

South Carolina Department of Health and Human Services

SFY 2023 Proviso 117.142 Report – Sickle Cell Disease

117.142 (GP: Sickle Cell Disease) From the funds appropriated to the Department of Health and Human Services, the department shall transfer \$1,000,000 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:

- (1) 'Health care professional' has the meaning as in Section 44-66-20 of the 1976 Code.
- (2) 'Hospital' means a facility organized and administered to provide overnight medical or surgical care or nursing care of illness, injury, or infirmity and may provide obstetrical care, and in which all diagnoses, treatment, or care is administered by or under the direction of persons currently licensed to practice medicine, surgery, or osteopathy.

In developing and implementing the South Carolina Statewide Telemedicine Network, the department and the authority shall include the goals set forth in this provision to bring better care to individuals with sickle cell disease or trait.

The Department of Health and Human Services shall be authorized to pursue a Health Services Initiative through the Children's Health Insurance Program for the purposes of improving child and maternal health when either or both exhibit the sickle cell disease or trait, and improve outreach, access to crisis stabilization, and coping resources for children with sickle cell disease.

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.

Status

Proviso 117.142 requires the South Carolina Department of Health and Human Services (SCDHHS) to transfer \$1,000,000 to the Medical University of South Carolina Hospital Authority (MUHA). SCDHHS has transferred \$1,000,000, through contractual means, to MUHA to continue developing a comprehensive approach to advancing the awareness, detection, treatment, and scientific knowledge of sickle cell disease or trait within South Carolina.

SCDHHS conducts quarterly discussions with MUHA to share lessons learned; best and effective practices; innovative strategies; challenges, and other issues that will ensure achievement of the goals stated in this proviso. Additional discussions will be conducted with other related organizations on a regional and national scale to benchmark methodologies where sickle cell disease or sickle cell trait have been implemented.

Proviso 117.142 also requires MUHA and SCDHHS to include the goals set forth in the proviso to bring better care to individuals with sickle cell disease when developing and implementing the South Carolina Statewide Telemedicine Network (SCSTN). SCDHHS will work with the SCSTN to achieve the goals stated in this proviso. Through this collaboration, SCDHHS will focus on using telehealth to increase access to health-related opportunities including healthcare services related to sickle cell disease and sickle cell trait.

Additionally, SCDHHS has collaborated with the University of South Carolina's Center for Community Health Alignment to continue a pilot program exploring the role of community health workers to address the needs of those affected by sickle cell disease and trait.

Through this multi-pronged effort, SCDHHS will continue to work with MUHA and other stakeholders to advance the comprehensive approach it has developed to achieve its goals related to improving outcomes for those affected by sickle cell disease and trait.