

CHILDHOOD CANCER SURVIVORSHIP, TREATMENTS, ACCESS, AND RESEARCH ACT
“Childhood Cancer STAR Act”

TITLE I—Maximizing Research Through Discovery

Subtitle A—Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act

Section. 101. Comprehensive children’s cancer biorepositories. (Sec. 3(a) of [H.R. 2607](#) in the 113th Congress)
Authorizes the NCI to establish childhood cancer biorepositories available to health care professionals and scientific researchers.

Section. 102. Improving Childhood Cancer Surveillance. (Sec. 3(b) of H.R. 2607 in the 113th Congress)
Authorizes HHS, working through the CDC, to award grants to State cancer registries to enhance and expand infrastructure to track the epidemiology of cancer in children, adolescents, and young adults.

Subtitle B—Ensuring Pediatric Expertise at NIH

Section. 111. Inclusion of at least one pediatric oncologist on the national cancer advisory board.
Requires that at least one individual knowledgeable in pediatric oncology be included on the National Cancer Advisory Board.

Section. 112. Sense of Congress regarding pediatric expertise at the National Cancer Institute.
Expresses the sense of Congress that the Director of the NCI should ensure that all applicable study sections, committees, advisory groups, and panels at NCI include one or more qualified pediatric oncologists, as appropriate.

Subtitle C—Report on Childhood Cancer Activities

Section. 121. Reporting on Childhood Malignancy Projects.
Requires the NIH Director to report to Congress on childhood malignancy projects undertaken as part of the Pediatric Research Initiative.

TITLE II—Availability of Promising Treatments

Section. 201. Expanded Access Policy. (Sec. 2082 of the [21st Century Cures Act](#))
Requires the manufacturer or distributor an investigational drug to make publicly available their policy on evaluating and responding to patient requests for expanded access.

Section. 202. Finalizing Draft Guidance on Expanded Access. (Sec. 2083 of the 21st Century Cures Act)
Requires HHS to finalize its May 2013 draft guidance on expanded access within 1 year, and to clearly define in such guidance how it interprets and uses adverse drug event data that is reported from use of unapproved drugs through expanded access.

TITLE III—Maximizing Delivery: Care, Quality of Life, Survivorship, and Caregiver Support

Subtitle A— Childhood Cancer Survivors’ Quality of Life Act

Section 301. Cancer Survivorship Programs. (Sec. 3 of [H.R. 2058](#) in the 113th Congress)

Allows for the Secretary to make grants to eligible entities to establish pilot programs to develop, study, or evaluate model systems for monitoring and caring for childhood cancer survivors throughout their lifespan.

This section also orders the Secretary to have a meeting, within one year of this Act's enactment, to convene a Workforce Development Collaborative on Medical and Psychosocial Care for Pediatric Cancer Survivors.

Section 302. Grants to Improve Care for Pediatric Cancer Survivors. (Sec. 4 of H.R. 2058 in the 113th Congress)

Requires the Director of the NIH to make grants to entities to conduct research relating to pediatric cancer survivors.

Section 303. Comprehensive Long-Term Follow-Up Services for Pediatric Cancer Survivors. (Sec. 5 of H.R. 2058 in the 113th Congress)

Requires the Secretary to establish a task force to develop and test standards, outcomes, and metrics for quality childhood cancer survivorship care in consultation with a full spectrum of representation of experts in late effects of disease and treatment of childhood cancers.

Section 304. Cancer Survivorship Demonstration Project.

Requires the Secretary to carry out a demonstration project designed to improve the quality and efficiency of care provided to childhood cancer survivors throughout their lifespan through improved care coordination as survivors transition to adult care.

Subtitle B— Coverage and Payment of High Quality Care

Section 311. Report by the Comptroller General.

Requires the GAO to conduct a review and submit recommendations to Congress on existing barriers to obtaining and paying for adequate medical care for pediatric cancer survivors.