Federal Sickle Cell Disease Legislation (September 2023)

SICKLE CELL DISEASE
PARTNERSHIP

Sickle cell disease (SCD) is an inherited blood disorder that disproportionately affects approximately 100,000 Black and Latino Americans. For far too long, individuals with SCD have lacked consistent access to high-quality, comprehensive care and treatment. Below is information on current legislative priorities related to ensuring individuals with SCD have access to timely, comprehensive, quality health care and treatments.

Comprehensive Care	Workforce	Expiring Program and Funding	Public Health
The Sickle Cell Disease Comprehensive Care Act (118th , S.996, H.R.1672)	**The Sickle Cell Care Expansion Act** (118th , S. 1423, H.R. 3100)	**The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023** (118th, H.R. 3884 , S. 1852)	**The Sickle Cell Disease Treatment Centers Act** (117th, S.4866, H.R. 8855)
This bill would direct CMS to create an SCD Medicaid demonstration program in up to 10 states that would: • Improve patient access to services and therapies; • Help reduce ED visits and inpatient hospital costs; • Support and improve the transition from pediatric to adult care; • Provide support to community-based organizations and other stakeholders; • Promote coordination through multidisciplinary teams; and • Develop infrastructure to recruit providers and provide specialized training.	• This bill would strengthen the medical workforce that treats SCD by creating a scholarship and loan repayment program within the Health Resources and Services Administration at HHS to incentivize clinicians to enter into the field of SCD care.	• This bill would the reauthorize the Health Resources and Services Administration (HRSA) SCD Treatment Demonstration Program FY 2023. • The Program is focused on improving care for persons with SCD by increasing access to care providers and knowledge of treatment options. • The 2018 law (P.L. 115—327) reauthorized the SCDTDP *through 2023*. • Without reauthorization, patient access to professionals specifically trained to provide this specialized care will be limited, potentially resulting in worse patient outcomes.	• This bill would establish infrastructure of SCD centers that serves patients in need and is *not* focused solely on patients enrolled in Medicaid. • Specifically, the bill would establish a nationwide network of more than 120 SCD Treatment Centers based on a hub-and-spoke framework and provide support for 100 community-based organizations.

If you are a member of Congress or work for a member of Congress, we encourage you or your boss to sponsor this critical legislation to improve the lives of those with SCD.

To learn more about the SCD Partnership and our efforts, please visit us at SickleCellPartnership.org.