

2017 Advisory Board Meeting

Louisiana Birth Defects Monitoring Network
January 20, 2017

• LA Birth Defects Monitoring Network

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Welcome & Introductions.

Thank you for joining. NOLA is experiencing extraordinary traffic conditions today with emergency closing of CCC. Several of our board members are unable to navigate to the building. Present are Dr. Susan Berry, Dr. Lyn Kieltyka, Dr. Yves LaCassie (also represents Drs. Narumanchi & Marble), Dr. Tri Tran, Sherry Langston, NP, RN, representing Dr. Niyazov, Julius Tonzel, Sean Simmons, Kate Streva, Kera Simmons, Dionka Pierce and Julie Johnston. Also, Dr. LaGarde and Melinda Peat are joining by phone from the Northshore. Absent are Drs. Buras, St. Amant, Superneau, Ursin and Judith Otto.

Agenda

- Program Updates- Dionka Pierce
 - Organization
 - Activities
 - Funding
- State of the Data- Dr. Tri Tran
- Congenital Zika Virus Surveillance- Julie Johnston
 - Zika Pregnancy Registry – Julius Tonzel

Program Updates

- **Organization**

- LA Dept. of Health>Office of Public Health> Center for Community & Preventive Health> Bureau of Family Health> Title V Programs for Children & Youth with Special Health Care Needs> LBDMN

- **Activities**

- Staffing
- Birth Defects Database LEERS Integrated Surveillance System (BDDLIS)

- **Funding**

- MCH Title V CYSHCN Block Grant
- MCH Block Grant
- CDC DD16-1605 Zika Surveillance, Intervention, Referral to Services (ZIKA-SIR)
- CDC DD16-1605 Zika Supplemental Award

Dionka Pierce, CSHS Program Manager and Principle Investigator of LBMDN program and Zika Surveillance Grant, explained LDH realignment of LBDMN as a Title V CYSHCN program under the Bureau of Family Health.

Staffing Updates include budgeting and performance measures to increase staff longevity and productivity within the program; development of Clinical Case Review Coding Specialist RN; and remote access data collection measures to compensate for long-term vacancy in Regions 4/5, which is posted currently at LPHI.org.

Activity updates include implementation of Birth Defects Database & LEERS Integrated Surveillance System.

Funding updates: LBDMN is 100% federally funded through the MCH block grant and the MCH Title V CYSHCN portion of the MCH Block grant. New funding includes CDC grant for Zika surveillance which will be addressed in detail later in this presentation.

State of the Data

	2008	2009	2010	2011	2012	2013	2014	2015	Nov 2016
Cases completed (01.19.17)	1745	1371	1248	1092	925	881	426	220	69
Births	62493	62601	60463	60079	60985	61505	62949	63111	57211
Rate per 100	2.8	2.2	2.1	1.8	1.5	1.4	0.7	0.3	0.1
Expected cases(3%)	1875	1878	1814	1802	1830	1845	1888	1893	1716
Completed (%)_3%	93.1	73.0	68.8	60.6	50.6	47.7	22.6	11.6	4.0
Completed (%)_2008	100.0	78.4	73.9	65.1	54.3	51.3	24.2	12.5	4.3

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Dr. Tran discussed the status of data collection for birth cohorts 2008-2016. LBDMN case definition includes live births only of 20 weeks gestational age or 350 grams in absence of known gestational age to LA residents and who are diagnosed with a major functional, structural or genetic birth defects prior to the third birthday. Therefore birth cohorts close at 3.5 years. A closed cohort by active surveillance includes case ascertainment, data collection of prenatal, birth, and postnatal history, coding and case review. Historically, LDMN has used hospital discharge data exclusively. Reviewing the table above, we see 2008 statewide data was complete at closing. Completeness begins to fall off for 2009-2012. Contributing factors for this include hospitals beginning to transition to the electronic health record in 2011-2012. Changing medical record keeping platforms resulted in many records prior to September 2012 becoming unavailable for review effectively becoming lost to follow-up. Therefore, at the end of January 2017, we will be closing birth cohorts 2009-2012 as is. 2013 birth cohort will close by definition and actuality June 30, 2017. Implementation of BDDLSS, hiring a case review coding specialist RN, and incorporating remote access for data collection where available, has made LBDMN more efficient and timely in all surveillance processes.

Zika Surveillance

- CDC grant awarded in August 2016 for 5 Years - \$400,000 annually
 - To develop a system for real-time/rapid surveillance, intervention, referral to services for infants adversely affected by maternal Zika virus exposure and to monitor their long-term health and developmental outcomes.
- Supplemental award of \$200,000 for FFY 2017
 - To make infrastructure integrations with LEERS, LA EHDI, and LBDMN databases

Julie Johnston, program manager, discussed funding, performance measures, and activities of the newest CDC grant for Zika surveillance.

Louisiana Birth Defects Monitoring Network was awarded a CDC Zika/Birth Defects Surveillance grant of \$400,000 annually for five years along with \$200,000 additional supplemental funding for FY 2017. The grant supports development of a system to support real-time rapid surveillance, intervention, and referral to services activities for infants with microcephaly or other adverse outcomes linked with maternal Zika virus exposure along with monitoring their long-term health and developmental outcomes. The supplemental funds will allow us to make infrastructure integrations with Louisiana Electronic Event Registration System and Louisiana Early Hearing Detection and Intervention databases for more efficient case ascertainment, data reporting, and collection to facilitate real-time rapid reporting and interventions for Louisiana infants affected by Congenital Zika Virus Syndrome.

Zika Surveillance

Brain abnormalities with and without microcephaly

- Confirmed or possible congenital microcephaly#
- Intracranial calcifications
- Cerebral atrophy
- Abnormal cortical formation (e.g., polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia)
- Corpus callosum abnormalities
- Cerebellar abnormalities
- Porencephaly
- Hydranencephaly
- Ventriculomegaly / hydrocephaly (excluding “mild” ventriculomegaly without other brain abnormalities)
- Fetal brain disruption sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)
- Other major brain abnormalities, including intraventricular hemorrhage in utero (excluding postnatal IVH)

Zika surveillance is based upon real-time tracking and response. Reportable diagnoses we will be tracking include the following conditions on the next three slides.

Zika Surveillance

Neural tube defects and other early brain malformations

- Neural tube defects (NTD)
- Anencephaly / Acrania
- Encephalocele
- Spina bifida
- Holoprosencephaly / Arhinencephaly

Eye abnormalities

- Microphthalmia / Anophthalmia
- Coloboma
- Congenital Cataract
- Intraocular calcifications
- Chorioretinal anomalies involving the macula (e.g., chorioretinal atrophy and scarring, macular pallor, gross pigmentary mottling and retinal hemorrhage); excluding retinopathy of prematurity
- Optic nerve atrophy, pallor, and other optic nerve abnormalities

Reportable Diagnoses we will be tracking

Zika Surveillance

Consequences of central nervous system (CNS) dysfunction

- Congenital contractures with associated brain abnormalities

- Arthrogryposis

- Club foot

- Congenital hip dysplasia

Congenital deafness documented by postnatal testing

Reportable Diagnoses we will be tracking

Zika Surveillance

Year One activities include:

- Staffing Zika Surveillance Project Manager, Health Communications Specialist, Regional Clinical Liaison Nurses, Clinical Case Reviewer
- Biweekly reporting to CDC
- Establishing a baseline prevalence of microcephaly

Supplemental activities include:

- Expanding LBDMN database to include Zika data collection
- Integrating LBDMN database with LA Early Hearing Detection & Intervention database
- Adding Zika Virus risk factor to LEERS database, birth certificate application, and newborn hearing screening report

Year One and supplemental funding activities to establish the Zika surveillance system include expanded staffing, surveillance systems, and reporting to CDC as outlined above.

LA Zika Pregnancy Registry

Managed by the Office of Infectious Disease Epidemiology

- **Criteria for testing pregnant women:**
 - Travel to Zika affected area
 - Unprotected sexual contact with a traveler from a Zika affected area
- **Specimens include when available maternal and infant:**
 - Serum and urine
 - Placenta and umbilical cord blood
 - Infant CSF
- **Inclusion in ZPR:**
 - Positive Zika rt-PCR
 - Positive or equivocal Zika IgM and Zika PRNT>10

Julius Tozel, LA Zika Pregnancy Registry Coordinator, discussed the database used to collect information on pregnant women and infants diagnosed with Zika virus disease that is used to update recommendations for clinical care to plan for services for pregnant women and families affected by Zika virus, and to improve prevention of Zika virus infection during pregnancy. LZPR conducts outreach to obstetricians and pediatricians to facilitate mandatory reporting of maternal Zika exposure and testing.

LA Zika Pregnancy Registry

- Collect information during second and third trimesters of pregnancy, at birth, and at two, six and twelve months after birth.

Ultrasound reports, physical examinations, hearing screenings, imaging studies
Maternal Health History Form, Neonate Assessment at Delivery Form and Infant follow up form

- Counsel patients and redirect to LBDMN for referral to services
- Weekly USZPR calls and biweekly reports ZPR

LA Zika Pregnancy Registry

- Louisiana ZPR Case Count = 7 (travel related)
- Birth Defects = 0
- 5 features that are rarely seen with other congenital infections or are unique to congenital Zika virus infection:
 - Severe microcephaly with partially collapsed skull
 - Thin cerebral cortices with subcortical calcifications
 - Macular scarring and focal pigmentary retinal mottling
 - Congenital contractures
 - Marked early hypertonia and symptoms of extrapyramidal involvement

Thank you!

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Julie Johnston

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Other discussion:

Dr. Gina LaGarde, Region 9 OPH Medical Director and Regional Administrator, updated us with regard to activities of Region 9 Zika Outreach Coordinator which included outreach to all OBGYNs in Slidell including providing Zika Kits and insect repellent for Slidell Memorial Hospital's prenatal classes, Nurse Family Partnerships participants, and St Tammany WIC recipients. Also they worked with St Tammany Mosquito Abatement program for neighborhood tip and turn canvassing in the Eden Isles/ Bayou St Catherine areas. Dr. LaGarde offered Region 9 Zika Outreach Coordinator's provider network for future distribution and education for LBDMN Zika activities.

Dr. Yves LaCassie, who has participated as the board's LSU-NOLA geneticist representative since 2005, announce his retirement. Dr. Marble will be filling this role in the future. LBMDN would like to thank Dr. LaCassie for his service and support since the board's inception.

Kate Streva, principle investigator for LA Environmental Public Health Tracking Network, updated the board on a project for tracking environmental datasets regarding Zika risk maps which will be very beneficial to the OHP Zika Task Force. These templates were created initially for use in Florida by an associate, Luke Martin, at Colorado School of Public Health and shared with us through the National

Environmental Health Association. The templates have been adapted for use by Louisiana and shared free of charge! LBDMN looks forward to continued collaboration with LAEPHT as we add Zika to our mutual environmental tracking interests. Incidentally, our current collaboration with LAEPHT has resulted in birth defects data being submitted for display on the national tracking portal as well as LAEPHT portal. These data should be displayed soon.

Dr. Lyn Kieltyka, MCH CDC Senior Epidemiologist, made suggestions for engaging providers for Zika surveillance reporting through contacts at the LA Hospital Associations' Hospital Engagement Network which works directly with the LA Perinatal Collaborative which has been successful in securing participation from 33/50 birthing hospitals in the state, AAP, and ACOG.

2017 Advisory Board Meeting

LBDMN Advisory Board Meeting
January 20, 2017
2:30-4:00 PM
Benson Tower New Orleans, LA

Please sign in

Dr. Floyd Buras	A
Dr. Gina LeGarde	A Phone
Amy Zapata	A - sent representative
Dr. Susan Berry	A
Dr. Lynn Kieltyka	A - sent representative
Dr. Tarachandra Narumanchi	A - sent representative
Dr. Yves Lacassie	A
Dr. Dymitry Nyasov	A - sent representative
Judith Otto, LOTE	A
Dr. Marshall St Amant	A
Dr. Duane Superneau	A
Dr. Susonne Urain	A
Dr. Tri Tran	A
Sherry Langston, NP, RN	A - sent representative
Julius Tonzel	A
Melinda Peat	A
Kate Steve	A
Betsy Snider, RN	A - sent representative
Cheryl Harris	A
Eman Williams	A
Sean Simonson	A
Kera Simmons	A
Dionka Pierce	A
Julie Johnston	A

SIGN-IN Sheet record of attendance