

The Honorable Brett Guthrie Chairman Committee on Energy and Commerce United States House of Representatives Washington, DC 20515 The Honorable Frank Pallone Ranking Member Committee on Energy and Commerce United States House of Representatives Washington, DC 20515

May 12, 2025

Dear Chairman Guthrie and Ranking Member Pallone,

The undersigned national organizations, representing individuals living with sickle cell disease and the healthcare providers who care for them, strongly urge you to reject proposed cuts and other harmful changes to Medicaid as you prepare to markup and vote on the reconciliation package. The draft legislation released by the Energy and Commerce Committee would significantly increase barriers to coverage for Medicaid beneficiaries through work reporting requirements and changes to Medicaid eligibility and enrollment; increase costs for the low-income community covered; and place a greater financial strain on states. These provisions and many others included in the bill, if finalized, will result in millions of Americans, including thousands of individuals with sickle cell disease, losing health insurance.

Sickle cell disease (SCD) 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 are available to prevent and manage these complications, many of which can be delivered through outpatient care.

More than half of individuals living with SCD in the United States rely on Medicaid for health coverage, with significantly higher rates 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.

We are calling on you to protect access to Medicaid for the sickle cell disease community and so many others who rely on it for access to health insurance coverage and reject cuts and other harmful Medicaid policies for *all* insured by Medicaid.

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, SCRED

CC: Members of the Committee on Energy and Commerce