

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 COMMUNICATION. IT IS NOT TO BE DISSEMINATED TO THE PUBLIC OR TO ANY OTHER SENATOR OR CONGRESSMAN WITHOUT THE WRITTEN PERMISSION OF THE SENATOR OR CONGRESSMAN WHO IS THE ORIGINATOR OF THIS MESSAGE.~~
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