



Critical Congenital Heart Disease: Recommended Minimum Data Set & Data Transfer from the Oximeter Device

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NewSTEPs CCHD Meeting

**Silver Spring, Maryland
February 27, 2014**



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United States Overview

- ♥ Human Resource Service Administration's Secretary's Advisory Committee on Heritable Disorders; October 2010
- ♥ HRSA Workgroup Meeting on Screening at ACC Heart House; January, 2011; Washington, DC. Outcomes published in *Pediatrics* which included recommended protocol for screening.
- ♥ CCHD Screening endorsed by Secretary Kathleen Sebelius, added to RUSP; September, 2011
- ♥ AHA, ACC, AAP and March of Dimes all endorse CCHD Screening



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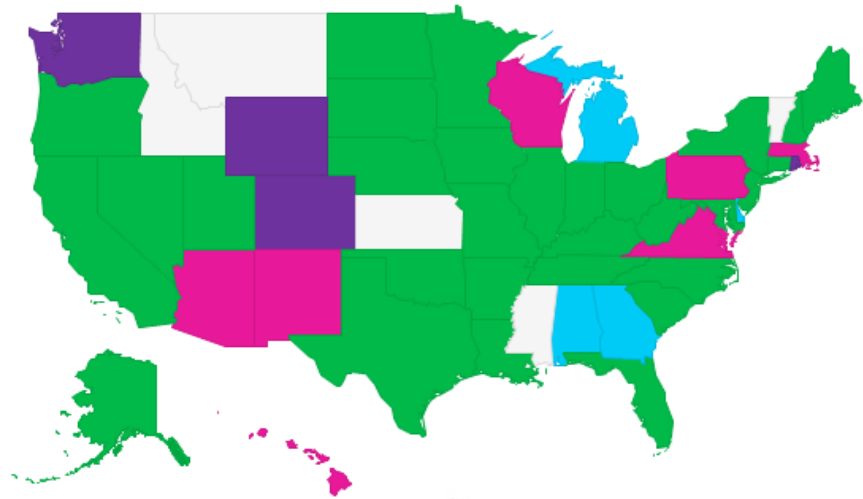
United States Efforts



Maryland Bill Signing May 19, 2011

VA and NM last week!

- 2011: Indiana and Maryland first states to pass CCHD screening legislation. New Jersey first state to implement universal CCHD screening.
- 20 states enacted legislation in the first half of 2013
- 34 states total with legislation pending in many more



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www.cchdscreeningmap.org



One in One Hundred

United States Efforts



2nd Stakeholders Meeting

February 10, 2012

- Industry
- Government
- Scientists
- Cardiologists
- Nursing
- Associations
- MCHB Programs
- State DOHs

Focused topics:

Research, Advocacy and Legislation, Equipment, **Reporting**, Education

Manuscript Published in Pediatrics



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Minimum Data Recommendations and Considerations

Birth Facility Data

1. Patient Level Data

- Pt Identification
- Age in hours
- All oximetry saturations
- Final screening result
- Obstacles encountered
- Diagnostic results

2. Screening Program Data

- Screening protocol used
- Type of pulse oximeter used

Public Health Program Data

1. Specific to mandate requirements of each state
2. Aggregate or individual data may be specified by public health programs
3. Birthing facilities required to report data sufficient to determine **whether all eligible infants were screened**, and information about evaluation performed in positive screens
4. Ideal for **positive screens**:
 - Track final dx and interventions
 - Include if infants needed transport for eval at birth facility and treatment
5. Ideal for **negative screens**:
 - Identification of CHD could be linked within NBS programs
6. **Summary statistics** provided by health depts and NBS programs to stakeholders



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Pediatrics 2013;132:e185–e192

The DC Critical Congenital Heart Disease Quality Improvement (QI) Collaborative



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Our Vision



All infants in the District of Columbia with Critical Congenital Heart Disease (CCHD) are detected before leaving the newborn nursery

District of Columbia:

- ♥ Approx. 14,000 births per year
- ♥ 140 infants/year with CHD
- ♥ 35 infants/year with CCHD
- ♥ As many as 5-10 infants/year could die or have missed diagnosis



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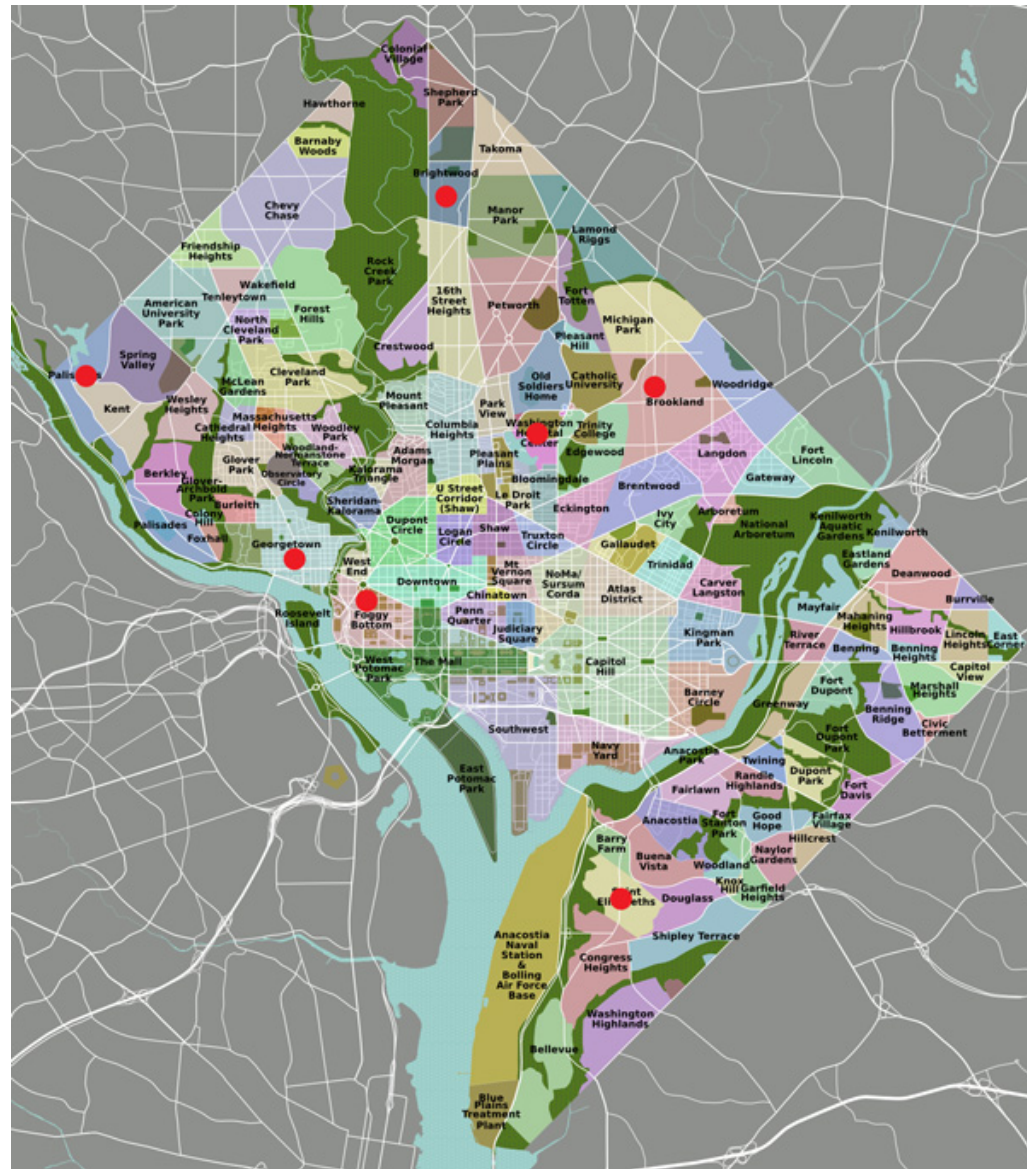
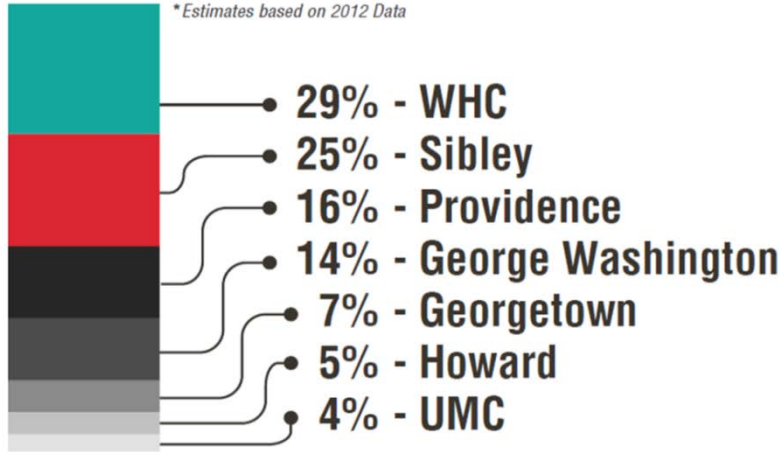
DC Birthing Hospitals at a Glance



D.C. BIRTHS BY HOSPITAL

Total number of births in D.C. ~14,000*

* Estimates based on 2012 Data



Map of DC Neighborhoods. Illustration. n.d. Washington, DC. Wikipedia. 11/6/2013.



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