



# State of Louisiana

Louisiana Department of Health  
Office of Public Health

## **RARE DISEASES ADVISORY COUNCIL Meeting Minutes**

February 6, 2024 | 3:00pm | Benson Tower

### **ATTENDANCE (\*VIA ZOOM)**

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

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

### **CALL TO ORDER**

Kelly Rouse called the meeting to order at 3:13 pm.

### **ROLL CALL**

Rouse called the roll, and a quorum was not established.

### **PRESENTATION**

Tara Britt, Associate Chair of the North Carolina Rare Disease Advisory Council & Network, spoke about the organization and some of their work in North Carolina. Britt shared helpful information on how to become better advocates for patients diagnosed with rare diseases. She also shared resources that will aid in engaging others in RDAC.

### **RDAC WEBSITE UPDATE**

Goldsmith gave a brief overview of what the communications team will need in order to update content on the RDAC website. Members were asked to email responses to the following questions by Fri, March 1: What are rare diseases? How do I locate a provider? Where can I find other resources? What type of support is available for people diagnosed with/affected by rare diseases?

### **RARE DISEASES DAY (FEBRUARY 29, 2024)**

Rouse announced that Lauren was able to arrange for the State Capitol building to light up in honor of Conner on Rare Diseases Day on February 29, 2024. Libby will inform everyone if there is an event/ceremony scheduled.

### **LEGISLATION IDEAS**

Members are encouraged to share ideas or suggestions for changing legislation related to rare diseases or RDAC. Members can contact legislative officials to be a resource or an advocate for legislation proposals.

**ANNOUNCEMENTS**

**RDAC Vacant Positions-** There are currently two vacant positions: a physician licensed and practicing in Louisiana and a LDH Representative. Members should have any qualified nominees to email [rdac@la.gov](mailto:rdac@la.gov).

**2024 NORD Living Rare Forum-** The 2024 NORD Living Rare, Living Stronger Patient & Family Forum will be held on June 8-9 in Los Angeles, CA. Airhart stated she would inform members if there were opportunities available to have travel sponsored.

**ANNOUNCEMENTS**

Rouse announced that the next RDAC meeting is scheduled on Tuesday, May 7, 2024, at 3:00 pm in Benson Tower, room 2024.

**ADJOURN**

The meeting adjourned at approximately 4:56 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](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.