

About National Brain Tumor Society

Mission Statement

National Brain Tumor Society is fiercely committed to finding better treatments, and ultimately a cure, for people living with a brain tumor today and anyone who will be diagnosed tomorrow.

Translating Science Into Survival

Why donate to NBTS?

- We develop strategic initiatives and fund programs aimed at actually transforming research findings into new and effective treatments, as quickly as possible. Many of our programs have resulted in real discoveries and true progress for future treatments for brain tumor patients.
- We are the largest and most influential nonprofit organization in the United States dedicated to the needs of the brain tumor community.
- We are the leaders and conveners, the ones who bring various constituents together (researchers, clinicians, legislators, patients, regulators, and the life science industry) in order to discover better treatments, and ultimately a cure, for brain tumors – because no one researcher or institution can cure brain tumors alone.
- Some of the most important developments and progress on research and treatments of brain tumors were influenced, driven, discovered and accomplished as a direct result of NBTS work, funding, advocacy, and/or initiatives.
- Our work is made possible by the generous support of our donors, partners, sponsors, event participants, patients, families, friends, and the brain tumor community. More than 85% of all proceeds donated goes to funding only the most promising research, trials, and public policy efforts in order to have the greatest impact on future treatments.



Key Facts

- **Nearly 700,000 Americans are living with a brain tumor.**
- **Nearly 16,000 deaths every year due to brain tumors.**
- **Leading cause of cancer-related death in children under the age of 14.**
- **Brain tumors can affect anyone at any age – they do not discriminate against age, gender, race, or ethnicity.**
- **More so than any other cancer, malignant brain tumors can have life-altering physical and cognitive effects.**

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Current Programs

Defeat GBM Research Collaborative: Connects world-class scientists together from different institutions with the objective of doubling the percentage of patients living beyond 5 years with glioblastoma.

Oligodendroglioma (Oligo) Research Fund: NBTS' first Community Research Fund dedicates money specifically for much needed research into this rare tumor type. To date, three rounds of high-impact scientific projects have been launched to gain a better understanding of ways to best target it with treatments.

Project Impact: A powerful, unique global research and drug discovery program which aims to improve clinical outcomes for pediatric brain tumor patients and develop a first-ever standard of care for treating pediatric high-grade gliomas.

Clinical Trial Endpoints Initiative: Seeks to create positive change in the process used to evaluate and approve potential new brain tumor treatments.

Public Policy & Advocacy: Our policy agenda seeks to strengthen and advance research, improve access to essential health care services, advocate for budgets and policies dedicated toward the research and treatment of brain tumors, and expedite therapy approvals.

The Cost is Too High to Not Act Now

- Only 4 FDA approved drugs are available for the more than 120 different types of brain tumors.
- The cost of developing a new cancer drug now is estimated to cost more than \$1 billion and take upwards of 15 years.
- It costs approximately \$1,000 to sequence the genome of one brain tumor patient.
- It costs approximately \$40,000 to fund the development of one new mouse model of brain cancer.
- It can cost well more than \$10,000 to fund one-month of laboratory research.
- A clinical trial alone can cost well in the tens-of-millions of dollars range.

The real word affect of these alarming statics is that survival rates for the most common and deadly malignant brain tumors have remained unacceptably low for decades with only incremental advances. NBTS is changing that.

“I think the National Brain Tumor Society throughout its whole existence has really had a critical part in the development of research programs in brain tumors, generally, as well as in pediatrics.”

- *Dr. Scott Pomeroy*
Boston Children's Hospital

“The [National] Brain Tumor Society was willing to intelligently vet new, cutting-edge ideas and invest in it. They are really a group that can identify transformational ideas and run with it.”

- *Dr. Evan Snyder*
Sanford-Burnham Medical Research Institute

“I decided just because medical treatment had ended, my fight against brain cancer didn't have to end, too. Enter the National Brain Tumor Society.”

- *Liz Salmi*
Brain Tumor Advocate and Founder of the Liz Army

History of Impact

Researchers are now more poised than ever to understand brain tumors, develop new treatments, and improve the lives of patients.

In just the past five years, emerging scientific discoveries – many happening as a direct result of NBTS funding or advocacy – combined with improved technology and research tools, are helping researchers and clinicians better understand brain tumors, and subsequently attack their vulnerabilities with new, more targeted treatments:

- NBTS research funding has led to the discovery of many of the most critical biomarkers in brain tumors – which can help predict survival; determine which patients are most likely to respond to new, precision treatments; and provide treatment targets.
- NBTS provided early funding to the Gliogene Consortium – which is discovering potential risk factors for certain brain cancers.
- NBTS provided funding for research that has led to six of the most promising potential new treatments currently in clinical trials for brain cancer.
- NBTS funding has helped scientists and clinicians better understand treatment resistance in brain cancer.
- NBTS advocacy helped make brain cancer the first tumor-type sequenced by the government’s massive Cancer Genome Atlas project.
- NBTS advocacy has helped introduce bills into Congress that, if approved, could improve the lives of brain tumor patients.

Now it’s time to translate this science into patient survival.

Get Involved

Attend our events: Participate as an individual, start a team, or join a team.

Volunteer your time: Help with planning, event day roles, or raise awareness of brain tumors in your community.

Make a gift: Fund the discovery of new brain tumor treatments and a cure.

Become an advocate: Let your voice be heard to support the critical needs of the brain tumor community.

Host a community event: Support our mission and host your own local fundraiser with family, friends, neighbors, and co-workers.



History & Leadership

Our roots date back to the 1980s, with the founding of our two legacy organizations: the National Brain Tumor Foundation and the Brain Tumor Society. In 2008, the two groups came together to form the National Brain Tumor Society.

As the brain tumor landscape has changed, we have adapted the Organization to be able to make the most impact given our unique core strengths and deep relationships. We leverage our size, breadth, unparalleled in-house scientific and public policy capacity, and strong base of key advisors across academia, industry and government, to drive change.

Today, NBTS is led by a team of senior nonprofit and business executives, with a wealth of experience in nonprofit management, patient advocacy, and biomedical research.

- David Arons, JD - *Chief Executive Officer*
- Samantha Masterson - *Chief Advancement Officer*
- Craig Strenger - *National Director of Field Operations*
- Michael Antonellis - *National Director of Marketing Communications*
- Wendi Nance - *National Development Officer*
- Ann Kingston - *Director of Scientific Operations*
- Kristina Knight - *Director of Research Program Strategy and Community Relations*

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