

Louisiana Birth Defects Monitoring Network Advisory Board Meeting Minutes

Friday, May 29, 2009, 2:30 pm
OPH State Laboratory

Attendees:

Dr. Floyd Buras, Chair

Michelle Dupont, OPH, LBDMN
Keybo M. Griffin, OPH, LBDMN*

Julie Johnston, OPH, LBDMN

Dr. Lyn Kieltyka, OPH, Maternal and Child Health

Dr. Gina Lagarde, OPH, Maternal and Child Health*

Darcy Olexia, OPH, Environmental Epi/Toxicology

Judy Otto, Spina Bifida of Greater New Orleans

Christy Patton, OPH, LBDMN*

Nancy Roach, OPH, MCH/LBDMN*

Dr. Duane Superneau, Woman's Hospital*

Dr. Louis Trachtman, OPH, Genetic Diseases Program

Jennifer Walgamotte, OPH, LBDMN

Kay Webster, OPH, LBDMN

* via teleconference

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

Dr. Floyd Buras called the meeting to order and asked for attendees to state their names and affiliations. He then called for general announcements. Ms. Webster stated that Region 2 Data Collection Specialist (DCS) Michelle Dupont has graduated from nursing school and accepted a job at LSU Earl K. Long Medical Center.

II. LBDMN Program Update: Kay Webster

- Beginning June 1, Julie Johnston will go to full time status; she will now cover DHH regions 2 and 9.
- Former LBDMN Family Resources Coordinator Dionka Pierce has been hired as the CSHS Program Manager. Interviews for her replacement concluded this week; we hope to hire someone soon.
- Pilot mailout of LBDMN Family Resource Guides has been put on hold until a new Family Resources Coordinator is hired.
- Registry database is still in limbo; we are hoping to get our IT contact back to work on it after June 1.
- Ms. Webster and Nancy Roach (Region 5 DCS) attended the annual meeting of the National Birth Defects Prevention Network in Feb.; news from meeting: CDC/NCBDDD may announce a new grant cycle soon. This could be a funding opportunity for LBDMN, but it's likely to be very competitive, with many state programs competing for a limited pool of funds.
- In May Ms. Webster attended a CDC-sponsored meeting of representatives from various state birth defects surveillance programs in the region; funding is a big issue for many programs. Alabama's program lost all funding to budget cuts and have stopped conducting surveillance activities altogether.

III. Budget: Kay Webster (for Dr. Susan Berry)

Ms. Webster reported that Children's Special Health Services (CSHS) is fully in support of the Birth Defects Monitoring Network and will continue to fund it to the extent possible. However, CSHS is slated to take a large budget cut in the next fiscal year, possibly as much as \$1 million. This may delay efforts to expand surveillance into new regions in the next fiscal year, and is likely to prevent hiring a much-needed epidemiologist/data manager. Dr. Floyd Buras also shared his concerns about the proposed 7% cut in Medicaid reimbursements to providers for the next fiscal year. There was general discussion on this topic.

IV. Proposed Case Definition Changes: Kay Webster

Ms. Webster circulated a draft of National Birth Defects Prevention Network (NBDPN) proposed "Core Conditions", or the minimum set of diagnoses that state birth defects surveillance systems should track. Conditions on the list that LBDMN does not currently include: holoprosencephaly, congenital glaucoma, cloacal exstrophy, craniosynostosis, sacral agenesis, clubfoot, and reduction deformities of unspecified limb. Ms. Webster also mentioned DiGeorge syndrome, which is not on the NBDPN list, and proposed that we consider

adding these diagnoses to the LBDMN case definition at some point in order to keep up with minimum standards. Dr. Buras recommended that the board move to add these conditions to the LBDMN case definition. Ms. Webster proposed that it might be better to wait until the NBDPN proposal is finalized, since communicating changes in reporting to the hospitals can cause considerable confusion and it would be better to do it all at once rather than piecemeal. There was general discussion on this topic.

V. Old Business/Other Business: *General*

Darcie Olexia gave an update on Bayou Sorrel. She reminded the group that Dr. T. C. Narumanchi offered to consult with families of Bayou Sorrel children born with congenital heart defects regarding concerns about environmental exposures. So far none of the families have followed up with him to receive a consultation.

Dr. Louis Trachtman announced that the Genetic Diseases Program will soon have a new Medical Director. Dr. Mark Dal Corso will begin working half-time on July 1. Dr. Trachtman also announced his pending retirement, scheduled for August 2009.

Dr. Lyn Kieltyka reported that the OPH Maternal and Child Health Data Book for 2001–2005 is complete and publication to the website is pending. Hard copies will be available in the near future.

Dr. Buras proposed that the next board meeting be scheduled for September. In the coming weeks Ms. Webster will email the permanent board members requesting their availability.

VII. Public Comment: *Public*.

There was no public comment. Dr. Buras declared the meeting adjourned.