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Expand Sickle Cell Disease Efforts at CDC

FACT SHEET

Request: Provide at least $5 million in dedicated funding for the Sickle Cell Disease (SCD) Data Collection program at 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. Screening for SCT should be voluntary and should take place in a setting that ensures privacy and is performed by a knowledgeable provider who is able to offer comprehensive counseling. People with SCT usually do not have any of the symptoms of SCD and live a normal life.

CDC Current Activities and Funding History

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, full implementation of the program has occurred only in two states – California and Georgia (approximately 10% of the U.S. SCD population). In FY 2019, $1.2 million in funding was provided to help seven additional states (Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Virginia) develop systems to collect data and build needed capacity to gather vital information about SCD. Data is being collected from multiple sources (e.g., newborn screening programs and Medicaid) in order to create individual healthcare utilizations profiles. In FY 2020, HHS transferred approximately $3 million of funding to help support the expansion of this CDC program, providing support for many of the same states to begin and/or expand efforts to collect data, adding Wisconsin to the list of states with funding.

$2 million was appropriated in the FY 2021 Consolidated Appropriations Act to allow the new states to join with California and Georgia in implementing their SCD data collection programs. With the addition of these states, data is being collected on 32% of the U.S. SCD population.

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. A provision in the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (P.L. 115—327), which was signed into law in December 2018, authorizes CDC to award SCD data collection grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience.

Additional federal funding for CDC's SCD Data Collection 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 five 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 establish cost-effective practices to improve and extend the lives of people living with SCD

The American Society of Hematology (ASH) represents more than 18,000 physicians, researchers, 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. In 2015, ASH has launched a transformative, multi-faceted, patient-centric initiative to improve outcomes for individuals with SCD, 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. Visit www.hematology.org/scd to learn more about ASH's efforts to make significant a difference in SCD access to care, research, and ultimately, cure.