



# The Comprehensive Cancer Survivorship Act (H.R. 4363/S. 2213)

## Pediatric Cancer Survivorship: Addressing A Lifetime of Health Challenges

To adequately care for the estimated half-million Americans who are childhood cancer survivors, we must provide better survivorship care. By age 45, 95% of childhood cancer survivors experience a significant side effect due to toxicities from their treatment. In the 2020 GAO Report, *Survivors of Cancer: Factors Affecting Access to Follow-up Care*, the GAO highlighted that many survivors “lack basic knowledge about the need to receive follow-up care or where to seek it.” Beyond patient knowledge, the GAO also found a large knowledge gap in physicians as well. In a study of 1,500 internal medicine and family practice physicians, “a majority of these primary care providers reported that they had never utilized the guidelines published by the Children’s Oncology Group.” Caring for a child cancer survivor requires a unique skill set. Yet, the GAO found that providers “may not be familiar with caring for this population, including the care needed to monitor for late effects” and that “providers may not appropriately prioritize the need for psychosocial and palliative care.”

By promoting state innovations to ease transitions for survivors to the primary care setting, we can address many of the problems found by the GAO. This includes developing new capacities and equipping primary-care providers and patients to address the multitude of health problems faced by survivors throughout their lifetime.

## The Solution

The bipartisan Comprehensive Cancer Survivorship Act aims to address the entire survivorship continuum of care by providing for coverage of cancer care planning and coordination and survivorship transition tools, and a study into an alternative payment model for survivorship care. For childhood cancer, in particular, the legislation would improve the knowledge gap for patients, their families, and physicians, and create a demonstration model for a standard of care based on the Children’s Oncology Group guidelines. Two key provisions in the bill include:

### Section 13: Promoting State Innovations to Ease Transitions to the Primary Care Setting for Children with Cancer

This section directs the Secretary of HHS to convene a stakeholder group of representatives of childhood cancer advocacy organizations, Medicaid beneficiaries, providers with childhood cancer expertise, the National Association of Medicaid Directors, and other relevant representatives to develop best practices for States to ease the transition from active oncological care to primary care of child or adolescent with cancer. The Secretary will create a report and work with states on innovative strategies to help children and adolescents with cancer who transition from oncological care to primary care.

### Section 14: Childhood Cancer Demonstration Model and Standard of Care

This section amends the CMS demonstration authority statute where there is a list of over 25 models that CMMI is encouraged to implement by including a new Medicaid pediatric survivorship care demonstration model. The model would promote a standard of care to manage the transition of children from active oncology care to primary care through the promotion and use of survivorship care plans.

For more information, please contact:  
Steve Wosahla, [swosahla@childrenscause.org](mailto:swosahla@childrenscause.org)  
Sue Emmer, [sue@emmerconsultinginc.com](mailto:sue@emmerconsultinginc.com)

---