SICKLE CELL DISEASE
PARTNERSHIP

Via Electronic Submission

August 26, 2025

Dr. Susan Monarez
Director
Centers for Disease Control and Prevention
U.S. Department of Health and Human Services
1600 Clifton Road NE
Atlanta, GA 30329-4027

Dear Dr. Monarez,

The Sickle Cell Disease Partnership (Partnership) congratulates you on your confirmation as Director of the Centers for Disease Control and Prevention (CDC) and looks forward to working with you to support individuals with Sickle Cell Disease (SCD). The Partnership[i] is a public policy and advocacy collaboration of patient advocates, health care providers, biopharmaceutical manufacturers, and other health care stakeholders committed to advancing policies that will improve the lives of those living with SCD. In 2022, the Partnership was founded under the leadership of Trump Administration former HHS Assistant Secretary for Health, Brett Giroir, M.D. The goal of the SCD Partnership is to support the SCD community in translating the Trump Administration-funded blueprint for SCD[ii] into concrete policy improvements by working with Congress and the Administration to effectuate policy and program improvements.

As you know, SCD is a chronic, debilitating disease that is also the most common inherited blood disorder in the United States.[iii] Although it is a rare disease, SCD affects approximately 100,000 Americans. Individuals living with SCD face severe health complications, including recurring and life-altering pain crises, repeat infection, acute chest syndrome, lung problems, severe and chronic pain, leg ulcers, organ damage, and stroke. Due to inadequacies in comprehensive care management, only about 1 in 4 patients with SCD receive a standard of care described in guidelines,[iv] resulting in individuals with SCD needing to visit the emergency department far more often than the average population.[v] These and other factors increase the cost of care for Americans with SCD and on the system overall. As a result of systemic inadequacies and the severity of the disease, individuals with SCD have an estimated life expectancy that is dozens of years shorter than the average life expectancy in the nation.

In support of the blueprint's recommendations and the Administration's continued focus on reducing chronic disease – including the severe health complications associated with SCD – the Partnership urges CDC to reinstate the Blood Division and support the continuation of the Sickle Cell Data Collection Program (SCDCP).

Earlier this year, CDC's Division of Blood Disorders and Public Health Genomics (DBDPHG), which administers the SCDCP, experienced significant reductions in force. The DBDPHG plays a vital role in working directly with states, patients, families, healthcare providers, and treatment centers to reduce the impact of serious blood disorders, including the SCD. As described in a letter[vi] from the American Society of Hematology, to which the Partnership and over 90 other organizations signed, the SCDCP has been critical in collecting and analyzing longitudinal data about people living in the United States with SCD. As the only national surveillance mechanism for SCD,[vii] the SCDCP currently covers 16 states (including approximately 50 percent of the SCD population in the country) and has been instrumental to ensuring individuals living with this disease receive adequate care and treatment.

The DBDPHG's sickle cell data collection, outreach, and education programs are necessary to help healthcare professionals and the state and federal governments to understand the effects of medical interventions, inform best practices for SCD, and establish cost-effective practices to improve and extend the lives of individuals with SCD.

For additional context, please reference ASH's community letter.[viii] The Partnership is also available to further discuss the importance of CDC's SCDCP. Please reach out to Advisors to the Partnership, Josh Trent (Josh.Trent@LeavittPartners.com), Clay Alspach (Clay.Alspach@LeavittPartners.com), or Liz Hassett (Elizabeth.Hassett@LeavittPartners.com) with any questions.

Sincerely,

The Sickle Cell Disease Partnership

---

[i] https://www.sicklecellpartnership.org/

[ii] https://www.nationalacademies.org/our-work/addressing-sickle-cell-disease-a-strategic-plan-and-blueprint-for-action

[iii] https://www.hematology.org/education/patients/anemia/sickle-cell-disease

[iv] https://minorityhealth.hhs.gov/news/coming-together-confront-sickle-cell-disease

[v] https://www.jscimedcentral.com/public/assets/articles/hematology-3-1037.pdf

[vi] https://www.hematology.org/newsroom/press-releases/2025/ash-and-90-organizations-call-for-hhs-to-immediately-restore-cdcs-division-of-blood-disorders

[vii] https://archive.cdc.gov/#/details?q=Sickle%20cell%20data%20sharing&start=0&rows=10&url=https://www.cdc.gov/ncbddd/hemoglobinopathies/data-reports/2018-summer/documents/sickle-cell-data-to-action-h.pdf

[viii] https://www.hematology.org/newsroom/press-releases/2025/ash-and-90-organizations-call-for-hhs-to-immediately-restore-cdcs-division-of-blood-disorders