



Children's National™

Critical Congenital Heart Disease Screening Program Toolkit



A Toolkit for Implementing Screening • 4th Edition



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



Acknowledgements

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User Agreement

A. Terms and Conditions

Please read this agreement in its entirety prior to use. The Critical Congenital Heart Disease Screening Program Toolkit (“Toolkit”) is designed to serve as a guide to healthcare providers seeking to use pulse oximetry as a screening tool for critical congenital heart disease in the newborn nursery. By utilizing this Toolkit, you agree to the terms and conditions that follow.

B. Disclaimer

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

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Section 1

Program Overview

Vision

Screening for Critical Congenital Heart Disease: Who, What, When, Where, and Why?

Opening Letter

Screening Recommendations

Letter to Providers

Supplies for Screening

Screening Form





Through our experience with research and helping hospitals to start CCHD screening programs in their nurseries we have learned a lot about best-practice for implementation. We hope that you find the contents in this toolkit helpful and we applaud you for raising the bar in your nurseries to improve the outcomes of patients and families with CCHD.

Elizabeth Bradshaw Mikula, RN, CPN

Advocate & Researcher in CCHD screening
2013 National Magnet Nurse of the Year for Empirical Outcomes in CCHD screening



After 8 years of research, I know that screening for CCHD makes a difference. The best reward one can receive is a parent's gratitude for offering this test.

Anne de-Wahl Granelli,

Biomedical Scientist, RDCS(PE), PhD in Medicine
Queen Silvia Children's Hospital,
Gothenburg University, Gothenburg

Vision

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

Who, What, When, Where, and Why?

What are critical congenital heart disease and pulse oximetry?

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

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

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

Why is pulse ox used to screen for critical CHD?

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

Who should be screened?

All infants should be screened.

When should critical CHD screening be performed?

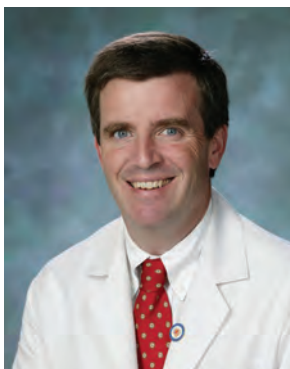
Screening should be performed before discharge from the nursery, after the infant turns 24 hours of age.

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

Where should critical CHD screening be performed?

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

Dear Provider,



Gerard R. Martin, MD, FAAP, FACC

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

Background and Significance

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



Joseph L. Wright, MD, MPH

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

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

Overview of Critical CHD Screening Guidelines

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

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

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

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

Sincerely,



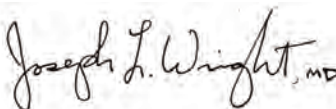
Gerard R. Martin, MD, FAAP, FACC
Senior Vice President
Center for Heart, Lung, and Kidney Disease
Children's National Health System

Toolkit Materials

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

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

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



Joseph L. Wright, MD, MPH
Senior Vice President
Child Health Advocacy Institute
Children's National Health System

Critical Congenital Heart Disease Screening Program:

Screening Recommendations

Section 1: Recommendations for Implementation Planning

1. Designate a program director and coordinator to facilitate planning and implementation of the screening program.
2. Establish an interdisciplinary team of organizational leadership and management, physicians, registered nurses, nursing assistants, and ancillary staff to participate in the planning process.
3. Schedule several planning sessions to facilitate education, communication, brainstorming, conflict resolution, and decision making.
4. Ensure that the organization's public relations and marketing department is involved in communication planning and efforts.
5. Discuss and establish a clear, complete, and concise evidence-based policy and procedure for screening methods and guidelines, including documentation and reporting of normal and abnormal results.
6. Discuss a plan for management and evaluation of infants requiring further evaluation if pediatric cardiology services are not available on site.
7. Establish guidelines for parents or guardians who wish to decline screening.
8. Research the accuracy and reliability of pulse oximetry equipment. Choose a vendor with equipment that is approved by the FDA for use with neonates.
9. Establish guidelines for informing, educating, and training providers and staff participating in and/or affected by implementation of the screening program.

10. Establish guidelines for education of and communication with parents and guardians before and after screening.
11. Establish plans for surveillance and reporting of program results and outcomes.
12. Birthing facilities at high altitudes may require revised protocols.

Section 2: Recommendations for Parental Education

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

Section 3: Recommendations for Educating and Informing Providers

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

Section 4: Recommendations for Screener Training

1. Provide all training prior to implementation of the screening program by an individual who has participated in the planning process.
 - a. Examples include the unit's nurse manager or assistant nurse manager, the nurse educator, the program coordinator, or a registered nurse who played an active role in the planning process.
2. Recommended components of the in-service education program include:
 - a. PowerPoint Presentation — Includes information on background and significance for CCHD screening methods and recommendations and may be obtained by emailing pulseox@childrensnational.org
 - b. Demonstration of correct and safe use of pulse oximetry equipment in obtaining an accurate infant reading by trainer or representative from pulse oximeter manufacturer.
 - c. Completion of knowledge assessment quiz.
 - d. Opportunity to practice CCHD screening.
3. Require that all individuals who will be performing the screening test complete the in-service education program.
4. Require that all individuals who will be performing the screening test complete the knowledge assessment quiz with a passing score of greater than or equal to 90 percent, and remediation of all questions answered incorrectly.
5. Require that all individuals who will be performing the screening test demonstrate proficiency in performing pulse oximetry and knowledge of screening guidelines through completion of defined competencies prior to participation. Require that they renew competencies on an annual basis.
6. Provide “booster” sessions quarterly to provide an opportunity to re-educate staff and answer any questions.
7. Ensure that all new employees receive training prior to participation in screening program methods.
8. Provide staff with regular updates on outcomes of screening to maintain engagement.

Section 5: Recommendations for Screening

1. Pair critical CHD screening with another standard-of-care screening performed following 24 hours of age, such as metabolic or hearing screening. If early discharge is planned, screening should occur as late as possible.
2. Consider assigning one or two nursing assistants or registered nurses to critical CHD screening on a daily basis.
 - a. If possible, provide continuity by scheduling one screener to conduct screening on several continuous days.
3. Conduct screening in a quiet area with the parent present to soothe and comfort the infant.
4. If possible, conduct screening while the infant is awake, quiet, and calm.
5. Do not attempt to perform pulse oximetry on an infant while he or she is in a deep sleep, crying or cold as oxygen saturations may be affected.
6. If using disposable pulse ox sensors, use one clean sensor for each infant screened. If reusable sensors are being used, clean sensor as instructed by manufacturer prior to and following screening. Dirty sensors may decrease the accuracy of a reading or transmit infection.
7. Perform pulse oximetry on the right hand and one foot after 24 hours of age; measurements should be taken in parallel or one after another. If infant was born prematurely, perform screening when medically appropriate. If an early discharge is planned conduct screening as close to 24 hours as possible.
8. Ensure that all readings are accurate by using pulse oximetry equipment confidence indicators.
9. If the oxygen saturation is 100-95% in either extremity, with a 3% or less absolute difference between the two, the infant will “pass” the

screening test and no additional evaluation will be required unless signs or symptoms of CHD are present.

- a. The physician or nurse practitioner caring for the infant does not need to be notified.
- b. The infant does not require additional cardiac evaluation in the newborn nursery unless indicated.

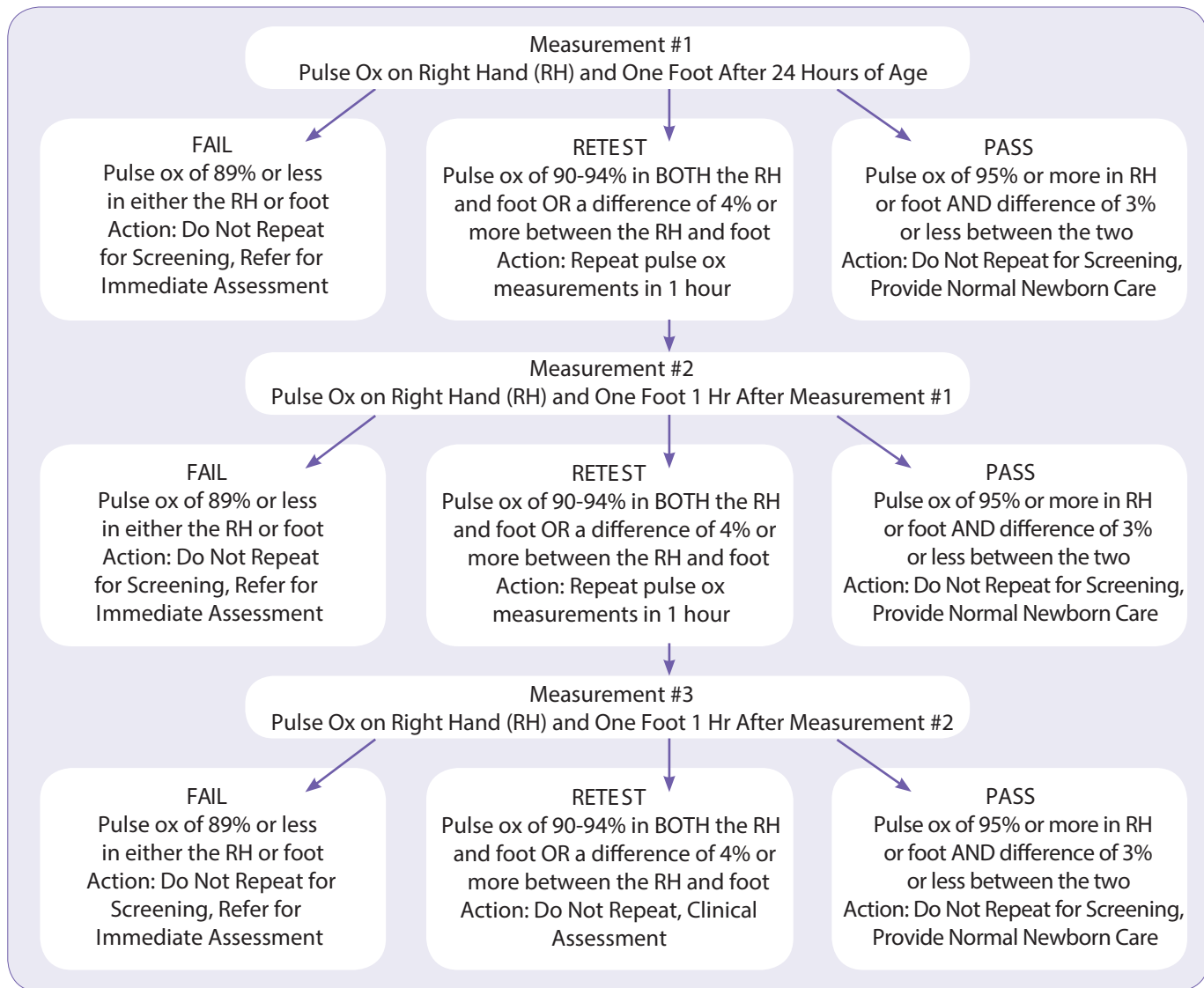
10. If the pulse ox reading is 89% or less in either the hand or foot, the infant should be immediately referred to his or her physician for additional evaluation.

11. If the oxygen saturations are 94-90% in both the hand and foot or there is a 4% or more absolute difference between the two on three measures each separated by one hour the newborn should be referred for additional evaluation.
 - a. The infant’s physician or nurse practitioner should be notified.
 - b. Infectious and pulmonary pathology should be excluded.
 - c. If cause of hypoxemia is not clear an echocardiogram and cardiology consultation should be obtained before discharge to rule out CHD.
 - d. Further evaluation should be ordered at the discretion of the physician or nurse practitioner caring for the infant.

Section 6: Recommendations for Follow-Up

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

Critical Congenital Heart Disease Screening Program: Screening Protocol Diagram



RH Application Sites



Foot Application Sites

REMINDER ALGORITHM FOR SCREENERS

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

ASSESSMENT OF BABIES WITH FAILING SATURATIONS

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

Critical Congenital Heart Disease Screening Program:

Template for Provider Letter of Program Intent

The following template is a suggestion for notifying providers of implementation of screening.



Dear Provider,

We are excited to inform you that we will be implementing the Critical Congenital Heart Disease Screening Program in our newborn nursery. The program involves the use of pulse oximetry as a screening tool for critical congenital heart disease (critical CHD) in the newborn nursery. The components of this program have been assembled by Children's National and are based on a review of current literature on pulse oximetry screening for critical CHD as well as outcomes of research on best-practice for implementation. This letter will inform you of the background and significance of screening for critical CHD using pulse oximetry and provide an overview of recommended guidelines.

Background and Significance

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

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. The United States Health and Human Services endorses the inclusion of screening for critical CHD in the recommended uniform screening panel. The American Heart Association, American Academy of Pediatrics, March of Dimes and American College of Cardiology also support critical CHD screening of newborns.

Overview of CHDSP Screening Guidelines

The Critical CHD Screening Program adds pulse oximetry to routine testing after 24 hours of life to detect critical CHD. It is recommended that critical CHD 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. Pulse oximetry should be performed on the right hand and one foot. If the newborn's oxygen saturation is 100-95% in either extremity, with a 3% or less absolute difference between the two he or she will be considered to pass the screening test and no additional evaluation will be required unless signs or symptoms of CHD are present.

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

If the oxygen saturations are 90-94% in both the hand and foot or there is a 4% or more difference between the two on three measures each separated by one hour the newborn should be referred for additional evaluation. All future decisions regarding care of newborns with lower than expected saturations will be made at the discretion of the physician or nurse practitioner caring for the infant. It is recommended that an echocardiogram be obtained to rule out structural abnormalities for newborns with abnormal pulse oximetry readings.

We are asking that you work with us to implement the program in our newborn nursery. 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,
(SIGNATURE)

Critical Congenital Heart Disease Screening Program:

Supplies for Screening

♥ Pulse Oximeters

- At least one pulse oximeter that has been approved by the FDA for use in neonates
- One pulse oximeter for back-up

♥ Infant Disposable or Reusable Pulse Ox Sensors

- If using disposable sensors, one disposable sensor for every infant screened
- If using reusable sensors, one reusable sensor for each pulse oximeter. Also consider additional reusable sensors for back-up
 - Disinfecting agent recommended by pulse oximetry equipment manufacturer
 - One wrap per infant screened to secure sensor to hand or foot

♥ Rolling Cart for Supplies**♥ Data Collection Forms**

- One for every infant screened

♥ Dedicated individual to perform screening**♥ Blankets for warming the infant and blocking extraneous light****♥ A parent for comforting infant during screening**

PLACE LABEL OR WRITE-IN INFORMATION

Medical Record # _____

Patient Name: Last _____ First _____

Date of Birth ____ / ____ / ____

Critical Congenital Heart Disease Screening Program:

Screening Form

Age at Initial Screening: _____ hours

Initial Screening:

Time _____

Pulse Ox Saturation of Right Hand _____ %

Pulse Ox Saturation of Foot _____ %

Absolute difference _____ % Pass Fail Retest

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

Time _____

Pulse Ox Saturation of Right Hand _____ %

Pulse Ox Saturation of Foot _____ %

Absolute difference _____ % Pass Fail Retest

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

Time _____

Pulse Ox Saturation of Right Hand _____ %

Pulse Ox Saturation of Foot _____ %

Absolute difference _____ % Pass Fail

* If pulse ox saturation is 89% or less in either the hand or foot the infant's MD or NP must be notified immediately. "Fail must be checked".

* If pulse ox saturations are 94-90% in both the hand and foot or there is a 4% or more absolute difference between the two on three measures each separated by one hour the MD or NP must be notified.

* If pulse ox saturations are 95-100% in either extremity, with a 3% or less absolute difference between the two the reading is expected for an infant. "Pass" should be checked".

Screener's Name: _____

Screener's Signature: _____ Date: ____ / ____ / ____



Section 2

Screeener Training

In-Service Education Program Components

Critical Congenital Heart Disease Screening Program: Education for Providers

Performing Pulse Oximetry with the Infant Patient: Education for Providers

Pulse Oximetry Sensor Placement Education

Knowledge Assessment and Answer Key

Competency Checklist

Training Log

CHDSP PowerPoint Presentation



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

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



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

Annamarie Saarinen, Mother of Eve and Advocate for CCHD Screening

Critical Congenital Heart Disease Screening Program:

In-Service Education Program Components and Recommendations

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

1. PowerPoint Presentation:

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

2. Education for Providers:

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

3. Pulse Oximetry Demonstration:

- a. Provide attendees with a demonstration of correct and safe use of pulse oximetry equipment in obtaining an accurate infant reading by in-service facilitator or representative from pulse oximeter manufacturer.
- b. Provide attendees with an opportunity to practice performing screening on a doll.
- c. Provide attendees with the opportunity to ask questions regarding correct and safe methods for performing critical CHD screening.

- d. Provide attendees with the “Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: Education for Providers” and “Pulse Ox Sensor Placement” education tools.

4. Knowledge Assessment Quiz:

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

5. Competency Checklist:

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

Critical Congenital Heart Disease Screening Program:

Education for Providers

What is pulse oximetry?

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

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

What is a normal pulse ox reading for infants?

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



What is congenital heart disease?

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

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

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

Why is pulse ox used to screen for critical CHD?

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

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

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

Critical Congenital Heart Disease Screening Program:

Performing Pulse Oximetry (Pulse Ox) with the Infant Patient: Education for Providers

Pulse Ox – Dos

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

7. If an infant requires pulse ox monitoring for an extended amount of time, assess the site where the sensor is placed at least every two hours. Monitor for signs of irritation.

Pulse Ox – Don'ts

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

Pulse Ox - Caution!

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

Critical Congenital Heart Disease Screening Program:

Pulse Ox Sensor Placement Education

1. Select appropriate site for sensor placement according to manufacturer instructions. Most common application sites include the great toe, thumb and the outer aspect of the hand or foot.



RH Application Sites



Foot Application Sites

2. Place the photodetector portion of the sensor on the top of the selected site.
3. Place the light emitter **directly opposite** of the photodetector on the fleshy portion of the site.
4. Remember that the photodetector and light emitter should be **directly opposite** of one another to obtain an accurate reading.
5. If you are using a reusable sensor, secure the sensor to the site using the appropriate wrap as recommended by the vendor. Do not use tape or your hand to secure the sensor to the site.



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Critical Congenital Heart Disease Screening Program:

Knowledge Assessment

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

Critical Congenital Heart Disease Screening Program:

Knowledge Assessment Answers

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

Critical Congenital Heart Disease Screening Program:

Competency Checklist

♥ Competency Title: Critical CHD 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 critical CHD screening		D VF T		
Identifies safe and correct methods for performing pulse oximetry on an infant		D VF T RD		
Describes methods to ensure that pulse oximetry reading is accurate		D VF T RD		
Explains and understands screening methods and guidelines for pulse oximetry screening		D VF T		
Discuss HIPAA confidentiality standards		D VF T		

Employee Signature: _____ Date: _____

Supervisor Name (Printed) _____

Supervisor Signature: _____

Critical Congenital Heart Disease Screening Program:

Training Log

(For the records of unit managers or nursing educators)

Employee Name and Title	Date	Completion of Competency Checklist		Manager Initials
		Yes	No	

** Each employee responsible for performing critical CHD screening methods should complete the competency checklist prior to participation.*

Unit: _____

Manager Name (Printed): _____

Manager Signature: _____

Critical Congenital Heart Disease Screening Program:

Program Overview Powerpoint Presentation



To access this presentation e-mail pulseox@ChildrensNational.org.





Section 3

Education for Parents

Checklist for Informing Mothers

Frequently Asked Questions (FAQs) for Patients and Families

Frequently Asked Questions (FAQs) for Patients and Families (Spanish)

Critical Congenital Heart Disease Screening Program: For Patients and Families

Critical Congenital Heart Disease Screening Program: For Patients and Families Spanish

CHD Resources

CHD Resources Spanish



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

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

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

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

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

Critical Congenital Heart Disease Screening Program:

Checklist for Informing Parents and Guardians

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



Critical Congenital Heart Disease Screening Program:

Frequently Asked Questions



♥ What is pulse oximetry?

Pulse oximetry (ox-eh-mah-tree) is a simple and painless test that measures how much oxygen is in the blood. Another term for pulse oximetry is “pulse ox.”

♥ How is pulse ox performed?

The pulse ox is placed by a sticky strip, like a band-aid™, with a small red light, or “sensor,” on the baby’s hand or foot. The sensor is attached to a wire, which is attached to a special monitor that shows the pulse ox reading. The pulse ox test takes just a few minutes to perform when a baby is still, quiet, and warm. If a baby is crying, squirming, or cold it may take longer or not be possible. You can help comfort your baby and keep him or her warm, calm, and quiet while the test is being performed.

♥ What is congenital heart disease (CHD)?

CHD is a problem in the structure of the heart or the blood flow through the heart. CHD is the most common birth defect and the cause is not really known. Some forms of CHD need to be detected and repaired early; these are called serious or “critical” CHDs.

♥ Why is pulse oximetry used to screen for serious CHD?

Pulse ox is used to measure how much oxygen is in the blood. Pulse ox is routinely used and can be used to monitor an infant’s oxygen level during a procedure or treatment. It can also be helpful in determining if an infant’s heart and lungs are healthy.

Pulse ox can also help to identify babies with low levels of oxygen in their blood that may have serious CHD. A doctor or nurse practitioner may ask for more testing such as an ultrasound of the heart, or echocardiogram (or “echo”) when a low pulse ox reading is identified. The echo will screen for a serious problem in the structure of the heart or the blood flow through the heart. Pulse ox can identify a baby with serious CHD before he or she leaves the newborn nursery.

♥ Can the pulse ox test hurt my child?

The pulse ox test is non-invasive and painless. It usually does not hurt the child.

♥ When will the pulse ox test be performed?

The pulse ox test will be done after the baby is 24 hours old.

♥ What is a normal reading?

Pulse ox readings in the hand and foot that are 95 to 100 percent and equal to or less than 3% different from than each other 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.

♥ If you notice any of the following signs or symptoms, you should contact your primary care provider promptly:

- Tires easily during feedings (i.e. falls asleep before feeding finishes)
- Sweating around the head, especially during feeding
- Fast breathing when at rest or sleeping
- Pale or bluish skin color
- Sleeps a lot - not playful or curious for any length of time
- Puffy face and/or feet
- Often irritable, difficult to console

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

If you have questions, 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.



Programa de evaluación de enfermedades cardíacas congénitas:

Preguntas más frecuentes



♥ ¿Qué es la oximetría de pulso?

La oximetría de pulso es una prueba simple y no dolorosa que mide cuánto oxígeno existe en la sangre. También conocido como “pulse ox” en inglés.

♥ ¿Cómo se mide la oximetría de pulso?

Se coloca el oxímetro de pulso con una cita adhesiva, como una Band-aid™, con una luz roja pequeña o “sensor” en la mano o en el pie del bebé. El sensor está conectado a un alambre, el cual está conectado a un monitor especial que muestra la medición. La prueba de la oximetría de pulso toma sólo unos minutos para realizarse cuando el bebé está tranquilo, callado y tibio. Si el bebé está llorando, retorciéndose o frío puede tardar más tiempo o que no sea posible hacerlo. Usted puede ayudar a consolar a su bebé y mantenerlo tibio, calmado y callado mientras se le realiza la prueba.

♥ ¿Por qué se usa la oximetría de pulso?

La oximetría de pulso se usa para medir cuánto oxígeno existe en la sangre. La oximetría de pulso es una prueba rutinaria y se usa para monitorizar el nivel de oxígeno del infante durante un procedimiento o tratamiento. También puede servir para determinar si el corazón y los pulmones del infante están sanos. La oximetría de pulso también puede ayudar a identificar a los bebés que tengan bajos niveles de oxígeno en la sangre que puedan tener problemas cardíacos graves. Un médico o enfermero/a practicante puede pedir más pruebas como ultrasonidos del corazón o ecocardiograma (o eco) cuando se identifique una medida baja de la oximetría de pulso. El eco revisaría problemas serios de la estructura del corazón o del flujo de sangre en el corazón. El oxímetro de pulso puede identificar a un bebé con una ECC sería antes de retirarse de la unidad neonatal.

♥ ¿Puede lastimar a mi hijo la prueba de la oximetría de pulso?

La prueba de oximetría de pulso no es invasiva y no es dolorosa. Normalmente no lastima a su hijo.

♥ ¿Qué es enfermedad cardíaca congénita (ECC)?

La ECC es un problema en la estructura del corazón o con el flujo de la sangre en el corazón. La ECC es el defecto congénito más común y se desconoce la causa.

♥ ¿Cuándo se le realizaría la oximetría de pulso?

La prueba de oximetría de pulso se realizará después de que el bebé tenga más de 24 horas de nacido.

♥ ¿Cuál es la medida normal?

La medida de la oximetría de pulso en la mano o en el pie que es de 95 a 100 por ciento e igual o menos de un 3% de diferencia entre cada una de ella es normal en

los niños sanos. Los niños con problemas cardíacos o pulmonares pueden tener medidas más bajas. Una medida de oximetría de pulso baja puede ser normal en los recién nacidos cuyos pulmones y 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.

♥ **¿Puede un bebé con una ECC grave 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 cardíacos?**

Si tiene preguntas se las debe hacer al médico o al/la enfermero/a practicante que le proporciona la atención prenatal o al 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 problemas cardíacos graves, 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.

Si nota alguna de las siguientes señales o síntomas, debería de contactar a su doctor primario inmediatamente.

- Se cansa fácilmente cuando come o se queda dormido antes de terminar de comer.
- Sudor alrededor de la cabeza, especialmente cuando está comiendo.
- Respiración rápida cuando está descansando o durmiendo.
- Piel pálida o azulada.
- Aumento de peso pobre.
- Duerme mucho y no está juguetón o curioso durante cualquier periodo de tiempo.
- Hinchazón en la cara y/o los pies.
- A menudo irritable o difícil de consolar.



Critical Congenital Heart Disease Screening Program:

Suggested Resources for Families

Support Groups and Online Resources

- | | |
|---|--|
| 1. American Heart Association | amhrt.org |
| 2. Children's Heart Association | www.heartchild.info |
| 3. Children's Heart Foundation | www.childrensheartfoundation.org |
| 4. Congenital Heart Information Network | tchin.org |
| 5. Congenital Heart Defects.com | www.congenitalheartdefects.com |
| 6. Kids with Heart | www.kidswithheart.org |
| 7. PediHeart | www.pediheart.org |
| 8. 1 in 100 | 1in100.org |

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

Programa de evaluación de enfermedades cardíacas congénitas:

Recursos sugeridos para las familias

Grupos de apoyo y recursos en la Internet

- | | |
|---|--|
| 1. American Heart Association | amhrt.org |
| 2. Children's Heart Association | www.heartchild.info |
| 3. Children's Heart Foundation | www.childrensheartfoundation.org |
| 4. Congenital Heart Information Network | tchin.org |
| 5. Congenital Heart Defects.com | www.congenitalheartdefects.com |
| 6. Kids with Heart | www.kidswithheart.org |
| 7. PediHeart | www.pediheart.org |
| 8. 1 in 100 | 1in100.org |

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

Notes



Section 4

Advocacy





I commend the Children's National Medical Center for producing an invaluable resource that will help save lives and improve detection of congenital heart disease. More than 35,000 children are born each year in the United States with this condition. The Congenital Heart Disease Screening Program Toolkit will assist providers in our community and across the nation to effectively screen for and diagnose congenital heart disease in newborns.

Congressman Chris Van Hollen, Maryland's 8th District



New parents have so many things to worry about. What a relief it must be to know that the Children's National Medical Center has now developed a terrific process to screen newborns for congenital heart disease. The Congenital Heart Disease Screening Program Toolkit is a great asset to parents and to our local health providers in Maryland, allowing us to identify and diagnose congenital heart disease earlier than ever before. This outstanding new tool will save the lives of many infants and allow thousands of parents to sleep better. Congratulations to Children's National; they are an outstanding asset to our state and a powerful advocate for children's health.

Delegate Tom Hucker, District 20, Montgomery County



In Virginia, nearly 4 out of every 1,000 live births are diagnosed with a congenital heart defect. Currently, only 74 percent of newborns are diagnosed at birth. But thanks to the efforts of the Children's National Medical Center, every baby born in Virginia will be screened for congenital heart disease. The Congenital Heart Disease Screening Program Toolkit is a valuable resource that will help educate and train health care providers to administer this quick and easy screening procedure to help save lives.

Delegate Patrick A. Hope, Virginia General Assembly

Critical Congenital Heart Disease Screening Program:

How to become an Advocate?

Congenital heart disease (CHD) is a health issue that can affect any child, any race, any socioeconomic status, in any community. This health issue affects not only the child, but the entire family. Screening for critical CHD on all eligible newborns is a way to detect congenital heart disease early. Universal use of this simple test after 24 hours of birth can lead to early diagnosis and treatment for critical CHD, and potentially save lives. There is a need for advocates to spread the word about screenings for critical CHD. There is power in advocacy.

Advocacy means to “speak up” or to champion a cause on another’s behalf.

Advocates influence the knowledge, attitudes, and actions of those who are in positions to bring change.

Clinical Advocacy is when physicians, nurses, and other healthcare professionals apply research findings, clinical data, and care to address an identified health issue. They use their clinical expertise to advocate for change. There are two primary forms of clinical advocacy:

- Bringing innovative health care, education, and research programs to the community to address disparities and other serious public health needs; and
- Sharing clinical experiences, along with research and data, with public officials to inform health policy decisions.

Currently, the Critical Congenital Heart Disease Screening Program (CHDSP) is offered at several birthing hospitals and centers in the world. Clinical advocates can share the benefits, results, findings, and personal experiences associated with the Critical Congenital Heart Disease Screening Program and research studies that support screening. By doing this, healthcare professionals, health professional organizations, and decision makers will become interested in the topic and screening program.

Community Advocacy means garnering support from colleagues, community groups, service clubs, and others. Community advocacy unites people who share a passion for the same cause or issue. Together, community advocates work to bring about change by establishing ties and forming coalitions with others in the community.

To become a community advocate for CHDSP, introduce the program to neighbors, community groups, service clubs, schools, and others to garner their support.

Tips:

- Talk with like-minded citizens.
- Garner support from community-based or neighborhood coalitions or groups.
- Work with parent groups.
- Bring personal view to the issue by organizing a testimonial at a community meeting.
- Ask healthcare professionals to speak at community meetings.

Legislative Advocacy is using the legislative process to influence public policy at the local, state, or federal levels of government.

Every law begins with an idea and elected officials work to create laws from your ideas! Our elected officials count on us to let them know what is important in our lives and communities, and to share with them our ideas about what kinds of policies and laws would most benefit patients and families.

Make your ideas known to elected officials by writing letters, making phone calls, sending e-mails, or meeting with the representative or staff members.

Advocacy in Action

Advocacy, when engaged to its fullest extent, can change the way we live, work, and go about our day-to-day activities. It can save lives and change society for the better.

Advocacy works. Consider the following:

- It takes only about 10 letters to get an elected official’s attention on a particular issue, an example of legislative advocacy.
- One mother whose daughter died at the hand of a drunk driver decided to take a stand and became founder of Mother’s Against Drunk Drivers (MADD); one of the country’s most influential advocacy groups, a type of community advocacy.
- An emergency medical physician who helped identify “lap belt syndrome” (injuries that occur when a small child is in a motor vehicle accident using an adult lap belt instead of a booster seat) worked with advocates to pass legislation requiring booster seats for children in his state, a form of clinical advocacy.





Section 5

References





Robert Koppel
Cohen Children's
Medical Center
of New York

During my residency, it was not uncommon to have babies readmitted to the hospital in critical condition with a delayed diagnosis of critical congenital heart disease. I can clearly recall cases of infants that had been discharged a day or two earlier by skilled and dedicated pediatricians who had no reason to suspect that their patient had a potentially lethal problem. I also remember how devastated these pediatricians felt as a result but it was understood that some infants won't show any critical signs until they begin to deteriorate. Many of these babies died and those that survived were at increased risk for brain injury. This is why I became so intrigued by the possibility of finding these babies before they get very sick. Although it has taken many years, pulse oximetry screening for critical congenital heart disease is an idea whose time has come. It's very exciting to have been involved in the development of this field from its early stages.

Advocacy Resources

Child Health Advocacy Institute – www.ChildrensNational.org/Advocacy

Identifies and studies threats facing children and develops and implements interventions to improve pediatric health outcomes.

The Congenital Heart Information Network – www.tchin.org

Provides information and support to families with children living with congenital heart defects and professionals that work with them.

Children’s Heart Foundation – www.childrensheartfoundation.org/advocacy

The Children’s Heart Foundation (CHF) advocates for increased CHD research and other significant CHD issues in both the private and public arenas.

It’s My Heart – www.itsmyheart.org

It’s My Heart advocates for those affected by acquired and congenital heart defects by spreading awareness and educating families, health care professionals and organizations, and the community.

Kids with Heart National Association for Children’s Heart Disorders –

www.kidswithheart.org

Provides support and educates families of children living with congenital heart defects and increases public awareness of the issues that these families deal with on a daily basis.

U.S. Congress – thomas.loc.gov

A website that makes federal legislative information freely available to the public, such as information about bills, resolutions, committee information, activity in congress, congressional record, and treaties.

National Conference of State Legislatures – www.ncsl.org


NCSL is a bipartisan organization that provides opportunities for policymakers to exchange ideas on critical state issues. The site includes website links to state legislatures.

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A newborn baby is wrapped in a pink blanket and wearing a pink hat. The baby is lying in a pink blanket. The background is a light purple wall. The text is overlaid on the left side of the image.

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

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



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