

November 23, 2020

Chairwoman Nita Lowey
House Appropriations Committee
2365 Rayburn House Office Building
Washington, DC 20515

Ranking Member Kay Granger
House Appropriations Committee
1026 Longworth House Office Building
Washington, DC 20515

Chairwoman Rosa DeLauro
House Labor-HHS Appropriations Subcommittee
2413 Rayburn House Office Building
Washington, DC 20515

Ranking Member Tom Cole
House Labor-HHS Appropriations Subcommittee
2207 Rayburn House Office Building
Washington, DC 20515

Chairman Richard Shelby
Senate Appropriations Committee
304 Russell Senate Office Building
Washington, DC 20510

Ranking Member Patrick Leahy
Senate Appropriations Committee
437 Russell Senate Office Building
Washington, DC 20510

Chairman Roy Blunt
Senate Labor-HHS Appropriations Subcommittee
260 Russell Senate Office Building
Washington, DC 20510

Ranking Member Patty Murray
House Labor-HHS Appropriations Subcommittee
154 Russell Senate Office Building
Washington, DC 20510

Dear Representatives Lowey, Granger, DeLauro, and Cole, and Senators Shelby, Leahy, Blunt, and Murray:

The undersigned organizations, all committed to improving the health of individuals living with sickle cell disease (SCD), ask that dedicated funding for the Centers for Disease Control and Prevention's (CDC) SCD Data Collection Program be included in the final House-Senate negotiated omnibus appropriations bill for fiscal year (FY) 2021. This program supports states in the collection and analysis of population-based surveillance data on people living with SCD in the United States. We are seeking \$5 million in dedicated funding to assure that the data collection program can be fully implemented in those states that have worked with CDC over the past several years to develop their state-based programs and to allow for an expansion to additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

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 causes severe pain and can lead to strokes, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and in some cases premature death. Barriers to receiving quality, comprehensive care for SCD are significant, resulting in health care disparities and inequities. COVID-19 has further disrupted care and increased these challenges and patient morbidity and mortality.

The National Academies of Sciences, Engineering, and Medicine (NAEM) recently released a new report entitled *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action*, which provides recommendations for improving health care for people in the U.S. with SCD. One of the top recommendations in the report highlights the need to establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the life span. The report recommends that the CDC work with all states to develop state public health surveillance systems to support a national longitudinal registry of all persons. Our organizations strongly support this recommendation and seek your support by providing \$5

million in FY 2021 for SCD data collection within the CDC's National Center for Birth Defects and Developmental Disabilities, Division of Blood Disorders (NCBDDD) to carry out this program.

The *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018* (P.L. 115—327) authorized CDC to award SCD data collection grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. The program was originally funded by the CDC Foundation and began in California and Georgia (approximately 10% of the U.S. SCD population). Starting in late 2019 and continuing in 2020, CDC and the HHS Office of Minority Health transferred approximately \$3 million to help seven additional states (Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Virginia) start to build the infrastructure needed to implement the program in 2019, and then start collecting data in late 2020. While this funding was a helpful step in initiating programs in additional states, it only provides about half of the resources needed to successfully implement data collection in each state and does not support other states that are poised to start collecting data. We ask for your leadership to help build on this investment by providing the dedicated funding at \$5 million for NCBDDD to fully carry out the SCD Data Collection Program in FY 2021 and ensure stability.

Please consider 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.

AABB
ADDMEDICA
American College of Emergency Physicians
American Red Cross
American Society of Gene & Cell Therapy
American Society of Hematology
American Society of Nephrology
American Society of Pediatric Hematology/Oncology
America's Blood Centers
ASH Research Collaborative
Association of Maternal & Child Health Programs
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Laboratories
Australian Sickle Cell Advocacy Inc
Axis Advocacy
bluebird bio
Cayenne Wellness Center
Charles W. Stark, Pharm.D.
Colorado Sickle Cell Association, Inc.
CRISPR Therapeutics
Dreamsickle Kids Foundation, Inc.
Foundation for Women & Girls with Blood Disorders
Functional Fluidics
G B Cooley
GlycoMimetics Inc.
Imara Inc

International Association of Sickle Cell Nurses and Professional Associates
Martin Center Sickle Cell Initiative
Medunik USA
Monroe City Council District 3
Muhimbili University of Health and Allied Sciences
National Institute for Children's Health Quality
National Marrow Donor Program/Be The Match
National Medical Association
New York State Sickle Cell Advocacy Network, inc. (formally QSCAN)
Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation Inc.
NOVA Workforce Institute of Northeast Louisiana
Novartis Pharmaceuticals Corporation
Ohio Sickle Cell Affected Families Association
Pediatric Hospital Sickle Cell Disease Collaborative
SCDAA / Ohio Sickle Cell and Health Association
SCDAA / St. Petersburg Chapter
Sickle Cell/Thalassemia Patients Network (SCTPN)
Sickle Cell 101
Sickle Cell Adult Provider Network
Sickle Cell Anemia Awareness of San Francisco
Sickle Cell Assn of Texas Marc Thomas Foundation
Sickle Cell Consortium
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of Illinois
Sickle Cell Disease Foundation
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Foundation of Minnesota
Sickle Cell Transplant Advocacy and Research Alliance
Smile Sickle Cell Foundation
Southwest Louisiana Sickle Cell Anemia, Inc.
SSCDA
Terumo Blood and Cell Technologies
The Association for the Prevention of Sickle Cell Anemia, Inc. Harford/Cecil Counties
The Maryland Sickle Cell Disease Association
The Sickle Cell Association of New Jersey
The Sickle Cell Foundation of Tennessee
TOVA Community Health
Uriel Owens Sickle Cell Disease Association of the Midwest

Cc: The Honorable Nancy Pelosi, Speaker, U.S. House of Representatives
The Honorable Kevin McCarthy, Minority Leader, U.S. House of Representatives
The Honorable Mitch McConnell, Majority Leader, U.S. Senate
The Honorable Charles Schumer, Minority Leader, U.S. Senate