



# AMERICAN SOCIETY OF HEMATOLOGY

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October 2, 2019

The Honorable Roy Blunt  
Chairman

Appropriations Subcommittee on Labor, Health and Human Services, Education, and  
Related Agencies  
United States Senate  
260 Russell Senate Office Building  
Washington, DC 20510

The Honorable Patty Murray  
Ranking Member

Appropriations Subcommittee on Labor, Health and Human Services, Education, and  
Related Agencies  
United States Senate  
154 Russell Senate Office Building  
Washington, D.C. 20510

Dear Chairman Blunt and Ranking Member Murray,

On behalf of the American Society of Hematology (ASH), I am writing to ask your Subcommittee to make individuals living with sickle cell disease (SCD) a priority by providing dedicated funding in fiscal year (FY) 2020 for the SCD data collection program in the Centers for Disease Control and Prevention's (CDC) Blood Disorders Division. This will allow Congress to build on the momentous progress that you and your colleagues made last December by passing the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2018 (Public Law 115-327).

ASH represents more than 17,000 physicians, researchers, and medical trainees committed to the study and treatment of blood and blood-related diseases and disorders, including SCD. ASH has launched a transformative, multi-faceted, patient-centric initiative to improve outcomes for individuals with the disease, both in the United States and globally, by bringing together stakeholders in the public and private sectors committed to significantly improving the state of SCD worldwide. Since 2015, ASH has invested resources that will make a significant difference in SCD access to care, research and global issues.

As you work with your colleagues in the U.S. House of Representatives to finalize FY 2020 appropriations, we urge you to adopt the provision in the House passed Appropriations Bill that dedicates \$2 million in funding for the CDC's SCD data collection program authorized by Public Law 115-327. This provision will add critical funding to the CDC's National Center for Birth Defects and Developmental Disabilities, Public Health Approach to Blood Disorders account. This program currently oversees SCD public health surveillance in the states of California and Georgia.

I am pleased to let you know that the CDC just announced the transfer of nearly \$1.2 million in FY 2019 funding to help seven additional states develop systems to collect data on

## 2019

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on the issues faced by people living with sickle cell disease. The new funding will cover grantees in Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Virginia. These sites will spend the next year building capacity by developing and implementing strategies to collect vital information about SCD. Georgia and California will also receive part of the funds to provide technical assistants to the new states. This bridge funding is an important step toward improving and expanding the CDC's SCD data collection efforts; however, it is only limited to one year and is focused on building the framework and a road map for recipients to gather unique data and conduct in-depth analyses to better understand the needs of individuals with SCD. The \$2 million provided in the House passed FY 20 Bill will provide the dedicated funding needed to sustain and expand this important program.

The CDC estimates that SCD affects nearly 100,000 Americans; however, absent a nationwide surveillance program, we are not confident of this estimate, nor do we know where individuals with SCD live, how they receive care or if they have access to healthcare providers with expertise in SCD. Surveillance is necessary to improve understanding of the health outcomes and health care system utilization patterns of people with SCD, increase evidence for public health programs, and establish cost-effective practices to improve and extend the lives of people with SCD.

SCD is an inherited, lifelong disorder that causes a person's red blood cells to become deformed and get stuck in veins, blocking oxygen flow throughout the body. This devastating disease can cause complications including severe pain, stroke, acute chest syndrome, organ damage, and in some cases premature death. The many complications of SCD can make every stage of life extremely challenging for individuals with the disease. This is compounded by the fact that many people living with SCD are unable to access quality care and are limited by a lack of effective treatment options.

Again, as you work with your colleagues in the House to finalize FY 20 appropriations, we urge to adopt the \$2 million provided funding for the CDC's SCD data collection program in the House passed FY 20 Bill. Expansion of CDC's work in SCD will significantly help improve our understanding of the disorder and in turn, improve healthcare outcomes for individuals with SCD. Please do not hesitate to contact ASH's Senior Manager, Legislative Advocacy, Tracy Roades (202-776-0544 or [troades@hematology.org](mailto:troades@hematology.org)) if you have any questions or need any additional information.

Sincerely,



Roy L. Silverstein, MD  
President

Cc: The Honorable Richard Shelby  
The Honorable Patrick Leahy  
Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and  
Related Agencies