



June 14, 2023

The Honorable Bernie Sanders  
Senate Committee on Health,  
Education, Labor and Pensions  
United States Senate  
Washington, DC 20510

The Honorable Bill Cassidy, M.D.  
Senate Committee on Health, Education,  
Labor and Pensions  
United States Senate  
Washington, DC 20510

## **The Sickle Cell Disease Partnership Applauds Recently Introduced *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023***

Dear Chairman Sanders and Ranking Member Cassidy, M.D.,

The Sickle Cell Disease Partnership (“The Partnership”) is a multi-sector collaboration 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 disproportionately impacts Black Americans and Hispanic Americans.<sup>1</sup> SCD causes a myriad of debilitating acute and chronic health issues and severely impacts quality of life.<sup>2</sup>

The Partnership applauds Senators Tim Scott (R-SC) and Cory Booker (D-NJ) for introducing the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023* in the Senate ([S.1852](#)) and applauds the HELP Committee for including the bill in its markup. This bill reauthorizes the critically important Health Resources and Services Administration (HRSA) Sickle Cell Disease Treatment Demonstration Program (SCDTDP) beyond FY2023, through 2028. SCDTDP is a HRSA grant program aiming to:

- (1) increase the number of clinicians knowledgeable about SCD care,
- (2) improve the quality of care provided to individuals with SCD,
- (3) improve care coordination with other providers; and
- (4) developing best practices for coordination of services during pediatric to adult transition.

For far too long, individuals with SCD have lacked access to high-quality, comprehensive care and treatment and data collection and research efforts have been inadequate, compared to other rare diseases. Throughout its existence, the centers involved in the SCDTDP have made progress in improving SCD care across the nation; however, without reauthorization, this progress may come to a halt. The

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<sup>1</sup> 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.

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

Partnership strongly supports the SCDTDP program and encourages lawmakers to reauthorize the SCDTDP at the appropriated level.

While the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023* marks a tremendous step forward in Congress' commitment to SCD, the Partnership encourages the Committee to consider additional actions that are necessary to support the SCD population. One of these actions includes providing adequate funding to the Centers for Disease Control and Prevention (CDC) SCD data collection program. Through its SCD data collection program, the CDC awards 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. Currently, 11 states participate in the program, with data being collected from multiple sources. However, these 11 states only account for an estimated 35 percent of the population of Americans living with SCD. The Partnership supports authorizing \$25 million for the CDC to continue to support data collection efforts in all of the states participating in the program and expand the program to additional states, with the goal of covering the majority of the SCD population in the next few years.

The Partnership supports this legislation and encourages lawmakers to reauthorize the SCDTDP at the appropriated level. The Partnership looks forward to working with Senators Scott and Booker, as well as other SCD Congressional champions, as they work to advance the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023* in Congress. Should you have any questions, please contact Clay Alspach at [clay.alspach@leavittpartners.com](mailto:clay.alspach@leavittpartners.com) or Josh Trent at [josh.trent@leavittpartners.com](mailto:josh.trent@leavittpartners.com).

Sincerely,

The Sickle Cell Disease Partnership

