

The Pediatric, Adolescent and Young Adult Cancer Survivorship Research and Quality of Life Act of 2011

Introduced by Representatives Jackie Speier (D-CA) and Michael McCaul (R-TX)

Two-thirds of the 300,000 childhood cancer survivors in the United States today are likely to experience at least one late effect of treatment, and almost one-fourth will face a late effect that is serious or life-threatening. Secondary cancers, heart and lung damage, osteoporosis, financial pressures, psychosocial issues, employment and fertility problems are among the many challenges faced by childhood cancer survivors.

The Institute of Medicine (IOM) stated in its report, "Childhood Cancer Survivorship: Improving Care and Quality of Life," that an organized system of follow-up care for childhood cancer survivors is needed. The Pediatric, Adolescent and Young Adult Cancer Survivorship Research and Quality of Life Act of 2011 would establish critical programs to improve care and the quality of life for childhood cancer survivors, consistent with the recommendations of the groundbreaking IOM report.

Evaluating Models of Care. The bill authorizes the Secretary of Health and Human Services (HHS) to create pilot programs to evaluate model systems of care and identify the most effective ways to provide follow-up care to childhood cancer survivors. In addition, it would promote the development of initiatives to improve coordination and the effective transition of care between providers.

Improving Access to Care. The bill authorizes grants for research on late effects and follow-up care for childhood cancer survivors. Special emphasis is given to research on the prevalence of and risk factors associated with late effects of childhood cancer, as well as the investigation of barriers to follow-up care facing childhood cancer survivors in minority or medically underserved communities.

Clinics for Long-Term Follow-Up Services. The bill authorizes grants to eligible medical schools, children's hospitals, and cancer centers to establish and operate clinics for comprehensive, long-term, follow-up services for pediatric cancer survivors.

Workforce Development Collaborative on Psychosocial Care. The bill authorizes the Secretary of HHS to convene a workforce of cross-specialty, multi-disciplinary educators, advocates, and providers to develop workforce competencies and models in relevant psychosocial services, establish curricula for continuing education, and strengthen the emphasis on psychosocial care for childhood cancer survivors.

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