Critical Congenital Heart Defects Screening

New Jersey Reference Guide

A collaborative effort of the New Jersey Department of Health (NJDOH), the New Jersey Chapter, American Academy of Pediatrics (NJAAP), and Rutgers, The State University of New Jersey. Published March 2016, revised April 2017.

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To download an electronic copy, check for updates, or connect to links in this Reference Guide, visit the NJDOH critical congenital heart defects web page http://www.state.nj.us/health/fhs/nbs/critical-congenital-heart-defects/.

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CCHD Screening Program Delivers Immediate Results

On September 1, 2011, only one day after New Jersey's newborn CCHD screening mandate became effective, a hospital pediatrician informed Lisa and Bill Gordon of Newton that their newborn son Dylan's pulse oximetry results were abnormal. Additional examination revealed that baby Dylan had a heart murmur, and he quickly received life-saving surgery and follow-up care to correct the abnormality detected by newborn pulse oximetry screening.

The Gordon family can attest to the importance of CCHD screening with pulse oximetry. In their own words, "it is because of your law that our son's life was saved. Our son Dylan is proof that the test is worth doing."

"A simple test that can detect a number of hidden heart defects has saved more than 25 newborns from potentially life threatening heart conditions and is making a significant difference in the lives of New Jersey newborns and their families.

More than 530,000 newborns have been screened since 201l, when New Jersey became the first to implement a law requiring all newborns to be tested for congenital heart defects."

New Jersey Commissioner of Health Cathleen D. Bennett

Introduction

Congenital heart defects (CHD) are the most common type of birth defect in the United States. They are the leading cause of infant death due to birth defects. Approximately 9 out of every 1,000 infants are born with CHD, and 25% of these defects are considered to be critical congenital heart defects (CCHD), requiring either a catheter intervention or surgery within the first year of life, usually shortly after birth. In the United States, about 7,200 (2 per 1,000) infants born each year have CCHD. Early diagnosis of a CCHD before hospital discharge allows for optimal treatment and the best outcomes[1].

Newborns with CCHD are at significant risk for disability and even death if their heart defects are not diagnosed and treated soon after birth. Some of these newborns may appear healthy and could be discharged home without the heart defect having been detected. At home, they are susceptible to sudden deterioration in their clinical status due to closure of the ductus arteriosus. In many forms of CCHD, patency of the ductus arteriosus is crucial for maintaining either systematic or pulmonary blood flow. The timing of the ductus closure explains why some newborns look well in the hospital but suffer cardiovascular collapse soon after being discharged. In the US, approximately 200 infants die each year from missed diagnoses of CCHD[2]. Many others suffer kidney, liver, and brain damage. Though pulse oximetry screening is unable to detect all infants with CCHD, studies have shown that it can reliably detect CCHD in a significant number of infants who otherwise might be discharged from the hospital prior to diagnosis[3, 4, 5].

Legislation

In August 2011, New Jersey became the first state in the nation to implement mandated newborn pulse oximetry screening. In accordance with P.L. 2011, Ch. 74, C.26:2-111.4, birthing facilities are required to perform a pulse oximetry screening a minimum of 24 hours after birth on every newborn in their care. In September 2011, the recommendation of the U.S. Department of Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) was approved, and CCHD screening using pulse oximetry was added to the Recommended Uniform Screening Panel (RUSP) in the United States. The American Academy of Pediatrics, the American Heart Association, and other leading professional organizations have endorsed this recommendation[6].

In New Jersey, pulse oximetry screening is required for all infants, even if a prenatal diagnosis of CHD or CCHD has been made, or a neonatal echocardiogram has been obtained. The mandate requires each birthing facility licensed by the Department of Health to perform a pulse oximetry screening a minimum of 24 hours after birth on every newborn in its care.

New Jersey's pulse oximetry screening legislation (*New Jersey Statutes Annotated - N.J.S.A.*) and regulations (*New Jersey Administrative Code - N.J.A.C.*) can be found in their entirety below.

LEGISLATION: N.J.S.A. 26:2-111.3

1. The Legislature finds and declares that:
    a. Congenital heart defects (CHDs) are structural abnormalities of the heart that are present at birth; CHDs range in severity from simple problems such as holes between chambers of the heart, to severe malformations, such as the complete absence of one or more chambers or valves; some critical CHDs can cause severe and life-threatening symptoms which require intervention within the first days of life;
    b. According to the United States Secretary of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children, congenital heart disease affects approximately seven to nine of every 1,000 live births in the United States and Europe; the federal Centers for Disease Control and Prevention states that CHD is the leading cause of infant death due to birth defects;
    c. Current methods for detecting CHDs generally include prenatal ultrasound screening and repeated clinical examinations; while prenatal ultrasound screenings can detect some major congenital heart defects, these screenings, alone, identify less than half of all CHD cases, and critical CHD cases are often missed during routine clinical exams performed prior to a newborn's discharge from a birthing facility;
    d. Pulse oximetry is a non-invasive test that estimates the percentage of hemoglobin in blood that is saturated with oxygen; when performed on a newborn a minimum of 24 hours after birth, pulse oximetry screening is often more effective at detecting critical, life-threatening CHDs which otherwise go undetected by current screening methods; newborns with abnormal pulse oximetry results require immediate confirmatory testing and intervention; and
    e. Many newborn lives could potentially be saved by earlier detection and treatment of CHDs if birthing facilities in the State were required to perform this simple, non-invasive newborn screening in conjunction with current CHD screening methods.

LEGISLATION: N.J.S.A. 26:2-111.4

a. The Commissioner of Health shall require each birthing facility licensed by the Department of Health to perform a pulse oximetry screening, a minimum of 24 hours after birth, on every newborn in its care.

b. As used in this section, "birthing facility" means an inpatient or ambulatory health care facility licensed by the Department of Health that provides birthing and newborn care services.

c. The commissioner shall adopt rules and regulations, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), necessary to carry out the purposes of this act.

REGULATION: N.J.A.C. 8:43G-19.15e

e. The hospital shall screen all newborns for high risk factors associated with hearing impairment pursuant to N.J.S.A. 26:2-103.4, biochemical disorders pursuant to N.J.S.A. 26:2-111, and congenital heart defects no sooner than 24 hours after birth by using pulse oximetry pursuant to N.J.S.A. 26:2-111.4.

1. The hospital shall report congenital defects and shall complete birth certificates and death certificates pursuant to N.J.S.A. 26:8-40.21 and 26:8-28, respectively.

Many other states have now adopted CCHD screening legislation as well. Newborn CCHD screening requirements in other states are available online at:

American Academy of Pediatrics

https://www.aap.org/en-us/advocacy-and-policy/state-advocacy/Documents/2016 CCHD Newborn Screening Bills, Regulations, and Executive Orders - AAP Division of State Govt Affairs.pdf

Newborn Foundation Coalition

http://cchdscreeningmap.org/

NewSTEPs

https://www.newsteps.org/cchd

A National Leader in CCHD Screening

New Jersey has been noted for its rapid and effective statewide implementation of CCHD screening. The New Jersey program collaborated with the Centers for Disease Control and Prevention (CDC) in examining issues related to screening and reporting. The results of this work were described in the CDC's April 13, 2013 Morbidity and Mortality Weekly Report, "Rapid Implementation of Pulse Oximetry Newborn Screening to Detect Critical Congenital Heart Defects — New Jersey, 2011[7]."

New Jersey earned national recognition with "Results from the New Jersey Statewide Critical Congenital Heart Defects Screening Program" that was e-published online July 15, 2013 in Pediatrics. This article was the first in the nation to evaluate the statewide implementation of pulse oximetry screening to detect CCHD in newborns[8]. Results showed that in the first 9 months after implementation, New Jersey achieved a high statewide screening rate; in this short period, 3 infants with previously unsuspected CCHD were identified, as were infants with serious non-cardiac conditions including sepsis and pneumonia.

Additional collaborative work with the CDC resulted in the findings of a cost survey and time and motion study that was published in the January-February 2014 issue of Public Health Reports. "A Public Health Economic Assessment of Hospitals' Cost to Screen Newborns for Critical Congenital Heart Disease" by Peterson et al. described the first state-level analysis of time and hospital costs for CCHD screening in the US. The report concluded that hospital costs for CCHD screening with pulse oximetry are comparable to cost estimates for other newborn screening tests[9].

Another study by Peterson et al. underscoring the cost-effectiveness of CCHD screening in newborns was published in August 2013, titled "Cost-Effectiveness of Routine Screening for Critical Congenital Heart Disease in US Newborns." This study reported on data obtained in New Jersey and Florida[10]. Study findings were featured on the CDC heart defects webpage[11]. The cost of screening compared to infants' future health benefits and healthcare costs was found to be favorable. Combining estimated numbers of and hospitalization costs of late detected CCHD and potentially avoidable deaths from Florida, plus screening costs from New Jersey, the authors projected that screening may cost approximately $40,000 per life-year saved.

In 2015, New Jersey led a 5 state, 21 site evaluation of CCHD screening in the NICU. Results from this evaluation have been presented at many scientific meetings in 2016-2017 adding valuable contributions to the national discussion and providing further specification to guide CCHD screening in New Jersey.

Section 1: Detection of CCHD

Critical congenital heart defects are the leading cause of infant deaths due to birth defects in the United States. CCHD affects up to 7,200 (2 per 1,000) births in the United States each year and accounts for 30% of infant deaths due to birth defects[12].

Importance of Early Detection

Early detection of critical defects (within 3 days of life) is crucial to reduced morbidity, better surgical outcomes, and improved survival. Infants with delayed or missed diagnosis of CCHD are at a substantially increased risk of severe complications and death. The severe hypoxemia and poor perfusion from heart defects can result in kidney, liver, and brain damage. Although estimates vary, up to 30% of newborns with CCHD could be missed at the time of hospital discharge[13, 14]. A 2015 report in Pediatrics projected that an estimated 1,755 infants would have a late diagnosis of CCHD, half of which would benefit from pulse oximetry screening[15].

Prenatal Detection

Successful detection of CCHD on prenatal ultrasound can be unreliable, typically only identifying approximately 50% of cases. Detection rates depend on such factors as type of heart defect present, imaging quality, fetal position, equipment, maternal body habitus, and sonographer experience. Even in areas with increased utilization of prenatal ultrasound and improved cardiac imaging, delayed diagnosis of CCHD was found to occur in over 10% of cases[16].

Physical Exam

CCHD detection in newborns is limited because infants with critical defects may be asymptomatic at birth, findings associated with CCHD may not be present before discharge, or symptoms may go unrecognized. Exam results also vary according to timing, setting, and experience of the provider. Blood pressure gradients and absent femoral pulses are suggestive of aortic arch anomalies such as coarctation and interrupted aortic arch, yet a clinician's ability to feel pulses or obtain accurate blood pressures may be restricted in a crying newborn. Physical examinations will, on average, only diagnose about 60% of infants with CCHD[17, 3].

Pulse Oximetry Screening

Although most infants with CCHD are diagnosed prenatally or shortly after birth, a substantial number still go undetected at the time of hospital discharge. **While pulse oximetry screening does not replace a complete newborn history and physical examination, it helps to close the gap in early detection of CCHD. The addition of pulse oximetry screening to prenatal ultrasound and newborn examination improves detection of CCHD**[2, 4].

For example, cyanosis is one physical sign that CCHD may be present. Cyanosis is a bluish discoloration of tissues that is only visible to the human eye when levels of deoxygenated hemoglobin rise to approximately 3 to 5 g/dL. In an average normal newborn with hemoglobin of 20 g/dL, the oxygen saturation must be less than 85% to produce visible cyanosis. But, anemic newborns may not exhibit visible cyanosis until oxygen saturations are much lower, and cyanosis in darkly pigmented infants can be even more difficult to detect. **Consequently, cyanosis in newborns with abnormal blood oxygen saturations of 78-95% may go unrecognized by clinicians.** This "cyanotic blind spot," as described by Hokanson, demonstrates the limitations of relying solely on physical findings to detect CCHD[1]. A physical examination may not identify a problem until the appearance of visible cyanosis, well after the newborn's saturation is at dangerously low levels.

Signs and Symptoms of Congenital Heart Disease:

- **Cyanosis**
- **Tachypnea (often with diaphoresis during feeding)**
- **Poor perfusion & pulses (femoral)**
- **Murmur (not as pertinent in isolation of other signs)**
- **Poor weight gain**

Pulse oximetry makes it possible to detect hypoxemia well before cyanosis is detectable by the human eye. A meta-analysis showed the overall sensitivity of pulse oximetry for detection of critical congenital heart defects was 76.5%. Specificity was 99.9% with a false-positive rate of 0.14%. The authors note a lower false-positive rate when pulse oximetry screening is done after 24 hours from birth, as compared to screening before 24 hours[19].

Signs and Symptoms of Congenital Heart Disease

Symptoms of heart disease are nonspecific and include difficulty in feeding, poor weight gain, cyanosis, respiratory findings, irritability, decreased activity, and excessive sweating. Cyanosis, diminished pulses, or other signs should prompt the clinician to suspect CCHD and obtain further evaluation, even if the infant appears healthy or the pulse oximetry screening is normal. Prompt referral to pediatric cardiology is recommended.

CCHD Screening Targets

While pulse oximetry cannot detect all cardiac defects, the screening has been shown to be an effective tool in the identification of previously unrecognized CCHD before hospital discharge. Hypoxemia is the basis for low oxygen saturation and a positive (failed) pulse oximetry screen; however, it is not present in all CCHD. It is possible for an infant with a passing screening result to have a CCHD or other CHD. Ductal-dependent defects such as critical coarctation of the aorta, interrupted aortic arch, tetrology of Fallot with large patent ductus arteriosus, and transposition of the great arteries with large ventricular septal defect can all be missed by pulse oximetry screening.

Pulse oximetry screening is most likely to detect the following seven CCHD, as these defects usually result in hypoxemia:

- Hypoplastic left heart syndrome
- Pulmonary atresia (with intact septum)
- Tetralogy of Fallot
- Total anomalous pulmonary venous return
- Transposition of the great arteries
- Tricuspid atresia with intact septum
- Truncus arteriosus

Other CCHD that may be detected via pulse oximetry screening, although not as consistently, include:

- Coarctation of the aorta
- Double-outlet right ventricle
- Ebstein anomaly
- Interrupted aortic arch
- Single ventricle

Newborn pulse oximetry screening can also aid in the detection of other serious, non-cardiac conditions that present with hypoxemia.

New Jersey CCHD Screening Results

Data from the New Jersey Birth Defects Registry shows that, since its inception, New Jersey's statewide CCHD screening program has improved early detection of CCHD, CHD, and non-cardiac conditions in newborns.

NJ BIRTH DEFECTS REGISTRY DATA	YEAR 1+	YEAR 2	YEAR 3	YEAR 4-	YEAR 5	TOTAL
	8/31/11-12/31/12	1/1/13-12/31/13	1/1/14-12/31/14	1/1/15-12/31/15	1/1/16-12/31/16	8/31/11-12/31/16
Failed screens with evaluation due to screening	**39**	**31**	**35**	**15**	**25**	**145**
Detected due to screening with pulse oximetry:						
CRITICAL CONGENITAL HEART DEFECTS	**3**	**6**	**6**	**5**	**6**	**26**
Coarctation of aorta	1	2	2	2	0	7
Ebstein anomaly	0	1	0	0	0	1
Interrupted aortic arch	0	0	0	0	1	1
Tetrology of Fallot	0	0	0	0	1	1
Total anomalous pulmonary venous return (TAPVR)	0	3	3	2	2	10
d-Transposition of great arteries (TGA)	1	0	0	0	2	3
Tricuspid atresia	1	0	0	0	0	1
d TGA+Double outlet right ventricle (DORV)	0	0	1	1	0	2
CONGENITAL HEART DEFECTS (not including PFO/PDA)	**4**	**3**	**6**	**3**	**5**	**21**
Atrial septal aneurysm	0	0	2	0	0	2
Atrial septal defect (ASD)	1	2	1	1	3	8
Peripheral pulmonary artery stenosis	0	1	1	0	1	3
Prolonged QT	0	0	0	0	1	1
Ventricular septal defect (VSD)	2	0	2	2	0	6
ASD + VSD	1	0	0	0	0	1
NON-CARDIAC CONDITIONS	**4**	**1**	**4**	**1**	**3**	**13**
Lung anomaly	0	0	1	0	0	1
Pneumonia	1	0	0	0	0	1
Pulmonary hypertension	2	1	3	1	3	10
Sepsis	1	0	0	0	0	1

*PFO - Patent foramen ovale; PDA - Patent ductus arteriosus

Source: http://www.nj.gov/health/fhs/nbs/documents/cchd_results.pdf.

For current New Jersey data on pulse oximetry screening, visit http://www.state.nj.us/health/fhs/nbs/critical-congenital-heart-defects/.

Section 2: Performing the Screen

Timing of the Screen

In the first 24 hours after birth, newborns are transitioning from fetal to neonatal circulation. Screening at minimally 24 hours of life reduces the frequency of false positive results. CCHD screening with pulse oximetry should be incorporated into routine care for newborns. The screening, however, should not take the place of customary clinical practice, evaluation, or intervention.

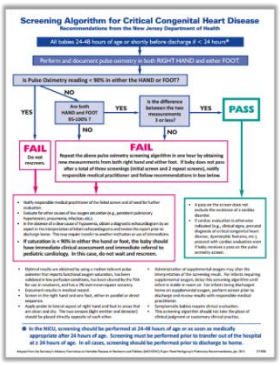
- Under normal circumstances, screening should take place between 24 and 48 hours of life.
- For infants being discharged at less than 24 hours after birth, the screening is performed shortly before discharge.
- Infants in Special Care Nurseries (SCN) or Neonatal Intensive Care Units (NICU) should be screened as soon as medically appropriate after 24 hours of age.
- If an infant is at least 24 hours old, screening must occur before discharge to home or transfer to another facility.

Screening Tips

- Secure the probe to the infant's right hand to obtain a pre-ductal reading and to either foot to obtain a post-ductal reading.
- Apply the pulse oximetry probe to the lateral aspect of the right hand and either foot in areas that are clean and dry.
- Refer to manufacturer's recommendations for appropriate sensor size and application.
- The light emitter and photo detector must be lined up opposite each other for proper readings.
- The hand and foot can be screened at the same time (in parallel) or one after the other (in direct sequence).
- Perform the screening in a quiet environment. If possible, have the parent hold and comfort the infant during the screening.
- Conduct the screening while the infant is awake, calm, and warm. Avoid screening when the infant is crying, cold, or in a deep sleep.
- Shield the sensor from extraneous light that may interfere with the signal.
- Discard disposable sensors after a single use, and properly clean reusable sensors between patients.
- Follow manufacturer's instructions for use, cleaning, and appropriate infection control practices.

Screening Procedure

1. Wrap the probe snuggly around outside of infant's right hand. Place the light emitter on the top of the hand, with the photo detector directly opposite on the bottom of the hand.
2. Turn on the pulse oximeter and connect the probe.
3. Depending on machine display, wait for the arterial pulse or pleth wave to stabilize without artifact and/or look for good detection and consistent display of heart rate.
4. Obtain pre-ductal saturation reading.
5. Remove probe from right hand and apply to either foot.
6. Wrap probe snuggly around the outside of infant's foot. Place light emitter on top of foot, with photo detector directly opposite on the bottom of the foot.
7. Wait for a stable display on the pulse oximeter.
8. Obtain post-ductal saturation reading.
9. Record results.
10. Interpret results using the New Jersey Recommended Algorithm to determine if the infant passed, failed, or requires re-screening.
11. If indicated, rescreen the infant in 1 hour up to 2 times.
12. Document final screening results.
13. If the infant failed the screen, refer for additional evaluation according to your hospital's protocol for failed screens.
14. Properly dispose of or clean supplies and equipment as indicated.



Interpreting Results

Perform an initial screen and up to two rescreens if indicated using the New Jersey Recommended Screening Algorithm. Refer to the abridged version of the Screening Algorithm for Critical Congenital Heart Disease on the following page, and review the full version on page 24 of this Guide.

Internal hospital audits are important to ensure accuracy of interpretation of screening results and appropriate follow up in response to an abnormal screen.

New Jersey Recommended Screening Algorithm (abridged)

PASS: 95%-100% in the right hand and either foot AND a difference of 3% or less between the readings.

RESCREEN IN 1 HOUR: 90%-94% in the right hand or either foot OR a difference of 4% or more between the readings (even if both readings are 95%-100%). Rescreen the infant up to 2 times, for a total of 3 screening attempts.

FAIL: 90%-94% in the right hand or either foot OR a difference of 4% or more between the readings after three screening attempts. Refer the infant for further evaluation.

IMMEDIATE FAIL: 89% or less in the right hand or either foot. Do not rescreen, and immediately refer the infant for further evaluation.

Important Reminders

- A passing screen does not rule out all heart disease. It is possible for an infant with CCHD to have a normal pulse oximetry reading at the time of the screen.
- If a cardiac evaluation is warranted due to clinical signs, prenatal diagnosis of CHD, dysmorphic features, or other indication, proceed with the cardiac evaluation even if the infant passes the pulse oximetry screen.
- A newborn with failed screening results requires further evaluation for hypoxemia before discharge. Newborns should not be discharged home until the underlying reason for hypoxemia has been identified or the hypoxemia has resolved.

Communicating Results

Effective communication of screening results among providers is important within the birth facility and upon transfer to another facility or discharge to home. The screening results should be included in the transfer report or discharge summary to communicate results to the specialist or primary care provider.

Evaluation for Failed Screens

There is variability in on-site access to pediatric cardiology in New Jersey. For those birthing facilities without on-site pediatric echocardiography and/or pediatric cardiology, procedures should be developed so that evaluation can be performed in a timely fashion. Options include telemedicine or transfer to a center with expanded capabilities in pediatric cardiac evaluation.

Immediate Fail

Any infant with a saturation less than 90% warrants immediate clinical evaluation. Pulse oximetry may be continued to monitor the infant's clinical condition; however, delay in further evaluation should not occur due to re-screening attempts. The evaluation should consider both cardiac and non-cardiac causes of hypoxemia in the neonate. Evaluation may reveal developing signs of sepsis, primary lung disease, or other non-cardiac pathology, and should be treated accordingly. Infants with signs of cardiac disease and those with an otherwise normal examination should be evaluated urgently for CCHD. This evaluation should include echocardiography with images obtained by an experienced pediatric echocardiographer and interpretation by a pediatric cardiologist.

Re-screen Fail

If the initial screen is positive due to a greater than 3% differential between extremities or a value from 90-94% in any extremity, the screen should be repeated up to 2 times. Repeating the screen decreases the rate of false positives without compromising the sensitivity of the test. If the subsequent screen meets criteria for passing, no further screening is necessary.

If the third screen remains abnormal, the screen is considered positive and the infant has failed the screening. The infant requires evaluation to determine if there is evidence of cardiac or non-cardiac pathology to explain the hypoxemia. Cardiac evaluation should be undertaken as above if a non-cardiac cause for the failed screen cannot be determined.

Section 3: Reporting Results

Data and Reporting

Data collection and analysis are essential to measure the effectiveness of the CCHD screening program. Evaluation of screening coverage for the statewide mandate is important to identify challenges in implementation and to ensure that all eligible births are being screened. The NJDOH utilizes the following two mechanisms for reporting of CCHD screening results.

Vital Information Platform (VIP)

The CCHD screening results for individual newborns are reported in the newborn screening section of the Vital Information Platform (VIP). All newborns' pulse oximetry screening values and results, or reason if not performed, are entered in the VIP.

Birth Defects Registry (BDR)

Many states, including New Jersey, have systems to monitor the frequency and characteristics of infants with birth defects. In New Jersey, this system is the Birth Defects Registry (BDR). Birth defects tracking systems identify children born with birth defects, including CHD, and collect information to learn more about the prevalence and characteristics of these conditions. This information is used by public health officials, policymakers, and scientists for planning, research, education, investigation, and resource allocation. The Centers for Disease Control and Prevention (CDC) and the National Birth Defects Prevention Network (NPDPN) work with State birth-defects surveillance programs to direct birth-defects prevention activities and identify and track newborns with CHD.

Health care professionals are required to report infants with CCHD (and other congenital defects) who are New Jersey residents to the NJBDR. All New Jersey infants with a reportable heart defect are required to be registered to the NJBDR, regardless of screening results.

Birthing facilities are required to register all infants born in New Jersey that fail pulse oximetry screening to the NJBDR. The registry includes a separate pulse oximetry module to determine if a diagnostic evaluation resulted solely from the screening. The module contains detailed questions about the failed screen including timing of the screen, pulse oximetry readings, presence or absence of symptoms, response to the failed screen (further evaluation, echocardiogram findings, and/or transfer), and final diagnosis attributable to the failed screen.

BDR registration for failed pulse oximetry screen and completion of the pulse oximetry module is required even in cases where the infant failed the pulse oximetry screening but CCHD was not identified. Accurate

completion of the BDR registration and the pulse oximetry module is essential to effective evaluation of the screening program and determination of the unique contribution of pulse oximetry screening in detecting CCHD and other conditions. The Pulse Oximetry Worksheets on pages 26-28 can assist with collection of the appropriate information prior to entry into the web-based BDR system.

Screening and Reporting Results in the Special Care Nursery (SCN) and Neonatal Intensive Care Unit (NICU)

The following recommendations provide further specifications for implementation of CCHD screening in the SCN/NICU and do not contradict current guidance on the New Jersey Recommended Screening Algorithm.

Who to Screen:

Infants cared for in the SCN/NICU are not exempt from CCHD screening including those with a prenatal diagnosis of CHD, receiving an echocardiogram before screening or transferred at ≥ 24 hours after birth.

When to Screen:

Screen **as early as possible at ≥ 24 hours**. At minimum, screen at 24-48 hours if medically appropriate. If not screened at 24-48 hours, screen as soon as possible when medically appropriate and when weaned from supplemental oxygen and respiratory support.

What to Report:

The pulse oximetry values and results of screening (up to 3 attempts) are entered into the VIP. Failed screening results are reported in the BDR. Refer to p. 18 Birth Defects Registry (BDR).

- For infants who are transferred ≥ 24 hours, at least one set of pulse oximetry measurements is entered in the VIP and failing results reported to the BDR. A single set of measurements by the sending facility is sufficient when additional attempts are not feasible. Where appropriate within hospital systems, the VIP record should be transferred to the receiving hospital to allow for the addition of screening results from the receiving hospital as applicable.
- For infants who are transferred < 24 hours, screening is not mandated; however, is recommended if feasible before transfer, especially if transferring out of state. If screening is performed, the results are entered into VIP and failing results reported to the BDR. Where appropriate within hospital systems, the VIP record should be transferred to the receiving hospital so that additional screening results can be added to the record.
- For infants with CCHD confirmed by echocardiography, at least one set of pulse oximetry measurements is entered into VIP and failing results are reported to the BDR. A single set of measurements is sufficient.

Understanding Final Screening Results – Clinical Care & Reporting

Positive Screen (Fail)

Fail with CCHD

- **Care:** Infants who are identified as having CCHD due to failed screening results should receive further care as directed by a pediatric cardiologist in cooperation with their primary care provider (medical home) to allow optimal ongoing care.
- **Reporting:** Failed screening results entered into VIP; failed screening and CCHD registered in BDR; pulse oximetry module completed in BDR.

Fail without CCHD (CHD or non-cardiac condition may be identified)

- **Care**: The clinical examination of the infant with low oxygen saturation may detect another cardiac or serious non-cardiac condition. Evaluation may also determine normal cardiac structure and functioning. Care is continued as appropriate to the condition and follow up is provided as necessary.
- **Reporting**: Failed screening results entered into VIP; failed screening registered in the BDR; pulse oximetry module completed in BDR; if applicable, reportable congenital defect registered in BDR.

Negative Screen (Pass)

Pass with CCHD

- **Care**: Pulse oximetry screening does not detect all CCHD. An infant with CCHD may pass the screening. If a cardiac evaluation is warranted due to history or clinical signs and symptoms, proceed with the cardiac work-up regardless of screening results.
- **Reporting**: Passing screening results entered into VIP; CCHD registered in BDR when identified.

Pass

- **Care**: Routine care of the infant with primary care follow up, ideally in a medical home, should continue. Pulse oximetry screening does not detect all CCHD. Parent education (see pages 29-34) should include signs of cardiac disease and encouragement to contact the primary care provider if these or other changes in behavior are noted.
- **Reporting**: Passing screening results entered into VIP.

Section 4: Parent Education

Parents are important partners in the early detection of congenital heart defects and other conditions that can jeopardize the health and well-being of newborns. The newborn's parent(s) should be made aware of the screening, the purpose of screening, how it is performed, and the final results. Although pulse oximetry screening is effective in detecting certain types of CCHD, it is possible for an infant with a significant heart defect to pass the screening. Because not all critical heart defects are detected with pulse oximetry, the parents should be instructed about the warning signs of CHD. Infants with CHD may present with feeding difficulties, poor weight gain, increased sleepiness, sweating about the head (especially during feeding), tachypnea, pallor, or cyanosis. Performing the screen with a parent present provides an opportunity for teaching. Parent information about CHD and screening from the NJDOH is available in English, Spanish, Arabic, Hindi, Korean, and Polish. See pages 29-34 or visit http://www.state.nj.us/health/fhs/nbs/critical-congenital-heart-defects/ to view or download.

References

1. **Congenital Heart Defects (CHD) - Data & Statistics.** Division of Birth Defects and Developmental Disabilities; Centers for Disease Control and Prevention. December 22, 2015. http://www.cdc.gov/ncbddd/heartdefects/data.html
2. **Hokanson, John.** Pulse Oximetry Screening for Unrecognized Congenital Heart Disease in Neonates. Neonatology Today. December 2010 Vol. 5 Issue 12. http://www.neonatologytoday.net/newsletters/nt-dec10.pdf
3. **de-Wahl Granelli 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. http://www.bmj.com/content/338/bmj.a3037
4. **Riede et al.** Effectiveness of neonatal pulse oximetry screening for detection of critical congenital heart disease in daily clinical routine—results from a prospective multicenter study. European Journal of Pediatrics. August 2010 Vol. 169 Issue 8. http://link.springer.com/article/10.1007/s00431-010-1160-4/fulltext.html
5. **Ewer et al.** Pulse oximetry screening for congenital heart defects in newborn infants (PulseOx): a test accuracy study. The Lancet. August 2011 Vol. 378 Issue 9793. http://www.ncbi.nlm.nih.gov/pubmed/21820732
6. **Mahle et al.** Endorsement of Health and Human Services Recommendation for Pulse Oximetry Screening for Critical Congenital Heart Disease. Pediatrics. January 2012 Vol. 129 Issue 1. http://pediatrics.aappublications.org/content/129/1/190
7. **Garg et al.** Rapid Implementation of Pulse Oximetry Newborn Screening to Detect Critical Congenital Heart Defects — New Jersey, 2011. MMWR. 2013;62(15); 292-294. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6215a4.htm
8. **Garg et al.** Results from the New Jersey Statewide Critical Congenital Heart Defects Screening Program. Pediatrics. July 2013 Vol. 132 No. 2. http://pediatrics.aappublications.org/content/early/2013/07/10/peds.2013-0269
9. **Peterson et al.** A Public Health Economic Assessment of Hospitals' Cost to Screen Newborns for Critical Congenital Heart Disease. Public Health Reports. January-February 2014 Vol. 129. http://www.publichealthreports.org/issueopen.cfm?articleID=3134
10. **Peterson et al.** Cost-Effectiveness of Routine Screening for Critical Congenital Heart Disease in US Newborns. Pediatrics. September 2013 Vol. 132 Issue 3. http://pediatrics.aappublications.org/content/132/3/e595.full
11. **New Study Findings: How Cost-Effective is Screening for Critical Congenital Heart Defects?** Division of Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. February 23, 2016. http://www.cdc.gov/ncbddd/heartdefects/features/keyfindings-cost-screening-cchd.html
12. **Critical congenital heart disease.** Genetics Home Reference. U.S. National Library of Medicine. February 29, 2016. https://ghr.nlm.nih.gov/condition/critical-congenital-heart-disease
13. **Peterson et al.** Late Detection of CCHD among US infants. JAMA Pediatrics. April 2014 Vol. 168, No. 4. http://www.ncbi.nlm.nih.gov/pubmed/24493342
14. **Mahle et al.** Role of Pulse Oximetry in Examining Newborns for Congenital Heart Disease: A Scientific Statement from the AHA and AAP. Pediatrics. August 2009 Vol. 124, No. 2. http://pediatrics.aappublications.org/content/124/2/823
15. **Ailes et al.** Estimated Number of Infants Detected and Missed by Critical Congenital Heart Defect Screening. Pediatrics. June 2015 Vol. 135 No. 6. http://pediatrics.aappublications.org/content/early/2015/05/06/peds.2014-3662
16. **Liberman et al.** Delayed diagnosis of critical congenital heart defects: Trends and associated factors. Pediatrics. 2014; 134;e373; originally published online July 28, 2014; http://pediatrics.aappublications.org/content/134/2/e373
17. **Wren C, Richmond S, Donaldson L.** Presentation of congenital heart disease in infancy: implications for routine examination. Archives of Disease in Childhood Fetal and Neonatal Edition. 1999;80(1):F49-F53. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1720871/
18. **Bakr, AF and Habib, HS.** Combining pulse oximetry and clinical examination in screening for congenital heart disease. Pediatric Cardiology. November 2005-December 2006 Vol. 26 Issue 6. http://www.ncbi.nlm.nih.gov/pubmed/16088415
19. **Thangaratinam et al.** Pulse oximetry screening for critical congenital heart defects in asymptomatic newborn babies: a systematic review and meta-analysis. Lancet. June 2012 Vol. 379 Issue 9835. http://www.ncbi.nlm.nih.gov/pubmed/22554860

Additional Resources

Additional CCHD Screening information:

- **New Jersey Department of Health**

  New Jersey Department of Health Critical Congenital Heart Defects: http://www.state.nj.us/health/fhs/nbs/critical-congenital-heart-defects/ (Resources include: Newborn Screening for Critical Congenital Heart Defects (CCHD) Using Pulse Oximetry course information; New Jersey Recommended Screening Algorithm; Quick Reference Guide; Birth Defects Registry (BDR) Worksheet; Parent Information; NJ Screening Results by Year)

- **American Academy of Pediatrics**

  Newborn Screening for CCHD: Frequently Asked Questions: http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Newborn-Screening-for-CCHD.aspx

- **New Jersey Chapter, American Academy of Pediatrics**

  CCHD Screening information for providers and parents: http://njaap.org/programs/critical-congenital-heart-defects/

New Jersey Department of Health Reference Documents:

- Page 24: Screening Algorithm for Critical Congenital Heart Disease - Recommendations from New Jersey Department of Health
- Page 25: Quick Reference Guide CCHD Screening
- Pages 26-28: NJ Birth Defects Registry (BDR) Pulse Oximetry Work Sheet
- Page 29: Newborn Screening For Congenital Heart Defects: Information for Parents (English)
- Page 30: Newborn Screening For Congenital Heart Defects: Information for Parents (Spanish)
- Page 31: Newborn Screening For Congenital Heart Defects: Information for Parents (Arabic)
- Page 32: Newborn Screening For Congenital Heart Defects: Information for Parents (Hindi)
- Page 33: Newborn Screening For Congenital Heart Defects: Information for Parents (Korean)
- Page 34: Newborn Screening For Congenital Heart Defects: Information for Parents (Polish)

For More Information, Contact:

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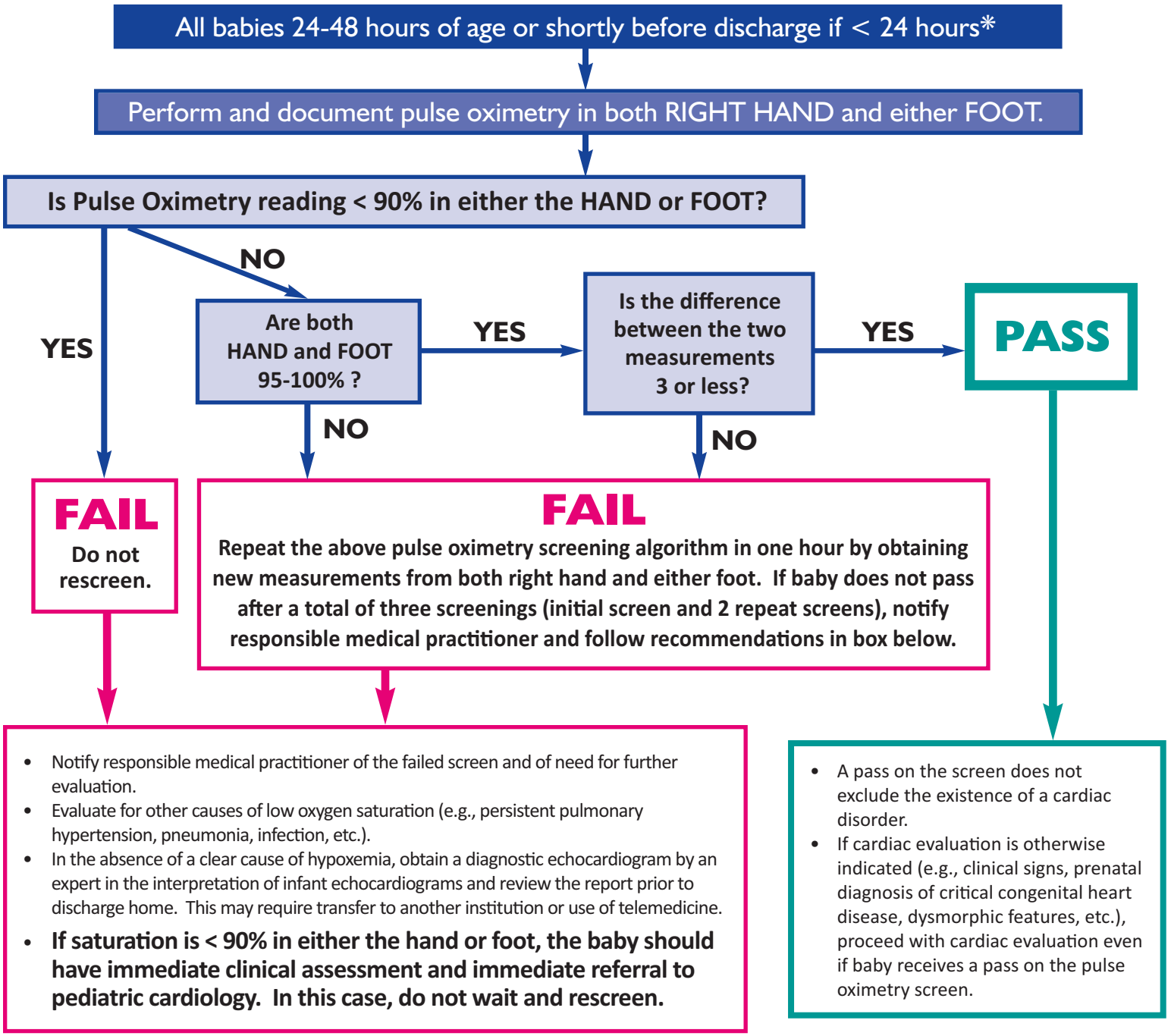
  rgrazel@njaap.org

Screening Algorithm for Critical Congenital Heart Disease

Recommendations from the New Jersey Department of Health



- Notify responsible medical practitioner of the failed screen and of need for further evaluation.
- Evaluate for other causes of low oxygen saturation (e.g., persistent pulmonary hypertension, pneumonia, infection, etc.).
- In the absence of a clear cause of hypoxemia, obtain a diagnostic echocardiogram by an expert in the interpretation of infant echocardiograms and review the report prior to discharge home. This may require transfer to another institution or use of telemedicine.
- **If saturation is < 90% in either the hand or foot, the baby should have immediate clinical assessment and immediate referral to pediatric cardiology. In this case, do not wait and rescreen.**

- A pass on the screen does not exclude the existence of a cardiac disorder.
- If cardiac evaluation is otherwise indicated (e.g., clinical signs, prenatal diagnosis of critical congenital heart disease, dysmorphic features, etc.), proceed with cardiac evaluation even if baby receives a pass on the pulse oximetry screen.

- Optimal results are obtained by using a motion-tolerant pulse oximeter that reports functional oxygen saturation, has been validated in low perfusion conditions, has been cleared by the FDA for use in newborns, and has a 2% root-mean-square accuracy.
- Document results in medical record.
- Screen in the right hand and one foot, either in parallel or direct sequence.
- Apply probe to lateral aspect of right hand and foot in areas that are clean and dry. The two sensors (light emitter and detector) should be placed directly opposite of each other.
- Administration of supplemental oxygen may alter the interpretation of the screening result. For infants requiring supplemental oxygen, delay this screening algorithm until infant is stable in room air. For infants being discharged home on supplemental oxygen, perform screen prior to discharge and review results with responsible medical practitioner.
- Symptomatic babies require clinical evaluation.
- This screening algorithm should not take the place of clinical judgment or customary clinical practice.

*** In the NICU, screening should be performed at 24-48 hours of age or as soon as medically appropriate after 24 hours of age. Screening must be performed prior to transfer out of the hospital at ≥ 24 hours of age. In all cases, screening should be performed prior to discharge to home.**

Adapted from the Secretary's Advisory Committee on Heritable Diseases in Newborns and Children (SACHDNC) Expert Panel Workgroup's Preliminary Recommendations, Jan. 2011. C1938

Quick Reference Guide CCHD Screening

- Congenital Heart Disease (CHD) is the most common birth defect affecting about 9/1,000 live births. Early detection of critical congenital heart defects (CCHDs) is crucial to reduced morbidity, better surgical outcome, and improved survival.
- Pulse oximetry screening detects heart defects that are usually associated with hypoxia. Screening is most likely to detect these seven types of CCHDs:
  - hypoplastic left heart syndrome, pulmonary atresia (with intact septum), tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, and truncus arteriosus.
- Other conditions causing hypoxemia may also be detected at the time of screening.
- CCHD screening using pulse oximetry is mandated even if a prenatal diagnosis of CHD has been made or a neonatal echocardiogram has been obtained.
- In all cases, a screening must be performed prior to discharge to home or transfer out of the hospital at greater than 24 hours of age. Screening should be performed as soon as medically appropriate in the NICU.
- In cases of early discharge to home before 24 hours of age, screening is recommended as close to discharge as possible.
- For best results, ensure the infant is calm, warm and awake (or not in deep sleep) for the screening.
- It is possible for an infant with CCHD to have a normal pulse ox reading at the time of the screen. A negative screen does not rule out all heart disease.
- Signs and symptoms of CHD include feeding problems, poor weight gain, sweating around the head especially during feeding, tachypnea , increased sleepiness, and color changes.
- The results of the screening should be communicated to the parents before discharge.
- Screening results should be included in the discharge summary for the primary care provider and in the hand off report to the receiving hospital if infant is transferred.
- **The screening should not take the place of customary clinical practice, evaluation or intervention.**
- **For all FAILED screens, refer to the NJ recommended screening algorithm and/or unit policy for timely evaluation before discharge.**
- **Failed screens must be reported to the NJ Birth Defects Registry.**

NJ Recommended Screening Algorithm (abridged)

FAIL= 89% or less pulse ox reading in EITHER hand or foot. Do not re-screen.

FAIL= 94% or less pulse ox in EITHER hand or foot, OR a difference of 4% or more between hand and foot after repeating X 2.

RESCREEN= 94% or less pulse ox in EITHER hand or foot, OR a difference of 4% or more between hand and foot. Repeat in 1 hour up to 2 X for total of 3.

PASS= 95-100% in BOTH hand and foot AND a difference of 3% or less (initial or repeat).

NJ Birth Defects Registry Pulse Oximetry Work Sheet

Child Demographics

Last Name: _____ First Name: _____

Date of Birth (mm/dd/yyyy): _____ Time of Birth (military e.g.14:00): _____

Residency: ☐ NJ Resident ☐Out-of-State Resident (Reminder: out of state residents who are born in a NJ facility must be registered with the BDR)

1. Location where infant was a patient at time of screen.

☐Mother-Infant Unit/Well Baby Nursery

☐NICU/Special Care Nursery:

_____weeks gestational age at birth

Reason for NICU/SCN admission:_____

2. Did the infant have a prenatal diagnosis of Congenital Heart Disease (CHD)?

☐Yes– Describe findings: _____

_____

☐No prenatal diagnosis of CHD

3. Was a cardiac consult or echocardiogram indicated or ordered PRIOR to the pulse oximetry screen?

☐ No

☐ Yes – Consult and echo ordered

☐ Yes – Consult only ordered

☐ Yes – Echo only ordered

Echo

Date _____ Time (military e.g.14:00)_____

Results _____

_____

Reason the consult or echo was ordered: ☐ Prenatal indication ☐ Routine unit test for premature infant if indicated

☐ Infant symptomatic/sick ☐ Other, please describe _____

4. Was a cardiac consult or echocardiogram done IN RESPONSE to the failed pulse oximetry screen?

☐ No

☐ Yes – Consult and echo done

☐ Yes – Consult only done

☐ Yes – Echo only done

Echo

Date _____ Time (military e.g.14:00)_____

Results _____

_____

5. Was the infant placed on pulse oximetry for any reason other than the mandated screening?

☐ No, pulse oximetry applied for screening only

☐ Routine monitoring in NICU/SCN

☐ Response to symptoms or clinical history. Describe_____

_____

6. Was the infant asymptomatic at the time of the screening?

☐ Yes, did not have symptoms when screening performed
☐ No, had symptoms at time of screening
Indicate symptoms present: ☐ Pallor ☐ Cyanosis ☐ Tachypnea ☐ Tachycardia
☐ Respiratory Distress ☐ Desaturations ☐Apnea ☐ Bradycardia
Other, please describe _____
☐ Unknown

7. Was infant transferred?

☐ NOT transferred ☐ Transferred to NICU/SCN in your facility
☐ Transferred INTO facility ☐ Transferred OUT of facility ☐ Transferred INTO AND OUT of facility

Transferred to:	Transferred from:
Name of hospital _____	Name of hospital _____
Date of transfer (mm/dd/yyyy) _____	Date of transfer _____
Time of transfer (military e.g.14:00) _____	Time of transfer (military e.g.14:00)_____

8. Reason for failed screen. What is the final diagnosis that explains the failed pulse oximetry screening?

Cardiac Defects:

☐ Aortic Arch Atresia	☐ Pulmonary Stenosis
☐ Aortic Arch Hypoplasia	☐ Single Ventricle
☐ Coarctation of the Aorta	☐ Tetrology of Fallot
☐ Double-outlet Right Ventricle	☐ Total Anomalous Pulmonary Venous Return
☐ Ebstein Anomaly	☐ Transposition of the Great Arteries
☐ Hypoplastic Left Heart Syndrome	☐ Tricuspid Atresia
☐ Interrupted Aortic Arch	☐ Truncus Arterious
☐ Pulmonary Atresia, intact septum	☐ Ventricular Septal Defect

Other Cardiac Defect(s) – Describe: _____

_____

Non-Cardiac explanation: _____

_____

Normal evaluation after failed screen, explanation: _____

_____

☐ Pending diagnosis – explain: _____

Pulse Ox Screening Results (Enter all screening results.)

Result 1

Screen Date (mm/dd/yyyy): _____
Screen Time (military e.g.14:00) _____

Reading 1: _____%
Site 1: ☐ Right Hand ☐ Left Hand ☐ Right Foot ☐ Left Foot ☐ Other: _____

Reading 2: _____%
Site 2: ☐ Right Hand ☐ Left Hand ☐ Right Foot ☐ Left Foot ☐ Other: _____

Result 2

Screen Date (mm/dd/yyyy): _____
Screen Time (military e.g.14:00) _____

Reading 1: _____%
Site 1: ☐ Right Hand ☐ Left Hand ☐ Right Foot ☐ Left Foot ☐ Other: _____

Reading 2: _____%
Site 2: ☐ Right Hand ☐ Left Hand ☐ Right Foot ☐ Left Foot ☐ Other: _____

Result 3

Screen Date (mm/dd/yyyy): _____
Screen Time (military e.g.14:00) _____

Reading 1: _____%
Site 1: ☐ Right Hand ☐ Left Hand ☐ Right Foot ☐ Left Foot ☐ Other: _____

Reading 2: _____%
Site 2: ☐ Right Hand ☐ Left Hand ☐ Right Foot ☐ Left Foot ☐ Other: _____

Newborn Screening
For Congenital Heart Defects

Information for Parents

A Lifesaving Law

NJ was one of the first states in the country to pass a law that all newborns need to have a screening test for Congenital Heart Defects (CHDs). Your baby will be tested for certain types of heart defects before leaving the hospital.

What are Congenital Heart Defects?

Congenital Heart Defects (CHDs) are problems with the way the heart formed or the way blood flows through the heart. Some CHDs can make a baby sick soon after birth. It is important that babies are tested for these heart defects before going home from the hospital.

How is the CHD screening test done?

The CHD screening test uses pulse oximetry or pulse ox for short. Pulse ox is a way to check the amount of oxygen in the baby's blood. This quick and simple test is done with a machine called a pulse oximeter. A sensor with a small light is placed on the baby's hand and foot and is attached to the pulse oximeter to check the baby's oxygen level. Low oxygen in the blood can be a sign of a CHD.

Test results

Sometimes a healthy newborn may have a low pulse ox reading. A low pulse ox reading could also mean there is a heart or breathing problem. If your baby's CHD screening test shows low oxygen levels in the blood, more tests may be needed to find out the cause.

Importance of Regular Check-ups

It is important to bring your baby to all regular check-up visits. The pulse ox test picks up many, but not all types of heart problems at birth. There is a chance that a baby may have a normal pulse ox test and still have a heart defect. Babies who have heart problems may seem very sleepy, have a hard time eating, breathe fast, or look pale or bluish in color. Call your baby's health care provider if you notice anything unusual about the way your baby looks or acts.

If you have any questions about CHD or pulse oximetry, talk to your baby's health care provider.

For more information about CHD screening contact:
NEW JERSEY DEPARTMENT OF HEALTH
Phone 609•292•1582
Fax 609•943•5752
www.newbornscreening.nj.gov

More information on **Congenital Heart Defects** is available at
www.cdc.gov/ncbddd/heartdefects/

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Exámenes a Recién Nacidos para Detectar Defectos Cardiacos Congénitos

Información para los Padres

Una Ley para Salvar Vidas

Nueva Jersey fue uno de los primeros estados del país en aprobar una ley que establece que todos los recién nacidos deben tener una prueba de detección de cardiopatías congénitas. Su bebé será examinado para detectar ciertos tipos de defectos cardíacos antes de salir del hospital.

¿Qué son los Defectos Cardiacos Congénitos?

Los Defectos Cardiacos Congénitos (CHDs, por sus siglas en inglés) son problemas relacionados con la manera en que el corazón se ha formado o la forma como la sangre fluye a través del corazón. Algunas cardiopatías congénitas pueden afectar a su bebé y enfermarlo al poco tiempo de haber nacido. Es importante que los bebés sean examinados para detectar estos defectos del corazón antes de salir del hospital.

¿Cómo se realizan los exámenes de detención de Defectos Cardiacos Congénitos?

Para realizar la prueba de detección de defectos cardiacos congénitos se efectúa una oximetría de pulso. La oximetría de pulso es una forma de comprobar la cantidad de oxígeno en la sangre del bebé. Esta prueba rápida y sencilla se hace con una máquina llamada oxímetro de pulso. Un sensor del oxímetro con una pequeña luz se coloca en la mano del bebé y en el pie para verificar el nivel de oxígeno del bebé. Un nivel bajo de oxígeno en la sangre puede ser un indicador de un defecto cardiaco congénito.

Resultados del Examen

A veces un recién nacido sano puede tener un nivel bajo de oxigeno en la sangre de acuerdo al oxímetro de pulso. Una lectura baja del oxímetro puede significar que hay un problema cardíaco o respiratorio. Si la prueba de detección de defectos cardiacos congénitos muestra niveles bajos de oxígeno en la sangre, será necesario hacer otros exámenes para determinar la causa de esto.

Importancia de las Revisiones Periódicas

Es importante llevar a su bebé a todos los chequeos regulares con el médico. La prueba con el oxímetro detecta muchos, pero no todos los tipos de problemas congénitos del corazón. Existe la posibilidad de que un bebé pueda tener una oximetría de pulso normal y aún tener un defecto cardíaco. Los bebés que tienen problemas del corazón pueden padecer de mucho sueño, tener dificultad para comer, respirar rápido o lucir pálidos o de color azulado. Llame a su pediatra si nota algo raro en la forma en que su bebé luce o se comporta.

Si usted tiene alguna pregunta acerca de los Defectos Cardiacos Congénitos o la oximetría de pulso, hable con su pediatra.

Para más información sobre los Exámenes de Defectos Cardiacos Congénitos contacte al:
DEPARTAMENTO DE SALUD DE NEW JERSEY
Teléfono 609•292•1582
Fax 609•943•5752
www.newbornscreening.nj.gov

Más información sobre los **Defectos Cardiacos Congénitos** está disponible en
www.cdc.gov/ncbddd/heartdefects/

6/2015

C2208

فحص حديثي

الولادة لعيوب القلب الخلقية

معلومات لأولياء الأمور

قانون منقذ للحياة

إن ولاية نيوجيرزي من أول الولايات في الدولة، التي اصدرت قانون بلزوم عمل فحص لجميع حديثي الولادة خاص بعيوب القلب الخلقية،سيتم فحص طفلك لأنواع خاصة في عيوب القلب الخلقية قبل أن يخرج من المستشفى.

ما هي عيوب القلب الخلقية؟

إن عيوب القلب الخلقية عبارة عن مشاكل في تكوين القلب أو بالطريقة التي يتم ضخ الدم إلى القلب. بعض العيوب الخلقية قد تجعل الطفل مريضاً بعد الولادة مباشرةً. من المهم ان يتم الفحص للأطفال لمثل هذه المشاكل الخلقية في القلب قبل الخروج من المستشفى و الذهاب إلى المنزل.

كيف يتم فحص القلب للعيوب الخلقية؟

إن فحص القلب للعيوب الخلقية يُستخدم فيه جهاز تأكسج النبض، حيث يتم فحص كمية الأكسجين في دم الطفل.هذا الفحص السريع و البسيط يتم بإستخدام جهاز النبض التأكسجي و هو عبارة عن جهاز استشعار مع ضوء صغير يوضع في يد الطفل و قدمه، و يتم ايصاله بالجهاز حتى نفحص مستوى الأكسجين في الدم للطفل. إن إنخفاض معدل الأكسجين في الدم قد يدل على عيوب قلب خلقية.

نتائج الفحص

يمكن لأحد الأطفال ان يحصلوا على قرائة نسبة قليلة من الأكسجين و لكن هذا قد يعني مشكلة في القلب أو مشكلة في التنفس، و إذا كان افحص قد أظهر قلة الأكسجين في الدم فيجب أن يتم عمل فحوصات أخرى لمعرفة السبب.

أهمية الفحوصات المنتظمة

من المهم أن يقوم طفلكبالفحوصات المنتظمة، إن فحص النبض التأكسجي قد يظهر كير من انواع عيوب القلب الخلقية و لكن ليس كلها. قد يحصل الطفل على نتائج فحص طبيعية و لكن يوجد عنده عيب في القلب. إن الأطفال ذوي المشاكل القلبية يكونوا عادة خاملين جداً، عنده صعوبة في الأكل، يتنفس بسرعة، أو يظهر عليه الشحوب او اللون الأزرق. عليك بالإتصال بمقدم الرعاية الصحية إذا لاحظت أي شكل أو تصرف غير طبيعي لطفلك.

إذا كانت لديك أي أسئلة حول عيوب القلب الخلقية أو النبض التأكسجي،
الرجاء التحدث مع مقدم الرعاية الصحية الخاص بك.

للمزيد من المعلومات حول عيوب القلب الخلقية الإتصال بِ:
قسم الصحة لولاية نيوجيرزي
هاتف رقم: 609-292-1582
فاكس: 609-943-5752
www.newbornscreening.nj.gov

و معلومات اضافية حول عيوب القلب الخلقية في الموقع التالي
www.cdc.gov/ncbddd/heartdefects/

नवजात स्क्रीनिंग जन्मजात हृदय दोष के लिए

माता पिता के लिए जानकारी

जीवन रक्षक कानून
न्यू जर्सी देश का पहला ऐसा प्रान्त है जिसने यह कानून बनाया है कि सभी नवजात शिशुओं को अस्पताल छोड़ने से पहले जन्मजात हृदय दोष का परीक्षण देना होगा।

जन्मजात हृदय दोष क्या है?
जन्मजात हृदय दोष वह समस्याय हैं कि किस प्रकार से हृदय का निर्माण होता है और किस प्रकार से रक्त का संचरण होता है। कुछ जन्मजात हृदय दोष नवजाता को जन्म के बाद जल्दी ही रोगी बना सकते हैं। यह महत्तपूर्ण है कि नवजात बच्चे का अस्पताल से जाने से पूर्व हृदय दोष के लिये परीक्षण किया जाए।

जन्मजात हृदय दोष का परीक्षण कैसे किया जाता है?
जन्मजात हृदय दोष की परख नाड़ी स्पंदन ऑक्ज़िमेट्री या नाड़ी स्पंदन ऑक्ज़ से किया जाता है। यह नवजात के रक्त मे आक्सीजन नापने की विधि है। यह परीक्षण आसान है और जल्दी से हो जाता है। एक संवेदक एक छोटे बल्ब के साथ बच्चे के हाथ और पैर पर रखा जाता है और इसको नाड़ी स्पंदन ऑक्ज़िमेट्री से जोड़ दिया जाता है। और शरीर के आक्सीजन स्तर का पता लगाया जाता है। शरीर मे आक्सीजन का कम स्तर जन्मजात हृदय दोष की निशानी है।

परीक्षण का परीणाम
कभी कभी एक स्वस्थ बच्चें में कम नाड़ी स्पदन का स्तर हो सकता हैं। एक कम नाड़ी स्पदन माप से हृदय और साँस की समस्यायें हो सकती हैं। अगर आपके बच्चे का जन्मजात हृदय दोष परीक्षण आक्सीजन का स्तर रक्त में दिखा रहा है तो इसका कारण जाननें के लिए और अधिक परीक्षणों की आवश्यकता होगी।

नियमित परीक्षण की महत्ता
नवजात को सभी नियमित परीक्षण के लिए लाना जरूरी है। नाड़ी स्पंदन ऑक्ज़िमेट्री बहुत सारे हृदय दोषों को बतस सकता है लेकिन सभी दोषों को नहीं। नाड़ी स्पंदन सामान्य होने पर भी हृदय दोष हो सकता है। जिन नवजात में हृदय दोष होता है वह नींद में दिखाई देते हैं, खाना खाने में समस्या होती है, साँस तेज चलती है और नीले या पीले रंग के दिखाई देते हैं। यदि आपको अपने बच्चें में कुछ भी असामान्य दिखे या महसूस हो या उसके क्रियाकालापों में दिखाई तो अपने क्षेत्र के स्वास्थ्य कर्मचारी को कॉल करें।

अगर आपको कुछ जन्मजात हृदय दोष या नाड़ी स्पंदन ऑक्ज़िमेट्री के बारे में पूछना है तो कृप्या अपने क्षेत्र के स्वास्थ्य कर्मचारी से बात करें।

जन्मजात हृदय दोष परीक्षण की अधिक जानकारी के लिए सम्पर्क करें।

न्यू जर्सी स्वास्थ्य विभाग
Phone 609•292•1582
Fax 609•943•5752
www.newbornscreening.nj.gov

जन्मजात हृदय दोष की अधिक जानकारी उपलब्ध है:
www.cdc.gov/ncbddd/heartdefects/

3/2016 Hindi

C2272

신생아 선별검사

선천성 심장결함

부모님들을 위한 정보

A Lifesaving Law 인명구조 법

뉴저지는 모든 신생아들의 선천성 심장결함 (CHDs) 선별검사를 위한 법을 최초로 통과시킨 주입니다. 새로 태어난 당신의 아이는 병원을 나가기 전에 심장에 어떤 종류의 결함이 있는가에 관한 검사를 하게 되어있습니다.

What are Congenital Heart Defects? 선천성 심장결함이란?

선천성 심장 결함 (CHDs)은 심장이 형성되는 것에 문제가 있거나 심장 혈류의 흐르는 방식이 비정상적인 경우를 말합니다. 어떤 종류의 선천성 심장결함(CHDs) 는 아기가 생후 질환을 갖게 할수 있습니다. 그러므로 신생아가 집으로 퇴원하기 전에 선별검사를 받는 것이 매우 중요합니다.

How is the CHD screening test done? 어떻게 CHD 선별검사를 받나요?

선별검사는 산소 포화도 정상범위 측정을 통하여 이루어 집니다. 이 검사는 비교적 간단하고 단시간에 이루어지며, 산소포화도 측정기라는 기계를 사용합니다. 불빛이 들어오는 작은 센서를 아기의 손과 발위에 올려놓고 산소포화도 측정기와 연결하여 아기의 산소 지수를 측정합니다.

Test results 검사결과

어떤 때는 건강한 신생아도 낮은 수치의 산소포화도 지수를 보일 때가 있습니다. 낮은 산소포화도 지수는 숨쉬기나 심장에 문제가 있다는 징후일 수 있습니다. 만일, 당신 아기의 CHD 선별검사가 낮은 산소포화도를 보인다면, 더 많은 검사를 통하여 원인을 알아야 할 필요가 있습니다.

Importance of Regular Check-ups 주요한 정기검진들

아기의 정기검진은 매우 중요합니다. 산소포화도 검사는 많은 문제들을 발견해 낼 수 있지만 신생아의 모든 심장이상을 알아낼 수는 없습니다. 아기가 정상적인 산소포화도를 가지고 있어도 때로는 심장에 결함이 있는 경우가 있습니다. 아기가 항상 졸려하거나, 음식을 먹기 힘들어 하거나, 숨쉬기를 힘들어 하거나, 또는 창백한 빛깔을 보인다면 심장에 문제가 있을 수 있습니다. 아기의 모습이나 행동이 정상과 다르게 보인다면 아기의 주치의에게 연락하시기 바랍니다.

CHD 선별검사, 또는 산소포화도 검진에 관한 질문이 있으시면 아기의 주치의에게 연락하세요.

선천성 심장결함 (CHDs) 선별검사에 관한 정보는 아래로 연락하시기 바립니다:

NEW JERSEY DEPARTMENT OF HEALTH 뉴저지 보건국

Phone 609•292•1582

Fax 609•943•5752

www.newbornscreening.nj.gov

More information on **Congenital Heart Defects** is available at
www.cdc.gov/ncbddd/heartdefects/

C2167

3/2015 Korean

Badanie noworodków w celu wykrycia Wrodzonych wad serca

Informacja dla rodziców

Prawo ratujące życie

New Jersey jest jednym z pierwszych stanów w kraju, który przyjął prawo mówiące o konieczności badania wszystkich noworodków w celu wykrycia wrodzonych wad serca. Twoje dziecko zostanie poddane testom na pewne rodzaje wad serca zanim opuści szpital.

Czym są wrodzone wady serca?

Wrodzone wady serca to problemy związane ze sposobem, w jaki jest uformowane serce lub sposobem, w jaki krew przepływa przez serce. Niektóre wrodzone wady serca mogą sprawić, że dziecko zachoruje niedługo po urodzeniu. Bardzo ważne jest, by dzieci były badane pod kątem występowania takich wad serca zanim zostaną wypisane ze szpitala do domu.

W jaki sposób jest przeprowadzane badanie w celu wykrycia wrodzonych wad serca?

Podczas badania na obecność wrodzonych wad serca stosuje się pulsoksymetrię lub w skrócie pulse ox. Pulse ox jest metodą sprawdzania ilości tlenu w krwi dziecka. To szybkie i proste badanie jest wykonywane przy użyciu maszyny nazywanej pulsoksymetrem. Czujnik z małym światełkiem jest umieszczany na dłoni i stopie dziecka i jest podłączany do pulsoksymetru by sprawdzić poziom tlenu dziecka. Niski poziom tlenu może być oznaką wrodzonej wady serca.

Wyniki badania

Czasami zdrowy noworodek może mieć niski odczyt pulse ox. Niski odczyt pulse ox może również oznaczać problemy z sercem lub oddychaniem. Jeśli badanie w celu wykrycia wrodzonych wad serca u twojego dziecka wykaże niski poziom tlenu we krwi, potrzebne mogą być dalsze badania w celu wykrycia przyczyny.

Istota regularnych badań

Ważnym jest, aby przyprowadzać dziecko a wszystkie regularne badania. Pulse ox wykrywa wiele, ale nie wszystkie rodzaje wrodzonych wad serca. Istnieje prawdopodobieństwo, że dziecko może mieć wyniki badania pulse ox w normie, ale nadal może mieć wadę serca. Dzieci, które mają problem z sercem mogą wydawać się bardzo ospałe, mieć trudności z jedzeniem, oddychać szybko lub wyglądać blado lub sino. Zadzwoń do lekarza twojego dziecka, jeśli zauważysz coś nietypowego w wyglądzie lub zachowaniu twojego dziecka.

Jeśli masz jakiekolwiek pytania odnośnie wrodzonych wad serca lub pulsoksymetrii, porozmawiaj z lekarzem twojego dziecka.

Po więcej informacji na temat badania w celu wykrycia wrodzonych wad serca skontaktuj się z:
NEW JERSEY DEPARTMENT OF HEALTH
Telefon 609-292-1582, Fax 609-943-5752
www.newbornscreening.nj.gov

Więcej informacji na temat **wrodzonych wad serca** jest dostępnych na stronie www.cdc.gov/ncbddd/heartdefects/

3/2015 Polish

C2168

New Jersey Department of Health
Division of Family Health Services
Special Child Health and Early Intervention Services
Critical Congenital Heart Defects (CCHD) Screening Program
P.O. Box 364
Trenton, NJ 08625
609-984-0755
http://www.state.nj.us/health/fhs/nbs/critical-congenital-heart-defects/

New Jersey Chapter, American Academy of Pediatrics
50 Millstone Road, Building 200, Suite 130
East Windsor, NJ 08520
609-842-0014
http://njaap.org/programs/critical-congenital-heart-defects/

Rutgers, The State University of New Jersey
Office of Continuing Professional Education
102 Ryders Lane
New Brunswick, NJ 08901
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