



Sickle Cell Disease Comprehensive Care Act

FACT SHEET

REQUEST: Cosponsor the Sickle Cell Disease Comprehensive Care Act (H.R. 1672/S. 904).

Affecting nearly 100,000 Americans, sickle cell disease (SCD) is an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle-shaped causing them to block blood and oxygen flow to the body. Individuals with SCD are living longer but unfortunately, many receive uncoordinated, inconsistent care, leading to poor clinical outcomes, avoidable complications, low quality of life, and increased costs to the healthcare system. Improving access to high-quality outpatient care will improve quality of life for individuals with SCD and reduce costs associated with visits to the emergency department (ED) and inpatient hospital stays.

A Centers for Medicare & Medicaid Services (CMS) report found that approximately 50% of individuals in the U.S. with SCD are covered by Medicaid. The Sickle Cell Disease Comprehensive Care Act directs CMS to create a demonstration program in up to 10 states to improve access to comprehensive, high-quality, outpatient care for individuals enrolled in Medicaid with SCD.

Key Components of the Legislation Include:

- ***Establishing planning grants and implementation grants to improve access to comprehensive outpatient care for individuals living with SCD.***
 - Priority given to states participating in the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection program (or precursor programs) and states with high prevalence of SCD.
 - Grant recipients required to perform an assessment of the treatment needs and gaps in care in the state for individuals with SCD and develop infrastructure to recruit and provide training to prospective providers with respect to treatment of SCD. All grantees must evaluate their programs and submit reports to CMS.
- ***Ensuring SCD patients have access to coordinated clinical, mental health, and ancillary services to address their physical, mental, and social needs.***
 - Creation and/or augmentation of multi-disciplinary care teams that include subspecialists such as hematologists.
 - Identification of best practices for improving health equity for individuals with SCD, and communication of such best practices to providers.
 - Guaranteeing access to primary and preventive services, including reimbursement for care coordinators, community health workers, and other non-traditional service providers.
 - Development of individualized, comprehensive, patient-centered care plans.
- ***Participating states would receive federal medical assistance percentage (FMAP) equal to 100% for providing medically necessary services to treat SCD patients cared for under the program.***

For additional information or to cosponsor the legislation in the House, please contact:

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