

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

Friday, September 19, 2008, 2:30 pm  
OPH State Laboratory  
3101 West Napoleon Street  
Metairie, LA

**Attendees:**

Dr. Floyd Buras, Chair

Ligia Ayala, March of Dimes, Louisiana Chapter\*  
Julie Johnston, OPH, LBDMN  
Dr. Lyn Kieltyka, OPH, Maternal and Child Health Program  
Dr. Yves Lacassie, Louisiana State University HSC  
Charlie Myers, OPH, Genetics  
Dr. TaraChandra Narumanchi, Tulane University Hospital\*  
Darcie Olexia, OPH, Environmental Epidemiology/Toxicology

Christy Patton, OPH, LBDMN\*  
Dionka C. Pierce, OPH, LBDMN  
Nancy Roach, OPH, LBDMN\*  
Betsey Snider, OPH, CSHS  
Dr. Duane Superneau, Woman's Hospital\*  
Jennifer Walgamotte, OPH, LBDMN  
Kay Webster, OPH, LBDMN

\*via conference call

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

Dr. Floyd Buras called the meeting to order and asked if there were any announcements. Dr. Susan Berry announced the death of the LBDMN Consumer Representative, Debbie Blanchard. Betsey Snider suggested that the board write a letter to Ms. Blanchard's mother expressing our appreciation for her service and enclose a copy of the LBDMN Family Resource Guide as Debbie's name appears as a member of its work group.

**II. LBDMN Program Update:** *Kay Webster, Dionka C. Pierce, Michelle Dupont (by Julie Johnston), Julie Johnston, Jennifer Walgamotte, Nancy Roach, Christy Patton, Keybo Griffin (by Dionka C. Pierce)*

Ms. Webster updated the group on recent accomplishments and progress. She introduced the new Region 1 Data Collection Specialist (DCS), Ms. Jennifer Walgamotte. Ms. Webster added that the LBDMN staff has now grown to 8 members. She also announced that LBDMN recently acquired a Tulane University SPH work-study student to assist with data entry, LBDMN Family Resource Guide mailings and other tasks.

Ms. Webster reported that there has been some recent movement toward obtaining a program database. Although progress toward a permanent database is on hold for now, an interim solution is in the near future. The interim solution will allow access from multiple sites. In the meantime, LBDMN data are entered into an Excel spreadsheet.

Ms. Webster reported on the progress toward obtaining vital records infant death data for matching with birth defects cases. She stated that the request for the most current infant death data is not able to be met due to a short staff of DHH mainframe programmers. However, Vital Records has offered

access to 2007 infant death data which is “fairly complete through August 2007.” These data will be somewhat useful since the pilot of the LBDMN Family Resource Guide will begin with year 2007 births.

Ms. Webster reported that she will submit an article to the Louisiana Morbidity Report on the results of the analysis of 2005 birth defects data.

Ms. Webster reported that LBDMN expansion continues in DHH Region 4 (Lafayette and 6 surrounding parishes) and stated that more detail on this topic would follow during Mr. Keybo Griffin’s report.

Ms. Webster announced the completion of the budget process for the next fiscal year and added that Dr. Susan Berry would elaborate further in her budget update.

Ms. Pierce reported that the LBDMN Family Resource Guide has been printed. She added that the distribution plan is in development and that the work group would be meeting within the upcoming weeks to finalize mailing criteria.

Ms. Pierce announced that she is serving as the LBDMN representative on the Folic Acid Project workgroup. The Folic Acid Project is a collaboration between the Maternal and Child Health and Family Planning programs. Its components include folic acid awareness information and materials, and distribution of 1 year’s supply of supplements to every female client of child-bearing age participating in the Family Planning program. In this capacity, Ms. Pierce has assisted with developing a folic acid educational card to be available in statewide WIC clinics. Other partners include March of Dimes and WIC.

Ms. Julie Johnston read the report of Ms. Michelle Dupont, Region 2 DCS. Ms. Dupont reported that she completed 2<sup>nd</sup> quarter year 2008 cases at both Baton Rouge General and Earl K. Long Medical Center. She is currently completing cases from April and May 2008 at Woman’s Hospital. Ms. Dupont added that she is working on a new program for all year 2008 cases. She is hopeful that this program will be able to sync with the LBDMN database in an effort to decrease the amount of data entry at the main office.

Ms. Julie Johnston, Region 2 DCS, reported that she has completed year 2008 cases for North Oaks Medical Center, St. Tammany Parish Hospital, Lane Regional Medical Center and River West Medical Center. She added that she is working on Children’s Hospital quarters 3 and 4 year 2006 and Ochsner quarters 1 and year 2007.

Ms. Johnston also reported that in her role as Outreach Coordinator for the Spina Bifida Association of Greater New Orleans, she recently spoke to a class of Occupational Therapy students and worked at Camp Friendship, a week long summer day camp for kids with Spina Bifida.

Ms. Jennifer Walgamotte, Region 1 DCS, reported that she has submitted quarter 1 and 2 year 2008 lists for East Jefferson General Hospital. She has 20 cases to review at Touro Infirmary. She also is in communication with Tulane University Hospital’s supervisor at the downtown clinic regarding getting charts copied that are located in several different clinics for quarters 1 and 2 year 2007. Ms. Walgamotte added that she has requested quarters 3 and 4 year 2007 discharge reports from Tulane as well. She has requested quarter 2 year 2008 discharge reports from West Jefferson Medical Center.

Ms. Nancy Roach, Region 5 DCS, reported that she has investigated 114 potential cases from May to August 2008. She has identified 76 potential cases for 3<sup>rd</sup> quarter year 2007 and has 20 potential cases remaining. Ms. Roach reported that she has 8 potential cases remaining from previous quarters. She added that Beauregard Memorial Hospital and Jennings American Legion Hospital will be added to the hospitals currently under surveillance.

Ms. Christy Patton, Region 7 DCS, reported that she is beginning quarters 3 and 4 year 2007, also quarter 1 year 2008 at Christus Schumpert Highland. At Christus Schumpert St. Mary, she is 15 months behind due to inaccurate reporting. The error has been resolved. Ms. Patton reported that she has completed quarter 2 year 2008 at Louisiana State University Hospital. She will begin quarter 2 year 2008 collection next week at Minden Medical Center. There were no cases to report for quarter 2 at North Caddo Medical Center. Ms. Patton has completed quarter 2 year 2008 at Willis Knighton Bossier, Pierremont and Willis Knighton South. She added that things are progressing well in Region 7.

Ms. Dionka C. Pierce read the report of Mr. Keybo Griffin, Region 4 DCS. Mr. Griffin reported that he is working on 2007 abstractions at Acadian Community Medical Center, Dauterive Hospital, and Lafayette General Medical Center. He has completed 2007 cases and is now working on 2008 at Women's & Children's Hospital, Iberia Medical Center, and Abbeville General Hospital. Mr. Griffin reported that he has requested discharge reports for the first half of 2008 from Dauterive Hospital and University Medical Center. Both are still pending. He has gained access to seven Region 4 hospitals in the last five months and is still working on getting access at Opelousas General, American Legion Hospital, Doctors Hospital of Opelousas, and Savoy Medical Center.

### **III. Budget** *Dr. Susan Berry*

Dr. Berry reported that CSHS received an additional \$229,500 and a TO (state position) for its 2008 budget. This one time increase was used to add a Region 4 DCS and to develop the LBDMN Family Resource Guide. These funds will now be assumed by CSHS. LBDMN's total budget of \$404,962 in personnel and contracts is assumed by CSHS.

Dr. Berry reported that CSHS recently received its 2009 budget. Although DHH received 10% in cuts, CSHS had an increase to its overall budget and only lost one vacancy. This budget will allow the addition of one more DCS FTE over the next year.

Although there was increase in the total budget, CSHS received cuts in certain categories including some types of contracts and in computer hardware. This will affect LBDMN statewide expansion which was planned for the next two years. A total of \$132,500 is needed over the next two years for statewide expansion. Dr. Berry added that designated funding in the state budget that is recurring is needed so that the LBDMN budget is not totally dependent on the CSHS budget.

A discussion was initiated by Dr. Buras about LBDMN being included as a separate line item in the budget instead of being lumped with other costs. Dr. Berry advised that such a change in the way the budget is written would need the approval of Dr. Alan Levine, Secretary of DHH. Dr. Buras volunteered to lobby for that change.

Ligia Ayala added that the MOD Public Affairs Committee is very interested in lobbying for LBDMN and is willing to assist wherever needed.

**IV. Old Business/Other Business: General**

Ms. Webster announced that Debbie Blanchard's passing leaves a vacancy in the Consumer Representative position on the board. She stated that LBDMN will be seeking nominations for this position from advocacy organizations and other partners in the coming months.

Dr. Lacassie reminded Ms. Webster of a set of parents who had been willing in the past to serve on the board. Ms. Webster added that historically this position was filled by an adult with a birth defect. A discussion ensued about whether the board would consider a parent for the position of Consumer Representative. It was the general consensus that a parent could potentially fill this position. Dr. Buras advised that the family be contacted to determine if they were still interested in serving on the board.

*Dr. Buras mentioned the problem of PKUs going bad after 10 days. Mr. Charlie Myers explained that this problem was due to post office problems. Dr. Buras added that PKUs performed before Hurricane Gustav were warehoused and therefore went bad. Mr. Myers stated that at OPH bad PKUs were down from 10 to 7-8%.*

*Mr. Myers mentioned the possibility of tracking Fragile X in the future. A discussion ensued on this topic with board members agreeing that Fragile X is rarely seen in their offices.*

Mr. Myers mentioned the topic of data sharing between LBDMN and Genetics. He asked if there was any interest from LBDMN in Genetics data. Ms. Webster expressed an interest in exploring the available data.

The next meeting date was tentatively set for January 9, 2008.

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

Dr. Buras declared the meeting adjourned.