



National Brain Tumor Society

2023 ANNUAL REPORT

Letter to the Community

Dear NBTS Community,

As we reflect on 2023, we are grateful for the unwavering support and dedication from each of you — donors, partners, supporters, advocates, and event participants — to come together and fuel the breakthroughs ahead. Thousands of brain tumor community members fundraised and found connection at NBTS-hosted and volunteer-driven events in nearly all 50 states plus the District of Columbia and U.S. territories, including our brand-new Georgia event and several Fundraise Your Way events. Your generosity and advocacy have been instrumental in advancing our efforts to improve the lives of everyone affected by brain tumors.

With your support, NBTS expanded our groundbreaking new collaboration, the DNA Damage Response Consortium, comprising nine world-class research hospitals all working together to bring forward a new class of treatments for adults and children with aggressive malignant brain cancer. We also saw the power of your consistent support for NBTS research efforts, as a positive final stage clinical trial demonstrating a new treatment's benefit for patients with diffuse gliomas may be approved this year. An NBTS research grant helped propel forward the earlier phase II clinical trial for this targeted therapy. Your contributions are vital in driving this important work and bringing us closer to cutting-edge treatments for patients and their loved ones facing this devastating disease.

Over the past year, we completed a comprehensive, volunteer-led initiative that listened to the brain tumor community and resulted in a new research agenda to improve the quality of life for patients and caregivers. The White House Cancer Moonshot recognized our Quality of Life Research program as the first of its kind in the brain tumor space.

Because of your support and advocacy, we mobilized to accomplish policy changes resulting in increased federal funding for brain tumor research and specific improvements to health care delivery. In 2023, we also successfully advocated for the expansion of patient navigation services under Medicare and improvements to health insurance plan provider networks under Marketplace plans.

Looking ahead, we are pleased to share that NBTS, in partnership with our board of directors, developed and implemented a revised and extended strategic plan to guide our organization through 2030. With this plan, NBTS aims to ensure that a patient who is diagnosed with a brain tumor has a better chance at survival, a better chance at a decent quality of life, and a better chance of finding community.

With your continued support, we are working tirelessly to drive discoveries forward, provide support to patients and care partners, and ensure the needs of this community are heard at the highest levels.

Together, we will be the community that conquers and cures brain tumors — once and for all.

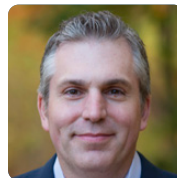
Edjah Nduom, MD

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
- Strengthened by Diversity, Equity, and Inclusion
- Relentlessly Results Driven
- Constructive, Candid, and Transparent
- Committed to Public Trust
- Collaborative and Inclusive
- 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.

NBTS Advances Brain Tumor Research

National Brain Tumor Society (NBTS) accelerates breakthroughs that will have a profound impact on the brain tumor community by advancing promising research with the potential to improve survival and quality of life.

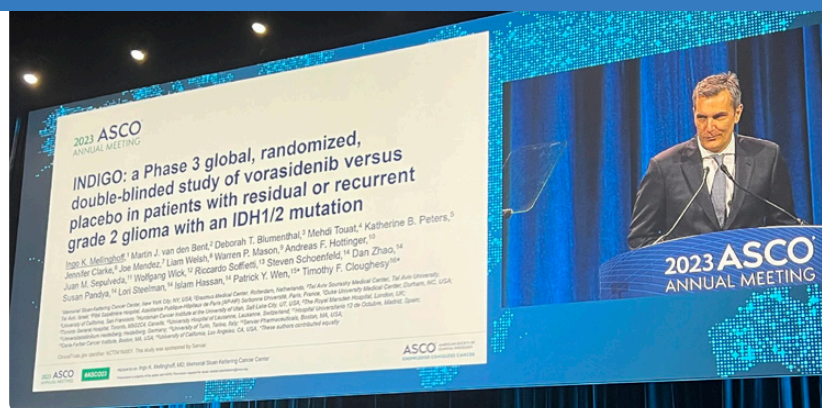
Exciting results from a major clinical trial for grade 2 oligodendroglioma and astrocytoma patients

AN INTERNATIONAL PHASE III TRIAL called INDIGO demonstrated for the first time ever that a targeted therapy could improve outcomes for low-grade glioma patients.

The drug, called vorasidenib and developed by Servier Pharmaceuticals, targets a mutation in IDH genes (called IDH1/2 mutations) in tumor cells that occurs in approximately 80% of grade 2 gliomas. The trial found that vorasidenib increased the length of time before patients with low-grade gliomas, including astrocytomas and oligodendrogliomas, needed further treatments. The FDA is expected to review the clinical trial data in 2024.

NBTS played multiple roles in advancing this discovery. Before Servier licensed vorasidenib from Agios, a pharmaceutical company, NBTS hosted a focus group with low-grade glioma patients and caregivers so Agios could better understand the burden of living with a low-grade glioma diagnosis as they began work on their drug development process. Agios, and then Servier, also frequently attended NBTS's Research Roundtable meetings, allowing them to discuss important issues related to developing brain tumor treatments with members of the FDA and other key opinion leaders convened by NBTS. These conversations helped inform their development and trial strategies. Additionally, NBTS funding to Memorial Sloan Kettering Cancer Center supported laboratory work that helped advance this research to move from a phase II to a phase III trial.

“The close collaboration between patients, clinicians, advocacy groups, and Servier has helped to propel the advancement of vorasidenib throughout the clinical development process. NBTS's support for research, its convening role in bringing people together, and shared vision of patient centricity has been integral in the efforts to bring vorasidenib from bench to bedside.”
— Islam Hassan, MD, Senior Medical Director, Vorasidenib Clinical Lead, Cancer Metabolism - LS/LCM, Servier Bio-innovation



DID YOU KNOW?



In 2023, NBTS funded research across many tumor types, including but not limited to astrocytoma, atypical teratoid rhabdoid tumor (AT/RT), craniopharyngioma, diffuse midline gliomas (DMG/DIPG), embryonal tumors, ependymoma, glioblastoma, medulloblastoma, meningioma, metastatic brain tumors, and oligodendroglioma.



NBTS issued \$2.9 million in grant dollars to researchers in 2023.

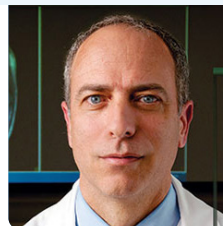
NBTS Funds Cutting-Edge Brain Tumor Research

Grants aim to advance two promising, novel strategies to take on glioblastoma

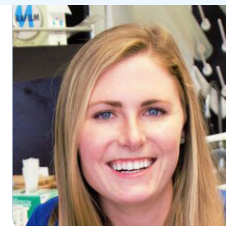
NATIONAL BRAIN TUMOR SOCIETY AND STACHESTRONG, a nonprofit devoted to raising funds and awareness for brain cancer research, provided nearly \$1 million combined to fund two innovative research projects targeting glioblastoma.

A team of researchers at the University of California, Los Angeles (UCLA) led by David Nathanson, PhD, will study the potential for a novel antibody-drug conjugate to overcome methods of cell-death resistance in glioblastoma laboratory models.

At Brigham and Women's Hospital, Dr. Anna Krichevsky's lab is developing an innovative approach to target a microRNA molecule that's been found to be a key driver of tumor growth in almost all glioblastoma tumors. The treatment will use cutting-edge CRISPR/Cas9 gene-editing delivered via lipid nanoparticles to target the microRNA. Her team hopes to demonstrate that RNA-based medicines and gene-editing approaches can serve as breakthrough therapies for malignant brain tumors.



▲ *Tim Cloughesy, MD, University of California, Los Angeles*



▲ *Elizabeth Fernandez, PhD Candidate, University of California, Los Angeles*



▲ *Anna Krichevsky, PhD, Brigham and Women's Hospital and Harvard Medical School*



▲ *David Nathanson, PhD, University of California, Los Angeles*

NBTS's Research Roundtable advanced clinical trial criteria

CLINICIAN RESEARCHERS RELY ON A STANDARDIZED SET OF CRITERIA TO MEASURE IF INVESTIGATIONAL drugs are working during clinical trials. This criteria is called the Response Assessment in Neuro-Oncology (RANO), and is widely used in brain tumor clinical trials and recognized by the FDA. In 2023, NBTS's Research Roundtable program served as the vehicle for facilitating an update to this criteria, RANO 2.0, leading to its publication and use across the field to standardize measures of whether a specific drug is helping a particular tumor type. RANO 2.0 will help drug developers better understand if an investigational drug is likely to durably shrink a patient's tumor, improving a critical aspect of the clinical trial process.

“In the discussions between the regulators, the scientists, and the doctors, I have an opportunity to provide the voice for the patient and say how I would feel about this or how this would impact me. It gave me a sense of purpose. It allows me to take an unfortunate situation that I had in my life, make the most of it, and hopefully help people in the future. I want to make sure that patients in the future have access to everything I had access to and don't have to go through the same hurdles and problems that my family and I had to go through.” — *JULIA VEITINGER, patient advocate*



▲ *Julia joined her father, Klaus Veitinger, MD, PhD, at NBTS's Research Roundtable as a patient advocate.*

DNA Damage Response (DDR) Consortium Expands to Accelerate Research

**Consortium convenes world-class researchers to
advance an emerging class of promising treatments**

NATIONAL BRAIN TUMOR SOCIETY'S BOLDEST COLLABORATION yet — the DNA Damage Response Consortium — added seven new member institutions in 2023. These renowned adult and pediatric researchers and treating physicians will test different drugs and drug combinations in the laboratory, share data, and then bring the most promising investigational treatments forward for evaluation in clinical trials.

The consortium is evaluating 15 experimental drugs in preclinical experiments for seven different tumor types — each with a range of different subtypes — to rapidly assess potential new treatments for children and adults. The tumor types include glioblastoma, diffuse midline glioma/DIPG, astrocytoma, oligodendroglioma, ependymoma, medulloblastoma, and atypical teratoid rhabdoid tumors (AT/RT).

“Because of the DNA Damage Response Consortium, we're able as scientists to collaborate at a level that we've never been able to do before. Many of us knew each other before the DDR Consortium was founded, but not all of us did. We only knew each other by reputation and the science that we focus on. This has allowed us to form new collaborations to work very closely together. The combination of these laboratories and clinicians has allowed us to innovate in ways that we just wouldn't have done otherwise.”

— ERIK SULMAN, MD, PhD,
New York University (NYU) Grossman School of Medicine



“NBTS leadership has found a productive balance between providing structure and guidance to maintain a very focused scientific program, gathering individuals with complementary expertise working on a well-defined common goal while still offering significant independence and resources to each group of the consortium to pursue their own goals.”

— NATHALIE AGAR, PhD,
Brigham and Women's Hospital and
Scientific Director of DDR Consortium



FAST FACTS

9

**World-Class
Institutions**

collaborating in NBTS's
DNA Damage
Response Consortium

15

**Experimental
Therapeutics**

for 7 different tumor types
under evaluation by
DDR Consortium investigators

800

Compounds

have been screened by
DDR Consortium investigators

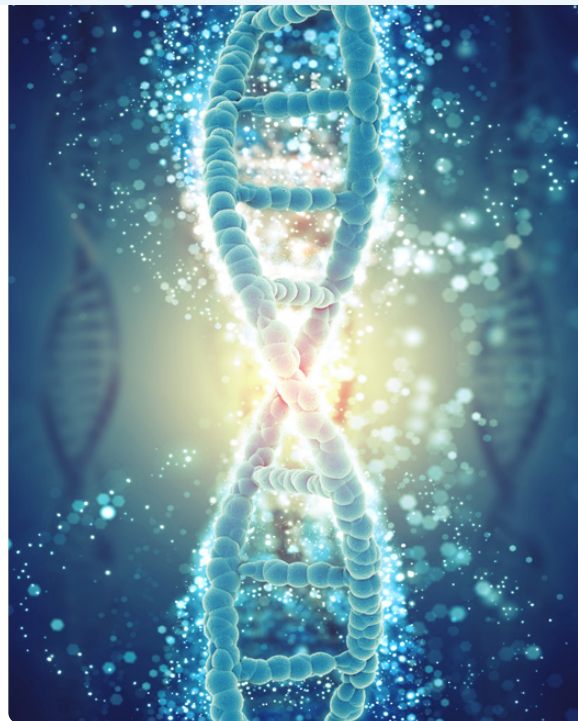
DNA Damage Response Consortium To Bring Forward New Treatments for Adults and Children with Brain Cancer

Phase II trial opens to evaluate a DNA damage response drug in combination with immunotherapy and standard chemotherapy

A PHASE II CLINICAL TRIAL HAS OPENED ENROLLMENT TO STUDY the combination of pembrolizumab (immunotherapy), olaparib (a DNA damage repair inhibitor), and temozolomide (DNA damaging chemotherapy that is part of the current standard of care for glioblastoma). Led by Patrick Wen, MD, at Dana-Farber Cancer Institute, this multi-pronged treatment aims to kill targeted tumor cells during treatment as well as stimulate the immune system's ability to identify and eradicate additional cancer cells to prevent recurrence.

Preclinical research discovers an effective novel drug delivery method for medulloblastoma tumors

WITH FUNDING FROM THE NATIONAL BRAIN TUMOR SOCIETY'S DNA Damage Response Consortium, researchers at Yale Cancer Center found that delivering nanoparticles of talazoparib (a DNA damage repair inhibitor drug) directly into the cerebrospinal fluid (CSF) of mice with medulloblastoma led to tumor regression. This preclinical research development represents a potentially promising new treatment strategy for medulloblastoma patients.



▲ 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; and Anang Shelat, PhD, at St. Jude Children's Research Hospital

NBTS'S DNA DAMAGE RESPONSE Consortium is a full-force effort that harnesses the latest evolution in our understanding of brain tumors — one that will provide hope to millions of patients and care partners. Watch to learn why and how. ▼



NBTS Launches First-Ever Brain Tumor Quality of Life Research Agenda



Survivor advocates for improved quality of life as a health care professional

AS A PATIENT RESOURCE

Coordinator at Henry Ford Hermelin Brain Tumor Center in Detroit, Nestelynn Gay works with patients to reduce or eliminate potential barriers to their care, assisting with transportation needs, financial resources, disability paperwork, and support groups. Her personal experience as a patient with a brain tumor in 2013 helps inform the work that she does professionally and as a participant at both of NBTS's Quality of Life Roundtable meetings in 2023.

Nestelynn shared, "At work, I am laser-focused on treatments. You want to extend life, and you want to cure this disease. These QoL meetings reinforced how important work around quality of life is. More work needs to be done to really drill down on ways to mitigate issues that cause diminished quality of life and to provide tools for folks to address those issues as quickly as possible."

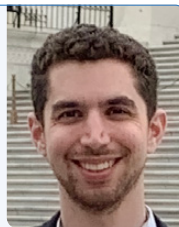
National Brain Tumor Society completes comprehensive initiative to bring forward quality of life issues facing patients and caregivers for future research

WITH GENEROUS SUPPORT FROM THE PATIENT-CENTERED Outcomes Research Institute, the National Brain Tumor Society, in collaboration with Liz Salmi and Bethany Kwan, PhD, held numerous quality of life (QoL) meetings with a stakeholder advisory group and later two major roundtables in 2023. The two in-person meetings involved more than 120 patients, caregivers, and researchers to produce a quality of life research agenda for future funding consideration. The information gathered in those meetings helped identify and prioritize the quality of life needs of adult, pediatric, adolescent, and young adult patients with brain tumors and their care partners and determine where research is most needed to drive progress.

The White House Cancer Moonshot program recognized NBTS's Quality of Life Research Agenda — the first of its kind in the brain tumor space — as an important and novel initiative to support its Cancer Moonshot program's goal to "end cancer as we know it." This work will foster strong patient, clinician, researcher, and industry partnerships to support future QoL research.

"I think it's important to advocate for quality of life because that's whole-person care. It's not just about the treatments, but it's about what you're doing in between the treatments. It's about what you're doing during the treatments. It's about making sure people have the best means to live their lives from diagnosis through survivorship long term."

— JEREMY PIVOR,
QoL Meeting Participant



This program was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (EACB-23261).



▲ From left to right: Daniel Myers, Bethany Kwan, PhD, and Nestelynn Gay

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.

Brain Tumor Investment Fund advances groundbreaking treatments and technology

THANKS TO GENEROUS DONORS WHO SHARE OUR VISION, BTIF invests in well-qualified early-stage projects that hope to deliver transformational treatments and technologies to patients with brain tumors. In 2023, BTIF invested in two new companies, Kiyatec and MimiVax.



“GBM took my father’s life after a long 7-year fight with the illness. During that time, he was willing to try every drug and treatment on the market to save his life. He participated in clinical trials and funded cutting-edge research. If he were still here, he would be funding the Brain Tumor Investment Fund to support more research to help cure this devastating disease. There’s not enough research money allocated to brain tumor research. In my father’s memory, I am supporting BTIF, as the evergreen fund is a creative way to recycle contributions and create drugs that are commercially viable to help future patients.”
— DAVINA B.

Connect with BTIF on LinkedIn:

 Brain Tumor Investment Fund

As of 2023, the Brain Tumor Investment Fund had six 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

KIYATEC

- Product:
3D Predict™ Glioma
- Strategic Area:
Precision Oncology

MIMIVAX

- Product:
SurVaxM
- Strategic Area:
Immuno-Oncology

MODIFI BIO

- Product:
MOD246
- Strategic Area:
DNA Damage Response

TELO THERAPEUTICS

- Product:
TSM1001
- Strategic Area:
Precision Oncology



“I wanted to bring awareness not just to my daughter but to the disease in general because a lot of people don’t know about it because it’s pretty rare. One child lost to this disease is too many. It’s unnatural for a parent to have to bury their child.” — *LaTosha C.*

NBTS Advocates for and Affects Policy Change

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

NBTS makes Moonshot commitment at White House Forum on Glioblastoma and Diffuse Intrinsic Pontine Glioma



▲ From left to right: NBTS board member Adam Hayden, NBTS CEO & President David Arons, DDR Consortium co-principal investigator Ranjit Bindra from Yale Cancer Institute, and DDR Consortium researcher Jann Sarkaria from Mayo Clinic

NBTS STAFF AND BOARD MEMBERS participated in the first-ever White House Cancer Moonshot Brain Cancers Forum on Glioblastoma (GBM) and Diffuse Intrinsic Pontine Glioma (DIPG) during Brain Tumor Awareness Month. The forum brought together patients, leading academic research institutions, cancer hospitals, federal agencies, biopharmaceutical companies, and other patient advocacy organizations to discuss the greatest challenges and opportunities that, if addressed, will result in achieving better outcomes for patients.

Researchers from NBTS's DNA Damage Response (DDR) Consortium also attended the

forum to share progress on work being undertaken and to explore ways to accelerate efforts to develop innovative treatments.

NBTS also brought a critical patient advocacy perspective and urged the Biden Administration to "end cancer as we know it" by speeding up research and improving the adequacy and affordability of specialized health care for patients with brain tumors.

"At the White House Forum on GBM and DIPG, the thing that was really interesting was just hearing different people's perspectives. What I came away from it was that we can get rid of all these roadblocks to progress if we have really strong data."

— Jann Sarkaria, MD, Mayo Clinic

Patient navigation services now have insurance billing codes

NBTS SUCCESSFULLY ADVOCATED FOR THE CENTERS FOR Medicare and Medicaid Services to create and implement billing codes that health insurers, including Medicare, can use to pay for patient navigation services. Before this change, many patients and caregivers could not use patient navigators, who could help guide them through the complex world of cancer, because there were no billing codes for health systems to bill insurers. This development means more patients can receive personalized support, ultimately reducing disparities and improving health outcomes.

NBTS advocacy fueled cancer research funding and peer review

EACH YEAR, CONGRESS CHARGES the Department of Defense to fund cancer research through the Peer

Reviewed Cancer Research Program (PRCRP). U.S. military members are at risk for the development of many cancer types due to the nature of their service, and the PRCRP aims to support research for cancer prevention, detection, treatment, and survivorship. In the last 10 years, NBTS's advocacy efforts have helped increase the PRCRP appropriation from \$15 million to \$130

million and have allowed pediatric brain tumors and brain cancer to be eligible for funding categories year over year.

Additionally, NBTS nominates patients and caregivers to serve as PRCRP research advocates each year. In 2023, eight research advocates recommended by NBTS were selected to represent the brain tumor community as they evaluated research applications submitted to the PRCRP. The research advocates then voted alongside other advocates and scientists to help determine how the \$130 million appropriated by Congress would be spent on cancer research.



▲ Tiffany C., who has anaplastic ependymoma, volunteers as an advocate reviewing research applications

NBTS and Advocates Make an Impact at Head to the Hill

Advocates meet with members of Congress at Head to the Hill

VOLUNTEER ADVOCATES FROM ACROSS THE COUNTRY CAME together at Head to the Hill in Washington, D.C., to create change on behalf of the brain tumor community. More than 360 brain tumor advocates — the highest number of patients, care partners, family, friends, providers, and researchers ever — met with their members of Congress and staff to urge for increased brain tumor research funding and to advocate for policies affecting the brain tumor community.

Advocating for the passing of the Stop the Wait Act was a key priority at Head to the Hill, as the bill directs the Social Security Administration to phase out the five-month waiting period to receive SSDI benefits and allow those who are uninsured or unable to afford health insurance to receive Medicare coverage immediately. Head to the Hill participants ensured the brain tumor community's voice was heard throughout Capitol Hill, and it resulted in a significant increase in Stop the Wait Act co-sponsors.

“Advocating for the brain cancer community is hard work. It takes perseverance, commitment, and sacrifice. It was empowering and energizing to be with all the brain tumor advocates who participated in the Head to the Hill 2023 event.”

— ALICE B.



NIH increases brain tumor research funding by \$20M

DUE TO THE NATIONAL BRAIN TUMOR SOCIETY'S ADVOCACY efforts in collaboration with the brain tumor community, NIH funding for brain tumor research increased by \$20 million in 2023. Over the past 12 years, funding has doubled to drive discoveries forward.

“We need more survivors like me walking around. The only way to do that is to find a cure. In order to find a cure, new treatments, and new discoveries, we need more funding for research.”

— BILLI E.



FAST FACTS

363

Participants

attended Head to the Hill
in the spring

42

States

represented by advocates at
Head to the Hill

113

Co-Sponsors

secured in Congress
to support the Stop the Wait Act
after Head to the Hill

“As a member of the brain tumor community, I can tell you that there is no other single brain tumor event as extraordinary as Head to the Hill. This event touches every emotion and, at the same time, inspires beyond belief. You are not alone in this diagnosis, and Head to the Hill is an example of NBTS's fierceness in the fight for a cure and better treatments.” — Matt G.



NBTS Provides Support and Navigation

NATIONAL BRAIN TUMOR SOCIETY EQUIPS PATIENTS AND CARE PARTNERS WITH TOOLS AND RESOURCES to navigate every step of their unique health care experience — from understanding their diagnosis and building their medical team to making decisions about treatment, including accessing clinical trial opportunities and palliative care.

For patients and care partners with a rare disease like a brain tumor, it can seem like a lonely experience. NBTS's virtual Brain Tumor Support Conversations and Grief Support Conversations help foster connections within the brain tumor community, showing patients and care partners that they are not alone.



◀ “Brain cancer really isn’t like anything else. It’s a unique and extremely isolating experience. I have been part of NBTS’s Brain Tumor Support Conversations and their Grief Support Group. The community has shown me that I’m not alone in this experience. Our situations may be different, but we all know the very specific struggles that come with brain cancer.” — Anna D.

“ While I am so grateful to my doctors for removing my mass and saving me a lot more heartache, I was left believing I should be ‘back to normal/fully recovered’ in three months. I thought something was wrong with me because I wasn’t recovering the way they said I would. I just had brain surgery when I was referred to this group. I cried the entire hour listening to my fellow fighters. I realized that I was not alone and that what I was experiencing was actually to be expected. I became motivated to keep fighting, to not be so hard on myself, and to appreciate life and my loved ones daily!”

— NAKESHIA C.



“ NBTS’s monthly Grief Support Conversation meetings have been my lifeline, the one hour per month when I don’t have to explain anything but feel so understood. Holly and Rachael masterfully foster a compassionate and healing space where I’ve found comfort since my earliest days of grief.

There is something profound about sharing this griever’s journey with others who just get it. There is no need to explain; no expression of love, sadness, joy, rage, etc. is too much. Tears, silence, celebration, and sorrow are all welcome. Without this NBTS group, I could have just been someone who lost her beloved mother three years ago to primary CNS lymphoma. But because of NBTS, I am a griever whose path has been illuminated by the grievers before me — not because there is a prescribed journey, but because I witness lives (and loves!) that grow around and accompany grief.”

— JAIME D.

FAST FACTS

32 Percent increase in instances of direct personalized support and navigation year over year

39 Percent of direct personalized support and navigation served the newly diagnosed

29 Percent increase in the number of Brain Tumor Support Conversations participants year over year

“I began participating in ► Meditation Mondays about a year and a half ago and have found this to be another great way to enhance my meditation practices.

Meditation keeps me centered and allows me to really take things in stride. Tori does an amazing job in her guidance. Her added nuggets of wisdom through readings are a real added bonus!” — Art K.



NBTS Raises Brain Tumor Awareness

NASDAQ Bell Ringing

National Brain Tumor Society was honored to bring patients and loved ones on-site to ring the NASDAQ bell with other brain tumor companies and organizations to raise awareness during Brain Tumor Awareness Month.



Georgia Brain Tumor Walk and Race

NBTS expanded its event footprint into Georgia with the brand-new Georgia Brain Tumor Walk and Race held in June at The Battery Atlanta. Hundreds of brain tumor community members joined NBTS, with the support of WSB-TV, for a morning of celebration, remembrance, and hope.



Glioblastoma Awareness Day Reception

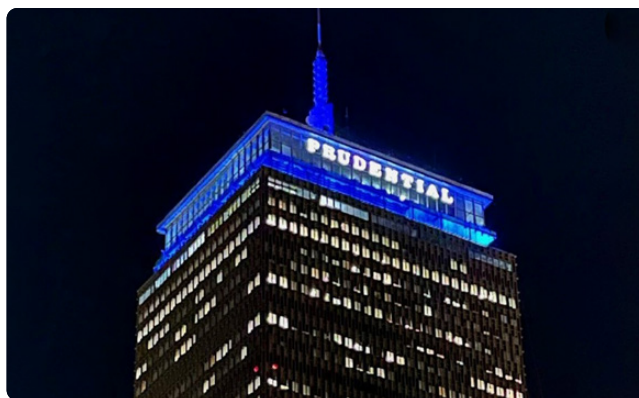
NBTS commemorated Glioblastoma Awareness Day on July 19, 2023, with an in-person reception in Washington, D.C. Members of Congress, patients, care partners, researchers, and other members of the brain tumor community gathered to shine a spotlight on glioblastoma — the most common, complex, treatment-resistant, and deadliest type of brain cancer.

Karen Roberts Turner, NBTS board member and glioblastoma survivor, shared her brain tumor experience at the reception. ►



Prudential Center Lighting

On December 24, 2023, the Prudential Center Boston was lit in blue to illuminate both the skyline and our mission to conquer and cure brain tumors — once and for all. NBTS is grateful for the commitment of our Boston-based brain tumor community.





“I want more research, more awareness, and more funds to find other treatments and cures. It’s ridiculous that we have so many advances in technology and medicine, yet we’re spinning in circles when it comes to treatment for glioblastoma.” —*Jessica D.*

Signature Events

TOP FUNDRAISING INDIVIDUALS

Race for Hope DC:
Stephen C. Conley – \$61,961

National Brain Tumor Ride:
Lisa Shapiro – \$29,944

New England Brain Tumor Walk:
Karolina Atsalis – \$26,798

Northern California Brain Tumor Walk:
Leah Recht – \$18,147

Race for Hope Philadelphia:
Allison Bishof – \$18,134

New York Brain Tumor Walk:
Will Roth – \$15,562

Carolina Brain Tumor Walk and Race:
Holly Gainsboro – \$14,125

Colorado Brain Tumor Walk and Race:
Russell Bruce – \$13,327

Southern California Brain Tumor Walk and Race:
Ashley Kendrick – \$10,605

Georgia Brain Tumor Walk and Race:
Kayre Lupo – \$9,711

New Jersey Brain Tumor Walk and Race:
Rachel Windman – \$9,157

Virginia Brain Tumor Walk and Race:
Alicia Moosally – \$7,495

TOP FUNDRAISING TEAMS: \$50,000+

Rachel's Racers: \$88,343

Lisa's Riders: \$81,463

Survivors: \$68,353

Rabbi's Runners: \$53,279



▲ RACE FOR HOPE DC

“This organization and this event have been a cornerstone moment on my calendar since [my brother sadly passed away the night before my first Race for Hope DC in 2009]. An annual trip to one of my worst memories, in hopes of using it to help bring about a reality in which no one ever has to accept the same fate as my brother and countless others. What an honor it is to partner with NBTS and Race for Hope DC.”

— David Cook



▲ VIRGINIA BRAIN TUMOR WALK AND RACE

“My wife, my two sons’ mother, was first diagnosed with glioblastoma in 2002, and she passed in 2017 after the cancer returned. She and I started fundraising every five years, starting in 2007. We are carrying on the legacy my wife and I started. Our boys (now 33 and 30 years old) are involved.” — Scott M.

Signature Events

TOP FUNDRAISING TEAMS: \$25,000+

ReMARKable Strides: \$47,524

Team Oligo: \$40,416

David Cook's Team for a Cure: \$40,202

Valero Gray Z's: \$39,750

Smiley Strong: \$39,693

Fiore's Fighting Force: \$37,332

Team E: \$35,025

TEAM DOV: \$34,660

Team Mawn: \$33,054

Allison's NumbSkulls: \$32,893

Cricket's Crusaders: \$29,494

Maryland Brain Tumor Treatment & Research Center:
\$28,215

Hope by the Bay: \$26,454

Penn Pioneers: \$26,187

TOP 10 RECRUITING TEAMS

New England Brain Tumor Walk:
Fiore's Fighting Force — 234

Race for Hope DC:
Rachel's Racers — 185

Race for Hope Philadelphia:
Chrissy's Crusaders — 104

New York Brain Tumor Walk:
Team E — 84

Virginia Brain Tumor Walk and Race:
Noëlle's Symphony — 80

National Brain Tumor Ride:
Lisa's Riders — 78

New Jersey Brain Tumor Walk and Race:
The Hamilton Group — 78

Northern California Brain Tumor Walk:
Team Stanford — 58

Colorado Brain Tumor Walk and Race:
Bang Bang Gang — 39

Georgia Brain Tumor Walk and Race:
Luck of the Irish — 39

Southern California Brain Tumor Walk and Race:
GCAR Glioma Getters — 35

Carolina Brain Tumor Walk and Race:
Craig's Adventurers — 28



▲ NORTHERN CALIFORNIA BRAIN TUMOR WALK

"I knew signing up for a brain tumor walk would be a great way to meet others in the brain tumor community, gain support, and raise money and awareness. The more funding they can get, the more research they can do."

— Danielle H.



▲ RACE FOR HOPE PHILADELPHIA

"Even though a cure was not in the cards for Mark, we want to find the cure. Seeing the breakthroughs that are coming out and the research that the National Brain Tumor Society is supporting gives us hope, and hope is what we all need."

— Mark & Sandy K.

Fundraise Your Way

Top Fundraising Events

\$100,000+

Jones'n for a Cure Golf Tournament: \$140,812
Team Billy Ride and Walk for Research: \$121,519
Fight for the Brain Happy Hour: \$104,336
McGuiness Memorial Golf Tournament by Brain Cancer Answer: \$102,322

\$50,000+

Madison Brain Tumor 5K: \$84,134

\$20,000+

5th Annual Childhood Brain Cancer Research Collaborative Golf Tournament: \$40,000
Chips for Kip Golf Tournament: \$33,000
Georgia Wireless Association David Downie Memorial Charity Golf Classic: \$30,000
Brain Cancer Research Alliance Events and Fundraising: \$24,558
Alston Construction Brain Tumor Awareness Month Fundraiser: \$23,952
50/31 Challenge: \$23,752
Tumor Takedown Tailgate: \$20,580

\$10,000+

Go Gray in May with Ulliman Schutte: \$19,388
Dips for Di: \$17,565
Stand-Up to Brain Cancer: \$13,840
Michael Cassidy Shamrock 'N' Run: \$13,500
Joggin' 4 the Noggin: \$13,000
Gandython: \$12,783
Mimosa March To Cure Brain Cancer: \$10,517
GBM Foundation Events: \$10,000
Papa's Run 4 Dray: \$10,000

\$5,000+

Adam's Annual Brain Fest: \$9,813
Birdies for Brain Tumors: \$8,682
Stew's Crab Feast: \$8,073
Wander to Wonder on Water: \$7,955
Matt Shackelford Memorial Golf Tournament: \$7,899
Rage Rage to 60 and Beyond: \$7,878
William Small Fishing Fundraiser in support of Taylor's Senior Project: \$7,695
Priya and Rohan's Fundraiser: \$7,279
St Vrain for the Brain 5K: \$7,142
Coaches Against Cancer: \$7,000
Grey Matters: Shenango Valley Walk & Run: \$6,639
Texas Hold 'em Fundraiser: \$6,250



◀ “I poured my heart and soul into that community, and they reciprocated it for my baby and for something that I love... We just wanted to raise \$3,000, and we ended up raising almost \$5,000. It’s just been a wonderful experience to be a part of the National Brain Tumor Society.”
— LaTosha C., *Lifting for Lavi*

“The heartbreaking passing ▶ of 29-year-old Nicholas McGuiness from a malignant brain tumor was compounded by his father’s death several weeks later from prostate cancer. Our small Brain Cancer Answer team united to create a fundraiser in memory of Nicholas. We were thrilled that our inaugural efforts raised more than \$102,000 for NBTS, thanks to the support of our entire neighborhood and the business community.”

— Christine E., *McGuiness Memorial Golf Tournament*



◀ “I initially saw fundraising for cancer as only 5Ks, 10Ks, benefits, and raffles. Having NBTS recognize selling my artwork as a fundraiser, I am grateful that I can create a lasting legacy in my beloved brother’s memory both with my art and the money it raises.” — Pat S.

True Blue JC Shootout for Dreams Charitable Lacrosse Tournament: \$6,000

Impact Golf: \$5,945

Holiday Light Spectacular on Briarcliff Place: \$5,346

1960's Toy Sales Fundraiser: \$5,150

NTS Walks for NBTS: \$5,000

Bob Burns Memorial 5K: \$5,000

Gray Nation Endurance®

\$20,000+

James Covey - Boston Marathon: \$90,432

Braden White - Play Hurt Project: Running for a Cure: \$52,433

Tory and Trevor Hoffberger - Big Sur 11-Miler: \$31,202

Team Cindy Fitzpatrick - ASICS Falmouth Road Race: \$29,920

Kristen Sherlock - TCS New York City Marathon: \$26,228

Jim Proferes - Boston Marathon: \$23,453

Maggie Gallagher-Lilly - TCS New York City Marathon: \$21,246

\$10,000+

Denise Nolan - ASICS Falmouth Road Race and United Airlines NYC Half: \$18,305

Alec Molloy - TCS New York City Marathon: \$18,233

Mike Squillante - Jersey City Marathon: \$18,121

Kurt Nelson - Big Sur International Marathon: \$17,449

Caroline Turner - United Airlines NYC Half: \$15,761

Joey Wolfe - TCS New York City Marathon and Los Angeles Charity Half: \$15,638

Kimberly Niemi - Boston Marathon: \$14,586

Richard Paisner - Boston Marathon: \$14,458

KJ McCarter - TCS New York City Marathon: \$13,668

Ron Clark - ASICS Falmouth Road Race: \$13,547

Bryant Kirkland - TCS New York City Marathon: \$13,232

Elizabeth Bramson-Boudreau - United Airlines NYC Half: \$12,826

Shea O'Donovan - ASICS Falmouth Road Race: \$12,313

Jessica Davis - Big Sur 11-Miler and ASICS Falmouth Road Race: \$12,095

Molly Pitzele - TCS New York City Marathon: \$11,898

Dina Jachi - United Airlines NYC Half: \$11,504

Catherine Bozzonetti - TCS New York City Marathon: \$11,465

Ben Rivitz - TCS New York City Marathon: \$11,425

Adam Herskovits - TCS New York City Marathon: \$10,971

Allen Frierson - Big Sur International Marathon: \$10,681

Anike Wariebi - Soul Ryeders Half Marathon: \$10,566

Michael Otway - TCS New York City Marathon: \$10,208



▲ “I decided to apply for Gray Nation Endurance when my husband was in hospice. I felt out of control and wanted something to give me control while raising awareness for what we were going through. It was expected that he would pass within weeks, but I was able to tell him that I was accepted to the team. My ‘why’ is to honor my husband and to channel my grief into something I love — running! Didn’t quite expect it to be so hard, but I’m so proud of myself for even making it to the race.”

— Devin R., 2023 TCS New York City Marathon



▲ “It meant the world to be a part of such a special experience. The race itself was incredible, but the cause and being a part of a team so much bigger than myself made it even more amazing. I made memories and relationships that will last a lifetime.”

— Braden W., 2023 Medtronic Twin Cities Marathon and 2023 TCS New York City Marathon

\$5,000+

Shawn Waybrant - United Airlines NYC Half: \$9,999
Erin Feeney - TCS New York City Marathon: \$9,663
Kevin McNamara - TCS New York City Marathon: \$9,410
Stacy Neri - TCS New York City Marathon: \$8,917
David Bourke - Big Sur 11-Miler: \$8,787
Kyle Caruso - United Airlines NYC Half: \$8,743
Morgan Otway - United Airlines NYC Half: \$8,459
Devin Rehm - TCS New York City Marathon: \$8,122
Megan Gebert - ASICS Falmouth Road Race: \$7,796
Renee Limpawuchara - TCS New York City Marathon: \$7,339
Laveta Stewart - TCS New York City Marathon: \$6,990
Sophie Nogue - TCS New York City Marathon: \$6,675
Jake Caruso - United Airlines NYC Half: \$6,560
Annie Radecki - TCS New York City Marathon: \$6,330
Todd Muller - ASICS Falmouth Road Race: \$6,096
Erica Wilson - Los Angeles Charity Half: \$5,946
Christen Connell - Big Sur International Marathon: \$5,905
Sean McNamara - TCS New York City Marathon: \$5,711
Dan Rouse - Medtronic Twin Cities 10 Mile: \$5,637
Katrina Parker - TCS New York City Marathon: \$5,585
Olivia Caruso - United Airlines NYC Half: \$5,450
Jennifer Londino - TCS New York City Marathon: \$5,288
Ann Novotny - TCS New York City Marathon: \$5,162
Vincent Wolfe - TCS New York City Marathon and Los Angeles Charity Half: \$5,079
Britta Idrees - United Airlines NYC Half: \$5,031
Emily Antworth - United Airlines NYC Half: \$5,012

FAST FACTS

1 Million Dollars

fundraised by GNE athletes

31 States

represented by GNE athletes

52 Percent

increase in GNE athletes
year over year



◀ “I could tell we’ve all been impacted. We all understand what it means to be in this little community, and it felt like such a safe space. As a 25-year-old caregiver, I am grateful to my entire community, who have shown up the way they can, but any traumatic experience can feel quite isolating sometimes. It felt validating and powerful to be part of a group that really understands the depth of your experience.”
— Karen, 2023 TCS New York City Marathon

Corporate and Foundation Partners

CORPORATE PARTNERS

\$100,000+

Danaher Foundation
IQVIA

\$50,000+

Genentech
Imvax
Northern Bank and Trust
Novocure
The Colony Group
Valero Energy Corporation & Valero
Benefit for Children

\$25,000+

Cravath Swaine & Moore LLP
Erasca Foundation
Ono Pharma
Stryker Corporation
University of Maryland School of Medicine
University of Pennsylvania Neurosurgery

\$10,000+

ADT
Anthony's Apparel
Jefferson Health
Medexus Pharma
Montefiore Einstein Cancer Center
Northwest Biotherapeutics
Servier Pharmaceuticals
ShopRites of Zallie Family Markets
Stephen Gould Corporation
Sterne Kessler Goldstein Fox
Ulliman Schutte Construction, LLC

\$5,000+

AON Corporation
Bass, Berry & Sims PLC
Capital Health System
Day One Biopharmaceuticals
Emory University
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Foundation Medicine
GEICO Philanthropic Foundation
Gerald J. Glasser Brain Tumor Center
The Hatman Show
Highland Yard
IN8bio
Integra Foundation
Katmai Pharmaceuticals, Inc.
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Kintara Therapeutics
Kiyatec
Larkmeade Strategies, LLC
Le-Vel Brands
Lot Sixteen LLC
Markel Corporation

“Danaher Foundation is proud to ► support the National Brain Tumor Society and the MyTumorID campaign. Through this partnership, we are able to enhance our shared commitments to improving quality of life for the brain tumor community and raise awareness about the importance of biomarker testing and clinical trials for patients with brain tumors.”

— Danaher Foundation

“The KM Legacy Foundation is ► proud to work with NBTS in our combined search for a cure to all forms of brain cancer. Through the KM Legacy Foundation’s Kindness Matters Thanksgiving Morning Walk, Virtual Wine Tasting Event, and Auction in May (#gograyinmay), and from dedicated donors, the KM Legacy organization has donated thousands of dollars to brain cancer research and student leadership opportunities. We are proud to partner together in this shared mission.”

— KM Legacy Foundation

Medicenna Therapeutics
Medtronic
Mimivax LLC
Neosoma
SBLI Legacy Foundation
Stanford Health Care
The University of Texas MD Anderson Cancer Center
UCI Health
UCLA Medical Center
UCSF
University of Miami Sylvester Cancer Center
University of Oklahoma Stephenson Cancer Center
University of Utah
VBI Vaccines
VCU Massey Comprehensive Cancer Center
Wharf Hospitality Group
Willis Towers Watson
xCures, Inc.



FOUNDATION PARTNERS

\$100,000+

The Novikoff Family Foundation
Rally Foundation for Childhood Cancer Research and Kids Join the Fight
Richard E. Capri Foundation
Robert Lloyd Corkin Charitable Foundation
StacheStrong
The Stringer Foundation

\$25,000+

GLK Foundation
KM Legacy Foundation
Students Supporting Brain Tumor Research (SSBTR)

\$10,000+

The Friends4Michael Foundation
The Hamilton Company Charitable Foundation
The Mark Foundation for Cancer Research

Individual Donors

National Brain Tumor Society thanks our donors who gave generously in 2023 to advance our mission.

VISIONARY SOCIETY

(\$250,000+ cumulative giving since 2008)

Ashley and Alan Dabbieri
The Claeys Family
The Corkin Family
Davina Bruckner
Bob and Deborah Newman Sharpe
The Hankin Family Charitable Foundation
Judi Rotenberg Ross Zuker and Edward Zuker
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Mary and Paul Nakayama
Michael and Dawn Nathanson and Family
Michael and Jamie Goguen
The Sadler Family
Stephen and Ellen Conley
The Hamill Family
Steven and Sally Lamb
Susan and Jeff Davis
William and Amy Reller
Anonymous

\$25,000+

Terry and Susan Anderson Family Foundation
Brakebush Family Foundation
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The Centurion Foundation
Dolores Claeys
Stephen and Ellen Conley
Michael and Lauren Corkin
Howard and Susan Elias
Michael and Jamie Goguen
The Hankin Family Charitable Foundation
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Maben-Davis Family Foundation
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Estate of Carol S. O'Dore
Estate of Loraine E. Perkins
Lido Ramadan
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Bob and Deborah Newman Sharpe
Estate of Melanie K. Wellner
Richard Wells
Anonymous (2)

\$10,000 - \$24,999

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Blossman Gas
Allison Brooks
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Margery Hoffman
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Yarborough/Sanzo family
Judi Ross Zuker and Edward Zuker
Anonymous (3)



▲ “I’m the newest member of the board of directors for the National Brain Tumor Society, and I’m excited to have this opportunity in honor of my wife, who passed away from a glioblastoma.” — Chris Brown

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.

Individual Donors

\$5,000

Mary and Richard Abbey
Sara Aiello
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AmazonSmile Foundation
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CATALYST CIRCLE

Members of the Catalyst Circle have made leadership gifts in support of the Nathanson Family Catalyst Fund for Brain Tumor Research: NathansonFund.org.

Amy Null and Andrew Budson
Andrew Merken
Jeanie and Jim Kirkiles
Judi Rotenberg Ross Zuker and Edward Zuker
Martin Bicknell
Michael and Dawn Nathanson
Michael and Julie Durbin
The Corkin Family
Michael Goss
Ronald Rubin
Sarah Durham and Craig Winer
The Sadler Family
Lowenstein Sandler LLP
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Shikiar Family Foundation

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Al Yung, MD,

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John Frishkopf

Rick Genderson

Ken Grey

Sheila Killeen

Michael Nathanson, JD

Chandri Navarro

Susan Pannullo, MD

Steve Sadler

Cord Schlobohm, DMD

Rabbi Eric Wisnia



▲ National Brain Tumor Society board chair Edjah Nduom, MD, has dedicated his life's work to defeating brain tumors. As a neurosurgical oncologist specializing in brain tumors and a researcher studying the effects of immunotherapy on glioblastoma, Dr. Nduom's experiences have led him to champion the breakthroughs ahead at NBTS.

"I think the work that I'm doing is critically important, and I'm very proud of the work that I get to do as an individual. But when I'm working with the National Brain Tumor Society, I have the opportunity to make real big differences across the entire landscape of the field."

— Edjah Nduom, MD



▲ NBTS ran a Glioblastoma Awareness Day campaign to raise critical funds to break down barriers today and forge opportunities to transform brain tumor research and health care for the future. NBTS board member Karen Roberts Turner highlighted the extraordinary challenges of people affected by glioblastoma and shared a message of hope for this community.

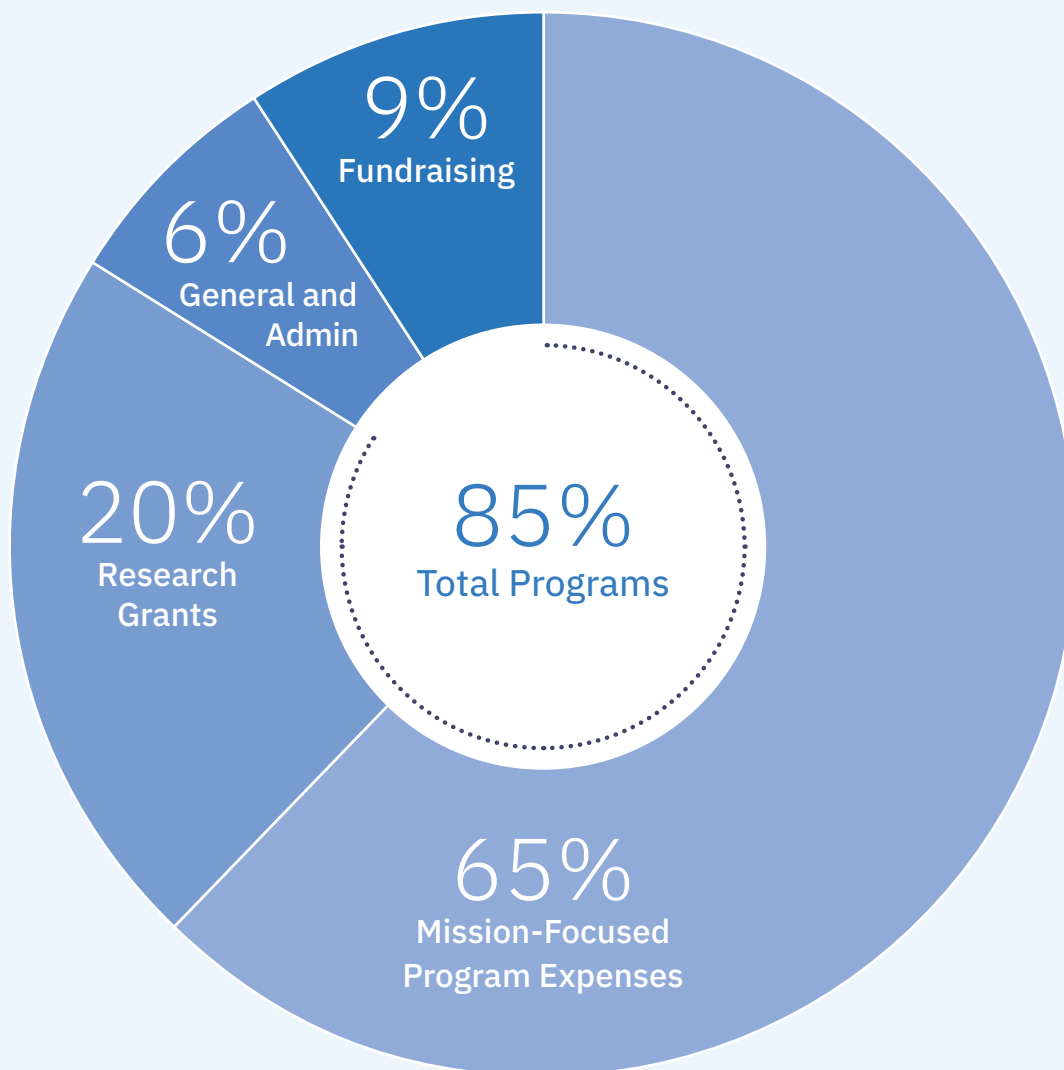
"Without people to make the change, there can be no change, and NBTS has been at the forefront of doing the work of mobilizing the effort of making the noise to make the change. I wanted to be a member of the NBTS board because they are the noisiest bunch out there, and I want it to be a noisemaker."

— Karen Roberts Turner



“Brain cancer is one of the lower-funded cancers. I understand that it affects maybe 5% of the general population, but it’s so deadly that we need better treatments. We’re still doing the basic standard of care for the last 20-30 years. Tumor Treating Fields are one of the very few things that has been approved. For us, and the people who come after us, the thing that will make the most difference is new and better treatments.” —Joseph E.

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. 85 percent of funds raised by NBTS goes directly to advancing our programs.



Statement of Financial Position and Statement of Activities

STATEMENT OF FINANCIAL POSITION

	2023	2022
Assets		
Cash	\$12,469,607	\$ 11,507,934
Employee Retention Credit Receivable	276,180	783,108
Investments & Convertible Notes	1,994,466	1,451,126
Pledges Rec	473,750	869,481
Prepays	280,305	195,673
Long-term Assets	467,663	615,846
Total	\$15,961,971	\$15,423,168
Liabilities		
AP & Accrued	\$398,767	\$327,199
Research Grants Payable	-	548,750
Other Liabilities	276,374	364,911
Total	\$675,141	\$1,240,860
Net Assets		
Without Donor Restrictions	\$10,148,462	\$8,867,565
With Donor Restrictions	5,138,368	5,314,743
Total	\$15,286,830	\$14,182,308
Total Liabilities and Net Assets	\$15,961,971	\$15,423,168

STATEMENT OF ACTIVITIES


	2023	2022
Revenue		
Events	\$7,639,318	\$7,014,771
Grants/Contributions	4,546,587	4,406,668
Bequests	575,529	1,096,032
Interest, Dividends & Other	373,625	18,168
Donated goods and services	60,496	31,660
Total	\$13,195,555	\$12,567,299
Operating Expenses		
Personnel	\$5,649,249	\$4,989,190
Research Grants	2,467,750	2,241,460
Special Events	1,089,287	1,096,281
Professional Services	859,342	751,562
Travel	415,554	196,371
Systems and IT	369,549	452,385
Other	1,399,523	671,133
Total	\$12,250,254	\$10,398,382
Change in Net Assets from Ops	\$945,301	\$2,168,917
Endowment and Other Revenue	\$159,221	\$626,822
Change in Net Assets	\$1,104,522	\$2,795,739

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
2023

Candid.



 National Brain Tumor Society

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