

# Congress of the United States

Washington, DC 20515

May 28, 2026

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

Administrator Thomas J. Engels  
Health Resources & Services Administration  
5600 Fishers Lane  
Rockville, MD 20857

Dear Secretary Kennedy and Administrator Engels:

As Members of Congress who support access to sickle cell screening, we are reaching out regarding the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau's Sickle Cell Disease Newborn Screening Follow-Up Program (Follow-Up Program). The current five-year grant cycle for this program ends August 31, 2026, but HRSA has yet to issue a new Notice of Funding Opportunity for the next grant cycle. We are worried that a delay in awarding grants will impact the continuation of the critical services provided by the community-based organizations that participate in the program and respectfully request that this funding notice be released quickly by HRSA to ensure there is no lapse in these important services.

While newborn screening for sickle cell disease (SCD) occurs in every state, many individuals are lost to follow-up care or face barriers to access high-quality care throughout their lifetime. HRSA's Sickle Cell Disease Newborn Screening Follow-Up Program works in tandem with HRSA's Sickle Cell Disease Treatment Demonstration Program (SCD TDP) to help address these access issues. The Follow-Up Program focuses on providing supportive services to individuals living with sickle cell disease and their families while the SCD TDP focuses on the clinical aspect of care for individuals with SCD and bolstering provider education related to SCD. Together, the two programs aim to support the social, behavioral, and clinical needs of the SCD community throughout the US. A five-year extension of the authority for these two programs was included in H.R. 1796, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2025. This bill was signed into law as part of the Consolidated Appropriations Act, 2026, which also maintained funding for both programs at current levels.

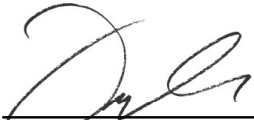
The Follow-Up Program is the only federal program that directly provides financial support to SCD community-based organizations (CBOs) and has been funded through the Congressional appropriations process every year since it began in 2002. For FY 2026, the program provides grants to 25 SCD CBOs across 22 states supporting activities such as using community health workers (CHWs) to conduct outreach and connect individuals in the SCD community with education and resources, and to provide for collaboration with state newborn screening programs to ensure that each family that receives a diagnosis of SCD is supported and connected to the appropriate primary and specialty care. SCD CBOs are the backbone of the SCD community. They are on the ground, serving the community everyday providing a myriad of services including education, transportation, financial support, behavioral health services/support, and much more. CBOs are trusted by the SCD community and are typically the first place an individual living with SCD will turn for help.

An estimated 100,000 individuals in the U.S. are living with SCD. SCD, an inherited disease, causes red blood cells to become sickle-shaped, making it difficult for the blood cells to pass through small vessels. This causes significant pain crises, the most common side effect of SCD, but individuals may experience other severe complications, including strokes, and damage to vital organs, such as the eyes, kidneys, lungs and heart. Life

expectancy at birth is 52.6 years, more than twenty years shorter than the life expectancy of the average American. While SCD disproportionately impacts Black and brown communities, it affects people of all ethnicities, and early screening is critical to early detection and treatment

We appreciate your continued support for the sickle cell disease community, and we call on you today to quickly issue the next funding opportunity for HRSA's Sickle Cell Disease Newborn Screening Follow-Up Program to ensure the next five-year grant cycle, set to start September 1, 2026, proceeds without delay.

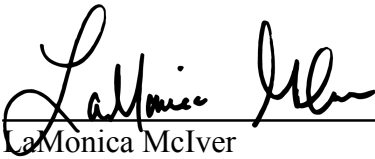
Sincerely,



Troy A. Carter, Sr.  
Member of Congress



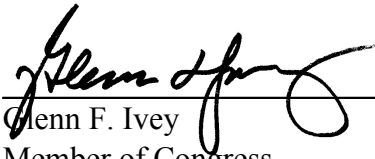
Alma S. Adams, Ph.D.  
Member of Congress



LaMonica McIver  
Member of Congress



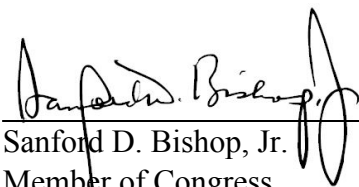
Rashida Tlaib  
Member of Congress



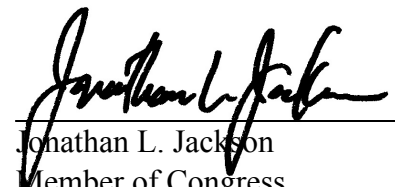
Glenn F. Ivey  
Member of Congress



Suzan K. DelBene  
Member of Congress



Sanford D. Bishop, Jr.  
Member of Congress



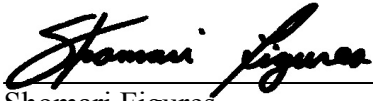
Jonathan L. Jackson  
Member of Congress



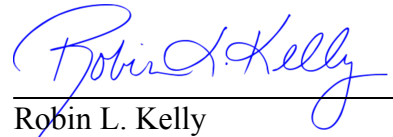
SETH MOULTON  
Member of Congress



Paul D. Tonko  
Member of Congress



Shomari Figures  
Member of Congress



Robin L. Kelly  
Member of Congress



Shri Thanedar  
Member of Congress



Yvette D. Clarke  
Member of Congress



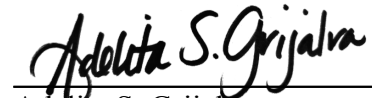
Summer L. Lee  
Member of Congress



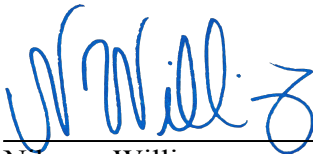
Al Green  
Member of Congress



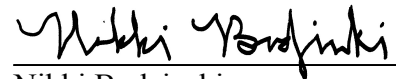
Marc A. Veasey  
Member of Congress



Adelta S. Grijalva  
Member of Congress



Nikema Williams  
Member of Congress



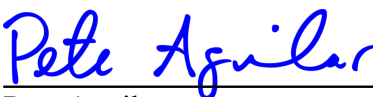
Nikki Budzinski  
Member of Congress



Emilia Strong Sykes  
Member of Congress



Kim Schrier, M.D.  
Member of Congress



Pete Aguilar  
Member of Congress



Steve Cohen  
Member of Congress

A handwritten signature in blue ink, reading "Steven Horsford", written over a horizontal line.

Steven Horsford  
Member of Congress

A handwritten signature in blue ink, reading "Terri A. Sewell", written over a horizontal line.

Terri A. Sewell  
Member of Congress

A handwritten signature in blue ink, reading "Shontel M. Brown", written over a horizontal line.

Shontel M. Brown  
Member of Congress