

2022 Regular Session

HOUSE BILL NO. 968

BY REPRESENTATIVE PHELPS

HEALTH/SICKLE CELL ANEM: Establishes a state sickle cell disease registry

1 AN ACT

2 To amend and reenact R.S. 36:259(B)(13) and R.S. 44:4.1(B)(26) and to enact Part XIII of

3 Chapter 5-B of Title 40 of the Louisiana Revised Statutes of 1950, to be comprised

4 of R.S. 40:1125.1 through 1125.33, relative to sickle cell disease; to provide for the

5 establishment of a state sickle cell disease registry; to provide for the purpose of the

6 registry; to provide for duties of the Louisiana Department of Health with respect to

7 operation of the registry; to authorize access to data in the registry; to provide for a

8 public records exception; to require promulgation of administrative rules with

9 respect to the registry; to provide for the redesignation and reorganization of certain

10 laws pertaining to sickle cell disease; to provide for a short title; and to provide for

11 related matters.

12 Be it enacted by the Legislature of Louisiana:

13 Section 1. R.S. 36:259(B)(13) is hereby amended and reenacted to read as follows:

14 §259. Transfer of agencies and functions to Louisiana Department of Health

15 * * *

16 B. The following agencies, as defined in R.S. 36:3, are placed within the

17 Louisiana Department of Health and shall perform and exercise their powers, duties,

18 functions, and responsibilities as otherwise provided by law:

19 * * *

1 (13) Louisiana Sickle Cell Commission (~~R.S. 40:2018.3~~ R.S. 40:1125.1).

2 * * *

3 Section 2. Part XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of
4 1950, comprised of R.S. 40:1125.1 through 1125.33, is hereby enacted to read as follows:

5 PART XIII. SICKLE CELL DISEASE

6 SUBPART A. LOUISIANA SICKLE CELL COMMISSION

7 §1125.1. Louisiana Sickle Cell Commission

8 [Section redesignated from R.S. 40:2018.3]

9 SUBPART B. SICKLE CELL DISEASE REGISTRY

10 §1125.11. Definitions

11 As used in this Subpart, the following terms have the meanings ascribed to
12 them in this Section:

13 (1) "Department" means the Louisiana Department of Health.

14 (2) "Healthcare facility" means a hospital licensed in accordance with the
15 provisions of the Hospital Licensing Law, R.S. 40:2100 et seq., or any other facility
16 that provides diagnostic or treatment services to patients with sickle cell disease.

17 (3) "Registry" means the sickle cell disease registry established by the
18 provisions of this Subpart.

19 §1125.12. Sickle cell disease registry; purpose

20 A. The department shall establish and maintain, in accordance with the
21 provisions of this Subpart, a registry of individuals diagnosed with sickle cell disease
22 which shall be known as the "Skylar-Cooper Database". The purpose of the registry
23 shall be to function as a single repository of accurate, complete records to aid in the
24 cure and treatment of sickle cell disease in this state.

25 B. The registry shall encompass, without limitation, all of the following:

26 (1) A record of individuals in this state who have been diagnosed with sickle
27 cell disease.

1 (2) All data and other information associated with individuals who have been
2 diagnosed with sickle cell disease that the secretary of the department deems
3 necessary and appropriate for inclusion in the registry.

4 §1125.13. Healthcare facilities; reporting of data

5 Upon making a diagnosis of sickle cell disease, a healthcare provider shall
6 provide to the department data regarding the individual who has been diagnosed with
7 the disease. The form and manner of the data shall be prescribed by the department
8 by rule duly promulgated in accordance with the Administrative Procedure Act.

9 §1125.14. Use of registry data

10 A. The secretary of the department shall facilitate access to data in the
11 registry as provided for in rule.

12 B. Notwithstanding any other provision of law to the contrary, the
13 department or its agent may access medical and vital records in the custody of
14 physicians, hospitals, clinics, other healthcare providers, and the office of public
15 health in order that it may conduct sickle cell disease studies. The data contained in
16 the registry as well as all such medical and vital records obtained by the department
17 or its agent in accordance with the provisions of this Subsection, as well as the
18 results of any sickle cell disease study, shall be confidential and shall not be
19 available for subpoena, nor shall such information be disclosed, discoverable, or
20 compelled to be produced in any civil, criminal, administrative, or other proceeding
21 nor shall such records be deemed admissible as evidence in any civil, criminal,
22 administrative, or other tribunal or court for any reason. Nothing in this Subsection
23 shall prohibit the publishing by the department of statistical compilations relating to
24 sickle cell disease which do not identify individual cases or individual physicians,
25 hospitals, clinics, or other healthcare providers.

26 §1125.15. Healthcare needs of persons with sickle cell disease; legislative findings;
27 use of registry data in care coordination

28 The legislature hereby finds that sickle cell patients who need care for sickle
29 cell disease and other health conditions often face lengthy wait times for that care,

1 and that these wait times contribute to poor health outcomes and excess morbidity
2 and mortality among populations that are impacted by sickle cell disease. The
3 legislature further finds that sickle cell patients may face greater barriers in accessing
4 the necessary care for their disease after reaching the age of majority or aging out of
5 health coverage furnished through the Louisiana Children's Health Insurance
6 Program. Therefore, the secretary of the department shall take such actions as are
7 necessary to support the facilitation of care coordination for sickle cell patients,
8 assist in reducing the wait times to access healthcare services, and assist in
9 promoting continuity of care for young people who age out of Louisiana Children's
10 Health Insurance Program coverage.

11 §1125.16. Administrative rules

12 A. The department shall promulgate in accordance with the Administrative
13 Procedure Act all such rules as are necessary to implement the provisions of this
14 Subpart.

15 B. The rules required by this Section shall include but not be limited to the
16 following:

17 (1) Data elements to be included in the registry.

18 (2) Guidelines and procedures for obtaining from healthcare providers
19 information regarding individuals diagnosed with sickle cell disease.

20 (3) Standards for ensuring that the registry is developed and operated in a
21 manner that comports with all applicable requirements of the Health Insurance
22 Portability and Accountability Act of 1996 (Pub. L. 104-191); regulations adopted
23 pursuant to that Act including but not limited to the HIPAA Privacy Rule, 45 CFR
24 Part 164; and other applicable laws and regulations governing disclosure of health
25 information.

26 SUBPART C. PATIENT NAVIGATOR PROGRAM

27 §1125.21. Sickle cell patient navigator program

28 [Section redesignated from R.S. 40:1081.8]

29 SUBPART D. CLINICS AND LOCAL PROGRAMS

1 redesignated section shall comprise Subpart C, entitled "Patient Navigator Program", of Part
2 XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of 1950.

3 (C) The Louisiana State Law Institute is hereby authorized and directed to
4 redesignate R.S. 40:1081.5, 1081.6, and 1081.7, respectively, as R.S. 40:1125.31, 1125.32,
5 and 1125.33 within Part XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes
6 of 1950, as enacted by Section 2 of this Act. The redesignated sections shall comprise
7 Subpart D, entitled "Clinics and Local Programs", of Part XIII of Chapter 5-B of Title 40 of
8 the Louisiana Revised Statutes of 1950.

9 (D) The Louisiana State Law Institute is hereby authorized and directed to revise the
10 citations appearing within R.S. 40:1081.7(C) and 2018.3(D)(5) to reflect the redesignation
11 of the laws cited therein, and to make any other changes and technical corrections
12 throughout the statutes and codes as may be necessary to reflect the redesignation of laws
13 effected by this Section.

14 Section 5. This Act shall be known and may be cited as the "Remington Skylar
15 Watts and Betty Cooper Phelps Act".

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

HB 968 Engrossed

2022 Regular Session

Phelps

Abstract: Requires the La. Dept. 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. Dept. 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 (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 that upon making a diagnosis of sickle cell disease, a healthcare provider shall provide to LDH data regarding the individual who has been diagnosed with the disease.

Proposed law requires LDH to facilitate access to data in the registry through administrative rules. Stipulates that registry data as well as medical and vital records obtained by LDH or its agent in accordance with proposed law, as well as the results of any sickle cell disease study, shall be confidential and shall not be available for subpoena, nor shall such information be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding nor shall such records be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.

Proposed law requires the secretary of LDH to take such actions as are necessary to support the facilitation of care coordination for sickle cell patients, assist in reducing wait times to access healthcare services, and assist in promoting continuity of care for young people who 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 establishes an exception to present law relative to public records, R.S. 44:1 et seq., exempting data in the registry from disclosure pursuant to present law.

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) and R.S. 44:4.1(B)(26); Adds R.S. 40:1125.1-1125.33)

Summary of Amendments Adopted by House

The Committee Amendments Proposed by House Committee on Health and Welfare to the original bill:

1. Delete proposed law requiring healthcare facilities to provide to LDH data regarding individuals who have been diagnosed with sickle cell disease; add in lieu thereof a requirement that upon making a diagnosis of sickle cell disease, a healthcare provider shall provide to LDH data regarding the individual who has been diagnosed with the disease.

2. Delete proposed law authorizing access to data in the sickle cell disease registry by certain specifically identified entities; add in lieu thereof a requirement that LDH facilitate access to data in the registry through administrative rules.
3. Authorize LDH or its agent to access medical and vital records in the custody of physicians, hospitals, clinics, other healthcare providers, and the office of public health in order that it may conduct sickle cell disease studies.
4. Stipulate that the data contained in the sickle cell disease registry as well as medical and vital records obtained by LDH or its agent in accordance with proposed law, as well as the results of any sickle cell disease study, shall be confidential and shall not be available for subpoena, nor shall such information be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding nor shall such records be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.
5. Establish an exception to present law relative to public records, R.S. 44:1 et seq., exempting data in the sickle cell disease registry from disclosure pursuant to that law.
6. Make technical changes.