



State of Louisiana

Louisiana Department of Health
Office of Public Health

Louisiana Rare Disease Advisory Council (RDAC) Meeting

October 28, 2021

11:00 a.m.-12:00 p.m.

<https://ldhophbfhgenetics.zoom.us/j/87837798360>

Conference Call info: (602) 333-0032

Access Code: 532143#

Roll Call taken; members present at the meeting were as follows:

- Libby N. Airhart, Caregiver for person diagnosed with a rare disease
- Hans C. Andersson, M.D., Physician with experience in researching, diagnosing, or treating rare diseases
- Marissa A. Benchea, Person diagnosed with a rare disease
- Jennifer L. Borillo, MSW, LCSW, MBA, Representative from an academic research institution that conducts rare disease research
- Deidra J. Garrett, M.D., Physician with experience in researching, diagnosing, or treating rare diseases
- Jonathan James, Appointed by the President of the Senate
- Ross C. Klingsberg, M.D., Representative from an academic research institution that conducts rare disease research
- Carolyn L. Moore, FNP-BC, MHA, Registered nurse or advanced registered nurse who has experience in treating rare diseases
- Kelly Rouse, MS, BCBA, LBA, Appointed by the House of Representatives
- Jantz Malbrue, MSPH, Representative from the Louisiana Department of Health

I. Call to Order and Welcome

Libby Airhart called the meeting to order at 11:01 a.m. and welcomed everyone to the council's first meeting.

II. Introductions

All attendees provided a brief introduction of themselves and their experiences with rare diseases.

III. Governor-Appointed RDAC Members

The governor-appointed members and their appointed seats were reviewed.

IV. Overview of RDAC

Libby Airhart provided an overview of the Rare Disease Advisory Council. Ms. Airhart also explained the role of the National Organization for Rare Disorders (NORD) along with other state and national resources and support available. Dr.

Hans Andersson suggested reviewing other states' RDACs for ideas and resources. The NORD's Project RDAC can be found at <https://rarediseases.org/projectrdac/>, which provides an overview, resources, and list other RDACs by state.

V. Legislation: House Bill No. 460

Jantz Malbrue provided an overview of the bill, including the quarterly meeting and annual reporting requirements. The bill indicates that the LA RDAC lies within the Department of Health. However, Mr. Malbrue will verify with the Governor's Office, Legislatures, and Department of Health on the placement of the RDAC and any other requirements. The link for House Bill No. 460 is <https://www.legis.la.gov/legis/ViewDocument.aspx?d=1235637>.

VI. Election: Chair and Vice-Chair

The governor will determine the chair and vice-chair for the LA RDAC. A list of interested candidates will be sent to the governor's office for selection. Members interested in either seat should email their nominations to Libby Airhart (lairhart@cfcsyndrome.org) or Jantz Malbrue (jantz.malbrue@la.gov).

VII. Discussion of Vision, Mission and Work Plan

Ms. Airhart discussed the development of the LA RDAC's vision and mission statement. These two statements will assist in the creation of a work plan to address awareness, diagnostic tools, and access to affordable treatments and cures throughout the state. In addition, the LA RDAC will establish bylaws as guiding procedures for appointed members and the council. The LA RDAC will schedule a quick meeting to begin developing these statements in November 2021.

VIII. RDAC Documents and Folder

A LA RDAC folder was created within google drive to share documents and resources for the council. The link for the documents is <https://drive.google.com/drive/folders/1L4H1btKpw-R-SBGys8riGKlpu43HK6TC?usp=sharing>.

IX. Meeting Schedule

The LA RDAC will follow a quarterly meeting schedule. Members will receive a survey poll to determine a suitable month, day, and time for reoccurring meetings.

X. Communication

Members shared that the best method of communication was through email. The LA RDAC will create a contact list to document each members' updated information.

XI. Closing Remarks

Ms. Airhart reminded members to submit appropriate appointee documents to the Louisiana Secretary of State and the Senate and Governmental Affairs Committee.

Adjournment 11:45 AM