Screening for Critical Congenital Heart Disease (CCHD)

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Overview

- *Critical Congenital Heart Disease (CCHD)*
  - CHDs with severe and life-threatening symptoms requiring intervention within the first year of life

- *Critical Congenital Cyanotic Heart Disease (CCCHD)*
  - CCHDs that present with hypoxemia in most or all cases

- **CHD affects**
  - 7 to 9 of every 1,000 live births in the US
  - Approximately 25% have CCHD
A critical congenital heart defect requiring surgery or catheter intervention in the first year of life that presents with hypoxemia in most or all cases:

- Hypoplastic left heart syndrome (HLHS)
- Pulmonary atresia, intact septum
- Tetralogy of Fallot (TOF)
- Total anomalous pulmonary venous return (TAPVR)
- Transposition of the great arteries (TGA)
- Tricuspid atresia
- Truncus arteriosus
Timeline

- **October 15, 2010** – Secretary’s Advisory Committee for Heritable Disorders in Newborns and Children (SACHDNC) recommends the addition of CCCHD to the Committee’s Recommended Uniform Screening Panel (RUSP)

- **September 21, 2011** – Secretary Kathleen Sebelius adopts the SACHDNC recommendation to add CCHD to the RUSP

- **November 2011** – *Strategies for Implementing Screening for Critical Congenital Heart Disease* published in *Pediatrics*
Evidence review – CCHD screening method

Simple, non-invasive, bedside test

Estimates percentage of hemoglobin in the blood that is saturated with oxygen

Routinely used to monitor infants
Strategies for Implementing Screening for Critical Congenital Heart Disease

- Renamed the target conditions Critical Care Heart Disease (CCHD)
- Screening to focus initially on screening in the well-infant nursery & intermediate care nurseries
- Not to focus on out-of-hospital births
- Proposed pulse oximetry monitoring protocol based on results for right hand and either foot
CCHD Screening represents **Point-of-Care** newborn screening

- **Point-of care testing** refers to those tests administered outside of a laboratory but close to the site of direct delivery of medical care for a patient.

- Different from bloodspot screening which involves a central laboratory.
Role of Public Health Agencies in Point-of-Care Newborn Screening

- Inform the public about a new screened condition
- Facilitate standardized implementation of screening
- Participate in quality assurance
- Developing systems for diagnostic confirmation, follow-up, and data collection
- Evaluate the degree to which newborn screening is effective