National Brain Tumor Society

2024 ANNUAL REPORT

Letter to the Community

Dear NBTS Community,

As we reflect on 2024, we are immensely grateful for the steadfast dedication of our donors, partners, volunteers, advocates, and event participants. Thanks to your generosity, the National Brain Tumor Society advanced the concept of precision medicine — an approach that matches the right patients to the right treatment — across its programs.

For the first time, three precision treatments for patients with brain tumors received FDA approval, each rooted in foundational research funded by the National Institutes of Health (NIH) — funding NBTS has long championed. Among them, vorasidenib became the first-ever precision therapy for adult and pediatric patients 12 years or older with diffuse low-grade glioma and an IDH1 or IDH2 mutation. NBTS played a critical role in advancing this treatment by providing early-stage funding during clinical trials, helping bring this breakthrough to patients.

Because of your support, NBTS launched a first-of-its-kind public health campaign called MyTumorID™ to educate and empower patients to understand their tumors' unique characteristics through biomarker testing, and to increase patient knowledge of clinical trials.

Our research programs made major strides in 2024. Funding and support from NBTS through our Brain Tumor Investment Fund (BTIF) and DNA Damage Response Consortium (DDR-C) helped propel a promising new glioblastoma therapy forward, which is now being developed further by the major biopharmaceutical company Merck. GBM AGILE, the adaptive clinical trial we helped launch in 2019, continues to offer patients access to multiple treatment options within a single study. We also supported a new biomarker-driven clinical trial for pediatric high-grade gliomas, including DIPG, led by Nationwide Children's Hospital.

Beyond research, NBTS remained a strong advocate for patient access to specialized care. We fought for improved health insurance coverage under Medicaid, Medicare, and the Affordable Care Act to make it easier for patients to access neurosurgeons and neuro-oncologists. Additionally, we introduced the Bolstering Research And Innovation Now (BRAIN) Act, a bill aimed at scaling up programs within the National Cancer Institute that directly fund brain tumor research and that aim to increase transparency in the research process.

While NBTS pushed forward research and policy, we also strengthened the fabric of our community, providing essential navigation and support to patients and caregivers to ensure no one faces this journey alone. At the most practical level, NBTS delivered critical new tools and resources on topics ranging from health insurance and fertility to wellness and second opinions.

As we look ahead to 2025, we recognize that change is on the horizon, both in the federal government and in technological advancements such as AI, imaging, and surgery that bring new opportunities to enhance research and patient care. Our research program will continue to serve as a proving ground to find exceptional therapies for evaluation in clinical trials while also utilizing the power of convening and investment to improve brain tumor research and development.

Thank you for being part of our work to give everyone living with a brain tumor a better chance — a better chance of survival, a better chance for improved quality of life, and a better chance at finding community.

Edjah Nduom, MD
Chair of the Board of Directors

David F. Arons
President & Chief Executive Officer

Mission, Vision, and Values

MISSION

National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and care partners.

VISION

Conquering and curing brain tumors — once and for all.

VALUES

- Patients First
- Best-In-Class Science and Service to Our Community
- Relentlessly Results Driven
- Constructive, Candid, and Transparent
- Committed to Public Trust
- Collaborative and Inclusive
- Strengthened by Diversity, Equity, Inclusion, and Belonging
- Positive (Can-Do) Attitude

DEFEAT

We drive and influence best-in-class medical research to develop and deliver new innovative treatments and potential cures to patients with brain tumors as quickly as possible.

CONNECT

We convene, educate, and unite the brain tumor community.

CHANGE

We fuel the voice and power of the brain tumor community to advocate and influence public policy.

“I’m coming to an age where I’m experiencing a lot of milestones, including graduating from high school this year, and he’s not here, so it’s very hard. I had been interested in the medical field prior to my dad’s passing [from glioblastoma], but everything that has happened has driven me toward it even more. I just would like to give back and help people in some way.”
— *Sarah H. (far right)*

Historic Advancements in Treatments for Brain Tumors

2024 was a landmark year in brain tumor research. National Brain Tumor Society and the greater brain tumor community saw three drug approvals by the the U.S. FDA that will benefit adult and pediatric patients with specific malignant brain tumors. These approvals mark a pivotal moment in brain tumor drug development, establishing a stronger foothold for our field to propel the next generation of targeted therapies — even for difficult-to-treat brain tumors.

NBTS fuels first-ever targeted therapy for grade 2 astrocytoma and oligodendroglioma

THE U.S. FOOD AND DRUG ADMINISTRATION (FDA) APPROVED vorasidenib (Voranigo) for the treatment of adult and pediatric patients 12 years of age and older with grade 2 astrocytoma or oligodendroglioma with an IDH1 or IDH2 mutation. This event marks the first FDA approval of a targeted therapy for patients with these low-grade gliomas. NBTS played multiple roles in advancing this discovery.

LEADING UP TO VORASIDENIB APPROVAL

1995: NBTS funding directly supports the discovery of the 1p19q chromosome co-deletion, which is the key characteristic for identifying and diagnosing low-grade gliomas, including oligodendrogliomas.

2009: NBTS funding leads to the discovery of the IDH (isocitrate dehydrogenase) mutation, which has become a critical means for neuro-oncologists to distinguish between different types of gliomas.

2016: The World Health Organization (WHO) updates brain tumor classifications, incorporating molecular data (e.g., IDH mutations and 1p/19q co-deletion) in classifying brain tumor types.

2016-2019: NBTS funds grants to Ingo Mellinghoff at Memorial Sloan Kettering Cancer Center that support preclinical work that help advance the trial from a phase II to a phase III trial.

2019: NBTS hosts a low-grade glioma patient and caregiver focus group with Agios to better understand the burden of living with a low-grade glioma diagnosis as they begin work on their drug development process.

2021: Servier completes acquisition of Agios Pharmaceuticals’ oncology business.

2023: Leaders of the phase III INDIGO trial present and publish data demonstrating that vorasidenib improves progression-free survival and delays the length of time before patients need radiation and chemotherapy.

2024: FDA approves vorasidenib.

Historic Advancements in Treatments for Brain Tumors

FDA greenlights first systemic therapy for pediatric low-grade glioma with BRAF rearrangements

THE FDA GRANTED ACCELERATED APPROVAL TO TOVORAFENIB (OJEMDA) for patients 6 months of age and older with relapsed or refractory pediatric low-grade glioma (LGG) harboring a BRAF fusion or rearrangement, or BRAF V600 mutation. This represents the first FDA approval of a systemic therapy for the treatment of patients with pediatric LGG with BRAF rearrangements, including fusions.

The first study to identify Ojemda as a potential treatment for pediatric low-grade gliomas was supported by three different NIH/NCI funding programs: the NIH's Brain Specialized Program of Research Excellence (SPORE) grant program, an NIH Research Program Project (P01) grant, and an NIH Director's New Innovator Award. NBTS has tirelessly championed for NIH and NCI funding year after year.

FDA approves targeted therapy for NTRK-fusion solid tumors, including certain brain tumors

THE FDA GRANTED ACCELERATED APPROVAL TO REPOTRECTINIB (AUGTYRO) FOR ADULT AND PEDIATRIC patients 12 years and older with solid tumors that have a neurotrophic tyrosine receptor kinase (NTRK) gene fusion, including primary and metastatic brain cancer.

NTRK-fusions, which Augtyro targets, have been noted to occur in somewhere between 1-5% of primary brain cancer patients. For individual tumor types — for example, pediatric gliomas — the percentage can be significantly higher. In the mid- and late-2010s, there were a handful of studies that made these findings across various adult and pediatric brain tumor types. All of this was made possible by NIH funding, which NBTS has advocated for year after year.

NBTS convenes key stakeholders to make brain tumor diagnosis and treatment less invasive

LIQUID BIOPSY HAS THE POTENTIAL TO ADVANCE THE FIELD OF NEURO-oncology therapy development as an additional tool for clinicians, researchers, regulators, and patients. Patients are eager for this science to become a reality because this technique would make diagnosis and treatment monitoring less invasive.

In July 2024, NBTS brought brain tumor experts, industry leaders, regulatory officials, and patient/caregiver representatives together at one of its annual Research Roundtables to discuss the opportunities and challenges of using liquid biopsy to propel neuro-oncology drug development and diagnostic practices. The meeting catalyzed research ideas and brought forward important regulatory considerations for developing new laboratory tests.

NBTS Launches MyTumorID™ Public Health Campaign

While guidelines from the World Health Organization (WHO) and the National Comprehensive Cancer Network (NCCN) highlight the importance of biomarker testing and clinical trial participation in brain tumor care, a 2023 NBTS-organized community survey revealed that many patients do not fully understand these critical topics.

In response, NBTS launched the MyTumorID public health campaign in 2024 to empower patients to identify their tumor's biomarkers and understand their treatment options, which may include clinical trials. This campaign — the first-ever public health campaign targeting the brain tumor community — equips patients and caregivers with clear, practical resources to understand these important concepts so they can make informed decisions.

Low enrollment in clinical trials remains a significant challenge in neuro-oncology, slowing progress toward new treatments and limiting access to cutting-edge care. Through MyTumorID, NBTS is tackling this issue head-on by raising awareness and delivering clinical trial education that empowers patients. As a result, clinical trial information has become the most requested resource in 2024 through our Personalized Support & Navigation program — a promising milestone in delivering innovative care to patients today.

MyTumor**ID**

ID my tumor's biomarkers.
ID my treatment options.
I Decide.

▶ *This poster is available for doctors and clinicians to request or print to educate patients and caregivers in their offices. Click to download.*

Every brain tumor experience is unique, which is why the National Brain Tumor Society is ensuring all patients and their care partners are equipped to make decisions that are right for them. Together with your health care team, it's time to identify your tumor's biomarkers and your treatment options.

MyTumor**ID**

1. **ID my tumor's biomarkers.** Biomarker testing is a way for your doctors to gather as much information as possible about your tumor.
2. **ID my treatment options.** Your biomarker testing results can help shed light on treatment options that may be available to you, including clinical trials.
3. **I Decide.** When you know your tumor's biomarkers and your treatment options, you can make informed decisions about what to do next.

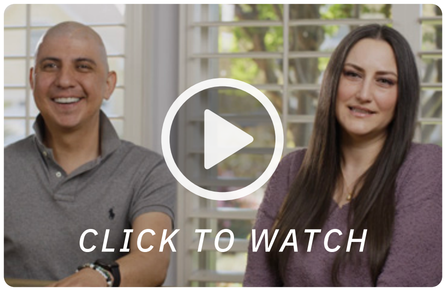
Talk to your doctor about biomarker testing and your clinical trial options.

#MyTumorID

National Brain Tumor Society

MyTumorID.org

> "Biomarker testing drastically changed everything. Before the testing came back, we didn't plan to do radiation or chemo because our neuro-oncologist thought it was low-grade. However, he sent it for testing because there are a lot of tumors that look good through imaging and initial pathology, but are like a wolf in sheep's clothing." — *JENNY B., caregiver*



▲ *In this video, brain tumor community members and experts explain why understanding your tumor through biomarker testing can provide access to innovative therapies.*

NBTS Fosters Brain Tumor Research Innovation

National Brain Tumor Society drives and influences best-in-class medical research to develop and deliver new innovative treatments and potential cures to patients with brain tumors as quickly as possible.

NBTS fuels innovative trials designs for adults and children

NBTS HAS BEEN AT THE FOREFRONT OF advancing innovative trial designs, most notably through GCAR's GBM AGILE (Glioblastoma Adaptive Global Innovative Learning Environment) trial and CONNECT's TarGeT (Targeted pediatric high-grade Glioma Therapy) trial led by Nationwide Children's Hospital.

Since its launch in 2019 with NBTS's support, GBM AGILE has grown into one of the largest biomarker-driven clinical trials for both **newly diagnosed and recurrent glioblastoma** (GBM) patients. This groundbreaking trial, designed to identify therapies that improve overall survival compared to standard treatments, now spans more than 60 trial sites across six countries.

This adaptive platform trial represents a revolutionary approach to clinical research. By focusing on a disease or condition rather than a single treatment, it allows for the simultaneous evaluation of multiple therapies against a common control, accelerating the pathway to new treatments by leveraging existing infrastructure.

Simultaneously, NBTS funds the CONNECT consortium as it leads an umbrella multi-arm adaptive pediatric trial, TarGeT, aiming to identify the most effective combinations of novel drugs and traditional therapies for high-risk pediatric brain tumors, such as **DIPG** and other **high-grade gliomas**. There are four biomarker-driven clinical trials open and actively recruiting, with ongoing discussions to add new investigational treatments arms.

Through trial innovation, NBTS is helping to fast-track promising therapies to patients.

connect

GBM AGILE
Adaptive Global
Innovative Learning
Environment

DNA Damage Response Consortium Accelerates Research

NBTS provides preclinical funding to support advancement to a phase I clinical trial for a drug that could improve survival and quality of life for patients with glioblastoma

▲ *Members of the DDR Consortium meet throughout the year to discuss their collective work. From left to right: Jann Sarkaria, MD, at Mayo Clinic; William Elmquist, PhD, at University of Minnesota; Kim Wallgren, Executive Director of the CERN Foundation, a program of the National Brain Tumor Society; and Anang Shelat, PhD, at St. Jude Children's Research Hospital*

THROUGH NBTS'S DNA DAMAGE RESPONSE CONSORTIUM, RESEARCHERS studying adult and pediatric brain tumors are testing a DNA damage response inhibitor called WSD-0628. Currently being evaluated in a phase I clinical trial at Mayo Clinic for adults with **recurrent glioblastoma**, WSD-0628 shows potential to greatly enhance the effects of radiation, which could significantly improve survival and quality of life for patients.

Dr. Jann Sarkaria (Mayo Clinic), Dr. William Elmquist (University of Minnesota), and the pediatric research group at St. Jude Children's Research Hospital (Drs. Anang Shelat, Chris Tinkle, and Stephen Mack) are conducting laboratory experiments to determine optimal dosages when combining the drug with radiation. This work will help guide future clinical studies in adults and inform the development of a phase I clinical trial for children with high-grade gliomas, including **diffuse midline glioma (DMG)** and **diffuse intrinsic pontine glioma (DIPG)**.

FAST FACTS

8
world-class institutions

13
published papers

27
drugs qualified

5
industry collaborations

2
associated clinical trials

NBTS Funds Cutting-Edge Brain Tumor Research

A new treatment combination triggers GBM cell death in lab models

GLIOBLASTOMA (GBM) TUMORS ARE HIGHLY RESISTANT TO THERAPY-INDUCED CELL DEATH, RESULTING IN a dismal prognosis for patients who have GBM. Through the support of NBTS and StacheStrong, the Nathanson Lab at UCLA identified that all GBM tumors have two molecular blocks to prevent GBM cell death. Common therapies for GBM, like radiation and chemotherapy, disable one of the two blocks, leaving a sole dependency on the other for GBM cell survival.

Working with pharmaceutical and biotech companies, the team discovered that combining an antibody drug conjugate (a newer class of drug) with radiation and chemotherapy could wear down both blocks, consequently triggering GBM tumor cell death and prolonging survival in laboratory models of GBM tumors.

This new class of drugs holds promise for what it could do as a potential novel therapy for patients with GBM while providing a foundation for other therapies trying to engage the cell death machinery in GBM.

> “Organizations like the National Brain Tumor Society are vital for the research that we do. The funding we receive allows us to pursue the most impactful and translational research, helping us move new therapies closer to the clinic.”
>
> *— ELIZABETH FERNANDEZ, PhD,*
> *University of California, Los Angeles*

New grant aims to jumpstart treatment development for patients with pediatric PFA ependymoma

NATIONAL BRAIN TUMOR SOCIETY ISSUED ITS FIRST-EVER CERN PFA EPENDYMOMA TRANSLATIONAL Research Award to Johannes Gojo, MD, PhD, of the Medical University of Vienna (Medizinischen Universität Wien). This grant aims to translate promising research into the clinic for **posterior fossa ependymoma (PFA)**, a particularly aggressive type of pediatric brain tumor.

The grant builds on previous research, which uncovered that a proportion of PFA cells within a tumor harbor stem-like features and give rise to recurrent tumors. Dr. Gojo refers to these stem-like cells as “persister cells.” Based on preliminary data from his lab, the project will investigate whether these “persister cells” can be attacked by adding DNA damage repair-inhibiting drugs to standard treatment with chemotherapy and radiation therapy.

> “We are excited to receive the award, which enables us to investigate how we can better eradicate therapy-resistant ependymoma cells, aiming at developing more effective therapies against this aggressive tumor type.”
>
> *— JOHANNES GOJO, MD, PhD,*
> *Medical University of Vienna*

NBTS Advances Innovative Brain Tumor Research

NBTS funds research to develop a reproducible method to create a personalized vaccine therapy for glioblastoma


▲ Adilia Hormigo, MD, PhD

NBTS, WITH SUPPORT FROM STACHESTRONG, funded the work of Adilia Hormigo, MD, PhD, Leader of the Neuro-Oncology Program at Albert Einstein College of Medicine, to make significant strides in the development of personalized vaccines. These vaccines have the potential to boost the body's immune system and mobilize specialized immune cells called dendritic cells and lymphocytes to fight **glioblastoma (GBM)**. The vaccines work by targeting tumor neoantigens, unique proteins produced by tumor cells due to tumor DNA mutations that are recognized by the patient's immune system. The vaccines then amplify the body's immune system response to eradicate the tumor and elicit a long-term immune reaction.

Dr. Hormigo's team has established individualized procedures for each patient that determine the patient's tumor neoantigens and, through the vaccines, train the body's immune system to fight the tumor cells and ideally defeat the cancer. Through this research, the team aims to offer hope for a much-needed, more effective treatment for brain cancer.

> "Novocure is proud to support the National Brain Tumor Society in its unrelenting work to advance research, deliver treatment, and advocate for people living with brain cancer and their families. Through our partnership with NBTS, we are part of the community committed to fighting this aggressive cancer." — *NOVOCURE*

DID YOU KNOW?

NBTS awarded $1.9 million in grant dollars to researchers in 2024.

In 2024, NBTS funded research across many tumor types, including but not limited to astrocytoma, atypical teratoid rhabdoid tumors (AT/RT), craniopharyngioma, diffuse midline gliomas (DMG/DIPG), embryonal tumors, ependymoma, glioblastoma, medulloblastoma, meningioma, metastatic brain tumors, and oligodendroglioma.

NBTS funded 24 named principal investigators across 15 health institutions in 2024.

NBTS hosted 199 professionals over three Research Roundtable meetings in 2024.

Brain Tumor Investment Fund®
Fuels Treatment Development

The Brain Tumor Investment Fund (BTIF), an affiliate of the National Brain Tumor Society, is a venture philanthropy fund supporting NBTS's vision to conquer and cure brain tumors by investing in biotechnology, pharmaceutical, and medical device companies to catalyze new and novel treatments.

2024 marks the first successful exit by a Brain Tumor Investment Fund portfolio company

BTIF FIRST INVESTED IN MODIFI BIOSCIENCES IN 2021 AND subsequently invested three more times as development milestones were achieved. In fall 2024, oncology powerhouse Merck acquired Modifi Bio. This exit of a portfolio company brings revenue back to BTIF, which can then be invested in additional start-ups in the brain tumor space to advance promising treatments for patients with brain tumors.

BTIF adds two companies to its portfolio

THANKS TO GENEROUS DONORS WHO SHARE OUR VISION, BTIF invests in well-qualified early-stage projects that aim to deliver transformational treatments and technologies to patients with brain tumors. In 2024, BTIF invested in two new companies, Enclear Therapies and Trogenix.

Enclear Therapies has a precision-dosing system called EnTrega CNS Drug Delivery System that enables some therapeutics to bypass the blood-brain barrier to increase the efficacy of the treatment and reduce the risk of severe side effects.

Trogenix is developing a gene therapy to deliver personalized immunotherapy to patients with **glioblastoma**. Their technology activates the body's own immune system against the tumor cells while leaving healthy cells untouched. Preclinical studies have demonstrated curative responses with no toxicity and evidence of persistent anti-tumor immunity, with phase I and II clinical trials planned for 2025.

> "We are grateful for the support of the Brain Tumor Investment Fund for enabling us to advance treatments and improve patient outcomes."
>
> *— ANTHONY DEPASQUA, CEO of EnClear Therapies*

As of Dec. 2024, the Brain Tumor Investment Fund had eight companies in its portfolio under active stewardship:

ALPHEUS MEDICAL
- *Product:* 5-ALA/Sonodynamic Therapy
- *Strategic Area:* Medical Device

CORDANCE MEDICAL
- *Product:* Focused Ultrasound System
- *Strategic Area:* Medical Device

ENCLEAR THERAPIES
- *Product:* EnTrega CNS Drug Delivery System
- *Strategic Area:* Medical Device

KIYATEC
- *Product:* 3D Predict™ Glioma
- *Strategic Area:* Advanced Diagnostics

MIMIVAX
- *Product:* SurVaxM
- *Strategic Area:* Immuno-Oncology

MODIFI BIO
- *Product:* MOD246
- *Strategic Area:* DNA Damage Response

TELO THERAPEUTICS
- *Product:* TSM1001
- *Strategic Area:* Precision Oncology

TROGENIX
- *Product:* TGX-007
- *Strategic Area:* Immunotherapy - Gene Therapy

Connect with BTIF on LinkedIn:
Brain Tumor Investment Fund

NBTS Announces First-Ever Quality of Life Research Grants

Quality of life (QoL) is a major concern among people living with brain tumors, as well as their families and other care partners. *Quality of life* may be defined as an individual's sense of well-being and ability to enjoy and participate in life. National Brain Tumor Society believes that the quest for cures must include the same drive for quality of life, and worked with the community to develop a Quality of Life Research Agenda in 2023 to guide future research efforts in this area.

New grants aim to improve quality of life for patients with brain tumors — and their caregivers

AS A RESULT OF THE EFFORTS TO CREATE A Quality of Life (QoL) Research Agenda, NBTS launched its first Request for Proposals for brain tumor QoL research grants. In response to the overwhelming interest generated by our first call for grant applications in 2024, the critical lack of funding in this area, and additional support from StacheStrong, NBTS announced two grants for patient-centered research.

▲ *From left to right, NBTS board member and survivor Adam Hayden; Brain Tumor Support Conversations co-facilitator and caregiver Lisa O'Leary; former NBTS board member Liz Salmi; survivor Sabine Schwab; survivor Emily McIntosh; care partner Marianne Bergman; and survivor Jeremy Pivor*

The first-ever Quality of Life Research grants are part of a concerted new program aimed at improving the lives of those facing brain tumors, both patients and their caregivers. The new grants will fund two projects, each for $200,000 over two years.

Through a competitive process, NBTS selected two projects:

1. Ashlee R. Loughan, PhD, and Sarah Ellen Braun, PhD, from Virginia Commonwealth University (VCU), will study the effects of a newly developed intervention, FearLess in Neuro-Oncology, aimed at reducing fear of recurrence or progression in patients with brain tumors and their caregivers.

2. Laurie Minns, PhD, from the University of North Carolina Wilmington (UNCW), seeks to provide resources to caregivers of people with brain tumors by adapting the broad PATH© (Preparedness Assessment for the Transition Home) tool specifically for caring for patients with high-grade brain tumors.

▲ *Ashlee R. Loughan, PhD, Virginia Commonwealth University*

▲ *Sarah Ellen Braun, PhD, Virginia Commonwealth University*

▲ *Laurie Minns, PhD, University of North Carolina Wilmington*

NBTS Delivers Personalized Support and Navigation

NBTS continues to expand access, supporting more patients and care partners

WHEN FACED WITH THE CHALLENGES OF A BRAIN TUMOR DIAGNOSIS, patients, care partners, and loved ones often feel overwhelmed and uncertain. That's why they turn to the NBTS's Personalized Support and Navigation team for help. Whether they are seeking answers to urgent questions, searching for clinical trial information, or requesting resources for next steps, NBTS is there to meet them where they are to provide personalized support at the moment it's needed most.

This free program is designed to respond to the unique needs of each person who reaches out, offering guidance, support, and practical resources to navigate the brain tumor journey. In 2024, the most common reasons for outreach included seeking clinical trial information, financial assistance, and navigating the complex health care system.

To ensure access for everyone in the brain tumor community, the Personalized Support and Navigation team also expanded its reach in 2024 by partnering with a company called Propio to offer free interpretation services. Now, community members can connect with NBTS in any language by phone or video call, increasing access to patient support and information.

FAST FACTS

811
personalized navigation sessions

47%
of inquiries served the newly diagnosed

#1
reason for outreach was seeking clinical trial information

> "I went from a feeling of uncertainty on any potential next steps or conversations to now feeling an abundance of options for how to proceed… None of this would have occurred without your active involvement, and I sincerely thank you for that." — *JOHN (pseudonym), patient email*

NBTS Provides Support to the Brain Tumor Community

For everyone living with a brain tumor diagnosis and their loved ones, finding community can be a lifeline.

That's why the National Brain Tumor Society offers three different virtual support groups — Brain Tumor Support Conversations, Caregiver Support Conversations, and Grief Support Conversations — to support community members socially and emotionally. Nearly 1,170 participants attended one of NBTS's virtual support groups in 2024.

NBTS launches new Caregiver Support Conversations group


▲ *Liz Piña*

IN 2024, NBTS WELCOMED CARE PARTNERS TO THE INAUGURAL meeting for Caregiver Support Conversations, where participants can talk virtually about the feelings and emotions accompanying any aspect of the brain tumor experience in a welcoming space. Volunteer co-facilitators Liz Piña and Kelly Theberge host this monthly support group for caregivers currently supporting a person living with a brain tumor to connect on topics that matter to them.


▲ *Kelly Theberge*

"My husband died on March 2, 2024, after a 9.5-month journey with glioblastoma. Once I saw there was a grief support group for those who have lost a loved one to a brain tumor, I decided to attend. I was barely a month out from his death, so it was very fresh. I found comfort in the fact there is no one way to grieve, that it was people from all walks of life and different ages, races, ethnicities, orientations, socioeconomic, demographic, geographic, etc. backgrounds, as well as the diversity of who they lost/their relationship to that person whether it was a partner, child, parent, or friend. I also appreciated Holly's positive, calm, and patient demeanor." — *LIZ W.*

"Brain Tumor Support Conversations is like going into a room with a whole bunch of people who have dealt with what you're dealing with and sitting down in a plush, comfortable chair and just feeling everybody's love through Zoom — because that's what I feel when I'm on those calls. I feel everybody's love and compassion coming through the call." — *JOELIN L.*

NBTS's blog offers educational content on a variety of topics important to the brain tumor community. In 2024, our blog addressed the importance of getting a second opinion before surgery, fertility preservation, improving balance and preventing falls, parenting with a brain tumor, Medicare, Social Security Disability Insurance, and more. The blog also profiled 16 individuals to help show others they are not alone in their brain tumor experience.

READ THE LATEST

“One of the fortunate things to come of Kai’s diagnosis has been the connections you make along this journey. Meeting Katherine, NBTS’s patient navigator, was a series of connections. Katherine was able to say, ‘Let me take this off your hands. Let me do that legwork and present you with some clinical trial information summaries.’ It took a load off because she took the time to do that when I didn’t have the time but needed the information.” — *Kari C.*

NBTS Drives Policy Change

National Brain Tumor Society, along with nearly 20,000 advocates across all 50 states and Washington, D.C., ensures the brain tumor community's needs are reflected in national medical research and health care policy.

NBTS urges the federal government to improve insurance networks to ensure health care access for patients

ON BEHALF OF THE BRAIN TUMOR COMMUNITY, NBTS HAS BEEN a strong advocate for expanding access to the nation's top brain cancer care centers. In a formal appeal to the Centers for Medicare and Medicaid Services (CMS), NBTS called for broader health insurance network adequacy to include leading hospitals specializing in brain tumor treatment.

NBTS also published a white paper documenting the challenges faced by patients navigating narrow insurance networks. This resource sheds light on the real-world impact of limited access to specialized care.

"My family moved to Texas so we could access a top tertiary cancer clinic, so my wife could receive the highest quality care," said Gary C. "In the middle of her treatment, we were informed that they weren't in-network with our marketplace plan. We ultimately had to resume treatment at a local hospital that — while having caring, competent doctors — just did not have the same resources and state-of-the-art technology as MD Anderson. Patients with brain tumors should not have to sacrifice quality of care due to out-of-network insurance status."

NBTS will continue to speak up to the federal Department of Health and Human Services to ensure that access to adequate and medically necessary cancer care keeps up with clinical advances and new treatments.

NBTS supports the renewal of the Gabriella Miller Kids First Pediatric Cancer Research Program

NATIONAL BRAIN TUMOR SOCIETY advocated for the successful renewal of the Gabriella Miller Kids First Research Act 2.0, securing $12.6 million per year for the next five years. This vital program, reauthorized through fiscal year 2028, will continue to provide funding for much-needed research on childhood cancer and other pediatric diseases to help drive progress. The legislation was named after Gabriella Miller, who was diagnosed with diffuse intrinsic pontine glioma (DIPG) at age 9, and bravely challenged elected officials to "stop talking and start doing" two weeks before she died of brain cancer at the age of 10.

NBTS Advocates Make a Difference

NBTS urges against a government shutdown and supports an end-of-year funding/legislative package

IN FALL 2024, NBTS AND ITS ADVOCATES URGED CONGRESS TO come together to pass a Fiscal Year 2025 budget and avoid a looming government shutdown. A government shutdown would have threatened to disrupt critical brain tumor research, treatment development activities, and patient access to care. NBTS led advocacy efforts to ensure that Congress understands the negative impact of government shutdowns on research.

As Congress adjourned in December, it did pass a bill that funded the government through March 14, 2025, allowing the National Institutes of Health (NIH) and the National Cancer Institute (NCI) to continue its research, clinical trials, and other patient services uninterrupted.

FAST FACTS

1,792
new advocates

16,434
legislator connections

431
meetings with Congress

NBTS Champions Introduction of the BRAIN Act

The Bolstering Research And Innovation Now (BRAIN) Act is a historic first for the brain tumor community. This landmark piece of legislation was first introduced with bipartisan support in July 2024 during the 118th Congress and aims to advance the quest to defeat brain tumors, once and for all, by increasing research funding, fostering collaboration, promoting critical awareness efforts, and supporting innovations in and access to care.

NBTS celebrates the introduction of the BRAIN Act in Congress

THE BRAIN ACT WAS THE FIRST PIECE OF legislation specifically developed to meet the unique needs of brain tumor researchers, clinicians, patients, and survivors. This comprehensive, bipartisan bill would span the spectrum of policy hurdles from basic research, drug development, and clinical trials, to awareness of critical treatment options, access to trials, and survivorship care.

Brain tumors are complex, hard to treat, and don't play by the same rules as cancers in other parts of the body. Nationally, much progress from cancer-related policy efforts has come as a result of focusing on early detection, prevention, and screening initiatives — measures that aren't currently applicable to brain tumors — as well as types of treatments that have, so far, been difficult to make work in the brain.

The situation was clear — legislation needed to be developed and tailored specifically to the unique needs of the brain tumor community.

The original BRAIN Act included five sections that addressed the spectrum of challenges facing the brain tumor community, from basic scientific research to early-phase drug discovery and development, clinical trials, diagnosis and treatment planning, and care and quality of life for those living with and surviving brain tumors. Specifically, federal policy changes in the legislation would:

- Bolster transparency of research resources, namely biospecimen collections
- Foster greater scale of funding and collaboration among leading cancer centers in brain tumor research
- Commit the federal government to play its part in educating patients with cancer about clinical trials and biomarker testing
- Enhance brain tumor survivorship by funding the development of better care models for patients living with brain tumors
- Require the FDA to develop new guidance to ensure patients with brain tumors and other aggressive cancers have better access to clinical trials related to other health conditions

NBTS Advocates for Support of the BRAIN Act

Community unites for policy change in support of the BRAIN Act

THANKS TO THE PASSIONATE EFFORTS OF OUR ADVOCATES AND partners, NBTS more than doubled the number of co-sponsors in the House of Representatives for the BRAIN Act after making it the exclusive ask at NBTS's Advocate From Your State event — a virtual Head to the Hill advocacy day held every fall. This surge in support reflects the growing momentum behind this critical legislation.

Our advocacy has also garnered support from numerous brain tumor-focused organizations and partners in the broader cancer community, including the American Brain Tumor Association, Brain Tumor Network, ChadTough, End Brain Cancer Initiative, Glioblastoma Research Organization, Head for the Cure, Making Headway Foundation, Our Brain Bank, the Alliance for Childhood Cancer, and the Society for Neuro-Oncology.

Together, we're building a powerful coalition to drive policy change that will advance research and improve care for patients with brain tumors and their families.

▲ *Rep. John Joyce, MD (right) became an original co-sponsor of the BRAIN Act after meeting with NBTS advocates at Head to the Hill*

BRAIN Act Co-sponsors in the 118th Congress

ORIGINAL CO-SPONSORS:

- Senator Richard Blumenthal (D-CT)
- Senator John Barrasso (R-WY)
- Senator Jack Reed (D-RI)
- Senator Mike Rounds (R-SD)
- Rep. Brian Fitzpatrick (R-PA)
- Rep. John Joyce (R-PA)
- Rep. Lori Trahan (D-MA)
- Rep. Susan Wild (D-PA)

SUBSEQUENT CO-SPONSORS:

- Senator Mark Kelly (D-AZ)
- Senator Kyrsten Sinema (I-AZ)
- Rep. Jake Auchincloss (D-MA)
- Rep. Nikki Budzinski (D-IL)
- Rep. Kathy Castor (D-FL)
- Rep. Sharice Davids (D-KS)
- Rep. Donald G. Davis (D-NC)
- Rep. Mark DeSaulnier (D-CA)
- Rep. Scott DesJarlais (R-TN)
- Rep. Derek Kilmer (D-WA)
- Rep. Young Kim (R-CA)
- Rep. Michael Lawler (R-NY)
- Rep. Summer L. Lee (D-PA)
- Rep. Mike Levin (D-CA)
- Rep. Ted Lieu (D-CA)
- Delegate Eleanor Holmes Norton (D-DC)
- Rep. Brittany Pettersen (D-CO)
- Rep. Jamie Raskin (D-MD)
- Rep. Deborah K. Ross (D-NC)
- Rep. Haley M. Stevens (D-MI)
- Rep. Eric Swalwell (D-CA)
- Rep. Debbie Wasserman Schultz (D-FL)
- Rep. Randy Weber (R-TX)

NBTS and Advocates Make an Impact at Head to the Hill®

Volunteer advocates from across the country united at Head to the Hill in Washington, D.C., to urge Congress to take action and address the urgent, unmet needs of the brain tumor community. More than 320 dedicated advocates — including patients, care partners, family members, friends, health care providers, and researchers — met with their members of Congress and staff to push for increased brain tumor research funding and advocate for policies that address the challenges faced by those impacted by brain tumors.

Brain tumor research funding increases by $16 million

THANKS TO NBTS'S COLLABORATIVE advocacy efforts within the brain tumor community, National Institutes of Health (NIH) funding for brain tumor research increased approximately $6 million. Additionally, Congress created a new glioblastoma-specific funding stream for the first time and dedicated $10 million to peer-reviewed glioblastoma (GBM) research in Fiscal Year 2024 (ultimately enacted in 2025) within the Congressionally Directed Medical Research Program (CDMRP) at the Department of Defense.

▲ *Congressman Roger Williams and Rep. Susan Wild spoke to advocates on the steps of the Capitol to kick off a day of Head to the Hill meetings.*

Ependymoma survivor inspires action at Head to the Hill

SHAWN W. NEVER IMAGINED HIS BRAIN TUMOR experience would lead him to Capitol Hill, sitting across from a congressman and making a direct impact on legislation. But in May 2024, that's exactly where he found himself — telling his story, advocating for the brain tumor community, and witnessing firsthand how personal experiences can drive real change.

When Shawn walked into his meeting with Congressman John Joyce, MD, he was ready to share his story as a posterior fossa (PFB) ependymoma survivor and advocate for the Bolstering Research And Innovation Now (BRAIN) Act. What he didn't expect was just how engaged Rep. Joyce would be.

"He had done his homework, so he already knew what the BRAIN Act was," Shawn recalled. "So when he sat down, he looked at us and said, 'I want to know why you're here.' That's when I realized I needed to tell him my story and explain why this bill mattered to me."

Shawn spoke about his diagnosis, the challenges he faced, and how the provisions of the BRAIN Act could help patients and survivors like him. Rep. Joyce listened intently, asked questions, and expressed serious interest in signing on as a co-sponsor by the end of the meeting. In July, Rep. Joyce became an original co-sponsor of the BRAIN Act, a landmark bipartisan bill aimed at addressing the unique needs of the brain tumor community.

> “As a brain tumor survivor, I got connected with NBTS after seeking out emotional support as I navigated this medical journey. NBTS encouraged me to become an advocate and share my story. So, at Head to the Hill 2024, I did just that. It was my first time attending, and the NBTS community made me feel welcome and safe to share my story. Head to the Hill was a very healing experience for me." — *BRANDY R.*

NBTS Raises Brain Tumor Awareness

Bravo's "Real Housewives of Potomac" Raise Funds and Awareness

Gizelle Bryant and Ashley Darby took their commitment to raising funds and awareness for the brain tumor community to the next level by hosting GnA Fusion, an NBTS Fundraise Your Way event. More than 230 members of the D.C. community gathered to take part in a HIIT workout, breath work, and yoga, raising over $15,000 for the National Brain Tumor Society.

This impactful event was held in tribute to Gizelle's father, Curtis Graves, who was diagnosed with glioblastoma in July 2023 and passed away just 12 days later. The day of celebration and remembrance not only united new and existing members of the brain tumor community but was also highlighted on Bravo's "Real Housewives of Potomac," further amplifying the cause and the importance of the mission nationwide. ▶

> "GnA was all about athleisure and fun clothes, but I felt a need to make it a little bit more meaningful. My father passed from a brain tumor. It was so tough. Because it was so tough, I wanted to do something in his memory and in his honor. I wanted to make sure that I could help anyone who might have a brain tumor or might be suffering. I wanted to plan this party for a purpose. I have been so happy that I have been able to dive in and really work with NBTS. It has really helped me." — *GIZELLE BRYANT, "Real Housewives of Potomac"*

Wisconsin Brain Tumor Walk & Race

NBTS brought together thousands of members of the brain tumor community at NBTS-hosted and volunteer-driven events in nearly all 50 states — including the inaugural Wisconsin Brain Tumor Walk & Race held in Madison, Wisconsin — and now internationally into Canada. ▶

Glioblastoma Awareness Day Reception

NBTS commemorated Glioblastoma Awareness Day with an in-person reception in July 2024, in Washington, D.C. Members of Congress, patients, care partners, researchers, and other members of the brain tumor community gathered to shine a spotlight on glioblastoma — the most common, complex, treatment-resistant, and deadliest type of brain cancer. The in-person event concluded NBTS's national campaign to spread awareness about this devastating disease. ▶

NBTS at a Boston Red Sox Game

In June 2024, the National Brain Tumor Society took to the iconic Fenway Park to spread awareness during a Boston Red Sox game. Our booth, positioned on the bustling concourse, attracted fans eager to learn about our mission and the impact of brain tumors on individuals and families. Volunteers and staff shared vital information, encouraged conversations, and distributed resources to fans in attendance. ▶

“We were together for 20 years. Once the funeral’s done, you’re sitting at home alone, and depression sets in. Doing these events and supporting these charities gave me a reason to live. Now, I continue to live and have a purpose — trying to do everything that I can to see that there’s a cure before I die of old age.” — *Alan B.*

Signature Events

TOP FUNDRAISING INDIVIDUALS

Race For Hope DC:
Katherine Savits - $78,416

Georgia Brain Tumor Walk & Race:
Pat Vaughan - $74,657

National Brain Tumor Ride:
Lisa Shapiro - $28,994

New England Brain Tumor Walk:
Karolina Atsalis - $22,869

Colorado Brain Tumor Walk & Race:
Russell Bruce - $17,476

Race For Hope Greater Philadelphia:
Krista Dankiw-Ludwig - $16,953

Virginia Brain Tumor Walk & Race:
Kevin Kokal - $13,746

Wisconsin Brain Tumor Walk & Race:
Mike Miller - $13,585

Southern California Brain Tumor Walk & Race:
Roxy Striar - $10,141

New York Brain Tumor Walk:
Reid Alper - $9,729

New Jersey Brain Tumor Walk:
Leanne Storer-Benvignati - $8,068

Northern California Brain Tumor Walk:
Leah Recht - $7,848

Carolina Brain Tumor Walk & Race:
Holly Gainsboro - $6,146

TOP FUNDRAISING TEAMS: $50,000+

Rachel’s Racers: $99,670

#SharonStrong: $89,024

Lisa’s Riders: $75,922

Survivors: $73,624

ReMARKable Strides: $60,449

▲ **NORTHERN CALIFORNIA BRAIN TUMOR WALK**
“The need for research is urgent. It has been and always will be. I feel like I have a part to play in this, so I try to raise funds and stay involved with the community.” — *Craig F.*

▲ **WISCONSIN BRAIN TUMOR WALK AND RACE**
“Our family has found so much healing in participating in different events in Nicholas’ name. The Wisconsin Brain Tumor Walk & Race has made us realize that we are not alone, and it gives us hope to know that we are helping to work towards a cure. Our hope and prayer is that no family would ever have to say goodbye to a loved one, as we did, because of brain cancer.” — *Heather B.*

Signature Events

TOP FUNDRAISING TEAMS: $25,000+

Tori’s Army: $45,488

Smiley Strong: $38,227

Team Mawn: $34,742

Team Oligo: $34,076

Penn Pioneers: $33,339

Fiore’s Fighting Force: $33,090

David Cook’s Team for a Cure: $32,913

Team Z Mac: $32,842

Rabbi’s Runners: $32,207

Kate’s Crew: $31,882

‘Rae’ of Sunshine: $30,523

The Lu Crew: $26,122

Team Coffman: $25,797

Maryland Brain Tumor Center: $25,627

TOP RECRUITING TEAMS

Virginia Brain Tumor Walk & Race:
Tori’s Army — 238

New England Brain Tumor Walk:
Fiore’s Fighting Force — 151

Race For Hope DC:
Rachel’s Racers — 145

Northern California Brain Tumor Walk:
Team Stanford — 106

New Jersey Brain Tumor Walk:
Ignite Wellness — 101

Race For Hope Greater Philadelphia:
Chrissy’s Crusaders — 94

Wisconsin Brain Tumor Walk & Race:
Fight On Mike — 73

National Brain Tumor Ride:
Lisa’s Riders — 62

Carolina Brain Tumor Walk & Race:
Amazing Grace — 60

New York Brain Tumor Walk:
Team E — 59

Georgia Brain Tumor Walk & Race:
#SharonStrong — 50

Southern California Brain Tumor Walk & Race:
Miles for Melanie — 46

Colorado Brain Tumor Walk & Race:
Tracy’s Troop — 42

▲ RACE FOR HOPE DC
“My wife described Race for Hope DC as an overwhelming feeling of community and connection. It gave us a chance to channel our energy into something positive. Fundraising for the National Brain Tumor Society is extremely important because this disease affects people on different levels — not just the patient but also family members.” — *Leo H.*

▲ RACE FOR HOPE PHILADELPHIA
“I leave these events with tears in my eyes. Being surrounded by patients and caregivers who’ve become like family to us is inspiring. It’s really meaningful to have an event where we can come together and connect outside of a hospital or support group. We’re not just talking about treatments or what happened on our last scan. We’re there having fun.” — *Melissa F.*

Fundraise Your Way

$100,000+

Team Billy Ride and Walk for Research: $132,091

McGuiness Memorial Golf Tournament by Brain Cancer Answer: $112,200

Fight for the Brain Happy Hour: $109,806

$20,000+

6th Annual Childhood Brain Cancer Research Collaborative Golf Tournament: $45,000

Sally and Lee Atwater Memorial Reception: $39,800

P&D Student Choreography Project: $30,020

Alston Construction Brain Tumor Awareness Month Fundraiser: $29,075

Georgia Wireless Association David Downie Memorial Charity Golf Classic: $25,000

Chips for Kip Golf Tournament: $24,996

Jones'n for a Cure Golf Tournament: $22,000

$10,000+

Tiltify Operation Magnetic Mayhem: $18,203

Michael Cassidy Shamrock 'N' Run: $18,000

GnA Fusion Event: $15,338

Gandython: $13,193

50/31 Challenge: $12,026

Peter Audia's Hope Fund: Supporting the Fight Against Glioblastoma: $11,196

Dips for Di: $11,113

Joggin' 4 the Noggin 5K Run/Walk: $10,500

Wander to Wonder on Water: $10,031

Coaches Against Cancer: $10,000

GBM Foundation Events: $10,000

▲ "I think it's easy to get wrapped up in the rarity of brain tumors, and it can feel like an isolating experience. It always surprises me how many people within my local area have experienced loss from a brain tumor, and it feels special to have a day to come, relate, and share grief. Beyond rallying together to fight for a cure, it feels good to dedicate time to remember, share, and smile."
— MacKenzie D., St. Vrain for the Brain 5K

▲ "Brews for Brains started because of Kevyn. I wanted to show support for my son, and I also wanted to show support for other people going through this, whether they lost a loved one, whether the loved one has recovered, and just to raise funds. Because I'm a father and I have a son who had a brain tumor, I don't know what's going to happen years from now. I don't know what's going to happen when I pass away, so if I can raise $100, $1,000, or $5,000 for research, I feel that will help his longevity, help him have his grandchildren, and help him have a life, even if [his brain tumor] comes back in the future."
— Jeff S., Brews for Brains & Brain Waves Hanover

Fundraise Your Way

$5,000+

Mimosa March To Cure Brain Cancer: $9,800

Bags and Brews for Brains: $9,685

Gray Games in Loving Memory of Greg Jeffris: $8,866

Brain Waves Hanover Brews for Brains: $8,356

Gray Matter Classic Golf Tournament: $7,898

Birdies for Brain Tumors: $7,853

Impact Golf: $7,189

St Vrain for the Brain 5k: $7,123

True Blue JC Shootout for Dreams Charitable Lacrosse Tournament: $7,000

10-13 Donations to Fight Glioblastoma: $6,963

North Texas Sweethearts Philanthropy Week & 5K: $6,669

JIMBO's Birthday Bash for Brain Cancer: $6,553

GOALS for GLIO: $6,471

Matt Shackelford Memorial Golf Tournament: $6,392

Gray May 5K in Memory of Kris Stunkel: $6,000

Lee, Ethan, and Eliana in loving memory of Papa Jack: $5,970

Patricia Strong Tinning Fundraiser: $5,005

Bob Burns Memorial 5K: $5,000

Glio Leo Lions Who Lunch Fundraiser: $5,000

Papa's Ride 4 Dray: $5,000

▲ "Honestly, it was NBTS's help almost four years ago to the day that got us to the place we're at with Megan's health and energy. It's not an exaggeration to say their guidance and support are why we're even here today, able to do this, and these events are the least I can do!"
— Mike P., Gray Matters Charity Golf Classic

FAST FACTS

$1.02 Million

raised through
Fundraise Your Way events

133

events took place in 2024

33

states welcomed volunteer
fundraisers + one in Canada

Gray Nation Endurance®

$20,000+

Braden White - Play Hurt Project: Running for a Cure: $76,947

Anna Mack - Philadelphia Half Marathon: $37,230

Van Haskell - Boston Marathon - $27,969

$10,000+

Michael Caruso - TCS New York City Marathon and United Airlines NYC Half: $19,798

Team Cindy Fitzpatrick - ASICS Falmouth Road Race: $19,527

Marieke Spence - TCS New York City Marathon: $19,459

Valerie Oswalt - TCS New York City Marathon: $17,262

Alec Molloy - TCS New York City Marathon: $17,055

Laura Brown - Big Sur 11-Miler: $15,301

Jack Coyne - TCS New York City Marathon: $15,193

Liz Starling - TCS New York City Marathon: $12,911

Chris DeMartino - TCS New York City Marathon: $12,481

Nicole Cutler - TCS New York City Marathon: $12,031

Michael Otway - TCS New York City Marathon: $11,465

Girlynda Gonzales - Big Sur 11-Miler and TCS New York City Marathon: $11,155

Mike Squillante - Jersey City Marathon: $10,575

Kieran Donohue - TCS New York City Marathon: $10,466

Emily Solomon - TCS New York City Marathon and United Airlines NYC Half: $10,374

$5,000+

Christen Connell - Big Sur 11-Miler: $9,100

Megan Gebert and Daniel Gilliam - ASICS Falmouth Road Race: $8,918

Ashley Witt - TCS New York City Marathon: $8,770

Emily Straehle - TCS New York City Marathon: $8,505

Shea O'Donovan - ASICS Falmouth Road Race: $8,255

Allie Bennett - Philadelphia Half Marathon: $8,100

Scott McGarrell - TCS New York City Marathon: $8,021

Jenny Brewer - TCS New York City Marathon: $7,974

Jean Slevin - Philadelphia Marathon: $7,697

CONT. ➤

▲ "I personally view the fundraising and running in the 2024 Boston Marathon as one of the greatest accomplishments of my life. I truly would not have been able to achieve it without the NBTS team. They supported me from the very beginning in securing a bib all the way through to race day, cheering me on. I feel honored to have run on behalf of NBTS's Gray Nation Endurance team and could not recommend it more highly to anyone else." — *Van H., 2024 Boston Marathon*

▲ "Being a part of Gray Nation Endurance meant more to me than just running a race. It was about honoring the person I love the most and raising awareness for the National Brain Tumor Society, an organization that has become incredibly meaningful to me. The support from Gray Nation and the opportunity to run with a cause that truly matters gave me strength every step of the way. I'm proud to have been part of such a powerful community and look forward to coming back in the future to continue raising awareness and supporting the fight against brain tumors." — *Lydia D., 2024 Philadelphia Marathon*

$5,000+ (cont.)

Matthew Giordano - United Airlines NYC Half: $7,675

Danielle Aftandilian - ASICS Falmouth Road Race: $7,473

Tallie Matte - TCS New York City Marathon: $7,450

Josh and Elizabeth Brooks - ASICS Falmouth Road Race: $7,272

Elizabeth Bryndza - TCS New York City Marathon: $7,200

Greg Kerr - Twin Cities Marathon: $7,150

Jacqueline Townsend - TCS New York City Marathon: $7,031

Brian Prunty - TCS New York City Marathon: $7,023

Barrett Fitzgerald - TCS New York City Marathon: $6,897

Running for DJ Guizar - LA Half Marathon: $6,705

Margaret Terwey - Big Sur Marathon: $6,700

Kim Niemi - TCS New York City Marathon: $6,672

Lauren Turner - United Airlines NYC Half: $6,405

Grace Hensel - TCS New York City Marathon: $6,363

Leanne Storer-Benvignati - Philadelphia Marathon: $6,325

Run like Anna Grace - 3 Bridges Marathon: $6,300

Victoria Bee - TCS New York City Marathon: $6,205

Laurence Williams - TCS New York City Marathon and Triathlon Efforts - $6,115

Team Margot Griesbach - Twin Cities 10-Mile: $6,030

Athena and Greg Merage - Big Sur 11-Miler: $6,000

Mary Kate Nemeth - TCS New York City Marathon: $5,999

Tom Whalen - ASICS Falmouth Road Race: $5,868

Chris Nguyen - TCS New York City Marathon and RBC Brooklyn Half Marathon: $5,640

Meri Mitsuyoshi - Big Sur 11-Miler: $5,545

Tim Scatterday - TCS New York City Marathon: $5,530

Lydia Deppman - Philadelphia Marathon: $5,420

Valerie Aguilar - TCS New York City Marathon: $5,369

Virginie Godin-Bergeron - United Airlines NYC Half: $5,170

Quinn Hourihan - TCS New York City Marathon: $5,135

Sydney Tritsch - TCS New York City Marathon: $5,090

▲ "I was able to run the 2024 NYC Marathon thanks to the National Brain Tumor Society and my supportive donors — all in memory of my incredible dad, Joseph Carbonaro. I am incredibly proud of running 26.2 miles throughout NYC to support brain tumor research. Every day, the funds we raise bring us one step closer to finding a cure." — *Sarah C., 2024 NYC Marathon*

FAST FACTS

$1 Million
fundraised by GNE athletes

28
states represented by GNE athletes + Canada

216
athletes participated in 2024

Donor Honor Roll

NBTS thanks our donors who gave generously in 2024 to advance our vision of conquering and curing brain tumors — once and for all.

VISIONARY SOCIETY:
$250,000+ cumulative giving since 2008

Anonymous (2)
Howard and Susan Elias and Family
Davina Bruckner
Mrs. Dolores Claeys
Stephen and Ellen Conley
Robert Lloyd Corkin Charitable Foundation
Maben-Davis Family Foundation
Jeff and Susan Davis
GCAR - Global Coalition for Adaptive Research
Genentech
Michael and Jamie Goguen
Hankin Family Charitable Foundation
Imvax
IQVIA Biotech
Mark and Sandra Kramer
Lamb Family Foundation
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Medical Research Charities
Northern Bank
Novocure
Rally Foundation for Childhood Cancer Research
The Sadler Family
Deborah Newman Sharpe and Today is a Good Day Foundation
StacheStrong
The Stringer Foundation
Students Supporting Brain Tumor Research (SSBTR)
Richard Wells
ShopRites of Zallie Family Markets

CIRCLE OF BREAKTHROUGHS: $250,000+

Anonymous
Howard and Susan Elias and Family
Michael and Jamie Goguen
Hankin Family Charitable Foundation
IQVIA Biotech
StacheStrong

◀ "While I have seen some positive outcomes and truly believe a breakthrough is coming, I know that research funding is costly. I have set up monthly donations and also included NBTS in my will so that I can be assured that my efforts will not end when I can no longer give directly." — *Jim G.*

CIRCLE OF CHANGE: $50,000 - $249,999

Anonymous
Brain Cancer Answer Foundation
Brain Tumor Research Trust
Davina Bruckner
Richard E. Capri Foundation
Mrs. Dolores Claeys
Stephen and Ellen Conley
Maben-Davis Family Foundation
Jeff and Susan Davis
Rebecca Engle Memorial Fund
Imvax
Dawn and Michael Nathanson Family Fund
The Novikoff Family Foundation
Novocure
Patient-Centered Outcomes Research Institute (PCORI)
Rally Foundation for Childhood Cancer Research
The Sadler Family
Servier Pharmaceuticals
The Colony Group
The Stringer Foundation
Stryker Corporation
University of Maryland School of Medicine
Robert V. Vitale
Richard Wells

NBTS strives to be accurate in publishing our donor names and their giving levels. If you believe your listing has an error or there has been an omission, please contact NBTS at donations@braintumor.org, as there can be a margin of error when data is entered into our system.

Donor Honor Roll

CIRCLE OF PROGRESS: $10,000 - $49,999

Anonymous (4)
Beth Alpern and Walter Kuhn
American Petroleum Institute (API)
Aminad Consulting
Carson Anderson
Terry and Susan Anderson
Bass, Berry & Sims PLC
Brian J. Bennett
Cooper-Siegel Family Foundation
Rebecca and Vinay Bhatt
Erica and Brian Birke
BlackRock Matching Gifts
Allison Brooks
Christopher Brown
Michael Cassidy Memorial Fund
Childhood Brain Cancer Research Collaborative
Chimerix
Coaches Against Cancer, Inc
Coca-Cola Matching Gifts
James and Peggy Conley
Jim Cooper
Robert Lloyd Corkin Charitable Foundation
Cravath, Swaine & Moore
DaBella
Jean Dalstad
Teri Day
Kasey Draper
Sarah Durham and Craig Winer
Emory Winship Cancer Institute
Bonnie Feldman
Jess Fin Foundation
GBM Foundation
GCAR - Global Coalition for Adaptive Research
Genentech
Georgia Wireless Assoc, Inc.
GLK Foundation
Google Matching Gifts Program
Drs. Matthew and Diana Gordon
Jim Graul
Amy and Steven Halvorsen
The Hamilton Company Charitable Foundation
William Hayes
Steph James
Jefferson Health
Johns Hopkins Medicine
Jones’n for a Cure
Northside Hospital Cancer Institute
Julie and Ralph B. Kimball
King & Spalding, LLP
KM Legacy Foundation
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Frank Macchiarola
The Maher Charitable Trust
Phyllis W. McGillicuddy Charitable Trust
Medical Research Charities
Sara Naison-Tarajano
Northern Bank & Trust
Oracle
Penn Medicine
Marta Ann Peterson
Porterfield, Fettig & Sears LLC
Jeremy Rabinovitz and Katherine Savits
The Rainwater Charitable Foundation
Lido and Leigh Ramadan
Nadia Ramadan
Jigar Raythatha
Ride 4 Dray
Michelle and Tom Roloff
Samuel Ross
Arlene Roth
Ms. Averi Schaubman
Scoops2U
Deborah Newman Sharpe and Today Is A Good Day Foundation
The Sontag Foundation
Stanford Health Care
David S. Stone Foundation
Jeffrey Storer
Leanne Storer-Benvignati
Students Supporting Brain Tumor Research (SSBTR)
Joohee Sul
Susquehanna Foundation
Sysco Corporation
The Washingtonian
Todoroff Giving Fund
The Jed Tyler Memorial Fund Inc.
Mrs. Nancy Ulrich
Wharf Casual Seafood
The Wilson Underwood Family Fund
Jennifer Wilson and John Underwood
Valero Benefit for Children
Valero Energy Corporation
WCVB-TV
Kierstan Whitsell
The Wilson Underwood Family Fund
Jennifer Wilson and John Underwood
Christopher Wright
Prateek Bajaj Legacy Fund

Donor Honor Roll

CIRCLE OF HOPE: $1,000 - $9,000

Anonymous (11)
Mary Abbey
Abbott Laboratories Employee Giving Campaign
ABC7 LA
Anam Adbo
Barb And Joe Abdoo
Abramson Family Foundation
Marc Aiello
Sara Aiello
Cheryl Albaugh
Aimee Albright
Kimberly Albro
Fay and Dan Alexander
Keith Allen
Elizabeth Allison
ALP Industries LLC / Lift Solution
Seth Alvord
Lisa Amato
American Clean Power
American Express Foundation - Matching Gifts
Ameriprise Financial Matching Gift Program
Dawn Amore
Eric Anderson
Keaton and Sydney Anderson
Miguel Anderson
Patricia Anderson
The Andrews Family
Allison, Brendan, Henry and Ryan Andrews
John Antonelli
APM Terminals
Pam Archer
Arlington Basketball Club LLC
Alexis Armenteros
Stephan Artusi
Ascape Landscape & Construction Corp.
Asher Family Fund
Rebecca and Glenn Asher
Tammy Asnes
Atlantic Health System
Christopher Atsalis
Elizabeth Atsalis
Alma Atwater
Alyssa Audet
Julie Audia
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Jeffrey Baab
Leonard Baczek
Zach Bahor
Jessica Bailey
Bob Baker
Baker and Sommer Family
Ellie Baker
Nicholas Baldick
Bandaru Charitable Fund
Lakshmi and Dr. Raja Bandaru
CyberGrants - Bank of America
Barnet Family Fund
Bruce Baron
Alicia Barrett Memorial Fund
Barrows-Flanagan Family Fund
Steve Barsanti
Barsz Gowie Amon & Fultz
Bridget Basehoar
Mara-Michelle Batlin
Dawn Bauleke
Ruth Bayley
Kory Beaber
David Beddow
William Beddow
Denise Bednarek
Joseph Bednarek
Dorothy and Christiaan Beeuwkes
Nancy Beeuwkes
Bellmawr Truck Repair Company
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Ellen Bergman
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BGR GROUP
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Michael Blefeld
John Blix
Bonnie Bloom
Bloomberg LP Matching Gifts
Susan Blue
Blue Cross Blue Shield of Massachusetts
BMS Matching Gift Program
BMS Employee Giving Program
Body and Soul Fitness
Robert Boland
C.E. Bond
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WSB Family Foundation
Michelle Borisenok
Carey Bosch
Dr. Thomas Bosserman
Naina Boveja
Lori Bowers
Athena Bowyer
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We extend our heartfelt gratitude to the founding members who joined the Legacy Society in 2024, as well as to all those who have been part of this generous group by including NBTS in their estate plans. Your visionary support lights the path forward and will make a lasting difference in the lives of countless patients and families for generations to come.

◀ “By making a legacy donation to the National Brain Tumor Society, I am continuing my fundraising efforts to support the battle against GBM and other brain tumors. This contribution ensures that future generations benefit from progress in research, treatment, and support services. Including NBTS in my estate planning is a way for me to leave a lasting impact that aligns with my dedication to this cause. My aim is for my gift to sustain advanced research efforts, enhance patient advocacy, and fund educational programs that lead to a cure and improve the lives of those affected by brain tumors.” — *Karen Roberts Turner*

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Edjah Nduom, MD, *Chair*
Erica Birke, *Vice Chair*
Leah Recht, JD, *Clerk*
Mil Parekh, CFP, CPWA, *Treasurer*

ACTIVE VOTING BOARD MEMBERS

Allison Bishof, CRNA
Chris Brown, CFA
Sarah Durham
Adam Hayden
Frank Macchiarola, JD
Jigar Raythatha, MBA
Kabir Sethi, MBA
Joohee Sul, MD
Karen Roberts Turner, JD
Jonathan Weinberg, JD
Rabbi Corie Yutkin

G. Bonnie Feldman,
Non-Voting Co-Founder

Al Yung, MD,
Non-Voting Honorary Board Member

EMERITUS BOARD MEMBERS

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Rob Burger
Michael Corkin
Rob Corrao
Dave Donabedian
Sarah Durham
John Frishkopf
Eva Galanis, MD
Richard Genderson
Ken Grey
Steve Karol
Sheila Killeen
Jeffrey Kolodin *(deceased)*
Ryan Lang
Michael Nathanson, JD, LLM
Chandri Navarro, JD
Eric Olson, PhD
Susan Pannullo, MD
Thomas Roloff
Allison Ross
Dennis Roth
Steve Sadler
Liz Salmi
Cord Schlobohm, DMD
Rabbi Eric B. Wisnia *(deceased)*
Charles B. Wilson, MD *(deceased)*
Salo Zelermyer, JD

▲ NBTS board members and staff leadership learned about advancements in CAR-T therapy work at Penn Medicine during the September board meeting.

◀ NBTS board member and glioblastoma survivor Karen Roberts Turner reunites with fellow board member Joohee Sul, MD, who was Karen's doctor during her active treatment phase.

◀ Board members Karen Roberts Turner, Chris Brown, and Leah Recht advocated for the needs of the brain tumor community at NBTS's Head to the Hill advocacy event.

FOUNDING BOARD MEMBERS

National Brain Tumor Society honors the founding members of the board, who came together in 2008 to conquer and cure brain tumors — once and for all.

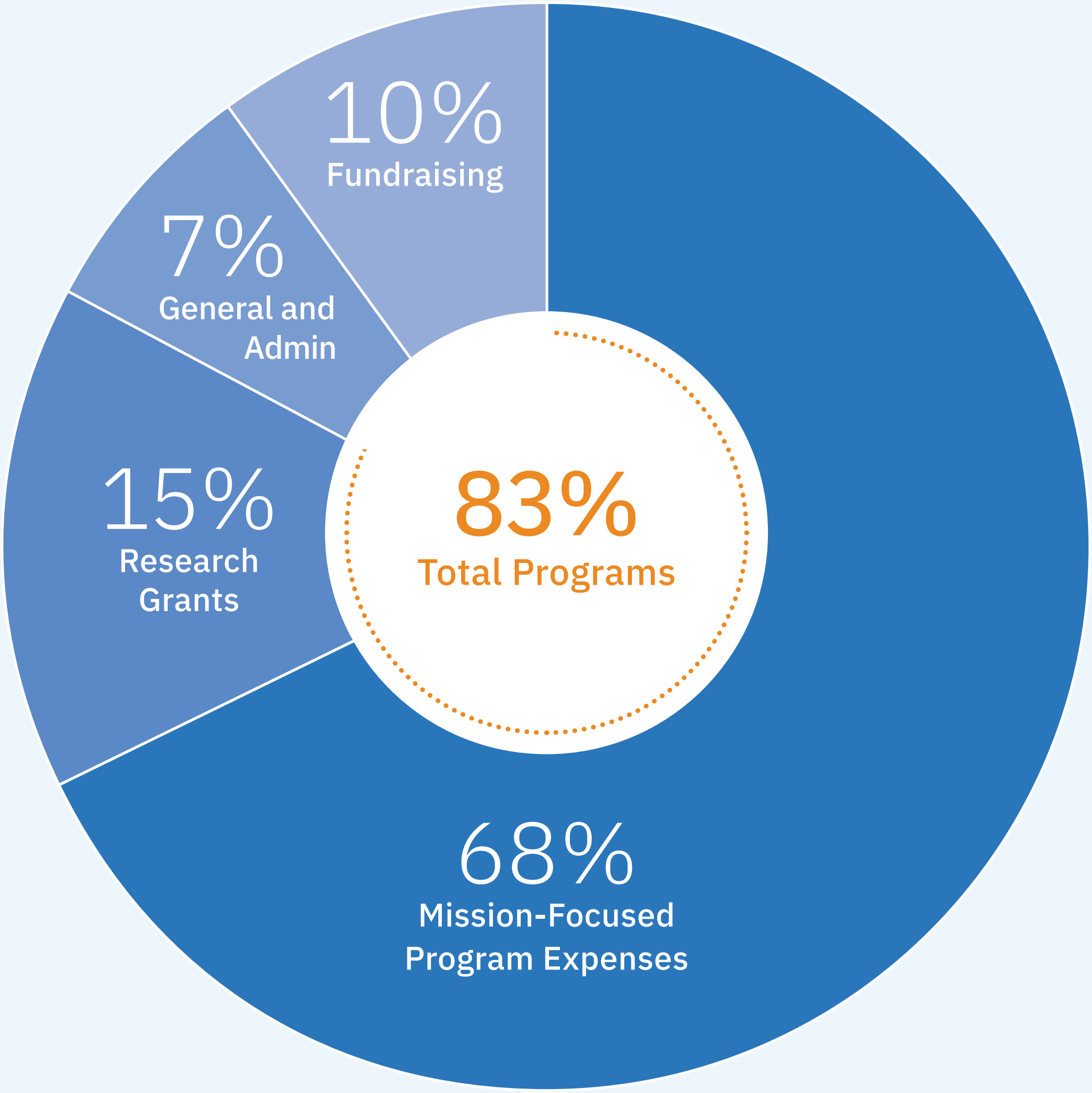
Elizabeth Abrahamson
Mary Catherine Calisto, *Co-Chair*
Michael Corkin
G. Bonnie Feldman
Paul Fisher
Nader Ghaffari, *Treasurer*
Barry Glassman
Ann Gordon, *Clerk*
Ken Grey, *Vice Chair*
Sheila Killeen
Jeff Kolodin

Sharon Lamb
Stephen Lanctot
Jan McCormack
Walter Newman
Susan Panullo, MD
Vincent Patrone
Cord Schlobohm
Bryon Sheets
Allison Jones Thomson, *Co-Chair*

Richard B. Ross,
Brain Tumor Society Co-Founder

“After Joe’s first surgery, I was surfing the internet while sitting next to Joe, who was out cold in his hospital bed. I felt like I couldn’t control anything, which I hate, and I found Race for Hope DC. It was only a few weeks away, so I joined, set up a team, and we had a bunch of people show up.” — *Melissa M.*

Financials



National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and caregivers. We advance our mission through three interconnected, programmatic strategies: Defeat, Connect, and Change. 83% of funds raised by NBTS go directly to advancing our programs.

Charity Navigator
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Statement of Financial Position and Statement of Activities

STATEMENT OF FINANCIAL POSITION

	2024	2023
Assets		
Cash	$8,351,614	$ 12,469,607
Employee Retention Credit Receivable	313,754	276,180
Investments & Convertible Notes	7,427,415	1,994,466
Pledges Rec	343,000	473,750
Prepaids	321,815	280,305
Long-term Assets	252,872	467,663
Total	**$17,010,470**	**$15,961,971**
Liabilities		
AP & Accrued	$ 509,434	$ 398,767
Research Grants Payable	250,000	-
Other Liabilities	153,388	276,374
Total	**$912,822**	**$675,141**
Net Assets		
Without Donor Restrictions	$10,577,674	$10,148,462
With Donor Restrictions	5,519,974	5,138,368
Total	**$16,097,648**	**$15,286,830**
Total Liabilities and Net Assets	**$17,010,470**	**$15,961,971**

STATEMENT OF ACTIVITIES

	2024	2023
Revenue		
Events	$7,250,797	$7,639,318
Grants/Contributions	4,579,107	4,546,587
Bequests	609,592	575,529
Interest, Dividends & Other	499,961	373,625
Donated goods and services	86,508	60,496
Total	**$13,025,965**	**$13,195,555**
Operating Expenses		
Personnel	$6,337,478	$5,649,249
Research Grants	1,905,000	2,467,750
Special Events	1,248,609	1,089,287
Professional Services	781,707	859,342
Travel	336,140	415,554
Systems and IT	394,683	369,549
Other	1,571,812	1,399,523
Total	**$12,575,429**	**$12,250,254**
Change in Net Assets from Ops	**$450,536**	**$945,301**
Endowment and Other Revenue	**$360,282**	**$159,221**
Change in Net Assets	**$810,818**	**$1,104,522**

National Brain Tumor Society takes great pride in our financial efficiency and accountability. We work to maximize the value of every dollar we receive. The GuideStar Platinum Seal of Transparency is the highest level of recognition offered by the organization. As this designation demonstrates, we are committed to transparent communication and responsible stewardship of donor investment.

Platinum
Transparency
2024

Candid.

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Brain Tumor
Society

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