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 in the fiscal year 2019 Labor, HHS, Education Appropriations bill.

**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. 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. SCT is when a person carries a single gene for SCD and can pass this gene along to their children.

**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 utilizations profiles.

**Expanding CDC’s SCD Surveillance and Outreach and Education Programs**
CDC’s SCD Surveillance Program should be expanded to include additional states with the goal of covering the majority of the US 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

CDC should develop a comprehensive, national public health awareness campaign for people with SCD and sickle cell trait, their families, and the general public along with an educational campaign for the medical professionals who provide health care for people living with SCD or SCT. The goals of this effort would be to:

- Improve overall awareness of SCD and SCT and knowledge about health outcomes and understanding of the implications for family planning
- Provide educational tools for healthcare professionals to help them understand the effects of medical interventions and inform best practices for SCD