



National Brain Tumor Society - Public Policy and Advocacy Update

Vol. 8, No. 2

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Legislative Agenda

National Brain Tumor Society's annual "Legislative Agenda" sets forth our priorities for public policy in the coming year, identifying ways to affect change for the brain tumor community through congressional advocacy. These priorities also reflect the larger strategy and goals of the organization and directly impact our ability to deliver on our vision to conquer and cure brain tumors - once and for all. [Click here to continue reading a recent blog](#) that outlines how we create our Legislative Agenda each year and an overview of our policy priorities in 2019.

Legislative Spotlight: Palliative Care and Hospice Education and Training Act

National Brain Tumor Society is a member of the Patient Quality of Life Coalition, which recently sent a letter to Congressional leadership to support the Palliative Care Hospice Education and Training Act (PCHETA). This bill, if passed, would directly impact the everyday lives of brain tumor patients and survivors who benefit from palliative care. Palliative care includes therapies to address pain, stress, and other symptoms associated with a brain tumor diagnosis and/or treatment.

The following excerpt from the letter to Congressional leadership provides greater detail on the contents of the legislation:

The Palliative Care Hospice Education and Training Act (PCHETA) would help to ensure that more individuals have access to palliative care services by addressing:

- The need to train more physicians, nurses, social workers, and other health professionals in the medical subspecialty of palliative care;
- The need to educate the public and providers about the availability of palliative care;
- The need for greater investment in evidence-based research specific to palliative care and symptom management.

By expanding the palliative care workforce, awareness, and research, this bipartisan legislation will improve quality of care and quality of life for millions of patients living with serious or life-threatening illness and their family/caregivers.

PCHETA passed unanimously in the House of Representatives last Congress and had strong bipartisan support in the Senate. The House bill, H.R. 647, was recently re-introduced and the Senate bill is expected to be re-introduced shortly.

White House Announces Funding for Childhood Cancer Research

We were honored to be included in a virtual meeting held last week by the Administration to discuss further details of an initiative the President recently announced to provide \$500 million in funding over the course of 10 years to accelerate childhood cancer research.

During that meeting, Dr. Ned Sharpless, Director of the National Cancer Institute (NCI), announced that a major focus of the initiative will be on how to improve the collection and sharing of data to advance

pediatric cancer research. Aggregating data to improve research on childhood cancers like brain tumors is critical, and we look forward to hearing more on this initiative in the coming months.

The driving force behind NCI's childhood cancer data effort is clearly the efforts of many dedicated pediatric cancer research advocates, including all of you who participate in our NBTS Advocacy program. Your advocacy also led to the [passage of the Childhood Cancer STAR Act](#) last year, and implementation of the STAR Act could be an important part of the new data aggregation effort at the NCI.

Head to the Hill: We Need Your Voice

If you've ever wondered how you can make even more of a difference as a brain tumor advocate, Head to the Hill could be right for you! Hear from fellow volunteer advocates who detail their experiences attending previous Head to the Hill events and learn how your story can make a difference for the brain tumor community by viewing [this pre-recorded informational webinar](#). To learn more and register for the event, [click here](#).

Brain Tumor Research Highlighted by PRCRP

We advocate for medical research funding through the Department of Defense's Peer Reviewed Cancer Research Program (PRCRP) each year. For the past few years, we've achieved increased funding for this program, as well as the ongoing inclusion of pediatric brain tumors and brain cancer as eligible topics for research via this program. The PRCRP recently published a report highlighting some of the recently funded brain tumor research through this program. [Click here to read about some of the research your advocacy helped fund](#).

Ensure Your State Proclaims May Brain Tumor Awareness Month

To recognize and honor those living with a brain tumor, and all of those who have lost their lives, May is observed nationally as Brain Tumor Awareness Month. This year, the National Brain Tumor Society is asking advocates to join in our efforts to raise awareness by requesting that May is proclaimed Brain Tumor Awareness Month in your state, as well.

What is a proclamation? A proclamation is issued by the Office of the Governor to provide recognition for special events or significant issues. The goal of a proclamation is to honor and celebrate events or to increase awareness of significant issues of importance.

[Click here to fill out a brief form](#) and begin the process of requesting a Brain Tumor Awareness Month Proclamation in your state. A member of the Public Policy & Advocacy staff will contact you shortly to assist in your efforts.

National Brain Tumor Society unrelentingly invests in, mobilizes, and unites our community to discover a cure, deliver effective treatments, and advocate for patients and care partners. Our vision is to conquer and cure brain tumors - once and for all.

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