Hematology-Related Research Advances
REQUEST: Cosponsor the Sickle Cell Disease Comprehensive Care Act.
Affecting nearly 100,000 Americans, sickle cell disease (SCD) is an inherited, lifelong disorder, which results in
patients’ red blood cells becoming rigid and sickle-shaped causing them to block blood and oxygen flow to the
body. Individuals with SCD are living longer but unfortunately, many receive uncoordinated, inconsistent care,
leading to poor clinical outcomes, avoidable complications, low quality of life, and increased costs to the
healthcare system. Improving access to high-quality outpatient care will improve quality of life for individuals
with SCD and reduce costs associated with visits to the emergency department (ED) and inpatient hospital stays.
A Centers for Medicare & Medicaid Services (CMS) report found that approximately 50% of individuals in the
U.S. with SCD are covered by Medicaid. The Sickle Cell Disease Comprehensive Care Act directs CMS to establish
a SCD Health Home to improve access to comprehensive, high-quality, outpatient care, which will be available to
Medicaid beneficiaries with SCD in states that submit a state plan amendment (SPA).
xAllowing states to submit a SPA to establish a Health Home for patients with SCD as the single
qualifying condition.