

## Amendment: 5

Representative **Cobb-Hunter** proposes the following amendment:

### SECTION 117 – X900 GENERAL PROVISIONS

New

**117.scd.** (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 (HSI) through the Children’s Health Insurance Program (CHIP) 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.