

# FISCAL YEAR 2021 APPROPRIATIONS REQUEST FOR SICKLE CELL DISEASE

As you consider the appropriations bill for Fiscal Year (FY) 2021, we respectfully request that you include robust funding for the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act (Public Law 115-327) to support and expand critical initiatives for research, surveillance, prevention, and treatment of sickle cell disease (SCD).

## CDC SURVEILLANCE DATA COLLECTION PROGRAM

- 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.<sup>1</sup>
- Key findings and recommendations from the NASEM report on SCD highlight the critical need to establish a national system for SCD data collection.<sup>2</sup>
- 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.<sup>3</sup>
- **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.

FY 2021 REQUEST:

**\$25**  
MILLION

## SCD TREATMENT DEMONSTRATION PROGRAM

- 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.
- **An annual appropriation of \$5.052 million is needed to conduct this program.**
- 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.<sup>4</sup>
- **Impact:** Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.

FY 2021 REQUEST:

**\$5.052**  
MILLION

### SOURCES

- 1 Centers for Disease Control and Prevention (CDC): Justification of Estimates for Appropriations Committees Fiscal Year (FY) 2021
- 2 National Academies of Sciences, Engineering, and Medicine: Addressing Sickle Cell Disease Report 2020
- 3 CDC's Sickle Cell Data Collection (SCDC) Program Report
- 4 Health and Human Services (HHS) Roundtable on Leveraging Data to Address Sickle Cell Disease Report 2020

## SICKLE CELL FACTS

SCD AFFECTS

**100,000**

PEOPLE IN THE  
U.S.<sup>1</sup>

THERE ARE ONLY

**4**

FDA-APPROVED  
THERAPIES  
AVAILABLE.<sup>2</sup>

MEDICAID SERVES

**42,000**

BENEFICIARIES  
WITH SCD.<sup>3</sup>

THE U.S HEALTH  
SYSTEM SPENDS

**\$2.98**

BILLION  
PER YEAR FOR SCD.<sup>4</sup>

- SCD is a **life-threatening genetic disorder** most common among African American and Hispanic American persons and is associated with many acute and chronic complications requiring immediate medical attention.
- **Structural racism and implicit bias** affect the allocation of resources toward research, health care delivery, and quality improvement. For example, SCD receives 7 to 11 times less funding than cystic fibrosis.<sup>5</sup>
- **This disease is costly;** expenditures for patients with SCD are six times higher than non-SCD patients on Medicaid.<sup>6</sup>

### REFERENCES

1. Centers for Disease Control and Prevention
2. The American Society of Hematology and the Sickle Cell Disease Coalition (SCDC)
3. Center for Medicaid and CHIP Services
4. Value in Health: The Burden of Sickle Cell Disease
5. Journal Blood 2013
6. HHS Health+ Sickle Cell Disease

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