



State of Louisiana

Louisiana Department of Health Office of Public Health

LOUISIANA RARE DISEASE ADVISORY COUNCIL Meeting Minutes

Tuesday, August 6, 2024 | 3:00pm | Benson Tower, Room 2024, 1450 Poydras St. New Orleans, La

MEMBER ATTENDANCE **via Zoom*

Present: James, Rouse & Williams*.

Absent: Airhart, Garrett, Moore, Andersson, Borillo, & Klingsberg.

CALL TO ORDER

Kelly Rouse called the meeting to order at 3:01 pm.

ROLL CALL

Rouse took attendance and announced that a quorum was not present.

REVIEW OF STATE REPORT CARD

Lindsey Viscarra, NORD State Policy Manager (Western Region), briefly discussed the National Organization for Rare Disorders (NORD) the State Report Card. This initiative was developed to assess how well states support people with rare diseases and to provide advocates with a tool for driving change. The report card covers the following nine key policy areas: Medicaid Financial Eligibility, Medical Nutrition, Newborn Screening, Protecting Patients in State Medicaid Programs, Protecting Patients in State-Regulated Insurance, Rare Disease Advisory Councils, Step Therapy (Fail First), Telehealth, & Prescription Drug Out-of-Pocket Costs. The recent edition, updated in November 2023, aims to guide patients, advocates, and policymakers in improving state policies to better meet the needs of the rare disease community.

Louisiana's Report Card

- ❖ Medicaid Financial Eligibility : B
 - Medicaid Eligibility for Childless Adults: A
 - Medicaid Eligibility for Parents of a Dependent Child: A
 - Medicaid Eligibility for Pregnant Women: D
 - Medicaid Eligibility for Children: B
- ❖ Medical Nutrition : B
- ❖ Newborn Screening : B
 - Screening for RUSP Core Conditions Grade: B
 - Adding Screens Grade: B
 - Funding Grade: B
 - AC Grade: B
- ❖ Prescription Drug Out-of-Pocket Costs : A

- ❖ Protecting Patients in State Medicaid Programs : P
- ❖ Protecting Patients in State-Regulated Insurance : F
 - Initial Plan Duration Grade: F
 - Renewals Grade: F
 - Maximum Duration Grade: F
- ❖ Rare Disease Advisory Councils : Yes
 - Has a Rare Disease Advisory Council?: Yes
- ❖ Step Therapy (Fail First) : A
 - Categories: A
 - Exceptions Process: B
 - Clinical Practice: A
 - Timeline: A
- ❖ Telehealth : Pass
 - Member of Interstate Medical Licensure Compact (IMLC)?: Pass

LEGISLATIVE BILLS

Lauren Williams shared details about legislation related to individuals diagnosed with a rare disease passed by Congress. The Creating Hope Reauthorization Act ([H.R. 7384 | S 4583](#)) reauthorizes the Rare Pediatric Disease Priority Review Voucher (PRV) program for six years, ensuring this vital incentive that has no cost to taxpayers can continue to spur innovation in rare diseases that disproportionately affect children.

The Accelerating Kids' Access to Care Act ([H.R. 4758 | S 2372](#)) requires state Medicaid programs to establish a process through which qualifying out-of-state providers may enroll as participating providers for five years without undergoing additional screening requirements, unless the state has an agreement with other states that governs coverage of children with medically complex conditions that is in accordance with specified guidance from the Centers for Medicare & Medicaid Services (CMS). Among other requirements, a qualifying provider must (1) serve individuals under the age of 21; (2) have previously been screened for Medicare participation or for participation in the Medicaid program of the state in which the provider is located; and (3) have been determined by the CMS or state Medicaid program to pose a limited risk of fraud, waste, or abuse.

The HELP Copays Act ([H.R. 830](#)) requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses toward the requirements.

RDAC WEBSITE & ANNUAL LEGISLATIVE REPORT CONTENT

Members will continue to review content for the RDAC website. Members agreed that more resources should be included and the overall list should be reorganized based on diagnosis to accommodate viewers. It was agreed the resources list must be revised and members' bios be added before submitting the draft for publishing.

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2025 LEGISLATION REVISIONS

The members discussed submitting a proposal to revise [RS 40:1122.1](#) for the 2025 Legislative Session. Members shared thoughts about current members being active and challenges with conducting official business due to low meeting attendance. BFH staff will get clarity about meeting quorum requirements and the status of membership applications. More details will be shared when they are available.

ADJOURNMENT

The meeting adjourned at approximately 4:13 pm.

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.