June 6, 2024

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