TALKING POINTS for SICKLE CELL DISEASE

1. Sickle Cell Disease

   • REQUEST: Cosponsor legislation related to sickle cell disease.

     ➢ Begin by talking about what SCD is, who it impacts, etc. Share a story about your experience treating individuals with SCD.

       o SCD is an inherited, lifelong disorder affecting nearly 100,000 Americans.
       o 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.
       o 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.
       o 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.

     ➢ Urge the Senator/Representative to cosponsor SCD legislation:

       o In the House: H.R. 2410, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act.
       o In the Senate: Bipartisan companion legislation to H.R. 2410 that is expected to soon be introduced.

     ➢ The legislation will reauthorize SCD treatment grants award by the Health Resources and Services Administration (HRSA) and authorizes the Centers for Disease Control and Prevention (CDC) to award surveillance grants to states.

     ➢ Explain the need for surveillance:

       o With funding from the CDC Foundation, CDC has established a population-based surveillance system to collect and analyze longitudinal data on people living SCD.
       o Due to limited funding data is collected only in two states – California and Georgia (approximately 10% of the US SCD population).
       o 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.
       o 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

     ➢ ASH would like to see two provisions added to the Senate bill:

       ▪ The authorization of an HHS Interagency Working Group on SCD
       ▪ Allowing academic institutions and non-profit entities to also compete for the CDC surveillance grants authorized in the bill
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● Wrap up the meeting
  ○ Summarize what you are asking for:

    1. Cosponsor legislation related to sickle cell disease.

       Ask the person you are meeting with if he/she has any questions.

       Invite the Senator/Representative to visit your institution.

       Thank the person you are meeting for his/her time.