



September 8, 2025

Statement Endorsing the House Reintroduction of the Sickle Cell Disease Comprehensive Care Act

The [Sickle Cell Disease Partnership](#) applauds Representatives Neal Dunn, MD (R-FL) and Danny Davis (D-IL) for reintroducing [H.R.5178](#), *Sickle Cell Disease Comprehensive Care Act*, in the House. Additional original cosponsors include Representatives Buddy Carter (R-GA), Shomari Figures (D-AL), Gus Bilirakis (R-FL), Julie Johnson (D-TX), Eleanor Holmes Norton (D-DC), LaMonica McIver (D-NJ), Cleo Fields (D-LA), Al Green (D-TX), Josh Gottheimer (D-NJ), Rashida Tlaib (D-MI), Hank Johnson (D-GA), Jonathan Jackson (D-IL), Donald Davis (D-NC), Darren Soto (D-FL), Nikki Budzinski (D-IL), Terri Sewell (D-AL), Bennie G. Thompson (D-MS), and Seth Moulton (D-MA). This is an important bipartisan step forward to supporting the over 100,000 Americans with Sickle Cell Disease (SCD) in the United States.

SCD is a chronic, debilitating blood disorder that is also the most common inherited blood disorder in the United States. Individuals living with SCD face severe health complications, including recurring and life-altering pain crises, repeat infection, acute chest syndrome, lung problems, severe and chronic pain, leg ulcers, organ damage, and stroke. Due to inadequacies in comprehensive care management, only about 1 in 4 patients with SCD receive a standard of care described in guidelines. As a result of the severity of the disease and systemic inadequacies, individuals with SCD ultimately have an estimated life expectancy that is more than 20 years shorter than the average life expectancy in the United States.ⁱ

The *Sickle Cell Disease Comprehensive Care Act* will improve access for individuals with SCD by incentivizing 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 has been used by states to improve quality, enhance care, and reduce unnecessary costs.ⁱⁱ The legislation also requires states that adopt an SCD-focused Health Home to provide dental and vision services, as, among other health issues, individuals with SCD can experience significant dental and vision complications. Additionally, based on informal conversations with the Congressional Budget Office, it is the Partnership's expectation that this legislation will slightly reduce Medicaid expenditures by helping to keep individuals with SCD out of the hospital.

The Partnership looks forward to continued work with Representatives Dunn and Davis to advance [H.R.5178](#), *Sickle Cell Disease Comprehensive Care Act*, through the legislative process, as well as work with Senators Cory Booker (D-NJ) and Tim Scott (R-SC), cosponsors of [S.721](#), the Senate version of the bill. By advancing the *Sickle Cell Disease Comprehensive Care Act*, members of Congress would take a necessary step to ensuring individuals with SCD in the United States have timely and sustained access to the high-quality and coordinated care and treatment that they deserve.

The Partnership is a public policy and advocacy alliance of more than fifteen healthcare and SCD organizations working together to advance federal policies to improve the lives of Americans with SCD. For additional information, email the advisors to the Partnership, Josh.Trent@LeavittPartners.com, Clay.Alspach@LeavittPartners.com, and Elizabeth.Hassett@LeavittPartners.com.

ⁱ <https://www.cdc.gov/sickle-cell/data/index.html>

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