

NJ Guidance for Implementation and Reporting of Critical Congenital Heart Defects Screening in the NICU/SCN



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Background

- In the U.S., about 7,200 (or 2 per 1,000) infants annually have a critical congenital heart defect (CCHD).
- Delayed detection of CCHD may result in significant morbidity or mortality.
- Screening for early detection of CCHD using pulse oximetry is near universal in the U.S.
- Most states requiring screening of all infants irrespective of clinical status or setting.
- Unique challenges in the NICU setting, yet limited evidence to guide implementation.



www: <https://www.aap.org/en-us/advocacy-and-policy/issue-advocacy/Documents/2016/2016CCHD%20Newborn%20Screening%20Bill,%20Regulations,%20and%20Executive%20Order%20-%20AAP%20Division%20of%20State%20Govern%20Affairs.pdf>

Evolution of NICU Evaluation: New Jersey CCHD Screening NICU Working Group

New Jersey CCHD Screening Legislation:
"The Commissioner of Health and Senior Services shall require each birthing facility licensed by the Department of Health and Senior Services to perform a pulse oximetry screening, a minimum of 24 hours after birth, on every newborn in its care." P.L.2011, Chapter 74, approved June 2, 2011



Recommendation from NJ Recommended Screening Protocol:
"In the NICU, screening should be performed at 24-48 hours of age or as soon as medically appropriate after 24 hours of age. Screening must be performed prior to transfer out of the hospital at ≥ 24 hours of age. In all cases, screening should be performed prior to discharge to home."

New Jersey CCHD Screening Findings August 31, 2011–March 31, 2017

- 338 Fails reported to the NJ Birth Defects Registry (BDR)
 - 39.1% (n=132) in Well-Baby Nursery
 - 60.9% (n=206) in NICU



| Gestational Age | Overall N = 338 (%) | NICU N = 206 (%) |
|-----------------|------------------------|---------------------|
| Extreme preterm | 32 (9.5) | 32 (15.5) |
| Preterm | 50 (14.8) | 47 (22.8) |
| Term | 256 (75.7) | 127 (61.7) |

Failed Screens in the NICU Registered to NJ BDR August 31, 2011–March 31, 2017

Pre-identified N=165 (80.1%)

- ❖ Prenatal diagnosis of CHD
- ❖ Signs or symptoms at or before the time of the screen
- ❖ Cardiac consult or echocardiogram prior to the screen

Total Fails in NJ N=206

Evaluation due to Screen
N=41 (19.9%)

CCHD
N=1

CHD
N=9

- 5 of 41 infants with an evaluation performed in response to the failed screen had an echo with normal findings

Conditions of NICU Infants Identified Due to Screening

- **CCHD (1):**
 - Coarctation of aorta
- **CHDs (9):**
 - VSD (3)
 - ASD (2)
 - Peripheral pulmonary artery stenosis (3)
 - Atrial septal aneurysm (1)
- **PFO/PDA (15)**
- **Incomplete screens (16)**

New Jersey CCHD Screening NICU Working Group Recommendations

- Continue current protocol
- Limited research on NICU screening
- Empiric evidence needed to guide recommendations
- Further study warranted



Objectives

To evaluate the feasibility and burden associated with

- 1) early timing options for screening and
- 2) exclusion of infants from universal CCHD screening in the NICU with
 - a) prenatal CHD diagnosis,
 - b) echocardiography conducted before screening, or
 - c) those born extremely premature.

Methods

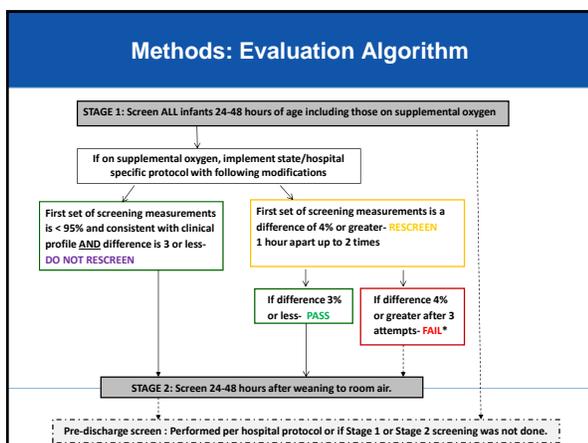
- Prospective evaluation of a multi-stage modified CCHD screening algorithm and implementation survey conducted in 21 NICUs: CA (1), IL (1), NJ (9), NY (5), and MN(5).
- Infants born February 1, 2015-September 30, 2015 with NICU stay of >23 hours (n=4,556).
- N=4120 infants with a complete set of appropriately timed screening results.



Methods: Evaluation Algorithm

Multi-stage algorithm modified for infants receiving oxygen

- Stage 1 targeted for 24-48 hours after admission
 - Modification for infants on oxygen at Stage 1:
 - Re-screening only required for >3% pre and post-ductal differential.
 - Saturations <95% consistent with clinical profile considered conditional passes.
 - Saturations <95% inconsistent with clinical profile regarded as fails.
- Stage 2 conducted optimally within 24-48 hours of weaning from oxygen
- Pre-discharge screen done only if Stages 1 or 2 were not completed



Results: Characteristics and Outcomes

- The majority of NICU infants were
 - ≥2500 grams (56%)
 - not on oxygen at 24-48 hours (72%)
 - did not have a pre-identifying factor (92%)
- 68% had neither pre-identifying factor and were not on oxygen comprising subgroup who may benefit.
- Overall fail rates for Stage 1 (0.9%) and Stage 2 (0.6%) were low.

Results: Supplemental Oxygen & Gestational Age

- Despite the modification, Stage 1 fail rates were significantly higher for infants on oxygen (2.1%) than on room air (0.7%).
 - Increased to 25.9% for infants on oxygen when conditional passes are considered fails.
- Stage 1 fail rates were highest among infants:
 - Born <1000 grams and/or < 28 weeks not on oxygen (7.4% & 9.5%)
 - Notably higher for these groups when conditional passes are considered fails (35.4% & 43.6%)

Results: Characteristics of Failed Screens

- Of the 32 infants that failed Stage 1
 - 63% were not on oxygen
 - 66% did not have a pre-identifying factor
 - One infant with previously unrecognized CHD was detected by screening
- Of the 5 infants that failed Stage 2
 - 40% did not have a pre-identifying factor
- No infants with CCHD identified by screening



Results: Feasibility and Burden

False Positive Rates

- Overall for both Stages = 0.8%
 - 0.6% for non-pre-identified infants overall
 - Compared with 0.2% for well-infants screened using upper and lower extremities at > 24 hours without a prenatal diagnosis (de Wahl Granelli et al, 2009).
- Highest among infants screened on oxygen (2.1%) and born extremely preterm (3.8%).
- Significantly lower for infants screened at Stage 1 not on oxygen (0.5%) and Stage 2 (0.6%).

Results: Feasibility and Burden

Unnecessary Echocardiography

- Approximately 13% of infants had an echocardiogram during hospitalization.
 - 0.2% (n=7) were performed in response to failed screens at any Stage; one identified a VSD.

Results: Feasibility and Burden

Implementation Survey (n=258)

- Nursing staff reported low burden during the evaluation (mean = 3.5)
 - Likert scale 0 = no burden to 10 = extremely burdensome.
- 80% reported a NICU specific CCHD screening protocol facilitated differentiation between screening and routine monitoring with pulse oximetry.
- 81% responded that utilization of the evaluation protocol increased awareness of unsuspected CHD in the NICU.
- Tracking screening & results from multi-stage algorithm quite challenging.

Conclusions

- Given the NICU population consists largely of normal birthweight infants not receiving oxygen, screening at 24-48 hours may provide benefit for early detection of CCHD.
- Exclusion of sub-populations introduces practice variation potentially leading to missed screens.
- Challenges when early screening infants born extremely premature and/or those receiving supplemental oxygen.
- Systematic, early screening does not incur significant burden.

Recommendations for Implementation and Reporting in New Jersey



NJHealth **Guidance for Critical Congenital Heart Defects (CCHD) Screening in the Special Care Nursery/Neonatal Intensive Care Unit**

The following recommendations provide further specifications for implementation of CCHD screening in the NICU and do not contradict current guidance on the New Jersey Recommended Screening Algorithm.

Who to Screen:

- Infants admitted to the NICU are not exempt from CCHD screening including those:
 - with a prenatal suspicion or diagnosis of CHD
 - with an echocardiogram performed before the CCHD screening
 - being transferred at ≥ 24 hours after birth

When to Screen:

- Screen as early as possible at ≥ 24 hours
- At maximum, screen at 24-48 hours if medically appropriate
 - If not screened at 24-48 hours, screen as soon as possible when medically appropriate
 - Screen as soon as possible after weaning from respiratory support including:
 - Supplemental oxygen
 - Room air CPAP

What to Report:

- Screening results (up to 3 attempts) entered into VIP (Vital Information Platform)
 - For all failed screens, results reported to NJ Birth Defects Registry (NJBDR)
- Transfers ≥ 24 hours
 - At least 1 set of measurements entered into VIP and failing results reported to NJBDR
 - One set of measurements by sending facility is sufficient when additional attempts are not feasible
 - VIP record should be transferred to receiving hospital, where appropriate, so that additional screening results can be added to the record
- Transfers < 24 hours
 - While not included in the mandate, screening is recommended if feasible before transfer, especially if transferring out of state
 - If done, results entered into VIP and failing results reported to NJBDR
 - VIP record should be transferred to receiving hospital, where appropriate, so that additional screening results can be added to the record
- CCHD confirmed with echocardiogram
 - At least 1 set of measurements entered into VIP and failing results reported to NJBDR
 - One set of measurements is sufficient; no additional screening attempts needed

Who to Screen



Infants admitted to the NICU are not exempt from CCHD screening including those:

- with a prenatal diagnosis of CHD
- with an echocardiogram performed before the screening
- being transferred at ≥ 24 hours after birth

When to Screen



Screen as early as possible at ≥ 24 hours

- Optimally screen at 24-48 hours, if medically appropriate
- If not screened at 24-48 hours, screen as soon as possible when medically appropriate
 - Screen as soon as possible after weaning from respiratory support including
 - Supplemental oxygen
 - Room air CPAP

What to Report




- Screening results (up to 3 attempts) are entered into VIP
- For failed screens, report all fail results to NJBDR
 - Complete Pulse Ox module in NJ BDR
- CCHD confirmed with echocardiogram
 - At least 1 set of measurements entered into VIP and failing results reported to NJBDR
 - No repeat screen needed

What to Report: Transfers

Transfers ≥ 24 hours

- At least 1 set of measurements entered into VIP and failing results reported to NJBDR
 - No repeat screen needed if not feasible
 - VIP record should be transferred to receiving hospital so that additional screening results can be added to the record

What to Report: Transfers

Transfers < 24 hours

- While not mandated, screening is recommended shortly before discharge or transfer
 - If done, results entered into VIP and failing results reported to NJBDR
 - VIP record should be transferred to receiving hospital so that additional screening results can be added to the record

Education & Resources

- NJ DOH
www.nj.gov/health/fhs/nbs/critical-congenital-heart-defects
- NJ AAP
www.njaap.org/programs/critical-congenital-heart-defects/
- Free online course for nurses
 - New revised edition with CNE through April 30, 2019
 - <https://trainingcourses.rutgers.edu/online/cchd/story.html>



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Questions & Thank You

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