

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