

Advancing the Maternal & Child Health **VISION** Leadership Quality & Action

ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS 2013 ANNUAL CONFERENCE

## Maryland CCHD Screening AMCHP Annual Conference Washington DC 02/12/13

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## THE JOURNEY BEGINS

- Advisory Council on Hereditary and Congenital Disorders following national events
- 2011 legislation introduced



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## LEGISLATION

- Required Advisory Council on Hereditary and Congenital Disorders to convene expert panel to evaluate and submit legislative report 12/31/11
- Required Maryland to follow recommendation of Secretary Sebelius
- Panel of experts invited from cardiology, public health, hospital administration, nursing and advocacy
- Divided panel into 3 committees to address:
  - Clinical feasibility
  - Education
  - Quality assurance

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## ADVISORY PANEL FOR CCHD SCREENING

- |                                  |                             |
|----------------------------------|-----------------------------|
| Carissa Baker-Smith, MD, MPH     | Debra Harper-Hill, RN       |
| Miriam Blitzler, PhD             | Sandra Heeley, RN           |
| Charlene Bennett, RN             | Kimberly Iafolla, MD        |
| Carrie Blout, MS, CGC            | Julie Kaplan, MD            |
| Elizabeth Bradshaw, MSN, RN, CPN | Edward Lawson, MD           |
| Joel Brenner, MD                 | Gerard Martin, MD           |
| David Bromberg, MD               | Neil Porter, MD             |
| Debbie Burke, RN                 | Geoffrey Rosenthal, MD, PhD |
| Maria Cardona, MD                | Ann Sober, RN, BSN          |
| Joann Cordeiro                   | Philip Spevak, MD           |
| Anne Eder                        | Johnna Watson, RN, BSN      |
| Julie Hoover-Fong, MD, PhD       | Anika Wilkerson             |
| Renee Fox, MD                    | S. Lee Woods, MD, PhD       |
| Maureen Gilmore, MD              | Cynthia Mueller, RN, BSN    |
| Tanya Green, MS, CCC-A           | Debbie Badawi, MD           |
| Carole Greene, MD                | Dianna Abney, MD            |
| Linda Grogan, RNC, BSN, MBA      |                             |



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## ADVISORY PANEL

- Recommended Screening be standard of care versus part of newborn screening.
- No changes recommended to AAP endorsed algorithm.
- Education needed to target expectant parents, hospital neonatal providers, community providers, and midwives.
- Quality assurance should ensure proper screening of all eligible babies and appropriate follow up for those with abnormal screen results.



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## LEGISLATION

- Legislative report available at <http://fha.dhmd.maryland.gov/genetics/docs/CCHDLegisRpt.pdf>
- In September 2011, CCHD Screening was adopted to RUSP
- CCHD screening became a National Leadership Academy for the Public's health project and 4 person team joined expert panel.



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## IMPLEMENTATION

**Screening**  
**Evaluation of Abnormal Results**  
**Recording Results**  
**Surveillance**



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## IMPLEMENTATION

**Stage was set for implementation**

- National conversation happening
- Legislative report outlined educational, surveillance and quality assurance activities needed
- Critical partners needed for implementation were assembled



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## PLANNING

- **The Goal for CCHD Screening**

Identify those newborns with structural heart defects that are usually associated with low blood oxygen in the newborn period and could result in morbidity or mortality early in life



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## PLANNING

### Vision

- Hospital and community providers educated so that screening and follow up of positive screens are done appropriately.
- Availability of online resources such as the screening algorithm and FAQ's.
- A protocol at each birthing facility that describes how the screening will be done; what steps to take if a baby fails the screen; and how to follow up on babies missed prior to discharge.



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## PLANNING

### Vision (continued)

- The ability to track data.
- At least 80% of babies to be reported as screened in the first quarter of implementation with an increase each quarter over the first year.
- Ability to analyze surveillance data to determine effectiveness of screening.



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## IMPLEMENTATION

### Critical Leadership Challenges

- Communicating information to the diverse groups involved (clinicians, administrators, data managers, parents).
- Data collection from birth facilities and out of hospital births (extra burden on them).
- Providing guidance for hospitals with fewest resources.



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### IMPLEMENTATION

Pathway to Change

- Engage and inform clinical providers and hospital administrators.
- Research reimbursement issues.
- Develop educational material for the community at large.
- Utilize existing funding to create mechanism for CCHD reporting.
- Develop surveillance and quality improvement methods.



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### PROJECT OUTCOMES

**We accomplished a lot!**

- Educational Webinars for hospital providers (2) - live and archived.
- Approved screening protocol.
- Brochure for parents.
- Website with resources for parents and providers.
- Continuing education and technical assistance for nurses and physicians.
- Description of program on public television to inform the public.
- Continuing medical education (CME) opportunities provided by team members to community primary care providers to inform them of the new legislation.



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### PROJECT OUTCOMES

- All birth hospitals are screening and now reporting on those screened.
- Over first 3 months, 78% of infants were reported as being screened; during November that number was 87%.
- Identified 2 infants with respiratory illness and 1 with non critical congenital heart disease.



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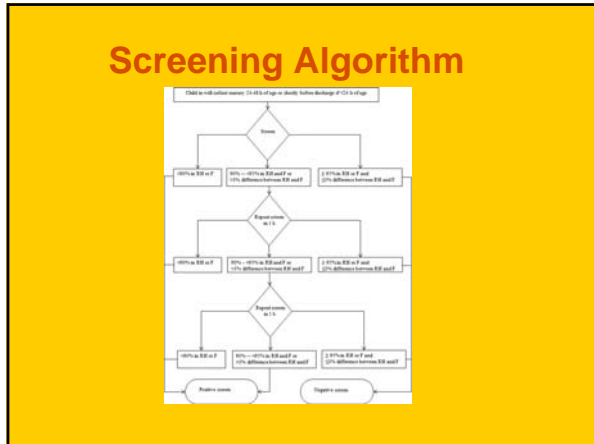
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## Mueller CCHD Screening Table

Green= Negative Screen (PASS)  
 Red=Rescreen in 1 hour  
 Red for 3 consecutive screens= Positive Screen (FAIL)  
 \*Red\* = Automatic Positive Screen (FAIL)

| RIGHT HAND | FOOT  |       |       |       |       |       |       |       |       |       |       |       |
|------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| 100        | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 99         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 98         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 97         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 96         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 95         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 94         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 93         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 92         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 91         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| 90         | 100   | 99    | 98    | 97    | 96    | 95    | 94    | 93    | 92    | 91    | 90    | * * * |
| * * *      | * * * | * * * | * * * | * * * | * * * | * * * | * * * | * * * | * * * | * * * | * * * | * * * |

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## The Future

- Surveillance and quality assurance to insure universal appropriate screening and evaluation of infants with abnormal screens (this work has begun).
- Critical partners to reach (midwives, pediatricians) to assure universal and appropriate screening.
- Evaluate effectiveness of screening.

*Leadership  
Quality &  
Action*

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**THANK YOU!**



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- Miriam Blitzer: [mblitzer@peds.umaryland.edu](mailto:mblitzer@peds.umaryland.edu)



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