



February 2, 2017

The Honorable Paul D. Ryan
Speaker of the House of Representatives
1233 Longworth HOB
Washington, DC 20515

The Honorable Nancy P. Pelosi
Minority Leader of the House of Representatives
233 Cannon HOB
Washington, DC 20515

The Honorable Mitchell McConnell
Senate Majority Leader
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Charles E. Schumer
Senate Minority Leader
322 Hart Senate Office Building
Washington, DC 20510

Dear Speaker Ryan, Leaders Pelosi, McConnell, Schumer,

On behalf of the thousands of patients, caregivers, families, and loved ones the National Brain Tumor Society represents, we write to encourage you to consider the needs of the brain tumor community as you discuss and deliberate changes to our national healthcare programs. There is no waiting around with a brain tumor – you must take immediate and aggressive action within the health care system to acquire an appropriate course of treatment. Brain tumor patients, adults and children, and their families deserve to have a health care system that delivers access to high quality, affordable health care and we urge you to ensure those needs are met. While statistically called a rare disease, there are nearly 700,000 Americans living with a primary brain tumor and even more with brain metastases (where the cancer started in another part of the body and has spread to the brain). Among children, brain tumors are tragically the leading cause of cancer death from the time of birth until the age of 19. In adults, many malignant types of brain tumors are among the deadliest forms of cancer. For example, glioblastoma – the most common form of malignant brain tumor – has a five-year relative survival rate of less than five percent. The more than 120 distinct types of brain tumors are not only life threatening, but also often jeopardize patients' sense of self as they can present neurological challenges resulting in permanent disability including hearing and/or vision loss, cognitive deficits, decreased motor function, and other significant challenges.

Brain tumor patients have a medical necessity for a wide range of healthcare services spanning from early access to medical imaging for detection; surgical biopsy for accurate diagnosis and treatment planning; emergency services in the event of seizures or other debilitating brain tumor symptom-related event; inpatient hospitalization; neurological surgery (craniotomy); to post-operative treatment and care, including potential rehabilitative physical, occupational, and/or speech therapy as well as psychosocial care. Standard of care is made up of a combination of different therapeutic modalities including surgical resection; chemo- or brachy- therapy treatment delivered during surgery; chemotherapy (oral and infused) delivered after surgery; radiation; and/or tumor-treating fields delivered by a medical device. In addition, brain tumor patients will need continued (post-diagnosis) access to some of the most advanced medical technologies including standard and advanced imaging. Furthermore, with few effective treatment options brain tumor patients need access to clinical trials, which often offer an essential opportunity to find a better therapy that may extend survival and improve quality of life.

In fact, reports have indicated that brain tumors have the highest per-patient initial cost of care for any cancer group, with an annualized mean net cost of care approaching \$150,000, as well as the highest annualized mean net costs for last-year-of-life care relative to other cancers at \$135-\$210K (depending on age and gender) per-patient. According to other studies, patients with malignant brain tumors accrued health care costs that were 20-times greater than demographically matched control subjects without cancer. Therefore, access to affordable, high quality, specialized care is paramount for brain tumor patients.

To this end, recent reforms, critically, have allowed for important provisions that benefit patients diagnosed with brain tumors. We ask for these to be preserved as you consider policy changes to the Affordable Care Act and public health insurance programs. Among them are the principles of:

- No denial of coverage due to pre-existing conditions
- No imposition of lifetime or annual limits on coverage
- No cancelling of coverage when a patient becomes sick
- No charging individuals with preexisting conditions more than those without
- Allowing dependent children to remain on their parents' health insurance plans up to age 26
- Limits on out-of-pocket costs including co-pays, coinsurance and pre-deductible expenses
- No denial of coverage because a patient enters a clinical trial
- No denial or limitation of coverage for routine patient costs for items and services furnished in connection with participation in the trial
- Expansion and maintenance of Medicaid and CHIP coverage so that low income patients have access
- No discrimination based on gender retaining equal premiums for men and women

Lastly, as you consider updates to America's healthcare system we urge you to consider ways to improve insurance coverage for procedures, providers, and the use of technology necessary in the era of precision medicine. Examples include the use of medical imaging during all stages of clinical care, use of molecular diagnostics, biopsy tissue/biofluid collection techniques essential for accurate diagnosis as well as informing first- and second-line treatment of diseases including brain tumors.

Please know that National Brain Tumor Society stands as a resource to you and the rest of Congress as you consider the needs of brain tumor patients throughout our United States of America.

Sincerely,

David F. Arons, JD
Chief Executive Officer
National Brain Tumor Society