



2025 IMPACT REPORT



National Brain Tumor Society

For everyone living with a brain tumor diagnosis, it's time for a better chance.

At the National Brain Tumor Society (NBTS), we're working unrelentingly to give everyone with a brain tumor diagnosis a better chance at survival, quality of life, and a strong, supportive community.

Thanks to the generosity of our community — donors, volunteers, advocates, and partners — NBTS is accelerating research, providing trusted support, and making sure the brain tumor community's voice is heard on Capitol Hill.

In 2025, we advanced promising science, championed policies that protect and empower patients, and guided patients and their loved ones through the challenges of a diagnosis. This report highlights the impact we've made as we work together to conquer and cure brain tumors — once and for all. ►



Defeat

NBTS drives and influences best-in-class medical research to develop and deliver longer survival, better quality of life, and ultimately cures through new innovative treatments for patients with brain tumors as quickly as possible.

Helped advance the first-ever drug approved to treat recurrent H3K27M-mutant diffuse midline glioma

The U.S. Food and Drug Administration (FDA) granted accelerated approval to Modeyso (dordaviprone, formerly known as ONC201), manufactured by Jazz Pharmaceuticals, Inc., as the first and only treatment for **recurrent H3K27M-mutant diffuse midline glioma** (DMG) — a rare, aggressive brain tumor that predominantly affects children and young adults. NBTS played multiple roles in advancing this discovery alongside the drug's previous developers, Oncoceutics and then Chimerix, including funding that helped advance foundational research and drug development of ONC201.



Funded two Quality of Life grants to support patients and caregivers

In 2025, NBTS launched its **first-ever Quality of Life Research grants**, a new program designed to improve the day-to-day lives of patients and care partners facing brain tumors. Supported in part by StacheStrong, NBTS awarded two grants: one to test FearLess in Neuro-Oncology, a new telehealth intervention to reduce fear of recurrence or progression among patients and caregivers, and another to adapt the Preparedness Assessment for the Transition Home (PATH) tool to better prepare caregivers of individuals with high-grade brain tumors. These projects mark an important milestone in NBTS's commitment to advancing research not only for cures, but also for quality of life.

Uncovered a glioblastoma vulnerability that led to a new clinical trial

NBTS-supported research at UCLA uncovered a vulnerability in **glioblastoma** by identifying how tumors rely on the protein BCL-XL to survive treatment. This insight led to a now open clinical trial testing the targeted therapies ABBV-155 and ABBV-637, antibody-drug conjugates designed to deliver cancer-killing drugs directly to tumor cells, alone or in combination with other therapies, including a drug called KTM-101 (which NBTS also helped fund). By strategically funding this work from early-stage discovery to clinical testing, NBTS is helping turn glioblastoma's resistance into a potential treatment opportunity.

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Fueled research that could improve survival and quality of life for pediatric high-grade glioma patients

Funding to NBTS's DNA Damage Response Consortium pediatric researchers at St. Jude Children's Research Hospital led to the discovery that targeting the DNA damage repair protein known as ATM significantly enhanced the effects of radiation across distinct molecular groups of **pediatric high-grade glioma**. Based upon the results of that funding, a phase I clinical trial in pediatric patients with high-grade glioma, including patients with **diffuse midline glioma** (DMG) and **diffuse intrinsic pontine glioma** (DIPG), has begun at multiple sites throughout the U.S. to test the side effects and identify the best dose of AZD1390 (a drug that targets ATM) when combined with radiation therapy. Radiation is the only therapy that consistently prolongs life for pediatric and young adults with DMG and DIPG, and it is hoped that by inhibiting the tumor's ability to repair DNA damage from radiation, this combination may help patients with this tumor type live longer.

Accelerated phase II clinical trial evaluating a promising new vaccine to treat glioblastoma

In early 2025, NBTS's Brain Tumor Investment Fund® (BTIF) invested in Diakonon Oncology, a company with a promising therapeutic vaccine, DOC1021, also known as dubodencel. Dubodencel is a dendritic cell vaccine, which is created using the patient's own dendritic cells that have been engineered to recognize their tumor as virally-infected and thus activate an immune response that targets and kills these cells. Their phase I trial showed overall positive immune responses and improved survival after treatment. The BTIF investment, alongside additional financing, helped to accelerate the company's phase II **glioblastoma** clinical trial, which opened in 2025 with eight sites and will eventually include 20 centers across the country.

Advanced the only brain tumor-specific research advocate training program in the U.S.

In 2025, NBTS expanded its Brain Tumor Research Advocate program — **the only one of its kind in the brain tumor space** — by adding a new Real-Time Research Review element that allows trained advocates to provide immediate input on emerging studies. As the first cohort concludes its third year and a new group prepares to begin training in 2026, the program continues to strengthen the connection between patients, caregivers, and the research community.

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Connect

NBTS convenes, educates, and unites the brain tumor community.

Expanded reach and impact of MyTumorID™ public health campaign

The MyTumorID campaign helps patients with brain tumors and care partners understand the importance of identifying tumor biomarkers and exploring treatment options for informed decision-making. In 2025, we expanded our educational offerings to include two live webinars on biomarker testing and clinical trials, materials in Spanish, new blog content, and an animated video explaining biomarker testing, making critical information more accessible to the brain tumor community. The initiative also grew by **welcoming five affiliate organizations** — AANS-CNS Section on Tumors, Dragon Master Initiative, Glioblastoma Research Organization, Head for the Cure Foundation, and the Pediatric Brain Tumor Foundation.



Helped patients and care partners navigate their brain tumor experience through one-on-one support services

In times of crisis and uncertainty, patients, care partners, and loved ones turn to NBTS's Personalized Support and Navigation team for guidance and support. Whether it's answering questions, providing information on second opinions or clinical trials, or connecting families with financial assistance resources, our team meets each person where they are. In 2025, we engaged nearly **30% more patients and care partners** than last year, reflecting the growing reach and impact of our personalized support.

Raised \$85k for brain tumor research, advocacy, and support at the Walt Disney World® Marathon Weekend

NBTS's Gray Nation Endurance program added a **new opportunity for runners to support the brain tumor community** during the 2025 Walt Disney World® Marathon Weekend. Participants could take on the 5K, 10K, half or full marathon, or challenge themselves with the Goofy's Race and a Half Challenge (half + full marathon) or the Dopey Challenge (all four distances). This year, 62 runners from 20 states joined the team to raise more than \$85,000 to fuel research, advocacy, and support for the brain tumor community.

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Gathered thought leaders to plan for the future of neuro-oncology therapy development

NBTS led a Research Roundtable that brought together 55 experts, industry leaders, regulators, and patient advocates to assess progress in neuro-oncology and shape strategies for the second half of the decade. Through workshops and small group discussions, NBTS guided participants in **identifying realistic, high-impact actions to overcome barriers and advance therapy development**, driving the field toward the goal of making brain tumors manageable — and ultimately survivable — by 2030.

Welcomed the Dallas-Fort Worth brain tumor community at new signature event

In March 2025, NBTS **re-established its presence in North Texas** with the DFW Brain Tumor Walk & Race at AT&T Stadium, home of the Dallas Cowboys. The event brought together patients, caregivers, and supporters from across the region to raise awareness and funds for the brain tumor community.

Change

NBTS fuels the voice and power of the brain tumor community to advocate, elevate our mission, and influence public policy.

Collaborated with members of Congress to re-introduce the Bolstering Research And Innovation Now (BRAIN) Act

NBTS worked with champions in Congress to strengthen and re-introduce the BRAIN Act (S.1330/H.R.2767) in April 2025. Since then, NBTS and its advocates at the 2025 Head to the Hill and Advocate From Your State events **have grown support for this bipartisan, bicameral legislation** — NBTS's signature policy priority — to more than 40 co-sponsors, improving its prospects for consideration in key committees.



Mobilized a record number of advocates to speak up for brain tumor research funding with Congress and the Administration

In 2025, NBTS advocates across the country took action on key policy issues by responding to our alerts in record numbers. **Three of this year's alerts ranked among the top five all-time**, with some of the highest response rates we've ever seen. Together, advocates urged Congress

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to protect National Institutes of Health (NIH) funding for brain tumor research, pressed the National Cancer Institute (NCI) to reverse its decision to stop funding the Pediatric Brain Tumor Consortium, and advanced the policy priorities outlined in our Head to the Hill event.

Worked to restore dedicated glioblastoma research funding and to achieve federal research funding increases

In the draft FY26 appropriations bill, NBTS advocacy helped **restore dedicated federal research funding for glioblastoma** (GBM) — one of the most complex, treatment-resistant cancers. At the same time, despite significant proposed budget cuts, we successfully secured modest funding increases for both the National Institutes of Health (NIH) and the National Cancer Institute (NCI). These gains, pending final approval by the House and Senate, represent a powerful example of how our community's collective advocacy continues to protect and expand federal investment in brain tumor research.

Advocated for childhood cancer legislation that would improve pediatric drug development, clinical trials, and access to care

At NBTS's Advocate From Your State event, brain tumor advocates nationwide urged Congress to advance a "Childhood Cancer Package" of critical legislation. This package included the **Accelerating Kids' Access to Care Act (AKACA)**, which would cut through bureaucratic barriers so children with complex medical conditions can more easily receive specialized out-of-state care, and the **Give Kids a Chance Act of 2025**, designed to strengthen pediatric cancer research. The latter, which was unanimously approved in committee, would extend key research incentives, ensure children have timely access to the newest treatments, and require pediatric studies to keep pace with scientific advances. Both bills are pending final approval by the House and Senate.

It's time for a better chance. Make a gift today.

For the more than 1 million Americans living with a brain tumor today, it's time for a **better chance**. Treatments remain limited, and far too many families are left wishing for more treatment options and more time with their loved ones. When you give to NBTS at [BrainTumor.org/Impact](https://www.brainumor.org/Impact), your generous gift has an immediate impact to fuel urgently needed breakthroughs ahead for the brain tumor community. Together, we will be the community to conquer and cure brain tumors — once and for all.

Want to learn more? Email your questions to donations@braintumor.org