

May 19, 2022

The Honorable Ron Wyden
Chairman
Senate Finance Committee
221 Dirksen Senate Office Building
Washington, DC, 20510

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

The Honorable Debbie Stabenow
Chair
Senate Finance Subcommittee on Health Care
731 Hart Senate Office Building
Washington, DC 20510

The Honorable Steve Daines
Ranking Member
Senate Finance Subcommittee on Health Care
320 Hart Senate Office Building
Washington, DC 20510

Dear Chairman Wyden, Ranking Member Crapo, Chair Stabenow, and Ranking Member Daines:

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 (S. 3389) introduced by Senators Cory Booker and Tim Scott. 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. Senators Cory Booker and Tim Scott