

Childhood Cancer STAR Act of 2017:

Expanding Research and Improving Treatment for Children with Cancer



Problem

Brain tumors are the leading cause of cancer-related death for children and adolescents ages 0-19. Brain tumors are now responsible for three out of every ten pediatric cancer deaths. 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. Pediatric brain tumor survivors also need care models that will appropriately help their long-term physical and psychosocial 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

We ask Congress to support the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act of 2017 (S.292 Capito/Reed/Van Hollen/Isakson, H.R.820 McCaul/Speier/Kelly/Butterfield). National Brain Tumor Society helped create this crucial piece of legislation as part of the Alliance for Childhood Cancer. The following provisions of the 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:

- **Expanding Opportunities for Childhood Cancer Research:** Due to the small population of children with cancer and the geographic distance between these children, researching childhood cancer can be challenging. The STAR Act would authorize the NCI to expand existing efforts to collect biospecimens for childhood cancer patients enrolled in NCI-sponsored clinical trials to collect and maintain relevant clinical, biological, and demographic information on all children, adolescents, and young adults with cancer.
- **Improving Efforts to Monitor Childhood Cancer Trends:** Building upon previous efforts, this bill would authorize grants to state cancer registries to identify and track incidences of child, adolescent, and young adult cancer. This funding would be used to identify and train reporters of childhood cancer cases, secure infrastructure to ensure early reporting and capture of child cancer incidences, and support the collection of cases into a national childhood cancer registry.
- **Improving Quality of Life for Childhood Cancer Survivors:** As many as two-thirds of childhood cancer survivors suffer from late effects of their disease or treatment, including secondary cancers and organ damage. This legislation would enhance research on the late effects of childhood cancers, including a study on insurance coverage and payment of care for childhood cancer survivors; improve collaboration among providers so that doctors are better able to care for this population as they age; and establish a new pilot program to begin to explore innovative models of care for childhood cancer survivors.
- **Ensuring Pediatric Expertise at the National Institutes of Health (NIH):** The Childhood Cancer STAR Act would require the inclusion of at least one pediatric oncologist on the National Cancer Advisory Board and would improve childhood health reporting requirements to include pediatric cancer.

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.