



National Brain Tumor Society 2020 Legislative Agenda

National Brain Tumor Society's 2020 Legislative Agenda supports the vision of our organization: to conquer and cure brain tumors — once and for all.

Today, an estimated 700,000 people in the United States are living with a primary brain tumor, and more than 86,000 more will be diagnosed in 2020. The average survival rate for all malignant brain tumor patients is only 35%. Further, hundreds of thousands more are diagnosed each year and are living with metastatic brain cancer, presenting both similar and different challenges from primary brain tumors.

The treatment landscape for brain tumor patients has seen improvements in surgical, chemotherapeutic, and radiation treatment approaches, but only marginal and insufficient to improve overall survival and quality of life for patients. However, scientific understanding of underlying tumor biology has increased exponentially through our own funded research as well as government-funded research. There are now rational, promising strategies to pursue toward the development of new medicines. Researchers are now primed to apply this knowledge and begin to develop a new wave of transformational treatments that will benefit brain tumor patients.

We are grateful for Congress's bipartisan commitment to fund vital medical research, as well as improving the quality of life for patients, in 2019. That commitment must continue into 2020 and beyond to turn past discoveries into future treatments.

National Brain Tumor Society urges Congress to pass legislation that invests in research, lays the foundation to develop new and innovative treatments, and improves health care for brain tumor patients and their families before the end of the 116th Congress.

Support Medical Research

- Appropriate a \$3 billion increase for the National Institutes of Health (NIH), and a \$500 million increase for the National Cancer Institute (NCI), to keep funding levels on pace with inflation as well as in line with the professional judgment of experts at 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 to guarantee that the programs inaugurated by the law are implemented and begin to make a difference for all those affected by childhood cancer, including pediatric brain tumors, now the leading cause of cancer-related death in children.
- Provide funding to continue the White House's Childhood Cancer Data Initiative, which will establish more efficient ways to share and use childhood cancer data.
- 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. In addition, continue to work on the 21st Century Cures 2.0 legislation with the ongoing input of key stakeholders, including patient advocacy organizations.

- 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 (H.R. 1730, S. 741) 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 the Palliative Care and Hospice Education and Training Act (PCHETA, H.R. 647/S. 2080), which establishes palliative care and hospice workforce training programs to enhance and improve the delivery of palliative care.
- Address the issue of drug pricing and shortages through legislative measures so that no brain tumor patients have to go without their doctor prescribed treatment or medication.
- Prevent price gouging by passing legislation to prevent companies from drastically increasing prices and thereby limiting access. This impacts the brain tumor community specifically as Lomustine, previously \$50 per dose, now is over \$1,000 due to one company's control of the market.
- 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.

Additional Areas of Interest

In addition to our active legislative agenda, we advocate for a number of issues facing the brain tumor community, as well as other bills currently before Congress. In 2020, we will be tracking the following areas of interest and take action as needed:

- Access to Precision Medicine and Gene and Cellular Therapies
- Pediatric Cancer Research Funding
- Pharmacy Benefit Step Therapy
- Access to Complementary Therapies and Other Quality of Life Issues

For more information or to discuss other priorities, please contact Danielle Leach, Chief of Community and Government Relations, at dleach@braintumor.org.