



Nevada Critical Congenital Heart Disease Annual Report 2017

BUREAU OF CHILD, FAMILY AND COMMUNITY WELLNESS

NEVADA DIVISION OF PUBLIC AND BEHAVIORAL HEALTH
DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Introduction

The Nevada Critical Congenital Heart Disease (CCHD) Registry is located within the Bureau of Child, Family and Community Wellness; Nevada Division of Public and Behavioral Health (DPBH) in the Nevada Department of Health and Human Services (DHHS).

The purpose of the Nevada CCHD Registry is to ensure all children born in Nevada are screened for critical congenital heart disease (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. Nevada Revised Statutes (NRS) 442.680 was passed in the 77th Legislative Session of the Nevada Legislature

(<https://www.leg.state.nv.us/Division/Legal/LawLibrary/NRS/NRS-442.html#NRS442Sec680>)

(Appendices B, C, D). The 2017 CCHD report represents the first full year of data with all nineteen birthing facilities reporting. The Nevada CCHD Registry follows national guidelines (http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/Congenital-Heart-Defects_UCM_001090_SubHomePage.jsp) and the infant screening procedural flow may be summarized as follows (see also appendices E and F):

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 three percentage points 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 and right foot. If the oxygen saturation is greater than 90% and less than 95% in the right hand and right foot, or there is more than a three percent 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 three screens (the initial and two repeat screens, all separated by one hour). A baby whose oxygen saturation is from 90% to less than 95% in either the right hand or right foot, or who has more than a three percent difference between the right hand and right foot after the third screen, will be considered to have failed screening.

Nevada CCHD Registry promotes American Heart Association (AHA) goals (Appendix A) and timelines developed by the Centers for Disease Control and Prevention (CDC)

(<https://www.cdc.gov/ncbddd/heartdefects/hcp.html#Kemper>):

1. All hospitals or obstetric 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 B).
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.

Funding

There is no funding allocation in the CCHD Nevada Revised Statute (NRS) 442.680 and the CCHD Registry receives no portion of newborn screening fees or dedicated federal funds, unlike other infant screens.

Partners and Stakeholders

Meeting the goals and purposes of NRS 442.680 requires a coordinated effort of multiple partners within national, state, public, and private sectors. The AHA and the Nevada Hospital Association were supporters of the original legislation and continue to be key partners.

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 time period, prior to discharge, and report this data to the state.

Nevada CCHD Registry is supported by the Children and Youth with Special Health Care Needs (CYSHCN) Program Coordinator who works collaboratively with a variety of DPBH and DHHS programs and partner agencies. These programs include, but are not limited to:

- Nevada Early Hearing Detection and Intervention (EHDI) Program
- Nevada Home Visiting Program
- Nevada Individuals with Disabilities Education Act (IDEA) Part C Office
- Nevada Early Intervention Services (NEIS)
- Interagency Coordinating Council (ICC)
- Nevada Office of Vital Records
- Nevada Office of Analytics
- University of Nevada, Reno (UNR) Newborn Screening (NBS) Program

Statistical Overview

Congenital heart defects (CHD) are malformations of the heart or major blood vessels occurring before birth.¹ These malformations may be identified provided the proper screenings take place. 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 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.⁵

¹ American Heart Association. Common Types of Heart Defects. 2012. Available at: http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/CommonTypesofHeartDefects_UCM_307017_Article.jsp. Accessed June 12, 2012.

² Reller MD, Strickland MJ, Riehle-Colarusso T, Mahle WT, Correa A Prevalence of congenital heart defects in metropolitan Atlanta, 1998–2005. *J Pediatric*. 2008; 153:807– 813.

³ Go AS, et al. Heart Disease and Stroke Statistics - 2014 update: a report from the American Heart Association. *Circulation*. Published online December 18, 2013.

⁴ Mahle WT, Newburger JW, Matherne GP, et al. Role of Pulse Oximetry in Examining Newborns for Congenital Heart Disease: A Scientific Statement From the American Heart Association and American Academy of Pediatrics. *Circulation*. 2009;120(5):447–458.

⁵ Chang R-KR, Gurvitz M, Rodriguez S. Missed Diagnosis of Critical Congenital Heart Disease. *Arch Pediatric Adolescent Medicine*. 2008;162(10):969–974.

In 2017, Nevada observed a prevalence rate of 9.7 infants per 10,000 live births documenting the need for follow-up care related to pulse oximetry results. On average, more than 91% of all infants born in Nevada hospitals receive required pulse oximetry screening prior to discharge.

In 2017, the Nevada CCHD database included a total of 35,142 births. A total of 32,173 (91.55%) were documented as receiving a pulse oximetry screening. Of those infants without documentation of a screen, 87 passed away, 1,181 were sent to a Neonatal Intensive Care Unit (NICU), 123 infants were transferred to a higher level of care outside the hospital at which they were born, 562 infants received echocardiograms, 458 were classified as unknown, 488 were believed to be home births, 64 were confirmed missed screens, and parents or family members declined services for six (6) infants. The confirmed missed screens were all documented as receiving either doctor or family notification from the birthing facility.

A total of 50 failed pulse oximetry screenings were reported in 2017. Fourteen of these infants failed the first screening but passed the second screening. Two of the failed screenings, failed both the first and second screenings but passed the third screening. These 16 infants did not require follow up care. Another 14 infants failed their first screening and were immediately recommended for follow up care. There were 10 screenings which failed both the first and second screenings. After failing the second screening, follow up care was initiated by hospital staff. The diagnosed condition is not collected in the CCHD Registry and is unknown for these 24 infants but follow-up and a higher level of care was sought to ensure these infants received appropriate medical interventions. There were nine (9) infants who failed all three screenings and follow up interventions were noted for all. There was one screening which did not contain pulse oximetry results, but hospital staff submitted a failed screening report and documented a known heart defect.

The 562 infants who received echocardiograms did not receive a pulse oximetry screening; however, they are noted as echocardiograms in hospital reporting and are not captured in the registry otherwise due to the diagnostic cardiac ultrasound they received. The 1,181 infants admitted to neonatal intensive care unit (NICU) do not receive screenings due to the higher level of care they receive being monitored in NICU. There were 123 infants transferred from the birthing facility to a higher level of care hospital. The health conditions of these infants are unknown; just as with the echocardiograms and NICU pools, it is possible some infants may have been diagnosed with CCHD, but this was not captured in the CCHD registry screening data as higher level care was initiated resulting in a data gap.

The CCHD registry collects screening information and does not necessarily capture confirmed cases of CCHD. Based on preliminary birth data, the DHHS Office of Analytics reported 43 diagnosed cases of CCHD in 2017. Of the 43 CCHD cases, 81% were term births, and 77% were in the normal birth weight range. Further investigation of the final birth data results is required to determine the presence of disparities. Demographic data indicates higher percentages of CCHD among Asian infants (14% of diagnoses as opposed to 4% of all births, according to 2016 final data) and African American infants (23% of diagnoses as opposed to an expected 14% of all births, according to 2016 final data) than would be expected based on population distributions among all births.

Challenges

Many challenges related to CCHD are seen nationwide. Of all newborns who present for an autopsy without an explanation for their cause of death, nearly 40% will be found to have had CCHD which was not diagnosed while they were alive.⁶ Diagnosing children with congenital heart disease (CHD) before they leave the hospital is a challenging problem which has been reduced but not eliminated by technology. One study demonstrated for every 700,000 live births, there will be 4,500 infants with CHD, 25% of these children will leave the hospital without a diagnosis, and roughly 30 infants will die from CHD before any cardiac diagnosis is made.⁷

Prenatal ultrasounds can detect fewer than half the cases of CCHD and predicting saturations based on visual examination of color may be unreliable.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 (<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Newborn-Screening-for-CCHD.aspx>).

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.

Nevada has experienced challenges with CCHD Registry data collection. Hospitals all began reporting on CCHD screening data at different times after legislation was enacted. Most facilities were reporting in January 2016, but some hospitals were only reporting when they had a failed screening and did not include monthly reports of their total number of births and screenings. All facilities were reporting their total number of births and screenings by May 2016; however, discrepancies in numbers were not included by all hospitals, as requested, until October 2016. A full year of data was only available from January 2017 through January 2018. Currently, home birth providers are not reporting CCHD screening data.

One additional challenge of CCHD data collection is the lack of details reported on follow-up care needed for infants who failed one or more screening, or those receiving higher level of care (echocardiogram and NICU admits).

⁶ Weber, MA, Ashworth, MT, Risdon, RA, et.al., "Sudden unexpected neonatal death in the first week of life: autopsy findings from a specialist centre." J Maternal Fetal Neonatal Medicine. 2009 May; 22(5):398-404.

⁷ Wren, C., Reinhardt Z, Khawaja, K, "Twenty-year trends in diagnosis of life-threatening neonatal cardiovascular malformations." Arch Dis Child Fetal Neonatal Ed., 2008 Jan 93(1):F33-5.

⁸ American Academy of Pediatrics. Program to Enhance the Health & Development of Infants and Children (PEHDIC). 2018. Available at: <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Newborn-Screening-for-CCHD.aspx>. Accessed May 16, 2018.

Improvement Strategies

Nevada CCHD is meeting these challenges by forming strong collaborative relationships with each of the birthing facilities. This collaboration is strengthened through regular communication, including sharing reporting guidance 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 reporting of data to Nevada CCHD by hospitals;
- Facilitate appropriate training to all providers (hospital screeners);
- Educate and encourage all professionals to incorporate the latest best practice guidelines in their practices;
- Facilitate open communication among all partners;
- Work to improve the functionality of the Nevada CCHD Registry data system;
- Standardize reporting via improvements to the form and CCHD data collection process;
- Include AHA recommendations including survey, evaluation and quality improvement.

In the first year of the Nevada CCHD Registry, surveillance has been a focus. Evaluation and quality improvement will be foci moving into year two. The need to decrease the number of not screened infants classified as unknown or missed will be a focus of quality improvement efforts, as will development of English and Spanish parent brochures to help decrease refusals and identify CCHD diagnosis in infants going to a higher level of care without screenings.

The Title V MCH team convenes monthly to discuss CCHD Registry reporting protocol and is exploring follow-up care, and referrals to services provided for infants with failed screenings currently in place with the Newborn Screening Program and Nevada Early Intervention Services (NEIS).

The feasibility of a website archived Project ECHO (<http://med.unr.edu/echo>) training for hospital staff will be explored as a route to address hospital staff training and transition planning with hospital staff turnover.

Decreasing CCHD and infant mortality remain key goals of the Nevada CCHD Registry efforts. Evaluation and quality improvement will be needed to increase the percent of all births screened and develop pathways and funding sources to better address referral, follow-up, loss to follow-up and loss to diagnosis as the CCHD Registry matures beyond first year goals of statewide universal screening and reporting.

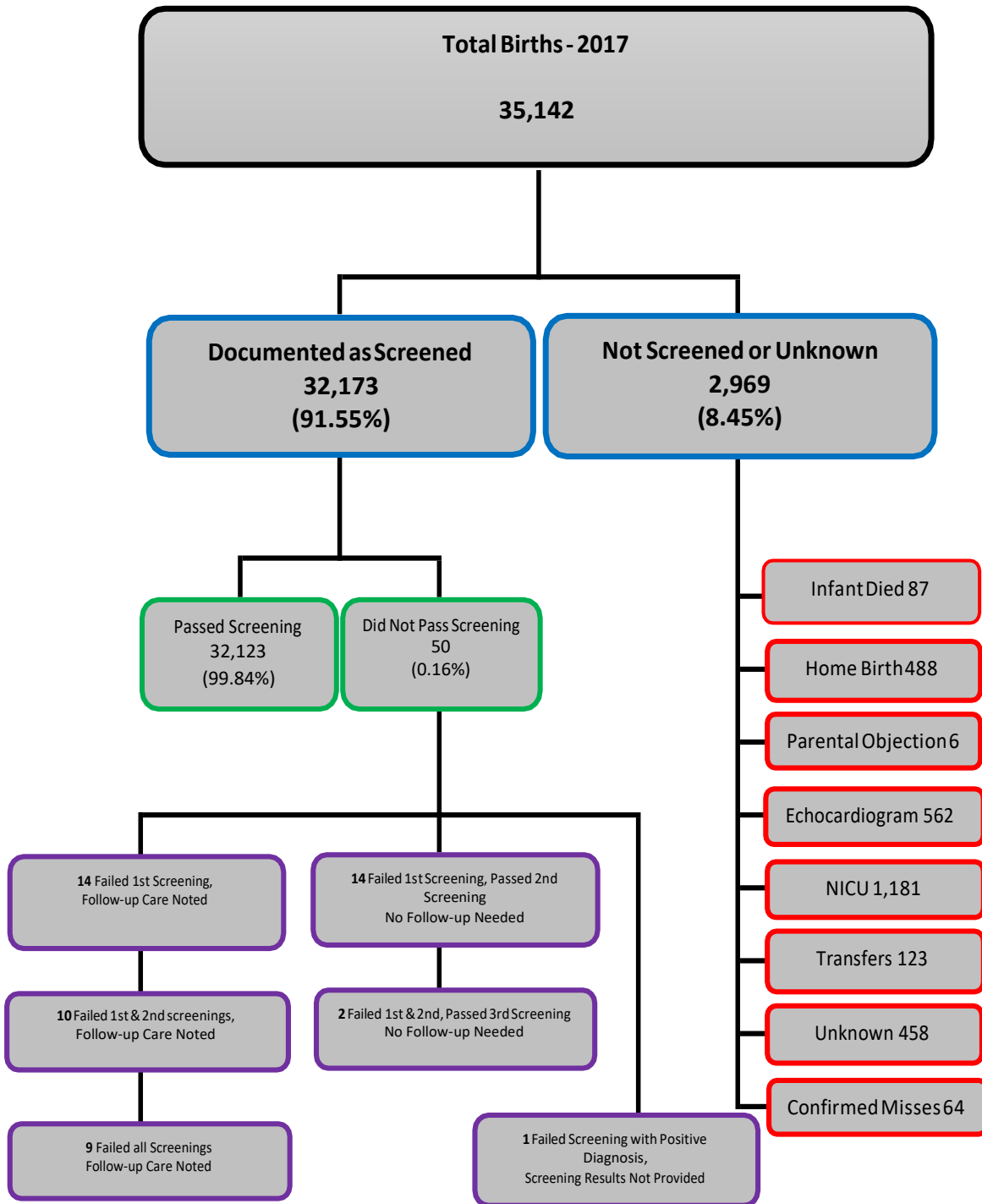
Recommendations

The following recommendations to improve upon the CCHD Registry include:

- Identify funding to support referral and follow-up relating to the CCHD Registry
- Dissemination of 2017 CCHD Report to stakeholders, including AHA, Nevada Hospital Association (NHA), parents of infants diagnosed with CCHD, CYSHCN, UNR NBS, EHDI, NEIS, ICC, providers (specialist and generalist) and Family TIES partners statewide.

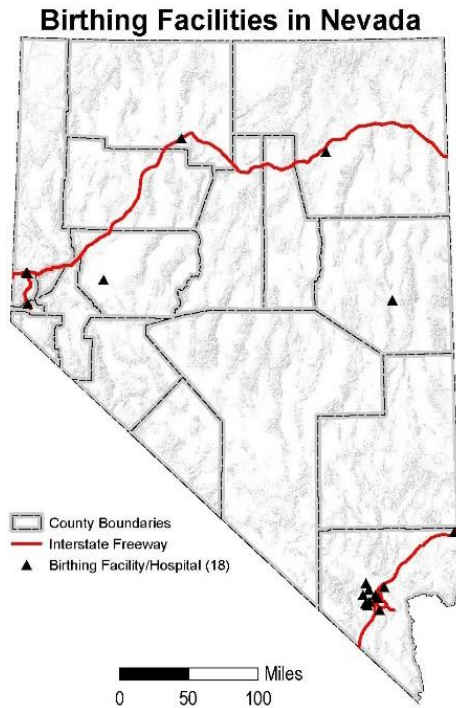
- If funds are identified, support focus groups and guidelines feedback from birthing hospital staff and families of infants diagnosed with CCHD would be helpful for continuous quality improvement.
- Establish data linkage between CCHD Registry and in-patient hospitalization data to address CCHD diagnosis in infants moved to a higher level of care before pulse oximetry screen can be performed.
- Developing means to identify infants diagnosed after hospital discharge or home birth.
- Tracking older children with CCHD.

Chart 1 – Nevada CCHD Registry Statistical Flowchart – Preliminary Data



Map 1: Birthing hospitals in Nevada

The location and distribution of all birthing hospitals 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
- Mesa View Regional Hospital
- Mountain View Hospital
- Northeastern Nevada Regional Hospital
- Renown Health
- Saint Mary's Regional Medical Center
- St. Rose Dominican Hospital - San Martin
- St. Rose Dominican Hospital - Siena
- Southern Hills Hospital and 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

American Heart Association Policy Recommendations

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

1. State adoption of mandatory CCHD screening using pulse oximetry for all newborns;
2. Collection of screening data to be used for surveillance, evaluation and continuous quality improvement of CCHD screening;
3. Development, dissemination, and validation of screening standards for CCHD;
4. Continued development of Food and Drug Administration's (FDA) guidance document regarding the safety and effectiveness of pulse oximeters.

Appendix B

Nevada State Policy

The state of Nevada worked with AHA, NHA, and other stakeholders to implement NRS 442.680, (<https://www.leg.state.nv.us/NRS/NRS-442.html#NRS442Sec680>) to require 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 obstetric centers 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 will be included in the next month's report, transfer to a higher level of care (another facility or NICU), echocardiogram ordered (higher level of care), or missed screenings.

Appendix C

Nevada Revised Statutes

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 an obstetric 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 obstetric 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

Nevada Administrative Code

INFORMATION CONCERNING BIRTH DEFECTS AND ADVERSE BIRTH OUTCOMES

NAC 442.052 Definitions. ([NRS 442.320](#)) As used in [NAC 442.052](#) to [442.058](#), inclusive, unless the context otherwise requires, the words and terms defined in [NRS 442.305](#), [442.310](#) and [442.315](#) have the meanings ascribed to them in those sections.

(Added to NAC by Bd. of Health by R176-99, eff. 2-10-2000)

NAC 442.054 Review of certain records; identification and contact of patient. ([NRS 442.320](#)) In carrying out the provisions of [NRS 442.300](#) to [442.330](#), inclusive, the Chief Medical Officer or a representative thereof:

1. May review any:

(a) Records of birth, stillbirth, death or fetal death maintained by the State Registrar of Vital Statistics;

(b) Records of examinations or tests conducted pursuant to [NRS 442.008](#); and

(c) Lists or records made available pursuant to [NRS 442.325](#), for any information pertinent to birth defects or adverse birth outcomes.

2. Shall, upon identifying a patient who has:

(a) A condition indicating that the patient may have a birth defect; or

(b) Been discharged with an adverse birth outcome,

contact the patient or, if the patient is a minor, a parent or legal guardian of the patient, to determine the extent to which the patient will participate in the activities of the system.

(Added to NAC by Bd. of Health by R176-99, eff. 2-10-2000)

NAC 442.056 Notice of inclusion of certain information in system; request for exclusion of name of patient. ([NRS 442.320](#))

1. Before including any information in the system that would reveal the identity of a patient, the Chief Medical Officer or a representative thereof shall advise the patient or, if the patient is a minor, a parent or legal guardian of the patient, that:

(a) The name of the patient will be used for research and referrals to related services unless the patient or his or her parent or legal guardian requests in writing to exclude the name from the system;

(b) Any information obtained by the system that would reveal the identity of the patient will remain confidential;

(c) Access to the information contained in the system is limited to persons who are:

(1) Employed by the Division of Public and Behavioral Health of the Department of Health and Human Services or the University of Nevada School of Medicine; and

(2) Authorized and approved by the Chief Medical Officer or the representative; and

(d) The information obtained by the system may be used only as set forth in [NRS 442.330](#).

2. The Chief Medical Officer and the representatives shall:

(a) Exclude from the system the name of a patient if the patient or, if the patient is a minor, a parent or legal guardian of the patient has requested in writing to exclude the name of the patient from the system; and

- (b) Cause the request to be maintained with the records for the patient.
(Added to NAC by Bd. of Health by R176-99, eff. 2-10-2000)

NAC 442.058 Access to and confidentiality of information in system. ([NRS 442.330](#))

The Chief Medical Officer shall establish appropriate procedures and take any other actions necessary to ensure that:

1. Access to the information contained in the system is limited to persons who are:
 - (a) Employed by the Division of Public and Behavioral Health of the Department of Health and Human Services or the University of Nevada School of Medicine; and
 - (b) Authorized and approved by the Chief Medical Officer or the representative;
2. Any information obtained by the system that would reveal the identity of a patient remains confidential; and
3. Except as otherwise provided in subsection 3 of [NRS 442.330](#), the information obtained by the system is used solely for the purposes set forth in subsection 1 of that section.

(Added to NAC by Bd. of Health by R176-99, eff. 2-10-2000)

INFORMATION OBTAINED IN ADMINISTRATION OF PROGRAMS

NAC 442.060 Confidential records. ([NRS 442.140](#), [442.190](#), [442.330](#))

1. Except as otherwise provided in subsection 2 or required to carry out [NRS 442.300](#) to [442.330](#), inclusive, and [NAC 442.052](#) to [442.058](#), inclusive:

(a) Any information concerning personal facts and circumstances obtained by the State or a local staff administering the program of services for maternal and child health and the care and treatment of children with special health care needs is a privileged communication and must be held confidential.

(b) The information must not be divulged without the consent of the person seeking or receiving services or the consent of his or her parent or guardian if he or she is a minor.

2. The information may be disclosed without consent if it is in a summary, statistical or other form which does not identify the person receiving or seeking services.

[Bd. of Health, Confidentiality of Records Reg. § 1, eff. 6-5-72; A and renumbered as § 1.0, 12-20-79] — (NAC A by R176-99, 2-10-2000)

NAC 442.070 Chief Medical Officer to control information. ([NRS 442.140](#), [442.190](#), [442.330](#)) The Chief Medical Officer shall control confidential information, designate persons who may utilize and disclose the information, and acquaint those persons with all regulations concerning confidential information.

[Bd. of Health, Confidentiality of Records Reg. § 2, eff. 6-5-72; A and renumbered as § 1.1, 12-20-79]

NAC 442.080 Chief of Bureau of Children's Services to inform employees of policy. ([NRS 442.140](#), [442.190](#), [442.330](#)) The Chief of the Bureau of Children's Services shall inform all employees of the Bureau of regulations relating to confidential materials.

[Bd. of Health, Confidentiality of Records Reg. § 3, eff. 6-5-72; A and renumbered as § 2.0, 12-20-79]

NAC 442.090 Chief Medical Officer to establish procedures for enforcement. ([NRS 442.140](#), [442.190](#), [442.330](#)) The Chief Medical Officer shall establish appropriate procedures to ensure the enforcement of [NAC 442.060](#), [442.070](#) and [442.080](#).

[Bd. of Health, Confidentiality of Records Reg. § 4, eff. 6-5-72; A 12-20-79]

Appendix E

PULSE OXIMETRY SCREENING FOR CRITICAL CONGENITAL HEART DISEASE



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 provided the proper screenings take place. 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 neonates undergoing surgery for CCHD will reach adulthood.⁹

PULSE OXIMETRY SCREENING

Pulse oximetry screening is a life-saving, 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

The state of Nevada worked with AHA and other stakeholders to implement Nevada Revised Statute (NRS) 442.680, (<http://www.leg.state.nv.us/Division/Legal/LawLibrary/NRS/NRS-442.html#NRS442Sec680>) to address CCHD screenings.

Since July 1, 2015, all hospitals or obstetric centers 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 an obstetric 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 obstetric 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 Division of Public and Behavioral Health (DPBH), Maternal and Child Health (MCH) Program receives the CCHD screening reports required by NRS 442.680, collecting screening data for surveillance, evaluation, and continuous quality improvement. All birthing hospitals in Nevada currently report; however, hospitals began reporting 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 evaluating 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 or not 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 three percentage points 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 and right foot. If the oxygen saturation is greater than 90% and less than 95% in the right hand and right foot, or there is more than a three percent 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 three screens (the initial and two repeat screens, all separated by one hour). A baby whose oxygen saturation is from 90% to less than 95% in either the right hand or right foot, or who has more than a three percent difference between the right hand and right foot after the third screen, 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.

References:

1. American Heart Association. Common Types of Heart Defects. 2012. Available at: http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/CommonTypesofHeartDefects_UCM_307017_Article.jsp. Accessed June 12, 2012.
2. Reller MD, Strickland MJ, Riehle-Colarusso T, Mahle WT, Correa A. Prevalence of congenital heart defects in metropolitan Atlanta, 1998–2005. *J Pediatr*. 2008;153:807–813.
3. Go AS, et al. Heart Disease and Stroke Statistics - 2014 update: a report from the American Heart Association. *Circulation*. Published online December 18, 2013.
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5. Chang R-KR, Gurvitz M, Rodriguez S. Missed Diagnosis of Critical Congenital Heart Disease. *Arch Pediatr Adol Med*. 2008;162(10):969–974.
6. Kemper AR, Mahle WT, Martin GR, et al. Strategies for Implementing Screening for Critical Congenital Heart Disease. *Pediatrics*. 2011;128(5):e1259–e1267.
7. Peterson C, Grosse SD, Cassell CH, Oster ME, Olney RS. Abstract 228: A Cost effectiveness Analysis Of Universal Pulse Oximetry Screening To Detect Critical Congenital Heart Disease In U.S. Newborns. *Circ Cardiovasc Qual Outcomes*. 2012;5:A228.
8. de-Wahl Granelli A, Wennergren M, Sandberg K, et al. Impact of pulse oximetry screening on the detection of duct dependent congenital heart disease: a Swedish prospective screening study in 39 821 newborns. *BMJ*. 2009;338(jan08 2):a3037–a3037.
9. US Food and Drug Administration. Draft Guidance for Industry and FDA Staff: Pulse Oximeters - Premarket Notification Submissions [510(k)s]. US Food and Drug Administration, Center for Devices and Radiological Health; 2007:1–21. Available at: <http://www.fda.gov/downloads/MedicalDevices/DeviceRegulationandGuidance/GuidanceDocuments/ucm071376.pdf>. Accessed June 12, 2012.

SECTION 2 PATIENT INFORMATION:

This section must be completed for each newborn who failed to pass the CCHD pulse oximetry screen.

Last Name: _____ First Name: _____

Date of Birth: _____ Medical Record #: _____

Mother's Last Name: _____ Mother's First Name: _____

Was CCHD detected in infant prior to pulse oximetry screening? (Circle or Highlight) Yes No

If CCHD was detected prior to pulse oximetry, how was it detected? _____

Screening Information:

Age at Initial Screening (hours): _____

Initial Screening

Screeener's Name: _____ Date: _____

Time: _____

Pulse Ox Saturation of Right Hand _____ %

Pulse Ox Saturation of Foot _____ %

Difference (Right Hand - Right Foot) _____ %

Circle or Highlight **Pass** **Fail**

Second Screening

Screeener's Name: _____ Date: _____

Time: _____

Pulse Ox Saturation of Right Hand _____ %

Pulse Ox Saturation of Foot _____ %

Difference (Right Hand - Right Foot) _____ %

Circle or Highlight **Pass** **Fail**

Third Screening:

Screeener's Name: _____ Date: _____

Time: _____

Pulse Ox Saturation of
Right Hand _____ %

Pulse Ox Saturation of
Foot _____ %

Difference (Right Hand -
Right Foot) _____ %

Circle or Highlight

Pass

Fail

Measures Taken by the Hospital because of a Positive Screening Result:

Measures Taken to
Verify Screening Result: _____

Provision of Follow-up
Care and Treatment to
Infant: _____

Other: _____

Comments: _____

