A bill to be entitled

An act relating to review and report on sickle cell disease medications, treatments, and services for Medicaid recipients; creating s. 409.91235, F.S.; requiring the Agency for Health Care Administration, in consultation with certain entities, to review sickle cell disease medications, treatments, and services for Medicaid recipients and develop a written report, post the report on its website, and submit a copy of the report to the Governor, the Legislature, and certain entities by a specified date and every 2 years thereafter; providing requirements for the report; providing an appropriation; providing an effective date.

Be It Enacted by the Legislature of the State of Florida:

Section 1. Section 409.91235, Florida Statutes, is created to read:

409.91235 Agency review and report on medications, treatments, and services for sickle cell disease.—

(1) The Agency for Health Care Administration, in consultation with the Florida Medical Schools Quality Network and a dedicated sickle cell disease medical treatment and research center that maintains a sickle cell patient database

and tracks sickle cell disease outcome measures, shall, every 2 years:

(a) Conduct a review to determine whether the available covered medications, treatments, and services for sickle cell disease are adequate to meet the needs of Medicaid recipients diagnosed with such disease and whether the agency should seek to add additional medications, treatments, or services for better outcomes.

(b)1. Develop a written report that details the review findings.

2. By November 1, 2024, and every other year thereafter, post the report on the agency's website.

3. Submit a copy of the report to the Governor, the President of the Senate, the Speaker of the House of Representatives, the Department of Health Office of Minority Health and Health Equity, and the Rare Disease Advisory Council.

(2)(a) The report must be based on the data collected from the prior 2 years and must include any recommendations for improvements in the delivery of and access to medications, treatments, or services for Medicaid recipients diagnosed with sickle cell disease.

(b) The report must provide detailed information on Medicaid recipients diagnosed with sickle cell disease, including:

1. The total number of Medicaid recipients diagnosed with

sickle cell disease.

2. The age and population demographics of the Medicaid recipients diagnosed with sickle cell disease.

3. The health care utilization patterns and total expenditures, both pharmaceutical and medical, for services provided by Medicaid for all Medicaid recipients diagnosed with sickle cell disease.

4. The number of Medicaid recipients diagnosed with sickle cell disease within the general sickle cell patient population who have experienced two or more emergency room visits or two or more hospital inpatient admissions in a 12-month period, including length of stay, and the expenditures, both pharmaceutical and medical, for those Medicaid recipients.

5. The number of clinical treatment programs available for the care of Medicaid recipients diagnosed with sickle cell disease which are specifically designed or certified to provide health care coordination and health care access for individuals diagnosed with sickle cell disease and the number of those clinical treatment programs, per region, with which managed care plans have contracted.

6. An assessment of the agency's existing payment methodologies for approved treatments or medications for the treatment of sickle cell disease in the inpatient setting and whether such payment methodologies result in barriers to access. If barriers to access are identified, an assessment of whether

<u>such methodologies may be modified or improved through the adoption of new or additional policies.</u>

Section 2. <u>For the 2023-2024 fiscal year, the sum of $250,000 in nonrecurring funds from the General Revenue Fund is appropriated for the Agency for Health Care Administration to conduct a review and develop a written report which identifies the total number of Medicaid recipients diagnosed with sickle cell disease. The agency shall conduct the review and develop the written report in consultation with the Florida Medical Schools Quality Network and a dedicated sickle cell disease medical treatment and research center that maintains a sickle cell patient database and tracks sickle cell disease outcome measures. The agency shall identify Medicaid recipients diagnosed with sickle cell disease within the general sickle cell patient population who have experienced two or more emergency room visits or two or more hospital inpatient admissions in a 12-month period. For both of those populations, the agency shall provide detailed information including age and population demographics, health care utilization patterns and expenditures for all pharmaceutical and medical services provided, and the number of clinical treatment programs available which are specifically designed or certified to provide health care coordination and health care access for individuals diagnosed with sickle cell disease and the number of those clinical treatment programs available and contracted with</u>

<u>managed care plans for the care of Medicaid recipients diagnosed with sickle cell disease. The agency shall submit the report to the Governor, the President of the Senate, the Speaker of the House of Representatives, the Department of Health Office of Minority Health and Health Equity, and the Rare Disease Advisory Council by November 1, 2024.</u>

Section 3. This act shall take effect July 1, 2023.