

# OURBRAINBANK FOR GLIOBLASTOMA 2024 ANNUAL REPORT

**REACHED**

**525**

**PATIENTS & CARE  
PARTNERS FOR OUR  
NATIONAL GBM HEALTHCARE  
DISPARITY SURVEY**

**PUBLISHED**

**3**

**ABSTRACTS/POSTERS  
ON GBM DISPARITIES**

**2**

**MEETINGS WITH THE  
NATIONAL CANCER  
INSTITUTE**

**INVITED TO  
PRESENT AT**

**1**

**BRAIN TUMOR NONPROFIT  
LEADERSHIP MEETING**

**12**

**ARTICLES ON GBM IN  
FORBES BY OBB  
STAFF & BOARD REACHED**

**103,953  
READERS**

**REACHED**

**13,000**

**PEOPLE AFFECTED BY  
GLIOBLASTOMA VIA  
OURBRAINBANK.ORG**

**ATTENDED**

**3**

**MAJOR CONFERENCES:  
SNO, ONS, AONN+**

**GAINED**

**1049**

**NEW SOCIAL MEDIA  
FOLLOWERS**

**ENGAGED**

**3**

**INVESTIGATORS (FROM DUKE,  
COLUMBIA & HARVARD)  
FOR OUR GBM  
DISPARITIES SURVEY**

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.



### **Glioblastoma Data & Research**

Our 2018 pilot study enabled patients and carers to track health indicators via a free mobile application that empowered people and gathered data in the US, UK, and Australia. Over 800 people participated. We presented at the Society for Neuro-Oncology in 2018, and published results in the Journal of Neuro-Oncology Practice.

We're now fundraising for a new project that will effortlessly generate data directly from GBM families. The project, called DANO-GBM ("Digital Assessment Neuro Oncology") uses passive data — data automatically generated on smartphones (e.g. number of calls or texts, physical activity) to indicate how social we are or, conversely, how isolated. We're proud to partner with neuro-oncologists at the Dana-Farber Cancer Institute and data scientists at the Onnela Lab at the Harvard T.H. Chan School of Public Health. Our vision is to use insights from this data to help patients and doctors predict recurrence prior to symptoms or the next MRI.

### **Survey on Disparities in GBM Treatment in the USA**

We help people in the GBM community share their pre- and post-diagnosis experiences through surveys and research. The published results raise awareness and empower people to demand the best care possible and advance change in how GBM is seen and treated.

Our large national research project, begun in 2024, will identify health disparities in GBM treatment across the United States. We'll use this data to demand better and equal treatment for every patient. More: [Survey on Disparities in GBM Treatment in the USA](#)

**GBM patients continue to face barriers to personalized and comprehensive care that may impact longevity and quality-of-life**

Quinn T. Ostrom, Ph.D., M.P.H., Fabio M. Iwamoto, MD, Lakshmi Nayak, MD, Kelli Duprey, RPh, MBA, Ed Pilkington, Jacob Ellen, MSc, David Robles, MA

**Objective**

- Assess the quality and accessibility of healthcare services provided to Glioblastoma (GBM) patients across the United States

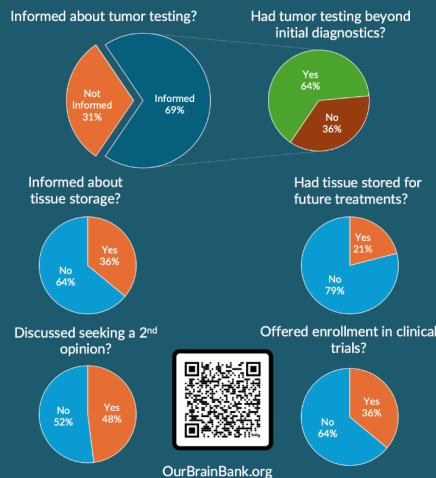
**Methods**

- Designed a 10-minute online survey containing 36 items with sections focused on aspects of patient experience, quality-of-life and demographic data
- Distributed to both current GBM patients as well as caregivers for current and recently deceased GBM patients through our community/partners, at outreach events and on social media

**Results**

- Total of 297 patients or caregivers completed the survey (85% caregivers; 15% GBM patients)
- Median age at diagnosis was 57, lower than the national average of 64
- 78% of our respondents described having some college education, and 69% had commercial insurance
- 69% were informed about tumor testing.
- Among those informed, 64% did not have any molecular testing beyond initial diagnostic tests
- 65% were not informed about storing tissue for future testing

**People living with glioblastoma face significant barriers to achieving comprehensive and personalized care**



**Results (continued)**

- 79% reported not having their tissue stored for possible treatments or clinical trial qualification
- 52% reported no discussion of seeking a second opinion
- 64% reported not being offered enrollment in any clinical trial

**Conclusion**

- Overall, people living with GBM face significant barriers to achieving comprehensive and personalized care
- Lack of tumor testing and storage present missed opportunities for future access to emerging therapies that could improve individual outcomes
- Over half of patients had no discussion about seeking a second opinion and were not offered enrollment in clinical trials, highlighting significant barriers to accessing life-extending or quality-of-life (QOL) improving treatments

**Limitations/Future Directions**

- Compared to the general population affected by GBM, survey respondents represented a disproportionately young and urban population, suggesting potential bias in who is able to respond to the survey and may underestimate the challenges faced by patients with additional barriers. We are implementing strategies to reach a more geographically diverse participant group, particularly in rural areas
- Ongoing targeted recruitment will further elucidate barriers to patient-centered care in GBM, with the potential for significant improvements in survival and QOL



**Conferences**

OBB presented posters, abstracts, and booths at **AONN+, ONS Congress, SNO, and the Brain Cancer Leadership Meeting**. This year's focus was recruiting for our Disparities Survey and also presenting our preliminary results.

(right) Kim Wallgren (National Brain Tumor Society), Laura Hynes (Brain Tumor Network), and OBB Executive Director Kelli Duprey at the OANN+ (Academy of Oncology Nursing and Navigators) Congress in Washington, D.C., 2024.



(left) OBB Lead Researcher David Robles with Kelli Duprey at the AONN+ (Academy of Oncology Nurse & Patient Navigators) conference in Las Vegas.





*UK staffer Matthew Wilson at the Brain Cancer Whole Genome Sequencing and Clinical Trials Summit.*

## Fundraising & Events

A benefit in Bristol, Connecticut featured the band Victrola featuring Ray Palagy, living with GBM, on drums.

Ray's favorite drummer was Neil Peart of Rush, who was sadly lost to GBM in 2020. Staffer Martha Wilkie joined the fun.





**Intimate wine tasting to benefit GLIOBLASTOMA research**

*Please join us for fine wines from Kistler Vineyard, appetizers & friends!*

**Monday June 10, 4-6pm**

**at the home of Kelli & Peter Duprey**  
222 Russell Drive  
Telluride, Colorado

Proud Sponsor  
*Kistler Vineyards*



**OurBrainBank**  
MOVING GLIOBLASTOMA FROM TERMINAL TO TREATABLE. POWERED BY PATIENTS

Executive Director **Kelli Duprey** put her Sommelier expertise to good use by hosting two wine-related fundraising events in Colorado.

Thank you to [Kistler Vineyards](#) for sponsoring!



*Board, medical advisors, and staff met in Brooklyn for a Strategy Meeting*

**Julia Hobsbawm**, a great friend of OBB in the UK, celebrated her 60th birthday by completing **60 SoulCycle sessions** in memory of OBB founder Jessica Morris, raising significant funds for OBB.

Thank you Julia!

### OurBrainBank Shop

We launched the [new OurBrainBank online shop with Bonfire](#). Check out our mugs, hats, totebags and more.





## Social Media & Community

We engage the global community of patients, care partners, medical professionals, and researchers via our [newsletter](#), [YouTube Channel](#), [Facebook page and group](#), [Instagram](#), [Linkedin](#), and [Twitter](#).

**New in 2024:** we joined the growing community on [BlueSky](#).

**OurStory Bank**

**Erika's Story**



 OurBrainBank

**Erika's Story** 2025

**My life changed forever on July 3, 2023, when I had a seizure and drove through a house.**

CT scan ruled out drunk driving; they found a golf-ball sized mass which was removed a few days later. I was 47 years old. My son was 18. I lived alone. Whoa.

I did enough research to know I likely wouldn't live to see 50. But I'm young, super healthy, and known for my resiliency, so I wasn't going down without a fight.

Friends took care of me until I could become independent again. Coworkers drove me to therapy and donated money for dog walkers. Friends accompanied me for my MRI results. All clear. Looks good. Rinse and repeat.

6 months of chemo stretched to 12 months. I was so sick of chemo, I kept going. That was my motto – "Keep Going."

And oh, did I mention, I'm 49 years old now! Well, if you hear about a massive party in Texas, that's probably me, outliving my prognosis and celebrating what I thought was impossible – turning 50 years old with glioblastoma!

**OurStory Bank** 

## Patient & Carer Advisory Board

We revived our Patient & Carer Advisory Board in 2024, meeting via Zoom with a small and dedicated group.

A candid discussion inspired this Instagram post (*right*) about the idea of designating a loved one to conduct research.

Did your doctor tell you  
"Don't Google glioblastoma"?

If you're overwhelmed or  
can't deal with the medical  
jargon, consider asking a  
trusted loved one to be your  
designated researcher.

OurBrainBank.org

## Press & Media

# GLIOBLASTOMA IN THE NEWS

Read our series of 12 articles in Forbes about GBM treatment disparities, the caregiver experience, and how smartphones could collect important data

### Inside The Mind Of A Brain Cancer Neurosurgeon

Forbes EQ

OurBrainBank Brand Contributor  
Forbes EQ BRANDVOICE |  
May 31, 2024

By Tess Pilkington



During a recent operation on a patient's brain, neurosurgeon Dr. Daniel Orringer noticed something peculiar: he could almost feel the patient's positivity emanating from

### Man's Search For Meaning: The Psychology Of Cancer Patients

Forbes EQ

OurBrainBank Brand Contributor  
Forbes EQ BRANDVOICE |

Updated May 24, 2024, 01:51pm EDT

By Tess Pilkington



A working mission of physicians is to cure illness and provide answers in

### From Patient To Million Dollar Woman: The Terrible Inequity Of Brain Cancer

Forbes EQ

OurBrainBank Brand Contributor  
Forbes EQ BRANDVOICE | Paid Program

Updated Apr 3, 2024, 01:06pm EDT

By Ed Pilkington and Matthew Wilson



About a year into her diagnosis with the most deadly form of brain cancer, glioblastoma (GBM), Jessica Morris did a calculation on the back of an envelope and found to her astonishment that she was a Million Dollar Woman.



OurBrainBank.org



ourbrainbank.org/forbes

Through a partnership with Forbes, we wrote [a series of 12 articles about the GBM experience](#) that reached more than 100,000 people.

The International Brain Tumor Alliance magazine featured [an article about our disparities survey](#) written by board member Jacob Ellen and OBB lead researcher David Robles.

### Glioblastoma care across the United States – a survey by OurBrainBank reveals gross disparities in care

Jacob Ellen, MSc, Board Member  
OurBrainBank, United States  
David Robles, MA, Project Manager/Researcher  
OurBrainBank, United States



**Patient Advocacy Led by Patients**  
OurBrainBank was founded in the United States in 2012 by Jessica Morris, who died in 2021 after a five-year fight against glioblastoma. Her mission in creating OurBrainBank was to turn glioblastoma from a terminal to a treatable disease through patient-powered advocacy and research. Her vision lives on in OurBrainBank's work today as we strive to amplify the voices of glioblastoma patients and caregivers and fight against inequities in glioblastoma treatment and care. In 2020, OurBrainBank introduced the Glioblastoma Bill of Rights, advocating for universal access to high-quality glioblastoma care regardless of geographical or financial barriers. From 2022 to 2023, the organization surveyed its community about these rights, revealing troubling disparities in glioblastoma care access. This discovery underscores the urgent need for a large-scale national survey in the United States to identify and address these healthcare inequities comprehensively.



Jacob Ellen

**Disparities in glioblastoma care survey launched**  
To gain a comprehensive view of glioblastoma treatment in the United States and uncover any disparities in care, OurBrainBank launched a nationwide survey under the guidance of leading experts: Dr. Quinn Ostrom (Duke University), Dr. Fabio Iwamoto (Columbia University), and Dr. Lakshmi Nayak (Dana-Farber Cancer Institute). This survey aims to hear the perspectives of 500 glioblastoma patients and their caregivers across the country to assess the quality and accessibility of their care. OurBrainBank intends to leverage these findings to advocate for improved, equitable care for glioblastoma patients and their families by collaborating with governmental bodies and policymakers. Hosted by Survey Global Healthcare, the survey comprises 36 items covering



David Robles

patient experiences, quality of life, and demographic information. It is open to current glioblastoma patients and caregivers of current or recently deceased patients. Distribution efforts included OurBrainBank's newsletters, events, and social media channels, reaching out to their community and partners.

**Preliminary Results**  
A total of 297 participants have completed the survey so far, comprising 85% caregivers and 15% glioblastoma patients, with a median age at diagnosis of 57. Of the respondents, 78% had some college education, and 69% reported having commercial insurance coverage. Preliminary results showed that while 69% of respondents were informed about tumor testing, 64% did not receive molecular testing beyond initial diagnostics. The majority of respondents

Brain Tumor 69

## **2024 in review**

*January:* **David Robles joined our team** as researcher and project manager. **Dr. Quinn Ostrom (Duke) came on as our survey Primary Investigator** along with Dr. Fabio Iwamoto (Columbia) and Lakshmi Nayak (Harvard)

*February:* **Launched our national GBM Healthcare Disparity Survey** with the goal of 500 patients/care partners.

*March/April:* **Recruited survey participants** via social media and outreach across the USA.

*May:* **Kelli and David attended the [ONS Congress](#)** to raise awareness about OBB and ask nurses for help with survey recruitment.

*June:* **Submitted two survey-related abstracts to [SNO](#)** for the annual conference.

*July:* **The Brain Tumor Nonprofit Leadership Meeting invited Kelli to present** preliminary survey results with [Kim Wallgren](#) (NBTS) and [Laura Hynes](#) (BTN). Six specialists educated the group about the vital need for tumor testing, how it could be improved (including noninvasive biomarker testing), and liquid biopsies.

*August/September:* **Met survey goal** with 525 patients/caregivers. Developed follow-up questions to get better clarity. **Two abstracts accepted** for SNO poster session.

*October:* **Submitted successful late-breaking abstract to [AONN](#).**

*November:* **Presented well-received posters at AONN and SNO.** Explored new funding sources (government, individuals) for our **Harvard [DANO](#) project**. Goal: collect passive data from smartphones (eg mobility, sociability) and compare it to self-reported quality-of-life endpoints.

*December:* **Began series of calls with [NCI](#) project managers** (to continue in 2025). Board and advisors meeting in Brooklyn to discuss our five-year vision and strategic plan for 2025.

## **OurBrainBank needs your support to:**

- **Educate** patients, healthcare professionals, the government, and insurance companies about our survey results so we can **Demand More!** for GBM patients
- **Analyze** our data for [ASCO](#) (the most prestigious oncology organization) and other outlets
- **Write and submit articles** to neuro-oncology journals
- **Find funding** to launch our passive data trial
- Continue to **build and support** our GBM patient and caregiver community
- Work with other brain cancer non-profits to propose **legislative changes** in GBM care



## **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

| Statement of Activity                               |                     |
|---|---------------------|
| OurBrainBank, Inc                                   |                     |
| January-December, 2024                              |                     |
|   |                     |
| Distribution account                                | Total               |
| Income  |                     |
| 4000 Individual Donations                           | 9,390.11            |
| 4005 PayPal US                                      | 5,005.92            |
| 4015 Stripe Donations                               | 18,684.33           |
| 4020 Individual Grassroots Fundraising              | 7,297.60            |
| <b>Total for 4000 Individual Donations</b>          | <b>\$40,377.96</b>  |
| 4200 Corporate Donations (Unrestricted)             | 50,077.44           |
| 4300 Foundation Donations (Unrestricted)            | 7,024.59            |
| 5900 Interest Revenue and CC Refunds                | 9,132.90            |
| Billable Expense Income                             | 182.00              |
| Sales of Product Revenue                            | 105.09              |
| <b>Total for Income</b>                             | <b>\$106,899.98</b> |
| Cost of Goods Sold                                  |                     |
| <b>Gross Profit</b>                                 | <b>\$106,899.98</b> |
| Expenses  |                     |
| 6050 Legal & Professional Fees                      | 1,508.60            |
| 6053 Executive Management Services                  | 75,000.00           |
| 6060 Admin Consultant                               | 23,628.50           |
| 6065 Accounting                                     | 6,232.13            |
| 6070 Fundraising and Development                    | 1,657.17            |
| 6073 Survey Consultant                              | 57,500.00           |
| <b>Total for 6050 Legal &amp; Professional Fees</b> | <b>\$165,526.40</b> |
| 6200 Operational Expenses                           | 0.00                |
| 6205 Phone, Zoom, Internet                          | 18.60               |
| 6212 Software / IT Subscription, Fees, and Support  | 2,287.15            |
| 6225 Bank Charges                                   | 60.95               |
| 6240 Office Supplies                                | 604.35              |
| 6260 Liability Insurance                            | 3,339.84            |
| <b>Total for 6200 Operational Expenses</b>          | <b>\$6,310.89</b>   |
| 6210 Computer Equipment                             | 296.55              |
| 6300 Travel   | 0.00                |
| 6305 In-town travel                                 | 1,382.18            |

|                                     |                      |
|-------------------------------------|----------------------|
| 6310 Transport                      | 3,242.11             |
| 6320 Food and Lodging               | 7,873.37             |
| <b>Total for 6300 Travel</b>        | <b>\$12,497.66</b>   |
| 6350 Conference Expenses            | 4,963.15             |
| 6900 Board Expenses                 | 189.92               |
| 6998 Uncategorized Expenditure      |                      |
| 7100 Program Costs                  | 0.00                 |
| 7125 Survey                         | 12,114.65            |
| 7140 Marketing / Dissemination      | 3,047.38             |
| <b>Total for 7100 Program Costs</b> | <b>\$15,162.03</b>   |
| Payroll Expenses                    | 0.00                 |
| Taxes                               | -28.85               |
| <b>Total for Payroll Expenses</b>   | <b>-\$28.85</b>      |
| Purchases                           |                      |
| <b>Total for Expenses</b>           | <b>\$204,917.75</b>  |
| <b>Net Operating Income</b>         | <b>-\$98,017.77</b>  |
| Other Income                        |                      |
| Other Expenses                      |                      |
| Unrealized Gain or Loss             |                      |
| 1851 Depreciation Expense Account   | 13,104.00            |
| <b>Total for Other Expenses</b>     | <b>\$13,104.00</b>   |
| <b>Net Other Income</b>             | <b>-\$13,104.00</b>  |
| <b>Net Income</b>                   | <b>-\$111,121.77</b> |

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

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