



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA RARE DISEASE ADVISORY COUNCIL

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

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

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

MEETING MINUTES

- I. **Call to Order** – The meeting was called to order at 11:03 am by the Jonathan James.
- II. **Roll Call** – A quorum was not present and no official business can be conducted.
 - a. **Present:** Hans Andersson (virtual), Jennifer Borrillo (virtual), & Jonathan James (virtual).
 - b. **Absent:** Ross Klingsberg, Kelly Rouse, & Lauren Williams.
- III. **Mandate Review** – The BFH Facilitator reviewed Revised Statute 40:1122.1 (see agenda).
- IV. **Vacancy Announcements** – The following positions are currently vacant: a Louisiana Department of Health representative, a licensed physician practicing in La with experience in treating rare diseases, a licensed geneticist practicing in La, a licensed/advanced practice registered nurse practicing in La with experience treating rare diseases, an adult residing in La that has been diagnosed with a rare disease and a caregiver for a person who has been diagnosed with a rare disease.

Members briefly discussed the Council's challenges to have a quorum due to filling vacant positions and delays with the application process. They also discussed potential candidates for each vacant position. Members were informed of the application process established by the Governor's office and were encouraged to share these vacancies with their networks and to have interested candidates email RDAC@LA.Gov.
- V. **Old Business**
 - a. **Rare Disease Day 2025 Recap-** Jonathan James recapped the event at the state capitol on February 28. There were nearly 300 attendees and several vendors from around the state. The Council plans to make this an annual event and will soon start planning for next year. Members discussed meeting with more legislators in hopes of bringing more awareness and resources to rare disease around the state.
 - b. **RDAC Website-** Council members reviewed the website content and discussed the importance of having a website exclusively for rare diseases and the RDAC. The RDAC [Facebook page](#) was also shared with members
- VI. **Public Comments** – None submitted.
- VII. **Adjournment** – The meeting was adjourned at 11:51 am.

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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.

DRAFT