



# 2023 Impact Report

Patients with brain tumors and their loved ones look to the National Brain Tumor Society (NBTS) to confront the toughest scientific and medical challenges today and fuel the breakthroughs of tomorrow. NBTS is a welcoming community that creates belonging, connections, and friendships and enables all those involved with us to make progress against this collection of diseases together.

Through the support of generous donors, volunteers, advocates, and partners, NBTS worked unrelentingly in 2023 to drive discoveries toward better treatments and quality of life, provide support and resources to patients and caregivers, and advocate for the needs of the brain tumor community.

The continued support of our community has NBTS poised to advance this research toward new treatments and make a lasting impact on the brain tumor community in the years to come.

## 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 major clinical trial achieve positive results

The 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, increased the length of time before patients with low-grade gliomas, including **astrocytomas and oligodendrogliomas**, needed further treatments.

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. We expect the FDA to review the clinical trial data in 2024.

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## **Added seven new member institutions with world-class investigators to the DNA Damage Response Consortium**

NBTS's boldest collaboration yet — the DNA Damage Response Consortium — brought together seven new member institutions in 2023. The consortium is evaluating 14 experimental therapeutics in translational preclinical experiments in seven different tumor types with a range of different subtypes to rapidly assess potential treatments for children and adults. The tumor types include **glioblastoma, diffuse midline glioma, astrocytoma, oligodendroglioma, ependymoma, medulloblastoma, and atypical teratoid rhabdoid tumors (ATRT)**.

## **Supported a phase II clinical trial evaluating a DNA damage response drug in combination with immunotherapy and standard chemotherapy**

A **phase II clinical trial has already 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). Investigated by Patrick Wen, MD, at Dana-Farber Cancer Institute, this multi-pronged treatment kills targeted tumor cells during treatment but can also stimulate the immune system's ability to kill cancer cells in the future to prevent recurrence.

## **Funded preclinical research that discovered an effective novel drug delivery method for medulloblastoma tumors**

With funding from NBTS'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.

## **Completed comprehensive initiative to identify and bring forward quality of life issues facing patients with brain tumors and their care partners 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 meetings and two major roundtables focusing on adults and children involving more than 120 patients, caregivers, and researchers to **produce a quality of life research agenda for future funding consideration**. The White House Cancer Moonshot program recognized NBTS's Quality of Life Research program — 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.”

## **Helped advance updated criteria for determining whether brain tumors are responding to treatments in clinical trials**

Clinician researchers use comprehensive criteria to know if investigational drugs are working, **CONT. >**

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which helps aid and expedite the evaluation process. The criteria called the Response Assessment in Neuro-Oncology (RANO) is widely used and recognized by the FDA. In 2023, **NBTS's Research Roundtable program served as the vehicle for facilitating an update to this criteria**, leading to its publication and use across the field to standardize whether a specific drug is helping a particular tumor type.

## Invested in diagnostic technology that can accurately predict patients' response to cancer drugs

Neuro-oncologists seeing patients with **glioblastoma and other high-grade gliomas** have too few treatment planning tools available to inform their treatment decisions. NBTS's Brain Tumor Investment Fund has invested in an established leader in the field of "functional precision oncology" that uses novel laboratory technology to predict the response of living tumor cells from a patient biopsy to different cancer drugs. By supporting investment in this innovative new approach, we aim to help patients get the right treatment for the best possible outcomes.

## CONNECT

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

## Represented patients with brain tumors and caregivers in the first-ever White House forum to discuss GBM and DIPG

NBTS participated in the first-ever White House Cancer Moonshot Brain Cancers Forum on glioblastoma (GBM) and diffuse intrinsic pontine glioma (DIPG) to explore ways to accelerate efforts to develop innovative treatments and reduce disparities in access to care and clinical trials. **NBTS brought a critical patient advocacy perspective** and urged the Biden Administration to end cancer as we know it by both speeding up research and improving the adequacy and affordability of specialized health care for patients with brain tumors.

## Expanded NBTS events to nearly all 50 states

NBTS gathered thousands of members of the brain tumor community at NBTS-hosted and volunteer-driven **events in nearly all 50 states**, including brand-new events in Arizona, Delaware, Georgia, Missouri, New Mexico, North Carolina, Northern California, and Virginia.

## Provided support to 34% more patients and care partners

NBTS was honored to extend personalized support and health care navigational services to **34% more patients and care partners** in 2023. In doing so, NBTS helped more patients connect with experienced neuro-oncologists, neurosurgeons, clinical trials, and palliative care.

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## CHANGE

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

### **Increased brain tumor research funding by \$20 million through NIH**

Thanks to the collaborative advocacy efforts of NBTS within the brain tumor community, National Institutes of Health (NIH) funding for brain tumor research saw a considerable increase of **approximately \$20 million**.

### **Advocated for brain tumor community amid potential shutdown**

This fall, NBTS advocated that Congress should come together to pass a Fiscal Year 2024 budget and avoid a looming government shutdown because it's of vital importance that the government can fund and conduct critical brain tumor research and treatment development activities. **NBTS led advocacy efforts** to ensure that Congress understands the negative impact on research from government shutdowns.

### **Urged federal government to improve health care access for patients**

On behalf of the brain tumor community, NBTS formally advocated to the Centers for Medicare and Medicaid Services (CMS) to improve reimbursement for patient navigation services and expand health insurance network adequacy. 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.

### **Championed 5th annual Glioblastoma Awareness Day in Congress**

In anticipation of the 5th anniversary of Glioblastoma Awareness Day, **NBTS once again worked with a dedicated bipartisan group** of U.S. Senators and Representatives led by Senators Graham, Markey, Warren, Sinema, Kelly, and Scott and Representatives Mast, Auchincloss, Schakowsky, and Gallagher to introduce and pass a resolution designating the third Wednesday in July as a day to honor those impacted by glioblastoma and to raise this disease on our national priority list.

## Community here. Breakthroughs ahead.™

While we still have much work to do to fuel the breakthroughs ahead, we have the community here to make it happen. With **a gift today**, you help NBTS make bold progress in driving discoveries that will improve the survival and quality of life for patients with brain tumors while continuing to provide support and advocacy for the unmet needs of our community. Together, we can leave a lasting impact in the year ahead.

*Want to learn more? Email your questions to [donations@braintumor.org](mailto:donations@braintumor.org).*