

The Childhood Cancer **STAR** Act of 2017, H.R. 820/S. 292



House Bill Sponsors: Congressman Michael McCaul (R-TX-10), Congresswoman Jackie Speier (D-CA-14), Congressman Mike Kelly (R-PA-3), and Congressman G. K. Butterfield (D-NC-1)

Senate Bill Sponsors: Senator Jack Reed (D-RI), Senator Shelley Moore Capito (R-WV), Senator Chris Van Hollen (D-MD), and Senator Johnny Isakson (R-GA)

Background: Cancer is the leading cause of disease-related death among children ages 1-19, and more than 10,000 children will be diagnosed with cancer in 2017. Despite an overall increase in survival rates, progress in treating certain pediatric cancers remains limited. Additionally, childhood cancer and its treatments often lead to lifelong side effects. To address these issues, the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act would advance pediatric cancer research, increase transparency and expertise for pediatric cancer research at the National Institutes of Health (NIH), and expand research into the long-term side effects due to childhood cancer and its treatments.

Bill Summary: The Childhood Cancer STAR Act of 2017

- **Childhood Cancer Research:** The majority of pediatric cancer research is conducted by the federal government, meaning federal funding is vitally important for further medical advances. This legislation reauthorizes the Caroline Pryce Walker Conquer Childhood Cancer Act, which expands efforts to collect biospecimens and clinical and demographic information for childhood cancer patients in clinical trials in order to understand the cause of pediatric cancers and the effects of treatments.
- **Childhood Cancer Surveillance:** The Childhood Cancer STAR Act will authorize grants to state cancer registries to track incidences of cancer in children, adolescents, and young adults. Funding for these registries would be used to expand early reporting of pediatric cancer, improve electronic reporting and infrastructure, submitting data to the Centers for Disease Control and Prevention's national childhood cancer database, and tracking the late effects of childhood cancers.
- **Pediatric Expertise and Transparency at the NIH:** This provision would require that at least one pediatric oncologist be included on the National Cancer Advisory Board and would enhance the reporting requirements for childhood cancer research at the NIH.
- **Quality of Life for Childhood Cancer Survivors:** Over 60 percent of childhood cancer survivors go on to experience a chronic health condition. This bill expands research on the late effects of childhood cancer treatments, calls for a report on medical and psychosocial care for pediatric cancer survivors, creates pilot programs to evaluate model systems of care, and initiates studies on insurance coverage and payment of care for childhood cancer survivors.