

July 18, 2018

The Honorable Lamar Alexander  
455 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Patty Murray  
154 Russell Senate Office Building  
Washington, DC 20510

Dear Chairman Alexander and Ranking Member Murray,

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), are writing in support of S. 2465, the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act of 2018, bipartisan legislation introduced by Senators Tim Scott (R-SC) and Cory Booker (D-NJ). We thank you both for your leadership in improving the public health of our country and ask that the bill be considered and passed by the Committee on Health, Education, Labor and Pensions (HELP) this summer.

S. 2465 authorizes a national SCD surveillance program with the goal of improving data collection on impacted patients in states with a higher prevalence of the disease. The Centers for Disease Control and Prevention (CDC) estimates that SCD affects nearly 100,000 Americans; however, absent a nationwide surveillance program, our confidence in this estimate is limited and we really do not know where these individuals live, receive care, or whether they have access to current treatments or specialists. Surveillance is critical to improving our ability to better serve and extend the lives of patients with SCD. SCD surveillance currently exists only in California and Georgia through a grant from the CDC Foundation. Maintaining this authorization specifically for SCD is crucial to allowing CDC to expand its efforts in this area.

The bill also reauthorizes the existing Health Resources and Services Administration's SCD Treatment Demonstration Program, which is important to improving patient access to the highest quality of care. The Demonstration Program continues to yield valuable results, increasing the number of SCD providers' knowledgeable about the most effective treatments for the disease.

Again, we thank you for your support for S. 2465. We are hopeful that the bill will advance through the HELP Committee this month, and through Congress this year. Please consider all of the organizations listed below as a resource, and keep us apprised on how we can assist you. Thank you for your efforts to improve the lives of individuals with this debilitating disease.

Sincerely,

AABB

American Academy of Emergency Medicine  
American Academy of Pediatrics  
American College of Emergency Physicians  
American Public Health Association  
American Red Cross  
American Society for Blood and Marrow Transplantation  
American Society of Gene & Cell Therapy  
American Society of Hematology

American Society of Pediatric Hematology/Oncology  
America's Blood Centers  
Ann & Robert H. Lurie Children's Hospital of Chicago  
ApoPharma  
Association of Public Health Laboratories  
Cerus Corporation  
Children's Healthcare of Atlanta  
Children's Hospital of Philadelphia  
Children's National Health System  
Children's of Alabama  
Faces of Our Children  
Foundation for Sickle Cell Disease Research  
Global Blood Therapeutics Inc.  
Howard University Center for Sickle Cell Disease  
Imara Inc.  
International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA)  
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 Medical Association  
Novartis Pharmaceutical Corporation  
Penn State Children's Hospital Pediatric Sickle Cell Program  
Prolong Pharmaceuticals, LLC  
Seattle Children's  
Sick Cells  
Sickle Cell 101  
Sickle Cell Affected Families of Greater Cincinnati  
Sickle Cell Disease Association – St. Petersburg Chapter  
Sickle Cell Disease Association of America – Central Alabama Chapter  
Sickle Cell Disease Association of America, Inc.  
Sickle Cell Disease Association of Florida  
Sickle Cell Disease Foundation  
Sickle Cell Foundation of Georgia, Inc.  
Sickle Cell Warriors  
Sickle Transplant Alliance for Research  
South Central PA Sickle Cell Council  
SSM Health Cardinal Glennon Children's Hospital  
St. Louis Children's Hospital  
The Sickle Cell Association of New Jersey  
The Sickle Cycle  
UPMC Children's Hospital of Pittsburgh  
Vanguard Therapeutics, Inc.

cc: Members of the Senate Committee on Health, Education, Labor and Pensions