July 23, 2026

Robert F. Kennedy, Jr.
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Kennedy,

The undersigned national, state and local organizations write to you today on behalf of the sickle cell disease community we serve to urge you to issue a one-year extension of the Health Resources and Services Administration's (HRSA) Sickle Cell Disease Newborn Screening Follow Up Program (FP). Congress included $7 million in statutory appropriations for this Program in the Consolidated Appropriations Act, 2026 (P.L. 119-75).

The FP provides grants to 25 sickle cell disease (SCD) community-based organizations (CBOs) across 22 states. The CBOs utilize these funds to provide direct services to individuals living with SCD. FP grant funding is often used to hire, train and maintain community health workers (CHWs), which have been proven to be effective and cost-saving when it comes to serving individuals living with a chronic disease. In fact, it was found that intervention by CHWs could save upwards of $5,900 per patient per year through reduced hospitalizations, shorter hospital stays, fewer emergency room visits, and better adherence to medication and preventative care recommendations.[1] FP grantees were given no notice of this grant being discontinued meaning the impact on the SCD community will be significant – jobs will be lost, services will be cut, and fewer SCD warriors will have access to support services that are crucial to their care.

We understand that HRSA is moving towards an integrated approach through the new Sickle Cell Disease Regional Care Excellence (SoRCE) Program. However, the SoRCE grant, as written, will actually result in fewer CBOs contracted with clinical sites and those that do receive contracts will be funded at levels significantly lower than the funding they received under the FP. A one-year extension will provide time for the SCD community to work with HRSA to strengthen the SoRCE Program and ensure that moving forward it adequately allows for access to high quality clinical care *and* community-based services for SCD warriors.

Throughout your time as Secretary, you have publicly voiced your support for the sickle cell disease community. We call on you now to use the $7 million Congress appropriated for sickle cell disease and provide a one-year extension to the current grantees of the SCD Newborn

[1] Avalon Health Economics. Commissioned by the Sickle Cell Disease Association of America. (2022 April 11). The Critical Role of Community Health Workers (CHW) and Health Navigators (HN) in Access to Care for Individuals with Sickle Cell Anemia.

Screening Follow Up Program or add this $7 million to the SoRCE Program and require that it be used to contract with additional CBOs to support services for the SCD community.

If you have any questions or need more information, please reach out to Ellen Riker, Federal Policy Advisor for the Sickle Cell Disease Association of America, Inc. at eriker@artemispolicygroup.com.

Sincerely,

Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America, Inc.'s Medical Research and Advisory Committee
Agios
American Society of Hematology
American Society of Pediatric Hematology/Oncology
Association for the Prevention of Sickle Cell Anemia, Inc.
Bridging the Gap-Adult Sickle Cell Disease Foundation of Nevada
Genetix Biotherapeutics
James R. Clark Memorial Sickle Cell Foundation
Martin Center Sickle Cell Inc.
National Alliance of Sickle Cell Centers
North Alabama Sickle Cell Foundation, Inc.
Piedmont Health Services and Sickle Cell Agency (Greensboro, NC)
SC RED (Sickle Cell Reproductive Health Education Directive)
SCDAA Ohio Sickle Cell and Health Association
Sick Cells
Sickle Cell Anemia Foundation of Oregon & Pacific Northwest
Sickle Cell Association (St. Louis, MO)
Sickle Cell Association of Kentuckiana
Sickle Cell Association, Inc. (Norfolk, VA)
Sickle Cell Disease Association of America, Michigan Chapter, Inc.
Sickle Cell Disease Association of America, Mobile, AL Chapter
Sickle Cell Disease Association of America, Philadelphia Chater
Sickle Cell Disease Association of Illinois
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Foundation of Minnesota
Sickle Cell Foundation of Palm Beach County and Treasure Coast
Sickle Cell Medical Advocacy. Inc. (Orlando, FL)
Sickle Cell Prodigy (Spokane, WA)
Sickle Cell Warriors of Wisconsin
Supporters of Families with Sickle Cell Disease, Inc. (Oklahoma)
The Sickle Cell Council of New Mexico, Inc.
TOVA Community Health