

**Office of Public Health Report to the DD Council
December 2015**

Agency Changes:

The Office of Public Health is saddened by the resignations of Dr. Takeisha Davis, OPH Medical Director and Center for Community and Preventive Health Director, and Matthew Valliere, CCPH Deputy Director. Both have contributed enormously to OPH for many years, and both have accepted exciting CEO positions elsewhere. We look forward to new leadership in the new administration.

Children's Special Health Services:

Family Resource Center (FRC) at Children's Hospital:

- The FRC continues to provide community-based resource information to clients: September-November 2015: 280 total client encounters; 534 resource needs identified; 553 resource needs met.
- FRC staff continue to provide direct services in Botox, Spasticity, MD, neuromuscular, Down Syndrome, and Spina Bifida clinics at CHNOLA. The FRC youth liaison continues to provide community resource information to families in inpatient rehab.
- Outreach events at CHNOLA during this period:
 - a. Broadcast 16th Annual Chronic Illness & Disability Conference from Baylor—15 attendees (October 1-2, 2015)
 - b. CHNOLA Ice Cream Social—Rehab Family Reunion (9/25/15)
 - c. Back to School Fair (10/13/15)
- The FRC maintains its Advisory Board, comprised mostly of parents of CYSHCN. The next Advisory Board meeting will be held April 2016.

FRC staff continue to participate on local and CHNOLA boards and committees: Thuy Nguyen, FRC Parent Liaison, participates in the CHNOLA Commission on Accreditation on Rehabilitation Facilities (CARF) Outcomes and Research Committees, providing family input. She is able to provide information to CHNOLA staff that will ultimately assist in getting resource information to families.

- 2016 FRC Programs Planned:
 - Habilitation Noon Conference: 504 Services for Children with Chronic Illnesses (planned for early 2016) Resource Fair for CHNOLA staff
 - Broadcast 17th Annual Chronic Illness & Disability Conference from Baylor (October 20 & 21, 2016)
 - Medicaid: Non-healthcare support services

Transportation Assistance Program (TAP): CSHS continues to provide needed transportation assistance to families; September-October 2015 travel stipends were provided to **122 families** totaling **\$16,393.77**.

Resource Information Workshops (RIWs):

- The CSHS Resource Information Workshop held on Tuesday, October 20th in Baton Rouge at the Jones Creek Library was a great success with 99 attendees! The audience gave positive evaluations of the CE offerings, agency presentations, and overall usefulness of the information received. Attendees included nurses and nursing students, social workers and social work students, and parents. The following programs made brief presentations of their services: Early Steps, Head Start/Early Head Start, CSHS, National Child and Family Services Wraparound Agency (CSoC), Capital Area Human Services, LRS, and DCFS. The RIW included a Lunch and Learn on Transition which offered CE to nurses and social workers.

The next RIW is tentatively planned for summer 2016 in Monroe, LA.

Medical Home—Care Coordination and Transition Activities

- CSHS continues to provide care coordination technical assistance to pediatric primary care physician practices. The emphasis for 2016 is Family Medicine practices. CSHS will provide staff training and resource materials for practices that want to implement or improve care coordination for children with special needs.

Louisiana Birth Defects Monitoring System:

Budget/Grant Update: LBDMN applied for the CDC/NCBDDD's next state -based birth defects Funding Opportunity on October 26, 2015. This is a 4 year project period with a 2/1/2016 start date. The focus is expanded surveillance methodologies and data utilization including peer-review publications, targeted prevention campaigns, and measurable referrals to resources. There will be 14 awards with an average of \$175,000. We expect award announcements in January 2016.

Surveillance Systems Development Update:

The vacant Data Collection Specialist position in Region 4/5 Southwest Louisiana was filled in October 2015. Bethany Bazar, LPN, comes to us not only with patient care experience but also with Health Information Management and Data Quality Initiatives experience. This completes our data collections specialist workforce for the extraction of birth defects data from hospital discharge data.

53 of 56 birthing hospitals have begun submitting discharge reports electronically through our Secure File Transfer Protocol site. We are working with the HCA network to implement in the remaining facilities which now includes Byrd Regional, Tulane, and

Women's & Children's Lafayette. Remote access will facilitate abstraction efficiency and reduce travel time and costs. We have also gained remote access to EHRs in 17 of 56 facilities to date. The birth cohorts from 2008 through 2011 (completed in 2014 at age 3 years) was submitted to NBDPN in May 2015 and to Environmental Public Health Tracking in June 2015.

DBSysgraph Contract: We are pleased to announce deployment of our new software system (BDDLIS)! We are working with DBS to refine user workflows and reporting within the new system. ICD-10 implementation began in October 2015, and has been incorporated into BDDLIS. With BDDLIS, families of children from the 2013 birth cohort going forward with selected diagnoses will receive specific clinical and peer support referrals and regional FHF referrals via an auto-generated letter.

LBDMN, EHDI, and Genetics received the approved Memorandum of Understanding for data sharing with the Office of Citizens with Developmental Disabilities' EarlySteps program. This data will be used for program implementation, administration, evaluation and monitoring, and research.

Prevention Update: January 2016 is National Birth Defects Prevention month. The January 2016 National Birth Defects Prevention Month packet is now available at <http://www.nbdpn.org/bdpm2016.php> (entire packet can be downloaded at http://www.nbdpn.org/docs/2016BDPMPacket_FINAL.pdf). The theme is "Making Healthy Choices to Prevent Birth Defects – Make a PACT for Prevention."

P – Plan ahead

A – Avoid harmful substances

C – Choose a healthy lifestyle

T – Talk to your doctor

This packet was developed in collaboration with many partners, including the Centers for Disease Control and Prevention (CDC), American Academy of Pediatrics (AAP), Teratology Society (TS), and state birth defects programs. There are several NEW resources, e.g., a handout on "paternal contribution to a developing baby's health" and a social media toolkit (appendix 1) The program invites you to tailor the resources and share with colleagues, policy makers, families, and others during National Birth Defects Prevention Month in January 2016 and throughout the year. The program plans to share the electronic package with more than 300 partners and stakeholders in all Louisiana public health units, school-based health centers, federally qualified health centers, all CSHS contract providers, and student health centers of all universities and colleges. In addition, the electronic version of the package will be sent to peer support organizations for electronic distribution to their constituents through their social media networks.

Hearing, Speech and Vision: Within the next six months, the LA EHDI Program (newborn hearing screening) will launch a collaborative effort with WIC to reduce loss to follow-up, including providing follow-up hearing testing at WIC clinics in areas of the state where infants who fail their initial hearing screens are frequently lost to follow-up.

They also plan to initiate training with out-of-hospital birth sites and nurse midwives to capture infants who are not currently screened.

On Jan. 25-27, 2016, LA EHDI will host advocacy training to parents, deaf and hard of hearing (D/HH) persons and professionals working with children with hearing loss. Advocacy Support and Training program (ASTra) is an intensive educational training focusing specifically on D/HH educational advocacy that covers the fundamentals of special education law, including advocacy strategies and case law. ASTra training is provided with a commitment to unbiased support to families, regardless of language and communication approaches used by their children. The training is funded by carryover funds from MCHB/HRSA and is free to attendees. The training will be in Baton Rouge at the Marriott. For more information, contact Terri Ibieta at 504-554-5980.

The LA EHDI team is preparing for a statewide conference for early interventionists, parents, audiologists, D/HH individuals and professionals working with children who are D/HH to be held on Feb. 22-24 at the Hyatt Regency in New Orleans. The main topic of the conference will be the Supplement to the Joint Committee on Infant Hearing (JCIH) 2007 Position Statement: Principles and Guidelines for Early Intervention after Confirmation that a Child is Deaf or Hard of Hearing. The supplement provides comprehensive guidelines for EHDI programs on establishing strong early intervention (EI) systems. **EI programs are the purpose and goal of the entire EHDI process.** For the infant or young child who is D/HH to reach his or her full potential, carefully designed individualized intervention must be implemented promptly, utilizing service providers with optimal knowledge and skill levels and providing services on the basis of research, best practices and proven models. This conference is also funded by carryover funds and is free to attendees. For more information on either of our upcoming conferences, contact Terri Ibieta at 504-554-5980.

GENETICS: The Genetics program has received a new CDC grant to implement Severe Combined Immunodeficiency (SCID) to the newborn screening panel. Many may remember the “bubble baby”, which was the first child to live to age 12 by being contained in a plastic inflatable bubble suit to prevent contact with germs. The disease is now curable if detected in the first few days of life, by treatment with a bone marrow transplant. This disease is on the DHHS Advisory Committee for Heritable Disorders in Newborns and Children (ACHDNC) uniform newborn screening panel of conditions that should be included in newborn screening. Its inclusion is also supported by the American College of Medical Genetics (ACMG). The program is working to change the LA Newborn Screening Rule and pertinent legislation to include SCID and working with Medicaid to ensure that testing for SCID will be a reimbursable activity. The lab test costs about \$7 per child, which will cost the state about \$287,000 per year to implement, but an undetected case could cost over \$2 mil if detected late. It is estimated that screening would detect .82 cases per year. Therefore money will be saved within two years of implementing the testing, in addition to enabling life- saving treatment.

CHILDHOOD LEAD & HEALTHY HOMES Program (LACLHHP) assisted with the National Healthy Homes Conference held in New Orleans in October. The program participated in several presentations including “Testing in WIC Clinics” and “Lead Testing in Water” (in conjunction with LSU).

LACLHHP had a successful Lead Poisoning Prevention Week, October 26th -30th, with several outreach events including a walk around the Mercedes Benz Superdome.

Additional activities included:

- A “Chat and Chew” at the Ashe’ Cultural Center to raise awareness about the importance of lead poisoning prevention
- Presentations to parents in WIC clinics
- The Lead Advisory Committee meeting
- Grand Rounds at Tulane University Medical Center

The goal of the program is to increase lead testing in children ages 12 and 24 months of age, to prevent lead poisoning which causes learning disabilities, ADHD, speech delays, and other problems.