Congress of the United States
Washington, DC 20515

March 9, 2018

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and Human Services
House Committee on Appropriations
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa L. DeLauro
Ranking Member
Subcommittee on Labor, Health and Human Human Services
House Committee on Appropriations
1016 Longworth House Office Building
Washington, DC 20515

Dear Chairman Tom Cole and Ranking Member Rosa L. DeLauro:

We appreciate your work in addressing health disparities in the United States. We share your goal of providing access to quality health care for African Americans and other historically underserved communities, particularly those families living with Sickle Cell Disease (SCD). SCD is an inherited blood disorder that is a major problem in the United States, causing episodes of severe pain, organ damage, serious infections, stroke, and repeated hospitalizations. An estimated 90,000-100,000 Americans live with the disease and more than 3 million Americans have the Sickle Cell Trait (SCT), including 1 in 12 African Americans. The average life span of an adult with SCD is 20-30 years shorter than an adult without the disease.

Firstly, we respectfully request $4.5 million in the fiscal year 2019 Labor, HHS and Education Appropriations bill, the Department of Health and Human Services, Health Resources and Services Administration account (Maternal and Child Health Bureau), for the Sickle Cell Anemia Demonstration Program and the Data Coordination Center pursuant to P.L. 108-357. This program request would (1) support four geographically distributed regional projects with nationwide exposure for enhanced access to comprehensive, coordinated, culturally-effective, and family-centered high quality services for individuals with sickle cell disease; (2) expansion and upgrade of data collection efforts, capacity and analysis to more fully acquire the evidence to evaluate the network activities and outcomes; and (3) focus on increasing the number of providers that are involved with the care of individuals with sickle cell disease by increasing the capacity of university medical centers and hematologists to provide technical assistance and educational opportunities.

Secondly, we respectfully request $4.5 million in the Fiscal Year 2019 Labor, HHS and Education Appropriations bill, the Department of Health and Human Services for the National Center on Birth Defects and Developmental Disabilities' Public Health Approach to Blood Disorders at the Centers for Disease Control and Prevention (CDC). The CDC's program focuses on specific blood diseases (Sickle Cell Disease, Hemophilia, Venous Thromboembolism, and Thalassemia) that will improve the quality of life for individuals.

Thirdly, we respectfully request $3 million in the Fiscal Year 2019 Labor, HHS and Education Appropriations bill to support the Department of Health and Human Services, Bureau of Maternal and

Child Health, Special Projects of Regional and National Significance (SPRANS) Sickle Cell Disease Community Outreach Demonstration Project pursuant to the Social Security Act, Title V, Section 502(a)(1) and (b)(1) and 501)(c)(1); Since 2002, the Sickle Cell Disease SPRANS project has supported a National Coordinating and Evaluation Center and 17 community-based demonstration sites across the country that provide SCD follow-up and other services to support the comprehensive care for newborns diagnosed with SCD. This program provides a continuity of medical services, education and counseling from birth to persons afflicted with SCD as well as those with the trait. These services are an invaluable resource to families and individuals suffering from this debilitating disease. Funding is needed to ensure the continuity of the programs.

Finally, we respectfully request that the Subcommittee commends the National Institute of Health (NIH) for its ongoing support of clinical research for Sickle Cell Disease (SCD), which imposes major morbidity on an estimated 90,000 to 100,000 individuals in the United States, with three million Americans carrying the sickle cell trait. The NIH is encouraged to support clinical trials for prenatal and postnatal treatment of SCD, which includes a wealth of promising approaches to eradicate this disease, save lives, and dramatically reduce the substantial health care costs associated with SCD for both children and adults. The NIH is encouraged to consider programs both domestically and globally to evaluate the effectiveness of screening technologies for infants and children with the sickle cell trait and disease.

Thank you for considering our request. We look forward to working with you to fund these three critical programs that will help African Americans and other historically-underserved children and families with Sickle Cell Disease to live longer and healthier lives.

Sincerely,

Danny K. Davis
Member of Congress

G. K. Butterfield
Member of Congress

Barbara Lee
Member of Congress

Terri A. Sewell
Member of Congress

Alma S. Adams, Ph.D.
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