National Brain Tumor Society

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Federal Legislative Agenda 2015

Accelerated Drug Development and Approval and Targeted Precision Medicine
With only four approved treatments for brain tumors in the past thirty years, none of which extend overall survival by than a few months, the National Brain Tumor Society has been pleased to see an increase in proposed policies that will expand on the promise of targeted, precision medicines for patients, as well as a process for accelerated drug development and approvals. We look forward to advocating on behalf of the brain tumor community as President Obama's Precision Medicine Initiative gets underway and the House Committee on Energy & Commerce and Senate Health, Education, Labor & Pensions (HELP) Committee develop legislative approaches to advancing medical research and the development of new treatments.

Funding for Medical Research and Drug Review and Approval
As the largest funder of brain tumor research, the Federal government's investment in the National Institutes of Health (NIH), including the National Cancer Institute (NCI) and National Institutes of Neurological Disorders and Stroke (NINDS), as well as its funding for the U.S. Food and Drug Administration (FDA), plays a vital role in the discovery, development and approval of potential new treatments. We ask Congress and the Administration, when preparing the FY 2016 federal budget, to prioritize funding for these agencies signaling a commitment to fighting brain tumors – one of the deadliest cancers. We request that NIH is funded at $33 billion in FY16, including $5.75 billion for NCI.

We also support the Accelerating Biomedical Research Act (DeLauro/Mikulski) in order to put the NIH on a more stable funding platform and lead to future increases in brain tumor research. Under the Act, any funding provided in excess of $29.4 billion would trigger a budget cap increase to accommodate the additional funding provided to the NIH. The bill would allow appropriations to increase NIH funding by 10 percent for the first two years and about six percent each year thereafter through 2021.

We also urge Congress to continue to increase support for the Peer Review Cancer Research Program, and continue to provide research funding for pediatric brain tumor research as part of the Department of Defense's Congressionally Directed Medical Research Programs.

Patient Access to Health Care
We ask for Congress' support of legislation that will allow brain tumor patients to access the care their doctors recommend for treatment of their disease.

The Cancer Treatment Parity Act and the Cancer Drug Coverage Parity Act
This legislation would correct a common problem in private health insurance coverage by requiring that cancer patients who are prescribed patient-administered anti-cancer medication (i.e. oral/self-injectable chemotherapy) are charged out of pocket co-pay/co-insurance on a no less favorable basis than if they were going to receive hospital provided anti-cancer medication (IV chemotherapy). Brain tumor patients do not generally have a choice because the chemotherapy (temozolomide) most often

prescribed is almost always administered in pill form. Moreover, many anti-cancer medicines being developed are going to be available only in a patient-administered form. Thirty-four states have passed an oral chemotherapy parity law, but a federal law is needed to correct the problem under self insured health plans.

Patients' Access to Treatments Act
The bipartisan Patients' Access to Treatments Act would restrain high cost-sharing for specialty medications, thereby enabling brain tumor patients to access the treatments they need. The legislation would limit cost-sharing requirements applicable to medications in a specialty drug tier (typically Tier IV or higher) to the dollar amount applicable to drugs in a non-preferred brand drug tier (typically Tier III). Specialty tiers are becoming more common, and current and future medications used to treat brain tumors or associated side effects are or could be included in specialty tiers.

Passage of the Patients' Access to Treatments Act will allow patients who currently endanger their health by having to skip doses or go without treatment altogether due to excessively high cost-sharing to access the medications they need, and that their doctors have prescribed.

Support Pediatric Brain Tumor Research
Malignant brain tumors are the second most common form of childhood cancer, and are the leading cause of cancer-related death for children under 10 years old. As part of our signature pediatric initiative, *Project Impact: Driving Discovery to a Cure for Pediatric Brain Tumors*, the National Brain Tumor Society is working with policymakers in Congress and with regulatory agencies to develop solutions to improve and accelerate pre-clinical and clinical research that could help identify new treatments for children with brain tumors.