

November 17, 2022

The Honorable Charles E. Schumer
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Nancy Pelosi
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Kevin McCarthy
2468 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader Schumer, Minority Leader McConnell, Speaker Pelosi; and Minority Leader McCarthy:

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), seek your leadership in including in any end-of-year legislative package the Sickle Cell Disease Comprehensive Care Act (S. 3389/ H.R. 6216) introduced by Senators Cory Booker and Tim Scott and Representatives Danny Davis and Michael Burgess. Our organizations strongly support the bill and believe it outlines important steps toward addressing the needs of the SCD community by authorizing the Centers for Medicare and Medicaid Services (CMS) to develop a demonstration program for Medicaid beneficiaries to improve access to comprehensive outpatient care for individuals with SCD.

We remain deeply concerned that those living with SCD have been impacted disproportionately by COVID-19 and continue to lack access to quality, state-of-the-art outpatient and preventive care for their disease. SCD is an inherited blood disorder that affects an estimated 100,000 Americans, primarily African Americans and Hispanics. SCD complications include severe pain, stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and in some cases premature death.

Sadly, many individuals living with SCD, especially young adults, are not able to access the care of specialists or primary care physicians that understand the disease and have the resources to effectively treat those affected. Preventive care starts with the development of a treatment plan and can include transfusions, lab tests, radiographic studies, and vaccines, which are critically needed to prevent infection or strokes, and to manage severe pain, in addition to needed treatment for COVID-related illness. We worry that there are many individuals with SCD at home living in severe pain and worsening heart, lung, and renal disease.

An organized approach to primary and preventive care for individuals with SCD is desperately needed to improve the health and quality of life for this population. The Medicaid demonstration program proposed in the bill would provide the essential focus needed on specialized and primary care in appropriate outpatient settings. With the recent publication of clinical practice guidelines in SCD and approvals of new treatments for SCD and more in the pipeline, there is no better time than now to improve the SCD community's access to state-of-the-art care.

The 117th Congress is the time to initiate this program. We need your leadership to move the legislation forward and improve care for people with SCD. Our organizations stand ready to support you and thank you again for your efforts to improve the lives of individuals with this debilitating disease.

AABB

Agios Pharmaceuticals

American Academy of Neurology

American College of Emergency Physicians

American College of Obstetricians and Gynecologists

American Psychological Association Services, Inc.

American Public Health Association

American Red Cross

American Society for Clinical Pathology

American Society for Reproductive Medicine

American Society for Transplantation and Cellular Therapy

American Society of Hematology

American Society of Pediatric Hematology/Oncology

American Thrombosis and Hemostasis Network

America's Blood Centers

Association of Maternal & Child Health Programs

Association of Pediatric Hematology/Oncology Nurses

Association of Public Health Laboratories

Axis Advocacy

Beam Therapeutics

bluebird bio

Cayenne Wellness Center

Cerus Corporation

CSL Behring

Foundation for Women & Girls with Blood Disorders

Functional Fluidics

Graphite Bio

Imara

International Alliance for Pediatric Stroke

International Association of Sickle Cell Nurses and Professional Associates

Lifespan Comprehensive Sickle Cell Center

Martin Center Sickle Cell Initiative

Medunik USA

National Black Nurses Association

National Institute for Children's Health Quality

National Marrow Donor Program/ Be The Match

National Medical Association

Novartis Pharmaceutical Corporation, USA

Pediatric Hematology Sickle Cell Program at University of Illinois at Chicago

Pediatric Hospital Sickle Cell Disease Collaborative

Sick Cells

Sickle Cell 101

Sickle Cell Adult Provider Network

Sickle Cell Association of Texas Marc Thomas Foundation
Sickle Cell Consortium
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America, Michigan Chapter
Sickle Cell Disease Association of Texas, Marc Thomas Foundation
Sickle Cell Transplant Advocacy & Research Alliance
South Carolina Children's Hospital Collaborative

cc. Chairmen Wyden and Pallone, Ranking Members Crapo and McMorris Rodgers, Senators
Booker and Scott and Representatives Davis and Burgess