



The Honorable Mike Johnson
Speaker
United States House of Representatives
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
United States House of Representatives
Washington, DC 20515

May 20, 2025

Dear Speaker Johnson and Minority Leader Jeffries,

The undersigned national organizations, representing individuals living with sickle cell disease and the healthcare providers who care for them, urge you to reject the reconciliation package as is currently written. If this bill becomes law, the impact on the sickle cell disease (SCD) community as well as millions of other Americans who rely on Medicaid and Marketplaces for healthcare insurance will be devastating.

The legislation would significantly increase barriers to coverage for Medicaid beneficiaries through work reporting requirements and changes to Medicaid eligibility and enrollment. Work reporting requirements when instituted at the state-level have led to thousands losing access to Medicaid insurance as a result of red tape – failure to report work status or document eligibility for an exemption. The bill would increase costs for the low-income community covered and place a greater financial strain on states, likely leading to reduced eligibility and limited services. These provisions, in addition to the changes to the Marketplaces, such as limiting the window for open enrollment, eliminating special enrollment periods and restricting eligibility for tax credits, will make it even harder for those who lose access to Medicaid to enroll in Marketplace coverage – leaving many with no other option for insurance coverage. These provisions, and many others included in the bill, would result in thousands of people with SCD and millions of other Americans, losing health insurance.

Sickle cell disease is a rare, inherited blood disorder that cannot be prevented. It causes red blood cells to become rigid and sickle-shaped, restricting their ability to move through small blood vessels. As a result, individuals with SCD may experience severe complications, including intense pain crises, strokes, and damage to vital organs such as the eyes, kidneys, lungs, and heart. Effective treatments, many of which can be delivered through outpatient care, are available to prevent and manage these complications. More than half of individuals living with SCD in the United States rely on Medicaid for health coverage, with significantly higher rates, reaching 80-90%, in some states. Without Medicaid, many in the SCD community would lose access to essential outpatient care and treatments that help prevent pain crises and serious complications. Patients are more likely to rely on emergency departments for routine needs when care is delayed or inaccessible. This worsens health outcomes and drives up healthcare costs due to avoidable hospitalizations.

There are currently two gene therapies approved for the treatment of SCD – these therapies offer significant promise to the SCD community and have the potential to not only be life-changing but also to drastically reduce the overall costs of treating SCD throughout someone’s lifespan. In fact, the Centers for Medicare and Medicaid Services’ Cell and Gene Therapy Access Model aims to increase access to these therapies for individuals living with SCD insured by Medicaid. Thirty-five states have applied to participate in this model. Enacting policies that will lead to millions losing access to Medicaid *will* impact the SCD Warriors who will be able to access gene therapy through this Model.

As the leaders of the U.S. House of Representatives, we ask that you not move this bill forward or that you encourage the Members of your party to vote NO on the reconciliation package as it is written – the substantial changes to Medicaid and the Marketplaces will lead to significant coverage losses for the sickle cell disease community and so many others who rely on these programs for access to health insurance coverage.

Sincerely,

Sickle Cell Disease Association of America, Inc.
American Society of Hematology
American Society of Pediatric Hematology/Oncology
National Alliance of Sickle Cell Centers

Sick Cells
Sickle Cell 101
Sickle Cell Reproductive Health Education Directive

CC: United States House of Representatives