**A** **BILL**

TO AMEND CHAPTER 33, TITLE 44, CODE OF LAWS OF SOUTH CAROLINA, 1976, RELATING TO SICKLE CELL DISEASE, SO AS TO ENACT THE “RENA GRANT SICKLE CELL DISEASE VOLUNTARY PATIENT REGISTRY ACT”; TO REQUIRE THE SOUTH CAROLINA DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL TO DEVELOP AND MAINTAIN A SICKLE CELL DISEASE VOLUNTARY PATIENT REGISTRY IN WHICH PATIENTS DIAGNOSED WITH SICKLE CELL DISEASE MAY REGISTER; TO ESTABLISH REQUIREMENTS FOR A PHYSICIAN TO SUBMIT THE NAME AND OTHER IDENTIFYING INFORMATION OF A PATIENT DIAGNOSED WITH SICKLE CELL DISEASE TO THE REGISTRY; TO PROHIBIT RELEASE OF INFORMATION CONTAINED IN THE REGISTRY, WITH EXCEPTIONS; TO ALLOW ACCESS TO INFORMATION IN THE REGISTRY BY, AMONG OTHERS, TREATING PHYSICIANS AND OTHER HEALTH CARE PRACTITIONERS TO VERIFY PATIENT REGISTRATION AND HEALTH CARE RESEARCHERS; TO ALLOW A PATIENT TO REVOKE A REGISTRATION; AND FOR OTHER PURPOSES.

Whereas, sickle cell disease is prevalent in South Carolina, but there is limited data collected or analyzed related to the incidence of the disease, available services to treat patients and ensure access to suitable care, the disease trajectory and available treatment options, and the impact of the disease on patients and their families; and

Whereas, despite the prevalence of the disease in South Carolina, the majority of primary care and emergency department physicians and other health care practitioners have not received education about sickle cell disease management, particularly for adult patients; and

Whereas, the lack of health care practitioner knowledge of and education about the symptoms, treatment, and management of sickle cell disease has resulted in inappropriate care of patients, including the failure to prescribe medication to manage pain during sickle cell disease crises; and

Whereas, a sickle cell disease patient registry through which physicians may register patients diagnosed with sickle cell disease upon a patient’s request would help coordinate and improve access to care, especially for patients who seek acute care, and improve the services provided to help patients manage the symptoms of the disease; and

Whereas, a sickle cell disease patient registry also would facilitate the collection of data about the incidence and nature of sickle cell disease in the State, which could be used to educate primary, specialty, and emergency care physicians and other health care practitioners to promote the coordination of appropriate services for patients suffering from the disease. Now, therefore,

Be it enacted by the General Assembly of the State of South Carolina:

SECTION 1. This act may be known and cited as the “Rena Grant Sickle Cell Disease Voluntary Patient Registry Act”.

SECTION 2. Chapter 33, Title 44 of the 1976 Code is amended to read:

“CHAPTER 33

Sickle Cell ~~Anemia~~ Disease

Article 1

General Provisions

Section 44‑33‑10. The Department of Health and Environmental Control is hereby authorized to initiate a sickle cell education and prevention program based entirely upon voluntary cooperation of the individuals involved. The program shall provide:

~~(a)~~(1) laboratory testing of ~~black~~ citizens in the reproductive ages to determine the presence of the sickle cell gene;

~~(b)~~(2) counselling for persons identified as carriers of the sickle cell gene, for the purpose of ~~preventing sickle cell anemia in the future offspring of such carriers~~ educating these persons about the risk of a child of the person inheriting sickle cell disease;

~~(c)~~(3) referral of persons with sickle cell ~~anemia~~ disease, as necessary, so that they may obtain proper medical care and treatment; and

~~(d)~~(4) basic education to the general public about sickle cell disease, so as to eradicate the stigma attached to ~~this malady~~ the disease.

Article 3

Sickle Cell Disease Voluntary Patient Registry

Section 44‑33‑310. The South Carolina Department of Health and Environmental Control shall develop and maintain the Sickle Cell Disease Voluntary Patient Registry for residents of the State who have been diagnosed with sickle cell disease. The purpose of the registry is to:

(1) enable individuals diagnosed with sickle cell disease to register so that physicians and other health care practitioners providing care to the patient may confirm whether the individual has been diagnosed with sickle cell disease; and

(2) collect and study data on the incidence and nature of sickle cell disease in the State to improve patient care and access to services.

Section 44‑33‑320. (A) If a physician diagnoses a patient with sickle cell disease, the physician shall notify the patient of the Sickle Cell Disease Voluntary Patient Registry and the right to register as a person having sickle cell disease. The physician shall provide the patient, or the patient’s parent or caregiver if the patient is a minor or is incapacitated, a form on which to request registration. Upon receipt of a patient registration request, the physician shall register the patient.

(B) To register a patient, the physician shall submit electronically on a form developed by the department the name, mailing address, and date of birth of the patient. If the patient is a minor or is incapacitated, the physician also shall submit the name and mailing address of the patient’s parent or caregiver.

(C) By submitting the form to the registry, the physician is affirming that the patient has a diagnosis of sickle cell disease and that the diagnosis was made by the physician or that the physician has reviewed the patient’s medical records which reflect a past diagnosis of sickle cell disease by another physician.

(D) The department may issue a waiver to a physician who is unable to submit the information by electronic means and permit registration by paper form or other means if all information required pursuant to subsection (B) is submitted in this alternative format.

Section 44‑33‑330. (A) The information submitted to the department to register a patient with the Sickle Cell Disease Voluntary Patient Registry is confidential and not subject to public disclosure under the Freedom of Information Act or any other provision of law, except as provided in subsection (C).

(B) The department shall maintain procedures to ensure that the privacy and confidentiality of patients and patient information collected, recorded, transmitted, and maintained is not disclosed, except as provided for in subsection (C).

(C) The department may provide a copy of the registration to:

(1) a physician or other health care practitioner licensed and in good standing in South Carolina or another state who is treating a patient and who requests the information after certifying that the patient, or the patient’s parent or caregiver if the patient is a minor or is incapacitated, has indicated that the patient has submitted a registration and would like the physician or other health care practitioner to verify the registration;

(2) a patient, or the patient’s parent or caregiver if the patient is a minor or is incapacitated, who requests the patient’s own sickle cell patient registry registration information in accordance with procedures established by the department;

(3) personnel of the department for purposes of administration and implementation of this article; and

(4) qualified health care researchers and other personnel for the purpose of bona fide research or education to promote the purposes of this article; however, data elements that would reasonably identify a specific patient, physician, or other health care practitioner, must be deleted or redacted from such information before disclosure. Further, release of the information only may be made pursuant to a written agreement between qualified personnel and the department in order to ensure compliance with this item.

Section 44‑33‑340. The information maintained in the Sickle Cell Disease Voluntary Patient Registry may not be released to or used by an entity responsible for the licensure, regulation, or discipline of physicians or other health care practitioners for any purpose.

Section 44‑33‑350. A patient, or the patient’s parent or caregiver if the patient is a minor or is incapacitated, may revoke the registration at any time by notifying the department in accordance with procedures established by the department.

Section 44‑33‑360. A physician or other health care practitioner is prohibited from accessing the registry if a patient, or the patient’s parent or caregiver if the patient is a minor or is incapacitated, has not requested the physician or other health care practitioner to verify the patient’s registration.

Section 44‑33‑370. A patient is obligated to update contact information that is maintained in the registry after initial registration by a physician in accordance with procedures established by the department.

Section 44‑33‑380. The department shall promulgate regulations and develop procedures and guidelines to implement the provisions of this article.”

SECTION 3. This act takes effect upon approval by the Governor.

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