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Sickle Cell Disease Partnership Supports Bipartisan Efforts to Advance The MVP Act (H.R. 2666)

(Washington, D.C.) – The Sickle Cell Disease Partnership (“The Partnership”), a multi-sector collaboration of more than a dozen healthcare organizations working together to advance federal policies to improve the lives of Americans with Sickle Cell Disease (SCD), commends the House Energy Commerce Committee for advancing H.R. 2666, *The Medicaid VBPs for Patients Act* or *The MVP Act*,¹ bipartisan legislation led by U.S. Representatives Guthrie (R-KY), Eshoo (D-CA), Joyce (R-PA), Auchincloss (D-MA), Miller-Meeks (R-IA), and Peters (D-CA).²

The Partnership is committed to advancing federal policies that improve access for individuals with SCD to comprehensive health care – including access to existing and future new therapies. SCD is a rare, genetic blood disorder that primarily affects Black Americans and Hispanic Americans³ and causes a myriad of debilitating acute and chronic health issues.

Unfortunately, individuals with SCD in the United States (U.S.) continue to face severe gaps in accessing high-quality, equitable, coordinated care and treatment. SCD not only severely impacts the quality of life for individuals with the disease, but it can lead to premature death.⁴ In fact, life expectancy for individuals in the U.S. with SCD is more than a decade shorter than it is in Europe.^{5,6}

The Partnership applauds Representatives Guthrie, Eshoo, Joyce, Auchincloss, Miller-Meeks, and Peters for their commitment to addressing barriers in Medicaid policy that can inhibit access to therapies that offer life-changing help to Medicaid beneficiaries. About 50-60% of the individuals in the U.S. who have SCD are enrolled in Medicaid.⁷ Thus, to the degree *The MVP Act* helps improve access to care and life-changing therapies in Medicaid, *The MVP Act* represents an important step forward in ensuring increased access to comprehensive health care and treatments for individuals with SCD and other vulnerable populations.

The Partnership believes that new gene therapies in development targeted at SCD hold significant promise. However, it is very important for federal policymakers in Congress to understand that only

¹ <https://www.congress.gov/bill/118th-congress/house-bill/2666?q=%7B%22search%22%3A%5B%22mvp+act%22%5D%7D&s=1&r=1>

² <https://www.congress.gov/bill/118th-congress/house-bill/2666?q=%7B%22search%22%3A%5B%22mvp+act%22%5D%7D&s=1&r=1>

³ The Partnership is comprised of sickle cell disease patient and community organizations, healthcare providers who have experience caring for sickle cell patients, manufacturers of medical products, health plans, researchers, and others interested in improving the lives of patients living with Sickle Cell Disease.

⁴ [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).)

⁵ <https://www.hematology.org/newsroom/press-releases/2016/rare-patients-with-sickle-cell-disease-live-nearly-twice-as-long-as-average>

⁶ <https://ashpublications.org/blood/article/128/10/1436/35319/Survival-in-adults-with-sickle-cell-disease-in-a>

⁷ https://assets.milliman.com/ektron/A_claims-based_analysis_of_sickle_cell_disease_Prevalence_disease_complications_and_costs.pdf

a fraction of individuals with SCD enrolled in Medicaid will be clinically eligible for new therapies currently in development. Therefore, the Partnership believes that any Congressional effort to improve access to care and therapies must also include policies that improve access to care and existing treatments for the majority of individuals with SCD who are enrolled in Medicaid. The Partnership has endorsed the *bipartisan Sickle Cell Disease Comprehensive Care Act* ^{8,9,10} and strongly encourages policymakers in Congress to adopt policies that incentivize state Medicaid programs to provide comprehensive access to high-quality outpatient care and existing treatments for Medicaid SCD beneficiaries.

In addition to the needed focus on Medicaid policies that will improve the lives of thousands of Americans with SCD, the Partnership strongly encourages policymakers in Congress to reauthorize and extend important SCD programs that are set to expire at the end of fiscal year (FY) 2023 under current law. These include:

- The Health Resources and Services Administration (HRSA) Sickle Cell Disease Treatment Demonstration Program (SCDTDP).¹¹ As a direct result of the SCDTDP, significant improvements have been made over the past decade in these aforementioned areas of need. Specifically, centers involved in the SCDTDP have reported increased Hydroxyurea use among individuals with SCD, increased provider knowledge on SCD through telehealth and telemonitoring initiatives, and an increased number of individuals with SCD seen by knowledgeable SCD providers.
- The Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) program.¹² Through the SCDC program, participating states have been able to collect critical information on where people with SCD live, how often they use healthcare services (*e.g.*, emergency department) and what factors may lead to high use of these services, and other key pieces of information that, before the program, were difficult to obtain and surveil.

As *The MVP Act* advances through the legislative process, the Partnership looks forward to working with Representatives Guthrie, Eshoo, Joyce, Auchincloss, Miller-Meeks, and Peters, the Committee on Energy and Commerce, and other Members of Congress to advance this important policy, along with policies that extend expiring SCD programs, and improve access to existing therapies and care in Medicaid.

⁸ Specifically, this bill would help address workforce-shortage related issues by: (1) Creating and/or augmenting multi-disciplinary care teams that include subspecialists such as hematologists; (2) Identifying of best practices for improving health equity for individuals with SCD, and communicating best practices to providers; and (3) Guaranteeing access to primary and preventive services, including reimbursement for care coordinators, community health workers, and other non-traditional service providers.

⁹ <https://www.congress.gov/bill/118th-congress/senate-bill/904?q=%7B%22search%22%3A%5B%22sickle+cell+disease%22%5D%7D&s=1&r=2>

¹⁰ <https://www.congress.gov/bill/118th-congress/house-bill/1672?q=%7B%22search%22%3A%5B%22sickle+cell+disease%22%5D%7D&s=1&r=1>

¹¹ The SCDTDP is a HRSA grant program aiming to (1) increase the number of clinicians knowledgeable about SCD care; (2) improve the quality of care provided to individuals with SCD; (3) improve care coordination with other providers; and (4) develop best practices for coordination of services during pediatric to adult transition.

¹² The 2018 law (P.L. 115—327) authorized the CDC through its SCD data collection program, to award grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. Currently, 11 states participate in the program, with data being collected from multiple sources. However, these 11 states only account for an estimated 35 percent of the population of Americans living with SCD. The Partnership strongly supports providing the CDC with additional funding to allow the CDC to continue to support data collection efforts in all of the states participating in the program and expand the program to additional states, with the goal of covering the majority of the SCD population in the next few years.



Our Partnership: The Sickle Cell Disease Partnership is a multi-sector collaboration of health care stakeholders committed to advancing actionable federal health care policies that will improve the lives of patients living with Sickle Cell Disease.

Our Vision: A day when every individual with Sickle Cell Disease in the United States lives to his or her fullest potential because the individual has timely, sustained access to high-quality, equitable, coordinated care and treatment.

Our Work: The Partnership's work is rooted in a 2020 report from the National Academies, "[Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action](#)." Our objective is to work collaboratively across the Sickle Cell Disease community to translate the recommendations of the National Academies' foundational report into positive action in Congress and in the Executive Branch

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Learn about our work at: SickleCellPartnership.org

