



State of Louisiana

Louisiana Department of Health

Office of Public Health

Louisiana Birth Defects Advisory Board Meeting Minutes
March 26, 2021
1:00-3:00pm

I. Welcome & Introductions

- a. **Members** present: Dr. Floyd Buras, Chair; Dr. Meredith Allain, Geneticist Ochsner New Orleans; Dr. Lyn Kieltyka, CDC Senior MCH epidemiologist assigned to Louisiana Office of Public Health.
- b. **Stakeholders & Partners** present: Dr. Gina Lagarde, Pediatrician/Office of Public Health Region 9 Medical Director; Alexis Williams, OPH Section of Environmental Epidemiology and Toxicology, Environmental Public Health Tracking Network; Cheryl Harris, Bureau of Family Health's Program Manager of Children & Youth with Special Health Care Needs including Genetics Diseases, Newborn Screening and Lead Prevention Programs; Betsey Snider, Director of the Family Resource Center for the Bureau of Family Health; Rachelle Boudreaux, Bureau of Family Health's Boards & Commissions Coordinator.
- c. **Staff** present: Jane Herwehe, Bureau of Family Health's Data to Action team lead; Dionka Pierce, Bureau of Family Health's Action team lead providing direct supervision for the LBDMN program; Julie Johnston, LBDMN Program Manager; Dr. Tri Tran, Bureau of Family Health's Senior Epidemiologist supporting LBDMN and Early Hearing Detection & Intervention; Michelle Whitmore, LBDMN's RN Case Review Coding Specialist; Christy Patton, Region 7 Data Collection Specialist; Curitessia Criff, Regions 6 & 8 Data Collection Specialist; Tracy Zehner, Regions 4&5 Data Collection Specialist.

II. Updates

- a. **LBDMN Activities:** Like everyone in state government, we were affected by the cyber-attack. Our data was not compromised however we lost access to our system and to our protected shared space for remote staff to access PHI. It was a full five months before new access and solutions were in place.
And then COVID came. Work from Home was not new to most of our data collection staff. But our access for onsite abstractions remains

limited or restricted at 24% of reporting hospitals where we do not have remote access to the EMR.

Still we strive to fulfill our mission *“To collect, analyze, and disseminate high quality, timely, actionable data to inform policy and systems-change to eliminate preventable birth defects, mitigate disability, and connect families with resources to improve their quality of life.”*

Keeping our mission in focus, 2020 was a year of strategic planning for LBDMN centered on touches in five areas beginning with:

Workflow realignment to produce timely actionable data: Using NBDPN Guidelines & Standards to critically assess every area of operations to realize efficiencies in data collection and case finding to produce timely actionable data. Examples include collecting codes and data variables that there was no call to report. Thereby eliminating 29 LBDMN codes of 102 total= 52 C&R + 21 LBDMN=73/102 ; realigning our data collection approach to meet the NBDPN standard of 95% core and recommended codes reportable within 24 months from delivery; expanding electronic access to more EMRs for DCS resulting in caseload equity.

Referral Project: Outsourcing referrals to BFH’s Family Resource Center for a personal contact with families to assess needs to inform resource facilitation.

Advisory board: Align with BFH Director Amy Zapata’s vision for all MCH boards and commissions to shift our focus from “making recommendations on the implementation and continuing operation of the surveillance system” to looking at reported data analysis (Reporting the What) and identifying the issues supporting trends in birth defects (Identifying the So What)

Legislative Reporting & Recommendations: Then using our annual legislative report to recommend evidence based interventions and best practices to address systemic gaps to prevent birth defects and mitigate disability in children with birth defects (Informing the Now What).

Upcoming Funding Opportunity: Much of this strategic planning informed our December 2020 application for a CDC grant to Advance Population-Based Surveillance of Birth Defects. Many of you gave us letters of support which we appreciate greatly. Originally, notifications of award were scheduled for February. That is now pushed back to mid-April with a May 1 start date, if awarded. Major elements of the grant focus on the expansion of data interoperability, epidemiology and evaluation, following referral and developmental outcomes, and developing our readiness to report Critical Congenital Heart Defects data

to NewSTEPS- the national newborn screening data repository. In the event we are not awarded the grant, Title V will continue to support birth defects surveillance.

- b. **Data Report:** Just a reminder as specified by our legislation, we follow children up to their third birthday. Therefore, our data is not considered final and reportable until 3-3.5 years.

As reported a year ago in the 2020 Legislative Report Summary: Of 169,699 children born in Louisiana between 2014 and 2016, 5,202 were diagnosed with at least one birth defect, yielding an overall prevalence of 305.6 per 10,000 live births or 3.1% (US, 3.0%). Among children with birth defects, cardiovascular system defects (about 48%) were the most common followed (in order of occurrence) by defects of the genitourinary, musculoskeletal, chromosomal, orofacial, central nervous, gastrointestinal, eye, and ear/face/neck systems. Other birth defects contributed about 5%. The data in this report are limited to children born to Louisiana residents and birth occurrence in state. Also only live births with birth weight \geq 350 grams or gestational age \geq 20 weeks were included. When stratified by race and ethnicity, rates of birth defects, both overall and by organ and chromosomal system, were similar for non-Hispanic White and non-Hispanic Black children.

See link for full report:

<https://ldh.la.gov/assets/docs/LegisReports/ACT194RS200172020.pdf>

2017cases will be reported in the 2021 Legislative Report in May.

Because of the shift in our data collection approach to only abstract NBDPN core and recommended cases, with the next report in 2022, we will report 2018-2020 cases. With data from three birth years, the board can begin to tackle special projects such as grouping types of cases for review to identify recommendations for better surveillance quality or evidence-based interventions to address systemic gaps to improve testing and follow up for moms and children affected by birth defects.

Discussion: Cheryl Harris: would like to explore a future data linkage and analysis project with newborn screening to ensure no missed cases in NBS.

Alexis Williams: Environmental Public Health Tracking Network appreciates the partnership with LBDMN to display birth defects data on the health portal at <https://healthdata.ldh.la.gov/>

The portal is currently being updated with a March 31, 2021 anticipated publish data.

Dr Buras inquired about how many families receive services in the State. Julie explained that this information will be available along with reasons services were not accessed and other data variables once one-to-one referral system begins in the near future with the Family Resource Center (FRC).

Betsey Snider discussed FRC duties. FRC already provides referrals from private pediatricians and now will also provide services to family referred by LBDMN. Betsey discussed FRC staff includes herself (retired OPH/CSHS nurse), a social services counselor from CSHS, among others including a parent educator who have already provided outreach to children with special health care needs.

III. Forecast of Advisory Board Activities

- a. **Member Recruitment:** Discussion of filling board vacancies as specified by law: Tulane, LSU New Orleans & Shreveport, Parent and Consumer positions need to be filled. Also we discussed additional expertise needed to move data to action such as a pediatric cardiologist, hospital health information management, information technology specialist and interoperability experts from LPHI's REACHnet program.

Comments: Dr. Buras wants to ensure LSU, Tulane, OLOL Children's Hospital are represented and recruited as members of Board. We need to update the law to reflect that the role of the board now has changed from initial establishment and operations into practice, so some restructuring of legislative language and board membership is needed due to current needs.

Dr. Buras said previously the board was established with institutional representation in mind; geographically most represented area is New Orleans. Dr. Buras says that we need to look more regionally, to do so by facilities that serve the region rather than by geographically seeking geneticists who serves rural areas (there are none). In any case, we have opportunities in several areas to diversify representation. Dr. Buras suggests seeking nominations from the currently specified institutions and sending our choice to Secretary. Rachelle Boudreaux will liaise with the Secretary's office for their package and process preferences.

Dr. Allain says Ochsner New Orleans genetics is covering genetic consults for Ochsner LSU Shreveport.

Cheryl Harris notes that Tulane and LSU have combined under LCMC umbrella. Previous board member, Dr. Marble left Tulane. So currently Hans Anderson and Jariya Upadia are only board-certified geneticists in state (with LSU).

Jane Herwehe discussed considering past participation for board member suggestions rather than achieving someone from each facility. Suggested reaching out to families for suggestions of clinicians to find champions who will actively support the work.

Dr. Allain suggested Dr. Zambrano at CHNOLA, who participated in board in the past, has now returned to the area. Betsey Snider mentioned the FRC working closely with Dr. Zambrano's genetics clinic until March 2020 when COVID restrictions began.

- b. **Scheduling 2021-22 Meetings:** There is nothing in our legislation that prescribes our meeting frequency. Based upon polling feedback, the majority voted for 3 times a year in a virtual format until the executive order is lifted by governor. At that time, we will resume a combination of in person and virtual meetings on the 3rd Friday January, June, and October 1-3 pm. Calendar invitations will follow.
 - c. Focus of Meetings i.e. data analysis presentations, surveillance operations and workflow, evidence-based recommendations, and special projects such as case reviews.
- IV. **Discussion & Public Comment:** Dr. Buras gave thanks to the team for this productive meeting. Julie Johnston thanked the team and board for their commitment to this work and appreciation for everyone's time and expertise. The board can expect meeting minutes, calendar invitations for future meetings, and surveillance operations information to follow via email within the week.
- V. **Adjournment:** 2:30pm. Minutes respectfully submitted by Julie Johnston.

