



New Partnership Launches to Advance Access to Care and Treatment, Improve Outcomes for Individuals with Sickle Cell Disease

Partnership Calls on Policymakers to Implement Proposals in 2020 Landmark Report

Washington, D.C. — In recognition of World Sickle Cell Day on June 19th, today more than a dozen organizations representing a diverse cross-section of patient advocates, health professional organizations, health insurers and biopharmaceutical companies announced the launch of the [Sickle Cell Disease Partnership](#). The newly formed public policy alliance will advocate for urgently needed federal policy actions to address the crisis of care facing the estimated 100,000 Americans living with Sickle Cell Disease.

“For too long, our nation has turned a blind eye to the devastating toll of Sickle Cell Disease on the lives of 100,000-plus Americans and their families. Today, one in 13 African Americans carry the trait for Sickle Cell, meaning their children are at risk for having the disease,” said Dr. Brett Giroir, senior advisor, Sickle Cell Disease Partnership. “The majority of people living with Sickle Cell Disease lack basic access to care, while our health care infrastructure and investments in research have failed to keep pace with the desperate need for treatment. It’s time for our nation’s leaders to prioritize individuals with Sickle Cell Disease and implement the recommendations of The National Academies’ 2020 Strategic Plan and Blueprint for Action.”

Partnership members issued a [Call to Action](#) to Congress and the Administration to implement The National Academies of Sciences, Engineering, and Medicine’s federal policy recommendations outlined in its report, “[Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action](#).”

About the Sickle Cell Disease 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. The Partnership’s main objective is to translate the recommendations of the National Academies’ landmark 2020 report into legislative and administrative actions in Congress and the Executive Branch. The Partnership is convened and managed by [Leavitt Partners](#), an HMA Company.

About Sickle Cell Disease

Sickle Cell Disease is a rare, genetic blood disorder that disproportionately impacts Black individuals. Sickle Cell Disease is inherited when a child receives two sickle cell genes—one from each parent.

Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone who has Sickle Cell Disease, the red blood cells become hard and sticky and look like a C-shaped farm tool called a “sickle.” The

sickle cells die early, causing a constant shortage of red blood cells, pain and other serious problems such as infection and stroke. Learn more about Sickle Cell Disease [here](#).

Contact Us

To learn more, please visit www.sicklecellpartnership.org. Members of the media may contact: sicklecell@720strategies.com