SOUTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES
Healthy Connections
MEDICAID

To: The Honorable Henry McMaster, Governor of the State of South Carolina
The Honorable Harvey S. Peeler, Jr., Chairman of the Senate Finance Committee
The Honorable Bruce W. Bannister, Chairman of the House Ways and Means Committee

From: South Carolina Department of Health and Human Services

Re: SFY 2024 - 2025 Proviso 117.136 – GP: Sickle Cell Disease Report

Date: January 15, 2026

1. Introduction

This report is submitted pursuant to Section 117.136, (GP: Sickle Cell Disease). The Proviso states:

> From the funds appropriated to the Department of Health and Human Services, the Department shall transfer up to $2,000,000 to the Medical University of South Carolina Hospital Authority to develop a comprehensive approach to advancing the awareness, detection, treatment, and scientific knowledge of sickle cell disease and trait within South Carolina. The Medical University of South Carolina Hospital Authority (MUHA) shall be authorized to partner with independent research entities to advance curative therapies for sickle cell disease and trait and shall be authorized to endow one or more nationally leading academic research centers with a research chair named the "Rena N. Grant Endowed Chair for Hematology" in furtherance of this goal. Additionally, to improve the quality of care provided to sickle cell patients, the authority shall perform statewide cultural competency training in all hospitals, including urgent care centers, in this State using its preexisting training model in order to educate and increase the awareness of health care professionals that are most likely to treat sickle cell patients on the symptoms and stigma associated with sickle cell disease and trait, especially pain relief.
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> For purposes of this proviso: a final report shall be provided no less than 30 business days after January 15, 2026. The Department and the authority shall each submit a report to the Chairman of the Senate Finance Committee, the Chairman of the House Ways and Means Committee, and the Governor outlining their progress on these initiatives.

2. Status

A. Transfer of Funds

SCDHHS has transferred $2,000,000.00, through contractual means to MUHA to continue developing a comprehensive approach to advancing the awareness, detection, treatment, and scientific knowledge of sickle cell disease and sickle cell trait in South Carolina.

B. Report of Goals for SFY 2025

To promote the goals stated in Proviso 117.136, SCDHHS requires MUHA to submit quarterly reports demonstrating its efforts to achieve the eight goals stated in the contract. In summary, the goals and reported activities are as follows:

1. Develop a comprehensive approach to advancing the awareness, detection, treatment, and scientific knowledge of sickle cell disease and trait in South Carolina.

- MUHA participated in the following activities to support awareness:
    - Circle of Hope Campaign: In partnership with the American Red Cross and News Station WCBD 2 Charleston, MUHA launched a statewide media campaign from January through September 2025, culminating just prior to the Evening of Action event on September 25.
    - Jeremiah Henry Kendrick Memorial Blood Drive and Health Fair in North Charleston: this event was held on February 1, 2025, and included screening for sickle cell trait/disease in partnership with the Committee on Better Racial Assurance (COBRA) Human Services Agency.
    - Development of a Sickle Cell Registry within the Epic electronic medical record software system is underway to comply with National Alliance of Sickle Cell Centers Globin Regional Data and Discovery requirements. This tool allows real-time tracking of critical metrics such as vaccinations, labs, and screenings.
    - More than 35 other community engagement activities across the state of South Carolina were conducted.
    - In addition to screening and access to gene therapy, MUHA has provided statewide access to hematology specialists though on site and telemedicine programs.

2. Endow a chair named the "Rena N. Grant Endowed Chair for Hematology" to drive education, advance care, and share information on the state-of-the-art clinical advances for the care of citizens who suffer from sickle cell disease and trait.

- The Rena N. Grant Sickle Cell Center opened January 2022 and is staffed with an interdisciplinary team, creating access to specialized care. Palliative care, behavioral resources, and programing to assist with transition of care from pediatric to adult services were added in March of 2024.
- Recruitment for the Endowed Chair is ongoing.
- A total of 1,035 patients have accessed the clinic this fiscal year (63 were new patients).

3. Hire one Community Liaison and one Community Health Worker to assist with addressing social determinants of health.

- The Community Liaison position was filled as well as one transition coordinator.
- Two additional positions will be created to include a hybrid Community Health Worker and Liaison to engage with the community and individuals living with sickle cell disease throughout the state. Provider recruitment is in progress (some positions have been hired while others are waiting to be filled).

4. Provide an additional clinic in Orangeburg and a transition clinic for adolescents in Charleston to support those suffering with sickle cell disease.

- The Orangeburg clinic is open and offers medical home care with the support of a physician 2 days per week. A provider has completed training and now is offering medical home care in Orangeburg. Acute care services were added in October 2025.

- Kingstree Clinic Development (Pee Dee Region) – In progress with the goal of opening in 2026.
- The transition clinic for adolescent and young adult patients was launched in 2025.
    - Transition Coordinator has been integrated into adult care appointments.
    - A physician joined the clinic to support complex pain management.
    - Earned National Alliance of Sickle Cell Center designation.
    - Expanded Behavioral Health services with the addition of two psychiatrists.
    - Creative therapies now include pet therapy and art therapy.

5. Partner with independent research entities to advance curative therapies for sickle cell disease and create a clearinghouse where best practices are distributed.

- Monthly research meetings include:
    1. Novo Nordisk
    2. Editas
    3. National Alliance of Sickle Cell Centers
    4. Cardeza Foundation for Hematologic Research at Thomas Jefferson University

6. Perform statewide cultural competency training in all hospitals, including urgent care centers to educate and increase the awareness of health care professionals on the symptoms and stigma associated with sickle cell disease, trait, and pain relief.

- On November 7, 2025, at the State School Nurses Meeting, MUHA presented best practices for supporting students living with sickle cell disease in the school setting.

7. Disseminate best practices, latest research, and emerging sickle cell disease therapies statewide.

- Focused education provided for emergency medicine and primary care/family practice providers in Columbia, with plans to expand statewide.

- Statewide Sickle Cell Clinical Board: The Tumor Board Model was adopted which provides an interdisciplinary resource of providers, pharmacists, nurses, behavioral health clinicians etc., who offer expertise on complex cases for providers throughout the state who may not have access to sickle cell experts. The first board review has been completed with plans to move forward with monthly meetings.

- Planning for the January 2026 statewide sickle cell summit is ongoing with the goal to launch the first session at the South Carolina Medical Association's Annual Meeting in April 2026 in Charleston, South Carolina.

8. Provide outreach to rural or underserved populations within South Carolina to address health disparities.

- Focused education for Emergency Medicine providers and Primary Care/Family Practice providers: The first round of educational sessions were completed in Columbia on December 13, 2024, March 14, 2025, June 5, 2025, September 4, 2025, and December 12, 2025.

- A partnership with Uber Health is in development to address transportation gaps when traditional options are unavailable. This aims to improve timely access to care and reduce missed appointments.

MUHA has shared with SCDHHS what it will continue to pursue for state fiscal year 2026 to ensure that the above goals will be met. SCDHHS will review and provide feedback on reports submitted by MUHA that will be used as evidence to evaluate goal achievement.

C. Development of Goals for SFY2026

The program has been tasked by SCDHHS to create a three-year strategic plan. The plan would include a compelling vision and mission statement as well as an action plan with measurable goals and objectives reflecting a comprehensive approach to furthering the awareness, detection, treatment, and scientific knowledge of sickle cell disease and trait in South Carolina.

3. **Conclusion:** SCDHHS will continue to work with MUHA and other healthcare partners to ensure the goals stated in this Proviso are achieved.