



# Western States Genetic Services Collaborative

## Overview of Western States Implementation and Cost Analysis for Newborn Screening for Critical Congenital Heart Defects



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# Overview

- Current status of implementation of newborn screening for Critical Congenital Heart Defects (CCHD) in the Western States Genetic Services Collaborative
- Review of costs associated with implementation of CCHD screening and follow-up in Hawaii



# Regional Genetics Collaboratives





## Western States Genetic Services Collaborative

### Region VII

- Alaska
- California
- Guam
- Hawai'i
- Idaho
- Oregon
- Washington

# CCHD Screening Update - Alaska



- steering committee of pediatric cardiologists, pediatricians, nurses, and nurse midwives was formed in February 2013
- Decision to not go the legislative route because of prior history with hearing screening legislation, but rather make it the standard of care
- Many hospitals have implemented screening or are in varying stages towards implementation

# CCHD Screening Update - Alaska



- In collaboration with the committee, the NBMS program is creating a toolkit for birthing centers/hospitals which will include information such as: the State of Alaska position statement of pulse oximetry screening, resources on equipment and referrals, training information, etc.
- In April 2013, a bill was passed in the Alaska Senate which will require pulse oximetry screening for newborns beginning 1/1/2014 for larger facilities.

# CCHD Screening Update - California



- Newborn screening for critical congenital heart disease bill signed 9/15/2012 which requires:
  - oversight by the Newborn Hearing Screening Program, within the California Department of Health Care Services and not by the California Department of Public Health (CDPH) Newborn Metabolic Screening Program.
  - general acute care hospitals with licensed perinatal services must offer to parents of a newborn, prior to discharge, a pulse oximetry test.

# CCHD Screening Update - California



- use of protocols approved by the department or its designee
- the Department of Health Care Services to phase in implementation of a comprehensive CCHD screening program on or after July 1, 2013, and require 100% participation by these hospitals by December 31, 2016.
- the hospitals to develop a CCHD screening program as prescribed



## CCHD Screening Update - California

- The Department of Health Care Services is in the process of gathering stakeholder perspectives and feedback prior to issuing guidance.
- They are also developing a data model and implementation plans for how to evaluate the screening program at the hospital-level and state level.
- The CDPH is implementing referrals for pregnancies at high risk for CCHD (NT) for fetal echocardiogram through their prenatal screening program.
- CDPH is also embarking on further research in this area using maternal serum.

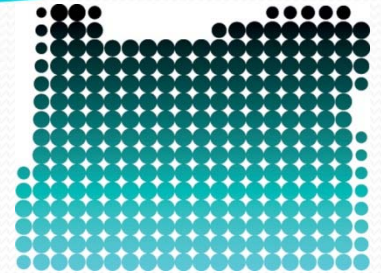


# CCHD Screening Update - Idaho



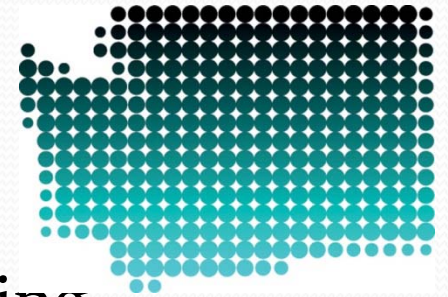
- Newborn metabolic screening program is not planning on implementing CCHD screening as part of the Idaho newborn screening package
- Supporting CCHD screening as a best practice for hospitals.

# CCHD Screening Update - Oregon



- No plans for the Oregon Newborn Screening Program to implement CCHD testing.
- CCHD screening similar to hearing screening which is handled by a separate Departmental office.
- Bills have been introduced in the 2013 legislative session to establish rules requiring CCHD screening for all infants born in birthing facilities, and requiring physicians and midwives to inform the parents after birth of the benefits of pulse oximetry to screen for CCHD.

# CCHD Screening Update - Washington



- No plans at this time for the state to take a direct role in this hospital based screening.
- One of the state's larger hospitals was given an award for implementing CCHD on their own.
- Major effort at this time is to acknowledge that CCHD screening is a good thing that hospitals should adopt.

# CCHD Screening Update - Hawaii



- In April 2012, the Department of Health organized CCHD Task Force (hospital administrators, primary care providers, neonatologists, pediatric cardiologists, nursery staff, public health, family advocates, community organizations, and third party payers).
- Task force in agreement with universal CCHD screening.
- Task force worked to develop core screening and follow-up protocols and educational materials.

# CCHD Screening Update - Hawaii



- Newborn point of care screening legislation drafted by DOH and introduced in Governor's administrative package in January 2013.
- DOH began to collect information and do analysis of cost of implementation for CCHD screening.
- To be continued...

# Cost of Implementing CCHD Screening & Follow-up

## What to consider?

- Planning efforts
- Screening
- Follow-up/Diagnosis
- Maintenance



# Cost of Planning CCHD Screening

## **Planning efforts:**

- Genetics and Newborn Screening program staff time
- Task Force time







## Cost of Planning CCHD Screening

Planning efforts:

- Newborn screening program staff time
  - NBS program coordinator 3 hrs/week x 52 weeks
  - **Estimated cost is \$8,500 for the past 12 months**



## Cost of Planning CCHD Screening

### **NBS program coordinator tasks:**

- Information gathering including ongoing reading of articles and research
- Assisting with brochure development
- Generating informational letters
- Assist with task force development
- Presentation to the Task Force
- Participate in monthly CCHD TA assistance calls
- Contact and meeting with Masimo representative



## Cost of Planning CCHD Screening

### **NBS program coordinator tasks continued...**

- Develop refusal form for pulse ox
- Activities with birthing facilities
  - Visits to the neighbor island facilities. CCHD/pulse ox included in training for staff and discussion with Nurse Managers.
  - Phone calls intermittently to all birthing facilities to update facility's progress toward implementation of routine pulse ox screening
  - Development and completion of survey of facilities
- Develop plans for out-of-hospital births



## Cost of Planning CCHD Screening

Planning efforts:

- Genetics program staff time
  - Genomics Section Supervisor 1 hr/week x 52 weeks
  - Genetic counselor 3 hrs/week x 52 weeks
  - Administrative assistant 2 hrs/week x 52 weeks
  - **Estimated cost is \$10,900 for the past 12 months**



## Cost of Planning CCHD Screening

### **Genetic counselor tasks:**

- Initial research
- Daily/weekly readings on new articles
- Participating on listserv/webinars for CCHD
- Preparation for internal and task force meetings
- Attending public hearings/tracking legislation
- Drafting written materials (STAR-G fact sheet, parent brochure, screening protocol, follow up guidelines, agendas, minutes, presentations, NBS newsletter)

## Cost of Planning CCHD Screening

### **Genetic counselor tasks continued:**

- Obtaining feedback and incorporating comments for written materials from families, pediatric cardiologists, hospitals, neonatologists, primary care providers, public health professionals.
- Organizing and participating on various calls to receive technical assistance from others.





## Cost of Planning CCHD Screening

### **Administrative assistant tasks:**

- Scheduling all meetings.
- Designing all written and website materials.

### **Genomics Section Supervisor tasks:**

- Convene task force.
- Review materials and work done by staff.
- Drafting legislation and developing testimony.
- Talking with DOH administration, the Attorney General's office, policy makers and health care providers about CCHD screening.



## Cost of Planning CCHD Screening

### **Task Force time:**

- Task Force (48 members) time
  - 3 in-person meetings
  - **Estimate \$3,000 per meeting with 2/3 attendance X 3 meetings = \$9,000 + lunch**

### **Task Force Review of protocols and materials**

- **Estimated cost = ?**



## Cost of Planning CCHD Screening

### **Approximate cost for planning efforts:**

- Staff time: \$ 19,400
- Task force time: \$9,000

**TOTAL: \$28,400**





## Cost of Implementing CCHD Screening

### **Screening\*:**

- Education materials
- Pulse oximeters
- Probes
- IT support for tracking and data transfer
- Out-of-hospital births
- Training and Education

\*Does not include hospital based internal costs for staff, training, etc.



## Cost of Implementing CCHD Screening

### **Educational materials:**

- Brochure about CCHD screening
- **Estimate \$2,000 for 26,000 brochures + cost of mailing batches of brochures to birthing facilities, district health offices, etc.**

## What if my baby passes the screening with normal oxygen saturation?

Most babies who pass this screening do not have a CCHD and will continue with normal newborn care. However, it is important to remember that pulse oximetry cannot detect all babies with CCHD. Therefore, you should contact your pediatrician or go to the emergency room if your baby has any signs or symptoms, including:

- a bluish color of the skin, lips, or fingernails
- fast breathing
- swelling or puffiness in the face, hands, feet, legs, or areas around the eyes
- shortness of breath or tires easily during feedings
- sweating around the head, especially during feeding
- poor weight gain



## How do I learn more about pulse oximetry screening for CCHD?

Ask your health providers or contact:

Hawaii Department of Health  
Newborn Metabolic Screening Program  
Phone (808) 733-9069 or TDD (808) 733-9055  
Email: [info@hawaiiogenetics.org](mailto:info@hawaiiogenetics.org)  
Website: [www.hawaiiogenetics.org](http://www.hawaiiogenetics.org)



Neil Abercrombie, Governor of Hawaii  
Loretta J. Fuddy, A.C.S.W., M.P.H., Director of Health

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March 2013

Hawaii State Department of Health  
Children with Special Health Needs Branch  
Newborn Metabolic Screening Program



**Newborn Pulse  
Oximetry Screening  
For Critical  
Congenital Heart  
Disease (CCHD)**

## Newborn Pulse Oximetry Screening

### What is Critical Congenital Heart Disease (CCHD)?

Critical Congenital Heart Disease (CCHD) describes a group of heart defects that can cause life-threatening problems. They require emergency care within the first days of life and surgery may be necessary in the first year of life. CCHD can usually be treated if found early.

About 2 in every 1000 babies in Hawaii are born with CCHD. CCHD occurs in all ethnic backgrounds.

### What is pulse oximetry?

Pulse oximetry is a simple, quick, and painless test that measures how much oxygen is in the blood (called "oxygen saturation") by using a sensor placed on the body. Another term for pulse oximetry is "pulse ox." Newborn screening using pulse oximetry can identify most infants with a CCHD before they leave the hospital or show signs of a CCHD.

### Why is pulse oximetry used to screen for Critical Congenital Heart Disease?

Pulse oximetry is used to screen for CCHD because it can be easily done soon after a baby is born and is painless. It is the best way to find a CCHD, along with a pediatrician's physical exam. A physical exam by itself will not always detect CCHD since some babies with CCHDs do not show physical symptoms.

### How is pulse oximetry screening done?

A pulse oximeter, made especially for newborns, is placed on your baby's right hand and on one foot. The screening usually only takes a few minutes. The reading is best if your baby is awake, warm, calm, and quiet. If your baby is crying, moving, or cold the screening may take longer.

### Will it hurt?

No, the pulse oximetry screen is painless and will not break the skin.

### When will the pulse oximetry screening be done?

The pulse oximetry test should be done when your baby is 24 hours (or 1 day) old. This means, your baby should have pulse oximetry screening before your baby is discharged home from the hospital or other birthing facility.

### What if I deliver at home or somewhere that does not have pulse oximetry newborn screening?

Ask your midwife or pediatrician about the closest facility that offers screening. You can also call the Hawaii State Department of Health Newborn Metabolic Screening Program at (808) 733-9069 who will help you find a facility where your baby can be screened.



Image used by permission from Nellcor Puritan Bennett LLC, Boulder, Colorado, doing business as Covidien

### How will I find out about the results?

Your baby's doctor or nurse will tell you the results of your baby's pulse oximetry screen.

### What if my baby *fails* the pulse oximetry screening?

If your baby fails the pulse oximetry screening or is suspected to have a CCHD, the pulse oximetry screening may be repeated. Your baby may then need to be examined by the doctor or specialist at the hospital.

Additional testing such as an X-ray, an electrocardiogram (a test that records the heart's electrical activity), or an echocardiogram (an ultrasound of the heart) may be done. The doctor will discuss the follow up care for your baby and any additional testing your baby may need. Your baby may be referred to a pediatric cardiologist or transferred to a different hospital.

# Cost of Implementing CCHD Screening

## Pulse oximeters:

- NBS program to purchase pulse oximeters for birthing facilities and district health offices:
  - 5V Masimo unit (\$445) X 24 units
  - 7V Masimo units (\$2085) plus docking stations (\$995) X 15 units
- **Total cost: \$56,880 (39 units)**



# Cost of Implementing CCHD Screening

## **Pulse oximeter probes:**

- Disposable (20 per box @ \$240 per box)
  - **1000 boxes of disposable = \$24,000**
- Reusable
  - Y sensors (\$195 each) X 39 = \$7,605.00
  - Foam wraps (12/\$17) X 1700 boxes = \$28,900
  - **Total for Reusable = \$36,505**



# Cost of Implementing CCHD Screening

## **Out-of-hospital births**

➤ ???

## **IT support for tracking and data transfer**

➤ ???

## **Training and Education**

➤ ???





# Cost of Implementing CCHD Follow-Up

## **Follow-up\*:**

- Airlifts from neighbor islands
- Tele-echocardiograms
- Training and continuing education

\*Does not include costs for follow-up done at larger birthing facilities with pediatric cardiology capabilities.





## Cost of Implementing CCHD Follow-Up

- **Airlifts from neighbor islands**

- \$15,000-\$20,000 per airlift from neighbor island to Honolulu

- **Tele-echocardiograms**

- Costs vary depending on whether tele-echocardiogram equipment available or have ability for cardiologist to have access to local hospital server to view stored images

- **Training and continuing education**

- Follow-up protocol/differential diagnoses
- Echocardiogram technicians on neighbor islands

# Cost of CCHD Screening Maintenance

## **Maintenance\*:**

- Oversight
- Training and continuing education
- IT support
- Payment issues
- Staffing
- Maintenance of equipment



\*Does not include birthing facility costs to maintain CCHD screening efforts

# CCHD Screening Update - Hawaii Continued...



- The hospital association and the two largest non-military hospitals in Hawaii blocked the CCHD screening legislation.
- Currently, the state DOH has no authority or responsibility to help implement, maintain or provide oversight for CCHD screening.
- The DOH will finish developing the follow-up protocol and then disband the task force.



# Western States Genetic Services Collaborative

## Mahalo

- WSGSC NBS Programs
  - Alaska
  - California
  - Hawaii
  - Idaho
  - Oregon
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