



**State of Louisiana**  
Louisiana Department of Health  
Office of Public Health

**LOUISIANA RARE DISEASE ADVISORY COUNCIL**

**Date:** Wednesday, September 3, 2025 **Time:** 1:00 pm – 2:00 pm

**Virtual Meeting:** ~~Register to Join~~ [ldhophbfhgenetics.zoom.us/j/99893515955](https://ldhophbfhgenetics.zoom.us/j/99893515955)

**Anchor Location:** 628 North 4th Street, Room 118, Baton Rouge, La 70802

**MEETING MINUTES**

- I. **Call to Order** – The BFH Facilitator, Rodney Goldsmith, called the meeting to order at 1:04 pm.
- II. **Roll Call** – Quorum not present.
  - a. **Present:** Hans Andersson and Jennifer Borrillo.
  - b. **Absent:** Jonathan James, Ross Klingsberg, Kelly Rouse, & Lauren Williams.
- III. **Mandate Review** – The BFH Facilitator reviewed Revised Statute 40:1122.1 (see agenda).
  - a. The statute mandates the RDAC submit an annual report that includes recommendations to Louisiana Department of Health, the Drug Utilization Advisory Board, and agencies providing services to individuals diagnosed with a rare disease.
  - b. The facilitator shared that the BFH Data to Action team has collected data for the Sickle Cell Disease Registry and their team has expressed interest in meeting with the RDAC to discuss RD data needs. The RDAC previously mentioned creating a survey to assess data needs of providers and patients in Louisiana. Will discuss further at a later meeting.
  - c. There was also a discussion to make updates to the current statute to restructure the Council's governance and to remove challenges with membership appointments. Will discuss further at a later meeting.
- 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. Dr. Andersson will contact the Governor's Office to discuss delays appointing new members. 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](mailto:RDAC@LA.Gov).
- V. **Adjournment** – The meeting adjourned at 2:00 pm.

**Next Meeting: Friday, October 17 | 11:00 am | Location: TBA**

**NOTE:** The order of the agenda is subject to change 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](mailto: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](#). Email statements to [RDAC@LA.GOV](mailto:RDAC@LA.GOV) at least 24 hours prior to the meeting to be included in the record for the meeting.