

Office of Public Health Report to the DD Council

June 2016

OPH news: Dr. Rebecca Gee has been confirmed as Secretary of Health, Michelle Olletto has been confirmed as Deputy Secretary, and Beth Scalco has been confirmed as Assistant Secretary of Health, from Interim Assistant Secretary. And of course, DHH has been renamed, Department of Health because it no longer runs hospitals.

Children's Special Health Services:

- **Family Resource Center (FRC)** at Children's Hospital, New Orleans
 - The FRC continues to provide statewide community-based resource information to clients: **March-May 2016: 194 total client encounters; 379 resource needs identified; 393 resource needs met (includes #s from past period needs).**
 - The FRC maintains its Advisory Board with >50% of members parents of CYSHCN. Advisory Board meeting was held April 26, 2016.
 - Staff continue educate physicians, staff, and families within Children's Hospital about transition resources for CYSHCN:
 - 3/22/2016 Noon Conference to LSU residents & students: Youth Health Transition (Patti Barovechio and Betsey Snider)
 - 5/4/2016 Presentation to CHNOLA Nurse Coordinators on Transition & overview of upcoming resource fair
 - Youth liaison, Steven Nguyen, encourages families receiving inpatient rehab services to visit the FRC either during their hospital stay or later when receiving outpatient services. The FRC links patients with FHF in their home region of the state.
 - FRC conducts community outreach:
 - 4/7/16 East Bank Head Start Health Fair @ Mike Miley Playground
 - 4/8/16 West Bank Healthy Start Health Fair @ Johnny Jacobs Playground
 - 4/14/16 Amerigroup Baby Fair in Harvey
 - 4/16/16 Jefferson Parish Resource Fair @ Clearview Mall
 - FRC Highlights:
 - FRC staff held a **resource fair** on May 24th: Healthcare Transition: It's More than Transfer of Services! The goals of the fair were to:
 - (a) Provide information on healthcare transition tools and resources; and (b) provide an opportunity for healthcare staff &

families to meet with organizations and agencies that provide healthcare transition information and services.

16 agencies/organizations participated. 324 attended the fair-278 CHNOLA staff and residents; 35 agency/organization staff; 11 family members.

- Steven Nuygen, Youth Liaison for the FRC, recently became a council member of the **Statewide Independent Living Council**. He was nominated by the Governor and confirmed by the Senate. This council meets quarterly for 1 ½ day meetings.
 - Steven has been asked to participate in a **Community and Family Support System Task Force of the Louisiana Developmental Disabilities Council**. This task force will review the current state of supports and services made possible by Act 378 of 1989 and make recommendations to improve and sustain the system to state policymakers. This task force will have 3 meetings between July & September.
 - Steven will attend the **Spina Bifida National Conference** in Bloomington, MN on June 24-28. Travel expenses will be paid by Spina Bifida of GNO.
- **Transportation Assistance Program (TAP):**CSHS continues to provide needed transportation assistance to families; February-April 2016 travel stipends were provided to **54 families** totaling **\$7,057.91**.
 - **Medical Home—Care Coordination and Transition**
 - *CSHS/Statewide CC Activities:*
 - Quarterly transition article for Family Matters Newsletter for families of CYSHCN
 - Collaborated with LPHI to hire a Care Coordinator for the Tulane Lakeside Pediatric Clinic and NOELA Community Center.
 - Developed a parent training on youth health transition (YHT) to adulthood for a FHF 6/10/16 workshop and 6/30/16 webinar.
 - Conducted 1 hour workshop on YHT during AMCHP conference
 - Poster presentation abstracts submitted/accepted on SmoothMovesYHT project for Baylor Transition Research Day and Ochsner EBP/Research Conference.
 - **New partnerships:** CSHS staff met with Gordon Wadge (president and CEO of YMCA) to discuss partnership opportunities for future initiatives focused on integration/expansion of community services for children/youth/adults on the

autism spectrum. The CSHS Care Coordinator Supervisor serves on the board of their autism workgroup.

- CSHS continues to provide **22 safety-net subspecialty clinics** in Regions 2-9 for CYSCHN that meet medical and financial eligibility. Clinics provide subspecialty care, family support, and care coordination that is coordinated with the medical home. Subspecialties include orthopedics, neurology, ENT, cleft lip and palate, cardiology, cystic fibrosis, and ophthalmology. Audiology clinics provide hearing aids in regions with no private audiologists that take hearing aids (Regions 5 and 8).

Louisiana Birth Defects Monitoring Network (LBMDN): The Louisiana birth defects surveillance system provides data that are used to determine the prevalence of birth defects in Louisiana, which can be used to help determine causes, target prevention efforts, and link families with resources.

- **Zika CDC Grant:** LBMDN is partnering with CSHS, Infectious Disease Epidemiology, Bureau of Family Health, and the OPH Zika Task Force to submit an application for a CDC grant to develop surveillance, intervention, and referral to services for infants with microcephaly or other adverse outcomes linked with the Zika virus. The application is due June 24, 2016 with awards expected in August 2016. Because Louisiana harbors the type of mosquito that carries the Zika virus, we are eligible to receive up to \$200,000 per year for the 5 year project period.

Hearing, Speech and Vision:

- **Vision Program:** At the end of December 2015, the Hearing, Speech & Vision (HSV) Program lost one of its two vision contractors to a sudden, health-related death. Jeff Robinson had been the Louisiana Lions Eye Foundation Cubsight State Coordinator for 25 years and built the Cubsight program into a primary health service for LA children in daycare programs, providing vision screening and needed referrals for children statewide between the ages of 11 months and 4 years. Shortly after Jeff's death, the decision was made to continue the program and begin the search for a new Cubsight Coordinator. It is anticipated that the new coordinator will take over the role this summer, continuing to provide vision services to LA children.
- **Early Hearing Detection and Intervention Program:** The LA EHD team is collaborating with the LSUHDC in its Deaf/Blind Project (LA DBP) for Children and Youth. The collaboration works to connect individuals and agencies that address the needs of the deafblind population, working to coordinate services,

provide technical assistance as needed and connect families to services throughout the state. A major goal is to identify all individuals in LA between birth to 22 years who have varying degrees of both hearing and vision loss.

LA EHDI was one of the co-sponsors of the first **CONNECTIONS Conference** in May, the first of what is hoped to be an annual conference sponsored by the LA DBP. The goal of the conference was to connect statewide resource agencies with the deafblind, deaf and blind population across the state. For more information contact Michael Norman, Coordinator LA DBP at 504-566-3455.

- The LA EHDI team continues to train outside stakeholders in accessing and using the state's new web-based LA EHDI Information System or LA EHDI-IS. This information system permits audiologists and physicians to upload audiology screening and assessment data and early intervention information into a web-based system and obtain information provided by other health professionals. This focus on training and support has resulted in increased use of the system by hospitals, physicians and other providers. This will significantly improve follow-up data for infants who screen positive for hearing loss at birth, ensuring that they receive appropriate assessments by 3 months and early intervention by 6 months of age. A total of 224 providers have been trained to date.

Genetics:

- The program is working to change the Newborn Screening Rule and pertinent legislation to include **Severe Combined Immunodeficiency Disease (SCID)** to the newborn screening panel. This has been added to the national advisory group's list of recommended diseases for newborn screening, and LA has received CDC funding for two years to initiate the testing. Testing should begin later this year.
- The program submitted letters as requested to the House and State Committees on Health and Welfare on the health costs and benefits of adding **X-linked Adrenoleukodystrophy (ALD) and Krabbe disease** to the newborn screening panel. Both are lethal diseases that cause neurologic deterioration and death in childhood. ALD is on the national list of recommended conditions for newborn screening, and adding this to the panel is really a matter of funding. If funding is available, it is anticipated that testing would begin in 2017. Krabbe's disease is not on the recommended list because there is no FDA approved laboratory test for the disease, nor cure for the disease.
- The **Louisiana Sickle Cell Commission** met on June 8, 2016. The Sickle Cell Commission is charged with improving care coordination and access to care for individuals with sickle cell disease. Dr. Renee Gardner, pediatric hematologist from LSU, has completed drafting a Standards of Care manual for treatment of patients with Sickle Cell Disease. The manual provides guidance to pediatricians

and hematologists on best practice for children with sickle cell disease and for any provider who does not have access to a hematologist with experience in sickle cell. The manual is also useful to adult providers who may be unfamiliar with treatment of SC Disease. The manual has been submitted to BMAC for approval.

CHILDHOOD LEAD & HEALTHY HOMES:

- The program has been awarded year 3 funds for the CDC Childhood Lead Poisoning Prevention Grant to decrease lead exposure and to improve lead testing in Louisiana. The program was part of a team of public health programs that responded to allegations of lead in the water system in St. Joseph, La. The home in question was tested by the Childhood Lead Program as well as the Water Program and no lead was found in the water.
- The next Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program Advisory Meeting will be held on July 29, 2016.