CHAPTER 33

Sickle Cell Disease

Editor's Note

2022 Act No. 206, Section 1, provides as follows:

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

ARTICLE 1

General Provisions

Editor's Note

2022 Act No. 206, Section 1, provides as follows:

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

**SECTION 44‑33‑10.** Sickle cell education and prevention program.

 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:

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

 (2) counselling for persons identified as carriers of the sickle cell gene, for the purpose of educating these persons about the risk of a child of the person inheriting sickle cell disease;

 (3) referral of persons with sickle cell disease, as necessary, so that they may obtain proper medical care and treatment, to include pain management; and

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

HISTORY: 1962 Code Section 32‑562; 1972 (57) 3013; 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

Effect of Amendment

2022 Act No. 206, Section 2, redesignated (a) to (d) as (1) to (4); in (1), substituted "citizens" for "black citizens"; in (2), substituted "educating these persons about the risk of a child of the person inheriting sickle cell disease" for "preventing sickle cell anemia in the future offspring of such carriers"; in (3), substituted "disease" for "anemia" and inserted ", to included pain management; and" at the end; in (4), substituted "the disease" for "this malady"; and made nonsubstantive changes throughout.

ARTICLE 3

Sickle Cell Disease Voluntary Patient Registry

Editor's Note

2022 Act No. 206, Section 1, provides as follows:

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

**SECTION 44‑33‑310.** Development and maintenance of Sickle Cell Disease Voluntary Patient Registry.

 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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑320.** Physicians shall notify patients of registry after diagnosis; registration requirements.

 (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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑330.** Confidentiality of information submitted to registry; permitted disclosures.

 (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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑340.** Prohibited use of registry information.

 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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑350.** Revocation of registration.

 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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑360.** Physicians prohibited from accessing registry without patients' request.

 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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑370.** Obligation to update contact information.

 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.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.

**SECTION 44‑33‑380.** Promulgation of regulations.

 The department shall promulgate regulations and develop procedures and guidelines to implement the provisions of this article.

HISTORY: 2022 Act No. 206 (H.3166), Section 2, eff May 23, 2022.