

2021 Regular Session

HOUSE BILL NO. 460

BY REPRESENTATIVE HOLLIS

1 AN ACT

2 To enact R.S. 36:259(B)(38) and Part XI of Chapter 5-B of Title 40 of the Louisiana
3 Revised Statutes of 1950, to be comprised of R.S. 40:1122.1, relative to diseases and
4 conditions; to provide for rare diseases; to create the Louisiana Rare Disease
5 Advisory Council; to place the advisory council within the executive branch of
6 government; to provide for definitions; to provide the criteria for appointments to the
7 advisory council; to provide for the purpose of the advisory council; to provide for
8 limitations on the advisory council; to require reporting; and to provide for related
9 matters.

10 Be it enacted by the Legislature of Louisiana:

11 Section 1. R.S. 36:259(B)(38) is hereby enacted to read as follows:

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

13 * * *

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

17 * * *

18 (38) The Louisiana Rare Disease Advisory Council (R.S. 40:1122.1). The
19 advisory council shall exercise and carry out all powers, duties, functions, and
20 responsibilities as provided in R.S. 36:802.

21 * * *

1 Section 2. Part XI of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of
2 1950, comprised of R.S. 40:1122.1, is hereby enacted to read as follows:

3 PART XI. RARE DISEASES

4 §1122.1. Louisiana Rare Disease Advisory Council

5 A. For the purpose of this Part, the following terms have the meanings
6 ascribed to them:

7 (1) "Board" means the Drug Utilization Review board established by the
8 Louisiana Department of Health.

9 (2) "Department" means the Louisiana Department of Health.

10 (3) "Rare disease" means any disease or condition that affects fewer than two
11 hundred thousand persons in the United States. Rare disease shall also mean sickle
12 cell disease and sarcoidosis.

13 B.(1) The Louisiana Rare Disease Advisory Council is hereby created within
14 the Louisiana Department of Health.

15 (2) The Louisiana Rare Disease Advisory Council hereby referred to as the
16 "advisory council" shall serve only in a resource capacity to any public and private
17 agency located in this state that provide services for a person who has been
18 diagnosed with a rare disease.

19 (3) The advisory council shall be composed of the following members:

20 (a) One member appointed by the president of the Senate.

21 (b) One member appointed by the speaker of the House of Representatives.

22 (c) Members appointed by the governor as follows:

23 (i) One representative from the department.

24 (ii) Two representatives from academic research institutions in this state that
25 conduct rare disease research.

26 (iii) Two physicians who are licensed and practicing in this state with
27 experience in researching, diagnosing, or treating rare diseases.

28 (iv) One geneticist who is licensed and practicing in this state.

29 (v) One registered nurse or advanced practice registered nurse who is
30 licensed and practicing in this state and has experience treating rare diseases.

1 (vi) Two residents of this state who are eighteen years of age or older and
2 who have either been diagnosed with a rare disease or is a caregiver for a person who
3 has been diagnosed with a rare disease.

4 (vii) One representative of a rare disease patient organization operating in
5 this state.

6 (4) The governor shall determine who serves as the chair and vice chair of
7 the advisory council.

8 (5) To the extent practicable, every organization or entity that provides a
9 nomination to the advisory council shall strive for diversity in its appointment on the
10 basis of race, ethnicity, sex, professional or educational background, and geographic
11 residency.

12 C. The advisory council shall hold its initial meeting no later than October
13 1, 2021. The advisory council shall meet at least quarterly in a calendar year and at
14 any other time as it deems necessary.

15 D. The purposes of the advisory council include all of the following:

16 (1) To provide input and feedback to the department and any other state
17 agency on matters that affect a person who has been diagnosed with a rare disease,
18 including but not limited to all of the following:

19 (a) Pandemic preparedness and response and its impact on a person living
20 with a rare disease.

21 (b) Research, education, diagnosis, and treatment relating to rare diseases
22 within this state.

23 (c) Rare diseases in general, the severity of rare diseases, and unmet medical
24 needs associated with rare diseases.

25 (d) The demographics and clinical description of patient populations.

26 (e) Timely access to screening, care, insurance or Medicaid coverage,
27 specialists, and other needed services for a patient who has been diagnosed with a
28 rare disease.

1 (f) The impact that coverage, cost-sharing, tiering, and any other utilization
2 management procedure has on providing treatment and services to a patient who has
3 been diagnosed with a rare disease.

4 (2) To provide expert and clinical advice to the board in its review of
5 treatments for a rare disease. The treatments may include drugs or biological
6 products emerging from fields of personalized medicine and non-inheritable gene
7 editing therapeutics.

8 (3) To provide a report to the governor, the Legislature of Louisiana, the
9 department, and any other relevant agency of both of the following:

10 (a) Any findings, activities, and progress of the advisory council pursuant to
11 the provisions of Paragraphs (1) and (2) of this Subsection.

12 (b) Any recommendations for addressing the needs of a person living with
13 a rare disease in this state.

14 E. The advisory council shall not have authority on any matter relating to the
15 department or the board.

16 F. Nothing in this Section shall require the board to follow the
17 recommendations of the advisory council.

18 G. Nothing in this Section shall require the advisory council, the board, or
19 any state agency to consult with a person on any matter or be required to meet with
20 any specific expert or stakeholder.

21 H. An advisory council member shall not receive any compensation for
22 serving on the advisory council.

SPEAKER OF THE HOUSE OF REPRESENTATIVES

PRESIDENT OF THE SENATE

GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: _____