



State of Louisiana

Louisiana Department of Health
Office of Public Health

Louisiana Rare Disease Advisory Council (RDAC) Meeting
January 18th, 2022
11:00 a.m.-1:00 p.m.

Join from PC, Mac, Linux, iOS or Android:

<https://ldhophbfhgenetics.zoom.us/j/85998818318>

Or Telephone: Dial USA 602 333 0032

Conference code: 532143

January Meeting Minutes

Call to order by Libby Airhart at 11:05

Roll Call: Libby Airhart, Marissa Benchea, Jantz Malbrue, Jennifer Borillo, Dr.

Klingsberg, Jonathan James, Dr. Anderson

Introduction of Tara Britt, Co-Chair of North Carolina RDAC.

Suggestions from Tara to the Council

- Is there a newborn screening time limit?
- Contacting lab director in state for Newborn Screening
- Reach out to La Bio – Biotechnology company
- Getting legislators to recognize the RDAC with outreach
- Setting up meeting schedule for the rest of the year
- Offer public to join zoom meetings when council is ready
- Check and see if we have a Life Science Caucus

RDAC Council coordinated a list of items to tackle for the next meeting:

- Gathering list of patient organizations in Louisiana
- Creating a website which would house a resource page
- Questionnaire for affected rare disease patients/organizations

OFFICE OF PUBLIC HEALTH
Genetic Diseases Program

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- Access to care and medications, including access to insurance
- Policy review and/or legislation affecting people with rare diseases,
- Overall awareness of rare diseases, including surveying patients, advocacy groups, as well as a review of state utilization patterns.
- Top Concerns your organization has

Meeting Closed at 12:46