AMERICAN SOCIETY OF HEMATOLOGY
2021 L Street, NW, Suite 900, Washington, DC 20036 ph 202.776.0544 fax 202.776.0545 e-mail ASH@hematology.org

American Society of Hematology
Statement for the Record
House Ways and Means Committee Hearing:
The Disproportionate Impact of COVID-19 on Communities of Color
June 5, 2020

Chairman Neal, Ranking Member Brady, and members of the Ways and Means Committee, the American Society of Hematology (ASH) appreciates the opportunity to submit a statement for the record as part of the committee's recent hearing entitled "The Disproportionate Impact of COVID-19 on Communities of Color."

ASH represents more than 18,000 physicians, researchers, and medical trainees committed to the study and treatment of blood and blood-related diseases such as leukemia, lymphoma, and myeloma; non-malignant conditions, including anemia and hemophilia; and congenital disorders, such as thalassemia. ASH members also include clinicians who specialize in treating children and adults with sickle cell disease (SCD) and researchers who investigate the causes of and potential treatments for SCD manifestations.

SCD is an inherited blood disorder that affects an estimated 100,000 Americans, primarily African Americans and Hispanics. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped and causing them to get stuck in blood vessels and block blood and oxygen flow to the body. 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.

ASH is gravely concerned that the COVID-19 crisis is exacerbating the already fragile system of care for many patients with sickle cell disease. As discussed at the Committee on Ways and Means hearing on the Disproportionate Impact of COVID-19 on Communities of Color, preliminary data are showing a disproportionate impact of the infection on the African American and Hispanic populations. For individuals living with SCD the impact can be more intense, due to existing barriers to primary and preventive care, and the suppressed immune system and co-existing medical conditions occurring in individuals with SCD, including long-term heart and lung problems, resulting in a much higher risk of severe complications stemming from infection with COVID-19.

ASH, working closely with the Sickle Cell Disease Association of America (SCDAA) and sixty-seven other organizations committed to improving the care and treatment of people living with SCD, ask the Committee to consider authorizing a demonstration program within the Centers for Medicare and Medicaid Services (CMS) to improve primary and specialized outpatient care for Medicare/Medicaid dual eligibles and Medicaid beneficiaries. As stated in the attached letter signed by these dedicated organizations, which was sent to the House Leadership during the debate on stimulus legislation, "With the recent publication of clinical practice guidelines in sickle cell disease 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."

Thank you again for the opportunity to submit testimony. Please contact ASH Senior Manager, Legislative Advocacy Tracy Roades at 202-292-0256 or troades@hematology.org, if you have any questions or need further information.

April 28, 2020

The Honorable Nancy Pelosi
Speaker of the House of Representatives
U.S. Capitol Building, H-222
Washington, DC 20515

The Honorable Mitch McConnell
Majority Leader
U.S. Capitol Building, H-230
Washington, DC 20510

The Honorable Kevin McCarthy
House Republican Leader
U.S. Capitol Building, H-204
Washington, DC 20515

The Honorable Charles Schumer
Senate Democratic Leader
U.S. Capitol Building, S-221
Washington, DC 20510

Dear Speaker Pelosi, Leader McConnell, Leader McCarthy, and Leader Schumer,

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), are gravely concerned about the impact COVID-19 is having on African Americans and Hispanics in the US and particularly, on individuals with SCD, who often live with long term heart and lung problems (multiple severe co-morbidities) and are at higher risk of life threatening complications if infected. As you consider legislative proposals for the next stimulus bill we ask that you include an authorization for the Centers for Medicare and Medicaid Services (CMS) to quickly develop a program for Medicare/Medicaid dual eligible and 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. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped and causing them to get stuck in blood vessels and block blood and oxygen flow to the body. 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. Many necessary services cannot be provided by telehealth, so it has become increasingly difficult to manage the individuals with the disease in their homes and these people are fearful of going to emergency departments or a hospital for care. 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 model CMS program will focus on providing specialized and primary care in appropriate outpatient settings. With the recent publication of clinical practice guidelines in sickle cell disease 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.

We ask for your leadership on this issue by including in the next stimulus bill an authorization for CMS to develop a demonstration program to improve outpatient services under Medicare and Medicaid to this vulnerable population. During this time of crisis, it is critical to initiate this program.

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

American Society of Hematology
Sickle Cell Disease Association of America
AABB
American College of Emergency Physicians
American Medical Association
American Public Health Association
American Red Cross
American Society of Pediatric Hematology/Oncology
American Society for Apheresis
ASH Research Collaborative
Association of Public Health Laboratories
Axis Advocacy
bluebird bio
Bridges Pointe Sickle Cell Foundation
Cayenne Wellness Center
Cerus Corporation
Colorado Sickle Cell Association
CRISPR Therapeutics
Dreamsickle Kids Foundation
Emergency Department Sickle Cell Care Coalition (EDSC3)
Foundation for Sickle Cell Disease Research
Global Blood Therapeutics Inc. (GBT)
Heart of Gold Sickle Cell Foundation of Northern Virginia
Hemex Health
Howard University Center for Sickle Cell Disease
International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA)
LIVING with Sickle Cell, Inc.
Medunik USA
MiOra
National Black Leadership Commission on Health
National Institute for Children's Health Quality (NICHQ)
National Medical Association
New York State Advocacy Network, Inc.
New York State Sickle Cell Advocacy Network, INC.
Newark Beth Israel Medical Center
North Alabama Sickle Cell Foundation, Inc.

Novartis Pharmaceuticals Corporation
Ohio Sickle Cell Affected Families Association
SCDAA Miami-Dade County Chapter, Inc.
SCDAA Ohio Sickle Cell and Health Association
Sick Cells
Sickle Cell 101
Sickle Cell Adult Provider Network
Sickle Cell Anemia Foundation of Oregon, Inc.
Sickle Cell Association – West Alabama Chapter, Inc.
Sickle Cell Association of Virginia, Inc.
Sickle Cell Awareness
Sickle Cell Disease Association of America Michigan Chapter
Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
Sickle Cell Disease Association of America, St. Petersburg Chapter, Inc.
Sickle Cell Disease Association of Broward County
Sickle Cell Disease Association of Illinois
Sickle Cell Disease Community Forum
Sickle Cell Foundation of Georgia, Inc.
Sickle Transplant Advocacy and Research Alliance (STAR)
SickleSMART Foundation
Smile Sickle Cell Foundation
South Central PA Sickle Cell Council
Southeast Alabama Sickle Cell Association, Inc.
SSM Health Cardinal Glennon Children's Hospital
Terumo BCT
Thalassaemia International Federation
The Children's Sickle Cell Foundation, Inc.
The North Carolina Sickle Cell Disease Provider Consortium NCSCD-PC
The Sickle Cell Association of New Jersey
The Sickle Cell Disease Enterprise, Levine Cancer Institute, Atrium Health
The Sickle Cell Foundation of Tennessee
Thomas Jefferson University
Vertex Pharmaceuticals