



National Brain Tumor Society 2019 Legislative Agenda

National Brain Tumor Society's 2019 Legislative Agenda supports the vision of our organization: to conquer and cure brain tumors - once and for all.

The 115th Congress brought positive change, including the passage of the Childhood Cancer STAR Act and a continued commitment to funding medical research. Moving forward, it is imperative that Congress continue its commitment to progress for the brain tumor community. More than 78,000 people received a primary brain tumor diagnosis in 2018, and for those whose diagnosis was a malignant tumor, the survival rate is less than 34%. There are more than 130 different types of primary brain tumors, as well as metastatic brain cancers, and too few significant advances have been made in treating this collection of diseases. The 2018 Annual Report to the Nation on the state of cancer from the National Cancer Institute states that although death rates decreased for many types of cancer, they increased for brain cancer in men and women. In addition, pediatric brain tumors continue to be the leading cause of cancer death in children.

Therefore, as the 116th Congress begins, the National Brain Tumor Society urges Congress to change the status quo by passing legislation that helps develop treatments and improve health care for brain tumor patients and their families.

Support Medical Research

- Appropriate full funding for the 21st Century Cures legislation, including the Cancer Moonshot, and the Food and Drug Administration's (FDA's) efforts to accelerate drug development.
- Appropriate \$41.6 billion for the National Institutes of Health (NIH), and \$6.522 billion for the National Cancer Institute (NCI), to raise funding levels to keep pace with inflation and the professional judgment of the NCI.
- Appropriate \$120 million for the Peer Reviewed Cancer Research Program of the Congressionally Directed Medical Research Programs of the Department of Defense, and include brain cancer and pediatric brain tumors as topics eligible for funding.
- Fund the Childhood Cancer STAR Act of 2017, which was passed in 2018, to guarantee that the programs contained in the law will be implemented and begin to make a difference for all those affected by childhood cancer.
- Break down barriers to clinical trial enrollment by enacting H.R. 913, the Clinical Treatment Act, which ensures coverage of routine medical costs associated with clinical trial participation for Medicaid recipients.

Provide Access to Care

- Enact the Cancer Drug Coverage Parity Act so brain tumor patients who must access patient-administered anti-cancer medicines can do so affordably.
- Improve quality of life, personal well being, and pain management for brain tumor patients by enacting H.R. 647, the Palliative Care and Hospice Education and

- Training Act (PCHETA), which establishes palliative care and hospice workforce training programs to enhance and improve the delivery of palliative care.
- Guarantee that patients diagnosed with the deadliest cancers, including brain tumors, are given the best chance to fight their disease by covering treatment at NCI designated cancer centers through the Affordable Care Act.

For more information, please contact Lainey Titus Samant, Director of Advocacy, at advocacy@braintumor.org.