By the Appropriations Committee on Health and Human Services

603-03523-24 20247070__

A bill to be entitled

An act relating to sickle cell disease research and treatment education; creating s. 381.814, F.S.; creating the Sickle Cell Disease Research and Treatment Grant Program within the Department of Health; defining terms; providing purposes of the program and its long-term goals; requiring the Office of Minority Health and Health Equity within the department to use funds appropriated to the program to award grants to community-based sickle cell disease medical treatment and research centers operating in this state; specifying the types of projects that may be funded under the program; limiting the percentage of grant funding which may be used for administrative expenses; authorizing certain appropriated funds to be carried over for a specified timeframe; specifying duties of the department; requiring the department to submit an annual report to the Governor and the Legislature; specifying requirements for the report; authorizing the department to adopt rules; 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; providing for the ability of the parent or guardian of a newborn to opt out of the newborn's inclusion in the sickle cell registry; specifying the manner in which a parent or guardian may opt out; requiring the department to notify the parent or guardian of the ability to opt out before including the newborn in the registry; authorizing certain persons other than newborns who have been identified as having sickle cell disease or carrying the sickle cell trait to choose to be included in the department’s sickle cell registry; creating s. 456.0311, F.S.; requiring the applicable licensing boards for specified health care professions to require a 2-hour continuing education course on sickle cell disease care management as part of every second biennial licensure or certification renewal; specifying requirements for the course; specifying the procedure for licensees and certificateholders to submit confirmation of completing the course; authorizing the applicable boards to approve additional equivalent courses to satisfy the requirement; authorizing the applicable boards to include the course hours in the total hours of continuing education required for the applicable profession, with an exception; authorizing health care practitioners holding two or more licenses or certificates subject to the course requirement to show proof of completion of one course to satisfy the requirement for all such licenses or certificates; providing for disciplinary action; authorizing the applicable boards to adopt rules; 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:

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

(1) DEFINITIONS.—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 consistent with criteria established by the department.

(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 the asymptomatic sickle cell trait.

(2) PURPOSE.—The purpose of the program is to fund projects that improve the quality and accessibility of health care 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) GRANTS.—Using funds appropriated for the program, the Office of Minority Health and Health Equity within the department shall award grants to community-based sickle cell disease medical treatment and research centers operating in this state to fund projects specific to sickle cell disease in the following project areas:

(a) *Sickle cell disease workforce development and education.*—Such projects include, but are not 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 include, but are not limited to, operational support for existing centers of excellence, facility enhancement of existing centers of excellence, and the establishment of new centers of excellence.

(c) *Surveillance and evaluation.*—Such projects include, but are not limited to, the maintenance of and improvements to an existing sickle cell disease and sickle cell trait registry.

(4) USE OF GRANT FUNDS.—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 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.

(5) DEPARTMENT DUTIES.—The department shall do all of the following:

(a) Publicize the availability of funds under the program and establish an application process for submitting a grant proposal.

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

(c) Develop a monitoring process to evaluate progress toward meeting grant objectives.

(6) ANNUAL REPORT.—By March 1 of each year, the department shall submit a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The report must include, at a minimum, the status and progress for each project supported by the program during the previous calendar year, any recommendations for improving the program, and all of the following components for each supported project:

(a) A summary of the project and the project outcomes or expected project outcomes.

(b) The status of the project, including whether it has concluded or the estimated date of completion.

(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) RULES.—The department may adopt rules to implement this section.

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 the 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), unless the parent or guardian of the newborn provides an opt-out form obtained from the department, or otherwise indicates in writing to the department his or her objection to having the newborn included in the registry. The department must notify the parent or guardian of the ability to opt out before including the newborn in the registry. ~~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 the 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 as having sickle cell disease or the sickle cell trait may choose to be included in the registry by providing the department with notification as prescribed by rule.

(c) 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. Section 456.0311, Florida Statutes, is created to read:

<u>456.0311 Requirement for instruction on sickle cell disease.—</u>

<u>(1)(a) The applicable board shall require each person licensed or certified under chapter 458, chapter 459, or part I of chapter 464 to complete a 2-hour continuing education course, approved by the board, on sickle cell disease care management as part of every second biennial licensure or certification renewal. The course shall consist of education specific to sickle cell disease and the sickle cell trait, including, but not limited to, evidence-based treatment guidelines for patients of all ages, continuing patient and family education, periodic comprehensive evaluations and other disease-specific health maintenance services, psychosocial care, genetic counseling, and pain management.</u>

<u>(b) Each licensee or certificateholder shall submit confirmation of having completed such course on a form provided by the applicable board when submitting fees for each second biennial renewal.</u>

<u>(c) The board may approve additional equivalent courses that may be used to satisfy the requirements of paragraph (a).</u>

Each licensing board that requires a licensee to complete an educational course pursuant to this section may include the hour required for completion of the course in the total hours of continuing education required by law for such profession unless the continuing education requirements for such profession consist of fewer than 30 hours biennially.

(d) Any person holding two or more licenses subject to this section may show proof of having taken one board-approved course to satisfy the requirements of paragraph (a) for purposes of relicensure or recertification for additional licenses.

(e) Failure to comply with the requirements of this section constitutes grounds for disciplinary action under each respective practice act and under s. 456.072(1)(k).

(2) Each applicable board may adopt rules to implement this section.

Section 4. This act shall take effect July 1, 2024.