

August 22, 2023

The Honorable Kay Granger
Chair
House Appropriations Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Patty Murray
Chair
Senate Appropriations Committee
U.S. Senate
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Susan Collins
Vice Chair
Senate Appropriations Committee
U.S. Senate
Washington, DC 20510

Dear Chair Granger, Chair Murray, Ranking Member DeLauro, and Vice Chair Collins:

The Sickle Cell Disease Partnership (“The Partnership”) is a multi-sector public policy and advocacy alliance of more than a dozen healthcare organizations working together to advance federal policies to improve the lives of Americans with sickle cell disease (SCD) – a rare, genetic blood disorder that primarily impacts Black Americans and Hispanic Americans.¹ SCD causes a myriad of debilitating acute and chronic health issues and severely impacts quality of life.²

As you work to finalize the fiscal year 2024 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) appropriations bill, the Partnership urges you to adopt the funding levels for the SCD programs included in the Senate Appropriations Committee approved FY 2024 Labor-HHS bill, which invests in SCD research, data, and improvements in access to high-quality comprehensive care.³ For far too long, individuals with SCD have lacked consistent access to high-quality, comprehensive care and treatment. Additionally, data collection and research efforts have been under resourced, compared to other rare diseases.

The Senate Appropriations Committee appropriated \$8 million to the Sickle Cell Anemia Demonstration Program in its FY 2024 Labor-HHS bill. *The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018* (P.L. 115—327)⁴ reauthorized the SCD Treatment Demonstration Program (SCDTDP) to help coordinate service

¹ The Partnership is comprised of sickle cell disease patient and community organizations, healthcare providers who have experience caring for sickle cell patients, manufacturers of medical products, health plans, researchers, and others interested in improving the lives of patients living with sickle cell disease.

² [https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20\(SC T\)](https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20(SC T)).

³ https://www.appropriations.senate.gov/imo/media/doc/fy24_lhhs_bill_text.pdf

⁴ <https://www.congress.gov/115/plaws/publ327/PLAW-115publ327.pdf>

delivery for individuals with SCD, train health professionals, and provide access to genetic counseling and testing. The Partnership is pleased that the Senate has maintained funding for the demonstration program. Such funding would allow continued efforts to accelerate the identification and implementation of best practices and procedures for SCD care. Without level funding as provided in the Senate bill, patient access to professionals specifically trained to provide this specialized care will be limited, potentially resulting in worse patient outcomes.

Additionally, the Senate Labor-HHS bill includes \$6 million to the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection program. The 2018 law (P.L. 115—327) also authorized the CDC, through the Sickle Cell Data Collection program, to award grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience.⁵

Currently, 11 states, which account for an estimated 35 percent of the population of Americans living with SCD,⁶ participate in the program, with data being collected from multiple sources. With \$6 million, the CDC would be able to maintain the program in the 11 participating states and add one new state to support data collection efforts in 12 states total. Should funding be cut, the CDC will not be able to maintain this effort, undermining efforts to target resources to the patients who need it most.

The Partnership urges you to include the Senate Appropriations Committee approved SCD program funding levels in the final FY 2024 Labor-HHS bill to support the delivery of care and resources this vulnerable patient population requires. We welcome the opportunity to serve as a resource to federal policymakers as they evaluate and advance policies that support individuals with SCD. Should you have any questions, please contact Clay Alspach at clay.alspach@leavittpartners.com or Josh Trent at josh.trent@leavittpartners.com.

Sincerely,

The Sickle Cell Disease Partnership



cc: The Honorable Robert Aderholt, Chair, House Labor-HHS Subcommittee
The Honorable Tammy Baldwin, Chair, Senate Labor-HHS Subcommittee
The Honorable Shelley Moore Capito, Ranking Member, Senate Labor-HHS Subcommittee

⁵ <https://www.congress.gov/115/plaws/publ327/PLAW-115publ327.pdf>

⁶ <https://www.hematology.org/-/media/hematology/files/advocacy/ash-cdc-data-collection-fact-sheet-fy-2023.pdf>