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TITLE 310. OKLAHOMA STATE DEPARTMENT OF HEALTH
CHAPTER 550. NEWBORN SCREENING ~~PROGRAM~~ AND RESOURCES FOR TRISOMY 13, 18, AND 21

RULEMAKING ACTION:
PERMANENT final adoption
RULES:
Subchapter 1. Newborn Screening General Provisions [AMENDED]
310:550-1-2. [AMENDED]
Subchapter 5. Newborn Screening Blood Specimen Collection [AMENDED]
310:550-5-2. [AMENDED]
Subchapter 7. Newborn Screening Hospital Records [AMENDED]
310:550-7-1. [AMENDED]
Subchapter 11. Advisory Committee for Newborn Screening [AMENDED]
Subchapter 13. Newborn Screening Parent and Health Care Provider Education [AMENDED]
Subchapter 17. Newborn Screening Follow-up for Physicians [AMENDED]
310:550-17-1. [AMENDED]
Subchapter 19. Newborn Screening Reporting [AMENDED]
310:550-19-1. [AMENDED]
Subchapter 21. Newborn Screening Information [AMENDED]
310:550-21-1. [AMENDED]
Subchapter 23. Newborn Screening Standards, Procedures, and Follow-Up for Certified Laboratories [AMENDED]
Subchapter 24. Resources for Trisomy 13, 18, and 21 [NEW]
310:550-24-1. [NEW]
310:550-24-2. [NEW]
310:550-25-3. [NEW]
310:550-24-4. [NEW]
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GIST/ANALYSIS:

The amendments changed the following: the Chapter 550 title was changed to NEWBORN SCREENING AND RESOURCES FOR TRISOMY 13, 18, AND 21. This change was needed due to the addition of the trisomy resources pursuant to 63 O.S. § 1-575; Subchapters 1, 5, 7, 11, 13, 17, 19, 21, and 23 were amended to add Newborn Screening to each title to clarify content for stakeholders; minor grammar corrections were made in 310:550-1-2, 310:550-5-2, 310:550-7-1, and 310:550-17-; 310:550-21-1 and 310:550-17-1 added updated the contact information for the Public Health Laboratory and the Newborn Screening Follow Up Program; and Subchapter 24 "Resources for Trisomy 13, 18, and 21" was added pursuant to 63 O.S. § 1-575. This includes the additions of sections 310:550-24-1 through 310:550-24-4 to state the purpose, define terms, describe the duty of the provider, and describe availability of information from the Department.

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PURSUANT TO THE ACTIONS DESCRIBED HEREIN, THE FOLLOWING RULES ARE CONSIDERED FINALLY ADOPTED AS SET FORTH IN 75 O.S., SECTIONS 250.3(7) AND 308(E), WITH AN EFFECTIVE DATE OF SEPTEMBER 11, 2023:

SUBCHAPTER 1. NEWBORN SCREENING GENERAL PROVISIONS

310:550-1-2. Definitions

The following words or terms, when used in this Chapter, shall have the following meaning, unless the context clearly indicates otherwise:

"Amino Acid Disorders" refers to a group of inherited metabolic conditions in which the body is unable to metabolize or process amino acids properly due to a defective enzyme function. This causes an amino acid or protein build up in the body. If not treated early in life, these defects can cause developmental disability or death. Each amino acid disorder is associated with a specific enzyme deficiency. Treatment depends on the specific amino acid disorder.

"Biotinidase Deficiency" means an inherited disease caused by the lack of an enzyme that recycles the B vitamin biotin, which if not treated, may cause serious complications, including coma and death.

"Birth Defects Registry" means a registry established by the Commissioner of Health to monitor and track birth defects for all infants born in Oklahoma.

"Birthing Facility" means a facility that provides care during labor and delivery, and to the newborn. This includes a unit of a hospital that is licensed and accredited to provide birthing services, or a freestanding birthing center.

"Certified Laboratory" refers to the Oklahoma State Public Health Laboratory and/or a laboratory approved by the Oklahoma State Department of Health to conduct newborn screening.

"CCHD Screening" means the screening test for the detection of critical congenital heart disease that is recommended by the United States Department of Health and Human Services.

"CLIA '88" means the Clinical Laboratory Improvement Amendments of 1988, public law 100-578. This amendment applies to the Federal Law that governs laboratories that examine human specimens for the diagnosis, prevention, or treatment of any disease or impairment, or the assessment of the health of human beings.

"Confirmatory Testing" means definitive laboratory testing needed to confirm a diagnosis.

"Congenital Adrenal Hyperplasia" or **"CAH"** means the most common form of CAH, 21-hydroxylase deficiency. This genetic disorder is caused by the lack of an enzyme that the adrenal gland uses to process hormones. Serious loss of body salt and water can result in death. In girls the genitalia may appear as those of a male, and can result in incorrect sex assignment. Hormone treatment is required for life.

"Congenital Hypothyroidism" means a disease caused by a deficiency of thyroid hormone (thyroxine) production, which if not treated, leads to developmental disabilities.

"Critical Congenital Heart Disease" means a congenital heart defect that places an infant at significant risk for disability or death if not diagnosed soon after birth.

"Cystic Fibrosis" means a multisystem genetic disorder in which defective chloride transport across mucous membranes causes dehydration of secretions. The result is a production of a thick, viscous mucous that disrupts the normal function of the lungs, gut, and pancreas. This leads to chronic lung infections, fatal lung disease, and problems with digestion. Early detection and treatment can prevent malnutrition, and enhance surveillance and treatment of lung infections.

"Days of Age" means the age of a newborn in 24-hour periods so that a newborn is one day of age 24 hours following the hour of birth for both blood spot screening and pulse oximetry screening.

"Department" refers to the Oklahoma State Department of Health.

"Discharge" means release of the newborn from care and custody of a perinatal licensed health facility to the parents or into the community.

"Disorder" means any condition detectable by newborn screening that allows opportunities, not available without screening, for early treatment and management to prevent developmental disability and/or reduce infant morbidity and mortality.

"Echocardiogram" means a test that uses ultrasound to provide an image of the heart.

"Fatty Acid Oxidation Disorders" refers to a group of inherited metabolic conditions in which the body is unable to oxidize (breakdown) fatty acids for energy due to a defective enzyme function. If not treated early in life, this defect may cause developmental disability or death.

"Galactosemia" means an inherited disease caused by the body's failure to break down galactose due to a defective enzyme function, which if not treated early in life, may cause developmental disability or death.

"Hemoglobin" means a protein in the red blood cell that carries oxygen.

"Hemoglobinopathy" means an inherited disorder associated with structural abnormality of hemoglobin, anemia, and variable impaired ability of the red blood cells to carry oxygen.

"Infant" means a child 6 months of age and younger.

"Infant's Physician" means the licensed medical or osteopathic physician listed by the submitter or the individual responsible for the medical care of the infant after discharge from the birthing facility.

"Initial Specimen" means the first blood specimen collected subsequent to birth, pursuant to these procedures.

"Long-term Follow-up" means follow-up services that begin with diagnosis and treatment and continues throughout the lifespan. This includes parent education, networking, referral, and care coordination.

"Medical Home" means a Planned Health Care Provider.

"Medium-chain acyl coenzyme A dehydrogenase deficiency" or **"MCAD"** means a genetic disorder of fatty acid metabolism. This disorder can cause metabolic crisis when an infant/child fasts.

This crisis can lead to seizures, failure to breathe, cardiac arrest, and death. Treatment is effective by preventing fasting.

"Mucopolysaccharidosis Type I" or **"MPS I"** means a condition in which individuals are missing an enzyme to break down large sugar molecules. This disorder can impact many different organs and tissue leading to developmental delays if not identified and treated early.

"Newborn" means an infant thirty (30) days of age and younger.

"Newborn Screening" means the use of various laboratory and clinical tests ~~toscreen~~ to screen infants for certain inherited disorders where a potential net benefit and availability of effective treatments have been demonstrated.

"Newborn Screening Form Kit" or **"Form Kit"** means a filter paper approved by the Department for collection of the newborn screening specimen and associated demographic data.

"Newborn Screening Laboratory" means a laboratory operated by the Department or a laboratory certified by the Department to conduct the tests and carry out the follow-up required by these procedures.

"Newborn Screening Program" or **"The Program"** refers to the Public Health Laboratory and Short-term Follow-up Program at the Department.

"Newborn Screening Program Coordinator" refers to the coordinator of the Short-term Follow-up Program at the Department.

"Organic Acid Disorders" refers to a group of inherited metabolic conditions in which the body is unable to metabolize or process organic acids properly due to a specific enzyme deficiency, which if not treated early in life, may cause developmental disability and death.

"Pediatric Subspecialist" means a physician licensed in Oklahoma, board certified in pediatrics and a pediatric subspecialty.~~.~~

"Phenylketonuria" or "PKU" means an inherited disease caused by the body's failure to convert the amino acid phenylalanine to tyrosine due to defective enzyme function, which if not treated early in life, causes developmental disability.

"Planned Health Care Provider" or **"Medical Home"** means the health care provider who will be providing health care for the infant after discharge from the hospital.

"Pompe" or **"Pompe Disease"** means a condition in which individuals are missing an enzyme to break down complex sugar molecules. This disorder can lead to muscle weakness, poor muscle tone and heart defects if not identified and treated early.

"Premature Newborn" means a newborn weighing less than 2500 grams or any live birth before the thirty-seventh week of gestation.

"Pulse Oximetry Screening" means a test using a device placed on an extremity to measure the percentage of oxygen in the blood.

"Repeat Specimen" means an additional newborn screening specimen to be collected after the initial specimen.

"Satisfactory Specimen" means a blood specimen collected using a single Form Kit that is suitable in both quantity and quality to perform newborn screening for the disorders approved by the Commissioner of Health and listed in 310:550-1-1. Federal CLIA '88 regulations require that the Form Kit includes the patient's name, date of birth, sex, date of collection, test(s) to be performed, and complete name and address of person requesting the test.

"Screened" means a specimen that has been collected and tested on an infant less than 6 months of age.

"Screening" means a test to sort out well persons who may have a disease or defect from those who may not. A screening test is not intended to be diagnostic.

"Severe Combined Immunodeficiency" means a group of potentially fatal inherited disorders related to the immune system, which if not treated, can lead to potentially deadly infections.

"Short-term Follow-up" includes services provided by the Department and the health care provider that begin when the laboratory reports an abnormal , unsatisfactory screen result, or a result is not reported due to specific collection criteria, and ends with a diagnosis of "normal", the infant is lost to

follow-up (repeat testing not achieved), the parent(s) or guardian(s) refuse follow-up, or the affected infant receives appropriate treatment and referral to a pediatric subspecialist.

"Sick Newborn" means a newborn with any condition or episode marked by pronounced deviation from the normal healthy state; illness.

"Sickle Cell Disease" means an inherited disease caused by abnormal hemoglobin(s)(hemoglobinopathy), which may cause anemia and variable impaired ability of the red blood cells to carry oxygen, and if not treated early in life, may result in severe illness, developmental disability or death.

"Specimen" means blood collected on the Newborn Screening Form Kit.

"Spinal Muscular Atrophy" or **"SMA"** means conditions in which the loss of specialized nerves cells leads to progressive weakness and atrophy of muscles, and developmental disability. In severe cases, the muscles used for breathing and swallowing may be affected.

"Submitter" means a hospital, other facility, or physician submitting a blood specimen on a Newborn Screening Form Kit.

"The Program" means the Newborn Screening Program in the Department.

"Transfer" means release of the newborn or infant from care and custody from one licensed health facility to another.

"Unsatisfactory Specimen" means a blood specimen submitted on a Form Kit that is not suitable in quantity or quality to perform screening for the disorders approved by the Commissioner of Health and listed in 310:550-1-1 and/or Federal CLIA '88 regulations are not followed and the Form Kit does not include the required patient's name, date of birth, sex, date of collection, test(s) to be performed, and the provider ordering the newborn screen.

"X-Linked Adrenoleukodystrophy" or **"X-ALD"** means a condition affecting the nervous system and adrenal glands in which the ability of the nerves to relay information to the brain and the adrenal glands to make certain hormones (adrenocortical insufficiency) are impacted. Affected individuals may experience learning and developmental disability, difficulty swallowing, muscle weakness, weight loss, skin changes, vomiting, and coma.

SUBCHAPTER 5. NEWBORN SCREENING BLOOD SPECIMEN COLLECTION

310:550-5-2. Guidelines for newborn screening blood specimen collection and pulse oximetry screening

(a) **Newborn screening blood specimen collection.**

(1) Specimens obtained with a Newborn Screening Form Kit should be collected in accordance with the standard for Blood Collection on Filter Paper for Newborn Screening Programs, NBS01-A6, Sixth Edition, as adopted and published by the Clinical and Laboratory Standards Institute on July 31, 2013, or most recent version. Failure to follow these methods of blood collection may cause inaccurate results, or unsatisfactory specimen results ,that require repeat collection.

(2) Submitters are responsible for submitting a satisfactory newborn screening blood specimen.

(b) **Pulse oximetry screening.**

(1) **Pulse oximetry screening.** Pulse oximetry screening will be performed utilizing the hospital protocol. A recommended protocol is provided by the Program.

(2) **Authorized provider.** An authorized health care provider shall perform the pulse oximetry screening.

(3) **Newborns receiving routine care.**

(A) The duties of the birthing facility or nurse include the following:

(i) Perform pulse oximetry screening on the newborn between twenty-four (24) hours and forty-eight(48) hours of life; or

(ii) Schedule the newborn to be screened at the facility between twenty-four (24) hours and forty- eight (48) hours of life, if unable to perform the pulse oximetry screening; or

(iii) Notify the infant's physician if screening was not performed.

(B) If the newborn is scheduled for discharge from a birthing facility after twelve (12) hours of life but before twenty-four (24) hours of life, the birthing facility shall perform pulse oximetry screening as late as is practical before the newborn is discharged and notify the infant's physician of the early screening.

(C) If the newborn is discharged before twelve (12) hours of life, the birthing facility shall perform the pulse oximetry screening between twenty-four (24) hours and forty-eight (48) hours of life.

(4) **Newborns in special care or intensive care settings.** For newborns who have been in special care or intensive care units, birthing facilities shall perform pulse oximetry screening prior to discharge utilizing the hospital protocol, unless the newborn has an identified congenital heart defect or has had an echocardiogram performed. A recommended protocol is provided by the Program. Continuous pulse oximetry monitoring may not be substituted for CCHD screening.

(5) **Circumstances in which pulse oximetry screening is not indicated.** If pulse oximetry screening is not performed, the reason shall be documented on the Newborn Screening Form ~~Kit.Instances~~ Kit. Instances where pulse oximetry screening is not indicated include but are not limited to:

(A) Clinical evaluation of the newborn has included an echocardiogram which ruled-out CCHD; or

(B) The newborn has confirmed CCHD based on prenatal or postnatal testing.

SUBCHAPTER 7. NEWBORN SCREENING HOSPITAL RECORDS

310:550-7-1. Hospital records

(a) **Newborn screening blood test results.**

(1) The hospital is responsible for implementing a procedure to ensure that a newborn screening blood specimen has been collected on every newborn and transported to the Newborn Screening Laboratory within twenty-four (24) to forty-eight (48) hours of collection. If more than one newborn screen is collected on an infant, each copy of the newborn screen kit should be placed in the infant's medical record. Specimens should be transported in the manner designated by the Department and/or receiving laboratory.

(2) The hospital shall immediately notify the infant's physician, parent(s) or guardian(s), and Newborn Screening Program Coordinator if an infant is discharged without a sample having been collected. ~~Thesenotifications~~ These notifications shall be documented in the infant's hospital record.

(3) If test results are not received by the hospital within fifteen (15) days after the date of collection, the hospital shall contact the Newborn Screening Laboratory to verify that a specimen was received. If a specimen was not received, the hospital shall notify the physician.

(4) Any hospital or any other laboratory that collects,-handles or forwards newborn screening blood specimens shall keep a log containing the name and date of birth of the infant, name of the ordering physician, name of infant's provider, medical record number, serial number of the Newborn Screening Form Kit, date of specimen collection, date specimen was sent to the certified laboratory, date that test results were transmitted or received and the test results.

(b) **Pulse oximetry screening results.**

(1) **Record of results.**

(A) All pulse oximetry screening results shall be recorded in the infant's medical record and the results reported to a parent(s) or guardian(s) prior to discharge from the hospital.

(B) All pulse oximetry screening results shall be recorded on the Newborn Screening Form Kit, along with the infant's name, date of birth, submitting facility, mother's name, and the infant's physician.

(C) If the newborn is not screened for CCHD prior to the Newborn Screening Form Kit being forwarded to the Newborn Screening Laboratory for testing, CCHD screen results shall be communicated to the Newborn Screening Program Coordinator utilizing the Pulse Oximetry Screening Result Form provided by the Program.

(D) The Pulse Oximetry Screening Result Form must be completed in its entirety.

(2) **Abnormal pulse oximetry screen results.**

(A) It is the responsibility of the authorized health care provider who conducted the pulse oximetry screening to communicate abnormal results to the attending physician or attending clinician immediately.

(B) The newborn shall be evaluated immediately by an attending physician in order to complete the recommended protocol.

(C) The newborn may not be discharged from care until:

(i) A cause for the abnormal pulse oximetry screen has been determined;

(ii) An echocardiogram has been performed, read, and determined not to indicate CCHD; and/or

(iii) A plan of care and follow-up has been established with the newborn's parent(s) or guardian(s).

(D) The birthing facility shall report pulse oximetry screening results to the Department as specified in this Chapter.

(E) It is the responsibility of the birthing facility to notify the newborn's parent(s) or guardian(s), the physician or clinician following the newborn in the hospital, and the infant's physician of abnormal pulse oximetry results.

(3) **Newborns not screened for CCHD.**

(A) If a newborn is not screened for CCHD secondary to discharge before 12 hours of life, the birthing facility shall:

(i) Follow-up with the parent(s) or guardian(s) to schedule screening of the newborn at the birthing facility between twenty-four (24) and forty-eight (48) hours of life; or

(ii) Follow-up with the parent(s) or guardian(s) to schedule referral of the newborn to an authorized facility for screening between twenty-four (24) and forty-eight (48) hours of life; and

(iii) Report screening results to the Department utilizing the Pulse Oximetry Screening Result Form provided by the Program, and indicating the reason for not screening which may be "early discharge".

(B) If pulse oximetry screening is not indicated for the newborn, the birthing facility shall report the reason for not screening, which may be "screening not indicated due to," and provide other CCHD findings for the newborn to the Department utilizing the Pulse Oximetry Screening Result Form provided by the Program.

(C) If the newborn is not screened for CCHD because of parent or guardian refusal, the birthing facility shall send the Newborn Screening Program Refusal Form to the Department utilizing the form provided by the Program and indicate the reason for not screening, which may be "parent refusal".

SUBCHAPTER 11. ADVISORY COMMITTEE <u>FOR NEWBORN SCREENING</u>

SUBCHAPTER 13. <u>NEWBORN SCREENING</u> PARENT AND HEALTH CARE PROVIDER EDUCATION

SUBCHAPTER 17. <u>NEWBORN SCREENING</u> FOLLOW-UP FOR PHYSICIANS

310:550-17-1. Follow-up for physicians

(a) If a physician examines ~~a~~ an infant in ~~it's~~ its first three months of life, the physician will verify that the infant has been screened, and document results in the infant's medical record. If the infant has not been screened or if results of screening are not available, the physician shall submit a satisfactory newborn screening blood specimen as soon as possible.

(b) On written notification by the Newborn Screening Program of follow-up requirements for a newborn screen result of abnormal, unsatisfactory, or for specimens collected from a newborn at or less than 24 hours of age; the infant's physician or designee will ensure that required repeat screening, confirmatory testing, or diagnostic studies are performed in the timeframe specified so that therapy, when indicated, can be initiated expediently.

(c) The infant's physician may selectively rescreen the infant as clinically indicated.

(d) Because patients may relocate without a forwarding address or contact information, physicians and birthing facilities have the burden to make a reasonable search and effort to locate and notify the parent(s) or guardian(s). If the parent(s) or guardian(s) are not contacted, then the Newborn Screening Program Coordinator will be notified of the inability to notify after efforts to contact the parent(s) or guardian(s) have been exhausted.

(e) For appropriate comprehensive medical care, all confirmed cases of a disorder on the newborn screening blood testing panel, should have a referral to a pediatric subspecialist, and the parent(s) or guardian(s) should be referred for enrollment in newborn screening long-term follow-up services as designated by the Newborn Screening Program. For referral information, contact the Newborn Screening Short-term Follow-up Program at ~~(405) 271-6617~~ (405) 426-8310 or 1-800-766-2223.

SUBCHAPTER 19. NEWBORN SCREENING REPORTING

SUBCHAPTER 21. NEWBORN SCREENING INFORMATION

310:550-21-1. Information

(a) For information regarding laboratory procedures, results of laboratory tests, or to order Form Kits, contact the Public Health Laboratory Service, Oklahoma State Department of Health, ~~P.O. Box 24106, Oklahoma City, Oklahoma 73124-0106, (405) 271-5070, FAX (405) 271-4850 or visit the website at http://phl.health.ok.gov.~~ 4615 W Lakeview Dr, Stillwater, OK 74075, (405) 564-7750, FAX (405) 900-7611 or visit the website at https://oklahoma.gov/health/locations/public-health-laboratory.html.

(b) For general information or information regarding follow-up for newborn screening or pulse oximetry screening, contact Newborn Screening Short-term Follow-up Program, Oklahoma State Department of Health, 123 Robert S. Kerr Avenue, Oklahoma City, Oklahoma 73102, ~~(405) 426-8220~~(405)-426-8310, ~~option 2~~ or 1-800-766-2223, option 2, FAX (405) 900-7556. General information about the Newborn Screening Program is available on the OSDH Newborn Screening website at ~~http://nsp.health.ok.gov~~https://Oklahoma.gov/health/newbornscreening.

SUBCHAPTER 23. NEWBORN SCREENING STANDARDS, PROCEDURES, AND FOLLOW-UP FOR CERTIFIED LABORATORIES

SUBCHAPTER 24. RESOURCES FOR TRISOMY 13, 18, AND 21

310:550-1-1. Resources for Trisomy 13, 18, and 21 Purpose

The rules in this Subchapter implement Courtney's Law, as codified in 63 O.S. § 1-575.

310:550-1-2. Resources for Trisomy 13, 18, and 21 Definitions

The following words or terms, used in this Chapter, shall have the following meaning unless the context of the sentence requires another meaning:

"Chromosomal disorder" means:

(A) Trisomy 13, otherwise known as Patau syndrome;

(B) Trisomy 18, otherwise known as Edwards syndrome; or

(C) Trisomy 21, otherwise known as Down syndrome.

"Department" means the Oklahoma State Department of Health.

"Genetic counselor" means any person who is licensed pursuant to the provisions of the Genetic Counseling Licensure Act or offers to or engages in genetic counseling. The term does not include those professions exempted by Section 1-566 of the Act.

"Health care facility" means a facility licensed or certified by the State Department of Health, but shall not include a nursing care facility, assisted living facility or home care agency.

"Health care provider" means a person who is licensed, certified or registered by this state to provide health care services or a medical group, independent practice association or professional corporation providing health care services.

310:550-1-3. Resources for Trisomy 13, 18, and 21 Duty to provide information

Any health care facility, health care provider, or genetic counselor, upon receipt of a positive test result from a test for a chromosomal disorder, shall provide the expectant or new parent with information provided by the Department if such information is made available by the Department for the specific disorder.

310:550-1-4. Resources for Trisomy 13, 18, and 21 Availability of information from the Department

To the extent the information is available, the Department shall maintain on its website:

(1) Up-to-date, evidence-based written information about chromosomal disorders that has been reviewed by medical experts and national advocacy organizations for people with intellectual and other developmental disorders. The written information will be compiled from credible sources and will include physical, developmental, educational and psychosocial outcomes, life expectancy, clinical course, and intellectual and functional development and treatment options; and

(2) Contact information for programs and support services including one or more hotlines specific to a chromosomal disorder, resource centers or clearinghouses, national and local organizations, and other education and support programs.