The Honorable Robert F. Kennedy Jr.
Secretary
United States Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dr. Mehmet Oz
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Secretary Kennedy and Administrator Oz,

We, the undersigned organizations and advocates dedicated to improving the lives of individuals and families affected by sickle cell disease (SCD), write to express urgent concern regarding the interim final rule with comment period (IFC) implementing the Medicaid community engagement requirement (CMS–2454–IFC), published June 3, 2026.

More than half of the approximately 100,000 Americans living with the disease are enrolled in Medicaid or the Children's Health Insurance Program[1]. As the Department of Health and Human Services (HHS) and the Centers for Medicare & Medicaid Services (CMS) move to implement work requirements under the 2025 Reconciliation Act (P.L. 119-21), we urge you to ensure that this medically vulnerable population is not swept into coverage losses that the medically frail exclusion was designed to prevent.

Recognition Without Protection

We are encouraged that CMS identified SCD directly in the preamble to this rule as an example of a condition that may significantly impair an individual's ability to comply with the community engagement requirement. This recognition reflects an assertion that our community has long promoted: SCD is a chronic, lifelong condition marked by severe pain episodes, frequent hospitalization, organ damage, and reduced life expectancy.

Nevertheless, this recognition in the preamble will not adequately protect SCD warriors. The rule requires a case-by-case, individualized determination of whether a person's condition currently significantly impairs their ability to meet the requirement. For a disease defined by unpredictable crises rather than a single, stable level of impairment, this standard risks excluding people between flares who are, in fact, one hospitalization away from being unable to comply.

An Episodic Disease Deserves an Episodic Standard

[1] https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement/improving-care-for-sickle-cell-disease.

A person living with SCD may go weeks or months with manageable symptoms, then experience a vaso-occlusive pain crisis that results in an emergency department visit or a multi-day hospitalization with no advance warning. That unpredictability is itself the defining feature of the disease. We urge HHS and CMS to direct states to treat the frequency and unpredictability of disease exacerbations as relevant evidence of significant impairment. We further urge CMS to ensure that the lists of diagnoses and diagnosis codes states must maintain under the rule explicitly include sickle cell disease and its major complications, including vaso-occlusive crisis, acute chest syndrome, stroke, and avascular necrosis.

Verification Should Reflect How Sickle Cell Disease is Actually Documented and Treated

The rule allows states to rely on an applicant's statement under penalty of perjury only where no other reliable information exists, and only once. Beyond that narrow circumstance, states must require documentation when documentation is reasonably available. For many people with SCD, the most reliable evidence of significant impairment is a pattern of care across emergency departments, hospitals, and specialty clinics, not a single document. We ask CMS to clarify that a documented history of SCD-related hospitalization or emergency care, even where fragmented, constitutes sufficient documentation and to permit a treating hematologist or sickle cell specialty provider's attestation as acceptable evidence in its own right to establish medical frailty for individuals with SCD.

Outreach Must Reach the People it is Meant to Protect

We support the rule's direction that states use plain language screening questions to identify beneficiaries who may be medically frail. We are concerned that screening questions designed without input from disease-specific communities risk failing to surface SCD as a qualifying condition. We urge HHS and CMS to consult with national and community based SCD organizations when developing screening questions and outreach materials. Furthermore, those materials must explicitly reference sickle cell disease as a qualifying example, consistent with its inclusion in the rule's preamble.

A Call for Data and Accountability

Finally, we worry that this verification regime, which requires heavy documentation, may portend coverage terminations for individuals who meet the medically frail standard but cannot produce records within the timeframes the rule allows. This regime could be especially burdensome for SCD patients, who already report difficulty obtaining timely diagnoses and consistent care. Given these concerns, and the disproportionate impact of SCD on Black Americans, we call on CMS to monitor and publicly report whether individuals with SCD and other conditions disproportionately affecting populations of color are losing coverage at rates inconsistent with the medical frailty exclusion's intended protections.

We appreciate your attention to these concerns and welcome the opportunity to serve as a resource to HHS and CMS as this rule is implemented.

Signed in alphabetical order:

[Organization signatures pending]