

TALKING POINTS for EXPANDING SICKLE CELL DISEASE EFFORTS AT CDC

- **Introduce yourself and your group**
 - The constituent(s) should begin the meeting by introducing him/herself, explain where you are from, what you do, they type of research you conduct, the kinds of patients you take care of, etc., and then let the others in the group introduce themselves.
 - Ask the person you are meeting with if he/she is familiar with hematology so you can gauge how to talk about the issues. If the staff person is not familiar with hematology, you can provide some examples of hematologic diseases/disorders and the patients you treat and major accomplishments of the field; if the staff person is familiar, you can briefly share some examples of exciting areas being explored and potential treatments and cures.
- **Indicate the issue you want to discuss:**

[The constituent in each meeting should take the lead on the issues and identify some local examples or some short stories to share of why the requests are important.]

1. Sickle Cell Disease

- **REQUEST: Provide new, dedicated funding (\$1-2 million) in FY 2020 for the Sickle Cell Disease (SCD) Data Collection program in the Centers for Disease Control and Prevention's (CDC) Blood Disorders Division.**
- Begin by talking about what SCD is, who it impacts, etc. Share a story about your experience treating individuals with SCD.
 - 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.
- Explain the need for surveillance/data collection:
 - Surveillance/data collection is necessary to:
 - Identify where patients with SCD live and receive their care to better understand gaps in care
 - 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
 - With funding from the CDC Foundation, CDC has established a population-based surveillance/data collection system to collect and analyze longitudinal data on people living SCD.
 - Due to limited funding data is collected only in two states – California and Georgia (approximately 10% of the U.S. SCD population).

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- CDC's SCD Data Collection Program should be expanded to include additional states with the goal of covering the majority of the U.S. SCD population over the next 5 years.
- The *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018* (P.L. 115—327) 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 the health outcomes, complications, and treatment that people with SCD experience.
- However, in order for expanded data collection to become a reality, funding must be provided to the Division of Blood Disorders of the CDC's National Center for Birth Defects and Developmental Disabilities.
- CDC estimates that \$5 million is needed for 10 states to implement the program, but \$1-2 million will allow for the needed training and start-up costs in the first year.
- CDC has shared a list of states that are poised to start data collection efforts with grant assistance. They include:
 - Alabama
 - Indiana
 - Michigan
 - Minnesota
 - New York
 - North Carolina
 - South Carolina
 - Tennessee
 - Texas
 - Washington