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Thomas O. Forslund
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MEMORANDUM

Date: November 1, 2017

To: Hospital Administrators and Staff, Newborn Care Providers, Primary Care Providers, Certified Professional Midwives and Certified Nurse Midwives

From: Alexia Harrist, MD, PhD, State Health Officer 
Wyoming Department of Health

Subject: Newborn Screening Rules Amended to Add Critical Congenital Heart Disease

Ref: AH-2017-023

The Wyoming Department of Health (WDH) recently amended Wyoming's newborn screening rules pursuant to Wyo. Stat. Ann. §§ 35-4-801 through -802 per the recommendation of the Wyoming Newborn Screening Advisory Committee. The amended rules require **Critical Congenital Heart Disease (CCHD)** screening. The amended rules can be located at www.wynewbornscreening.org.

What is CCHD?

CCHD is a term that refers to a group of serious heart defects that are present from birth. These abnormalities result from problems with the formation of one or more parts of the heart during the early stages of embryonic development.

Why is CCHD screening important?

CCHD requires prompt diagnosis and treatment for the best outcome. Babies with undetected critical congenital heart defects are at risk for death or significant disability. Because prenatal ultrasound examinations and newborn physical examination fail to identify a significant number of CCHD cases, late diagnosis may occur. Delayed diagnosis can result in significant morbidity, permanent injury of vital organs including the brain, and, in some cases, death. Well-designed screening of newborns with pulse oximetry improves detection of CCHD before it becomes clinically apparent.

How does this rule change affect your facility or practice?

- Beginning December 1, 2017, it is expected that all babies born in Wyoming will be screened for CCHD.
- All babies shall receive pulse oximetry screening for CCHD according to best medical practice.
- The results of the pulse oximetry screening shall be reported on the birth certificate.
- Screening shall take place between 24 and 48 hours of life for healthy term babies. If early discharge/release is planned, screening shall occur as late as possible prior to discharge. Pulse oximetry screening should not replace a complete history and physical exam.
- A consent/waiver form shall be completed by the baby's parent or guardian before performing blood spot specimen collection or pulse oximetry screening. The form shall be submitted to the WDH Newborn Screening Program Coordinator within 10 days of birth.
- Under the amended rules, and per the recommendations of the Wyoming Newborn Screening Advisory Committee, the cost of a child's initial blood spot specimen collection has increased from seventy-seven dollars (\$77.00) to eighty-four dollars (\$84.00). The cost of the first and second screen are covered by the fee. The fees assessed cover the reasonable costs of the initial and second blood spot specimen collection for the same child, initial confirmatory testing, courier services, laboratory services, specialty follow-up services, program education, and other services necessary to maintain functionality and sustainability of this self-funded program.

What resources are available to a hospital or healthcare providers that are not currently screening for CCHD or for those who need more information?

Healthcare providers and hospitals can visit the WDH Newborn Screening Program webpage at www.wynewbornscreening.org. The website includes comprehensive CCHD information, resources and training, and toolkits that will help guide implementation.

Important notes on CCHD screening:

- CCHD screening and reporting should not delay the submission of the newborn screening blood spot specimen card. Please continue to ensure that the blood spot cards are sent via courier to the Colorado laboratory within 24 hours of collection.
- CCHD screening does not screen for all forms of significant neonatal heart disease. Clinicians should continue to consider the possibility of heart disease in infants based on the clinical scenario.
- **Failed CCHD screens** should result in a complete clinical evaluation to assess for the cause of the hypoxia, and treatment should begin as indicated. A neonatal intensive care unit or pediatric cardiologist should be consulted for further care. To learn more about the CCHD screening process, visit wynewbornscreening.org.

For Additional Information:

If you have questions regarding CCHD implementation, or need additional resources, please contact Carleigh Soule, Wyoming Newborn Screening and Genetics Coordinator, at (307) 777-6297 or carleigh.soule@wyo.gov.

References:

- U.S. National Library of Medicine, Genetics Home Reference;
<https://ghr.nlm.nih.gov/condition/critical-congenital-heart-disease>
- Wisconsin Screening Hearts in Newborns (SHINE) Project; <http://wisconsinshine.org/>
- State of California Health and Human Services Agency, Guidelines for Critical Congenital Health Disease Screening Services;
<http://www.dhcs.ca.gov/services/ccs/Documents/ccsnl040314.pdf>
- Michigan Department of Health and Human Services, CCHD Screening Program;
<http://www.michigan.gov/mdhhs/0,5885,7-339--278046--,00.html>

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