

## FOR IMMEDIATE RELEASE

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## National Brain Tumor Society Calls on State and Federal Officials to Include Critical Services for Brain Tumor Patients In Essential Health Benefits Packages

**BOSTON, MA –** National Brain Tumor Society, the largest nonprofit dedicated to the brain tumor community in the United States, has submitted letters to the health insurance commissioners of all 50 states, as well as United States Department of Health and Human Services Secretary Kathleen Sebelius, advocating for coverage of critical treatments and services for brain tumor patients and survivors in the Essential Health Benefits packages, currently being established as part of the Affordable Care Act.

National Brain Tumor Society's public policy agenda seeks to drive change by advocating for resources and policies that will result in a better quality of life, and ultimately a cure for those affected by brain tumors. The Organization's public policy work complements its diverse and robust research initiatives, which are aimed at advancing new therapy developments.

"We believe the Affordable Care Act's Essential Health Benefits packages must include specific coverage to accommodate the vast and costly medical needs of brain tumor patients and survivors," said N. Paul TonThat, Executive Director, National Brain Tumor Society. "This community faces a diagnosis that often will necessitate life-long medical, psychological, physical, and cognitive health care services, for which they must be granted affordable access to improve their quality of life, and extend overall survival."

For example, National Brain Tumor Society is asking Federal and State policymakers charged with designing the essential health benefits packages to include services which ensure affordable coverage for patient-administered, anti-cancer medications, including oral temozolomide, the standard-of-care chemotherapy for many brain tumor patients, which often carries a high out-of-pocket expense. Additionally, National Brain Tumor Society is calling for coverage in the areas of habilitative, rehabilitative, and mental health services, among others, to recognize the permanency of the health issues experienced by brain tumor survivors.

In all, National Brain Tumor Society developed a list of services in the ten categories set out in the Affordable Care Act to provide brain tumor patients with access to affordable care such as, emergency services, hospitalization, ambulatory patient services, mental health services, pediatric care, and chronic disease management.



More than 688,000 Americans are currently living with a primary brain tumor, and an estimated 13,700 people with die because of the disease this year. Brain tumors are the second leading cause of cancer-related death in children under age 20, and third leading among young adults age 20-39. Only one out of three adults diagnosed with a malignant brain tumor today will be alive in five years. More so than any other cancer, a brain tumor can have life-altering psychological, cognitive, behavioral, and physical effects. Yet, with only four FDA-approved therapies in the past 30 years, treatment options are limited and often come with adverse side effects. There is no cure.

## **About National Brain Tumor Society**

National Brain Tumor Society (NBTS) is the largest nonprofit organization dedicated to the brain tumor community in the United States. We are fiercely committed to finding better treatments, and ultimately a cure, for people living with a brain tumor today and those who will be diagnosed tomorrow. This means aggressively driving strategic research and advocating for public policies, which meet the critical needs of this community. To learn more visit <a href="https://www.braintumor.org">www.braintumor.org</a>

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