

March 19, 2021

*Sent via E-mail to:*

Chairman Patrick Leahy  
Senate Appropriations Committee  
Washington, DC 20510

Vice Chairman Richard Shelby  
Senate Appropriations Committee  
Washington, DC 20510

Chairwoman Patty Murray  
Senate Labor-HHS Appropriations Subcommittee  
Washington, DC 20510

Ranking Member Roy Blunt  
Senate Labor-HHS Appropriations Subcommittee  
Washington, DC 20510

Chairwoman Rosa DeLauro  
House Appropriations Committee  
House Labor-HHS Appropriations Subcommittee  
Washington, DC 20515

Ranking Member Kay Granger  
House Appropriations Committee  
Washington, DC 20515

Ranking Member Tom Cole  
House Labor-HHS Appropriations Subcommittee  
Washington, DC 20515

Dear Chairman Leahy, Ranking Member Shelby, Chairwoman Murray, Ranking Member Blunt, Chairwoman DeLauro, Ranking Member Granger, and Ranking Member Cole: ~~THIS IS A PRIVATE AND CONFIDENTIAL MESSAGE. If you have received this message in error, please do not disseminate, distribute, copy, or otherwise use the information contained herein. If you have received this message in error, please notify the sender immediately by e-mail at [redacted].~~  
Hispanics. Individuals with the disease produce abnormal  
strokes, acute chest syndrome (a condition that lowers the l  
cases premature death. Barriers to receiving quality, comp

from the HHS Office of Minority Health and CDC's Office of the Director. Currently eleven states participate – including California and Georgia, which have been collecting data under this program since 2015. Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Wisconsin were able to begin their programs in FY 2021 with the inclusion of \$2 million in the FY 2021 Consolidated Appropriations Act for this program. In early March 2021, the program expanded to Colorado and Virginia with funding from the CDC Foundation. These eleven states are estimated to include just over 35% of the U.S. SCD population. CDC estimated in its FY 2020 budget justification that \$25 million is needed to fully implement the data collection program in the U.S. We are seeking at least \$5 million in FY 2022 to continue to phase in the data collection program in the currently participating states and to allow for an expansion to additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

Additionally, our organizations are supportive of maintaining funding for the SCD programs within HRSA's Maternal and Child Health Bureau, including the SCD Treatment Demonstration Program (SCDTDP) and SCD Newborn Screening Program. The grantees funded by these programs work to improve access to quality care for individuals living with SCD and sickle cell trait. The SCDTDP funds five geographically distributed regional SCD grants that support SCD providers to increase access to high quality, coordinated, comprehensive care for people with SCD. The SCD Newborn Screening Program provides grants to support a National Coordinating and Evaluation Center and community-based demonstration sites across the country that support the comprehensive care for newborns diagnosed with SCD.

Please consider the organizations listed below as a resource on SCD and keep us apprised on how we can assist you. Thank you for your consideration and

Emmaus Medical  
European Sickle Cell Federation  
Forma Therapeutics  
Foundation for Sickle Cell Disease Research  
Functional Fluidics  
Global Blood Therapeutics  
GlycoMimetics  
Hemex Health  
Imara Inc.  
International Association of Sickle Cell Nurses and Professional Associates  
Levine Cancer Institute, Atrium Health  
Martin Center Sickle Cell Initiative  
Medical University of South Carolina Shawn Jenkins Children's Hospital  
Medunik USA  
National Institute for Children's Health Quality  
National Marrow Donor Program/Be The Match  
National Medical Association  
New York State Sickle Cell Advocacy Network  
Northeast Louisiana Sickle Cell Anemia Foundation  
Novartis Pharmaceuticals  
SCDAA / Ohio Sickle Cell and Health Association  
Seattle Children's  
Sick Cells  
Sickle Cell 101  
Sickle Cell Adult Provider Network  
Sickle Cell Aid Foundation  
Sickle Cell Anemia Awareness of San Francisco  
Sickle Cell Association Harford  
Sickle Cell Association of Texas-Marc Thomas Foundation  
Sickle Cell Disease Association of America  
Sickle Cell Disease Association of America/ST Petersburg Chapter  
Sickle Cell Disease Association of Illinois  
Sickle Cell Disease Foundation  
Sickle Cell Foundation of Georgia  
Sickle Cell Foundation of Minnesota  
Sickle Cell Thalassemia Patients Network  
Sickle Cell Transplant Advocacy & Research Alliance  
SSM Health--Cardinal Glennon Children's Hospital  
St. Louis Children's Hospital  
Terumo BCT  
The Emmes Company  
The Maryland Sickle Cell Disease Association  
The Sickle Cell Foundation of Tennessee  
UPMC Children's Hospital of Pittsburgh  
Uriel E. Owens Sickle Cell Disease Association of the Midwest  
Vanguard Therapeutics  
Vertex Pharmaceuticals