June 6, 2024

The Honorable Cathy McMorris Rodgers Chair Committee on Energy and Commerce House of Representatives 2125 Rayburn House Office Building Washington, D.C. 20515 The Honorable Frank Pallone, Jr. Ranking Member Committee on Energy and Commerce House of Representatives 2322A Rayburn House Office Building Washington, D.C. 20515

Dear Chair McMorris Rodgers and Ranking Member Pallone:

We, the undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), strongly urge the House Energy and Commerce Committee to markup H.R. 7432, the *Sickle Cell Disease Comprehensive Care Act* of *2024*, as soon as possible. SCD is the most common inherited red blood cell disorder in the United States. This legislation provides an opportunity to appreciably improve the care delivered to these individuals that the committee and Congress 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 and 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 of 2024 would enable state Medicaid programs to provide comprehensive, coordinated care through a health home model for individuals with SCD. 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* of 2024 will reach more people living with SCD by allowing any state the opportunity to participate in the SCD health home with SCD as the sole qualifying condition as well as the accompanying eight quarter federal medical assistance percentage (FMAP) match. 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.

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 markup the *Sickle Cell Disease Comprehensive Care Act of 2024* and incorporate it into legislation that will reach the president's desk.

Thank you.

American Society of Hematology

Agios Pharmaceuticals

American Academy of Pediatrics

American College of Emergency Physicians

American College of Obstetricians and Gynecologists

American Psychological Association Services

American Public Health Association

American Red Cross

American Society for Apheresis (ASFA)

American Society for Clinical Pathology

American Society for Reproductive Medicine

American Society of Gene and Cell Therapy

American Society of Nephrology

American Society of Pediatric Hematology/Oncology

American Thrombosis and Hemostasis Network

America's Blood Centers

Andrews Counseling and Family Resource Center

Association for Prevention of Sickle Cell Anemia INC. Harford, Cecil, Eastern Shore

Association for the Advancement of Blood and Biotherapies (AABB)

Association of Maternal & Child Health Programs

Association of Pediatric Hematology and Oncology Nurses

Association of Public Health Laboratories

Beam Therapeutics

bluebird bio

Breaking The SSickle Cell Cycle Foundation

Bridging the Gap-Adult Sickle Cell Disease Foundation of Nevada

Cayenne Wellness Center

Cerus Corporation

Colorado Sickle Cell Association, Inc.

Editas Medicine

Emergency Department Sickle Cell Care Coalition

Foundation for Sickle Cell Disease Research

Foundation for Women and Girls with Blood Disorders

Global Action Network for Sickle Cell & Other Hereditary Blood Disorders (GANSID)

Global Sickle Cell Alliance, Inc

Hemanext Inc

Hemex Health

International Alliance for Pediatric Stroke

International Association of Sickle Cell Nurses and Professional Associates

James R. Clark Memorial Sickle Cell Foundation

Lifespan Comprehensive Sickle Cell Center

Martin Center Sickle Cell Initiative

Medunik USA Inc.

National Alliance of Sickle Cell Centers

National Black Nurses Association

National Institute for Children's Health Quality (NICHQ)

NMDP (National Marrow Donor Program)

North Alabama Sickle Cell Foundation, Inc.

Piedmont Health Services and Sickle Cell Agency

Sanofi US

SCDAA: Miami-Dade County Chapter, Inc.

Sick Cells

Sickle Cell 101

Sickle Cell Adult Provider Network (SCAPN)

Sickle Cell Anemia Foundation of Oregon & P.NW

Sickle Cell Assn of Texas Marc Thomas Foundation

Sickle Cell Association - West AL Chapter

Sickle Cell Association (St. Louis, MO)

Sickle Cell Association of South Louisiana

Sickle Cell Association of Texas, Marc Thomas Foundation

Sickle cell Awareness Group of Ontario

Sickle Cell Community Advisory Council

Sickle Cell Disease Association of America CT, Michelle's House

Sickle Cell Disease Association of America, Inc.

Sickle Cell Disease Association of America, Michigan Chapter

Sickle Cell Disease Association of America, Philadelphia/ Delaware Valley Chapter

Sickle Cell Disease Association of Florida, Inc.

Sickle Cell Disease Association of Illinois

Sickle Cell Disease Foundation

Sickle Cell Foundation of Georgia, Inc.

Sickle Cell Foundation of Greater Montgomery

Sickle Cell Foundation of Minnesota

Sickle Cell Foundation, Inc.

Sickle Cell Warriors of Wisconsin

Southeast Alabama Sickle Cell Association Inc.

Supporters of Families with Sickle Cell Disease, Inc.

Terumo Blood and Cell Technologies

The Center for Inherited Blood Disorders

The Sickle Cell Anemia Foundation of Oregon & PNW

The Sickle Cell Association of New Jersey

The Sickle Cell Council of New Mexico, Inc.

The Sickle Cell Foundation of Tennessee

TOVA Community Health, Inc.

Uriel E. Owens Sickle Cell Disease Association of the Midwest

Vertex Pharmaceuticals