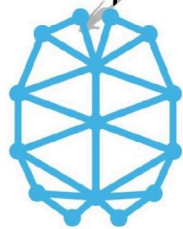




# Annual Report 2021



**OurBrainBank**

Moving 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 pilot study using a free smartphone app was 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.

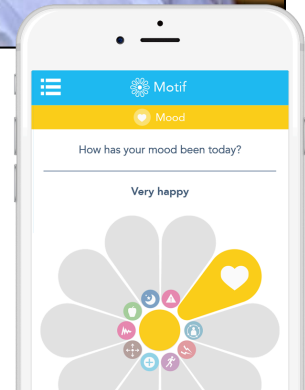


## Our study & app

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.

## Conferences & speaking engagements

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

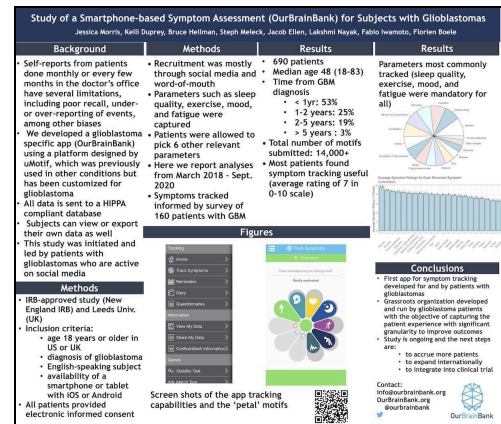
- SNO2020 (virtual) — we partnered with Dr. Laura Donovan in her abstract on mindfulness-based interventions for GBM patients
- ABTA Virtual Annual Conference
- ASCO Virtual Annual Conference
- NBTS Virtual Head to the Hill
- EBCI Virtual “Together and Action Day”
- AONN+ Virtual Annual Conference
-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

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.



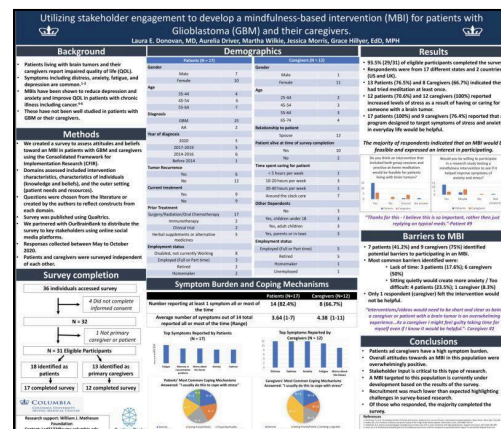
**OurBrainBank**  
Study of a smartphone-based symptom assessment for subjects with glioblastoma

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. Florian Boele

Use the uMotif to capture your symptom data

AONN+  
A Network of Oncology Nurses (AONN) National



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.”



## 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](https://twitter.com/ourbrainbank): 1170 followers (404 new)
- [Facebook.com/OurBrainBank](https://facebook.com/OurBrainBank) (page): 1461 followers (454 new), 100+ fundraisers
- [Facebook.com/groups/OurBrainBank](https://facebook.com/groups/OurBrainBank): 1331 members
- [YouTube.com/c/OurBrainBankForGlioblastoma](https://youtube.com/c/OurBrainBankForGlioblastoma): 192 followers, 51 videos (40 new followers, 24 new videos)
- [Instagram.com/OurBrainBankForGlioblastoma](https://instagram.com/OurBrainBankForGlioblastoma): 128 posts, 555 followers
- [Newsletter](#): 1576 subscribers (520 new subscribers)
- [LinkedIn.com/company/OurBrainBank](https://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](http://ElephantLotusBrainTumor.com)

**MONTHLY LIVE GBM SUPPORT CHATS**  
Second Tuesday of each month at noon (ET)

 OurBrainBank VOICES

*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

 Moving glioblastoma from terminal  
to treatable, powered by patients



OurBrainBank Founder,  
Jessica Morris

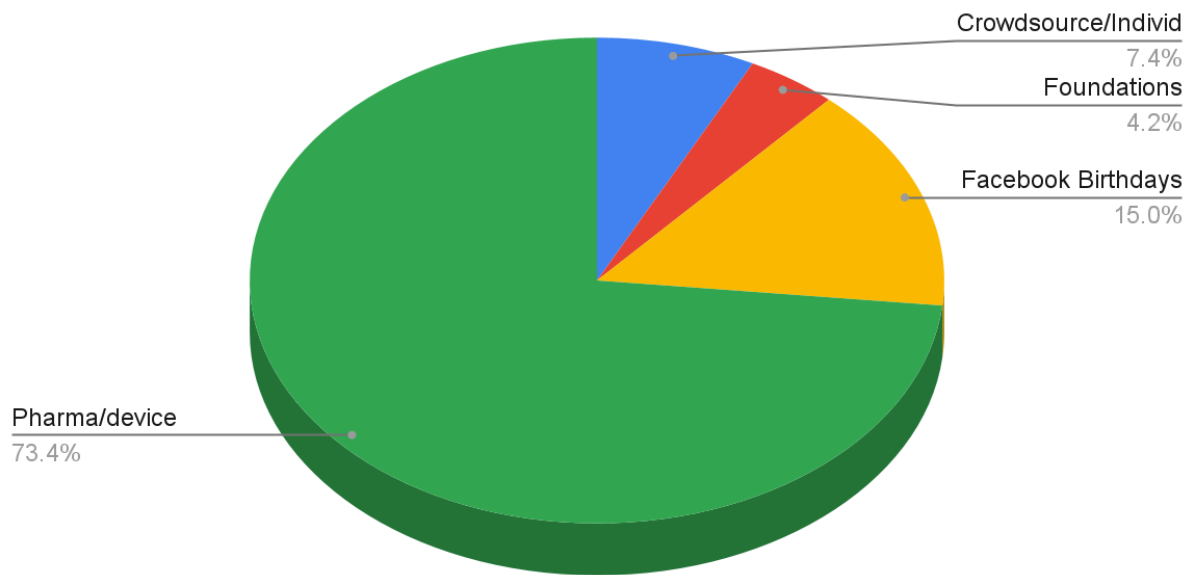
### 2020 Financials

**Funding sources: total: \$272,696.21**

- Crowdfunder/ individuals: \$20,179.88
- Foundations: \$11,555.00

- Facebook Birthdays: \$40,914.92
- Pharma/device companies: \$200,000

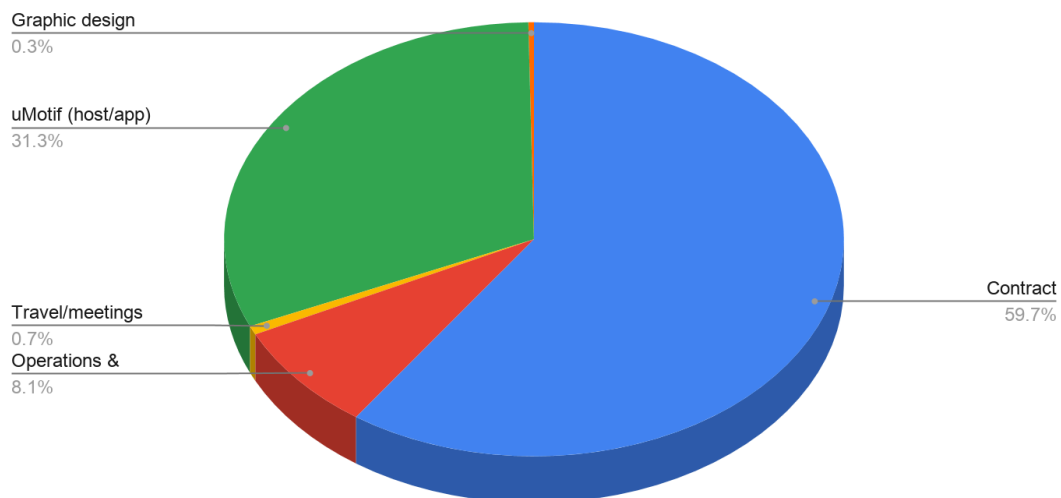




**Expenses: total: \$131,884**

- 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).