



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA RARE DISEASE ADVISORY COUNCIL

Wednesday, February 12, 2025
2:00 pm – 3:00 pm

Location

Benson Tower, Rm 2024, 1450 Poydras Ave, New Orleans, LA 70112
Zoom: zoom.us/j/97420178007 | **Meeting ID:** 974 2017 8007 | **Passcode:** MtT2re

Meeting Minutes

- I. **Call to Order** – The meeting was called to order at 2:00 pm by the Chair, Kelly Rouse.
- II. **Roll Call – A quorum was not present.**
 - a. The following members were present:
 1. Kelly Rouse (virtual)
 2. Jennifer Borrillo
 3. Jonathan James (virtual)
 4. Lauren Williams (virtual)
 - b. Absent Members: Hans Andersson & Ross Klingsberg
- III. **Public Comment** – No public comments made at this time.
- IV. **Approval of Minutes** – No quorum present. Tabled to the next meeting.
- V. **Mandate Review**

BFH Facilitator reviewed Revised Statute 40:1122.1 and led the discussion about the council's recommendations to agencies included in the latest annual report. Members responded favorably and continued sharing ideas for creating outreaches, workshops, and other resources for the rare disease community.
- VI. **Vacancy Announcements** – RDAC has the following 6 seats available:
 - 1 representative from the Louisiana Department of Health.
 - 1 licensed physician practicing in La with experience in treating rare diseases.
 - 1 licensed geneticist practicing in La.
 - 1 licensed registered nurse or advanced practice RN practicing in La with experience treating rare diseases.
 - 2 adults residing in La that have either been diagnosed with a rare disease or is a caregiver for a person who has been diagnosed with a rare disease.

VII. New Business

a. RDAC Patient/Advocate Story | Dr. Latasha Holt

Dr. Latasha Holt is an assistant professor at the University of Louisiana at Lafayette. Her daughter, Blakely, was diagnosed with adrenal insufficiency and epilepsy. Adrenal insufficiency is when the adrenal glands don't produce enough cortisol and aldosterone. Epilepsy is a chronic brain disorder characterized by recurrent seizures, which are brief episodes of involuntary movements, loss of consciousness, or altered awareness. She shares her experiences of managing Blakely's care in hopes of helping families and teachers avoid misinformation and potential errors in care.

b. Rare Disease Day 2025/Event at the State Capitol

Rouse and Williams announced that the RDAC is hosting a Rare Disease Day event on February 28 at the Louisiana State Capitol Formal Gardens in Baton Rouge, La. This event is designed to promote advocacy, inclusivity, and strengthen the rare disease community in the state. The event is free and open to the public. Guests expected to attend include Miss. Wheelchair Louisiana, Miss. LSU, Miss. Southeastern University, state government officials, industry representatives, RDAC members, medical providers, and many more. Vendors and volunteers are encouraged to sign up. The deadline for vendors to register is 2/21/25.

VIII. Public Comment

Dionne Stalling emphasized the importance of connecting and building upon existing resources. She shared that the Immune Deficiency Foundation has school programs for children with primary immune deficiencies and the Kansas City Hospital hosts an annual event on transitioning from pediatric to adult care.

IX. Adjournment – The meeting was adjourned at 3:00 PM.

Next Meeting

Date: Friday, April 25

Time: 11:00 am

Location: Benson Tower, Rm 2024, 1450 Poydras Ave, New Orleans, LA 70112