



Louisiana Birth Defects Monitoring Network

Advisory Board Meeting Minutes

March 1, 2013 2:30-3:30 PM

1450 Poydras Street
New Orleans, Louisiana 70112
Benson Tower Conference Room 2024

Attendees:

*Dr. Floyd Buras, Chair**

*Dr. Susan Berry, Children's Health Services
Kizzy, Battley, OPH, LBDMN*
Keybo Griffin, OPH, LBDMN*
Julie Johnston, OPH, LBDMN
Makesha Judson, March of Dimes*
Adrienne Katner, OPH, SEET
Dr. Lyn Kieltyka, OPH, Maternal and Child Health*

*Dr. Yves Lacassie, LSU Health Sciences Center
Gina LaGarde, OPH, Region 9*
Darcie Olexia, OPH, SEET*
Casey Smith, OPH, LBDMN
LaTanya Thompson, OPH, LBDMN*
Dr. Tri Tran, OPH, LBDMN*
Dr. Regina M. Zambrano, LSU Health Sciences Center**

**via teleconference*

I. Welcome/Introductions: *Dr. Floyd Buras*

Dr. Buras called the meeting to order. Those present and participating via teleconference introduced themselves and stated their affiliations.

II. Announcements: *Dr. Susan Berry*

In light of Dr. Joseph Hicks' resignation in July 2012, Dr. Berry announced management team restructure. Dionka Pierce, CSHS Program Manager, is LBDMN interim program manager at this time. Dionka is mentoring Julie Johnston, Surveillance Supervisor, while we await a hiring freeze exemption approval to permanently fill the program manager position.

III. Budget Update: *Dr. Susan Berry*

Title V Budget: Programs funded by the Title V Block Grant which service Children and Youth with Special Health Care Needs received a \$794,000 budget cut on Friday, February 22, 2013. These cuts forced reduction of direct clinical services. In addition, sequestration affected additional cuts of 5.2-9% to the Title V Block Grant resulting in another \$200,000 reduction. These cuts forced additional clinic eliminations. LBDMN receives \$500,000 from the block grant. However, these funds have not been targeted for budget reductions.

LBDMN Budget: CDC Cooperative Agreement Carryover Years 1-3 awarded= \$122,098.00. The majority of these funds are dedicated to the DBS contract for LEERS integrated web based surveillance system. CDC Cooperative Agreement Year 4 was funded at 80%=\$148,000.00 due to lack of FY 2013 federal budget. There is a possibility the remaining 20% may be resubmitted and funded in April or May. This means filling the Region 6/8 DCS position remains on hold.

IV. Program Update: *Julie Johnston*

CDC Cooperative Agreement Technical Review Report: While acknowledging our Year 3 program challenges, the reviewer was complimentary of our adjustment measures, progress and Year 4 goals. The reviewer requested two pieces of information regarding our in-kind support calculation formula and LPHI contractual elements. The following outlines updates for each performance indicator:

Surveillance

1) Staffing: To decrease DCSs turnover, in July 2012, all staff received an hourly wage increase within the existing contract. This was the first increase received since 2008. In September 2012, a revision of the staffing plan was proposed to include salary increases based upon longevity of existing staff, redistribution of workload and territorial responsibilities to accommodate two additional full-time positions. These changes required a contract amendment which has been submitted to DHH. We have received initial budget authorization for the amendment retroactive to October 1, 2012. Upon final approval and sequestration restoration, a full-time DCS will be hired for the Northeast and Central territories in addition to a part-time DCS for the Capitol Region of the state. Previously, this region has been the responsibility of the DCS Surveillance Supervisor.

Additional mentoring and training protocols have been established to improve abstractor training and support for new DCS. New staff will be afforded an opportunity to attend the annual NBDPN Conference as well. Five of our staff attended in Atlanta, February 23-27, 2013. Three of these were first time attendees.

2) Systems: Data Abstraction forms have been entered electronically since November 2011.

The second component of Phase II is the integration of data from all existing LBDMN data sources of Phase I into SharePoint. This contract is with Geocent. Deliverables will include: 1) moving the LBDMN SharePoint from the DHHnet server into a separate database server for enhanced security and controls which are more appropriate for a production database; 2) a bulk loading of 7800 records with demographics and coding data from Phase I into the electronic abstraction form library; and 3) the development of a fast entry data form compatible with Infopath to be used for the second data entry project. This will be outsourced to temporary staff with LBDMN direct supervision for project management and quality control. This data entry project will be the final step in digitizing all LBDMN data including maternal risk factors, and prenatal and birth and postnatal history. Scheduled to begin March 4- May 2013.

Final component of Phase II is an electronic Case Ascertainment Module. This is required linking 35657 rows of data to unique identifiers for each potential case. Only 137 remain prior to final quality review for completeness of all potential cases from 2005 to present. Implementation of the Secure File Transfer Protocol site for reporting hospitals is underway. When complete, all hospital discharge indices will be received electronically with uniform formatting enabling the initial review for potential cases to be done electronically.

Phase III: DBSysgraph, DHH approved contractor, for development of a web-based electronic data management system integrated with LEERS birth and death records. LBDMN has requested Carryover of Unobligated Funds from Year 1 to Year 3 in the amount of \$122,098 to be allocated for this use. With the completion of this contract, LBDMN, Newborn Hearing Screening, and Newborn Metabolic Screening will share data integration through LEERS.

Capacity Development

- 1) DCS have attended Regional Informational Workshops in two regions with plans to attend in all regions in 2013.
- 2) Although we have delayed staffing in the Northeast and Central regions, implementation of the SFTP will enable us to begin receiving reports from the remaining 11 of 60 birth hospital in the state.
- 3) The review of additional administrative databases including LAHDD hospital discharge data, LEERS death data, and Medicaid will expand case ascertainment capacity through passive surveillance.
- 4) We are exploring collaborations with the Perinatal Commission, FIMR, and Partnership for Healthy Babies.
- 5) Newborn screening for Critical Congenital Heart Defects (CCHD) remains on our radar. We have been in discussion with the American Heart Association, March of Dimes, and our Newborn Screening partners. AHA has drafted sample legislation to pursue in this session. We requested additional wording to require mandatory reporting by hospitals. Also, this must be a funded mandate. Due to federal and state budget cuts, we do not have funds or staff to develop and conduct surveillance of CCHD screening at this time.

Prevention

We participated in the NBDPN National Birth Defects Prevention Campaign in January 2013 introducing more than 300 partners to free materials available at <http://www.nbdpn.org/bdpm2013.php>. This included a social media campaign in partnership with DHH, LPHI, our population servicing stakeholders, universities, school-based health programs, and regional

OPH units to name a few. The message: Birth defects are Common, Critical and Costly. In the US, every 4.5 minutes a baby is born with birth defects affecting 1 in 33 babies born. Birth Defects affect us all. What effect will you have on birth defects?

Referral

- 1) We are working with DHH's Bureau of Media and Communication (BMAC) to revise the Family Resource Guide into web document within our web page. Once this is complete, they will revise the FRG Flier we use for distribution and advertisement. Finally, they will produce a program brochure.
- 2) There will be a referral component in the DBS LEERS integrated web system to refer families to appropriate agencies including Families Helping Families, Early Steps, Genetics, Early Hearing Detection Intervention, and the CSHS Family Resource Center at Children's Hospital.

Please see page 4 to review Year 4 Performance Indicators objectives and activities with projected dates.

V. Other Business

SEET Update: Adrienne Katner, Environmental Public Health Tracking Program

As soon as the contract is done with ULL, the birth defect data is next in line to be added to the portal for interactive querying.

The static website is up and can be viewed at: <http://lephtauth.dhh.la.gov/Pages/LA%20EPHT%20Program.aspx>

Static birth defect data is already available at: <http://lephtauth.dhh.la.gov/Pages/QuickReports.aspx>

Right now the functional portal (with queryable data) is scheduled to be up in March along with the secure portal. Data that are going up first include asthma, heart attack, carbon monoxide poisoning and childhood lead poisoning. We anticipate having queryable birth defect data up by April.

Birth defect data were aggregated and submitted to CDC. Comments from the Data Owners (Tri) about data coverage and limitations were shared with CDC to enable more accurate reporting.

VI. New Business Dr. Tri Tran, LBDMN Epidemiologist

2006-2008 Data Results (see attachment for poster and page 5 for abstract)

VII. Public Comment -Please visit the following links for information regarding medication use during pregnancy.

The Problem: Too Many Pills in Pregnancy http://well.blogs.nytimes.com/2013/02/25/too-many-pills-in-pregnancy/?nl=health&emc=edit_hh_20130305 A version of this article appeared in print on 02/26/2013, on page D5 of the NewYork edition with the headline: Too Many Pills in Pregnancy.

The Research: Safe lists for medications in pregnancy: inadequate evidence base and inconsistent guidance from Web-based information, 2011. Article first published online: 29 JAN 2013. <http://onlinelibrary.wiley.com/doi/10.1002/pds.3410/abstract>

The Lists: <http://www.otispregnancy.org/otis-fact-sheets-s13037> A reliable online resource for both women and their doctors, are fact sheets prepared by OTIS, the Organization of Teratology Information Specialists, which are continually updated as new facts become available

What does the CDC say? <http://www.cdc.gov/pregnancy/meds/index.html>

VIII. Closing Remarks: *Dr. Floyd Buras*

Dr. Buras inquired about parking at Benson Tower. Currently, Champions Garage adjacent to the Arena and in the rear of the Superdome remains the best option. However, a fee is required. Dr. Lacassie suggested Children's Hospital. The OPH State Laboratory on West Napoleon at Causeway remains an option as well.

The next meeting will be May 31, 2013 at 3:00 PM location to be determined. The meeting was adjourned at 3:45 PM

**Louisiana Birth Defects Monitoring Network
Program Indicators Grant Year 4 February 1, 2013-January 31, 2014**

Surveillance

Cooperative Agreement Objective:

- Produce and disseminate quality and current data
- Assure quality data through ongoing improvement efforts using statistical methods

LBDMN Objective: To implement timely statewide, population-based birth defects surveillance and reporting.

Outcome: Achieve and retain statewide staffing

Proposed Activities and Timelines:

- SA 1.1: SFTP Implementation -1st Quarter
- SA 1.2: Achieve Statewide Surveillance Staffing -1st Quarter
- SA 1.3: Incorporate Passive Surveillance/Expand Data Sources- 2nd Quarter
- SA 1.4: 2009 Data Analysis -3rd Quarter
- SA 1.5: DBS Phase III Web-based Software -4th Quarter

Capacity Development

Cooperative Agreement Objective: Build capacity for public health action

LBDMN Objective: Develop state and local partnerships for birth defects prevention and referral to services.

Outcome: Achieve surveillance in 100% LA Birthing Facilities

Proposed Activities and Timelines

- CA 1.1: Statewide Participation in Regional Information Workshops -Quarterly
- CA 1.2: Expand Reporting Facility Agreements to remaining 11 of 60 LA Birthing Hospitals- 4th Quarter
- CA 1.3: Achieve Data Sharing with all Title 5 Programs -4th Quarter

Prevention

Cooperative Agreement Objective: Outreach to target audiences with prevention messages and implement activities

LBDMN Objective: Use of birth defects data to develop targeted prevention messages to at -risk populations.

Outcome: Develop Regional Prevention Messages

Proposed Activities and Timelines

- PA 1.1: National Birth Prevention Campaign -1st Quarter
- PA 1.2: Regional Profiles 2005-2008 data -2nd Quarter
- PA 1.3: Investigations Protocol and Training -4th Quarter

Referral

Cooperative Agreement Objective: Increase access to appropriate referrals for improved health outcomes

LBDMN Objective: Use timely data to refer children to partner agencies for healthcare, case management, early intervention, and for peer support.

Outcome: Develop and produce program literature

Proposed Activities and Timelines:

- RA 1.1: Update Annual Family Resource Guide -1st Quarter
- RA 1.2: Data Sharing Agreement & Implementation with Family Resource Center -1st Quarter
- RA 1.3: Program Literature -2nd Quarter

Results from Louisiana 2006-2008 birth defects surveillance system

Tri Tran, Anthony Kondracki, Julie Johnston, Joe Hicks, Nicole Richmond, Dionka Pierce, Susan Berry*

Objective: Major birth defects are those that affect survival, require substantial medical care, and result in marked physiologic and/or psychological impairment. The objective of this study is to utilize Louisiana linked birth defect and birth records data to describe (1) the prevalence of selected birth defects stratified by body system and newborn and maternal characteristics, and (2) co-occurrence of multiple defects.

Methods: The 2006-2008 linked birth defect and live birth records data were analyzed. Only children born by Louisiana resident mothers in regions 1, 2, 4, 5, 7, and 9 between 2007 and 2008, and regions 1, 2, 5, and 7 in 2006 were included in the study. Birth defect data were collected beginning at birth to age 3 through an active surveillance system by Louisiana Birth Defects Monitoring Network (LBDMN). Abstracted diagnoses were expert reviewed and defined using CDC code based on the British Pediatric Association Classification of Diseases and the ICD-9-CM. Chi-square test was used to define associations between birth defects and newborn and maternal characteristics, and occurrence of multiple birth defects. Fisher exact test was used when at least 25% of cells in contingency tables contained expected frequencies less than 5. Data analysis was conducted by using SAS 9.3.

Results: There were 4,271 live births with selected birth defects with an overall rate of 313.6 per 10,000 live births. Cardiovascular (49.7%) and genitourinary defects (23.8%) were the most common. The distributions of more common birth defects by body system were as follows: cardiovascular system: atrial septal defect (45.1%), ventricular septal defect (39.2%), and patent ductus arteriosus (27.0%); genitourinary system: hypospadias (52.0%) and obstructive genitourinary defect (39.4%); central nervous system (CNS): microcephalus (51.7%) and hydrocephalus without spina bifida (27.2%); oral-facial system: cleft lip with and without cleft palate (47.4%) and cleft palate without cleft lip (43.9%); gastrointestinal system: pyloric stenosis (51.1%); musculoskeletal system: congenital hip dislocation (27.9%) and gastroschisis (24.0%); chromosomal system: Down syndrome (56.5%). Cardiovascular defects were found statistically more frequently in newborns whose maternal characteristics were white, aged 35+, and diagnosed with anemia, diabetes, or hypertension during pregnancy. While white newborns had a higher prevalence of defects in cardiovascular, gastrointestinal, and chromosomal systems, birth defects of CNS were higher in black newborns. Chromosomal defects were more likely among newborns to mothers aged 35+, and who resided in urban areas. Prevalence of birth defects was higher in newborns who were very low birth weight or very premature. Newborns with birth defects were more likely to be born by c-section and had low Apgar scores. Associations between birth defects in different body systems were strongly significant (P values < .0001).

Conclusions: Findings from this study provided the Louisiana Children's Special Health Care Needs Program and LBDMN a more comprehensive picture on the prevalence of birth defects in the state. The information may be used to refine strategies on identification and incidence reduction of children born with birth defects.