

Presentation to Health and Human Services Committee

By

Rachel Berroth, Director
Bureau of Family Health

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Chairman Crum and members of the Committee, I am Rachel Berroth, Director for the KDHE Bureau of Family Health which includes the Kansas Newborn Screening and Birth Defects Programs. Thank you for the opportunity to appear before you today to provide information about the Critical Congenital Heart Defect (CCHD) public health quality initiative.

Also known as Critical Congenital Heart Disease, CCHD is one of the most common birth defects among infants in the United States (approximately 7,200 infants diagnosed annually), accounting for 30 percent of infant deaths due to birth defects. According to National prevalence data, Kansas could expect to identify up to eight (8) cases of CCHD each year, based on recent birth rates. Infants born with a CCHD are at a significant risk for death or disability if their condition goes undiagnosed after birth. Unlike other Newborn Screening tests that are screened using blood spots from heel sticks, the preferred method of screening for CCHD is pulse oximetry, a non-invasive, low-cost test.

The Department engaged key stakeholders including the Kansas Hospital Association, American Heart Association, and March of Dimes for this CCHD public health quality initiative which stemmed from a 2013 Kansas Newborn Screening Advisory Council recommendation. The CCHD Work Group was convened in November 2013 and consists of 18 stakeholders, including those named above, physicians from private and hospital-based practice (including Wesley, Children's Mercy, KU Medical Center, and more), and Newborn Hearing Screening program staff. The initiative's comprehensive approach is inclusive of education, screening, diagnosis, short- and long-term follow-up, systems to support hospital-based data collection, management, evaluation and quality assurance.

The goal is to address this as population-based screening in Kansas to ensure all babies are screened for CCHD after birth. The outcome is implementation of a well-designed program to screen for, ensure prompt care and connections to resources and long-term follow-up, and improve health outcomes for infants with CCHD. Preliminary data collected by the program since 2012 reveals Kansas is well-positioned to reach these goals. Survey results suggest approximately 78% of Kansas infants are currently screened for CCHD prior to discharge; however, this only represents 30% of birthing facilities so there is room for improvement. This initiative affords the opportunity to educate and train the remaining birthing facilities and midwives so every infant is screened, no matter where they are born.

There are many benefits to the State Public Health Department leading the initiative for CCHD screening through education and partnership versus a mandate. This approach allows for:

- Engaging stakeholders and birthing facilities more broadly to provide input on the design of the final process and quality improvement methods;

- Supporting successful implementation and sustainability at the facility level by addressing barriers (lack of education and training along with inability to read pediatric echocardiograms, funding, lack of equipment, competing priorities);
- Raising awareness and developing educational interventions;
- Establishing a benchmark to monitor improvement;
- Standardizing pulse oximetry equipment adequate to conduct the test;
- Establishing recommended protocols for when and how the test is done; and
- Developing the reporting mechanism and data source for monitoring and evaluation.

The action items to be completed between February and July 2014 for Phase I implementation include:

- Reviewing and analyzing additional survey data from birthing facilities and midwives;
- Researching options to collect and report data;
- Selecting pilot sites;
- Developing a training plan in cooperation with the Kansas Hospital Association;
- Conducting site visits and assessments; and
- Conducting on-site trainings for screening and reporting.

The initial effort (Phase I) establishes a baseline for monitoring; follow-up evaluations are expected to demonstrate improvements in screening and follow-up care. Phases II and III are planned to be complete by the end of 2014 and will involve education, training, and implementation of screening for additional sites as well as efforts to improve based on analysis and evaluation from Phase I.

Thank you for this opportunity to appear before you. I will now stand for questions.