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