

# United States Senate

WASHINGTON, DC 20510

June x, 2021

The Honorable Patty Murray  
Chairwoman  
Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies  
U.S. Senate Appropriations Committee  
Washington, D.C. 20510

The Honorable Roy Blunt  
Ranking Member  
Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies  
U.S. Senate Appropriations Committee  
Washington, D.C. 20510

Dear Chairwoman Murray and Ranking Member Blunt:

As you consider the Senate Labor, Health and Human Services, and Education Appropriations bill for Fiscal Year (FY) 2022, we respectfully request that you include robust funding for the implementation of the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act (P.L. 115-327), which passed the Senate unanimously in 2018.

Sickle cell disease (SCD) is a rare, inherited disorder that causes a person's red blood cells to become deformed and get stuck in their veins, blocking oxygen flow throughout the body. It is estimated that SCD affects 100,000 Americans, many of whom are African American. This devastating disease can cause serious complications, including severe pain, stroke, acute chest syndrome, and organ damage, and it often leads to premature death. Further compounding these challenges, many people living with SCD lack sufficient access to quality care and face few, if any, effective treatment options.

The Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act authorizes grants for public health activities and data collection on the health outcomes and complications of SCD and other heritable blood disorders. Enhanced data collection will prove vital as we seek to generate improved information on incidence and prevalence, as well as to better identify health disparities, assess the utilization of therapies, and evaluate strategies to prevent complications and risk factors.

In the FY 2020 appropriations legislation, Congress requested that the Centers for Disease Control and Prevention (CDC) include in its FY 2021 Congressional Justification a report on the resources the agency would require to implement this provision of the 2018 SCD law. In the Congressional Justification, the agency estimated that an annual investment of \$25 million would be needed to implement this provision. An annual investment of \$25 million would, among other things, enable the agency to:

- Conduct nationwide data collection, covering 80 percent of people with SCD in the U.S., which would then facilitate the production of national and state-based incidence and prevalence data and allow the CDC to track key health indicators and identify health disparities;

- Improve health outcomes for individuals with SCD over their lifespan by developing guidelines for screening, prevention, treatment and management of complications;
- Increase and support efforts to improve SCD-related health care, education, awareness, and systems for delivering care through policy development, community engagement, and partnerships with national and community-based organizations; and
- Support state and regional laboratories with comprehensive SCD screening beyond the newborn period, and develop training programs for implementing lab technology.

We greatly appreciate the Committee’s allocation of funding for this program for FY 2021. That said, there is still a significant unmet need for public health activities and data collection to better understand and address the long-term health outcomes, complications, and care needs of people living with SCD. **Therefore, to fully implement this provision of the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act, we respectfully request \$25 million for FY 2022.**

The 2018 law also reauthorized the Sickle Cell Disease Treatment Demonstration Program (SCDTDP) at the Health Resources and Services Administration. This program helps coordinate service delivery for individuals living with SCD, including through health professional training, genetic counseling, and testing. As a result of the SCDTDP, a number of SCD clinics have opened in areas of high need throughout the country, and hundreds of providers have received training and education on SCD. **We respectfully request \$7.205 million for this program in FY 2022.**

Thank you for your consideration of this request. We look forward to continuing to work together on improving health outcomes for individuals living with SCD.

Sincerely,

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Cory A. Booker  
United States Senator

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Tim Scott  
United States Senator