

2022 Regular Session

HOUSE BILL NO. 968

BY REPRESENTATIVES PHELPS, ADAMS, BOYD, ROBBY CARTER, CORMIER, DUPLESSIS, FISHER, GLOVER, GREEN, HUGHES, JEFFERSON, JENKINS, JORDAN, LAFLEUR, LANDRY, LYONS, NEWELL, PIERRE, SELDERS, WHITE, AND WILLARD AND SENATOR BARROW

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, 1125.11 through 1125.16, 1125.21, and 1125.31 through 1125.33,
5 relative to sickle cell disease; to provide for the establishment of a state sickle cell
6 disease registry; to provide for the purpose of the registry; to provide for duties of
7 the Louisiana Department of Health with respect to operation of the registry; to
8 authorize access to data in the registry; to provide for a public records exception; to
9 require promulgation of administrative rules with respect to the registry; to provide
10 for the redesignation and reorganization of certain laws pertaining to sickle cell
11 disease; to 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, 1125.11 through 1125.16, 1125.21, and 1125.31 through
5 1125.33, is hereby enacted to read as follows:

6 PART XIII. SICKLE CELL DISEASE

7 SUBPART A. LOUISIANA SICKLE CELL COMMISSION

8 §1125.1. Louisiana Sickle Cell Commission

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

10 SUBPART B. SICKLE CELL DISEASE REGISTRY

11 §1125.11. Definitions

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

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

15 (2) "Registry" means the sickle cell disease registry established by the
16 provisions of this Subpart.

17 §1125.12. Sickle cell disease registry; purpose

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

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

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

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

1 §1125.13. Healthcare facilities; reporting of data

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

6 §1125.14. Use of registry data

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

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

23 §1125.15. Healthcare needs of persons with sickle cell disease; legislative findings;
24 use of registry data in care coordination

25 The legislature hereby finds that sickle cell patients who need care for sickle
26 cell disease and other health conditions often face lengthy wait times for that care,
27 and that these wait times contribute to poor health outcomes and excess morbidity
28 and mortality among populations that are impacted by sickle cell disease. The
29 legislature further finds that sickle cell patients may face greater barriers in accessing
30 the necessary care for their disease after reaching the age of majority or aging out of

1 health coverage furnished through the Louisiana Children's Health Insurance
2 Program. Therefore, the secretary of the department shall take such actions as are
3 necessary to support the facilitation of care coordination for sickle cell patients,
4 assist in reducing the wait times to access healthcare services, and assist in
5 promoting continuity of care for young people who age out of Louisiana Children's
6 Health Insurance Program coverage.

7 §1125.16. Administrative rules

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

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

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

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

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

22 SUBPART C. PATIENT NAVIGATOR PROGRAM

23 §1125.21. Sickle cell patient navigator program

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

25 SUBPART D. CLINICS AND LOCAL PROGRAMS

26 §1125.31. Sickle cell anemia; clinic established

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

28 §1125.32. Sickle cell anemia; clinics established statewide

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

1 Subpart D, entitled "Clinics and Local Programs", of Part XIII of Chapter 5-B of Title 40 of
2 the Louisiana Revised Statutes of 1950.

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

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

SPEAKER OF THE HOUSE OF REPRESENTATIVES

PRESIDENT OF THE SENATE

GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: _____