

RÉSUMÉ DIGEST

ACT 321 (HB 460)

2021 Regular Session

Hollis

New law provides that "rare disease" means any disease or condition that affects fewer than 200,000 persons in the United States. "Rare disease" also means sickle cell disease and sarcoidosis.

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

New 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.

New law provides that the advisory council shall be composed of the following 12 members:

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

New law requires the governor to determine who serves as the chair and vice-chair of the advisory council.

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

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

New law provides that the council shall not have authority on any matter relating to LDH or its Drug Utilization Review board (board).

New law provides that nothing in new law requires the board to follow the recommendations of the advisory council.

New law provides that nothing in new 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.

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

Effective August 1, 2021.

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