

## TALKING POINTS

### [DO NOT DISTRIBUTE]

- **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 issues 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 Medicaid Demonstration Legislation

- **REQUEST: Cosponsor the Sickle Cell Disease Comprehensive Care Act (H.R. 1672/S. 996)**
  - Begin by talking about what sickle cell disease (SCD) is, who it impacts, etc. Share a story about your experience treating individuals with SCD; ask others in your group to share stories.
  - This bipartisan legislation creates a demonstration program in up to 10 states to improve access to comprehensive, high-quality, outpatient care for individuals with SCD enrolled in Medicaid, with a focus on young adults and pregnant women.
  - Currently, many individuals living with SCD face barriers to appropriate, quality care such as a shortage of specialized providers, a lack of coordination among health care providers, and challenges relating to health insurance cost and coverage.
  - A Centers for Medicare and Medicaid Services (CMS) report found that approximately 50% of individuals living with SCD in the United States are covered by Medicaid.
  - The bill seeks to bolster access to primary and preventive services in participating states by providing reimbursement for care coordinators, community health workers, and other non-traditional service providers, with the goal of developing individual patient-centered care plans.
  - In selecting states for participation in the demonstration program, priority will be given to those states that also participate in the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection program or precursor programs, as well as states with a high prevalence of individuals living with SCD.

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- If passed, the legislation would establish full federal reimbursement for services and care coordination provided under the demonstration program.
- We believe the demo will lead to fewer emergency department visits and inpatient hospital stays, providing savings to the states that participate.
- **Wrap up the meeting:**
  - Summarize what you are asking for:
    1. **Cosponsor the Sickle Cell Disease Comprehensive Care Act (H.R. 1672/S. 996).**
  - 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.