

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.