April 14, 2026

The Honorable Mike Crapo
Chairman, Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member, Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Morgan Griffith
Chair, Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Diana DeGette
Ranking Member, Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Crapo, Chairman Griffith, Ranking Member Wyden, and Ranking Member DeGette:

We, the undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), strongly urge the Senate Finance Committee and House Energy and Commerce Subcommittee on Health to include the *Sickle Cell Disease Comprehensive Care Act* (S. 721/H.R. 5178) in an upcoming hearing or markup. We were pleased to see this important legislation reintroduced last year in the Senate by Senators Tim Scott and Cory Booker, and in the House by Representatives Neil Dunn and Danny Davis. SCD is the most common inherited red blood cell disorder in the United States. This bipartisan legislation provides an opportunity to appreciably improve the care delivered to Medicaid beneficiaries living with SCD that your Committee and Subcommittee must act on.

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. We believe that 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.

In addition to improving care, the bill would also save money in the Medicaid program. The Congressional Budget Office estimated that the legislation as saving $4 million in the 10-year budget window.

Together, we have an opportunity to profoundly impact care for people living with SCD on Medicaid. Adopting SCD as an eligible condition for health homes will change the care paradigm for impacted individuals and save our health care system millions of dollars, while providing a better quality of life for a very under-represented patient population. We strongly urge you to prioritize the *Sickle Cell Disease Comprehensive Care Act* in the Committee's and Subcommittee's upcoming deliberations.

Thank you.

AABB
Agios
America's Blood Centers
American Academy of Emergency Medicine
American Academy of Pediatrics
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
American Society for Reproductive Medicine
American Society of Gene and Cell Therapy
American Society of Hematology
American Society of Nephrology
American Society of Pediatric Hematology/Oncology
Association of Maternal & Child Health Programs
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Laboratories
Axis Advocates
Beam Therapeutics
Black Women's Health Imperative
Breaking the Sickle Cell Cycle
Bridging the Gap Adult Sickle Cell Disease Foundation of Nevada
Brown University Health Comprehensive Sickle Cell Center
Cayenne Wellness Center
Center for Inherited Blood Disorders
Cerus Corporation
CSL Behring
Emergency Department Sickle Cell Care Coalition
Emmaus Medical, Inc.
Foundation for Sickle Cell Disease Research
Foundation for Women & Girls with Blood Disorders
Fulcrum Therapeutics
Functional Fluidics

Genetix Biotherapeutics
Global Sickle Cell Alliance
Hemex Health
Hemanext, Inc.
Hudson Valley New York Black Nurses Association, Inc.
International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA)
James R. Clark Memorial Sickle Cell Foundation
Martin Center Sickle Cell, Inc.
Maryland and District of Columbia Society of Clinical Oncology
Medunik USA Inc.
Mount Sinai Hospital
National Alliance of Sickle Cell Centers
National Black Nurses Association
National Institute for Children's Health Quality (NICHQ)
NMDP (formerly National Marrow Donor Program)
Novo Nordisk
Pathways To Trust
Rare Disease Diversity Coalition
SCDAA, Michigan Chapter
Sick Cells
Sickle Cell 101
Sickle Cell Adult Provider Network (SCAPN)
Sickle Cell Association (St. Louis, MO)
Sickle Cell Association of Texas - Marc Thomas Foundation
Sickle Cell Awareness Group of Ontario
Sickle Cell Consortium
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of Florida
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 Prodigy
Sickle Cell Warriors, Inc.
Supporters of Families with Sickle Cell Disease, Inc. - Oklahoma
Terumo Blood and Cell Technologies
The National Medical Association
The Sickle Cell Association of New Jersey
The Sickle Cell Council of New Mexico
TOVA Community Health
Vertex Pharmaceuticals Incorporated

cc: Members of the United States Senate Committee on Finance
Members of the United States House Energy and Commerce Subcommittee on Health