

**Louisiana Birth Defects Monitoring Network
Advisory Board Meeting Minutes**

Friday, January 28, 2010, 3:00 pm
OPH State Laboratory
3101 West Napoleon Ave
Metairie, LA

Attendees:
Dr. Floyd Buras, Chair

Dr. Susan Berry, Children's Health Services
Jasmine Gregoire, OPH, LBDMN
*Keybo Griffin, OPH, LBDMN**
Dr. Joseph Hicks, OPH, LBDMN
Julie Johnston, OPH, LBDMN
Dr. Lyn Kieltyka, OPH, Maternal and Child Health
Dr. Yves Lacassie, LSU Health Sciences Center

Brianna Lyons, OPH, LBDMN
Judy Otto, Spina Bifida
*Bonnie Braswell, OPH, LBDMN**
Cheryl Harris, Genetics
Adrienne Katner, OPH, SEET
*Christy Patton, OPH, LBDMN**
Dr. Regina M. Zambrano, LSU Health Sciences Center

**via teleconference*

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

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

II. Announcements: *General*

There were no general announcements.

III. LBDMN Program Update: *Dr. Joseph Hicks*

Dr. Hicks announced that there has been a great amount of progress within the program including a successful CDC Site Visit in September 2010, the reallocation of CDC funding, the development of a electronic filing cabinet for Abstraction Forms, the increase of surveillance coverage to 100% statewide and the addition of an epidemiologist to the program.

Dr. Hicks introduced the new staff members; Bonnie Braswell Data Collection Specialist (DCS) for Region 6, Laura Baudin Data Collection Specialist (DCS) for Region 8, Mike Duran Data Collection Specialist (DCS) Region 5 (to replace Nancy Roach who has left to work for exclusively for FIMR) and Lauren Granen, MPH Epidemiologist (currently out on maternity leave). Cheryll Sheard, the Program Monitor, was promoted to the Program Manager for WIC fiscal office and has left the program. She will be greatly missed.

Dr. Hicks discussed the information obtained from the CDC Site Visit. The CDC grant is anticipated to continue for five years, but is dependent on progressing toward the goals set out in the cooperative agreement. Dr. Berry noted that the visit went very well and they were impressed with our dedication and progress in spite of the lack of funding and support. Dr. Hicks presented a PowerPoint presentation of our logic model, strategic plan, and progress to date. It outlined necessary actions for maintenance of grant support and goals for the program moving forward.

Birth Defects Prevention Month pamphlets promoting prevention messages were distributed to all Data Collection Specialist to deliver to health units and health care providers within their regions. The Family Resource Guide will be updated this year, and will continue to be a guide to assist families in navigating the healthcare system and obtaining needed services.

The bottleneck of handwritten, paper Abstraction Forms is the largest barrier to timely completion of data analysis. This barrier is being reduced by scanning paper Abstraction Forms and creating an Electronic File Cabinet. Also, to stop the ongoing flow of paper, an electronic Abstraction Form is being developed with consultants and DHH-IT. This electronic Abstraction Form will upload information directly into a web based database. Future projects for this year include partnering with LEPHT to performing geospatial analyses and promoting increased folic acid supplementation in the African American and Hispanic populations.

Dr. Hicks discussed another goal for the second year of the grant regarding referral to services. Working with CSHS and Medicaid, LBDMN will initiate its referral to services activities and strengthen relationships with community partners. We will continue our prevention activities year-round such that birth defects is a community focus throughout the year and not solely during the month of January. We will begin to plan deepening relationships with doctors and clinics to assure we can find children with birth defects seen in the outpatient setting, not just children with inpatient hospital stays.

Dr. Buras and Dr. Lacassie discussed the need for doctors to be aware of conditions which meet the LBDMN case definition. Education of healthcare providers is required to increase reporting from outpatient settings because some conditions are not recognized as reportable birth defects. There was general discussion of the best ways to compile this information possibly using a spreadsheet that could be sent weekly or monthly, or a card system similar to the one used by infectious diseases.

IV Budget Update: *Dr. Susan Berry*

The LBDMN Program is supported by both the Title V CSHS block grant (57% federal and 43% state) and the new CDC grant (100% federal). While the midyear DHH budget cut did result in the closing of Region 1 CSHS subspecialty clinics at Children's Hospital, it did not affect the LBDMN program. However, there may be a substantially larger cut for FY 2012 (beginning July 2011). The Governor will announce his proposed budget in March but the final budget will not be approved until the end of the next legislative session. Even if CSHS is severely impacted, this is unlikely to have a major affect on the LBDMN program. There is a strong possibility that the program will lose the state funding for the Program Monitor position but Dr. Berry believes the program can function without it.

The CDC budget is 100% federal and not being targeted by state. However, there was an 11% midyear budget cut nationally in the CDC funding. For our grant, this will be absorbed in the carry over funds at the end of FY 2011 that resulted from the timing of the grant award. Remaining unspent funds can be carried over each year until they are spent.

V. New Business: *Dr. Joseph Hicks*

Dr. Hicks suggested exchange of information among DHH programs and even developing automated referrals for family services. A first project might be obtaining genetic testing results because these results are often not found in children's charts. We often find the request for testing or that testing has been completed, but the actual results are only available at the physician's office. There was general discussion of the best ways to resolve this general issue of getting data from physician's office. One of the problems we have is how to capture children with birth defects who are diagnosed after they leave the hospital. The possibility of reporting children born with birth defects but diagnosed during outpatient visits was discussed. The Board approved the development of a pilot project modeled after 'Reportable Infectious Diseases'. We will present a proposal at the next

VI. Old Business/Other Business: *Dr. Joseph Hicks*

Dr. Hicks revisited the issue of data sharing which is still a work in progress in obtaining files from various DHH programs. There was also discussion of reviewing cancer registry and data forms from other

surveillance systems to determine if changes need to be made to the abstraction form used to track birth defects.

The advisory board must be registered with the Division of Administration and the Legislative Auditor; Dr. Hicks will complete this task.

VII. Public Comment: *Public*

There was no public comment.

VIII. Closing Remarks: *Dr. Floyd Buras*

Dr. Buras stated the next board meeting would be in three months. Dr. Hicks will email board members regarding their availability for the next meeting. Dr. Buras declared the meeting adjourned at 4:25 pm.