June 28, 2016

The Honorable Andrew M. Slavitt
Acting Administrator
Centers for Medicare & Medicaid Services (CMS)
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Acting Administrator Slavitt:

We ask that the CMS-Center for Medicare and Medicaid Innovation (CMMI) develop a demonstration program with several state Medicaid programs focused on improving outpatient care for individuals with sickle cell disease (SCD) with the goal of improving routine chronic care and reducing emergency department visits and hospitalizations.

Since its establishment, CMMI has designed innovative payment models to facilitate care improvement. However, most projects have focused on common conditions found in the Medicare population and few projects have included issues or patient populations living with more rare chronic conditions largely served by states under Medicaid. SCD is a deserving candidate for a Medicaid model program.

SCD is an inherited blood disorder that affects an estimated 100,000 Americans, primarily African-Americans and Hispanics. According to the Centers for Disease Control and Prevention, they reported more than 50% of the population living with the disease is on Medicaid. In addition, many adults with SCD also qualify for Medicare, due to disability cause by severe manifestations of this disease. Most individuals with SCD live to adulthood; however, the median life expectancy for those affected by SCD is still quite young, with most individuals dying before the age of 50.

The challenge is in getting patients access to providers that understand state of the art care for SCD because of the complexities of SCD and affects multiple organ systems which, few patients have access to providers who specialize in SCD or can assume primary responsibility for a patient’s care. We believe coordinated treatment across multiple settings is essential for patients to receive adequate care.

With an annual cost of care for SCD estimated at 1.1 billion (largely borne by Medicaid and Medicare), we strongly believe that a model program to improve outpatient coordinated chronic disease care will meet the CMMI triple aim for improving patient outcomes, enhancing community health, and lowering cost. According to the Agency for Healthcare Research and Quality (AHRQ), SCD was the 5th most common discharge diagnosis for hospital “super users” for Medicaid patients under 64 and people with SCD are higher utilizers for emergency department services. We believe a model program for individuals with SCD can steer patients...
into more appropriate outpatient settings for primary and specialized care. With the recent release of NIH clinical practice guidelines in SCD (Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014), tools are in place to improve care significantly.

We ask CMMI to invest the necessary resources to test payment models to help individuals suffering from SCD and work directly with the national patient and provider organizations interested in improving care for individuals with SCD in undertaking this effort.

Thank you for your consideration.

Sincerely,

Danny K. Davis
Member of Congress

Jim Sensenbrenner
Member of Congress

Joseph P. Kennedy
Member of Congress

Maxine Waters
Member of Congress

John Conyers
Member of Congress

Sanford D. Bishop
Member of Congress

Brenda L. Lawrence
Member of Congress

Yvette D. Clarke
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Barbara Lee
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