



## **ACTION DAYS 2024 REQUESTS FOR CONGRESS**

### **1. Federal Funding for Childhood Cancer Programs**

In December 2022, Congress unanimously passed the Childhood Cancer STAR Reauthorization Act, allowing the programs from the STAR Act – the most comprehensive childhood cancer bill in history – to continue for five more years. The STAR Act expands opportunities for childhood cancer research, improves efforts to identify and track childhood cancer incidences, and enhances the quality of life for childhood cancer survivors.

Created in 2019, the Childhood Cancer Data Initiative is enhancing childhood cancer care and research data to improve preventive measures, treatment, quality of life, and survivorship, as well as ensure that researchers learn from every child with cancer.

To continue this important work, we ask Congress to provide:

- **\$30 million** to fully fund the Childhood Cancer STAR Act
- **\$50 million** to fully fund the Childhood Cancer Data Initiative

#### **1a. NIH and NCI Funding**

We urge Congress to provide significant funding increases for the National Institutes of Health (NIH) and the National Cancer Institute (NCI). Specifically, we ask Congress to provide:

- **\$51.303 billion** for the NIH
- **\$7.934 billion** for the NCI

### **2. The Accelerating Kids' Access to Care Act**

Children with cancer often require specialized care from a specific provider or facility that may not be available in their home state. Some patients face burdensome, unnecessary delays in accessing time-sensitive care, including clinical trial enrollment, outside of their home state, which can unfortunately cause a child's condition to worsen.

We ask members of Congress to cosponsor **the Accelerating Kids' Access to Care Act (H.R. 4758/S. 2372)**, which reduces regulatory burdens to allow children with

complex medical needs greater access to out-of-state providers who can best meet their needs.

**3. The Pediatric Cancer Drug Supply Act – *For House Members Only***

Drug shortages significantly impact children with cancer and the health professionals who care for them. Providers are forced to prioritize some patients over others, delaying treatment for children and creating a disruption to clinical trials. In a 2023 survey, more than half of childhood patients, survivors, and families reported experiencing a drug shortage during their treatment.

We ask members of the House to cosponsor **the Pediatric Cancer Drug Supply Act (H.R. 6963)**, which creates a pilot program that directs HHS to establish and maintain a 6-month reserve of essential childhood cancer chemotherapy drugs.