

November 14, 2024

The Honorable Ron Wyden  
Chairman  
Senate Finance Committee  
221 Dirksen Senate Office Building  
Washington, D.C., 20510

The Honorable Mike Crapo  
Ranking Member  
Senate Finance Committee  
239 Dirksen Senate Office Building  
Washington, D.C. 20510

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 Wyden, Ranking Member Crapo, 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 Senate Finance Committee and House Energy and Commerce Committee to support the inclusion of the *Sickle Cell Disease Comprehensive Care Act of 2024* ([S. 5097/H.R. 7432](#)), in an end-of-year legislative package. 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 Medicaid beneficiaries living with SCD that your Committees 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* 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 of 2024* 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 as well as the accompanying eight quarters of a 90% 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.

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 recently 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 of 2024* and incorporate it into legislation that will reach the President's desk by the end of the year.

Thank you.

American Society of Hematology  
Agiros Pharmaceuticals  
American Academy of Emergency Medicine  
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 Sickle 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  
Functional Fluidics  
Global Action Network for Sickle Cell & Other Hereditary Blood Disorders (GANSID)  
Global Alliance of Sickle Cell Disease Organizations (GASCDO)  
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 Medical Association  
National Institute for Children's Health Quality (NICHQ)  
NMDP (National Marrow Donor Program)  
North Alabama Sickle Cell Foundation, Inc.  
Novartis  
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 Anemia Resource Foundation  
Sickle Cell Assn of Texas Marc Thomas Foundation  
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 Connecticut, 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 Association - West Alabama Chapter  
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, 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 Clinton Health Access Initiative  
The Emmes Group  
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

Cc: Senators Cory Booker and Tim Scott  
Representatives Michael Burgess and Danny Davis  
Members of the Senate Finance Committee  
Members of the House Committee on Energy and Commerce  
Senate Majority Leader Chuck Schumer  
Senate Minority Leader Mitch McConnell  
Speaker of the House Mike Johnson  
House Minority Leader Hakeem Jeffries