

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

Friday, March 7, 2008, 2:30 pm
OPH State Laboratory
3101 West Napoleon Street
Metairie, LA

Attendees:

Dr. Floyd Buras, Chair

Dr. Susan Berry, OPH, Children's Special Health Services
Michelle Dupont, OPH, LBDMN
Keybo M. Griffin, OPH, LBDMN
Julie Johnston, OPH, LBDMN
Angie Myers, OPH, Children's Special Health Services
Dr. T. Narumanchi, Tulane University Hospital
Darcie Olexia, OPH, Environmental Epidemiology/Toxicology
Judy Otto, LOTR, CDRS
Dionka C. Pierce, OPH, LBDMN

Nancy Roach, OPH, LBDMN
Connie Simonson, OPH Genetics
Dr. Duane Superneau, Woman's Hospital
Dr. Louis Trachtman, OPH, Genetics
Kay Webster, OPH, LBDMN
Dolinda Werling-Baye, OPH, Genetics

I. Welcome/Introductions/Announcements: *Dr. Floyd Buras, General.*

Dr. Floyd Buras called the meeting to order and asked if there were any announcements. There were none.

II. LBDMN Program Update: *Kay Webster, Dionka C. Pierce, Julie Johnston, Keybo Griffin, Nancy Roach, Michelle DuPont.*

Ms. Webster updated the group on recent accomplishments and progress. She introduced Dionka Pierce as the Family Resources Coordinator and explained that Ms. Pierce would be heading the program's efforts to provide services information to families and coordinating birth defect prevention and education efforts. She then reported that the contract with the Louisiana Public Health Institute had been renewed for the period: 2008-2011. Ms. Webster explained that the contract has been expanded from 3 to 5 FTEs. She also informed the group that LBDMN would be expanding into DHH Region 4 (Lafayette and the 6 surrounding parishes). The decision about where to go next would be based on the trend in # of births since 2002.

Ms. Pierce reported on her progress since January 2008. She reported that the first draft of the LBDMN Family Resources Guide was complete and now being edited based on the feedback received from a work group assembled to assist with the development of the guide. She reported that the group consisted of 3 parents, a consumer, a nurse, a social worker, Ms. Webster and Dr. Berry. Ms. Pierce also reported that folic acid brochures had been delivered to OPH Region 1 Health Units, UNO and Dillard Universities and to LBDMN data collectors in Baton Rouge and Lake Charles (for distribution to area health units and at local events).

Ms. Johnston, Region 2 Data Collection Specialist, reported that she has been in contact with St. Tammany Parish Medical Center and they agreed to allow her to abstract data. In addition, data collection at other sites was running smoothly.

Mr. Griffin, Region 1 Data Collection Specialist, reported that he was wrapping up year 2006 cases at Ochsner Medical Center and Children's Hospital. He will soon abstract cases for the final quarter of 2007 at Touro, East Jefferson and West Jefferson Medical Centers. He added that data collection was going well and that he would be transitioning from Region 1 to Region 4 within the upcoming weeks. Mr. Griffin expressed his pleasure in working in Region 1 and stated that he has witnessed its growth.

Ms. Roach, Region 5 Data Collection Specialist, reported that she has been working on resolving the abstraction backlog in Region 5. She noted that she has completed 2006 cases and is well into first quarter of 2007 cases, and that data collection is moving smoothly.

Ms. Dupont, Region 2 Data Collection Specialist, reported that she has nearly completed abstraction of 2007 cases. She stated that she has been having some trouble finalizing cases of children with minor heart defects who are referred to pediatric cardiologists because essential diagnostic information often does not make it back to the hospital medical record. Ms. Dupont noted that she and Ms. Webster have discussed approaching pedi cardiologists for follow-up information, and that she is putting together a list of those specialists in the Baton Rouge area.

III. Genetics Update: *Connie Simonson, Dr. Louis Trachtman*

Regarding Newborn Heelstick Screening, Ms. Simonson reported that the age cut off for requiring a repeat screen was reduced from 48 to 24 hours and that the policy for repeating post transfusion was changed from 2, 7 and 90 days to 3 and 90 days. Ms. Simonson distributed a copy of the emergency rule containing the changes. She also distributed a 2007 table of Newborn Screening Detection, which contained numbers of confirmed cases of congenital hypothyroidism, sickle cell disease, and other conditions tracked by newborn screening. Dr. Buras requested figures on the overall number of individuals tested.

Dr. Buras expressed concern about the rule changes for repeat screens and suggested that some physicians might not interpret the new guidelines correctly. He recommended that OPH release a statement clearly stating the recommendation regarding repeats, or perhaps give a CME to educate private physicians. Dr. Superneau expressed his agreement and suggested that some kind of clarification might be needed, which could perhaps be issued as a bulletin enclosed in routine screening reports. Dr. Trachtman expressed that he was aware of "mixed reviews" with regard to the rule changes. There was further general discussion on this topic.

IV. Gastroschisis Investigation Update: *Kay Webster*

Ms. Webster reported that the original statement that raised concern came from a physician at Women's & Children's Hospital in Lafayette, who contacted OPH with a report of 10 children born with the birth defect gastroschisis within a few months at that facility. After requesting a query of the hospital discharge database for 2007, it was found that the total number of cases for the year was 14. Ms. Webster reported that the suspected cluster investigation is ongoing. So far, 6 of the original 10 mothers have been interviewed. The latest report from Pam Kreyling, Regional Epidemiologist in Region 4, is that investigators are trying to arrange chart review and abstraction on the 14 cases. Ms. Webster added that either Nancy Roach or Keybo Griffin will work with regional staff on the case abstraction. The next step will be to locate and interview the remaining 8 mothers.

V. Old Business/Other Business: *General*

Dr. Buras requested items for Old Business and Other Business. Dr. Trachtman announced the appointment of Dr. Rony Francois as Assistant Secretary of OPH. Ms. Webster gave an update on our progress filling Advisory Board vacancies:

- Clinical Geneticist, Tulane: Dr. T. Narumanchi has agreed to participate
- Clinical Geneticist, Ochsner: Ms. Webster reported that Dr. Dimitri Niyazov is the new clinical geneticist for Ochsner Health System. She added that Ms. Pierce would be initiating contact with him to inquire about his possible interest in serving on the board.
- Parent Representative: Ms. Judy Otto, LOTR, CDRS has agreed to participate on the board.

Ms. Webster proposed that the number of meetings be changed from four to three per year. She suggested February, June and October. In the event of a scheduling conflict, Dr. Superneau suggested January, May and September as alternate months.

VI. Public Comment: *Public*. There was no public comment.

Dr. Buras declared the meeting adjourned.