



Alabama Department of Public Health

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## HOSPITAL GUIDELINES FOR IMPLEMENTING PULSE OXIMETRY SCREENING FOR CRITICAL CONGENITAL HEART DISEASE



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May 2012



Critical Congenital Heart Disease

# HOSPITAL GUIDELINES FOR IMPLEMENTING PULSE OXIMETRY SCREENING

**Disclaimer:** The information included in this document is for informational and educational purposes only. Users of the guidelines should not substitute information contained herein for professional judgment, nor should they rely solely on the information provided. Furthermore, this document does not reflect the optimal medical practice for all circumstances. Users are advised to seek professional counsel on the issues raised by consulting with medical staff for matters involving clinical practice.

The information in this manual was used with permission from Children's National Medical Center, Washington, D.C.

February 22, 2012

Dear Provider:

The Alabama Department of Public Health is pleased to provide this resource to assist you with implementing Critical Congenital Heart Disease (CCHD) screening in your newborn nursery. As you may know, congenital heart defects are the most common type of birth defect. Pulse oximetry has been proven to be successful in detecting certain forms of congenital heart defects in the newborn nursery. This screening targets seven specific anomalies classified as CCHD. Failure to detect such defects in the nursery setting may subsequently lead to critical events such as cardiogenic shock or infant death.

This resource was developed through the collaboration of many stakeholders. Their expertise and genuine concern for the welfare of Alabama's youngest citizens was crucial to the development of these guidelines.

We are asking that you partner with us to voluntarily implement CCHD screening in your newborn nursery. We are excited to have the opportunity to work with you on this initiative which has the potential to save lives and improve outcomes for many of our babies. If you have any questions or concerns, please feel free to contact the Newborn Screening Program staff at 1-866-928-6755.

Sincerely,



Donald E. Williamson, M.D.  
State Health Officer



DEW/CA  
Enclosure

# ACKNOWLEDGEMENTS

The Alabama Newborn Screening Program would like to thank the following organizations and individuals for their participation and contributions.

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## **Baptist Medical Center South - Montgomery**

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## **Blue Cross and Blue Shield of Alabama**

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## **March of Dimes**

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# INTRODUCTION

In September 2011, U.S. Department of Health and Human Services (HHS) Secretary Kathleen Sebelius approved adding Critical Congenital Heart Disease (CCHD) to the Recommended Uniform Screening Panel (RUSP). This recommendation was endorsed by the Alabama Chapter of the American Academy of Pediatrics. Donald E. Williamson, M.D., Alabama's State Health Officer, supported implementation of screening for CCHD in Alabama's birthing facilities. The Newborn Screening Program convened a CCHD Work Group that met on November 30, 2011, and again on December 13, 2011, to create a protocol for pulse oximetry screening on well infants in Alabama's fifty-three birthing facilities with a goal to implement by April 2012.

According to the Centers for Disease Control and Prevention (CDC), congenital heart defects account for 24% of infant deaths due to birth defects. In the United States, about 4,800 (or 11.6 per 10,000) babies born every year have CCHDs. In Alabama, approximately seventy infants are expected to be diagnosed with a CCHD each year. Babies with a CCHD are at significant risk for death or disability if their CCHD is not diagnosed and treated soon after birth. Pulse oximetry, which is a test to determine the amount of oxygen in the blood, is the recommended screening method to detect CCHDs in newborns.

## **There are seven defects classified as CCHD:**

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

This manual serves as a guide to assist each birthing facility to establish its own policy and procedures to implement a Critical Congenital Heart Disease Screening Program (CHDSP). These policies and procedures should establish clear, complete, and concise evidence-based policy and address the components listed below:

- Equipment
- Training
- Screening
- Education

It is recommended that each facility designate a program coordinator to facilitate the planning and implementation of the screening program, including the establishment of an interdisciplinary team. Members of this team should participate in the planning process and should represent hospital executives, physicians, nurses, and ancillary staff.





# SECTION 1 – EQUIPMENT

## SECTION 1 – EQUIPMENT

Each birthing facility will be responsible for selecting and securing pulse oximeter equipment for screening newborns for CCHD, if appropriate equipment is not already available. Such equipment must be compliant with national standards and adhere to the following:

- Must be motion-tolerant and report functional oxygen saturation.
- Must be validated in low-perfusion conditions.
- Must have been cleared by the FDA for use in newborns.
- Must have 2% root, mean-square accuracy.
- Must be calibrated regularly based on manufacturer guidelines.



## SECTION 2 – TRAINING

- ♥ IN-SERVICE EDUCATION PROGRAM COMPONENTS
- ♥ PULSE OX PROBE PLACEMENT EDUCATION
- ♥ PERFORMING PULSE OX WITH THE INFANT PATIENT: EDUCATION FOR PROVIDERS
- ♥ KNOWLEDGE ASSESSMENT AND ANSWER KEY
- ♥ COMPETENCY CHECKLIST
- ♥ TRAINING LOG
- ♥ CCHD SCREENING PROGRAM: POWERPOINT PRESENTATION

## SECTION 2 – TRAINING

Training should be performed by qualified personnel who have participated in the planning process (e.g., unit nurse manager or assistant nurse manager, nurse educator, the program coordinator, or a registered nurse). This training should be hands-on and competency based. The training of personnel should include:

- Overview of screening protocol
- Education on the use, care, maintenance, and trouble-shooting of screening equipment
- A review of general nursery policies and procedures
- Education on the differences between adult and pediatric oximeter probes
- An explanation on the importance of adequate circulation
- The effects of hypothermia and phototherapy on pulse oximetry screening
- Facility resources for pediatric echocardiogram and referral sources when not available in house

## IN-SERVICE EDUCATION PROGRAM COMPONENTS

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. Educational tools discussed are included.

### 1. PowerPoint Presentation:

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

### 2. Education for Providers:

- a. Provides attendees with educational tool, “Congenital Heart Disease Screening Program: Education for Providers,” which includes an overview of pulse oximetry, congenital heart disease, and pulse oximetry screening for critical congenital heart disease.

### 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 pulse ox screening on a doll.
- c. Provide attendees with the opportunity to ask questions regarding correct and safe methods for performing pulse ox screening.
- d. Provide attendees with the “Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: Education for Providers” and “Pulse Ox Placement” educational 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.

## PULSE OX PROBE PLACEMENT EDUCATION

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



*RH Application Site*



*Foot Application Site*

2. Place the photodetector portion of the probe on the fleshy portion of the outside of the infant's hand or foot.
3. Place the light emitter portion of the probe on the top of the hand or foot. Place the photodetector directly opposite of light emitter, on the bottom of the hand or foot.
4. Remember: The photodetector and emitter must be directly opposite each other in order to obtain an accurate reading.
5. Secure the probe to the infant's hand or foot using the adhesive or foam tape recommended by the vendor. It is not recommended to use tape to secure probe placement.
6. Some vendors use visual images such as a star or bar to specify which side of the probe should be placed on top of the hand or foot. You may choose to use a helpful statement such as, "Raise the bar" to help you to remember proper probe placement.



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# PERFORMING PULSE OXIMETRY (PULSE OX) WITH THE INFANT PATIENT: EDUCATION FOR PROVIDERS

## **Pulse Ox – Dos**

1. If you are using disposable pulse ox probes, use a new, clean probe for each infant. If you are using reusable pulse ox probes, clean the probe with recommended disinfectant solution between each infant. Dirty probes can decrease the accuracy of your reading and can transmit infection. A disposable wrap should be used to secure the probe to the site.
2. The best sites for performing pulse ox on infants are around the palm and the foot. An infant pulse ox probe (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 probe 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 probe on the infant. Skin color and jaundice do not affect the pulse ox reading.
5. Movement, shivering and crying can 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 probe is placed at least every two hours. Monitor for signs of irritation and burning of the skin.

## **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 probe with a blanket to ensure that extraneous light does not affect the accuracy of your reading.
4. Do not use tape to apply the pulse ox probe to the infant's skin.

## **Pulse Ox - Caution!**

5. 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!
6. 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.



## KNOWLEDGE ASSESSMENT

1. The following can affect the accuracy of the pulse oximetry (pulse ox) reading:
  - a. Movement
  - b. Cold extremities or shivering
  - c. Crying
  - d. Bilirubin lamps and surgical lights
  - e. All of the above
2. One clean, disposable pulse ox probe 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 probe 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. Pulse ox screening should be performed when the infant is what age?:
  - a. Less than 8 hours
  - b. Between 8 hours and 18 hours
  - c. Greater than 24 hours
  - d. Less than 24 hours
7. An infant's pulse ox readings should be reported to the physician or nurse practitioner caring for the infant if:
  - a. Pulse ox readings are greater than 94% for both right hand and one foot and there is a difference of 4 or more between the two on three measures each separated by one hour
  - b. Pulse ox readings are less than 95% for both right hand and one foot or there is a difference of 4 between the two on three measures each separated by one hour
  - c. Pulse ox reading is less than 90% for either or both the right hand and one foot
  - d. All of the above
8. Pulse ox screening results can be shared with individuals that are not directly involved in the patient's care:
  - a. True
  - b. False



## KNOWLEDGE ASSESSMENT ANSWERS

- The following can affect the accuracy of the pulse oximetry (pulse ox) reading:
  - Movement
  - Cold extremities or shivering
  - Crying
  - Bilirubin lamps and surgical lights
  - All of the above
- One clean, disposable pulse ox probe can be used on up to five patients.
  - True
  - False
- All of the following can affect the accuracy of the pulse ox reading except:
  - Placing the pulse ox probe on the same extremity that you are taking the blood pressure
  - Performing the pulse ox test while the infant is crying
  - Using a clip on the finger of an infant
  - Infant skin color or jaundice
- Pulse ox screening will detect all forms of CHD
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  - Pulse ox readings are greater than 94% for both right hand and one foot and there is a difference of 4 or more between the two on three measures each separated by one hour
  - Pulse ox readings are less than 95% for both right hand and one foot or there is a difference of 4 between the two on three measures each separated by one hour
  - Pulse ox reading is less than 90% for either or both the right hand and one foot
  - All of the above
- Pulse ox screening results can be shared with individuals that are not directly involved in the patient's care:
  - True
  - False

## COMPETENCY CHECKLIST

- Competency Title: Congenital Heart Disease Screening Process
- Competency Criteria includes the following:
  - (1) Completion of the in-service education.
  - (2) Accomplishment of 90 percent or more on the knowledge assessment quiz with remediation as necessary.
  - (3) Appropriate application of pulse oximetry.
  - (4) Accurate reading and documentation of the pulse oximetry readings.
- Competency Statement: Proficiently perform the required activities defined in research protocol.
 

Validation Criteria:   A. Discussion (D)                      C. Written Test (T)  
                                   B. Verbal Feedback (VF)    D. Return Demonstration (RD)

*Directions for completing evaluation form: Evaluator, please circle the appropriate method of validation, initial each line and place signature in the appropriate place at the end of the document.*

Name: \_\_\_\_\_ Job Title \_\_\_\_\_

Competency	Date	Method of Validation	Supervisor Initials	Comments
Explains screening eligibility guidelines for pulse oximetry screening		D VF T		
Identifies safe and correct methods for performing pulse oximetry		D VF T RD		
Describes methods to ensure that pulse oximetry reading is accurate		D VF T RD		
Explains screening methods and guidelines for pulse oximetry screening		D VF T		
Discuss HIPAA confidentiality standards		D VF T		

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Supervisor Name (Printed): \_\_\_\_\_

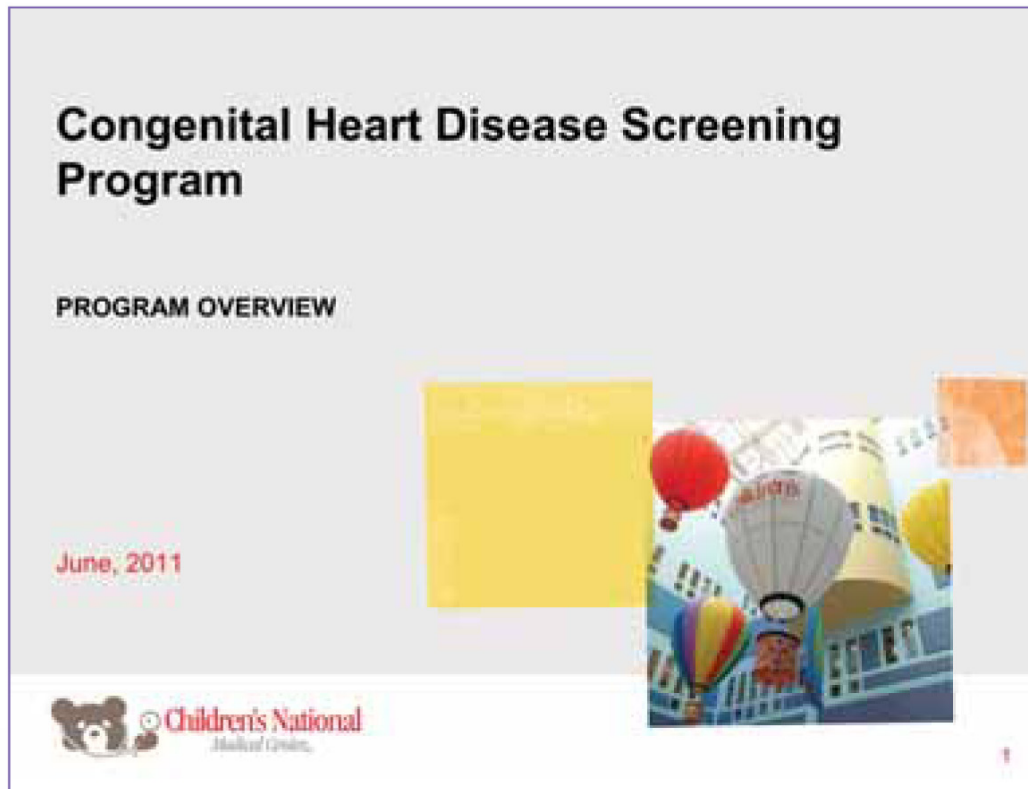
Supervisor Signature: \_\_\_\_\_



## PROGRAM OVERVIEW POWERPOINT PRESENTATION

Visit the following link to access this presentation:

<http://www.adph.org/newbornscreening/Default.asp?id=2201>



# SECTION 3 – SCREENING

- ♥ SUPPLIES FOR SCREENING
- ♥ PULSE OX SCREENING ALGORITHM
- ♥ FAILED SCREEN REPORTING FORM
- ♥ REFERRAL SOURCES

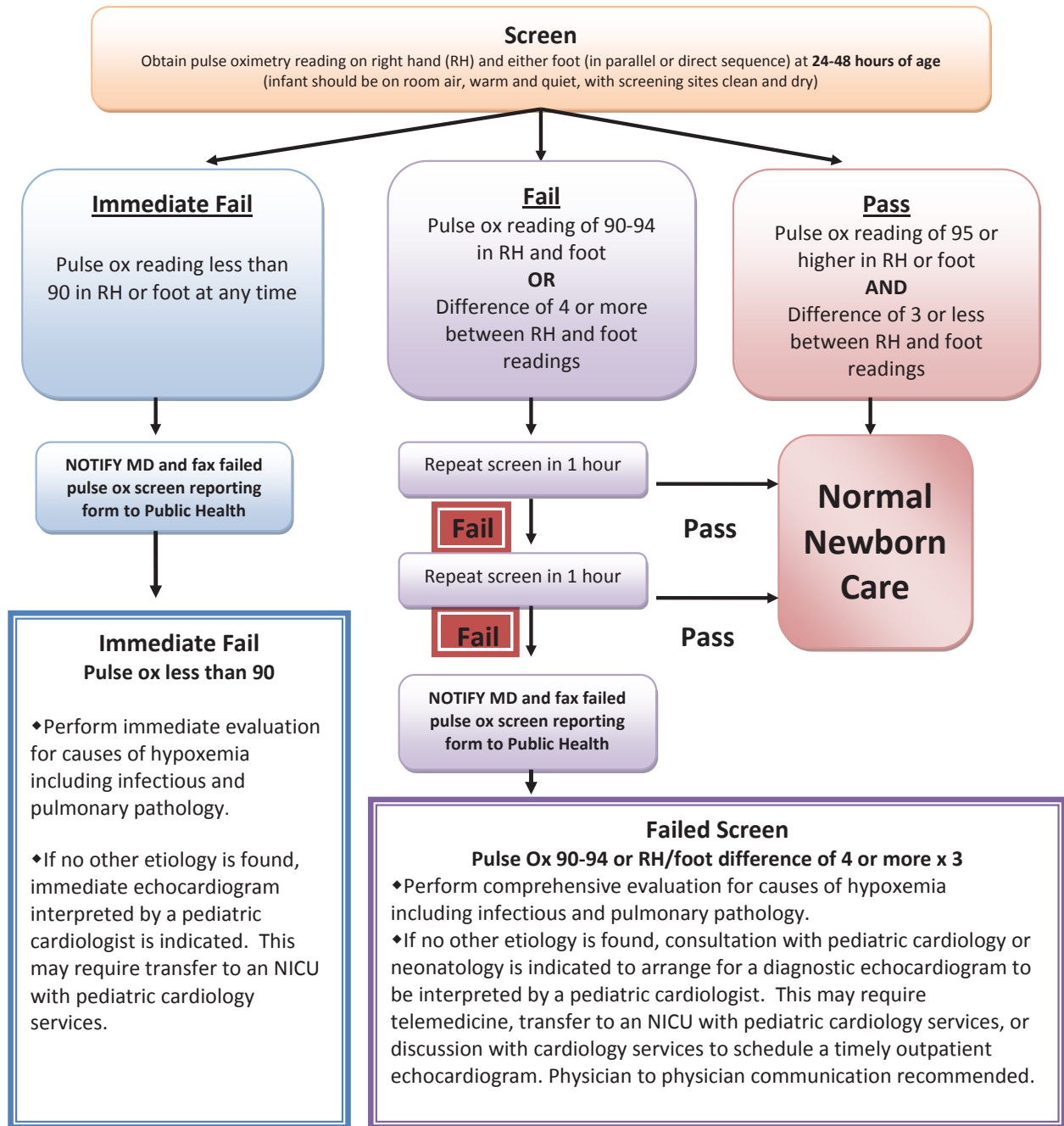
## SECTION 3 – SCREENING

### SUPPLIES FOR SCREENING

- Pulse Oximeters
  1. At least one motion-tolerant pulse oximeter to be used for screening
  2. One motion-tolerant pulse oximeter for back-up
- Infant Disposable or Reusable Pulse Ox Sensors
  1. If using disposable sensors, one disposable sensor for every infant screened
  2. If using reusable sensors, one reusable sensor for each pulse oximeter. Also consider additional reusable sensors for back-up
    - a. Disinfecting agent recommended by pulse oximetry equipment manufacturer
  3. One disposable wrap per infant screened to secure sensor to hand or foot
- Rolling Cart for Supplies
- Data Collection Forms
  1. One for every infant screened
- Dedicated individual to perform screening
- Red Heart-Shaped Stickers
  1. One red heart-shaped sticker for every infant who has been screened (optional)
- Blankets for warming the infant and blocking extraneous light
- A parent for comforting infant during screening (optional)



# PULSE OX SCREENING ALGORITHM



➤ This screening algorithm should not take the place of clinical judgment or customary clinical practice.

➤ A negative screen does not rule out heart disease.

➤ Optimal results are obtained 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, has a 2% root mean-square accuracy, and is calibrated regularly.

➤ For more information see: Kemper, AR, Mahle, WT, Martin, GR et al; **Strategies for Implementing Screening for Congenital Heart Disease.** *Pediatrics.* 2011. available at: <http://pediatrics.aappublications.org/content/early/2011/10/06/peds.2011-1317>

## FAILED SCREEN REPORTING FORM INSTRUCTIONS

Hospitals will provide **failed** results to the Alabama Newborn Screening Program as soon as the screening is completed.

- The reporting form should be used to report **failed** pulse ox screening results to the Alabama Department of Public Health Newborn Screening Program.
- Please be sure all information is legible to ensure that the patient is identified properly.
- If infant is transferred to another facility or referred to a specialist, please include the name of the hospital/provider to which the baby is transferred or referred to.



## FAILED SCREEN REPORTING FORM

PLACE LABEL OR WRITE-IN INFORMATION

Medical Record # \_\_\_\_\_

Patient Name: Last \_\_\_\_\_ First \_\_\_\_\_

Mother's Name: \_\_\_\_\_ Date of Birth \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Hospital: \_\_\_\_\_ Medical Provider: \_\_\_\_\_

### ALABAMA NEWBORN SCREENING PROGRAM

Fax failed screens to **334-206-3791**

Age at Initial Screening: \_\_\_\_\_ hours

Initial Screening:

Time \_\_\_\_\_

Pulse Ox Saturation of Right Hand \_\_\_\_\_

Pulse Ox Saturation of Foot \_\_\_\_\_

Difference (right hand – foot) \_\_\_\_\_  Fail

Second Screening (*1 hour following initial screen if fail initial screen*)

Time \_\_\_\_\_

Pulse Ox Saturation of Right Hand \_\_\_\_\_

Pulse Ox Saturation of Foot \_\_\_\_\_

Difference (right hand – foot) \_\_\_\_\_  Fail

Third Screening (*1 hour following second screening if fail second screen*)

Time \_\_\_\_\_

Pulse Ox Saturation of Right Hand \_\_\_\_\_

Pulse Ox Saturation of Foot \_\_\_\_\_

Difference (right hand – foot) \_\_\_\_\_  Fail

Other etiology identified:  Pulmonary  Infection  Unknown  Other: \_\_\_\_\_

Transferred: \_\_\_\_\_

Provider referred to: \_\_\_\_\_

Screeener's First Initial/LastName: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

## REFERRAL RESOURCES

### **Pediatric Cardiology Groups**

- UAB Pediatric Cardiology (Birmingham)  
205-934-3460 (direct)  
1-800-UAB-MIST (paging)
- Pediatric Specialists of Montgomery (Montgomery)  
334-612-2111 (direct and paging)
- Cardiology Associates (Mobile)  
251-434-9177 (direct and paging)
- Diagnostic & Medical Clinic (Mobile)  
251-435-1200

### **Neonatal Intensive Care Units with Pediatric Cardiology available onsite**

- UAB RNICU (Birmingham)  
205-934-7310 (direct)  
1-800-UAB-MIST (paging)
- Baptist Medical Center South NICU (Montgomery)  
1-800-221-9040 (direct)
- USA Children's & Women's NICU (Mobile)  
251-415-1270 (direct)
- Huntsville Hospital for Women & Children NICU (Huntsville)  
256-265-7317 (direct)  
1-800-325-6210 (paging)

## SECTION 4 – EDUCATION

- ♥ CHECKLIST FOR INFORMING PARENTS AND GUARDIANS
- ♥ FREQUENTLY ASKED QUESTIONS FOR PATIENTS AND FAMILIES – ENGLISH
- ♥ FREQUENTLY ASKED QUESTIONS FOR PATIENTS AND FAMILIES – SPANISH
- ♥ SUGGESTED RESOURCES FOR FAMILIES – ENGLISH
- ♥ SUGGESTED RESOURCES FOR FAMILIES – SPANISH
- ♥ CCHD BROCHURE ORDER FORM

## SECTION 4 – EDUCATION

### **Recommendations for Parental Education:**

- Establish a plan to educate parents prior to screening.
- Have written materials available in the obstetrics and gynecology clinics, labor and delivery, and maternity suites.
- Provide education in both written and verbal methods; written materials should be easy to read and understand, and should not contain excessive medical language that may confuse parents.
- Include program contact information on all communication to provide parents/families the opportunity to seek additional information and clarification.
- Inform parents/families of the right to decline screening. Refer to your Newborn Screening Provider Manual or our website for the refusal form.

## 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 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.





**What is a normal reading?**

Pulse ox readings in the right hand and foot that are 95 or higher and have a difference of three or less between the right hand and foot are normal in healthy children. Children with heart or lung problems may have lower readings. A low pulse oximetry reading can be normal in newborns whose lungs and heart are adjusting after birth. If your child has a problem with his or her heart or lungs, your doctor or nurse will tell you what a normal pulse ox range is for your child. It is possible that your baby's doctor will order additional tests.

**Can a baby with serious CHD have a normal pulse ox reading?**

It is possible that the pulse ox test will not detect all forms of problems in the baby's heart. Your baby should continue to have normal visits with his or her primary care doctor. If a problem with the heart is suspected, your primary care doctor will advise you.

**What if I have questions or do not want to have my baby screened for serious heart problems?**

If you have questions about pulse ox or CHD, you should ask the doctor or nurse practitioner that is providing your prenatal care or the doctor or nurse caring for your baby after he or she is born. If you do not want your baby screened for serious heart problems you should tell your doctor or nurse when you are in the hospital to deliver your baby.







### **¿Cual es la medida normal?**

La medida de la oximetría de pulso en la mano derecha o en el pie derecho que es de 95 a 100 por ciento o tienen una diferencia igual o menor de 3 entre la mano y pie derecho es normal en los niños sanos. Los niños con problemas cardiacos o pulmonares pueden tener medidas más bajas. Una medida de oximetría de pulso baja puede ser normal en los recién nacidos el cual los pulmones y el corazón se están ajustando después de haber nacido. Si su hijo tiene problemas con el corazón o con los pulmones, su médico o enfermero/a le dirá cual es la escala de oximetría de pulso normal para su hijo. Es posible que el médico de su bebé ordene pruebas adicionales.

### **¿Un bebé con un grave ECC puede tener una medida de oximetría de pulso normal?**

Es posible que la prueba de oximetría de pulso no pueda detectar todas las formas de problemas del corazón del bebé. Su bebé debe continuar con las citas regulares con su doctor primario. Si se sospecha un problema con el corazón, su doctor primario le aconsejará.

### **¿Qué tal si tengo preguntas o no quiero que mi bebé se someta a alguna revisión para detectar graves problemas cardiacos?**

Si tiene preguntas acerca de la oximetría de pulso o ECC, usted le debe preguntar al médico o al/la enfermero/a practicante que le proporciona la atención prenatal o el médico o personal de enfermería que atenderá a su bebé después de que nazca. Si no quiere que su bebé se someta a una revisión para detectar graves problemas cardiacos, usted debe decirle a su médico o al personal de enfermería cuando esté en el hospital para dar a luz.

### **¿Qué tal si tengo preguntas?**

Si tiene preguntas acerca de la oximetría de pulso, usted debe preguntarle al médico o al personal de enfermería atendiendo a su bebé.



## SUGGESTED RESOURCES FOR FAMILIES

### Support Groups and Online Resources

- |   |  |
|---|--|
| 1. American Heart Association           | <a href="http://amhrt.org">amhrt.org</a>   |
| 2. Children’s Heart Association         | <a href="http://www.heartchild.info">www.heartchild.info</a>                           |
| 3. Children’s Heart Foundation          | <a href="http://www.childrensheartfoundation.org">www.childrensheartfoundation.org</a> |
| 4. Congenital Heart Information Network | <a href="http://tchin.org">tchin.org</a>   |
| 5. Congenital Heart Defects.com         | <a href="http://www.congenitalheartdefects.com">www.congenitalheartdefects.com</a>     |
| 6. Kids with Heart                      | <a href="http://www.kidswithheart.org">www.kidswithheart.org</a>                       |
| 7. PediHeart                            | <a href="http://www.pediheart.org">www.pediheart.org</a>                               |
| 8. 1 in 100                             | <a href="http://www.1in100.org">www.1in100.org</a>                                     |

### Books for Parents

1. “Heart Defects in Children: What Every Parent Should Know,” by Cheryl J. Wild
2. “Heart of a Child,” by Catherine A. Neill, Edward B. Clark and Carleen Clark
3. “It’s My Heart,” by Children’s Heart Foundation
4. “The Heart of a Mother,” by Anna Marie Jaworski and Judy Norwood

### Books for Children with Heart Defects

1. “Blue Lewis and Sasha the Great,” by Carol Donsky Newell
2. “Matty’s Heart,” by C.J. Hribal
3. “Nathan’s Special Heart,” by Jessica Ennis (available as a virtual book)
4. “Pump the Bear,” by Gisella Olivo Whittington

### Books for Siblings

1. “Cardiac Kids,” by Vicci Elder
2. “My Brother Needs an Operation,” by Anna Marie Jaworski & Sarah Lualdi Moran
3. “When Molly was in the Hospital,” by Debbie Duncan

## RECURSOS SUGERIDOS PARA LAS FAMILIAS

### Grupos de apoyo y recursos en la Internet

- |   |  |
|---|--|
| 1. American Heart Association           | <a href="http://amhrt.org">amhrt.org</a>   |
| 2. Children's Heart Association         | <a href="http://www.heartchild.info">www.heartchild.info</a>                           |
| 3. Children's Heart Foundation          | <a href="http://www.childrensheartfoundation.org">www.childrensheartfoundation.org</a> |
| 4. Congenital Heart Information Network | <a href="http://tchin.org">tchin.org</a>   |
| 5. Congenital Heart Defects.com         | <a href="http://www.congenitalheartdefects.com">www.congenitalheartdefects.com</a>     |
| 6. Kids with Heart                      | <a href="http://www.kidswithheart.org">www.kidswithheart.org</a>                       |
| 7. PediHeart                            | <a href="http://www.pediheart.org">www.pediheart.org</a>                               |

### Libros para los padres

1. "Heart Defects in Children: What Every Parent Should Know," por Cheryl J. Wild
2. "Heart of a Child," por Catherine A. Neill, Edward B. Clark y Carleen Clark
3. "It's My Heart," por Children's Heart Foundation
4. "The Heart of a Mother," por Anna Marie Jaworski y Judy Norwood

### Libros para niños con defectos cardíacos

1. "Blue Lewis and Sasha the Great," por Carol Donsky Newell
2. "Matty's Heart," por C.J. Hribal
3. "Nathan's Special Heart," por Jessica Ennis (disponible como libro virtual)
4. "Pump the Bear," por Gisella Olivo Whittington

### Libros para los hermanos

1. "Cardiac Kids," por Vicci Elder
2. "My Brother Needs an Operation," por Anna Marie Jaworski & Sarah Lualdi Moran
3. "When Molly was in the Hospital," por Debbie Duncan

# CCHD MATERIAL ORDER FORM

Hospital/Practice Name: \_\_\_\_\_  
(Please spell out complete name)

Mailing Address: \_\_\_\_\_  
(No P.O. Boxes please)

City/Zip Code: \_\_\_\_\_

Telephone: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Congenital Heart Disease Screening Program: Frequently Asked Questions  
(English version)

Quantity Requested (comes in packets of 100): \_\_\_\_\_

Congenital Heart Disease Screening Program: Frequently Asked Questions  
(Spanish version)

Quantity Requested (comes in packets of 100): \_\_\_\_\_

Failed Pulse Ox Screen Reporting Form

Quantity Requested (comes in packets of 100): \_\_\_\_\_

Please call or fax this order form to:

334-206-7065 (phone)

1-866-928-6755 (toll-free phone line)

334-206-3791 (fax)

# RESOURCES

- ♥ CENTERS FOR DISEASE CONTROL (CDC) ARTICLE:  
PULSE OX SCREENING FOR CRITICAL CONGENITAL  
HEART DEFECTS

# Pulse Oximetry Screening for Critical Congenital Heart Defects

- Babies with critical congenital heart defects (CCHD) are at significant risk for death or disability if their condition is not diagnosed soon after birth.
- Pulse oximetry newborn screening can identify some infants with a CCHD before they show signs of the condition.
- Once identified, babies with a CCHD can be seen by cardiologists and can receive special care and treatment that can prevent death or disability early in life.
- Certain hospitals routinely screen all newborns using pulse oximetry screening. However, pulse oximetry screening is not currently included in most state newborn screening panels.

## Understanding Critical Congenital Heart Defects

- **Congenital heart defects (CHDs) account for 24% of infant deaths due to birth defects.**
- **In the United States, about 4,800 (or 11.6 per 10,000) babies born every year have critical congenital heart defects (CCHDs).**
- **The seven defects classified as CCHDs (which also are known collectively in some instances as critical congenital heart disease) are:**
  - » **Hypoplastic left heart syndrome**
  - » **Pulmonary atresia (with intact septum)**
  - » **Tetralogy of Fallot**
  - » **Total anomalous pulmonary venous return**
  - » **Transposition of the great arteries**
  - » **Tricuspid atresia**
  - » **Truncus arteriosus**



Babies with a CCHD are at significant risk for death or disability if their CCHD is not diagnosed and treated soon after birth. CCHDs among some babies potentially can be detected using *pulse oximetry screening*, which is a test to determine the amount of oxygen in the blood and pulse rate.

## The Importance of Screening for Critical Congenital Heart Defects

Some babies born with a heart defect can appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that at least 280 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States. These babies are at risk for having serious complications within the first few days or weeks of life and often require emergency care.

Pulse oximetry newborn screening can identify some infants with a CCHD before they show signs of a CCHD. Once identified, babies with a CCHD can be seen by cardiologists and can receive specialized care and treatment that could prevent death or disability early in life. Treatment can include medications and surgery.



National Center on Birth Defects and Developmental Disabilities  
Division of Birth Defects and Developmental Disabilities



## When and How Babies Are Screened

Pulse oximetry is a simple bedside test to determine the amount of oxygen in a baby's blood and the baby's pulse rate. Low levels of oxygen in the blood can be a sign of a CCHD. The test is done using a machine called a *pulse oximeter*, with sensors placed on the baby's skin. The test is painless and takes only a few minutes. Screening is done when a baby is 24 to 48 hours of age, or as late as possible if the baby is to be discharged from the hospital before he or she is 24 hours of age.



Pulse oximetry screening does not replace a complete history and physical examination, which sometimes can detect a CCHD before the development of low levels of oxygen in the blood. Pulse oximetry screening, therefore, should be used to complement the physical examination.

## Pulse Oximetry Screening Results

If the results are "negative" (in-range result), it means that the baby's test results did not show signs of a CCHD. This type of screening test does not detect all CCHDs, so it is possible to still have a CCHD or other congenital heart defect with a negative screening result. If the results are "positive" (out-of-range result), it means that the baby's test results showed low levels of oxygen in the blood, which can be a sign of a CCHD. This does not *always* mean that the baby has a CCHD. It just means that more testing is needed.

The baby's doctor might recommend that the infant get screened again or have more specific tests, like an *echocardiogram* (an ultrasound picture of the heart), to diagnose a CCHD. Babies who are found to have a CCHD also might be evaluated by a clinical geneticist. This could help identify genetic syndromes associated with CCHDs and inform families about future risks.



## Centers for Disease Control and Prevention Activities

The Centers for Disease Control and Prevention (CDC) is part of the U.S. Department of Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). SACHDNC was authorized by Congress to provide guidance to the HHS Secretary about which conditions should be included in newborn and childhood screening programs, as well as how systems should be developed to ensure that all newborns and children are screened and, when necessary, receive appropriate follow-up care. SACHDNC recommended that the HHS Secretary add pulse oximetry screening for CCHDs (i.e., the heart defects listed previously) to the Recommended Uniform Screening Panel. In September 2011, HHS Secretary Sebelius approved adding CCHD to the Recommended Uniform Screening Panel and outlined specific tasks assigned to NIH, CDC, and HRSA.

**For more information on pulse oximetry screening for CCHDs, please visit**  
**<http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html>**

### National Center on Birth Defects and Developmental Disabilities

For more information please contact the Centers for Disease Control and Prevention  
1600 Clifton Road NE, Atlanta, GA 30333  
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-63548  
Email: [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov) Web: [www.cdc.gov](http://www.cdc.gov)

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