



**State of Louisiana**  
Louisiana Department of Health  
Office of Public Health

**Genetic Diseases Program Advisory Committee**

October 28, 2023

2:00pm-3:30pm

Benson Tower 1450 Poydras Street, 20<sup>th</sup> Floor, Room 2024  
Zoom Link: <https://ldhophbfhgenetics.zoom.us/j/89076697817>

**I. Roll Call and Introductions**

- a. Heiki Griffin welcomed everyone to the meeting.
- b. 24 participants
- c. Members present were Cheryl Harris, Dr. Hans Andersson, Dr. Joseph Bocchini, Michelle Duplantier, Alyson Saadi and Tiffany Allemand
- d. A quorum was not established.
- e. Without a quorum, statement given as to purpose of meeting is informational session.

**II. Align minutes with agenda**

- a. The minutes from 7/28/23 were attached to the invitation prior to the meeting. Attendees were asked for any corrections, revisions, or questions – none voiced
- b. Bureau of Family Health updates
  - Act 393- Heiki Griffin gave update on SB201/Act 393. Rulemaking in progress and will be available in February. At this time, all meetings are still to be held in person until further guidance. If any member, guest, or caretaker requiring an ADA form to attend virtually may do so by contacting Committee Facilitator, Heiki Griffin. Future vision for this committee is to improve membership/attendance and begin voting process for bylaws. Due to the nature of the committee, with specialists located in various parts of the state and country, the allowance of successive virtual meetings will be helpful in attaining this goal. Heiki will keep the attendees updated on these amendments.
  - Region 9 Neurology contract on track to begin December 1, 2023
  - Genetic Diseases Program Updates- Cheryl Harris gave brief update about the NBS Rulemaking in process
- c. Laboratory Updates –Alyson Saadi, OPH Assistant Lab Director
  - X-ALD Verification – in progress
    - i. Software updates
    - ii. Upgrade of database
  - NBS messaging, Electronic order/electronic result, CDC Pilot
    - i. Collaboration with eligible hospitals for pilot in progress

**III. Public Comment**

- a. Miranda McAuliffe
  - Presentation on X-ALD, parent perspective, ALD Alliance, and toolkits
- b. Kim Tuminello

- Presentation on GAMT, parent perspective, Association of Creatine Deficiencies
- c. X-ALD future steps
  - Identify individuals for X-ALD treatment plan discussion

#### **IV. New Business**

- a. Other Committee Updates – Rodney Goldsmith
  - a. Rare Diseases Advisory Committee - Introductory meeting held to establish future meeting dates and agendas

#### **IV. Announcements**

- a. Upcoming Meetings, Webinars, Workshops
  - HHS Advisory Committee on Heritable Disorders in Newborns & Children Meeting
    - November 2, 2023 9am-3pm CST virtual
    - November 3, 2023 9am-12pm CST virtual
    - Registration Link: <https://www.achdncmeetings.org/registration/>
- b. Upcoming Meeting Dates for 2024
  - April 26, 2024
  - July 26, 2024
  - November 1, 2024

#### **V. Adjournment – 3:10 pm**