NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

NEVADA

CRITICAL CONGENITAL HEART DISEASE

ANNUAL REPORT

2022

BUREAU OF CHILD, FAMILY AND COMMUNITY WELLNESS

MATERNAL, CHILD AND ADOLESCENT HEALTH

NEVADA DIVISION OF PUBLIC AND BEHAVIORAL HEALTH

DEPARTMENT OF HEALTH AND HUMAN SERVICES

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NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

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INTRODUCTION

The Nevada Critical Congenital Heart Disease (CCHD) Registry is administered by the Maternal, Child and Adolescent Health Section of the Bureau of Child, Family and Community Wellness, Nevada Division of Public and Behavioral Health (DPBH), Nevada Department of Health and Human Services (DHHS) to implement Nevada Revised Statutes (NRS) 442.680.

The purpose of the Nevada CCHD Registry is to ensure all children born in Nevada are screened for CCHD at birth and those identified with CCHD receive timely and appropriate medical intervention. A pilot project began in 2013 after the need for a CCHD Registry was identified. NRS 442.680 was passed in the 77th Legislative Session of the Nevada Legislature (Appendix A). The 2022 CCHD Report represents the seventh full year of data with all eighteen (18) birthing facilities reporting. The Nevada CCHD Registry follows national guidelines and the infant screening procedural flow used in 2022 may be summarized as follows (see also Appendix E):

> A newborn passes pulse oximetry screening if the oxygen saturation is 95% or greater in the right hand and right foot and the difference is 3% or less between the right hand and right foot. The screen is immediately failed if the oxygen saturation is less than 90% in the right hand or right foot. If the oxygen saturation is 90% or greater, but less than 95% in the right hand and right foot, or there is more than a 3% difference between the right hand and right foot, the screen is repeated in one hour and follows the same process as above. Some newborns will require two screens (the initial and one repeat screen separated by one hour if the pulse oximetry reading is not greater than or equal to 95% at both sites or the difference is less than 3%). A baby whose oxygen saturation is <90% in either the right hand or foot (in an initial or repeat screen), or whose oxygen saturation is <95% in either the right hand and right foot (after 2 screens separated by one hour), or who has a >3% oxygen saturation difference between the right hand and right foot (after 2 screens separated by one hour), will be considered to have failed screening.

The Nevada CCHD Registry utilized the standards outlined in the 2011 American Academy of Pediatrics (AAP) guidelines for the duration of the 2022 reporting year which advised 2 retests (3 total) before an infant is considered to have a failed screen. AAP guidelines for CCHD changed in 2025 and Nevada CCHD processes will now follow the updated guidance and protocols which can be found here.

The Nevada CCHD Registry promotes timelines endorsed by the AAP outlined in Appendix B and promoted by the Centers for Disease Control and Prevention (CDC).[1]

1. All hospitals or freestanding birthing centers must screen all newborns after 24 hours of birth and prior to 48 hours of life to determine if the newborn exhibits CCHD (Appendix A).
2. If it is determined the infant exhibits CCHD, the attending physician must report the condition to the DPBH Chief Medical Officer or a representative thereof and discuss the condition with those responsible for the care of the infant.

PROGRAM FUNDING

There is no funding allocation for the CCHD Registry which receives no portion of newborn screening fees or dedicated federal funds, unlike other newborn screens.

PARTNERS AND STAKEHOLDERS

Meeting the goals and purposes of NRS 442.680 requires a coordinated effort by multiple partners within national, state, public, and private sectors. The American Heart Association (AHA) and the Nevada Hospital Association (NHA) were supporters of the original legislation.

All birthing facilities in Nevada provide CCHD screenings through pulse oximetry tests given to infants as close as possible to the recommended 24-48-hour period after birth, prior to discharge, and report this data to the State using a standardized data template. Facilities report whether the newborn received screening, passed or failed screening, how many screenings occurred, and if the newborn was referred to higher levels of care such as to the neonatal intensive care unit (NICU), for an echocardiogram, etc. These data are then entered into a secure registry database. DPBH staff provide technical assistance to all Nevada Birthing Facilities as necessary.

The Nevada CCHD Registry is supported by the Title V Maternal and Child Health (MCH) Children and Youth with Special Health Care Needs (CYSHCN) Program Coordinator who works collaboratively with a variety of programs and partner agencies to ensure compliance to the statute. These programs include, but are not limited to:

- Nevada State Birthing Facilities
- Nevada Chapters of AHA
- NHA
- University of Nevada, Reno (UNR), Newborn Screening (NBS) Program and Advisory Board
- Nevada Office of Vital Records
- Nevada DHHS Office of Analytics
- Nevada Early Hearing Detection and Intervention (EHDI) Program
- Nevada Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program
- Title V MCH Maternal and Infant Health Program (MIP)

STATISTICAL OVERVIEW

Congenital heart defects (CHDs) result when the heart, or blood vessels near the heart, don't develop normally before birth.[2] About 40,000 births per year in the United States are affected by CHDs, accounting for 4.2% of all infant deaths.[1,3] About one in four babies born with a heart defect has a critical congenital heart defect (CCHD).[4]

CCHD represents a group of heart defects, abnormal or absent chambers, holes in the heart, abnormal connections in the heart, and abnormalities in the function of the heart. Some babies affected by CCHD may look and act healthy at first, but within hours or days after birth they can have serious complications. CCHD is a life-threatening condition requiring intervention within the first year of life.[4]

In 2022, the Nevada CCHD Registry included a total of 28,391 screens and 62 failed screens (Chart 1). Of the 62 reported failed screens (Table 1):

- 10 were failed first screens that did not undergo a second screen
- 10 were failed first screens that passed a second screen
- 21 were failed first and second screens
- 10 were 3 consecutive failed screens
- 3 were a passing first screen and failed second screen, and
- 8 were failed screens with no additional information.

It should be noted the number of screens does not equate to the number of children screened, as some infants were screened and counted more than once. Also, some infants with a positive screen had a second screen due to reasons such as ordering a repeat screen by mistake.

There are several reasons why some infants were not screened (Table 2). In 2022, 212 infants died before they could be screened, 185 infants were transferred from a facility without receiving a test, 10 parents objected to a CCHD screening for their child, and 68 infants had no information on why they were not screened. Furthermore, facilities may also select echocardiograms and NICU transfers as reasons for infants not being screened. In 2022, reporting facilities administered 1,765 echocardiograms and arranged 3,473 NICU transfers, which may have occurred multiple times for any number of infants (Table 2).

The CCHD Registry collects screening information but does not necessarily capture confirmed cases of CCHD. Confirmed cases are determined by examining electronic birth and hospital inpatient billing data. For the 2022 reporting period, a total of 32,768 infants were born in Nevada. Of the infants born in 2022, 28,391 (86.64%) are documented as having received a pulse oximetry screening, and 4,377 were either not screened, or their screening status is unknown. Within the 2022 reporting period, 39 infants were diagnosed with a CCHD (Chart 1).

Of the 39 confirmed CCHD cases, 69.23% were term births, and 53.85% were in the normal birth weight range (>=2,500g, <=8,000g). Demographically, in 2022, White infants comprised most diagnoses (38.46%), followed by Hispanic infants (23.08%), Black infants (12.82%), Asian infants (10.26%), and infants who belong to some other race (2.56%). The race/ethnicity is unknown for 12.82% of the screened population. Newborns which would be categorized as Native Hawaiian, Pacific Islander, American Indian, or Alaskan Native were not included in the 2022 data.

For reference, 4.4% of Nevada's estimated 2022 population are children under 5 years of age. Of the population of individuals in Nevada aged 0 to 4 years, 28% are estimated to be White, 43% Hispanic, 12% Black, 7% Asian, 1% American Indian, 1% Native Hawaiian and other Pacific Islander and 8% belong to 2 or more race groups.[5]

CHALLENGES

Despite the benefits of prenatal detection, nationally only 50% to 70% of patients with CCHD are diagnosed before birth and there exists significant variability across regions.[6] Diagnosing infants with CCHD before they leave the hospital is a challenging problem which has been reduced, yet not eliminated, through the utilization of advancements in technology. One study demonstrated that from 2004 to 2018, despite advancements in

prenatal screening and increases in prenatal diagnosis rates, there was no reduction in delayed diagnosis amongst infants diagnosed postnatally.[7]

Because fetal blood circulation bypasses the lungs, fetuses with cyanotic heart defects can survive in utero but need prompt intervention to survive after birth, and early perturbations in blood flow can independently lead to critical heart defects.[8] Prior to discharge, some infants with CCHD will have normal exams and not appear cyanotic. Often the ductus arteriosus does not close until after the infant goes home. Before closing, the ductus arteriosus may provide a significant amount of blood flow to the lungs or body. As a result, babies with CCHD can quickly decompensate when the ductus arteriosus closes.

Pulse oximetry can accurately detect the lower oxygen saturations associated with CCHD with ductal-dependent systemic or pulmonary blood flow. Current guidance from the AAP for pulse oximetry screenings suggest a failed screening be followed up by only one, as opposed to two additional screenings.[9]

If left undetected, heart defects in infants may result in death; however, CCHD is often treatable if detected early. Problems can range from mild to severe, requiring little intervention to multiple stages of open-heart surgeries.

Although Nevada has made significant progress since the inception of the CCHD Registry, several challenges remain with data collection. Although all facilities are reporting total number of births, screenings, and discrepancies, homebirth providers are not reporting CCHD screening data. An additional challenge is the lack of details reported on follow-up care needed for infants who failed one or more screenings or those receiving higher levels of care (i.e., echocardiogram and NICU admissions).

IMPROVEMENT STRATEGIES

Nevada CCHD Registry continues to address these challenges by sustaining strong collaborative relationships with each of Nevada's birthing facilities. These relationships are strengthened through regular communication, including sharing reporting guidance, disseminating updated information, and a Nevada-specific factsheet.

To ensure the CCHD protocol and associated timeframes are followed with fidelity, the following strategies have been incorporated:

- Facilitate timely and accurate data reporting to Nevada CCHD by hospitals.
- Facilitate appropriate training to all current and incoming providers (hospital screeners).
- Identify and disseminate the latest best practice guidelines to providers.
- Facilitate open communication among all partners.
- Work to improve the functionality of the Nevada CCHD Registry.
- Standardize reporting via improvements to the CCHD data collection process.

In 2022, increasing the efficacy of reporting methods and training new employees within partnering hospitals were the primary areas of focus for the Nevada CCHD Registry. These goals will continue, and any new updates or information relevant to the collection of CCHD data will be relayed to all birthing facilities in Nevada.

Decreasing annual CCHD-related mortality rates remains a key goal of the Nevada CCHD Registry. Evaluation and quality improvement of current processes will continue to increase the overall percentage of all births screened and help to develop new pathways and funding sources to better address referral, follow-up, loss to follow-up and loss-to-diagnosis.

RECOMMENDATIONS

The following recommendations to improve the Nevada CCHD Registry include:

- Issue the updated 2025 Oster guidance[9] to all reporting facilities with new guidelines on screening protocol and the determination of a passing/failing screen.
- Begin collecting a recommended minimum uniform dataset to aid in surveillance and monitoring of newborn CCHD screenings.
- Educate stakeholders on the limitations of pule oximetry screenings the significance of non-CCHD screenings, and the importance of protocol adherence.
- Disseminate the final 2022 CCHD Report to partners statewide, including AHA, NHA, University of Nevada, Reno Newborn Screening Program, Heart Disease and Stroke Program of the Chronic Disease Prevention and Health Promotion Section, Nevada Early Hearing Detection and Intervention Program, Nevada Early Intervention Services, Nevada Interagency Coordinating Council, Family Navigation Network, and health care providers.
- Establish data linkages between CCHD Registry and in-patient hospitalization data to address CCHD diagnosis in infants moved to higher levels of care before pulse oximetry screen can be performed.
- Develop standardized processes to identify all infants diagnosed after hospital discharge or home birth.
- Finalize and implement an updated digital CCHD data management system and provide appropriate training for key staff at participating hospitals on the new data uploading process.

Chart 1 – Flow Diagram of the Infant Screening Distribution and Results, 2022 Nevada Critical Congenital Heart Disease (CCHD) Registry

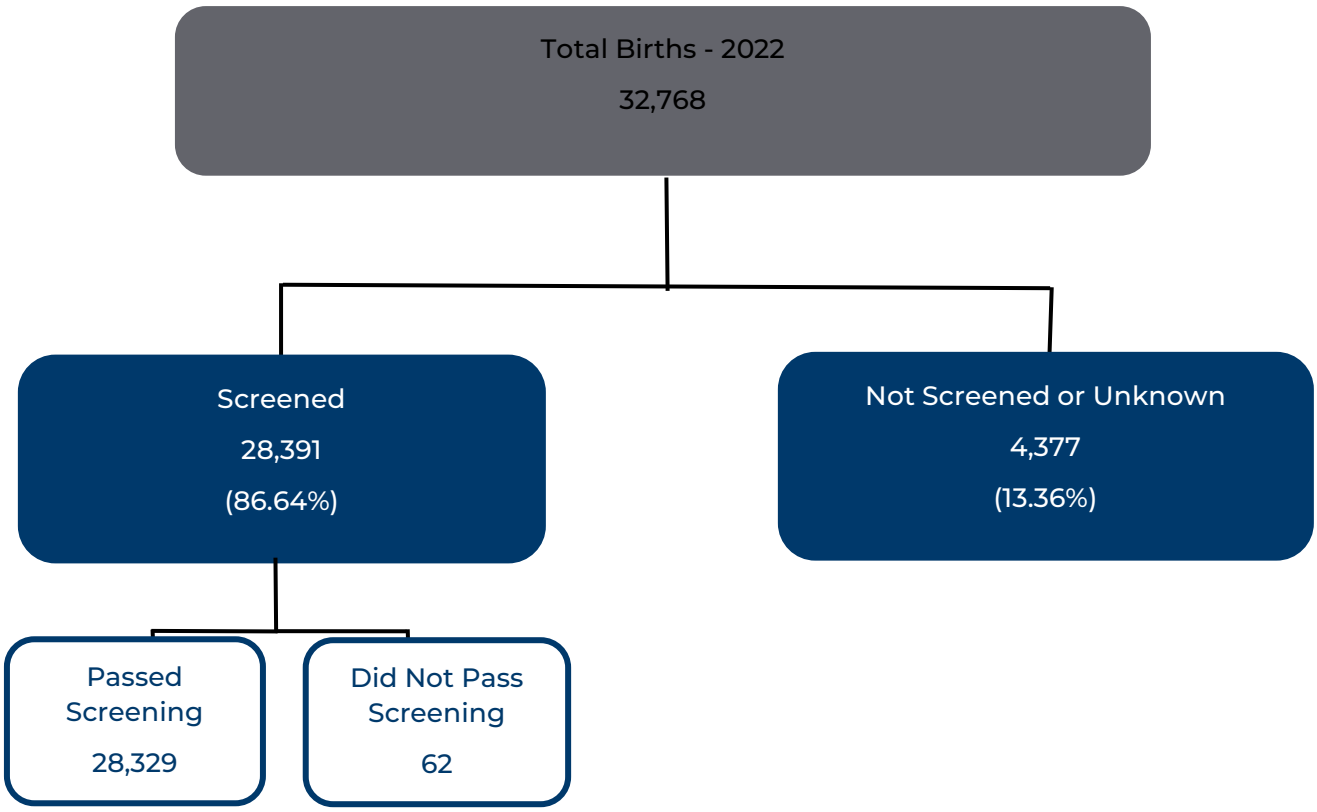


Table 1 – Distribution of Failed CCHD Screenings, Nevada

Details of Failed Screenings*	Count
Total Failed Screens	62
Failed First Screen	10
Failed First Screen, Passed Second Screen	10
Failed First and Second Screenings	21
Failed Three Screenings	10
Passed First Screen, Failed Second Screen†	3
Unknown	8

* Infants may have been screened more than once, and included in multiple screening counts.
† For various reasons, such as ordering repeat screenings by mistake, some infants initially had a positive screening and subsequently received a failed screening result

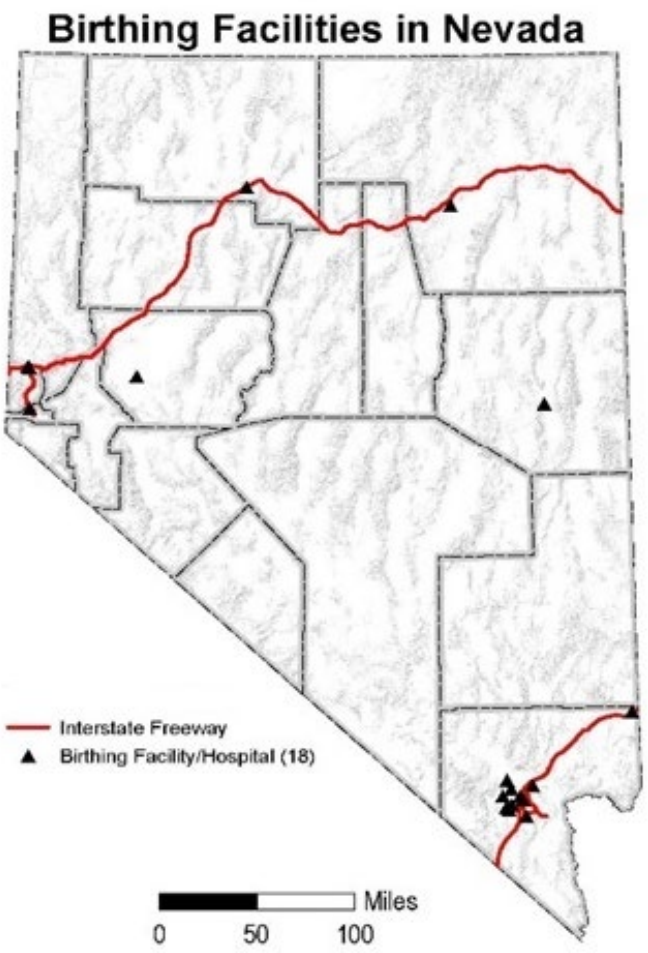
Table 2 – Distribution of Potential Reasons Why An Infant May Have Not Been Screened

Potential Reason	Count
Admitted to the NICU *	3,473
Received an echocardiogram *	1,765
Infant Died	212
Transfers	185
Parental Objection	10
Missing Screenings / Unknown	68

* Some infants may have been counted multiple times

Map 1 – Birthing Hospitals in Nevada

The location and distribution of all birthing facilities in Nevada are detailed in the map below.



Nevada Birthing Facilities:

- Banner Churchill Community Hospital
- Carson Tahoe Regional Medical Center
- Centennial Hills Hospital
- Henderson Hospital
- Humboldt General Hospital
- Mountain View Hospital
- Northeastern Nevada Regional Hospital
- Renown Health
- Saint Mary's Regional Medical Center (closed in 2022)
- St. Rose Dominican Hospital - San Martin
- St. Rose Dominican Hospital – Siena
- Serenity Birth Center (opened in 2020)
- Southern Hills Hospital & Medical Center
- Spring Valley Hospital
- Summerlin Hospital
- Sunrise Hospital and Medical Center
- University Medical Center
- William Bee Ririe Hospital
- Mike O'Callaghan Federal Hospital

APPENDIX A

Nevada State Policy Recommendations

The State of Nevada worked with the American Heart Association (AHA), Nevada Hospital Association (NHA), and other partners to implement Nevada Revised Statutes (NRS) 442.680, to require critical congenital heart disease (CCHD) screening reporting.

As a requirement of NRS 442.680, the Nevada CCHD program collects data from all birthing facilities on all infants born in the State.

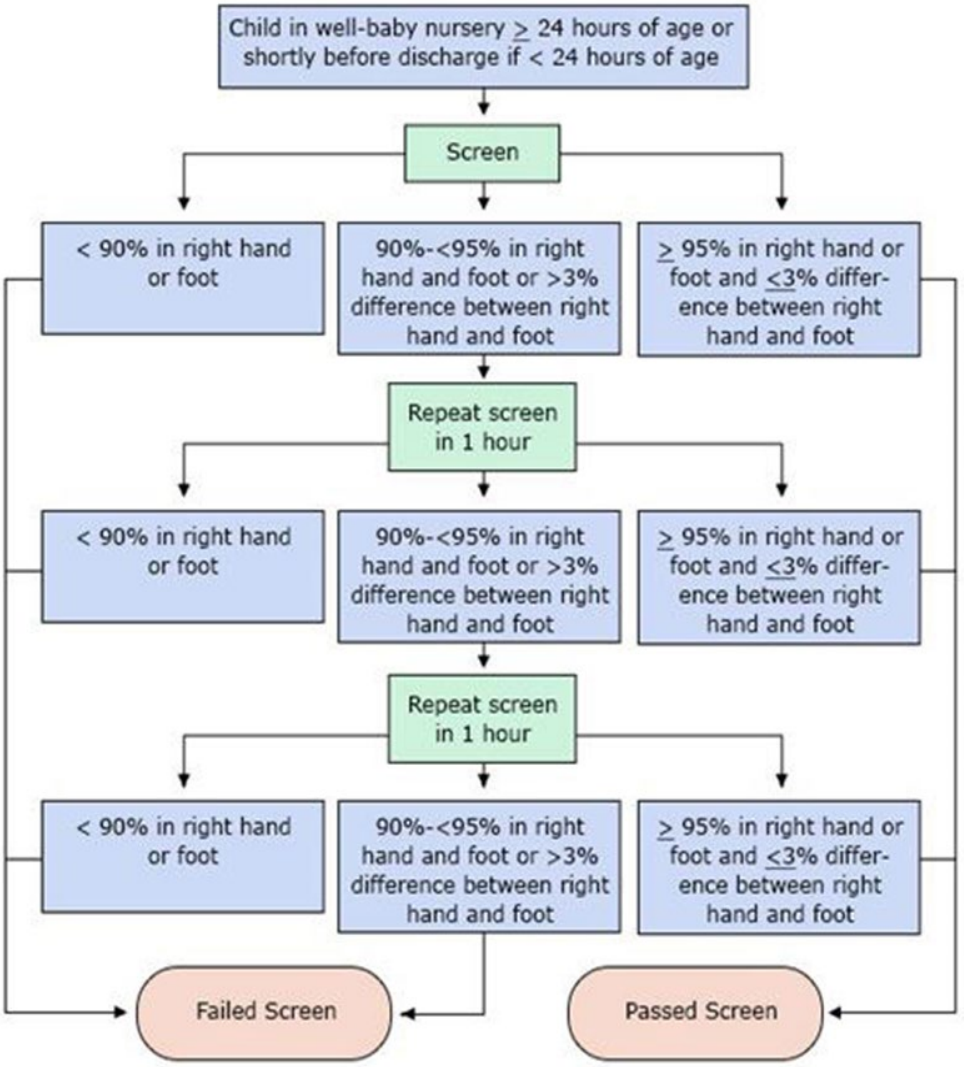
All hospitals or freestanding birthing center must screen all newborns after 24 hours of birth and prior to 48 hours of life to determine if the newborn suffers from CCHD. All birthing facilities report the total number of infants born each month at their facility and the total number of pulse oximetry screenings performed. If there is a discrepancy in these numbers, hospitals are asked to explain the reason. Explanations provided by hospital staff include fetal demise, parent or family refusal, infants born at the end of the month prior to the 24-48-hour recommendation were to be included in the next month's report, transfer to a higher level of care such as another facility or a neonatal intensive care unit (NICU), echocardiogram ordered (higher level of care) or missed screenings.

APPENDIX B

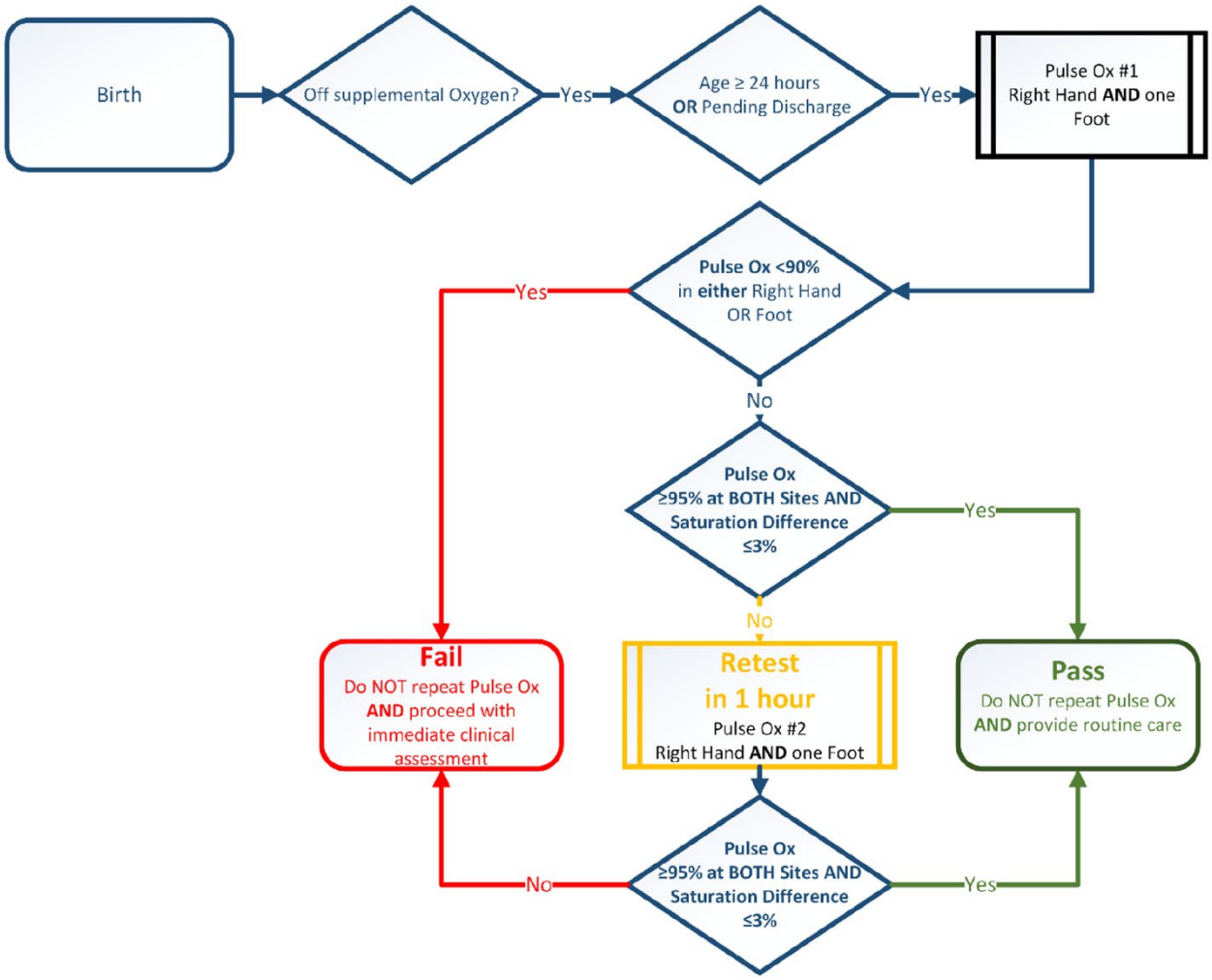
Centers for Disease Control and Prevention Screening Guidelines

2020 and 2025 Algorithms

*Oster, et al. 2020 Algorithm**



*Oster, et al. 2025 algorithm**



Source: [Critical Congenital Heart Defects Screening Methods | CDC]

*For 2022 CCHD Data, Oster et al. 2020 algorithm was utilized

APPENDIX C

Nevada Revised Statutes (NRS)

EXAMINATION OF INFANTS FOR CRITICAL CONGENITAL HEART DISEASE

NRS 442.680 Examination required; confirmation of results; exception to requirement; regulations.

1. Except as otherwise provided in subsection 3, any physician, midwife or nurse attending or assisting in any way any infant at childbirth at a freestanding birthing center or a hospital which regularly offers obstetric services in the normal course of business and not only on an emergency basis shall make or cause to be made an examination of the infant, to determine whether the infant may suffer from critical congenital heart disease, including, without limitation, conducting pulse oximetry screening. If the physician, midwife or nurse who conducts the examination is not the attending physician of the infant, the physician, midwife or nurse shall submit the results of the examination to the attending physician of the infant.

2. If the examination reveals that an infant may suffer from critical congenital heart disease, the attending physician of the infant shall conduct an examination to confirm whether the infant does suffer from critical congenital heart disease. If the attending physician determines that the infant suffers from critical congenital heart disease, the attending physician must:

(a) Report the condition to the Chief Medical Officer or a representative of the Chief Medical Officer; and

(b) Discuss the condition with the parent, parents or other persons responsible for the care of the infant and inform them of the treatment necessary for the amelioration of the condition.

3. An examination of an infant is not required pursuant to this section if either parent files a written objection with the person responsible for conducting the examination or with the freestanding birthing center or hospital at which the infant is born.

4. The State Board of Health may adopt such regulations as necessary to carry out the provisions of this section.

(Added to NRS by 2013, 2115)

APPENDIX D

PULSE OXIMETRY SCREENING FOR CRITICAL CONGENITAL HEART DISEASE

2022 NEVADA FACT SHEET

OVERVIEW

Congenital heart defects are malformations of the heart or major blood vessels occurring before birth[1]. These malformations may be identified with proper screenings. Congenital heart defects occur in 8 out of 1,000 live births,[2,3] and are the most common cause of infant death, accounting for 27% of infant deaths caused by birth defects.[4] A quarter of infants who have congenital heart defects will be diagnosed with critical congenital heart disease (CCHD). CCHD is a life-threatening condition requiring surgery or catheter intervention within the first year of life.[5]

Fortunately, an emerging body of evidence suggests measuring blood oxygen saturation can increase the chances for early diagnosis and detection of CCHD.[8] Once detected, many heart defects can be surgically repaired. It is estimated 85% of newborns undergoing surgery for CCHD will reach adulthood.[9]

PULSE OXIMETRY SCREENING

Pulse oximetry screening is a lifesaving, low-cost (at just under $4 per infant), non-invasive, and painless bedside diagnostic test which can be completed by a technician in as little as 45 seconds.[5,7] The American Heart Association (AHA), the American Academy of Pediatrics (AAP), and the American College of Cardiology Foundation (ACCF) recently made recommendations for standardized pulse oximetry screening and diagnostic follow-up. The recommended screening is performed on asymptomatic newborns after 24 hours of birth and before 48 hours of life, in order to avoid false-positive results.[6]

Studies show pulse oximetry screenings have less than one percent chance of giving a false positive result when used for CCHD screenings. Although prenatal ultrasounds and postnatal physical exams successfully detect many heart defects, and detection rates have improved since their advent, they are not sufficient to diagnose all cases of CCHD. Prenatal ultrasounds detect less than 50% of CCHD,[5] and screening rates vary based on differing levels of access to prenatal ultrasound equipment and degree of practitioner training.

Pulse oximetry testing is conducted to estimate the percentage of hemoglobin in the blood saturated with oxygen. When pulse oximetry screening identifies newborns with low blood oxygen levels, echocardiography can be used for definitive diagnosis of heart defects. Research suggests when all infants are screened using pulse oximetry in conjunction with routine newborn screening practices, CCHD can be detected in over 90% of affected newborns.[8]

AMERICAN HEART ASSOCIATION (AHA) POLICY ADVOCACY

The AHA is committed to advancing public policies allowing children and adults with heart defects to live longer and fuller lives. These policies include:

- State adoption of mandatory CCHD screening using pulse oximetry for all newborns;

- Collection of screening data to be used for surveillance, evaluation and continuous quality improvement of CCHD screening;[6]

- Development, dissemination, and validation of screening standards for CCHD;

- Continued development of Food and Drug Administration's (FDA) guidance document regarding the safety and effectiveness of pulse oximeters.[9]

NEVADA STATE POLICY

To address CCHD screenings, the State of Nevada worked with AHA and other partners to implement Nevada Revised Statutes (NRS) 442.680.[10]

Since July 1, 2015, all hospitals or freestanding birthing center must screen all newborns, after 24 hours of birth and prior to 48 hours of life, to determine if the newborn suffers from CCHD. If it is determined the infant suffers from CCHD, the attending physician must also report the condition to the Division of Public and Behavioral Health (DPBH) Chief Medical Officer, or a representative thereof, and discuss the condition with those responsible for the care of the infant.

NRS 442.680 Examination required; confirmation of results; exception to requirement; regulations.

1. Except as otherwise provided in subsection 3, any physician, midwife or nurse attending or assisting in any way any infant at childbirth at a freestanding birthing center or a hospital which regularly offers obstetric services in the normal course of business and not only on an emergency basis shall make or cause to be made an examination of the infant, to determine whether the infant may suffer from critical congenital heart disease, including, without limitation, conducting pulse oximetry screening. If the physician, midwife or nurse who conducts the examination is not the attending physician of the infant, the physician, midwife or nurse shall submit the results of the examination to the attending physician of the infant.

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3. An examination of an infant is not required pursuant to this section if either parent files a written objection with the person responsible for conducting the examination or with the freestanding birthing center or hospital at which the infant is born.

4. The State Board of Health may adopt such regulations as necessary to carry out the provisions of this section.

(Added to NRS by 2013, 2115)

SCREENING DATA COLLECTION

The Maternal, Child, and Adolescent Health Program of DPBH receives the CCHD screening reports required by NRS 442.680. All birthing hospitals in Nevada currently report but report on different dates. Once a full year of data from all Nevada birthing hospitals has been collected, the DPBH will generate a report on CCHD screening data and interpret the results. Prior to the first full year of data collection from all birthing hospitals, improvements to the reporting form have been identified and made. DPBH completed the process of passing regulations in September 2016.

Question about the CCHD registry may be directed to Vickie Ives, 775-684-2201, vives@health.nv.gov.

DATA COLLECTED FROM SCREENINGS

Working in partnership with Nevada birthing hospitals, Nevada Hospital Association (NHA), and AHA, the DPBH has been able to provide technical assistance and ensure all Nevada birthing hospitals are reporting.

The data points collected with CCHD reporting include monthly counts for number of screens, number of births, number of failed screens, and percent of failed screens. The reporting form also includes discrepancy explanation for differences in number of screens and births for the month reported, patient information for failed screenings, and whether the failed screening was found via prenatal detection.

A newborn passes pulse oximetry screening if the oxygen saturation is 95% or greater in the right hand and right foot and the difference is 3% or less between the right hand and right foot. The screen is immediately failed if the oxygen saturation is less than 90% in the right hand or right foot. If the oxygen saturation is 90% or greater, but less than 95% in the right hand and right foot, or there is more than a 3% difference between the right hand and right foot, the screen is repeated in one hour and follows the same process as above. Some newborns will require two screens (the initial and one repeat screen separated by one hour if the pulse oximetry reading is not greater than or equal to 95% at both sites or the difference is less than 3%). A baby whose oxygen saturation is <90% in either the right hand or foot (in an initial or repeat screen), or whose oxygen saturation is <95% in either the right hand and

right foot (after 2 screens separated by one hour), or who has a >3% oxygen saturation difference between the right hand and right foot (after 2 screens separated by one hour), will be considered to have failed screening.

After a failed screening is recorded, the hospital must take measures to follow-up with further testing. The follow-up actions must be documented on the CCHD screening report form with failed patient information.

The Nevada CCHD Registry utilized the standards outlined in the 2011 American Academy of Pediatrics (AAP) guidelines for the duration of the 2022 reporting year which advised 2 retests (3 total) before an infant is considered to have a failed screen. AAP guidelines for CCHD changed in 2025 and Nevada CCHD processes will now follow the updated guidance and protocols which can be found here.

N.B., the fact sheet is being revised to reflect the Oster, *et al.,* 2025, changes.

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