SICKLE CELL DISEASE
PARTNERSHIP

January 6, 2025

Re: HRSA Public Comment Request: Request for Information Regarding HRSA Sickle Cell Disease Programs

The Sickle Cell Disease Partnership[i] (Partnership) is a multi-sector public policy and advocacy collaboration of patient advocates, health care providers, biopharmaceutical manufacturers, and other health care stakeholders committed to advancing policies that will improve the lives of those living with Sickle Cell Disease (SCD).

As you know, SCD is the most common inherited blood disorder in the United States,[ii] affecting approximately 100,000 individuals. Individuals living with SCD face severe health complications, including recurring pain crises, infection, acute chest syndrome, lung problems, severe and chronic pain, and stroke. SCD primarily affects Black and Hispanic individuals, and individuals with SCD experience racial disparities, provider biases, and inequities in their care.[iii] Individuals with SCD ultimately have an estimated life expectancy that is 20 years shorter than the average expected life expectancy in the United States.[iv]

The Partnership is especially appreciative of the efforts of HRSA's Maternal and Child Health Bureau's efforts to address Sickle Cell Disease, including the Newborn Screening Follow-Up Program and the Sickle Cell Disease Treatment Demonstration Program. These programs are critical to identifying individuals with SCD and to establishing greater comprehensive care for the SCD population.

The Partnership urges HRSA and the Maternal and Child Health Bureau to continue to strengthen these programs focused on advancing comprehensive, coordinated, and equitable care for individuals with SCD. The Partnership looks forward to engaging in continued conversations with HRSA in 2025 to identify policy priorities and engage stakeholders across the SCD community in order to advance health care needs for individuals with SCD.

Please reach out to Advisors to the Partnership, Josh Trent (Josh.Trent@LeavittPartners.com), Clay Alspach (Clay.Alspach@LeavittPartners.com) or Liz Hassett (Elizabeth.Hassett@LeavittPartners.com), with any questions or to further discuss.

Sincerely,

The Sickle Cell Disease Partnership

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[i] https://www.sicklecellpartnership.org/

[ii] https://www.hematology.org/education/patients/anemia/sickle-cell-disease

[iii] https://pubmed.ncbi.nlm.nih.gov/36400531/

[iv] https://www.cdc.gov/sickle-cell/data/index.html