



OB Constituency Group Webinar

Wednesday, November 13, 2013



Chloe's Law - Congenital Critical Heart Disease Reporting Requirements

Dr. Sharmini Rogers, MBBS, MPH
Chief
sharmini.rogers@health.mo.gov

Jamie Kiesling, R.N., BSN
Newborn Screening Manager
Jami.Kiesling@health.mo.gov

Julie Raburn-Miller
Program Coordinator, Genetics and Early Childhood
Julie.Raburn-Miller@health.mo.gov

Bureau of Genetics and Healthy Childhood
Missouri Department of Health and Senior Services
573/751-6266



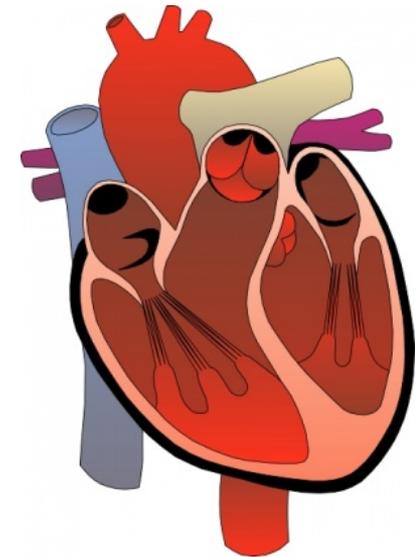
Critical Congenital Heart Disease Screening



Bureau of Genetics and Healthy Childhood
Missouri Department of Health and Senior Services
November 13, 2013

Background

- Congenital Heart Defects (CHDs) account for 30% of infant deaths due to birth defects.
- Critical Congenital Heart Defects (CCHDs) make up about 17-31% of all CHDs.
 - Hypoplastic left heart syndrome
 - Pulmonary atresia (with intact septum)
 - Tetralogy of Fallot
 - Total anomalous pulmonary venous return
 - Transposition of the great arteries
 - Tricuspid atresia
 - Truncus arteriosus
- Babies with one of these seven CCHDs are at significant risk for death or disability if their heart defect is not diagnosed and treated soon after birth.



Background

- On September 27, 2011, Health and Human Services Secretary, Kathleen Sebelius, adopted the recommendation of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) that Critical Congenital Heart Disease (CCHD) be included on the Recommended Uniform Screening Panel (RUSP).
- The RUSP is the national recommendation informing states of the congenital conditions that should be included in each state newborn screening program.



Chloe's Law

- During the 2013 legislative session, Senate Bill 230, also known as Chloe's Law, was passed.
- <http://www.senate.mo.gov/13info/pdf-bill/tat/SB230.pdf>
- Senate Bill 230 became law on August 28, 2013.



Chloe's Law

- Chloe's Law requires that all newborns born in Missouri be screened for CCHD beginning January 1, 2014.
- Screening shall be done by pulse oximetry or in another manner as directed by the Department of Health and Senior Services and in accordance with the American Academy of Pediatrics and the American Heart Association.
- Screening results shall be reported to the parents or guardians of the newborn and the Department of Health and Senior Services in a manner prescribed by the Department for surveillance purposes.
- Facilities shall develop and implement plans to ensure that newborns with positive screens receive appropriate confirmatory procedures and referral for treatment as indicated.

Hospital Requirements

- Beginning January 1, 2014, all hospitals will be required to:
 - Screen all newborns for CCHD using pulse oximetry
 - Follow the screening guidelines established by the American Academy of Pediatrics and the American Heart Association
 - Ensure that screening results are provided to the parents or guardians of the newborn
 - Develop and implement plans to ensure that newborns with positive screens receive appropriate confirmatory procedures and referral for treatment as indicated





Reporting

- The Department plans to collect CCHD screening data from hospital EMRs via Health Level Seven (HL7) messaging.
- A Missouri HL7 Implementation Guide for CCHD will be developed based upon national HL7 standards.
- Rules will be established specifying the required data elements to be reported to the Department.
- Until such rules are in place, the Department requests that all hospitals voluntarily report aggregate CCHD screening results.
- Without Rules in place, any baby level data reported to the Department would be in violation of HIPAA.

Voluntary Aggregate Reporting



Missouri Department of Health and Senior Services
P.O. Box 570, Jefferson City, MO 65102-0570 Phone: 573-751-6400 FAX: 573-751-6010
RELAY MISSOURI for Hearing and Speech Impaired 1-800-735-2966 VOICE 1-800-735-2466
Gail Vasterling
Acting Director



Jeremiah W. (Jay) Nixon
Governor

Critical Congenital Heart Disease Aggregate Reporting Form

The Department of Health and Senior Services requests that all ambulatory surgical centers, hospitals, birthing centers, and midwives who attend home births voluntarily provide aggregate Critical Congenital Heart Disease (CCHD) screening data monthly. Please complete the form below and mail to the Department of Health and Senior Services, Bureau of Genetics and Healthy Childhood, PO Box 570, Jefferson City, MO 65102 or fax to 573-751-6185.

For questions or concerns, please contact the Bureau of Genetics and Healthy Childhood at 573-751-6266.

Ambulatory Surgical Center/Birth Hospital/Birthing Center/Midwife: _____

Contact Name: _____

Contact Phone Number: _____

Reporting Period for Month of: _____

Total Number of Newborns Screened	
Total Number of Newborns with a Negative Screen (Pass)	
Total Number of Newborns with a Positive Screen (Fail)	
Total Number of Newborns Not Screened Due to:	
Prenatal CCHD diagnosis	
Condition Unstable/Required Critical Intervention	
Parents Refused	
Transferred	
Expired	

www.health.mo.gov

Healthy Missourians for life.
The Missouri Department of Health and Senior Services will be the leader in promoting, protecting and partnering for health.

AN EQUAL OPPORTUNITY / AFFIRMATIVE ACTION EMPLOYER. Services provided on a nondiscriminatory basis.

(10/13)

- Number of Newborns Screened
- Number with a Negative Screen (Pass)
- Number with a Positive Screen (Fail)
- Number Not Screened
 - Prenatal CCHD diagnosis
 - Condition Unstable
 - Parents Refused
 - Transferred
 - Expired

Additional Resources

- American Academy of Pediatrics, Newborn Screening for CCHD – Answers and Resources for Primary Care Pediatricians

<http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Newborn-Screening-for-CCHD.aspx?>

- American Heart Association – About Congenital Heart Defects

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects_UCM_001217_Article.jsp -

- Baby's First Test

<http://www.babysfirsttest.org/newborn-screening/conditions/critical-congenital-heart-disease-cchd>

Additional Resources

- Centers for Disease Control and Prevention - Screening for Critical Congenital Heart Defects
<http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html>
- NewSTEPS – CCHD Educational Resources
<https://newsteps.org/critical-congenital-heart-diseases>
- Pulse Oximetry Calculator
<http://pedspulseox.com/>



MO HealthNet Early Elective Delivery Draft Payment Rule Overview

Timothy G. Kling, M.D., FACOG
Physician Consultant
MO HealthNet



Overview

- EED is defined as any delivery prior to 39 weeks gestation that is not medically indicated.
- Morbidity and mortality rates are greater among neonates and infants delivered during the early term period compared to those delivered between 39 and 40 weeks gestation.
- Decreasing these early deliveries has been shown to improve neonatal outcomes.
- However, we must balance the risks of letting a pregnancy go to full term against those associated with early term delivery if there is no medical indication for an earlier delivery.



Methodology

- MO HealthNet is in the process of establishing a rule regarding early elective delivery.
- We are working with several groups of providers to establish a fair rule with appropriate indications for early delivery. These indications will be evidence based and flexible.
- Ranges of diagnostic codes have been prepared to allow for a smooth billing procedure for providers.
- Simple codes are being created for providers to use to be able to have their claims go through our system.
- Medicaid covers 49% of the deliveries in Missouri so it will have some impact.



Results

- Hard Stops are being used by providers in MO as well as other states to lessen the number of EEDs on a voluntary basis.
- MO HealthNet is in the process of establishing contacts with MO ACOG, MO pediatricians, and MO Medical Association to inform the providers in this state about the benefits as well as the process when it is instituted.
- The process itself will be simple and straightforward and the providers will not have to make many changes with their billing procedures.
- The purpose of all this is to lessen the risks to infant and mother due to EED.



Contact

Timothy Kling, MD, FACOG

Physician Consultant

573/751-5210

Timothy.G.Kling@dss.mo.gov

