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

For the 300,000 survivors in the United States today, as many as two-thirds of these survivors 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. The Institute of Medicine (IOM) has stated that an organized system of follow-up care for childhood cancer survivors is needed. With well-designed research and focused pilot health delivery programs, we can answer questions about the best ways to address the unique needs of this population, and how to improve the quality of care and quality of life for childhood cancer survivors.

Evaluating Models of Care. The bill authorizes the Secretary to create pilot programs to explore models of care and find the best ways to provide follow-up care to childhood cancer survivors. In addition, it would promote the development of initiatives to improve care coordination and the effective transition of care between providers.

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

Improving Access to Care. The bill authorizes grants for research on follow-up care for childhood cancer survivors, including the prevalence, causes and risk factors associated with late effects, as well the causes of health disparities in childhood cancer survivorship.

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.