

**HOUSE SUMMARY OF SENATE AMENDMENTS****HB 460****2021 Regular Session****Hollis**

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

**Synopsis of Senate Amendments**

1. Expands the definition of "rare disease" to include sickle cell disease and sarcoidosis.
2. Places the Louisiana Rare Disease Advisory Council within the executive branch of government.
3. Makes technical changes.

**Digest of Bill as Finally Passed by Senate**

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

Proposed law provides that "rare disease" means any disease or condition that affects fewer than 200,000 persons in the United States.

Proposed law creates the Louisiana Rare Disease Advisory Council ("advisory council") within the La. Dept. of Health.

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. 36:259(B)(38) and R.S. 40:1122.1)