

## South Carolina Department of Health and Human Services FY 23-24 Proviso 117.138 – Sickle Cell Disease

### 1. Introduction

This Report is submitted pursuant to Section 117.138, (GP: Sickle Cell Disease). The Proviso states:

*From the funds appropriated to the Department of Health and Human Services, the department shall transfer \$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: By January fifteenth of the current fiscal year, 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 117.138 requires the South Carolina Department of Health and Human Services (SCDHHS) to transfer \$2,000,000.00 to the Medical University of South Carolina Hospital Authority (MUHA). 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 from 2022-2023

- 1) Partner with research entities to advance curative therapies.
  - a. Current research projects are ongoing with the establishment of a registry, and monthly collaborative meetings are occurring.
  - b. Grand rounds were completed via technology platforms and will continue on a quarterly basis.
  - c. A statewide Sickle Cell Clinical Board was implemented using the Tumor Board model, allowing for an interdisciplinary resource of providers, pharmacists, nurses, and behavioral health clinicians, to offer expertise on complex cases for providers throughout the state who may not have access to sickle cell experts.
  - d. AgileMD, a clinical care pathway created by MUSC to assist healthcare institutions that use EPIC as their electronic medical record, was implemented.
  
- 2) Endow one or more nationally leading academic research centers with a research chair.
  - a. The Rena N. Grant Sickle Cell Center was opened in January 2022 and has been staffed with an interdisciplinary team, creating access to specialized care. This includes palliative care and behavioral health resources, and programming to assist with transition of care from pediatric to adult services will be implemented in March 2024.
  
- 3) Perform statewide training to educate and increase awareness of healthcare professionals.
  - a. Focused education was provided for emergency medicine and primary care/family practice providers in Columbia, with plans to expand training statewide.
  - b. Sickle Cell Awareness Day/Month activities focused on healthcare providers were completed, with plans to expand this initiative in 2024.
  - c. Sickle cell education for residents, medical students and nursing students is ongoing and will be expanding in the coming year.
  - d. Partnership with community agencies for vocational efforts on behalf of patients has been created and it is anticipated to be expanded in 2024 to specifically address the multidisciplinary transition clinic team.

Outcomes achieved in 2022-2023 demonstrate that progress has been made, and the achievement of future goals will ensure that South Carolinians will benefit from the investments made in this sickle cell disease initiative.

### C. Development of Goals for 2023-2024

To promote the goals stated in Proviso 117.138, SCDHHS requires MUHA to submit quarterly reports that demonstrate its efforts to achieve the eight (8) goals stated in the contract that covers SFY 2023-2024. In summary the goals 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;
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;
3. Hire one Community Liaison, and one Community Health Worker to assist with addressing social determinants of health;
4. Provide additional clinic in Orangeburg, and a Transition Clinic for adolescents in Charleston to support those suffering with sickle cell disease;
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;
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;
7. Disseminate best practices, latest research, and emerging sickle cell disease therapies statewide and;
8. Provide outreach to rural or underserved populations within South Carolina to address health disparities.

SCDHHS will continue to review reports submitted by MUHA to evaluate achievement of stated goals and strategies.

### 3. Conclusion

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