



CCHD Pulse Oximetry Newborn Screening: State Program Perspectives

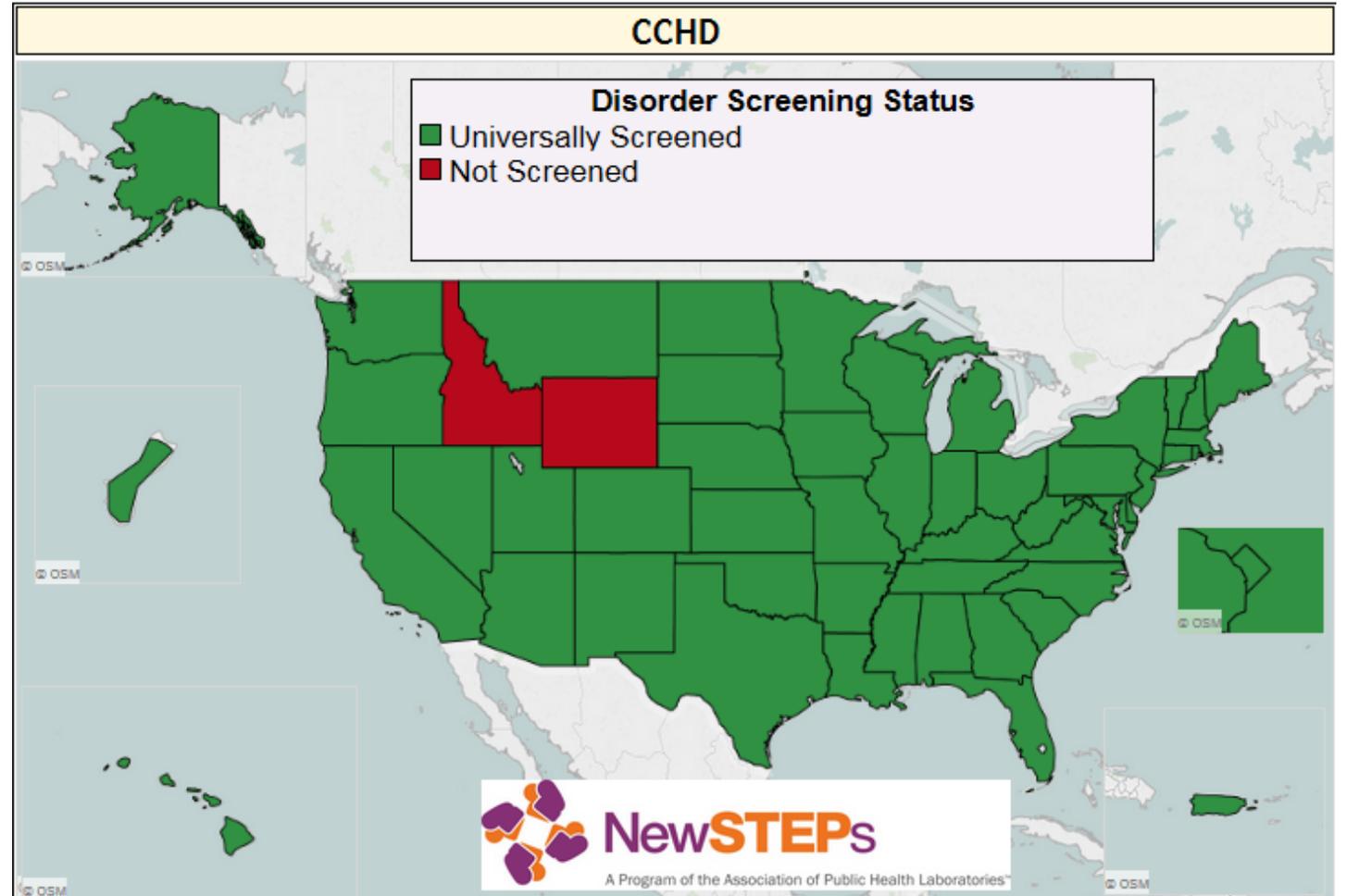
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A picture may be worth a thousand words...

... but with CCHD...

...the devil is in the details.



- **Utilizes pulse oximetry to detect lower oxygen saturations often associated with ductal-dependent Critical Congenital Heart Disease (CCHD)**
 - Critical= surgery or catheter intervention in first year of life
- **The screen detects HYPOXEMIA**
 - Associated with non-critical CHD
 - Associated with Pulmonary Conditions
 - Pneumonia
 - Persistent Pulmonary Hypertension
 - Associated with Bacterial Infections
 - Sepsis
 - Associated with CCHD
 - Originally 7 primary targets – now 12

PRIMARY TARGETS OF CCHD PULSE OXIMETRY SCREENING

- **Hypoplastic Left Heart Syndrome (HLHS)**
- **Pulmonary Atresia**
- **Tetralogy of Fallot**
- **Total Anomalous Pulmonary Venous Return**
- **Transposition of the Great Arteries**
- **Tricuspid Atresia**
- **Truncus Arteriosus**
- **Coarctation of the Aorta**
- **Double-Outlet Right Ventricle**
- **Ebstein's Anomaly**
- **Interrupted Aortic Arch**
- **Single Ventricle**



CCHD PULSE OXIMETRY SCREENING IS....

- **One of the least uniform of the conditions on the RUSP**
 - States utilize various:
 - Screening Algorithms
 - Follow-up practices
 - Data collection requirements and analysis

TABLE 2 Common Algorithms for Newborn Screening for CCHD With the Use of Pulse Oximetry in the United States

Algorithm Source	Cutoff for Passing With First Measurement	Retest Criteria for Subsequent Measurements	Fail Criteria
AAP	O ₂ sat ≥95% (in either RH or F) AND hand-foot O ₂ sat ≤3%	O ₂ sat <95% (in both RH and F) OR hand-foot O ₂ sat >3%	O ₂ sat <90% (either RH or F) OR fail retest criteria × 3
New Jersey	O ₂ sat ≥95% (in both RH and F) AND hand-foot O ₂ sat ≤3%	O ₂ sat <95% (in either RH or F) OR hand-foot O ₂ sat >3%	O ₂ sat <90% (either RH or F) OR fail retest criteria × 3
Tennessee	O ₂ sat ≥97% (F)	O ₂ sat <95% (in both RH and F) OR hand-foot O ₂ sat >3%	O ₂ sat <90% (either RH or F) OR fail retest criteria × 3

F, either foot; O₂, oxygen; RH, right hand; sat, saturation.

CCHD PULSE OXIMETRY SCREENING IS...

- **Unique to all other NBS conditions**
 - Pulse Oximetry Screening is the third line of defense
 - And the first two lines are getting better (though unlikely to ever be 100%)
 - Other Public Health Programs are involved (e.g., Birth Defects Registries)
 - In most states, identified cases of primary CCHD targets are being reported
- **Necessity of the screen itself varies by individual and location**
 - Dependent upon prenatal and clinical care availability and accessibility

SUCCESSSES IN CCHD PULSE OXIMETRY SCREENING

- **Infants who may have otherwise gone home undetected have been picked up by screening**
 - Many, if not most eligible infants appear to be getting screened
- **Significant other diseases like PPHN and pneumonia are being detected**
- **The addition of CCHD screening has not appeared to “shock” the system as some had feared (anecdotal)**
- **Addition of CCHD has resulted in stronger relationships with other Public Health Programs like Birth Defects Registries**

EXISTING CHALLENGES IN CCHD PULSE OXIMETRY SCREENING

- **Data Collection: Buy-In; Timeliness; Quality; Border Babies**
 - Initial screening results
 - Echocardiogram results
 - Non-cardiac findings
 - Reasons for not screening
- **Uniform case definitions still being developed**
- **Education regarding limitations of CCHD screening**
- **Screening devices**
 - Concerns over accuracy and precision of currently available screening devices

EXISTING CHALLENGES IN CCHD PULSE OXIMETRY SCREENING

- **Unknown best practices/algorithm**
 - Also unknown, in many cases, if algorithm is being followed correctly
 - In 2016, Minnesota had a misinterpreted algorithm in 0.6% of cases (despite building algorithm into software)
- **Infants in the NICU**
- **Out-of-Hospital Births**
 - How to incorporate algorithm into existing workflows
- **Facility versus Program roles/responsibilities**
 - Individual level QI/QA
 - System level QI/QA
 - Varying from traditional roles and responsibilities

PROGRAM NEEDS FOR CCHD PULSE OXIMETRY SCREENING GOING FORWARD

- **Support for robust data collection and analysis**
 - Resources for follow-up (inclusive of long term follow-up) and quality assurance
 - Will allow for better evidence-based recommendation to improve upon current implementation efforts
- **A fresh perspective**
 - CCHD screening does not appear to fit into typical NBS paradigm
 - Metrics and expectations need to be different

- **CCHD screening has value – just not yet quantifiable**
 - Overall mortality from CCHDs appears to be going down

The question remains – as newborn screening programs – how do we best approach this screening program with the ultimate end goal of improving outcomes in mind?

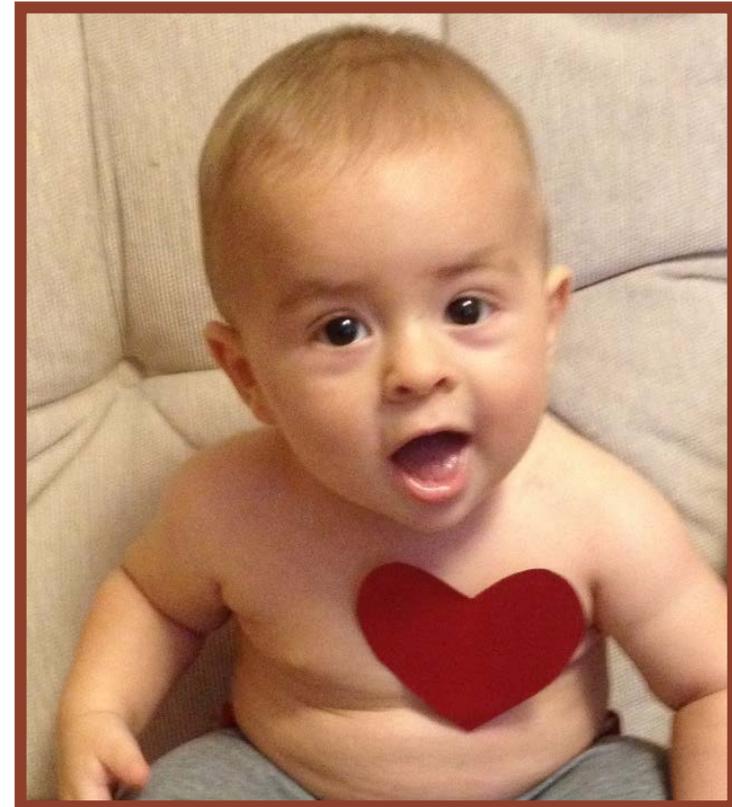
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Thank you

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