

2021 Regular Session

HOUSE BILL NO. 460

BY REPRESENTATIVE HOLLIS

Prefiled pursuant to Article III, Section 2(A)(4)(b)(i) of the Constitution of Louisiana.

HEALTH/LDH: Establishes the Rare Disease Advisory Council within the Louisiana Department of Health

1 AN ACT

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

8 Be it enacted by the Legislature of Louisiana:

9 Section 1. Part XI of Chapter 5-B of Title 40 of the Louisiana Revised Statutes of  
10 1950, comprised of R.S. 40:1122.1, is hereby enacted to read as follows:

11 PART XI. RARE DISEASES

12 §1122.1. Louisiana Rare Disease Advisory Council

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

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

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

18 (3) "Rare disease" means any disease or condition that affects fewer than two  
19 hundred thousand persons in the United States.

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

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

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

8           (a) One member appointed by the President of the Senate.

9           (b) One member appointed by the Speaker of the House of Representatives.

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

11          (i) One representative from the department.

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

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

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

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

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

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

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

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

1           C. The advisory council shall hold its initial meeting no later than October  
2           1, 2021. The advisory council shall meet at least quarterly in a calendar year and at  
3           any other time as it deems necessary.

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

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

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

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

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

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

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

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

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

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

27          (a) Any findings, activities, and progress of the advisory council pursuant to  
28          the provisions of Paragraphs (1) and (2) of Subsection D.

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

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

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

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

10           H. An advisory council member shall not receive any compensation for  
11           serving on the advisory council.

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#### 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)]

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HB 460 Original

2021 Regular Session

Hollis

**Abstract:** Establishes the Rare Disease Advisory Council within the Louisiana Department of Health.

Proposed law provides that "board" means the Drug Utilization Review board established by the La. Dept. of Health.

Proposed law provides that "department" means the La. Dept. of Health.

Proposed law provides that "rare disease" means any disease or condition that affects fewer than two hundred thousand persons in the United States.

Proposed law provides that the Louisiana Rare Disease Advisory Council is hereby created within the La. Dept. of Health. Proposed law further provides that the La. Rare Disease Advisory Council is referred to as the "advisory council".

Proposed law provides that the advisory council shall only serve in a resource capacity to any public and private agency located in this state that provides services for a person who has been diagnosed with a rare disease.

Proposed law provides that the advisory council shall consist of 12 members as follows:

- (1) One member appointed by the president of the Senate.
- (2) One member appointed by the speaker of the House of Representatives.
- (3) Members appointed by the governor shall include the following:

- (a) One representative from the La. Dept. of Health.
- (b) Two representatives from academic research institutions in this state that conduct rare disease research.
- (c) Two physicians who are licensed and practicing in this state with experience in researching, diagnosing, or treating rare diseases.
- (d) One geneticist who is licensed and practicing in this state.
- (e) One registered nurse or advanced practice registered nurse who is licensed and practicing in this state and has experience treating rare diseases.
- (f) Two residents of this state who are 18 years of age or older and who have either been diagnosed with a rare disease or is a caregiver for a person who has been diagnosed with a rare disease.
- (g) One representative of a rare disease patient organization operating in this state.

Proposed law provides that the governor shall determine who serves as the chair and vice chair of the advisory council.

Proposed law provides to the extent practicable, every organization or entity that provides a nomination to the advisory council shall strive for diversity in its appointment on the basis of race, ethnicity, sex, professional or educational background, and geographic residency.

Proposed law provides that the advisory council shall hold its initial meeting no later than Oct. 1, 2021. Proposed law further provides that the council shall meet, at least, quarterly in a calendar year and at any other time as it deems necessary.

Proposed law provides that the council shall not have authority on any matter relating to the department or the board.

Proposed law provides that nothing in proposed law shall require the board to follow the recommendations of the advisory council.

Proposed law provides that nothing in proposed law requires the advisory council, the board, or any state agency to consult with a person on any matter or be required to meet with any specific expert or stakeholder.

Proposed law provides that an advisory council member shall not receive any compensation for serving on the advisory council.

(Adds R.S. 40:1122.1)