Protect Federal Sickle Cell Disease (SCD) Programs

Advocacy Days, 2025

Maintain critical federal programs: Sickle Cell Data Collection Program, Sickle Cell Disease Treatment Demonstration Program and Sickle Cell Disease Newborn Screening Follow Up Program

Co-sponsor H.R. 1796/S. 735, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act

The **Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection (SCDC) Program** collects data on individuals living with SCD in 16 states (AL, AZ, CA, CO, FL, GA, IN, MI, MN, NC, NJ, RI, TN, TX, WI), which represents about half of the U.S. sickle cell population. The program collects data to better understand where individuals with SCD are living, how they access health care, or what might be preventing them from accessing care. Ultimately, this information is used to help improve access to care, thereby decreasing costs for the health care system as a whole.

- *As a result of the April 1 reductions in force, the CDC SCDC Program, which has traditionally been housed under the CDC's Division of Blood Disorders and Public Health Genomics, was left with no staff. The Administration has proposed moving the SCDC Program to the new Administration for a Healthy America (AHA). We call on Congress to ensure this program is maintained.*

The **Health Resources and Services Administration's (HRSA)/Maternal and Child Health (MCH) Sickle Cell Disease Newborn Screening Follow Up Program** funds 25 SCD community-based organizations (CBOs). Through the program, SCD CBOs provide services, such as educational and social support services, to individuals living with sickle cell disease.

The **HRSA/MCH Sickle Cell Disease Treatment Demonstration Program (SCD TDP),** originally created by Congress in 1972 and reauthorized as recently as 2018, funds five comprehensive SCD centers that provide care directly to people in their region and award subgrants to additional SCD centers using a hub-and-spoke model. The SCD TDP aims to increase the number of clinicians and other health professionals specializing in SCD care, improve the quality of care provided to individuals living with SCD and improve care coordination with other providers.

- *The Administration's budget incorporates some MCH programs into the new AHA and states that others will be eliminated. It does not provide details on the future of the SCD HRSA programs. We ask Congress to maintain these programs at their current funding levels, $7 million and $8.205 million, respectively.*
- **Co-Sponsor:** The **Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act (H.R. 1796/S. 735)** is bipartisan legislation which would reauthorize the HRSA Sickle Cell Disease Treatment Demonstration Program for an additional five years and provide authority for CBO services and for data collection. This authorization is critical for the continued funding of the programs.

To co-sponsor, please contact Meghan McCully with Sen. Scott (Meghan_mccully@scott.senate.gov), Nadia Laniyan with Sen. Booker (nadia_laniyan@booker.senate.gov), Shiraz Baig with Rep. James (shiraz.baig@mail.house.gov) or Caleb Gilchrist with Rep. Davis (caleb.gilchrist@mail.house.gov).

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