



February 29, 2024

Statement for the Record for the House Energy & Commerce Hearing on “Legislative Proposals to Support Patients with Rare Diseases”

The Sickle Cell Disease Partnership (“The Partnership”) is a multi-sector collaboration of more than a dozen health care organizations working together to advance federal policies to improve the lives of Americans with Sickle Cell Disease (SCD). The Partnership commends the House Energy & Commerce’s Health Subcommittee for holding a legislative hearing on rare disease legislative proposals and including H.R. 7432, the *Sickle Cell Disease Comprehensive Care Act* and other rare disease legislation.

SCD is a rare, genetic blood disorder that disproportionately impacts Black and Hispanic Americans.¹ SCD causes a myriad of debilitating acute and chronic health issues, severely impacting quality of life² and often leading to premature death.³ Unfortunately, individuals with SCD in the United States continue to face severe gaps in accessing high-quality, equitable, and coordinated care and treatment.

Reps. Michael Burgess (R-TX) and Danny Davis (R-IL) introduced [H.R. 7432](#) to improve access for individuals with SCD by enabling State Medicaid programs to provide comprehensive, coordinated care through a Health Home model to individuals with SCD. Health Homes are a proven care delivery model in Medicaid that have been used by states to improve quality, enhance care, and reduce unnecessary costs.⁴ Incentivizing state Medicaid programs to create Health Homes to coordinate care for individuals with SCD will help to alleviate the disparities in care that individuals with SCD have faced for far too long.

In addition to the SCD-focused legislation, the Partnership also appreciates the Committee’s consideration of the policy issues that Rep. Guthrie’s legislation, [H.R. _____](#), *Patient Access Act*, seeks to address related to the Anti-Kickback Statute. This draft legislation presents an opportunity to think about new ways to address certain social drivers of health that can be barriers for individuals with SCD receiving timely access to care.

The Partnership looks forward to working with Reps. Burgess and Davis, the Committee on Energy and Commerce, and other Members of Congress to advance and improve these important policies through the legislative process. While H.R. 7432, as drafted, takes an important step towards providing comprehensive care to individuals living with SCD, the Partnership hopes to work with the bill sponsors and the Committee to ensure all individuals in any SCD Health Home have coverage for dental, vision, and non-emergency transportation services in addition to other comprehensive care services. By advancing H.R. 7432, the *Sickle Cell Disease Comprehensive Care Act*, with these proposed changes, the Committee and Congress would take a necessary step to ensuring individuals with SCD in the United States have timely and sustained access to the high-quality, equitable, coordinated care and treatment that they deserve.

For questions, please contact josh.trent@leavittpartners.com or clay.alspach@leavittpartners.com.

¹ The Partnership is comprised of sickle cell disease patient and community organizations, healthcare providers who have experience caring for individuals with SCD, manufacturers, health plans, researchers, and others interested in improving the lives of patients living with SCD.

² [https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20\(SCT\).](https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20(SCT).)

³ [https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20\(SCT\).](https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20(SCT).)

⁴ <https://www.medicaid.gov/sites/default/files/2020-02/medicaidhomehealthstateplanoptionrtc.pdf>

Learn more about our work at SickleCellPartnership.org.

