



SCDAA's 2021 Federal Legislative Priorities

The Sickle Cell Disease Association of America (SCDAA), our partners, 53 member organizations, advocates, and clients and patients across the country respectfully request that you strongly consider the sickle cell disease (SCD) community in your work as a member of this 117th Congress. Below, we have outlined **4 priorities** for your reference, which would robustly fund the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act's (Public Law 115-327) critical provisions for research, surveillance, prevention, and treatment of SCD, as well as generate the necessary awareness and momentum in Congress for future legislative gains.

- 1. \$25 million in dedicated funding for the Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection program be included in the fiscal year (FY) 2022 appropriations bill.**
 - In their FY 2021 Congressional Justification, the CDC estimates that an annual investment of \$25 million is needed to implement the SCD surveillance provision of the 2018 SCD law.ⁱ
 - Key findings and recommendations from the NASEM report on SCD highlight the critical need to establish a national system for SCD data collection.ⁱⁱ
 - Dedicated appropriations for SCD will allow the CDC to continue and expand state public health surveillance and support a national longitudinal registry of all persons with sickle cell disease.ⁱⁱⁱ
 - **Impact:** Data collection is necessary to improve national incidence and prevalence data, better identify health disparities, and evaluate strategies to improve quality of life and lower costs associated with treating the population.
- 2. \$15 million in funding for the Sickle Cell Disease Treatment Demonstration Program (SCDTDP), which is overseen by the Health Services and Resources Administration, be included in the fiscal year (FY) 2022 appropriations bill.**
 - The 2018 SCD law reauthorized the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) to help coordinate service delivery for individuals with SCD, train health professionals, and provide access to genetic counseling and testing.
 - The reauthorization also calls for SCDTDP to develop best practices for the coordination of services for adolescents transitioning from pediatric to adult healthcare. Due to the lack of adequate protocols and care coordination, people with SCD struggle with transition to adulthood.^{iv}
 - **Impact:** Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.
- 3. Congress mandate an annual hearing on the 2020 National Academy of Science, Engineering, and Medicine's (NASEM) report, "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action," within the House Committee on Energy and Commerce, calling the following witnesses: Admiral Brett Giroir, former Assistant Secretary for Health; Ashley Valentine, Co-founder and**

President of Sick Cells; Beverley Francis-Gibson, President and CEO of SCDAAC; a NASEM staff member; a sickle cell disease patient advocate.

- Based on the NASEM report’s review of the current needs for treating SCD and input from public comments, the committee developed a strategic plan and blueprint for SCD action and identified strategies and specific actions for improving care and outcomes, including:
 - Expansion of nationwide data collection
 - Establish national registry
 - Provide clinical and nonclinical support through health programs (SSA, OMH, etc.)
 - Address disparities by reducing barriers to access care and treatment
- **Impact:** The NASEM blueprint for addressing SCD in the United States is an important milestone toward improvement. Mandating an annual hearing would enable Congress to perform oversight and ensure progress is made to improve care and outcomes for individuals with SCD.

4. Members of Congress reinvigorate and expand the Sickle Cell Caucus.

- The Sickle Cell Caucus, which was created in 2014, seeks to bring public and congressional awareness to the unique needs of the Sickle Cell Disease community – patients, physicians, scientists and industry, and to develop opportunities to address barriers in access to and development of crucial treatments.
- **Impact:** With the elections in 2018 and 2020 bringing in dozens of new elected officials, it is critical to incorporate these new members into the conversation on SCD. A Sickle Cell Caucus that meets regularly—with expanded membership—will generate and sustain the momentum necessary to address SCD through policy changes and legislation at the federal level.

Key Sickle Cell Facts

- SCD is a life-threatening, genetic disorder most common among African American and Hispanic American persons, with many acute and chronic complications requiring medical attention.
- SCD affects 100,000 people in the US.^v
- There are only 4 FDA-approved therapies available for SCD^{vi}
- Medicaid serves 42,000 beneficiaries with SCD^{vii}
- The U.S. health system spends \$2.98 billion per year on SCD^{viii}
- Structural racism and implicit bias affect the allocation of resources toward research, care delivery, and quality improvement. For example, SCD receives 7 to 11 times less funding than cystic fibrosis.^{ix}
- SCD is costly; expenditures for SCD patients are six times higher than non-SCD patients on Medicaid.^x

The contents of this document were developed in collaboration with Sick Cells



References

ⁱ Centers for Disease Control and Prevention (CDC): Justification of Estimates for Appropriations Committees Fiscal Year (FY) 2021

ⁱⁱ National Academies of Sciences, Engineering, and Medicine: Addressing Sickle Cell Disease Report 2020

ⁱⁱⁱ CDC's Sickle Cell Data Collection (SCDC) Program Report

^{iv} Health and Human Services (HHS) Roundtable on Leveraging Data to Address Sickle Cell Disease Report 2020

^v Centers for Disease Control and Prevention

^{vi} The American Society of Hematology and the Sickle Cell Disease Coalition (SCDC)

^{vii} Center for Medicaid and CHIP Services

^{viii} Value in Health: The Burden of Sickle Cell Disease

^{ix} Journal Blood 2013

^x HHS Health+ Sickle Cell Disease