



# Annual Report 2022



**OurBrainBank**

Moving glioblastoma from terminal  
to treatable, powered by patients

OurBrainBank is a patient-led movement designed to move glioblastoma (GBM), the deadliest type of brain tumor, from terminal to treatable. We're on a mission to support, inform, and empower every person with GBM and their loved one. We're the first non-profit created by, for, and with people with GBM, and the only GBM-focused non-profit conducting patient/carer-led data collection and research.

OurBrainBank's founder, Jessica Morris (1963-2021), survived for five years after her GBM diagnosis — only 5% of people do. She knew more data was needed to tackle this terrible disease. We continue to build on her vision today as new and better treatments are still urgently needed. Our goal is to give GBM patients a voice — in clinical trials, research, and at all stages of treatment.

### **Data and Community: Pilot Study and Next Steps**

In 2018, OurBrainBank launched its pilot glioblastoma study using a free smartphone app that patients or care partners used to track health indicators, play neurological games, and more. The success of the pilot study demonstrated that people living with GBM would contribute health data to a central database using mobile technology.

### **Milestones:**

- 2018: Fabio Iwamoto, MD et al presented a poster about the pilot study at the Society for Neuro-Oncology conference
  - 2019: OurBrainBank published "The Potential of Patient Power"
  - 2021: "Pilot study of smartphone-based health outcome tracking (OurBrainBank) for glioblastoma patients" published in the journal Neuro-Oncology Practice
- In 2021, OurBrainBank closed the pilot study and researched new technologies to continue to harness the power of patients — both by collecting data and helping people day-to-day. Our goal: accelerate research for tomorrow and improve the outcomes and quality of life of people living with GBM.

### **Our achievements in 2022 and ambitions for 2023**

*From our Chair, Ed Pilkington, widow of our founder Jessica Morris*

We have supercharged our outreach to patients and caregivers to make sure that when they receive that first terrifying diagnosis they are not alone. Our soon-to-be launched upgraded website will provide information and support, and act as a hub where together we can push for more resources and attention for this often-forgotten cancer.

We are fueling cutting-edge research with neuroscientists at Harvard University to expand our data collection effort and enhance understanding of the disease and its impact on families, building on our pilot study.

We are launching advocacy campaigns to make our groundbreaking GBM Bill of Rights a reality.

We are connecting different healthcare systems and approaches to expand our international reach, with a very active presence in the UK.

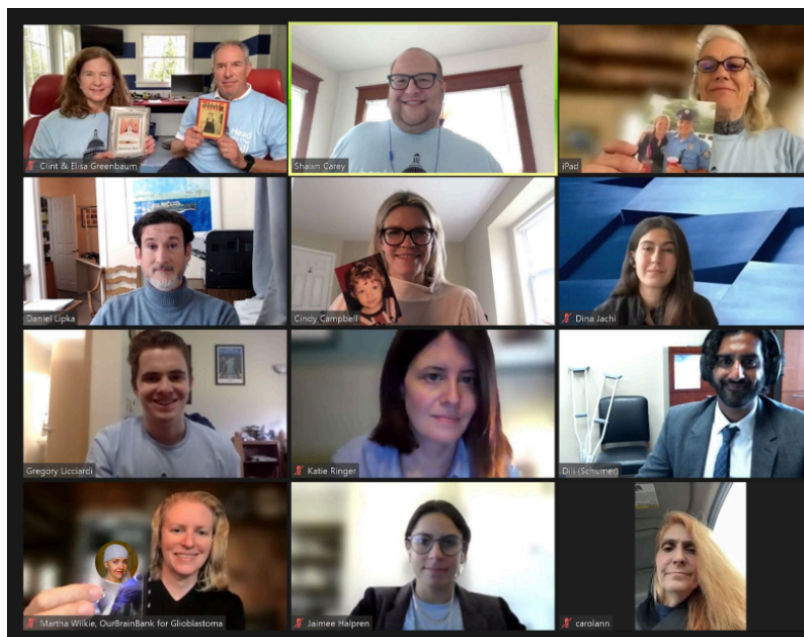
## Glioblastoma Awareness Day

Dozens of people shared photos of their loved ones living with GBM or lost to this terrible disease. OurBrainBank staff created custom graphics to share on social media.



## OurBrainBank at SNO

OurBrainBank board member Kelli Duprey attended SNO (the Society for Neuro-oncology annual meeting) to learn about the latest developments in GBM treatment and spread the word about OurBrainBank.



## Head to the Hill

OurBrainBank joined the National Brain Tumor Society and hundreds of fellow Americans to lobby and advocate on Capitol Hill (virtually) for increased funding and research into brain tumors.

OurBrainBank Outreach Director Martha Wilkie met with staffers from NY Senators Gillibrand and Schumer, plus Representative Nadler. It was an emotional and powerful day of sharing our stories with our elected officials in almost all 50 states.



## UK Board Member Rides to Raise Funds

Kudos to our UK board member Andy Coulson! He biked 1000 miles to raise funds to help people living with GBM today and tomorrow in memory of his sister Deb. "It was an amazing 12 day ride almost entirely in glorious British sunshine. Was remarkable how many people I met along the way who had been impacted by GBM. Thanks to all those who supported and as a result helped raise £8,000 for OBB in Deb's name. She would want to say thanks too." [Gifts most appreciated.](#)

Like to challenge yourself like this? Set up your own peer-to-peer fundraiser on [GiveLively \(US\)](#) or [JustGiving \(UK\)](#).



Listen to Andy in conversation with fellow OBB UK board member Richard Clemmow on the "Crisis What Crisis?" podcast: [The terror of brain cancer, fighting for time and the desperate need for a new approach.](#)

## Glioblastoma Stories: Laura

When Nicola Nuttall's college-age daughter was diagnosed with GBM, Nicola became a strong voice advocating for better treatment for everyone living with brain cancer in the UK.

*We feel that it's deeply unfair that access to novel and innovative treatments are restricted to those who have the finances to pay for them and the ability to travel to other countries to access them.* [Read more on OurBrainBank.org.](#)



Her website [DoingItForLaura](#) contains more about Laura, GBM treatment in the UK and Germany, plus useful tips and recommendations. Follow her on Twitter [@Sh\\*tScaredMum](#).

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.

## GBM Survey

In 2022, we began our survey about personalized Care — the #1 Right on the [GBM Bill of Rights](#).

## **Resources on [OurBrainBank.org](https://OurBrainBank.org) and via our Social Media**

We shared guides to GBM, information on finding a clinical trial, and articles like *How to find a Caregiver When You Have Cancer* on our social media.

## **Clinical Trial using AI for Precision Trial Matching**

In our GBM Bill of Rights, #1 is the Right to Personalized Care.

If you (or a loved one) is considering a GBM clinical trial, this trial [offers the option to use AI](#) (artificial intelligence) to analyze your EHR (electronic health record) to match your unique case with potentially effective trials.

This study is not only for GBM, but all solid tumors. It's open to pediatric and adult patients globally. You don't need to travel to participate, although the trials recommended may be at different treatment center.

## **Medical Advisors**

Dr. Fabio Iwamoto chairs our exceptional team of multi-disciplinary advisors from Harvard Medical School, Dana-Farber, Northwell, Hartford HealthCare, and other institutions.

**Fabio Iwamoto**, MD, Deputy Head of Neuro-Oncology, Columbia University. Chair of OurBrainBank Medical & Tech Advisors

**Ann Berger**, MD, MSN, Chief of Pain and Palliative Care Service, National Institutes of Health (retired)

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

**E. Antonio Chiocca**, MD, Harvey Cushing Prof. of Neurosurgery, Harvard Medical School; Neurosurgeon-in-Chief and Chairman, Dept. of Neurosurgery, Brigham and Women's Hospital

**Alexis Demopoulos**, MD, Neuro-Oncologist, Hartford HealthCare Cancer Institute

**Mario Lacouture**, MD, Dermatologist, NYU Langone

**Lakshmi Nayak**, MD, Neuro-Oncologist, Dana-Farber Cancer Institute; Assistant Professor of Neurology, Harvard Medical School

**Daniel Orringer**, MD, Neurosurgeon, NYU Langone Health

**David A. Reardon**, MD, Clinical Director, Center for Neuro-Oncology, Dana-Farber Cancer Institute; Professor of Medicine, Harvard Medical School

## **Board**

**Ed Pilkington**, Chair, Chief reporter, The Guardian US

**Kelli Duprey**, Executive Director and Vice Chair, Senior Pharmaceutical Executive

**Jacob Ellen**, Harvard Medical Student

**Sundas Hashmi**, Consultant. Brain Tumor (Oligodendroglioma) Patient. Sister of GBM patient Fawad Hashmi (1979-1998)

**Richard Micali**, Pharmaceutical Executive

**Kate Onk**, Analytics leader, and daughter of GBM patient Howard Onk (1954-2020)

**Tess Pilkington**, daughter of OBB founder Jessica Morris

**Laura Simpson**, CEO. Proud aunt of brain cancer warrior Liam (2000-2020); husband had GBM

**Edward Westfall**, Consultant, lost a family member to GBM

## Financials 2022

Statement of Activity	
OurBrainBank, Inc	
January 1-December 31, 2022	
Distribution account	Total
Income	
4000 Individual Donations	17,402.37
4005 PayPal US	1,276.17
4015 Stripe Donations	13,944.31
4050 Facebook Donations	14,718.15
<b>Total for 4000 Individual Donations</b>	<b>\$47,341.00</b>
4200 Corporate Donations (Unrestricted)	102,500.00
4300 Foundation Donations (Unrestricted)	1.12
5900 Interest Revenue and CC Refunds	62.07
<b>Total for Income</b>	<b>\$149,904.19</b>
Cost of Goods Sold	
<b>Gross Profit</b>	<b>\$149,904.19</b>
Expenses	
6000 Personnel Expenses	0.00
6005 Payroll	28,614.00
6010 Payroll Taxes	2,982.02
6020 Benefits	1,585.68
6049 PEO Fees	949.52
<b>Total for 6000 Personnel Expenses</b>	<b>\$34,131.22</b>
6050 Legal & Professional Fees	0.00
6051 Recruitment	399.00
6060 Admin Consultant	15,157.50
6065 Accounting	2,492.02
6099 Misc Legal and Professional	4,113.57
<b>Total for 6050 Legal &amp; Professional Fees</b>	<b>\$22,162.09</b>
6200 Operational Expenses	0.00
6205 Phone, Zoom, Internet	99.84
6212 Software / IT Subscription, Fees, and Support	1,192.23
6220 Subscriptions (deleted)	669.72
6225 Bank Charges	321.37
6240 Office Supplies	724.60

6260 Liability Insurance	3,254.83
6299 Misc Operational	-17.10
<b>Total for 6200 Operational Expenses</b>	<b>\$6,245.49</b>
6300 Travel	0.00
6310 Transport	771.02
6320 Food and Lodging	929.37
<b>Total for 6300 Travel</b>	<b>\$1,700.39</b>
6350 Conference Expenses	475.00
7100 Program Costs	80.00
<b>Total for Expenses</b>	<b>\$64,794.19</b>
<b>Net Operating Income</b>	<b>\$85,110.00</b>
Other Income	
Other Expenses	
Unrealized Gain or Loss	
<b>Total for Other Expenses</b>	
<b>Net Other Income</b>	<b>0.00</b>
<b>Net Income</b>	<b>\$85,110.00</b>

## Learn more about OurBrainBank: [OurBrainBank.org](http://OurBrainBank.org)

OurBrainBank, Inc. is a registered 501c3 non-profit organization in the USA and UK  
 PO Box 835 Telluride, CO 81435-0835  
 US: 501c3 EIN 822307232; founding date: 2017  
 UK: OurBrainBank UK 41 Cheverton Road, London, N19 3BA and 12 Beverley Road London  
 W4 2LP (cheques)  
 UK: Charity no. 1184699