

September 29, 2021

The Honorable Cory Booker
717 Hart Senate Office Building
Washington, DC 20510

The Honorable Tim Scott
104 Hart Senate Office Building
Washington, DC 20510

The Honorable Danny Davis
2159 Rayburn House Office Building
Washington, DC 20515

The Honorable Michael Burgess
2161 Rayburn House Office Building
Washington, DC 20515

Dear Senators Booker and Scott and Representatives Davis and Burgess:

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), look to you for needed leadership in addressing the needs of this community. As we recognize the SCD patient and provider communities during Sickle Cell Disease Awareness Month, 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. The four of you have a history of working in a bicameral and bipartisan manner to better the lives of people with SCD. Today, we write to ask you to join forces again and introduce legislation authorizing the Centers for Medicare and Medicaid Services (CMS) to quickly develop a program for Medicaid beneficiaries to improve access to comprehensive outpatient care for individuals with SCD.

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.

Sadly, not enough individuals living with SCD are 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 includes 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 we are proposing be authorized will focus on providing 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.

During this time of crisis, it is critical to initiate this program. We ask for your leadership on this issue by introducing the draft legislation that we have worked on with your staff. Once introduced our

organizations are committed to seeking co-sponsors 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 for your consideration and for all of your efforts to improve the lives of individuals with this debilitating disease.

AABB

Agios Pharmaceuticals

American Academy of Emergency Medicine

American College of Emergency Physicians

American Psychological Association

American Red Cross

American Society for Clinical Pathology

American Society for Transplantation and Cellular Therapy

American Society of Hematology

American Society of Pediatric Hematology/Oncology

America's Blood Centers

ASH Research Collaborative

Association of Pediatric Hematology/Oncology Nurses

Association of Public Health Laboratories

Axis Advocacy

Bluebird bio

Foundation for Sickle Cell Disease Research

Global Blood Therapeutics

International Association of Sickle Cell Nurses and Professional Associates

Martin Center Sickle Cell Initiative

Medunik USA

National Marrow Donor Program/Be The Match

National Medical Association

Novartis

Sanofi US

Sick Cells

Sickle Cell 101

Sickle Cell Adult Provider Network

Sickle Cell Association of Delaware

Sickle Cell Association of Texas Marc Thomas Foundation

Sickle Cell Disease Association of America Inc.

Sickle Cell Disease Association of America, Michigan Chapter

Sickle Cell Disease Enterprise, Levine Cancer Institute / Atrium Health

Sickle Cell Foundation

Sickle Cell Foundation of Georgia, Inc.

Sickle Cell Transplant Advocacy and Research Alliance

Terumo Blood and Cell Technologies

The Emmes Company, LLC

Vanguard Therapeutics, Inc.

Vertex Pharmaceuticals Incorporated