

# FEDERAL REQUESTS FOR SICKLE CELL DISEASE (FISCAL YEAR 2023)

## Request #1: Cosponsor the Sickle Cell Disease Comprehensive Care Act

## SICKLE CELL DISEASE COMPREHENSIVE CARE ACT

FY 2023 REQUEST:

# SUPPORT

## H.R. 6216/S. 3389

JOIN THE OFFICES OF:  
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REP. MICHAEL C. BURGESS  
SENATOR CORY BOOKER &  
SENATOR TIM SCOTT

- H.R. 6216/S. 3389 would establish a Medicaid demonstration program in **up to 10 states** through the Centers for Medicare and Medicaid Services (CMS).
- This demonstration program would improve access to "**comprehensive, high-quality, outpatient care**" for Medicaid beneficiaries with SCD.

This demonstration program will:

- **Improve patient access** to services and therapies needed to treat SCD including clinical, mental health, and ancillary and support services
- **Promote coordination** through multidisciplinary teams and access to services provided by subspecialists
- Utilize enhanced outpatient & preventative care services to **reduce emergency department visits** and inpatient hospital costs.
- Provide **support to community-based organizations**, community health centers, hospitals, and academic health centers
- Develop infrastructure to **recruit providers** and provide specialized training

## Request #2: Support FY 2023 Appropriations for Sickle Cell Disease

As you consider the appropriations bill for Fiscal Year (FY) 2023, 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). We thank Congress for appropriating \$2M for the CDC SCD Data Collection Program and \$5.205M for the HRSA SCD Treatment Demonstration Program in FY2021. (Funding levels for FY2022 remain undecided.)

### CDC SICKLE CELL 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 2023 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 \$15 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 2023 REQUEST:

# \$15

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#### 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

