October 27, 2026

The Honorable John Thune
Senate Majority Leader
511 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Johnson
Speaker of the House of Representatives
521 Cannon House Office Building
Washington, DC 20515

The Honorable Charles E. Schumer
Senate Minority Leader
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Hakeem Jeffries
House Minority Leader
2267 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader Thune, Minority Leader Schumer, Speaker Johnson, and Minority Leader Jeffries:

We, the undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), strongly urge you and your colleagues to adopt the *Sickle Cell Disease Comprehensive Care Act* (S. 721/H.R. 5178) as part of an end-of-year legislative package. Led by Senators Tim Scott and Cory Booker and Representatives Neil Dunn and Danny Davis, this bipartisan, bicameral legislation would appreciably improve care for Medicaid beneficiaries living with SCD, the most common inherited red blood cell disorder in the United States.

According to the Centers for Disease Control and Prevention (CDC), SCD affects one out of every 365 Black or African American births and one out of every 16,300 Hispanic American births, affecting an estimated 100,000 people. Individuals with SCD are living longer but, unfortunately, many receive uncoordinated, inconsistent care, leading to poor clinical outcomes, avoidable complications, low quality of life, and increased costs to the healthcare system. Additionally, individuals with SCD suffer from acute pain episodes and chronic pain and may be affected by an array of other organ complications, which can cause disability or even death. A Centers for Medicare & Medicaid Services (CMS) report found that approximately 50% of individuals living with SCD in the United States are covered by Medicaid.

The *Sickle Cell Disease Comprehensive Care Act* authorizes state Medicaid programs to submit a state plan amendment to establish SCD health homes to deliver coordinated and comprehensive care. The health home model is a proven care delivery model in Medicaid that has been widely used by states to improve quality, enhance care, and reduce unnecessary costs. Health homes for SCD will help to alleviate the many challenges and disparities in care that individuals with SCD have faced for far too long. This bill ensures a multi-faceted approach to care, ensuring SCD patients have access to coordinated clinical, mental health, and ancillary services to address their physical, mental, and social needs.

By building on existing programs for qualified Medicaid enrollees, the *Sickle Cell Disease Comprehensive Care Act* will reach more people living with SCD by allowing any state the opportunity to establish a health home with SCD as the sole qualifying condition. This health home eligibility expansion will also benefit people living with SCD who are transitioning from pediatric to adult care, where studies demonstrate there are often significant challenges maintaining continuity of care.

Congress has an opportunity – and an urgent responsibility – to transform care for Medicaid beneficiaries living with SCD. By establishing SCD as a single qualifying condition for health homes, this legislation will fundamentally change how care is delivered, improving access to comprehensive, coordinated care, reducing preventable complications and costly hospitalizations, and improving quality of life for individuals who too often been overlooked by our health care system. With the end of the 119th Congress rapidly approaching, we cannot let this opportunity slip away. We strongly urge you to prioritize passage of the Sickle Cell Disease Comprehensive Care Act before the end of the year and deliver meaningful, long-overdue improvements in care for people living with SCD.

Thank you.

Agios
American Academy of Emergency Medicine
American College of Emergency Physicians
American College of Obstetricians & Gynecologists
American Psychological Association Services, Inc.
American Red Cross
American Society for Apheresis
American Society for Clinical Pathology (ASCP)
American Society of Gene & Cell Therapy
American Society of Hematology
American Society of Nephrology
American Society of Pediatric Hematology/Oncology
America's Blood Centers
Association for the Advancement of Blood and Biotherapies (AABB)
Association for the Prevention of Sickle Cell Anemia, Inc.
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Laboratories
Axis Advocacy
Beam Therapeutics
Bridging the Gap-Adult Sickle Cell Disease Foundation of Nevada
Cayenne Wellness Center and Children's Foundation
Cerus Corporation
Connecticut Oncology Association
Emergency Department Sickle Cell Care Coalition
Florida Society of Clinical Oncology
Foundation for Sickle Cell Disease Research
Foundation for Women & Girls with Blood Disorders
Genetix Biotherapeutics Inc.
Global Sickle Cell Alliance, Inc.
Hemex Health
James R. Clark Memorial Sickle Cell Foundation
Martin Center Sickle Cell Inc.
Maryland-DC Society of Clinical Oncology
Massachusetts Sickle Cell Association
Medunik USA, Inc.
Michigan Society of Hematology and Oncology
Mississippi Oncology Society

National Alliance of Sickle Cell Centers
National Medical Association
NMDP
North Alabama Sickle Cell Foundation, Inc.
Novo Nordisk Inc.
Ohio Hematology Oncology Society
Piedmont Health Services and Sickle Cell Agency (NC)
Sick Cells
Sickle Cell Adult Provider Network
Sickle Cell Association (St. Louis, MO)
Sickle Cell Association of Kentuckiana
Sickle Cell Association of Texas, Marc Thomas Foundation
Sickle Cell Disease Association of America - Central Alabama
Sickle Cell Disease Association of America Ohio Sickle Cell and Health Association, Inc.
Sickle Cell Disease Association of America, Michigan Chapter
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America:Miami-Dade County Chapter, Inc.
Sickle Cell Disease Association of America-Mobile Chapter, Inc.
Sickle Cell Disease Association of Florida
Sickle Cell Disease Association of Illinois
Sickle Cell Disease Foundation
Sickle Cell Disease Partnership
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Foundation, Inc.
Sickle Cell Knowledge and Information Network
Sickle Cell Medical Advocacy Inc.
Sickle Cell Prodigy
Society of Utah Medical Oncologists (SUMO)
Supporters of Families with Sickle Cell Disease
Terumo Blood and Cell Technologies
The Arizona Clinical Oncology Society
The Sickle Cell Association of New Jersey
The Sickle Cell Council of New Mexico, Inc.
TOVA Community Health
Uriel E. Owens Sickle Cell Disease Association of the Midwest
Wisconsin Association of Hematology and Oncology

CC: Members of the United States Senate Committee on Finance
Members of the United States House Energy and Commerce