



## National Brain Tumor Society Federal Legislative Agenda 2016

### **Accelerating Drug Development and Approval and Advancing Precision Medicine**

With only five approved treatments for brain tumors in the past 30 years, none of which extend overall survival by more 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 for inclusion in President Obama's Precision Medicine Initiative as well as the House Committee on Energy & Commerce and Senate Health, Education, Labor & Pensions (HELP) Committee's attempts to accelerate drug development and cures.

### **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 were pleased with the increase in medical research funding in the Fiscal Year 2016 budget and ask Congress and the Administration, when preparing the FY 2017 federal budget, to once again prioritize funding for these agencies, signaling a commitment to fighting brain tumors – one of the deadliest cancers.

We also urge Congress to continue to increase support for the Peer Reviewed 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.

### **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 14 years old. National Brain Tumor Society has joined with the Alliance for Childhood Cancer to determine the barriers to pediatric brain tumor research and drug development, and along with the Alliance we are urging Congress to pass the *Childhood Cancer Survivorship, Treatment, Access, Research (STAR) Act* in the House (H.R. 3381, Reps. McCaul, Speier, Van Hollen) and Senate (S. 1883, Sens. Reed and Capito).

### **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 Drug Coverage Parity Act* (H.R.2739, Reps. Lance and Higgins; S.1566, Sens. Kirk and Franken) 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-nine states have passed an oral chemotherapy parity law, but a federal law is needed to correct the problem under self-insured health plans.

For more information, please contact David Arons, Chief Executive Officer, at [darons@braintumor.org](mailto:darons@braintumor.org)