

# Newborn Screening for Critical Congenital Heart Disease: CDC Activities

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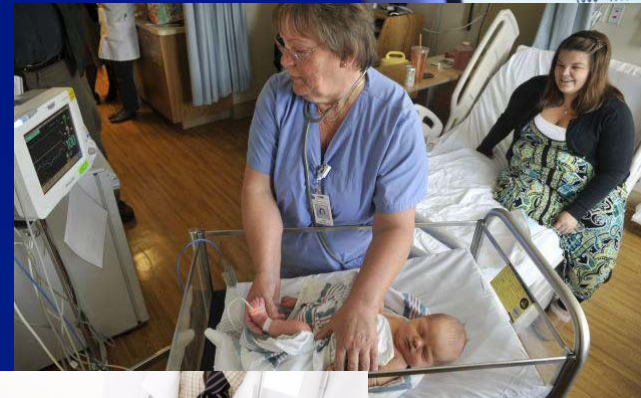
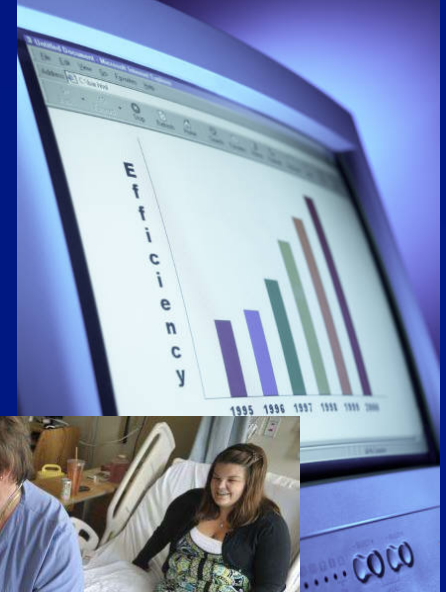
Centers for Disease Control and Prevention

Critical Congenital Heart Disease (CCHD) Stakeholders Meeting

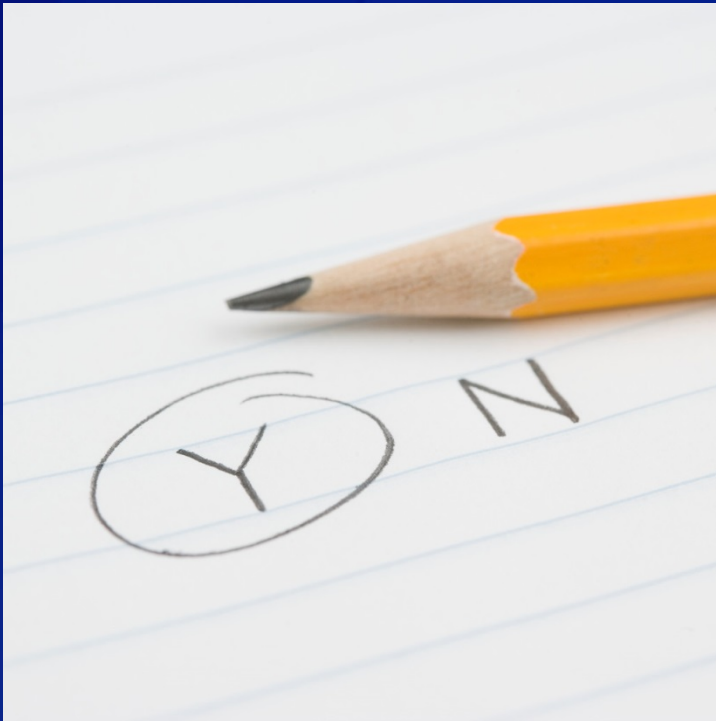
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# Tasks Assigned to CDC by HHS Secretary, Kathleen Sebelius (2011)

- ❑ Evaluate state surveillance to monitor the effectiveness of CCHD newborn screening programs
- ❑ Conduct a cost-effectiveness analysis of newborn screening by pulse oximetry for the early identification of CCHD
- ❑ Leverage an electronic health record framework for congenital heart defects, including CCHD



# Evaluate State Surveillance to Monitor the Effectiveness of CCHD Screening Programs



- ❑ Collaborated on a survey of state birth defects surveillance programs to assess programs' potential roles, capabilities, and readiness to assist with newborn screening activities for CCHD (2011)

# Evaluate State Surveillance to Monitor the Effectiveness of CCHD Screening Programs

- Worked with state birth defects surveillance programs, hospitals, and state health departments to understand how to implement and improve screening (2012)
  - Epi-Aid and Econ-Aid in New Jersey to evaluate the first three months of their state-mandated CCHD screening
  - Epi-Aid in Georgia to evaluate voluntary CCHD screening

Assess:

Screening data flow and tracking at each facility

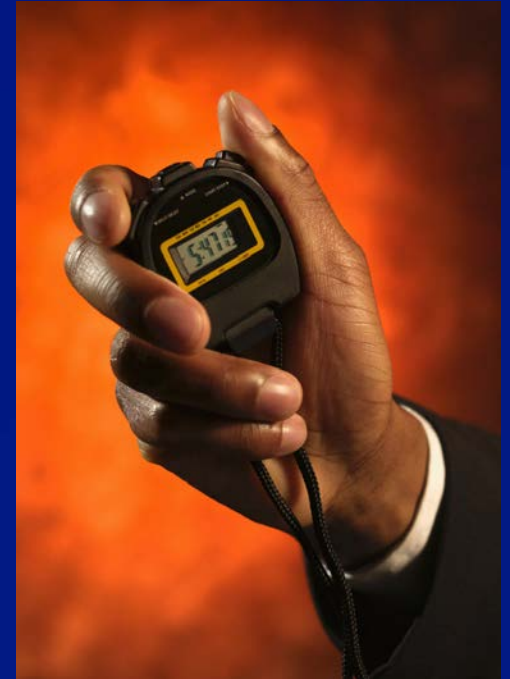
Electronic health records (EHR) capabilities at each facility

Process of communicating screening data to the state birth defects registry



# Cost-Effectiveness Analysis of CCHD Screening by Pulse Oximetry (2013)

- ❑ CCHD screening appears to be cost effective
- ❑ Time-motion studies and resource utilization questionnaire to assess hospital cost burden
- ❑ Screening time ~9 minutes per newborn (including documentation and cleaning)
- ❑ Screening costs ~\$14 per newborn
- ❑ In New Jersey
  - Hospital costs for CCHD screening were much lower among hospitals that used reusable screening equipment
  - Nursing staff reported that pulse oximetry was a familiar skill, and screening all newborns for CCHD was easily added to other routine tasks





# Leverage an Electronic Health Record Framework for Congenital Heart Defects, Including CCHD

- ❑ CDC collaboration with the National Library of Medicine and the National Heart Lung and Blood Institute
- ❑ Mapping CCHD conditions to various coding systems
  - Highlight similarities and differences between codes
- ❑ Goal: Facilitate meaningful data exchange between stakeholders



# Evaluation and Optimization of CCHD Screening Algorithms

- Goal: compare performance of CCHD screening algorithms and to design an optimal algorithm for CCHD using mathematical modeling
- Use existing data from healthcare systems that are already conducting CCHD screening and have available data (not prospectively collecting data)
  - CDC will serve as data repository
  - Participating sites will submit de-identified, individual-level data



# Evaluation and Optimization of CCHD Screening Algorithms



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- Data elements: age at screen, sex, race/ethnicity, saturation percentages, extremity tested, pass/fail, false or true positive, false or true negative
- Apply different algorithms to these data to identify how children would have performed using other screening algorithms
- Current/Tentative Timeline:
  - April 2014 to Summer – Hospitals/healthcare systems send data
  - Fall 2014-Winter 2014/2015 – Mathematical modeling, data analysis
  - Early 2015 – Results available
  - Spring 2015 – Publish results





**For more information please contact Centers for Disease Control and Prevention**

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*The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.*

# Publications

- ❑ Ailes EC, Gilboa SM, Riehle-Colarusso T, Johnson CY, Hobbs CA, Correa A, Honein MA; The National Birth Defects Prevention Study. Prenatal diagnosis of nonsyndromic congenital heart defects. *Prenat Diagn*. 2013 [Epub ahead of print]
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- ❑ Centers for Disease Control and Prevention. Assessment of Current Practices and Feasibility of Routine Screening for Critical Congenital Heart Defects - Georgia, 2012. *Morb Mortal Wkly Rep (MMWR)*. 2013;62(15):288-91.
- ❑ Dawson AL, Cassell CH, Riehle-Colarusso T, Grosse SD, Tanner JP, Kirby RS, Watkins SM, Correia JA, Olney RS. Factors Associated with Late Detection of Critical Congenital Heart Disease in Newborns. *Pediatrics*. 2013; 132(3):e604-11.
- ❑ Garg LF, Van Naarden Braun K, Knapp MM, et al. Results From the New Jersey Statewide Critical Congenital Heart Defects Screening Program. *Pediatrics*. 2013; 132(2):e314-23.

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- ❑ Olney RS, Botto LD. Newborn screening for critical congenital heart disease: essential public health roles for birth defects monitoring programs. *Birth Defects Res A Clin Mol Teratol.* 2012 Dec;94(12):965-9.
- ❑ Oster M, Kim C, Kusano A, Cragan J, Dressler P, Rougeux A, Mahle W, Correa A. A Population-Based Study of the Association of Prenatal Diagnosis with Survival for Infants with Congenital Heart Defects. *American Journal of Cardiology.* [Epub ahead of print]
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- ❑ Oster ME, Lee KA, Honein MA, Colarusso T, Shin M, Correa A. Temporal Trends in Survival Among Infants with Critical Congenital Heart Defects. *Pediatrics.* 2013; 131(5):e1502-8.

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- ❑ Peterson C, Grosse SD, Oster ME, Olney RS, Cassell CH. Cost-Effectiveness of Routine Screening for Critical Congenital Heart Disease in US Newborns. *Pediatrics*. 2013;132(3):e595-603.
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- ❑ Peterson C, Dawson A, Grosse SD, Riehle-Colarusso T, Olney RS, Tanner JP, Kirby RS, Correia JA, Watkins SM, Cassell CH. Hospitalizations, costs, and mortality among infants with critical congenital heart disease: how important is timely detection? *Birth Defects Res A Clin Mol Teratol*. 2013;97(10):664-72.
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