



H.R.6216/S.3389 Sickle Cell Disease Comprehensive Care Act

FACT SHEET

Request: Co-sponsor H.R. 6216/S. 3389, which direct the Centers for Medicare and Medicaid Services (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 sickle cell disease.

Sickle cell disease (SCD) is an inherited, lifelong disorder affecting nearly 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped causing them to block blood and oxygen flow to the body. SCD complications include severe pain, stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and in some cases premature death. A Centers for Medicare and Medicaid Services (CMS) report found that approximately 50% of the U.S. SCD population are covered by Medicaid.

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.

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, including recommended clinical, mental health, ancillary, and support services, 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 would be given to states which participate 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 would be 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 prospective providers and provide training and technical assistance to providers with respect to treatment of SCD. All grantees must evaluate their programs and submit reports to CMS.
- Ensuring coordination of, and access to, clinical, mental health, and ancillary and support services to address the physical, mental, and social needs of individuals with SCD. This includes coordination of and access to services provided by subspecialists, including hematologists, needed to treat the many complications of SCD, as well as access to supportive clinical services, including vision and dental care, mental health services, and substance use disorder treatment, and access to transportation, and community and social support services.
- Participating states would receive federal medical assistance percentage (FMAP) equal to 100% with respect to amounts expended for medical assistance for 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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