HEMATOLOGY

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Expand Sickle Cell Disease Data Collection Efforts at CDC

FACT SHEET

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

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:

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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.