REQUEST: Cosponsor S. 2465, the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2018, to enhance federal government activities in sickle cell disease SCD research, training and services.

**Sickle Cell Disease (SCD) and Sickle Cell Trait (SCT)**

SCD is an inherited, lifelong disorder affecting nearly 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped and causing them to get stuck in blood vessels and block blood and oxygen flow to the body. SCD complications include severe pain, stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and in some cases premature death.

Sickle cell trait (SCT) is **not** a disease. Having SCT simply means that a person carries a single gene for sickle cell disease (SCD) and can pass this gene along to their children. People with SCT usually do not have any of the symptoms of SCD and live a normal life.

**Steps Needed to Bridge the Gap in Care Through Enhanced Surveillance and Treatment**

There is a critical need to improve outcomes for patients suffering with this disease. With funding from the CDC Foundation, the Centers for Disease Control and Prevention (CDC) has established a population-based surveillance system to collect and analyze longitudinal data about people living in the U.S. with SCD. Due to limited funding, however, implementation of the program has occurred only in two states – California and Georgia (approximately 10% of the U.S. SCD population). Expanded surveillance is necessary to improve understanding of the health outcomes and health care system utilization patterns of people with SCD, to increase evidence for public health programs, and to establish cost-effective practices to improve and extend the lives of people with SCD. Given the exciting and promising new SCD research currently underway, now is the time to make the investment to ensure that patients have access to state of state-of-the-art clinical care.

Strengthening and expanding current efforts will help enable individuals living with this disease receive adequate care and treatment. Legislation has been introduced in the Senate by Senators Tim Scott (R-SC) and Cory Booker (D-NJ) – S. 2465, the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2018 – that seeks to enhance federal government activities in sickle cell disease SCD research, training and services. Specifically, the legislation reauthorizes SCD prevention and treatment grants awarded by the Health Resources and Service Administration (HRSA). These grants fund regional programs that work to improve the care of individuals with SCD by providing genetic counseling and testing, bundling technical services, training health professionals, and expanding and coordinating education, treatment, and continuity of care for individuals with SCD. The legislation also authorizes the CDC to award SCD surveillance grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and the health outcomes, complications, and treatment that people with SCD experience. Similar bipartisan legislation, sponsored by Representatives Danny Davis (D-IL) and Michael Burgess (R-TX), passed the House in February 2018.

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The American Society of Hematology (ASH) represents more than 17,000 physicians, researcher, and medical trainees committed to the study and treatment of blood and blood-related diseases. ASH members include clinicians who specialize in treating children and adults with SCD and researchers who investigate the causes and potential treatments of SCD manifestations. ASH is committed to addressing the burden of SCD and recently released a *Call to Action on SCD* along with other stakeholders, founded the Sickle Cell Disease Coalition, and a public relations campaign. ASH’s *State of SCD 2016 Report* and Report Card identified outlines the most pressing areas of need and provides a blueprint to advance these actions related to access to care, research and clinical trials, and global issues in sickle cell disease (SCD). For more information about the report, the report card and the new Sickle Cell Disease Coalition visit [www.scdcoalition.org](http://www.scdcoalition.org) and for more information on SCD visit ASH’s website ([www.hematology.org/SCD](http://www.hematology.org/SCD)).