

Office of Public Health: Title V CYSHCN
Report to the DD Council
March 2013

Database News: Database development is underway for the Early Hearing Detection and Intervention (EHDI) program of HSV, the Genetics Program, and the Louisiana Birth Defects Monitoring Network. The database programming should be complete in June and ready for testing. When this is complete, all programs will have web-based software that interfaces with vital records through LEERS (Louisiana Electronic Event Registration System). By providing data linkage from all three programs and vital records, the new system will provide programs with more complete, accurate data including more current demographic data, which will help to minimize loss to follow-up of families in all three programs.

I. 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. From December 2012-February 2013 they had 237 total client encounters and provided information on 1132 resources.
 - Steven Nguyen began serving as CHNOLA Rehab Department Youth Liaison in January 2013. Steven visits patients that are referred by the Physical Therapy (PT) Director and provides information about the FRC and Families Helping Families (FHF). Some of his activities have included: information to rehab clients on transitioning from high school to college, LRS and medical care transitioning, and planning an annual event for former rehab clients that would provide information about recreational activities and summer camp.
 - **Steven Nguyen, the FRC Youth Liaison, received the 2013 Ryan Colburn Scholarship** to attend the Association of Maternal & Child Health Programs (AMCHP) Conference in Washington, DC in February 2013. Only 1 youth nationally is selected per year for this scholarship. The purpose of the Ryan Colburn Scholarship is to provide:
 - A leadership development opportunity;
 - Opportunities to network with Maternal and Child Health (MCH) professionals and families nationally; and
 - A forum to learn about emerging and national MCH issues.

AMCHP assigned a family mentor to engage with Steven before, during and after the AMCHP conference on a monthly basis. The FRC Youth Liaison, Parent Liaison, Parent Facilitator, and CSHS Parent Liaison Consultant visited Senators Vitter and Landrieu and presented information on Louisiana Title V services for Children and Youth with Special Health Care Needs. They brought back some great photos of their meetings with Senators Landrieu and Vitter. One of the expectations is that Steven will share his experiences with other youth in Louisiana after attending the conference.

More on Steven: Steven is a board member/youth representative of Spina Bifida of Greater New Orleans and is active in fundraising /outreach activities and organizing social events for young adults. He currently participates in Champions of Greater New Orleans. He has also participated in New Orleans Rollin' Hornets, Games Uniting Mind and Body Organization (GUMBO) and the Regional Paralympics Experience. Steven is a student at Delgado community college, majoring in Computer Information Technology.

- The FRC Nurse Coordinator met with CHNOLA's Social Services Director regarding engaging her staff in connecting families to community resources. It was decided to present one or more Resource Information trainings as Habilitation Conference programs. Presenters would include FHF, LRS, OCDD and the Advocacy Center.
- Efforts continue to promote the FRC at Children's Hospital: FRC brochures have been submitted for translation into Spanish and sent to the CHNOLA Parenting Center for distribution. FRC information was presented during a FHF webinar and to school nurses from Orleans Recovery School District, Jefferson Parish Schools, and Orleans Charter Schools. FRC articles were submitted to CHNOLA Small World, CSHS Family Matters, and each of the 10 FHF center newsletters.
- **Transportation Assistance Program-** During this quarter, requests were received from all DHH regions of LA except for 1 and 9. CSHS assisted 29 families with transportation assistance to medical appointments/medically necessary services totaling \$7,984.27 in disbursements. In February, the transportation **program brochure** was completed and distributed to CSHS clinics, FHF Centers, the Genetics program (for distribution to Sickle Cell Foundations) and the CSHS Family Resource Center.

CSHS expanded this initiative to include Sickle Cell Foundations statewide.

Each foundation was invited to enter into a MOU with FHF at the Crossroads in order to participate in the program. A brief training call was conducted by the CSHS Program Manager and the FHF at the Crossroads Director to discuss project protocol. To date, one foundation has signed and returned the MOU; no requests have been made for transportation assistance from that office.

- **Medical Home – Care Coordination and Transition-** We are in Year 2 of the 3 year MCHB Systems Integration Grant, which funds contracts with 3 academic medical practices per year to enhance care coordination in the practices.
 - Two new practices received training and contracts to provide care coordination in outpatient academic settings: LSU Family Medicine in Alexandria and LSU Med-Peds on St. Charles in New Orleans
 - Third practice which is starting up is LSU Family Medicine- Shreveport.
 - The Statewide Care Coordinator Supervisor is collaborating with a Spanish physician in Region 1 to provide a translation of the CSHS transition handout for Youth with special health care needs. She also provided an overview of the Medical Home twice per month for LSU and Tulane pediatric residents who were

completing the Development Rotation. She has begun the process of getting CE approval for future lunch and learn events for medical social workers and nurses on providing care coordination for children and you with special healthcare needs in primary care physician practices (medical homes).

- **Resource Information Workshops (RIWs)** – These are regional workshops provided through contracts with FHF from the CSHS Systems Integration Grant. Each grant year, 27 RIW's are held (3 per region) to familiarize staff from community and public health programs for families of children with special healthcare needs with each other's services and eligibility criteria. Grant year 2 RIWs are being held across the state.

II. Hearing, Speech and Vision: LA Early Hearing Detection and Intervention

- The parents on the HSV team are becoming more active within the community and nationally. Our **bilingual parent, Marbely Barahona** has been active in the National Initiative for Children's Healthcare Quality, focusing on follow up after newborn hearing screening, including diagnosis and referral into early intervention. Nationally, parent involvement has proven invaluable and Marbely has won the hearts and minds of our federal granting agencies. She has been invited by the National Center for Hearing Assessment & Management (NCHAM) & MCHB to present at a plenary session at the annual 13th National EHDI Conference next month in Phoenix.
- Our **other parent, Mariah Ranko**, is busy organizing a **La Chapter of Guide By Your Side, a program from Hands & Voices** that provides support and information from trained Parent Guides to families of newly identified children who are deaf or hard of hearing. The parent guides are parents of children with hearing loss who know how to share their personal story concisely and appropriately. The parent guides provide unbiased, non-judgmental emotional support, sharing resources and information in a comprehensive equitable manner. Guides maintain ethical standards and actively develop their knowledge-base to help families make informed decisions. New parents are matched with guides close to home who are familiar with resources within the community. They help families identify their options and goals for their child.

III. La Birth Defects Monitoring Network

- In January 2013, LBDMN participated in the **National Birth Defects Prevention Network National Birth Defects Prevention Campaign**. The program introduced more than 300 partners to free materials available at <http://www.nbdpn.org/bdpm2013.php>. This included a social media campaign in partnership with DHH, LPHI, our population servicing stakeholders, universities, school-based health programs, and regional OPH units to name a few. **The campaign message is:**

Birth defects are Common, Critical and Costly. In the US, every 4.5 minutes a baby is born with birth defects affecting 1 in 33 babies born. Birth Defects affect us all. What effect will you have on birth defects?

- In February 2013, five of ten staff attended the National Birth defects Prevention Network Annual Conference in Atlanta, GA. **Critical Congenital Heart Defects (CCHD)** was the focus. LBDMN epidemiologist, Dr. Tri Tran presented a poster detailing analysis of Results from Louisiana 2006-2008 birth defects surveillance system.
- The La Chapter of the American Heart Association is interested in introducing screening for critical congenital heart defects in Louisiana. This bill will be filed by Representative Ladricka Thierry from Opelousas and will require hospitals to do a pulse oximetry test on every infant born in LA to rule out cyanotic heart disease. No surveillance will be required by DHH in the current version of the bill. This is a simple screening that and could potentially save lives, and as long as surveillance for this screening is not required of DHH, we are very supportive of this bill. Infants with a positive screen will need pediatric cardiology evaluation and if indicated, an echocardiogram. In hospitals that do not have a pediatric cardiologist available, the infant will need to be transferred to another hospital for evaluation.
- LBDMN has a collaborative with the Environmental Public Health Tracking Program. Regional birth defects data will be added to the online GIS mapping of environmental toxins. This will permit the public to query region-specific data regarding birth defects and toxins at their website:
<http://lephtauth.dhh.la.gov/Pages/LA%20EPHT%20Program.aspx> . Static birth defect data is already available at:
<http://lephtauth.dhh.la.gov/Pages/QuickReports.aspx> . Currently, the queryable portal is scheduled to be up in March. Data that are going up first include asthma, heart attack, carbon monoxide poisoning and childhood lead poisoning. We anticipate having birth defect data up by April.
- The governor has proposed merging the LBDMN Advisory Board with the Perinatal Commission. Although our boards have different goals and compositions as mandated by legislation, both have a preventive education component in our missions targeted to pregnant women. It is expected that our Advisory Board will remain intact through the merger in order to provide continued oversight of the statewide implementation of the LBDMN, but will increase collaboration with the Perinatal Commission, possibly as a sub-board and hopefully to include LBDMN representation on the Perinatal Commission. Since birth defects are the number one cause of infant mortality, collaboration could be beneficial to both parties.
- **Budget Update:** CDC Cooperative Agreement Year 4, which funds the LBDMN program along with the Title V MCH block grant, CYSHCN portion, was funded at 80%=\$148,000.00 due to lack of FY 2013 federal budget. There is a possibility the remaining 20% may be resubmitted and funded in April or May. This means filling the Region 2 and 6/8 Data Collection Specialist positions remains on hold which negatively impacts our Surveillance Performance Measure to achieve statewide surveillance.

IV. Genetics Program

- **Elimination of the VFC program** and immunization provision in the health units may limit access to pertinent vaccines to patients with Sickle Cell Disease such as H Influenza and Meningococcal Vaccine. People with SS are more vulnerable to these bacteria and disease can be much more severe. Patients are urged to obtain needed vaccines through their primary care providers, who can still participate in the VFC program. The pneumococcal -23 vaccine should continue to be available in health units since this is not a VFC vaccine.
- **Budget Update:** The Genetics Program received a midyear cut to SGF of \$345,000. An attempt was made to distribute cuts evenly across eligible contracts, which included a Genetics Services Contract, 3 Sickle Cell Clinical Contracts and 5 Sickle Cell Foundations Contracts. Cuts will not impair access to care but could limit funds available for genetics testing for Medicaid and uninsured populations. The Genetics Program will not be affected by the federal sequestration cuts.
- **Childhood lead and Healthy Homes:** Lead is a neurotoxin that is frequently found in paint in old houses and in dirt in older neighborhoods, particularly in cities. Children living in older homes and all children on Medicaid should be screened for lead. Toddlers are especially prone to lead exposure when they put their fingers in their mouths while playing in an environment that is contaminated with lead. If this goes undetected, lead that is ingested can enter the blood stream, affecting many organ systems but especially the brain. Very high lead levels lead to seizures, encephalopathy, and even death. Lower levels are much more common and can affect learning and behavior. In particular, elevated lead levels are associated with ADHD, anti-social behavior, and reading problems. All children in LA should be screened for lead by their primary care physician at ages 12 and 24 months, and up to age 6 years if they have never been tested. When a high lead level is detected, the state's lead program, located in OPH, takes appropriate action to ensure that the child is removed from the source of lead or that the lead is removed from the home and when necessary, from the child through a process called chelation.

Since the CDC lowered the blood lead level for concern regarding exposure to lead from 10 µg/dl to 5 µg/dl earlier this year, the program has sent over 500 letters to families with children with blood lead levels between 5 and 9µg/dl. Parents are provided with instructions for removing common sources of lead from the home. At levels greater than 20, a sanitation worker goes into the home to determine the exact source of the lead. It is the responsibility of the owner to remove the source of lead from the environment. At levels greater than 45, hospitalization and chelation of the child to remove the lead is recommended. The lead program receives labs from children with elevated lead levels and ensures that appropriate action is taken. In 2011, 674 children in LA were detected to have elevated lead levels. 93 of these children had levels ≥ 20 ug/dl.