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