

Online Educational Materials

John S. Hokanson MD
Wisconsin SHINE Project

Sources of Information

- Parents
 - Social media
 - Brochures
 - Website content
- Providers and Institutions
 - Medical Literature
 - AAP/CDC Websites
 - State/Institution based websites
 - Children's National
 - Virginia

AAP Resources

- Newborn Screening for CCHD: Answers and Resources for Primary Care Pediatricians
 - Targeted to primary care physicians
 - Content + FAQs
 - Mechanism to submit questions
- PediaLink Essentials: Newborn Screening for Congenital Heart Defects
 - CME course

www.aap.org/pehdic/cchd

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Newborn Screening for CCHD

ANSWERS AND RESOURCES FOR PRIMARY CARE PEDIATRICIANS

Approximately 18 out of every 10,000 babies are born with a critical congenital heart defect (CCHD). CCHD is life threatening and requires intervention in infancy. However, CCHD is not always detected prenatally or upon exam in the nursery. As a result, some infants with CCHD are discharged from the nursery to home, where they quickly decompensate. To improve the early detection of CCHD, the Secretary of Health and Human Services (HHS) recommended that CCHD screening be added to the uniform newborn screening panel.

Frequently Asked Questions

The following guidance, in question and answer format, was developed by a [technical advisory panel](#) comprised of experts representing various AAP entities with a broad range of CCHD expertise.

Topic 1: Rationale for CCHD screening

[How common is CCHD?](#)

[Won't CCHD be detected prenatally or by my exam in the nursery?](#)

[Why is CCHD screening so prominent now? Is it really a good use of limited resources](#)

[Why is CCHD screening considered to be part of newborn screening?](#)

[If an asymptomatic infant fails their pulse-oximetry screening, what is the likelihood that CCHD or some other serious disease is present?](#)

Topic 2: Implementation of CCHD

http://bit.ly/nbs-cchd

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Activity Details

PediaLink essentials

Newborn Screening for Critical Congenital Heart Defects

Activity Format: Online Course
[Technical Requirements](#)
Starts: 11/22/2013 **Expires:** 11/22/2016

[Register](#)

Description

Delayed diagnosis of Critical Congenital Heart Defects (CCHD) may result in death or poorer preoperative condition and worse cardiopulmonary and neurological outcomes after treatment. Because newborns with CCHD may appear normal, adding CCHD screening with pulse oximetry to the battery of newborn screening tests has been endorsed by the US Secretary of Health and Human

Credit Information

AMA PRA Category 1 Credit(s)[™]: 0.50
AAP Credit: 0.50
NAPNAP Credit: 0.50
Pharmacology Rx: 0.00

Registration Fees

AAP Member: \$10
Non-Member: \$12

Authors

Alex Kemper, MD, MPH, MS, FAAP

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http://www.cdc.gov/ncbddd/pediatric/genetics/cchdscreening.html

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► Screening for CCHDs

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Screening for Critical Congenital Heart Defects

Congenital heart defects (CHDs) account for nearly 30% of infant deaths due to birth defects.¹ 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 as *critical congenital heart disease*).² 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, and truncus



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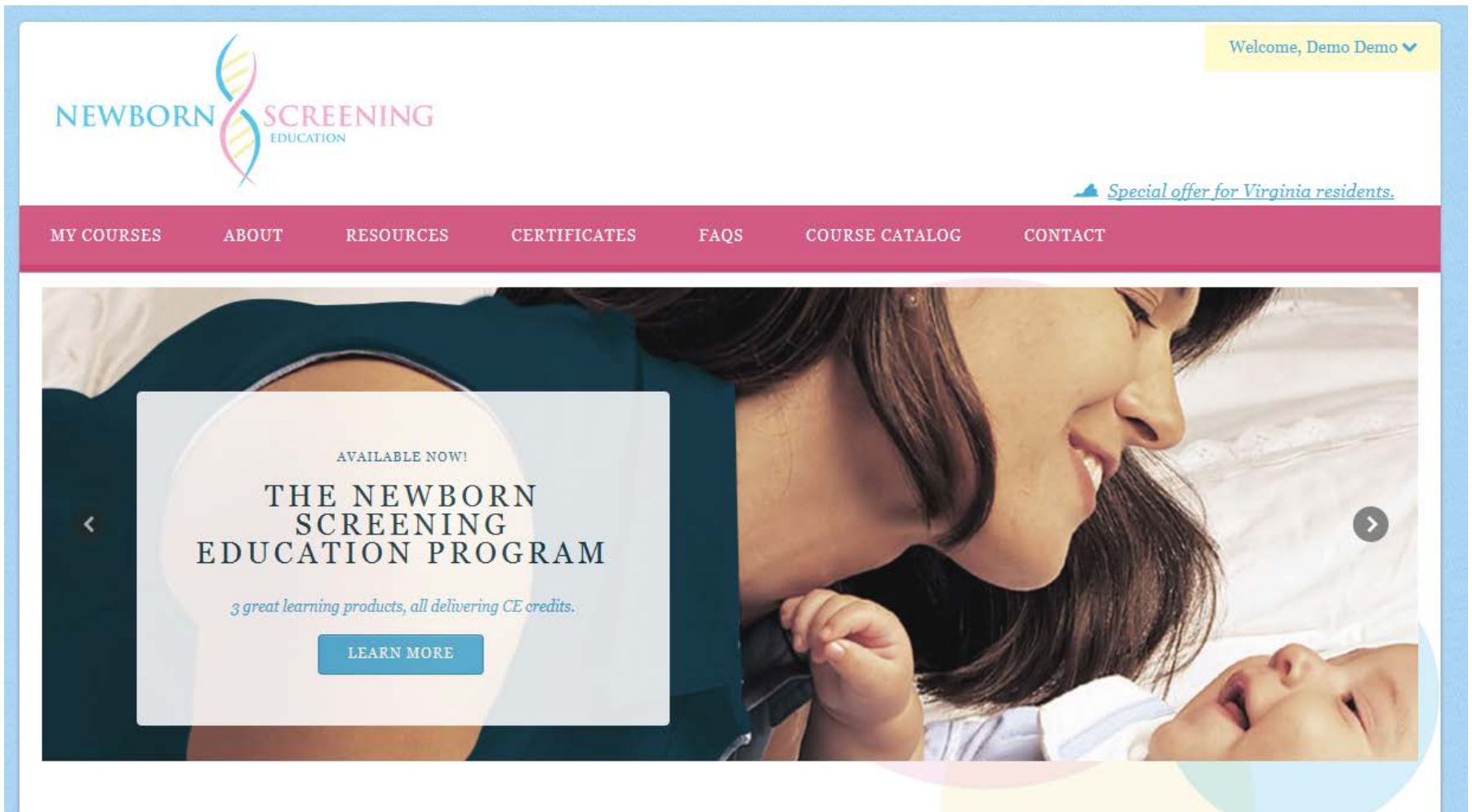
Information For...

[Media](#)

Contact Us:

Centers for

<http://www.newbornscreeningeducation.org/>



The image shows a screenshot of the website for Newborn Screening Education. The header features the organization's logo, which consists of a stylized DNA double helix in blue and pink, followed by the text "NEWBORN SCREENING EDUCATION". In the top right corner, there is a yellow box with the text "Welcome, Demo Demo" and a dropdown arrow. Below the logo, a blue banner contains the text "Special offer for Virginia residents." with a small blue icon of a mountain. A dark red navigation bar contains the following menu items: "MY COURSES", "ABOUT", "RESOURCES", "CERTIFICATES", "FAQS", "COURSE CATALOG", and "CONTACT". The main content area features a large image of a smiling woman with long dark hair looking down at a baby lying in a hospital bed. Overlaid on the left side of this image is a white call-to-action box with a light blue border. The text inside the box reads: "AVAILABLE NOW!" in all caps, followed by "THE NEWBORN SCREENING EDUCATION PROGRAM" in a larger, bold, serif font. Below this, it says "3 great learning products, all delivering CE credits." in a smaller, italicized font. At the bottom of the box is a blue button with the text "LEARN MORE" in white. There are also small grey navigation arrows on the left and right sides of the image area.

NEWBORN SCREENING EDUCATION

Welcome, Demo Demo

Special offer for Virginia residents.

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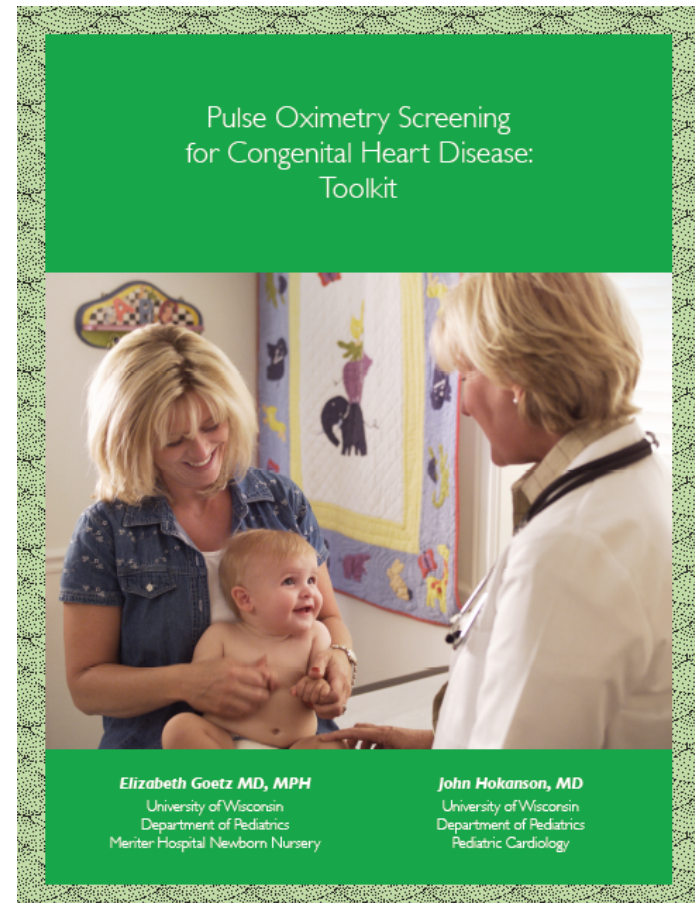
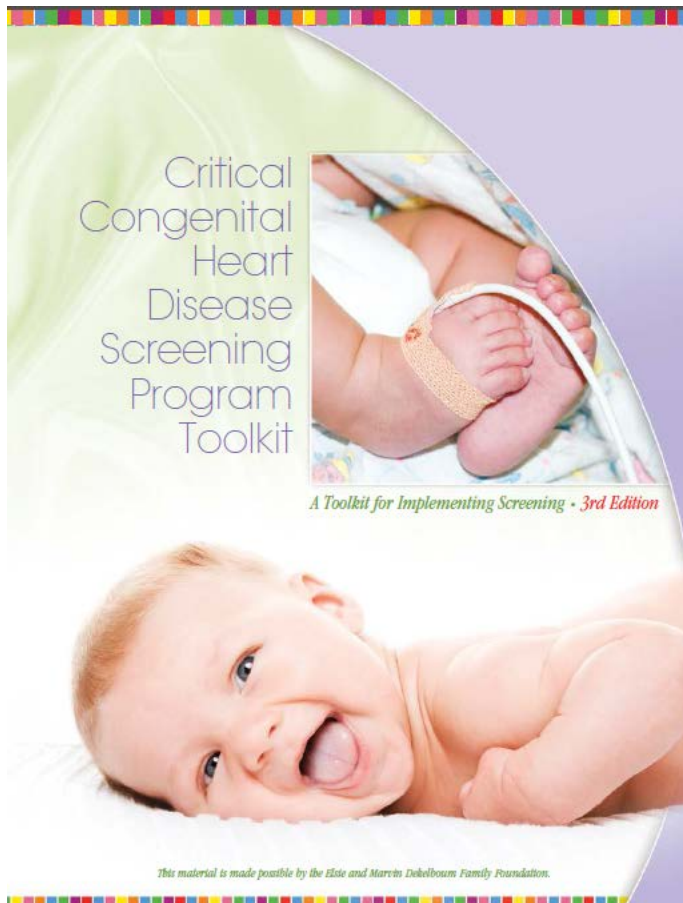
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LEARN MORE

Toolkits from Children's National & Wisconsin SHINE Project

<http://www.childrensnational.org/PulseOx/request-tool-kit.aspx>

<http://wisconsinshine.org/study/Pulse-Oximetry-Toolkit.pdf>

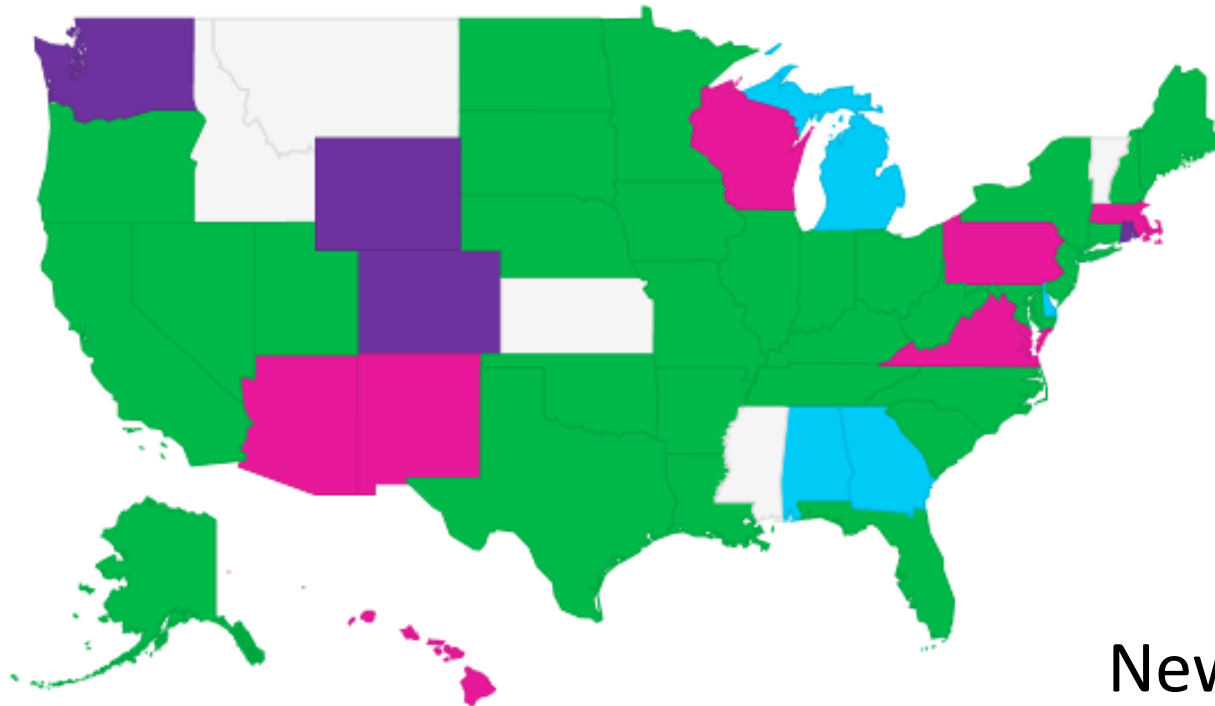


Newborn CCHD Screening Progress

Click on a state for additional details.



newborn foundation | coalition



Newborn Coalition

<http://cchdscreeningmap.org/>

Active Legislation

Legislation Enacted

Regulatory Addition to NBS Panel

Multi-Center Screening or Pilot Project

Wisconsin SHINE Project Website

- Patient Information
- Provider Information and Training Videos
- Sonographer Training Course
- Heart Atlas
 - All content for the Patient Information and Heart Atlas sections have Spanish language translations.
- <http://wisconsinshine.org/>

Information for Families



Have a question about a failed screen?

Call us directly: 1-608-262-2122

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Information for Families

Congratulations on the birth of your baby! Becoming a new parent is a wonderful and challenging time filled with unexpected joys and uncertainties.

After your baby is born, your health care team will do some exams and tests. One of the newest tests is for serious heart problems that your baby may have at birth. Health care providers call these problems "Critical Congenital Heart Disease (CCHD)."

This test for serious heart problems is called pulse oximetry. This test:

- measures oxygen in your baby's blood.
- is easy and painless.
- is usually done when your baby is between 24 to 48 hours old. (If your child is on supplemental oxygen in the first days after birth, the pulse oximetry testing may be postponed.)

To do this test, your nurse will put a small sticker, called a probe, on your baby's right hand and on your baby's foot. The probe measures the oxygen in your baby's blood.

Most babies will pass this screening test the first time and will not need any more tests. A small number of babies will need to have the pulse oximetry screening repeated. Babies with very low oxygen levels or moderately low oxygen levels on repeated testing will usually need to have another test called an echocardiogram to determine if they have an important heart problem.

• [Information for Families](#)

• [What is CCHD?](#)

• [Pulse Oximetry FAQ](#)

• [Failed Screen](#)

• [Common Questions](#)

• [Wisconsin SHINE Overview for Parents](#)

[Heart Smart Videos for Family Education](#)

[Heart Smart: CCHD Screening for Parents](#)

These resources are offered by [Baby's First Test](#). Baby's First Test houses the nation's newborn screening

Información para las Familias
¡Felicitaciones por el nacimiento de su bebé! Ser padres por primera vez es una experiencia maravillosa y llena de retos con alegrías e incertidumbres inesperadas.

Information for Families/Información para las Familias

Information for Families

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An echocardiogram is an ultrasound test of your baby's heart. An echocardiogram is painless and is like the ultrasound some mothers have when they are pregnant. Many hospitals can perform an echocardiogram for babies, but some babies may need to go to a different health care facility to have an echocardiogram.

It is important to remember that pulse oximetry screening will not identify babies who have problems with their hearts but who have normal oxygen levels.

The reason to do pulse oximetry screening is to find and treat babies with serious heart problems that are not found during prenatal care or newborn care.

What is CCHD?

Congenital Heart Disease is one of the most common abnormalities found in newborn babies. Congenital Heart Disease, or CHD, describes a wide range of heart defects and may be very mild or may be life threatening in the first days of life. Critical Congenital Heart Disease defines more severe forms of CHD that can lead to serious illness or even death soon after the baby is born.

Critical Congenital Heart Disease, or CCHD, happens when a baby's heart does not develop normally before birth. Although it is rare, affecting only 2-3 of every 1,000 babies born, CCHD can quickly lead to serious illness and even death in the first few days of life. Some babies with CCHD are discovered early in pregnancy by prenatal ultrasound, but many babies with CCHD are diagnosed after they are born. Unfortunately, some of these babies can appear perfectly normal until they become critically ill.

Información para las Familias

¡Felicitaciones por el nacimiento de su bebé!
Ser padres por primera vez es una experiencia maravillosa y llena de retos con alegrías e incertidumbres inesperadas.

Después que nace su bebé, su equipo médico le realizará algunos exámenes y pruebas. Una de las pruebas más nuevas es para detectar problemas serios del corazón que su bebé pudiese tener al nacer. Los médicos llaman a estos problemas la "Enfermedad Cardíaca Congénita Grave (o sus siglas en inglés CCHD)".



Esta prueba para problemas cardíacos serios es llamada oximetría de pulso. Esta prueba:

- Mide el oxígeno en la sangre de su bebé.
- Es fácil y no es dolorosa.
- Usualmente se hace cuando su bebé tiene entre 24 y 48 horas de nacido. (Si su bebé está con oxígeno suplementario en los primeros días después de nacido, la prueba de oximetría de pulso podría ser pospuesta.)

Para hacer este examen, su enfermera colocará una pequeña etiqueta adhesiva llamada un sensor, en la mano derecha o en el pie de su bebé. El sensor mide el oxígeno en la sangre de su bebé.

La mayoría de los bebés pasan la prueba la primera vez y no necesitarán ninguna otra prueba. Un número pequeño de bebés necesitarán que se les repita la prueba oximetría de pulso. Los bebés que tienen bajos niveles de oxígeno o niveles moderados de oxígeno al repetir las pruebas, usualmente necesitarán otra prueba llamada un ecocardiograma para determinar si tienen un problema importante en el corazón.

Un ecocardiograma es una prueba de ultrasonido del corazón de su bebé. Un ecocardiograma no es doloroso y es como el ultrasonido que les hacen a algunas madres cuando están embarazadas. Muchos hospitales pueden ejecutar un ecocardiograma para bebés pero algunos bebés podrían tener que ir a un centro de salud diferente para que les hagan un ecocardiograma.

Es importante recordar que la prueba de oximetría de pulso no identificará a los bebés que tienen problemas con su corazón sino a los que tienen niveles normales de oxígeno.

La razón para hacer la prueba de oximetría de pulso es para encontrar y tratar a los bebés con serios problemas cardíacos que no se encuentran durante el cuidado prenatal o de recién nacido.

¿Qué es la Enfermedad Cardíaca Congénita Grave (siglas en inglés CCHD)?

La Enfermedad Cardíaca Congénita es una de las anomalías más comunes encontradas en los bebés recién nacidos. La Enfermedad Cardíaca Congénita, o CHD (en inglés), describe un amplio rango de defectos cardíacos los cuales pudiesen ser muy leves o pudiesen poner en riesgo la vida del bebé en los primeros días de nacido. La Enfermedad Cardíaca Congénita Grave define las formas más severas del CHD que pueden llevar a enfermedades serias o hasta la muerte al poco tiempo después de que el bebé nace.

La Enfermedad Cardíaca Congénita Grave, o CCHD (en inglés) sucede cuando el corazón de un bebé no se desarrolla normalmente antes del nacimiento. Aun cuando es rara, afectando solo de 2 a 3 de cada 1,000 bebés que nacen, la CCHD puede conllevar rápidamente a enfermedades serias y aún la muerte en los primeros días de vida. Algunos bebés con la CCHD son descubiertos temprano en el embarazo con ultrasonidos prenatales, pero muchos bebés con la CCHD son diagnosticados después de nacer. Desafortunadamente, algunos de estos bebés pudiesen parecer perfectamente normales hasta que se enferman gravemente.

Video Tutorial



- [Information for Hospitals](#)
- [Information for Providers](#)
- [Equipment Overview](#)
- [Data Collection](#)
- [Screening Protocol](#)
- [Video Tutorial](#)
- [Online Learning Module](#)

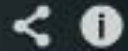
Online Learning Module

1. Introduction
2. What is CCHD?
3. Who is affected by CCHD
4. How is CCHD detected?
5. Pulse Ox and CCHD
6. Screening for CCHD
7. What to do with a failed Screening

What is CCHD?

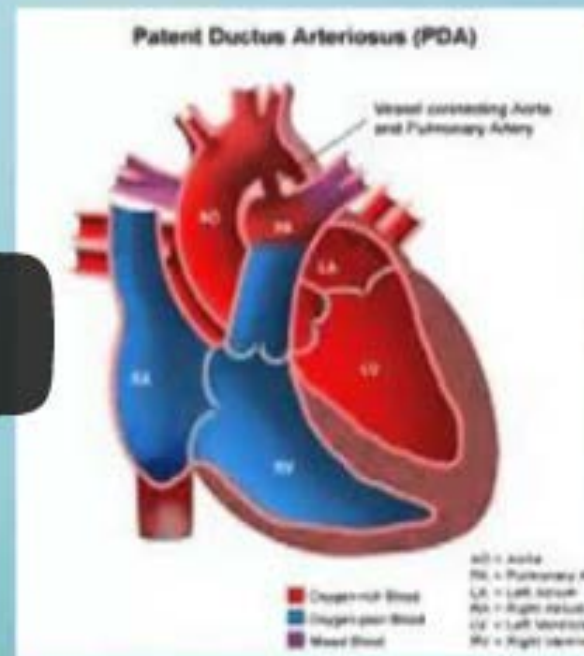
Review of the basic anatomy and physiology of CCHD.

What is CCHD - Online Learning Module for Healt...



What does "Ductal Dependent" Mean?

- Heart depends on patent ductus for adequate function
 - Left sided obstructive lesions
 - Some or all of systemic cardiac output is supplied from the right heart via the ductus arteriosus
 - Closure of the ductus arteriosus results in obstruction to systemic output
 - Cyanotic lesions
 - May become MORE cyanotic at ductal closure if some or all of pulmonary blood flow has been supplied from the left heart via the ductus



www.childrenshospital.org

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SHINE



00:00 / 10:28



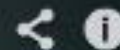
YouTube



Screening for CCHD

Describes how pulse oximetry can be used to screen newborns for CCHD.

Screening for CCHD - Online Learning Module for...



Tips for Screening

- Try to measure when baby is in quiet awake state
- Wait long enough to establish a good wave form
 - Recommend waiting 1 full minute with good wave form before recording measurement



00:00 / 11:39



YouTube



Sonographer Training Course

WISCONSIN
SHINE
Screening Hearts In Newborns



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Call us directly: 1-608-262-2122

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Families

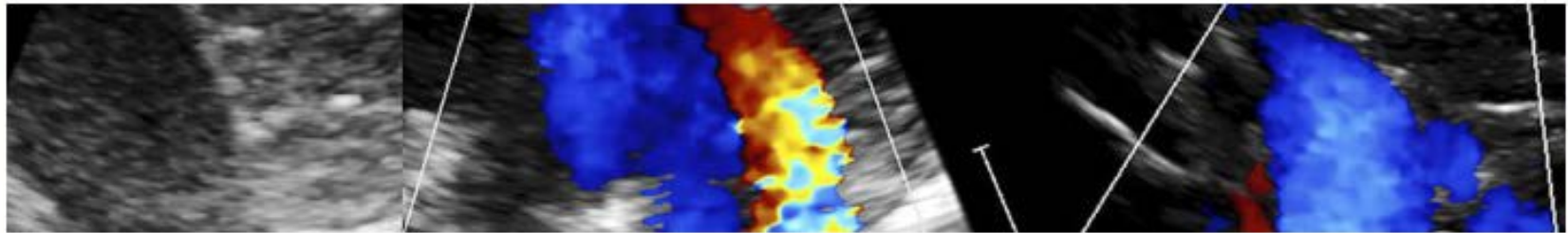
Hospitals

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ECHO Training

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Information for ECHO Training

The Sonographer Education portion of the SHINE website is designed to assist cardiac sonographers in performing the initial neonatal echocardiogram as part of a comprehensive evaluation for hypoxia. Sonographers performing these echocardiograms may not regularly image pediatric patients and may have limited familiarity with the differences between congenital echocardiography and adult echocardiography. The program reviews "The Terrible Ten" echo findings of critical congenital heart disease and helps the sonographer generate a differential based on those findings. The program also discusses common forms of critical congenital heart disease in more detail.

The program is organized into an introduction and overview portion, detailed discussion of the "Terrible Ten" findings, and individual sections on each form of critical congenital heart disease. To assist in learning,



• *Information for ECHO Training*

CME Credit

This activity is available for 2 SDMS CME credit hours for sonographers. This activity is not eligible for AMA PRA Category 1 Credit™.

In order to receive CME credit for this learning activity, you are required to complete the following steps:

<http://wisconsinshine.org/echo-training/>

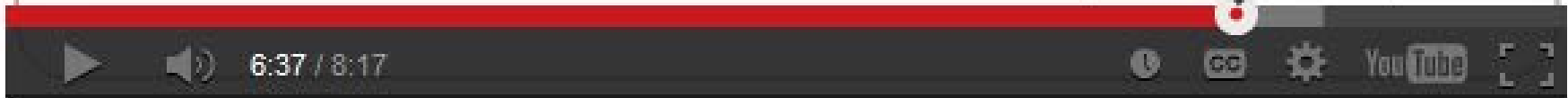
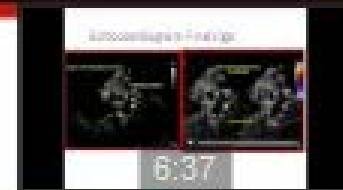
- The Terrible Ten
 - Ten findings that suggest CCHD
 - Directed toward the adult cardiac sonographer
- Sections on each of the 12 target lesions as well as a few other significant neonatal cardiac clinical scenarios (cardiomyopathy, critical aortic stenosis, L-TGA, etc.)
 - Diagrams
 - Discussion
 - Echocardiographic examples

Coarctation of the Aorta (CoA)

Coarctation of the Aorta (CoA)



Echocardiogram Findings



Single Ventricle Lesion

Single Ventricle Lesion

ME

RA LA LV

JPEG

4:32 / 6:03

YouTube

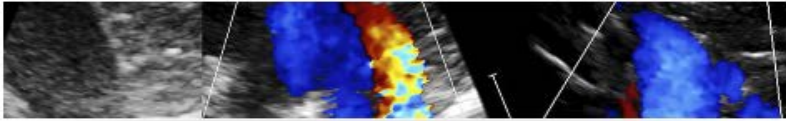
This is a screenshot of a video player displaying a medical MRI scan. The scan shows a cross-section of the heart with three chambers labeled in yellow: RA (Right Atrium), LA (Left Atrium), and LV (Left Ventricle). The LV is notably enlarged. A white arrow points to a dark, irregular mass within the LV, representing a lesion. To the right of the scan is a vertical grayscale calibration bar labeled 'ME' at the top. Below the scan is a video player interface with a red progress bar, a play button, a volume icon, and a timestamp of 4:32 / 6:03. The YouTube logo and other interface icons are visible at the bottom.

Heart Atlas

WISCONSIN SHINE Saving Hearts & Homes

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Home Families Hospitals Home Births ECHO Training **Heart Atlas** Study



Information on the Heart & CCHD

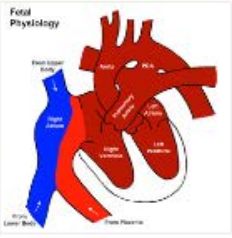
Diagrams and brief descriptions of the 12 target diagnoses of critical congenital heart disease (CCHD) are given here. It is important to remember that there is a wide variability within each of the diagnoses. For example, some babies with coarctation of the aorta may become critically ill or even die within a few days after birth, yet in some people, their coarctation might go unrecognized for years. To make things more complicated, more than one of these heart problems can be present in the same baby. These diagrams aren't meant to be a precise anatomical guide, but to give a general idea of the problems associated with each heart problem.

Helpful Terms

Hypoplasia	Something that is too small.
Atresia	Something is missing or closed. This term is applied both to valves that won't open and valves that never formed at all.
Stenosis	A narrowing in a blood vessel or a valve that won't open as easily it should.
Atrium	The upper chambers of the heart that receive blood from the body or the lungs.
Ventricle	The lower chambers of the heart that pump blood to the lungs or the body.

Before birth, the arteries giving blood to the lungs (Pulmonary Artery) and to the body (Aorta) are connected by a large blood vessel called ductus arteriosus. This normal part of the body is designed to close in the first few days after a baby is born.

In many forms of critical congenital heart disease, the normal parts of the heart use the ductus arteriosus to help out the abnormal parts of the heart. These babies can appear to be healthy while this connection is open and one side of the heart can help the other. However, when the ductus arteriosus closes, the baby's heart problem can show itself very quickly.



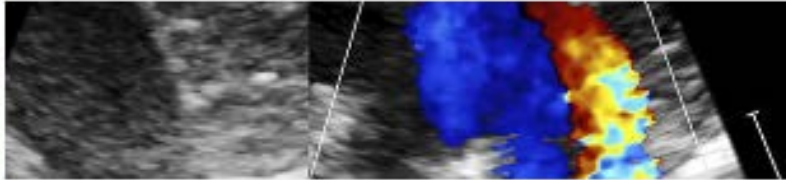
Fetal Physiology

Normal Heart Connections Before Birth

- **Information on the Heart & CCHD**
- **Hypoplastic Left Heart Syndrome (HLHS)**
- **Pulmonary Atresia (PA)**
- **Tetralogy of Fallot (ToF)**
- **Total Anomalous Pulmonary Venous Return (TAPVR)**
- **Transposition of the Great Arteries (TGA)**
- **Tricuspid Atresia (TA)**
- **Truncus Arteriosus (Truncus)**
- **Coarctation of the Aorta (CoA)**
- **Double Outlet Right Ventricle (DORV)**
- **Ebstein's Anomaly**
- **Single Ventricle & Hypoplastic Right Heart Syndrome**
- **Interrupted Aortic Arch (IAA)**

Información acerca del corazón y la Enfermedad Cardíaca Congénita Grave (siglas en inglés CCHD)

Aquí damos los diagramas y descripciones breves de los 12 diagnósticos de enfoque de la enfermedad cardíaca congénita grave (CCHD). Es importante recordar que existe una amplia variabilidad entre cada uno de los diagnósticos. Por ejemplo, algunos bebés con estrechamiento de la aorta podrían enfermarse gravemente o aun morir muy pocos días después de nacidos, y sin embargo en algunas otras personas, el estrechamiento podría pasar desapercibido por muchos años. Para complicar más las cosas, más de uno de estos problemas podrían estar presentes en el mismo bebé. El propósito de estos diagramas no es el de ser una guía anatómica precisa sino de dar una idea general de los problemas asociados con cada uno de los problemas cardíacos.



Hypoplastic Left Heart Syndrome (HLHS)

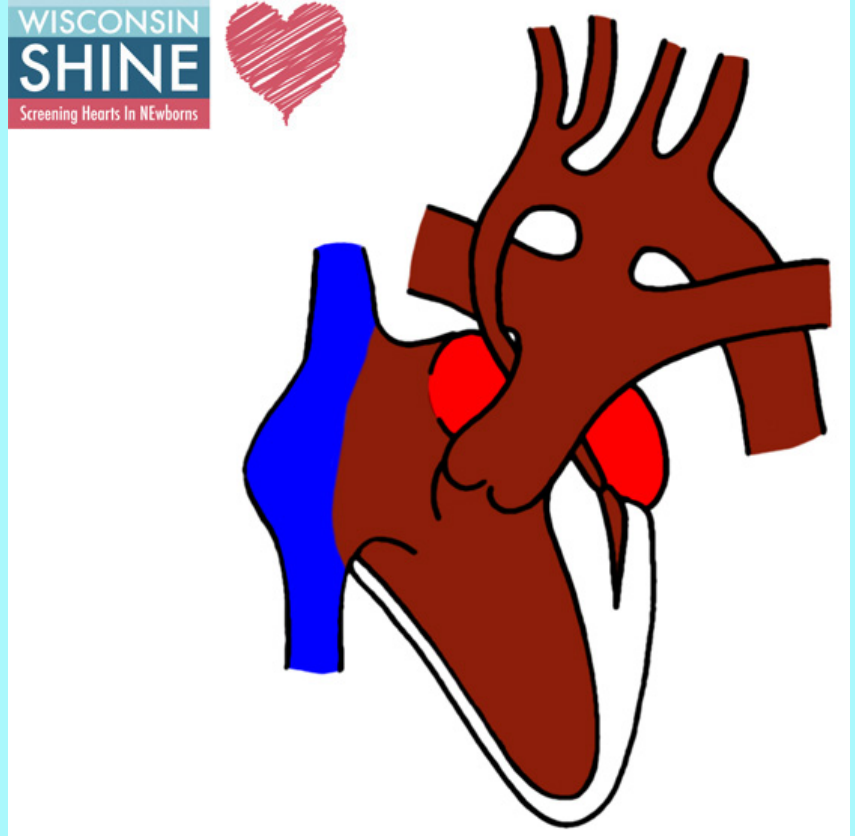
The structures of the left heart are too small to provide all of the body's blood supply. Sometimes, the left heart structures might be so small that the diagnosis is obvious. However, there are some babies where it is hard to tell if the left heart is just barely too small or just barely big enough.



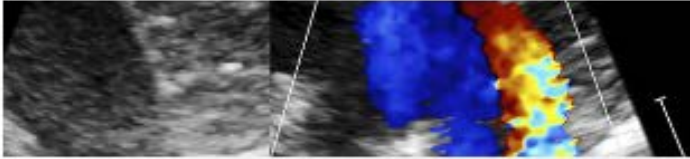
HLHS with Mitral and Valve Atresia

Síndrome del Corazón Izquierdo Hipoplástico (HLHS siglas en inglés)

Las estructuras del lado izquierdo del corazón son muy pequeñas para proporcionar todo el suministro de sangre al cuerpo. Algunas veces, las estructuras del lado izquierdo del corazón podrían ser tan pequeñas que el diagnóstico sería obvio. Sin embargo, hay algunos bebés en los cuales es difícil decir si el lado izquierdo del corazón es justo apenas muy pequeño o justo lo suficientemente grande.

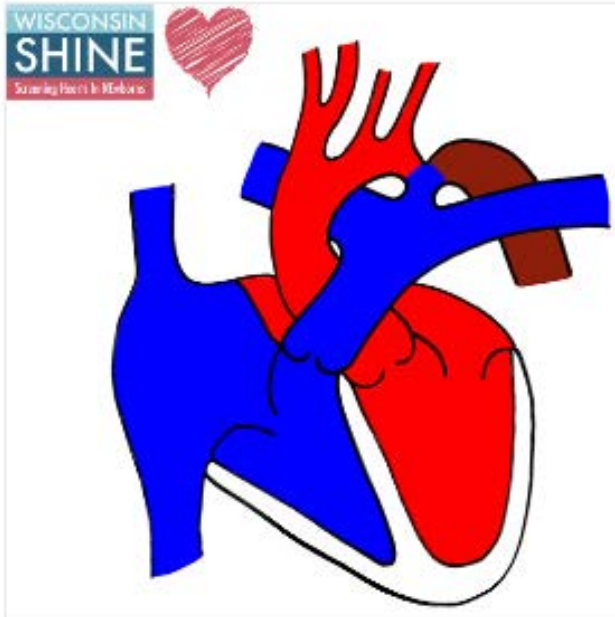


HLHS con Atresia Mitral y de Válvulas



Coarctation of the Aorta (CoA)

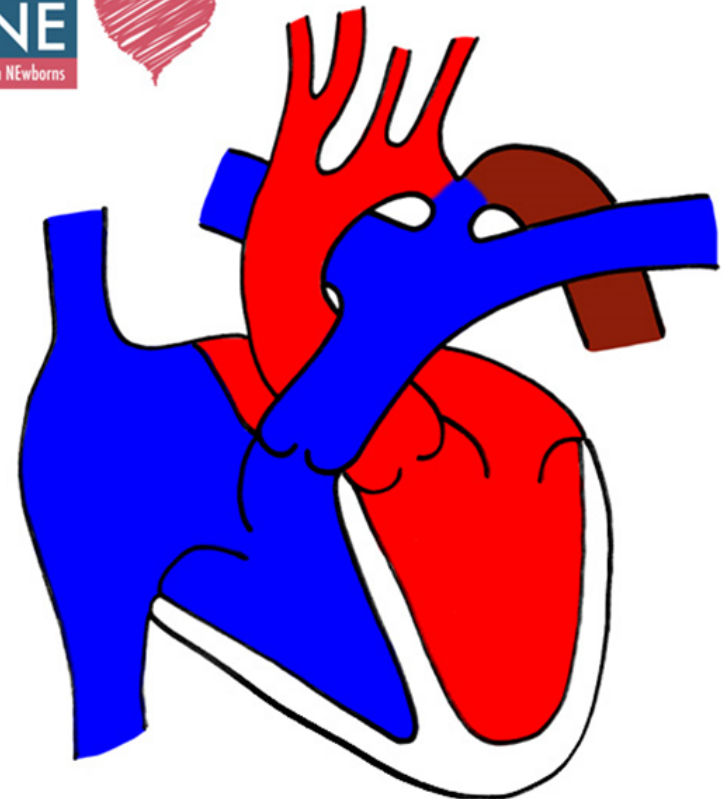
This is a narrowing of the aorta, the large blood vessel that takes blood from the heart to the body. There is a wide range of how badly the aorta is narrowed and there are often other heart problems present in addition to the coarctation. Despite being one of the more common potentially dangerous heart problems, Coarctation of the Aorta is one of the more difficult to detect before birth.



Coarctation of the Aorta (CoA)

Estrechamiento de la Aorta (CoA siglas en inglés)

Esto es un estrechamiento de la aorta, el vaso sanguíneo grande que lleva la sangre desde el corazón hasta el cuerpo. Hay un rango bastante amplio al determinar cuán estrecha está la aorta y a menudo hay otros problemas cardíacos presentes además del estrechamiento. A pesar de ser uno de los problemas cardíacos potencialmente peligrosos más comunes, el Estrechamiento de la Aorta es uno de los más difíciles de detectar antes del nacimiento.



Estrechamiento de la Aorta (CoA)

- CDC
- <http://www.cdc.gov/ncbddd/pediatricgenetics/cchdscreening.html>
- Newborn Coalition
- <http://cchdscreeningmap.org/>
- Children's National
- <http://www.childrensnational.org/pulseox/>

- Indiana
- <http://www.in.gov/isdh/25347.htm>
- Minnesota
- <http://www.health.state.mn.us/divs/phl/newborn/resources.html>
- Missouri
- <http://health.mo.gov/living/families/genetics/birthdefects/cchd.php>

- Maryland
- http://phpa.dhmh.maryland.gov/genetics/SitePages/CCHD_Program.aspx
- Virginia
- <http://www.newbornscreeningeducation.org/>
- Alaska
- http://www.dhss.alaska.gov/dph/wcfh/Documents/toolkit_CCHD.pdf