

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 to enact Part XIII of Chapter 5-B of Title 40
3 of the Louisiana Revised Statutes of 1950, to be comprised of R.S. 40:1125.1
4 through 1125.33, relative to sickle cell disease; to provide for the establishment of
5 a state sickle cell disease registry; to provide for the purpose of the registry; to
6 provide for duties of the Louisiana Department of Health with respect to operation
7 of the registry; to require reporting of data to the registry by certain healthcare
8 facilities; to authorize certain entities to access data in the registry; to require
9 promulgation of administrative rules with respect to the registry; to provide for the
10 redesignation and reorganization of certain laws pertaining to sickle cell disease; to
11 provide for a short title; and to provide for 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 Each healthcare facility shall provide to the department, in the form and
6 manner prescribed by the department in rule, data regarding individuals who have
7 been diagnosed with sickle cell disease.

8 §1125.14. Entities authorized to access registry data

9 The secretary of the department shall facilitate access to data in the registry
10 by all of the following entities:

11 (1) The Louisiana Sickle Cell Commission.

12 (2) Any charitable foundation or other nonprofit organization that focuses
13 exclusively or primarily on serving people with sickle cell disease approved by the
14 secretary of the department.

15 (3) The sickle cell patient navigator program established pursuant to the
16 provisions of Subpart C of this Part.

17 (4) Any sickle cell anemia clinic established pursuant to the provisions of
18 Subpart D of this Part.

19 (5) Any managed care organization as defined in R.S. 46:460.51.

20 §1125.15. Healthcare needs of persons with sickle cell disease; legislative findings;
21 use of registry data in care coordination

22 The legislature hereby finds that sickle cell patients who need care for sickle
23 cell disease and other health conditions often face lengthy wait times for that care,
24 and that these wait times contribute to poor health outcomes and excess morbidity
25 and mortality among populations that are impacted by sickle cell disease. The
26 legislature further finds that sickle cell patients may face greater barriers in accessing
27 the necessary care for their disease after reaching the age of majority or aging out of
28 health coverage furnished through the Louisiana Children's Health Insurance
29 Program. Therefore, the secretary of the department shall take such actions as are

1 necessary to ensure that the entities authorized by R.S. 40:1125.14 to access registry
2 data shall utilize such data, to the greatest extent practicable, to do all of the
3 following:

4 (1) Facilitate care coordination for sickle cell patients and minimize the wait
5 times that these persons face in accessing health care.

6 (2) Provide for continuity of care for young people with sickle cell disease
7 who reach the age of majority or age out of Louisiana Children's Health Insurance
8 Program coverage.

9 §1125.16. Administrative rules

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

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

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

16 (2) Guidelines and procedures for obtaining from healthcare facilities
17 information regarding individuals diagnosed with sickle cell disease.

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

24 SUBPART C. PATIENT NAVIGATOR PROGRAM

25 §1125.21. Sickle cell patient navigator program

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

27 SUBPART D. CLINICS AND LOCAL PROGRAMS

28 §1125.31. Sickle cell anemia; clinic established

29 [Section redesignated from R.S. 40:1081.5]

1 §1125.32. Sickle cell anemia; clinics established statewide

2 [Section redesignated from R.S. 40:1081.6]

3 §1125.33. Sickle cell anemia; local programs

4 [Section redesignated from R.S. 40:1081.7]

5 Section 3.(A) The Louisiana State Law Institute is hereby authorized and directed
6 to redesignate R.S. 40:2018.3 as R.S. 40:1125.1 within Part XIII of Chapter 5-B of Title 40
7 of the Louisiana Revised Statutes of 1950, as enacted by Section 2 of this Act. The
8 redesignated section shall comprise Subpart A, entitled "Louisiana Sickle Cell Commission",
9 of Part XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of 1950.

10 (B) The Louisiana State Law Institute is hereby authorized and directed to
11 redesignate R.S. 40:1081.8 as R.S. 40:1125.21 within Part XIII of Chapter 5-B of Title 40
12 of the Louisiana Revised Statutes of 1950, as enacted by Section 2 of this Act. The
13 redesignated section shall comprise Subpart C, entitled "Patient Navigator Program", of Part
14 XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of 1950.

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

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

26 Section 4. This Act shall be known and may be cited as the "Remington Skylar
27 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 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)