**Talking Points for Sickle Cell Disease**

**Introduce yourself and your group.**
- The constituent(s) should begin the meeting by introducing him/herself, explain where you are from, what you do, the 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.

1. Sickle Cell Disease
   - **REQUEST:** Provide dedicated funding in fiscal year (FY) 2020 for sickle cell disease (SCD) surveillance, outreach, and education programs to 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:
     - With funding from the CDC Foundation, CDC has established a population-based surveillance 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).
     - CDC’s SCD Surveillance Program should be maintained and expanded to include additional states with the goal of covering the majority of the U.S. 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

   - Explain the need for education and outreach programs:
CDC should also develop a comprehensive, national public health awareness campaign for people with SCD and sickle cell trait (SCT is when a person carries a single gene for sickle cell disease (SCD) and can pass this gene along to their children), 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

Two different versions of legislation have passed both the House and Senate (H.R. 2410/S. 2465, the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act) that 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 that people with SCD experience. The Society is currently waiting for either the House to pass the updated Senate version or a conference committee to be formed to reconcile the two bills.

However, in order for these surveillance programs to become a reality, Congress must provide the funding necessary for CDC to award the grants.