Problem

Brain tumors are the leading cause of cancer-related death for children under 14 years old. Nationally an estimated 4,620 or more children are diagnosed with a brain tumor each year. There is currently no cure and for many types of childhood brain tumors there is no standard of care treatment. There is a critical need for more research to be funded through the National Institutes of Health (NIH) and for a greater emphasis on the development of new treatments through clinical research. At the same time, childhood brain tumor patients that are not eligible for clinical trials should be able to understand in a timely manner if they can access potential new medicines through expanded access programs offered by biopharmaceutical companies. Pediatric brain tumor survivors also need care models that will appropriately help their long-term physical and psycho-social needs. Yet such services are sorely underfunded. Finally, there is a need to improve childhood cancer expertise at the National Cancer Institute (NCI) so that it can better address the scientific challenges and opportunities.

Solution

National Brain Tumor Society helped craft and advocate for the introduction of the Childhood Cancer Survivorship, Treatment, Access, Research (STAR) Act. The following provisions of the Childhood Cancer STAR Act will help stimulate more effective pediatric brain tumor research and lead to better treatments that extend life and improve patients’ quality of life:

- **Improving Access to Critical Tissue Samples:** National Brain Tumor Society strongly supports the provision encouraging the NIH to invest in childhood cancer biorepositories, which would store high-quality, donated tissue samples, and associated clinical and demographic information. This information is vital for effective and efficient future research efforts.

- **Funding State-Level Pediatric Epidemiology Efforts:** Supports the authorization of grant awards to state cancer registries, which would better track disease rates in children and help researchers understand trends in pediatric cancer prevalence, incidence and survival.

- **Understanding Life Beyond Childhood Cancer:** Provides authority to the Secretary of the U.S. Department of Health and Human Services to make grants to pilot programs, which will develop models to study childhood cancer survivors throughout their lives.

- **Expanding Research:** Requires the Director of the NIH to make grants to entities to conduct research that addresses both the physical and the psychological needs of childhood cancer.

- **Requiring Transparency for Expanded Access Policies:** Requires more clarity to the process for parents to seeking compassionate-use waivers (Expanded Access Protocol) for children with aggressive cancers, so that they can access potentially life-saving treatments outside of clinical trials.

We ask Congress to support the Childhood Cancer STAR Act (H.R. 3381/S.1883).

About National Brain Tumor Society

National Brain Tumor Society 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. It’s time to build on progress and transform tomorrow, today.

www.braintumor.org