

Report to SACHDNC

**Workgroup on Screening for
Critical Congenital Cyanotic Heart
Disease**

American College of Cardiology Heart House

January 13-14, 2011

Washington, DC



Participating Organizations

- ▶ American Academy of Pediatrics
- ▶ American College of Cardiology
- ▶ American College of Medical Genetics
- ▶ American Heart Association
- ▶ Association of Maternal & Child Health Programs
- ▶ Association of Public Health Laboratories
- ▶ Centers for Disease Control and Prevention
- ▶ Center for Medical Home Improvement
- ▶ Federal Drug Administration
- ▶ Health Resources and Services Administration
- ▶ March of Dimes
- ▶ National Institutes of Health
- ▶ Newborn Coalition/1in100
- ▶ Bless Her Heart/Congenital Heart Information Exchange
- ▶ Secretary's Advisory Committee on Heritable Disorders in Newborns and Children
- ▶ Utah and New York State Birth Defects Programs
- ▶ A.I. duPont Hospital for Children

Participating Organizations

- ▶ Baylor College of Medicine
- ▶ Cincinnati Children's Hospital Medical Center
- ▶ Children's National Medical Center
- ▶ Indiana Children's Health Services Research
- ▶ Mary Bridge Children's Hospital
- ▶ Mayo Clinic
- ▶ Monroe Carell Jr Children's Hospital @ Vanderbilt
- ▶ New York State Department of Health
- ▶ Queen Silvia Children's Hospital – Sweden
- ▶ Santa Clara Valley Medical Center
- ▶ Steven and Alexandra Cohen Children's Medical Center
- ▶ University of Birmingham, United Kingdom
- ▶ University of Maryland School of Medicine
- ▶ University of Minnesota
- ▶ University of Utah
- ▶ University of Virginia Health System

Invited Speakers

- ▶ Andrew Ewer
 - ▶ Marcia Feldkamp
 - ▶ Anne Grannelli
 - ▶ R. Rodney Howell
 - ▶ Alex Kemper
 - ▶ Lazaros Kochilas
 - ▶ William Mahle
 - ▶ Gerard Martin
 - ▶ Mathew Park
 - ▶ Annamarie Saarinen
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Overview

- ▶ Wide support to begin screening
- ▶ Recent unpublished evidence suggests that the number of additional echocardiograms will be small if appropriate thresholds are selected
- ▶ Messaging is critical
 - Not all types of heart disease will be picked up
 - Important, but non-cardiac conditions could be identified
- ▶ Group addressed the key issues needed to begin implementation in a safe, effective, and coordinated manner

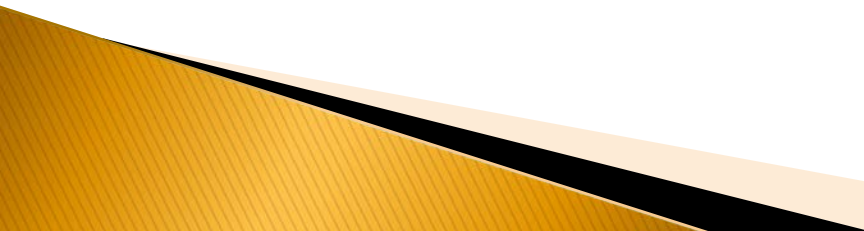
Screening Specifications

- ▶ **Pulse oximeter:** technology is key to assure that screening can be done quickly (e.g., not sensitive to motion) and accurately
- ▶ **Probe:** re-usable probes can decrease costs of screening
- ▶ **Probe placement:** right hand and foot seems to be most effective
- ▶ **Timing/Population:** 24 hours of life for full-term infants not treated in the NICU setting
- ▶ **Optimal cut off value:** current data suggest that $<95\%$ or $>3\%$ difference between extremities - - need to evaluate the impact of high altitude; abnormal repeated up to 3 times

Short-term Follow-up / Diagnosis

- ▶ Examine to rule-out non-cardiac cause
- ▶ Echocardiogram
 - In-house
 - Transfer
 - Via telemedicine
- ▶ Development of protocols within nurseries before screening begins

Training & Education

- ▶ Protocols for opt in/opt out for screening
 - ▶ Training for screeners
 - ▶ Training needs for newborn care providers
 - ▶ Training for sonographers
 - ▶ Public / Parent education
 - ▶ Some material already developed, such as the toolkit developed at Children's National Medical Center
 - ▶ Need for a “clearinghouse of information”
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Nursery Costs

- ▶ Set-up Costs
 - Oximeters, probes
 - Systems for diagnostic evaluation, when needed
- ▶ Maintenance of equipment
- ▶ Screening
 - Primarily screening time
 - Some cost related to probes
- ▶ Diagnostic costs
- ▶ Insurance coverage
 - In general, covers diagnosis, treatment
 - No CPT code for oximetry screening

Surveillance and Quality Improvement

- ▶ Results of screening and diagnosis should be
 - Embedded into electronic records
 - Using existing codes where possible
- ▶ Health information exchanges should be promoted to facilitate surveillance
- ▶ Public health programs can participate in quality assurance / quality improvement
- ▶ Birth defect registries could track impact of screening

Next Steps

- ▶ White paper describing implementation plans for consideration by the Advisory Committee
 - ▶ Development of consensus screening algorithm
 - ▶ Identification of research gaps
 - ▶ Central clearinghouse of information for policymakers, healthcare providers, parents, public
 - ▶ Roll out to nurseries once implementation and surveillance plans are in place
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