Sickle Cell Disease Treatment Centers Act of 2022

Frequently Asked Questions

1. How is this legislation different than the Sickle Cell Disease Treatment Demonstration Program?

It dramatically expands access to specialized sickle cell disease (SCD) care, improves data collection and research, and supports education and assistance for patients, families, providers, and communities.

2. The legislation's $535 million is a significant funding request. What is the basis for the figure?

- Patients with SCD, health care providers, community-based organizations, and others with expertise in sickle cell disease and sickle cell trait convened to determine the funding amount that would be required to meet the needs of patients. The $535 million figure reflects a state-by-state breakdown of the need plus estimated costs.

- Funding for research and treatment of SCD and sickle cell trait is extremely limited compared to that for other diseases. For example, there are stark disparities between the funding and treatment resources dedicated to SCD and to hemophilia.

  SCD
  - Number of Americans diagnosed (estimated)[1]: 100,000
  - Number of federally-funded treatment centers[2]: 0

  Hemophilia
  - Number of Americans diagnosed (estimated)[3]: 33,000
  - Number of federally-funded treatment centers[4]: 130

- Currently, the majority of federal funding dedicated to SCD and sickle cell trait treatment and education is provided through an annual appropriation under the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018. Both the FY21 and FY 222 appropriations provided $7,205,000 for activities authorized under this law. The Centers for Disease Control and Prevention (CDC) also has limited resources for sickle cell data collection. While these programs are important, this funding is inadequate to support the direct care necessary to ensure the well-being

[1] CDC, Data & Statistics On Sickle Cell Disease, https://www.cdc.gov/ncbddd/sicklecell/data.html (last reviewed Dec. 16, 2020).
[2] HRSA, *Sickle Cell Disease Treatment Demonstration Program*, https://www.hrsa.gov/grants/find-funding/hrsa-21-032 (last accessed Mar. 8, 2022).
[3] CDC, What is Hemophilia?, https://www.cdc.gov/ncbddd/hemophilia/facts.html (last reviewed July 17, 2020).
[4] LaTasha Lee, et al., *Reducing Health Care Disparities in Sickle Cell Disease: A Review*, 134 Pub. Health Rep. 599 (Oct. 10, 2019), *available at* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6832089/

of most Americans living with sickle cell disease, sickle cell trait, and other heritable hemoglobinopathies.

3. How is this legislation different than H.R.6216/S.3389, The Sickle Cell Disease Comprehensive Care Act?

The two bills are complimentary because they have similar goals but use different mechanisms to support patients and providers. Notably, the Sickle Cell Disease Comprehensive Care Act proposes a new, five- year demonstration project offering grants to a limited number of states to improve outpatient care for Medicaid beneficiaries with sickle cell disease. In contrast, the Treatment Centers Act would establish grants offered to eligible treatment centers nationwide, through a hub and spoke model, that will be accessible to all patients.

Additional information on H.R.6216/S.3389, The Sickle Cell Disease Comprehensive Care Act, is available at https://www.hematology.org/advocacy/sickle-cell-disease-advocacy

4. What is meant by a "hub and spoke" framework?

The legislation funds a network of health care delivery sites across the nation to help provide care for individuals with SCD. These sites use a 'hub and spoke model." The hub and spoke framework is a framework for delivery of health care services in which a medical hub and community hub co-manage a community-based health care network of 'spokes', or other subsidiary entities, to provide comprehensive SCD care. Subsidiary entities serving as spokes may initially provide more limited sickle cell disease care services and may evolve into hubs and connect with new spokes.

The term 'medical hub' means a hospital, clinic, or university health center that has an outpatient treatment clinic, an infusion center, telehealth capability, and a history of serving individuals living with SCD.

The term 'spoke' means a federally qualified health center, a Federally qualified health center look-alike, or a hospital, clinic, or university health center that provides clinical care and has telehealth capability.

5. How does the legislation ensure that the treatment cites (hubs or spokes) are in the "right" places, e.g., established in areas that have a sufficient concentration of individuals with SCD, and are accessible to such individuals?

The legislation requires grants to focus on regions where a disproportionate number of patients with SCD or other heritable hemoglobinopathy patients per capita reside, and with the intention of awarding grants nationwide so that patients can access more comprehensive SCD treatment services no matter where they reside.

6. What types of services will the medical hubs, community hubs, and spokes provide?

The types of services will vary based on which entity is providing them. Examples of each include:

Community Hub:

- Education and outreach
- Testing or coordinate testing for sickle cell conditions

Medical Hub:

- Educate providers on treatment standards and protocols
- Provide the approved standards of care as detailed in widely acceptable guidelines
- Coordinate specialty care services, whether provided at the hub or spoke

Spoke:

- Provide the approved standards of care for patients
- Provide primary care services and/or specialty care
- Provide medical and surgical treatment

7. To what degree does this legislation create new "bricks and mortar" delivery sites, vs. build on a current network of health care providers who can expand their ability to help patients?

The intent of the legislation is to build upon the current network of providers and expand their reach and ability to meet the needs of patients.