



June 14, 2023

The Honorable Cathy McMorris Rodgers  
Chair  
Subcommittee on Health  
House Energy and Commerce Committee  
United States House of Representatives  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member  
Subcommittee on Health  
House Energy and Commerce Committee  
United States House of Representatives  
Washington, DC 20515

## **Statement for the Record on “Examining Proposals that Provide Access to Care for Patients and Support Research for Rare Diseases”**

Dear Chair Rodgers and Ranking Member Eshoo,

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 the Committee for holding this hearing on providing access to care for patients and supporting research for rare diseases. 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.

The Partnership also applauds Representatives Burgess, Davis and Carter for their recent introduction of the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023* ([H.R. 3884](#)) and applauds the Committee for including this bill in the hearing discussion. 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.

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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).)

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 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.

In addition to timely reauthorization of the SCDTDP and adequately funding the CDC SCD data collection program, Congress also must enact the following SCD-related pieces of legislation:

- **Sickle Cell Disease Comprehensive Care Act (S.904, H.R.1672)**. This bill authorizes the federal government to establish a demonstration program in up to ten states to provide comprehensive care to Medicaid SCD beneficiaries.
- **The Sickle Cell Care Expansion Act (S.1423, H.R.3100)**. This bill would authorize a scholarship and loan repayment program to incentivize medical physicians to enter into the field of SCD research and treatment.

By reauthorizing the SCDTDP and enacting the legislation, Congress will have taken the steps necessary to ensure individuals with sickle cell disease in the United States have the timely, sustained access to high-quality, equitable, coordinated care and treatment that they deserve.

We look forward to working with you, other Energy and Commerce Committee members, and our Congressional champions on this issue. 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). Thank you.



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