

MICHIGAN DEPARTMENT OF COMMUNITY HEALTH

Guidelines for Implementing Pulse Oximetry Screening for Critical Congenital Heart Disease



2013





STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH
LANSING

RICK SNYDER
GOVERNOR

JAMES K. HAVEMAN
DIRECTOR

Dear Newborn Care Provider:

The Michigan Department of Community Health (MDCH) Newborn Screening (NBS) Program has put together this toolkit to help your hospital with implementation of critical congenital heart disease (CCHD) screening in newborns.

Congenital heart defects (CHD) are the most common type of birth defect, and account for 30% of deaths in infants with birth defects. 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% of pregnancies or 11% of live births affected by CHD. Detection during the postnatal period currently occurs after physical examination and/or by presentation of symptoms during the first 24 hours of life. These methods have proven successful in identifying 50% of infants with CCHD. **Pulse oximetry** has been shown to detect some forms of congenital heart defects in the newborn. This screening targets twelve specific anomalies classified as CCHD. Failure to detect such heart defects while in the hospital puts the baby at risk for serious complications within the first few days or weeks of life, often requiring emergency room care.

The MDCH NBS Program recommends that pulse oximetry screening for CCHD be implemented as a part of routine care for all infants. The screening should be performed as close to 24 hours of age as possible, or when medically appropriate if the infant was born prematurely. All infants should be screened prior to discharge. It is recommended that pulse oximetry 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.

This toolkit was assembled with assistance from Michigan's CCHD Advisory Committee and Children's National Medical Center in Washington DC. The content is based on a review of current literature and recommendations, as well as results of studies to identify best practices for implementation.

Our NBS Program is asking you to become a partner in implementing CCHD screening in your hospital. We are excited to have the opportunity to work with you on this initiative which has the potential to save lives. If you have any questions or concerns, please feel free to contact us at 1.866.673.9939.

Sincerely,

William Young, PhD
Newborn Screening Follow-up
Manager

Kerl Urquhart, RN, BSN
Critical Congenital Heart Disease
Nurse Educator

CRITICAL CONGENITAL HEART DISEASE HOSPITAL TOOLKIT FOR IMPLEMENTING PULSE OXIMETRY SCREENING

CCHD Toolkit is
available for download
on our website
www.michigan.gov/cchd

Disclaimer:

The information included in this document is for informational and educational purposes only. The contents of this toolkit should not substitute for professional judgment, nor should the user rely solely on the information provided. Furthermore, this document does not reflect the optimal medical practice for all circumstances. Users are advised to follow your hospital or unit's policy and seek professional counsel on the issues raised by consulting with medical staff on matters involving clinical practice.

Michigan Newborn Screening Program
Capitol View Building , 201 Townsend St.
Lansing, Michigan 48913

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CDC Article: “Pulse Ox Screening for Critical Congenital Heart Defects”

References

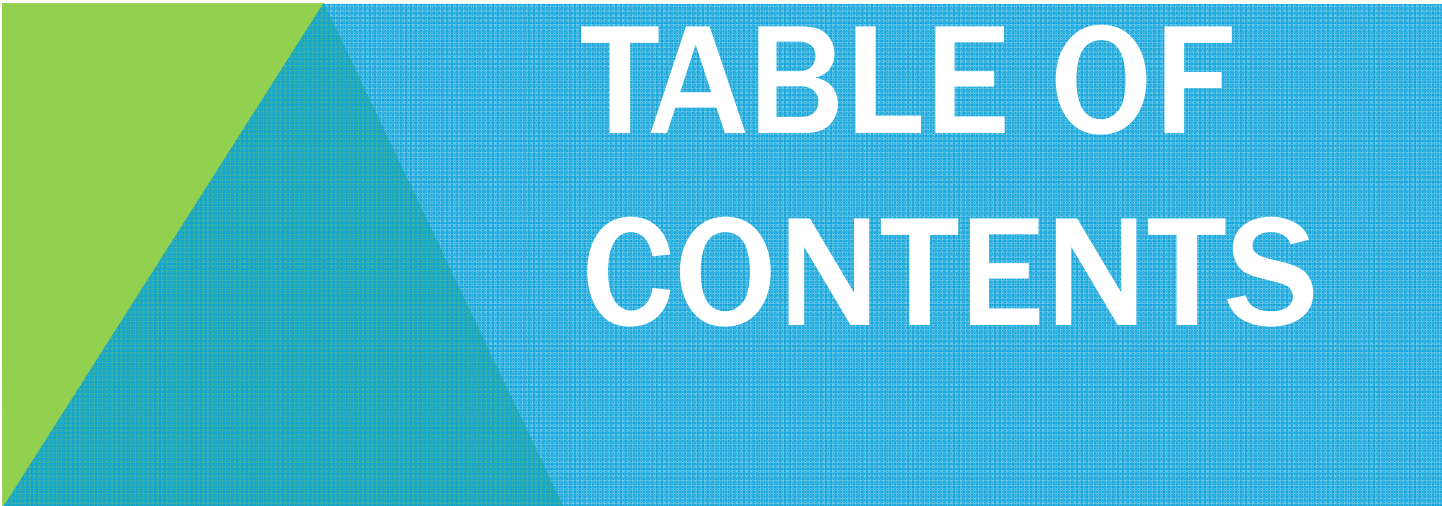


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MICHIGAN CCHD SCREENING PROGRAM CONTACTS

Karen Andruszewski, BS
Newborn Screening Data
Manager
517-335-8532
andruszewskik@michigan.gov

Janice Bach, MS, CGC
CCHD Demonstration Program
Director
517-335-8497
bachj@michigan.gov

Joan Ehrhardt, MS, CGC
Birth Defects Program
Coordinator
517-335-6498
ehrhardtj@michigan.gov

Mary Kleyn, MSc
Newborn Screening
Epidemiologist
517-335-9296
kleynm@michigan.gov

Robin Stottlemyer, MPH
CCHD Program Coordinator
517-373-4245
stottlemyerr@michigan.gov

Keri Urquhart, RN, BSN
CCHD Nurse Educator
517-335-8135
urquhartk1@michigan.gov

William Young, PhD
Newborn Screening Follow-up
Manager
517-335-8938
youngw@michigan.gov

MICHIGAN CCHD SCREENING INTRODUCTION

Congenital heart defects are the most common group of birth defects, affecting 9 in 1,000 newborns. *Critical* Congenital Heart Defects (CCHDs) are those requiring surgery or catheter intervention in the first year of life. CCHD remains one of the most significant causes of infant death in the United States.

In 2011, pulse oximetry was recommended by the U.S. Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children as an important screening tool for detection of CCHD in asymptomatic newborns. This recommendation was subsequently endorsed by the American Academy of Pediatrics as a standard of care. The Michigan Department of Community Health (MDCH) is implementing a demonstration program to promote the screening of all Michigan newborns for CCHDs using pulse oximetry prior to hospital discharge.

Critical Congenital Heart Defects (CCHDs) detected by pulse oximetry

<i>Most likely to be detected:</i>	<i>Less likely to be detected:</i>
○ Hypoplastic left heart syndrome	○ Coarctation of the aorta
○ Pulmonary atresia (with intact septum)	○ Double-outlet right ventricle
○ Tetralogy of Fallot	○ Ebstein anomaly
○ Total anomalous pulmonary venous return	○ Interrupted aortic arch
○ D-Transposition of the great arteries	○ Single ventricle
○ Tricuspid atresia	
○ Truncus arteriosus	

This toolkit serves as a guide to help each birthing facility establish its own policies and procedures for implementing a Critical Congenital Heart Disease Screening Program (CCHDSP). Your hospital should establish clear, complete, and concise evidence-based policies and procedures.

It is recommended that each facility designate a 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.

MICHIGAN CCHD SCREENING SCREENING RECOMMENDATIONS

Section 1: Recommendations for Program Planning and Implementation

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 including 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 identification and management of infants requiring further evaluation; onsite if available or referral to pediatric cardiology services elsewhere.
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 motion-resistant equipment approved for use in 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 and communication with parents and guardians before and after screening.
11. Establish plans for surveillance and reporting of program results and outcomes for internal use and to MDCH.

Section 2: 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 nurse manager, the nurse educator, program coordinator, or a registered nurse who played an active role in the planning process.
2. Include the following components as part of the in-service training:
 - a. MDCH PowerPoint presentation- with information on background and significance of screening, MDCH screening methods and recommendations. Accessible through www.michigan.gov/cchd
 - b. Demonstration of correct and safe use of pulse oximetry equipment in obtaining an accurate infant reading by a trainer or representative from pulse oximeter manufacturer.

- c. Completion of knowledge assessment quiz.
- d. Opportunity to practice pulse oximetry screening.

3. Require that all individuals who will be performing the screening complete the in-service education program.

4. Require that all individuals who will be performing the screening complete the knowledge assessment quiz with a passing score, with remediation for 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 renewal of competencies on an annual basis.

6. Offer “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 performing screening on newborns.

8. Provide staff with regular updates on outcomes of screening to maintain interest and engagement.

Section 3: Recommendations for Educating and Informing Providers

1. Inform and educate all hospital and community providers working in the newborn nursery, neonatal intensive care unit, postpartum unit, and pediatrics who will be affected by the screening program prior to implementation.

- a. Consider sending out a letter of program intent several weeks prior to implementation.
- b. Provide program contact information to allow providers to seek additional information and clarification.
- c. Provide a grand rounds session for the education of hospital and community providers.
- d. Request time at department meetings to inform and educate hospital and community providers prior to implementation.
- e. Provide frequent updates to hospital and community providers on screening program progress and outcomes at department meetings or through written communication.

Section 4: Recommendations for Educating and Informing Parents

1. Establish a plan to inform parents of the screening program prior to delivery through:
 - a. Prenatal classes and tours provided by the hospital
 - b. Information on the hospital’s website
 - c. Written materials available in the obstetrics and gynecology clinics, labor and delivery, and maternity suites.
2. Provide education through both written and verbal methods; written materials should be easy to read and understand and should not contain excessive medical language that may be confusing to parents. (Available from MDCH)
3. Provide written materials in English and Spanish; consider additional languages based on patient population.
4. Include program contact information on all communication to provide parents/guardians the opportunity to seek additional information and clarification prior to delivery.
5. Inform parents/guardians of the right to decline screening.

EQUIPMENT



MICHIGAN CCHD SCREENING EQUIPMENT

Each birthing facility is 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 approved by the FDA for use in newborns.
- Must be validated in low-perfusion conditions.
- Must have 2% root, mean-square accuracy.
- Must be calibrated regularly based on manufacturer guidelines.

FDA CLEARANCE FOR PULSE OXIMETER USE IN NEONATES

<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfpmn/pmnmn.cfm>



MICHIGAN CCHD SCREENING SCREENING SUPPLIES

- ♥ Pulse oximeter(s)
- ♥ Infant disposable or reusable pulse oximeter sensors
 - ♥ One disposable sensor and disposable wrap for every infant screened or
 - ♥ One reusable sensor for each pulse oximeter and disinfection agent recommended for equipment
- ♥ Rolling cart for supplies
- ♥ Qualified individual to perform screening
- ♥ Blankets for warming the infant and blocking extraneous light
- ♥ A parent/guardian for comforting infant during screening



SCREENER TRAINING



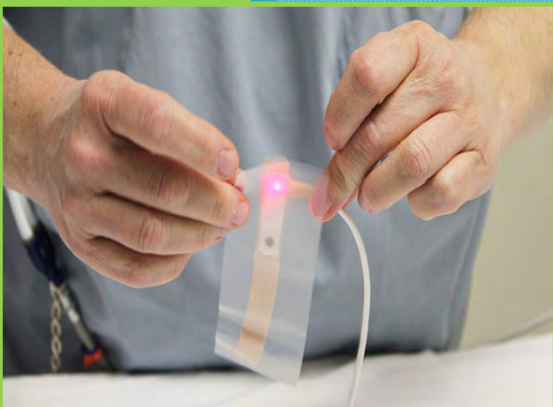
MICHIGAN CCHD SCREENING TRAINING OBJECTIVES

Training should be provided by qualified personnel who have participated in the planning process such as the unit nurse manager, assistant nurse manager, nurse educator, the program coordinator, or a registered nurse. This training should be hands-on and competency based and should include at a minimum:

- Overview of screening protocol
- Education on the use, care, maintenance, and troubleshooting of screening equipment
- A review of general birthing center and/or nursery pulse oximetry screening 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
- Causes of failed screens; primary and secondary targets
- Facility resources for pediatric echocardiogram and referral sources when not available in house

Other educational topics could include:

- Overview of CHD
- Basic physiology of cardiovascular circulation
- State and National Statistics
- Case Studies



Available from MDCH:

- PowerPoint presentations
- Staff training handouts
- Staff in-service
- "Train the trainer" sessions

www.michigan.gov/cchd

MICHIGAN CCHD SCREENING PULSE OX PROBE PLACEMENT

PULSE OX PROBE PLACEMENT EDUCATION

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



RH Application Site



Foot Application Site

2. Place the photo detector portion of the probe on the fleshy portion of the outside of the infant's right hand or foot.
3. Place the light emitter portion of the probe on the top of the right hand or foot.
4. Remember the photo detector and light emitter must be directly opposite each other in order to obtain an accurate reading.
5. Secure the probe to the infant's right 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 the top of the hand or foot.



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MICHIGAN CCHD SCREENING MI HEART

M MAKE SURE INFANT IS AT LEAST 24 HOURS OLD AND HAS NO CARDIAC OR RESPIRATORY SIGNS OR SYMPTOMS

I INFANTS IN THE NICU SHOULD BE SCREENED WHEN MEDICALLY APPROPRIATE OR PRIOR TO DISCHARGE FROM THE UNIT

H HELP PARENT TO WARM AND CALM THE INFANT. KEEP THE INFANT IN A QUIET ENVIRONMENT DURING SCREENING

E EDUCATE THE PARENT ON THE SCREENING PROCESS AND POSSIBLE OUTCOMES

A APPLY CLEAN PULSE OX PROBES TO PROPER SITES ON **RIGHT HAND** AND **EITHER FOOT** FOR SCREENING

R RE-SCREEN OR REFER FOR FOLLOW-UP WHEN NECESSARY

T TAKE STEPS TO ENSURE PROPER DOCUMENTATION AND NOTIFICATION PER HOSPITAL POLICY



MICHIGAN CCHD SCREENING

PERFORMING PULSE OX- DOs & DON'Ts

PULSE OX DO's

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 skin. The sides of the probe should be directly opposite 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 to obtain a reading for an infant. Using an adult clip on an infant will produce inaccurate results.
2. Blood flow is needed to obtain an accurate pulse ox reading. Never attempt to obtain a pulse ox reading on the same extremity where an automatic blood pressure cuff is located.
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

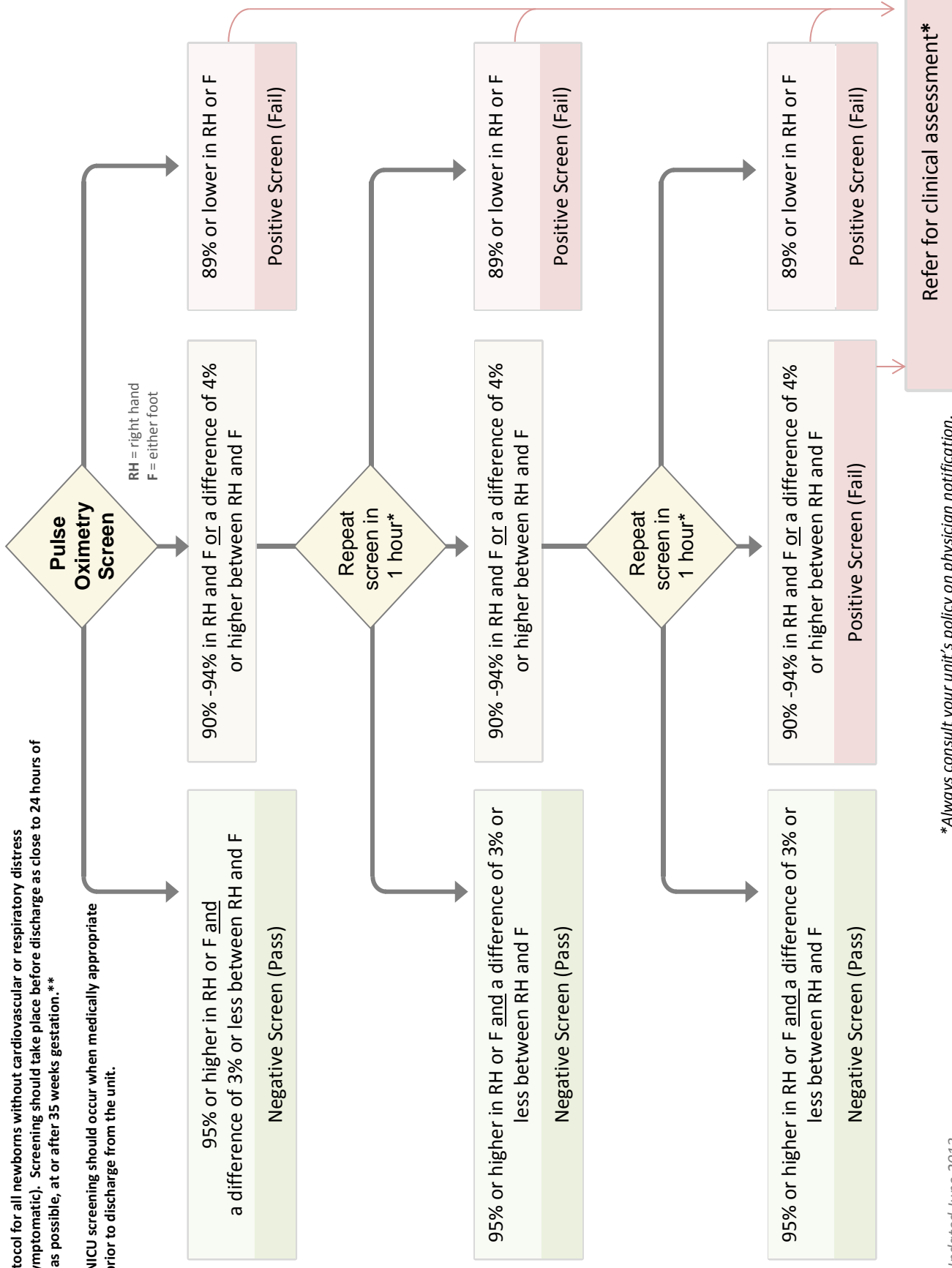
1. A pulse is needed to determine the oximetry reading. Pulse ox is not accurate if the patient is coding or has a cardiac arrhythmia. Remember: No pulse, no oximetry!
2. Pulse ox readings are not instantaneous. The oximetry reading that is displayed on the monitor is an average of readings over the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



Michigan Algorithm for Pulse Oximetry Screening

Protocol for all newborns without cardiovascular or respiratory distress (asymptomatic). Screening should take place before discharge as close to 24 hours of life as possible, at or after 35 weeks gestation.**

** NICU screening should occur when medically appropriate or prior to discharge from the unit.



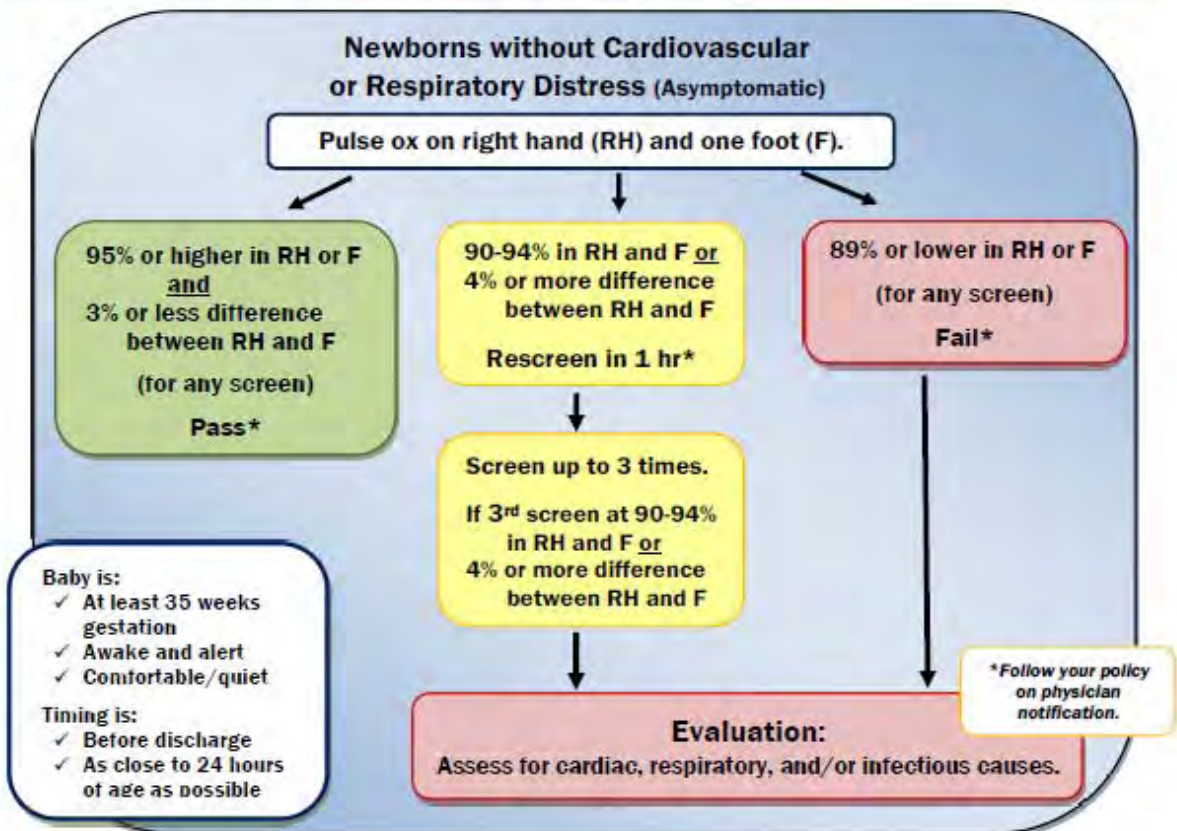
* Always consult your unit's policy on physician notification.

MICHIGAN CCHD SCREENING SCREENER TIP SHEET

Pulse Oximetry Screening

For Critical Congenital Heart Defects (CCHD)

Michigan Newborn Screening Tip Sheet



RIGHT HAND

Pre-Ductal Screen

Place the sensor on the back of the RIGHT HAND below the 4th or 5th finger. Wrap the tape around the hand. Align the emitter and the detector.



EITHER FOOT

Post-Ductal Screen

Place the sensor on the back of EITHER FOOT below the 4th or 5th toe. Wrap the tape around the foot. Align the emitter and the detector.



You might say:

Screen/Rescreen: "Pulse oximetry (pulse ox) is a way to check the oxygen level in the blood. It is painless and will only take a few minutes. If blood oxygen is a little low, we will recheck it later."

Fail: "Pulse ox showed that the blood oxygen level is low. The medical team needs to follow-up right away to find out why. Sometimes a low pulse ox result is a sign of health problems. If there is a problem, it's good to find out before your baby goes home."

Available for download on our website www.michigan.gov/cchd



MICHIGAN CCHD SCREENING INTERPRETATION OF PULSE OXIMETRY RESULTS

MICHIGAN DEPARTMENT OF COMMUNITY HEALTH

CCHD Screening for Newborn without Cardiovascular or Respiratory Distress Interpretation of Pulse Oximetry Results

Oxygen Saturation

(O2 Sats; %)

Right Hand (RH)	99	98	97	96	95	94	93	92	91	90	89% or lower
100	99	98	97	96	95	94	93	92	91	90	89% or lower
99	99	98	97	96	95	94	93	92	91	90	89% or lower
98	99	98	97	96	95	94	93	92	91	90	89% or lower
97	99	98	97	96	95	94	93	92	91	90	89% or lower
96	99	98	97	96	95	94	93	92	91	90	89% or lower
95	99	98	97	96	95	94	93	92	91	90	89% or lower
94	99	98	97	96	95	94	93	92	91	90	89% or lower
93	99	98	97	96	95	94	93	92	91	90	89% or lower
92	99	98	97	96	95	94	93	92	91	90	89% or lower
91	99	98	97	96	95	94	93	92	91	90	89% or lower
90	99	98	97	96	95	94	93	92	91	90	89% or lower
89% or lower	99	98	97	96	95	94	93	92	91	90	89% or lower

Pass 95% or higher in right hand (RH) or either foot (F) AND difference of 3% or less between RH and F.

Rescreen 90-94% in RH and F or difference of 4% or more between RH and F. Screen up to 3 times.

89% or lower in RH or F (at any time)

OK

3rd screen: 90-94% in RH and F or difference of 4% or more between RH and F.

Available for download
on our website
www.michigan.gov/cchd

Adapted from Critical Care Medicine
Lakshminarayanan S, et al
Neonatal Heart Disease Screening with Pulse Oximetry in the Neonatal Intensive Care Unit
e-Journal of Neonatology Research 2012(2): 96-101.

1-M19-13
MDCH

MICHIGAN CCHD SCREENING CCHD CHARTING FORM

Infant's label goes here.

NBS Kit #: _____

1st screen results:

Date: _____ Time: _____

RH: _____ Foot: _____

*PI: _____ Pass Rescreen Fail

2nd screen results:

Date: _____ Time: _____

RH: _____ Foot: _____

*PI: _____ Pass Rescreen Fail

3rd screen results:

Date: _____ Time: _____

RH: _____ Foot: _____

*PI: _____ Pass Fail

*Perfusion index (PI), if available.

Notes: _____

For information on CCHD
education and educational
materials

Contact:
Keri Urquhart, RN, BSN
CCHD Nurse Educator
517.335.8135
Email: urquhartk1@michigan.gov

Available for download
on our website
www.michigan.gov/cchd

MICHIGAN CCHD SCREENING SCREENER 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 congenital heart disease:

- a. True
- b. False

5. The screening guidelines state that pulse ox should be performed on:

- a. The right hand
- b. Either foot
- c. The left hand
- d. Both a and b

6. Pulse ox screening should be performed when the infant is what age:

- a. Less than 8 hours
- b. No later than 32 hours
- c. After 48 hours
- d. At least 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 95% or higher for both right hand and one foot **and** there is a 4% or more difference between the two on three measures each separated by one hour
- b. Pulse ox readings are 94% or less for both right hand and one foot or there is a 4% **or** more difference between the two on three measures each separated by one hour
- c. Pulse ox reading is 89% or less for either or both the right hand and one foot on any reading
- d. All of the above

8. An infant's pulse ox readings at 24 hours of life are R hand 99% and left foot 95%. What do these results tell you?

- a. The infant passed the pulse ox screening and needs no further follow up
- b. The infant should be rescreened in 1 hour and the physician should be notified per your hospital policy
- c. This is a failed screen- notify a physician immediately

MICHIGAN CCHD SCREENING SCREENER KNOWLEDGE ASSESSMENT ANSWERS

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**

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- a. Placing the pulse ox probe on the same extremity that you are taking the blood pressure
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- c. Using a clip on the finger of an infant
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- c. Pulse ox reading is 89% or less for either or both the right hand and one foot on any reading
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MICHIGAN CCHD SCREENING SCREENER COMPETENCY CHECKLIST

♥ **Competency Title: Critical Congenital Heart Disease Screening Process**

♥ **Competency criteria includes the following:**

- (1) Completion of the in-service education.
- (2) Completion of knowledge assessment quiz with remediation as necessary.
- (3) Appropriate application of pulse oximeter.
- (4) Accurate reading and documentation of the pulse oximetry readings.

♥ **Competency statement: Proficiently perform pulse oximetry as defined in hospital protocol**

Validation criteria:

- A. Discussion (D)
- B. Verbal feedback (VF)
- C. Written test (T)
- 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.

Employee Name: _____

Job Title: _____

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

Employee Signature: _____ Date: _____

Supervisor Signature: _____

INFORMATION FOR PROVIDERS



MICHIGAN CCHD SCREENING INFORMATION FOR PROVIDERS

All physicians associated with newborn or pediatric care should be notified of your implementation or plans to implement a CCHD pulse oximetry screening program.

The information should include:

- Overview of screening protocol
- Education on the use, care, and trouble-shooting of screening equipment
- A review of general birthing center and/or nursery policies and procedures; including evaluation of babies with a failed screen
- Education on the differences between adult and pediatric oximeter probes
- Facility resources for pediatric echocardiogram and referral sources when not available in house

Consider a Grand Rounds
presentation on CCHD
Screening

MDCH can help you with this
www.michigan.gov/cchd



Dear Provider:

We are excited to inform you that we will be implementing a Congenital Heart Disease Screening Program (CHDSP) in our newborn nursery. The CHDSP involves the use of pulse oximetry as a screening tool for critical congenital heart disease (CCHD). The components of this program have been reviewed by the Michigan Department of Community Health (MDCH) with the help of Children's National Medical Center in Washington DC. The program is based on a review of current literature on pulse oximetry screening for CCHD as well as research on best-practices for implementation. This letter will inform you of the background and significance of pulse oximetry screening for CCHD and provide an overview of recommended guidelines.

Background and Significance

Congenital heart defects (CHD) are the most common type of birth defect, and account for 30% of deaths in infants with birth defects. 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% of pregnancies or 11% of live births. Detection during the postnatal period currently occurs after physical examination and/or by presentation of symptoms during the first 24 hours of life. These methods have proven successful in identifying 50% of infants with CCHD. Pulse oximetry has been shown to detect some forms of congenital heart defects in the newborn. This screening targets specific anomalies classified as CCHD. Failure to detect such heart defects while in the hospital puts the baby at risk for serious complications within the first few days or weeks of life, often requiring emergency room care.

Failing to detect critical CHD while in the 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. Early detection of critical CHD can potentially improve the prognosis and decrease the mortality and morbidity rate of affected infants. Health and Human Services Secretary Kathleen Sebelius endorses the inclusion of screening for critical CHD in the recommended uniform newborn screening panel. The American Heart Association, American Academy of Pediatrics and American College of Cardiology also support pulse oximetry screening of newborns.

Overview of CHDSP Screening Guidelines

The CHDSP adds pulse oximetry to routine testing after 24 hours of life to detect critical CHD. It is recommended that pulse oximetry screening be done in conjunction with another standard-of-care newborn screening that requires the infant be at least 24 hours of age. All newborns should be screened. The MDCH has developed an algorithm for CCHD Screening we are following as part of our procedure.

If the infant should fail their CCHD our policy will be to notify a physician and all future decisions regarding care of newborns with lower than expected oxygen saturations will be made at the discretion of the physician or nurse practitioner caring for the infant. It is recommended that a physical exam be done along with obtaining an echocardiogram to rule out structural abnormalities for newborns with abnormal pulse oximetry readings. We are asking that you work with us to implement the CHDSP in our birthing center. We are excited to have the opportunity to work with you to implement a screening program that has the potential to save the lives and improve outcomes for many of our babies. Please feel free to contact us with any additional questions or concerns.

Sincerely,

(your signature)

Example of letter to send to providers notifying them of CCHD screening program

MICHIGAN CCHD SCREENING STATISTICS- MICHIGAN

On average, 267 Michigan babies are born each year with a CCHD*

	Prevalence (per 10,000 live births)	Count (average per year)
CCHD most likely detected		
Hypoplastic Left Heart	3.7	46.9
Pulmonary Atresia, Intact Septum	1.9	23.5
Tetralogy of Fallot	4.5	56.9
Total Anomalous Pulmonary Venous Connection	1.1	14
D-Transposition of the Great Arteries	3.2	41
Tricuspid Atresia	1.4	17.2
Truncus Arteriosus	1.3	15.9
Additional CCHD detected		
Coarctation of the Aorta	5.6	70.9
Double-outlet Right Ventricle	2.0	25.5
Ebstein Anomaly	1.4	17.2
Interrupted Aortic Arch	0.9	11.5
Single Ventricle	1.4	17.2
TOTAL (Infants with CCHD)		267

*ESTIMATES ARE PER MICHIGAN BIRTH DEFECTS REGISTRY REPORTING 2000-2010. VARIATION IS BASED ON CHANGES IN THE BIRTH RATE, TIMELY DIAGNOSIS AND REPORTING. A CHILD MAY HAVE MORE THAN ONE CCHD. REVISIONS IN DIAGNOSIS MAY OCCUR DUE TO THE COMPLEXITY OF CCHDS.

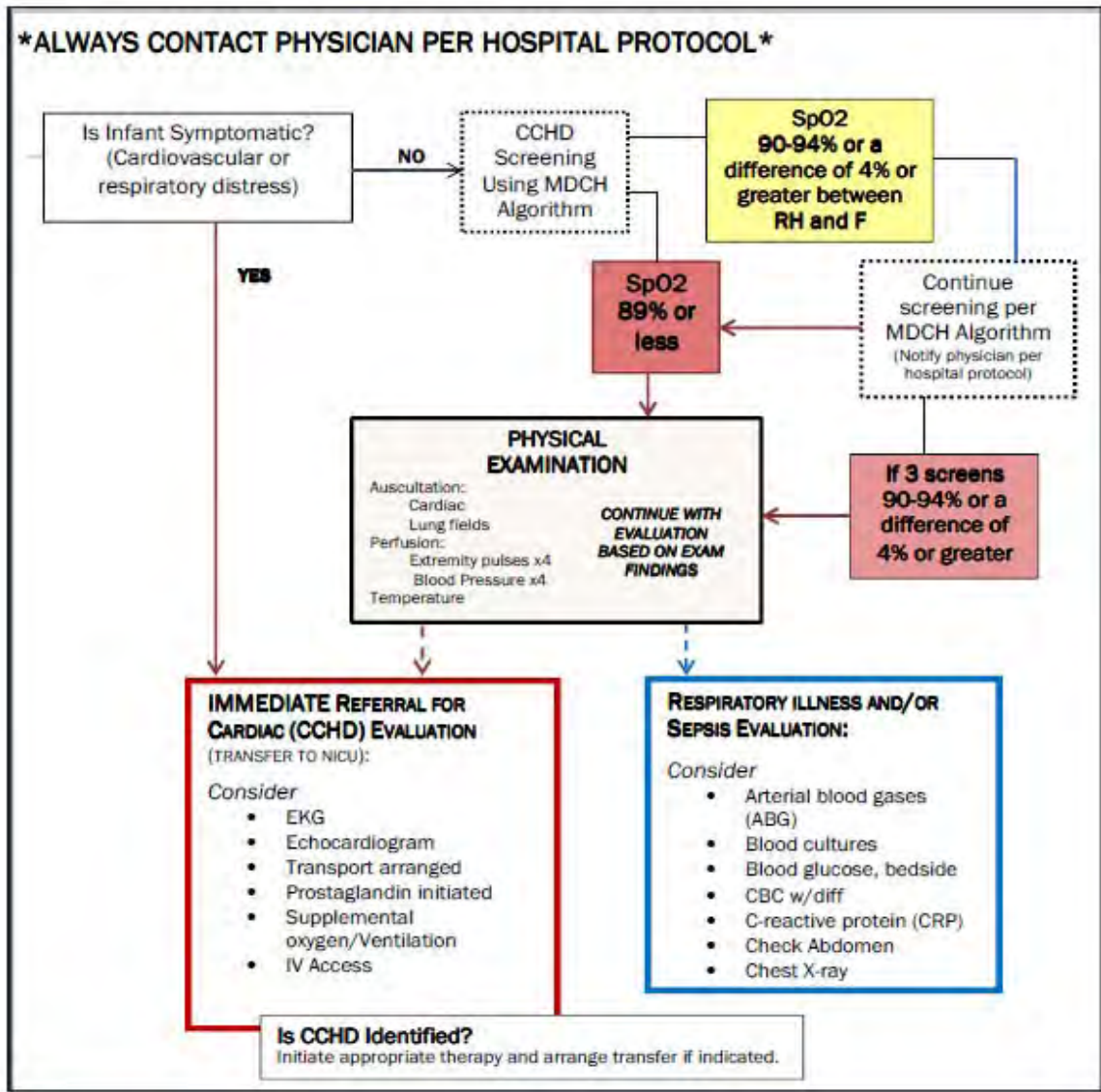
MICHIGAN CCHD SCREENING POSITIVE SCREEN EVALUATION

CCHD Evaluation—Worksheet

Name: _____

MR#: _____

Michigan Newborn Screening Follow-up Worksheet



Resources

Notes: _____

Michigan Newborn Screening
 1.866.673.9939
www.michigan.gov/cchd

American Heart Association
 www.heart.org
 www.americanheart.org

Available for download
 on our website
www.michigan.gov/cchd



PARENT EDUCATION

"As a mother of a child born with a CCHD I am thankful there is a screening tool for newborns. Just knowing that children just like my daughter can be given a chance at life by catching their defects soon after birth shows the importance of screening. It gives these children their chance to fight and early diagnosis is key."

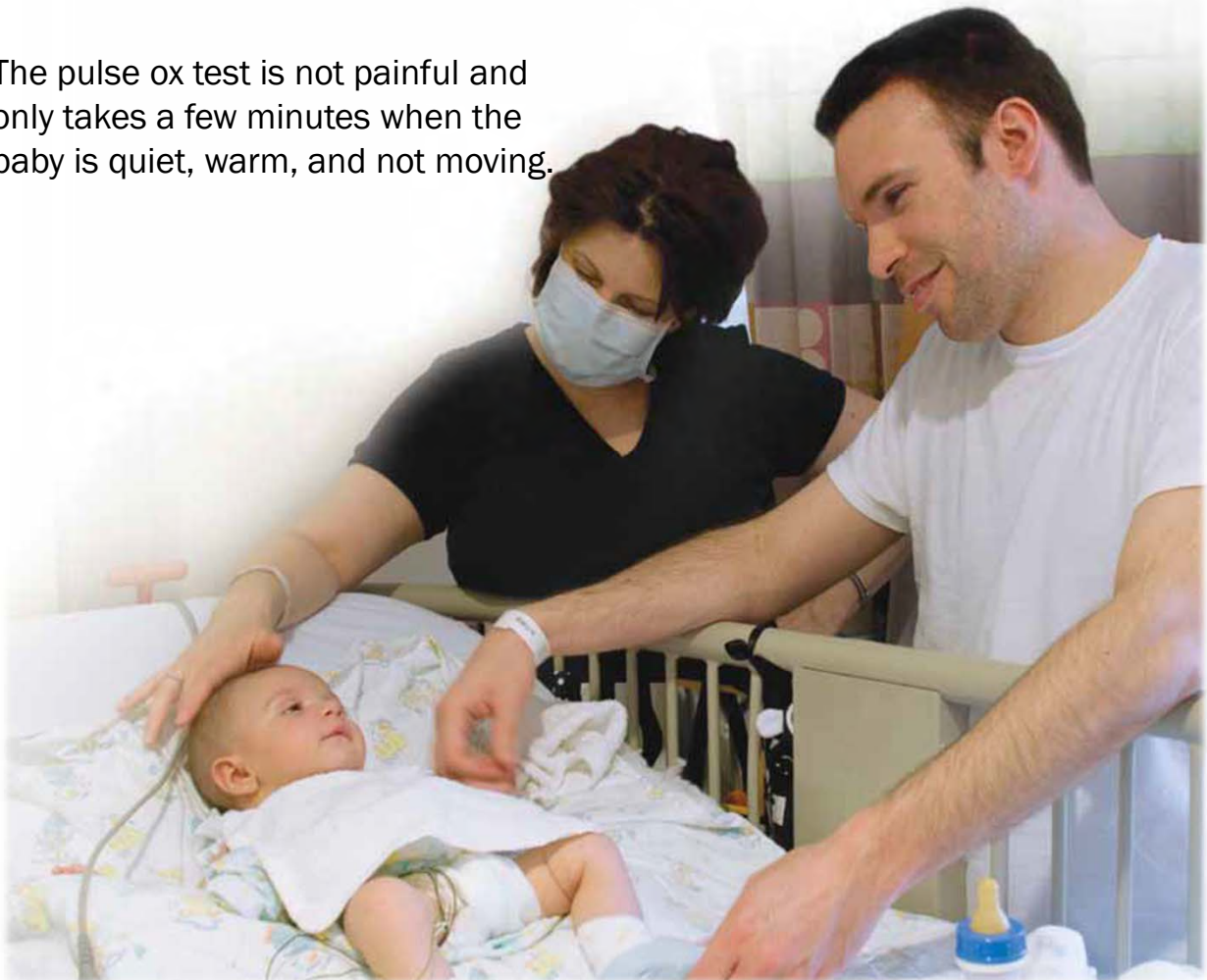


Jenny Lincoln
Mom to Aly Jean and
Parent Advocate for CCHD
screening
www.alyjeansspecialheart.com

MICHIGAN CCHD SCREENING CHECKLIST FOR INFORMING PARENTS

INFORM THE PARENT/GUARDIAN:

- ♥ The purpose of screening is to detect serious heart defects in babies.
- ♥ The baby will be screened after 24 hours of life (or as close to as possible) prior to discharge.
- ♥ The pulse ox test will be done on the baby's right hand and one foot, if possible.
- ♥ The pulse ox test is not painful and only takes a few minutes when the baby is quiet, warm, and not moving.
- ♥ It is possible that a baby with a heart problem may have a normal pulse ox reading.
- ♥ They have the right to decline screening.
- ♥ They may ask questions at the time of screening or anytime before or following the screening.



EDUCATION FOR PARENTS AND GUARDIANS

CCHD- PARENT FACT SHEET

Newborn Pulse Oximetry Screening

For Critical Congenital Heart Disease (CCHD)

What is Newborn Screening?

Newborn screening is a way to find babies who have serious medical conditions that need urgent treatment. Most babies are born with no serious health problems. But for those who **do** have a serious health problem, newborn screening can be life-saving.

What is CCHD?

Critical congenital heart disease (CCHD) occurs when a baby's heart or major blood vessels do not form properly. There are many types of heart defects. They range from mild to severe. A "critical" heart defect is one that needs urgent treatment in order to have the best outcome for the baby. Treatment can include medical and surgical procedures.

Why screen for CCHD?

Most babies are born with healthy hearts, and have enough oxygen in their blood. A few are born with CCHD. Although babies are checked very carefully by a doctor after they are born, some babies with CCHD may not have symptoms until later. Screening can help find babies with CCHD before they go home from the hospital.

How is screening for CCHD done?

Pulse oximetry is used to screen babies for CCHD. Pulse oximetry is fast, easy and does not hurt. A small sensor is placed on a baby's right hand and one foot to measure the oxygen level in the blood. Your baby's doctor or nurse will discuss low pulse oximetry readings with you. Screening for CCHD is done for well newborns sometime during the first 32 hours after birth. Screening is done while a baby is warm and quiet. If a baby is crying, moving, fussing or cold, then screening will take longer. It may need to be repeated.

What happens if pulse oximetry reading is low?

Healthy babies may have a low oxygen reading. Babies with low oxygen levels in their blood **may** have CCHD. Other conditions like breathing problems or infections may also cause a low blood oxygen level. The doctor will check the baby carefully. An ultrasound of the heart (also called "echocardiogram" and "heart echo") may be done to look for CCHD. The heart echo may need to be done in a different hospital or doctor's office. It is read by a children's heart doctor (pediatric cardiologist). If the heart echo shows problems, then a baby's medical team will discuss next steps with parents.

What do parents need to know?

Most babies who pass the pulse oximetry screen will not have a CCHD. **It is important for parents to know that newborn screening cannot identify every child with a critical heart problem.** Warning signs that all parents should watch for are: bluish color to the lips or skin, grunting, fast breathing, poor feeding, and poor weight gain. If you notice any of these signs in your baby, please contact your baby's health care provider right away.

For questions contact:

Michigan Newborn Screening Program Nurse Consultant

Toll-free: 1-866-673-9939

Email: newbornscreening@michigan.gov

www.michigan.gov/cchd

Michigan Newborn Screening Follow-up, 201 Townsend St., Lansing, MI 48906
Michigan Department of Community Health

Available for download
on our website
www.michigan.gov/cchd

EDUCATION FOR PARENTS AND GUARDIANS

CCHD- POSITIVE SCREEN FACT SHEET

Newborn Pulse Oximetry Screening For Critical Congenital Heart Disease (CCHD) What does a low result mean?

What is a pulse oximetry screen?

Pulse oximetry (also called "pulse ox") is a simple test to measure oxygen in the blood. Pulse ox is done using a small sensor placed on the baby's right hand and one foot. Pulse ox looks for low oxygen levels in the blood. Screening is a way to find critical heart conditions in newborns.

Your baby has a low pulse ox screen. Now what?

A low pulse oximetry result does not mean your baby has critical congenital heart disease (CCHD). It means more tests are needed.

A low blood oxygen level means that your baby **may** have critical congenital heart disease (CCHD) or other problems. You will discuss plans for more testing with your baby's medical team. Different types of tests may be needed, for example:

- Heart ultrasound (also called "echocardiogram" or "heart echo")
- Blood tests
- Chest x-ray
- Tests for infection

What is a heart echo?

A heart echo is an ultrasound of the heart. It uses sound to make a picture of the heart. The picture will be read by a doctor. You will discuss results and next steps with your baby's medical team. For the safety of your baby it is important to follow the medical team's instructions for testing and follow-up.

Michigan Resources and Support

For questions contact:
Michigan Newborn Screening Program
Nurse Consultant
Toll-free: 1-866-673-9939
Email: newbornscreening@michigan.gov
www.michigan.gov/cchd

What is CCHD?

Critical congenital heart disease (CCHD) means that the heart or major blood vessels did not form correctly before birth. The heart may not work well. A baby with CCHD may not have enough oxygen in the blood. The body needs oxygen to grow and be healthy.

CCHD may or may not run in families.

What problems can CCHD cause?

CCHD is different for each child. CCHD needs urgent care. Some babies with CCHD may have:

- Fast, difficult breathing
- Grunting sounds with breaths
- Bluish coloring of lips
- Poor eating
- Extreme sleepiness
- Heart murmur

What if my child has CCHD?

Children with CCHD should see their regular doctor and a doctor who specializes in children with heart disease (called a "pediatric cardiologist"). Your child's medical team will talk to you about treatment options, if needed.

Treatment for CCHD varies. It can include:

- Medicine
- Medical procedures
- Surgery

Prompt and careful treatment helps most children with CCHD live the healthiest lives possible.

American Heart Association
www.heart.org/congenital
Children's Health Services
Toll-free: 1-800-368-5737
www.michigan.gov/cchd

Available for download
on our website
www.michigan.gov/cchd

MICHIGAN CCHD SCREENING

SUGGESTED RESOURCES FOR FAMILIES

Support Groups and Online Resources

American Heart Association	www.amhrt.org
Children's Heart Association	www.heartchild.info
Children's Heart Foundation	www.childrensheartfoundation.org
Congenital Heart Information Network	www.tchin.org
Congenital Heart Defects.com	www.congenitalheartdefects.com
Kids with Heart	www.kidswithheart.org
PediHeart	www.pediheart.net
1 in 100	www.1in100.org
Mended Little Hearts	www.mendedlittlehearts./org
Hearts of Hope	www.heartsofhopemi.org

Books for Parents

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


Books for Children with Heart Defects

- "Blue Lewis and Sasha the Great" by Carol Donsky Newell
- "Matty's Heart" by C.J. Hribal
- "Nathan's Special Heart" by Jessica Ennis (available as a virtual book)
- "Pump the Bear" by Gisella Olivo Whittington

Books for Siblings

- "Cardiac Kids" by Vicci Elder
- "My Brother Needs an Operation" by Anna Marie Jaworski & Sarah Lualdi Moran
- "When Molly was in the Hospital" by Debbie Duncan



The background features a large, light blue triangle with a fine grid pattern, pointing downwards from the top left. Below it, a darker teal triangle points upwards from the bottom left. At the bottom left corner, there is a smaller, solid green triangle pointing upwards. The right side of the page is a plain white background.

RESOURCES

CRITICAL CONGENITAL HEART DEFECTS:

*Pulse oximetry screening is **most likely** to detect seven of the CCHDs.*

These seven main screening targets are:

D-transposition of the Great Arteries

A heart in which the two main arteries carrying blood away from the heart are reversed. In a normal heart the blood flows in a cycle: body-heart-lungs-heart-body. When a d-transposition occurs, the blood pathway is impaired because the two arteries are connecting to the wrong chambers in the heart.

Tetralogy of Fallot

A heart defect that features four problems. They are: a hole between the lower chambers of the heart; an obstruction from the heart to the lungs; the aorta (blood vessel) lies over the hole in the lower chambers; and the muscle surrounding the lower right chamber becomes overly thickened.

Total anomalous pulmonary venous return (TAPVC)

A defect in the veins leading from the lungs to the heart. In TAPVC, the blood does not take the normal route from the lungs to the heart and out to the body. Instead, the veins from the lungs attach to the heart in abnormal positions and this problem means that oxygenated blood enters or leaks into the wrong chamber.

Truncus Arteriosus

When a person has one large artery instead of two separate ones to carry blood to the lungs and body. In a normal heart, the blood follows in a cycle: body-heart-lungs-heart-body. When a person has a truncus arteriosus, the blood leaving the heart does not follow this path. It has only one vessel, instead of two separate ones for the lungs and body. With only one artery, there is no specific path to the lungs for oxygen before returning to the heart to deliver oxygen to the body.

Hypoplastic Left Heart Syndrome (HLHS)

An underdeveloped left side of the heart. The aorta and left ventricle are too small and the holes in the artery and septum did not properly mature and close.

Pulmonary Atresia

A non-existent pulmonary valve, so that the only blood receiving oxygen is the blood that is diverted to the lungs through openings that normally close during development.

Tricuspid Atresia

A missing tricuspid valve in the heart so blood cannot flow from the body into the heart in the normal way. The blood is not being properly refilled with oxygen and it does not complete the normal cycle of body-heart-lungs-heart-body.

These defects are less likely to be detected through pulse oximetry screening:

Coarctation of the Aorta

A narrowing of the major artery (the aorta) that carries blood to the body.

This narrowing affects blood flow where the arteries branch out to carry blood along separate vessels to the upper and lower parts of the body. CoA can cause high blood pressure or heart damage.

Ebstein Anomaly

A malformed heart valve that does not properly close to keep the blood flow moving in the right direction. Blood may leak back from the lower to upper chambers on the right side of the heart. As a result, the right atrium becomes enlarged. If the tricuspid regurgitation (leak) is severe enough, congestive heart failure can result. This syndrome also is commonly seen with an atrial septal defect, or ASD (a hole in the wall dividing the two upper chambers of the heart).

Double-outlet right Ventricle

In double outlet right ventricle, something goes wrong during the formation of the heart and both great arteries are attached to the right ventricle. No arteries, or only a part of the aorta, are attached to the left ventricle. In some cases, because more blood than normal is flowing into the right ventricle, this heart defect means that too much blood is pumped to the lungs. Over time this uncontrolled flow can damage the lungs and heart, and heart failure can result.

Interrupted aortic arch

An absence or discontinuation of a portion of the aortic arch. IAA is classified by the site of the interruption, and is thought to be a result of faulty development of the aortic arch system during the fifth to seventh week of fetal development. This defect is almost always associated with a large ventricular septal defect (VSD).

Single ventricle

The term "single ventricle anomaly" is purposely non-specific. It is used to describe a group of cardiac defects that may differ quite dramatically from each other but share the common feature that only one of the two ventricles is of adequate functional size. Because of this feature, the ultimate plan for reconstruction is actually quite similar for most of these anomalies. All will generally undergo staged reconstructive procedures.



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Cincinnati Children's Hospital. (2013). Heart Institute Encyclopedia: Congenital Heart Defects. Available from <http://www.cincinnatichildrens.org/patients/child/encyclopedia/defects/default/>

***Images and Video of Defects available online from above resources. ***

MICHIGAN CCHD SCREENING SUGGESTED RESOURCES FOR PROVIDERS

**Michigan Department of
Community Health**
www.michigan.gov/cchd

American Academy of Pediatrics
www.aap.org
AAP Strategies for Implementing Screening
<http://pediatrics.aappublications.org/content/128/5/e1259.full.html>

American Heart Association
www.aha.org

**Children's National Medical Center-
Washington DC***
(Videos available for parents and providers)
www.childrensnational.org

**Children's Hospital of Philadelphia
(CHOP)***
www.chop.edu

Atlanta Children's Hospital *
(CCHD Mobile App available)
www.pulsextool.com

Cincinnati Children's Hospital *
www.cincinnatichildrens.org

**Center for Disease Control and
Prevention**
www.cdc.org

**Congenital Heart Information
Network***
www.tchin.org/professionals/index.htm

Baby's First Test*
(Videos available for parents and
providers)
www.babysfirsttest.org

**Inclusion on the list does not necessarily imply endorsement, nor do we guarantee the accuracy of the information contained on these sites. Always consult your institution and its physicians with questions and concerns.*

MICHIGAN Treatment Centers for CCHD:



Children's Hospital of Michigan
3901 Beaubien
Detroit, MI 48201
(313) 745-KIDS
1-888-362-2500
www.childrensdmc.org



**Helen DeVos Children's Hospital
Congenital Heart Center**
100 Michigan Street NE, Floor 10,
Grand Rapids, Michigan 495031
616-267-9150
866.989.7999
www.helendevoschildrens.org



**University of Michigan
C.S. Mott Children's Hospital**
**Congenital Heart Center at
C.S. Mott Children's Hospital**
1540 East Hospital Drive Floor 11
Ann Arbor MI 48109
1-877-308-9111
www.mottchildren.org

Screening for Critical Congenital Heart Defects

- Babies with a critical congenital heart defect (CCHD) are at significant risk for death or disability if their condition is not diagnosed soon after birth.
- Newborn screening using pulse oximetry 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 for CCHDs. However, CCHD screening is not currently included in most state newborn screening panels.

Understanding Critical Congenital Heart Defects

- **Congenital heart defects (CHDs) account for nearly 30% of infant deaths due to birth defects.**
- **In the United States, about 7,200 (or 18 per 10,000) babies born every year have *critical congenital heart defects* (CCHDs, which also are known collectively in some instances as *critical congenital heart disease*). These CCHDs are **coarctation of the aorta, double-outlet right ventricle, D-transposition of the great arteries, Ebstein anomaly, hypoplastic left heart syndrome, interrupted aortic arch, pulmonary atresia (intact septum), single ventricle, total anomalous pulmonary venous connection, tetralogy of Fallot, tricuspid atresia, and truncus arteriosus.****
- **Babies with CCHDs usually require surgery or catheter intervention in the first year of life.**
- **CCHDs can potentially be detected using *pulse oximetry screening*, which is a test to determine the amount of oxygen in the blood and pulse rate.**
- **Pulse oximetry screening is most likely to detect seven of the CCHDs. These seven main screening targets 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**



Other heart defects can be just as severe as the main screening targets and also require treatment soon after birth. However, pulse oximetry screening may not detect these heart defects as consistently as the seven disorders listed as the main screening targets.

The Importance of Screening for Critical Congenital Heart Defects

Some babies born with a heart defect appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that

about 300 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.

Newborn screening using pulse oximetry 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 special 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

Available for download
on the CDC Website
(also available in Spanish)



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 along with the physical examination.

CCHD Screening Results

If the results are "negative" ("pass" or 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" ("fail" or 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. In September 2010, SACHDNC recommended that the HHS Secretary add screening for CCHDs (i.e., the heart defects listed previously) to the Recommended Uniform Screening Panel. Some states currently are developing their own policies on screening for CCHDs. As this screening is implemented, CDC will play an important role in the surveillance and tracking of babies with a CCHD found through newborn screening.

**For more information on 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 Web: www.cdc.gov

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201 Townsend St.
Lansing, Michigan 48913
1.866.673.9939

www.michigan.gov/cchd