

JOIN US!

Louisiana Rare Disease Advisory Council Vacancies:

- Two (2) adult residents with a rare disease or caregiving for a person diagnosed with a rare disease
 - One (1) Louisiana physician with experience in researching, diagnosing, or treating rare diseases
- One (1) Louisiana Registered or Advanced Practice Registered Nurse with experience treating rare diseases
 - One (1) Geneticist practicing in Louisiana

THESE POSITIONS REQUIRE:

Attendance of 4 in-person meetings each year
in New Orleans.

Apply here: gov.louisiana.gov/index.cfm/form/home/14

LOUISIANA RARE DISEASE ADVISORY COUNCIL RESPONSIBILITIES

1. Provide expert and clinical advice to the board in its review of treatments for rare diseases.
2. Provide input to the department and any other state agency on matters that affect a person who has been diagnosed with a rare disease such as:
 - Pandemic preparedness, response and its impact.
 - Research, education, diagnosis and treatment.
 - Severity of rare diseases and associated unmet medical needs.
 - Demographics and clinical description of patient populations.
 - Timely access to screening, care, insurance or Medicaid coverage.
 - Impact of coverage, cost-sharing, tiering, and more.