Screening for Critical Congenital Heart Disease Using Pulse Oximetry

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Association of Maternal & Child Health Programs Webinar
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Outline

- Federal role in implementation of CCHD Screening
- State activities with CCHD Screening
- Survey of birth defects surveillance programs
Federal Activities

- **Screening Standards and Infrastructure:** HRSA to guide the development of screening standards/infrastructure

- **Education and Training:**
  - HRSA to fund the development of appropriate education/training materials
  - FDA to provide guidance to industry and FDA staff on pulse oximeters

- **Research:** NIH to determine the screening technology, diagnostic processes, care provided and health outcomes

- **Surveillance:** CDC to monitor infant mortality and other health outcomes (clinical utility and program evaluation)
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**CDC Activities**

- **Evaluate state surveillance and tracking**
  - National Birth Defects Prevention Network (NBDPN) survey of states
  - Collaboration with New Jersey, Epi-Aid to assess surveillance, tracking

- **Conduct a cost-effectiveness analysis CCHD screening**
  - Collaboration with New Jersey, Econ-Aid to assess total cost burden
  - Ongoing evaluation activities

- **Leverage an electronic health record framework**
  - NCBDDD working group on EHRs
  - Creating a strategic plan on leveraging EHRs for public health activities, focus on CHD
  - Collaboration with National Library of Medicine
Bills Introduced During 2011-2012 Legislative Sessions
(As of February 29, 2012)
Survey of Birth Defects Surveillance Programs

- To assess the potential role of state birth defects surveillance programs with screening for critical congenital heart disease (CCHD)

- First distributed in October 2010 by NBDPN

- Revised in November 2011 following the addition of CCHD to uniform newborn screening panel

- States were asked to confirm or change responses from 2010
Does your state have a birth defects surveillance program?

NBDPN survey, 2011
Is your state engaged in pulse oximetry screening for CCHD?

Yes: 10 (2010), 10 (2011)
No: 30 (2010), 21 (2011)
Don't know: 12 (2010), 3 (2011)

NBDPN survey, 2010 & 2011
If state is engaged in screening activities, is the screening:

- Universal, statewide: 4
- Regional: 1
- Hospital-based: 9
- Other: 1

NBDPN survey, 2011
If your state is engaged in screening activities, what components are included?

- **Screening only**: 4
- **Screening and followup of positive screens**: 5
- **Other**: 3

NBDPN survey, 2011
If your state adopts NBS for CCHD, how could the birth defects surveillance program assist with the confirmed cases of CCHD?

<table>
<thead>
<tr>
<th>Possible Options for Assistance</th>
<th>Number of States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link children identified by screening to support services</td>
<td>16</td>
</tr>
<tr>
<td>Report on healthcare utilization by affected children</td>
<td>13</td>
</tr>
<tr>
<td>Report on support services utilization by affected children</td>
<td>7</td>
</tr>
<tr>
<td>Report on enrollment of affected children into special education services</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
</tr>
</tbody>
</table>

NBDPN survey, 2010 & 2011
**How could the birth defects surveillance program assist with evaluation of CCHD newborn screening?**

<table>
<thead>
<tr>
<th>Possible Options for Assistance</th>
<th>Number of States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluate mortality associated with CCHD</td>
<td>28</td>
</tr>
<tr>
<td>Evaluate morbidities associated with CCHD</td>
<td>16</td>
</tr>
<tr>
<td>Evaluate interventions associated with CCHD</td>
<td>11</td>
</tr>
<tr>
<td>Compare outcomes of children with CCHD</td>
<td>14</td>
</tr>
<tr>
<td>Evaluate all true and false positive screens</td>
<td>13</td>
</tr>
<tr>
<td>Evaluate false negative screens</td>
<td>13</td>
</tr>
<tr>
<td>Assist with economic evaluation of screening</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
</tr>
</tbody>
</table>

NBDPN survey, 2010 & 2011
What is the working relationship between your state’s birth defects surveillance program and newborn screening program?

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Number of States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizationally located together</td>
<td>11</td>
</tr>
<tr>
<td>Contained within the same bureau/program</td>
<td>15</td>
</tr>
<tr>
<td>Physically located in the same building</td>
<td>14</td>
</tr>
<tr>
<td>Currently share same database/data system</td>
<td>8</td>
</tr>
<tr>
<td>None/No working relationship</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>

NBDPN survey, 2010 & 2011
What are the likely barriers in your state to your program’s involvement with newborn screening for CCHD?

- Lack of legislative/regulatory language/authority: 19
- Inadequate staffing: 29
- Insufficient funds: 27
- Information technology/data linkage needs: 19
- Other: 8

NBDPN survey, 2010 & 2011
Summary

- Many state birth defects surveillance programs have the data needed to evaluate implementation of CCHD screening.

- Opportunity for collaboration between state newborn screening and birth defects programs.

- Barriers to involvement in CCHD screening exist in many states regardless of legislative activity.
Resources

- CDC, National Center on Birth Defects and Developmental Disabilities: Screening for Critical Congenital Heart Defects
- National Birth Defects Prevention Network
  - http://www.nbdpn.org/
- Congenital Heart Public Health Consortium
  - http://chphc.org/hostedsites/Pages/default.aspx
- Toolkit for Providers: Children’s National Medical Center Congenital Heart Screening Program
  - http://www.childrensnational.org/PulseOx/HealthCareProvidersResources.aspx
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**NBDPN**
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**All state BD & NBS Programs**
Thank You

For more information please contact Centers for Disease Control and Prevention

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