



CCHD Screening in Maryland - Year 1 Results

**APHL NBSGTS Meeting
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Prevention and Health Promotion Administration**



Mission And Vision

MISSION

- The mission of the Prevention and Health Promotion Administration is to protect, promote and improve the health and well-being of all Marylanders and their families through provision of public health leadership and through community-based public health efforts in partnership with local health departments, providers, community based organizations, and public and private sector agencies, giving special attention to at-risk and vulnerable populations.

VISION

- The Prevention and Health Promotion Administration envisions a future in which all Marylanders and their families enjoy optimal health and well-being.

The Journey Begins

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





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



Advisory Panel for CCHD Screening

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



Advisory Panel

- Screening as standard of care versus part of newborn screening.
- No changes to AAP/AHA algorithm.
- Education needed for: 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.



Legislation

- Legislative report available at:

<http://phpa.dhmm.maryland.gov/genetics/docs/CCHDLegisRpt.pdf>

- In September 2011, CCHD Screening was adopted to RUSP



Implementation

- Regulations developed: (COMAR 10.52.15)
- Hospital and community providers educated so that screening and follow up of positive screens are done appropriately (webinars, newsletter articles).
- Protocol at each birthing facility should describe 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.



Implementation

- Website with resources for parents and providers
http://phpa.dhmfh.maryland.gov/genetics/SitePages/CCHD_Program.aspx
- Technical assistance provided to birth facility staff regarding protocol and documentation.



Parent's Corner:

- *Watch Video on How Your Baby Gets Screened*
- FAQs Fact Sheets on “top 7” congenital heart defects
- CCHD Brochure
- Pulse Oximetry Brochure Resources



Provider's Corner:

- Webinar
- Video on “How to perform pulse oximetry screening”
- How to document pulse oximetry results into the Electronic database
- Program Spotlight



Implementation

- Goal: 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.
- Goal: Ability to analyze surveillance data to determine effectiveness of screening.



Implementation

- Data Collection!
- Web-based data collection for EHDI (OZ™ Systems)
- Updating for Birth Defects
- Added Pass/Fail/PO





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.



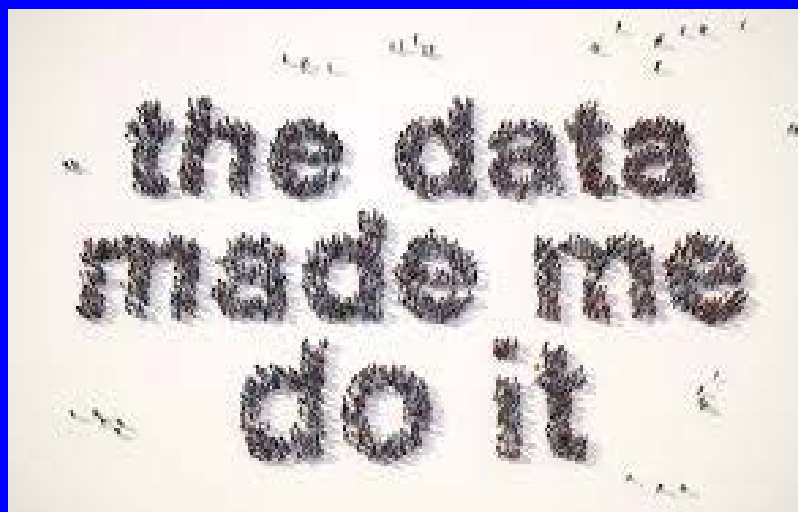
Goal for CCHD Screening

- Identify those newborns with structural heart defects usually associated with hypoxia in the newborn period that could have significant morbidity or mortality early in life with closing of the ductus arteriosus or other physiologic changes early in life.

How Did We Do?

16 Months:

September 2012 – December 2013





The Data

- 83,381 well baby births documented
- 78,542 well babies received pulse-ox screen (94.2%)
- 61 Physician Override for total 94.3% documented as evaluated for CCHD
- Identified **1 primary and 9 “secondary” conditions** in well babies.



The Data - Nursery

Diagnosis of Primary Target Condition

Screen

	Positive	Negative	Unknown	
Fail	1	18	9	28
Pass	4	78510	0	78514
	5	78528	9	78542

Sensitivity = 20% Specificity = 100%

The Data - Nursery

Diagnosis of Primary Target or Secondary Condition

Screen

	Positive	Negative	Unknown	
Fail	10	9	9	28
Pass	11	78503	0	78514
	21	78512	9	78542

Sensitivity = 47.6% Specificity = 100%



The Data - Nursery

61 Physician Overrides

- 4 Normal echos (41 done)
- 8 babies sent to NICU
- 4 conditions identified (2 PDA, 1 PFO, 1 AV canal)
- 1 infant expired



The Data

- 9,347 NICU births documented
- 6,091 NICU babies received pulse-ox screen (65.2%)
- 546 Physician Override for total 71% documented as evaluated for CCHD.
- Identified 3 primary and 10 “secondary” conditions in NICU babies.

The Data- NICU

Diagnosis of Primary Target Condition

Screen

	Positive	Negative	Unknown	
Fail	3	17	2	22
Pass	1	6068	0	6069
	4	6085	2	6091

Sensitivity = 75% Specificity = 99.7%

The Data - NICU

Diagnosis of Primary Target or Secondary Condition

Screen

	Positive	Negative	Unknown	
Fail	13	7	2	22
Pass	6	6063	0	6069
	19	6070	2	6091

Sensitivity = 68.4% Specificity = 99.9%



The Data – NICU

546 Physician Overrides

- 148 had clinical signs: 101 normal echos; 13 primary target conditions; 23 secondary; remainder unknown outcome
- 111 echos without clinical signs noted
- 36 prenatal diagnosis
- Others mostly and “prematurity” and 26 transfers in or out.

Summary

- Total of **50 babies** out of 85,509 births (0.06% of births) diagnosed with a primary target condition.
- **4** (0.08%) were identified by screening.
- **25** (50%) diagnosed prenatally.
- **13** (26%) diagnosed clinically.
- **5** (10%) passed screening.

Summary

- Identified **1** well baby with a primary target condition and at least **2** more requiring treatment.
- **11** well babies passed screening and later had conditions identified (3 Tetralogy of Fallot; 1 TAPVR; 6 coarctation; 1 VSD requiring surgery

Summary

- Identified **3** NICU babies with primary target condition and **2** more that required treatment.
- **6** NICU babies passed screening and later had conditions identified (1 Tetralogy of Fallot; 2 Coarctations; 1 pulmonary stenosis; 2 VSD)



Lessons Learned

- Hospitals in Maryland had few barriers to screening for CCHD.
- Complete documentation (follow up info) is a challenge.
- 8 babies needing treatment identified.
- Educate parents and physicians that CCHD screening does not assure a healthy heart (low sensitivity).



Prevention and Health Promotion Administration

<http://phpa.dhmh.maryland.gov>