

Federal Funding for Childhood Cancer Programs

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.¹ While significant progress has been made against certain forms of childhood cancer, advances in other types have been absent. Most survivors of childhood cancer also develop chronic conditions or have experienced a severe or life-threatening condition due to their treatment.² Progress in improving childhood cancer outcomes relies on regular, federal investment in childhood cancer research, including continued funding for the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act and Childhood Cancer Data Initiative (CCDI).

Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act

The STAR Act, first signed into law in 2018 and reauthorized in 2023, is the most comprehensive childhood cancer bill passed by Congress. This legislation increases opportunities for childhood cancer research, improves the quality of life for childhood cancer survivors, and expands efforts to track childhood cancer incidences.

- **Childhood Cancer and Survivorship Research** – The STAR Act expands efforts to collect biospecimens, clinical, and demographic information for childhood cancer patients in National Cancer Institute (NCI) clinical trials to better understand the causes of childhood cancers and the effects of treatments. Additionally, this law expands research on the late effects, including medical and psychosocial, for childhood cancer survivors and creates pilot programs to evaluate models of care for survivors. Progress to date includes support for several biospecimen research projects through the Children’s Oncology Group (COG) to collect data on rare and underrepresented childhood cancers.³
- **Tracking Pediatric Cancer** –The STAR Act authorizes grants to state cancer registries to track incidences of cancer in children, adolescents, and young adults. The grants are used to expand early reporting of childhood cancer, improve electronic reporting and infrastructure, and track the late effects of childhood cancer. Progress to date includes the expansion of the Centers for Disease Control and Prevention’s (CDC) capacity within the National Program of Cancer Registries (NPCR) to collect and make data on childhood cancer more readily available which can help improve understanding of childhood cancers, increase enrollment in clinical trials, and connect patients and families to resources.⁴

Childhood Cancer Data Initiative (CCDI)

Data, including information on diagnosis, treatment and outcomes for children and young adult cancer, is often stored across individual databases, institutions or hospitals which can make it challenging to share data to inform research. Established in 2019, the NCI Childhood Cancer Data Initiative (CCDI) is focused on establishing more efficient ways to gather, share and use childhood cancer data to learn from every child with cancer to accelerate the development of new treatments. Progress to date includes the launch of the Molecular Characterization Initiative (MCI) which provides molecular testing to children and adolescents with certain cancers to help select the most appropriate treatment options, identify potential clinical trials, and inform future research studies.⁵

ACS CAN Position

ACS CAN is urging Congress to continue to make investments in improving childhood cancer outcomes in final FY24 appropriations, including fully funding the STAR Act and CCDI at \$30 million and \$50 million, respectively, and providing the National Institutes of Health (NIH) with no less than \$47.7 billion, including \$7.38 billion for the National Cancer Institute (NCI).

¹ American Cancer Society. Cancer Facts & Figures 2023. Atlanta: American Cancer Society; 2023

² 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.

³ Childhood Cancer STAR (Survivorship, Treatment, Access, Research) Act (Public Law No: 115-180) and the Childhood Cancer STAR Reauthorization Act (Public Law No: 117-350). National Cancer Institute. Accessed at: <https://www.cancer.gov/about-nci/legislative/recent-public-laws/star-act>

⁴ Tracking Pediatric and Young Adult Cancer Cases. Centers for Disease Control and Prevention. Accessed at: <https://www.cdc.gov/cancer/npcr/pediatric-young-adult-cancer.htm>

⁵ About the Childhood Cancer Data Initiative Molecular Characterization Initiative. National Cancer Institute. Accessed at: <https://www.cancer.gov/research/areas/childhood/childhood-cancer-data-initiative/data-ecosystem/molecular-characterization>