By Senator Rouson

16-01044-23 20231352__

A bill to be entitled

An act relating to Medicaid enrollees with sickle cell disease; creating s. 409.9129, F.S.; requiring the Agency for Health Care Administration to conduct a biennial review of Medicaid enrollees with sickle cell disease to determine if the available covered medications, treatment, and services are adequate to meet their needs; providing minimum requirements for the review; requiring the agency to submit a report of its findings to the Governor, the Legislature, the Office of Minority Health and Health Equity, and the Rare Disease Advisory Council by a specified date every 2 years; requiring the agency to publish the report on its website in an easily accessible manner; requiring the agency to develop its review and report in consultation with a certain dedicated sickle cell disease medical treatment and research center; providing an effective date.

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

Section 1. Section 409.9129, Florida Statutes, is created to read:

409.9129 Biennial review of Medicaid enrollees with sickle cell disease.—

(1) Every two years, the agency shall conduct a review of Medicaid enrollees to determine if the available covered medications, treatment, and services are adequate to meet the needs of enrollees who are diagnosed with sickle cell disease

<u>and whether the agency should seek coverage of additional medications, treatment, or services to adequately meet their needs.</u>

<u>(2) Using data collected under the Medicaid program from the preceding 2-year period, the agency's review must provide for all of the following, at a minimum:</u>

<u>(a) The total number of Medicaid enrollees diagnosed with sickle cell disease.</u>

<u>(b) The age and other demographic characteristics of Medicaid enrollees diagnosed with sickle cell disease.</u>

<u>(c) Health care utilization patterns and total expenditures, both pharmaceutical and medical, for services provided by the Medicaid program for all enrollees diagnosed with sickle cell disease.</u>

<u>(d) Of the enrollees diagnosed with sickle cell disease, the number of enrollees who experienced two or more emergency room visits or two or more hospital inpatient admissions in a 12-month period, including the length of stay and the total related expenditures, both medical and pharmaceutical, for those enrollees.</u>

<u>(e) The number of clinical treatment programs available for the care of Medicaid enrollees which are specifically designed or certified to provide health care coordination and health care access for individuals with sickle cell disease and the number of those clinical treatment programs contracted, per region, with managed care plans.</u>

<u>(f) An assessment of the agency's existing payment methodologies for approved treatment or drug products for the treatment of sickle cell disease in the inpatient setting and</u>

<u>whether such payment methodologies result in barriers to access. If barriers to access are identified, an assessment of whether such methodologies may be modified or improved through the adoption of revised or new policies.</u>

<u>(3) By November 1, 2024, and every 2 years thereafter, the agency shall submit a report of its findings and recommendations from the preceding 2-year review to the Governor, the President of the Senate, the Speaker of the House of Representatives, the Office of Minority Health and Health Equity, and the Rare Disease Advisory Council. The agency shall also publish the report on its website in a manner easily accessible by the public.</u>

<u>(4) The agency shall develop its review and report in consultation with a dedicated sickle cell disease medical treatment and research center that maintains a sickle cell patient database and tracks sickle cell disease outcome measures.</u>

Section 2. This act shall take effect July 1, 2023.