

## Childhood Cancer

In 2024, an estimated 9,620 children (ages 0-14 years) and 5,290 adolescents (ages 15-19 years) will be diagnosed with cancer, and 1,040 children, and 550 adolescents will die from cancer.<sup>1</sup> Cancer is the leading disease-related cause of death among children and adolescents.<sup>1</sup> Although cancer in children is much rarer than in adults, the effects can be worse since it occurs so early in life, and the late effects from the disease and treatments can last a lifetime.

The largest share of funding for late-stage drug development for adult cancers typically comes from private industry. However, because the patient population for childhood cancers is much smaller and any drugs developed would have fewer customers, there isn't the same financial incentive for private companies to invest in pediatric research. This means that childhood cancer research and drug development are more dependent on the federal government and philanthropies than is the case for adult drugs.

While significant progress has been made against certain forms of childhood cancer, advances in other types have been absent. Most survivors of childhood cancer develop chronic conditions or have experienced a severe or life-threatening condition due to their treatment.<sup>2</sup> Some childhood cancers have no treatment options and remain incurable. Further actions need to be taken by the White House and Congress to develop new treatments and improve the quality of life for children with cancer.

### Cancer Moonshot

As part of his renewed Cancer Moonshot initiative, President Biden has set the goal of reducing cancer deaths by 50% by 2050. The American Cancer Society (ACS) and The American Cancer Society Cancer Action Network (ACS CAN) are committed to helping achieve that goal by working to improve the lives of people with cancer and their loved ones. In February 2023, the White House unveiled a partnership between National Cancer Institute (NCI), the ACS and other partners to bring patient navigation services to families facing pediatric cancer. The partnership, *Childhood Cancer – Data Integration for Research, Education, Care, and Clinical Trials (CC-DIRECT)*, will help connect patients to clinical trials, promote access to patient navigation services, and support patient data access.

### Appropriations

ACS CAN has been involved in a number of significant successes for childhood cancer appropriations including The Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act and Childhood Cancer Data Initiative (CCDI). The STAR Act which was signed into law in 2018 and reauthorized in 2023, increases funding for childhood cancer research, expands efforts to track childhood cancer incidences, and improves the quality of life for childhood cancer survivors. The Childhood Cancer Data Initiative (CCDI) is focused on establishing more efficient ways to share and use childhood cancer data to accelerate the development of new treatments.

**Because childhood cancer research is so dependent on federal dollars, ACS CAN leads the fight for regular, significant funding increases for the National Institutes of Health, the National Cancer Institute, and the Centers for Disease Control and Prevention and ensuring full funding for the STAR Act and CCDI.**

<sup>1</sup> American Cancer Society. Cancer Facts & Figures 2023. Atlanta: American Cancer Society; 2023

<sup>2</sup> Bhakta, Nickhill, et al. "The Cumulative Burden of Surviving Childhood Cancer: An Initial Report from the St Jude Lifetime Cohort Study (SJLIFE)." *The Lancet*, vol. 390, no. 10112, 2017, pp. 2569–2582.