

May 19, 2022

The Honorable Frank Pallone
Chairman
House Energy and Commerce Committee
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
House Energy and Commerce Committee
1035 Longworth House Office Building
Washington, DC 20515

The Honorable Anna Eshoo
Chairwoman
House Energy and Commerce Health Subcommittee
272 Cannon House Office Building
Washington, DC 20515

The Honorable Brett Guthrie
Ranking Member
House Energy and Commerce Health Subcommittee
2434 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pallone, Ranking Member McMorris Rodgers, Chairwoman Eshoo, and Ranking Member Guthrie:

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), seek your leadership in marking up the Sickle Cell Disease Comprehensive Care Act (H.R. 6216) introduced by 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. The suppressed immune system and co-existing medical conditions occurring in individuals with SCD result in a much higher risk of severe complications stemming from infection with COVID-19. As we continue to see positive changes in the state of the pandemic, we remain concerned about the health of individuals with SCD.

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 blood 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.

Additionally, the proposed demonstration program addresses the priority areas highlighted in CMS' recently released action plan to address health equity. The SCD demonstration program has the capability to eliminate disparities in health care quality and access for this extremely vulnerable population, which in turn, could serve as a model for CMS' multifaceted efforts to improve health equity and eliminate disparities.

Now is the time to initiate this program. We need your leadership to advance the bill in your committee. Our organizations are committed to seeking cosponsors and working with the committees of jurisdiction to move the policy and program forward.

Please consider all of the organizations listed below as a resource and keep us apprised on how we can assist you. Thank you again for your efforts to improve the lives of individuals with this debilitating disease.

AABB

Agios Pharmaceuticals
Alpert Medical School of Brown University
American Academy of Pediatrics
American College of Emergency Physicians
American College of Obstetricians and Gynecologists
American Heart Association
American Psychological Association
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 Thoracic Society
ASH Research Collaborative
Association of Pediatric Hematology/Oncology Nurses
Association of Maternal & Child Health Programs
Association of Public Health Laboratories
Axis Advocacy
Beam Therapeutics
Black Women's Health Imperative
bluebird bio
Bridging the Gap-Adult Sickle Cell Disease Foundation of Nevada
Cayenne Wellness Center | Sickle Cell Education, Support, and Advocacy
Forma Therapeutics
Foundation for Sickle Cell Disease Research
Global Blood Therapeutics
Graphite Bio
Greater Boston Sickle Cell Disease Association
Hemex Health, Inc.
Imara
International Association of Sickle Cell Nurses and Professional Associates
Martin Center Sickle Cell Initiative
Medunik USA

National Institute for Children's Health Quality - NICHQ
National Marrow Donor Program/ Be The Match
National Medical Association
New York State Sickle Cell Advocacy Network Inc.
North Alabama Sickle Cell Foundation, Inc.
RedMoon Project, Inc.
Sanofi US
SCDAA, Michigan Chapter
Sick Cells
Sickle Cell 101
Sickle Cell Association - West Alabama Chapter, Inc
Sickle Cell Association of Texas-Marc Thomas Foundation
Sickle Cell Consortium
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America - Mobile Chapter, Inc.
Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
Sickle Cell Disease Association of Illinois
Sickle Cell Disease Foundation
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Warriors, Inc.
Terumo Blood and Cell Technologies
The Maryland Sickle Cell Disease Association
The Sickle Cell Association of New Jersey
TOVA Community Health
Vertex Pharmaceuticals Incorporated

cc. Representatives Danny Davis and Michael Burgess