caregiver journey.

The International Brain Tumour Alliance is proud to be working with the National Brain Tumor Society, OurBrainBank and many other brain tumour patient and caregiver organisations around the world to produce a Charter for the rights, challenges and aspirations of the global brain tumour community.

— Kathy Oliver, Chair and Co-Director, International Brain Tumour Alliance

National Brain Tumor Society is pleased to be collaborating with OurBrainBank to identify and ultimately act on patient-centered health care principles that benefit glioblastoma patients and hopefully all brain tumor patients and caregivers.

— David Arons, CEO, National Brain Tumor Society

OBB Empower

Led by Daniel Orringer MD, neurosurgeon at NYU Langone and OBB Medical Advisor, we're investigating a new venture to close the gap between patient need and trial supply. Our clinical trial survey revealed:

- 95% of patients believe that trial enrollment would enhance their sense of wellbeing and longevity
- fewer than 10% of patients enroll in clinical trials
- fewer than 30% of patients were able to find a trial for which they were eligible
- the majority of patients have not been offered a clinical trial
- when patients asked physicians about clinical trials, 80% were told to stick with standard treatment or discouraged from pursuing a clinical trial

These statistics are alarming because we know that clinical trials and experimental treatments are essential to saving lives. OBB Empower is working towards a human-centered clinical trial matching program for patients with GBM.

Our collaborative team

Board

Jessica Morris, Founder and Chair

Kelli Duprey, Treasurer, Senior Pharmaceutical Executive

Andi Phillips, CEO, Maycomb Capital

Claire Wright, Entrepreneur and Attorney

Stacy Chick, Commercial Biotechnology and Diagnostics Executive

Meredith Moore, Founder and Principal of Moore & Associates Wealth Management. Living with GBM since 2005

Nancy Kuhn, Fundraising and Development Consultant. Living with GBM since 2014

Gail Fosler, President of The GailFosler Group LLC



Medical and technical advisors

Fabio Iwamoto, MD, Neuro-oncologist, Columbia University

Terri Armstrong, Senior Investigator, NIH

Marina Benaur, MD, Assistant Clinical Professor of Psychiatry, Columbia University-New York Presbyterian

Alexis Demopoulos, MD, Neuro-oncologist, Northwell Hospital

Bruce Hellman, CEO, uMotif, developer of OurBrainBank App

Mario Lacouture, MD, Dermatologist, Memorial Sloane Kettering

Lakshmi Nayak MD, Neuro-Oncologist, Dana-Farber Cancer Institute

Daniel Orringer, MD, Neuro-surgeon, NYU Langone

Joshua Silverman, MD, Radiotherapist, NYU Langone

