

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: December 4, 2024

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 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.

For purposes of this proviso: a final report shall be provided no less than thirty (30) business days after January 15, 2025. 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

Proviso 117.136 requires the South Carolina Department of Health and Human Services (SCDHHS) to transfer an amount not to exceed \$2 million to the Medical University of South Carolina Hospital Authority (MUHA). From July 1, 2024, to present, SCDHHS has transferred \$741,496.94, 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 from 2023-2024

MUHA's 2023-2024 contract stipulated eight goals were to be achieved. MUHA has continued to report progress toward achieving these eight goals during the current reporting period and anticipates achieving these goals by the end of the current state fiscal year. Updates on progress made by MUHA toward each goal is included below.

1. Develop a comprehensive approach to advancing the awareness, detection, treatment, and scientific knowledge of sickle cell disease and trait in South Carolina.
 - Results of goals 2-8 demonstrate progress toward this overarching goal.
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 in January 2022 and has been staffed with an interdisciplinary team. This created access to specialized care. palliative care, community 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.
 - 1,035 patients have accessed the clinic this fiscal year.
3. Hire one community liaison, and one community health worker to assist with addressing social determinants of health.
 - The community liaison position was hired, as well as one transition coordinator.
 - Two additional positions will be created to include a hybrid community health worker and a liaison to engage with the community and individuals living with sickle cell disease throughout the state. The goal is to have these positions approved and posted during the first quarter of 2025.
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 space is ready. Interviews for providers to staff the clinic are ongoing. Additionally, analysis has demonstrated value in opening a clinic in the Pee Dee region as well. The goal is to open the Pee Dee and Orangeburg locations in 2025.
 - The launch for the transition clinic for adolescent and young adult patients in Charleston is planned for May 2025.
5. Partner with independent research entities to advance curative therapies for sickle cell disease and create a clearinghouse where best and effective practices can be distributed.
 - Monthly research meetings are occurring to include:
 1. Novo Nordisk (pharmaceutical company developing drugs to treat sickle cell disease)
 2. Editas (biotechnology company developing therapies for rare diseases)
 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.

- State-wide Provider Summit: The summit was held Nov. 6, 2024, including a keynote speaker from John Hopkins University with the target audience of healthcare providers. The summit also included a patient and caregiver panel.
 - World Sickle Cell Awareness Day: This day was recognized on June 19, 2024. Activities focused on healthcare providers. This was achieved with the program educating over 250 staff members across the Charleston ED and Inpatient Settings. MUHA launched a statewide campaign aimed at raising awareness for sickle cell disease across all MUSC Divisions in South Carolina, in addition to social media platforms to include Instagram, Facebook, and LinkedIn. The program also wrote a Proclamation for World Sickle Cell Day on June 19th and there are plans to expand this initiative in 2025.
 - Grand rounds offered via technology platforms: The first grand rounds were completed by Dr. Abrams with plans to move forward on a quarterly basis.
7. Disseminate best practices, latest research, and emerging sickle cell disease therapies statewide.
- Focused education was provided for emergency medicine and primary care/family practice providers in Columbia, with plans to expand statewide.
 - The Statewide Sickle Cell Clinical Board adopted the Tumor Board Model, which allows for an interdisciplinary resource of providers, pharmacists, nurses, behavioral health clinicians etc., who will 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.
8. Provide outreach to rural or underserved populations within South Carolina to address health disparities.
- Focused education for: The first round of focused education for emergency medicine and primary care/family practice providers was completed in Columbia with plans to move forward across the state.

Development of Goals for 2024-2025

Going forward, the program will be tasked with creating a three-year strategic plan that will create an action plan with measurable goals and objectives to create a comprehensive approach to further drive sickle cell awareness statewide.

3. **Conclusion:** This report documents progress achieved toward the goals established in 2023-2024. SCDHHS will continue to work with MUHA and other health care partners to ensure the goals stated in this proviso are achieved.