



State of Louisiana

Louisiana Department of Health

Office of Public Health

Genetic Diseases Program Advisory Committee Minutes

April 26, 2024 from 2:00pm-3:30pm

Location: Zoom (virtual)

Meeting link:

<https://us06web.zoom.us/j/81969153818>

Phone: 602-333-0032 Conference code: 479083

I. Roll Call and Introductions

- a. Heiki Griffin welcomed everyone to the meeting.
- b. 20 participants
- c. Members present were Dr. Hans Andersson, Dr. Richard Tulley (proxy for 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. Department Updates – Heiki Griffin

- a. The minutes from 10/28/23 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
 - **Region 9 Pediatric Neurology CSHS clinic**, this is in our Hammond PHU – we have a signed and executed contract as of February 1st with 4 physicians from OLOL – Dr. Shah, Dr. Lorenzo, Dr. Manuel, and Dr. McGuire . This new contract was the result of Dr. Hollman retiring. Reports are that this clinic is going well and they have been able to receive all of Dr. Hollman’s patients in that region. So happy to report that transition of care was successful.
 - **Act 393**, Virtual Meeting law amendment and allowances. LDH’s rule for Act 393 has been promulgated. However, this rule that was published in the March 20, 2024 Louisiana Register only speaks to ADA accessibility. I did ask BFH Legal team for updates on the other pieces of this, specifically the advisory committee allowances, and they are still working on it.
 - As it stands, the law has been amended for a reasonable amount of virtual meetings and that members may be able to attend in-person meetings virtually – what *reasonable* means to LDH is still the unknown, it is up to the LDH legal team to promulgate what the specifics will be in rule. What we hope is that we will be able to scale down the number of mandatory in person meetings and count members that join an in person meeting virtually as part of the quorum. Updates to come.
 - **Genetics Program Updates**, focus on streamlining our process and operation so that we can really effectively communicate about conditions. We have established internal leadership meetings focused on NBS to really look at our progress and assess barriers. I’ve taken a step back to work on the framework for these operations so that our intent is better understood especially for our partners, stakeholders, and the public.

- **NBS Rule Edits** – one of the projects we’ve been working on is updating and modernizing the NBS Rule. From the 2023 legislative session we were able to remove the list of conditions from law and place them into rule, which makes it an easier process and really a more efficient and timely way to add conditions. From this, we have been really focusing on ways to more clearly identify the process and procedures surrounding NBS as a whole. So Dr. Amanda Dumas joined us and had a great idea of simplifying the rule and creating a policy and procedure manual for reference so if you can introduce yourself and talk to us a little about it.
- **NBS Website Updates** - Another way we have been trying to streamline operations is by clearly identifying where we are in the process when adding conditions. We want to increase our transparency with the public, as well as our team, so I’ve been working with our communications team to expand our website. When this launches, we will have a space to reference our committee’s role and the work being done regarding conditions.

Draft shown to committee via Heiki Griffin Please let me know if you have any input or edits you would like to see on this web page.

- **Legislative Report** – On February 26th, we submitted an annual report to the legislature on NBS. This was the first legislative report and was mandated in the 2023 Legislative Session. This was a joint effort by our team and OPH lab to really study the process and timelines that we are facing with the current conditions. The report is not public yet but I will house this and all of the future annual reports on the website as they become available. Again, this is another step to clearly define a process and communicate the circumstances surrounding NBS at this time.
 - The report has prompted several **action steps**, such as the website survey portal and the establishment of a new steering committee. The purpose of this is continuous collaboration among stakeholders which would make bringing any condition from deliberation to the point of implementation more efficient and it ensures that all entities affected by decisions are made aware concurrently. This also creates a space for all sections to offer solutions to barriers we face when trying to implement conditions in a 2 year timeline.
- c. Laboratory Updates –Alyson Saadi, OPH Assistant Lab Director
- LSD (MPS 1 and Pompe)- validation study complete, final report development in progress, need to send for all appropriate approvals
 - Training on new mass spec machine June 3, up and running date set for July
 - X-ALD Verification – in progress
 - Software updates
 - Upgrade of database
 - Intro of possibility of testing for GAMT

III. Public Comment

- a. None

IV. New Business

- a. Production of an outcomes report and/or tracking report to present to committee in future meetings
- b. Addition of BMT expert, adult specialists and ethicist to assist in committee decision making
- c. Other Committee Updates – Rodney Goldsmith

Name

Date

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- Rare Diseases Advisory Committee – May 7, 2024 in Benson meeting, Bylaws and web page establishment
- Sickle Cell Commission - preparation for upcoming symposium

IV. Announcements

- a. Upcoming Meetings, Webinars, Workshops
 - HHS Advisory Committee on Heritable Disorders in Newborns & Children Meeting
 - May 10, 2024 9am-3pm CST virtual
 - May 11, 2024 9am-12pm CST virtual
 - Registration Link: <https://www.achdncmeetings.org/registration/>
- b. Upcoming Meeting Dates for 2024
 - July 26, 2024
 - November 1, 2024

V. Adjournment – 3:04 pm