



# State of Louisiana

Louisiana Department of Health  
Office of Public Health

## LOUISIANA RARE DISEASE ADVISORY COUNCIL

### Meeting Minutes

Tuesday, May 7, 2024 | 3:00pm | Benson Tower, Room 2024, 1450 Poydras St. New Orleans, La

#### **MEMBER ATTENDANCE** *\*via Zoom*

**Present:** Andersson, Borillo\*, James, Klingsberg\*, Rouse, & Williams.

**Absent:** Airhart, Benchea, Garrett, & Moore.

#### **CALL TO ORDER**

Kelly Rouse called the meeting to order at 3:03 pm.

#### **ROLL CALL**

Lauren Williams took attendance. It was announced that a quorum was not present.

#### **GUEST PRESENTATION**

Rouse introduced Dr. Randy Davidson. Davidson briefly shared his family's journey of his daughter being diagnosed with Ehlers-Danlos syndrome (EDS) and how it led to the discovery of his wife's diagnosis of the same disease. He stated the hematologist went above and beyond by educating his wife and daughter, and made them feel comfortable the diagnosis. He discussed the importance of having people advocating for those affected by rare diseases. Council members offered several suggestions for treatment and resources available for him and his family.

#### **GOOD GOVERNMENT TRAINING RECAP**

Goldsmith provided a brief recap of the training. Some of the topics highlighted are the changes mandated by the newly passed Sunshine law and the requirements for electronic access to open meetings. Members discussed the importance of attending meetings on a regular basis. Rouse plans to contact members that do not attend meetings regularly to confirm membership status. Members also discussed approaching the legislature about making changes to R.S. 40:1122.1 to include travel reimbursement for members and revising the composition of the Council's membership (revising positions, mix of adult and pediatric physicians).

#### **RDAC WEBSITE & SOCIAL MEDIA UPDATE**

Members reviewed a draft of 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. Members will start collecting all links for the website and filter through them before the next meeting. Members were advised that all social media content related to RDAC must be submitted to BFH communications. The creation of social media accounts for individual boards and commissions is prohibited. Williams emphasized the importance of having a presence on the web and social media and how people affected by rare diseases often find community with others this way.

**Name:** Louisiana Rare Disease Advisory Council Meeting

**Date:** Tuesday, May 7, 2024

**Page:** 2

**VACANT POSITION UPDATE**

Applications have been submitted for the vacant positions and are awaiting a decision from the DOA. More details will be shared when they are available.

**ANNOUNCEMENTS**

Rouse announced that the next RDAC meeting is scheduled on Tuesday, August 6, 2024, at 3:00 pm.

**ADJOURNMENT**

The meeting adjourned at approximately 4:30 pm.

DRAFT

**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](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. Statements should be emailed to [rdac@la.gov](mailto:rdac@la.gov) and must be received at least 24 hours prior to the meeting to be included in the record for the meeting.