
DIGEST

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HB 968 Original

2022 Regular Session

Phelps

Abstract: Requires the La. Department of Health to establish and maintain a sickle cell disease registry to be known as the "Skylar-Cooper Database" which shall function as a repository of accurate, complete records to aid in the cure and treatment of sickle cell disease.

Proposed law requires the La. Department of Health (LDH) to establish and maintain a registry of individuals diagnosed with sickle cell disease which shall be known as the "Skylar-Cooper Database". Provides that the purpose of the registry shall be to function as a single repository of accurate, complete records to aid in the cure and treatment of sickle cell disease in this state.

Proposed law requires that the sickle cell disease registry encompass, without limitation, all of the following:

- (1) A record of individuals in this state who have been diagnosed with sickle cell disease.
- (2) All data and other information associated with individuals who have been diagnosed with sickle cell disease that the secretary of LDH deems necessary and appropriate for inclusion in the registry.

Proposed law requires all hospitals and other healthcare facilities that provide diagnostic or treatment services to patients with sickle cell disease to provide to LDH, in the form and manner prescribed by the department in rule, data regarding individuals who have been diagnosed with sickle cell disease.

Proposed law requires the secretary of LDH to facilitate access to data in the registry by all of the following entities:

- (1) The La. Sickle Cell Commission.
- (2) Any charitable foundation or other nonprofit organization that focuses exclusively or primarily on serving people with sickle cell disease approved by the LDH secretary.
- (3) The sickle cell patient navigator program established pursuant to present law.
- (4) Any sickle cell anemia clinic established pursuant to present law.
- (5) Any Medicaid managed care organization.

Proposed law requires the secretary of LDH to take such actions as are necessary to ensure that the entities authorized by proposed law to access registry data shall utilize such data, to the greatest extent practicable, to do all of the following:

- (1) Facilitate care coordination for sickle cell patients and minimize the wait times that these persons face in accessing health care.
- (2) Provide for continuity of care for young people with sickle cell disease who reach the age of majority or age out of La. Children's Health Insurance Program coverage.

Proposed law requires the secretary of LDH to promulgate all such rules as are necessary to implement the provisions of proposed law. Provides that these rules shall include but not be limited to the following:

- (1) Data elements to be included in the registry.
- (2) Guidelines and procedures for obtaining from healthcare facilities information regarding individuals diagnosed with sickle cell disease.
- (3) Standards for ensuring that the registry is developed and operated in a manner that comports with all applicable requirements of the Health Insurance Portability and Accountability Act (HIPAA), the HIPAA Privacy Rule, and other applicable laws and regulations governing disclosure of health information.

Proposed law consolidates certain sections of present law relative to sickle cell disease (R.S. 40:1081.5 through 1081.8 and 2018.3) within the new part of law established by proposed law which pertains exclusively to sickle cell disease.

Proposed law provides that proposed law shall be known as the "Remington Skylar Watts and Betty Cooper Phelps Act".

(Amends R.S. 36:259(B)(13); Adds R.S. 40:1125.1-1125.33)