# The Sickle Cell Disease Treatment Centers Act of 2022 (H.R. 8855/S. 4866)

Approximately 100,000 Americans are currently living with sickle cell disease (SCD), an inherited blood disorder that causes pain, infection, and stroke. The disease disproportionately affects Black Americans but is found among people from different racial and ethnic backgrounds, occurring in approximately one in every 365 Black or African American births and one out of every 16,300 Hispanic American births.

Despite the need for consistent and coordinated treatment, few patients with SCD have access to multidisciplinary care teams. The life expectancy of a patient with SCD is 45, which is 25 to 30 years shorter than the rest of the population, due, at least in part, to limited access to specialized care. Newborns are routinely screened for sickle cell disease at birth, but many of their health care providers lack the knowledge and resources to address patients' unique health challenges over the course of their life.

In addition, as many as 1.5% of babies born in the United States have sickle cell trait, which means they have one sickle cell gene and one normal gene. Americans with sickle trait may experience some complications of SCD and may pass sickle cell trait or SCD on to their children. Yet many Americans who may have sickle cell trait do not know they have it or do not have access to counseling, and, as a result, may not receive the care they need to respond to these potential complications.

Funding for education and treatment for SCD and sickle cell trait is extremely limited compared to other disabling chronic diseases.

The **Sickle Cell Disease Treatment Centers Act of 2022** (H.R. 8855/S. 4866) would address the unmet needs of patients with SCD, sickle cell trait, and other heritable hemoglobinopathies 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.

Key provisions of the bill include:

- ***National Sickle Cell Disease Treatment Center Program*.** The program would include a nationwide network of more than 120 Sickle Cell Disease Treatment Centers based on a hub-and-spoke framework to treat patients with SCD or other hemoglobinopathies as well as 100 community-based organizations to support patients, families, and communities to provide training and education to providers, patients, and families
- ***National Coordinating Center*.** The Center would coordinate the National Sickle Cell Disease Treatment Center Program infrastructure, collect, coordinate, monitor, and distribute data, best practices, and findings regarding the activities funded by the grants, and develop educational materials, public awareness campaigns, or other outreach programs, and submit a report to Congress regarding the effectiveness of the Centers.
- ***Funding*.** Authorizes $535,000,000 for fiscal year 2023 and each fiscal year thereafter

## Request: Co-sponsor the Sickle Cell Disease Treatment Centers Act of 2022 (H.R. 8855/S. 4866)

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