July 28, 2026

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.

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

An Episodic Disease Deserves an Episodic Standard

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:

Sick Cells
Advancing Sickle Cell Advocacy Project, Inc.
American Society of Hematology
Amina K. Sickle Cell Support Circle of Harlem
Arizona Blood Alliance
Association for the Prevention of Sickle Cell Anemia Inc.
Axis Advocates
Ayana's Hope Cells
Breaking the Sickle Cell Cycle Foundation
Bridges Pointe, Inc.
Cayenne Wellness
Colorado Sickle Cell Association, Inc.
Crescent Foundation
Delta Phi Lambda Alumni Chapter of Alpha Phi Alpha Fraternity, Inc.
Discovering Moorer2life
Dreamsickle Kids Foundation
Harford Belair Community Mental Health
International Association of Sickle Cell, Nurses and Professional Associates
Kids Conquering Sickle Cell Disease Foundation
Massachusetts Sickle Cell Association
Metropolitan Seattle Sickle Cell Task Force
MTS Sickle Cell Foundation
North Alabama Sickle Cell Foundation, Inc.
Red Moon Project, Inc.
Salaam Ali Sickle Cell Moyamoya Foundation
Seth Usifo Nwosu Incorporated
Sickle Cell Advocates of Rochester
Sickle Cell Association of Kentuckiana
Sickle Cell Association of New Jersey
Sickle Cell Association of St. Louis
Sickle Cell Association of Texas Marc Thomas Foundation
Sickle Cell Disease Association of America
Sickle Cell Disease Association of America – West Alabama Chapter, Inc
Sickle Cell Disease Association of America – Philadelphia/ Delaware Valley Chapter
Sickle Cell Disease Association of America – Michigan Chapter
Sickle Cell Disease Association of America – Mobile Chapter, Inc.

Sickle Cell Disease Association of America – Ohio Sickle Cell and Health Association, Inc.
Sickle Cell Disease Association of America – Illinois
Sickle Cell Disease Association of America – St. Petersburg, Florida
Sickle Cell Foundation of Georgia
Sickle Cell Medical Advocacy
Sickle Cell Reproductive Health Education Directive
Sickle Cell Thalassemia Patients Network
Sickle Cell Warriors of Buffalo
Sickle Cell Warriors of Wisconsin
Supporters of Families with Sickle Cell Disease Oklahoma
The Levi Long Sickle Cell Association
The Riley Foundation for Sickle Cell Disease
Tova Community Health
Westchester Sickle Cell Outreach