

# ACT No. 647

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

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AN ACT

To amend and reenact R.S. 36:259(B)(13) and R.S. 44:4.1(B)(26) and to enact Part XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of 1950, to be comprised of R.S. 40:1125.1, 1125.11 through 1125.16, 1125.21, and 1125.31 through 1125.33, relative to sickle cell disease; to provide for the establishment of a state sickle cell disease registry; to provide for the purpose of the registry; to provide for duties of the Louisiana Department of Health with respect to operation of the registry; to authorize access to data in the registry; to provide for a public records exception; to require promulgation of administrative rules with respect to the registry; to provide for the redesignation and reorganization of certain laws pertaining to sickle cell disease; to provide for a short title; and to provide for related matters.

Be it enacted by the Legislature of Louisiana:

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

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

\* \* \*

B. The following agencies, as defined in R.S. 36:3, are placed within the Louisiana Department of Health and shall perform and exercise their powers, duties, functions, and responsibilities as otherwise provided by law:

\* \* \*

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           §1125.33. Sickle cell anemia; local programs

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

3           Section 3. R.S. 44:4.1(B)(26) is hereby amended and reenacted to read as follows:

4           §4.1. Exceptions

5   \*       \*       \*

6                       B. The legislature further recognizes that there exist exceptions, exemptions,  
7                       and limitations to the laws pertaining to public records throughout the revised  
8                       statutes and codes of this state. Therefore, the following exceptions, exemptions, and  
9                       limitations are hereby continued in effect by incorporation into this Chapter by  
10                      citation:

11    \*       \*       \*

12                               (26) R.S. 40:3.1, 31.14, 31.27, 39.1, 41, 73, 95, 96, 526, 528, 973.1, 978.2.1,  
13                      1007, 1061.21, 1079.18, 1081.10, 1105.6, 1105.8, 1125.14, 1133.8, 1168.3, 1171.4,  
14                      1203.4, 1231.4, 1379.1.1(D), 1379.3, 2009.8, 2009.14, 2010.5, 2017.9, 2018, 2018.5,  
15                      2019, 2020, 2106, 2109.1, 2138, 2175.7(B)(1), 2532, 2845.1

16    \*       \*       \*

17           Section 4.(A) The Louisiana State Law Institute is hereby authorized and directed  
18           to redesignate R.S. 40:2018.3 as R.S. 40:1125.1 within Part XIII of Chapter 5-B of Title 40  
19           of the Louisiana Revised Statutes of 1950, as enacted by Section 2 of this Act. The  
20           redesignated section shall comprise Subpart A, entitled "Louisiana Sickle Cell Commission",  
21           of Part XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of 1950.

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

27           (C) The Louisiana State Law Institute is hereby authorized and directed to  
28           redesignate R.S. 40:1081.5, 1081.6, and 1081.7, respectively, as R.S. 40:1125.31, 1125.32,  
29           and 1125.33 within Part XIII of Chapter 5-B of Title 40 of the Louisiana Revised Statutes  
30           of 1950, as enacted by Section 2 of this Act. The redesignated sections shall comprise

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".

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SPEAKER OF THE HOUSE OF REPRESENTATIVES

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PRESIDENT OF THE SENATE

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GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: \_\_\_\_\_