Jeff Landry
GOVERNOR

Drew P. Maranto
INTERIM SECRETARY

State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA RARE DISEASE ADVISORY COUNCIL

Friday, April 25, 2025
11:00 am – 12:00 pm

LOCATION

628 North 4th Street, Room 117, Baton Rouge, La 70802

ZOOM DETAILS

zoom.us/j/97420178007
Meeting ID: 974 2017 8007 **Code:** MtT2re

MEETING AGENDA

I. **Call to Order**

II. **Roll Call**

III. **Approval of Minutes**

IV. **Mandate Review**

V. **Vacancy Announcements**

VI. **New Business**
   a. Gene Sequence-Based Treatment
   b. Rare Disease Patient/Advocate Story

VII. **Old Business**
   a. Rare Disease Day 2025 Recap
   b. Future RDAC Events Discussion
   c. RDAC Website

VIII. **Public Comments**

IX. **Adjournment**

Next Meeting
Friday, July 11 | 11:00 am | Location: TBA

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 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.