Critical Congenital Heart Disease
Newborn Screening
National Implementation and Data Reporting

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Critical Congenital Heart Disease Newborn Screening

- CCHD added to Recommended Uniform Screening Panel in September 2011
- Demonstration Project Funding from HRSA funded 6 projects (2012-2015, ~$300,000/year)
- State approaches to implementation are varied
Overview

• Current status of CCHD screening
  – Legislative Needs and Progress
  – Pilot Studies and Local Implementation
  – Challenges and Barriers
• Data collection efforts
• The next steps
Sources of Data

• Newborn Coalition
• NewSTEPs Survey of states completed in January 2013
• Regional Genetics Collaboratives (HRSA)
Legislative Process

Requirements for adding new conditions vary by state (Responses received from 43 states)

- Legislative action required in 23/43 (53%)
- Board of health/advisory committee in 20/43 (47%)

Legislation has been introduced in 29/50 states

- Pending in current legislative sessions in 10
- Others have tabled discussion awaiting more information
- Only 2/28 states mention funding attached to legislation
Status of Successful Legislation to implement CCHD Screening

Map showing states where legislation has been introduced and passed.
Status of Mandated CCHD Screening through other mechanisms

* Alabama will add CCHD in early 2013
Status of Legislation Introduction for CCHD Screening – Active Bills

- Hawaii
- Alaska

Map showing states with introduced and passed legislation.
Activity in State NBS Committees

- Hawaii
- Alaska

Map showing states with activity in State NBS Committees, with stars indicating states where legislation has been introduced or passed.
Status of Pilot Studies and Localized Hospitals CCHD Screening (as reported to Health Departments)

Hawaii
Alaska

Legislative Data and Map provided by Newborn Coalition
Location of HRSA Pilot Demonstration Projects

Legislative Data and Map provided by Newborn Coalition
All CCHD Activities

Legislative Data and Map provided by Newborn Coalition
Challenges and Barriers

• Funding
  – Set up of data systems
  – Development of surveillance system

• Convincing Public Health Decision Makers
  – Algorithm
  – Resources
Challenges and Barriers to Implementation

Based on Responses from individuals in 41 states
Timing of Implementation

Based on Responses from individuals in 41 states

Typically, once your state undertakes the decision about the addition of a new condition, how long does the process take to reach a decision?

- Less than 6 months: 5.0%
- Between 6 months and 1 year: 45.0%
- More than 1 year but less than 3 years: 50.0%
- At least 3 years: 5.0%
Determining the ‘minimal data set’ for state collection

• What is the role of Public Health?
  – Quality assurance, surveillance, quality improvement
  – Types of data to be collected
    • Testing done/not done
    • Data on babies who failed screening
    • All data on all screens

• National partners joining efforts for data
  – Centers for Disease Control and Prevention (CDC)
  – Association of Maternal and Child Health Programs (AMCHP)
  – National Library of Medicine (NLM)
  – American College of Medical Genetics (ACMG)
  – NewSTEPs (Newborn Screening Technical assistance and Evaluation Program)
Data collection locally and nationally

- Developing data systems for collection at the state level
  - Modifications of existing systems
    - EHDI (Early Hearing Detection and Intervention)
    - Electronic Birth Certificate
  - Commercial systems
  - New data collection systems

- NewSTEPs national newborn screening repository
  - Data on babies with disorders identified by newborn screens
  - Quality indicators to track metrics in state newborn screening programs
Current Resources for States and Next Steps

• Technical assistance
  – Monthly webinars with timely topics at ‘advanced’ and ‘basic’ levels
  – National Children’s Medical Center online resource
    http://www.childrenshealthcommunities.org/pulse_ox
  – Listserv to post questions and offer solutions
  – NewSTEPs identifying resources and partners to assist states
Questions