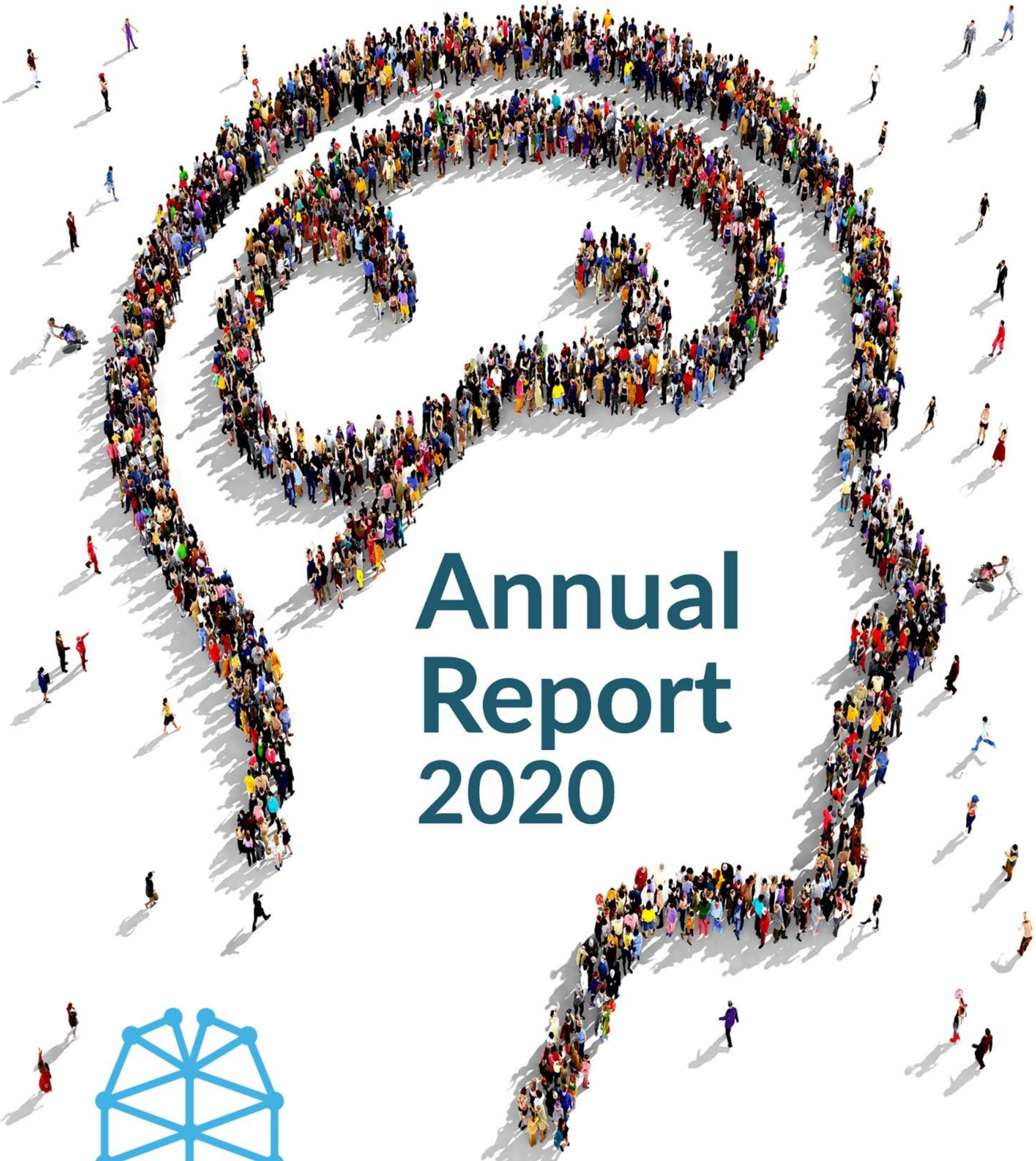


Annual Report 2020

OurBrainBank

Moving glioblastoma from terminal to treatable, powered by patients

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

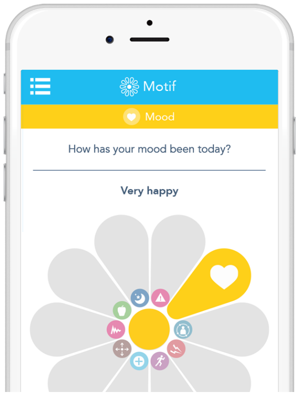
Overview

OurBrainBank launched in 2018 — the first non-profit created by, with, and for people living with glioblastoma.

Our mission: to move glioblastoma from terminal to treatable, powered by patients. Our key tool is a study using a free smartphone app. The app is used by people living with GBM or their care partners to track symptoms and health indicators. The de-identified data generated is then donated for research. Studies show that symptom tracking improves quality of life and has the potential to extend survival. This powerful research supports our self-tracking methodology.

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. Founder Jessica Morris (above) has been living with GBM since 2016.

Our study & app



Since our launch in 2018, more than 700 patients and carers have downloaded the app. In 2020, 98 people in the US, and 55 in the UK, downloaded the app, joining the hundreds of fellow travellers already in the study.

The app helps people cope with their disease day by day, by providing them with an efficient way to track and share health data with their medical teams. Also by turning their symptoms into data for researchers, their experience could help others in the future.

People love the way the app empowers them as individuals, and they want more: there's a real desire to connect with other patients and care partners.

Key features:

- free from the App Store or Google Play
- allows patients/carers to monitor symptoms and quality of life indicators
- allows patients/carers to track neurological function with games that test memory, balance, and processing time
- allows patients to view their data, compare their symptoms (e.g. exercise can improve mood), and view changes over time
- allows patients to share data with others, including their healthcare team
- can be paired with health trackers like FitBit and Garmin

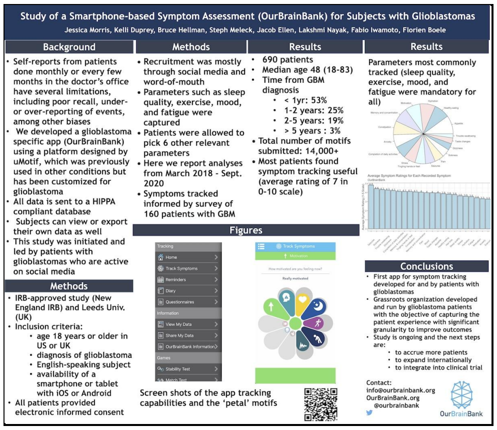
- has a journal feature and medication reminders

> *The OurBrainBank app has helped me to monitor my progress. My data is there for me to review during the ups and downs of my journey.*
> — Bratton Fennell

Study recruitment

We have real-time access to app download numbers and the ability to track the success of our methods of outreach. Our Facebook group is larger than our pool of app users, but there is significant overlap between the two. Facebook — our page and our group — is currently the most successful means of recruiting for our study.

We are constantly working to build our brand in order to drive recruitment. This work is done through social media, press and media coverage, conferences and awards, collaboration with other nonprofits, and outreach to medical professionals and academics.



Study of a Smartphone-based Symptom Assessment (OurBrainBank) for Subjects with Glioblastomas

Jessica Morris, Kelli Duprey, Bruce Hellman, Steph Meleck, Jacob Ellen, Lakshmi Nayak, Fabio Iwamoto, Florien Boele

Background

- 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

Methods

- IRB-approved study (New England IRB) and Leeds Univ. (UK)
- Inclusion criteria:
    - age 18 years or older in US or UK
    - diagnosis of glioblastoma
    - English-speaking subject
    - availability of a smartphone or tablet with iOS or Android
- All patients provided electronic informed consent

Methods

- Recruitment was mostly through social media and word-of-mouth
- Parameters such as sleep quality, exercise, mood, and fatigue were captured
- Patients were allowed to pick 6 other relevant parameters
- Here we report analyses from March 2018 - Sept. 2020
- Symptoms tracked informed by survey of 160 patients with GBM

Results

- 690 patients
- Median age 48 (18-83)
- Time from GBM diagnosis
    - < 1yr: 53%
    - 1-2 years: 25%
    - 2-5 years: 19%
    - > 5 years : 3%
- Total number of motifs submitted: 14,000+
- Most patients found symptom tracking useful (average rating of 7 in 0-10 scale)

Figures

Screen shots of the app tracking capabilities and the 'petal' motifs

Results

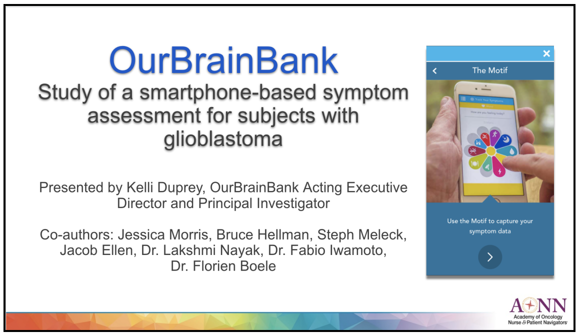
Parameters most commonly tracked (sleep quality, exercise, mood, and fatigue were mandatory for all)

Conclusions

- First app for symptom tracking developed for and by patients with glioblastomas
- Grassroots organization developed and run by glioblastoma patients with the objective of capturing the patient experience with significant granularity to improve outcomes
- Study is ongoing and the next steps are:
    - to accrue more patients
    - to expand internationally
    - to integrate into clinical trial

Contact:
info@ourbrainbank.org
OurBrainBank.org
@ourbrainbank

OurBrainBank



OurBrainBank

Study of a smartphone-based symptom assessment for subjects with glioblastoma

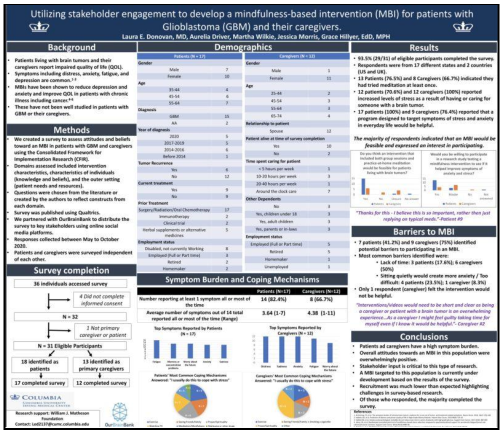
Presented by Kelli Duprey, OurBrainBank Acting Executive Director and Principal Investigator

Co-authors: Jessica Morris, Bruce Hellman, Steph Meleck, Jacob Ellen, Dr. Lakshmi Nayak, Dr. Fabio Iwamoto, Dr. Florien Boele

Conferences & speaking engagements

We presented/participated/published at the following conferences in 2020

- SNO2020 (virtual) — we partnered with Dr. Laura Donovan in her abstract on mindfulness-based interventions for GBM patients
- ABTA Virtual Annual Conference
- ASCO Virtual Annual Conference
- NBTS Virtual Head to the Hill
- EBCI Virtual "Together and Action Day"
- AONN+ Virtual Annual Conference
- GBM Drug Development Summit — Meredith Moore, OBB board member, offered the patient voice



Utilizing stakeholder engagement to develop a mindfulness-based intervention (MBI) for patients with Glioblastoma (GBM) and their caregivers.

Laura E. Donovan, MD, Aurelia Driver, Martha Wilkie, Jessica Morris, Grace Hillyer, EdD, MPH

Background

- Patients living with brain tumors and their caregivers report impaired quality of life (QOL).
- Symptoms including distress, anxiety, fatigue, and depression are common.[1-3]
- MBIs have been shown to reduce depression and anxiety and improve QOL in patients with chronic illness including cancer.[4-6]
- These have not been well studied in patients with GBM or their caregivers.

Methods

- We created a survey to assess attitudes and beliefs toward an MBI in patients with GBM and caregivers using the Consolidated Framework for Implementation Research (CFIR).
- Domains assessed included intervention characteristics, characteristics of individuals (knowledge and beliefs), and the outer setting (patient needs and resources).
- Questions were chosen from the literature or created by the authors to reflect constructs from each domain.
- Survey was published using Qualtrics.
- We partnered with OurBrainBank to distribute the survey to key stakeholders using online social media platforms.
- Responses collected between May to October 2020.
- Patients and caregivers were surveyed independent of each other.

Survey completion

36 individuals accessed survey
4 Did not complete informed consent
N = 32
1 Not primary caregiver or patient
N = 31 Eligible Participants
18 identified as patients
13 identified as primary caregivers
17 completed survey
12 completed survey

COLUMBIA
Columbia University Irving Medical Center

Research support: William J. Matheson Foundation
Contact: Led2137@cumc.columbia.edu

OurBrainBank

Demographics

Patients (N = 17)	
Gender	
Male	7
Female	10
Age	
35-44	4
45-54	6
55-64	7
Diagnosis	
GBM	15
AA	2
Year of diagnosis	
2020	5
2017-2019	5
2014-2016	6
Before 2014	1
Tumor Recurrence	
Yes	6
No	12
Current treatment	
Yes	9
No	9
Prior Treatment	
Surgery/Radiation/Oral Chemotherapy	17
Immunotherapy	2
Clinical trial	2
Herbal supplements or alternative medicines	5
Employment status	
Disabled, not currently Working	8
Employed (Full or Part time)	3
Retired	2
Homemaker	2

Caregivers (N = 12)	
Gender	
Male	1
Female	11
Age	
25-44	2
45-54	3
55-64	3
65-74	4
Relationship to patient	
Spouse	12
Patient alive at time of survey completion	
Yes	10
No	2
Time spent caring for patient	
< 5 hours per week	1
10-20 hours per week	3
20-40 hours per week	1
Around the clock care	7
Other Dependents	
No	3
Yes, children under 18	3
Yes, adult children	3
Yes, parents or in-laws	3
Employment status	
Employed (Full or Part time)	5
Retired	5
Homemaker	1
Unemployed	1

Symptom Burden and Coping Mechanisms

	Patients (N=17)	Caregivers (N=12)
Number reporting at least 1 symptom all or most of the time	14 (82.4%)	8 (66.7%)
Average number of symptoms out of 14 total reported all or most of the time (Range)	3.64 (1-7)	4.38 (1-11)

Results

- 93.5% (29/31) of eligible participants completed the survey.
- Respondents were from 17 different states and 2 countries (US and UK).
- 13 Patients (76.5%) and 8 Caregivers (66.7%) indicated they had tried meditation at least once.
- 12 patients (70.6%) and 12 caregivers (100%) reported increased levels of stress as a result of having or caring for someone with a brain tumor.
- 17 patients (100%) and 9 caregivers (76.4%) reported that a program designed to target symptoms of stress and anxiety in everyday life would be helpful.

The majority of respondents indicated that an MBI would be feasible and expressed an interest in participating.

"Thanks for this - I believe this is so important, rather then just replying on typical meds."-Patient #9

Barriers to MBI

- 7 patients (41.2%) and 9 caregivers (75%) identified potential barriers to participating in an MBI.
- Most common barriers identified were:
    - Lack of time: 3 patients (17.6%); 6 caregivers (50%)
    - Sitting quietly would create more anxiety / Too difficult: 4 patients (23.5%); 1 caregiver (8.3%)
- Only 1 respondent (caregiver) felt the intervention would not be helpful.

"Interventions/videos would need to be short and clear as being a caregiver or patient with a brain tumor is an overwhelming experience...As a caregiver I might feel guilty taking time for myself even if I know it would be helpful."- Caregiver #2

Conclusions

- Patients ad caregivers have a high symptom burden.
- Overall attitudes towards an MBI in this population were overwhelmingly positive.
- Stakeholder input is critical to this type of research.
- A MBI targeted to this population is currently under development based on the results of the survey.
- Recruitment was much lower than expected highlighting challenges in survey-based research.
- Of those who responded, the majority completed the survey.

References

Our poster was awarded the *AONN+ Outstanding Poster Award* in the category of "Patient Advocacy and Patient Awareness." As an award-winner, Acting Executive Director Kelli Duprey was invited to present our abstract.

OurBrainBank founder & chair, Jessica Morris, and staff members, Aurelia Driver and Martha Wilkie, were co-authors on a study done with Columbia University.

OurBrainBank Explore

OBB Explore works to meet the demand from scientists who want to use the data we've collected to drive progress, as well as the demand from doctors and patients outside the US and UK who want to bring the app to their communities.

In July 2020, we launched in Australia for patients participating in a study at the Chris O'Brien Lifehouse. Ethics approval was granted by the University of Sydney; principal Investigator is Dr. Kim Kaufman, Head of Brain Cancer Research, Department of Neuro-surgery, Chris O'Brien Lifehouse.

Everyone using the app donates their de-identified data to research. Data is freely available to researchers worldwide, subject to the approval of our Data Access Committee. Access to the data was granted to seven new GBM researchers in 2020.

OurBrainBank Empower

Led by Daniel Orringer MD, neurosurgeon at NYU Langone and OBB Medical Advisor, OBB Empower is a program to investigate a new venture to close the gap between patient need and trial supply. Our 2019 survey about clinical trials revealed that there is a huge unmet need for GBM patients to get into a trial.

In 2020, OBB hired a consulting agency, S2N Health, to research the potential of a GBM-specific clinical trial matching program. S2N made an extensive presentation with recommendations to the board and staff. In 2021, we hope to explore the best way to ensure that patients have access to clinical trials in the US.

OurBrainBank Engage

Engage is our advocacy program — we support people living with GBM, promote awareness about GBM, and work with fellow brain cancer advocacy groups to encourage the developments of new and better treatments.

> *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

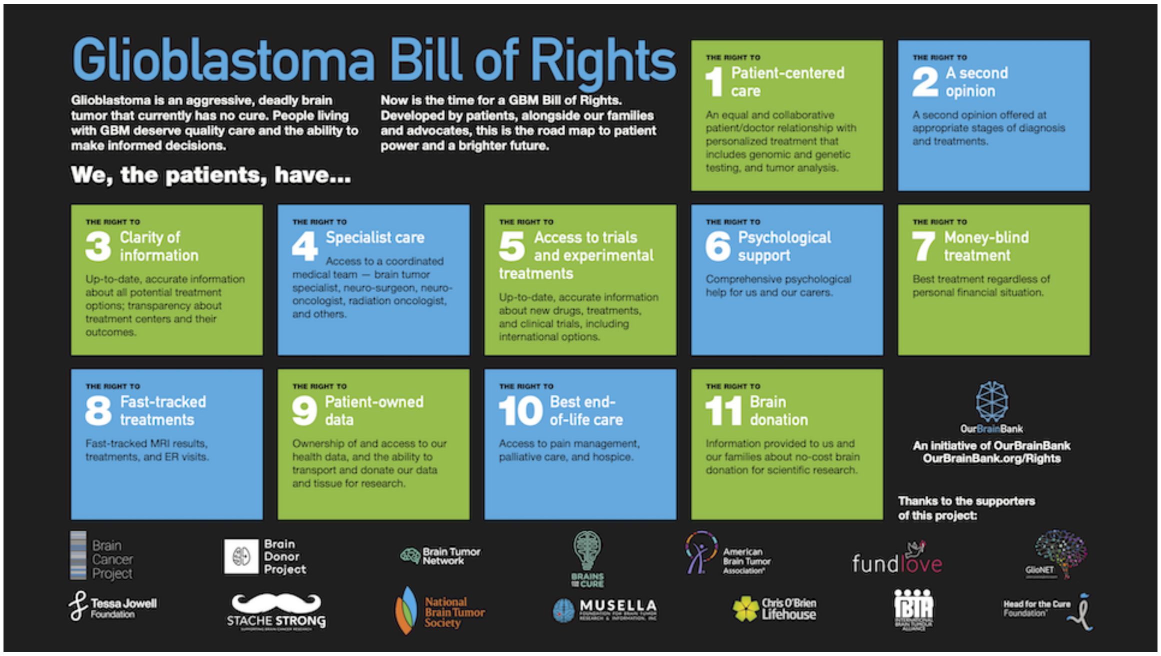
> *National Brain Tumor Society is pleased to be collaborating with OurBrainBank to identify and ultimately act on patient-centered health care principles that benefit glioblastoma patients and hopefully all brain tumor patients and caregivers.*
> — David Arons, CEO, National Brain Tumor Society

Glioblastoma Bill of Rights

July 22nd, 2020 was GBM Awareness Day, a day to honor everyone affected by this disease and raise awareness. To mark this day, we launched the Glioblastoma Bill of Rights. This initiative is supported by major global cancer nonprofits, including the International Brain Tumour Alliance, the American Brain Tumor Association and the National Brain Tumor Society, the Tessa Jowell Foundation, and the Chris O'Brien Lifehouse.

The graphic was widely shared on social media using #GBMRights. An accompanying video with patients, carers, and advocates reading the rights received hundreds of views and the National Brain Tumor Society featured it in their virtual event.

Founder Jessica Morris said, "The GBM Bill of Rights is a practical and aspirational tool for all of us. Empowered to demand these rights, we have the ability to improve quality of life and outcomes, and to move the needle on this devastating disease."



Glioblastoma Bill of Rights

Glioblastoma is an aggressive, deadly brain tumor that currently has no cure. People living with GBM deserve quality care and the ability to make informed decisions.

Now is the time for a GBM Bill of Rights. Developed by patients, alongside our families and advocates, this is the road map to patient power and a brighter future.

We, the patients, have...

THE RIGHT TO **1 Patient-centered care**
An equal and collaborative patient/doctor relationship with personalized treatment that includes genomic and genetic testing, and tumor analysis.

THE RIGHT TO **2 A second opinion**
A second opinion offered at appropriate stages of diagnosis and treatments.

THE RIGHT TO **3 Clarity of information**
Up-to-date, accurate information about all potential treatment options; transparency about treatment centers and their outcomes.

THE RIGHT TO **4 Specialist care**
Access to a coordinated medical team — brain tumor specialist, neuro-surgeon, neuro-oncologist, radiation oncologist, and others.

THE RIGHT TO **5 Access to trials and experimental treatments**
Up-to-date, accurate information about new drugs, treatments, and clinical trials, including international options.

THE RIGHT TO **6 Psychological support**
Comprehensive psychological help for us and our carers.

THE RIGHT TO **7 Money-blind treatment**
Best treatment regardless of personal financial situation.

THE RIGHT TO **8 Fast-tracked treatments**
Fast-tracked MRI results, treatments, and ER visits.

THE RIGHT TO **9 Patient-owned data**
Ownership of and access to our health data, and the ability to transport and donate our data and tissue for research.

THE RIGHT TO **10 Best end-of-life care**
Access to pain management, palliative care, and hospice.

THE RIGHT TO **11 Brain donation**
Information provided to us and our families about no-cost brain donation for scientific research.

OurBrainBank
An initiative of OurBrainBank
OurBrainBank.org/Rights

Thanks to the supporters of this project:

Media coverage

In 2020, we secured significant attention both in the US and the UK, including an op-ed in ***The New York Times***.

- *Health facts: Patient's app can teach medics about brain cancer* The Irish News, October 16, 2020
- *We Are Living With Brain Cancer. Here's How Biden Could Help Us* The New York Times (Op-ed by Jessica Morris and Jana Bennett), Aug. 22, 2020
- *Connecting OurBrainBank* MyHealthAppsBlog.com, April 2020

GBM community

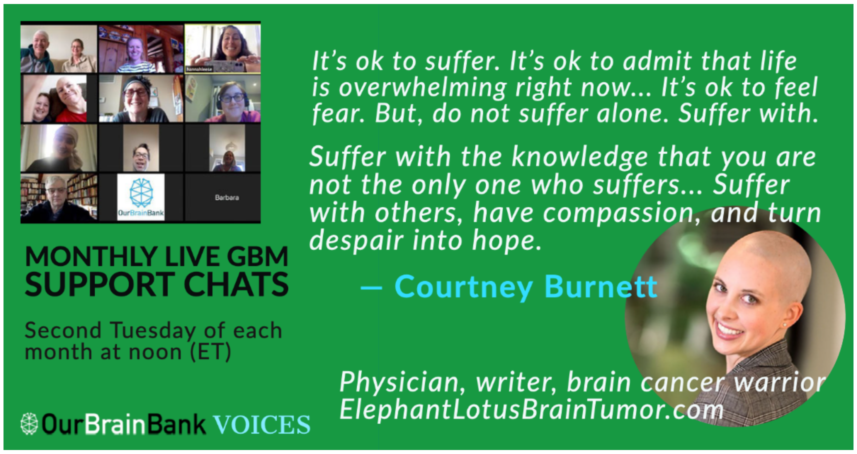
Our community is growing — people living with GBM and their loved ones engage on a daily basis with support, advice, and resources. In 2020, our Facebook group grew from 729 to 1331 members — an increase of nearly 100%. Our community represents a significant portion of the GBM community at large — a ready-made patient pool for researchers offering the potential to speed up trial recruitment.

Our other platforms showed remarkable growth in 2020:

- Twitter.com/ourbrainbank: 1170 followers (404 new)
- Facebook.com/OurBrainBank (page): 1461 followers (454 new), 100+ fundraisers
- Facebook.com/groups/OurBrainBank: 1331 members
- YouTube.com/c/OurBrainBankForGlioblastoma: 192 followers, 51 videos (40 new followers, 24 new videos)
- Instagram.com/OurBrainBankForGlioblastoma: 128 posts, 555 followers
- Newsletter: 1576 subscribers (520 new subscribers)
- LinkedIn.com/company/OurBrainBank: 85 followers

OurBrainBank Voices chats and focus groups

In this pandemic year, the power of online groups to provide connection and support grew exponentially. Along with our regular Voices chats, we held focus groups with GBM patients and carers to improve our understanding of their needs and priorities.



It's ok to suffer. It's ok to admit that life is overwhelming right now... It's ok to feel fear. But, do not suffer alone. Suffer with.

Suffer with the knowledge that you are not the only one who suffers... Suffer with others, have compassion, and turn despair into hope.

— Courtney Burnett

Physician, writer, brain cancer warrior
ElephantLotusBrainTumor.com

> *Connecting with people in the same situation is crucial in finding hope.*
> — Courtney, living with a brain tumor (focus group 11/22/20)

> *In the beginning, I was clamouring for community engagement. I needed to know that the symptoms I was experiencing were common, anticipated, and likely to pass.*
> — Ken, living with GBM (focus group 11/22/20)

> *Doctors don't prepare the caregivers for what is going to happen in terms of symptoms and side effects. I googled at the beginning but the real data, what really happens — that I've got from the online support groups. I would have been a horrible caregiver without that.*
> — Dana, caregiver (focus group 11/29/20)

In 2020, we held 16 Voices chats, some hosted by people living with GBM. Hosts included:

- Renae Adams, Thought Leader Liaison, Novocure
- Dr. Courtney Burnett, physician and author, living with a brain tumor
- Dr. Laura Donovan, Columbia Medical School, on mindfulness for cancer patients
- Dr. Alexis Demopolous, Norwell Health, neurologist and neuro-oncologist
- Dr. Rohan Ramakrishna, Neurosurgeon, Weill Cornell, “Ask a Doctor”
- Dr. Lakshmi Nayak, neuro-oncologist, Dana-Farber
- Dr. Adrienne C. Scheck, Institute of Molecular Medicine at Phoenix Children’s Hospital, on the ketogenic diet for cancer
- Tammy Bernard, Yoga Therapist, University of Florida Hospital
- Tish Hevel, CEO, Brain Donor Project
- Tracy Edwards, Social Worker, Brain Tumor Network
- Rachael Kittleson, Director of Community Relations, NBTS
- Colin Gerner, GBM advocate, StacheStrong
- Lynn Oxenberg, GBM patient, how she stays inspired
- Hannah Leese, GBM patient, on being newly diagnosed
- Patrick Koskie-McBride, GBM patient and research scientist
- Yaron Butterfield, GBM patient and research scientist

Surveys

Online surveys are an excellent tool to gather opinions; patients want their voices heard. In advance of GBM Day July 22, 2020, we asked people to share their individual experiences as they relate to the GBM Bill of Rights. More than 100 people responded.

The results show that while some people get excellent treatment, others do not. Also key “rights” such as receiving information about palliative care and tissue donation, aren’t communicated to most people.

Boards

We have active, multi-disciplinary, highly skilled boards composed of professionals with experience in healthcare marketing, strategic communications, media, patient advocacy, non-profit management and social impact financing; several are GBM patients or carers.

This year we had three excellent additions to the Board:

- Rod Nordland, living with GBM (diagnosed in 2019), is an international correspondent for *The New York Times*. Rod is writing a book on his experiences as a war correspondent and on GBM.
- Theresa Schaub, living with GBM (diagnosed in 2017), is co-founder and CCO of Meru Biotechnologies
- Ed Pilkington is a GBM carer and Chief Reporter at The Guardian US

Medical and technical advisors

OurBrainBank benefits from a robust group of Medical Advisors co-headed by leading neuro-oncologists Fabio Iwamoto, MD of Columbia University, and Lakshmi Nayak, MD of the Dana-Farber Cancer Institute. This committee brings specialists in neuro-surgery, neuro-oncology, psychiatry, dermatology, and radiology.

In 2020, we added two world-class experts to this team:

- E. Antonio Chiocca, MD, PhD, Harvey Cushing Professor of Neuro-surgery at Harvard Medical School, Neurosurgeon-in-Chief and Chairman, Department of Neuro-surgery at Brigham and Women's Hospital and Director of Surgical Neuro-oncology, Dana Farber Cancer Institute
- David A. Reardon, MD, Clinical Director, Center for Neuro-Oncology at the Dana-Farber Cancer Institute, and Professor of Medicine, Harvard Medical School

Next Steps

As we enter 2021, OurBrainBank founder and chair Jessica Morris, OBB staff, and board members are continuing and expanding our work. We hope to expand, help more people living with GBM and their families, and work with researchers of all stripes — including emerging technology such as artificial intelligence and machine learning — to meet our goal: moving GBM from terminal to treatable, powered by patients.

Fundraising

In 2020, our donations came from (in order of amount): pharmaceutical/device companies, Facebook birthday fundraisers, individual and family foundation giving, GoFundMe campaigns, speaking engagement honorariums, and donor advised funds.

For 2021, we hope to increase individual giving as well as explore new opportunities such as on-line gaming, Instagram giving, and foundation and grant-making institutions.

Please consider OurBrainBank in your end-of-year giving

Thank you to all who support us!

OurBrainBank.org

Ask your employer about gift-matching plans

OurBrainBank Founder, Jessica Morris

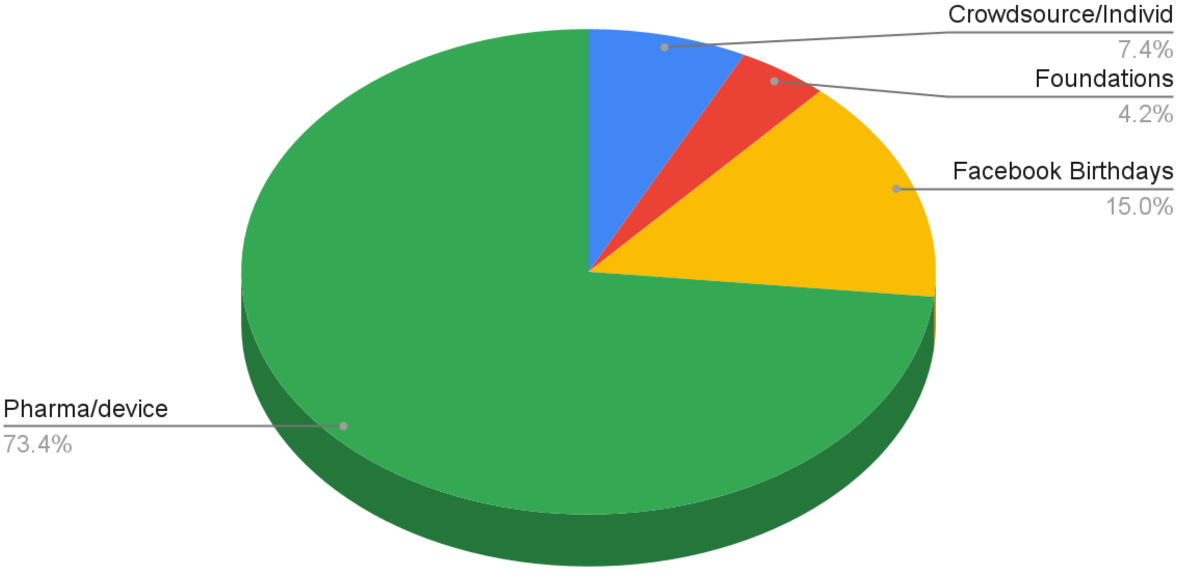
OurBrainBank

Moving glioblastoma from terminal to treatable, powered by patients

2020 Financials

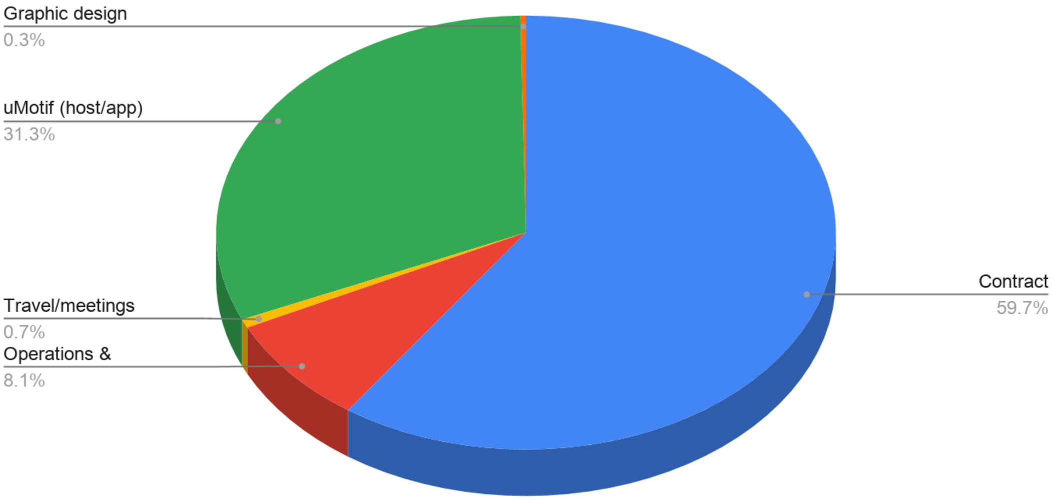
Funding sources: total: $272,696.21

- Crowdsource/ individuals: $20,179.88
- Foundations: $11,555.00
- Facebook Birthdays: $40,914.92
- Pharma/device companies: $200,000



Expenses: total: $131,884

- Contract services (uMotif, salaries): $114,588
- Administration & Operations: $15,458
- Travel and meetings: $1,254
- Web hosting, subscriptions: $1,838



Board
Jessica Morris, Founder and Chair, living with GBM since 2016
Kelli Duprey, Treasurer, Acting ED, Senior Pharmaceutical Executive
Andi Philips, CEO, Maycomb Capital
Claire Wright, Entrepreneur and Attorney
Stacy Chick, Founder & Principal, Synthesis Advisory Consulting LLC
Meredith Moore, Founder and CEO of Artisan Financial Strategies LLC, diagnosed with GBM in 2005
Gail Fosler, President of The GailFosler Group LLC
Ed Pilkington, Chief Reporter at The Guardian US, caregiver for GBM patient
Rob Nordland, Int'l correspondent at The New York Times, living with GBM since 2019
Theresa Schaub, Co-founder/CCO at Meru Biotechnologies, living with GBM since 2017
Michael J. Zaccagnino, Founder & President, Lucania Partners

UK Trustees
Jessica Morris, Founder and Chair, living with GBM since 2016
Julia Hobsbawm, Writer and Editor
Jake Arnold-Forster, CEO
Simon Matthews, Communicator and CEO, co-founder Cohere Partners
Jana Bennett, Trustee, TV Executive, living with GBM since 2019
Richard Clemmow, TV and Radio Producer and Journalist, caregiver for GBM patient

Medical and Technical Advisors
Fabio Iwamoto, MD, Neuro-oncologist, Columbia University
Lakshmi Nayak, MD, Neuro-oncologist, Dana-Farber Cancer Institute
Joshua Silverman, MD, Radiotherapist, NYU Langone
Mario Lacouture, MD, Dermatologist, Memorial Sloan Kettering
Dan Orringer, MD, Neuro-surgeon, New York University
Alexis Demopoulos, MD, Neuro-oncologist, Northwell Hospital
Marina Benaur, MD, Assistant Clinical Professor of Psychiatry, Columbia University-New York Presbyterian
Bruce Hellman, CEO, uMotif, developer of OurBrainBank App
E. Antonio Chiocca, MD, PhD, Neuro-surgeon, Brigham and Women's Hospital and Director of Surgical Neuro-oncology and Dana Farber Cancer Institute
David A. Reardon, MD, Clinical Director, Neurologist, Dana-Farber Cancer Institute

Staff
Aurelia Driver, Director of Fundraising and Administration
Stacey Shackford, UK Outreach
Martha Wilkie, Director of Outreach

OurBrainBank is a registered 501(c) 3 nonprofit in the US (#82-2307232), and a registered charity in the UK (#1184699). Our study has ethics approval from the New England IRB (US), University of Leeds (UK), and from the University of Sydney (Australia).