REQUEST: Provide dedicated funding for sickle cell disease (SCD) surveillance, outreach, and education programs to the Centers for Disease Control and Prevention’s (CDC) Blood Disorders Division, within the National Center on Birth Defects and Developmental Disabilities.

Sickle Cell Disease (SCD) and Sickle Cell Trait (SCT)
Sickle Cell Disease (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. Though new approaches to managing SCD have led to improvements in diagnosis and supportive care, many people living with the disease are unable to access quality care and are limited by a lack of effective treatment options.

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.

CDC Current Activities
With funding from the CDC Foundation, 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, implementation of the program has occurred only in two states – California and Georgia (approximately 10% of the US SCD population). Data is being collected from multiple sources (newborn screening programs and Medicaid) in order to create individual healthcare utilization profiles.

Expanding CDC’s SCD Surveillance and Outreach and Education Programs
Strengthening and expanding current efforts will help enable individuals living with this disease to receive adequate care and treatment. Legislation has passed both the House and Senate that would authorize CDC to award SCD data collection 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. In the Senate, legislation introduced by Senators Tim Scott (R-SC) and Cory Booker (D-NJ) – S. 2465, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018, passed in October 2018; – similar bipartisan legislation, sponsored by Representatives Danny Davis (D-IL) and Michael Burgess (R-TX), passed the House in February 2018. Because of differences between the House and Senate bills, the House must either pass the Senate bill when Congress returns following the November elections or the House and Senate must negotiate and pass a compromised final bill before the President can sign the legislation into law.

Dedicated federal funding for CDC’s SCD Surveillance Program is necessary to allow the program to be expanded to include additional states with the goal of covering the majority of the U.S. SCD population over the next 5 years. 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 to establish cost-effective practices to improve and extend the lives of people with SCD

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)).