

TALKING POINTS for EXPANDING SICKLE CELL DISEASE EFFORTS AT CDC

1. Funding for the Sickle Cell Data Collection Program at CDC

- **REQUEST: Provide at least \$10 million in FY 2024 for the Sickle Cell Data Collection program at the Centers for Disease Control and Prevention (CDC).**

- Begin by talking about what SCD is, who it impacts, etc. Share a story about your experience treating individuals with SCD; ask others in your group to share stories.
- 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
- In 2020, the National Academies of Sciences, Engineering, and Medicine (NASEM) released a report entitled Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action, which provides recommendations for improving health care for people in the U.S. with SCD.
 - One of the top recommendations in the report highlights the need to establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the life span.
 - The report recommends that the CDC work with all states to develop state public health surveillance systems to support a national longitudinal registry of all persons.
- CDC has established a population-based surveillance system to collect and analyze longitudinal data about people living in the U.S. with SCD.
 - Currently 11 states participate in the data collection program, with data being collected from multiple sources (e.g., newborn screening programs and Medicaid) in order to create individual healthcare utilization profiles.
 - Funding through the CDC Foundation has allowed Georgia and California to collect data since 2015.
 - Additional CDC Foundation funding, along with discretionary funding from CDC and the Department of Health and Human Services (HHS) and \$2 million in funding provided by Congress in the FY 2021 Consolidated Appropriations Act has allowed 9 additional states (Alabama, Colorado, Indiana, Michigan, Minnesota, North Carolina, Tennessee, Virginia, and Wisconsin) to begin their data collection programs.
 - These 11 states are estimated to include just over 35% of the U.S. SCD population.

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- \$6 million was provided for the program in the FY 2023 Omnibus Appropriations bill, which should allow CDC to continue its efforts in these 11 states.
 - Additional federal funding for CDC's Sickle Cell Data Collection program in FY 2024 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.
- **Wrap up the meeting**
 - Summarize what you are asking for:
 1. **Provide at least \$10 million in FY 2024 for the Sickle Cell Data Collection program at the CDC.**
 - Ask the person you are meeting with if he/she has any questions.
 - Invite the Senator/Representative to visit your institution. Let them know that you (and ASH) can be a resource!
 - Thank the person you are meeting for his/her time.