



State of Louisiana

Louisiana Department of Health
Office of Public Health

Louisiana Rare Disease Advisory Council Meeting Minutes

Date: October 24, 2023

Time: 3:00 pm – 4:00 pm

Location: Benson Towers Rm 2024
1450 Poydras St. New Orleans, LA

Zoom Link: zoom.us/j/96186369823

Meeting ID: 961 8636 9823
Access Code: f7WMpd

Libby Airhart (Chair)	A	Jennifer Borrillo	P	Carolyn Moore	V
Meredith Allain	A	Deiadra Garrett	A	Kelly Rouse (Vice Chair)	Y
Hans Andersson	V	Jonathan James	V	Lauren Williams (Secretary)	A
Marissa Benchea	A	Ross Klingsberg	A	QUORUM PRESENT?	N

Call to Order & Welcome

Rouse called the meeting to order at 3:22 pm. A quorum was not present.

Roll Call & Introductions

All RDAC members and guests in attendances briefly introduced themselves.

Quarterly Meeting Requirements (2023 & 2024)

Goldsmith gave an overview of the meeting requirements in listed in RS 40:1122.1 and how SB 201/Act 393 of the 2023 Regular Legislative Session impacts the Open Meetings Law. After a robust discussion, members stated they understood the requirements and expressed they were in favor of continuing to meet in a hybrid format.

Dionne Stalling (Executive Director, Rare & Black)

Stalling, the executive director of Rare & Black and a newborn screening ambassador, reached out to Louisiana to improve accessibility and awareness of newborn screening in areas heavily populated by African Americans. She also expressed interest in understanding how Louisiana supports parents in the event of a positive screen result.

Public Comments

Dr. Pooja M. Rao a neurology specialist at Ochsner Health in New Orleans expressed interest in joining and working with RDAC.

Adjourn

The meeting was adjourned at 3:53 pm.