February 28, 2018

The Honorable Tim Scott  
United States Senate  
717 Hart Senate Office Building  
Washington, DC 20510

The Honorable Cory Booker  
United States Senate  
359 Dirksen Senate Office Building  
Washington, DC 20510

Dears Senators Scott and Booker:

On behalf of the American Society of Hematology (ASH), which 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 sickle cell disease (SCD), I am writing to extend the Society’s sincere thanks and appreciation for your introduction of the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2018. This important legislation reauthorizes SCD treatment grants awarded by the Health Resources and Services Administration (HRSA) and authorizes the Centers for Disease Control and Prevention (CDC) to award surveillance grants.

As you know, SCD is an inherited, lifelong disorder that causes a person’s red blood cells to become deformed and get stuck in blood vessels, 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.

In 2015, ASH launched a multifaceted initiative to address the burden of SCD, both in the United States and globally. Throughout the initiative, ASH has engaged a broad array of stakeholders to identify unmet medical needs for people with SCD and identify the highest priorities needed to improve outcomes for individuals with SCD. The Society issued the State of Sickle Cell Disease: 2016 Report, evaluating the disease in four priority areas - access to care, training and professional education, research and clinical trials, and global health. The report shows that significant improvements are needed across all areas and that, though patients are living longer, the system of care needs to change to ensure a better quality of life. To address these challenges, ASH launched the Sickle Cell Disease Coalition along with more than 50 other organizations to help amplify the voice of the SCD stakeholder community, promote awareness, and improve outcomes for individuals with SCD.

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. ASH believes that surveillance is essential 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.
The *Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2018* would provide CDC with the authority needed to expand its surveillance efforts currently in California and Georgia in additional states. 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. The HRSA provisions in the legislation, which reauthorizes the Sickle Cell Disease Treatment Demonstration Program (SCDTDP), are essential to continuing the Agencies important work to improve access to care and quality of care for individuals with SCD. The SCDTDP continues to yield valuable results aiming to increase the number of SCD providers and number of providers prescribing disease modifying therapies.

Thank you again for your leadership. ASH remains committed to working with you and your colleagues to alter the course of SCD and improve treatment, care, and quality of life for individuals with SCD. Please do not hesitate to contact ASH Legislative Advocacy Manager Tracy Roades (202-776-0544 or troades@hematology.org) or ASH Senior Manager of Government Relations and Public Health (202-776-0544 or skaplan@hematology.org) if you have any questions or need any additional information.

Sincerely,

Alexis Thompson, MD
President