



IMPACT REPORT – 2021

National Brain Tumor Society (NBTS) has made significant progress over the past year through three interconnected, programmatic strategies: Defeat, Connect, and Change.

- The **Defeat** programmatic strategy drives and influences best-in-class medical research to develop and deliver new innovative treatments and potential cures to brain tumor patients as quickly as possible.
- The **Connect** programmatic strategy convenes, educates, and unites the brain tumor community.
- The **Change** programmatic strategy fuels the voice and power of the brain tumor community to advocate and influence public policies that affect research and access to specialized brain tumor care.

Results in these areas have been made possible by the generous support of donors, volunteers, advocates, and partners, and are critical stepping stones to achieve our goal of making the 2020s the decade of progress toward cures and a better quality of life for brain tumor patients and their loved ones.

PROGRESSING TOWARD BETTER TREATMENTS

GBM AGILE clinical trial expands, offering new opportunities for glioblastoma patients

With support from NBTS, the GBM AGILE clinical trial has expanded to more than 30 sites across 22 states and into Canada, is evaluating three promising drugs simultaneously, and is poised to expand further internationally.

Anti-depression drug shows potential value to glioblastoma treatment

Based on data from NBTS's Defeat GBM Research Collaborative and with support from the Sharpe family, Dr. Paul Mischel (Stanford University) and his lab team found that the antidepressant fluoxetine (common brand name: Prozac) potentially inhibits epidermal growth factor (EGFR), triggering the killing of glioblastoma. Dr. Mischel's research also found that "combining fluoxetine with temozolomide, a standard of care for GBM, causes massive increases in GBM cell death and complete tumor regression in mice." These findings call for a prospective human clinical trial to be conducted, the results of which may lead to adding fluoxetine to standard treatment.

New application of a diabetes drug is poised to help stop ependymoma

With support from the CERN Foundation, a program of NBTS, Dr. Sriram Venetti (University of Michigan) and his lab discovered that in laboratory models, the common diabetes drug metformin suppressed tumor growth in group A posterior fossa ependymomas and that pediatric brain tumors harboring a mutation called H3.3G34R/V may benefit from an experimental drug that inhibits a protein called STAT3. These results open up potential new clinical trial possibilities.

Common cold virus approach to brain tumors yields new directions for combination treatments

With funding from NBTS and the Sharpe family, Dr. Richard Vile (Mayo Clinic) and his team completed research revealing that the common cold virus combined with antibody therapy significantly increases overall survival of laboratory mice with brain tumors. Their research also found that the viral approach may be combined with cell therapy and used as an anti-cancer strategy, potentially opening up next-stage translational and clinical research to evaluate the approach.

INNOVATING THE FIELD OF NEURO-ONCOLOGY RESEARCH

Lessons learned from COVID-19 improve brain tumor clinical trials

NBTS's Research Roundtable program brought together leaders from cancer centers, the FDA, National Institutes of Health, and biopharmaceutical companies, as well as patients and advocates, to identify opportunities to improve trials based on lessons learned during the COVID era. The group developed a plan of action to improve access to trials through the use of remote monitoring, telemedicine, and better involvement of local medical providers, culminating in a paper in the journal [Neuro-Oncology](#).

Pediatric brain tumor experts develop a plan to use historical data in new clinical trials

NBTS's Research Roundtable program convened experts to develop a plan for using previously-captured patient data to prove the safety and efficacy of treatments. This work will propel forward the piloting of future pediatric brain tumor clinical trials designed to ensure that all children in the study receive the investigational treatment and potentially speed up the clinical trials process.

Partnership explores scientific approaches to immunotherapy in brain tumors

The field of immunotherapy for brain tumor treatment continues to evolve and expand rapidly. NBTS partnered with the [Parker Institute for Cancer Immunotherapy](#) to explore the most promising scientific approaches to immunotherapy in brain tumors.

ADVOCATING AND AFFECTING POLICY CHANGE

Record advocacy participation by NBTS volunteers leads to over 50% increase in federal funding of brain tumor research over the past decade

This May, NBTS held its largest Head to the Hill advocacy day to date, with more than 410 participants from 46 states. We followed up in August with a robust in-district advocacy program, with 141 advocates from 33 states taking part in over 100 meetings with legislators at their district offices. Congress responded with increases to federal funding of medical research through the National Institutes of Health, National Cancer Institute, and the Department of Defense's cancer research program. While more funding from the government is still needed, this milestone marks an increased

investment of more than \$3.5 billion in brain and central nervous system tumor research (for children and adults) over the last decade.

Congress unanimously supports Glioblastoma Awareness Day and Brain Tumor Awareness Month Resolutions

For the third consecutive year, Congress took swift, bipartisan action to recognize Glioblastoma Awareness Day in July and Brain Tumor Awareness Month in May. NBTS advocates and other brain tumor organizations joined together to raise the visibility of our cause through virtual events including NBTS's GBM Awareness Day panel, which showcased how our mission is embraced by Congress, federal agencies, companies, patients, doctors, and media.

NBTS stands up for brain tumor patients' financial challenges

We proactively took on issues related to the affordability of brain tumor patients' care, helping persuade the maker of Lomustine, a standard of care chemotherapy drug, to rejoin Medicare.

Brain tumor community issues are brought to the Biden Administration

President Biden's major cancer-related proposal to date is the creation of a new funding program called ARPA-H that will take on specific, yet-to-be-determined initiatives. NBTS was invited to deliver comments on brain tumor research and diversity priorities during several "listening sessions" by the NIH and White House Office of Science and Technology Policy.

PROVIDING SUPPORT, NAVIGATION, AND CONNECTION

Expanded services offer unique support and navigation opportunities for brain tumor patients

The NBTS patient navigation team continued to provide support to patients and families through its array of individualized, group, and educational services. NBTS was pleased to add to its resources a new video program called *Informed in 30*, educating patients on cutting-edge treatment options.

Teams unite for first-ever National Brain Tumor Walk and National Brain Tumor Ride

Thanks to the vision of our volunteers, NBTS held the first virtual National Brain Tumor Walk and National Brain Tumor Ride, connecting teams from across the country to raise funds, awareness, and support of our mission while honoring loved ones who have experienced this devastating disease.

Thank you for your unrelenting support

Together, we will ensure that this continues to be a decade of transformative progress for the brain tumor community. We are so grateful for the many talented and passionate people that work alongside us to advance our shared mission — our advocates, team captains, donors, volunteers, advocates, Board of Directors, and staff who are all-in, every day. Thanks to your generous support, we are poised to help more patients, fund more research, and hold the government more accountable in the year ahead — so that we can realize all of the potential breakthroughs ahead.