



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA RARE DISEASE ADVISORY COUNCIL

Tuesday, December 3, 2024
3:00 pm – 4:00 pm

Location

Benson Tower, Rm 2024
1450 Poydras St. New Orleans, LA 701121

Meeting Link

<https://zoom.us/j/97420178007?pwd=MFPDO00zRxPXeG8rHABSaaawiiFWeE.1>

Phone: 312 626 6799 **Code:** MtT2re

Meeting Agenda

- I. Call to Order
- II. Roll Call
- III. Public Comment
- IV. Approval of Minutes
- V. Mandate Review
- VI. Vacancy Announcements
- VII. Old Business
- VIII. New Business
 - a. RDAC Patient/Advocate Presentation
 - b. Recap of NORD Conference
 - c. End of Year Recap/Next Steps for 2025
- IX. Public Comment
- X. Adjournment

Note: The order of the agenda may not be followed exactly, to accommodate presenter schedules.

Presenters, members, and guests may submit requests for accessibility and accommodations prior to a scheduled meeting. Please submit a request to rdac@la.gov at least 2 weeks prior to the meeting with details of the required accommodations.

In lieu of verbal public comment, individuals may submit a prepared statement in accordance with Senate Rule 13.79. Statements should be emailed to rdac@la.gov and must be received at least 24 hours prior to the meeting to be included in the record for the meeting.

R.S. 40:1122.1 | Louisiana Rare Disease Advisory Council

- A. For the purpose of this Part, the following terms have the meanings ascribed to them.
- 1) "Board" means the Drug Utilization Review board established by the Louisiana Department of Health.
 - 2) "Department" means the Louisiana Department of Health.
 - 3) "Rare disease" means any disease or condition that affects fewer than two hundred thousand persons in the United States. Rare disease shall also mean sickle cell disease and sarcoidosis.
- B. 1) The Louisiana Rare Disease Advisory Council is hereby created within the Louisiana Department of Health:
- 2) The Louisiana Rare Disease Advisory Council, referred to hereafter in this Part as the "advisory council", shall serve only 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.
 - 3) The advisory council shall be composed of the following members:
 - a. One member appointed by the president of the Senate.
 - b. One member appointed by the speaker of the House of Representatives.
 - c. Members appointed by the governor as follows:
 - i. One representative from the department.
 - ii. Two representatives from academic research institutions in this state that conduct rare disease research.
 - iii. Two physicians who are licensed and practicing in this state with experience in researching, diagnosing, or treating rare diseases.
 - iv. One geneticist who is licensed and practicing in this state.
 - v. One registered nurse or advanced practice registered nurse who is licensed and practicing in this state and has experience treating rare diseases.
 - vi. Two residents of this state who are eighteen 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.
 - vii. One representative of a rare disease patient organization operating in this state.
 - 4) The governor shall determine who serves as the chair and vice chair of the advisory council.
 - 5) 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.
- C. The advisory council shall hold its initial meeting no later than October 1, 2021. The advisory council shall meet at least quarterly in a calendar year and at any other time as it deems necessary.
- D. The purposes of the advisory council include all of the following:
- 1) To provide input and feedback to the department and any other state agency on matters that affect a person who has been diagnosed with a rare disease, including but not limited to all of the following:

- a. Pandemic preparedness and response and its impact on a person living with a rare disease.
 - b. Research, education, diagnosis, and treatment relating to rare diseases within this state.
 - c. Rare diseases in general, the severity of rare diseases, and unmet medical needs associated with rare diseases.
 - d. The demographics and clinical description of patient populations.
 - e. Timely access to screening, care, insurance or Medicaid coverage, specialists, and other needed services for a patient who has been diagnosed with a rare disease.
 - f. The impact that coverage, cost-sharing, tiering, and any other utilization management procedure has on providing treatment and services to a patient who has been diagnosed with a rare disease.
- 2) To provide expert and clinical advice to the board in its review of treatments for a rare disease. The treatments may include drugs or biological products emerging from fields of personalized medicine and non-inheritable gene editing therapeutics
 - 3) To provide a report to the governor, the Legislature of Louisiana, the department, and any other relevant agency of both of the following:
 - a. Any findings, activities, and progress of the advisory council pursuant to the provisions of Paragraphs (1) and (2) of this Subsection.
 - b. Any recommendations for addressing the needs of a person living with a rare disease in this state.
- E. The advisory council shall not have authority on any matter relating to the department or the board.
- F. Nothing in this Section shall require the board to follow the recommendations of the advisory council.
- G. Nothing in this Section shall require 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.
- H. An advisory council member shall not receive any compensation for serving on the advisory council.