January 26, 2026

Honorable Senator Corey Booker
306 Hart Senate Office Building
Washington, DC 20510

Re: Group Letter of Support S. 721: The Sickle Cell Disease Comprehensive Care Act

Dear Senator Corey Booker,

On behalf of the undersigned organizations, we write to express our strong support for S. 721: The Sickle Cell Disease Comprehensive Care Act. We deeply appreciate your leadership, along with your colleague Senator Tim Scott, for championing legislation that directly addresses the profound and longstanding inequities faced by individuals living with sickle cell disease (SCD).

For far too long, sickle cell care in the United States has been limited and inconsistent. SCD affects approximately 100,000 Americans, primarily those of African descent and Hispanic heritage, and is the most common inherited blood disorder. Yet historically, SCD has received far less research funding and policy attention than other genetic disorders. The consequences are stark: while advances in cystic fibrosis care have increased the average age of death from 31 to 48 years, life expectancy for those with sickle cell disease has risen by only six years, from 40 to 46.

Although individuals living with SCD are living longer, they continue to navigate a fragmented health care system where stigma, discrimination, and the dismissal of their pain too often shape their experience. These challenges contribute to delayed or missed diagnoses, mistrust in the health care system, and poorer outcomes overall. These gaps are especially severe for young adults transitioning into adult care, who often struggle to find specialists to maintain continuity of care and must rely on emergency departments to manage acute complications and pregnant women, who experience heightened risks and limited access to specialized providers.

The Sickle Cell Disease Comprehensive Care Act represents a critical step toward correcting these disparities and will improve access to high-quality, specialized care for people living with SCD by allowing states to establish a Medicaid Health Home. This model would give people living with SCD the wrap-around services they need and deserve, including a team of trusted doctors, nurses, social workers, and mental health providers, and other specialists who work together and share information, so patients get their care in a coordinated way. Our organizations have seen first-hand that with comprehensive specialty sickle cell care, lives can be changed.

By building on prior federal efforts, including the Sickle Cell Treatment Act of 2003, the 2018 SCD Research and Treatment Act, and the Sickle Cell Disease Comprehensive Care Acts of 2024, S. 721 offers a meaningful path forward for the estimated 50 percent of Americans living with SCD covered by Medicaid. This is especially important for rural communities, where shortages of SCD specialists make it difficult to meet multidisciplinary care needs. By investing in coordinated outpatient care, S. 721 offers an evidence-based solution that will improve outcomes while reducing unnecessary costs to the health care system.

We stand ready to support you in advancing the Sickle Cell Disease Comprehensive Care Act this Congress. Thank you again for your leadership and for your dedication to improving the lives of those living with this debilitating disease.

Sincerely,

LaNiece Jones
State President/CEO
BWOPA ONE
www.bwopatileleads.org