Children's Hospital Colorado
Heart Institute

4th Edition

CRITICAL CONGENITAL Heart Disease Screening Program Toolkit

This material is made possible by the Elsie and Marvin Dekelboum Family Foundation.

ACKNOWLEDGEMENTS

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Critical Congenital Heart Disease Screening Program

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USER AGREEMENT

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B. Disclaimer

Recommendations provided by Children's National and Children's Hospital Colorado are derived from a review of evidence-based literature on screening for critical congenital heart disease using pulse oximetry and outcomes of the clinical research study titled "Feasibility of Implementation of Pulse Oximetry as a Screening Tool for Critical Congenital Heart Disease in the Newborn Nursery." Institutional Review Board approval was sought and obtained in this study.

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Section 1 Program Overview

"The guidelines in this toolkit have been invaluable in implementing a screening program for critical congenital heart disease in our nursery. It has allowed us to provide the best and safest care for our newborn patients. We hope that it will do the same for you!"

Mary Kohn, MD
Director, Level I Nursery
University Of Colorado Hospital

"Practicing medicine for 14 years as both a pediatrician and neonatologist, I have seen the benefit of early recognition of critical congenital heart disease on patients and their families. Anything we can do as providers to lessen the repercussions of delayed diagnosis is well worth the investment."

Jason Wright, MD
Clinical Instructor of Neonatal Medicine
Children's Hospital Colorado and University of Colorado Hospital

"Early detection of critical congenital heart disease with pulse oximetry is quick, painless, and saves lives."

Christopher M. Rausch, MD
Director, Pediatric Cardiology Fellowship Program
Director, Cardiopulmonary Exercise Laboratory
Children's Hospital Colorado and University of Colorado Hospital

VISION

All infants with critical congenital heart disease are detected before leaving the nursery.

Who, What, When, Where, and Why?

What are critical congenital heart disease and pulse oximetry?

Congenital heart disease (CHD) is the most common birth defect. Infants with CHD have abnormal structure to their heart, which creates abnormal blood flow patterns. Approximately eight of every 1,000 infants born have a form of CHD. Some forms of CHD cause no or very few problems in the health, growth, and development of the infant.

Critical CHD (also called CCHD) includes more serious forms of CHD and usually requires intervention in the first year of life. Critical CHD can bring a significant risk of morbidity and mortality if not diagnosed soon after birth. Failing to detect critical CHD while in the newborn nursery may lead to critical events, such as cardiogenic shock or death. Survivors who present late are at greater risk for neurologic injury and subsequent developmental delay.

Pulse oximetry, or "pulse ox," is a simple, non-invasive, and painless test that is used to measure the percent oxygen saturation of hemoglobin in the arterial blood and the pulse rate. Pulse ox was invented in the 1970s and is now widely used and accepted in clinical care; it is often thought to be a basic vital sign.

Why is pulse ox used to screen for critical CHD?

Pulse ox can help to identify infants with critical CHD that may have low levels of oxygen in their blood. Pulse ox may help diagnose critical CHD before an infant becomes sick. Pulse ox will not detect all forms of CHD and critical CHD.

Who should be screened?

All infants should be screened.

When should critical CHD screening be performed?

Screening should be performed before discharge from the nursery, after the infant turns 24 hours of age.

If the infant was born prematurely, screening should be performed when medically appropriate. If early discharge is planned, screening should occur as close to 24 hours of age as possible.

Where should critical CHD screening be performed?

Critical CHD screening should be performed while the infant is in the nursery, before he or she goes home. The pulse ox test should be performed on the right hand and one foot.

James Jaggers, MD

D. Dunbar Ivy, MD

DEAR PROVIDER,

Thank you for your interest in the Critical Congenital Heart Disease Screening Program. We are excited to provide you with the resources that you will need to implement the program in your newborn nursery. Components are based on a review of current literature and recommendations, outcomes for research on best-practice for implementation, and our experience helping nurseries to implement screening.

Background and Significance

As you know, congenital heart disease (CHD) is the most common birth defect and may be detected during either the prenatal or postnatal period. Prenatal testing, utilizing ultrasound technology, is an important early screening mechanism for life threatening heart disease; however it has been shown that diagnosis may be made in only 23 percent of pregnancies or 11 percent of live births. Detection during the postnatal period is currently done by either physical examination, or by detection of symptoms during the first 24 hours of life. These methods have proven to be successful in identifying only 50 percent of infants with CHD.

Failing to detect critical CHD while in the newborn nursery may lead to serious events such as cardiogenic shock or death. Survivors who present late are at greater risk for neurologic injury and subsequent developmental delay. Early detection of critical CHD can potentially improve the prognosis and decrease the mortality and morbidity rates of affected infants. Pulse oximetry has been investigated and proven to be successful in detecting some forms of critical CHD in the newborn nursery when used in addition to existing mechanisms for detection.

Health and Human Services Secretary Kathleen Sebelius endorses the inclusion of screening for critical CHD in the recommended uniform screening panel. The American Heart Association, American Academy of Pediatrics, American College of Cardiology, and March of Dimes also support newborn screening for critical CHD. In January 2011, the Health Resource Service Administration's Advisory Council on Heritable Diseases in Newborns and Children hosted a workshop to discuss implementation recommendations surrounding screening. The outcome of this meeting included a screening protocol based on the most current evidence. This protocol is reflected in the recommendations that follow.

Overview of Critical CHD Screening Guidelines

This screening program adds pulse oximetry testing of the right hand and one foot to routine testing performed on all infants. The test should be performed after the infant turns 24 hours of age, or when medically appropriate if the infant was born prematurely. It is recommended that critical CHD screening be done in conjunction with other standard-of-care newborn screening that requires the infant be at least 24 hours of age, such as metabolic or hearing screening.

If the newborn's oxygen saturation is 95% or greater in either extremity with a 3% or less absolute difference between the two, he or she will be considered to pass the screening test, and no additional evaluation will be required unless signs or symptoms of CHD are present.

If the newborn's oxygen saturation is 89% or less in either the hand or foot at any time, he or she should be immediately referred for additional evaluation.

If the oxygen saturations are 94-90% in both the hand and foot or there is a 4% or more absolute difference between the two on three measures, each separated by one hour, the newborn should be referred for additional evaluation.

Toolkit Materials

This toolkit will provide you with the initial resources needed to start the critical CHD screening in your nurseries. The toolkit includes information regarding implementation, resources for training individuals responsible for screening, and resources for educating families. In addition, all materials for the education of families are provided in both English and Spanish. Education materials are evidence-based.

The toolkit also includes simple ways that parents, families, healthcare professionals, and others can become advocates for patients with critical CHD.

We are excited to work with you to implement critical CHD screening in your newborn nursery. There is the potential to save the lives and improve outcomes of many babies.

Sincerely,

James Jaggers, MD
Chief of Pediatric Cardiothoracic Surgery
Co-Medical Director, Heart Institute
Children's Hospital Colorado

D. Dunbar Ivy, MD
Chief of Pediatric Cardiology
Co-Medical Director, Heart Institute
Children's Hospital Colorado

Critical Congenital Heart Disease Screening Program

SCREENING RECOMMENDATIONS

Section 1: Recommendations for Implementation Planning

1. Designate a program director and coordinator to facilitate planning and implementation of the screening program.
2. Establish an interdisciplinary team of organizational leadership and management, physicians, registered nurses, nursing assistants, and ancillary staff to participate in the planning process.
3. Schedule several planning sessions to facilitate education, communication, brainstorming, conflict resolution, and decision making.
4. Ensure that the organization's public relations and marketing department is involved in communication planning and efforts.
5. Discuss and establish a clear, complete, and concise evidence-based policy and procedure for screening methods and guidelines, including documentation and reporting of normal and abnormal results.
6. Discuss a plan for management and evaluation of infants requiring further evaluation if pediatric cardiology services are not available on site.
7. Establish guidelines for parents or guardians who wish to decline screening.
8. Research the accuracy and reliability of pulse oximetry equipment. Choose a vendor with equipment that is approved by the FDA for use with neonates.
9. Establish guidelines for informing, educating, and training providers and staff participating in and/or affected by implementation of the screening program.
10. Establish guidelines for education of and communication with parents and guardians before and after screening.
11. Establish plans for surveillance and reporting of program results and outcomes.
12. Birthing facilities at high altitudes may require revised protocols.
    a. Large studies of infants born at moderate altitude (5,000-7,000 ft. elevation) have shown slightly higher but tolerable failure rates for CCHD screening when compared with infants born at sea level.
    b. No large scale studies of CCHD screening have been performed in infants born above 7,000 ft. elevation. Based on the available unpublished data and small samples at higher altitudes, screening failure rates using the protocol described in this toolkit may result in significantly higher false positive rates at elevations above 7,000 ft.

Section 2: Recommendations for Parental Education

1. Establish a plan to inform parents of the screening program prior to delivery and screening of the infant through:
    a. prenatal classes and tours provided by the hospital,
    b. information on hospital's website, and
    c. written materials available in the obstetrics and gynecology clinics, labor and delivery, and maternity suites.
2. Provide education in both written and verbal methods; written materials should be easy to read and understand, and they should not contain excessive medical language that may be confusing to parents.
3. Provide written materials in English and Spanish; consider additional languages based on patient population that is served and use an interpreter when appropriate.
4. Include program contact information on all communications to provide mothers the opportunity to seek additional information and clarification prior to delivery.
5. Educate parents of signs and symptoms of CHD.
6. Inform parents of the right to decline screening.

Section 3: Recommendations for Educating and Informing Providers

1. Prior to implementation, inform and educate all hospital and community providers who work in the newborn nursery, neonatal intensive care unit, postpartum unit, and pediatrics and will be affected by the screening program.
   - Consider sending out a letter of program intent several weeks prior to implementation.
   - Provide program contact information to allow providers to seek additional information and clarification.
2. Provide a Grand Rounds session for the education of hospital and community providers.
3. Request time at department meetings to inform and educate hospital and community providers prior to implementation.
4. Following implementation, provide frequent updates to hospital and community providers on the screening program progress and outcomes at department meetings or through written communication.

Section 4: Recommendations for Screener Training

1. Provide all training prior to implementation of the screening program by an individual who has participated in the planning process.
   a. Examples include the unit's nurse manager or assistant nurse manager, the nurse educator, the program coordinator, or a registered nurse who played an active role in the planning process.
2. Recommended components of the in-service education program include:
   a. PowerPoint Presentation — Includes information on background and significance for CCHD screening methods and recommendations and may be obtained by emailing pulseox@childrensnational.org
   b. Demonstration of correct and safe use of pulse oximetry equipment in obtaining an accurate infant reading by trainer or representative from pulse oximeter manufacturer
   c. Completion of knowledge assessment quiz
   d. Opportunity to practice CCHD screening
3. Require that all individuals who will be performing the screening test complete the in-service education program.
4. Require that all individuals who will be performing the screening test complete the knowledge assessment quiz with a passing score of greater than or equal to 90 percent, and remediation of all questions answered incorrectly.

5. Require that all individuals who will be performing the screening test demonstrate proficiency in performing pulse oximetry and knowledge of screening guidelines through completion of defined competencies prior to participation. Require that they renew competencies on an annual basis.
6. Provide "booster" sessions quarterly to provide an opportunity to re-educate staff and answer any questions.
7. Ensure that all new employees receive training prior to participation in screening program methods.
8. Provide staff with regular updates on outcomes of screening to maintain engagement.

Section 5: Recommendations for Screening

1. Pair critical CHD screening with another standard-of-care screening performed following 24 hours of age, such as metabolic or hearing screening. If early discharge is planned, screening should occur as late as possible.
2. Consider assigning one or two nursing assistants or registered nurses to critical CHD screening on a daily basis.
   a. If possible, provide continuity by scheduling one screener to conduct screening on several continuous days.
3. Conduct screening in a quiet area with the parent present to soothe and comfort the infant.
4. If possible, conduct screening while the infant is awake, quiet, and calm.
5. Do not attempt to perform pulse oximetry on an infant while he or she is in a deep sleep, crying, or cold, as oxygen saturations may be affected.
6. If using disposable pulse ox sensors, use one clean sensor for each infant screened. If reusable sensors are being used, clean sensor as instructed by manufacturer prior to and following screening. Dirty sensors may decrease the accuracy of a reading or transmit infection.
7. Perform pulse oximetry on the right hand and one foot after 24 hours of age; measurements should be taken in parallel or one after another. If infant was born prematurely, perform screening when medically appropriate. If an early discharge is planned, conduct screening as close to 24 hours as possible.
8. Ensure that all readings are accurate by using pulse oximetry equipment confidence indicators.
9. If the oxygen saturation is 100-95% in either extremity with a 3% or less absolute difference between the two, the infant will "pass" the screening test and no additional evaluation will be required unless signs or symptoms of CHD are present.
   a. The physician or nurse practitioner caring for the infant does not need to be notified.
   b. The infant does not require additional cardiac evaluation in the newborn nursery unless indicated.
10. If the pulse ox reading is 89% or less in either the hand or foot, the infant should be immediately referred to his or her physician for additional evaluation.
11. If the oxygen saturations are 94-90% in both the hand and foot or there is a 4% or more absolute difference between the two on three measures, each separated by one hour, the newborn should be referred for additional evaluation.
    a. The infant's physician or nurse practitioner should be notified.
    b. Infectious and pulmonary pathology should be excluded.
    c. If cause of hypoxemia is not clear, an echocardiogram and cardiology consultation should be obtained before discharge to rule out CHD.
    d. Further evaluation should be ordered at the discretion of the physician or nurse practitioner caring for the infant.

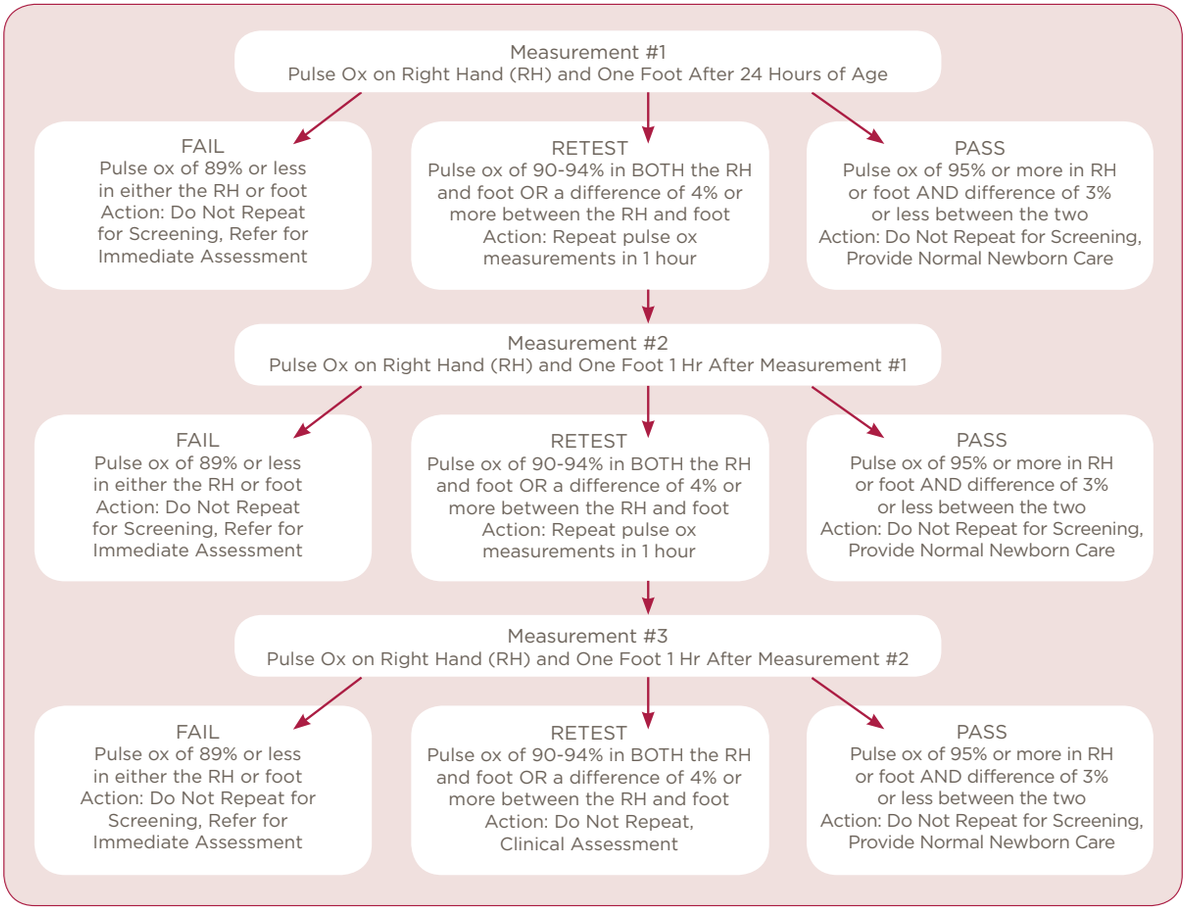
Section 6: Recommendations for Follow-Up

1. Establish guidelines for documentation and communication of results and plan of care (if necessary) with infant's parents and pediatrician.
2. Establish guidelines for individuals performing screening if asked questions by parents.
3. Establish guidelines for addressing screening of missed infants.

Pulse ox has been shown to be a safe and effective screening tool for CCHD in newborns.

Critical Congenital Heart Disease Screening Program

SCREENING PROTOCOL DIAGRAM



RH Application Sites

Foot Application Sites

Reminder Acronym for Screeners

- Confirm that the infant is at least 24 hours of age and eligible for screening.
- Help the parent to warm and calm the infant in a quiet and peaceful environment.
- Describe the pulse ox test to the parent.
- Select a site on the right hand and one foot that is clean and dry.
- Place the pulse ox sensor and perform the pulse ox test.

Assessment of Babies with Failing Saturations

1. Babies with saturation of 89% or less in RH or foot should have immediate assessment.
2. Babies with Failing Saturations:
   - Clinical assessment
   - Complete echocardiogram
   - Infectious and pulmonary pathology should be excluded
   - If symptomatic, referral to pediatric cardiology immediately
   - If asymptomatic, referral to pediatric cardiology in timely manner

Critical Congenital Heart Disease Screening Program

PROVIDER RESOURCES

The following resources and templates for notifying providers of implementation of screening are available on our website at **childrenscolorado.org/CCHDScreening**

- Screening Supplies List
- Sample Screening Form
- Competency Checklist
- Training Log
- Toolkit References

The following patient resources are also available for download at **childrenscolorado.org/CCHDScreening**

- Frequently Asked Questions (FAQs) for Patients and Families
- Frequently Asked Questions (FAQs) for Patients and Families (Spanish)
- CHD Resources (English/Spanish)
- Advocacy Resources
- Cardiothoracic Surgery at Children's Hospital Colorado

Contact Us

CARDIOLOGY
p: 720-777-6820
f: 720-777-7290
appts: 720-777-6355

NEONATOLOGY
p: 720-777-6857
f: 720-777-7207

ONE CALL 24/7 CONSULTATION
p: 720-777-3999 or 800-525-4871

Section 2 Screener Training

In-Service Education Program Components

Critical Congenital Heart Disease Screening Program: Education for Providers

Performing Pulse Oximetry with the Infant Patient: Education for Providers

Pulse Oximetry Sensor Placement Education

Knowledge Assessment and Answer Key

"Pulse oximetry screening for critical congenital heart disease will save lives. I would do anything to go back in time and have this simple test performed on my daughter. She might be with us today."

Olivia Easley, advocate and mother of Veronica Easley, who passed away at 7 weeks old from undetected critical congenital heart disease.

"Eve is a testament to what works...she was diagnosed before discharge from the newborn nursery - getting the right medical intervention at the right time. Early detection of critical heart defects allows the medical teams to do what they do best - plan and treat babies so they can heal and thrive."

Annamarie Saarinen, Mother of Eve and Advocate for CCHD Screening

Critical Congenital Heart Disease Screening Program:

In-Service Education Program COMPONENTS AND RECOMMENDATIONS

The following is an overview of educational tools and components that may be used to educate staff who will be directly involved in screening implementation.

1. PowerPoint Presentation:

- **a.** Provides attendees with education on background, significance, and need for screening.
- **b.** Provides attendees with education on critical CHD screening methods and guidelines.

2. Education for Providers:

- **a.** Provide attendees with educational tool, "Critical Congenital Heart Disease Screening: Education for Providers."

3. Pulse Oximetry Demonstration:

- **a.** Provide attendees with a demonstration of correct and safe use of pulse oximetry equipment in obtaining an accurate infant reading by in-service facilitator or representative from pulse oximeter manufacturer.
- **b.** Provide attendees with an opportunity to practice performing screening on a doll.
- **c.** Provide attendees with the opportunity to ask questions regarding correct and safe methods for performing critical CHD screening.
- **d.** Provide attendees with the "Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: Education for Providers" and "Pulse Ox Sensor Placement" education tools.

4. Knowledge Assessment Quiz:

- **a.** Allow time for attendees to complete the "Knowledge Assessment Quiz."
- **b.** Review the correct answer for each question.
- **c.** Allow time for remediation of questions answered incorrectly.
- **d.** Allow time for attendees to re-take quiz, if necessary.

5. Competency Checklist:

- **a.** Allow adequate time for completion of competency checklist.
- **b.** Provide each attendee with a copy of the complete competency checklist to forward to his or her manager.

Critical Congenital Heart Disease Screening Program

EDUCATION FOR PROVIDERS

What is pulse oximetry?

Pulse oximetry, or "pulse ox," is a simple, non-invasive and painless test that is used to measure the percent oxygen saturation of hemoglobin in the arterial blood and the pulse rate. Pulse ox was invented in the 1970s and is now widely used and accepted in clinical care. It is often thought to be a basic vital sign.

Traditionally, pulse ox has been used to monitor an individual's oxygen saturation during acute and chronic illness as well as during procedures requiring general anesthesia or sedation.

What is a normal pulse ox reading for infants?

A pulse ox reading of 95 to 100 percent is normal in healthy infants. Infants with heart or lung problems may have lower readings. A low pulse oximetry reading can also be present in newborns whose circulation is adjusting to life outside of the womb.

What is congenital heart disease?

Congenital heart disease (CHD) is the most common birth defect. Infants born with CHD have abnormal structure to their heart which creates abnormal blood flow patterns. Approximately eight of every 1,000 babies born have a form of CHD. Some forms of CHD cause no or very few problems in the health, growth, and development of the infant. Many times, these forms of CHD do not require surgical repair or cardiac catheterization.

Critical CHD includes more serious forms of CHD that usually require intervention in the first year of life. Critical CHD occurs in 3-4 of every 1,000 babies and can bring a significant risk of morbidity and mortality. This risk is greater if an infant is not diagnosed soon after birth.

Failing to detect critical CHD while in the newborn nursery may lead to critical events such as cardiogenic shock or death. Survivors who present late are at greater risk for neurologic injury and subsequent developmental delay.

Why is pulse ox used to screen for critical CHD?

Physical examination is performed during the first 24 hours of life in most institutions and currently the only method used to screen for critical CHD. Physical examination is only 50 percent effective in detecting CHD after the baby is born.

The US Department of Health and Human Services, the American Heart Association, the American Academy of Pediatrics, the March of Dimes, and the American College of Cardiology endorse screening for critical CHD. It has been shown to increase the chances that infants with critical CHD are identified before leaving the newborn nursery.

It is possible that a baby with critical CHD can have a normal pulse ox reading. CHD cannot be completely ruled out by a normal pulse oximetry reading.

Pulse oximetry increases the ability to identify CCHD in newborns with a 15-fold greater positive predictive value than physical examination alone.

Critical Congenital Heart Disease Screening Program:

Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: EDUCATION FOR PROVIDERS

Pulse Ox – DOs

1. If you are using disposable pulse ox sensors, use a new, clean sensor for each infant. If you are using reusable pulse ox sensors, clean the sensor with recommended disinfectant solution between each infant. Dirty sensors can decrease the accuracy of your reading and can transmit infection. A disposable wrap should be used to secure the sensor to the site if you are using reusable sensors.
2. The best sites for performing pulse ox on infants are the great toe, thumb, and the outer aspect of the palm and the foot. An infant pulse ox sensor (not an adult pulse ox clip) should always be used for infants.
3. When placing the sensor on the infant's skin, there should not be gaps between the sensor and the infant's skin. The sides of the sensor should be directly opposite of each other.
4. Nail polish dyes and substances with dark pigmentation (such as dried blood) can affect the pulse ox reading. Assure that the skin is clean and dry before placing the sensor on the infant. Skin color and jaundice do not affect the pulse ox reading.
5. Movement, shivering, and crying may affect the accuracy of the pulse ox reading. Ensure that the infant is calm and warm during the reading. Swaddle the infant and encourage family involvement to promote comfort while obtaining the reading. If possible, conduct screening while the infant is awake.
6. Pulse oximeters have different confidence indicators to ensure that the pulse ox reading is accurate. Determine the confidence indicators for the pulse oximetry equipment that you are using.
7. If an infant requires pulse ox monitoring for an extended amount of time, assess the site where the sensor is placed at least every two hours. Monitor for signs of irritation.

Pulse Ox – DON'Ts

1. Never use an adult pulse ox clip when obtaining a pulse ox reading for an infant. Using an adult clip on an infant will give you an inaccurate reading.
2. Blood flow is needed to obtain an accurate pulse ox reading. Never attempt to obtain a pulse ox reading on the same extremity that you have an automatic blood pressure cuff.
3. Bright or infrared light, including bilirubin lamps and surgical lights, can affect the accuracy of the reading. Ensure that the infant is not placed in bright or infrared light while pulse ox is being performed. You may cover the pulse ox sensor with a blanket to ensure that extraneous light does not affect the accuracy of your reading.
4. Do not use tape or your hand to apply the pulse ox sensor to the infant's skin.

Pulse Ox - CAUTION!

1. The pulse is needed to determine the oximetry reading. Pulse ox is not accurate if the patient is coding or is having a cardiac arrhythmia. Remember: No pulse, no oximetry!
2. Pulse ox readings are not instantaneous. The oximetry reading that is displayed on the monitor is an average of readings over the past few seconds.

Critical Congenital Heart Disease Screening Program

Pulse Ox Sensor PLACEMENT EDUCATION

1. Select an appropriate site for sensor placement according to manufacturer instructions. Most common application sites include the great toe, thumb and the outer aspect of the hand or foot.
2. Place the photodetector portion of the sensor on the top of the selected site.
3. Place the light emitter directly opposite of the photodetector on the fleshy portion of the site.
4. Remember that the photodetector and light emitter should be directly opposite of one another to obtain an accurate reading.
5. If you are using a reusable sensor, secure the sensor to the site using the appropriate wrap as recommended by the vendor. Do not use tape or your hand to secure the sensor to the site.

RH Application Sites

Foot Application Sites

Prenatal ultrasound currently identifies less than 50% of all congenital heart disease in utero.

Critical Congenital Heart Disease Screening Program

KNOWLEDGE ASSESSMENT

1. The following may affect the accuracy of the pulse oximetry (pulse ox) reading:
   a. Cold extremities or shivering
   b. Crying
   c. Bilirubin lamps and surgical lights
   d. All of the above
2. One clean, disposable pulse ox sensor can be used on up to five patients.
   a. True
   b. False
3. All of the following can affect the accuracy of the pulse ox reading except:
   a. Placing the pulse ox sensor on the same extremity that you are taking the blood pressure
   b. Performing the pulse ox test while the infant is crying
   c. Using a clip on the finger of an infant
   d. Infant skin color or jaundice
4. Pulse ox screening will detect all forms of CHD.
   a. True
   b. False
5. The screening guidelines state that pulse ox should be performed on:
   a. The right hand
   b. One foot
   c. Both a and b
   d. Neither a or b
6. Screening for CCHD was endorsed as a test that should be included in the recommended uniform screening panel (RUSP).
   a. True
   b. False
7. Pass, Fail, or Retest?
   Right Hand Saturation – 100%
   Foot Saturation – 94%
8. Pass, Fail, or Retest?
   Right Hand Saturation – 96%
   Foot Saturation – 95%
9. Pass, Fail, or Retest?
   Right Hand Saturation – 96%
   Foot Saturation – 94%
10. Pass, Fail, or Retest?
    Right Hand Saturation – 89%
    Foot Saturation – 82%

Critical Congenital Heart Disease Screening Program

KNOWLEDGE ASSESSMENT ANSWERS

1. The following may affect the accuracy of the pulse oximetry (pulse ox) reading:
   a. Cold extremities or shivering
   b. Crying
   c. Bilirubin lamps and surgical lights
   d. All of the above

2. One clean, disposable pulse ox sensor can be used on up to five patients.
   a. True
   b. False

3. All of the following can affect the accuracy of the pulse ox reading except:
   a. Placing the pulse ox sensor on the same extremity that you are taking the blood pressure
   b. Performing the pulse ox test while the infant is crying
   c. Using a clip on the finger of an infant
   d. Infant skin color or jaundice

4. Pulse ox screening will detect all forms of CHD.
   a. True
   b. False

5. The screening guidelines state that pulse ox should be performed on:
   a. The right hand
   b. One foot
   c. Both a and b
   d. Neither a or b

6. Screening for CCHD was endorsed as a test that should be included in the recommended uniform screening panel (RUSP).
   a. True
   b. False

7. Pass, Fail, or Retest?
   Right Hand Saturation – 100%
   Foot Saturation – 94%

8. Pass, Fail, or Retest?
   Right Hand Saturation – 96%
   Foot Saturation – 95%

9. Pass, Fail, or Retest?
   Right Hand Saturation – 96%
   Foot Saturation – 94%

10. Pass, Fail, or Retest?
    Right Hand Saturation – 89%
    Foot Saturation – 82%

Section 2 Education for Parents

Checklist for Informing Mothers

Parent Resources

Less than a month after Amani's second birthday, he had surgery at Children's National to correct a serious congenital heart defect. The condition, which caused unoxygenated blood to flow directly back to the body instead of to the lungs for oxygenation, may have gone undetected if he had not received a CCHD screening as a part of the Congenital Heart Disease Screening Program. Amani's was the first and most serious congenital heart defect diagnosed as a result of the program.

His condition did not require surgery right away, but after he had time to grow. Even though the two-year wait was sometimes torture for Amani's parents, they were comforted knowing his heart defect was detected early and that he would receive appropriate care and monitoring in the meantime. "The diagnosis was difficult to hear, but the screening helped us avoid the pain of not knowing the root cause of the problem," said Amani's father, Zeggai.

When his parents asked him how he felt just a day after surgery, they were surprised when Amani answered, "I'm okay!"

"Today he is as active and talkative as a two-year old kid can be," said Zeggai.

Amani Andemariam (center, front) **and his family**

Critical Congenital Heart Disease Screening Program

Checklist for Informing PARENTS AND GUARDIANS

- ◯ Inform the parent or guardian that the purpose of the screening program is to screen for serious heart problems in babies.
- ◯ Inform the parent or guardian that the baby will be screened after he or she is 24 hours old.
- ◯ Inform the parent or guardian that if she agrees to have the baby screened, the pulse ox test will be done on the baby's right hand and one foot, if possible.
- ◯ Inform the parent or guardian that the pulse ox test is not usually painful and that it only takes a few minutes when the baby is quiet, warm, and not moving.
- ◯ Inform the parent or guardian that it is possible that a baby with a heart problem may have a normal pulse ox reading.
- ◯ Inform the parent or guardian that they have the right to decline screening.
- ◯ Inform the parent or guardian that they may ask questions at any time before, during, or following the screening.

Inform the parent or guardian that it is possible that a baby with a heart problem may have a normal pulse ox reading.

Critical Congenital Heart Disease Screening Program

PARENT RESOURCES

The following resources for parents can be found in the back pocked of this booklet:

- Frequently Asked Questions (FAQs) for Patients and Families
- Frequently Asked Questions (FAQs) for Patients and Families (Spanish)
- CHD Resources (English/Spanish)
- Advocacy Resources
- Cardiothoracic Surgery at Children's Hospital Colorado

Digital copies of these resources can be downloaded and printed from our website at **childrenscolorado.org/CCHDScreening**

Contact Us

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p: 720-777-6820
f: 720-777-7290
appts: 720-777-6355

NEONATOLOGY
p: 720-777-6857
f: 720-777-7207

ONE CALL 24/7 CONSULTATION
p: 720-777-3999 or 800-525-4871

"Over the eleven years since I started C.H.I.N., hardly a day goes by when I do not hear from a distraught parent whose child was not diagnosed at birth, leading to tragic or serious life-long consequences.

Mona Barmash,
President of Congenital Heart Information Network (C.H.I.N.)
Joint Council on Congenital Heart Disease Meeting, Fall 2007

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