SICKLE CELL DISEASE
PARTNERSHIP

Sickle Cell Disease Congressional Action Plan

The Partnership's 2023 legislative Policy Plan for sickle cell disease (SCD) is built on several pillars.

Medicaid	Public Health	Workforce	Expiring Program and Funding
The Sickle Cell Disease Comprehensive Care Act (118th, S.996, H.R.1672)	**The Sickle Cell Disease Treatment Centers Act (117th, S.4866, H.R. 8855)**	**The Sickle Cell Care Expansion Act (117th, S.4425, H.R. 7177)**	**Extend the 2018 Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act (Public Law 115-327)**
This bill authorizes the federal government to establish a demonstration program in up to 10 states to provide comprehensive care to Medicaid SCD beneficiaries. Specifically, the bill will: • Improve patient access to services and therapies needed to treat SCD including clinical, mental health, and ancillary and support services • Promote coordination through multidisciplinary teams and access to services provided by subspecialists • Utilize enhanced outpatient & preventative care services to reduce emergency department visits and inpatient hospital costs. • Provide support to community-based organizations, community health centers, hospitals, and academic health centers • Develop infrastructure to recruit providers and provide specialized training	The bill would address the unmet needs of patients with SCD, sickle cell trait (SCT), and other heritable blood disorders through the establishment of and funding for a nationwide system of treatment centers as well as much needed provider and patient training and education resources. Specifically, the bill will: • This bill establishes a nationwide network of more than 120 Sickle Cell Disease Treatment Centers based on a hub-and-spoke framework and provides support for 100 community-based organizations. • This bill also creates a National/Regional Coordinating Center to coordinate the National Sickle Cell Disease Treatment Center Program.	This bill would authorize a scholarship and loan repayment program to incentivize medical physicians to enter into the field of SCD research and treatment. Specifically, the bill will: • Expand the National Health Service Corps to provide scholarships and loan repayment assistance for those studying benign hematology; • Provide for the creation of competitive grants that would increase awareness about sickle cell disease and the resources available to those with SCD; and • Build on the House version by funding grants to hospitals that offer comprehensive sickle cell care to further fund support services, including mental health, for young adults ages 18-29 transitioning from pediatric to adult care.	Passed by Congress on a bipartisan basis in 2018, The Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act (Public Law 115-327) included two important provisions: • The law established the CDC SCD data collection program to expand state public health surveillance and support a national longitudinal registry. In their FY 2021 Congressional Justification, the CDC estimates that an annual investment of $25 million is needed to implement this SCD surveillance provision. • The law reauthorized the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) to help coordinate service delivery for individuals with SCD, train health professionals, and provide access to genetic counseling and testing. An annual appropriation of $15 million is needed to conduct this program.

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