A bill to be entitled

An act relating to sickle cell disease medications, treatment, and screening; creating s. 383.147, F.S.; requiring certain health care providers to notify primary care physicians of newborns and infants of certain screening results relating to sickle cell hemoglobin variants and to submit such results to the Department of Health for a specified purpose; requiring such physicians to provide certain information to certain parents and guardians; requiring the department to contract with a specified center to establish and maintain a sickle cell registry; providing the purpose of the registry; authorizing certain parents and guardians to request to have their children removed from the registry; providing duties of the department and the center; providing requirements for certain notification; requiring the department to adopt rules; 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 appropriations and authorizing positions; providing an effective date.

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

Section 1. Section 383.147, Florida Statutes, is created to read:

<u>383.147 Newborn and infant screenings for sickle cell hemoglobin variants; registry.—</u>

<u>(1) If a screening provider detects that a newborn or infant, as those terms are defined in s. 383.145(2), is carrying a sickle cell hemoglobin variant, it must notify the primary care physician of the newborn or infant and submit the results of such screening to the Department of Health for inclusion in the sickle cell registry established under paragraph (2)(a). The primary care physician must provide to the parent or guardian of the newborn or infant information regarding the availability and benefits of genetic counseling.</u>

<u>(2)(a) The Department of Health shall contract with a community-based sickle cell disease medical treatment and research center to establish and maintain a registry for newborns and infants who are identified as carrying a sickle cell hemoglobin variant. The sickle cell registry must track sickle cell disease outcome measures. A parent or guardian of a</u>

newborn or infant may request to have his or her child removed from the registry by submitting a form prescribed by the department by rule.

(b) The Department of Health shall also establish a system to ensure that the community-based sickle cell disease medical treatment and research center notifies the parent or guardian of a child who has been included in the registry that a followup consultation with a physician is recommended. Such notice must be provided to the parent or guardian of such child at least once during early adolescence and once during late adolescence. The department shall make every reasonable effort to notify persons who are 18 years of age and who have been included in the registry that they may request to be removed from the registry by submitting a form prescribed by the department by rule. The department shall also provide to such persons information regarding available educational services, genetic counseling, and other beneficial resources.

(3) The Department of Health shall adopt rules to implement this section.

Section 2. 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

<u>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:</u>

<u>(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.</u>

<u>(b)1. Develop a written report that details the review findings.</u>

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

<u>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.</u>

<u>(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.</u>

<u>(b) The report must provide detailed information on Medicaid recipients diagnosed with sickle cell disease,</u>

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 such methodologies may be modified or improved through the adoption of new or additional policies.

Section 3. 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 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.

Section 4. For the 2023-2024 fiscal year, five full-time equivalent positions with associated salary rate of 254,408 are authorized and the sums of $1,060,804 in recurring funds and $21,355 in nonrecurring funds from the General Revenue Fund are appropriated to the Department of Health for the purpose of implementing this act.

Section 5. This act shall take effect July 1, 2023.