



April 18, 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 Existing Federal Programs to Build a Stronger Health Workforce and Improve Primary Care”

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 affects Black Americans and Hispanic Americans.¹ SCD causes a myriad of debilitating acute and chronic health issues and severely impacts quality of life.² Unfortunately, individuals with SCD in the United States (U.S.) continue to face severe gaps in accessing high-quality, equitable, coordinated care and treatment. We believe Congress must take these actions now to reauthorize existing demonstration and data collection programs as well as establish new federal programs to support the delivery of comprehensive care and the workforce required to deliver this care to the SCD community.

Specifically, Congress must:

- 1. Reauthorize and appropriate adequate funding to the Health Resources and Services Administration (HRSA) Sickle Cell Disease Treatment Demonstration Program (SCDTDP) beyond fiscal year (FY) 2023.** The 2018 law (P.L. 115—327) reauthorized the SCDTDP through 2023. The 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) develop best practices for coordination of services during pediatric to adult transition.

“The time for Congress to act is now. For too long, our nation’s efforts to address this painful, debilitating disease have been woefully inadequate, leaving patients and families behind – without access to high-quality care....”³

Dr. Brett Giroir, Former Assistant Secretary of HHS and Senior Advisor to the Partnership

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

³ <https://www.sicklecellpartnership.org/sickle-cell-disease-partnership-calls-for-passage-of-key-legislation/>

- 2. Reauthorize and appropriate adequate funding to the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) program.** The 2018 law (P.L. 115—327) authorized the CDC through its SCD 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. 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 strongly supports reauthorizing and providing the CDC with additional funding to allow 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.
- 3. Enact the following SCD-related pieces of legislation:**
- a. Sickle Cell Disease Comprehensive Care Act (118th, [S.996](#), [H.R.1672](#)).** This bill authorizes the federal government to establish a demonstration program in up to ten states to improve access to comprehensive care, high-quality, outpatient care for Medicaid SCD beneficiaries. Specifically, this bill would help address workforce-shortage related issues by:
 - i. Creating and/or augmenting multi-disciplinary care teams that include subspecialists such as hematologists.
 - ii. Identifying best practices for improving health equity for individuals with SCD, and communicating best practices to providers.
 - iii. Guaranteeing access to primary and preventive services, including reimbursement for care coordinators, community health workers, and other non-traditional service providers.
 - b. Sickle Cell Treatment Centers Authorization Act (117th, [S.4866](#), [H.R.8855](#)).** The bill would address the unmet needs of patients with SCD, sickle cell trait (SCT), and other heritable blood disorders through the establishment of, and funding for, a nationwide system of treatment centers as well as much needed provider and patient training and education resources.
 - c. The Sickle Cell Care Expansion Act (117th, [S.4425](#), [H.R.7177](#)).** 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 and appropriating adequate funding to the SCDTDP and SCDC programs and enacting these pieces of legislation, Congress will have taken the steps necessary to ensure individuals with SCD in the U.S. 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 or Josh Trent at josh.trent@leavittpartners.com.

Sincerely,

The Sickle Cell Disease Partnership



Partnership Members

American Academy of Pediatrics

American Society of Hematology

AmeriHealth Caritas

Beam Therapeutics

Black Women's Health Imperative

bluebird bio

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Learn about our work at: SickleCellPartnership.org

