



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA RARE DISEASE ADVISORY COUNCIL

Tuesday, December 3, 2024
3:00 pm – 4:00 pm

Location

Benson Tower, Rm 2024
1450 Poydras Avenue
New Orleans, LA 701121

Meeting Minutes

- I. **Call to Order**
 - a. The meeting was called to order at 3:03 PM by Chair Kelly Rouse.
- II. **Roll Call – A quorum was not present.**
 - a. The following members were present:
 1. Kelly Rouse (Chair) (virtual)
 2. Hans Andersson, M.D. (virtual)
 3. Jennifer Borrillo
 4. Jonathan James (virtual)
 5. Ross Klingsberg, M.D. (virtual)
 6. Lauren Williams (virtual)
 - b. **Absent:** None
- III. **Public Comment**
 - a. None at this time. It was announced that there will be another opportunity for public comments at the end of the meeting.
- IV. **Approval of Minutes**
 - a. No quorum present. Tabled to the next meeting.
- V. **Mandate Review**
 - a. BFH Facilitator led a review of the council's mandate, which includes providing input and feedback on matters affecting those with rare diseases, offering expert and clinical advice on treatments for rare diseases, and reporting findings and recommendations to the Governor, legislature, and any other relevant agencies.

VI. Vacancy Announcements

- a. It was announced that there are six vacant seats on the board. Members are encouraged to continue spreading the word within their networks.

VII. New Business

- a. RDAC Patient/Advocate Presentation
 1. Rouse introduced Abbey Benjamin, a parent of a patient with a rare disease from North Louisiana. Benjamin shared that she has an 8 year old daughter diagnosed with a rare, inherited metabolic disorder, adenylosuccinate lyase deficiency (ASLD) that affects the brain and nervous system. Her daughter experiences seizures and currently undergoes outpatient therapy. Her daughter participates in extra-curricular activities such as dance and attends events regularly. Benjamin continued to say that she has connected with other families of patients with a similar diagnosis to her daughter via social media platforms. She also shared her and her family's coping strategies and how they rely heavily on their support system. Council members shared resources for support with Benjamin and thanked her for sharing her story.
- b. 2024 NORD Conference Recap
 1. Rouse and Williams recapped their experience at the latest NORD Conference. Both stated the importance continuously communicating RDAC's goals and progress (internally & externally). They both learned the importance of understanding desired verbiage changes in legislation and by-laws. Rouse shared a goal for the next year to complete these changes before the end of February 2025 to ensure there is enough time to submit to the Louisiana Legislature to review during the 2025 Regular Session.

VIII. Public Comment

- a. Dionne Stalling encouraged members to attend the Virtual Community Congress Meeting in Washington, D.C. Will share details via email.

IX. Adjournment

- a. The meeting was adjourned at 4:06 PM.

Next Meeting Details

Date: TBA

Time: TBA

Location: TBA