

October 29, 2025

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 Griffith and Ranking Member DeGette:

We, the undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), strongly urge the United States House Energy and Commerce Subcommittee on Health to include the *Sickle Cell Disease Comprehensive Care Act* ([H.R. 5178](#)) in an upcoming hearing or markup. We were pleased to see this important legislation reintroduced in the House last month during Sickle Cell Awareness Month by Representatives Neal Dunn and Danny Davis, with support from nearly 20 original co-sponsors and additional members joining since. SCD is the most common inherited red blood cell disorder in the United States. This bipartisan legislation, which has already been introduced in the Senate ([S. 721](#)) by Senators Tim Scott and Cory Booker, provides an opportunity to appreciably improve the care delivered to Medicaid beneficiaries living with SCD that your Subcommittee and the full Energy and Commerce Committee 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 provide comprehensive, coordinated care through a health home model for individuals with SCD based on their SCD status alone. 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. We are pleased to let you know that the Congressional Budget Office scored 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 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

Cerus Corporation

Emergency Department Sickle Cell Care Coalition

Emmaus Medical, Inc.

Foundation for Sickle Cell Disease Research

Foundation for Women & Girls with Blood Disorders

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)  
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 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 House Energy Subcommittee on Health