

February 26, 2018

The Honorable Tim Scott
717 Hart Senate Office Building
Washington, DC 20510

The Honorable Cory Booker
359 Dirksen Senate Office Building
Washington, DC 20510

Dear Senators Scott and Booker,

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), are writing to express their sincere appreciation for your efforts to enhance federal government activities in SCD surveillance, prevention and treatment services, with the introduction of the Sickle Cell Disease Surveillance, Prevention, and Treatment Act of 2018. The many complications of SCD can make every stage of life extremely challenging for individuals with the disease. This is compounded by the fact that many individuals living with SCD are unable to access quality care and are limited by a lack of effective treatment options.

This legislation will provide the Centers for Disease Control and Prevention (CDC) with much needed authority to carry out programs related to SCD, the complications related to the disease, and sickle cell trait. Specifically, we are very supportive of furthering CDC's population-based surveillance system for SCD, which is critically important to (1) improving the understanding of the health outcomes and health care system utilization patterns of individuals with SCD; and (2) increasing evidence for public health programs to establish cost-effective practices to improve and extend the lives of individuals with SCD. Additionally, the legislation reauthorizes the SCD treatment grants awarded by the Health Resources and Services Administration (HRSA), which help to improve access to care and quality of care for individuals with SCD.

We are hopeful that your bill and the companion bill in the United States House of Representatives, H.R. 2410, will advance through Congress this year. Please consider all of the organizations listed below as resources, and keep us apprised on how we can assist you. Thank you again for all of your efforts and leadership to improve the lives of individuals with this debilitating disease.

Sincerely,

AABB

American Academy of Emergency Medicine
American Academy of Pediatrics
American Public Health Association
American Red Cross
American Society for Blood and Marrow Transplantation
American Society for Clinical Pathology
American Society of Gene & Cell Therapy
American Society of Hematology
American Society of Nephrology
American Society of Pediatric Hematology/Oncology
American Thoracic Society
America's Blood Centers
Ann & Robert H. Lurie Children's Hospital of Chicago
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Laboratories

BJC St. Louis Children's Hospital
Cerus Corporation
Children's Healthcare of Atlanta
Children's National Health System
Children's Hospital of Philadelphia Sickle Cell Parents Network
Community Blood Center of the Carolinas
Foundation for Sickle Cell Disease Research
Global Blood Therapeutics Inc.
Greater Boston Sickle Cell Disease Association, Inc
Howard University Center for Sickle Cell Disease
Imara, Inc.
International Association of Sickle Cell Disease Nurses and Professional Associates (IASCNAPA)
James R. Clark Memorial Sickle Cell Foundation
Martin Center Sickle Cell Initiative
Medical University of South Carolina
National Institute for Children's Health Quality (NICHQ)
National Marrow Donor Program/ Be The Match
National Minority Quality Forum
Newark Beth Israel Medical Center
Novartis Pharmaceuticals Corporation
Ohio Conference of Branches of the NAACP
Ohio Sickle Cell Affected Families Association, Inc.
Ohio Sickle Cell and Health Association, Inc.
Pediatric Hospital Sickle Cell Collaborative
Piedmont Health Services and Sickle Cell Agency
Prolong Pharmaceuticals
Sickle Cell Anemia Awareness of San Francisco (SCAASF)
SCDAA Miami-Dade County Chapter
Seattle Children's
Sick Cells
Sickle Cell Adult Provider Network
Sickle Cell Association of Hillsborough County
Sickle Cell Association
Sickle Cell Association of Florida
Sickle Cell Association of Houston
Sickle Cell Association of New Jersey
Sickle Cell Association of Texas Marc Thomas Foundation
Sickle Cell Community Consortium
Sickle Cell Disease Association of America - Mobile Chapter
Sickle Cell Disease Association of America Central Alabama Chapter
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
Sickle Cell Disease Association St. Petersburg Chapter
Sickle Cell Disease Foundation of California
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Foundation of Tennessee
Sickle Cell Warriors
Sickle Cycle
Sickle Transplant Alliance for Research
South Central PA Sickle Cell Council
Southeast Alabama Sickle Cell Association Inc.