March 19, 2021

Sent via E-mail to:

Chairman Patrick Leahy
Senate Appropriations Committee
Washington, DC 20510

Vice Chairman Richard Shelby
Senate Appropriations Committee
Washington, DC 20510

Chairwoman Patty Murray
Senate Labor-HHS Appropriations Subcommittee
Washington, DC 20510

Ranking Member Roy Blunt
Senate Labor-HHS Appropriations Subcommittee
Washington, DC 20510

Chairwoman Rosa DeLauro
House Appropriations Committee
House Labor-HHS Appropriations Subcommittee
Washington, DC 20515

Ranking Member Kay Granger
House Appropriations Committee
Washington, DC 20515

Ranking Member Tom Cole
House Labor-HHS Appropriations Subcommittee
Washington, DC 20515

Dear Chairman Leahy, Ranking Member Shelby, Chairwoman Murray, Ranking Member Blunt, Chairwoman DeLauro, Ranking Member Granger, and Ranking Member Cole:

The undersigned organizations, all committed to improving the health of individuals living with sickle cell disease (SCD), ask that at least $5 million in dedicated funding for the Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection program be included in the fiscal year (FY) 2022 Labor HHS Appropriations Bill. This important program supports states in the collection and analysis of population-based surveillance data on people living with SCD in the United States. In addition, we request that funding be maintained for the Health Resources and Services Administrations' (HRSA) SCD grant programs – the SCD Treatment Demonstration Program and SCD Newborn Screening Program.

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.

Last fall, the National Academies of Sciences, Engineering, and Medicine (NASEM) released a 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 with SCD. Our organizations strongly support this recommendation and seek your support by providing at least $5 million in FY 2022 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 with transfers

from the HHS Office of Minority Health and CDC's Office of the Director. Currently eleven states participate – including California and Georgia, which have been collecting data under this program since 2015. Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Wisconsin were able to begin their programs in FY 2021 with the inclusion of $2 million in the FY 2021 Consolidated Appropriations Act for this program. In early March 2021, the program expanded to Colorado and Virginia with funding from the CDC Foundation. These eleven states are estimated to include just over 35% of the U.S. SCD population. CDC estimated in its FY 2020 budget justification that $25 million is needed to fully implement the data collection program in the U.S. We are seeking at least $5 million in FY 2022 to continue to phase in the data collection program in the currently participating states 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.

Additionally, our organizations are supportive of maintaining funding for the SCD programs within HRSA's Maternal and Child Health Bureau, including the SCD Treatment Demonstration Program (SCDTDP) and SCD Newborn Screening Program. The grantees funded by these programs work to improve access to quality care for individuals living with SCD and sickle cell trait. The SCDTDP funds five geographically distributed regional SCD grants that support SCD providers to increase access to high quality, coordinated, comprehensive care for people with SCD. The SCD Newborn Screening Program provides grants to support a National Coordinating and Evaluation Center and community-based demonstration sites across the country that support the comprehensive care for newborns diagnosed with SCD.

Please consider the organizations listed below as a resource on SCD and keep us apprised on how we can assist you. Thank you for your consideration and 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 Center
Association of Maternal & Child Health Programs
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Laboratories
Australian Sickle Cell Advocacy
Axis Advocacy
bluebird bio
Cayenne Wellness Center
Cerus Corporation
Chiesi Global Rare Diseases
Children's Healthcare of Atlanta
Children's Hospital of Philadelphia
Children's National Hospital
Cincinnati Children's Hospital
Crispr Therapeutics
Dreamsickle Kids Foundation
Duke Health

Emmaus Medical
European Sickle Cell Federation
Forma Therapeutics
Foundation for Sickle Cell Disease Research
Functional Fluidics
Global Blood Therapeutics
GlycoMimetics
Hemex Health
Imara Inc.
International Association of Sickle Cell Nurses and Professional Associates
Levine Cancer Institute, Atrium Health
Martin Center Sickle Cell Initiative
Medical University of South Carolina Shawn Jenkins Children's Hospital
Medunik USA
National Institute for Children's Health Quality
National Marrow Donor Program/Be The Match
National Medical Association
New York State Sickle Cell Advocacy Network
Northeast Louisiana Sickle Cell Anemia Foundation
Novartis Pharmaceuticals
SCDAA / Ohio Sickle Cell and Health Association
Seattle Children's
Sick Cells
Sickle Cell 101
Sickle Cell Adult Provider Network
Sickle Cell Aid Foundation
Sickle Cell Anemia Awareness of San Francisco
Sickle Cell Association Harford
Sickle Cell Association of Texas-Marc Thomas Foundation
Sickle Cell Disease Association of America
Sickle Cell Disease Association of America/ST Petersburg Chapter
Sickle Cell Disease Association of Illinois
Sickle Cell Disease Foundation
Sickle Cell Foundation of Georgia
Sickle Cell Foundation of Minnesota i
Sickle Cell Thalassemia Patients Network
Sickle Cell Transplant Advocacy & Research Alliance
SSM Health--Cardinal Glennon Children's Hospital
St. Louis Children's Hospital
Terumo BCT
The Emmes Company
The Maryland Sickle Cell Disease Association
The Sickle Cell Foundation of Tennessee
UPMC Children's Hospital of Pittsburgh
Uriel E. Owens Sickle Cell Disease Association of the Midwest
Vanguard Therapeutics
Vertex Pharmaceuticals