Toolkit for Implementation of Pulse Oximetry Screening for Critical Congenital Heart Disease



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About Critical Congenital Heart Disease (CCHD) & Pulse Oximetry Screening

Congenital Heart Disease (CHD) is the most common birth defect. Infants born with CHD have an abnormal heart structure which creates abnormal blood flow patterns. A group of heart defects that often cause life-threatening symptoms soon after birth are known as Critical Congenital Heart Disease (CCHD). Approximately 18 per 10,000 infants in the United States have CCHD. Infants diagnosed with CCHD will often require surgical interventions within the first year of life; however, CCHD is often treatable if detected early. The complications of CCHD can vary widely. In mild cases, the infant may not require surgery, but in severe cases, the infant may need multiple surgeries during their childhood.

A challenge of diagnosing CCHD is that some infants who have CCHD look and act healthy during the first few days of life. Physical examination alone can diagnose almost half of CCHD cases. Pulse oximetry screening also detects many cases of CCHD. A pulse oximetry screening includes performing pre-and post-ductal saturations (pulse ox of the right hand and either foot) on an infant after 24 hours of age. Not all infants who do not pass the pulse oximetry screening have CCHD; there are other reasons for decreased oxygen saturations such as pulmonary or vascular transitioning problems. It is also possible that a baby with CCHD can have a normal pulse oximetry reading, thus resulting in a false negative screening.

The seven most frequently occurring CCHD conditions that pulse oximetry screening can identify are:

- hypoplastic left heart syndrome
- pulmonary atresia
- tetralogy of fallot
- total anomalous pulmonary venous return (TAPVR)
- transposition of the great arteries (TGA)
- tricuspid atresia
- truncus arteriosus

Pulse oximetry screening for CCHD is recommended by the United States Department of Health and Human Services (HHS), the American Academy of Pediatrics (AAP), the American College of Cardiology Foundation (ACCF), and the American Heart Association (AHA).

CCHD SCREENING PROTOCOL

Critical Congenital Heart Disease (CCHD) Screening Protocol for Non-NICU Population

Policy: All newborns admitted to the newborn nursery will receive a screening for CCHD by trained

RNs/CNAs prior to discharge.

Purpose: A safe, effective, and reliable method to detect cases of CCHD using pulse oximetry screening.

1. Upon admission to the maternity unit, the mother and/or family will receive information on CCHD screening from HEALTH's Newborn Screening Brochure.

2. Infants will be screened after 24 hours of age or as close to discharge as possible for newborns who will be discharged early.

- **3.** Screenings should be completed when the infant is awake, quiet, and calm. If the infant is under phototherapy lights, he/she needs to be removed for the duration of the screening.
- **4.** Pre-ductal and post-ductal saturations will be taken on the right hand and on either foot. They can be conducted separately or simultaneously.
- **5.** To confirm an accurate reading, the pulse oximeter will be observed for a PI value (confidence index) that is equal to or above 1, or for color-coded equipment, green lights should be observed.
- **6.** The pulse oximetry screening algorithm will be posted to help interpret results.
- 7. Pulse oximeter(s) will be stored in a designated area of the newborn nursery when not in use.
- **8.** Reusable pulse oximetry probes need to be properly disinfected after each use with an approved disinfectant, as instructed by the manufacturer.
- **9.** If a parent refuses a CCHD screening, ask them to speak with their pediatric provider. If they still refuse after receiving more information, the parents must complete HEALTH's refusal form.

Result Interpretation:

Pass: • Pulse oximetry saturations are equal to, or greater than, 95% in either extremity with less than a 4% difference between the readings from the right hand and from the foot.

Fail (and corresponding action):

- Any pulse oximetry saturation level equal to or less than 89% in either extremity.
 - Contact newborn's provider immediately and transfer the infant to the NICU.
- Three consecutive pulse oximetry saturation levels of 90%-94% in the right hand and in either foot or a 4% or more difference between the two readings.
 - Notify newborn's provider and contact a pediatric cardiologist for a consult and to perform an echocardiogram.

Critical Congenital Heart Disease (CCHD) Screening Protocol for NICU Population

Policy: All newborns admitted to the Neonatal Intensive Care Unit (NICU) will receive a screening for

CCHD by trained RNs or CNAs prior to discharge.

Purpose: A safe, effective, and reliable method to detect cases of CCHD using pulse oximetry screening.

1. During the infant's NICU stay, the mother and/or family will receive information regarding CCHD screening from HEALTH's Newborn Screening Brochure.

2. Infants will be screened after 24 hours of age. Typically, the screening will be performed one or two days prior to the anticipated discharge date.

- **3.** For infants who are receiving oxygen, the screening should not be performed until the infant has been on room air only for at least 24 hours.
- **4.** Screenings should be completed when the infant is awake, quiet, and calm. If the infant is under phototherapy lights, he/she needs to be removed for the duration of the screening.
- **5.** Pre-ductal and post-ductal saturations will be taken on the right hand and on either foot. They can be conducted separately or simultaneously.
- **6.** To confirm an accurate reading, the pulse oximeter will be observed for a PI value (confidence index) that is equal to or above 1, or for-color-coded equipment, green lights should be observed.
- **7.** The pulse oximetry screening algorithm will be posted to help interpret results.
- **8.** For patients who are being discharged on oxygen, an echocardiogram (ECHO) should be performed instead of the CCHD screening. If an ECHO has already been performed, during the infant's NICU stay, a CCHD screening does not need to be done. (On the CCHD screening form, check off "ECHO performed" in the "patient ineligible section".)
- **9.** For patients who were diagnosed with CHD Disease prenatally, a CCHD screening does not need to be completed. (On the CCHD screening form, check off "CCHD diagnosis" in the "patient ineligible section".)
- **10.** If a parent refuses a CCHD screening, ask them to speak with their pediatric provider. If they still refuse after receiving more information, the parents must complete HEALTH's refusal form.

Result Interpretation:

Pass: Pulse oximetry saturations are equal to or greater than 95% in either extremity with less than a 4% difference between the right hand and from the foot.

Fail (and corresponding action):

- Any pulse oximetry saturation level equal to or less than 89% in either extremity.
 - Notify the newborn's pediatric provider, consult a pediatric cardiologist, and perform ECHO.
- Three consecutive pulse oximetry saturation levels of 90%-94% in the right hand and in either foot or a 4% or more difference between the two readings.
 - Notify the newborn's pediatric provider, consult a pediatric cardiologist, and perform an ECHO.

Equipment needed for CCHD/Pulse Oximetry Screening

Each birthing facility in Rhode Island is responsible for selecting and purchasing pulse oximetry equipment for CCHD screening of its newborn population if the appropriate equipment is not already available. Equipment must comply with national standards and meet the following requirements:

- Approved by the FDA for use in newborns and neonates
- Validated for use in low-perfusion conditions
- Have a 2% root, mean-square accuracy
- Calibrated on a regular basis based on manufacturer's guidelines

Read FDA clearance for Pulse Oximeter use in Neonates: http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfpmn/pmn.cfm

Supplies for CCHD screening:

- Pulse Oximeter
- Disposable or reusable probe(s)
- Disposable wraps (if utilizing reusable probes)
- Supply cart
- Disinfectant for equipment and reusable probes
- CCHD educational pamphlet for parent/guardian

Critical Congenital Heart Disease (CCHD) Screening: In-Service Training Agenda

Learning Objectives

Upon completion of the training, participants will be able to:

- Explain what CCHD screening is and why it is important.
- List CCHD screening protocols.
- Demonstrate the safe use of pulse oximetry equipment and the use of methods to obtain accurate readings.
- Understand HIPPA standards as they relate to CCHD screenings.
- Explain the CCHD screening algorithm.

Background and Significance

- Congenital Heart Disease (CHD) is the most common birth defect. Infants born with CHD have an abnormal heart structure which creates abnormal blood flow patterns. A group of heart defects that have life-threatening symptoms are referred to as Critical Congenital Heart Disease (CCHD). Cases of CCHD often require surgical interventions within the first year of life.
- CCHD may go undiagnosed because:
 - Prenatal ultrasound identifies less than 50% of all CHD in utero.
 - Physical examination alone is only 50% accurate in diagnosing heart defects.
 - Many infants with CCHD look and act healthy.
- Research has shown that performing a pulse oximetry screening can detect many cases of CCHD. A pulse oximetry screening involves obtaining pre-and post-ductal saturations (pulse oximetry of the right hand and of either foot) after the infant is 24 hours of age.
- Not all infants that fail pulse oximetry screening have CCHD as there are other reasons for decreased oxygen saturations. It is also possible that a baby with CCHD can have a normal pulse oximetry reading, due to a false negative screen.
- Pulse oximetry screening for CCHD has been recommended by the United States Department of Health and Human Services (HHS), the American Academy of Pediatrics (AAP), the American College of Cardiology Foundation (ACCF), and the American Heart Association (AHA).

Protocols:

- Upon admission to the maternity unit, the mother/parents will be provided with the purple Newborn Screening Brochure. The admitting nurse will educate the mother/parents on the metabolic screening, hearing screening and CCHD screening.
- Screening will be completed when the infant is between 24 and 48 hours of age. According to AAP guidelines, the infant must be older than 24 hours. For early discharges, perform screening as close to discharge as possible.
- When possible, conduct the screening while the infant is awake, quiet, and calm.
- ▶ Do not perform pulse oximetry screening on an infant while he/she is crying, cold, or under phototherapy because any of these could affect pulse oximetry saturations.
- Equipment needed: pulse oximeter, reusable or disposable probe, CCHD screening form
- Once completed, the nurse or nursing assistant will complete the Pulse Oximetry Screening Form and give the results to mother/parents (in writing and verbally).

Glossary of Critical Congenital Heart Disease terminology:

- **Ductus Arteriosus:** a fetal blood vessel that connects the aorta and the pulmonary artery before birth
- **Pre-ductal saturation:** the blood-oxygen saturation of blood leaving the aorta before the ductus arteriosus. This blood perfuses the brain. Pre-ductal saturation in newborns is measured on the right hand.
- **Post-ductual saturation:** the arterial blood-oxygen saturation after the blood leaves the heart and before it reaches the ductus arteriosus in the aorta and is related to the part of the aorta distal to the aortic opening of the arterial canal. Post-ductal saturation in newborns is measured on either the right foot or the left foot.

Safe and Accurate Use of Pulse Oximetry:

Using a pulse oximeter

- Turn on equipment.
- Place probe on the right hand and secure with disposable wrap (if using disposable probes).
- Connect cable to pulse oximeter.
- Check the confidence indicator to ensure the equipment is functioning properly.
- Read the saturation results and record the results on the screening form or in the electronic medical record (EMR).
- Disconnect cable from pulse oximetry. (The machine does not need to be turned off.)
- Place the probe on either foot and secure with disposable wrap (if using disposable probe).
- Reconnect cable to pulse oximeter and check confidence indicator again.
- Read saturation results and record on the screening form or in the EMR.
- Provide results to the mother/parent(s)/guardian(s) in writing and verbally.

Before performing pulse oximetry on an infant:

- Review the placement education sheet in your training packet.
- Make sure that the sensor is flush on the infant's skin. There should be no gaps between the infant skin and the sensor.
- Ensure that the infant's skin is clean and dry.
- Ensure that the infant is calm and warm. Swaddle the infant while the pulse oximetry is being done. Cold temperatures, crying, and movement can all impact the accuracy of the reading.
- Check the confidence indicator to make sure the pulse oximeter reading is accurate.
- Never perform pulse oximetry and a blood pressure check at the same time. The blood pressure check will interfere with pulse oximetry reading.
- Phototherapy lights can impact the accuracy of the pulse oximetry reading. If the infant is under phototherapy lights, remove the infant for the duration of the CCHD screening.
- Pulse oximetry readings are not instantaneous. The reading displayed is an average of several measurements.

Health Insurance Portability and Accountability Act (HIPPA)

• As with all medical information, results may only be shared with those participating in the infant's care.

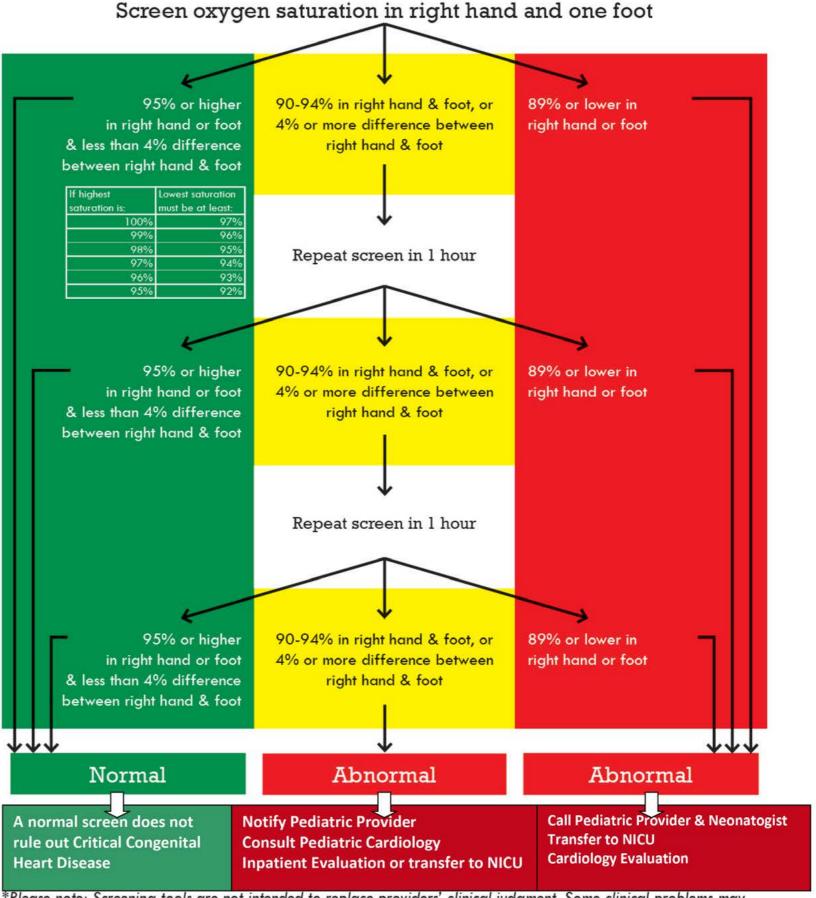
Review Algorithm

See attached algorithm

Newborn Pulse Oximetry Screening for Critical Congenital Heart Disease*

Infant in Well Baby Nursery at age 24 hours to 48 hours

If discharged at less than 24 hours age, perform screening and notify pediatric provider for appropriate outpatient screening.



*Please note: Screening tools are not intended to replace providers' clinical judgment. Some clinical problems may not be adequately addressed in this algorithm.

Suggested Script for Explaining Newborn Screenings to Parent(s)

I am giving you some information on the newborn screenings that your baby will have before you leave the hospital. There are three different screenings:

The first is a newborn blood screening. This is a blood test that all newborns have. He/she will have a small amount of blood collected from his/her heel. The blood is tested to help diagnose metabolic (how the baby digests food) conditions, endocrine (how the body controls its own functions) conditions, and hemoglobin (blood) conditions.

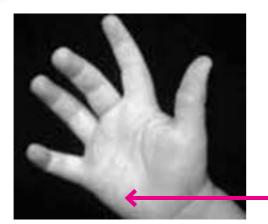
In this purple brochure there is a list of all of the conditions. This blood screening is done after your baby is 24 hours old and the results will be sent to your baby's doctor after you are discharged from the hospital.

The second is the newborn hearing screening. The hearing screening is done by placing a small microphone in your baby's ear. This screening takes about 15 minutes and does not hurt the baby. (Often times the infant sleeps right through the screening.) You will get the results of the hearing screening before you leave the hospital. This procedure is only a screening tool and is not used to diagnose hearing loss. If your baby does not pass this screening, it does not mean he/she has hearing loss. It means that your baby needs further evaluation.

The third screening is for Critical Congenital Heart Disease (CCHD). This screening looks for serious heart problems in newborns. The test is painless and should take only a few minutes. It is done by performing a pulse oximetry (pulse ox) screening. A sensor is placed on your baby's right hand and one of his/her feet. The sensor is then connected to a machine (the pulse oximeter) and measures your baby's oxygen level. This procedure is only a screening tool and is not used to diagnose a heart problem. If your baby does not pass this screening it does not mean he/she has a heart problem. It means that he/she needs further evaluation. Also, this screening is not guaranteed to detect all problems in a baby's heart.

Pulse Oximeter Probe Placement

1. Select application site on the outside, fleshly area of the infant's right hand or of either foot.



Right-hand application site



Foot application site

- 2. Place the photodetector portion of the probe on the fleshy portion of the outside of the infant's right hand or either foot.
- **3.** Place the light emitter portion of the probe on the top of the right hand or either foot. Place the photodetector directly opposite of light emitter, on the bottom of the right hand or either food. The photodetector and emitter must be directly opposite each other in order to obtain an accurate reading.
- **4.** Secure the probe to the infant's right hand or either foot using adhesive or foam tape recommended by the vendor. It is not recommended to use tape to secure probe placement.
- **5.** Some vendors use visual images, such as a star or a bar, to specify which side of the probe should be placed on top of the right hand or either foot.





Critical Congenital Heart Disease (CCHD) Screening: KNOWLEDGE ASSESSMENT

- 1. The following can affect the accuracy of pulse oximetry (pulse ox) reading:
 - a. Movement
 - b. Cold extremities or shivering
 - c. Crying
 - d. Bilirubin lamps and surgical lamps
 - e. All of the above
- 2. True or False: One clean, disposable pulse oximeter probe can be used on up to five patients.
- 3. All of the following can affect the accuracy of the pulse oximeter reading except:
 - a. Placing the pulse oximeter probe on the same extremity that you are taking the blood pressure
 - b. Performing the pulse oximeter screening while the infant is crying
 - c. Using a clip on the finger of an infant
 - d. Infant skin color or jaundice
- 4. True or False: Pulse oximetry screening will detect all forms of Congenital Heart Disease (CHD).
- 5. The screening guidelines state that pulse oximetry should be performed on:
 - a. The right hand
 - b. One foot
 - c. Both a and b
- 6. Pulse oximetry screening should be performed when the infant is:
 - a. Less than 8 hours
 - b. Between 8 and 18 hours
 - c. Greater than 24 hours
 - d. Less than 24 hours
- 7. An infant's pulse oximetry readings should be reported to the infant's pediatric provider if:
 - a. Pulse oximetry readings are greater than 95% (>95%) for both right hand and foot with more than 3% difference between the two or three screenings, each separated by one hour
 - b. Pulse oximetry readings are less than 95% (<95%) for both right hand and foot or there is more than 3% difference between the two or three screenings, each separated by one hour
 - c. Pulse oximetry reading is less than 90% (<90%) for either or both the right hand and foot
 - d. All of the above scenarios
- 8. True or False: Pulse oximetry screening results can be shared with individuals that are not directly involved in the patient's care.

Critical Congenital Heart Disease (CCHD) Screening: KNOWLEDGE ASSESSMENT - ANSWERS

- 1. The following can affect the accuracy of pulse oximetry (pulse ox) reading:
 - a. Movement
 - b. Cold extremities or shivering
 - c. Crying
 - d. Bilirubin lamps and surgical lamps
 - e. All of the above
- 2. True or False: One clean, disposable pulse oximeter probe can be used on up to five patients.
- 3. All of the following can affect the accuracy of the pulse oximeter reading except:
 - a. Placing the pulse oximeter probe on the same extremity that you are taking the blood pressure
 - b. Performing the pulse oximeter screening while the infant is crying
 - c. Using a clip on the finger of an infant
 - d. Infant skin color or jaundice
- 4. True or False: Pulse oximetry screening will detect all forms of Congenital Heart Disease (CHD).
- 5. The screening guidelines state that pulse oximetry should be performed on:
 - a. The right hand
 - b. One foot
 - c. Both a and b
- 6. Pulse oximetry screening should be performed when the infant is:
 - a. Less than 8 hours
 - b. Between 8 and 18 hours
 - c. Greater than 24 hours
 - d. Less than 24 hours
- 7. An infant's pulse oximetry readings should be reported to the infant's pediatric provider if:
 - a. Pulse oximetry readings are higher than 95% for both right hand and foot with more than 4% difference between the two or three screenings, each separated by one hour
 - b. Pulse oximetry readings are lower than 95% for both right hand and foot or there is more than 4% difference between the two or three screenings, each separated by one hour
 - c. Pulse oximetry reading is lower than 90% for either or both the right hand and foot
 - d. All of the above scenarios
- 8. True or False: Pulse oximetry screening results can be shared with individuals that are not directly involved in the patient's care.

Resources

For Providers:

Rhode Island Department of Health: www.health.ri.gov/newbornscreening/pulseoximetry/for/providers

New England Genetics Collaborative: http://negenetics.org/special-projects/cchd-project.aspx

American Academy of Pediatrics: www.aap.org or http://pediatrics.aappublications.org/content/128/5/e1259.full.html

American Heart Association: www.amhrt.org

Center for Disease Control and Prevention: www.cdc.gov

For Parents:

Rhode Island Department of Health: www.health.ri.gov/newbornscreening/for/parents

Baby's First Test: www.babysfirsttest.org

American Heart Association: www.amhrt.org

Support Groups:

Children's Heart Association www.heartchild.info

Children's Heart Foundation www.childrensheartfoundation.org

Congenital Heart Information Network www.tchin.org

Kids with Heart www.kidswithheart.org

March of Dimes www. shareyourstory.org

Critical Congenital Heart Disease Team

Christelle Farrow, MPH
Newborn Screening Manager
Rhode Island Department of Health
401-222-5950
Christelle.Farrow@health.ri.gov

Karen Lemke, RN
Newborn Screening Coordinator
VNA of Care New England
401-921-7619
KLemke@VNACareNewEngland.org

Ellen Amore, MS KIDSNET Manager Rhode Island Department of Health 401-222-4601 Ellen.Amore@health.ri.gov

William Arias, MPH
Birth Defects Program
Rhode Island Department of Health
401-222-7930
William.Arias@health.ri.gov

James F. Padbury, MD
Newborn Screening Task Force Chair
Pediatrician-in-Chief
Women & Infants Hospital
401-274-1122
JPadbury@wihri.org

Marcia W. VanVleet, MD, MPH
Director of Newborn Service Team
Women & Infants Hospital
401-274-1122
MVanVleet@wihri.org

James W. Ziegler, MD Pediatric Cardiologist Hasbro Children's Hospital 401-444-4612 JZiegler@Lifespan.org

Erin Wilbur, MBA
Project Coordinator
Women & Infants Hospital
401-274-1122
EWilbur@wihri.org

The following pages can be printed for your reference and use.

Critical Congenital Heart Disease (CCHD) Screening: COMPETENCY CHECKLIST

- * Competency criteria includes the following:
 - 1) Completion of the in-service education
 - 2) Accomplishment of 90% or higher on the Knowledge Assessment Quiz
 - 3) Appropriate application of pulse oximetry through return demonstration
 - 4) Accurate reading and documentation of the pulse oximetry screening results
- Validation criteria:
 - Discussion (D)
 - Verbal Feedback (VF)
 - Written Test (T)
 - Return Demonstration (RD)

Directions: Evaluator should	circle the appropriate method of validation,	, initial each line, and sign at the bottom of
the document		
Name:		ob Title:

Competency	Date	Method of Validation	Evaluator Initials	Comments
Can explain screening				
eligibility guidelines for		D VF T		
pulse oximetry screening				
Can identify safe and				
correct methods for		D VF T RD		
performing pulse				
oximetry				
Can describe methods to				
ensure that pulse oximetry		D VF T RD		
reading is accurate				
Can explain screening				
methods and guidelines		D VF T		
for pulse oximetry				
screening				
Can discuss HIPAA				_
confidentiality standards		D VF T		

Employee Signature:	Date:
Evaluator Name (Printed):	
Evaluator Signature:	

Critical Congenital Heart Disease (CCHD) Screening: TRAINING LOG

Each employee who will perform pulse oximetry/CCHD screening should complete the Competency Checklist prior to performing any screenings.

Employee Name & Title	Date	Completion of Competency Checklist	Evaluator Initials
•			
Unit:			
Manager Name (Printed):			
Manager Signature:			

For Inpatients: AFFIX PATIENT LABEL <u>OR</u>	For Outpatients: WRITE IN BOTH PATIENT NAME AND DOB		
WRITE IN BOTH PATIENT NAME AND MR NUMBER	Patient Name:		
Patient Name:	DOB:/		
MR#:			

PULSE OXIMETRY SCREENING

Guidelines

- If pulse oximetry saturation is 89% or lower in right hand or foot, contact newborn's provider immediately and record
- If pulse oximetry saturation is 90-94% in right hand and foot, or 4% or more difference between the right hand and foot for all three screening attempts then record as **FAIL** and notify the provider.
- If pulse oximetry saturation is 95% or higher in right hand or foot with less than 4% difference between right hand

and foot, record as a PASS.				ū
	Patient I	neligible	(CCHD	diagnosis or ECHO)
RN / CNA to complete				
Screening # 1				
Date:/ Time: Ag	ge in hours:			
Pulse Oximetry Saturation of Right Hand:%				
Pulse Oximetry Saturation of Foot:%	FAIL			
Difference (Right Hand - Foot):%				
Screener's Signature:	Date:	/	/	Time:
Printed Name:				
Screening # 2 (1 hour following initial screen if the ne	wborn fails in	itial scre	en):	
Date:/ Time: Ag	ge in hours:			
Pulse Oximetry Saturation of Right Hand:%				
Pulse Oximetry Saturation of Foot:%	FAIL			
Difference (Right Hand - Foot): %				
Screener's Signature:	Date: _	/	/	Time:
Printed Name:				
Screening # 3 (1 hour following second screen if the r	ewborn fails	second	screen):	
Date:/ Time: Ag	ge in hours:			
Pulse Oximetry Saturation of Right Hand:%				
Pulse Oximetry Saturation of Foot:%	FAIL			
Difference (Right Hand-Foot):%				
Screener's Signature:	Date: _	/	/	Time:
Printed Name:				
Final Interpretation: PASS				
PASS Results: I told the parent(s)/guardians and gave	them a writte	n copy (of the sc	creenina results.
				3
FAIL Results: I called and faxed results to:				
Decision of Primary Care Provider: Transfer to	NICU [Call C	ardiolog	y to evaluate as IP
Signature:			_	
Drintod Namo:	_			



Refusal of Consent for Pulse Oximetry Screening

the parent/guardian of, born on,		
Full name of infant	į	Date of birth
refuse to have my child (check all that apply)):	
 □ Receive Pulse Oximetry screening □ Receive Echocardiogram evaluation □ Transported to another facility, if need 		
I understand that Pulse Oximetry screening is Disease. This dangerous heart condition can		
I have read the Newborn Screening Pulse Ox Screening with my baby's doctor, midwife, a provider.		
I understand the benefits of screening, evaluation these services have been explained to me. Moreover was made freely and without force or encour hospital staff, or state officials.	y decision to refuse s	screening, evaluation, and/or transport
I accept all responsibility, legal and otherwis	e, for this decision.	
Full printed name of mother	Signature	Date
Full printed name of father	Signature	Date
Full printed name of healthcare provider*	Signature	Date
* Healthcare providers include physicians in	urses and midwives	

Healthcare provider instructions:

- 1. Have the parent(s) read the Critical Congenital Heart Disease insert in the Newborn Screening and Services brochure. Discuss Pulse Oximetry screening and potential follow up services (echocardiogram evaluation, transport to another facility) with the parent(s). Review the benefits of these services and the potential dangers of not receiving them.
- 2. Complete this form for each infant when the parent(s) refuse(s) Pulse Oximetry screening, echocardiogram evaluation, and/or transport to another facility.
- 3. Provide a copy of the form to the parents and send a copy to the baby's primary care provider.
- 4. Keep the original for your records
- 5. fax a copy of this form to (401)-222-1088 attn Newborn Screening
- 6. For additional forms, please print from the Rhode Island Department of Health website at http://www.health.ri.gov/forms/refusalofconsent/PulseOximetry.pdf

Healthcare providers include physicians, nurses, and midwives.



Screening for Critical Congenital Heart Disease (CCHD) with Pulse Oximetry: Frequently Asked Questions

Screening for CCHD by checking pulse oximetry (also known as pulse ox) is recommended and supported by the U.S. Department of Health and Human Services, the American Heart Association, the American College of Cardiology, the American Academy of Pediatrics, and the March of Dimes.

What is Critical Congenital Heart Disease (CCHD)?

Congenital Heart Disease (CHD) is when a baby's heart develops in a different way before birth. Congenital means that the baby is born with the birth defect. CHD is the most common type of birth defect. Some forms of CHD are more serious than others and need treatment sooner. These more serious forms are called Critical Congenital Heart Disease or CCHD.

How common is CCHD?

In the US, about 7,200 (or 2 per 1,000) babies born each year have CCHD.

What causes CCHD?

We do not know what causes CCHD in most babies.

What is pulse oximetry (also known as pulse ox)?

Pulse oximetry is a simple way of measuring how much oxygen your baby's blood is carrying. It involves attaching a small, sticky sensor to your baby's hand and foot for about 1 minute. It is painless. It has no side effects.

What is a normal pulse oximetry reading?

In healthy babies, normal pulse oximetry readings are between 95%-100%, with less than a 4% difference between the reading from the right hand and either foot. A baby with CCHD can have a normal pulse oximetry reading, so a passing result of the pulse oximetry screening does not rule out CCHD.

What does it mean if my baby does not pass the pulse oximetry screening?

If the pulse oximetry screening shows a low oxygen level, this does not automatically mean your baby has CCHD. Sometimes a newborn's lungs and heart are still adjusting after birth. This can also lead to a low pulse oximetry reading.

What happens next if my baby does not pass the pulse oximetry screening?

Your baby's doctor or nurse will speak with you and order other tests. These tests might include another pulse oximetry reading, a chest x-ray, and/or an ultrasound (echocardiogram or "ECHO") of the heart.

Who will perform the follow-up tests?

Your baby's nurse or a nursing assistant will complete a follow-up pulse oximetry. A radiology technician will perform a chest x-ray. A cardiologist or an echocardiography technician will perform an ECHO. Your baby may need to be transferred to another hospital to get these tests.

When will we get the results?

You will have the results of any tests soon after they are done, usually before your baby leaves the hospital. Your doctor will let you know when the tests will be done and when you will get the results.

What is the treatment for CCHD?

CCHD usually requires surgery to repair the heart. Your baby may not need surgery during this hospital stay. A pediatric cardiologist (heart doctor) will explain what happens next.

Support Groups and Online Resources:

American Heart Association www.amhrt.org

Baby's First Test www.babysfirsttest.org Children's Heart Association www.heartchild.info

Children's Heart Foundation www.childrensheartfoundation.org

Congenital Heart Information Network www.tchin.org

Kids with Heart www.kidswithheart.org

March of Dimes www.marchofdimes.org/baby/congenital-heart-defects.aspx

March of Dimes www. shareyourstory.org