



June 23, 2025

The Honorable John Thune
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Chuck Schumer
Minority Leader
U.S. Senate
Washington, DC 20510

Dear Majority Leader Thune and Minority Leader Schumer,

The undersigned national organizations, representing individuals living with sickle cell disease and the healthcare providers who care for them, urge you to reject proposals in any budget reconciliation bill, which would cut critical healthcare programs, including Medicaid, and limit access to Marketplace plans. The recently released Senate Finance Committee draft legislation makes even deeper cuts to the federal contribution to the Medicaid program than those included in House-passed H.R. 1, the One Big Beautiful Bill Act. If these provisions become 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. **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.**

Specifically, we call on you to reject provisions that would place a greater financial strain on states as this would almost certainly lead to reduced eligibility and limited services. It will also likely force states to abandon Medicaid expansion resulting in millions losing access to healthcare insurance, including many young adults with SCD – young adulthood, specifically the transition from pediatric to adult care is a critical time for someone living with SCD. We call on you to oppose provisions which would increase barriers to coverage for Medicaid beneficiaries, such as 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. Even if someone qualifies for an exemption from the work requirements, they are not exempt from the paperwork burden. We call on you to reject the provisions which would increase costs for the low-income community covered, such as the proposal for mandatory cost-sharing for the Medicaid expansion population for all services and prescription drugs.

For Marketplace coverage, we ask that you oppose policies that would make it harder to enroll in Marketplace plans, including changes to the open enrollment period, elimination of special enrollment periods and new restrictions on the eligibility for tax credits. These provisions, if enacted, 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. The Congressional Budget Office has reported that the Medicaid and Marketplace provisions, in addition to the lack of inclusion of the extension of the enhanced advance premium tax credits (eAPTCs) that make Marketplace premiums affordable for millions of Americans, will result in 16 million coverage losses over the next 10 years.

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. 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’ (CMS) 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 – CMS plans to release the list of participating states this month. 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. Senate, we ask that you reject policies that will harm access to Medicaid and Marketplace coverage and protect access to healthcare insurance for the sickle cell disease community and so many others who rely on these programs.

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 Senate*