



State of Louisiana

Louisiana Department of Health

Office of Public Health

Louisiana Birth Defects Advisory Board Meeting Minutes

January 21, 2022

1:00-3:00pm

Meeting link:

<https://us06web.zoom.us/j/84203017026?pwd=TXErd2hRZVJyYbE9kTExQdmNZWGCZz09>

Join by phone: 602 333 0032 Conference code: 530169

I. Welcome & Introductions

- a. Members present: Dr. Meredith Allain, Geneticist Ochsner New Orleans; Dr. Lyn Kielyka, State MCH Epidemiologist; Dr. Dimitry Niyazov, Geneticist Ochsner New Orleans;
- b. Stakeholders & Partners present: Dr. Gina Lagarde, Pediatrician/Office of Public Health Region 9 Medical Director; Kathleen Aubin and Kate Friedman, OPH Section of Environmental Epidemiology and Toxicology, Environmental Public Health Tracking Network; Betsey Snider, RN BFH Family Resource Center; Cheryl Harris, BFH CYSHCN & Genetic Diseases Newborn Screening Program Manager;
- c. Staff present: Jane Herwehe, BFH Data to Action Team (DAT) Lead; Dionka Pierce, BFH Data to Action; Julie Johnston, LBDMN Program Manager; Dr. Tri Tran, BFH Senior Epidemiologist supporting LBDMN and Early Hearing Detection & Intervention; Christy Patton, Region 7 Data Collection Specialist (DCS); Curitessia Criff, Regions 6 & 8 DCS; Tracy Zehner, Regions 4&5 DCS, Jasmine Luter, Region 1 DCS, Rachele Boudreaux, BFH Boards & Commissions Liaison;

II. Updates

- a. LBDMN\Family Resource Center Referral Pilot –Ready to test our first batch load into the new FRC database. Once that is accomplished, postcards will be mailed to the first 250 families to pilot the process.

We are working with the database developer to retrieve data from the new system for data analysis and program evaluation.

In 2021, we identified 1160 children born in 2018-2021 with qualifying birth defects to connect to resources.

- b. It is time to write the annual report to the legislature. This report will include findings of the 2018 births data analysis. There were no other suggestions for modifications to the report format or content.
- c. Kate Friedman, EPHT program manager, announced 2015-2017 birth defects data will be published on the [health portal](#) in January.

- d. Cheryl Harris announced the addition of Spinal Muscular Atrophy (SMA), Mucopolysaccharidosis Type I (MPS I), and Glycogen Storage Diseases Type II (Pompe Disease) to the newborn screening panel beginning with January 2022 births. https://ldh.la.gov/assets/oph/Center-PHCH/Center-PH/cshs/genetics/NBS_Update_2021_GoLiveAnnouncement1.pdf

Also the Genetic Diseases Advisory Committee meets February 4, 2022 at 2pm
<https://ldhophbfhgenetics.zoom.us/j/87052496361>

- e. Rachelle Boudreaux announced a new BFH Legislative Coordinator, Ayesha Umrigar, began this week.
- f. Jane Herwehe- highlighted the extraordinary work of the LBDMN Data Collection Specialists who have been working short-staffed to review approximately 7,500 cases per year to certify the 1,500 cases added to the birth defects registry each year.

- III. Prevention Case Review Pilot Update - The advisory board met with board members, stakeholders, partners, and staff to continue to develop a birth defects prevention case review process. We are using 2015-2019 orofacial cleft data to develop the pilot.*

Purpose Statement: The purpose of the case review is to move our data to action by identifying preventable birth defects to make evidence-based recommendations for systems level changes to improve primary prevention and intervention efforts in Louisiana's maternal health system.

We have developed the following frameworks to support robust case review:

- a. Evidence base – conduct a broad literature review to identify risk factors and interventions for prevention (October 2021)
- b. Data – use the following to understand birth defects in Louisiana and identify criteria for case selection review
 - Maternal Health State of the State-use multiple statewide datasets to develop a picture of maternal health for specified time period, i.e., Vital Records, LABoRS, PRAMS (October 2021)
 - Analyze a 5 year sample size of birth defects data by overall prevalence, prevalence by population characteristics, and by specified birth defects variables including known risk factors, maternal exposures, health conditions, family history, and co-occurring birth defects. (January 2022)
- c. Data Visualization – Environmental Public Health Tracking will map birth defects data and overlay with health outcomes, environmental quality, county health rankings, exposures, and occupational health data. This will contribute to an environmental equity piece to the maternal health state of the state picture as well as potentially identify exposure prevention data. (June 2022)

- d. Preparing for Case Review-
 - Refine case review tools –Case Summary Template and Considerations for Birth Defect Prevention Case Review (October 2021)
 - Recruit subject matter experts for panel discussion of identified preventable risk factors. For pilot: Endocrinologist, Maternal Fetal Medicine, OBGYN to discuss effects of maternal diabetes upon birth outcomes (June 2022)
 - Prepare cases for review based upon selection criteria identified from data analysis and evidence-based preventable risk factors. (October 2022)
 - e. Pilot the case review process and develop evidence-based prevention recommendations (October 2022)
- IV. Discussion & Public Comment – There were favorable comments for progress made and the potential of this project. No public comments.
- V. Next steps for June 2022 meeting include:
- a. Simplify data table slides
 - b. Develop data visualization presentation with EPHT
 - c. Send an SME recruitment request to the Perinatal Commission for an MFM and OBGYN to participate on a maternal diabetes discussion panel. Cheryl Harris shared a list of endocrinologists from genetics newborn screening program.
 - d. Contact Medicaid to discuss identify variables and the availability of claims data regarding maternal access to care (MFM, endocrinologist, dietitians, glucose monitoring, etc.)
 - e. Consider the additional variables suggested for data collection and prioritize each for potential database modification for 2021 births data collection.
- VI. Adjournment- Next meeting is June 24, 2022 1-3 pm. Meeting adjourned at 3:00pm.

Minutes respectfully submitted by Julie Johnston. Please email Julie.Johnston@la.gov with corrections or additions.