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NEBRASKA DEPARTMENT OF
HEALTH AND HUMAN SERVICES

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TITLE 181 SPECIAL HEALTH PROGRAMS

CHAPTER 10 SCREENING OF NEWBORNS FOR CRITICAL CONGENITAL HEART
DISEASE

001. SCOPE. These regulations implement the law governing screening of newborns for critical congenital heart disease set out in Nebraska Revised Stats.(Neb. Rev. Stats.) §§ 71-553 through 71-557.

002. DEFINITIONS. Definitions set out Neb. Rev. Stats. §§ 71-553 through 71-557 and the following apply to this chapter.

002.01 CRITICAL CONGENITAL HEART DISEASE (CCHD). One of seven targeted lesions for which newborn screening by pulse oximetry is intended to detect. The seven lesions are hypoplastic left heart syndrome, pulmonary atresia, tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, and truncus arteriosus.

002.02 ECHOCARDIOGRAM. A diagnostic test that uses ultrasound waves to create an image of the heart muscle. Echocardiograms can show the size, shape, and movement of the heart's valves and chambers as well as the flow of blood through the heart.

002.03 HOSPITAL. Any facility defined under Neb. Rev. Stat. § 71-419.

002.04 HYPOPLASTIC LEFT HEART SYNDROME. A structural birth defect that involves a number of underdeveloped or too small of structures on the left side of the heart including the left ventricle, mitral valve, aortic valve, ascending portion of the aorta. Often babies with this syndrome will also have an atrial septal defect, or hole between the left and right atria.

002.05 INCONCLUSIVE SCREEN RESULT. A result of the screening algorithm which is neither positive (failed) or negative (passed) but requires further screening to make a determination of positive or negative.

002.06 NEGATIVE SCREEN RESULT. An oxygen saturation screening test result that is above the cut-off, and the difference in measurement of the oxygen saturation between the right hand and foot is below a specified percent. A passed screen is a negative screen result for critical congenital heart disease.

002.07 NEONATAL INTENSIVE CARE UNIT (NICU). A hospital unit staffed and equipped to provide intensive care to premature, low birthweight and seriously ill newborns.

002.08 PHYSICIAN. A person licensed to practice medicine and surgery or osteopathic medicine and surgery.

002.09 POSITIVE SCREEN RESULT. An oxygen saturation screening test result that is below the cut off, or the difference in measurement of the oxygen saturation between the right hand and foot exceeds a specified percent. A failed screen is a positive screen result for possible critical congenital heart disease.

002.010 PRENATAL CARE PROVIDER. A licensed health care professional providing care to pregnant women before delivery of the newborn.

002.011 PULMONARY ATRESIA. A structural birth defect in which the pulmonary valve between the right ventricle and pulmonary artery is abnormal and does not open. This may also result in a small or missing right ventricle.

002.012 PULSE OXIMETRY. A non-invasive method of measuring the percent oxygen saturation of hemoglobin in the arterial blood.

002.013 TETRALOGY OF FALLOT. Structural birth defects of the heart affecting four parts. Ventricular septal defect is a hole in the wall between the two lower chambers of the heart. Pulmonary stenosis is a narrowing of the pulmonary valve and main pulmonary artery. The aortic valve is enlarged and open to both ventricles instead of just the left ventricle. Right ventricular hypertrophy is a thickening of the lower right chamber muscle wall.

002.014 TOTAL ANOMALOUS PULMONARY VENOUS RETURN. A condition present at birth in which the oxygen rich blood returns from the lungs to the right atrium or a vein flowing to the right atrium instead of the left side of the heart.

002.015 TRANSPOSITION OF THE GREAT OF ARTERIES. A birth defect in which the two main arteries going out of the heart, the pulmonary artery and the aorta, are switched in position.

002.016 TRICUSPID ATRESIA. A structural birth defect in which the tricuspid heart valve is either missing or abnormally developed.

002.017 TRUNCUS ARTERIOSIS. A structural birth defect in which only one vessel comes out of the right and left ventricles instead of the two normal vessels (pulmonary artery and aorta). There is usually also a ventricular septal defect or large hole between the two ventricles.

003. HOSPITAL AND BIRTHING FACILITY RESPONSIBILITIES. All hospital and birthing facilities must:

- (A) Have and implement policies and procedures consistent with this chapter to screen all newborns for critical congenital heart disease. Screening must be done using pulse oximetry at 24 hours of life or soon after on day 2 of life, or prior to discharge whichever occurs first.
- (B) Document that it notified the receiving hospital of the critical congenital heart disease screening results for every newborn transferred. If no results were available, the

- transferring facility must document it notified the receiving facility that the critical congenital heart disease screen needs to be completed.
- (C) Complete screening for critical congenital heart disease using pulse oximetry. The probe and sensors must be placed on the right hand and one foot. If reusable probes and sensors are used, proper sanitation to prevent infection and communicable disease must be maintained. False negatives are possible, so negative screening results must not delay referral for pediatric cardiology evaluation of an infant otherwise suspected of having critical congenital heart disease. The results of all screening must be recorded in the newborn's medical record.
 - (D) Consider newborns with oxygen saturation percentages of 95 percent or more in the right hand or foot and the difference between the hand and foot is 3 percent or less as having passed the screen.
 - (E) Consider oxygen saturation percentages between 90 percent and less than 95 percent on both the right hand and foot, or a difference of more than 3 percent between the hand and foot as an inconclusive result. The newborn must not be discharged and must be rescreened in one hour. If the rescreen remains inconclusive a third screen must be done in one hour. If on the third screen the results continue to not meet the pass criteria, this is a failed screen. The hospital or birthing facility must immediately notify the newborn's physician of the failed screen for critical congenital heart disease.
 - (F) Consider oxygen saturation percentages less than 90 percent on any screen, initial or rescreen, as a failed screen. This is an indication of possible critical congenital heart disease. The hospital or birthing facility must immediately notify the newborn's physician of this failed screen.
 - (G) Screen all newborns admitted to a neonatal intensive care unit for critical congenital heart disease. Screening of any newborn admitted to a neonatal intensive care unit for less than 8 days must follow the protocol set out in this chapter. For any newborn in a neonatal intensive care unit longer than 7 days, the screening requirement may be met by the level of care the newborn otherwise routinely receives in the unit, which may include including prolonged pulse oximetry monitoring, chest x-rays and echocardiogram, and continuous intensive monitoring and repeated physician exams.
 - (H) Maintain a method of verifying every newborn in its care received a screen for critical congenital heart disease. For any newborn discharged without such a screen, the hospital or birthing facility must notify the newborn's physician and parents or legal guardian, and must reschedule an appointment to complete the screen.
 - (I) Monitor quality indicators which must include at a minimum the number and percent of newborns with failed screens, newborns transferred without a screen, newborns referred for a pediatric echocardiogram, and the age at screening for all newborns who failed a screen.

004. PHYSICIAN DUTIES. All physicians and prenatal care providers must:

- (A) Provide information to expecting parents about newborn screening for critical congenital heart disease. The information must include the importance of screening for critical congenital heart disease, how it is done and that all newborns must have the test whether they are born in a hospital or birthing facility or not.
- (B) If he or she is a newborn's attending physician, the physician must verify the newborn screen for critical congenital heart disease has been completed and ensure the results are documented in the newborn's medical record including any discharge summaries prior to discharge. Upon notification of a failed screen, the attending physician shall

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assess the infant, obtain or refer for echocardiogram and neonatal intensive care unit or cardiology evaluation.

- (C) If a transfer to another facility is made, the attending physician must ensure the results of all screening, tests, and evaluations for critical congenital heart disease are provided to the receiving facility and physician.

005. BIRTHS OCCURRING OUTSIDE A HOSPITAL OR BIRTHING FACILITY. The parent or person registering the birth of a newborn not born in a hospital or birthing facility must ensure that all required screening for critical congenital heart disease occurs not sooner than 24 hours of life and prior to 48 hours in accordance with procedures specified in this chapter.