A bill to be entitled

An act relating to sickle cell disease; creating s. 381.814, F.S.; creating the Sickle Cell Disease Research and Treatment Grant Program within the Department of Health for a specified purpose; specifying the types of projects that are eligible for grant funding; authorizing the department to adopt rules; providing for the carryforward for a limited period of any unexpended balance of an appropriation for the program; amending s. 383.147, F.S.; revising sickle cell disease and sickle cell trait screening requirements; requiring screening providers to notify a newborn's parent or guardian, rather than the newborn's primary care physician, of certain information; authorizing certain persons other than newborns who have been identified as having sickle cell disease or carrying a sickle cell trait to choose to be included in the registry; providing an effective date.

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

Section 1. Section 381.814, Florida Statutes, is created to read:

<u>381.814 Sickle Cell Disease Research and Treatment Grant</u>

Program.—The Sickle Cell Disease Research and Treatment Grant Program is created within the Department of Health.

(1) As used in this section, the term:

(a) "Center of excellence" means a health care facility dedicated to the treatment of patients with sickle cell disease which provides evidence-based, comprehensive, patient-centered coordinated care.

(b) "Department" means the Department of Health.

(c) "Health care practitioner" has the same meaning as provided in s. 456.001.

(d) "Program" means the Sickle Cell Disease Research and Treatment Grant Program.

(e) "Sickle cell disease" means the group of hereditary blood disorders caused by an abnormal type of hemoglobin resulting in malformed red blood cells with impaired function. The term includes both symptomatic manifestations of sickle cell disease and asymptomatic sickle cell trait.

(2) The purpose of the program is to fund projects that improve the quality and accessibility of health care services available for persons living with sickle cell disease in this state as well as to advance the collection and analysis of comprehensive data to support research of sickle cell disease. The long-term goals of the program are to:

(a) Improve the health outcomes and quality of life for Floridians with sickle cell disease.

(b) Expand access to high-quality, specialized care for sickle cell disease.

(c) Improve awareness and understanding among health care practitioners of current best practices for the treatment and management of sickle cell disease.

(3) Funds appropriated to the program shall be awarded by the Office of Minority Health and Health Equity, within the department, to community-based sickle cell disease medical treatment and research centers operating in this state.

(4) The Office of Minority Health and Health Equity shall award grants under the program to community-based sickle cell disease medical treatment and research centers to fund projects specific to sickle cell disease in the following project areas.

(a) Sickle cell disease workforce development and education.—Such projects shall include, but need not be limited to, facility-based education programs, continuing education curriculum development, and outreach and education activities with the local health care practitioner community. Workforce development and education projects must be based on current evidence-based clinical practice guidelines for sickle cell disease.

(b) Sickle Cell Disease Treatment Centers of Excellence.—Such projects shall include, but need not be limited to, operational support for existing centers of excellence, facility

<u>enhancement of existing centers of excellence, and the establishment of new centers of excellence.</u>

<u>(5) The department shall:</u>

<u>(a) By July 15, 2024, publicize the availability of funds, establish an application process for submitting a grant proposal, and initiate a call for applications.</u>

<u>(b) Develop uniform data reporting requirements for the purpose of evaluating the performance of the grant recipients and demonstrating improved health outcomes.</u>

<u>(c) Develop a monitoring process to evaluate progress towards meeting grant objectives.</u>

<u>(6) The department shall submit an annual report to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the State Surgeon General by March 1 and publish the report on the department's website. The report shall include the status and progress for each project supported by the program during the previous calendar year. The report shall include, at a minimum, recommendations for improving the program and the following components for each project supported by the program:</u>

<u>(a) A summary of the project and the project outcomes or expected project outcomes.</u>

<u>(b) The status of the project, including whether it is completed or the estimated date of completion.</u>

(c) The amount of the grant awarded and the estimated or actual cost of the project.

(d) The source and amount of any federal, state, or local government grants or donations or private grants or donations funding the project.

(e) A list of all entities involved in the project.

(7) The department may adopt rules as necessary to implement the provisions of this section.

(8) The recipient of a grant awarded under the program may not use more than 5 percent of grant funds for administrative expenses. Notwithstanding s. 216.301 and pursuant to s. 216.351, the balance of any appropriation from the General Revenue Fund for the program which is not disbursed but which is obligated pursuant to contract or committed to be expended by June 30 of the fiscal year in which the funds are appropriated may be carried forward for up to 5 years after the effective date of the original appropriation.

Section 2. Section 383.147, Florida Statutes, is amended to read:

383.147 ~~Newborn and infant screenings for~~ Sickle cell disease and sickle cell trait ~~hemoglobin variants;~~ registry.—

(1) If ~~a screening provider detects that~~ a newborn ~~or an infant,~~ as ~~those terms are~~ defined in s. 383.145(2)~~,~~ is identified as having sickle cell disease or sickle cell trait through the newborn screening program as described in s. 383.14,

the department ~~carrying a sickle cell hemoglobin variant, it~~ must:

(a) Notify the parent or guardian of the newborn and provide information regarding the availability and benefits of genetic counseling ~~primary care physician of the newborn or infant and~~

(b) 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.~~

(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 individuals ~~newborns and infants~~ who are identified as carrying a sickle cell disease or sickle cell trait ~~hemoglobin variant~~. The sickle cell registry must track sickle cell disease outcome measures, except as provided in paragraph (1)(b). A parent or guardian of a newborn or an infant in the registry may request to have his or her child removed from the registry by submitting a form prescribed by the department by rule.

(b) In addition to newborns identified and included in the registry under subsection (1), other persons living in this state who have been identified with sickle cell disease or sickle cell trait may choose to be included in the registry by providing the department with notification as prescribed by rule.

(c) ~~(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 follow-up 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 included in the registry who are 18 years of age 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 3. This act shall take effect upon becoming law.